The challenges experienced by mothers with children suffering from cerebral palsy: A study conducted at Mutale Municipality, South Africa

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Abstract: Cerebral palsy (CP) is a developmental disorder, characterized by movement disorders that appear in early childhood. Children with CP experience poor motor coordination and have problems with sensation, vision, hearing, swallowing and speaking. A qualitative study was conducted at Mutale Municipality to ascertain the challenges faced by mothers with children who have CP. Unstructured interviews were conducted with 12 participants and data were analysed using interpretative data analysis. The results showed that the challenges faced by mothers, with cerebral palsy children were social and psychological, hence, the study concluded that these specific types of support should be given to these mothers. The findings also indicated that cerebral palsy is condition that requires a lot of care from parents and that there is lack of support and understanding of the condition from family and friends. Parents raising children with cerebral palsy require the support of friends and family members, therefore, the lack of that support leads to psychological problems, such as feelings of isolation, worries and stress. The researchers recommend that campaigns must be undertaken to help the society to understand cerebral palsy, as this might enhance the societal acceptance and motivate support for those with the condition.

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PUBLIC INTEREST STATEMENT
Raising a child with cerebral palsy is a challenge for both the parents and the family. Cerebral palsy is a condition that affects the family socially, psychologically, and financially. Research indicated that families with children with cerebral palsy are prone to psychological issues such as depression, isolation, and stress; moreover, they have social challenge such as relationship challenges, divorce and bankrupt. Cerebral palsy in South Africa has surpassed global average, and with an increasing number of children who are born with cerebral palsy it is important to conduct study which will help the familiy a rural community understand the condition. Hence, this study explores the challenges experienced by mothers with children suffering from cerebral palsy in rural communities.
1. Introduction

Cerebral palsy is a physical impairment usually appearing in childhood and affecting the development of movement; it is a condition that affects people differently (Rosenbaum, 2005). According to Stanley et al. (2000) around 2.5 of every 1000 children born in the Western world have cerebral palsy, and it is mostly found in children who are born prematurely. Population-based studies from around the world show that the statistics on cerebral palsy worldwide range from 1.5 to more than 4 per 1,000 live births (Mandal, 2019).

Cerebral palsy, as a neurological disorder, causes a non-progressive brain injury that occurs when the child’s brain is underdeveloped (Dixon, 2011). Children with cerebral palsy are noticeable by symptoms, such as loss of motor function. This affects body movement, muscles tone, muscles coordinator, posture, body balance; sometimes it may also affect fine motor skills, oral and gross motor functioning (Mayston, 2001). Children with cerebral palsy find it difficult to walk, sit, grasp objects, and may experience problems from intellectual impairment, seizures and swallowing. These symptoms may appear during infancy or at preschool years (Nelson, 2002).

Cerebral palsy is divided into three subtypes: spastic, dyskinetic and ataxic; these categories are based upon the predominant motor impairment. The spastic cerebral palsy also has subdivisions based on the number of limbs affected, for example, hemiplegia affects one side of the body, diplegia affects the legs only, while quadriplegia impacts on all four limbs. Dyskinetic cerebral palsy is associated with fluctuating or rigid muscle tone, while the ataxic conditions are associated with problems with co-ordination, muscle tone and balance (Donna, 2012).

According to the World Health Organisation (WHO), neuro deficits are major global problems in children (World Health Organization, 2006). The neurodeficits include, head injury, trauma to spinal cord and parasitic infection (Batal, 2011) and according to Idro et al. (2010), these deficits commonly cause cerebral palsy. Cerebral palsy is caused by brain damage that may happen before birth, during birth or just immediately after birth. The brain damage may be caused by an accident, abuse or medical malpractice. Medical causes include being born too early (premature birth), not getting enough blood, oxygen or other nutrients before or during birth, a serious head injury or infection during pregnancy that can affect the brain, for example, meningitis.

