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CHALLENGES FACED BY MOTHERS OF CHILDREN WITH
CEREBRAL PALSY (CP) ATTENDING THE JAIROS JIRI
ASSOCIATION (JJA) FIRST-STEP INCLUSIVE PRE-SCHOOL, IN
BULAWAYO

BY

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A DISSERTATION SUBMITTED TO THE FACULTY OF SOCIAL SCIENCES IN PARTIAL FULFILMENT OF THE REQUIREMENTS FOR THE BSc HONOURS DEGREE IN PSYCHOLOGY

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FACULTY OF SOCIAL SCIENCES

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RELEASE FORM

NAME OF AUTHOR: Chibvongodze Talent TITLE OF DISSERTATION: Challenges faced by mothers of children with cerebral palsy (CP) attending the Jairos Jiri Association (JJA) First-Step Inclusive Pre-school, in Bulawayo. **DEGREE FOR WHICH DISSERTATION WAS PRESENTED:** BSc Honours in Psychology **YEAR GRANTED:** 2018 Permission is hereby granted to the Midlands State University library to produce copies of this dissertation and to lend or sell such copies for scholarly purposes only. The author reserves other publication rights and neither the dissertation nor extensive extracts from it may be printed or otherwise reproduced without the author's written permission. **SIGNED:** **ADDRESS:** 71496 Lobengula West P. O. Magwegwe Bulawayo

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DEDICATION

This dissertation is dedicated to my parents, Mr. J. and Mrs. R. Chibvongodze, for their unwavering support throughout my course and all mothers who have taken up the heroic role of caring for their children with cerebral palsy.

ABSTRACT

This study aimed to explore challenges faced by mothers of children with cerebral palsy (CP) attending the Jairos Jiri Association (JJA) First-Step Inclusive Pre-school, in Bulawayo. Relevant literature was reviewed, inclusive of Bourdieu's theory of practice which formed the theoretical framework of the study. Previous studies were discussed from which a knowledge gap was identified. The researcher used a qualitative research paradigm and an exploratory design. Targeted were mothers of children with CP attending JJA First-Step Inclusive Preschool, in Bulawayo. Stratified sampling was used with a population sample of 12 mothers. Data was collected using semi structured in-depth interviews which were presented using descriptive analysis and analysed using thematic analysis. The researcher observed ethics which included informed consent, anonymity, confidentiality and privacy. Major findings were that mothers of children with CP faced psychological, social and financial challenges. Recommendations made included that there was need for the government, non-governmental organisations, relatives and the community to offer mothers social, emotional, and financial support and to raise disability awareness so as to reduce stigma and discrimination.

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CHAPTER ONE: INTRODUCTION

1.1 Introduction

Covered in this chapter is the background to the study, statement of the problem, significance of the study, research questions, assumptions, purpose of the study, delimitations of the study, limitations and definition of terms.

1.2 Background to the study

According to the Centers for Disease Prevention and Control (CDCP) (2017), cerebral palsy CP is the most common motor disorder in childhood worldwide. Novak, Hines, Goldsmith and Barclay (2012) further posit that 350 million people are closely connected to a child or adult with CP globally. Sankar and Mundkur (2005) report that the worldwide incidence of CP is 1.55 in rural areas and 3.3 in urban areas per 1 000 live births, with 40% of these having severe cases. The (CDCP) (2017) highlights that CP is common among boys. Burton (2015) notes that little has been published about CP in Africa but its prevalence is 10 per 1 000 births showing a high regional prevalence. In confronting the problems of children and caregiving, mothers are more affected than fathers note Oh and Lee (2009). Dambi, Jelsma and Mlambo (2015) cite Finkenflugel et al (1996) who says that the prevalence of CP in Zimbabwe is 1.55 per 1000 and 3.3 per 1000 in rural and urban areas respectively. In a research conducted by United Nations Children's Fund (UNICEF) (2005-2011) at Harare Child Rehabilitation Unit, findings showed that cerebral Palsy was the most commonly clinically diagnosed condition at Harare Child Rehabilitation Unit, with about 71.6% of the children less than 12 years diagnosed of the condition. The same research report by UNICEF (2005-2011) highlighted that there was a general increase in cerebral palsy cases from 55.9% in 2005 to 76.9% in 2011 in Zimbabwe.

In a study conducted in the USA, 86% of cases of children with CP had their mothers as primary caregivers indicating that the caregiving responsibility largely remains women's duty, (Ones, Yilmaz, Cetinkaya and Caglar, 2005). According to Singongo, Mweshi and Rhoda (2015), mothers of children with CP face psychological, social and financial challenges in carrying out their caregiving duty. WHO (2011), cited by Singongo, Mweshi and Rhoda (2015), indicate that the daily life of mothers in care of children with CP is often more negatively affected because they are usually the primary caregivers and they face many

challenges in their caregiving responsibilities. In a study conducted in Canada, Brehaut, Cohen, Raina, Walter, Russel, Swinton, (2004) note that caring for children with CP affects the physical health of mothers. In Iran, due to lack of assistive devices such as wheelchairs for use by the children at home and outdoors, mothers mentioned lifting and carrying their children and even those with assistive devices reported that the environment was not adapted for wheelchairs to navigate (Dalvand, Hosseini, Rassafiani, Samadi, Khankeh & Kelly, 2015). This occupation entailed taking the child up and down stairs, transfers, accompanying the child to and from school. As a result, the mothers suffered fatigue and back pains.

The (CDCP) (2017) posits that in USA, medical costs for children with CP alone were 10 times higher than for able bodied children. This is because children with CP require frequent medical attention since their immune system is weak and vulnerable to infections. As such, mothers of children with CP face financial challenges owing to doctor's consultations, transport fees for the child, mother and the wheelchair, and additional basic needs such as diapers and a special diet. Shearn and Todd (2000) also add that these mothers have low chances of getting employed as their time is mostly invested in taking care of their children thereby foregoing income generating opportunities.

Nimbalkar, Raithatha, Shah, and Panchal (2014) note that in India having a child with CP results in social challenges ranging from lack of participation in social gatherings, sour family relationships, time constraints in caring for the affected child and other siblings. According to the same source, mothers of children with CP are highly at risk of marriage breakdown as some male figures disappear upon the delivery of a child with such a condition. Thus, making CP caregiving, a burden for women who not only have to bear taunts, discrimination and blame from the society but also have to raise the child alone with little or no social support.

In addition, Nimbalkar et al (2014), highlights that mothers of children with CP have negative emotional well-being characterised by feelings of guilt, despair, anger, frustration and fatigue and are highly vulnerable to social isolation resulting in stress and depression. Olawale, Deih and Yaadar (2013) note that in Ghana the society expressed opinions such as that having a child with CP was blamed on mostly the mother's wrongdoing or witchcraft because women are traditionally weak and vulnerable. With such blames and labels, the women are discriminated against and isolated.

According to Ones et al (2005), in a study investigating the relationship between the psychological well-being of mothers and having a child with CP, it was observed that these

mothers mostly presented with depression and anxiety symptoms. These symptoms were attributed to all the problems that they face emotionally, socially and physically and their inability to control the conditions of their children as well as lack of sleep and feelings of hopelessness since CP is a lifelong caregiving responsibility which is incurable and difficult to manage.

In a study carried out in Harare by Dambi, Chivambo, Chiwaridzo and Matare (2015), results indicated that challenges faced by mothers of children with CP in Zimbabwe were more-orless the same as those faced by any other mothers of children with CP globally as they experience physical, health, psychological, economic and social problems. Dambi et al (2015) point out that mothers of children with CP experience deterioration in their health-related quality of life. The authors further postulate that there is no adapted transport for children with CP, as such when traveling mothers pay for the child, herself and the wheelchair. The acquisition of wheelchairs for children with CP adds financial constraints to mothers of children with CP who are rarely even employed to afford these. Given such a scenario, mothers generally rely on the traditional method of carrying their children with CP on their backs resulting in back pain and fatigue. Further, in a research conducted at Parirenyatwa Group of Hospitals by Dambi and Jelsma (2014), indicated that primary caregivers (mothers) reportedly show signs of depression, anxiety, stress and low self-efficacy. Caregiving by mothers of children with CP may result in decreased opportunities to socialize and to gain formal employment hence mothers are often overwhelmed by this role.

Notably, having a child with CP results in physical, psychological, economic and social challenges. These challenges disproportionately mostly experienced by mothers who provide primary care thereby imposing upon them an intersection of challenges.

1.3 Statement of the problem

The main problem which the study sought to address was that mothers of children with CP face challenges in their caregiving responsibility, especially those in urban areas. As much as sensitisation on disability issues has reached an alarming stage, it remains a fact that the CP caregiving role remains a burden for women resulting in them facing a myriad of challenges. Despite efforts by the government and non-governmental organisations (NGOs) to lessen the caregiving burden, this remains heavily resting on the shoulders of mothers. UNICEF (2013) indicate that the caring of children with CP puts additional strain on mothers who face

comparatively higher costs of living and poverty as they are forced to quit or limit their opportunities of employment to care for their children with CP. Therefore, by virtue of being women in a patriarchal society, mothers of children with CP in a country under economic constraints, inhabitants of an urban area and wives with set gender roles, women take the central role in the life of a child with CP and this role comes with a lot of challenges which negatively impact on the quality of life of these mothers.

