

MOTHERS CARING FOR CHILDREN LIVING WITH CEREBRAL PALSY: SUGGESTIONS FOR PSYCHO-SOCIAL SUPPORT

Raphulu Phumudzo, Modjadji Linda Shirindi, Mankwane Daisy Maria Makofane

Ms Phumudzo Raphulu, Department of Social Work, University of South Africa, Pretoria, South Africa.
Prof. Modjadji Linda Shirindi, Department of Social Work, University of South Africa, Pretoria, South Africa,
Prof. Mankwane Daisy Maria Makofane, Department of Social Work, University of South Africa, Pretoria, South Africa.

Phumudzo Raphulu: phumudzor@gmail.com

Modjadji Linda Shirindi: shiriml@unisa.ac.za

Mankwane Daisy Maria Makofane: nase.melale@gmail.com

Caring for children with cerebral palsy presents numerous circumstances which may contribute to mothers' inability to cope with the demands of meeting their children's needs. A qualitative study supported by explorative, descriptive and contextual designs was undertaken. Purposive and snowball sampling facilitated the identification of twelve participants who were interviewed through semi-structured interviews. The enquiry was based on the ecosystems approach. Thematic data analysis was followed through Tesch's eight steps and Guba's model was used for data verification. The findings highlighted the necessity to enhance the psycho-social functioning of mothers through collaboration of social workers, health professionals and various organisations.

Keywords: caring, cerebral palsy children, mother, psycho-social support, responsibilities, social well-being

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*Ms Phumudzo Raphulu, Department of Social Work, University of South Africa, Pretoria, South Africa.
Prof. Modjadji Linda Shirindi, Department of Social Work, University of South Africa, Pretoria, South Africa,*

Prof. Mankwane Daisy Maria Makofane, Department of Social Work, University of South Africa, Pretoria, South Africa.

INTRODUCTION

Caring for a child with cerebral palsy (CP) is demanding and requires effort, dedication, time and resources. Mothers caring for children with CP face various situations that may have an adverse effect on their social well-being. Demanding caring responsibilities may also lead to “an imbalance in their daily activities when compared to mothers with healthy children” (Hosseini & Sahaf, 2012:73: Rassafiani, Kahjoogh). This imbalance is likely to result in physical and emotional distress, subsequently affecting their social functioning.

CP is one of the common developmental disabilities in South Africa (Couper, 2002:549). It is a neurological disorder that comprises a group of disabilities that hinders a child’s ability to exercise control over body movements (Masood, Arshad & Mazahir, 2015:1). The legs and hands may become worse due to inadequate brain development (Centers for Disease Control and Prevention, 2020b:1). CP is considered the most severe form of physical disability affecting children (Ketelaar, Volman, Gorter & Vermeer, 2008:825).

According to Centers for Disease Control and Prevention ([CDC), 2020a:1), the latest “population-based studies from around the world report prevalence estimates of CP ranging from 1 to nearly 4 per 1,000 live births or per 1,000 children⁹” In Europe, the CP prevalence is 2-2.5 per 1 000 (Al-Gamal & Long, 2013:624). Later, a systematic review was conducted to identify data on the prevalence, etiology, comorbidities, outcomes, screening tools and treatment of CP in Africa (Donald, Samia, Kakooza-Mwesige & Bearden, 2014:30-35). The incidence differs from country to country with approximately 2-10 per 1 000 live births globally (El Tallawy, Farghaly, Metwaly, Rageh, Shehata, Elfetoh, Hegazy, El-Moselhy, Rayan, Al-Fawal, & Abd Elhamed, 2010:185). South African studies show a high prevalence rate for CP (10 per 1 000) (African Child Policy Forum (ACPF), 2011:15; Couper, 2002:549).

The contributory factors of CP vary in developed and developing countries (Cooper, 2015:107). Prenatal causes are common in developed countries (Cooper, 2015:107; Nelson & Blair, 2015:946), whereas perinatal (i.e., complicated labour due to lack of oxygen, infections such as tuberculosis meningitis related with HIV) and postnatal causes (i.e., uncontrolled epilepsy or head injuries) are common in developing countries such as South Africa (McLaren, 2014:1).

When a mother learns that her child has a disability, this information comes as a blow to her. Feelings of loneliness and isolation emerge and she may not know where to search for more information, assistance and support (National Information Centre for Children and Youth with Disabilities, 2003). The reactions of parents who are informed about the diagnosis of their children vary. They may experience shock, panic, anger and anxiety, and have difficulty accepting the diagnosis (Huang, Kellet & John, 2010:1213). Even though the child with a disability may be a source of joy in the family, their special needs may contribute to the emotional and financial strain and social needs of the family (Dambi, Jelsma & Mlambo, 2015:1; Mukushi, 2018:48).