Raina et al. (2005) indicate that children with cerebral palsy encounter challenges because they experience functional limitations and long-term dependency on their mothers. The Center for Children Development (Center for Child Development, 2007) further maintained that these challenges do not only affect the child with the condition, but also the entire family. Cerebral palsy affects developmental milestones in speech, vision and learning and causes prolonged dependence on a caregiver, thus, affects psychological and social functioning of the parents (Idro et al., 2010). Parents of children with cerebral palsy undergo social, psychological and economic exhaustion (Mungo et al., 2007). Mungo et al. (2007) add that marital relationship may also suffer due to stress, guilt and blame, hence, cerebral palsy affects marriages and family organizations (Vijesh and Sukumaran, 2007). Among the social challenges that the parents experience, is inadequate support from the family, parents and the society (Ambikile & Outwater, 2012). The condition also causes psychological issues, such as fear of rejection by the extended families and friends (Vijesh & Sukumaran, 2007). Families of children with the condition also suffer from financial problems since the condition requires special care that is difficult in getting insurance coverage for doctor’s
medication and treatment, hence, parents have to pay for the child’s treatment (Lawal et al., 2014). Most of the aforementioned were not conducted within the Limpopo Province; therefore, the current study sought to explore the challenges in the context of Mutale Municipality, a rural area in the Limpopo Province.

2. Methodology

2.1. Research design
A qualitative phenomenological design was employed to explore and describe the experiences of mothers with children suffering from cerebral palsy (Burn & Grove, 2010).

2.2. Population and sampling
The population of this study comprised mothers who have children suffering from cerebral palsy in the Mutale Municipality; 12 participants were selected purposively from three villages—Masisi, Tshenzhelani and Ha-Gumbu. Only participants with children between the ages of 3 and 5 years were included in the study.

2.3. Data collection
Data were collected using semi-structured interviews conducted at the residential places of the participants; these were recorded using a voice recorder and data were transcribed verbatim, later (Brink, 2006). Interviews were conducted in Tshivenda and lasted between 60 to 70 minutes and a language expert was employed to translate the transcribed data from Tshivenda to English.

2.4. Data analysis
Data were analysed using interpretative phenomenological analysis and the collected data were clustered into themes with similar meanings and tabulated.

2.5. Trustworthiness of the study
Credibility was ensured by prolonging the engagement between the researcher and participants during data collection (Babbie & Mouton, 2001). Participants were given enough time to express their experiences as the interviews were in-depth and face-to-face sessions. The methodology and results were also discussed with the peers who have knowledge on qualitative research (Guba & Lincoln, 1995).

2.6. Ethical consideration
The topic is sensitive, therefore, voluntary participation was strictly adhered to. Participants were informed comprehensively about the purpose of the study before they signed informed consent forms. Additionally, ethical issues such as anonymity and confidentiality were explained to the participants and adhered to, by the researcher. Debriefing was done after the study and those affected were referred to a psychologist.

2.7. Findings
This section presents the results obtained from the different participating mothers who outlined their experiences in parenting children with cerebral palsy. The data with same meaning were grouped together into themes and later, these emerged themes are discussed and supported by relevant literature. The table below shows the themes and their sub-themes from the data collected.

The findings are categorized into two themes—social and psychological challenges. Social challenges were further divided into—lack of facilities and services, financial problems, limitation of parents’ social life, unsupportive interaction with relatives and conflicts with relatives. The psychological challenges were divided into—being worried, stress, as well as loneliness and isolation.
2.8. Themes and subthemes

| Themes                | Sub-themes                              |
|-----------------------|-----------------------------------------|
| Social challenges     | • Lack of facilities and services       |
|                       | • Financial problems                    |
|                       | • Limitation of parents’ social life    |
|                       | • Unsupportive interaction with relatives |
|                       | • Conflicts with relatives              |
| Psychological challenges | • Being worried                      |
|                       | • Stress                                |
|                       | • Loneliness and isolation              |

2.9. Discussion of the findings

The participants indicated a number of factors that contribute towards the social and psychological challenges that one encounters while raising a child with cerebral palsy. The following are the social and psychological challenges that emerged from the data collected:

3. Theme 1: Social challenges

3.1. Lack of facilities and services

Children who suffer from cerebral palsy need medication in their developmental stages. Those children need to attend clinic on a weekly basis. The participants indicated that there is a lack of facilities and services at the hospital to help those children. “I have to go to Tshilidzini hospital for checkup of my baby every week, but sometimes I return home with the baby not checked because of lack of facilities and medication, sometimes I am forced to buy some medicines” said Participant 2.

