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The Livelihoods and Challenges Faced by Caregivers of Children with Disabilities in South Africa

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Abstract

This qualitative research attempted to describe the livelihoods and challenges of caregivers of children with disabilities in the Mpumalanga Province of South Africa. Caregivers of children with disabilities face challenges in providing financial, social, and psychosocial care for their disabled children. Caregivers also face an enormous burden in raising their disabled children, primarily due to a lack of services and resources from government and non-governmental organizations dedicated to supporting caregivers of children with disabilities. For the study, nine female caregivers of children with disabilities aged 1 to 17 in Mbombela were purposefully selected as participants to pursue the goal of the current research. Data was collected through semi-structured interviews and analyzed thematically to connect the common themes and the overall content theme. Issues emerging from the data were the lack of accessibility of services and the notion of absentee fathers as men do not want to be associated with disabled children, which also plays a role in the financial constraints faced by women caregivers. The stigma of caregivers was also an issue the study revealed, as well as the coping mechanisms that caregivers use when raising their disabled children. In summary, caregivers of children with disabilities stand in their struggle to educate their children. There is also a lack of support structures for caregivers of children with disabilities. Therefore, strategies need to be put in place to help caregivers of children with disabilities to reduce their burden and to be able to cope with the challenges of their everyday life.

Keywords: *Disabilities; Livelihoods; Children; Challenges; Caregivers*

1. Introduction

Caring for children with disabilities can be an overwhelming experience as it places a constant financial, psychological, social, and health burden on the primary caregiver (Ndadzungira, 2016).

Zahaika, Daraweesh, Shqerat, Arameen, and Halaweh, (2021) posit that caregivers of children with disabilities may experience negative physical health while feeling socially isolated and less involved with their children due to increased physical stress leading to exhaustion and fatigue which also makes them communicate less with people because of a lack of understanding of their needs. Zahaika et al. (2021) also indicate that families of children with disabilities suffered from psychological and parental stress affecting their anxiety levels, this may be related to caregivers having to devote more time and effort to caring for their children.

Caring for a child requires significant resources, and the demands on those resources are often increased when a child is born with a disability (Zahaika et al., 2021). Bingham (2017) points out that in South Africa several children with disabilities are excluded from education and health services, alongside additional support structures essential to their development, and that caregivers who care for these children typically face a shortage of resources to care for themselves and their children. Disabilities are different, which complicates the definition of the term, as different people perceive disability from different perspectives and therefore define it depending on their collaboration and perspective.

However, Francis and Silvers (2016) define disability as a person with a physical or mental disability that significantly limits one or more important life activities of that person. It can be difficult for a family member or caregiver to balance personal, caring, and everyday needs while caring for a child with a disability. Caregiving is not a job or calling for most caregivers, but an obligation they must face (Ndirangu & Midigo, 2018). Therefore, the researchers felt it appropriate to examine the issue to show the path that caregivers face in raising their children with disabilities.

To achieve the study's main objective, the researchers collected qualitative data from nine female caregivers who were purposively and conveniently selected to participate in the study. For the data collection process, data was collected through semi-structured interviews guided by an open-ended interview guide. To make meaning of the data, the thematic analysis technique was applied. This technique was used to find, analyse, and report patterns in a data set, enabling descriptive arrangement of the data to make it easier to understand different parts of the data.

The described introduction presented the general area of this study, by introducing and defining the phenomenon of caring for children with disabilities. The data collection process and the methodological process were also outlined. The following literature details several aspects of the livelihood of caregivers for children with disabilities. The literature review in this paper is followed by the methodology section which describes the methodology used by the researchers to gather data, including the sampling techniques, procedures and instruments used. Furthermore, the paper concisely discusses the findings of the research, including the data collected and equally provides an interpretation of the data from the perspective of previous relevant studies. Through the comprehensive discussions, the researchers also highlight future research stemming from the findings of this research. This paper concludes by briefly discussing the limitations of the undertaken study.

