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Mothering Children with Neurological Disability: Focus on Vhembe Rural Community South African

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Abstract

Mothering a child with a disability is by no means a small challenge, especially for mothers as often they tend to take a greater responsibility for the child. This article mainly aims to provide an understanding challenge encountered by mothers when mothering their children with neurological disability in a rural South African setting. The study used a phenomenological research design. Authors of this article purposefully recruited eight mothers of children with neurological disability between the ages of 39 and 55 in a rural South African Limpopo setting. Interpretive data analysis method was employed to provide valuable data on encountered by mothers of children with neurological disability. Data were collected using semi-structured interviews. Semi-structured face-to-face interviews were conducted, and the data results were thematically analysed on mothering children with neurological disabilities. The results show conform to grassroots realities. The findings revealed the following three themes and two sub-themes emerged: (1) health services (sub-themes: health services as an important aspect to mothers of children with ND; lack of adequate knowledge about disability and resources) (2) religious beliefs; and (3) the mother's reaction to neurological disability. Additionally, results have revealed mothering a child with a neurological disability triggered several changes in family dynamics. This study contributes to the experiences of individuals' understanding of the challenges of mothering children with neurological disabilities in a rural South African setting.

Keywords: *Mothering, children, disability, neurological, rural*

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1.Introduction

South Africa has a population of 51,8 million people of which 7,5% comprise children over the age of five with a disability, according to the 2011 census data (Statistics South Africa 2014). This statistic on the national prevalence of disability should be interpreted with caution since psychosocial and neurological disabilities are not accounted for in the census (Statistics South Africa 2014). Disability is caused by the way society is organized, rather than by a person's disability or difference. The social model of disability if adopted, will enable society to address the systemic barriers, derogatory attitudes, structures of society and social exclusion (Lee 2022). Disability studies and significant disability studies view that disability is erected as a social issue that must be attended by taking away the obstacles which contribution that persons with disabilities experience in the earth (Brady et al 2023). The social model of disability considers that disability is a within society constructed challenge (Constantino et al 2022). This model allows us to realise the restricting impacts of structural, social and attitudinal obstacles on persons with disabilities existences as isolated from the isolated encounters, for example, physical or sensory impairments (Brady et al 2023).

A neurological disability (ND) is any condition that results in brain injury to the intellect that the individual is unable to execute other responsibilities (Brandt, Takeuchi & Kamata 2022). ND is an important cause of impairment and death (Mahmoud, Mansour, Roshdy & Srour 2022). Mothering children with neurological disability present a myriad of difficulties for parents, the household and caregivers (Huang, Kellett & St John 2010). Motherhood represents one of the most important stages in women's lives, which is filled with positive and fulfilling experiences (Deave et al 2008; Umberson et al 2010). While the role of mothering is central to any discussion of child rearing, the vicissitudes of mothering are arguably amplified when the child is disabled (Watermeyer & McKenzie 2014). According to the observations by Okwan et al (2023), the burdens of mothering a child with ND in Non-Western countries were worse due to the absence of appropriate medical records and administration. This

study investigated the lived experiences of mothering a child with ND in a rural context. Pelentsov, Laws and Esterman (2015) highlight the fact that those mothering children with ND tend to experience distress. Mothers frequently reported that when the results of the diagnosis of their children with ND were shared with them, they were given little hope and information on how to parent their children with ND (Bedell et al 2013). Moreover, obtaining a diagnosis may take a long time (Abdel-Basset et al 2020), during which the child's emotional and behavioural problems could escalate to enormous proportions (Crane, Sumner & Hill 2017). Parents, being the primary caregivers, are expected to exert the original and, perhaps, the most significant influence on the development of the child with ND (Hayden & Hastings, 2022). Children with ND are not continuously and adequately supported by their parents (who are their main support system) and have an increased risk of developing anxiety, depression, decreased self-esteem, decreased physical fitness and childhood obesity (Logan & Ward-Ritacco 2022; Kang & Kwack 2020).

By mothering a child with ND, the experience of motherhood is affected and the expectations about the child and the future may have to be revised (Tigere & Makhubele 2019). The birth of a child with ND to able-bodied parents is often met with disappointment or even anger, due to the loss of the idealised child. Moreover, the birth of a disabled child often leads to a period of grief (Disasa 2022). A study conducted by Choque et al (2022) revealed that the most frequently experienced emotions of parents when they learned that they had a child with a disability, include, and are not limited to, shock, helplessness, hopelessness, and utter disappointment. In a review of the literature, it became apparent that more mothers were the primary caretakers of their children with disabilities than fathers (Kehinde et al 2022). Having a child with a disability has a negative effect on parental functions, and the daily life of mothering is affected at a higher rate than that of fathers (Wang et al 2023). Studies further revealed that mothers are more affected emotionally by their children's condition than fathers (Wang et al 2020). The is dearth of knowledge or information on how rural mothers should mother their children with

neurological disabilities. Through this article, authors are attempting to plug this information or knowledge gap. It further raises awareness and advocates for services of this disability group.

2.The revision of the speciality literature

2.1 Mothering practices in the rural context

Other studies on mothering children with ND in areas far from large towns or cities asserted that parents had to identify a disease or condition and deal with the threat, while some parents abandon their children (Faugli et al 2021; Gona, Newton, Hartley & Bunning, 2018; Masulani-Mwale et al 2016; Bunning et al 2017; Perrotta 2019). It is estimated that every seven to eight families have a child or adult member with a disability (WHO 2022; Zhong, Wang & Nicholas 2020). A study by Sadiki and Kibirige (2020) found that mothers of children with ND go to the extent of pursuing the assistance of witch doctors and religious worship to heal neurological impairment. Previous studies established that having a child with ND, to some mothers, means the shuttering of parents' dreams of their ideal child (Meiri & Raz 2021). Generally, families experience embarrassment when other people show that they are concerned about the well-being of their children with a disability (Lee et al 2022). Mostly, parents will not easily accept that their children are disabled, even if they receive information and help from professionals (Oti-Boadi et al 2022). Authors of this study concur with Gona et al (2011) and Bunning et al (2017) who suggest that it is important to develop programmes related to children with neurological impairment to highlight the challenges that mothers of children with ND encounter. The study under discussion aims to highlight the mothering of children with ND in a rural setting in Limpopo Province, South Africa.

