Mothers caring for children with cerebral palsy: Suggestions for social work support

by

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DECLARATION

I declare that the study: **Mothers caring for children with cerebral palsy: Suggestions for social work support**, is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references.

	April 2021
SIGNATURE	DATE

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ABSTRACT

Caring for children with cerebral palsy present numerous challenges. Tension may arise which may contribute to mothers' inability to care for themselves as well as to cope with the demands of meeting basic needs of their children. This research study aims to develop an in-depth understanding of the experiences of mothers caring for children with cerebral palsy to proffer suggestions for social work support. A qualitative study supported by explorative, descriptive and contextual research designs were undertaken. Data were collected by means of semi-structured interviews with mothers caring for children living with cerebral palsy, aided by open-ended questions contained in an interview guide. Thematic analysis was utilised following Tesch's eight steps (cited in Creswell 2014:196) to analyse data and Lincoln and Guba's classic model (in Loh, 2013:5) was employed for data verification. The study adhered to ethical standards such as confidentiality, informed consent, anonymity and management of information.

The major findings highlighted that the birth of a child with cerebral palsy presents pleasant (e.g. siblings helps in caregiving; mother's love and care to the child and community support) and unpleasant experiences (e.g. mother's limited movements and leaving employment to care for the child) for mothers. The findings further revealed that some participants had little knowledge about the role and services of social workers. This raises a cause for concern that social workers do not market their services effectively. In addition, lack of support from the children's fathers was a huge concern which requires social work support. Despite the challenges and unpleasant experiences encountered by mothers, they have adopted a positive attitude towards caregiving. The findings culminated in the presentation of suggestions for social work support, recommendations for social work practice, policy, education and future research.

Key terms

Children, caring, mother, cerebral palsy, social work support.

LIST OF ACRONYMS

CP	Cerebral Palsy
CDC	Centers for Disease Control and Prevention
DSD	Department of Social Development
DWCPD	Department of Women, Children and People with Disabilities
IASSW	International Association of Schools of Social Work
ICSW	International Council on Social Welfare
IFSW	International Federation of Social Workers
ACPF	The African Child Policy Forum
CRPD	The convention on the Rights of persons with Disabilities
CRC	The convention on the Rights of the child
UNCRPD	UN Convention on the Rights of Persons with Disabilities
UNCRC	UN Convention on the Rights of the Child
UNICEF	United Nations Children's Fund
UNDP	United Nations Development Programme
WHO	World Health Organization

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CHAPTER ONE

GENERAL ORIENTATION TO THE STUDY

1.1 Introduction and Background

One of the most common developmental disabilities in South Africa is Cerebral Palsy (CP) (Couper, 2002:549). According to Masood, Arshad and Mazahir (2015:1) CP is a neurological disorder that comprises a group of disabilities, which influences a child's inability to exercise control over body movements. This difficulty with the timing of motor movements increases due to inadequate brain development. Ketelaar, Volman, Gorter and Vermeer (2008:825) state that CP is considered the most severe form of physical disability affecting children. Furthermore, Ribeiro, Sousa, Vandenberghe and Porto (2014:441) postulate that among the "chronic conditions in childhood, cerebral palsy is the most common cause of disability, with a prevalence of 2 to 3 cases per 1000 live births".

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 children" (Centers for Disease Control and Prevention ([CDC], 2020:1). According to Al-Gamal and Long (2013:624) the prevalence of CP in Europe is 2-2.5 per 1 000 live births. Donald, Samia, Kakooza-Mwesige and Bearden (2014:30-35) conducted a systematic review to identify data on the prevalence, etiology, comorbidities, outcomes, screening tools, and treatment of CP in Africa. The incidence differs broadly from country to country with approximately 2-10 per 1 000 live birth globally (Couper, 2002:549; Mung'ala-Odera & Newton, 2006:249; El Tallawy, Farghaly, Metwaly, Rageh, Shehata, Elfetoh, Hegazy, El-Moselhy, Rayan, Al-Fawal & Abd Elhamed, 2010:185).

South African studies (Couper, 2002:594; The African Child Policy Forum [ACPF], 2011:15) show *a high prevalence rate for CP* (10 per 1 000). One of the main causes of CP is birth-related trauma is and it is mainly manifested in intellectual impairment (Couper, 2002:549). The contributory factors of CP differ according to developed and developing countries (Cooper, 2015:107). Prenatal causes are common in developed countries (Cooper, 2015:107; Nelson & Blair, 2015:946), whereas perinatal causes (i.e. complicated labour due to lack of oxygen, infections such as Tuberculosis

Meningitis related with HIV) and postnatal (i.e., uncontrolled epilepsy or head injuries) and postnatal (i.e., uncontrolled epilepsy, or head injuries) are common in developing countries such as South Africa (McLaren, 2014:1).

A study on the challenges experienced by mothers caring for children with CP was conducted in Zambia (Singogo, Mweshi & Rhoda, 2015:4). The study revealed that mothers who care for children with CP, experience economic, psychological, physical and social challenges. Moreover, with these challenges mothers find themselves unable to cope with the demands of meeting the basic needs of their children with CP. Mothers of children with CP, experience financial instability due to lack of employment opportunities (Borst, 2010:467; Dambi, Jelsma & Mlambo, 2015:2). Children with CP need a lot of special care, they are expected on a monthly basis to visit medical specialists or a hospital for medical check-ups and this may cause financial stress to mothers. When looking at the realities, the majority of mothers caring for children with CP rely on CDG. The hospital visitations require a special transport, in which the mother has to hire at times. The child may require social assistance in the form of a social grant, regular medical attention or major surgery. Mathebane's (2016:169) observation is that the birth of a child with disabilities (down syndrome or CP) does not only "create financial, social and medical burdens for the individual or family, however, it also places fiscal strain on the state". The child may require social assistance in the form of a social grant, regular medical attention or major surgery. In some instances, the child may be institutionalised in cases where there is serious disability.

Care of a child with CP may create tension (Alaee, Shahboulaghi, Khankeh, Mohammad & Kermanshahi, 2015:2147) and other health problems for the mother. The children become reliant on their mothers. For instance, the children cannot bath, eat and dress on their own. Consequently, this places an enormous strain on the mother. According to Wang and Jong (2004:334-335) children with CP display *prominent motor dysfunction* associated with other developmental disorders. Researchers have demonstrated elevated levels of stress in mothers of children with developmental disability (Tonga & Duge, 2008:219; Mathebane, 2016:180). For instance, mothers end up having more feelings of incompetence, sickness, and inability to cope with parenting, than mothers of developmentally normal children.

The caregiving role may be overwhelming, bringing grief and sadness given the reality of lost expectations, hopes and dreams (Huang, Kellet & St John 2010:1218). No mother expects or wishes to give birth to a child with disability (Taub, 2006:52). Mathebane (2016:167) stated that giving birth to a child with disabilities may cause trauma and subsequently affect the psycho-social functioning of mothers. Olawale, Deih and Yaadar (2013:160) investigated the psychological impact of families with children living with CP. Fifty-two (52) mothers participated in this research and the findings revealed that caring for children with CP creates an imbalance of family finances due to job loss and thus affects the family 's social functioning. In addition to the emotional problems, mothers have to deal with the undesirable insolences of friends, families and the community at large (Ngubane & Chetty, 2017:36). They may be blamed and discriminated against for giving birth to a child with CP (Baker & Heller, 1996:513; Lecavalier, Leone & Wiltz, 2006:172). Blaming the mother for giving birth to a child with disability is a challenge that is seen in certain traditions in developed (Colker, 2015:1206) and developing countries (Singogo *et al.,* 2015:2). From the moment of pregnancy, if the child is born with a disability, mothers are blamed for any difficulties their child or fetus faces. She is considered either negligent for failing to do enough to assist her child (Colker, 2015:1206).

It is known that mothers' physical and mental health are connected to the child's overall development. Therefore, mothers' psychological stress may likely disturb the parent's functioning and consequently affects the child's development (Wang & Jong, 2004:334). Physical health problems originating from undue stress (Tonga & Duge, 2008:219) can also be a concern. Hence, it is apparent to note that the social functioning of mothers could be negatively affected due to the demands of caring for their children with CP (Olawale, Deih & Yaadar, 2013:160; Singogo *et al.,* 2015:1). Family has been a strong institution in every society. They serve the purpose of development of generations. Many mothers have positive attitudes towards their children living with disabilities, and social support is an important coping resource. Ritchie (2013:1) mentioned that families "learn to tolerate, accept and hopefully celebrate children who are not what they originally had in mind." Adequate social services such as special education and health care remain accessible to children with disabilities, especially with communication disorders. Therefore, it is essential that the mothers become informed and exposed to such social services in order to cope with the challenges of caring a child with CP.

In some cases, mothers are not trained to look after their children with special needs. Moreover, the situation becomes worse when there is a lack of support from family members and community at large. There is an African proverb, which says: *It takes a village to raise a child.* The community plays an integral part in accepting and caring for children with CP. In the African culture, people have a belief that when a parent gives birth to a child with disability, it means that the parents have wronged the ancestors or have sinned (Haihambo & Lightfoot, 2010:76). Some community members have negative attitudes towards people with disabilities (Ngubane & Chetty, 2017:36). Some families perceive giving birth to a child with disabilities as a punishment from *gods* (Bunning, Gona, Newton & Hartley, 2017:3) for a wrong act committed by a family member, most especially the mother is blamed. It is not surprising, that many households hide their children living with disabilities as a means of escaping the external stigma associated with disability (Carr, Linehan, O'Reilly, Walsh & McEvoy, 2016:663). External stigma refers to the experience of unfair treatment by others (Gray, 2002:72). Stigma can be felt internally, leading to secrecy and denial. Internal stigma (felt stigma or self-stigmatization) prevents people to talk about their experiences. People also fear to ask for help due to discrimination (Gray, 2002:72; Dehnavi, Malekpour, Faramarzi & Talebi, 2011:252). External stigma can be as harmful as internal stigma since it leads to withdrawal and restraint of social support. Mothers caring for children with CP may opt not to share their challenges, experiences and fears, in order to avoid being rejected or causing more suffering.

According to Masasa, Irwin-Carruthers and Faure (2004:42), South Africa is a multiethnic and bilingual nation with many diverse morals, customs and cultural beliefs. There is a belief that a child’s disability *is one’s fault* if one does not take the child to the clinic for immunisation, whereas others believe that disability is due to ‘witchcraft’ (Cowles, 2003:13; Mathebane, 2016:177). In some cultures, congenital abnormalities are perceived largely as a curse, or the result of witchcraft (Cowles, 2003:13). Against this background, social workers in health care are distinctively positioned to help communities to improve the psycho-social and cultural dynamics associated with disabilities. One of the standards and indicators for cultural competence in social work practice pointed out by the National Association of Social

Workers (NASW) (2016:1) is that cultural competence requires social workers to recognise the strengths that exist in all cultures while renouncing cultural practices and beliefs that violate human rights and dignity.

In many instances, mothers end up opting for placement in various Non-Governmental Organisations or Stimulation Centres due to lack insufficient information on how to provide care to a child with CP (American Academy of Paediatrics, 2017:1). Children with CP need support and to be treated like any other person, irrespective of their disability. One of the important component used in interventions is self-efficacy. It promotes empowerment and self-reliant (Guillamon, Nieto, Pousada, Redolar, Munoz, Hernandez, Boixados & Gomez-Zuniga, 2013:1).

The South African president declared the outbreak of Covid-19 a national state of disaster in terms of the Disaster Management Act (No 57 of 2002). This pandemic has affected everyone in the world. Some of its ripple effects in families with children living with disabilities include among others; the parents' inability to observe social distancing which is regarded as the best strategy to avoid transmission of the virus. Generally, children are less likely to show symptoms of COVID-19 and therefore those with disabilities may be at *high risk* due to secondary health conditions (Halfon, Houtrow, Larson & Newachek, 2012:13).

Based on the above experiences and challenges, mothers caring for children with CP require social work support to cope with the needs and demands of caring for children with CP. To effectively offer support, social workers may collaborate with health professionals through educational talks. Social workers employ a broad spectrum of knowledge, values and skills, to improve the child with CP and his/her mothers' social functioning (Bridge, 2008:15). Children with disabilities are given attention by various South African legislations (Children Act 38 of 2005 (section 11); South African constitution, 1996; White Paper for Social Welfare, 1997; White Paper on the rights of Persons with Disabilities Act No. 39792 of 2016). The aforementioned legislations put emphasis on the rights of children with disabilities and their families. Social workers may advocate for the rights of children living with disabilities and their families.

Social workers as case managers may identify service users' strengths and needs in order to determine the type of support system and services required to improve their social functioning (Cowger, 1994:262; Reckrey, Gettenberg, Ross, Kopke, Soriano &

Ornstein 2014:334). During the assessment process, an individualized plan to support the children with CP is created in order to improve their sense of well-being (Taylor, 2012:1293; Reckrey, Gettenberg, Ross, Kopke, Soriano & Ornstein 2014:334). Various roles are employed by social workers during the helping process to address the various needs and challenges of parents and their children with CP. Social workers serve as brokers by linking mothers and their children with disabilities with available and relevant resources and services. They offer support to parents by referring them to health professionals to comprehend their children's diagnosis, by explaining the implications of their children's disability and how it will affect their daily lives, and in making lifestyle adjustments to accommodate their disability. Social workers are helpful by locating community assistance and educational programme for children with CP and their families. This enables parents to cope with the stresses and demands of severe CP.

Support groups are essential in meeting the emotional and social needs of the affected mothers. Support groups are facilitated by social workers to provide relevant information and support. It also serves as a platform for group members to share their experiences to uplift one another. The African Child Policy Forum (ACPF) (2011:43) calls for Community education on discrimination against children with disabilities. There is a need for collaboration between various social and health professionals to empower and strengthen mothers' caring for CP children's resilience through information dissemination on how to care for children with CP. Social workers in collaboration with health professionals such as nurses, occupational therapists and psychologists may provide mothers with support, medical information and guidance.

1.2 Problem statement

When a mother learn that her child has a disability, this information comes as a s blow to her. She "begin a journey that takes them into a life that is often filled with strong emotions, difficult choices, interactions with many different professionals and specialists, and an ongoing need for information and services" (National Information Centre for Children and Youth with Disabilities, 2003:2). Feelings of loneliness and isolation emerge and mothers may not know where to begin their search for information, support and assistance.

Caring for a child with disabilities such as CP, is accompanied by numerous challenges such as extra financial constraints (Olawale, Deih & Yaadar, 2013:161; Mathebane, 2016:169). Furthermore, some mothers of children living with disabilities are often marginalised and perceived as being 'unable' in all spheres of life. They may also face resistance and negative attitudes from the family and society (Ngubane & Chetty, 2017:36). Consequently, the challenges may affect mother's physical and psychological health (Tonga & Duge, 2008; Guyard *et al.,* 2011; Al-Gamal & Long, 2013; Mathebane, 2016).

According to Lindsay (2016:153), CP affects the child's social functioning and how the child relates to other children. 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). These experiences do not only affect the children, but also affect the mothers who sometimes do not even know how to help their children, subsequently, becoming depressed (Ketelaar *et al.,* 2008:825). In some cases, they may not have assistance and support with daily activities of caring for a child with CP. Consequently, they may become overwhelmed, experience fatigue and ultimately unable to take proper care of their own health (Garip, Ozel, Tuncer, Kilinc, Seckin & Arasil, 2016:757). At times, they might use self-medication to treat the physical symptoms (such as headache and body pains) experienced, in order for them to be there for their children.

Social workers acknowledge the association between individuals and their social, economic, psychological, cultural, physical and natural environments. Social workers are committed to harness the social functioning of families caring for children with disabilities. Through assessments using casework, group work and community work, social workers function from a holistic Person-In-Environment (PIE) perspective when offering interventions (Australian Association of Social Worker, 2016:3) to mothers and their children living with disabilities. Accordingly, social workers maintain a dual focus on improving both the well-being and addressing any external issues that lead to injustice and discrimination (Australian Association of Social Worker, 2016:3).

Social work support focuses on sustaining and improving the quality of life of service users. They apply a variety of knowledge and skills to assist vulnerable groups in various settings. During the intervention process, social workers use evidence based and empowerment framework (Australian Association of Social Worker, 2016:3). Due to complex social, psychological, family and institutional dynamics, a multidisciplinary team intervention is offered.

The birth of a child with disability may bring changes in the family functioning. Such changes bring anguish and uncertainties regarding the future of both the child and family (Masood *et al.,* 2015:1). Globally, in various disciplines, several studies have been conducted on the experiences of mothers of children with CP (Wang & Jong, 2004:334-335; Moore, 2005: 1-125; Ketelaar *et al.,* 2008:825; Alaee *et al.,* 2015: 2147; El-sayed Youssef, Ahmed & Mahmoud, 2013:1099-1104; Ribeiro, Sousa, Vandenberghe & Porto, 2014: 440-447; Dambi, Jelsma & Mlambo, 2015:1-10); and coping strategies of mothers of children with CP (Krstić, Mihić & Oros, 2017:385-395; Kumari & Singh, 2013). In South Africa, some studies on coping mechanisms (for example; Draper, 2009; Burg, 2016) and experiences (for example, Steadman, 2015; Quinn & Gordon, 2011:191-197) of mothers with CP have been identified. Regardless of extensive research conducted on the experiences of caregivers caring for children with CP, there has been relatively little attention paid to the role of social workers (Oppé, 1967:170; Bridge, 1999; 2008:15; Stanton, 2012:70) and suggestions for social work support (Rapodile, 1998) in providing services to mothers caring for children with CP. Therefore, this study was conducted to inform suggestions for social work support when rendering services to mothers with CP.

Singogo (2015:5) recommends that programmes and policies to support mothers of children with CP may be developed and implemented. In addition, a family-centred approach focusing on the management of children with CP should be taken into account due to the challenges that do not only affect mothers alone, but also affects the family as a whole.

In this study, the problem statement was lack of sufficient information on the experiences of mothers caring for children with CP in a particular township situated in the City of Johannesburg Metropolitan Municipality (Gauteng province).

1.3 Rationale for the study

The researcher is an employee at a Non-Governmental Organisation that offers services to mentally and physically handicapped individuals. From observations, mothers caring for children with CP are hopeless, drained and scared to seek help due to the stigma attached to children with disabilities. This observation is consisted with the findings by researchers (Gray, 2002:72; Dehnavi, Malekpour, Faramarzi & Talebi, 2011:252). Furthermore, when mothers are not informed and empowered on how to cope with the demands of looking after children with CP, they may become stressed and anxious, subsequently, becoming unable to assume their parental role. Children are being placed in residential care facilities, due to lack of family support and resources such as transport and other aid to assist in taking care of the children. Some children with CP are emotionally and physically abused, and community members report such cases to social workers. Consequently, in some instances, community members prefer to remain anonymous. This may directly affect the social functioning of the mother and child; moreover, the immediate family may also be affected. When mother’s health is compromised, there could be an imbalance in one or more systems. Taylor, Pallant, Law and Howie (2012:1732) mentioned that many mothers of children with developmental disabilities are known to experience high levels of stress, and compromised mental health. According to Wang and Jong, (2004:335) understanding the factors associated with parental stresses can help social workers and other health professionals develop appropriate strategies and supportive resources, which could help mothers to cope when caring for children with CP.

In 1995, South Africa’s ratification of the UN Convention on the Rights of the Child (UNCRC) and the UN Convention on the Rights of Persons with Disabilities (UNCRPD) (2007) has facilitated the implementation of programmes towards the fulfilment of the rights of children with disabilities. In addition to the above mentioned reasons, based on the researcher’s own experience, there is a need to obtain the necessary information to assist in filling the gap with regard to the situation of children with disabilities and the basic contributory factors of their situations (Department of Social Development (DSD), Department of Women, Children and People with Disabilities (DWCPD) and the United Nations Children's Fund (UNICEF), 2012:9). Another reason that motivated the researcher to undertake this study, is the necessity to obtain deeper insights that could be valuable to medical and generic social workers who play a vital role in offering direct services to mothers with CP. Social workers are at the forefront in promoting and protecting the rights of mothers caring for children with CP and to raise awareness to change negative attitudes that stigmatize and marginalize children with disabilities.

Social workers and other health professionals will gain an understanding of the suggestions for social work support for mothers caring for children with CP. The research findings will further enable social workers to improve service delivery when providing services to mothers and children with CP. In addition, this research will serve as a baseline for future in-depth studies for researchers who are interested in a similar or related topic. The study will also contribute to the body of knowledge of the social work profession.

1.4 Research Methodology

Qualitative data was collected as the researcher needed a well-informed of the the challenges of mothers caring for children with CP. This is confirmed by Holton and Walsh (2017:191) who pointed out that there is need to discern '*emerging relationship between concepts'*.

According to Rubin and Babbie (2013:40), the qualitative research approach is "more likely to tap the deeper meanings of particular human experiences, and generate theoretically richer observations that are not easily reduced to numbers.'' The approach assisted the researcher to uncover various factors involved under study, meanings of complex phenomena were developed and conceptualised. A qualitative study was supported by an explorative, descriptive and contextual designs. Data were collected by means of semi-structured interviews with twelve mothers caring for children with CP, aided by open-ended questions contained in an interview guide. Thematic analysis was utilised following Tesch's eight steps (cited in Creswell 2014:196) to analyse data and Lincoln and Guba's classic model (in Loh, 2013:5) was employed for data verification. The study adhered to ethical standards such as confidentiality, informed consent, anonymity and management of information.

A more wide-ranging presentation on the application of the research methodology, that is, the qualitative research approach, research designs, method of data collection and analysis, as well as verification of data is provided in chapter three.

1.5 Theoretical framework

Theories are developed to explain different aspects of people's behavior. Neuman (2014:57) defines a theory as a system of interconnected ideas, which condenses and organizes knowledge about the social world. It serves as a type of systematic ’story telling’ that explains how some aspect of the social world works and why. A theoretical framework helps with clarifying how research findings can be analysed and interpreted. Various scholars have utilized the concepts ecosystem *approach* (e.g. Pardeck, 1988; Dionne & Dupras, 2014; Nazar, 2020) or ecosystem *perspectives* (e.g. Teater, 2014; Ahmed, Amer & Killawi, 2017) to understand a particular situation. For the purposes of this study, the ecosystem *approach* is applied to understand the phenomenon under study.

In this study, the theoretical basis for mothers living with children suffering from CP is found in the ecosystems approach, which describes the relationship that exists between individuals and their environment. The word *ecosystem* is an abbreviation of the term, ecological system, which originates from the work of Bronfenbrenner (2005:106). The ecosystems approach integrates concepts from both systems theories and the ecological perspective, which focus on the environment (Zastrow & Kirst-Ashman, 2016). Moreover, it conforms to the concept of person-in-environment (PIE), a foundational conception in social work practice, which emphasizes the understanding of the dynamics of human behavior (Sheafor & Horejsi, 2012:12). The concept ’person in environment’ is grounded on the idea that an individual and his or her behavior cannot be understood sufficiently without reflecting on the various aspects of that individual’s environment (social, political, familial, temporal, spiritual, economic, and physical) (Kondrat, 2011:2).

The ecosystems approach is applied at multiple levels, that is, micro, mezzo, exo, and macro levels (Wolf-Branigin, 2013:17). The ecosystems approach is utilized in social work in order to understand the interconnected networks and their complexity (Mattaini, 2008:355). The “client's ecosystem is composed of numerous overlapping systems including the family, the workplace, and the community, as well as other critical subsystems unique to each client" (Pardeck, 1988:137). Social workers use concepts of micro (individual), mezzo (family), and macro (community) levels (Wolf-Branigin, 2013:17; Lacasse & Gambrill, 2015:69; Ebue, Uche & Agha, 2017:84) interaction to assess how illness or disability affects the individual and other interrelated systems. The ecosystem approach requires social workers to bridge the micro, mezzo and macro levels in service delivery, with the aim of promoting and empowering the well-being (Saleebey, 2013:43) of individuals. The "micro, mezzo and macro systems affecting the service user's system creates a lens that broadens understanding of their situation" (Clemons, 2014:1). The levels conform to the three social work methods, namely casework, group work and community work. Casework is directly linked to the micro level of social work practice as the services are directed at individuals and families; group work is targeted at the mezzo level; while community work is rendered at the macro level of practice.

At the micro level, social work intervention is largely therapeutic and geared towards providing support and resolving the emotional problems experienced by service users; the social worker usually helps people to explore feelings, confront problematic issues and make life plans. In this case, the social worker addresses the challenges experienced by mothers caring for children with CP.

At the mezzo level, intervention is geared towards the family (Clemons, 2014:11) of a child with CP. The family is seen as the most valuable source of support for the child (Neely-Barnes & Dia, 2008:93). The family also serves as part of a societal context where the child develops (Gallimore, 1993). Therefore, if the mother is stressed and not coping well, this may affect the child's development. The social worker educates family members about the disability. Education is an essential tool in empowering individuals with the knowledge, skills and self-confidence necessary to cope with their everyday situations. Moreover, social workers link the family with relevant and available resources that will enhance the way of life and that of the child diagnosed with CP. Therapeutic or support groups are also established in this regard to assist family members to deal with their own emotions resulting from the diagnosis of their child (Zuurmond, Nyante, Baltussen, Seeley, Abanga, Shakesphere, Collumbien & Bernays, 2018:2).