Literature Review

Disability affects not only the disabled child but also affects the whole family as disabled children need help to carry out their daily activities and take medication (Ghazawy, Mohammed, Mahfouz & Abdulrahim, 2020). The various challenges that caregivers face are collectively referred to as caregiver burden, an umbrella term used to describe a caregiver's physical, emotional, and financial response to the challenges and demands of serving a child with a disability (Muller -kluits & Slabbert, 2018). Studies have shown that caregivers' experiences of raising children with disabilities are influenced by several elements, and these aspects can be observed through caregivers' demands (Nowak, 2017).

Disability has an extensive effect on the life of one diminishing the ability to carry out normal activities. The term disability refers to a physical, mental, or sensory disability, whether temporary or permanent, that limits the ability to do one or is made worse by the economic and social environment (Tigere & Makhubele, 2019). According to Tederera and Hall (2017) based on their research from Opuwo, Namibia, parents are those who have custody of a child and take multiple steps to encourage the child's growth. Thus, from infancy through adulthood, parenting involves nurturing and encouraging a child's emotional, physical, social, intellectual, and spiritual growth (Taderera & Hall, 2017). The caregiving role for children with disabilities from children without disabilities places a greater caregiving burden on their caregivers, especially over a long period, and this results in caregivers having greater responsibilities compared to normal children (Zulfia & Allenedikania, 2020). Such a condition also requires caregivers to adapt to the situation and choose appropriate coping strategies when performing their caregiving role. However, Zulfia and Allenedikania (2020) go on to explain that caregivers are in children's world, which requires them to play balanced roles as parents, facilitators, and navigators, and thereafter learn to manage stigma and try to protect their children at all costs to protect.

Makura (2018) asserts that being a primary caregiver for a child with a disability can be emotionally demanding, which can occasionally lead to emotions of hopelessness, remorse, and contempt. (Mazibuko, 2019) agrees that caring for children with disabilities is more challenging, and requires more time, effort, and patience, which can be exhausting for caregivers. Bahry, Mat, Kori, Ali, Munir and Salleh (2019) averred that caregiving for a child with disabilities extends beyond "regular" parenting, and caregivers must deal with a variety of shifting demands relating to their child's unique requirements. Bahry et al. (2019), further note that the challenges of providing care vary based on the child's disabilities and the socioeconomic status of the family. Thus, the primary caregiver's emotional and physical capacity to perform their work effectively is affected by their understanding of their tasks and responsibilities in caring for children with disabilities (Ndadzungira,2016).

The pressure of raising a child with special needs can lead to a crisis event and how mothers respond to this pressure depends on several factors affecting their ability to cope, such as how they interpret family sources of support, the crisis event, family structure, and community resources (Elnabawy & Nabawy, 2012). According to Diseko (2017), there is a variety of coping strategies used by caregivers of a disabled child at different times and in response to different circumstances, as well as acceptance of a child's strategy and social support, including seeking outside support such as family members and relatives, is seen by caregivers as helpful in overcoming the challenges of raising a disabled child. Avoiding uncomfortable situations is also seen as important for the adjustment of caregivers of children with disabilities.

In the area of coping with livelihoods and the challenges faced by caregivers, social workers use the role of a facilitator to provide appropriate support and connect caregivers with resources, including providing caregiver training needs as this will enable caregivers would be able to provide quality care to their disabled children (Maphosa & Chiwanza, 2021). Muller Kluits and Slabbert (2020) suggest that a social worker plays a central role in the delivery of services to people with disabilities and their caregivers. These roles include being an educator, facilitator, and enabler. Social workers, therefore, are responsible for ensuring that caregivers have adequate support and resources to reduce the burden on caregivers. The above literature is critical to providing an understanding of the day-to-day challenges faced by caregivers of children with disabilities. The description of the challenges provided the framework for this study as the researchers aimed to answer the following question. The central question this research paper aims to answer is *"What are the livelihoods and challenges caregivers face when caring for children with disabilities?",* particularly from the perspectives of the caregivers.

Theoretical Framework

The Social Model of Disability

The theoretical foundation for this study was The Social Model of Disability, in which Shekwa (2019,p.39) claimed that the challenge encountered by people with disabilities is not the disability itself but a socially constructed problem that is political and must be addressed socially. Ndadzungira (2016,p.4) outlined that the social model of disability assumes that when societal barriers are addressed, the problem of disability does not become apparent even though the disabilities exist. According to Matambanadzo (2021,p.7), when viewed through the prism of the social model, disability is characterized as the outcome of environmental factors, psychological obstacles, and social barriers that limit how effectively people with disabilities may engage in societal activities.