Studies have reported that parents need to work with health practitioners to support their children's acquisition of the same functional abilities as typically developing children (Pedro, Goldschmidt & Daniels 2019). The rehabilitation team provide support to people with neurological disabilities (Muller-Kluits &

Slabbert 2020). Internet, support groups and healthcare professionals could be more helpful than only a single source (Shechter et al 2020). Furthermore, support groups are instrumental in the provision of a valuable form of emotional and informational support (Benson et al 2020). The support that a family could receive from a professional could facilitate the family's adjustment to a child with a disability to cope with the stress and difficulties the family experiences (Franck & O'Brien 2019).

3. Research methodology

3.1 Research design and data collection

The authors of this article employed a phenomenological research design method to detail real-life experiences of mothering neurologically disabled children. The chosen research design enables one to gain insight into the informants' life or lived experiences (Creswell 2009; McMillan & Schumacher 2010). Phenomenological research design with its interpretive data analysis tool enables researchers to interpret human experience. It requires the researchers to recognise themselves as co-constructors of knowledge, which will be in part shaped by their identities, perspectives and personal histories (Denzin & Lincoln 2011). Phenomenological research that uses interviews is useful in developing a deep understanding of a phenomenon within its unique set of circumstances (Silverman 2013).

3.2 Participants and setting

This study comprised eight (females = 8) participants who were purposively selected because they are mothering children with ND. Their ages ranged from 39 to 55 years. All these participants lived in a rural context and they speak their home language. The authors-maintained confidentiality to safeguard the participants' privacy and identity by using pseudonyms to ensure their anonymity. To adhere to the principle of anonymity and confidentiality, the participants' real names had been coded and alphabetical references were assigned.

TABLE 1: Biographical profile of participants (n = 8)

Participant	Gender	Marital status	Occupation	Relationship with child	Description of the child's disability
A	Female	Single	Unemployed	Biological parent	Paralysed right hand and leg (able to walk without using any assistive devices)
B	Female	Single	Unemployed	Biological parent	Paralysed hands and legs (using a wheelchair)
C	Female	Single	Unemployed	Biological parent	Using wheelchair
D	Female	Single	Unemployed	Biological parent	Cerebral palsy (CP) paralysed left hand and leg
E	Female	Single	Unemployed	Biological parent	CP paralysed right hand and right leg
F	Female	Single	Unemployed	Biological parent	Paralysed right hand and right leg
G	Female	Single	Unemployed	Biological parent	Quadriplegic, paralysed from shoulders down (using a wheelchair)
H	Female	Single	Unemployed	Biological parent	Paraplegic

Source: Sadiki 2022

3.3 Procedure and data collection

The selected mothers of the children with ND consented to take part in the research study individually. Participants were made aware of the right to excuse themselves from participating in the study at any time without consequence and that their information would be deleted from

the investigation information record. Participants replied to in-depth semi-structured face-to-face interview questions on the experience of mothering a neurologically disabled child in a rural setting. Data were recorded on audio tapes and the face-to-face consultation took place in the candidates' residences. The interviews lasted about 60 minutes. The period allocated for the interviews was deemed suitable as it did not, in any way, cause fatigue. The responses were then translated from Tshivenda into English.

3.4 Data analysis

The lead author transcribed the gathered information and translated interviews from Tshivenda to English for data analysis. Data employed were analysed and interpreted by applying thematic data analysis method (Creswell 2013). All transcriptions were read to arrange sense, and a list of similar topics or ideas was put together. Data were clustered per themes and sub-themes, and field records were coded and grouped. Ideas that related to the main theme were grouped as sub-themes to enhance the flow of ideas. A literature control was conducted to control the results of the study. The researcher generated three themes from the data analysis that represent the consensus of the authors and they are presented in the discussion below.

4. Analysis and interpretation of the research data

Three themes and sub-themes were generated, namely health services (sub-themes: health services as an important aspect to mothers of children with ND; lack of adequate knowledge about disability and resources); religious beliefs; and mother's reaction to ND. In the following sections, each theme will be discussed, utilising verbatim quotations.

4.1Theme 1: Health services

Mothers reported that they experienced both positive and negative experiences health services because of their children with ND. The positive experiences health services were about ample opportunities, which enabled them to share social identities with other mothers of

children with ND, common concerns in a support group and learn from the experiences of others' knowledge, personal growth, and support to each other. The negative experiences health services, to a large extent, related to poor communication and inadequate health services regarding assistive devices and high expectations from health professionals, which disappointingly did not bear much-anticipated fruits.

4.1.1 Sub-theme 1.1: Health services as an important aspect to mothers of children with ND

The health services were not a resource mentioned by some the participants. Another participant who was given false hope angrily uttered the following words:

"They gave me the reassurance that his situation would get better which sounded promising. I was in and out of the hospital for therapy sessions with no help. They kept on telling me that "Do not worry, she will be fine. Those words strengthened my hope because I had trust in the therapists as they knew best about health issues. I do not see any difference in the development of my child; I am just wasting my transport money. It is now four years of the ins and outs of hospital without any progress. They should have told me that my child will not be able to walk on his own, however, they raised my hope for nothing. For me, I thought the therapy sessions had to do with the healing process (Participant I, female, 48 years old)".