1.4 Significance of the study

Findings of this research might benefit the following:

- **Community:** Knowledge of the challenges experienced by mothers in the care of their children with CP may enable necessary support to be offered.
- Government and Non-governmental organisations: Knowledge of challenges faced by mothers of children with CP may assist the government and NGOs in crafting policies and implementing community development programmes that support and empower mothers of children with CP.
- Mothers of children with CP and their children: Information gained from the research may attract organisations that may invest their resources in cushioning mothers of children with CP and their children against the challenges they face.
- Other researchers: Knowledge obtained from the research may widen other researchers' knowledge on challenges experienced by mothers of children with CP.

1.5 Research Questions

The study was guided by the following research questions:

- What psychological challenges do mothers of children with CP face?
- What social challenges do mothers of children with CP experience?
- Do mothers of children with CP face financial challenges in caring for their children?

1.6 Assumptions

The researcher made a number of assumptions. It was assumed that caring for children with CP in an urban area posed psychological, social and financial challenges to mothers.

1.7 Purpose of the study

The purpose of the study was to determine challenges faced by mothers of children with CP in an urban set up. The challenges faced by mothers of children with CP include psychological, social and financial challenges. The financial challenges experienced include failure to meet basic needs like education, health, food, transport and washing detergents as a result of unemployment and limited time to even venture into informal employment. Social challenges faced comprise marriage break down, stigma and discrimination and social isolation due to time constraints. Psychological challenges encompass depression, disturbed sleep patterns, anxiety, stress, guilt, shame and negative self-criticism.

1.8 Delimitations of the study

The research explored challenges faced by mothers of children with CP attending First-Step Inclusive Pre-school in Nguboyenja, a high density suburb in Bulawayo. Additionally, the study explored the human gender biased caregiving burden impact of CP.

1.9 Limitations

The researcher faced some challenges during the course of the research. During interviews, there was communication breakdown with some mothers of children with CP who were illiterate. The researcher countered this by translating to either Shona or Ndebele. Further, the population sample only sampled mothers of children with CP who brought their children to the First-Step Pre-school for inclusive education. The scenario of mothers whose children were not attending the pre-school could be different.

1.10 Definition of terms

• Cerebral palsy: Martin, Murray, Peter, Alan and Nigel (2005) define cerebral palsy as a group of disorders of the development of movement and posture, which cause activity limitations, attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. Motor disorders in cerebral palsy are often accompanied by disturbances of sensation, cognition, communication, perception, and/or behaviour, and/or seizures. The researcher defined cerebral palsy as a neurodevelopmental disorder common in childhood that causes movement and postural impairments.

- Child: The Constitution of Zimbabwe Amendment (No. 20) of (2013) states that a child is an individual under the age of eighteen. The researcher defined a child as of pre-schooling ages between 5 and 11. It should be noted that due to delayed milestones and lack of resources to go to higher level education, children with CP take longer in pre-school than their non-disabled counter parts.
- **Challenges:** The Longman dictionary of Contemporary English (2017) defines challenges as those activities or situations that are highly demanding in dealing with, in terms of skill, strength, and ability. The researcher defined challenges as hardships faced by urban mothers as they provide care to their children with CP. These hardships were categorised under psychological, social and financial and were defined as follows:
 - Psychological challenges: These involve challenges negatively affecting mental processes such as thoughts and emotions of mothers of children with CP for example depression, anxiety, guilt and hopelessness.
 - **Social challenges:** These are negative personal interactions which impact on how mothers of children with CP interact with other people. Examples of these are stigma, discrimination, social isolation and marriage breakdown.
 - **Economic challenges:** To do with non-availability and availability of money and resources to cater for the needs of the mother and the child with CP. Financial challenges may be in provision of transport, school and medical fees, constraints in providing sanitary wear and special diet.
 - Inclusive Pre-school: Cate, Diefendorf, McCullough, Peters, and Whaley (2010) define an inclusive pre-school as a childhood education institution that accommodates, supports, benefits and encourages full participation of all children with or without a disability. This research adopted the same definition. Within this research, reference was made to the First-Step Preschool which is manned by the Jairos Jiri Association (JJA) department of Community Based Rehabilitation (CBR). It caters for both CwDs and able bodied children offering both academics and functional therapy through physio and skills training on activities of daily living.

1.11 Conclusion

This introductory chapter has presented the background to the study, the statement of the problem, significance of the study, research questions, and purpose of the study, delimitations of the study, limitations and definition of terms.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This chapter reviews relevant literature on challenges faced by mothers of children with CP attending the JJA First-Step Inclusive Pre-school in Bulawayo. The first section of this chapter unpacks CP as a condition covering common types and symptoms, causes and risk factors. The chapter then presents challenges faced by mothers of children with CP from the following perspectives: global, regional, and finally zeroing in on the Zimbabwean context. Also given is the theory that explains the problem under study and previous studies from which the knowledge gap is identified.

2.2. Cerebral palsy

The word "cerebral" refers to the brain while "palsy" entails weakness or paralyzed body muscles, (CDCP, n.d.). Therefore, according to Rosenbaum, Paneth, Leviton, Goldstein and Bax (2007), cerebral palsy is a form of disability that describes a group of permanent disorders of the development of muscle movement and posture that are attributed to non-progressive disturbances that occurred in the developing foetal or infant brain. Hoon and Faria (2010) further state that the motor disorders of cerebral palsy are often accompanied by disturbances of sensation, perception, cognition, communication, and behaviour; epilepsy, and secondary musculoskeletal problems.

2.2.1 Causes and risk factors of CP

The development of CP results from injury to the brain that often occurs before the completion of cerebral development (Krigger, 2006). According to Eunson (2012), the causes of CP are attributed to three main factors which are improper brain development (malformation), brain damage and infections to the brain that was otherwise developing normally. Often, not a single factor causes the disorder but rather multiple concurrent risk factors predispose individuals to CP, (Nelson, 2008).

Hoon and Faria (2010) postulate that a number of risk factors are linked to CP and these can be grouped into prenatal, perinatal and post natal. Prenatal risk factors of CP are those that occur before and during birth accounting for 70% of CP cases worldwide according to (My Child without Limits Organisation, 2014). Post natal risk factors of brain damage which

result in acquired CP occur after birth and account for 20% of CP cases usually noticed within 2 years from birth as noted by the same source.

The prenatal precursors of CP include insufficient oxygen supply to the foetus, congenital malformation, maternal infections, exposure to radiation, blood diseases, maternal bleeding, maternal seizures, genetic abnormalities, exposure to environmental toxins, multiple births, intrauterine growth restriction, abnormalities of the brain structure, irregularities of blood flow to the brain, nutritional deficits, and pre-eclampsia (high blood pressure before 20 weeks gestation), (Sankar & Mundkur, 2005; Myers & Shapiro 1999; Noetzel & Miller, 1998).

Premature birth is a high perinatal risk factor of CP notes Eunson (2012). Polani (1958) highlights that there is a positive correlation between premature birth and CP. The reason behind this being that prematurity is frequently accompanied by an underdeveloped respiratory system resulting in insufficient oxygen supply to the foetus, (Griffin, Fitch and Griffin, 2002). A low birth weight of less than 2.5 kg has also been associated with CP with such infants at a risk of hypoxic-ischaemic encephalopathy, an injury caused by asphyxia when the brain receives insufficient oxygen during labour (Eunson, 2012). Other perinatal risk factors include breech births, lengthy or short labour, placental complications, maternal fever during labour, delayed onset of breathing as well as perinatal infection (Eunson, 2012; Sankar & Mundkur, 2005).

Postnatal risk factors occur after birth resulting in acquired CP which accounts for 10 to 20% of CP cases, (Sankar and Mundkur, 2005). Among the postnatal risk factors are severe jaundice, viral/bacterial infections, seizures, motor vehicle accidents, falls, physical abuse and traumatic life events such as drowning, Krigger (2006); Sankar & Mundkur, (2005).

Among African studies, the most frequently reported causes of CP were kernicterus (a condition of severe jaundice which is associated with high levels of bile pigment in the brain and nerve tissue), neonatal infections, and birth asphyxia (Karumuna and Mgone, 1990; Ogunlesi and Ogundeyi, 2008). These findings are in contrast with the majority of studies that have been conducted in Europe and the US, where almost all studies have identified low birth weight or prematurity as one of the major risk factors for CP (Gladstone, 2010). It is possible that infants who are born prematurely in low-income areas do not survive to an age where CP can be determined due to lack of antenatal care, which could account for the discrepancy in these etiologies (Bangash, Hanafi, Idrees, & Zehra, 2014; Gladstone, 2010).