Regarding environmental factors, the model argues that infrastructural discrimination occurs where public services, buildings, and transport are deliberately not designed to accommodate people with disabilities, and then psychological factors see disabilities as stemming from the community's perceptions of how disabled people see them when the progress or persons with disabilities is impeded by laws or institutions that do not fully uphold their rights, says that people cannot carry out certain activities while the institutional factors arise (Ndadzungira, 2016,p.4).

Physical barriers, personal attitudes, and other aspects of the social environment are all thought to play a role in the development of disabilities in people with disabilities. Inaccessibility to buildings and difficulty using public transportation are two such barriers that prevent people with disabilities from fully participating in society (Shekwa, 2019,p.39). Shekwa (2019,p.39) claims that the goal of this model is to improve the conditions in which disabled people live, play, and work because these individuals face disadvantages as a result of widespread discrimination, especially in institutional settings.

Institutional barriers, according to Ndadzungira (2016,p.4), occur when the rights of people with disabilities or those who care for them are not fully reflected in laws or institutions. The fundamental presumptions that underlie society's operations and how they might have been adversely influenced by this prejudice. Shekwa (2019,p.39) outlined the key components of the social model in the White Paper on the Rights of Persons with Disabilities (2016, p. 21):

- Recognizing that the social environment in which people with disabilities live affects their ability to participate fully, be included, and be accepted in society as a whole,
- Recognizing that disability is a social concept brought about by the interaction of different actual or perceived disabilities with environmental constraints,
- With an emphasis on the abilities of those with disabilities, respect for their variety, and a goal to remove social obstacles that contribute to prejudice,
- Promoting wider structural and attitudinal societal changes
- Encouraging the mainstreaming of people with disabilities, and
- Increased engagement in a transformation process is crucial for improving the quality of life for individuals with disabilities.

Shekwa (2019, p.40) saw that, as opposed to seeing people as individual victims of the tragedy, the social model of disability views them as collective victims of an oppressive and callous society. The researcher added that this model asserts that there are numerous elements, like marginalization, stigma, and exclusion, to consider when determining who is disabled in a certain group. This paradigm encourages persons with disabilities to participate actively in significant issues rather than to be passive recipients and to contribute because doing so will help them get better off in the present (Shekwa, 2019, p.40).

Shekwa (2019,p.40) added that the social model of disability presupposes that for the needs of individuals with disabilities to be satisfied, changes in society must occur; if this does not occur, the society itself must change. People with disabilities require a platform to make decisions about issues that directly affect them personally and their community as a whole.

As a theoretical foundation for attempting to alter societal attitudes and infrastructure to better the lives of children with disabilities, the Social Model of Disability is presented. Since society has abandoned them, they are unable to access the services they require to improve their life. Shekwa (2019,p.41) observed that because of discrimination in society, disabled children are particularly at risk and should be placed in alternative care, but society's institutional framework forbids this. Shekwa (2019,p.41) went on to state that marginalization and discrimination of people with disabilities create an environment that is difficult for prevention and treatment, which is directly related to the role that social service professionals play in offering adequate and successful services to children with disabilities and their families.

The majority of the foundations for disability and caregiving can be seen in this model, which is why the researcher chose it. As a result, the social model of disability was helpful to the researcher in this study in understanding how to think about disability as a characteristic influenced by the context of an individual's life. This model assisted the researcher in realizing that to reduce the barriers facing people with disabilities, intervention is fundamentally required to bring about social change. Ndadzungira (2016,p.5) claims that these interventions can be taken in a way that will enable various groups of caregivers for children with disabilities to demand the removal of obstacles to care, giving them the ability to fight for policy changes in the areas that directly affect them. Thus, the model offers a pertinent theoretical framework for the research because it allowed the researcher to contextualize the care load and offer suggestions for how to address the requirements of carers and children with disabilities.