Another participant asserted:
"It is not easy to get assistive devices from this hospital because you have to be on the waiting list for a year, which makes life difficult to carry my child on my back. I remember when I applied for a wheelchair, I waited for a year on the waiting list. When I enquired, I was told that there is a backlog of wheelchairs, as a result, I just have to wait (Participant A, female, 41 years old)".

However, those who mentioned it considered it to be an important aspect. Some mothers reported that health services are helpful and

makes a huge difference in the lives of their children with disabilities. Mothers reported that they always make an effort to return to the hospital for health services and they feel comfortable attending therapy sessions. Furthermore, they can ask questions about the health services that should be provided to their children with disabilities. The findings by Meaney et al (2022), O'Connor & McCabe (2011), and Peters et al (2013) report that social support and guidance can be provided by healthcare professionals and social services in the form of counselling or multidisciplinary care. The following excerpts from the mothers affirm this:

"This hospital is the best compared to the previous one I used when I was still staying in Gauteng. With this one, their service is excellent and all of them are friendly. I am happy with the hospital service because my child received a wheelchair within a month. The physiotherapy and the occupational therapist are teaching me the exercises I should train my child on when I am at home. I can see progress because my child is learning how to sit on his own (Participant B, female, 45 years old)".

Another participant echoed the following sentiments:
"My occupational therapist referred me to a support group of mothers with children with disabilities. I had an opportunity to share my experiences with those mothers. At the hospital, I found other mothers with children with the same problems. It feels good to know that I am not alone in this journey of experiencing this challenge of knowing a disability of a child at a later stage (Participant D, female, 46 years old)".

On the other hand, participant E stated*:*
"I have gained a lot of knowledge because all this time I have been living with my child. I was stressed about her situation (meaning disability) and her future, and not being able to teach her anything that would help her. The occupational therapist at the hospital taught me how to teach my child so many things such as how to bathe and dress herself, including things that will help her to be independent. I

am grateful to have received this kindness from the health services (Participant E, female, 49 years old)".

A study by Duma, Tshabalala & Mji (2021) concurs with the findings of this study in that medical experts are believed to be reliable with help and information in understanding related disability. According to Muller-Kluits and Slabbert (2020), social services have significant therapy groups for disability by providing knowledge and enhancement to resolve challenges.

4.1.2 Sub-theme 1.2: Lack of adequate knowledge about disability and resources

According to these findings, mothers of children with neurological disabilities have one way or the other experienced lack of adequate knowledge about disability and resources from health personnel. The lack of adequate knowledge about disability and resources pose a major threat to the rapport between the health professionals and mothers with CWD. While Gona et al (2018) contend that health professionals underestimate the emotional distress and need for information experienced by parents and carers of children with impairment. This emotional distress is further amplified by social factors such as fear for the future, stress, rumour mongering and poverty (Duma et al 2021). Another participant conveyed in the following extracts:

"I am stressed and very sad that I don't have any information about my child's disability. The health professionals don't know what I am experiencing about parenting my child with disability. I am the one who is frustrated because when I die no one will be able to take care of my child and I don't know what will happen to my child's future and to me is a serious concern. (Participant F, female, 45 years old)".

Parents of children with disabilities, who happen to face serious difficulties of shortage and lack of reaching therapy facilities, to them, this means that it advances daunting assignment in considering

inclusion of their children with children without disabilities and respective communities. Consequently, the child with a disability is marginalised (Onuora-Oguno et al 2022). Therefore, the child remains secluded (Vergunst et al 2017; Bunning et al 2017). In a situation analysis of children living with impairment in South Africa from 2001 to 2011, the DWCPD and UNICEF (2012), interested parties in the rehabilitation area, confirmed the essential absence of professionals for the review of children (for example, neurodevelopmental paediatricians). This result is consistent with the previous research of Dong et al (2022), which reported that mothers experience more parenting stress than fathers.

Several studies show that health personnel have negative attitudes towards persons with disabilities (VanPuymbrouck et al 2020; Ravim & Handicap International 2010; Coomer 2012; Maart & Jelsma 2013; Munthali et al 2013a). Similarly, Booyens et al (2015) found that caregivers in Botswana, Malawi and Mpumalanga Province in South Africa experienced difficulties in accessing information and services for children with disabilities. These sentiments are conveyed in the following extracts:

"When my child was born, he appeared healthy with no signs of disability. I was discharged from the hospital and neither the doctors nor the nurses told me that my child was disabled. I was hurt because I started to realise after a year my child had begun to learn to walk, that he continued to fall occasionally and suddenly started crawling. He was not developing physically like other children of his age (Participant C, female, 47 years old)".

"Due to his delay in development, I took him to the hospital, and the doctor (paediatrician) conducted several tests on him. The conclusions were that my son has brain damage and that it is preventing him from developing normally. I gave birth to a normal child; I was not told after birth; they should have told me after the birth of my child. It is sad … how will I live with a disabled child. My

life will never be the same again (Participant H, female, 48 years old)".

Mothers of children with ND confirmed that they experience limited psychotherapy health amenities for their children's impairment. Mostly, access to rehabilitation facilities remains challenging (Cartledge et al 2022). As noted by Tigere and Makhubele (2019), wheelchairs in rural areas are limited because of the long application process as well as a lack of adequate funding. WHO (2022) notes that assistive technologies for disabled children living in rural settings hinder their rehabilitation and progress in their livelihoods.