At the macro level, social workers assume the advocacy role to “seek to improve the treatment of people with disabilities through influencing legislation and agency provision of services to be suitable to the needs of people living with disabilities” (Kirst-Ashman 2013:342). At this level, social workers can also, through campaigns, educate community members by providing them with information about disability and related issues (Kirst-Ashman 2013:342). As part of the multi-professional team, for instance, social workers may consult with other professionals such as occupational therapists, speech therapists, psychologists, nurses and medical personnel to develop a coordinated team plan for a family of children with CP.

Notably, during the helping process, an ecosystem approach can be pictorialized as an eco-map or a genogram (Hartman, 1995:34). These graphic representations display detailed information about individuals and their environment. These tools are utilised by social workers to illustrate a diagram or sketch of where a parent caring for a child with CP discovers herself with regard to surrounding systems. This will enable mothers to become self-reliant and assume control of their lives, regardless of their situation. Considering the challenges facing mothers of children with CP, the ecosystems approach was appropriate to guide and inform the study as it recognises the relationship that exists between individuals and their environment.

1.6. RESEARCH QUESTION, GOAL, AND OBJECTIVES

The following section focus on the research question, research goals and objectives of the study.

1.6.1 Research question

A research question is the all-encompassing question to which the researcher pursues to answer (Blaikie, 2010:8). Hence, a research question gives direction, guidance and structure on the choice of data to be collected and analysed. Andrews in Trafford and Leshem (2008:90) postulates that a “research question(s) serves as a tool to focus on the choice of research methods”. Research questions enabled the researcher to narrow down her research literature based on the research topic. Moreover, prevent her from drifting her original purpose, but to keep focused on the goals of the study.

According to Creswell, Ebersohn, Ferreira, Ivankova, Jansen, Nieuwenhuis, Pietersen, Plano Clark & Van der Westhuizen, (2011:3) there are two reasons why researchers need a research question. For instance, to give direction to the researcher and to provide a focus for data collection (Neuman, 2014:125).

Creswell *et al.* (2011:3-4) identified the requirements for a good research question. The research question should be *concise*, focusing sharply on the issue of interest. The research question formulated for this research is *clearly* formulated and understandable and leaves no uncertainty as to what is being planned for the study. It is operationalisable and easy to implement in practice. The question is *open-ended*, as the 'what' question was asked to ensure that no obvious answer can be posed. The question is *elegant*. It is posed in a way that is parsimonious (limited words) and conveys reach meaning. It should be *timely*, addressing a pressing issue of importance at the point in time. The research question must be *theoretically rich* to raise and generate other interesting questions. It is *self-explanatory*. In other words, it does not need further elaboration, but speaks for itself. It should be *grammatically correct*, that is, attentive to accuracy of grammar. A good research question has *panache; it* is therefore provocative, stimulating and interesting.

The following two concise interrogative questions directed the study (Grove, Grey and Sutherland, 2017:691):

1. What are your experiences of caring for a child with CP?
2. What possible suggestions would you recommend for social work support in response to challenges of mothers caring for children with CP.

1.6.2 Research goals

According to Fouché and De Vos (2011:94), a 'goal' often implies the broader, more abstract conception of 'something which you plan to do or achieve'. Thomas and Hodges (2010:38) refer to a research goal as the "overarching purpose of the research project which sets the stage for the objectives of the study". A research goal gives a broad indication of what the researcher wishes to achieve and to determine the type of the study to be conducted (Klopper, 2008:66). It is an end product that the researcher wants to get. It is a dream or an aim for the study.

The following research goals aim to specify what the study intends to achieve (Braun & Clarke, 2013:53):

- To develop an in-depth understanding of the experiences of mothers caring for children with CP.
- To proffer suggestions for social work support.

1.6.3 Research objectives

Research objectives describe what the researcher expects to achieve from a research project. Whittaker (2012:18) stated that for research to be successful, the objectives should be formulated to give outline of what should be done. Gilbert and Stoneman (2016:51) explains that research objectives “are often embedded in the form of the research question itself and state what purpose the collection of data will accomplish and the types of knowledge to emerge, whether descriptive or analytical”. A research objective is a clear, concise and declarative statement, which provides direction and accurate description of the specific actions the researcher undertook in order to achieve the goals of the research study.

Objectives formulated in respect of this study are as follows:

- To explore and describe the experiences of mothers caring for a child with cerebral palsy.
- To establish coping mechanisms of mothers caring for a child with cerebral palsy.
- To describe suggestions for social work support of mothers caring for children with CP.
- To draw conclusions and make recommendations based on findings of the study

1.7. ETHICAL CONSIDERATIONS

Research that involves human subjects or participants raises distinctive and multifaceted ethical issues (Blaikie, 2010:31). Research ethics is interested in the analysis of ethical issues that are raised when participants are involved in research (Fouka & Mantzorou, 2011:4). Social research ethics are described as a set of ethical principles that should be taken into account when conducting research (Neuman, 2011:502). The purpose of research ethics is to protect human participants (Yip, Han, Hng, 2016:684). It ensures that a research is conducted in a way that serves the interests of individuals, groups, and/or communities as a whole. Furthermore, research ethics examine specific research activities for their ethical soundness, looking at issues such as the management of risk, protection of confidentiality, and the process of informed consent (Atkinson, 2012:188; Sanjari, Bahramnezhad, Fomani, Shoghi, Cheraghi, 2014:1). In this study, the researcher completed the risk assessment form. The research topic is deemed a low risk, since the focus of the study is based on mothers caring for children with CP. The following ethical issues were considered during the process of the planned research project:

1.7.1 Informed consent

Informed consent refers to a process of research which highlights that participants are afforded an opportunity to acquaint themselves with information, details and objectives of the research project and they agree to be part of it. It also refers to a "procedure that is utilised to safeguard the participant rights when they approve their participation in the conducted research" (Homan in Franklin, Rowland, Fox & Nicolson, 2012:1731). Patton (cited in Strydom, 2011:117) have suggested that, prior the interview, participants must be informed about the importance of the information they will share. In this research study, an informed consent of participants was obtained as follows:

- Participants were provided an informed consent letter (Cf Addendum A) from the researcher by hand
- To protect the integrity of the participants, the researcher ensured that participants' names were changed to pseudonyms.
- When interviews are transcribed from local languages into English and data obtained is sifted and sorted, the researcher used code numbers for the

information to be quoted in the research report, thereby ensuring confidentiality and participants' anonymity.
- Participants were told that their signed consent form would be stored in a confidential place.

1.7.2 Confidentiality

During fieldwork, the researcher is expected to have a strong moral obligation to uphold the confidentiality of data (Neuman, 2014:469). This obligation includes keeping information confidential as well as disguising participants' names in field notes. Confidentiality means to reassure participants by preserving the promise of not sharing their stories to someone else without their permission (Goredema-Braid, 2010:51). This also implies that the researcher cannot directly quote a person in a research report. Moreover, the researcher has ensured that participants' information is not released to anyone without their permission. The information that participants have shared, was kept confidential, the audio recordings and transcripts made were safely kept and were only accessed by the researcher, supervisor and an independent coder. The participants' real names were not used and all information that was linked to participants were removed.

1.7.3 Anonymity

Participants' identities throughout the research process must be protected (Goredema-Braid, 2010:51). Furthermore, Thyer (2010:164) says that anonymity arises when the researcher cannot link a participant to their data. Anonymity means that the researcher protects "privacy by not disclosing a participant's identity after information has been gathered" (Neuman, 2014:154). King *et al.* (2017:262) are of the view that anonymity is seen when a person's identity, or his or her "personally identifiable information" is publicly unknown. Researchers are encouraged to be careful with regard to the manner in which sensitive information is portrayed. In this study, anonymity was preserved by using alphabets instead of real names of the participants.

1.7.4 Debriefing of participants

According to Babbie (2016:68) a “debriefing entails interviews to discover any problems generated by the research experiences so that those problems can be addressed”. This is especially important if participants have been affected emotionally by that participation. Debriefing of participants is offering counselling in case participants are not coping emotionally during the process of data collection. According to De Vos *et al.* (2011:122) debriefing usually refers to sessions which research participants get an opportunity to work through their experiences and its aftermath after the study. Although arrangements have been made for debriefing, the services of a debriefer, were not utilized in this study (Cf Addendum G).

1.7.5 Management of information

It is essential for the researcher to ensure that “relevant procedures are in place for the collection, handling, transfer, storage and disposal of data” (Van den Eynden, Corti, Woollard, Bishop & Horton, 2011:17). The researcher used a computer to develop an electronic database. A password was created to reduce the risk of access to data by unauthorized persons. Field notes and transcripts were kept in a lockable filling cabinet to protect the data obtained from participants (Flick, 2011:75). The researcher ensured that participants’ information is protected and is not accessed by other people.

Participants were asked permission to publish their information (Cf Addendum C). To maintain anonymity, the researcher was vigilant when presenting the results, that is, the researcher assigned each participant a unique quote such as a letter of the alphabet when reporting results.

1.8 CLARIFICATION OF KEY CONCEPTS

In this section, the following key concepts relevant to the study are clarified.

1.8.1 Mother

A mother is a generous, loving human who sacrifices many of her wants and needs for the sake of her children (Diranian, 2015:1); a female parent of the child (Taylor, 2011:124). Mothers perform the role of a disciplinarian and protector (Brooks, 2012:18). Thus, dependent on the context, women can be considered mothers by virtue of having given birth, by raising their child(ren), supplying their ovum for fertilization, or some combination thereof. In this study mothers refers to carers who support the physical, emotional, social, and intellectual development of a child with CP from infancy to adulthood.

1.8.2 Child

The Children's Act No. 38 of 2005 (2006: section 1) defines a child as "any person who is under the age of 18". Similarly, a child is defined as any person under the age of 18 by the United Nations Convention on the Rights of the Child (2010:1). According to Hornby (2006:245), a 'child' means a young human who is not yet an adult. In this study, a child is a young individual who is under the age of 18 diagnosed with CP.

1.8.3 Caring

Caring means being a "bridge to the child on the edge, through building a safe atmosphere in order to meet the child's basic needs" (Mattsson, Arman, Castren, Forsner, 2014:336). The overall impression is that the phenomenon of caring is seen when providing physical care, emotional needs and daily parental care for the child with special needs. Waruta and Kinoti (2000:1) states that 'caring' is the physical, emotional and spiritual nurturing by parents or guardians during infancy and childhood development. According to Masango (2005:916), the African concept of caring (Ubuntu) involves all the members of the village or community, family and relatives. In this study, caring means the practice of looking after children with CP, who are unable to look after themselves.

1.8.4 Cerebral palsy (CP)

CP is a heterogeneous condition with various causes such as multiple neuropathological patterns in brain images, and a number of associated developmental pathologies including autism, mental disability, alterations in perception, communication and behaviour, epilepsy and visual deficiencies (MacLennan, Thompson & Gecz, 2015:779; Hiratuka & Matsukura, 2010:537). Cerebral palsy is one of the most common causes of physical disability in childhood (Lindsay, 2016:153). Furthermore, Rosenbaum (2007:9) stated that the motor disorder of CP is often accompanied by disturbances of sensation, perception, cognition, communication and behaviour. In this study, CP refers to a group of disorders affecting a child’s ability to move due to damage of the developing brain.

1.8.5 Suggestions

A suggestion refers to a ‘proposal’ or ‘idea’. Suggestions allows one to have an “option to accept or reject what is being suggested” (Al-Aadeli, 2013:15). The reader may decide to acknowledge the suggestion or not. It is essential, for researchers to avoid enforcing any suggestion or proposal to readers (Kratzer, 1991:645). In this study, a suggestion refers to a proposal made or an idea that has been put forth for social workers to consider when rendering services to mothers caring for children living with CP.

1.8.6 Social worker

The term ‘social worker’ in the South African context "is a protected title in that no person without the requisite qualification and registration with the South African Council for Social Service Professions may use the title or practice as a social worker” (SACSSP, n.d.:5). The term SOCIAL WORKER has been defined by the National Association of Social Workers as: “Graduates of schools of social work (with either bachelor’s, master’s or doctoral degree) who use their knowledge and skills to provide social services to service users” (who may be individuals, families, groups, communities, organisations, or society in general) (Zastrow, 2010:5). In this study, social workers are helping professionals who utilize the primary methods of intervention guided by a broad range of knowledge, skills, values, ethics and techniques in order to enhance and support mothers caring for children with CP.

1.8.7 Social work support

Social Work is defined as “the professional activity of helping individuals, groups, or communities to enhance or restore their capacity for social functioning and to create societal conditions favourable to their goals” (Zastrow, 2010:61). Social workers using the five methods (casework, group work, community work, social work research and social work administration) provide a range of support and assistance that may be needed to improve the social functioning of individuals, groups and communities (Rwomire, 2011:1). For instance, a support may be offered through the provision of information on available resources and services, advocacy, assisting children with disabilities and their families during periods of hospitalization. Other sources of support may include, referral to community organisations’, liaising with relevant stakeholders and multi-professional team. When providing support, social workers are expected to assist in restoring, maintaining and enhancing the social functioning of individuals and the society (South African Council for Social Service Profession, n.d.:8). This obligation involves the development and equal distribution of resources and services to meet diverse needs of service users (Dolgoff, Harrington, Loewenberg, 2012:180). In this study, social work support, means providing social welfare services to support and empower mothers caring for children with CP.

1.9. STRUCTURE OF THE REPORT

This research report consists of the following chapters.

Chapter 1 serves as an introduction and general orientation to the research report. The content of this chapter consists of introduction and background of the study, problem formulation and problem statement. Rationale for the study, research question, goal and objectives; research approach and design, ethical considerations, key concepts and the outline of the research report are discussed.

Chapter 2 provides an overview of the theoretical frameworks that informed this research study. Theoretical perspectives and models based on women caring for children with CP are discussed in detail. The theories and models include the ecosystems' approach, empowerment model, resilience and strengths-based perspective. The chapter further provides detailed account of previous research based on literature review. For instance, the meaning of CP, its causes and symptoms are discussed and the challenges encountered by women caring for children with CP.

Chapter 3 discusses a detailed research methodology, which comprises the application and implementation of qualitative research approach.

In **Chapter 4** the research findings are presented, contrasted and compared with current and existing literature related to the topic.

Chapter 5 presents a summation of the research report and thereby outlines the overall conclusions and recommendations thereof.

1.10 Conclusion

This chapter has presented an overall introduction and background of the study, which encompasses an overview of the challenges facing women caring for children with CP. The chapter further discuss the problem statement. Researcher's experiences and observations that prompted the researcher to conduct the study are clearly captured under the rationale for the study. A qualitative research approach was applied and implemented. Ethical considerations were considered as values, principles and obligations to protect participants from all harm throughout the research process. Each chapter provides a brief introduction. Chapter two below provides the theoretical perspectives on mothers caring for children with CP.

CHAPTER TWO

THEORETICAL PERSPECTIVES ON MOTHERS CARING FOR CHILDREN WITH CEREBRAL PALSY

2.1 Introduction

Literature review on the theoretical perspectives on mothers caring for children with CP is presented in this chapter.

2.2 The concept CP, its causes and symptoms

CP means *brain paralysis*. It is a disability that affects movement and body position. CP is a neurological non-progressive disorder permanently affecting body movement and muscle coordination and leading to limitations in activities (Yilmaz, Erkin & Ali, 2013:4). The Department of Health (2020) provides the following information with regard to, amongst others, the causes, signs and symptoms as well as treatments of CP. Detailed information is found on the link below: http://www.health.gov.za/index.php/131-diseases/266-cerebral-palsy.

2.3 Multiple factors affecting the social functioning of mothers caring for children with CP

Caring for a child with CP is demanding and therefore requires effort, dedication and time. Mothers caring for children with CP face various challenges that may affects their social well-being. Moreover, these challenges may contribute to the mothers' inability to care for themselves as well as to cope with the demands of meeting the basic needs of their children.

According to Rassafiani, Kahjoogh, Hosseini & Sahaf, (2012:73) mothers who have children with CP often have demanding caring activities for their children, therefore, "this may lead to an imbalance in their daily activities when compared to mothers with healthy children". This imbalance may lead to physical and emotional distress and affect their mental health (Sawyer *et al.,* cited in Rassafiani, Kahjoogh, Hosseini &

Sahaf, 2012:73). These challenges may at times lead to mothers' being frustrated and stressed. Various challenges are presented below in support of literature.

- Financial constraints

Living with CP presents various challenges (Singogo, Mweshi & Rhoda, 2015:4) especially if complications are severe. Caring for a child with disabilities can be an enormous and overwhelming task on the family. An important aspect of living with a child diagnosed with CP is the cost associated with the condition (Nimbalkar *et al.,* 2014:3). Living with a severe disability can be expensive. Therefore, it is essential for families to begin thinking about managing their financial costs, taking into consideration the best interests of the child with disability. For instance, physical therapy, healthcare, medications, surgical procedures, and other relevant services are costly (Warmbrodt, 2019:1) for a child with CP. Ignjatovic, (2019) revealed that mothers often had to resign their jobs to take care of their child(ren). In most cases, the financial instability makes it difficult for mothers to hire a caregiver to look after the child with special care (Ignjatovic, 2019:4). Even though the child with a disability may be a source of joy in the family, their special needs may contribute to the emotional, physical and financial strain (Dambi, Jelsma & Mlambo, 2015:1) especially in families with insufficient source of income. Furthermore, Park and Nam, (2018) mentioned that families of individuals with CP experienced increased psychological anxiety due to financial problems. Consequently, parents' social functioning is affected.

- Psychological strain

The psychological heath of some mothers is negatively influenced by the reality of knowing the diagnosis of the child with special needs. Subsequently, mother's physical and emotional health is affected. In a study by Yilmaz *et al.* (2013:9: 22), it has been revealed that Health-Related Quality of Life (HRQoL) of mothers (especially mental components) with children living with CP is negatively affected and deteriorating due to high levels of depression. Furthermore, parents of children with disabilities are often stressed than their counterparts (Tonga & Duge, 2008:219; Mathebane, 2016:180). Moreover, the mother's distress is further exacerbated when the child is solely dependent. Children with CP need an ongoing care (Olawale, Deih & Yaadar, 2013:7160) and continuous support. In a study conducted in Japan about *"the* *relationship between raising a child with a disability and the mental health of mothers compared to raising a child without disability",* the findings encourages health professionals to focus on the mental health of every mother of a child with a disability (Yamaoka, Tamiya, Izumida, Kawamura, Takahashi and Noguchi, 2016:542). The needs of mothers should be assessed in order to provide psycho-social and emotional support. Emotional and physical challenges

Looking after a child with CP on daily basis may affect parents emotionally and physically. If the child is in a severe state where he is unable to move or do anything by themselves, it can become a real challenge. In most cases the mother is left to their own devices. Some parents become physically and emotionally overburdened which manifests into physical health problems such as chronic fatigue, headache and backache. Parents of children with multifaceted and special needs find the role of caregiving very challenging due to the physical demands expected (Smith, Cheater & Bekker, 2012:459). Therefore, continuous support and care from both families and health professionals will enable mothers to meet the child's basic needs.

According to Guyana, Penar-Zadarko, Pieciak-Kotlarz, Warder, Lewicka-Chomont, Futyma-Ziaja, and Opera (2019:1), in most families the birth of "a child is associated with immense joy and happiness, but also with a need to adjust to new responsibilities and tasks". Parental roles and responsibilities takes a different meaning, when physical or intellectual disabilities are identified in the life of a child. Although some mothers cope well with their new caregiving role, the responsibility to take care of a child with special needs may become strenuous, and adversely affect the mother's overall social functioning. For instance, Ignjatovic, (2019:4) is of the view that moving the child around, bathing and taking the child to the toilet may be demanding physically.

- Social and cultural factors

Families have different preferences as far as their involvement with child-care is concerned. Parents' thoughts about care and illness of the child may be adversely influenced by culture. Moreover, different disability diagnoses have different meanings for parents from various cultural backgrounds (Hanson, Lynch & Poulsen, in Hanson, Lynch & Poulsen, 2013:1). Smith, Cheater and Bekker (2013:468) conducted a study on *'parents' experiences of living with a child with a long-term condition: a rapid structured review of the literature at the United Kingdom'*. The study revealed that family relationships are strained. Moreover, parents' who are living with a child with a "long-term condition, place them at risk of marital breakdowns" (Smith, Cheater & Bekker, 2013:468). It becomes difficult to maintain family cohesion due to more time needed to care for the child with special needs. Subsequently, at times parents spent less time together. With all the demands that come with looking after the child with CP, parents end up not finding time to bond and strengthen their relationship. According to Olawale, Deih & Yaadar (2013:160) negative attitudes and stigmatization towards children with disabilities, may contribute to the family's psychological trauma. In the "African society, health conditions such as CP are normally associated with witchcraft and sorcery" (Olawale, Deih & Yaadar, 2013:160). Most families perceive it as a punishment from '*gods'* (Bunning, Gona, Newton & Hartley, 2017:3) for a wrong act committed by a family member, most especially the mother is blamed. Moreover, the demanding and persistent caregiving work required of them may possibly not recognized and acknowledged (Home, 2008:156). Furthermore, their children are seen as *social problems* (Green, 2007:150), and mothers may be blamed for their children's shortcomings (Francis, 2010:837). Disability has been "presented as a culturally embedded socially accepted form of oppression against people with disabilities and to date, some community members still encounter difficulties in accepting people with disabilities" (Chitereka, 2010:82).

2.4 Absent fathers of children with disabilities

Little is known about absent fathers of children with disabilities in South Africa. Statistics and research only show generic biological fathers who are absent in the lives of their children as presented below. For instance, the Statistics South Africa (SSA) (2013:25) report on *South Africa's young children: Their family and home environment*, shows that "42,5% of children aged below five years lived with their biological mother only; 36,4% lived with both their biological parents; 2,0% lived with their biological fathers only and 18,7% lived with neither of their biological parents". Eddy, Thomson-de Boor, and Mphaka (2013:7) mentioned that, one father out of two is absent from his child's life in South Africa. The "magnitude of the problem differs according to race groups as the proportion of children under 15 years living with a father is 30% for

Africans, 53% for coloured children, 83% for whites and 85% for Indians" (Eddy, Thomson-de Boor, and Mphaka, 2013:7). This phenomenon is more prevalent in rural areas than in urban areas "with 55% of African rural children under the age of 15 having absent living fathers compared to 43% of African children in urban areas" (Holborn & Eddy cited in Eddy, Thomson-de Boor, and Mphaka, 2013:7).

2.5 Knowledge of mothers about the child's diagnosis

Parents are regarded as the first to make a judgement concerning their child's illness and what to do next. They reflect on the nature and signs of the illness in order to describe it. Parents makes an effort to read the signs of illness and make a common-sense reflection in an attempt to explain the nature of the illness (Ertmann, Reventlow & Soderstrom, 2011:1-5). In a study *Involving parents in managing their child's long-term condition: a concept synthesis of family-centered care and partnership-in-care*, it was noted that parents should become experts in managing their child's condition, even though their expertise is often developed overtime (Smith, Swallow & Coyne, 2015:143). Schuster *et al.* (2011:91) indicated that parents are expected to provide care and support for children with chronic conditions. Communicating treatment plans and supporting caregivers are essential to healthcare. Most importantly, psychological support for mothers of children with CP should not be underemphasized. Therefore, communication between mothers and medical doctors is very crucial to strengthen patient-parent-doctor relationship.

2.6 Social Services rendered to mothers caring for children with CP

Section 28 of the Bill of Rights, indicates that "every child has a right to basic health care services and social services. In addition, every child has a right to be protected from maltreatment, neglect, abuse or degradation" (Constitution of the Republic of South Africa, 1996).

Mothers caring for children with CP require support in order to meet their caregiving role and needs (Rassafiani, *et al.,* 2012:70). Without support and assistance, mothers will not be able to perform their caring role to the best of their ability.

2.6.1 Child protection services

Developmental statutory social services “are protection services aimed at providing, in an integrated manner, all the core social welfare services” (Lombard & Kleijn, 2006:217). The protective services include services required to address the needs of the child to improve his or her social functioning (Lombard & Kleijn, 2006:217). Social workers are directly positioned to offer statutory services to families of children with CP. For instance, in a situation where a child is not looked after or abused, protection services and intervention should be provided. Moreover, collaboration is essential to address various challenges families of children with CP faces (Darlington, Feeney and Rixon, 2005).

2.6.1.1 Child protection services and children living with disability

Children with CP are also children who need protection and support. Child protection services should also be offered to them as much as it is being offered to children without any disabilities. Given the Constitution of the Republic of South Africa (1996)’s mandate on protecting the basic rights of children with disabilities, it is imperative for social workers to strengthen their intervention programmes through the use of advocacy and social justice principles. They deserve attention given the complexity of their situation (Department of social development, 2009:55) by involving various multi-disciplinary team from different departments.

Esposito (2015:501) alluded that various studies show that “children with disabilities represent a significant proportion of children receiving child protection services”. Stalker and McArthur (2012:2) in their study on “Child abuse, child protection and disabled children in Britain, revealed that little is known about abused children with disabilities and the services offered to address their needs. According to the World Health Organization (2012), children with disabilities are “nearly four times more likely to be abused than their non-disabled counterparts”. UNICEF, mentioned that child protection is comprised of “preventing and responding to violence, neglect and exploitation against children” (Breen, 2018).

Berg *et al.* (2015:564) argue, that children with disabilities are less likely to participate in developmentally salient activities. The impact of a disability often restricts participation of such activities.

The Department of Social Development (DSD) Child Care and Protection Programme provides services to children who:

- need care and protection.
- have special needs (this may include chronic illness, disabilities and those children who display behaviours that are difficult to manage.