Methodology

This research study followed a qualitative research approach which, according to Kothari (2004), consists of discovering underlying motives and desires and using in-depth interviews for this purpose. This research approach allowed the researchers to examine and obtain detailed information on the challenges faced by caregivers caring for disabled children. The researchers followed a phenomenological design that allowed the researchers to gain more knowledge about the studied phenomenon by conducting interviews and visiting places and events to understand the meaning that the participants of the study expressed.

Nine female caregivers were specifically selected to participate in this study. For the data collection process, data was collected through semi-structured interviews guided by an open-ended interview guide, and they were analyzed thematically. The semi-structured interviews made it easier to better understand participants' experiences through research and asking follow-up questions. To ensure the quality of the results, attention was paid to credibility, conformity, transferability, and reliability. Credibility was ensured through prolonged engagement and consent of participants, and field notes were taken during each caregiver’s interview for audit purposes to ensure consistency of results. The data has been correctly encoded for reliability.

Findings and Discussion

The table demonstrates that all interviewees served as the primary caregivers for the disabled child.

Table 1. Participants as primary caregivers of children with disabilities

Participants	Age	Marital status	Occupation	Relationship with the child	Child's age	Gender of the child	Child's type of disability
1	38-42	Married	Self-employed	Mother	8	Male	Autism
2	26-31	Single	Employed	Mother	7	Male	Physical disability
3	43-47	Married	Self-employed	Mother	12	Male	Speech impairment
4	48-50	Single	Unemployed	Mother	10	Male	Down syndrome
5	26-31	Single	Employed	Mother	8	Male	Deaf
6	38-42	Single	Employed	Mother	17	Female	Cerebral palsy
7	48-50	Single	Employed	Mother	13	Female	Autism
8	32-37	Married	Employed	Mother	8	Female	Intellectual disability
9	48-50	Single	Self-employed	Mother	17	Male	Angelman syndrome

Of the nine (9) children depicted, three (3) were females, and six (6) were males. In addition, the table indicated that the children whose caregivers were questioned had autism, physical disability, speech impairment, Down syndrome, deafness, cerebral palsy, intellectual disability, and Angelman syndrome. Six (6) of the participants were single, while three (3) were married, and the participants' ages ranged from twenty-six to thirty-one (26-31), and forty-eight to fifty (48-50). The table also reveals that five (5) of the participants were employed, one (1) was unemployed, and three (3) of the participants were self-employed.

The following are themes that emerged after the interviews with the female caregivers of children with disabilities.

Theme 1: The Challenges That Caregivers Face

Examining the livelihoods and difficulties experienced by caregivers of disabled children was the study's initial goal. The absence of the father, financial difficulties, and unemployment because of spending more time on the health of the disabled child were all noted as sub-themes. From the inputs of the significant participants, sub-themes were derived, and new themes were established. The study's findings depicted the following notions as sub-themes.

Sub-theme 1.1: Financial and Employment Challenges

Financial difficulties frequently result from the caregiver's failure to look for work because of their urgent need to care for the child. Participants in the study stated that because they are the biological mothers of children who have disabilities, they are immediately responsible for providing their children with the greatest care possible, which is what they do for their children. Although the unemployed participant claimed to get the R1800.00 child disability allowance, this was insufficient to cover the child's needs. Although participant 4 appreciated the value of the disability grant, she commented that

> *"We receive the child's disability grant to help with his living costs, but because we also rely on the grant to do so, we face the challenge of helping him with daily expenses like paying for clothing,*

> *school supplies, and transportation because the grant also must pay for the family's insurance and food. Even if I receive a job offer, I will not accept it because no one can take care of him without me because his siblings are rarely home. Since I need to purchase him clothes and I cannot afford them while I must pay for his school fees and transportation, I also considered keeping him from going to school for the next month."*

Sub-theme 1.2: Absent Father

Father absenteeism is caused by the fact that fathers of disabled children may opt to leave the family for several reasons. This could be choosing consciously to raise a child, having the erroneous belief that a child with disabilities is a bad omen, or just rejecting the child because of their condition (Matambanadzo, 2021). The child with a disability is not his, according to the biological father. The mother of the child is consequently forced to try to make ends meet on her own, which worsens her financial situation.