In situations where mothers do not have assistance and support with daily activities of caregiving, they may become overwhelmed, fatigued and ultimately unable to take proper care of their own health (Garip,

Ozel, Tuncer, Kilinc, Seckin & Arasil, 2016:757). Lack of support is attributed to the fact that some mothers of children with disabilities are often marginalised and face resistance and negative attitudes from family and society (Ngubane & Chetty, 2017:36). It is not surprising that many households hide their children with disabilities in their homes as a means of escaping the external stigma associated with disability (Carr, Linehan, O'Reilly, Walsh & McEvoy, 2016:163).

The financial instability makes it difficult for mothers to hire a caregiver to look after a child with special needs (Ignjatovic, 2019:1). In some instances, mothers are unable to run errands because they cannot leave the children on their own. Hence, some siblings may assume the caregiving role in this regard. However, Heller and Arnold (2010:16) note that in such instances, a close and long-lasting relationship is established between a child with a disability and their siblings. Furthermore, siblings may tend to take on the supportive role as they grow older (Heller & Arnold, 2010:16).

Even though research has been conducted confirming the benefits of father involvement in the child's upbringing (Isacco & Garfield, 2010:109; Kaufman, 2013:1), little is known about absent fathers of children with disabilities in South Africa. It has been noted that fathers have a positive impact on the overall health of their children (Kaufman, 2013:1). In addition, a father's role is significant in every child's development and family to complement the caring role of mothers (Gežová, 2015:46). Barriers contributing to lack of a father's involvement in the child's life is well documented in literature (Bateson, Darwin, Galdas & Rosan, 2017:124; Roberts, Coakley, Washington & Kelley 2014:1).

This inquiry was motivated by observations of mothers showing strain and discouragement about their situation. Some were scared to seek assistance from organisations due to the stigma attached to having a child with disabilities.

PSYCHO-SOCIAL SUPPORT

Psycho-social support (PSS) is "a process of facilitating resilience within individuals, families and communities" (IFRC Reference Centre for Psychosocial Support, 2009:25). It is also regarded as "processes and actions that promote the holistic well-being of people in their social world. It includes support provided by family and friends" (Inter-Agency Network for Education in Emergencies (INEE), 2010a:121). PSS conforms to the concept *resilience* (INEE, 2018:14), since it aims to help individuals recover after a crisis has disrupted their lives and to enhance their ability to return to normality after experiencing adverse events.

The Southern African Development Community (SADC) (n.d:19) uses the term "psycho-social" to describe "...the close connection between psychological aspects of an individual's experience (that is, their thoughts and emotions) and the wider social experience (that is, relationships, practices, traditions and culture). It also takes into account the physical and spiritual dimensions (value systems, beliefs and self-awareness) of an individual." PSS reinforces the social and cultural connectedness, enhances the well-being of an individual, a family and a community and positively influences the individual and the social environment in which the person lives (Regional Psychosocial Support Initiative (REPPSI) 2013:6). Research has found that PSS is beneficial to enhance the social functioning of caregivers (Masulani-Mwale, Kauye, Gladstone & Mathanga, 2019). Therefore, its effective use enhances the cognitive, emotional and spiritual well-being of an individual, a family and the community.

PSS is also associated with the ecosystems approach which considers the importance of the relationship between individuals and their environment such as the family, community and society, including how their social functioning is affected. Caregivers may require a different support at the micro, meso and macro level. The psycho-social intervention may include empowering caregivers on the effects of the affected person's health condition, increasing social support, marshalling available resources and addressing any psychological stress; thus, lessening the caregiver burden (Raju, Lukose, Raj & Reddy, 2016:206). Additionally, medical and psychiatric social workers should offer psycho-social intervention to caregivers in emergency and trauma care settings (Raju *et al.*, 2016:206).

THEORETICAL FRAMEWORK

The concept *ecosystem* originates from the work of Bronfenbrenner (2005:106) who developed the ecological systems theory, currently referred to as a “bio-ecological model”. The model is critical to social work, as it is used to understand human development based on the contribution of the environment and the effects it has on this development process (Bronfenbrenner & Morris, 2006:793-823). The ecosystems approach integrates concepts from the systems theory and the ecological perspective which describes the relationship between individuals and their environment (Zastrow & Kirst-Ashman, 2016:23, 33). This approach also conforms to the concept of person-in-environment (PIE) which is foundational in social work practice that facilitates the understanding of underlying forces of human behaviour (Sheafor & Horejsi, 2012:12).

Even though the ecosystems approach is a hierarchical system based on four levels, namely micro, meso, exo and macro (Rosa & Tudge, 2013:243), three levels (micro, meso and macro) were considered for this study (Jaspal, Carriere & Moghaddam, 2016:265). There are slight variations in the presentation of the different levels. For example, Wolf-Branigin (2013:86) asserts that the individual, family and friends are considered at the micro level, organisations offering services at the meso level while the macro level focuses on how policies at different tiers of government affect provision of services. On the other hand, Kail and Cavanaugh (2010:63) maintain that the meso level focuses on the family, school and neighbourhood while the macro level, according to Jaspal *et al.* (2016:265), includes societal ideologies, values, socio-economic status and ethnicity as well as social representations. Irrespective of these discrepancies, during assessment, social workers are expected to ensure a broad understanding of the individual’s relationship with the environment at the micro, meso and macro levels.