Through this programme the DSD is committed to building families and communities that care and protect children in order to reach their full potential (Western Cape Government, Department of Social Development, 2018).

2.6.1.2 The guidelines of Children's Act 38 of 2005

The Children's Act No. 38 of 2005 is one of the most important legislations outlining guidelines for the provision of children's care and protection services (Department of Social Development, 2010; Sibanda & Lombard, 2015). The Children's Act 38 of 2005 (section 11) ensures a number of rights which all children are afforded:

- The right to basic nutrition, shelter, basic health-care services and social services
- The right to family and protective care
- The right to be protected from maltreatment, neglect, abuse and degradation
- The right to participate in decision-making

Cournoyer (2008:96-102), outlines six legal obligations that social workers must observe during the helping process. Amongst other obligations, include the duty to report. Social workers have the responsibility to report any child abuse cases and always act in the best interests of the child.

In South Africa there is a national Child Protection Week which happens every year from the last week of May to first week of June and these weeks are used to raise awareness on child protection, however, the awareness about children with disabilities is somehow not enough because its only done by organizations or NGOs that work with children with disabilities. Therefore, protection of children with disabilities should be strengthened so that the safety of children with disabilities can be a national issue and not an issue only to families who are raising children with disabilities such as CP.

The Act provides information on the necessary support services that must be provided to enable children with disabilities have equal access to services and protection. References to services for children with disabilities and chronic illnesses can be found chapter 2 section 11of the Children's Act No. 38 of 2005.

2.6.1.3 Social Assistance Act

The South Africa's social assistance system makes a valuable contribution to the welfare of vulnerable children and their families (Guthrie, 2008:122).

The government of South Africa has implemented the disability grant (DG) and care dependency grant (CDG) system. The social grants are provided under the Social Assistance Act (Act 59 of 1992/Act 13 of 2004) as a result of a mental health or physical disability. Children with any type of a disability from the ages of 0 until 18 are entitled for a CDG which is given to their carers, subject to an assessment by a medical practitioner (ACPF, 2011:4; South African government, 2021a). According to the Western Cape Department of Social Development (2020) recipients of the Disability grant receives an additional grant if they require personal assistance or personal care, which is Grant-in-Aid.

In South Africa, there are comprehensive legislation and policies that protects and promote the rights of people with disabilities. For instance, the policies include:

- White Paper on the Rights of Persons with Disabilities (Act No. 39792 of 2016)
- The Constitution of the Republic of South Africa (Act No. 108 of 1996).

2.7 Social Work Services in South Africa

According to Miley & Du Bois, (2007:31) social workers assists individuals to enhance their social functioning, "to access social supports and resources, to create humane and responsive social services, to influence social policy, and to expand the structures of society that provide opportunities for all citizens". Social work is a practice-based professional discipline that seeks to improve the social functioning of communities, groups, and families. Social workers in South Africa work in government departments and non-governmental organizations (NGOs) where they provide various services to people with disabilities (Strydom, 2015:380)

As part of a multi-disciplinary team, social workers provide effective services to families of children living with disabilities. According to Graham, Selipsky, Moodley, Maina and Rowland's (2010:51) study, "31% of participants with a disability indicated that social workers are professionals with a predominant form of social support available to them". Moreover, "some young people with disabilities seem to be aware of social workers" (Lorenzo & Cramm, 2012:568). Table 1 below shows some studies conducted in South Africa on caregiving and people with disabilities.

Table 1: Examples of some studies conducted in South Africa on caregiving and people living with disabilities

Authors	**Topic**	**Field of study**	**Country**	**Type of research**
Dangale (2019)	Challenges of mothers caring for cerebral palsy children at Thulamela Local Municipality, in the Vhembe district	Public Health	South Africa	Qualitative
Muller-Kluits & Slabbert, (2018)	Caregiver burden as depicted by family caregivers of persons with physical disabilities	Social work	South Africa	Qualitative
Mdlankomo, Figlan, Mharadze, Njongi, Chiwara, Zibonele & Oyelana, (2017)	Investigating the impact and attitudes of social workers in assisting people with disabilities in Alice in the Eastern Cape of South Africa	Social work	South Africa	Qualitative
Strydom, (2015)	Views of service providers on services rendered to people with disabilities and on the need for family preservation services	Social work	South Africa	Qualitative
Grut, Mji, Braathen & Ingstad, (2012)	Accessing community health services: challenges faced by poor people with disabilities in a rural community in South Africa	Health	South Africa	Qualitative

Rapodile, (1998)	Guidelines for social work with cerebral palsy patients and the parental system.	Social work	South Africa	Qualitative research

Various organizations and professions in South Africa render services to persons with disabilities (Strydom, 2015:380). Some of these organizations are facing various challenges. For instance, it was revealed in a National Stakeholder workshop at Kwazulu Natal in May 2011, that some “NGOs working in the disability sector have expressed concerns regarding accessing government funding” (DSD, DWCPD and UNICEF, 2012:11). Lack of funding to NGOs (Velaphi, 2012:25) may become a huge setback for social workers as this might affect payment of their monthly salaries (SANGONeT, 2016:1) subsequently, their moral and drive to work hard (Dlamini & Sewpaul, 2015:468) may become negatively affected. Another major dilemma in the sector is that the role of social workers is still invisible in the provision of psycho-social services to families of children with CP.

The researcher had an opportunity to review existing literature relevant to the title of this study. For example, as shown in table 1, Rapodile (1998)’s research study was based on *‘guidelines for social work with cerebral palsy patients and the parental system’*. Some of the factors observed in Rapodile (1998)’s study was parental lack of knowledge and understanding about CP as well as lack of specific social work programmes for parents. Consequently, Rapodile (1998) recommended possible guidelines for needs assessment relevant for social workers in hospitals (health care) working with parents of children with CP. The findings of Rapodile’s (1998) study is still relevant today, as helpful recommendations for social workers were developed. Significantly, Mdlankomo *et al*.’s (2017) study has revealed some constrictions in the provision of services for people living with disabilities, and thus the authors’ findings have informed future interventions to improve the social functioning of people living with disabilities. Hence, the researcher (this current study) was motivated to conduct this study to conscientise social workers on various circumstances encountered by mothers caring for children with CP. In this case, where parents are caring for children with CP, social workers are expected to serve as advocates to protect the rights of children living with disabilities. Moreover, play the role of an educator in providing more awareness to parents about the roles and functions of social workers working with children and adults living with disabilities and also work as the link between parents and other services that parents need.

Conducting the study was thus significant especially, taking into cognizance that the world is changing at a rapid speed; thus, social workers are encouraged to keep abreast with current knowledge, in order to conduct scientific research to produce responsive suggestions for consideration in practice when offering services to mothers of children with special needs. Insights from this study has thus yielded some valuable suggestions for social work support.

2.7.1 Case management process

Case management “is a process practiced by social workers that support or guide the delivery of social service support to vulnerable children and families and other populations in need” (Global Social Service Workforce Alliance, 2018:7). Case management process stages include (1) identification of the child and family; (2) assessment of the child’s situation; and development and implementation of an individual plan (Reckrey, Gettenberg, Ross, Kopke, Soriano & Ornstein 2014:334; Global Social Service Workforce Alliance, 2018:10), such as referral to rehabilitation services, advocacy with the education department for the child or referral to SASSA. During the case management process, the child and family well-being must be monitored, the planning progress must also be checked if the agreed goals have been achieved or to make any changes or close the case if necessary.

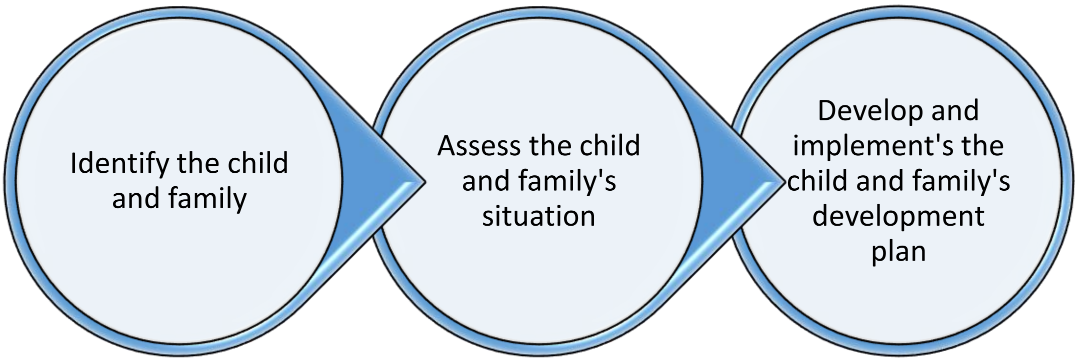

Figure 1: Case management for social work intervention (Source: Global Social Service Workforce Alliance, 2018:10)

During the identification process, social workers use the standard assessment tools developed by the organization in which they work. The assessment will cover aspects on families' living conditions and child-family relationships. A genogram and eco-map may be utilized in this regard. During the assessment process, a holistic approach is employed, social workers make sure that they address the needs of children with various role players. For example, health professionals, schools or any other relevant stakeholders. The last stage of development and implementation is when a case plan is developed to respond to the needs and strengths identified during the assessment process. A case plan “describes the specific actions which need to be taken to meet the needs of a child with a disability” (Sammon & Burchell, 2018:32). The plan may change over time, therefore, it should be frequently updated and reviewed. The plan is developed with both the child and family. It should specify actions required to meet the needs and goals that have been identified, recognize the family’s strength and resilience (Global Social Service Workforce Alliance, 2018:11. The 5WH theory **(Who, What, Where, When, Why and How)** (Hart, 1996:139-145) must be utilized to answer who is responsible for a specific task and when action needs to be taken to ensure the appropriate assistance and support is provided (Reckrey, Gettenberg, Ross, Kopke, Soriano & Ornstein 2014:334). Various roles (broker, advocate, case manager, educator, enabler, change agent) values (respect, confidentiality, self-determination and individuality) and theories (strength based perspective, systems theory, task centered theory, empowerment models) may be employed by social workers during the case management process to address the various needs and challenges of parents and their children with CP.

2.8 Social work services in other countries

People with disabilities often need a variety of services and resources such as financial assistance, wheelchairs, and prosthetic services. Social workers link people with disabilities with such community resources.

Table 2: Examples of various studies conducted on caregivers and people with disabilities

Authors	Topic	Field of study	Country	Type of research
Diseko (2017)	Experiences of caregivers caring for children with Cerebral Palsy in Mahalapye, Botswana	Social work	Botswana	Qualitative research
Mavole, Mutisya & Wambulwa	The role of social workers in education for children with special needs in Nairobi city County, Kenya	Social work	Kenya	A systematic review
Tederera & Hall (2017)	Challenges faced by parents of children with learning disabilities in Opuwo, Namibia	Social work	Namibia	Qualitative research
Chitereke (2010)	People with Disabilities and the Role of Social Workers in Lesotho	Social work	Lesotho	Concept paper

Amongst, the papers read, in Lesotho, social workers collaborate with various NGOs (World Vision, Care Lesotho and Lesotho Red Cross Society) to provide services to people with disabilities. One of the services offered is counseling. The Counseling service is provided to both children and their families Working with families assists in providing information about the nature of disability and prognosis. This affords, people with disabilities and their families to make the necessary improvements and to deal any disability related concerns (Zastrow cited in Chitereke, 2010:82).

Mavole, Mutisya and Wambulwa, (2017:39) conducted a study on *the role of social workers in education for children with special needs* in Kenya. In conclusion of their paper, it was noted that "there is a general lack of sufficient professional recognition of social workers in Kenya and by extension in Africa" (Mavole, Mutisya and Wambulwa, 2017:45). This serves as a wakeup call for social workers across Africa to market their services in order to be known for their worth and recognition.

South Africa's ratification of the UN Convention on the Rights of the Child (UNCRC) in 1995 and the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2007 has facilitated the implementation of programmes towards the fulfillment of the rights of children, and also those of people with disabilities in the country. However, "significant knowledge gaps remain with regard to the situation of children with disabilities, their family and community environment, the underlying causes of their situations, and the adequacy of efforts by government and non-government actors to fulfil their right" (DSD, DWCPD and UNICEF, 2012:9). It is imperative for social workers to strengthen their support towards families of children and adults living with disabilities.

In USA, Grossman & Magana (2016:246) wrote an article on "the introduction to the special issue: family support of persons with disabilities across the life course". The article has provided a baseline information about what research exists on the topic of family support of persons with disabilities. Grossman & Magana (2016:246) have indicated that there is a large gap in the literature on family support of children and adults across the life course, which is an area that needs future research. Practical guidelines for *frontline workers* in both low- and middle-income countries for family care of children with disabilities have been developed by Sammon & Burchell (2018:1-54) in consultation with "people who work directly and indirectly with children, including children with disabilities, all over the world" (Sammon & Burchell (2018:2). The guidelines can be utilized by various multi-professional team (such as social workers, paraprofessional social workers, health professionals, school teachers, community workers) who work directly with children and families in a government, non-governmental organization (NGO) or community-based system and "who have limited or no training specifically on disability" Sammon & Burchell (2018:2;6). The guidelines cover issues on the rights of children with disabilities, types and effects of disabilities, and how to overcome stigma and discrimination. Most importantly, the process of case management is outlined, where social service practitioner is expected to identify a family, assess the situation, develop and implement an individual plan. This guidance is an important tool for use in support of families of children with disabilities.

Very interestingly, Bean & Krcek (2012:633) have written a paper on '*the integration of disability content into social work education: an examination of infused and dedicated models'*. The authors' argument was based on the reality that the social work curricula should infuse issues on disabilities. This will enable social workers to serve people with disabilities and their families effectively.

2.9 Theoretical perspectives informing and guiding the study

The following theories were utilized to guide the study.

2.9.1 Ecosystem approach

The ecosystem approach seeks to understand persons and their environment. When working with mothers raising children with CP, it is important to remember that the mother and her child are also part of other systems, primarily a family system. This system is essential for an effective intervention. A system is a complete whole entailing numerous parts. These parts (in this study, family members) are concurrently independent on each other. For instance, the birth of a child with special needs in a family can be a devastating experience with adverse social, emotional, psychological, economical, physical and cultural effects (Mathebane, 2016:167). This may take a tangible toll on the mother and family's **overall's functioning**. In some instances, mothers may often be blamed for giving birth to a child with disability. At times, they may find it difficult to **socialize** (attend social clubs or family gatherings) with family and friends. Moreover, some may fail to go for shopping as they cannot leave the child alone. **Emotionally and psychologically** they may be stressed due to financial constraints. **Economically** (financially), the issue of being unemployed makes life even harder, especially if the mother is the breadwinner in the family. **Physically**, the mother, may suffer from fatigue and headache due to emotional strains.

Moreover, most of them do not have sufficient information on the caregiving role. However, they use information gained from health professionals and their instincts to execute their caregiving role. All these factors become a source of tension which affect the social functioning of the whole family (Alaee, Shahboulaghi, Khankeh, Mohammad & Kermanshahi, 2015:2147).

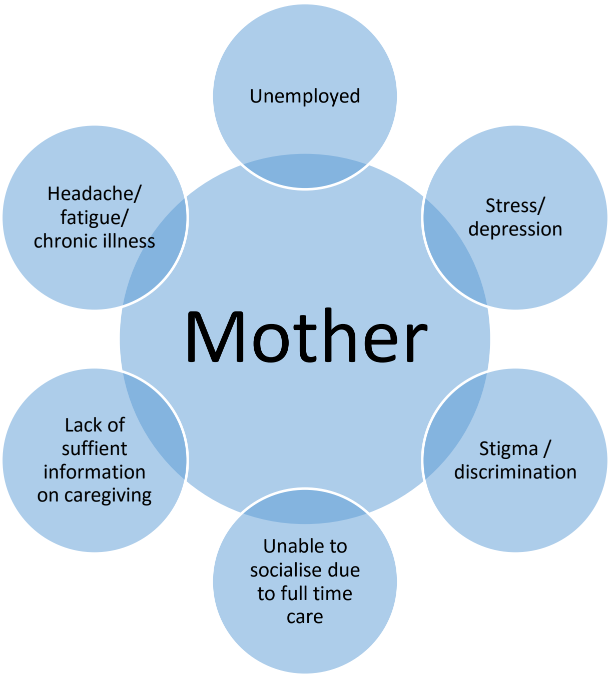

Figure 2: Illustration of ecosystems affecting mothers caring for children with CP

As a metaphor for practice, the figure above provides a holistic insight into the nature and consequences encountered by mothers given the psycho-socio, emotional, economic, physical, cultural and environmental spheres in which they function. For a holistic understating of various factors affecting the lives of parents caring for children with CP, an ecosystem approach was employed. Other theories and models have been incorporated and integrated in this study to compliment the ecosystems approach in order to better explain the phenomenon.

2.9.2 Empowerment perspective

The term *empowerment* as derived from the word *empower* means to give authority or power, strength and confidence to (Oxford South African Concise Dictionary, 2010). In this study, power, strength and confidence should be given to mothers caring for children with CP. According to Weidenstedt, (2016:2), the concept empowerment is often used to assess the individual's capabilities and potential needed to cope with the changing world and the circumstances in which one lives. However, empowerment is also used as an umbrella term for various support structures required to bring positive change in people's lives (Duflo 2012). Furthermore, the aim of empowerment is to improve people's lives. For instance, information on education, employment opportunities, health care, or housing may be shared. Mothers caring for children with disabilities may also be empowered by strengthening their sense of belonging and support through friendship networks, recognition of abilities, potential and achievements (Weidenstedt, 2012:1)

According to Lee & Hudson, (2011:159), the empowerment approach to social work practice enables practitioners to assist service users to face reality and challenge obstacles. Social workers should empower mothers caring for children with CP to take control over their situations in order to restore power through support and celebration of their strengths. To discover the power within parents of children with disabilities, social workers must believe in their strength and capabilities so that they can be able to stand on their own and know what to do when faced with challenges.

2.9.3 Resilience theory

Resilience theory is grounded on the idea that individuals has the capability to bounce back to normality in the face of adversity (Van Breda, 2018:2). A resilient person is someone who handles adversity after experiencing a devastating situation. (Cherry 2019) mentioned that "resilience is a mental reservoir of strength that people employ in times of need to carry them through without falling apart". According to Collins

Dictionary (2015), resilience is the ability of an ecosystem to return to its original state after being disturbed. With the help and support of social workers, mothers caring for children with CP will always think positively, embrace their strength and capabilities despite their challenges.

According to Elizabeth (2019), the importance of resilience is to:

- transform failure into success
- develop an Internal Locus of Control
- build positive beliefs
- help individuals embrace change
- have a close relationship with family and friends
- have positive view about one’s strengths and abilities
- have the ability to manage emotions
- have a good problem-solving and communication skills
- take control over one’s situations
- seek help and resources
- see the self as resilient rather than a victim
- cope with stress in healthy ways
- help others
- learn to accept the situation
- find positive meaning in life despite the current situation

2.9.4 Strength-based theory

The strengths perspective in social work practice has become relevant and appropriate. With the strengths-based perspective, social workers assist parents caring for children with CP recognize and strengthen their inherent strengths and abilities. Makofane, (2017:146) mentions that social work empowerment intervention services are essential in responding to the needs of individuals, families, groups communities and organizations. This means that the services that social workers offer to the society should be able to empower them and make a difference in their lives.

2.10 Conclusion

This chapter discusses the theoretical perspectives on mothers caring for children with CP. Theories are the foundation of ideas and concepts that form the basis of perspectives, approaches, and models. They help in explaining why the problem is arising and where the most efficient intervention should take place. The concept CP, its causes and symptoms are discussed, multiple challenges affecting the well-being of mothers as well as social services available to children of disabilities and their families are discussed. Chapter three provides the outcome of the application of the research methodology.

CHAPTER THREE

APPLICATION OF THE QUALITATIVE RESEARCH PROCESS

3.1 INTRODUCTION

Thorough description on the process and application of qualitative research is presented in this chapter. Qualitative research has enabled the researcher to gather detailed information on the experiences of mothers caring for children with CP. The chapter provides detailed description of research approach and designs, population sampling, participants' preparation for data collection, pilot testing, data analysis, and verification of data.

3.2 RESEARCH METHODOLOGY

This section discusses the methodological requirements of the research employed throughout the study, and how the study will be structured, designed, organized, and conducted. The process involves "the application of a variety of standardized methods and techniques in the pursuit of valid knowledge" (Mouton & Marais, 1990:154). Research methodology focuses on the steps of the research which the researcher decided to undertake in conducting the research project from the start to the end. In describing the research methodology to be applied in this research, this section discusses the research approach to be followed in the study and the research designs of the study.

3.2.1 Research approach

A qualitative research approach was employed in this study. Qualitative research is used to explore a problem or an issue (Creswell, 2018:45). The process of qualitative research "is flowing from philosophical assumptions and interpretative or theoretical frameworks that inform the study of research problems addressing the meaning individuals or groups ascribe to a social or human problem" (Creswell, 2013:44). Qualitative researchers study this research problem by collecting data in a natural setting and analyze data through the establishment of patterns or themes. Subsequently, they present and interpret the findings based on the process of qualitative research. According to Rubin and Babbie (2013:40), a qualitative research approach is “more likely to tap the deeper meanings of particular human experiences, and generate theoretically richer observations that are not easily reduced to numbers.’’ Qualitative research explores the meanings individuals attach to a social or human problem (Creswell, 2014:4). Qualitative research “is an inquiry process that enables a researcher to develop complex, a holistic picture, analyses of words, reports detailed views of informants, and conducts the study in a natural setting” (Creswell *et al.,* 2011:259). Qualitative research strives to apprehend the participants’ experiences from their own frame of reference. This approach has enabled the researcher to uncover suggestions for social work support of mothers caring for children with CP.

Creswell and Poth (2018:43-44) highlighted the following characteristics of qualitative research:

- *Natural setting*. Qualitative researchers tend to collect data in the field at the site where participants experience the issue or problems under study. The researcher collected data through conducting face to face interviews with mothers caring for children with CP.
- *Researcher as key instrument*. The qualitative researcher is the key instrument in collecting data through interviewing participants, examining documents and observing behavior. In this study, the researcher utilized semi-structured interviews consisting of open-ended questions to uncover suggestions for social work support of mothers caring for children with CP.
- *Multiple methods.* Qualitative researchers do not rely on a single data source, but gather multiple forms of data. In addition to obtaining information by conducting semi-structured interviews, observation of the participants during the interviews was also utilized to collect data. This has enabled the researcher to record the behavior of mothers in their natural environment (Lambert, Glacken & McCarron, 2013:602). During the interviews, the researcher furthermore payed attention to the non-verbal behavior, impressions, thoughts and ideas of the prospective participants, which are not explicitly expressed.
- *Participants’ multiple perspectives and meanings.* In the entire qualitative research process, the researchers keep a focus on learning the meaning that

the participants hold about the problem or issue being researched, not the meaning that the researcher brings into the research or that of writers from the literature concerned.

- *Context dependent*. Qualitative research is a form of inquiry in which researchers make an interpretation of what they see, hear and understand. The researchers' interpretation cannot be separated from their own background, history, context and prior understandings.
- *Holistic account*. Qualitative researchers try to develop a complex and holistic view of social phenomena. This involves reporting multiple perspectives.

Applying the qualitative approach was suitable for the planned research, as it enabled the researcher to generate deeper understandings and rich descriptions of the suggestions for social work support by mothers caring for children with CP.

3.2.2 Research designs

Polit, Beck and Hungler (2001:167) define a research design as "the researcher's overall plan for answering the research question or testing the research hypothesis." Nieuwenhuis (2011:70) defines a research design as, "a plan or strategy, which moves from the underlying philosophical assumptions to specifying the selection of respondents, data gathering techniques, and data analysis to be done". Perri and Bellamy (2012:20) describe research design as a specified way in which data will be collected, created, coded and interpreted to enable the researcher to draw necessary explanatory, descriptive interpretations. In support of the aforementioned definitions, a research design can be regarded as a technical document that is developed by researchers to be used as a guide or plan for carrying out a research project. The aim of the intended study is to develop an in-depth understanding of the suggestions for social work support expressed by mothers caring for children with CP. For this purpose, exploratory, descriptive and contextual designs were undertaken as strategies in this research study**.**

3.2.2.1 Exploratory research design

An exploratory research design is often used when the research question or problem is not particularly well-defined. This type of research often aims at clarifying concepts, gathering explanations, gaining insight, refining problems and ideas (Damon, Pedersen & Mc Evoy, 2011:8). According to Neuman (2014:38), an exploratory research design is applied when the subject is new and little or nothing is known about it, and when no one has yet explored it. Babbie (2016:90) adds that explorative studies are mostly done with three purposes in mind, namely,

- The researcher's inquisitiveness is gratified;
- Assessment of the applicability to conduct an extensive study; and
- The development of various methods to be utilised in any subsequent study.

In this study the *what* questions were asked by applying an explorative research design, as the researcher seeks to understand mothers caring for children with CP's experiences, which may inform suggestions for social work support.

3.2.2.2 Descriptive research design

In qualitative research, description refers to a thicker examination of phenomena and their deeper meanings, "providing rich details about individuals' environments, interactions, meanings, and everyday lives" (Rubin & Babbie, 2013:51). According to Neuman (2014:38), the purpose of descriptive research includes:

- The provision of detailed, highly accurate picture;
- The location of original data that contradict past data;
- The creation of set of categories;
- Sequence or classification is clarified;
- The causal process is documented; and
- The background of the situation is reported.