Participant 4 further noted that:

> *"The child's father said the child was not his, he insulted me, and it hurts me, even though I told him to go see the doctors for counseling about the child's condition, he refused. Although he has warmed up to the idea of the child being his, I refuse for him to play with the child because he denied him."*

Participant 2 noted that:

> *"The child's father left me with the child when he was one year and 3 months and he never looked back, though I see his relatives around the area. The fact that he left the child without taking responsibility hurts me a lot, but now I do not care, my child is my responsibility and I have him to worry about."*

Matambanadzo (2021) asserts that to guarantee that they are supported with the expenses related to caring for a child with disabilities, main caregivers should be made aware of the potential for appeal.

Theme 2: The Accessibility of Service

The study's findings revealed that while some participants were unhappy with the services they received, particularly healthcare, others were content because they only took their children to check-ups when necessary. When asked about the services offered to the caregivers, almost all of them said they were unaware of the ones that should be made available to them to help them deal with the difficulties of caring for their disabled children.

Sub-theme 2.1: Disability-related Services Accessible to Children (Healthcare)

Hospital visits are common for children with disabilities since they require specialized care and medication. As a result, the responsibility of the caregivers is to make sure that the children get to the medical facilities. One of the functions that the study participants play in the caregiving process was described by them. The participants said that it was their responsibility to take the children to various health facilities so they could have medical examinations.

Participant 2 Noted:

> *"My child does not have a physical disability only, he also has a problem with his eyesight and ears, and the hot weather is affecting him worse. I wish I could receive eyeglasses and a hearing aid to*

> *assist him, but it is difficult to get such things at the hospital because we receive appointments for the child that will take a long time to take place while the child continues to suffer"*

Participant 1 Noted That:

> *"Due to the lack of medical services in our close hospital, I experience quite a challenge when it comes to taking my child to Pretoria for therapy because it cost me a lot. Yes, our government provides us with transportation at the hospital near us, but the transport is not good for my child's condition because having to wait for the transport up until 2 am at the hospital affects my child, he fails to sleep because he only knows that he sleeps on a bed so sleeping on the hospital benches frustrates him a lot."*

Participant 1 Further Noted That

> *"Another problem was the medication that they give him, it made him drowsy and quiet a lot which gave me a challenge in terms of understanding what he needed or want"*

Theme 3: The Support That They get From Their Families and Communities

Belief systems, social structures, and the management of disability knowledge all significantly impact how people view children with disabilities (Matambanadzo, 2021). Participants expressed dissatisfaction with how families and communities treat their disabled children. The emotional connections caregivers make with their children and how positively they engage in interactions with them are more likely to be improved when caregivers receive social assistance.

Sub-theme 3.1: Family-based Stigmas around Disabilities

Matambanadzo (2021) asserts that family support is crucial since it aids the caregiver in accepting their child and locating practical childcare options. The absence of family support may cause the caregiver to reject the child, place the blame on themselves, or wonder how they came to be the parent of a disabled child. This was made obvious in participant 3's perspective when she stated that

> *"I was concerned about why and how I ended up with a disabled child and that I would get jealous if I saw someone playing with a normal child because I couldn't comprehend why my child was disabled."* Caregivers frequently blame themselves for the child's disability because they believe it is their fault.

Participant 1 noted**:**

> *"My family has accepted, and they are supportive of the child's disability. My problem is towards the extended families because they feel pity for me and my child, and I do not like that because I do not see anything wrong with my child......(annoyed)*

Sub-theme 3.2: Communities-base Stigmas around Disability

Children with disabilities may be stigmatized by the community, and this stigma can be attributed to a lack of understanding of the disability. Matambanadzo (2021) pointed out that for the inclusion of children with disabilities to be enforced in schools, it must first be established within the community. Dangale (2019) discovered that the community ignores disabled children and expresses disparaging remarks. The community at large should abstain from stigmatizing children with disabilities and instead work to comprehend their nature and provide supportive services. Additionally, being in line with Ubuntu's embodied constitutional ideals fosters a climate in which the caregiver and the disabled child will not feel abandoned and alone (Matambanadzo, 2021).

