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PARENTING CHILDREN WITH DISABILITIES IN RURAL SOUTH AFRICA

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Abstract

Parenting Children with Disabilities (CWD) is a challenge. This study explored experiences of parenting CWD in rural South Africa. A qualitative approach using a phenomenological design was used with four participants. Semi-structured personal interviews were used to get the experiences of parenting CWD. Data were analysed thematically to gain experiences of parenting CWD experiences. The results show that parenting CWD was challenging and caused stress to parents and the rest of society. Five themes emerged from the data analysis: peer support groups; exhaustion; public transport systems within communities; parental distress and embarrassment; stigma, and discrimination. Peer support groups helped parents of CWD to cope with parenting challenges. Parenting roles for CWD rested more on females than males, possibly due to the constant care CWD need. CWD was a burden because it stressed the mothers, parents, and relatives. Parents with disabled children experienced stigmatisation and isolation from the community.

Keywords: Disability, Parenting, Rural, Burden, Experiences

1 INTRODUCTION AND BACKGROUND

The International Classification of Functioning (ICF) show that disability is difficult to explain in different social contexts (United Nations – UN, 2006). Research in the United States reported that carers of disabled persons experience high mood disorders and clinical psychological issues during the pandemic (Maunder & McNicholas, 2021; Rakap et al., 2022). Literature from Canada reflects that chronic emotional stress increases marital disruption and family dysfunction in families of CWD (McConnell & Savage, 2015; Mbatha & Mokwena, 2023). A few studies show that disabled children and carers experience emotional stress (Muller-Kluits, 2020; Fu et al., 2023). Rogers et al. (2021) revealed that carers of CWD reported negative experiences and great emotions. Disability is perceived as a myth, shameful, and a disgrace (Setume, 2016). For example, Zimbabwe shows that disability is viewed as a supernatural force (2006; Mutepfa et al., 2007). Furthermore, Tigere and Makhubele (2019) assert that parents with CWD are deprived of some social services in Zimbabwe.

Kyeremateng et al. (2019) in Ghana contend that parents of CWD wanted to understand disability diagnosis from health professionals but did not get satisfactory answers. Research across the globe shows that parents receive insufficient healthcare services (Kyeremateng et al., 2019). Thomas (2021) shows that parenting children with disability make parents strong and resilient in managing the situation. Studies in the United Kingdom (UK) show that parenting CWD weakens parents' morale (Galpin et al., 2018), and Blake (2021) suggests that debriefing boosts parents' morale. Tigere and Makhubele (2019) conducted a study that interviewed carers of CWD who experienced hardships due to inadequate primary healthcare. In Giyani, South Africa, Chauke et al. (2021) show that carers of disabled children experience poor services.

Similarly, Duma et al. (2021) indicate that the care needs of CWD in rural South Africa vary depending on contextual and personal factors. These varying views and myths regarding parenting CWD suggest a knowledge gap regarding experiences of parenting CWD in rural South Africa. Therefore, this study explored experiences of

parenting CWD in rural South Africa, which was guided by one question: What are the experiences of parenting children with disabilities in rural South Africa?

2 THEORETICAL FRAMEWORK

This study used the sociological theory framework of Ferfolja et al. (2018) to interpret experiences of parenting CWD. The theory describes the understanding of sociological theory for educational practices. The field of study concerns a particular location in a community that affects individual human beings (Ferfolja et al., 2018). It includes appropriate actions such as social support from the community. Hence, the community must know firsthand CWD, which is uncommon. To date, a knowledge gap exists regarding experiences of parenting CDW. Therefore, the researchers explored the experiences of parenting CWD.

3 METHODOLOGY

The study used a qualitative approach (Creswell & Creswell, 2018). to gather in-depth information on experiences of parenting CWD. The researcher used a phenomenological design to profile the lived experiences (Creswell & Creswell, 2018) regarding parenting children with disabilities. The design was chosen because it aims at getting detailed issues, which many of us know little about (Creswell & Creswell, 2018). Two experts checked researcher-designed interview questions for face and content validity before piloting them. The valid questions were piloted to four learners, and the two researchers compared notes. There was an agreement of 90%, suggesting that those questions were suitable for the study. Informants comprised four female mothers of CWD purposively selected because they parented children with physical disabilities. Each participant had a physically disabled child. Four Participants aged 40 to 50 from Vhembe District were coded as A-D for confidentiality (Table 1).

TABLE 1: Biographical profile of participants and their children.

Participant	Gender	Marital status	Occupation	Age of parent	Parent Relationship with child	Description of the child's disability
A	Female	Single	Unemployed	41	Biological	Paralysed right hand and right leg.
B	Female	Single	Unemployed	39	Biological	Paralysed hand and legs (using a wheelchair)
C	Female	Single	Unemployed	52	Biological	Using wheelchair and paralysed hands and legs
D	Female	Single	Unemployed	49	Biological	Cerebral palsy (CP) paralysed left hand and left leg.