2.2.2 Types and symptoms of CP

There are two major categories of CP (spastic/pyramidal CP and non-spastic/extrapyramidal) CP classified on the basis of location and extent of brain damage, body movement parts affected and posture problems presented, (Gillette children's speciality healthcare, n.d.).

Spastic CP is a type of CP which results from injuries to the cerebral motor cortex causing abnormally stiff body muscle tone, bone deformities and contractures, (Cerebral Palsy Alliance, n.d.). The National Institute of Neurological Disorders and Strokes (n.d.) states that spastic CP is the most common form of CP affecting around 70% to 80% of all diagnosed cases of CP. Spastic CP is further classified as diplegia, hemiplegia, quadriplegia, monoplegia and triplegia depending on the affected limbs. Non-spastic CP is a form of CP marked by decreased muscle tone that tends to fluctuate, (My Child Cerebral Palsy Foundation, 2016). It is divided into dyskinetic, ataxic and mixed non-spastic CP.

Generally, common symptoms for all types of CP depending on severity as illustrated by the Cerebral Palsy Alliance (n.d.) are increased muscle tone or tension leading to muscle stiffness and floppiness although there are cases where normal or reduced muscle tone is observed, (Smith & Kurian, 2012. The Centers for Disease Control and Prevention (2014) states that CP is linked to delayed developmental milestones and poor motor development, movement and coordination. Most children with CP can literally do nothing on their own even when grown up and require assistance with daily activities such as mobility (lifting/wheelchair), bathing, toileting and eating. Such physically demanding activities take a toll on the well-being of primary caregivers who are mostly the mothers resulting in them facing a plethora of challenges.

Moreover, children with CP present with uncontrolled mouth muscles which results in drooling of saliva, failure to chew and swallow properly and the need to eat soft food, Smith and Kurian (2012). These difficulties necessitate the mother's consistent attention as the child may choke and the need for the purchase of soft food though it is expensive.

2.3 Challenges faced by mothers of children with CP

The World Bank and WHO (2011) in The World Report on Disability admit to the complexities underpinning disability, citing its multidimensionality, attributed to varying perspectives on how it is understood and what it constitutes. Coupled with this idea is the fact that recent evidence suggests that CP has always been researched and conceptualised in

isolation of other social characteristics such as gendered experiences and the caregiving responsibility (Graham and Selber, 2003). Mothers of children with CP are victims of moreor-less the same challenges faced by their children.

Challenges are defined as a situation of being faced with something that tests one's capabilities in terms of resources or mental capacity in order to be successfully handled, (Winch, 2014). For the purposes of this study, challenges refer to the difficulties experienced by mothers of children with CP residing in an urban area in the day to day upbringing of their children. Given the complexities associated with CP as a form of disability, children with CP are highly dependent on their caregivers who for the current study are their mothers. Such dependency result in the mothers facing a myriad of challenges which they have to content with on a daily basis. These may include psychological, social and economic challenges.

2.3.1 Psychological challenges

According to Nimbalkar, Raithatha, Shah and Panchal (2014), challenges faced by mothers of children with CP include psychological challenges. These are problems that affect or arise in the mind and are associated with mental and emotional well-being. Singongo et al (2015) cite Huang, Kellet and John (2010), who state that caring for a child with CP may be overwhelming, resulting in sorrow and grief as the reality of lost hopes and dreams becomes apparent. Nimbalkar et al (2014), further add that mothers of children with CP experience a wide variety of negative emotional reactions ranging from shame to anger and guilt, frustration and helplessness. Dambi et al (2015), highlight that long term caregiving has been associated with depression, anxiety, stress and low self-efficacy in mothers who constantly evaluate their caregiving responsibility and come up with own perceived failures on their abilities to provide the needs of their children emotionally, socially, and economically. Also, Glinac, Matovic, Delalic, and Mesalic (2017), report that mothers of children with CP are faced with various disability related demands which lead to the feeling of incompletely executed parental obligations and guilt.

Ones et al (2005) further postulate that mothers of children with CP experience depressive symptoms such as insomnia and anxiety with a high psychiatric morbidity. Sleep problems such as difficulty in falling asleep, excessive daytime sleep and sleep breathing problems are a common occurrence among children with CP, (Cerebral palsy Guidance, n.d.). Such sleep challenges not only affect the child's overall development, but also cause sleep disturbances within the entire family especially to mothers. As a result, mothers face issues with

concentrating and functioning in the following day which may lead to depressive moods. The level of dependence of a child on others in daily activities significantly affects a mother's psychological distress; and the more dependent the child, the greater the mother's distress, (Olawale, Deih, and Yaadar, 2013).

Although the defining feature of CP is diminished motor ability, which result in limited activity, many children with CP often show deficits in cognition, communication, perception, speech, and sensation, (Bax et al, 2005). Nimbalkar et al (2014) states that mothers of children with CP are constantly anxious of what tomorrow holds for their future and that of their children. Given such a scenario, mothers are not only anxious but also helpless and hopeless especially when the child does not develop from one stage to the other and learning one thing to the other as expected. Additionally, Glinac, et al. (2017) highlight that mothers of children with cerebral palsy are exposed to psychological pressure, such as stress and depression as they are worried about their children's future.

The communication barrier between the child and their mother causes anxiety and depression to the mother who finds it difficult to effectively deliver their duties because they do not know what the child needs. The child communicates through crying thus necessitating consistent presence and attention of the mother as any other caregiver may not necessarily tolerate crying as a means of communication. Smith and Kurian (2012) also note that a child with CP also display a high level of irritability and difficulty in feeding (sucking, swallowing or chewing) and sleeping, or vomits frequently with inability to control bladder or bowels. Given such a scenario, the child needs to be fed and requires to be constantly lifted to the toilet or to use diapers.

The financial and time demands of a child with CP result in psychological problems in mothers. According to Ribeiro et al (2016), the caregiving responsibility requires that a mother forego certain employment opportunities in order to provide care to their child. Olawale et al (2015) supports this idea highlighting that the provision of care to any child demands considerable resources and caring for a child with CP requires even an increased amount of resources and failure to sufficiently meet these result in psychological disturbances.

2.3.2 Social challenges

According to the Longman dictionary of Contemporary English (2017), social challenges refer to problems emanating from interacting with other people in society or engaging in any social behaviour. Munsaka (2012) highlights that the same social challenges experienced globally by mothers of children with CP are faced by regional mothers though in a different manner due to how CP as a form of disability is viewed and perceived in an African context.

According to Olawale, Deih, and Yaadar (2013), people's negative attitudes towards children with CP and their families worsens the social trauma experienced by mothers of these children who are left isolated. Such attitudes and stigmatization can be very disturbing. Mothers as primary caregivers often endure the burden of seeing their child being deprived of social opportunities, recreational facilities, and even opportunities to develop friendships. The child's deprivation of engagement in social activities extends to the primary caregiver who is the mother and constantly with their child. Community and family members shun away from both the mother and her child in churches and other social gatherings and this leaves them isolated and would rather stay indoors than to be stigmatised and discriminated. Further, Papalia, Olds and Feldman (2009) posit that caregivers need a life of their own beyond their loved one's disability, however attaining such a life is almost impossible because caregiving time demands live caregivers confined to the home and socially isolated.

Singongo et al. (2015), highlight that in a typical African society, the cause of a condition like cerebral palsy is somehow associated with witchcraft. In essence, most families and societies perceive it as a form of punishment from ancestors for a wrong act committed by a family member, especially the mother. The blame is normally shifted to women who are vulnerable, thereby causing family and marriage breakdown. To further buttress this is Dambi et al. (2015), who states that myths such as CP being caused by witchcraft and maternal promiscuity are still prevalent and mothers bear the brunt shed by the society. Society does not want to be associated with either the mother or child with CP. A study in Canada that investigated marital relations amongst families of children with disabilities reported that relationships suffered unduly from the added stress of blame, guilt, and anxiety, (Sobbey, 2004). Further, Glinac et al. (2017), report that CP caregiving pressures often lead to conflict and crisis in the family.

Children with CP also present with uncontrolled flow of saliva and other oral contents outside the mouth (drooling) as a result of weak or underdeveloped mouth muscles, (Aisen, 2011).

Leung and Kao (1999), highlight that drooling carries a considerable social stigma and discrimination as it is socially embarrassing. To avoid such embarrassment, caregivers of children with CP withdraw from family and societal social activities as many would rather not associate with them. This becomes a challenge to mothers who are forced to stay away from social gatherings to avoid such stigma and discrimination.

In an article by Holland (2017), mothers of children with CP were found to face housing challenges with their children as there are no disability friendly houses, and they cannot afford their own houses and landlords are not always willing to take them in as tenants. This leaves mothers of children with CP and their children vulnerable.