Participant 6 stated that:

> *"I do not receive any support from community members or rather people, even when I am facing difficulties on the road with my child......(sad) they just pass by and look at me with disgust"*

Participant 9 noted that:

> *"People do not care about the challenges that I am facing, instead they see me and my child as a joke which also makes them call my child a crazy person." Community members' inconsiderate remarks are offensive to the caregiver as well as to the child. The stigma, verbal abuse, and strange looks can all degrade the caregiver's mental condition, and as a result, the caregiver may experience depression or other mental illnesses (Matambanadzo, 2021).*

Participant 4 stated that:

> *"The fact that my child cannot play with other children it is hurting me because the children treat him badly, and they chase him away. For instance, one day I heard that my child was given faeces to eat and that made me realize that whenever I am not around this is what my child experiences......(sad). I cannot blame the children because they know nothing about my child's disability, it would be better if their parents could educate them about such conditions"*

Theme 4: The Coping Mechanisms Employed by Caregivers

Studies have highlighted the difficulties of being a caregiver, financial difficulties, and stigmatization (Matambanadzo, 2021). Prayer and self-counselling were mentioned by study participants as cornerstones for coping with caregiving despite their reporting of sentiments of stigma and pain in the face of community perceptions.

Sub-theme 4.1: Acceptance

The emotional health of the caregiver is affected by accepting the role of the caregiver. All participants stated that it was extremely difficult for them to accept the fact that their children were born with a disability, yet they all reported having varied experiences with acceptance. Here are some of the solutions:

Participant 2 noted that:

> *"I won't lie I was hurting when I received the news that my child has a disability......as you see me, I also suffer from the same disability and I had a bad upbringing, people were calling me names and I would get angry and beat them, and that always landed me to suspension, so thinking about my child having a disability brought back the fears that he will be called with mean names and discriminated by people. But now I have accepted his disability and I try to teach him what he might encounter from people outside"*

Participant 5 noted that:

> *"When I learned about my child's disability, I was in denial at first and hurt, because I gave birth to him as a healthy baby, but as time went by, he started having a hearing problem which led to him being deaf. When I realized that he has a disability I started being overprotective of him, secluding him from people, but now I have learned to accept his disability through the help of talking with other caregivers experiencing such challenges."*

Participant 8 noted that:

> *"I felt sad when I received the news that my child has an intellectual disability because, from the look of my eyes, my child was just like any other child who can do anything, meanwhile she could not do anything with the pace of other children. It hurts......I won't lie, because I always asked myself what went wrong with my child, I had questions asking myself how she got to have this disability, or what I did wrong, sadly I never received any answer, so to accept her disability I had to counsel myself and that has helped me a lot since now I understand my child's disability a lot better than before"*

Participant 4 mentioned that:

> *"I felt hurt the day I received the news that my child has a disability, and I cried I will not lie. What made me accept the child's disability was that Counselled myself at the hospital telling myself that I am not the first one to give birth to a disabled child, so today God tested me with this child to see how I will take care of the child and that made me develop so much love for him."*

Sub-theme 4.2: Strong Support from Families

Family support offers stability to the family, according to Dangale (2019), therefore, family members need to support one another during trying times. After the birth of challenged children, a family comes together and cooperates, with everyone playing a part (Dangale, 2019). According to the participants, the support network was crucial in assisting them in adjusting to their child's diagnosis.

Participant 2 noted that:

> *"I am very happy and proud of my family for the support that they give me and my child, with their help I manage to accept my disability as well as my child's disability. My mother helps me by taking him to doctor's appointments and my child is very fond of my father."*

Participant 3 noted that:

> *"My family is supportive in an amazing way, they helped me and my husband in terms of seeking help for the child's disability, both medical and traditional."*

Participant 5 stated that:

> *"My family is supportive towards my child, when I am at work; I know that they are looking after him."*

Sub-theme 4.3: Support from Organizations

Some of the participants reported that they got assistance to understand their children's disabilities and improve their children's capabilities from organizations. Below are some of their responses:

Participant 5 stated that:

> *"I received assistance to learn sign languages from Hope Organization because another challenge I had was failing to communicate with my child because I couldn't understand what he wanted, so he would grab my arm and take me towards what he wanted"*

This was corroborated by Participant 7 who stated that:

> *"The educational toys from Dasha Foundation help us a lot, especially my child to utilize his strength and express herself towards drawings she also likes music a lot, the high sound of music doesn't affect her, instead it makes her happy and she would dance in her world."*

Theme 5: The Support That Social Workers Can Provide

The participants were unaware of the social workers' services. Participants said that they had never considered asking for support from social workers to lessen their caregiving concerns, but they expressed a willingness for social workers to assist them. This suggested that they had not requested help from social workers regarding their circumstances. The following sub-themes cover these desires.