Mothers, as caregivers of children living with CP, need assistance from family members and organisations to lessen the burden of caring. The study was conducted in a township located in the City of Johannesburg Metropolitan Municipality (Gauteng) characterised by moderate health resources. The ecosystems approach regards the family as a valuable source of support for its members, especially children (Piel, Geiger, Julien-Chinn & Lietz, 2016:1034). Hence, the study was adopted to facilitate an exploration and description of the mothers’ situations regarding their caregiving experience as well as the available community and psycho-social support. Of the twelve participants, ten were heading families. Thus, the ecosystems approach facilitated the exploration and understanding of the role and assistance provided by siblings and the stimulation centre.

PROBLEM STATEMENT

Mothers of children living with CP experience a myriad of challenges. Their dreams and aspirations regarding career development or seeking employment are thwarted by their demanding caregiving responsibilities. The challenge is that most children with CP cannot walk due to stiffness or floppiness but can roll around when they are older than six months (Masood *et al.*, 2015:1).

Caring for a child with CP has psychological, social and financial impacts on caregivers and families (Garip *et al.*, 2016:757). The psychological, social and physical dimensions of individuals are interrelated; hence, an imbalance in one dimension affects the psycho-social functioning of an individual (Stoewen, 2017:861). Therefore, psycho-social functioning “reflects a person’s ability to perform the activities of daily living and to engage in relationships with other people in ways that are gratifying to her” (Mehta, Mittal & Swami, 2014:1).

Unfortunately, CP affects children’s social functioning and how they relate with other children (Lindsay, 2016:143). Similarly, the mother’s psycho-social functioning is affected, as she may sometimes not even know how to assist the child. Thus, she becomes depressed (Ketelaar *et al.*, 2008:825). Furthermore, due to lack of support, mothers’ movements are curtailed, making it difficult for them to interact with other people or participate in relatives’ funerals and festive occasions, including community activities. Similarly, the outcome of a study also found a common problem caregivers experience when caring for

children with disabilities to be an inability to take part in social gatherings such as marriages and other important ceremonies (Nimbalkar, Raithatha, Shah & Panchal, 2014:2).

The presence of a father in the life of a child has a positive influence on the child and the mother's psychological growth and development (Shulman & Seiffge-Krenke, 2017:5). However, a father's presence does not guarantee his involvement in caring for a child's physical, emotional, intellectual and spiritual well-being (Dowd, 2006:917-919). Some of the barriers towards a father-child (with special needs) relationship and his involvement include lack of accurate information about the child's condition, community attitudes towards fatherhood, lack of parental guidance, lack of a platform for men to talk about issues affecting them, and a mothers' inability to involve fathers based on their relationship problems (Bateson *et al.*, 2017:124; Roberts *et al.*, 2014:1).

Regrettably, unmarried mothers are more likely to lack support from the children's fathers and the extended family system, especially when they do not have relatives in their neighbourhood. The mothers' caregiving burden is also compounded by the general lack of support services in townships. Thus, the problem statement is the lack of information and understanding of the circumstances of mothers caring for children with CP in a particular township located in the City of Johannesburg Metropolitan Municipality (Gauteng).

RESEARCH QUESTION AND GOAL

The overarching research question informed by the research problem was: What are the circumstances encountered by mothers caring for a child with CP? The primary goal was to gain an in-depth understanding of the circumstances of mothers caring for children with CP.

RESEARCH METHODOLOGY

A qualitative approach supported by explorative, descriptive and contextual designs was utilised to generate rich and deeper meanings of participants' experiences (Rubin & Babbie, 2013:40). A non-probability purposive sampling technique was employed (Blaikie, 2010:23) to recruit mothers of children with CP aged between 1 and 18 years, living in a township located in the City of Johannesburg Metropolitan Municipality (Gauteng) to participate in the study. Snowball sampling was also utilised in which participants with whom contact had already been made referred the researcher to potential participants (Creswell, Ebersohn, Ferreira, Ivankova, Jansen, Nieuwenhuis, Pietersen, Plano Clark & Van der Westhuizen, 2011:80).

Open-ended questions were used to gather data from the twelve participants through semi-structured interviews after ethical approval had been received from the Social Work Departmental Research and Ethics Committee at the University of South Africa (UNISA). Ethical standards of informed consent, confidentiality and management of information were observed. A journal was kept during data gathering and used to record thoughts, feelings and assumptions upon which researchers reflected to avoid tampering with the findings (Sutton & Austin, 2015:226). The interviews were recorded digitally, transcribed verbatim and analysed following Tesch's eight steps (cited by Creswell, 2014:196). Furthermore, the services of an independent coder were utilised to ensure trustworthiness.