4.1 Theme 2: Religious beliefs

These findings were similar to those reported by Tilahun et al (2016) who found that participant coping mechanisms included talking to a supportive adult and seeking religious guidance. Several mothers confirmed that they depended on spiritual principles after their children were diagnosed with ND. Thus, they sought spiritual healing for their children living with ND from the main churches. Interestingly, most of the articles reviewed recently (Lamptey 2019), open with a discussion of superstition and reliance on religious interventions. They sought healing from famous prophets and charismatic churches where people worshipped in large groups and where there were claims of miracles occurring. Consistent with Sango and Forrester-Jones (2017), some mothers of children with ND used both Western and indigenous health systems but this is not a feature of African parents in particular throughout the world; people seek to understand children's disabilities in a range of ways and they may use a range of help, including services based on spiritual beliefs that are quite at odds with biomedical services. These sentiments are conveyed in the following extracts:

"I have trust and believe that God can make miracles using pastors and prophets. How can I not have faith in prayer … I am pulling very hard with this disabled child. I have faith in this great man of God and as a mother, I need my child to look like other children (Participant F, female, 45 years old)".

"I believe in miracles because I have seen them working in my community. My girl is doing well…much better. I have totally surrendered my situation to the pastors' prayers and senior prophets to help me go through the challenges. My church members and pastor are a very strong source of support; I won't give up. I won't lose faith to prayers and miracles because one day I will celebrate (Participant H, female, 48 years old)".

"Personally referred to this senior prophet by my uncle who was a church member. On my arrival, I paid R10 and I was given water that had been blessed in a two-litre container and a tennis ball by the prophet. I was given instructions to bathe him with the water in the morning and at night. The instruction of the tennis ball was to bump it in front of him twice for three days and that he would be able to stand up and walk, and this indeed happened. This was a miracle to me and I will not forget it in my life; faith works, I am telling you the truth (Participant C, female, 47 years old)".

Participants originate reassurance in God as the foundation of strength (Sadiki & Kibirige 2022). The circumstances of mothers are grounded in their belief or faith and apply to deal with an effort to acknowledge the disabilities of the children by trusting that they are gifts from God (Masulani-Mwale et al 2016; Bunning et al 2017). Religion is a resource that is usually used positively, and it is widely associated with improved psychological adjustment concerning serious illnesses (Phelps et al 2009). Their religion helped them to make sense of their situation and provide a form of support (Du Plooy et al 2014; Issaka 2022). For many of the mothers, the faith they reposed in God strengthened them (Aldersey 2012; Durà-Vilà et al 2010). Religion was also found to be an effective coping resource for mothers (Gull & Husain 2023).

Consistent with the findings of Pelentsov et al (2015), the researchers contend that other mothers who had undergone emergencies, believe it is a result of experiencing links or attachment to a religious group

because of their children's impairment. Individuals with higher levels of perceived social support are less likely to appraise a particular situation as stressful, compared to those with lower levels of social support (Chidi et al 2018). Contrary to the findings by Sadiki and Kibirige (2020), they found that mothers of children living with disabilities who required assistance from religious principals had diverse understanding viewing namely; perception of church leaders providing support while others expected church leaders to pray for their children so that they can be cured of their disabilities. Others understood that religious advisers support therapy. In Kenya, mothers of children with spina bifida struggled with the financial implications of the children's disability; most of them received some support from other mothers and religious communities (Kim et al 2021).

4.3 Theme 3: Mothers' reaction to neurological disability

All eight participants have reported psychological distress associated with ND. Mothers exhibited sadness, apportioned blame to themselves, denial, depression and shock. The first experiences of mothers being exposed to impairment were astonishment to deal with the impairment (Upoma et al 2020). This resulted in denial of the pronounced disability annoyance and anxiety of the unfamiliar new life to navigate (Lee et al 2022). Relatives have doubts about the impairment and could not get a recognised analysis. When they have information, they may feel relieved that the disability is not as serious as anticipated. For example, assuming the child is hard of hearing and discovering that he or she is only hearing impaired on one side (Shearer et al 2019). Other researchers point out that through a parent's experience while trying to understand and acknowledge the disability, traditional faith applies more force on the parent than supporting them (Duma et al 2021). Upon the diagnosis of ND, relatives may undertake reduced support and rehabilitation therapy by creating unrealistic possibilities for complete or substantial development of the child's challenges (Jackman et al 2022). Below are the sentiments echoed by parents after realising that their children had neurological disability:

"The day I was told, "I cried". I was not happy at all because I have two boys and I wanted a girl as my first child. So when my doctor told me that I am expecting a baby girl, I was so excited because that was what I wanted. It was a shock when I was informed that my child is like this, meaning is disabled. I did not like it and I cried a lot and asked myself why me. I regretted to have given birth to the third child. I wish I had known before that that the child would be like this; Otherwise, I was not going to have a third child. It is unfortunate I cannot reverse anything now (Participant A, female, 46 years old)".

"I could not believe. It is very painful. It is painful that my first child had to have such a condition, this is my first-born girl, my only first girl… I have planned so many things for this child … I do not think I will fulfil all my plans. This is bad … Is this a punishment or what? I do not know where this comes from. For nine months carrying a child like this. I do not think I will have another child; I am already scared with my first child (Participant E, female, 43 years old)".

"I was told by my grandmother, no one in our family gave birth to a disabled child. I thought it was a heredity. I am worried…I cannot even tell the cause of this disability and it makes me feel guilty. I feel jealous when I see his age group running around with their mothers (participants C, female, 47 years old)".

The emotional reactions reported by mothers in this study resonate with research that mothers of children were emotionally burdened by their children's condition. The articulated reaction has been deliberate in an extensive variety of settings globally (Zhong 2019), and it is true that for this method to be practised successfully, medical practitioners need to realise the specific socio-cultural context in which convalescent and their relatives live (Gupta & Etzkowitz 2021). Once they later find out about abnormalities in their children, this vision may be abandoned, and numerous reactions may arise (Gull & Nizami 2015). Consequences of conscience can occur as parents may consider that they contributed immensely to the child's impairment through inheritance, substance abuse or anxiety (Trollope 2013).