Sub-theme 5.1: Support Groups

Most participants said they had never been a part of a support group but would like one to be established so they could discuss their struggles with others who were in a similar situation and so learn to understand and deal with such struggles. The importance of support groups should not be understated, according to Matambanadzo (2021), as they inspire caregivers to do more for their children.

Participant 7 stated that:

> *"I am not sure if there are existing support groups that help caregivers like us in addressing our challenges, but if there is none, I wish one can be formed so that I can be able to vent out my frustrations and get help on how to overcome them"*

Participant 8 notes that

> *"I would like to receive support and counselling in support groups, I think that would help me a lot, knowing that I am not alone in this situation and getting help on how I can lessen the burden that I am having."*

Participant 9 stated that

> *"I wish social workers would teach us about parenting techniques when dealing with disabled children because we lack discipline, spoil our children, and give them too much attention, which weakens them and prevents them from achieving their goals."*

Sub-theme 5.2: Awareness Campaign

Some of the participants reported that they would like for awareness campaigns to be conducted in their communities, and schools so that people can learn about disability and reduce the stigmas towards disabled persons.

Participant 4 stated that

> *"I think social workers can help us by addressing such issues related to disabled children at schools and tell children how to treat other children who are disabled or rather when the school holds parent meetings or community meetings social workers should be invited so that they can address such situation."*

Participant 6 stated that:

> *"Social workers should educate people about disabilities, a word out there needs to be spread out for the whole world to hear, just like how we were educated about the coronavirus. People need knowledge about disabilities, for instance, charts around communities or rather a day in every month need to be created whereby people will be educated about a certain disability, so that the stereotypes towards disabled persons can be lessened".*

In a nutshell, the participants believe there is a need for awareness to capacitate people and society at large about disabilities.

Conclusion

Overall, this study demonstrated that social, physical, psychological, and financial challenges faced by caregivers of children with disabilities result from a lack of family support, persistent stigma, and a lack of government services and resources to assist them Caregiver's deal with the burdens they have while caring for their disabled children. A limitation is the lack of fathers who were not selected for the study. Fathers may not have had the same perceptions and experiences as mothers. The study results might have been more comprehensive if a sample from a larger population consisting of both fathers and mothers had been used. The results show that little is known about disability as disabled people and their caregivers are stigmatized in our communities and some caregivers reported a lack of support from community and family members.

Therefore, the following recommendations are put forward in this article:

i. There is a need to educate families and communities about disabilities to dispel the stigma of children with disabilities and their caregivers.
ii. Important factors such as support services, including health care, support groups, and awareness campaigns must be considered to encourage better care for caregivers.
iii. There should be policy discussions and formulations around the social assistance afforded for caregivers of people with disabilities

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Informed Consent Statement: The researchers took the following into account to ensure ethicality: University of Limpopo research ethics policies and exercising honesty in terms of acknowledging 'all' sources used in this study, aided by the list of references and avoiding plagiarism.

Data Availability Statement: The data presented in this study is available on request from the corresponding author.

Conflicts of Interest: The authors declare no conflict of interest

Ethical Approval

Ethical clearance was obtained from the University of Limpopo Turfloop Research and Ethics Committee (TREC) with project number TREC/117/2022:UG; Permission to conduct the research was granted by a Stimulation Center one Foundation for Children with Disabilities. The aim of this study as well as the voluntariness of the participants' participation were clearly explained to the participants and after they verbally agreed to participate in the study, they also signed informed consent forms. The confidentiality of the study was ensured by keeping the names and identities of the participant's secret.