FINDINGS

Twelve mothers whose ages ranged between 25 to 63 years took part in the study. Their mean age was 40,25 years. Of the twelve participants, ten were not married and living with their children. Of the twelve participants, four were employed while eight were unemployed. Of the eight unemployed mothers, two had left their employment to care for their children. Unemployed mothers rely on the care dependency grant for the child with CP of R1 890,00 and the childcare grant of R460,00 per month per child under 18 years which they receive from the South African Social Security Agency (SASSA). However, their financial situation was dire, considering the high cost of living, transportation for children travelling to stimulation centres and hospital for medical care, to mention but a few expenses.

TABLE 1
DEMOGRAPHIC DETAILS OF PARTICIPANTS¹ AND THE AGE OF CHILDREN WITH CP

Participant	Age	Marital status	Ethnicity	Highest qualification	Employment	Number of children, age and gender	Gender and age of child with CP in years ²	Periodical stages of diagnosis in months and years
P1	63	Single	Tswana	Grade 7	Unemployed	6 (adult children - 3 girls and 3 boys - 2 deceased)	Boy, 8	After birth
P2	55	Single	Zulu	Grade 8	Unemployed	3 male children (34, 15 and 13) and girl, 10	Girl, 10	After birth
P3	44	Married	Venda	Honours in Teaching	Educator	3 girls (10, 6 and 3)	Girl, 10	2 years
P4	43	Separated	Xhosa	Grade 12 and Admin Certificate	Administrative clerk	3 girls (21, 9 and 9)	Girl, 9	4 months
P5	38	Single	Venda	Grade 10	Unemployed	3 (boy 16, girl 14 and boy 11)	Boy, 11	8 months
P6	37	Married	Xhosa	Grade 12 and Security Certificate	Security officer	2 boys (12 and 4) and a girl, 8	Girl, 8	After birth
P7	36a	Single	Zulu	Grade 11	Unemployed	2 (boy 16 and girl 13)	Boy, 16	2 days after birth
P8	36b	Single	Zulu	Grade 12	Unemployed	2 (boy 13 and girl 10)	Boy, 13	Less than a year
P9	36c	Single	Venda	Grade 12 and Paramedic Certificate	Shop assistant	2 (girl 14 and boy 3)	Girl, 14	After birth
P10	35	Single	Zulu	Grade 8	Unemployed	3 boys (14, 10 and 8)	Boy, 8	At birth
P11	32	Single	Zulu	Grade 12	Unemployed	2 boys (7 and 4)	Boy, 7	After birth
P12	28	Single	Sotho	Grade 12	Unemployed	3 (2 boys of 10 and 2, and girl, 4)	Boy, 10	2½ years

Four themes and sub-themes derived from the research findings and are presented below.

Theme 1: Reactions of mothers after knowing the diagnosis of their children

Every mother expects to give birth to a normal child (Taub, 2006:52). Mothers whose children are diagnosed with CP are likely to experience loss and grief. They may grieve for a loss of dreams they had for their children. Huang *et al.* (2010:1213) reported expressions of Taiwanese mothers after learning about their children's diagnosis that they felt out of control and powerless, mistrusted health professionals, relieved after knowing the diagnosis of their children and accepted their condition, including feeling blamed for not following traditional practices during pregnancy.

Mothers may also feel uncomfortable or be in despair after the birth of a child with CP while maintaining their husbands' family honour and prosperity (Huang *et al.*, 2010:1213; Pawlus, 2016:306). Of the twelve participants, ten experienced pain and deep sadness when they found out about their children's condition.

They [health professionals] did explain but maybe by then.... I didn't believe it, that my child had CP, because he cannot even walk but the speech is alright. Yes. I become angry because of the whole situation... (P, 28 years)

¹ Numbers were used in Table 1 to protect the identity of the participants.

² All the children were recipients of Care Dependency Grant.

It was bad, very bad. Yes. Imagine all those big plans I had about my first born and everything was just shuttered like that, boom! Yes. It was very, very bad, I was struggling to accept, I used to cry every day, every day of my life. It was not easy. I used to ask God why me, why not everyone else but me. (P, 44 years)

It was not nice. I was hurt and it was not easy to accept that my child will be like that for the rest of her life. (P, 37 years)

Likewise, outcomes from other studies established that mothers had experienced a range of difficult reactions, including disbelief, rejection, feeling overwhelmed, shock, confused, anger, self-blame, sadness and uncertainty about their children's future after knowing the diagnosis of the children (Huang *et al.*, 2010:1213; Krstić, Batić, Mihić & Milankov, 2016:467).

Denial is a defence mechanism that manifests when a person cannot or may not accept an unpleasant truth. In other instances, parents tend to display a negative attitude toward the diagnosis of the child by being in denial, rejecting the child and blaming themselves (Sahu, Bhargava, Sagar & Mehta, 2018:406). The participants who were struggling to come to terms with their children's diagnosis shared the following:

I was still in denial hoping that one day he will be okay and be like other children. (P, 28 years)

...it takes time for one to adjust to the situation. At some point I used to ask myself if the child was mine but I would also tell myself he is mine because he looked exactly like his father, no one could have swapped him at the hospital. (P, 36b years)

Similar experiences were reported from a study in which mothers expressed disbelief after learning about the health condition of their children (Marian, Magesa & Phillipine, 2020:72). Mothers' denial and disbelief may culminate into an emotional strain (Sajedi, Alizad, Malekkhosravi, Karimlou, & Vameghi, 2010:250). This is attributed to the unpreparedness to handle various challenges and expectations of raising a child with special needs. The consequences may be unintentional deprivation of motherly love and care for other children (Macinnes, 2008:758; Starc, 2014:108) and impaired social functioning.