5. Limitations and suggestions for further research

The major limitation of the study is that the scope was not broad enough for the authors of this article to engage seriously in certain debates such as the experiences of children with ND. This study's views were limited predominantly to mothers of children with ND, therefore, the authors cannot conclude for other categories of disability, sex and tribe. The phenomenological nature of this study does not allow the findings to be generalised to other contexts. The results of this study will inspire other researchers to explore different areas before general assumptions can be concluded. Future studies could draw on a larger sample of racially diverse groups or communities. Therefore, the authors of this article strongly recommend that future studies should focus on the challenges of fathers of children with ND as the main participants to interrogate how they understand the challenges of mothering children with ND. Therefore, future studies should consider using a quantitative survey to explore mothering children with ND in a rural South African setting.

6. Conclusion

The real-life experiences of mothers of children with ND have been investigated. Results of this study suggest that the emotional distress that mothers of children with ND encounter include both positive and negative experiences of health services. Mothers of children with ND pinned their hopes on prophets and ministers to perform miracles that would result in their children being restored to normality. They also thought that their rescue would be found in hospitals and health professionals. However, their rescue from healthcare facilities, health professionals and/or practitioners, religious beliefs and churches in some instances proved daunting a task. The study recognised that mothers employ diverse approaches to manage living with children with ND impairment to reduce tension accompanying impairment. Health policies are reviewed and formulated from time to time, they must include information on how ND disabilities should be mothered. Mothers of children with ND will know what to expect from health

service practitioners and providers while health services practitioners and providers will precisely know the kind of support, they should provide to service recipients and services to be specific services to be rendered when and how. This article provides valuable information on the experiences of mothers of children with disabilities living in a rural area of South Africa. There is a dearth of information regarding social support to mothers of children with disabilities, therefore, this article contributes to the understanding of mothering a child with neurological disability.

References

Abdel-Basset, M., Gamal, A., Manogaran, G., Son, L. H., & Long, H. V. (2020). A novel group decision making model based on neutrosophic sets for heart disease diagnosis. *Multimedia Tools and Applications*, *79*(15), 9977-10002. https://doi.org/10.1007/s11042-019-07742-7

Aldersey, H. M. (2012). Family perceptions of intellectual disability: Understanding and support in Dar es Salaam. *African Journal of Disability*, *1* (32).

Bedell, G., Coster, W., Law, M., Liljenquist, K., Kao, Y. C., Teplicky, R. & Khetani, M. A. (2013). Community participation, supports, and barriers of school-age children with and without disabilities. *Archives of Physical Medicine and Rehabilitation*, *94*(2):315–323. https://doi.org/10.1016/j.apmr.2012.09.024

Benson, J. J., Oliver, D. P., Washington, K. T., Rolbiecki, A. J., Lombardo, C. B., Garza, J. E., & Demiris, G. (2020). Online social support groups for informal caregivers of hospice patients with cancer. *European Journal of Oncology Nursing*, *44*, 101698. https://doi.org/10.1016/j.ejon.2019.101698

Booyens, M., Van Pletzen, E. & Lorenzo, T. (2015). 'The complexity of rural contexts experienced by community disability workers in three southern African countries', *African Journal of Disability*, *4*(1):1–9. https://doi.org/10.4102/ajod.v4i1.167

Brady, G., Franklin, A., & RIP: STARS Collective. (2023). 'I am more than just my label': Rights, fights, validation and negotiation. Exploring theoretical debates on childhood disability with disabled young people. *Sociology of Health & Illness*.

Brandt, R. E., Takeuchi, A., & Kamata, H. (2022). Long-Term Survival in Traumatic Brain Injury and Near Death Experience Increases Suicide Risks: A Personal Experience and Related Literature. *Open Journal of Medical Psychology*, *11*(3), 112-124.

Bunning, K., Gona J. K., Newton C. R. & Hartley, S. (2017). The perception of disability by community groups: Stories of local understanding, beliefs and challenges in a rural part of Kenya, PLoS ONE. 2017; 12(8): e0182214. https://doi.org/10.1371/journal.pone.0182214

Cartledge, S., Rawstorn, J. C., Tran, M., Ryan, P., Howden, E. J., & Jackson, A. (2022). Telehealth is here to stay but not without challenges: a consultation of cardiac rehabilitation clinicians during COVID-19 in Victoria, Australia. *European Journal of Cardiovascular Nursing*, *21*(6), 548-558.

Chidi, M. C., Onyedibe, Leonard I., Ugwu, Philip, C. Mefoh & Onuiri, C. (2018). Parents of children with Down Syndrome: Do resilience and social support matter to their experience of carer stress? *Journal of Psychology in Africa*, 28(20:94-99. https://doi.org/ 10.1080/14330237.2018.1455308

Choque, P. M. G., Arellano, E. G. R., Navarro, E. R., Vergaray, J. M., Huayta-Franco, Y. J., & Toledo, M. F. M. (2022). Children with severe disabilities: adaptation, virtual education, and prospects. Experiences of three Peruvian mothers, COVID-19 context. Journal of Medicine and Life, 15(1), 43. https://doi.org/10.25122%2Fjml-2021-0330

Coomer, R.A. (2012). "The experiences of parents of children with mental disability regarding access to mental health care". *African journal of Psychiatry*, (16):271–276. https://doi.org/ 10.4314/ajpsy.v16i4.36

Constantino, C., Campbell, P., & Simpson, S. (2022). Stuttering and the social model. *Journal of Communication Disorders, 96,* 106200

Crane, L., Sumner, E. & Hill, E. L. (2017). Emotional and behavioural problems in children with Developmental Coordination Disorder: Exploring parent and teacher reports. *Research in Developmental Disabilities, 70*: 67–74. https://doi.org/10.1016/j.ridd.2017.08.001

Cresswell, J.W. (2013). Research Design: Qualitative, Quantitative, and Mixed Approaches; London SAGE Publications, Inc.: London, UK.