Source: Sadiki 2015.

These parents consented to participate in the study and were briefed about the study and its implications and that they had a choice to continue. The Ethics Committee of the University of Cape Town granted permission (Clearance No. HREC/REF; 359/2004). Data from participants were collected using semi-structured interviews, which lasted 50-60 minutes and were audio-recorded. Data analysis started with transcribing and translating from Tshivenda to English and back-translating to English to ascertain consistency. Transcripts were read several times, line by line, to get codes (Rubin & Babbie, 2011). Similar codes were grouped to form subthemes later used as main themes.

4 RESULTS

Results show that parenting CWD in rural South Africa is challenging. The results show that females cared more for CWD than males. Parenting CWD was burdensome and caused stress due to stigmatization and isolation from the community. Five themes from the interviews emerged: 1) peer support groups, 2) Exhaustion, 3) public transport challenges, (4) parental anger and embarrassment (5) stigma and discrimination. The themes will be discussed and illustrated with verbatim quotations from the study participants.

4.1. Peer support groups

The study shows that all participants agreed that support groups assist in dealing with the challenges of parenting CWD. The formation of peer support groups played an important role. The extract below shows evidence of this claim:

I could not go out and seek for employment because of my child with disabilities. As support group we intend to start agricultural backyard gardening which will make a difference in our lives and community, because care dependency grant is not enough for our family (Participant A).

My life was miserable before I was introduced to the support group. I thought I was alone experiencing the difficulties of parenting a disabled child. Yes! I share the same experience with other carers of children with disabilities (Participant D).

The support group was valuable because I gained lots of information about parenting a disabled child, which I can share with other parents of children with disabilities. (Participant C).

I have accepted my child's condition because I realised that I was not alone, and other parents inspired me to cope with the situation. I was also introduced to a care dependency grant by one of the parents from the support group. (Participant B).

4.2. Exhaustion

Parenting a disabled child is exhausting. The parents reported that parenting children with disabilities was a burden because of their CWD, who cannot do anything independently. For instance, participants made the following observations.

I have to do everything for her; she sleeps. It is a burden because you are unable to socialize with others. She is a grown-up, and her age group are in grade nine. I have to bathe her every day, although her body is bigger than mine. You can see the challenge here. (Participant D).

This child cannot sit, speak, walk, bathe or feed himself. I wish I could have a helper to help me with this burden, hey! (Participant B).

I cannot even get a job like other women. Things are very expensive these days, and I must depend on the care dependency grant, which is not making any difference to our lives....the responsibility is too much (Tears rolling from her eyes). (Participant A).

There is no one willing to take care of my child. My boyfriend moved on with his life after I told him that the child is disabled, so I am the only one to carry all the burden on my own. She is big. I have to carry this child on my back, move her from the wheelchair to her bed. My back is aching. (Participant C).

4.3. Public transport challenges

The results show that it was difficult for CWD to move around using public transport as they experienced negative attitudes from passengers and taxi drivers. The extracts below show evidence of this claim.

I stopped taking my child to the hospital for physiotherapy and occupational therapy sessions because of inaccessible public transport and negative attitudes from passengers and taxi drivers. The last time I went to the hospital, I was charged money to transport the wheelchair because it occupied space for other passengers. (Participant A).

My child is denied the right to use public transport like other children.... 'Why is this not for free I pay like other passengers. The Government gives us a Care dependency grant for food, not for transport. What is the use of spending the care dependency grant on door-to-door special transport and yet I need to buy food? (Participant D).

Let me tell you this scenario.... dear, "Sometimes I used to hire special transport when I had to go to the hospital every time using a care dependency grant for my child, but now I have stopped since I have to prioritise basic needs". I cannot afford transport is expensive for me (Participant C).

Please, please! Talk to this Government (referring to the researcher) to arrange rehabilitation teams from the hospitals to do home visits to unemployed parents of CWD because not all of us can afford transport money to the hospital! Home visits can work. (Participant B).

4.4 Parental distress and embarrassment

The study shows that participants were angry, frustrated, embarrassed, worried, disappointed and could hardly believe their children were disabled. For instance, some participants remarked:

I always feel pain when I see my son's age group playing soccer and running around {tears rolling down her cheeks}. I feel like taking this child back to my stomach. I always avoid associating myself with other mothers who have children of the age group like my son because they keep on asking me funny questions. Another woman at church asked me the other day, "Why your child can not walk at his age? I always see you carrying him on your back". Can you believe it? I was very upset; I stopped attending church that day because I felt embarrassed (Participant B).