Theme 2: Circumstances encountered by mothers caring for children with CP

The demands of caring for a child with CP may include intensive physical engagement and the need to cope with emotional reactions brought about due to the child's condition (Krstić & Oros, 2012:373). Families who care for their children diagnosed with CP are faced with many challenges, including sufficient information about the children's diagnosis, lack of awareness of available services and programmes of children with learning disabilities, single parenthood without employment, prejudice and stereotyping by community members (Tederera & Hall, 2017:1) as well as additional daily parenting tasks, parenting under public scrutiny and coping with grief related to the diagnosis (Whittingham, Wee, Sanders & Boyd, 2011:1558). In this study, some of the circumstances encountered by the mothers included lack of support from their children's fathers, leaving their employment to care for their children with CP as well as limited movement, as these children could not be left alone.

Subtheme 2.1: Leaving employment to care for a child with CP

Raising a child with a disability may affect family life in relation to time, expenses, work and social relations (Guyard, Michelsen, Arnaud, Lyons, Cans & Fauconnier, 2012:1594). In some situations, mothers are compelled to leave their employment to care for their children as illustrated in the following excerpts:

Yes. I had to leave my job and stay at home to look after him. Due to his Asthma diagnosis, I couldn't take him to crèche because I was the only one who knew how to handle him when it attacks him. In 2011, I was working and at work they told me to go and stay at home and look after the child because I was always complaining to them and always took off when he has to go for treatment and when he is in and out of hospital. (P, 35 years)

When you have a child with CP it is very difficult to work. (P, 36b years)

Similarly, Ignjatovic (2019:1) states that mothers often have to resign their jobs to take care of their children. Thus, families' finances may be unfavourable (Dambi *et al.*, 2015:2), considering hospital visitations that may require hiring special transport coupled with maintenance of other children.

Subtheme 2.2: Lack of support from the children's fathers

Lack of support from the children's fathers is characterised by abandonment, being uncaring, rejection and neglect of responsibilities. A study by Pelchat, Levert and Bourgeois-Guerin (2009:239) on *how do mothers and fathers who have a child with a disability describe their adaption/transformation process?* found that the children's condition was likely to be perceived differently by the mother and father. When parents cooperate, they are likely to adjust to the situation (Pelchat *et al.*, 2009:239). Salami and Okeke (2018:1) likened absenteeism of fathers to that of a pair of eyes, ears, hands or legs that, when any of these organs become dysfunctional, other organs become affected negatively. Ten participants did not receive support from their children's fathers.

Yes. We are separated, he does not even support the children. I do everything on my own, he does nothing nje [just like that]. (P, 43 years)

At least I know what is going on [referring to the condition of the child], unlike his father who said that he does not want anything to do with a disabled child, and it was his first time seeing the child, he was six months old by then. He told me straight to my face that I should take back the child where I got him and that was the last day I saw him in my life until now and the child is 8 years. (P, 35 years)

When the father finds out that the child is diagnosed with CP, he left me... He mentioned that at his home they never had a person with a disability so he doesn't understand why his child has CP. (P, 32 years)

Blaming the mother for the birth of a child with a disability is a long-standing cultural tradition in developed (Colker, 2015:1206) and developing countries (Singogo, Mweshi & Rhoda, 2015:2). The blaming is attributed to lack of knowledge and negative attitudes towards disability. On the other hand, lack of support from fathers heavily increases the burden on mothers who might already be struggling to cope with the demands of caring for a child with CP.

Subtheme 2.3: The importance of fathers' involvement in the upbringing of children with CP

There is dearth of research on the involvement of fathers in the upbringing of their children with disabilities in South Africa. Statistics only show generic biological fathers who are absent in the lives of their children. For instance, the Statistics South Africa's (SSA, 2019:11) report based on the General Household Survey, shows that "one-third (32,7%) of children lived with both parents. Most children, however, lived only with their mothers (42,0%) while a much smaller percentage (4,0%) of children lived only with their fathers". The involvement of fathers in the upbringing of children with special needs is still a heated debate among scholars (Whitney, Prewett, Wang & Haigin, 2017:101). However, fathers' involvement in the family has multiple benefits such as empowering mothers economically, improved maternal health and promotion of positive child development (Kaufman, 2013:1).

Since caring for a child with CP is demanding, the fathers' involvement will assist mothers, irrespective of their marital status, to cope with the needs and demands of caregiving. Of the twelve participants, ten were not married. Furthermore, the children's fathers were not involved in their upbringing. This finding confirmed the reality in South Africa that many children live in households without a father (SSA, 2019:11).