A descriptive research design presents and describes a picture of the specific details of a situation, social setting, or relationship under research. It does not comprise adjusting a situation under study (Leedy & Ormrod, 2010:81). However, it endeavours to establish a picture of the types of people or of social activities involved and focuses on ’how’ and ’who’ questions. For instance, by asking ‘How often does it happen’? ‘Who is involved?’ Thus, exploring new issues or explaining why something happens (Neuman, 2014:39). Neuman (2014:38) also states that the primary purpose of a descriptive research design is to “paint a picture” using words or numbers and to present a profile, a classification of types, or an outline of steps to answer questions such as who, when, where, and how.

In view of this design, the researcher provided a detailed description of mothers caring for children with CP’s suggestions for social work support. To obtain the required data the researcher visited participants in their natural settings, to conduct and record interviews and describe the situation.

3.2.2.3 Contextual research design

A contextual research design seeks to understand phenomena within the participants’ natural environment. Various tools and techniques are considered by qualitative researchers to develop profound meanings of how individuals ascertain their social realities. They seek to make connections between events, perceptions and actions so that their analyses become holistic and contextual. A contextual inquiry is an observational qualitative research technique where the participant is observed in the context of the environment that they would normally feel comfortable (O’neill, 2015:1). This research design was relevant for the study, as the researcher has requested mothers caring for children with CP residing in a township located in the City of Johannesburg Metropolitan Municipality (Gauteng), to voluntary participate in the study. The researcher was able to observe and understand the mother’s experiences through the eyes of their world and various factors influencing the meaning they attach to their children’s condition. Furthermore, the researcher was afforded an opportunity to observe how they interact with the environment.

Thus, applying the exploratory, descriptive and contextual research designs greatly assisted the researcher in acquiring accurate, precise, and detailed information about the experiences of mothers caring for children with CP.

3.3 RESEARCH METHOD

The research method was discussed in terms of the following aspects, namely, the population and sampling, method of data collection, pilot testing, method of data analysis, data verification and the ethical considerations. According to Blaikie (2010:8) research methods include “the procedures and activities for selecting, collecting, organising and analysing data”. Research methods include generally accepted procedures such as data collection methods, a family of analysis techniques and ethical standards (Wallingman, 2011:57; Information Resources Management Association, 2015: 372). Research methods is a broad term that encompasses the methods of data collection and data analysis. The following section detail the proposed research methods that are going to be employed during the study, namely the research population, sampling, method of data collection, piloting, data analysis, data verification and ethical considerations.

3.3.1 Population

According to Teddlie and Tashakkori (2009:170), the term *population* refers to the totality of all elements, subjects, or members that possess a specified set of characteristics that define it. Bless, Higson-Smith, and Sithole (2013:161) define a population as “the entire set of objects or people and their characteristics that are the focus of research”. Babbie (2016:116) defines the population as a group of people about whom the researcher wants to draw conclusions. Furthermore, Blaikie (2010:172) has stated that a population refers to “an aggregate of all cases that conform to some designated set of criteria”. Population refers to a large group of people from which a researcher draws a sample. In this study, the population comprised of all South African black mothers between the ages of 25-50 years who have children diagnosed with CP, residing in a township situated in the City of Johannesburg Metropolitan Municipality (Gauteng province). Due to time and financial constraints the whole population cannot be included as participants in the research, therefore, a sample needs to be drawn.

3.3.2 Sampling

Babbie (2016:182) states that sampling is the process of selecting units of observations. Sampling is seen when the researcher chooses from a big pool, a lesser set of cases to serve as the population for his/her study (Neuman, 2014:246). A sample is when individuals are carefully chosen from the total population. In qualitative research, sample size should not be too small to a point that it is difficult for the researcher to achieve data saturation, which is also referred to as data adequacy. Data saturation refers to a point during the interviews when the researcher realizes that no new information is generated from the participants (Green & Thorogood, 2014: 121). The employment of data saturation has enabled the researcher to terminate data collection process. Neuman (2014:249) points out that in qualitative research, the purpose of research may not require having a representative sample from a huge number of cases. Instead, a non-probability sample often better fits the purposes of a study. In non-probability sampling, the researcher did not have to determine the sample size in advance, but was guided by the principle of data saturation. Therefore, the researcher discusses the sample and sampling methods below to be employed for the intended study.

3.3.3 Sampling methods

Non-probability sampling is a sampling technique where individuals are not given equal chances of being chosen (Blaikie, 2010:23). Purposive and snowball non-probability sampling techniques were employed in this study.

3.3.3.1 Purposive sampling

Sometimes it is appropriate to select a sample based on knowledge of a population, its elements, and the purpose of the study. This type of sampling is called purposive or judgemental sampling (Babbie, 2016:187). Purposive sampling is grounded on the decision of the researcher. A sample is collected based on the characteristic and attributes of population who will participate in the study (Neuman, 2014: 273). Furthermore, Neuman (2014:274), states that purposive sampling is suitable to select seldom and distinctive cases that represent the entire population. In support, Johnson and Christensen (2012:231) stipulates that in purposive sampling, the researcher identify prospective applicants' based on specified characteristics. Only participants who met the following criteria for inclusion were included in this study:

- Participants of children with CP
- Participants whose children with CP are between the ages of 0 - 16 years
- Participants whose age ranges between 25 to 63 years.
- Participants who are available and willing to participate in the study.
- Participants who are able to communicate in three different official languages (Isizulu, Northern Sotho and English) of South Africa.

The researcher personally recruited participants using a chain referral and purposive sampling techniques. As a practicing social worker, she is thoroughly knowledgeable about the study and the most appropriate person to contact prospective participants. This enabled her to answer questions participants have about the topic or study. Ideally, recruitment letter was used to inform prospective participants about the study. The recruitment letter was clear and specific. It has provided information about the topic of the study, the rationale of conducting the study, research questions to be asked and contact details of the research coordinator and researcher in case participants needs clarity or would like to know more about the study.

The participants were mothers caring for children with CP residing in a township situated in the City of Johannesburg Metropolitan Municipality (Gauteng). The researcher was given permission to gain entry into a stimulation centre to recruit participants. The researcher wrote a letter to the manager of the stimulation centre to ask permission to recruit mothers of children living with CP. In a written formal letter permission was granted to access and recruit mothers who meets the inclusion criteria of the study and willing to participate. The researcher used stimulation center's parents' meeting as a platform to introduce herself, explain the purpose of the study and how the participants would benefit from the study. An invitation letter was written to participants by the researcher specifying the reason for the study. Mothers who volunteered to participate in the study signed the consent form and included their contact numbers. The researcher then called the participants one by one to establish if they will be comfortable being interviewed at their homes. They agreed to conduct interviews at their homes. Subsequently, an appointment was made and the researcher went to their homes to conduct face to face interviews.

3.3.3.2 Snowball sampling

Snowball sampling (also called network, chain referral, reputational, and participant-driven sampling) is a method for selecting the cases in a *network* (Neuman, 2014:275). Snowball or accidental sampling is a non-probability sampling technique. Participants with whom contact has already been made may assist “to ‘penetrate’ their social networks to refer the researcher to other participants who could potentially take part in or contribute to the study” (Creswell *et al.,* 2011:80). In other words, snowball sampling is often applied in field research, whereby every participant interviewed can suggest other people to participate in the study (Babbie, 2016:188). (Sadler, Lee, Lim & Fullerton, 2010:369) further mentioned that because such participants are traditionally undeserved, vulnerable, or because they fit within a set of narrowly defined characteristics, and difficult to reach.

Creswell *et al.* (2011:80) is in support of the aforementioned statement by stating that when participants are difficult to locate or not easily accessible the snowball sampling technique become more appropriate. Babbie (2016:188) further indicates that snowball is commonly used for exploratory purposes. In the study Snowball sampling was applied to afford participants an opportunity to recruit others. From the few mothers interviewed who are caring for children with CP, the researcher was able to locate participants with ease who are available and volunteering to participate in the study.

3.4 PREPARATION FOR DATA COLLECTION AND METHOD OF DATA COLLECTION

This section presents a discussion on how the researcher planned and prepared participants for data collection. In addition, the method of data collection employed is introduced.

3.4.1 Preparation for data collection

The participants were prepared for the data collection process (Cf Addendum A). The researcher started with making contact with prospective participants, getting to know them and then set the first appointment with the voluntary participants to fulfill the following aspects (Office of the Human Research Protection Program, 2012:1-8; Doody & Noonan, 2013:28).

- Build a conducive, working and trusting relationship with the voluntary participants, the researcher made sure that she earned trust from the participants (Råheim, Magnussen, Sekse, Lunde, Jacobsen & Blystad, 2016:1). Details of the research and participation procedures were explained to them.
- The researcher shared the purpose of the study and that it was a voluntary participation.
- Informed consent for participating in the study was given by participants, and the researcher allowed participants to choose a suitable venue where they would be comfortable. A date, time, and place for semi-structured interviews was arranged based on the participants' availability.
- The researcher explained the reason why the researcher wanted them, in particular, to participate in the study.
- The researcher and the participants arranged the time to meet and for how long the interview would last.
- The researcher informed the participants that full and undivided attention during the interview(s) would be provided, and since she might forget some of the valuable information that would be shared, the researcher requested participants' permission to record the interview(s) using a digital recorder. Digital recorders are useful to capture the exact words of the interview, and this enabled the researcher to recollect important information shared. The collected data was then transcribed verbatim to avoid possible bias.
- The participants were informed that after the interview(s), all recordings would be kept in a lockable filling cabinet to protect the data obtained.

The audio recording would then be erased. Some of the information that the participants would have shared would be documented in a research report and nowhere would their names or any personal information be shared. No-one would be able to identify them.

3.4.2 Method of data collection

Unstructured and semi-structured interviews are considered by many qualitative researchers when they gather qualitative data (Blaikie, 2010:207). The qualitative interview assists researchers to uncover the participants' meanings and interpretations of the phenomenon.

In this study, data were collected by means of conducting semi-structured interviews aided by open-ended questions contained in an interview guide. Semi-structured interviews were employed in this study. Interviews are commonly used in exploratory and descriptive studies (Fox, 2009:4). An interview is an important data gathering technique involving verbal communication between the researcher and the participant. In semi-structured interviews, questions to be asked are planned (Fox, 2009:9). Semi-structured interviews encompass a series of open-ended questions centred on the topic of the study. The open-ended nature of the question defines the subject under study but provides opportunities for both interviewer and interviewee to discuss some topics in more detail. Furthermore, in a semi-structured interview, the interviewer has the freedom to use prompts in order to elaborate on the original response or to follow a line of inquiry introduced by the interviewee (Mathers, Fox & Hunn, 1998:2).

Open-ended questions were utilized to elicit the experiences of the participants on the phenomenon. The questions enabled participants with an opportunity to freely express their own experiences and to share their understanding of the issue being studied. The advantage of using open-ended questions is when a problem is relatively unexplored or unknown to the researcher (Fouché, 1998:160). Qualitative researchers are encouraged to acquire communication skills such as listening, clarifying, questioning and being able to control the interview process (Fox, 2009). Preparation of participants is essential to alleviate any fears they might have about the research study (Feldman, Bell & Berger, 2003). The following interviewing skills mostly used in social work enabled the researcher to gather rich and detailed information about the phenomenon.

Listening

Active listening can be best described as attentive listening with tenacity (Pearson Pearson, Nelson, Titsworth & Harter, 2006:1). Mathers, Fox & Hunn (1998:10) are of the views that listening skills affords the researcher an opportunity to indicate interest in building a good working relationship that is characterized by trust; listen to answers of previous questions in order to assist in framing the next question, as well as knowing when to pause and prompt. In this study, researcher used the following elements to enhance listening skills:

Hearing - There is a difference between hearing and listening. Hearing is an automatic physiological process in which auditory stimuli are received. It is imperative for a researcher to concentrate on what the participants are expressing and listen to them from their own frame of reference.

Remembering - Remembering occurs when information is stored in memory for later retrieval. A report was compiled as soon as possible for record-keeping.

Listening to and understanding nonverbal behaviour - Communication without using words is the most basic way of conveying information to another person. Non-verbal communication is a continuous process that may or may not be accompanied by verbal communication. It is crucial for the researcher to convey positive attitudes and feelings.

Minimal encouragers - Minimal encouragers are verbal and non-verbal messages that a facilitator/researcher uses to encourage participants to continue sharing their experience. From time to time the researcher was unobtrusively using non-verbal encourages by nodding her head and using body gestures to keep the conversation going without interrupting the person speaking. *Verbal encouragers* include expressions such as *uh-huh*, *I see* and *please continue*.

The researcher not only listened, but payed attention to the views of the participants regarding the phenomenon under study. Posture, verbal cues and eye contact are important when applying attentiveness (Norton & Pettegrew, 2009:13).

Questioning

This skill has enabled the researcher to ask open-ended questions using prompts to explore and describe suggestions for social work support by mothers caring for children with CP. Consequently, the researcher managed to elicit more information, stimulate thinking, increase clarity and focus, and provide further self-exploration.

Clarifying

Clarifying helps in grasping the essence of a message at both feeling and thinking levels. The researcher was able to unravel conflicting and confused feelings and thoughts, and to arrive at a meaningful understanding of what is being communicated (Gilham, 2005:37).

Summarizing

The researcher displayed gestures during the end of every interview and reviewed the main pointers of the discussion. She requested participants to accurate clarify any misunderstanding or to add any mission pointers (Mathers, Fox & Hunn, 1998:10).

The interview guide comprised of questions on the biographical data of the participants and those related to the research topic.

The following biographical questions were asked.

- How old are you?
- What is your marital status?
- What is your main language?
- What is your highest qualification?
- How old is your child with CP?

The following interview guide questions focused on the topic were asked:

- How did you learn that your child had CP?
- Who explained to you the condition of your child?
- Tell me how you reacted when you learned that your child had CP.
- Share with me how your family members reacted after discovering that you were caring for a child with CP.
- Share with me your experiences of caring for a child with CP (Prompts: What happens when you care for a child, attention, needs, demands?).
- Share with me challenges you have experienced while caring for the child.
- Tell me coping mechanisms you used to overcome the challenges you have encountered

- Who supports you in caring for your child? (Prompts: Family, community members, organisation).
- What type of support did you receive? (Prompts: Family, community members, organisation).
- What type of social work support would like to receive?
- If you have utilised the services of social workers in the past, what sort of services were offered to you and the child?
- How you would like social workers to assist you and your child?
- In your opinion, do you have sufficient information about the condition of your child?
- If no, who should provide you with the information?
- Is there anything else you would like to discuss with me regarding this topic?

3.5 Pilot testing

Pilot testing means finding out if the researcher’s key informant interview guide will work in the *real world* by trying it out first on a few people. The purpose of conducting a pilot testing is to ensure that participants not only understand the questions, but also feel uncomfortable about the questions asked. By conducting a pilot testing, the researcher has learned the duration of completing the research guide questions in real time. Johanson & Brooks, (2010:395) postulates that pilot testing usually involves a small sample to test research protocol, such as the data-collection method. It is useful in various ways in that it provides the researcher with a valuable opportunity to make adjustments and revision in the main study. According to Hennik, Hutter and Bailey (2011:120) it is often challenging to predict how participants will interpret the questions included in an interview guide. A pilot test served as a trial run prior to the implementation of the study and thus enabled the researcher to determine if there were any adjustments to be made in the interview guide (Kim, 2010:191; Dikko, 2016:522). Pilot testing also afforded the researcher an opportunity to uncover ethical as well as practical issues, which may otherwise hinder the main study. The testing similarly assisted the researcher to affirm, revise or sharpen the research tool/s in order to accomplish the goals in the intended study (Kim, 2010:199). It has further enabled the researcher to establish any possible challenges or areas that require modifications from the pilot test sample (Dikko, 2016:522).

The researcher involved voluntarily two mothers who match the criteria of the main study to pilot the research questions. The piloted data was excluded in the main study, since pilot testing is not intended to produce results.

3.6 Method of data analysis

Qualitative data analysis denotes “the analysis of various forms of narrative data, including data stored in audio, video and other formats” (Tedllie & Tashakkori, 2009:251). Narrative data are usually prepared for analysis by converting raw material into partially processed data, which are then subjected to a particular analysis scheme. According to Tedllie and Tashakkori (2009:252), Qualitative data analysis is *eclectic*. Researchers employ a wide range of available data collection methodologies and analysis strategies. Data analysis is one of the most significant steps in the research process. Qualitative data analysis is described as messy, ambiguous and time consuming, but it is also a creative and fascinating process. For the purpose of the indented study, the researcher analysed data guided by the following eight steps suggested by Tesch’s eight steps (cited in Creswell 2014:196):

- The researcher transcribed the interviews word-for-word. Upon completion, the researcher’s aim is to form an overview of the gathered information by reading through all the transcriptions and making notes about important information in the margins.
- The researcher then chose one transcript and read it through while asking questions about it (i.e. ‘’what am I reading here’’, and ‘’what is it all about?’’ The generated ideas were noted in the margins.
- The previous step was completed in respect of the rest of the transcriptions and a list comprising of the themes and the sub-themes were compiled.
- With this list the researcher returned to the transcribed data. A fitting abbreviation for each theme were made, and the abbreviated codes were written in the margins next to the segments of data that match a particular code.

- Subsequently related themes were grouped together.
- The researcher took a final decision about the abbreviations for each theme and its related code/abbreviation and arranged them alphabetically.
- By using the cut-and-paste method, the researcher assembled the data material (story lines) belonging to each theme, categorized it in one place and conducted a preliminary analysis of it.
- The researcher re-coded the data where necessary.

3.7 Method of data verification

Researchers use data verification to ensure that no errors occur in the data before processing takes place. It is crucial for the researcher to ensure that the findings/results remain similar (consistent) even when they are obtained on different occasions. In other words, the researcher needs to *facilitate quality assurance* (Creswell *et al.,* 2011:37). It was ensured that the phenomenon was explained in a congruent way. Rigour is essential in qualitative research. It must be ensured through the truth value (Struwig & Stead, 2013:12). Rigour is measured by validity and reliability in research.

Bryman (2012:47) indicated that validity seeks to preserve the integrity of the research results and conclusions, drawn from a completed research project. Reliability means dependability or consistency. It suggests that the "same thing is repeated or recurs under the identical or very similar conditions" (Neuman, 2014:212). Similarly, Bryman (2012:46) alludes that reliability is mostly concerned with questioning whether the research findings can be repeated. Furthermore, the term 'reliability' is commonly used to clarify questions of whether the measures devised for concepts are consistent throughout the research process. The following concepts (Lincoln and Guba's classic model cited in Loh, 2013:5) enabled the researcher to address trustworthiness in this study.

3.7.1 Credibility

Credibility seeks to ensure that “the study measures or tests what is actually intended to test” (Shenton, 2004:64). Babbie (2016:405) indicates that some researchers prefer to use the term credibility instead of validity. Credibility addresses the question, “How congruent are the findings with reality?” (Merriam in Shenton, 2004:64). Credibility was ensured by utilising triangulation of data (various sources and methods) (Loh, 2013:5). Triangulation is defined as the combination and comparison of multiple data sources, data collection and analysis procedures, and inferences that occur at the end of the study (Teddlie & Tashakkori, 2009:27). The participants’ accounts of various perspectives facilitated the convergence of data around a particular theme. Semi-structured interviews were used to gather detailed information on mothers caring for children with cerebral in order to inform suggestions for social work support.

3.7.2 Transferability

Transferability “is concerned with the extent to which the findings of one study can be applied to other situations” (Merriam in Shenton, 2004:69), that is, the transferability of research findings to other contexts (Moon, Brewer, Januchowski-Hartley, Adams & Blackman, 2016:19). It also refers to the philosophical assumptions underpinning the study which recognize that it can never be known to which extent an account is certainly true because it is accepted that social research provides multiple constructions of social reality (Merriam, 2002:4). In this study, the researcher “ensured that the findings are understood within the context of the characteristics of the geographical area in which the fieldwork was carried out” (Shenton, 2004:70). This enabled the researcher to state the extent to which “findings may or may not be relevant to other contexts” (Moon *et al.,* 2016:19).

3.7.3 Dependability

Dependability is a reasonable criterion of quality (Babbie, 2016:405), and meaningful for qualitative research. Dependability requires that the conducted research should be able to produce almost similar results if repeated. The concept of dependability, is more elusive, because what the “researcher is observing may be constantly changing”

(Babbie, 2016:405). Dependability enabled the researcher to assess the extent to which proper research practices have been followed, so as to enable readers of the research report to develop a thorough understanding of the methods employed and their effectiveness (Shenton, 2004:71). Dependability was achieved through the utilisation of the services of an independent coder, who objectively identified eight themes derived from the qualitative data gathered.

3.7.4 Confirmability

To achieve confirmability, researchers demonstrate that the results are linked to conclusions (Loh, 2013:5), as this may assist future researchers to follow or replicate the research process (Moon *et al.,* 2016:18). Confirmability attempts to "bring awareness into the researcher's influences, by ensuring that the research findings represent the experiences, ideas, and feelings of the research participants and not the biases of the researcher" (Shenton, 2004:72). In this regard, the researcher ensured that the findings represent the experiences and ideas of the participants, rather than the characteristics and preferences of the researcher (Shenton, 2004:72; Moon *et al.,* 2016:19). The researcher considered the role of triangulation in promoting confirmability, in order to avoid bias.

3.8 Reflexivity

Qualitative research requires "reflection on the part of researchers, both before and during the research process, as a way of providing context and understanding for readers" (Sutton & Austin, 2015:226). Babbie (2016:294) postulates that the researchers' characteristics may affect what they see and interpret. The research setting could also affect the participant's responses. It means different results may be acquired depending on the setting where the interviews took place. According to Creswell (2018:44), reflexivity means that the researchers 'position themselves' in qualitative research by conveying how their experiences (work, cultural and history) informs their interpretation of the information in the study.

Reflexivity entails viewing, perceiving, articulating, enunciating and reflecting upon one’s *position* about the world and biases. This will enable persons who reads the research report to better understand the rationale of the overarching research question asked, data collected and analyzed, and reported findings (Sutton & Austin, 2015:226). Reflexivity also reminds the researcher that when he or she they are deeply involved in the lives of the participants. In this study, the researcher ensured that her responses did not influence her analysis and interpretation of data. She had a journal to diarise her own thoughts, feelings and assumptions, which may tamper with the findings.

Chapter four presents a summation of the research report and outlines the general conclusions and recommendations.

CHAPTER FOUR

THE EXPERIENCES OF MOTHERS CARING FOR CHILDREN WITH CEREBRAL PALSY

4.1 Introduction

This chapter presents an analysis and interpretation of qualitative data collected from twelve mothers caring for children living with CP. A descriptive, exploratory and contextual research designs were utilized for the purpose of this study. A purposive and snowball sampling were used to recruit suitable participants who were voluntarily willing to participate in the study. Data were obtained through face to face semi-structured-interviews. To achieve credibility in this study, the researcher and the independent coder identified possible themes (from qualitative data) independently of each other. The researcher, the independent coder and the supervisor reached an agreement on eight themes that emerged from data analysis. The themes and demographic characteristics are discussed in a tabular format in table 3.

4.2.1 Age range of participants

The ages of participants range from twenty-eight (28) and sixty-three (63) with a mean of 40 years. Cohen (2014:102) in his study on *Parental age and cognitive disability among children in the United States* specified that "biological parents' age is linked to a wide variety of cognitive disabilities and mental health conditions for their children". For instance, older mothers are susceptible to give birth to children with intellectual disabilities, probably due to "a high risk of low birth weight" (Griffith, Mann & McDermott, 2011:108).

4.2 Demographic characteristics of participants[1]

Table 3: Demographic characteristics of participants and the age of children with CP

Participant	Age	Marital status	Ethnicity	Employment	Highest qualification	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 a 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	36	Single	Zulu	Grade 11	Unemployed	2 (boy 16 and girl 13)	Boy, 16	2 days after birth
P8	36	Single	Zulu	Grade 12	Unemployed	2 (boy 13 and girl 10)	Boy, 13	Less than a year
P9	36	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

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[1] In order to preserve anonymity and confidentiality of participants, numbers were used in the above table to protect or conceal their identity (Neuman, 2014:469).

[2] All the children were recipients of Care-Dependency-Grant.

4.2.2 Employment

Out of twelve participants, four were employed and eight were unemployed. Unemployment in South Africa is an issue with a serious concern. Hence, the prevalence of developmental disabilities and intellectual disability is thus higher in low-income families as stated by Cohen (2014:103).

4.2.3 Marital Status

Two (2) participants were married, one (1) was separated and seven (9) of them were not married. Out of the twelve participants, only two participants were staying with the biological fathers of their children. Fifty-four percent of men between the age of 15 and 49 in South Africa are fathers, “but nearly 50% of these fathers, in 2004, did not have daily contact with their children” (Richter & Morrell cited in Eddy, de Boor, Mphaka, 2013:7). Therefore, mothers are left with the burden of looking after the children. According to Fourie (2018:1), the birth certificates of 61,7% children born in South Africa did not include their fathers’ details.

4.2.4 Age of children living with CP

In this study, the ages of children ranged between 1 - 18. The aetiology of “cerebral palsy can be described as prenatal, perinatal or post-natal and this can often be determined by physical examination” (Russman & Ashwal cited in Coombe, 2017:14). The diagnosis of children living with CP was discovered after birth, which is the post-natal period. The post-natal period refers to after birth, and risk factors include infections and trauma (Coombe, 2017:14). The prevalence of disability appears unusually high among young children. For instance, 28 percent of children between the ages group 0-4 and 10 percent in the age group 5-9 were classified as having a disability (DSD, DWCPD & UNICEF, 2012:6).