2.3.3 Financial challenges

The scarcity of financial resources to meet daily needs and wants signals financial challenges. Mothers of children with CP face financial challenges owing to the fact that CP caregiving responsibilities compromise and limit employment opportunities, Dambi et al (2015) and Singongo et al (2015). Generally, mothers of children with CP forego certain potentially income generating activities as they prioritise provision of care for their children who require consistent attention. With such a time demanding role, it becomes difficult for them to gain meaningful employment thereby resulting in financial struggles with a highly financially demanding life with no source of income. Besides time constraints, some employers are just not ready to employ someone with a child with a lifelong care demanding disability like CP as they feel this may compromise the quality of work delivered. Patel, Baier, Baranov, Khurana, Gambrah- Sampaney, Johnson, Monokwane and Bearden (2017) report that mothers of children with CP face financial challenges to meet special educational needs, assistive devices and therapy costs.

Generally, raising a child is financially demanding and the demand is higher if the child has CP (Ribeiro et al., 2016). A child with CP requires diapers since they cannot independently walk to the toilet and neither can they effectively communicate the need for toileting except crying. Given such a scenario, mothers make use of diapers for sanitation and this requires money. Despite this highly demanding life of a child with CP, the Contact a family organisation (n.d.) posits that mothers of children with CP suffer economic discrimination in terms of denial to access to employment as well as inflexible work schedules. The issue of unemployment among mothers of children with CP is also reported by Glinac et al. (2016)

who state that in Bosnia and Herzegovina, 86% of mothers of children with CP are unemployed.

Mothers of children with CP face medical financial challenges. CP is associated with some comorbidities which require doctor's consultations. Among them is hydrocephalus (accumulation of fluid in the brain), epilepsy, as well as visual and hearing difficulties; gastrointestinal problems, including swallowing difficulties and constipation; behavioural or learning problems, comprising of autistic features, depression, and skin problems, such as pressure sores (Aisen et al., 2011; Bax et al., 2005; Smith & Kurian, 2012). Individuals with CP are also susceptible to dental decay and poor oral hygiene, brittle bones, as well as respiratory infections (Smith & Kurian, 2012). The high susceptibility of children with CP to CP related comorbidities necessitates regular medical attention which requires funds thereby adding to the financial challenges mothers of children with CP face.

To add on, the Cerebral Palsy Alliance (n.d.) notes that some children with CP have poor digestive systems as such cannot take solid food often lest they have a tummy upset. In such a situation mothers of children with CP make efforts to ensure the child with CP has a special diet consisting light food such as instant porridge, milk and potatoes which are expensive to a mother who is most probably unemployed.

To add on, Singongo et al (2015) highlight that transport fees for a child with CP are doubled as the child cannot independently travel to and from school. Given the aforementioned symptoms of CP, it is difficult if not impossible for children with CP to cope in local mainstream schools yet their right to education still needs to be promoted. In such a scenario, special schools or inclusive schools like the First-Step pre-school become handy. However, to access the school, it means on a daily basis mothers of children with CP need transport money for their child, the mother who accompanies the child, and the wheelchair to and from school. This is financially straining on the mothers who are hardly employed and even in situations where they are, their salary is not enough to cater for the whole family needs. Thrush and Hyder (2014) highlight that providing care to a child with CP come with more expenses usually including medical visits and treatments, cost of physiotherapy and medication and assistive devices.

2.4 Bourdieu's theory of practice

This research advances Bourdieu's sociological theory of practice as a framework of analysis. The theory of practice is synonymous with a French social theorist and Sociologist, Pierre Bourdieu. It emphasises how power dynamics, cultural reproduction and social positioning in society impose social injustices and inequalities on the lives of vulnerable people in a society. The theory is based on the notion that the disadvantages or challenges faced by people are a result of the unequal access to resources as well as internalized cognitive cultural experiences. It should be noted that although the theory of practice has been chosen as a framework of analysis for this study on the basis of its relevance, the theory did not emerge as an approach to address CP caregiving issues but the theory has been used in a variety of disciplines including psychology, sociology, education, anthropology and philosophy Bourdieu's theory is generally recognized as a way to account for human social life through the synthesis of societal structures and a person's individual dispositions resulting in social injustice. The theory is constituted by three key concepts: capital, habitus, and field.

According to Riley (2017) Bourdieu defines capital as simply resources and identifies three main capital varieties: economic (understood basically as income and ownership), social (basically understood as connections), and cultural (informal education, cultural objects, and credentials). Bourdieu acknowledges the influence of Marx's economic theory defining capital as the useful resources that can be used by social actors to distinguish and compete with each other. Bourdieu argued that capital which is income ownership, formed the basis of social life and dictated one's position within the social order.

This concept is applicable to the current study where from Bourdieu's perspective mothers of children with CP face a myriad of challenges because they lack economic capital. Economic capital involves income and other financial resources and assets that are a means and an end to survival, (Bourdieu, 1986).

Additionally, applicable to this research from Bourdieu's theory of practice is that mothers of children with CP face challenges because they lack cultural capital consisting symbolic (assets) and institutional (educational qualifications). By virtue of being women in a patriarchal society and belonging to a vulnerable group of mothers of children with CP, most mothers neither have skills nor educational qualifications to qualify them into well-paying jobs so that they meet their children's needs. Education and employment are matters of social justice which immensely contribute towards social inclusion and equal access to

opportunities, (Suminar, 2013). Thus for Bourdieu, mothers of children with CP need skills and qualifications to address their challenges pointing out that cultural capital is a major source of inequality

To add on, the theory of practice has it that mothers of children with CP are deprived of social capital. Bourdieu emphasises that economic survival in the social arena is dictated by whom one interacts with for connections, (Swartz, 2002). In the context of this study, mothers of children with CP experience challenges of deprivation and failure to access or create opportunities as a result of social exclusion, which bars them from achieving their potential, coupled with the challenges of failing to participate in society. Mothers of children with CP hardly have time to interact as they invest much of their time in caregiving. Even if they wish to interact, the society has made it difficult if not impossible for them to engage in social activities due to stigma and discrimination.

The habitus is one of Bourdieu's most influential yet controversial concepts. According to Bourdieu (1990), habitus is derived from a Latin word *hebere* which means to have or to hold. Bourdieu (1976) cited by Swartz (2002) posits that habitus refers to a social actor's internalised and strongly held cultural dispositions, which correspond to social space life experiences. Bourdieu sought to address the question of how human behaviour is regulated without rules. This concept follows that social actors follow unwritten rules of the game of life that is doxa. Thus the habitus is a strategy-generating principle which enables social actors to solve and cope with unforeseen and ever changing situations.

The habitus helps form a basis upon which mothers of children with CP have been shaped and internalised that they are an excluded group and have accepted such injustice as their fate. Swartz (2002) notes that the society's attitudes and perceptions have created social barriers which can hardly be broken. The discourses of normalcy as experienced in cultural beliefs and practices as well as the global discourse on knowledge emphasise individual differences. It is even worse in an African context where disability is associated with witchcraft and punishment from "gods". Reay (2015) argues that there is a strong link between psychosocial wellbeing and Bourdieu's concept of habitus. In this regard, affective aspects of living in an unequal society help in the understanding of how mothers of children with CP internally process what the wider social structures dictate. The Theory of Practice brings out the gendered social inequalities that exist within the CP caregiving role as a result

of personal experiences and dispositions referred to by Lizardo (2004) as the schemata of perception.

Mothers of children with CP have psychologically accepted the abnormal situation where society consistently label, gossip and stigmatise them causing within them untold suffering from depression to anxiety and sleepless nights of worry and hopelessness. Based on past experiences, these mothers know that the society do not accept or tolerate their children, an unwritten rule and ideology enforced by the dominant classes of those with able bodied children. To avoid breaking this rule they stay in isolation at home or avoid being in intimate relationships not by choice. The isolation serves as a psychological buffer against potentially mentally threatening situations such as being isolated at a bench in church because their child is drooling saliva or being dumped by an intimate partner because they have a child with CP who is economically, socially and psychologically burdening. This mentality justifies social injustice where mothers of children with CP believe and accept that other people deserve and are destined to live a non-discriminatory life and not them. Yet they too equally deserve to live a fulfilling life free from any inequalities or exclusions.

According to Bourdieu in Wacquant (2013), habitus and doxa occur in a field and that is where they are conditioned and made meaningful. The field which is characterised by struggles, competition and conflict for specific authority represents the daily life of social actors. Individuals and groups struggle in an attempt to maintain or change their position in a field, (Bourdieu, 1977).

Applicable to the current study is that the social field of interaction and competition is not a levelled one for mothers of children with CP and other social actors. Mothers of children with CP find themselves worse off because from the onset they are already faced with multiple oppressions from being women in a patriarchal society to being mothers of children with CP and inhabitants of an urban area. According to Suminar (2013), if the field is not equally levelled, it serves as an advantage or disadvantage to one party. Thus there is unequal access to financial, social and cultural capital with those with capital and authority amassing more at while vulnerable mothers of children with CP face challenges as the field of life has little to offer them especially when CP caregiving is a gendered individual burden thereby rendering it a social injustice.