I have noticed most of the time when I go for meetings at school, I only find mothers who are attending and not fathers. When the child came into the world, both the mother and the father were involved, so I do not understand why the mother should take the responsibility alone.

Besides children with CP need support of both parents. Children with special needs require more support and fathers should also take the responsibility to care for them. (P, 28 years)

He does not care. He buys stuff for his niece and nephews but he does not buy for his child and during winter he is always warm but our child does not have clothes. (P, 28 years)

...even the father of the child did not want anything to do with the child. He just said that at his home they do not give birth to children like this and he left the child like that. (P, 63 years)

A study on *a support programme for caregivers of children with disabilities in Ghana* showed that challenges experienced by caregivers of children with disabilities were exacerbated by the absence of their fathers (Zuurmond, Nyante, Baltussen, Seeley, Abanga, Shakespeare, Collumbien & Bernays, 2018:45). Conversely, from their study on parenting children with intellectual disabilities, Beighton and Wills (2017:325) found that when parents shared caregiving responsibilities, positive aspects such as a sense of greater appreciation, inner strength and closer intimate connections occurred. A child deserves the love of both parents. Unfortunately, some fathers have a negative attitude towards children with CP. Consequently, they abdicate their responsibilities and deprive them of the love and care they deserve.

Subtheme 2.4: Limited movement of participants

The participants enjoyed limited movement due to caregiving. A study conducted in India of parents caring for children with CP confirmed one common problem encountered by caregivers, namely the inability to take part in social gatherings such as marriages and other important ceremonies (Nimbalkar *et al.*, 2014:2). Some mothers further indicated that caring for a child with disabilities was strenuous and often interfered with other household duties (Nimbalkar *et al.*, 2014:3) like doing laundry, washing dishes and preparing food for the family (Dangale, 2019:7). Likewise, the findings of Chiluba and Moyo's (2017:5) study in Zambia on caregivers' perspectives on caring for a child with CP found that parents had stopped attending social gatherings due to stigma from community members. The participants explained that:

I used to go with her to church when she was still young because it was easy to put her on my back but now that she is grown up, it is very difficult to hold her... (P, 36c years)

...especially when I want to go to church, we take turns with my eldest daughter. She will attend a 7am service and when she comes back, I will go for the 11 am service ... When I want to go somewhere, I leave her with my mother so that's how we do it. (P, 43 years)

When you want to go somewhere, it is very difficult because you cannot walk around with him. (P, 36a years)

A study on the *experiences of mothers of children born with cerebral palsy in Namibia* showed how their trust and belief in the Creator assisted them to cope and accept the condition of their children (Marian *et al.*, 2020:77). Another study on *churches as a source of support for families with children on the autism spectrum* also revealed the unique support played by churches (Webb, 2012:10). Therefore, mothers who are unable to attend church services may feel deprived of an opportunity to become spiritually nourished.

Subtheme 2.5: Siblings help in caring for children with CP

When parents are committed to other responsibilities, siblings often take the responsibility of providing care (Nimbalkar *et al.*, 2014:3) to their siblings with CP. However, Lostelius, Ståhle-Öberg and Fjellman-Wiklung, (2018:164) purport that "siblings of children with developmental disabilities are more likely to develop negative feelings and behaviours compared to siblings of non-disabled children." On the contrary, the storylines below capture mothers' pride for the assistance they receive from siblings of the affected child.

Yes, my firstborn child [14-year-old sibling of the child with CP] is the one who helps me a lot even when it comes to taking care of his brother. He baths him every morning and prepares him for school. So, he is very helpful and understanding. (P, 35 years)

She [10-year-old sister to the child with CP] is very helpful towards him. More especially when I am sick. I know that I can rely on her. And sometimes when her brother has messed up, she does assist by changing his nappies, she is very helpful. She started long ago looking after her brother even bathing him. Even when you ask her to make him food, she makes him food and also feeds him. (P, 36b years)

Even though looking after a sibling with CP may be demanding and strenuous, especially when siblings are younger than the affected child, the findings confirm the assertion that caring creates bonds and strengthens feelings of belonging among siblings (Lostelius *et al.*, 2018:164).

Interestingly, a study *on the well-being of sibling caregivers and the effects of kinship relationship and race* showed that the sibling caregivers of the minority groups had physical health challenges while their white counterparts experienced depression (Namkung, Greenberg & Mailick, 2017:626; 632).

Theme 3: Community support for participants

Consistent with the ecosystems approach is an African adage that says, “It takes a community to raise a child”. Therefore, it is imperative for communities to care for children with disabilities (Omu & Reynolds, 2012). The acceptance and support of affected children by community members have a positive impact on their personal growth and development.