Table 4: Themes, sub-themes and categories

Themes	**Sub-themes**	**Categories**
1: Participant's knowledge about their children's condition	1.1: Source of information about the children's condition	
2: Reactions of parents after knowing the diagnosis of their children	2.1: Reactions of mothers	2.1.1: Denial 2.1.2: Difficulty connecting with the child
	2.2: Reactions of fathers	
	2.3: Positive and negative reactions of other family members towards a child with CP	2.3.1: Help received from a mother whose child has CP 2.3.2: Special gift of a child with CP
3:The relationship between children with CP and their siblings	3.1: Siblings help in caring for the child with CP	
4:Type of support received by the participants	4.1: Financial support 4.2: Emotional support and assistance received by the participants when caring for their children	
5: Challenges experienced by the participants caring for children with CP	5.1: Lack of support from children's fathers 5.2: Limited movement of the participants 5.3: Leaving children at home on their own 5.4: Leaving employment	

	5.5: Participants' views on the sufficiency and insufficiency of the care dependency grant	
	5.6: Misuse of child's social grant by parents of the child with CP 5.7: Challenges with medical treatment and therapy	
	5.8: Challenges experienced by children with CP at schools and centres	5.8.1: Lack of proper education 5.8.2: Negligence on the part of school staff 5.8.3: Physical abuse of children by the staff at the centre 5.8.4: The child's aggression
	5.9: No future plans for the care of children with CP beyond 18 years	
	5.10: Participants' health challenges due to stress	
6: Medical care of children with CP	6.1: Training required by parents in order to train their children	
7: Coping mechanisms of the participants	7.1: Offering love and care to the children	7.1.1: Acceptance 7.1.2: Faith in God 7.1.3: Community support
8: Social work services	8.1: Lack of sufficient information about social work services 8.2: Participants' lack of knowledge about roles and functions of social workers	

	8.3: Type of services needed by the participants	8.3.1: Food and clothing supply 8.3.2: Encourage father’s involvement in the upbringing of children with CP 8.3.3: Housing 8.3.4: Offer social support

4.3 THEMES

Themes are details of participants' accounts demonstrating a particular experience that the researcher perceives as appropriate to the research question. The following themes, sub-themes and categories emerged from findings.

4.3.1 THEME 1: PARTICIPANTS' KNOWLEDGE ABOUT THEIR CHILDREN'S CONDITION

The term *knowledge* refers to facts and information about an issue or phenomenon gained through experience or education (Loose, 2014:78). Parental knowledge about the child diagnosis is essential (Taderera & Hall, 2017:1). Parents of children with CP must be knowledgeable about the disease (Arora *et al.,* 2014:1) in order to manage the challenges that comes with it. This would enable mothers to execute their caring role without fear and doubt. Subsequently, the parents' behavior towards the management of the disease as well as the child's overall development will be positively affected. All participants knew about their children's condition after giving birth, in different age stages. The following extract describes the points expressed:

> *It was found that she has TB Meningitis. Yes, they discovered it late when she was four months, I think it started when she was one month old. We have noticed her condition, because she would cry a lot, and her temperature will be too high… that is when the medical doctors told us that she has brain damage, in her brain there is water. So that means her brain is damaged.*
>
> *It was after she was born, I think she was 2 years old. I noticed that my child's physical and mental development was delaying compared to other children of her age and again she would have fits, moreover, she would shake and shiver a lot. So, I went to the medical doctor and then he told me that my child has CP and by then I did not know what CP is.*
>
> *I gave birth to him at the clinic, …and when I gave birth to him, you know children are supposed to cry, he did not cry and I was very worried,*

> *asking myself what might have gone wrong. I told God that you are the only one who knows what is happening, and by that time I had accepted that my child is not okay. After fifteen minutes, that is when my child started crying*.

Medical specialists and therapists play a crucial role in the treatment of children with CP. They are encouraged to explain the condition of the child to the parents. Understanding the needs of families of children with CP is essential for positive family's social functioning. Health professionals have a vital role to play in providing relevant information about the disease (Huang, Kellet & St John, 2010:1213; Palisano, Almasri, Chiarello, Orlin, Bagley & Maggs, 2010:85). Moreover, they may assist in locating existing community services and resources (Palisano, Almasri, Chiarello, Orlin, Bagley & Maggs, 2010:85)

4.3.1.1. Sub-theme 1.1: Source of information about the children's condition

In most cases, parents receive information from health professionals about various health conditions (Ribeiro, Barbosa and Porto, 2011:2099). Five mothers mentioned that the medical doctor explained the condition of the child to them. The following storylines illustrates the point expressed by some participants:

> *pediatrician at … Hospital. They said it was caused by lack of oxygen (not being enough) during birth…of which for me it was a bit confusing and it made me to be in denial. Yes, because I was in a hospital and they could have done something to prevent it and I discovered his condition when he was 2 years old.*
>
> *It seems like she was born like that because she has a twin sister and the other twin is alright. To be honest I don't want to lie, I do not know what CP is and I am the one who takes her for check-up at the Hospital. Even the medical doctor told me that I should come when I have time so that he can explain to me what CP is all about. But with her,* [child with CP] *it's only a physical disability. She can talk a lot*.

> *…He was one year and 11 months. I told the medical doctor that I do not know what CP is. The medical doctor was kind enough to explain everything about what CP is. He showed me his scans and told me that his brain was developing slow that is why his growing development is also slow but eventually he will do some of the things like walking and talking. His hand also cannot carry things well.*

One of Rapodile's (1998:50) recommendations regarding parents' knowledge about the diagnosis of the child was that "the diagnosis should be clearly explained to the parents in a language they best understand". One of the participants did not honor the hospital appointment scheduled when the child was less than a year old because his father left the country with the child. Upon his [father] return when the child was three years old, the mother took the child to the Hospital and unfortunately, she was not told about the child's condition. The following storyline exemplifies the point expressed:

> *No one really explained what it means to me and even now I do not know what it means. I just know that it is some sort of a disability. They never explained how it came about and what causes it. … what they told me was that they do not see anything wrong with my child because his thong* [umbilical cord] *is normal like that of a normal person and also when you talk to him he can hear you and when he hears sounds he react so they said they don't know any more what is causing the delay and they do not know what to do going forward, there is no more help that they can help with. Then they transferred me to a stimulation centre ……One day I even took a dictionary trying to look for the meaning of this word but even today I haven't got the right answer. At least if they can just have explained the meaning of the word* [CP], *I can be grateful. … on the file they wrote that my child is mad. They wrote 'mad' and I felt that perhaps having cerebral palsy means that the child is 'mad'. I therefore decided to leave it like that.*

Knowledge is power. When mothers are informed, they will be able to execute their caregiving role effectively.

Poor compliance on treatment, "interferes with the process of rehabilitation" (Arora *et al.,* 2014:1) especially when parents lack knowledge about the child's health condition. Few mothers mentioned that they stopped taking their children for therapy. The inability to take the child for therapy, may probably due to lack of knowledge on how important treatment and therapy is for children with special needs. When parents are not empowered on the medical condition of children, their queries about the disease may "remain unanswered" (Huang *et al.,* 2010:1217; Arora *et al.,* 2014:1). One participant stated the following:

> *The medical doctor only explained that when the child lacks oxygen during birth, it means her development is affected because the oxygen makes the brain to function well so it means that my child's brain will develop slow because of that. I could see when she was growing up that her development was moving slowly, and when I went to the Hospital they booked her for OT, physiotherapy and speech therapy*.

Four participants who gave birth through a caesarean section seem to be having questions regarding their children's condition taking into consideration what they were told by health professionals.

> *I gave birth through a Caesarean section because they said that the child was getting tired, but it was not lack of oxygen. I was discharged after two days, after having given birth just like any other person and during birth they did not pick up anything wrong with the baby.*

> *I gave birth through caesarean section, and the medical doctor who was present during birth did not explain anything to me. The medical doctor who explained the condition was a General Practitioner. I blame the hospital if my daughter's condition occurred during birth. I feel that they have hurt me a lot because they could have explained to me that 'your child has CP and this is the condition.' So, I still blame the hospital.*

> *It was very painful and I blamed the doctors. Because when I gave birth, they used steel tools to deliver the child. I personally feel that the hospital is at fault…*

> *The doctor explained the condition. They told me that my child had a lack of oxygen during birth that is why he has CP. They said it does happen and sometimes they cannot prevent it. When I look at the children who were born during the same year with my child, things were not going well at the hospital, there were a lot of negligence cases that were reported.*

Medical practitioners are encouraged to inform parents about their children's medical conditions, that is, to explain in detail the causes of the child's illness and treatment (Arora *et al.,* 2014:1). This will prepare parents to address any challenge they may encounter during the caregiving process. Open communication is the key to building a working relationship with health professionals. With mothers knowing their children's condition, life becomes a lot easier and more manageable unlike when they are not informed. Additional training is essential for the care of pregnant mothers during pregnancy, labour and delivery. The training may be offered by health professionals (Department of Health, 2012:5). Adequate resources and relevant measures need to be put in place to ensure efficient and seamless provision of health care to mothers and babies.

4.3.2. THEME 2: REACTIONS OF PARENTS AFTER KNOWING THE DIAGNOSIS OF CHILDREN

Parents who are informed about the diagnosis of their children, may have feelings of anxiety (Schuenge, Rentinck, Stolk, Voorman, Loots, Katelaar, Gorter & Becher, 2009:673). For some parents, it is a predicament, to learn that their child has a disability. Their reactions may vary, including being in shock, panic, angry and have difficulties to accept the diagnosis (Huang, Kellet & John, 2010:1213). For the historically disadvantaged black African community the experience of giving birth to a child with abnormalities is challenging, "given the South African historical, social and economic difficulties that characterise black African communities" (Department of Social Development, Department of Women, Children and People with Disabilities and the United Nations Children's Fund cited in Mathebane, 2016:167).

4.3.2.1. Sub-theme 2.1: Reactions of mothers

Mothers may experience a sense of loss and grief when the child is diagnosed with CP. For instance, grieving for a loss of dreams they had about the child. Huang *et al.* (2010:1213) indicated expressions of Taiwanese mothers after learning about their children's diagnosis, that they felt helpless, lost trust in health professionals, found relieve after knowing the diagnosis of their children, hence accepted their condition, including blaming themselves for not following traditional practices during pregnancy. Mothers' may have feelings of despair and discomfort. In a study by Sajedi, Alizad, Malekkhosvari, Karimlou and Vameghi, (2010:250), mothers of children living with CP may probably have higher chances of developing depression. Six participants in this regard mentioned that they felt pain and deeply saddened when they found out about their children's condition.

> *At the beginning it was painful but, I had to accept because* such *situations you can never change them right?! Such a situation is very painful.*
>
> *They did explain but maybe by then…. I didn't believe it, that my child was like that [had CP] because he cannot even walk but the speech is alright. Yes. I become angry because of the whole situation… but mostly I get angry at his paternal family.*
>
> *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.*
>
> *I was very stressed when I saw that my child is not growing up like other children. At the age of 3 he started walking.*
>
> *As a parent it is not easy to see your child like that; however, you learn to adjust with the situation, because there is no parent who gets happy by having a child with CP but you have to accept it as it is.*

> *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*.

Every mother expects to give birth to a normal child (Taub, 2006:52). Hence when mothers find out that their children are diagnosed with CP, they are in denial. Even though, it was not easy for some parents to accept the condition of the child, they showed resilience by learning to accept the condition.

4.3.2.1.1. Category 2.1.1: Denial

Denial is seen when a person cannot or will not accept an unpleasant truth. Most parents tend to display a negative attitude toward the diagnosis of the child, by being in denial, rejecting the child, and subject themselves to self-blame (Sahu, Bhargava, Sagar & Mehta, 2018:406). According to Sajedi *et al.* (2010:250), mothers of children with CP may experience emotional strain. The strain may be exacerbated by the reality that they were not prepared to deal with various challenges and expectations of raising a child with special needs. Subsequently, they end up in denial. The following participants mentioned that they were struggling to come to terms with the fact that their children were diagnosed with CP.

> *I was still in denial hoping that one day he will be okay and be like other children.*
>
> …*it takes time for one to adjust with the situation. At some point I used to ask myself if the child was mine but I would also tell myself that he is mine because he looked exactly like his father, no one could have swapped him at the hospital.*

Knowledge is a powerful tool that may be used to alleviate any uncertainties and fears. One participant has gained strengths and learned to accept the condition after having read about it.

> *It took me some time to accept and understand why my child was like this. Even at home it was hard for them to understand. I had to start reading a lot so that I will know what CP is and what to do with the situation*

It is not easy to accept that a child has a disability, especially when support from the father as well as both paternal and maternal families.

4.3.2.1.2. Category 2.1.2: Difficulty connecting with the child

A child's diagnosis may at times affect the bond (Kearney, Britner, Farrell & Robinson, 2011:334), between the mother and child. If the mother struggles to accept the child's diagnosis from the start, it becomes difficult to connect with the child and give care and love to the child. Huang, Kellet & St John, (2012:189) mentioned that *"Taiwanese mothers face the strain of managing barriers to care giving in contexts which their children are not supported or acknowledged as being important contributors to family and Chinese society at large*". One mother had difficulty connecting with her child.

> *I would sit down and look at him and ask God why me, what did I do to deserve this. To be honest for the first year I was not connecting with my child.*

Mothers will connect with their children when they experience care and love from the community and family members.

4.3.2.2. Sub-theme 2.2: Reactions of fathers

According to Barak-Levy and Arzaba-Poria, (2013:2040) parents' reaction towards their children's diagnosis may vary. A study by Rodriguez, Dunn, Zuckerman, Vannatta, Gerhardt and Compas (2012:185) found that mothers and fathers experience similar stressors when caring for an ill child, but mothers experience higher stress levels, probably due to them being the child's primary caregiver. Interestingly, the presence of a father has a positive influence on the child and mother's psychological growth and development. Perception of the father as a distant figure, yet a powerful one, in the development of his children is found in the major streams of psychoanalytic and neoanalytic thought (Shulman & Seiffge-Krenke, 2017:5). Of the twelve participants, only two participants mentioned that the father of their children were more supportive.

> *He didn't have any problem. He was very supportive.*

> *Their father is very supportive because whenever he is at home, he will come and take us so that we can go to church together or go to the mall.*

Support from both parents is essential due to the fact that each parent has got a unique role to play in the life of a child. Fathers were greatly laid back and not much getting involved in the lives of their children. Only mothers were involved in this study, therefore, nothing was said about the reactions of fathers because they were not present during the interviews.

4.3.2.3. Sub-theme 2.3: Positive and negative reactions of other family members towards a child with CP

The social functioning of parents caring for children with CP may be positively and negatively affected in various spheres of life. This is supported by the ecosystem approach which highlights that any major life stressors experienced by a caregiver may have an influence on the health and psycho-social functioning of all family members. Service delivery should be targeted at both the child and mother with the aim to improve the Quality of life (QOL) for all family members (Davis, Shelly, Waters, Boyd, Cook & Davern, 2010:63).

> *My grandmother* [child's great grandmother] *is the one who was mostly affected, when she found out that the child has CP. Her high blood* [blood pressure] *sky rocketed, went very high. Her heart was so painful. Even now she does not want anything happening to him, she loves him very much.*
>
> *All of them were supportive. Apparently on my husband's side, my children's grandfather was diagnosed with a mental health condition. The family felt that she inherited the illness from her grandfather*. *My family is my family; they were all very supportive. They take her as a normal child, they do not treat her differently from others.*

The stress level in some families who raise a child with disabilities, may be exacerbated by lack of knowledge about the disease. Parental attitudes of the parents towards their children with CP depends also on the child's level of disability, parental income and the type of school that the child would be attending (Al-Dababneh & Al-

Zboon, 2018:731). Lack of knowledge may promote negative attitude towards the diagnosis. Therefore, empowerment is vital in ameliorating myths and negative behaviours towards disabilities (Abasiubong, Ansa, Udoh, Edemeking & Akpan, 2010:413). There are a few problems/or challenges that a family encounters when looking after the child with CP. The challenges may include:

- Lack of knowledge and understanding in relation to the child's diagnosis
- Difficulty in taking care of the child
- Mixed feelings (negative and positive) about having a disabled child
- Stigma

The following reactions were expressed.

> *They were not pleased by it, even though they did not say anything about it but their actions I could see that they are not happy about it. You see he is child.*
>
> *The last time when the child visited her maternal grandmother, she did not want to go back there, she even said it herself that she felt like her maternal grandmother does not like/want her there.*
>
> *After seeing that the child has CP, it was difficult for them to understand but eventually they learned to accept and love her like any other child. Everything starts with you as a parent, if you cannot love your child as a parent, how do you expect other people to love her.*

Apart from for the discussion mothers had with the health professionals, most did not receive counseling after learning that their children had been diagnosed with CP.

> *I remember my dad used to tell me that I was not supposed to cry for my child because she is not dead and she is not sick, she has a health condition, and I should just accept.*

The manner in which family members react towards the diagnosis of CP, may negatively or positively influence the mother's response towards coping with the condition of the child. Positive reactions from family members encourage the mother to accept the medical condition of the child, whereas the negative reactions discourage the mother to accept her child.

4.3.2.3.1. Category 2.3.1: Help received from a mother whose child has CP

Helping is one of the best fulfilling gifts one can offer. Sharing one's experiences with a mother may help. Some parents are able to execute their caregiving role effectively when support and assistance is provided. Moral support may possibly stimulate a positive attitude of mothers towards their caregiving role. Asking a parent how she feels about her challenges and the type of support required is crucial. One participant felt gratified as she was able to assist a mother with a similar situation.

> *Yes, it still hurt but not like before because now I am able to talk about it to someone else and I can advise somebody with the child with CP, although it is not easy…I am working with a certain lady who has a girl child diagnosed with CP and she is always crying. I told her that it is not easy. I was talking from experience and not from theory. I know what she is going through because I am living it every day of my life. I have a child with CP and she always tell me that my child's condition is better than her child and I told her that there is no such.*

Having support from mothers who have gone through the same experience is important for personal growth and development. Support gives hope and courage to deal with everyday challenges without fear.

4.3.2.3.2. Category 2.3.2: Special gift of a child with CP

Every child is unique. Therefore, it is important for every parent and society to recognise any special talents observed in a child's life. Many children are also distinctively gifted, and it is beneficial to identify and develop those special gifts (Hanning, 2018:1). It is important for parents to start at an early age to encourage and reward a variety of special talents the child possesses (Miller & Bachrach, 2017:131).

> *She loves music, when she is at home, we are always watching her favourite channel. She is always playing music. We all know that and we*

> *are now used to it*. *I have a problem that I cannot go with her to church because when we are in church and they start a song, when they stop singing* [she wants to continue singing], *she will cry nonstop, throw herself on the floor and it becomes a chaos.*

Children with disabilities have special gifts. All they need is support. Children succeeds because there is someone who believes in them. Subsequently, their self-esteem and confidence becomes boosted. However, to become autonomous and responsible, children with CP need support from educators to assist in the identification of the child's strength, capabilities, talents and resilience. Parents, therapists and teachers play an important role in the promotion of the autonomy of children with CP. Therefore, researchers may consider exploring the role of educators in the lives of children with CP.

4.3.3. THEME 3: THE RELATIONSHIP BETWEEN CHILDREN WITH CP AND THEIR SIBLINGS

A study was conducted to investigate siblings of adults with intellectual and developmental disabilities. The authors (Heller & Arnold, 2010:16) noted that a close and long-lasting relationships is established between a child with disability and their siblings. Furthermore, siblings may tend to take on the supportive roles as they grow older (Heller & Arnold, 2010:16). Most siblings worry about the future of their brother or sister with a disability. Feeling protected and trust are the main characteristics observed among siblings. Parents are valued and acknowledged for their attempts to treat all children equally, although it takes effort and dedication. Some of the children have a good relationship with their siblings.

> *It is good, they love each other, they have accepted her as she is.*

> *I can say its normal, because they play with him the same way they play with others. The one who is four years, is very handy and helpful, especially when it is time to eat since* ***K*** *has his own chair. She will help prepare him. Even the young one when it is time for drinking tea, he does help by giving him his cup*.

> *Ijooh! They love each other so much. Her brother calls her all the time and you will hear her telling her bother to come and see her*.
>
> *He and his second born brother … do everything together.*
>
> *They do have a good relationship and her siblings understand her very well and the kind of person she is. They really have a strong bond.*

However, as a result of their condition, some children may not be regarded as getting along with their siblings.

> *He is also violent he beats his siblings and when they beat him back, he cries*. *He does get frustrated that is why he always shouts because he becomes angry that he is unable to do what others are doing so it is very painful.*

Various limitations have been noted as far as the diagnosis of CP is concerned. For instance, the child's inability to function independently, communicating with others, and being responsible. Therefore, frustrations sometimes cause children with CP not to get along with their siblings because they cannot do what their siblings are able to do.

4.3.3.1. Sub-theme 3.1: Siblings help in caring for children with CP

When parents are committed with other responsibilities, siblings often take the responsibility of providing care (Nimbalkar, *et al.,* 2014:3), to their brother or sister 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". However, the following storylines confirm positive outcomes of siblings who support their mothers during the caregiving process.

> *Yes, my firstborn child* [14-year-old sibling] *is the one who helps me a lot even when it comes to taking care of his brother* [8 years]*. He baths him*

> *every morning and prepares him for school. So, he is very helpful and understanding.*
>
> *She* [10-year-old sibling] *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 him 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 feed [s] him.*

Looking after a sibling with CP can be strenuous, especially when siblings are younger than the child with CP. Caregivers in general including sibling caregivers have reported poorer physical and psychological well-being (Namkung, Greenberg & Mailick, 2017:626). However, according to Lostelius, et al. (2018:164) caring creates bonds and strengthens the feeling of belonging between parents and children. Even though looking after the sibling with CP may take away the feeling of being a child, it also helps siblings to understand each other. Possibly, at times, siblings may be deprived of the experiences of being a ‘child’ as they will be unable to play with other children due to being committed to executing the caregiving role.

4.3.4 THEME 4: TYPE OF SUPPORT RECEIVED BY PARTICIPANTS

Mothers of children with CP may effectively execute their caregiving role with confidence when attention and support is provided (Rassafiani, Kahjoogh, Hosseini & Sahaf, 2012:70). Furthermore, in order to show care and concern, mothers may be consulted on the type of assistance and support required. This may include the identification of ‘respite’ care sources, as well as stress and time management trainings (Sawyer, Bittman, La Greca, Crettended, Borojevis, Raghavendra & Russo, 2011:338). These trainings may be offered by social workers in health care in collaboration with relevant health professionals.

Caregiving can be greatly gratifying but tremendously strenuous at times. Mothers of children with CP requires all the support available to assist them in carrying their caregiving role effectively. This includes support related to financial, emotional, and mental health needs. Participants have shared various support systems provided to them as presented in the following sub-themes.

4.3.4.1. Sub-theme 4.1: Financial support

Different needs and expectations emerges in families raising a child with special needs. Besides the emotional and psychological effects during and after diagnosis of CP the family's financial standing will be affected (Davis *et al.,* 2010:63; Yousafzai, Lynch & Gladstone, 2014:840). In a qualitative study conducted on the needs of families of children with cerebral palsy in Bangladesh (Nuri, Aldersey & Ghahari, 2018:36), participants stated that a financial need was the greatest in their families. A financial need was mostly affecting the educational needs of the child with disability (Nuri, Aldersey & Ghahari, 2018:36).

In this study participants mentioned a financial need as one of the biggest demands when caring for a child with CP. Participants' financial instability was similar to the findings of Nuri, Aldersey, and Ghahari, (2018:36). The study had practical implications for social workers and policy makers. Social workers are thus encouraged to work closely with families to ascertain and prioritise their needs for effective social work interventions (Nuri, Aldersey & Ghahari, 2018:36). Mothers caring for children with CP may be consulted when guidelines and policies that cater for the needs of special children are developed and implemented. Although some parents appreciate the difference that the CDG makes in their lives. Half of the participants mentioned that the social grant is not enough to benefit the whole family. Moreover, the money is able to cover some of the necessities of the child with CP (for instance, sending the child to school and buying nappies).

The following excerpts illustrate the point expressed:

> *it has become our way of living for us to come to terms with the fact that we have a child with CP. Even when the school transport is late, she will be looking outside non-stop waiting for him to come from school. It is her life every day, she is used to it.*
>
> *She does receive a CDG. But it is all spent on school fees and transport because it is R850.00. School fees, school transport and Napkins, I*

> *spend R750 on napkins every month because I buy three packets and they are 30 inside and at school they want 3 for a day. So, R1700 is gone for a month with those three items.*
>
> *Hmmh, at first it was difficult but now I think we are coping financially. I am used to it now I do not have a problem anymore*.

The physical and emotional demands of caring for a child with disability require effort, time and dedication. Financial distress is another setback experienced by families (Dezoti, Alexandre, Freire, das Merces and Mazza, 2015:3) raising children with disabilities. In a study conducted in India by Nimbalkar, Raithatha, Shah & Panchal, (2014:2), it was noted that most parents agreed that "money plays an important role in the upbringing of the child who is sick". The costs ranges from medical consultations, medication and transportation of the child. In some cases, parents hire a special vehicle every time in order to take the child to and from the hospital (Nimbalkar *et al.,* 2014:4). Financial constraints end up putting a lot of strain on the mother given the basic needs of the child. Getting financial support from family is a huge relief. The study by Majnemer, Shevell, Law, Poulin and Rosenbaum, (2012:1202), have revealed the need (by health professionals) to monitor family functioning through appropriate resources to enhance the child and family well-being. Helping the mother of the child financially may be a continuous arrangement. It was observed by the researcher that participants are not aware of the distinction between disability grant and care dependency grant[3].