Creswell, J.W., 2009, *Research design: Qualitative, quantitative, and mixed methods approaches,* University of Nebraska-Lincoln, Los Angeles, CA.

Deave, T., Johnson, D. & Ingram, J. (2008). Transition to parenthood: The needs of parents in pregnancy and early parenthood. *BMC Pregnancy and Childbirth, 8,* Article 30.https://doi.org/10.1186/1471-2393-8-30

Denzin, N.K. & Lincoln, Y.S., 2011, *Handbook of qualitative research,* 4th ed., Sage, Thousand Oaks, CA.

Disasa, B. (2022). Families of Children with Disabilities: Challenges and Coping Strategies in Some Selected Towns of Arsi Zone. *Journal of Disability & Religion*, 1-17. https://doi.org/10.1080/23312521.2022.2078759

Dong, S., Dong, Q., & Chen, H. (2022). Mothers' parenting stress, depression, marital conflict, and marital satisfaction: The moderating effect of fathers' empathy tendency. *Journal of affective disorders*, *299*, 682-690.

Duma, V. V., Tshabalala, N. & Mji, G. (2021). 'The black hole of dealing with a disability diagnosis: Views of South African rural parents', *African Journal of Disability*, 10(0):a951. https://doi.org/10.4102/ajod.v10i0.951

Du Plooy, D. R. & Pretorius, C. (2014). The caregiver experience: a South African perspective on caring for people with multiple sclerosis, *Journal of Psychology in Africa*, *24*(4): 361–369. https://doi.org/ 10.1080/14330237.2014.980623

Durà-Vilà, G., Dein, S. & Hodes, M. (2010). Children with intellectual disability: A gain not a loss: Parental beliefs and family life. *Clinical Child Psychology and Psychiatry*, 15:171–184. https://doi.org/10.1177%2F1359104509341009

DWCPD & UNICEF. (2012). *Children with Disabilities in South Africa: A Situation Analysis: 2001-2011.*

Faugli, A., Kufås, E., Haukland, M., Kallander, E. K., Ruud, T., & Weimand, B. M. (2021). 'I have cried a lot': a qualitative study on children experiencing severe parental illness. *Scandinavian Journal of Caring Sciences*, *35*(4), 1196-1206.

Fiske, K., & Austin, A. (2022). Family relationships and individuals with autism. In *Handbook of Quality of Life for Individuals with Autism Spectrum Disorder* (pp. 37-55). Springer, Cham.

Franck, L. S., & O'Brien, K. (2019). The evolution of family-centered care: From supporting parent-delivered interventions to a model of family integrated care. *Birth defects research*, *111*(15), 1044-1059. https://doi.org/10.1002/bdr2.1521

Gona, J. K., Mung'ala-Odera, V., Newton, C. R., & Hartley, S. (2011). Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience? [Research Support, Non-U.S. Gov't]. *Child Care Health Dev*, *37*(2): 175–183. doi: 756 10.1111/j.1365-2214.2010.01124.x

Gona, J. K, Mung'ala-Odera, V, Newton, C. R. & Hartley, S. (2010). Caring for children with disabilities in Kilifi, Kenya: what is the carer's experience? *Child care*, health *and development*, *37*(2): 175–83. ttps://doi:1111/j.1365-22.2010.01124.X.

Gona J. K, Newton, C.R, Hartley, S. & Bunning, K. (2018). Persons with disabilities as experts-by experience: Using personal narratives to affect community attitudes in Kilifi, Kenya', *BMC Int Health Human Rights*. 2018; 18: 18. https://doi.org/10.1186/s12914-018-0158-2

Gull, M., & Nizami, N. (2015). Comparative study of hope and psychological well-being among the parents of physically and intellectually disabled children *International Journal of Modern Social Sciences.*, *4*(42)143–152

https://wwwresearchgate net/publication/292141502_Comparative Study of Hope and Psychological Well-being among the Parents of Physically and Intellectually Disabled Children

Gull, M., & Husain, A. (2023). Development and initial psychometrics of the Mental Health Scale of Parents with Differently-abled Children (MHSPDC). *Mental Health, Religion & Culture*, 1-13. https://doi.org/10.1080/13674676.2021.2019207

Hashemi, G., Wickenden, M., Bright, T., & Kuper, H. (2022). Barriers to accessing primary healthcare services for people with disabilities in low and middle-income countries, a Meta-synthesis of qualitative studies. *Disability and Rehabilitation*, *44*(8), 1207-1220. https://doi.org/10.1080/09638288.2020.1817984

Issaka, Z., Mprah, W. K., Owusu, I., Acheampong, E., & Ofori, B. (2022). Parenting children with mental disorders: challenges and coping strategies of parents of children with mental disorders at Komfo Anokye teaching hospital, Kumasi. *Social Work in Mental Health*, *20*(2), 129-148. https://doi.org/10.1080/15332985.2021.2002230

Jackman, M., Sakzewski, L., Morgan, C., Boyd, R. N., Brennan, S. E., Langdon, K. & Novak, I. (2022). Interventions to improve physical function for children and young people with cerebral palsy: international clinical practice guideline. *Developmental Medicine & Child Neurology*, *64*(5), 536-549.

Gupta, N., & Etzkowitz, H. (2021). Women founders in a high-tech incubator: negotiating entrepreneurial identity in the Indian socio-cultural context. *International Journal of Gender and Entrepreneurship*. https://doi.org/10.1108/IJGE-11-2020-0181

Hayden, N. K., & Hastings, R. P. (2022). Family theories and siblings of people with intellectual and developmental disabilities. *International Review of Research in Developmental Disabilities*, *63*, 1-49. http://dx.doi.org/10.1016/bs.irrdd.2022.09.001

Huang, Y., Kellett, M. & St John, W. (2010). Experiences of mothers after learning their child has been diagnosed with cerebral palsy, *Cerebral Palsy, 66* (6), 766 p:1213–21.