Yes. Even the community around here, they do not want to hear anything about her [meaning that they are protective of her]. I do not want to lie; they are very supportive. ... she is a celebrity around here they even have a good name that they call her with. If you are coming here and you ask for Toto, they will tell you that it is her. (P, 55 years)

...even the community members know him [child with CP] and they do interact well with him. (P, 35 years)

Similarly, most of the 493 parents from 53 families in a study by Muderedzi, Eide, Braathen and Stray-Pedersen (2017:9) on *perceptions and treatment of children with cerebral palsy among the Tonga of Binga in Zimbabwe* reported on people’s positive attitudes towards disability. Perspectives of parents of children with disabilities from a study by Kovalčíková, Banovcinova and Levicka (2020:1) also showed the importance of informal support by a partner and close people.

However, one participant reported having experienced scrutiny from family members and the community.

Ijooh! it is very difficult. For instance, community and family members will be guarding me to observe or check as to whether I am properly looking after the child. At times I could feel that I am not doing enough to care for the child but I am trying. For them, there is nothing good that I am doing. Not even one person ever asked me how I was feeling, not even one. All they do was to judge me. Sometimes before you judge someone you must try put yourself in their shoes you may then say something or judge them. (P, 36a years)

Similar findings emerged from a study conducted in Zambia (Singogo *et al.*, 2015:1) where mothers of children with CP felt socially isolated owing to lack of support from their families, community members and health care providers. In some instances, judgemental and negative attitudes towards these mothers may be attributed to superstition as shared by one of the participants.

...the biggest challenge I came across was when the father of the child mentioned that because I have given birth to the child with a disability, it means that I do practice witchcraft or at home where I come from they practice witchcraft. (P, 38 years)

Beliefs that link disability with witchcraft are influenced by an association of disability with evil spirits or the devil (Groce & McGeown, 2013:2) which is misleading. Such accusations may trigger rejection and abandonment of mothers by relatives; thus, exacerbating their emotional and caregiving challenges.

Theme 4: Social work services

Social work develops, empowers and liberates communities (International Federation of Social Workers [IFSW], 2021:1). Most importantly, two key features of social work are the desire and the ability to see an individual as unique and as a complete entity and not merely as a set of problems (Engelbrecht, 1999:30). The profession also seeks to understand the interconnectedness of people's lives (Mattaini, 2008:355), and to recognise rather than ignore the constraints and discrimination they experience from society (IFSW, 2021:1). Eight participants did not use or request social work services due to a variety of reasons. One of which was lack of sufficient information about the role and functions of social workers in families of children affected by CP. Moreover, participants were confusing the services provided by the South African Social Security Agency (SASSA) responsible for social security with those of social workers.

Subtheme 4.1: Lack of sufficient information about social work services

A study on psycho-social challenges faced by mothers caring for children with CP in Zimbabwe showed that participants had little knowledge about child protection issues and programmes (Mukushi, 2018:48). Similarly, of the twelve participants, it was disconcerting that eight had not received social work services. A participant who received assistance from a social worker expressed her unhappiness with the service and discontinued consultation. Despite probing, the participant did not disclose specific reasons for her dissatisfaction. Understandably, mothers of children with CP may opt not to share their fears to avoid rejection and discrimination (Odongo, 2018:25).

No, at the first one [simulation centre] ... So, the social worker was not productive. For instance, she would promise me that she will call and never did. She was never active for me, never. (P, 43 years)

I knew that when you have a child with CP you must have a social worker who will assist you but I was scared to consult one because I was no longer taking the child to the hospital for check-ups. (P, 36a years)

In certain instances, the social worker's failure to fulfil promises may be attributed to the lack of human resources which may result in inadequacy of social work services. However, a mother's failure to take her child for regular follow-up treatment may disadvantage her from receiving the required social work services.

Subtheme 4.2: Participants' lack of knowledge about roles and functions of social workers

It was concerning that participants did not know the rationale of consulting social workers to assist with their situation. The responses from eight participants showed little or inadequate information about the profession which was disturbing.

I also did not know about social workers and what they do, to be honest. (P, 36c years)

I have never been to a social work office before, I do not even know what they do. (P, 37 years)

No. I don't know at all, it has never even crossed my mind, I do not even think about it. (P, 55 years)

Likewise, a systematic review in Kenya on *the role of social workers in education for children with special needs* noted that "there is a general lack of sufficient professional recognition of social workers in Kenya and by extension in Africa" (Mavole, Mutisya & Wambulwa, 2017:45). This is due to the fact that most people do not understand the roles and functions of social work, even among some government officials.

DISCUSSION

The study set out to understand the circumstances of mothers with children living with CP. It highlights the psychological, emotional, financial and social difficulties they encounter. Even though they may feel overwhelmed by caregiving responsibilities at times their resilience is remarkable. They have adopted a positive attitude towards caregiving despite lack of support from the children's fathers and close relatives.

Their resolve is not deterred by these unfavourable circumstances; hence, they should be supported for sustenance.

Four themes have emerged from the data analysis. The first theme is on various reactions of parents after being informed about their children's condition. They express anger, disbelief, guilt, disappointment and denial which affect their social functioning.