The above findings are supported by Alaee et al. (2015), who observed that there is a shortage of social and therapeutic services to help children with cerebral palsy. These shortages included social services, such as daycare, wheelchairs in public places and a lack of public toilets that are suitable for children with cerebral palsy.

3.2. Financial problem

Parents raising children who suffer from cerebral palsy encounter financial problems. One of the participants indicated that there are times when she buys the medication for her child and some of the medications are expensive, yet she cannot afford not to buy them. “The medication for children with cerebral palsy are expensive, although I try to buy some of the medication some of the medication are so expensive that I am not able to buy them for my child; sometimes I end up using the money that I should use to support my first child with, so that I can buy some medications” Participant 4.

Alaee et al. (2015), state that lack of financial support and limited access to medical service are some of the problem faced by mothers who are raising children with cerebral palsy. Correspondingly, Ambikile and Outwater (2012) indicate that expensive treatments that exceed most families’ income make it difficult to access sanitary facilities such as toilets and other necessary equipment for the child. Sen and Yurtsever (2007) added that there is a load of expensive treatment and care for a child with cerebral palsy. The findings of McNally and
Mannan (2013) indicate that lack of money for healthcare is a major financial challenge experienced by families with a child who has this condition.

3.3. Inability of parents to have a social life
The current study shows that parents raising children with cerebral palsy are limited in their social life events. The limitation arises as a result of the child’s physical incapacity and difficulties arising from the parents’ inability to accept their children’s condition. Lack of acceptance of the children’s condition by the parents prevents them from engaging in activities and social events as they believe they have to closely monitor the children. “I always put my child at home, if I want to go out I make sure there is a close relative who will be at home looking after the child for me, if there is an event to attend I rather not attend the event because I cannot go to the event with the child” Participant 3. The above statement is supported by Yantzi et al. (2007), who indicated that lack of trained caregivers who will look after the children in the absence of the mothers results in them seeking help from friends and family members whenever they want to leave the house. The findings of a study done by Alaee et al. (2015) also show that lack of formal temporary day-care facilities for children with cerebral palsy makes it difficult for mothers to perform daily activities.

3.4. Unsupportive environment
The findings indicate that there is lack of support from friends, relatives and in-laws. The participants indicated that the in-laws blame the mother for the condition of the child. The participants also indicated that some friends show sympathy, however they ask lots of questions due to lack of knowledge about the child’s condition and this can be irritating. “Ever since people noticed that my child has problems, people start to react differently, some show sympathy for me in such a way that it bothers me, my in-laws are not accepting the child, they think I am the cause of the condition” Participant 1. A previous study revealed that there is a lack of supportive interaction/environment from families, and mothers experience stigma from raising children with cerebral palsy from family and friends (Alaee et al., 2015). Park et al. (2009) also found that Korean families with children who have chronic illnesses such as cerebral palsy face more negative responses from families and friends as opposed to families in Western countries. The findings of McNally and Mannan (2013) show that spousal or immediate family support was absent because the family blames the mother.

3.5. Social conflicts
Participants in the present study reported that they experience social conflicts with friends and families. Social conflicts emerge when friends and families begin to talk negatively about the child with cerebral palsy. “Sometimes people talk very badly about my child, some blame me, they think that I am the one who is causing my child not to walk or sit, and when they talk to my child in a bad way, I react negatively which is affecting the relationship that I have with many people” Participant 5. The responses show that the parents are subjected to lack of understanding from society that affects social and family relationships (Nimbalkar et al., 2014).