Kang, N. R., & Kwack, Y. S. (2020). An update on mental health problems and cognitive behavioral therapy in pediatric obesity. *Pediatric gastroenterology, hepatology & nutrition*, *23*(1), 15.

Kehinde, O. A., Lindly, O. J., Ntombela, B., & Hermann, C. (2022). Brief Report: Gender-Based Stereotypical Roles of Parents Caring for Autistic Children in Nigeria and South Africa. *Journal of Autism and Developmental Disorders*, 1-12.

Kim, S., Kim, H., Kim, J., Nichols, S. C., & Kang, V. Y. (2021). Experiences and impact of having children with autism spectrum disorder on the lives of their Korean-American mothers. *Exceptionality*, *29*(5), 327-343.

Lamptey, D. (2019). 'Health beliefs and behaviours of families towards the health needs of children with intellectual and developmental disabilities (IDD) in Accra, Ghana', *Journal of Intellectual Disability Research, 63*(1):12–20. https://doi.org/10.1111/jir.12545

Lee, J., Benjamin, S., & Childs, M. (2022). Unpacking the emotions behind TripAdvisor travel reviews: the case study of Gatlinburg, Tennessee. *International Journal of Hospitality & Tourism Administration*, *23*(2), 347-364. https://doi.org/10.1080/15256480.2020.1746219

Lee, W. Y., Tan, J. T. A., & Kok, J. K. (2022). The struggle to fit in: A qualitative study on the sense of belonging and well-being of deaf people in Ipoh, Perak, Malaysia. *Psychological Studies*, *67*(3), 385-400.

Logan, N. E., & Ward-Ritacco, C. L. (2022). The Developing Brain: Considering the Multifactorial Effects of Obesity, Physical Activity & Mental Wellbeing in Childhood and Adolescence. *Children*, *9*(12), 1802.

Maart, S. & Jelsma, J. (2013). "Disability and access to health care – a community based descriptive Study". *Disability and Rehabilitation.* https://doi.org/10.3109/09638288.2013.807883

Mahmoud, F. H., Mansour, D. A. H., Roshdy, A. I., & Srour, O. A. W. A. (2022). Comparative Study between Glasgow Coma Scale and Full Outline of Unresponsiveness Scale in Clinical Outcomes Prediction of Neurological Disorders Patients. *The Egyptian Journal of Hospital Medicine*, *89*(1), 5248-5257.

Masulani-Mwale C., Kauye F., Gladstone, M. & Mathanga, D, (2016). Parenting children with intellectual disabilities in Malawi: the impact that reaches beyond coping? *Child: Care, Health Develop*. 2016; 42:871–784 880. https://doi.org/10.1111/cch.12368

McMillan, J.H. & Schumacher, S., 2010, *Research in education: Evidence-based inquiry*, *My Education Lab Series*, Pearson, New Jersey.

Meaney, S., Leitao, S., Olander, E. K., Pope, J., & Matvienko-Sikar, K. (2022). The impact of COVID-19 on pregnant women's experiences and perceptions of antenatal maternity care, social support, and stress-reduction strategies. *Women and Birth*, *35*(3), 307-316. https://doi.org/10.1016/j.wombi.2021.04.013

Meiri, S., & Raz, O. K. (2021). Dream and Fantasy in Shutter Island: Trauma, Historical Guilt, and Ethics. *The Journal of Holocaust Research*, *35*(1), 1-19.

Muller-Kluits, N., & Slabbert, I. (2020). The role of social workers in addressing caregiver burden in families of persons with disabilities. *South African Health Review*, *2020*(1), 137-145. https://hdl.handle.net/10520/ejc-healthr-v2020-n1-a17

Munthali, A., Tsoka, M., Milner, J. & Mvula, P. (2013a). *From exclusion to inclusion- promoting the rights of children with disabilities in Malawi*. Unicef and Government of Malawi Retrieved from http://www unicef org/malawi/MLW_resources_cwdreportfull pdf

Narayan, A., Muhit, M., Whitehall, J., Hossain, I., Badawi, N., Khandaker, G., & Jahan, I. (2023). Associated Impairments among Children with Cerebral Palsy in Rural Bangladesh—Findings from the Bangladesh Cerebral Palsy Register. *Journal of Clinical Medicine*, *12*(4), 1597.

O'Connor, E. J. & McCabe, M. P. (2011). Predictors of quality of life in carers for people with a progressive neurological illness: a longitudinal study. *Quality of Life Research, 20*(5):703–711. https://doi.org/10.1007/s11136-010-9804-4

Onuora-Oguno, A., & Onuora-Oguno, N. (2022). Protecting the Marginalised Child in Nigeria: Social Protection of Children with Albinism in Nigerian Schools Examined. In *Promoting Efficiency in Jurisprudence and Constitutional Development in Africa* (pp. 165-181). Cham: Springer International Publishing.

Oti-Boadi, M., Osei-Tutu, A., & Mate-Kole, C. C. (2022). Challenges and support needs of parents of children with developmental disabilities (DD) in Accra, Ghana. *Research in Developmental Disabilities*, *128*, 104274.

Pedro, A., Goldschmidt, T., & Daniels, L. (2019). Parent-carer awareness and understanding of dyspraxia: Implications for child development support practices. *Journal of Psychology in Africa*, 29 :(1):87-91. https://doi.org/ 10.1080/14330237.2019.1568092

Pelentsov, L. J., Laws, T. A., & Esterman, A. J. (2015). The supportive care needs of parents caring for a child with a rare disease: A scoping review. *Disability and Health Journal, 8*(4):475–491. https://doi org/10 1016/j dhjo 2015 03 009

Perrotta, G. (2019). Psychological trauma: definition, clinical contexts, neural correlations and therapeutic approaches. *Curr Res Psychiatry Brain Disord CRPBD-100006*.