I did not know I would give birth to this kind of child. I had so many plans for this child but now.... All my plans vanished [Saying this with a soft voice]. I am disappointed, sister [referring to the researcher] (Participant A).

I feel embarrassed about this situation. I talk about my child.... did not choose to have this child with a disability. It was not my wish and did not expect to give birth to a child eish.. disability. Eish.... this child is frustrating my life because I am a laughingstock to my family and friends, a frustrating moment I never thought of. I will have this kind of a child (Participant D).

Everywhere I go, people look at me. I feel embarrassed myself since I did not expect this. I feel small (Participant C).

4.5 Stigma and discrimination/ Social isolation and stigma

The results show that CWD parents felt socially isolated and stigmatised due to the treatment they got from the community. The parents of CWD experienced stigma, which was caused by the community. For instance, some participants made the following observations:

My child is called names by people living next door to my house because of his disability (Participant A).

I am isolated by my community (Participant B).

My community discriminates against me because of my child's disability (Participant D).

I do not attend family gatherings because I will have to take my child with me, and some family members refuse their children to interact with my child, so I decided to stop attending family gatherings (Participant C).

5 DISCUSSION

The study explored experiences of parenting CWD in rural South Africa. The results show that caring for children with disabilities rested more on females than on males. Parenting was a burden and stressful because of the stigmatisation and isolation from the community. Five themes emerged from the data: 1) peer support groups, 2) exhaustion, 3) public transport challenges, 4) parental distress and embarrassment 5) stigma, discrimination, and isolation. These themes are discussed below.

5.1 Peer support group

The results from the study highlight that peer support groups assisted parents in functioning better with their children's disabilities. It means that we are social beings who depend on one another, and stories from friends

make us feel better. Talking to each other and working together as a team is vital, as the adage states, “United we stand and divided we fall” (Ibabor, 2012, p. 83). Therefore, working as a team helped parents with CWD to manage challenging situations. This observation aligns with the sociological theory framework (Ferfolja et al., 2018), where individual actions support someone to overcome societal challenges.

Furthermore, this agrees with Tigere and Makhubele (2019) that coming together to care for CWD relieves the unpleasant responsibility of raising a child. For example, Participant A got assistance from a support group *to start agricultural backyard gardening, while Participant D got a sense of acceptance and felt empowered to appreciate the challenges of parenting a disabled child*. All parents finally found empathy; others felt the same difficulties parenting a disabled child. Sharing experiences made it easier and encouraged carers to find solutions to the challenges of parenting CWD. It suggests that parenting CWD is complex, where the relationship between parents and children should be considered a contextual process. No wonder the model developed by Billen et al. (2022) includes parents’ background, characteristics, formal and informal social support, unease, and anxiety.

5.2. Exhaustion

The results show that parenting CWD is a burden and causes exhaustion. It means family members have an important role in supporting parents of CWD to participate in society like any other community member. This observation concurs with Rogers et al. (2021) that getting support from family members or peers comforted CWD. Furthermore, this agrees with Chen and Bonanno (2020), who found that families are essential for adjustment. Also, this observation aligns with the sociological theory framework (Ferfolja et al., 2018) that helping someone with the appropriate social support makes a difference. Participants B and D showed negative sentiments about taking huge responsibility for doing everything for their children and presented emotions of not getting enough support from their families.

Conversely, Participant A was positive that if she can get a helper to care for a child, she can get a job. From these statements, support is necessary for those parenting disabled children. For example, the results show that participants C and D were empowered with the information they received from other parents of CWD. It implies that parental support is very important to parents of CWD. According to (Opoku et al., 2020), few emotional and material resources are provided to parents with CWD. Support from the welfare community also enhances the dignity of parents of CWD. Not surprisingly, participants C and D reported the primary reasons for coping with CWD and sharing knowledge of parenting CWD and the welfare community support. These structures augment the quality of life in personal development and aspirations (Ali et al., 2021). In addition, parents increased their skills, which positively affected the lives of children with disabilities. Thus, support structures encourage parents of CWD (Naudé & de Beer, 2022).

Organised structures of CWD represent children. However, parents of CWD had a moment to share the social identity of common concerns in the support group settings. The support structures state of related human beings in society is important for positive change (Ferfolja et al., 2018). Through support structures, carers recognise the difficulties in parenting children with disabilities. Support groups were an opportunity to learn from one another to overcome parenting CWD challenges (Billen et al., 2022). Thus, support groups minimised the feelings of guilt and anxiety. CWD have the right to use public transport in their community equally with others. The study should have included the drivers of public transport and passengers. It suggests that persons with disabilities are still excluded from our community because they cannot have separate transport. The lack of accessible and affordable public transport creates exclusion and challenges for persons with disabilities to access health facilities.