The participants also reported marital conflicts that may lead to separation. The findings show that fathers find it difficult to accept children with cerebral palsy; therefore, some may separate from the mothers. “After the birth of my child the father of the child was there for us, but as time went on and after we realise that the child was not sitting and talking like other children, he slowly turned his back on us, when the doctor reveals to us that our child has cerebral palsy and explained the condition to us, the father of my child broke off with me” Participant 2.

4. Theme 2: Psychological challenges

4.1. Being worried
The findings show that mothers who are raising children with cerebral palsy worry about the condition of their children and have great difficulty in accepting their children. The participants indicated that they sometimes wish their children were like other children. “It is very difficult to accept that the child condition will never change, every time when I go for checkups, I wish the
doctor can tell me that my child will be normal and walk like other children, the condition of my child worries me a lot, I want my child to have a better life and be able to sit and walk like others”, Participant 4. Ambikile and Outwater (2012), posit that mothers raising children with cerebral palsy experience inner pain and worry about the future of their children. “I do worry a lot about my child, I always ask myself about the future that my child will have, if I die now who will look after my child, I wish she can learn to do few activities so that she can be able to look after herself” Participant 2.

The above findings are similar to those of Alaee et al. (2015), who opine that mothers worry a lot about their children’s condition, and their worries decrease when their children start to improve. The above statement is supported by Nimbalkar et al. (2014), when they also maintain that most of the parents are worried about the child’s future, wondering who will take care of the child in the mothers’ absence.

The findings also show that the mothers sometimes feel guilty about the condition of their children and think is a punishment for their sin and disobedience of the ancestors. “I sometimes feel guilty about my child’s condition, I think I contributed by not praying to my ancestors, or maybe it is the punishment for the wrong things that I did in the past” Participant 5.

Fourie (1992), reports that ancestors are seen as benevolent spirits who preserve the honour and traditions of a tribe, and they usually protect their people against evil and destructive forces, however, they can punish their people by sending illnesses and misfortunes to people who do not listen to ancestors’ wise counsel. Alaee et al. (2015) add that parents with children who have cerebral palsy consider themselves as the causes of the child’s condition.

4.2. Stress
The findings of this study show that mothers who are raising children with cerebral palsy are stressed by a number of concerns, such as the condition of a child, lack of social support, financial constraints and treatment they get from other people. “The condition of my child stresses me a lot, currently, I am not working and I am not looking for a job because no one accepts to take care of my child, people think my child is a burden” Participant 3.

The study of Nimbalkar et al. (2014) revealed that the parents raising children with cerebral palsy suffer from psychological problems such as stress, anger, tiredness and frustration.

4.3. Loneliness and isolation
The findings also demonstrate that these mothers feel lonely and isolate themselves from other people because of the children’s condition. “I usually do not attend social events, even if I attend I will make sure that I stay far from other people so that people do not see my child and notice the child’s condition” Participant 2.

Mothers raising children with cerebral palsy isolate themselves from friends and families because of lack of support (Dixon, 2011). This is inconsistent with the study conducted by Nelson (2002), where mothers isolate themselves from family members and friends because the latter do not understand and accept the condition of their children. The study of Nimbalkar et al. (2014) indicates that there is a reduction in attending ceremonies such as family gatherings among affected mothers.

5. Conclusion and recommendation
The study investigated the experience of mothers who are raising children with cerebral palsy. The findings show that the mothers encounter challenges, such as financial, social and psychological. Cerebral palsy is a condition that requires lot of care from parents and support from various groups of people; however, the study revealed that there is lack of support and understanding of the condition from family and friends; this leads to psychological problems such as isolation, worries and stress. The researcher recommends that a quantitative study should be done with a large number of participants to provide comprehensive information on the topic. It is also recommended
that campaigns must be undertaken to help the society to understand cerebral palsy; this might enhance societal acceptance and support for those with the condition.

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