2.5 Previous studies

Begum and Desai (2010) refer to a comparative study which sought to evaluate the psychological status of 30 mothers of children with CP and 70 mothers of children without CP. Data was collected in interviews using the Beck Depression Inventory (BDI) and Sinha Anxiety Scale (SAS) and was analysed using Statistical Package for Social Sciences (SPSS). Findings showed that mothers of children with CP suffered more from psychological depression than mothers of children without CP. These findings were attributed to the understanding that the presence of a child with CP in a family is accompanied by profound emotional distress as a result of lifelong evolving burdens that are financial, physical or social and demand great adaptation and coping mechanisms. The current study similarly uses interviews to find out the psychological challenges experienced by mothers of children with CP but also covers social and economic challenges.

In Istanbul Turkey, Ones, Yilmaz, Cetinkaya and Caglar (2005) describe a qualitative study which assessed the quality of life of 46 mothers of children with CP and 46 mothers of able bodied children through face-to-face interviews. Findings were that mothers of children with CP were bound to face psychological challenges owing to time-consuming demands of in home care, lack of information and resources, poor sleep, low energy, negative emotional reactions, social and isolation. The present study differs from Ones, et al's 2005 study as it only samples mothers of children with CP without comparing them with mothers of able bodied children.

Brazilian, Ribeiro, Vandenberghe, Prudente, Vila and Porto (2016) refer to an exploratory and descriptive study held with 19 mothers to comprehend how the age group and the severity of the motor impairment of children with cerebral palsy modify the mothers' experiences of stress and to understand the coping strategies they use. The study used semi structured interviews to collect data. Findings showed that mothers of children with CP were worried and afraid of dying and leaving their children with no support since they only trusted their own care and no one else's not even their husbands. The current study is similarly descriptive in nature though the sample size is 12.

Olawale, Deih and Yaadar (2013) sought to identify and describe, from an African perspective, the psychological impact of CP on families and determine the strategies adopted by families in coping with it. The study was a questionnaire based cross-sectional descriptive survey held at a tertiary hospital in Accra, Ghana with 52 parents of children with CP.

Findings revealed that parents of children with CP experienced psychological challenges owing to inadequate knowledge of CP to cope well with the demands of taking care of children with CP. 38.5% of parents also reported psychological challenges arising from discouraging societal attitudes where people labelled and accused them of some wrongdoing that has made their child have CP. More psychological challenges were also reported to result from loss of job, loss of family joy, and derangement of financial affairs of the family. Though the current study also looks into the psychological challenges faced by caregivers, it differs from Olawale et al's research as it targets the gendered experiences of mothers of children with CP and not the whole family.

Between August 2014 and June 2015 Dambi, Chivambo, Chiwaridzo and Matare conducted a comparative descriptive cross- sectional study at Parirenyatwa Group of Hospitals in Harare, Zimbabwe. The researchers sought to determine the perceived health related quality of life (HRQoL) of 68 Zimbabwean caregivers of children with CP by comparing to that of 65 caregivers of children with minor health problems. Convenience sampling was used to recruit the participants at the department of rehabilitation and questionnaires were used for data collection. The researchers found that compared to caregivers of children with minor health problems, caregivers of children with CP reported more problems in usual activities, physical pain, and anxiety/depression. This is in accordance with other literature which posits that long term caregiving is linked to low Health Related Quality of Life (HRQoL) with caregivers reportedly experiencing anxiety depression, low self-efficacy and stress.

The Cerebral Palsy Alliance (n.d.) states that from a global perspective, mothers of children with CP were found to face social challenges which include stigma and discrimination. An in-depth interview based research which was conducted by Huang, Kellet and John (2011) in Taiwan China bears credence to this. The research purposefully sampled 15 mothers of children with CP. Similarly, the current study also makes use of in-depth interviews

Rassafiani, Kahjoogh, Hosseini and Sahaf (2012) found out that in Iran mothers of children with CP were more socially isolated due to the fact that they spent significantly longer time taking care of their children without engaging in any personal and social development activities with family or friends as their children demand high levels of attention and care. Their study was descriptive, cross-sectional and used a matched case control design. They measured the time spent in different social activities by 30 mothers who had children with cerebral palsy (CP), in comparison to 37 mothers of non-disabled children. A time Use

Questionnaire was used to measure the time allocations for different activities in both groups. A similar study conducted in Canada by McAndrew (1976) reported that 75% of the mothers reported being socially isolated as well. Similarly, the current study is descriptive but neither uses questionnaires nor is it comparative.

In North-west Nigeria, Lawal, Anyebe, Obiako and Garba (2014) sought to find out the socio-economic challenges of parents with children with neurological dysfunctions including CP. Sixty parents were selected for the study using non-probability availability sampling using a semi-structured questionnaire. Findings revealed that 55% reported facing stigma and discrimination at social gatherings where people do not associate with them due to the nature of their children's disability characterised by drooling saliva. Moreso, the same research reported that mothers faced marriage break down after having a child with CP and even those who had endured in marriage still reported sour relations arising from being blamed for the child's condition. Just like the Nigerian research study, the present study also looks into the socio-economic challenges but with a bias towards those faced by mothers of children with CP and not parents in general.

In their Zambian interview-based exploratory qualitative research on challenges experienced by 16 mothers caring for children with CP in Ndola, Singongo, Mweshi and Rhoda (2015) found out that mothers of children with CP experienced social isolation which led to stigma and discrimination. The mothers were selected using stratified random sampling. Social isolation was evidenced in marriage breakdown, alienation by friends, family and the community due to attitudes and limited time for interaction.

A Zimbabwean survey based longitudinal research by Dambi, Jelsma and Mlambo (2015) with conveniently sampled 46 caregivers from Chitungwiza hospital and Harare central hospital rehabilitation departments found out that caregivers of children with CP face social challenges. The social challenges may result from cultural beliefs on the causes of CP which result in social isolation thereby perpetuating stigma and discrimination. Since a child with CP may be drooling saliva, people may not be comfortable with interacting or being close to the mother and her child. Mothers of children with CP internalise this kind of treatment and withdraw from any interactions.

A cross-sectional study with 14 randomly selected clinics in Iran by Ahmadizadeh, Rassafiani, Khalili and Mirmohammadkhani (2015) used cluster sampling to assess the quality of life (QOL) of Iranian mothers who have a child with CP, compared to mothers with

able bodied children. Findings were that having a child with CP with intellectual disability is significantly related to a worse level of QOL of mothers. This was attributed to stress related to unemployment which means no source of income and results in failure to meet the child's additional needs such as diapers and a special diet. Unlike the Iranian research which used cluster sampling, the current research uses total population sampling.

Thrush and Hyder (2014) used an electronic literature review in USA at Bloomberg to review literature on the neglected burden of caregiving in low- and middle-income countries. The findings were that there are adverse financial consequences in playing a caregiving role. In as much as the current research does review previous literature, it does not base conclusions on this as such it is different from the Bloomberg research.

Nigerian Lawal et al (2014) set out to discover the socio-economic challenges of parents with children with neurological dysfunctions including CP. Based on their findings, the researchers concluded that the provision of care to a child with CP pose economic challenges on parents resulting from medical bills, transport fares, special school fees. This economic burden was worsened by the fact that caregiving interfered with parents' income generating activities such as employment. Unlike the research by Lawal et al (2014) in Nigeria which targeted parents of children with neurological dysfunctions, the present research specifically targets experiences of mothers and not parents, and it also singles out CP as a neurological condition of study.

In Botswana, Patel et al. (2017) describe a qualitative study which utilized semi structured interviews with 62 caregivers of children with CP. The study aimed at finding out the health beliefs and challenges of caregivers regarding pediatric cerebral palsy. Findings were that caregivers faced financial challenges in providing medical, educational and assistive devices to children, the current study similarly makes use of semi structured interviews for data collection.

A descriptive and longitudinal designed study by Dambi, Jelsma and Mlambo (2015) found out that caregivers of children with CP in Harare, Zimbabwe, exhibited poor HRQoL. Half of the participating caregivers experienced psychosocial burden with high levels of stress, complaining of pain or discomfort, anxiety or depression, economic burden and being overwhelmed by the care-giving role. Three quarters of participating mothers reported an increased financial burden as care-giving leads to compromised working opportunities due to the conflicting demands of care-giving and employment as well as the need for the provision

of special diet and sanitary wear. The study targeted 46 mothers of children with CP who were conveniently sampled from Chitungwiza hospital and Harare central hospital rehabilitation departments.

Moreso, the research by Dambi et al (2015) also revealed that most mothers could not afford assistive devices such as wheelchairs since they were not employed. As a result, they relied on carrying their children on their backs even though the children were grown up and this resulted in chronic pains and fatigue. The present study similarly samples mothers of children with CP in an endeavour to discover the caregiving strains associated with CP.

2.6 Knowledge gap

Studies on the challenges faced by caregivers of children with CP have been conducted in quite a number of countries. Much attention was previously drawn to the subject of general caregiver experiences of caring for a child with CP. In Zimbabwe, very few studies have explored the heterogeneous challenges faced by mothers of children with CP in their caregiving roles. Where information is available, it is limited to challenges faced by the whole family in caring for a child with CP not considering the unique burden carried by mothers by virtue of being women in a patriarchal society, wives, primary caregivers of children with CP and inhabitants of an urban area.