4.3.4.2. Sub-theme 4.2: Emotional support and assistance received by the participants when caring for their children

According to Dezoti *et al*. (2015:1) among the chronic diseases that directly impact children, "cerebral palsy cause singular damages to families by altering several of their lives such as time, finance, family and social relationships, physical and psychological

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[3] Any persons with a severe functional limitation aged 18-59 years receive the disability grant (South African government, 2021b). Any child with a disability of the ages between 0-17 years is legible for care dependency grant (South African government, 2021a).

health”. Therefore, mothers need support from their family members to ease out the burden and challenges that they face when raising a child with CP. Mothers also need assistance from social and health professionals like social workers and medical doctors. Emotional intervention is essential for mothers who encounter any caregiving challenges during the upbringing of their child with disability (Fernandez-Alcantara, Garcia-Caro, Laynez-Rubio, Perez-Marfil, Marti-Garcia, Benitez-Feliponi, Berrocal-Castellano & Cruz-Quintana, 2014). Some participants did receive support from family members.

> *I get support from my cousin and the lady who is renting out a room here at home.* Yes. *they are very supportive, both emotionally and psychologically. I was given an advice on what I can do and they don’t judge me. They always tell me that my child is in a God’s image and I should accept him and not believe the fake pastors who will tell me lies. They are very supportive in every way I do not want to lie. They are the ones who encouraged me to take the child to school and now that my child is at school, I am happy.*
>
> *My grandmother is my biggest supporter. She is the one who looks after her and whenever I want to go somewhere, she is the one who looks after her.*
>
> *The challenges that I have encountered, was that children with CP need attention all the times. When the child is unable to do basic things for herself such as bathing, walking and so on, I always have to be there to do all those things. At least my mother-in-law is staying here with us so she helps me sometimes…Yes, in terms of support, I cannot really complain. I am staying with my younger sister, who came this side of Johannesburg to look for a job after she completed her studies. She helps me a lot. When I am not at home, I know that my child is safe. Besides, during the day, the child is at school, she only comes back home around 3pm*.

It is crucial to have a support system (family, health professionals) to rely on. For instance, mothers caring for children with CP may need to express their fears, discomfort, and uncertainties about their journey. Therefore, these support systems may help during the caregiving process and subsequently improve the child and mother's quality of life. A study in Australia showed that families with children diagnosed with genetic metabolic disorders benefited from a specialized multi-disciplinary clinic (Anderson, Elliott & Zurynski, 2013:22; Gomez-Zuniga, Moyano, Fernandez, Oliva & Ruiz, 2019:2). Multi-disciplinary team is essential in dealing with challenges faced by children with CP and their parents.

4.3.5. THEME 5: CHALLENGES EXPERIENCED BY THE PARTICIPANTS CARING FOR CHILDREN WITH CP

The demands of caring for a child with CP may include exhaustive physical engagement and the need to cope with emotional reactions brought about by the child's condition (Krstic and Oros, 2012). Families who care for children diagnosed with CP are faced with many challenges. For instance, they may experience financial instability due to lack of employment opportunities (Borst, 2010:467; Dambi, Jelsma & Mlambo, 2015:2), lack support from the fathers of their children and leave employment to care for the child. Mothers sacrifice their time and energy to ensure that the child is well-taken care of. Moreover, it becomes stressful when a child is crying without knowing how to comfort him/her.

> *Due to her inability to communicate that she wants to go to the toilet so we often use nappies. Another challenge, is that when it is time for bathing, she sometimes doesn't want. Moreover, when you have to feed her, one struggles because she wants to be fed the way she wants and again she cries a lot, and sometimes you do not even know what to do.*
>
> *It is very difficult, especially because he is the oldest of his siblings, he cries a lot, not that I am comparing him with them but he cries a lot…the challenge that I am encountering is also the one of helping him to use the toilet. …we use a potty toilet because he is able to sit on it.*
>
> *As I have said, a child with CP wants attention a lot because at the end of the day if you don't give him attention who will give it to him. Like now, it is winter and his Asthma gets worse, I know that I have to be there.*

> *Even during the night when people are sleeping, I do not sleep because he will cough the whole night and I have to be awake so that I can help him with asthma spray.*
>
> *I have to feed him, bath him and every time I have to change his nappy*.

The storylines above confirm that some limitations of children with CP to perform certain self-care functions have an effect on the quality of family life. Family members may feel physically and emotionally exhausted. Moreover, poverty may worsen the enduring care for the child with severe disability (Ignjatovic, 2019:1).

4.3.5.1. Sub-theme 5.1: Lack of support from the children's fathers

Lack of support from the children's father is characterized by abandonment, rejection and neglect of responsibilities. A study was conducted by Pelchat, Levert, and Bourgeois-Guerin, (2009) to explore the adaptation and transformation process of both mothers and fathers who have a child with disability. The study revelaved that the child's medical condition is likely to be seen differently by both the mother and father (Pelchat, Levert & Bourgeois-Guerin, 2009). When parents cooperate, they are likely to adjust to normalise the situation (Pelchat *et al.,* 2009). Salami and Okeke (2018:1) likened absenteeism of fathers to that of a pair of eyes, ears, hands or legs. When any of these organs is dysfunctional, other organs become negatively affected. The statement above is associated with the ecosystem approach, where the family is seen as the most valuable source of support for the child (Neely-Barnes & Dia, 2008:93). Therefore, if the mother is stressed due to lack of support from the child's father, this may affect the child's development and subsequently affect the well-being of both the child and mother. It is not an easy duty for a father to raise a child with special needs, as it may be mentally and physically strenuous at times (Cerebral Palsy Guide, 2016). Five participants mentioned that lack of support from the father of their children is a common challenge:

> *We are separated, he does not even support the children. I do everything on my own, he does nothing nje* [just like that]. *All I hear is that he has other children with other women wherever he is.*

> *He does not care. He buys stuff for his niece and nephews but he does not buy for his child and during winter he* [father] *is always warm but the child does not have clothes. His niece and nephews have their fathers and they wear Nike and Adidas brands (clothes) but my child does not have.*
>
> *Right now I can say that 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 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.*
>
> *He will always complain and tell me that the child gets paid* [receives CDG]*. He doesn't do anything for him, he does for the girl. And when I ask why he is not doing the same thing for him he tells me that I receive a social grant.*
>
> *The father when he 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.*

Lack of support from fathers makes it difficult for mothers to cope because they are left alone to raise the child. In most cases, mothers do not look after a child with CP only, but other siblings (Macinnes, 2008:758) who also need attention. Therefore, it puts a heavy burden on the mother as she is left alone to deal with daily challenges.

4.3.5.2. Sub-theme 5.2: Limited movement of participants

The participants had limited movements due to the demands of caring for a child with disability. A study conducted in India (Nimbalkar, Raithatha, Shah & Panchal, 2014:2) of parents caring for children with CP confirmed one common problem that caregivers encountered when looking after their children with disabilities which was inability to take part in social gatherings such as marriages and other important ceremonies. 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). Interestingly, the findings by Chiluba and Moyo's (2017:5) study in Zambia on caregivers' perspectives on caring for a child with CP found that parents had stopped going for social gatherings due to stigma from community members. The following excerpts illustrate some of the participants' views:

> *…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. And also, when I want to go somewhere, I leave her with my mother so that's how we do it.*
>
> *Again, when you want to go somewhere, it is very difficult because you cannot walk around with him.*
>
> *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. Even in the morning when she goes to school, the transport guy is the one who comes and support her to the car and does the same when she comes back from school.*

In many instances, children with CP are unable to feed, bath and dress themselves, as a result, they rely on the mother to assist with these self-care functions. Faced with this limitation that children experience, it puts a great deal of strain on mothers, hence they cannot enjoy their social lives. Lack of resources makes life for mothers caring for children with disabilities even more difficult.

4.3.5.3. Sub-theme 5.3: Leaving children at home on their own

Children with disabilities cannot be left alone at home. Yantzi, Rosenberg, and McKeever (2007:45) mentioned that getting out of the house was a challenge for some mothers, hence they attempted to leave with the child. Such unfortunate situations occur when mothers have to run errands and have no one to look after them. In some instances, mothers leave children with disabilities alone which places them at greater risk. For example, in this study, only one participant left her child alone at home as illustrated by the storyline below:

> *It is not easy at all because sometimes you will find that you want to go out to buy some stuff but there is no one to look after your child so I do what I always do, I leave him inside* the *house and lock the burglar door and make sure that the door is open for fresh air, and I make sure I leave for only 1 hour and 30 minutes.* I *make sure that I have left him with food and switch on the TV and when I come back, I will find him sitting down watching his TV. Sometimes you get held up at the shops because of the queue so I find myself worried. So, it is not easy at all because if I do not lock the door, he goes off the streets wondering.*

Family and community support is essential in situations where mothers would want to leave the house to buy grocery or attend an important event.

4.3.5.4. Sub-theme 5.4: Leaving employment to care for a child with CP

In the study by Guyard, Michelsen, Arnaud, Lyons, Cans, and Fauconnier, (2012) it was indicated that raising a child with disability may affect family life in various ways. For instance, a family's time, expenses, work and social relations may be negatively affected. Hence, some mothers are compelled to leave their employment to care for their children as illustrated in the excerpts below:

> *I had to leave my job and stay at home to look after him. Due to her 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. I even decided to stop working so that I can look after 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 the hospital.*
>
> *When you have a child with CP it is very difficult to work*.

For mothers who are full-time employees on retail stores, it becomes very difficult to work and care for a child with a special need as they are expected to work long hours. As a result, the child ends up not getting all the attention required or is left with his/her sibling as a full-time caregiver. 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.

4.3.5.5. Sub-theme 5.5: Participants' views on the sufficiency and insufficiency of Care Dependency Grant

Social assistance in South Africa consists of seven non-conditional and non-contributory cash grants (Wright, 2015:1). Eligible families depend on social grants for survival, particularly if there is no one in the family who is working. Disability and Care Dependency grants are some of the social grants implemented by the South African government benefiting many adults and children with disabilities and their families (Goldblatt, 2009). This is provided under the Social Assistance Act (Act 59 of 1992/ Act 13 of 2004) in which individuals who are eligible for a Disability Grant (DG) or Care Dependency grant should pass a means-test and if, as a result of a mental or physical disability, they are unable to provide for themselves (Nattrass, 2006:7).

Only two participants expressed positive views towards the social grant received.

> *It really helps in terms of paying for the school fees and transport for her [A child with CP]. As for other needs I try and patch here and there with what I get from work and also her dad also helps in supporting her*.
>
> *For me it is okay, because I am able to pay my child's school fees and transport. I am also working; her father is also working, hence, we are grateful for it [CDG] because it really makes a difference.*

However, many participants were of the opinion that the CDG is insufficient to cater for the needs of the children. This may also be attributed to the fact that eight mothers are unemployed and rely entirely on the child's social grant. The Grant-in-Aid is the only benefit in South Africa that resembles a carer's benefit. Again, there is an insufficient sample in the General Household Survey (GHS) (2015) dataset to gain reliable information on its coverage (Statistics South Africa, 2018). However, the "number of recipients -137,000 - appears very low given that it is on offer to all recipients of the disability and old age grants" (Kidd, 2018:50) who meets the requirements. All participants did not mention anything about Grant-in-Aid. This serves as a confirmation that they have inadequate information about Grant-in-Aid. The following views were expressed given the concern about the insufficiently of the social grant received.

> *All the money is spent on him alone. His transport to school is R600.00, school fees is R450.00*. *When there is a death case at school, they contribute R20.00. The nappies are expensive and he loves fruits, and other things. He is very choosy so one must always have extra cash for him*.
>
> *Financially I rely on his CDG which covers school fees and other things. in terms of other things, I mean groceries. But at times, I have to make a plan. I am not working, I had to resign because my younger sister was taking a strain from looking after the child since I was working in one of the retail store. This contributed to her failing her* [sister] *school grade at the end of the year. So, I decided to resign so that she can concentrate on her studies.*
>
> *When I was still working, financially it was better, but now that I am no longer working, we are having some difficulties there and there, it is hard because we are depending on her grant. Her father does not work and does not stay at home. He is renting somewhere. As you can see our houses here is small, there is no space*. *He* [father] *is in his 40s. He does come a lot to visit us. He does help but he is also not working full time, he only gets piece* [casual] *jobs*…
>
> *Hey, as I have mentioned before, when I was still working, I couldn't notice the expenses because I would cover some of the expenses with my money but now, I have a serious financial problem. It becomes difficult because the child is growing up, the clothes are becoming small.*

> *It is very difficult, especially when it comes to buying the nappies. I also don't work, I must buy food to eat, like everything. It was never enough but it does assist.*

The constitution of South Africa recognizes the connection between financial support and basic human rights. For instance, children have the rights to receive social grants in order to meet their needs (Hall, 2010). Social grants make a positive impact in the lives of children and families. The findings of Wright's (2015:1) qualitative study have revealed that although a social grant is an individual grant, it is used to meet the needs of the whole family. Parents who are unemployed depend on social grants which in most cases is not sufficient to cater for the whole family.

4.3.5.6. Sub-theme 5.6: Misuse of child's social grant by parents of the child with CP

The South African Social Security Service Agency (SASSA) provides social assistance in a form of social grants. The grants assist many families to buy grocery, electricity and other basic needs. However, the best interest of the children receiving a social grant is compromised because some family members sees the social grant as a pocket money for their own personal use (Khosa & Kaseke, 2017:356). Some participants shared their observations in the community regarding some parents who abuse social grants received on behalf of children with disabilities.

> …*the boyfriend would come and take her* [caregiver of the child] *with the child, they will go and misuse the grant money, buy alcohol and when she comes back home after misusing the money, the child will be without food, nappies and food. Her sister was the one who told me to go and report what she was doing to social workers.*
>
> *He* [father of the child with CP] *was always demanding the disability grant of the child*.

Social grants such as CDG and child support grant are mainly received by mothers on behalf of their children and it becomes a challenge when the mother/father no longer use the money for the benefit of the child. Grandparents are mostly left to be the ones who utilize their old age grant to support the whole family.

4.3.5.7. Sub-theme 5.7: Challenges with medical treatment and therapy

During the first few years of life or after diagnosis, a child with CP usually begin with therapies. Physical therapy is one of the primary care treatments, which involves activities that improves muscle strength, balance and movement (Jiandani & Mhatre, 2018:69). Children are trained to walk, sit or utilise a wheelchair by a physical therapist (National Institute of Health [NIH], 2016). In the study conducted by Davis, Shelly, Waters, Boyd, Cook & Davern, (2010:63), parents felt not sufficiently supported by the services they receive. Nurses and therapists have a vital role (Sen & Yurtsever, 2007) to play in providing support and information for families of children with CP. One participant expressed the following:

> *The only thing that made me stop taking my child to attend therapy was because at the Hospital they transferred me to the clinic for therapy and at the clinic they were only doing group sessions and not giving the child the attention that he needs so I felt that it was not working for my child so I stopped*.

Lack of sufficient support from health professionals who are involved in the treatment and therapy of children with CP is the biggest concern. Majority of mothers have reported that they are reluctant to take their children for monthly checkups due to lack of support from health professionals.

Financial constraint has been one of the reasons mothers face, which contributes as a hindrance for them to travel using transport for child treatment and therapy. All participants depend on social grants for taking care of the children, therefore having to use the same money for transport to go to the hospital for treatment becomes too much and they end up not complying.

4.3.5.8. Sub-theme 5.8: Challenges experienced by children with CP at schools and centres

It was discovered in this study that some children are taken to school or at a special care facility during the week. Some challenges such as lack of proper education, negligence by staff and physical abuse were shared.

4.3.5.8.1 Category 5.8.1: Lack of proper education

Education is vital in every child's life. Support offered by the department of education for children with disabilities (Paleeri, 2010:11) is always appreciated. In a study by Saloojee, Phohole, Salloojee and IJsselmuiden, (2007), a small number of children with disabilities attends school (44%), pre-school (35%) and children who needs rehabilitation services (26%) are offered such services. It was fascinating to discover that various NGOs in collaboration with academic institutions conducted an 'early inclusive education pilot projects' which afforded the Department of Education to 'test' some of the strategies enclosed in the White Paper on inclusive education. Children with disabilities and their families were supported by various organisations in receiving good and quality education (African Child Policy Forum, 2011:31). In this study, participants expressed the need for a better education among children with CP.

> *At school so far, I am happy, the only thing is that they do not write. In terms of education they are lacking, they only sit like at the day care centres.*
>
> *For now, I feel that they are not getting the best education, the centre is like a crèche. Due to the fact that they are not being taught*. *Other parents have raised it a lot of times. The caregiver said that they do try to teach them the basics because sometimes I do hear her them counting from 1 to 10.*

The severity of the condition of the child with CP also determines if the child will receive the education that the parent wishes for the child. Furthermore, the availability of trained educators who knows what to teach the children and how to handle them in class should be explored.

4.3.5.8.2. Category 5.8.2: Negligence on the part of school staff

Special care and frequent monitoring of children with disabilities by educators is essential. Educators are responsible to execute the duty to care, that is, to ensure that students are protected from harm (Newnham, 2000:46). One participant felt that an educator did not take care of her child and she expressed the following view:

> *So, he started attending school at one of the schools …that accommodates children with CP and he was coping well until one day …When we arrive* [mother and transport driver] *at school at least there were still other educators available and we went to another class and we went to his class and the class was opened, there he was, bleeding through his nose. I raised the issue with the principal because the teacher who was available that day …was giving me attitude. So, after all the investigations it was discovered that his class teacher was not present on that particular day and the teacher who was looking after that class didn't check the class after school so that is why he was left in class...I was so angry that I decided to take him out of that school.*

A study was conducted to assess primary school teachers' knowledge about special learning disabilities in the Kingdom of Saudi Arabia and the results showed that the majority of teachers have average knowledge about specific learning disabilities (Alahmadi & El-Keshky, 2019:9). Educators' attitude towards children with disabilities matters. Moreover, paying attention to different kinds of attributes that children with disabilities have contributes a great deal in the life of the child. Lack of communication between staff members about their learners and challenges they face on a daily basis makes it difficult for them to do what is right and necessary. The situation expressed by the participant can be avoided, by being observant and always paying special attention to children with disabilities at schools.

4.3.5.8.3. Category 5.8.3: Physical abuse of children by staff at the centre

Physical abuse is unacceptable. In South African schools' corporal punishment is banned. Corporal punishment is regarded as an act of violence towards someone and one can be charged and sentenced to jail. A teacher is no longer allowed to hit a child physically (South African Schools Act 84 of 1996). According to Knox, (2010:103), in the United States whipping a child is regarded as an act of violence and thus defile the children's rights. Possibly, children with mental, learning and physical disabilities may be susceptible to sexual abuse and neglect (DSD, DWCPD and UNICEF, 2012:12). Only one participant narrated the story below:

> Last year July, *I started noticing marks on her body that shows that she was beaten, especially when you take off her napkins. When I called them at the creche and asked about the marks on the thighs, they reported that she does not like to sit on the wheelchair so they always have to tie her to the wheelchair so the wheelchair is the one that is causing the marks. So, one day she came back home with a mark of a slap on the face and the mark was visible. I could see that she was beaten.*

Abuse cannot be tolerated, especially among children living with disabilities. It is essential to strengthen the monitoring measures that are already put in place at various centres or schools of children with disabilities. Inspectors from the Department of Education are encouraged to make spontaneous visits in order to observe any mismanagement and mistreatment of children with disabilities.

4.3.5.8.4. Category 5.8.4: The child's aggression

Parents have observed feelings of anger, resentment and bitterness, in the life of a child with CP. In the study conducted by Sigurdardottir, Indredavik, Eiriksdottir, Einarsdottir, Gudmundsson and Vik, (2010:1056) children with CP were assessed based on their behaviour and emotional symptoms. The findings of the study showed possible anxious symptoms, lack of concentration and hostile behavior. It was further noted that a greater number of "preschool children with CP have extensive behavioural and emotional difficulties” (Sigurdardottir *et al.,* 2010). The storylines below support the findings of the above-mentioned study.

> *But he [a child with CP] beats us sometime…At times, he can just start fighting from nowhere, and he is very strong. He does want to be shouted at or tell him what not to do. He is too hyper-active. He gets very angry when you tell him what to do.*
>
> *…especially playing with children younger than her, sometimes they are afraid of her because she beats them, and it’s not because she wants to beat them…, she loves playing with people and holding their hair so to them it comes as if she is beating them.*

Frustrations may serve as a factor that plays a role in children behavioural and emotional difficulties. In particular, the behaviour may be observed when children with CP play with their peers who are able to do everything and they could not.

4.3.5.9. Sub-theme 5.9: No future plans for the care of children with CP beyond the age of 18 years

It was observed that it is not easy for young people with multifaceted healthcare needs to transfer from child to adult health services (Watson, Parr, Joyce, May, Le Couteur, 2011). According to South African constitution (1996) when a person reaches the age of 18 is considered an adult. Therefore, children with disability after reaching the age of 18, they have to exit from a stimulation centre or a special school. Young, Barden, Mills, Burke, Law and Boydell (2009:345), indicates that it is difficult for individuals with disabilities to transit to adulthood. Based on participants’ responses, it appears as though they have not considered or planned for the future after their child’s 18th birthday.

> *At the place of safety, I was told that they do refer children to adult placement after turning 18 years. So, I haven’t thought of anything yet*.
>
> *I haven’t thought about it thus far. However, I will never send my child to an institution. I will see when time goes on what to plan*.

Sufficient information and support is required during the period of transferring a child from stimulation centers to adult-orientated health care to ensure an efficient move (Young, Barden, Mills, Burke, Law and Boydell, 2009:345). Parents also gets frustrated during the transition phase because they have to start looking for an alternative care for their children who are now referred to as adults. Schools, or residential care facility placements that cater for young adults with disabilities must be established.

4.3.5.10. Sub-theme 5.10: Participants health challenges due to stress

Parents of children with CP often experience stress (Ketelaar, Volman, Gorter & Vermeer, 2008). In a study conducted by Whittingham, Wee, Sanders and Boyd, (2011:1557) parents stated that it is a challenge to know whether a particular behavior is the result of having a child with special needs. It was perceived that stress affects the psychological and emotional well-being of parents and subsequently lead to poorer quality of life (Guyard *et al.,* 2011; Al-Gamal & Long, 2013). Consequently, social support may serve as a stress relief. Without support, families may find it difficult to face any adversity (Whittingham, Wee, Sanders & Boyd, 2013:366; Polita & Tacla, 2014:75). In support of the aforesaid, participant 2 echoed the following challenge:

> *The other day when I was driving, lucky enough I was with my older daughter, I started feeling pain and my hand was starting to cramp as if I am having a stroke. At least I was able to stop a car and there was another guy who came and helped me. It is stressing because I am all alone (current life situation). I was even admitted at the hospital for few days.*

4.3.6. THEME 6: MEDICAL CARE RECEIVED BY CHILDREN WITH CP

Children with CP have different challenges concerning their health. Their health condition may range from mild to severity. For instance, some children cannot feed and walk on their own. This put a great deal of strain on caregivers who also need strength to do all the duties. As Adams, Khan, Begum, Wirz, Hesketh, and Pring, (2012:878) pointed out that the majority of children with CP have feeding complications, which, if not addressed, result in stressful mealtimes, chronic malnutrition, respiratory disease, reduced quality of life for care-giver and child. However, the health institutions in South Africa do try to offer the needed medical services for the children. The following participants mentioned a variety of services that children were receiving from the hospital.

> *…the child receives treatment at the Hospital and physiotherapy at the clinic. The physiotherapist is the one who informed us about the school centre where the child was later admitted…They* [health professionals] *saw that his age was not corresponding with his development and they wrote me a letter and sent me to a…stimulation centre.*
>
> *It was not nice at all, now that she had fits all the time. Now her fits are controlled by the medication that she takes. She went for an operation and they inserted a tube in her head to drain the water in the brain and she lives with the tube…She took treatment for TB for 1 year 6 months but the medication for the fits she is still taking.*
>
> *…the child attends physiotherapy training at the Hospital.*

It should be borne in mind that lack of conducive public transport for children with special needs to health care facilities pose a challenge to some mothers and children with CP. One participant said:

> *The challenge is when I have to take him to the hospital for check-up, I use public transport so I have to put him on my back and now that he is growing up, he is very heavy and it is very difficult.*

Compliance may at times become limited due to lack of knowledge and money (Adams *et al.,* 2012). With the financial strains that mothers come across, they end up not following up on the treatment appointments, which in the long run affects the well-being of the child.