References

Bahry, N.S., Mat, A., Kori., N.L., Ali, A.M., Munir, Z.A. & Salleh, M.Z.M. (2019). Challenges faced by Malaysian Parents in Caregiving of a Child with Disabilities. *Global Journal of Business and Social Science Review*. 7(2), 118-124.

Bingham, J.R. (2017). *Experiences of caregivers of children with disabilities in semi-rural areas near Cape Town, South Africa*. (Masters Dissertation). Stellenbosch University.

Dangale. T.M. (2019). *Challenges of mothers caring for cerebral palsy children at Thulamela Local Municipality, in the Vhembe district, South Africa*. (Masters Dissertation). University of Venda.

Diseko, T. N. (2017). *Experiences of caregivers caring for children with Cerebral Palsy in Mahalapye, Botswana.* (Masters Mini dissertation). University of Pretoria.

Elnabawy, G., & Nabawy, A. (2012). Coping Strategies of Mothers having children with special needs. *Journal of Biology, Agriculture, and Healthcare*. 2(8), 77-84.

Francis, L., & Silvers, A. (2016). Perspective on the Meaning of "Disability". *AMA Journal of Ethics*. 18(10), 1025-1033.

Ghazawy, E. R., Mohammed, E. S., Mahfouz, E.M., & Abdulrahim, M.G. (2020). Determinants of caregiver burden of a person with disabilities in a rural district in Egypt. *BMC Public Health*. 20-1156.

Kothari, C.R. (2004). *Research Methodology: Methods and Techniques* (2nd ed). New Age International Publisher, New Delhi.

Makura, H. (2018). *Factors influencing the burden of caregivers of children with cerebral palsy in Namibia. Namibia.* (Masters Dissertation). University of South Africa.

Maphosa, N., & Chiwanza, V. (2021). Caregiver experiences and the perceived role of social workers in caring for people with disabilities in South Africa. *African Journal of Social Work*. 11(3), 155-163.

Matambanadzo, P. (2021). *Perceptions, experiences, and coping strategies of families caring for children with special needs within Western Cape communities*. (Master's Thesis). University of the Western Cape.

Mazibuko, N. (2019). *Experiences of caregivers for children diagnosed with an autism spectrum disorder in the Ehlanzeni District, Mpumalanga Province*. (Maters Mini dissertation). University of Venda.

Muller-kluits, N., & Slabbert, I. (2018). Caregiver burden as depicted by family caregivers of persons with physical disabilities. *Journal of social work*. 54(4), 493-50.

Muller-kluits, N., & Slabbert, I. (2020). The role of social workers in addressing caregiver burden in families of persons with disabilities. *Journal of Social Work*. 45(5), 144.

Ndadzungira, A. (2016). *The experiences of primary caregivers for children with physical disabilities in the hardap region of Namibia*. (Masters Dissertation). University of the Waters Rand.

Ndirangu, E., & Midigo, R. (2018). Caregiving for children living with disability in the informal settlements in Kenya: Exploring the Social experience of the Urban Poor Living in Mukuru Slums in Nairobi. *Open Access Journal of Nursing*. 1 (1), 33-39.

Nowak, H.I. (2017). *Parents of children with Developmental Disabilities and their experiences of formal support*. (Doctoral Dissertation). University of Gothenburg.

Shekwa, P.P. (2019). *Experiences of social service professionals in the iLembe Municipality in rendering services to children with disabilities*. (Masters Dissertation). University of Cape Town.

Taderera, C., & Hall, H. (2017). Challenges faced by parents of children with learning disabilities in Opuwo, Namibia. *African Journal of Disability*, 6(0),1-10.

Tigere, B., & Makhubele, J.C. (2019). The experiences of parents of children living with disabilities at Lehlaba Protective Workshop in Sekhukhune District of Limpopo province. *African Journal of Disability*. 8(0), 1-9.

Zahaika, D., Daraweesh, D., Shqerat, S., Arameen, D., & Halaweh, H. (2021). Challenges facing family caregivers of children with disabilities during Covid- 19 Pandemic in Palestine. *Journal of Primary Care & Community Health*. 12, 1-8.

Zulfa, R., & Allenedikania, A. (2020). Mothers' experience in taking care of children with special needs: A literature review. *Indonesian Journal of Disability Studies*. 7(1), 8-18.

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