Previous studies on the challenges experienced by mothers of children with CP were biased towards how disability is conceptualised and understood from the perspective of the medical, social and cultural models of disability. However, the current study employed Bourdieu's theory of Practice as a framework of analysis to bring out the CP caregiving role challenges as a form of social injustice experience emanating from unequal access to resources.

The present study seeks to localise the challenges to the mothers who are in care of their children who attend the JJA inclusive pre-school, in Bulawayo. There is not enough knowledge about the experiences of mothers of children with CP in an urban set up. Findings from previously conducted researches in other parts of Zimbabwe may not be generalised to the sample of mothers who brought their children to the First Step inclusive pre-school because their cases maybe slightly different. Thus, this study shall provide knowledge on the challenges experienced by mothers of children with CP attending First-Step Inclusive Pre-school in Bulawayo.

2.7 Conclusion

The literature review chapter acknowledged the valuable body of literature on CP covering its definition, types and symptoms, causes and risk factors. The researcher also gave the theory that helps in explaining mothers' CP caregiving role challenges and also given were previous studies which helped in identifying the knowledge gap.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter presents the research paradigm, the research design, target population, population sample, research instrument, data collection procedures, and data presentation and analysis procedures.

3.2 Research paradigm

As defined by Kuhn (1962), a research paradigm is a strongly held perspective of thought or practice which directs thinking, feeling and actions within a field, to the extent that such becomes the norm and any deviation can easily be noticed. This research was based on a qualitative approach. Denzin and Lincoln (2000) hold that a qualitative research is a naturalistic and interpretive approach which is concerned with understanding the different meanings that people attach to phenomena actions, decisions, beliefs and values in their social worlds. The study adopted the qualitative approach due to its naturalistic nature. It provided the researcher with rich natural and unspoilt reports of subjective experiences of mothers' personal views, feelings and experiences coupled with the meanings and interpretations they give to their life events forming lenses through which they viewed and made sense of their experiences. The researcher also employed a qualitative research design due to its richly descriptive nature of what the researcher understood about the phenomenon of challenges faced by mothers of children with CP living in an urban area.

3.3 Research design

Burns and Grove (2003) define a research design as a blueprint of how a research is conducted with maximum control over any interfering factors which may affect the validity findings. The researcher used an exploratory research design. According to Shields and Rangarjan (2013), an exploratory study is a study which aims to explore the nature of existing phenomena or problems for enhanced understanding without offering conclusive solutions. The researcher realised the power of an exploratory research design to bring an understanding of what was otherwise not known or where little was known about the subjective nature of challenges faced by mothers of children with CP attending First-Step pre-school in Bulawayo urban.

3.4 Target population

According to Cox (2008), a target population is a group of people to whom the research results apply and can be generalized as they usually share common characteristics. In this study the target population comprised of mothers of children with CP attending the JJA First-Step Inclusive Pre-school, in Bulawayo. There were 12 mothers of children with CP. Three of them were married while 9 were single (7 divorcees, 2 widows). Their children's ages ranged between 5 and 11 years. Of the 12 mothers, 10 were unemployed while 2 were employed.

3.5 Population sample

A population sample is defined as a subset of individuals in a target population (Hanlon & Larget, 2011). The researcher used stratified sampling of mothers of children with CP. According to the Research Methodology (n.d.) stratified sampling is a probability method of sampling in which the total population is divided into smaller groups called strata based on one or more common attributes to complete the sampling process. The sample included 12 mothers of children with CP who were grouped into two strata, A and B based on their children's ages. Strata A had mothers of children of ages 5 to 7 while strata B had mothers of children of ages 8 to 11 years. Strata A had 5 mothers and strata B had 7 mothers. Stratification of mothers by children's ages was necessary because their challenges varied depending with the age of their children. Since the total of 12 mothers comprised all mothers of children with CP at the pre-school except the three in pretesting, the researcher went on to interview all mothers starting with the group with children aged 5 to 7 years. The respondents were of varying statuses in terms of marital status, age of child and employment status.

3.6 Research instrument

As defined by Seaman (1991), a research instrument is a measurement tool designed to obtain data on a particular topic of interest from research participants. The researcher used semi structured in-depth interviews. Jamshed (2014) defines an in-depth interview as a detailed conversation with a purpose where the respondents have to answer pre-set open-ended questions based on an interview guide. The in-depth interviews allowed the researcher access to facial expressions and other emotional non-verbal cues. The use of open-ended questions in in-depth interviews gave mothers of children with CP a flexible platform to explain their challenges. The researcher took the role of a facilitator, enabling mothers to talk about the challenges they experienced and bring out their views and thoughts. The fact that the in-depth

interviews were done in a natural and informal atmosphere encouraged the mothers to freely open up.

However, in-depth interviews had some drawbacks as they proved to be time-consuming with interviews lasting from 45 to 60 minutes on average. This limited the researcher's control over the flow duration of interviews. The researcher however, tried to direct and keep conversations relevant through asking probing questions and paraphrasing. There was also subjective bias as mothers gave out information shaped by what questions they were asked and what they felt comfortable to talk about. To check for consistency in responses, the researcher had to repeat certain questions in an effort to curb this bias. Furthermore, raw data from interviews took time to transcribe and analyse.

3.7 Data collection procedures

The researcher used a research letter obtained from the Department of Psychology of the Midlands State University. The letter was used to seek permission from the Provincial Programmes Officer at the JJA Department OF CBR which runs the First-Step inclusive Preschool in Bulawayo. Of assistance to the researcher in identifying mothers of children with CP was the community rehabilitation worker and the pre-school teacher. Thereafter, interview guides which had already been translated from English to indigenous languages, Ndebele and Shona were administered to the mothers and audio taped.

All mothers were booked for interviews three days in advance. The mothers were then interviewed as follows: 5 mothers from strata A with children with CP aged between 5 and 7 years were interviewed in one day in a spare office after attending a parents' meeting. Seven mothers from strata B with children aged between 8 and 11 were interviewed over 2 days as follows: 3 mothers were interviewed at their homes after they expressed that they were not comfortable being interviewed at the school office and they could not afford to miss customers at home since they are into out of the gate informal vending. The other 4 mothers were interviewed after attending an organic garden project meeting. On average, the interviews lasted 45-60 minutes.

3.7.1 Ethical considerations

The researcher observed the following ethics:

- Informed consent: The researcher informed the selected mothers about the study and who the researcher was and also on procedures of participation, and confidentiality of findings from the research. This was done to allow mothers to decide whether or not to participate in the study. Even after they were engaged, mothers were still given latitude to withdraw from the study at any time if they felt that their integrity or confidentiality was being compromised and have their information destroyed in their presence. Informed consent ensured informed cooperation and freedom of the mothers.
- **Anonymity**: The researcher made use of pseudo-names for mothers to remain anonymous and unidentified. This was done to ensure free expression of experiences as mothers knew they would not be identified.
- Confidentiality: Mothers who participated in the research were ensured that the information they provided would not be shared with anyone without their approval. The assurance for confidentiality of information to mothers made them feel secure and allowed them to freely express themselves.
- Privacy: The researcher ensured that the right of participating mothers to privacy was not invaded. This was achieved by holding interviews indoors so as to make sure no one knew or heard they participated in the study. Promoting privacy encouraged the mothers to participate with no fear of being labelled by other mothers within the Preschool community and outside.

3.7.2 Pre-testing

In an effort to test the validity and reliability of interviews, the researcher carried out a pretest. It also aided in determining the amount of time it took to conduct each interview. The pre-testing was held at the First Step Inclusive pre-school in Bulawayo with 3 randomly selected mothers of children with CP who were later excluded from the main study but who fitted the study's criterion. Through pre-testing, the researcher managed to correct and rephrase unclear questions. For example, question number 8 under social challenges was initially written as describe your experience in getting a house to rent with your child's condition. The researcher realised that the question was biased towards mothers who were tenants yet others owned houses as such the researcher had to rephrase the question to be general.

3.8 Data presentation and analysis procedures

Data gathered from the interviews was presented in its raw form using descriptive analysis. Thematic analysis was then used for analysing the gathered data. The process involved reading through the written notes from responses repeatedly, and breaking the data down by thermatizing and categorising. Key points were constructed by elaborating and interpreting in order to identify emerging themes and their relationships to the main objectives of the study. The researcher reviewed data, made notes and sorted it into categories for easy interpretation.

3.9 Conclusion

The chapter has described how the study was conducted with reference to the research paradigm, the research design, target population, population sample, research instruments, target population, data collection procedures, data presentation and analysis procedures employed by the researcher.

CHAPTER FOUR: DATA PRESENTATION, ANALYSIS AND INTERPRETATION

4.1 Introduction

The chapter presents, analyses and interprets data gathered from mothers of children with CP through semi structured in-depth interviews on challenges they faced.

4.2 Mothers' responses

The researcher personally conducted interviews with 12 mothers of children with CP. The 100% response rate significantly implied that the obtained data was reliable.