4.3.6.1. Sub-theme 6.1: Training required by parents in order to properly care for their children

In this study, it was noted that most parents did not get enough training or information on how to deal with children diagnosed with CP. Boyd, Mitchell, James, Ziviani, Sakzewski, Smith, Rose, Cunnington, Whittingham, Ware, Comans and Scuffham, (2013:366), mentioned that resourceful intensive interventions are required by families of children with CP. Health professionals such as social workers in health care, nurses, speech and physio-therapists are encouraged to work collaboratively with parents. They may support parents by organizing workshops or seminars on care giving of children with CP. In support one of the participants mentioned that

> *If there can be people who comes maybe one day in a week to check on the children, how they are doing and assist. Someone who should provide more information about the children with CP, how to train him, how to massage him/her for her to be flexible. They always mention at school that the therapists are coming but, we don't get to see what the therapists are doing with the children so it does not help us a lot. So, if they call us and teach us what to do with them it would be very helpful and also the speech therapists should also give us some information and train us on how to communicate with her.*

New methods to deliver intensive rehabilitation therapies are needed to strengthen and support the health care system (Boyd *et al.,* 2013:1). Working together with mothers to managing their caregiving role will subsequently improve their social functioning.

4.3.7. THEME 7: COPING MECHANISMS OF THE PARTICIPANTS

Offering love and care to children, acceptance of the child's condition, faith in God, financial and family support are some of the coping mechanisms used by participants.

4.3.7.1. Sub-theme 7.1: Offering love and care to the children

According to Gona, Mung'ala-Odera, Newton and Hartley (2011:175), feelings of discrimination, stigma and exclusion have been reported by caregivers of children with disabilities. The mother's expectations and hopes about the life's journey of the child may be strayed. The parent's fear of the future and uncertainty may emerge and subsequently experience restlessness. Regardless of parent's reactions, it is heartwarming and inspiring to learn that mothers of children continue to offer their children love and care. When mothers try to deal with *lost expectations*, they bounce back by seeking support and exploring possible solutions to their problems (Gona *et al.,* 2011:175; Lima, Cardoso & Silva, 2016:207).

> *I give him love in everything that I do. …he is my son…, I have accepted him. Sometimes when you are eating you will find that he has messed up the nappy, one has to stop eating and go change him the nappy. …not only change him the nappy, but will have to bath him.*
>
> *…a lady … advised me to go to the hospital to get help. … She comforted me saying that I should not hate my child … I should accept him and love him the way he is.*

4.3.7.1.1. Category 7.1.1: Acceptance

Parents respond differently towards their children's illness (Barak-Levy & Atzaba-Poria, 2013:2040). Acceptance of the child with disabilities needs time and as a parent one should be emotionally stable to be able to accept the child. McLeod, Wood & Weisz, cited in Jankowska, Wlodarczyk, Campell & Shaw, (2015), mentioned that children raised by controlling and emotionally distant parents, may experience anxiety and depression. Hence, parental attitudes (either positive or negative) towards their children have an impact on the mental and physical development of the child. Some parents went through feelings of denial before accepting their children's condition as demonstrated below:

> *Hey, sometimes I stress, I stress but I have to accept the gift that God has given me but sometimes there are things that happens around you*

> *and I feel that this is too much. I feel that God has chosen me for a reason to go through this, which means He saw that I was strong enough to handle it… there are many of us but he chose me, Yah!*
>
> *One day when I was thinking alone, I told myself that this is my child and there is no one who will love him. I then started accepting him, fell in love with my son, even now I do not want to hear anything about him* [meaning over protective of him]. *Other children with similar condition, you will find him/her dirty, neglected and all that.*
>
> *When I started taking her to the hospital for* OT, physiotherapy and speech therapy treatment, *it became easier because I could meet other parents of children with CP and other health conditions which were worse than that of my child. As a result, I was motivated to start accepting my child for who she is.*
>
> *As I have said before it was not easy at all to accept but eventually, I had to accept that my child has got this condition.*

4.3.7.1.2. Category 7.1.2: Faith in God

Culture integrates beliefs and traditions for a specific group. Culture guides the family's interactions and influence their views on health issues (New South Wales (NSW) Government, 2018:11). Parents may begin accepting their child's diagnosis when they understand the nature of the illness (Krstic, Mihic and Mihic, 2015:135). Mothers draw their strengths, through the application of spiritual interventions and sharing their experiences (Gona *et al.,* 2011:175). In this study mothers have faith in God, and thus helps them to accept their child's condition. Although some of them were struggling to accept the situation but eventually learned to live with the situation.

One participant was devastated when she learnt about her child's condition, her faith in God sustained her. She stated that *maybe we just need to depend on God, because if God wanted your child to be born in a different way he could have done so. So now we have to trust, believe and have faith in Him.* Some mothers have shared similar sentiments as expressed below:

> *It took me some time to accept that my child has a disability. Eventually, I have accepted and told myself that God could have given this child to someone else but he chose to give me. That is how I got to accept my child and started to love her.*
>
> *If God saw that I would not be able to handle the situation, he could not have allowed it to happen to me so that is how I accepted her. I believe in God and he is the one who saw me through this whole ordeal.*

Two participants who found it difficult to handle stress expressed the following views:

> *Through prayer. I sometimes pray but not always. I used to go to church a lot but I stopped. Honestly I used to stress a lot about things, I would even struggle to sleep and it was not changing the situation. I then told myself that if I am able to solve my problem, it is fine and if I cannot solve it, it is still okay. I had a lot of questions for God. I do not have answers so that is why I have stopped going to church.*
>
> *I do not cope at all. Even at the clinic they were complaining about my weight loss because I stress a lot. Even the dietician told me that the pills*. *I am taking do not go along with stress that is why I am not gaining weight. But I told her that I am not working due to situation at home. So, she suggested that she will only help by giving me supplements and immune booster but still they are not helping. Instead of gaining weight, I am losing it.*

A mother may lose hope in her faith, hence stop attending church. A participant who was unemployed at the time of the interview was struggling to accept her child's diagnosis. She had to leave work in order to look after her child. Moreover, she is living with a chronic illness, which makes the situation worse. Consequently, the stress was too much for her to handle.

4.3.7.1.3. Category 7.1.3: Community support

In an African culture, there is an adage that says, *"It takes a community to raise a child*", hence it is the responsibility of the community to look after children with disabilities (Omu & Reynolds, 2012). Sawyer, Bittman, Greca, Crettenden, Borojevic, Raghavendra and Russo, (2011:338), have mentioned that it is important to support mothers of children with disabilities through community awareness campaigns to establish various ways of listening to their needs in order to reduce the real and perceived impact of care-giving. These awareness campaigns may be facilitated by social workers in collaboration with health professionals. This might include identifying sources of 'respite care'. The need for respite care was noted in the study by Chiluba and Moyo (2017:5) as well as Muller-Kluits & Slabbert (2018:498). The acceptance and support of the child by community members will positively improve personal growth and development of the child. Some participants mentioned that they get support community members.

> *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*.
>
> …*even the community members know him and they do interact well with him*.

However, one participant reported having received negative judgment from family members and the community. The participants' experience is supported by a study conducted in Zambia (Singogo, Mweshi & Rhoda, 2015:1) where mothers conveyed that having a child with CP has made them feel socially isolated owing to lack of support from the family, community members and health professionals. The participant said:

> *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*.

Judgmental attitude towards mothers raising children with disabilities affects their coping mechanisms and thus negatively affect their overall well-being. Negative attitude makes it harder for mothers to accept their children and love them irrespective of the health condition.

The birth of a child normally brings joy and celebration to the family. On the other hand, the birth of a child with disability may bring shocking reactions to family members. Consequently, family members may become resistant to provide support. A study conducted in Zimbabwe found that mothers of children with disabilities face various psychological, social, and economic challenges, which requires the attention of policy makers and development practitioners (Rugoho & Maphosa, 2017:2). From the study, one of the challenges encountered by mothers of children with disabilities was witchcraft accusation.

> *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.*

The excerpt confirms the assertion that in “African society, the medical condition such as cerebral palsy is normally associated with witchcraft and sorcery” (Olawale, Deih and Yaadar, 2013:160).

The following participants expressed lack of support from family members and community.

> *There is no support... the only child who was supportive was the daughter who passed away.*
>
> *My family members are alright they do understand but with my husband’s side they do not even get involved, I don’t even remember when last did they see her, am sure they last saw her after she was born and that was it.*
>
> *I am so angry at them* [father’s family]*, they are not even supportive, I only communicate with them when we are at the (maintenance) court,*

> *that is when I will talk to them if I can bring the child to his paternal grandmother, we live on the same street.*
>
> *Yes, she* [his paternal grandmother] *is still alive, they are not* [supportive], *even when I call them to ask if I can drop off the child, they always have excuses. When I need to visit somewhere and they agree that I can drop him, they will from time to time call me to pick K up. I think they just do not want to spend time with him.*
>
> *Yes, I did receive help from my family even now from my mother's side I do receive help, but with her father's side I cannot say much because most of my in-laws are at home in Limpopo and I am here in Gauteng. Moreover, even when I am in Limpopo when I take my child to them it seems like it is a burden to them*.

Regardless of the challenges experienced by mothers caring for children with disabilities, some mothers have admitted that although caring for a child with a disability requires efforts and dedication, the journey is complemented by different gratifying and jubilant experiences (Munsell & O'Malley, 2019: 269). Nimbalkar *et al.* (2014), reiterated that the presence of additional family members who provide a helping hand is beneficial.

4.3.8. THEME 8: 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 every individual as unique (Engelbrecht, 1999:30). The profession pursues to understand the 'interconnectedness networks' (Mattaini, 2008:355), of people's lives and to recognise rather than ignore the constraints and discrimination they experience from society (IFSW, 2021:1). Many participants (n=8) did not use or ask for social work services due to a variety of reasons. One of the reasons include lack of sufficient information about the role and functions of social workers. Moreover, participants were confusing the services provided by the South Africa Social Security Agency (SASSA) with those of social workers.

4.3.8.1. Sub-theme 8.1: Lack of sufficient information about social work services

Of the twelve (12) participants, only eight, mentioned that they have never received any services from social workers. One mother who received assistance from the social worker, expressed her dissatisfaction about the services. Despite probing the reasons for her dissatisfaction, the participant did not disclose. The mother had this to say about her encounter with the social worker:

…the social worker was not productive. For instance, she would promise me that she will call and never does. ***S****he was never active for me, never.*

4.3.8.2. Sub-theme 8.2: Participants' lack of knowledge about roles and functions of social workers

Social workers regardless of their practice settings, understand illness and its impact on individuals and society. Moreover, social workers are ethically obliged to react and respond to health disparities. This may be possible through working collaboratively with health professionals and other relevant organisations to address and minimize health disparities in societies (National Association of Social Workers, (NASW) 2016:30). 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.

> *No. I don't know at all, it has never even crossed my mind, I do not even think about it.*
>
> *I also did not know about social workers and what they do, to be honest.*
>
> *From the social workers, no. I have never been to a social work office before, I do not even know what they do.*
>
> *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.*

In a study by Hayles, Harvey, Plummer & Jones, (2015:1144) on *parents' experiences of health care for their children with cerebral palsy,* parents' mentioned that "challenges to navigating the systems included a lack of information about what is available…and availability of different services." The *policy guidelines for course of conduct, code of ethics and the rules for social workers* alludes that open and transparent information about services should be accessible to clients (South African Council on Social Service Profession, n.d: 8). Hence, marketing social work services is essential.

4.3.8.3. Sub-theme 8.3: Type of services needed by the participants

Food and clothing supply, fathers' involvement in the upbringing of children with CP, housing and social support were some of the services required by participants.

4.3.8.3.1. Category 8.3.1: Food and clothing supply

Food and clothing are essential basic needs for every human being. Social relief of distress is a "form of social assistance aimed at assisting needy individuals" by providing food voucher, food parcel or cash-in-kind (Department of Social Development, 2010:2; Sehlabane, 2014:27). Social Assistance Act 13 of 2004, stipulates various requirements expected for one to qualify for the social relief of distress. Miley and Du Bois, (in Chitereka, 2010:90) argue that social work interventions reinforces human functioning and improves the efficiency of societal structures that provide resources and opportunities for beneficiaries such as people with disabilities. It is essential for social workers to educate parents of children with CP about various Social Assistance Programmes, that is, information on who qualifies, how to apply for it and which offices to visit.

> *You see this child can eat. I would be happy if social workers can assist with groceries.*
>
> *They must give out napkins. I do not know but I heard that some hospitals used to give out napkins and baby formula but they would start by checking your background if you deserve to get them but lately it seems like they have stopped. One of the clients, went there for napkins and she was deserving to have them but, unfortunately, she did not get them.*

> *Now that I am not working, if they* [social workers] *can assist with grocery, I can be glad*.
>
> *I would like assistance with clothes for the child because she grows so fast.*

According to Almasri, Palisano, Dunst, Chiarello, O''Nell and Polansky, (2011:798) service providers may collaborate with families when providing services. Social workers may help with fundraising campaigns to assist mothers with children diagnosed with CP in meeting their family needs. For instance, get donations of clothing and food parcels. Social workers may serve as a bridge between health professionals and mothers of children with CP.

4.3.8.3.2. Category 8.3.2: Encourage fathers' involvement in the upbringing of children with CP

Little is known about the involvement of fathers in the upbringing of their children with CP, especially in South Africa. Fathers play an important role in child development, from birth to adulthood. The involvement of fathers in the upbringing of children with special needs is still a heated debate among scholars (Adamsons & Johnsons, 2013:589; 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).

Mothers mentioned that fathers of children with CP were not involved in child rearing and care. Therefore, caring for children with CP as a single parent becomes intolerable due to financial constraints. Hence, mothers of children with CP suffer a great deal emotionally and financially (Sajedi, *et al.,* 2010:250). Given the reality that caring for a child with CP has psychological, social and financial impacts on carers and families (Garip, Ozel, Tuncer, Kilinc, Seckin & Arasil, 2016), father involvement will assist mothers to cope with the needs and demands of caring for children with CP.

> *I have noticed most of the time when I go for meetings at school, I only find mothers who are attending and not fathers. But 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. Social workers should assist fathers get involved. Children with special needs require more support and fathers should also take the responsibility to care for them.*
>
> *The only issue I want to raise is that social workers should assist mothers with children of CP by ensuring that fathers are involved. That is the most important issue that I would want to see social workers pushing.*
>
> *Fathers of these children really need to take part in taking the responsibility and help mothers with the caring role. It is not our fault as mothers that we have children with CP, no one asks to have a child like this. We didn't know that when we give birth, we will give birth to a child with CP. We should be grateful that we came back from the hospital with a child, some people don't come with anything.*

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). It is essential to establish the causes of non-involvement of fathers in the lives of their children living with CP, through formal and informal conversations with mothers. The child deserves both the love of the mother and father.

4.3.8.3.3 Category 8.3.3: Housing

Lack of proper shelter is one of the challenges facing some South African citizens. It becomes difficult to raise a child with special needs without a proper shelter. Social workers may serve as liaison officers and advocates for families raising children with CP by writing motivations for housing applicants. Researchers (Gitterman, 2014; Allen & Spitzer, 2015) indicates that, in the event of non-availability of resources, social workers support initiatives to inform and educate communities on how to access and utilize physical and human resources.

> *They could start by assisting with giving houses so that they* [mothers] *can stay with their children. At the hospital they do encourage us to have other children*.

The participant who applied for an RDP house said:

> *It is 8 years now. And the way I see it, it is still going to take some time for us to receive the houses because even people who applied during 2006 have not yet received them. I am struggling with paying rent every month plus again other expenses. Yes, it is at home but I pay rent every month*.

4.3.8.3.4. Category 8.3.4: Social work support

Social workers who manage cases of children have the duty to conduct home visits on a monthly or quarterly basis to check how the children and mothers are holding up, as well as observing the living circumstances and the holistic progress of the children.

> *Social workers should come and check up on the child. It makes things easier when people like you come and check on us at some point*. *Yes, you must sometimes come and check on how we are surviving.*

According to Huang, Kellet and St John, (2010:1213) to promote better understanding of the child's condition, "emotional support and information may be provided to the mother and family, both when informing them of the diagnosis and in the period after diagnosis". Therefore, visiting and supporting the family may not happen only once, it could be a continuous process that social workers may take very seriously. Rapodile (1998:23) in her study on 'guidelines for social work with cerebral palsy patients and the parental system' emphasized the need for social workers to understand the psycho-social issues affecting communities. This will enable social workers to mobilize and examine the relationship between people and problems within their environment.

It is important for mothers caring for children with disabilities to stay vigilant when at home. It appears that unknown people visit and seek information from families of disabled children under the false pretext of working for government. This concern was raised by one participant.

> *…there were social workers who came to my home and they said that they want particulars of the child, and I asked them where they were coming from and they did not give me clear answers and I refused with child's particulars then they left. They come again now with another social worker, when they enter my house, they again asked for the particulars of the child and when I interrogate them again they never gave me a clear answer to why they want the child's particulars, they just said that they want to help the child because he has special needs and I refused again with the particulars and then they left and never came back and I saw that those people were crooks. So I am very vigilant because people are being robbed every day in their homes.*

It is important for social workers to maintain a good relationship with service users so that even when people come to service users under a false pretext, they might know what to say and avoid being robbed of their belongings.

4.4. CONCLUSION

This study sought to explore and describe the experiences of mothers caring for children with CP. The findings of this study have informed the development of suggestions for social work support. The biographical profile of participants was presented in a table format, followed by a discussion of eight themes, 20 sub-themes, and 19 categories, aligned with storylines from the transcribed interviews while supported and contrasted with literature control. Eight themes emanated from the transcribed interview recordings conducted with 12 mothers who are caring for children with CP.

Theme one focused on participants' knowledge about their children's condition. Most parents felt that they lacked sufficient information about the condition of their children's diagnosis. Theme two focused on the reactions of parents after knowing the diagnosis of their children. Various emotions were expressed. Mothers felt pain, hurt, stressed and sad when they found out about their children's condition. Although mothers experienced some negative emotions by participating in the study, the researcher was very conscious on the questions asked. Moreover, the researcher had made arrangements with the Debriefer in case, participants needed debriefing or further counselling. The relationship between children with CP and their siblings was presented under theme 3. The findings showed that in some cases, siblings take the role of an assistant care giver and get more involved in the upbringing of their CP sibling. Theme four concentrated on the type of support received by participants. Valuable contributions and support from medical specialists, social workers, family and community members were embraced by participants.

Theme five focused on the challenges experienced by participants in caring for children with CP, amongst other challenges expressed included, lack of support from children's fathers, limited movement of participants (for instance, finding it difficult to work, go for shopping and attending social events and so on) and participants' views on the sufficiency and insufficiency of Care Dependency Grant. Theme six discussed the medical care of children with CP while theme seven discussed coping mechanisms of participants. Lastly, theme eight focused on social work services. In this theme, it is disheartening to learn that participants have little and lack of knowledge on the role and services offered by social workers. Moreover, suggestions for social work support based on the findings were formulated.

CHAPTER 5

SUMMARIES OF FINDINGS, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This chapter highlights the major findings of the study by means of summaries, conclusions and recommendations. A qualitative approach was employed. The findings are based on the responses of twelve (n=12) parents caring for children with CP. Data were gathered through semi-structured interviews. This chapter reflects back on the previous chapters and also focus on summaries of findings of the study, conclusions and recommendations. To transcribe, sift, sort and analyse the data obtained, eight steps of qualitative data analysis constructed by Tesch (cited in Creswell 2014:196) were used. The services of an independent coder were outsourced to objectively identify and confirm (8) themes, twenty (20) sub-themes and nineteen (19) categories.

5.2 Summaries, conclusions and recommendations of the research study

Summaries of the qualitative research process, the major findings, the conclusions reached, as well as recommendations for practice, policy, education, and future research are presented in this section.

5.2.1 Summaries and conclusions based on the research process

The researcher was able to achieve the goals of the study by employing a qualitative research approach in support of exploratory, descriptive and contextual research designs. The goals of the research study were:

- To develop an in-depth understanding of the experiences of mothers caring for children with CP’s.
- To proffer suggestions for social work support.

In order to obtain the required information, semi-structured interviews were conducted with participants aided by open-ended questions contained in an interview guide.

Twelve participants were interviewed and the size of the sample was guided by the principle of data saturation. Thematic analysis was used following Tesch's eight steps (cited in Creswell 2014:196) to analyse data and Lincoln and Guba's classic model (in Loh, 2013:5) was employed for data verification. The study adhered to ethical standards such as confidentiality, informed consent, anonymity and management of information. Insights from this study are valuable in understanding the experiences of mothers caring for children with CP by means of formulating suggestions, which will inform intervention for social work practice. The objectives of the study were achieved since a sample of twelve mothers who are caring for children with CP voluntarily participated in this study.

- To explore and describe the experiences of mothers caring for a child with CP

Participants have shared their experiences of caring for a child with CP. Amongst other experiences, participants shared their knowledge about their children's condition, challenges encountered during their journey of raising a child with special needs and the type of support received. Moreover, participants have expressed their reactions after knowing the diagnosis of their children.

- To establish coping mechanisms caring for a child living with CP

Offering love and care to the children, acceptance of the child's condition, faith in God and family support were some of the coping mechanisms used by participants.

- To explore suggestions for social work support of mothers caring for children with CP.

Suggestions for social work support were derived from the findings, such as empowerment and awareness about CP, marketing of social work services, strengthening the referral system, adoption of a holistic approach to respond to the needs and challenges of caregivers, reaching out to communities through voluntary work father's involvement in the life's of their children and embracing the use of technology to offer services in order to reach every family either in remote or urban areas.

- To draw conclusions and make recommendations based on findings derived from mothers caring for children with CP.

A qualitative research process was followed in this study. The recommendations and conclusions were presented based on the major research findings of eight themes.

5.3 Summaries and conclusions based on the research findings of the study

The summaries of (8) themes, twenty (20) sub-themes and nineteen (19) categories that emerged from the findings are discussed below.

5.3.1. Theme 1: Participants’ knowledge about their children’s condition

All participants knew about their children’s condition after birth, although some of them felt that the information given regarding the child’s condition was not sufficient. Participants felt that medical practitioners may provide enough information about the health condition of the child to the parent. This does not only help a parent alone, it also helps their families and community members who are expected to support the child and their mother. Mothers who know about the health condition of the child, will be able to take care for herself and the child.

5.3.2. Theme 2: Reactions of parents after knowing the diagnosis of their children

Eight participants mentioned that they felt pain, hurt, bad, stressed and sad after being informed about their children’s condition. Giving birth to a child with special needs can never be easy for any parent, and not only a parent but also family members. Every parent does not expect to give birth to a child with disability. Hence, when a mother gives birth to a child with special needs, they experience difficulty connecting with the child and in some instances blaming God for having that child. In addition, four participants’ blames health professionals for negligence (see subtheme 1:1). Family support is essential. Furthermore, an outcry on absent fathers was raised as a concern. Fathers of eight children were absent. Therefore, the involvement of a father in the upbringing of the child still needs to be explored.

5.3.3. Theme 3: The relationship between children with CP and their siblings

Little information was shared about the relationship between children with CP and their siblings. However, the findings show that in some cases, siblings take the role of an assistant (Webster, 2018:204) caregiver and get more involved in the upbringing of their CP sibling. In this study, some positive outcomes were shared by two participants regarding sibling-support. For instance, siblings may assist in bathing and feeding. Siblings do play a big role, and in some cases the bond between them is strengthened.

5.3.4. Theme 4: Type of support received by the participants

Support is what every person need in life. It can be either family or community support. Moreover, financial and emotional support is crucial in the lives of parents caring for a child with special needs. In this study, half of participants mentioned that they need emotional and financial support from family members. Valuable contributions and support from medical specialists and social workers are always appreciated.

5.3.5. Theme 5: Challenges experienced by the participants caring for children with CP

The following challenges were identified by participants during the study.

- Abandonment and rejection of a child with CP by parents

Learning that a child has a physical or mental disability can be one of life's most significant stressors for parents (Logsdon, 2019:1). Socio-economic and other difficulties experienced by the family with a child living with disability may affect parental acceptance-rejection behaviour (Aydin & Yamac, 2014:79). The study showed that some mothers struggled to accept that the child’s diagnosed with CP. When expectations of having a healthy baby are not met, this lead to rejection and abandonment of their children.

- Lack of support from children’s fathers

Insufficient support from children’s fathers was a huge concern. Of the 12 participants only two had support from their children’s biological fathers. On other hand, eight participants were upset that fathers were not involved and did not contribute financially and emotionally to the lives of their children. Therefore, lack of support from fathers may affect the well-being of both the child and mother.

- Lack of support from the child’s maternal and paternal relatives

In this study, it became evident that when the father of the child decides to distance himself because of the child’s disability, the father’s family also decide not to get involved. From the findings it was noted that, in African culture, when a mother gives birth to a child with disability, people believe that she has done something wrong in the past and she is being punished. Therefore, it becomes difficult for families to support the mother. Notably, the involvement of the father in the child’s life is crucial as it motivates the paternal family to get involved and support the child and the mother.

- Limited movement of the participants

Looking after the child living with CP is a full-time responsibility, especially if the child cannot walk or able to do some of the things on his/her own. Therefore, at times, mothers are unable to do other activities such as going for shopping because they cannot leave the child on their own. Family support will strengthen mothers’ resilience and fosters development of social relationships.

- Participants’ views on the sufficiency and insufficiency of the CDG

The study has revealed that eight participants felt that CDG is not enough. Their financial instability is worsened by the fact that most of them are unemployed and therefore the grant serves as the source for survival of everyone in the house. The CDG may assists employed participants with other expenses while caring for the child. The researcher has observed that all participants are not aware of a Grant-in-Aid.