Muller-Kluits (2020) highlights that parenting CWD for an ongoing period causes emotional depression. All parents confirmed that parenting CWD causes a lot of work and worries. Some parents shared the experience of taking responsibility as single parents. Participant C showed difficulty in parenting CWD without support from the spouse. Mothers of CWD are left behind with spouses when they discover a child's disability (Duma et al., 2021). Some parents indicated that when they can get work, they ask another family to care for the child for a short period. Parenting CWD causes physical and mental stress (Musuka, 2022; Fu et al., 2023). The findings align with the view that parenting CWD affects the mental and emotional state of the individual, social interactions, and financial strain (Duns, 2022). According to Brydges and Mkandawire (2020), women are responsible for raising children with disabilities. It shows gender imbalance because any child with a disability belongs to parents (father-male and mother-female).

5.3 Public transport challenges

The results from the study highlight that public transport is expensive and not affordable. It is a challenge to take their children to the hospital. Hence, transport to CWD was often limited by unaffordable transport. Access to public conveyors is a basic need (Park & Chowdhury, 2018). Therefore, social support from the community with

public transport drivers and passengers is significant to ensure that CWD access healthcare facilities like other community members. Participants A, B, C, and D showed negative attitudes towards using public transport when they had to go to healthcare facilities. This observation aligns with the sociological theory framework (Ferfolja et al., 2018) that community public transport, which is unaffordable and inaccessible, affects individual human beings. Furthermore, Bennett et al. (2019) assert that the drivers were unwilling and hesitant to assist persons with disabilities, particularly those using wheelchairs.

Some participants experience negative behaviour from other commuters when travelling using public transport. Parents expressed exclusion of CWD from accessing public transport due to the design of transport, which is not user-friendly. Hence, participants C and D tried to hire special transport. Khan et al. (2020) reported financial problems among parents of CWD as a reason for non-attendance of therapy in Orange Farm, South Africa. In Muller-Kluits (2020), parents of CWD require public transport to move from one point to another.

5.4. Parental distress and embarrassment

The results show that Participants A and D indicated embarrassment to themselves and from family and friends. Kulasinghe et al. (2021) reported that parenting CWD creates nervousness, anxiety, and displeasure (Lasco et al., 2022). This study highlights that parenting CWD affects relatives and society. The study revealed that when carers realised their children were not developing like other children resulted in distress. This finding is similar to Nakra (2018), who contends that it is difficult to endure denial because they did not expect CWD. Participant C' stated that her child was not allowed to interact with normal children, and this has been reported that CWD are not easily integrated into society (Polivara et al., 2017).

The results show that Participant D was frustrated and worried about the future of her child with disabilities. Reaction from some participants was Anger, embarrassment, and a sense of losing an imagined or expected child. Their reactions are not surprising because (Rensfeldt Flink et al., 2022) reported that parents did not expect to parent CWD. Also, as Sivabalan et al. (2022) contend, that could be victimisation, which is unfair. Locatelli et al. (2022) show that CWD cause anxiety about what will happen tomorrow concerning occupation and their financial implications. The denial was to defend their children from discrimination (Verdugo-Alonso et al., 2022). These denying actions prevent carers from dealing effectively with their children with disabilities (Gumede et al., 2022). Despite the condition of CWD, carers are indirectly afflicted by the child's condition (Sadiki & Kibirige, 2020). For example, participants A and D indicated they did not plan to have a CWD.

5.5. Stigma, discrimination and social isolation

The results show that Participants A and D carers and parents experienced mental and emotional distress from the neighbourhoods, relatives, and the community. These results suggest that parenting CWD creates isolation from parents with normal children. It is no wonder parenting such children creates social stigmatisation and discrimination (Baden et al., 2022), negative perception from society (Antunes et al., 2022), and there was feeling that CWD were not welcome in society (Irawati, 2021). Also, The outlook of CWD carers experience shame at a societal level. All these undermine the rights of people with disabilities (Celik, 2021). Also, this practice is contrary to the concept of UBUNTU, which advocates for human understanding and acting in favour of everyone in the community (Shutte, 2001). Nevertheless, how all the parents developed resilience to cope with their situation is unknown and requires further study.

6 Concluding remarks

This study shows that family members and the community stigmatised carers of CWD by discriminating against their children. There were negative attitudes from relatives and the community. Parents with CWD comforted each other as peers. This study established that females took the greatest time caring for disabled children compared to their male counterparts. Public transport was a challenge due to discrimination and stigmatisation; therefore, it was not inclusive of everyone. Generally, parenting children with disabilities was a burden. Finally, the community overlooked carers and parents of disabled children, which gave them mental and emotional stress.

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