4.2.1 Section A: Demographic data

Table 4.1 is on the mothers' marital status, child's age as well as their employment status. All participants were biological mothers of children with CP.

Table 4.1: Demographic data

Pseudo-Name	Marital status	Child's	Employment status
		age	
Susan	Married	8	Formally employed
Ntando	Widowed	7	Informally employed
Fadzai	Divorced	9	Informally employed
Vuyiswa	Divorced	5	Informally employed
Tatenda	Married	10	Unemployed
Mavis	Divorced	11	Informally employed
Manelisi	Divorced	5	Informally employed
Gugulethu	Married	10	Informally employed
Rumbidzo	Divorced	8	Informally employed
Shalom	Divorced	7	Unemployed
Pamela	Widowed	6	Informally Employed
Maria	Divorced	9	Informally employed

Nine (75%) of the interviewed mothers reported that they were single, divorced or widowed. This may reflect that most of the challenges faced were those of mothers who solely provided caregiving without spousal support.

Nine (75%) of the interviewed mothers had children aged between 5 and 9 years. This may imply that findings were more biased towards the challenges of mothers with children in this age range.

Of the 12 interviewed mothers of children with CP, 10 (83%) of them were informally employed, relying on income from vending. This implies that research findings might have been influenced by challenges faced by financially-constrained mothers of children with CP.

4.2.2 Section B: Challenges faced by mothers of children with CP.

Interviews yielded the following themes and respective sub-themes:

- Psychological disturbances
 - Worry about uncertain future of children
 - Disturbed sleep patterns
 - Loss of interest in daily activities
 - Negative self-criticism of caregiving capability
- Dysfunctional social relations
 - Social exclusion
 - Stigma and discrimination
 - Broken intimate relations
 - Poor home living experiences
- Financial constraints
 - Poor sources of income
 - Inability to meet children's special needs
 - Missed employment opportunities

Responses to questions pertaining to the challenges faced by mothers of children with CP are presented under three research questions, which are also used as sub-headings. The researcher makes use of direct quotations to illustrate sub-themes.

Psychological challenges

On the question on whether or not the mothers were worried about the future of their children, 10(83%) of them reported that they were worried. This is illustrated by one mother who lamented saying:

"I always worry about what will happen to him if I die since he depends on me for everything from feeding, bathing, toileting, dressing to even mobility. I will not always be around yet I don't trust anyone else's care, not even his father".

This could imply that mothers of children with CP worried about the oblique future of their children.

Regarding the question on whether or not mothers of children with CP experienced sleep disturbances since they started caring for their children, 12 (100%) of them reported experiencing sleeplessness due to unmet financial needs and foregone employment opportunities. The following sentiment by one mother illustrates this:

"My soul is not at peace so how can I sleep, knowing that I have no income. My child relies on me for everything but my efforts are never enough. I sleep very late in the night and I wake up very early in the morning trying to figure out how best I can provide for him".

This could mean that caring for a child with CP resulted in mothers experiencing depression.

Responding to the question on their interests in daily activities, 7(58%) of mothers of children with CP reported having lost interest in most leisurely activities that they used to enjoy doing. One mother expressed this saying:

"I used to find pleasure in visiting friends to share community stories as well as in participating in community gardening projects but now I see this as a waste of time as I feel my child needs me more. I don't have the time".

This could be an indication that the mothers suffered from depression

With regards to the question on how mothers of children with CP rated their success in carrying out their motherhood role, 7(58%) stated that they had been unsuccessful as they failed to provide their children's needs. The mothers expressed guilt self-criticism. The following sentiments were made by one widow who said:

"How can I say I have been a successful mother when I have not paid his school fees and he crawls in sand because he does not have a wheelchair? No, I have been a failure and my late husband is disappointed in me. I have failed him".

This could imply that mothers of children with CP considered themselves as unsuccessful caregivers.

Social challenges

Regarding the question on their relationships with friends and family, 11 (93%) of mothers complained that they felt socially excluded by their family and friends. This can be illustrated by one mother who said:

"Family and friends withdrew association with me. They do not see me as a mother like any other but as a sinner who either had extra marital affairs or bewitched resulting in my child's CP. They even call me the ghost's mother with the ghost being my son".

This may be a reflection that mothers of children with CP felt socially excluded by family and friends.

About the question on the level of participation in family and community social activities, 12(100%) of mothers of children with CP reported having stopped engaging in any. This is illustrated by one mother who said:

"My son drools saliva and saliva becomes smelly with time, I have realised that when at family gatherings or church if I sit with my son on a bench with five people, within five minutes we will be alone on that bench with my son. To avoid such embarrassment we would rather keep our social distance".

This might indicate that mothers of children with CP faced stigma and discrimination and as a result did not participate in social activities at family and community level.

When asked to describe how their intimate relationships have been since having a child with CP, 7(78%) of divorced mothers attributed their divorce to the birth of a child with CP. This is illustrated in the following remarks by one mother who said:

"As soon as I brought home a child with CP, my husband's attitude towards me changed. He became a hostile and violent drunkard. He blamed our son's condition to be a curse from my family because in his family no one had such a condition. He would not come back home some nights. One day he came and ousted us from the house"

This could imply that having a child with CP resulted in intimate relationship breakdown.

Regarding their home living experiences with their children with CP, 8(67%) of mothers who were tenants cited varying difficulties. One mother echoed the following sentiments:

"Since I moved in my landlord complaints that my son's wheelchair leaves snake-like trails in his yard so I should follow him with a broom rubbing off the trails. He says that I waste water washing for my son daily. To get rid of us, he even hiked the rentals yet his home is not disability friendly, it does not have ramps but steps and the rooms are too small for a wheelchair to navigate.

This might reflect that mothers of children with CP experienced difficulties in home living conditions.

Financial challenges

Concerning the question on their sources of income, 10(83%) of mothers of children with CP reported that they had no stable source of income. This is illustrated by one mother who said:

"I sell fruits and vegetables outside my gate to generate income. This is my only source of income and only hope but it is never enough because my family needs are too many. Sometimes I run a loss because I sell perishables".

This may be an indication that mothers of children with CP did not have reliable sources of income as they were informally employed.

Regarding the question on their ability to provide for their children's special needs, 9(75%) of mothers of children with CP reported that they were failing to provide these. The following statement by one mother illustrates this:

"I owe the school cumulative debts in groceries and school fees and I stopped him from doing physiotherapy at the hospital because I could not afford it. For mobility, I either carry him or he crawls because he

does not have a wheelchair. Sometimes I absent him from school because I can't afford to pay transport fees for him".

This implies that mothers of children with CP failed to meet the special needs of their children such as school fees, medical fees, food and transport fares so as to promote their rights.

On the question on their experiences with their efforts to generate income, 11(93%) of mothers of children with CP highlighted that income generation had been difficult. This is illustrated in following statement from one mother who said:

"Employers are not willing to employ us, at one point I had gotten a job and when I explained that I had a child with CP, before I could go any further they told me that my child needed me more at home and besides I would compromise their work by my caregiving role".

This implies that mothers of children with CP face hardships in efforts to gain income generating opportunities.

4.3 Conclusion

The chapter presented, analysed and interpreted data collected from semi-structured interviews. Thematic analysis guided the analysis.

CHAPTER FIVE: DISCUSSION, CONCLUSIONS AND RECOMMENDATIONS

5.1 Introduction

This chapter discusses, gives conclusions and recommendations based on research findings on challenges faced by mothers of children with CP attending Jairos Jiri Association First-Step pre-school, in Bulawayo.

5.2 Discussion of results

The discussion is guided by research questions which are used as sub-headings.

Psychological challenges

Findings were that 10(83%) of the mothers of children with CP reported that they were worried about the future of their children in case of their death. The findings are supported by Ribeiro et al (2016), who states that Brazilian mothers of children with CP are worried about dying and leaving their children with no reliable support. Nimbalkar et al (2014) also reports that mothers of children with CP are constantly worried about what tomorrow holds for their children. Additionally, Singongo et al (2015) cite Huang, Kellet and St John (2010) who state that caring for a child with CP is potentially overwhelming and as a result caregivers, who are mostly mothers, are worried about the reality of lost hopes and dreams of a bright future for their children. Also, Bourdieu's (1984) theory of practice states that mothers have been "habituated" by experience into the mentality that the rule of the game "doxa" of life is that caregiving is a female function which no one else can assist with, hence their worry that if they die no one else can adequately care for their children.

Findings were that 12 (100%) of mothers of children with CP experienced sleep disturbances. In support of these findings is Ones et al (2005), who state that mothers of children with CP experience depressive symptoms such as insomnia and anxiety with a high psychiatric morbidity. In further support is the Cerebral Palsy Guidance (n.d.) which highlights that children with CP experience sleeping problems which do not only affect them, but also cause sleep disturbances within the entire family, especially mothers who have to stay awake to attend to them. Olawale et al (2015), similarly postulate that caring for any child involves considerable resources, but the demands for these resources are often increased when caring for a child with a disability like CP and failure to sufficiently meet these may result in psychological disturbances such as poor sleep patterns. Bourdieu's (1990) theory of practice

holds that mothers of children with CP face psychological challenges due to the imbalance between CP caregiving resource needs and available limited resources.