- Challenges with medical treatment and therapy

Going for therapy every month requires money for transport, which most participants have indicated that they do not have. Due to lack of money for transport, mothers end up not taking their children for check-ups, and their decision impacts heavily on the development and well-being of the child. Moreover, according to participants in this study medical practitioners lack sympathy and emotional support. Participants believe that some of the reasons for lack of emotional support could be that medical practitioners are overworked, short staffed and exhausted due to shortage of medical doctors and therapists in local clinics. The KwaZulu Natal Department of Health's Strategic Plan 2010-2014 noted "high vacancy rates for occupational therapists (58.8%), physiotherapists (60%), psychologists (63.6%) and social workers (58%) in the province" (DSD, DWCPD & UNICEF, 2012:61). The participant's' believe was also supported by a Sunday times reporter, Child (2019:1) who indicated that "Gauteng hospitals have a critical shortage of nurses and doctors".

- Challenges experienced by children with CP at schools and centres.

In this study, participants expressed the need for proper potty training and writing for children with CP. Mother's wish is for their children to be taught the basics of reading and writing. Negligence on the part of school staff was also raised. One participant indicated a plea for special care and frequent monitoring by educators to children with disabilities. Moreover, mentally and physically disabled children are prone to sexual, physical and emotional abuse.

- No future plans for the care of children with CP beyond 18 years

All participants mentioned that they do not have future plans with regard to education for their children diagnosed with CP when they reach the age of 18 years. In South Africa children with special needs who attend special schools are left stranded when they reach the age of 18 years as they may not be skilled enough to attend any special workshops for people with CP or start their own business. Therefore, without proper planning, children and parents are left frustrated. Special schools and workshops for children with CP are highly needed. Mothers caring for CP children are encouraged to share their future plans with social workers for support and any assistance.

- Participants' health challenges due to stress

The findings of this study showed that mothers caring for children living with CP find themselves under immense amount of pressure due to the huge responsibility of raising a child with special needs. To some extent, two participants had to leave employment in order to look after their children. Participants mentioned that looking after the child with CP is too demanding as compared to looking after the child without the diagnosis of CP. Therefore, with all the pressure that they get, they end up having body pains, stressed and frustrated and at times blame themselves for giving birth to a child with disability.

5.3.6. Theme 6: Medical care of children with CP

Participants confirmed that they receive medical and other relevant services provided by government departments. Access to basic health and education services for all children (including children with special needs) becomes the main priority for South African governments. The participants appreciated the efforts made by relevant departments to ensure that services are rendered to both children with CP and them. For instance, the Department of Social Development in South Africa makes provision s for the social protection services and social assistance programmes. The South African Social Security Agency (SASSA) regulates and administer social grants. The effect of poverty is lessened by social grants.

5.3.7. Theme 7: Coping mechanisms of the participants

- Offering love and care to the children

Believing in God played a big role and served as one of the strategies for coping with the challenges of caring for children with CP. The participants' relationship with God makes it easier for them to accept the health condition of their children and make the most out of it. They felt that God would not give them a child with CP for no reason. As a result, this played a huge role in the love, care and effort that they put in caring for their children. Support received from family members, community, medical doctors and SASSA was commended by some participants.

5.3.8. Theme 8: Social work services

The findings have revealed that all participants had little or no knowledge on the role and services of social workers. This raises a concern and a wakeup call for social workers to market their services. Based on the findings of the study, suggestions for social workers are presented below:

5.4 SUGGESTIONS FOR SOCIAL WORK SUPPORT

Based on the findings the following suggestions are critical for social work support. These guidelines however, may be too ambitious to achieve, but they are nevertheless achievable.

- **Empowerment and awareness about CP**

Chronic conditions such as CP are not freely spoken about in many communities. Moreover, citizens do not have enough knowledge on what to do when they encounter challenges related to such conditions. Social workers in health care may collaborate with health and psychology departments to empower individuals, families and communities, through conscientising them about permanent chronic conditions and where to seek help. Moreover, communities may be informed about the services and resources available.

- **Marketing of social work services**

From the findings it was noted that participants have little or lack sufficient information on the services and roles of social workers. Participants have suggested that social workers may create more awareness about their services. Consequently, the community will be able to refer service users to receive such services. Social workers may use community centres, churches, local clinics, hospitals and others NGOs to disseminate information through pamphlets about their services. Having a website, WhatsApp chats and social media accounts may also improve creating an awareness since many people are utilising social media platforms for communication. Moreover, social workers may utilise social networks platforms to conscientise the community about their functions and roles. They may critically assess how such networks can be incorporated into social work interventions as a strengths-based resource for mothers caring for children with CP. Moreover, social workers may use World Cerebral Palsy Day as a platform to empower communities on issues of disabilities. Marketing social work services needs to be a priority for social workers so that they can be known for what they are doing.

- **The referral system must be strengthened**

Getting service users to come to where the services are, it means getting out of the comfort zones. When social workers go out to reach mothers who are affected, awareness is raised and people will get to know more about services and be able to refer other people. Social workers and other health professionals are encouraged to demonstrate value for others. Going out and creating awareness will enable people to know about the profession, its mission and what it entails. If someone is doing good, people knows about it. Health professionals are encouraged to refer patients and their families to social workers for psycho-social support. Some ailments may be lessened if patients receive support from social workers.

- **Adopt a holistic approach to respond to the needs and challenges of caregivers**

Social workers may provide a holistic approach when rendering services to mothers caring for children with CP. For instance, social work is a profession with multidimensional roles, therefore, it must develop and implement responsive and innovative interventions to effectively address community ills (Anthony & Austin cited by Makofane, 2017:146). The society will realise the value of the profession, when social workers demonstrate its relevance through safeguarding its mission and vision (Starr cited by Makofane, 2017:146).

- **Reaching out to communities through voluntary work**

Efforts may be made by social workers to reach out to mothers caring for children with CP through media, and community awareness campaigns. Previous studies showed that in most instances high caseloads makes it difficult for some social workers have sufficient contact with vulnerable families (Mashigo, 2007:91; Krane, Davis, Calton & Mulcahy, 2010:158-159; Matthias & Zaalcited in Nhedzi & Makofane, 2015:356). In 2003, social work was declared as a scarce skill due to shortage of social workers

(Earle, 2008a:66;80; Recruitment and Retention Strategy for Social Workers in South Africa, 2006; Nhedzi & Makofane, 2015:356). Moreover, the Department of Social Development introduced bursaries for qualifying student social workers to benefit. Notably, social workers who are currently employed are still overburdened with work caseload. Therefore, social workers may inspire community members to cultivate the spirit of voluntary work, to assist in identifying families that require social work services. The families may be referred to the area social worker or arrangements be made for social workers to visit the family. Community based organisations and Faith Based Organisations may also be helpful in this regard.

- **Strengthening social work morale and zeal to stay in the profession**

Some social workers find themselves in a position where they move from one organization to another due to the working conditions that they find themselves in. Many NGOs lack funding for paying good salaries and this demoralises social workers not to perform optimally. Whenever they get an opportunity to work in an organization that has better salaries and working conditions they do not hesitate to resign. This moving around create lack of sustainability in the organization and proper management of cases especially for service users. In this case, mothers of children with CP may feel demoralised after having been allocated a newly appointed social worker to take over the case, not knowing that the same newly appointed social worker might possibly leave the organization. Therefore, funding strategies may be considered in various welfare NGO's. For instance, private and business sectors may be approached for funding.

- **Father's involvement in the life's of their children**

It was recommended that social workers may intervene by ensuring that fathers are taking the responsibility of being a caring parent. For instance, social workers may arrange community meetings or presentations in local radio stations about the relevance of fathers' involvements in the lives of their children. It was observed that mothers are the only parents who have to face all challenges of raising a child with special needs. This becomes difficult when they are not financially stable and not having enough support from both maternal and paternal families.

- **Technology as a key factor**

Technology has become essential to connect with people across the globe. Social workers may incorporate technology services to address the psycho-social needs of children with disabilities and their families. During the process of analyzing the findings of this study, the researcher has noted that Covid 19 has affected the lives of many people in multiple ways. The pandemic had adversely changed people's lives and the way they interact with one another. The impact will be long-lasting. People are encouraged to practice social distancing. Given the current crisis the country is facing due to Covid 19, options for providing services using electronic devices (such as a computer, tablet, smartphone or landline) or any electronic format (including the Internet, social media, online chat, text, video, or email) may be considered by social workers.

Social workers may have limited resources to reach the most vulnerable. However, today, scholars are debating about the Fourth Industrial Revolution (4IR). The 4IR represents a fundamental change in the way people live, work and relate to one another. This revolution encourages various role players in health care to reconsider how intervention is offered. For instance, social and health professionals may utilize radio stations to disseminate relevant information about CP in the language understood by parents. Some trainings on caregiving of children with CP may also be offered via media (radio/tv) once per month in order to reach every family either in remote or urban areas.

5.5. Recommendations based on the research study

Based on the research findings and research process, the researcher makes the following recommendations for practice, policy, education, and future research in this field.

5.5.1 Recommendations for social work practice

Recommendations for social work practice are as follows:

- Participants felt that social workers may assist in providing food and clothing vouchers. The social grant received by families with children with CP, may be used for other expenses like nappies, school fees and other necessities.

- Social workers may create a conducive atmosphere that will allow mothers to feel the need and urgency to seek assistance from them. Subsequently a good reputation of the profession will be build.

- Pamphlets about the services that social workers offer may be distributed at schools, local clinics, community halls, hospitals and churches. This will give the community members an opportunity to know the roles and services offered by social workers. A resource booklet must be created for all relevant health and social care practitioners in case, there is none.

- Social workers may play a role of being the bridge between different health and social care practitioners that offer other services to similar service users. For instance, referring a service user to SASSA for social relief of distress or to the Department of Housing for housing assistance. Social workers are encouraged to collaborate with the South African Social Security Agency (SASSA) to disseminate information about various social assistance grants available to assist South African families with low income. Furthermore, social workers may promote the spirit of volunteerism in collaboration with various health professional' veterans (physiotherapist, medical doctors, dieticians and other relevant health professionals) by offering free hours of their services to families of children with special needs and care.

- Fathers of children with disabilities need social work support on how they can get involved in raising their children. Mothers in every community are known to serve as caregivers, it is crucial to strengthen their capacity by ensuring that fathers get involved (Zuurmond *et al.,* 2018:2) through the provision of financial and emotional support.

- Support groups may be established in communities and clinics through using technology (WhatsApp multiple call or group charts) as an avenue for mothers to receive peer support. This will help them better cope with the challenges and stress. Zuurmond *et al.* (2018:2) conducted a study in Ghana, on a support programme for caregivers of children with disabilities in Ghana…. The study revealed that a support group provides a *social safety net* for parents who are isolated in their communities'. A support group can offer education on how to handle a child living with CP and to share available resources.
- Social workers may have a special day every month to take their services to communities, to reach mothers who might have financial problems. The Department of Health may consider placing health therapists and other specialists at various health care centres for children with CP to receive therapy. This suggestion might assist parents who stay very far from the hospital.
- The Department of Health may consider placing health therapists and other specialists at various health care centres for children with CP to receive therapy when required. This suggestion may assist parents who stays very far from the hospital.

5.5.2 Recommendations for policy

- The South African Constitution (2006) gives 'everyone' the right to basic education (Section 29). The Sustainable Development Goals (SDGs) 4 has included equitable access to education which *ensures inclusive and equitable quality education and promote lifelong learning opportunities for all* (United Nations Development Programme, 2020). Therefore, policy makers should ensure that an inclusive education for children with disabilities is accessible. Parents may be conscientised about the rights and responsibilities of all children with disabilities.
- Maintenance Amendment Act No. 9 of 2015 and the Children's Act No. 38 of 2005 governs the laws relating to the care, contact and the protection of all children. Every child is entitled to reasonable maintenance by his/her parents to provide for clothing, housing, medical care and education. Both a mother and

father have the responsibility and duty to maintain the child. The responsibility remains irrespective of whether the parents of the child are unmarried, whether the child is from a first marriage or adopted. Social workers may serve as advocates on behalf of children with special needs and their mothers. For instance, they may conscientise fathers of children about parental responsibilities and rights outlined by the Maintenance Act No 9 of 2015. a

- In order to achieve sustainable development goals, families should serve as key partners, as acknowledged by human rights, and without families, it is impossible to achieve the rights of children (Martin, Hall & Lake, 2018:113). Social workers in collaboration with health professionals may empower mothers and their families about the rights of children with disabilities, care-giving and self-care through educational talks offered at clinics and hospitals. The more the family is involved and informed, the easier it becomes for the mother to carry out the caregiving role.
- The department of education in collaboration with the department of health and social development may work together by establishing enough centers that caters for children with CP even after the age of 18 years.
- Mothers who are raising children with severe special needs such as CP may get first preference when applying for a house. Local municipalities in collaboration with housing department may further disseminate information to communities on how to apply for a house (RDP). The Reconstruction and Development Programme (RDP) “is a South African socio-economic policy framework implemented by the African National Congress (ANC) government of Nelson Mandela in 1994 after months of discussions, consultations and negotiations between various stakeholders” (White Paper on Reconstruction and Development 1994:6). Chapter 2 of the Bill of Rights, section 26 (1) says *‘everyone has the right to have access to adequate housing’*. In order to achieve the realisation of this right, the government may ensure as promised, to build RDP houses for the low income families, especially disadvantage families of children with disabilities.

5.5.3 Recommendations for education

- Short Learning Programmes (SLPs) should be developed by academics (collaboration between health and social work disciplines) on psycho-social support when offering services to mothers caring for children with CP.
- Seminars and workshops must be conducted by social work academics in collaboration with health professionals to discuss burning issues (such as basic facts and myths about CP, stigma and support services) encountered in various communities.
- Social work academics may consider using community engagements projects as platforms to offer psycho- social support targeting special schools of children with CP.

5.5.4 Recommendations for future research

- Perspectives of fathers may be solicited to unpack their needs, fears and challenges of having a child living with CP.
- To establish the importance of father's involvement in the upbringing of their children with disabilities.
- Perspectives of mothers on the future plans of children with CP after reaching 18 years may be explored.
- An exploratory study on the role of various social and health professionals in providing effective services to children with severe cerebral palsy and their mothers.

5.6 Limitations for the study

This study represented a limited sample of 12 African women caring for children living with CP, residing in a township in one province of South Africa. Therefore, the findings cannot be generalized to the entire population.

5.7. Conclusion

The summaries of the qualitative research process are presented in this chapter. Furthermore, the recommendations and conclusions based on the major research findings of eight themes are also presented. The discussion culminated in the presentation of suggestions for social work support, recommendations for social work practice, policy, education and future research.

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ADDENDUM A: LETTER REQUESTING A PARENT'S PARTICIPATION IN THE RESEARCH PROJECT

Dear research participant

I, ________________________________invite you to participate in a research project to be conducted at the University of South Africa, titled: **Mothers caring for children with cerebral palsy: Suggestions for social work support.**

The goals of the research study were:

- To develop an in-depth understanding of the experiences of mothers caring for children with CP's.
- To proffer suggestions for social work support.

Should you agree to participate in this research project, I would like to have an interview with you at a time and place that would suit you. This interview will not take longer than 60 minutes. As I might forget some of the valuable information that you will share with me, I would kindly like (with your permission) to record the interview(s) using a digital recorder. During the interview, the following biographical questions and interview guide questions will be asked.

The following biographical questions will be asked.

- How old are you?
- What is your marital status?
- What is your main language?
- What is the highest qualification?
- How old is your child with CP?
- Is the child attending a special school or not? If Yes, please provide the name of the special school

The following interview guide questions focused on the topic will be asked.

- How did you learn that your child has CP?
- Who explained to you the condition of your child?
- Please tell me how you reacted when you learned that your child had CP.

- Please share with me how your family members reacted after discovering that you were caring for a child with CP
- Please share with me your experiences of caring for a child with CP (Prompts: what happens when you care for a child, attention, needs, demands).
- Please share with me your challenges you have encountered while caring for the child.
- Tell me your coping mechanisms you use to overcome the challenges you have encountered
- Who supports you in caring for your child? (Prompts: family, community members, organisation).
- What type of support did you receive? (Prompts: family, community members, organisation).
- Share with me the type of social work support you would like to receive.
- If you have utilised the services of social workers in the past, please share with me the services that were offered to you and the child?
- Please share with me how you would like social workers to assist you and your child.
- In your opinion, do you have sufficient information about the condition of your child?
- If No, who should provide you with the information?
- Is there anything else you would like to discuss regarding this topic?

Please note that your participation in this research is voluntary. In case, I notice that the information you have shared has opened emotional wounds, I am required to refer you to a counselor for debriefing or counseling (if you agree). Ultimately, the findings of the research will be published in a professional journal. I wish to emphasize that pseudonyms will be used to protect your confidentiality and anonymity. Please do not hesitate to ask for clarification on any matter relating to the study. My contact details are as follows:

Phumudzo Raphulu

Thank you

ADDENDUM B: CONSENT FORM TO PARTICIPATE IN A RESEARCH STUDY

I, ____, agree that I may participate in this research topic, which focuses on **mothers caring for children with cerebral palsy: suggestions for social work support.**

I understand that the information that I will share will be used for research purposes only and that my identity will be in nowhere made known in any research report or publication. I am also aware of the fact that I can withdraw at any time during the study without incurring any penalty.

____

Signature of research participant

____

Date

ADDENDUM C: CONSENT FORM REQUESTING PERMISSION TO PUBLISH

Name of researcher: Miss Raphulu Phumudzo

Title of research study: Mothers caring for children with cerebral palsy: suggestions for social work support.

- ☐ I agree to participate in this research project.
- ☐ The researcher has explained the consent form and the purpose of the study, and I had the opportunity to ask questions about them.
- ☐ I understand that I was selected to participate in this study due to my current situation as a mother caring for a child with Cerebral Palsy.
- ☐ I understand that I was selected randomly from a large group of people.
- ☐ I agree to my responses being used for education and research purposes as long my privacy is respected.
- ☐ I understand that I am under no obligation to take part in this research project.
- ☐ I understand that this research might be published in a research journal or book. In the case of dissertation or thesis research, the document will be available to readers in the university library in printed form, and possibly in electronic form as well.

Name of participant ___________________________

Date ___________________________________

ADDENDUM D: DECLARATION BY THE PARTICIPANT

Title of the research: Mothers caring for children with cerebral palsy: Suggestions for social work support

Reference: R & EC: 06/02/18/46468196_24

Researcher: Ms P Raphulu

DECLARATION BY THE PARTICIPANT: I, THE UNDERSIGNED, ______________________________ (name), [ID No: _______________________] the participant of _____________________ ____ ____(address) **A. HEREBY CONFIRM AS FOLLOWS:** I was invited to participate in the above research project which is being undertaken by Phumudzo Raphulu of the Department of Social Work in the School of Social Science and Humanities at the University of South Africa, Pretoria, South Africa.	Initial
1. The following aspects have been explained to me: 1.1 The researcher is conducting study on *Mothers caring for children with cerebral palsy: Suggestions for social work support.* 1.2 The information will be used to harness and strengthen social work support for mothers caring for children with CP.	Initial
2. I understand that: Information about the goals and purpose of the research study is explained to me. The reason for being selected for this project and that my participation is voluntary. I will not be pressured to participate in the research project I will participate in semi-structured interviews during the time that is convenient for me and the interview will not exceed more than 90 minutes. The information that I will share will be audio-recorded and subsequently transcribed and documented The information that I will share will be made public through research report and might be used in subsequent scholarly presentations, printed publications or further research. I have the right to ask for clarification or more information throughout the study. I have the right to withdraw from the study at any point.	

3. Risk and benefits: I do not see any risks associated with this study	<u>Initial</u>
4. Possible benefits: As a result of my participation in this study, suggestions for social work support will be formulated based on the findings of the study.	<u>Initial</u>
5. Confidentiality: Every effort will be made by the researcher to ensure that my identity is not be revealed in any discussion, description or scientific publications by the researcher.	<u>Initial</u>
6. Access to findings: Any new information benefit that emerges during the course of the study will be shared with me. All information gathered from the participants will only be used for the purpose of this study	<u>Initial</u>
7. Voluntary participation, refusal and discontinuation: My participation is voluntary. I am free to withdraw or discontinue participating from the research study at any time with no negative consequences.	<u>Initial</u>
8. The information above was explained to me by Phumudzo Raphulu in English and I am in command of this language. I was given an opportunity to ask the questions and were answered .	<u>Initial</u>
9. No pressure was exerted on me to consent to this study and I am aware that I can withdraw from the study at anytime without penalty.	<u>Initial</u>
10. There are no financial costs directed to me for participating in this study.	<u>Initial</u>
I hereby consent voluntarily to participate in the above project Signed at ____________________on _______________________ 0f 20 _________________________ __________________________ Signature of participant Signature of witness	

ADDENDUM E: STATEMENTS AND DECLARATIONS

STATEMENT BY OR ON BEHALF OF INVESTIGATOR(S)

I, …….., declare that

- I have explained the information given in this document to____ (name of participant);
- he/she was encouraged and given ample time to ask me any questions;
- this conversation was conducted in English and no translator was used.

Signed at ____________________ on _______________20___
(place) (date)

___________________________________ _________________
Signature of investigator/representative Signature of witness

IMPORTANT MESSAGE TO PARTICIPANT

Dear Participant

Thank you for your participation in this study. Should at any time during the study

- an emergency arises as a result of the research, or
- you require any further information with regard to the study, or
- you need to refer someone who is a potential participant in this study, kindly contact me (Phumudzo Raphulu)

ADDENDUM F: BIOGRAPHICAL DETAILS AND QUESTIONS TO BE ASKED

The biographical details and questions regarding the parents will include the following:

- How old are you?
- What is your marital status?
- What is your main language?
- What is the highest qualification?
- How old is your child with CP?
- Is the child attending a special school or not? If Yes, please provide the name of the special school

The following questions in the interview guide focused on the topic will be asked:

- How did you learn that your child has CP?
- Who explained to you the condition of your child?
- Please share with me how you reacted when you learned that your child has CP.
- Please share with me how your family members reacted after discovering that you were caring for a child with CP
- Please share with me your experiences of caring for a child with CP (Prompts: what happens when you care for a child, attention, needs, demands).
- Please share with me challenges you have encountered while caring for the child.
- Tell me your coping mechanisms you used to overcome the challenges you have encountered
- Who supports you in caring for your child? (Prompts: family, community members, organisation).
- What type of support did you receive? (Prompts: family, community members, organisation).
- Share with me the type of social work support you would like to receive.
- If you have utilised the services of social workers in the past, please share with me the services that were offered to you and the child?
- Please share with me how you would like social workers to assist you and your child.

- In your opinion, do you have sufficient information about the condition of your child?
- If No, who should provide you with the information?
- Is there anything else you would like to discuss regarding this topic?

ADDENDUM G: REQUEST FOR DEBRIEFING SERVICES

Request for debriefing services

My name is Phumudzo Raphulu and I am a postgraduate student in the School of Social Sciences (Faculty of Humanities) at the University of South Africa. I am conducting a research on **mothers caring for children with cerebral palsy: suggestions for social work support. in** partial fulfillment of Master of Social Work degree**.**

I am kindly requesting that you assist me with the debriefing of my research participants, should it become necessary for them to receive such debriefing. A qualitative study supported by exploratory, descriptive and contextual designs will be undertaken. Data will be collected using semi-structured interviews. The research will be conducted in the City of Johannesburg Metropolitan Municipality (Gauteng province). The population of the study will consist of mothers caring for children with CP. The goals of the research study were:

- To develop an in-depth understanding of the experiences of mothers caring for children with CP’s.
- To proffer suggestions for social work support.

Prior to conducting research comprising human participants, an approval from the Departmental Research and Ethics Committee (DR&EC) is required. The research study will only be conducted following an approval from the above-mentioned committee.

If you can assist me, kindly accept my request in a formal letter as confirmation that I solicited your debriefing services. For further clarity, please email me on 46468196@mylife.unisa.ac.za

Your assistance will be greatly appreciated.

Kind regards

Phumudzo Raphulu
Master of Social Work Student

ADDENDUM H: LETTER ASKING PERMISSION TO RECRUIT PARENTS OF CHILDREN WITH CP IN STIMULATION CENTRES

Attention: Stimulation Centre Manager

My name is Phumudzo Raphulu and I am a postgraduate student (student registration number: 4646-8196) in the School of Social Sciences (Faculty of Humanities) at the University of South Africa. I am conducting a research on *mothers caring for children with cerebral palsy: suggestions for social work support,* in partial fulfilment of the Master of Social Work degree. The goals of the research study were:

- To develop an in-depth understanding of the experiences of mothers caring for children with CP's.
- To proffer suggestions for social work support.

I am requesting permission or access to recruit mothers whose children are placed in your organization, since your centre/organization caters for children with CP. I will use the organization's quarterly meetings as a platform to recruit mothers who would like to participate voluntary in my study.

The research study will only be conducted following the approval of the UNISA Department of Social Work's Research and Ethics Committee. I will appreciate it if you could accept my request in a formal letter confirming that I would be granted permission to recruit mothers caring for children with CP in your organization. If you have any further enquiries, please contact me on my e-mail: 46468196@mylife.unisa.ac.za

Your assistance will be greatly appreciated.

Kind regards

Phumudzo Raphulu
Master of Social Work Student

ADDENDUM I: TURNITIN REPORT

Digital Receipt

This receipt acknowledges that Turnitin received your paper. Below you will find the receipt information regarding your submission.

The first page of your submissions is displayed below.

Submission author: Phumudzo Raphulu
Assignment title: Revision 3
Submission title: Mothers caring for children with cere...
File name: 30_October_2020.docx
File size: 244.49K
Page count: 155
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