The second theme shows circumstances encountered by mothers, namely lack of support from the children's fathers and their having to leave employment to care for their children which has resulted in their limited movement and interaction with other people. Ten mothers were unmarried. Except for the stimulation centre, these mothers had little support from their relatives who lived far from them and the community. Instead, some of the community members were sceptical about one of the participant's ability to care for her child. Conversely, it was heart-warming to learn that some siblings offered support to their mothers regarding caregiving responsibilities, even though this might be construed as depriving them of an opportunity to interact with peers. The involvement of fathers in the development of their children is beneficial for their psycho-social well-being. Of the twelve participants, eight were concerned that the biological fathers of their children were not involved in their upbringing in any way. This had a negative effect on the social functioning of these mothers. Mothers need respite care to allow them time to take a break from caregiving responsibilities. Moderate social services such as a stimulation centre, residential care facilities and health care facilities remain accessible to mothers and children with disabilities. Therefore, they should be informed and encouraged to utilise the available facilities to alleviate pressure on caregiving.

Theme three indicates community support from some members that serves to strengthen mothers. Community support is essential to alleviate negative perceptions towards disability. Theme four shows that eight participants did not use or request social work services due to lack of sufficient information about available services and the roles and functions of social workers.

SUGGESTIONS FOR PSYCHO-SOCIAL SUPPORT

Needs assessments should be conducted to identify the available social and health resources for children with CP, mothers' needs, challenges and the type of services they require. This information will assist a multi-disciplinary team consisting of health professionals and social workers in establishing responsive intervention strategies and support to harness the psycho-social functioning of mothers. Enlightenment of families, relatives and communities about the causes of disabilities should be expedited to eliminate stigmatisation and discrimination directed at people with disabilities (PWDs) (Amadasun, 2020:66). Therefore, social workers should keep abreast of new information on CP.

Psycho-social services can be grouped into three domains that affect children, their families and communities. These are to empower them to have skills and knowledge regarding problem solving, decision making and stress management; enhance their emotional and spiritual well-being to enable them to know and understand themselves, and to have a social well-being that would facilitate social interaction with peers, family and social networks (Southern African Development Community (SACD), (n.d.:30).

Support groups are essential in meeting the emotional and social needs of the affected mothers. Establishment of such groups for fathers is equally important for promoting mutual aid. There is also a need to develop or enhance a proper referral system and to encourage health professionals and educators at centres for children with CP to refer mothers of children with CP to social workers.

To offer effective psycho-social support to parents of children with CP, a social network must be established consisting of relatives, voluntary stakeholders from the community, faith-based and other organisations, unemployed youth, social workers as well as auxiliary social workers, including child and youth care workers. Social workers should facilitate training by health professionals of those involved on the nature of CP, its treatment and related topics. Trainees should also be familiarised with ethical principles and the South Africa POPI Act (Act No. 4 of 2013).

The celebration of the annual World Cerebral Palsy Day should serve as a platform to empower communities on issues of disabilities. Mothers of children with CP may be encouraged to share their experience. Furthermore, the roles and functions of social workers, support groups and social networks should be clarified and advertised in indigenous languages on different media platforms. Marketing of these services should be done on a continuous basis.

Since the introduction of the Fourth Industrial Revolution (4IR) fundamental changes have occurred in the way people live, work and relate to one another. Therefore, consideration should be given to offer some training via print media, radio, television or virtual platforms.

Below is a summary of practical support that may be offered to mothers to address their plight, alleviate their stress and caregiving burden. Volunteers such as retired social workers, nurses, educators and community members may be recruited to participate.

TABLE 2
SUMMARY OF CHALLENGES AND PRACTICAL SUGGESTIONS TO ADDRESS THESE

Challenges	Support required to enhance the well-being of mothers
Disappointment, rejection of the child, guilt, depression, confusion, fear, disbelief, anger and denial	<ul style="list-style-type: none"> • Conduct home visits and create a conducive environment for mothers to ventilate frustrations regarding their situation. • Listen actively and empathise during assessment of the problem and decision making. • Provide information and/or link mothers with professionals to provide the required information.
Burden of caregiving	<ul style="list-style-type: none"> • Link and encourage mothers to embrace community members or organisational support. Veterans may donate their time to help buy groceries, help children with school work, care for them in pairs (veteran) while mothers take respite outside the home.
Family or friends' support	<ul style="list-style-type: none"> • Encourage mothers not to alienate themselves but to rather accommodate those who volunteer their service for the benefit of the family.
Community social networks and organisations	<ul style="list-style-type: none"> • Link and encourage mothers to accept assistance from faith-based organisations for their spiritual well-being. • Embark on a fundraising drives to offer a transport allowance to network with members in need. • Arrange getaways and excursions for mothers, children and relatives to assist mothers with caregiving.

CONCLUSION

Children with CP require love and care like all other children. However, their disability presents a challenge to mothers as caregivers. To alleviate the pressure on these mothers, social workers, health professionals and communities should join forces in providing the needed psycho-social support to enhance the mothers' social functioning and to sustain their resilience. Further research is needed on first, the involvement of fathers in the upbringing of their children with disabilities in South Africa and second, on the fathers' needs, fears and challenges of having a child with CP.

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