Peters, M., Jenkinson, C., Doll, H., Playford, E. D. & Fitzpatrick, R. (2013). Carer quality of life and experiences of health services: a cross-sectional survey across three neurological conditions. *Health and Quality of Life Outcomes*, *11*(1):103.

Phelps, A. C., Maciejewski, P. K., Nilsson, M., Balboni, T. A., Wright, A. A., Paulk, M. E., et al. (2009). Religious coping and use of intensive life-prolonging care near death in patients with advanced cancer. *Journal of the American Medical Association*, *301*(11):1140–1147.

Ravim & Handicap international Mozambique (2010). People with disabilities in suburban areas of Maputo and Matola. *Handicap International.*

Sadiki, M. C. & Kibirige, I. (2020). Parent-carers of children with physical disabilities in a rural South African setting: Their cultural and social resourcing, *Journal of Psychology in Africa, 30*(4):336-341. https://doi.org/10.1080/14330237.2020.1796029

Sadiki, M.C. & Kibirige, I., (2022), 'Strategies employed in coping with physical disabilities acquired during adulthood in rural South Africa', *African Journal of Disability* 11(0), a907. https://doi.org/10.4102/ajod. v11i0.907

Sango, P.N. & Forrester-Jones, R. (2017). 'Intellectual and developmental disabilities, spirituality and religion: A systematic review 1990–2015', *Journal of Disability & Religion, 21*(3):280–295. https://doi.org/10.1080/23312521.2017.1317224

Shearer, A. E., Shen, J., Amr, S., Morton, C. C., & Smith, R. J. (2019). A proposal for comprehensive newborn hearing screening to improve identification of deaf and hard-of-hearing children. *Genetics in Medicine*, *21*(11), 2614-2630.

Shechter, A., Diaz, F., Moise, N., Anstey, D. E., Ye, S., Agarwal, S., ... & Abdalla, M. (2020). Psychological distress, coping behaviors, and preferences for support among New York healthcare workers during the COVID-19 pandemic. *General hospital psychiatry*, *66*, 1-8.

Silverman, D., 2013, *Doing qualitative research: A practical handbook*, Sage, Thousand Oaks, CA.

Statistics South Africa. 2014, '*Profile of persons with disability in South Africa*. [Online], Available: http://www.statssa.gov.za/publications/Report-03-01-59/Report-03-01-592011.pdf. [Accessed: 14 February 2016].

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), a528. https://doi.org/10.4102/ajod.v8i0.

Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y. & Hoekstra, R.A. (2016). 'Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: A cross-sectional facility-based survey', *BMC Health Services Research, 16*(1):152. https://doi.org/10.1186/s12913-016-1383-9

Trollope, A. M. (2013). The impact of socio-economic factors on raising a child with mental disability in the Northwest of Pretoria. University of Pretoria. https://doi.org/ 10.15270/54-4-676

Upoma, T. F., Moonajilin, M. S., Rahman, M. E., & Ferdous, M. Z. (2020). Mothers initial challenges having children with autism spectrum disorders in Bangladesh. *Bangladesh Journal of Medical Science*, *19*(2), 268-272. https://doi.org/10.3329/bjms.v19i2.45006

Umberson, D., Pudrovska, T. & Reczek, C. (2010). Parenthood, childlessness, and well-being: A life course perspective. *Journal of Marriage and the Family, 72*:612–629. https://doi.org/10.1111/j.1741-3737.2010.00721.x

VanPuymbrouck, L., Friedman, C., & Feldner, H. (2020). Explicit and implicit disability attitudes of healthcare providers. *Rehabilitation psychology*, *65*(2), 101. https://psycnet.apa.org/doi/10.1037/rep0000317

Vergunst, R., Swartz, L., Hem, K-G., Eide, A. H., Mannan, H., MacLachlan, M., Mji, G., Braathen, S. H. & Schneider, M. (2017). Access to health care for persons with disabilities in rural South Africa. *BMC* Health *Services Res,* 2017; 17:741. https://doi.org/10.1186/s12913-017-2674-5

Wang, H., Hu, X., & Han, Z. R. (2020). Parental stress, involvement, and family quality of life in mothers and fathers of children with autism spectrum disorder in mainland China: A dyadic analysis. *Research in Developmental Disabilities*, *107*, 103791. https://doi.org/10.1016/j.ridd.2020.103791

Wang, H., Liu, S., Xu, J., Hu, X., & Han, Z. R. (2023). Daily experiences and well-being of Chinese parents of children with autism. *Autism*, 13623613221144191. https://doi.org/10.1177/13623613221144191

Watermeyer B. & McKenzie, J. A. (2014). Mothers of disabled children: in mourning or on the march? Journal of Social Work Practice: Psychotherapeutic Approaches in Health, Welfare and the Community, https://doi.org/10.1080/02650533.2014.889103

WHO, (2011). *World disability report*, World Health Organization, Geneva, viewed 21 July 2016, from https://www.who.org/worlddisabilityreport.

World Health Organization. (2022). *Global report on health equity for persons with disabilities*. World Health Organization.

Zhong, P., Wang, D., & Miao, C. (2019). Knowledge-enriched transformer for emotion detection in textual conversations. *arXiv preprint arXiv:1909.10681*. https://doi.org/10.48550/arXiv.1909.10681

Zhong, Y., Wang, J., & Nicholas, S. (2020). Social support and depressive symptoms among family caregivers of older people with disabilities in four provinces of urban China: the mediating role of caregiver burden. *BMC geriatrics*, *20*(1), 1-10.