Findings were that 7(58%) of mothers of children with CP had lost interest in activities which they used to enjoy and this may be suggestive of depression. In agreement are Ribeiro et al (2016), who state that time demands of CP caregiving makes mothers of children with CP lose interest in activities that they previously enjoyed as they choose to provide care to their children than to engage in leisurely activities. Findings are further supported by Olawale et al (2013), who assert that CP caregiving can be depressive resulting in loss of enjoyment of previously enjoyed activities. Additionally, Papalia, Olds and Feldman (2009), report that long-term caregiving results in caregiver burnout, a condition characterised by physical, emotional and mental exhaustion thereby leading to low energy and loss of interest in previously enjoyed hobbies.

Findings were that 6(50%) of mothers of children with CP highlighted that they were unsuccessful in carrying out their caregiving role. A study by Dambi et al (2015) supports these findings arguing that mothers of children with CP in Harare reported that long-term caregiving made them constantly evaluate their caregiving responsibility and come up with their own perceived failures on their abilities to provide the needs of their children emotionally, socially, and economically. Findings are further supported by Olawale et al (2013), who assert that CP caregiving can be depressive resulting in low self-efficacy. Nimbalkar et al (2014), also support these findings highlighting that mothers of children with CP experience a wide variety of self-criticisms of their ability to provide care to their children.

Social challenges

Findings were that 12(100%) of mothers of children with CP reported dysfunctional social relationships with friends and family characterised by social exclusion. A Zambian research by Singongo et al (2015) agrees with the current research findings reporting that mothers of children with CP were socially isolated with no support from family, friends and community members as a result of non-acceptance and being blamed for the condition of their children. Also, Papalia et al. (2009) posit that being a caregiver robs one of their own social life which is beyond their loved one's CP care needs. Olawale et al (2013), also state that mothers of children with CP suffer the same social exclusion as that suffered by their children who are denied play with their age mates. From a point of view of Bourdieu's (1990) theory of

practice, disrupted relationships faced by mothers of children with CP are a result of lack of social capital. By virtue of being mothers of children with CP, they automatically are reduced to a low social status and are only eligible for relationships with those who share the same experiences as theirs who are as busy as they are and equally do not have time to socialise. In such a situation creating and maintaining friendships becomes difficult.

Findings were that 11(93%) of mothers of children with CP reported facing stigma and discrimination. These findings are congruent with findings by Aisen et al (2011), and Leung and Kao (1999) who highlight that saliva drooling carries a considerable social stigma and discrimination to both the child and the mother as it is socially embarrassing. Also, Dambi et al (2015) and Singongo et al (2015), state that myths such as CP being caused by witchcraft and maternal promiscuity are still prevalent in Africa and mothers bear the brunt of blame and shame shed by the society which manifest in stigma and discrimination. Mothers of children with CP have internalised discrimination based on experience as such they withdraw interaction from society. These unwritten rules and strongly held dispositions that dictate their behaviour is what Bourdieu's theory of practice refers to as the habitus. Lizardo (2004) highlights that the cognitive origin of societal social withdrawal is experience. It is no wonder that mothers of children with CP use social withdrawal as a buffer against psychologically threatening situations such as discrimination.

Findings were that 7(78%) of divorced mothers attributed their divorce to the birth of a child with CP. These findings are supported by Nigerian Lawal et al (2014), who report that mothers of children with CP face marriage break down after giving birth to a child with CP and even those who endure in marriage still report sour relations arising from being blamed for the child's condition. Also, a Zambian study by Singongo et al (2015) is in support of these findings pointing out that the birth of a child with CP resulted in marriage break down and conflict with spouses because of a lack of acceptance of the child and embarrassment, by the male spouses, as well as influence from relatives. Also, Sobbey (2004), reports that marital relations amongst couples with children with CP suffered unduly from the added stress of blame, guilt, and anxiety. From Bourdieu's (1986) theory of practice, the social field of interaction is not a levelled one in CP caregiving. Mothers carry more of the burden of caregiving compared to men who seem to be free to walk away when in the face of CP. This ideology reveals the injustice faced by mothers due to their gender roles thereby imposing upon them multiple challenges.

Findings were that 8(67%) of mothers of children with CP reported various challenges in home living conditions. These research findings are supported by Singongo et al (2015) who state that there is neither adapted transport nor adapted houses for mothers to easily move with their children and their wheelchairs. Further in support of the findings is Holland (2017), who states that mothers of children with CP face housing problems as the landlords are not always willing to take them in as tenants and most houses are not disability friendly in terms of space and ramps. Within the "field" of housing as alluded to by Bourdieu (1990), those with houses and have never experienced disability do not make any efforts to ensure accessibility of their environments because they are not affected. On the other hand, mothers of children with CP continue to face poor living conditions. Thus, inequalities in accessing resources perpetuate the living hardships faced by mothers of children with CP.

Financial challenges

Findings were that 10(83%) of mothers of children with CP highlighted that they had no stable source of income. The findings are supported by Rassafaini et al (2012), who argues that mothers of children with CP have limited time to engage in formal employment due to pre-occupation with caregiving roles as such their sources of income are unstable. Further in support of the findings are Dambi et al (2015), who assert that mothers of children with CP face financial challenges owing to the fact that CP caregiving responsibilities compromise and limit their employment opportunities. Further, Ribeiro et al. (2016), agree that the time demands of CP caregiving leave mothers with no time to engage in any meaningful income generating activities. Also, Glinac et al. (2016) report that in Bosnia and Herzegovina, 86% of mothers of children with CP were unemployed. Bourdieu's (1986), theory of practice attributes this inability to secure stable sources of income to lack of cultural and financial capital. The mothers of children with CP have no institutionalised capital which is the qualifications that make them eligible for employment as a result they can hardly be employed. Additionally, they do not own any assets referred to by Bourdieu (1986), as symbolic capital which may serve as mortgage for possible financial aid hence the informal trade which is an unstable and unreliable source of livehood. The notion that Bourdieu advances is that capital forms the basis for social life and dictate one's position in social life and lacking such predisposes one to challenges such as those being faced by mothers of children with CP.

Findings were that 9 (75%) of mothers reported that they failed to meet their children's basic needs such as school and medical fees, food and transport fares. These findings are similar to those found by Singongo et al (2015), in Zambia where mothers faced challenges in efficiently providing specialised inclusive education school fees, assistive devices and commuting fees which are usually higher than of non-disabled children. Concurrent with these research findings are findings from Thrush and Hyder (2014), who highlight that providing care to a child with CP come with more expenses usually including medical visits and treatments, cost of physiotherapy and medication. Also, current research results agree with results from Nigerian Lawal et al (2014), who posits that the provision of care to a child with CP pose economic challenges on parents resulting from regular doctors' visits for medical attention. Similarly, Rassafiani et al (2015), reports CP caregiving responsibility led to an increased financial burden due to additional disability related costs such as diapers, special diet and washing detergents. The situation is worsened by conflicting demands of care-giving and employment with Lee (2006), noting that raising a child is generally financially demanding and the demand is higher if the child has CP. This economic burden is worsened by the fact that caregiving interferes with parents' income generating activities such as employment thereby making mothers of children with CP vulnerable to financial challenges.

Findings were that 11(93%) of mothers of children with CP indicated that they suffered discrimination in their efforts to generate income. In agreement with these findings are Patel et al (2016), who found that Tswana mothers of children with CP experienced difficulties in either gaining or maintaining employment due to the caregiving responsibility and inflexible working schedules as employers lack consideration of those with caring responsibilities. Findings are also supported by Papalia et al. (2009), who point out that the caregiving role limits employment opportunities for mothers. Bourdieu (1984) alludes to such social injustice being a result of the social field which is unequal. Suminar (2013), states that if the field is not equally levelled, it serves as an advantage or disadvantage to one party who in this case are the mothers of children with CP. Bourdieu (1986) further states that mothers' discrimination in efforts to generate income is due to lack of social capital, which are connections necessary for networking to access income generating opportunities.

5.3 Conclusions

The following conclusions were reached based on research questions:

The research found out that mothers of children with CP experienced depressive symptoms of psychological challenges as indicated by 12(100%) of them who reported having disturbed sleep patterns while 10(83%) experienced constant worries. Others also reported loss of interest in previously enjoyed activities and negative self-criticism.

Findings also showed that mothers experienced social challenges with stigma and discrimination being reported by 12(100%) of the mothers while 11(93%) reported being socially excluded as most of their time was invested in caregiving. Seven (78%) of divorcees attributed their divorces to the birth of a child with CP and mothers also reported lack of social support.

Research findings also indicated that mothers of children with CP faced financial challenges as 10(83%) of mothers indicated that they were unemployed and had no stable income which made it difficult for them to provide their children with educational, medical, basic needs as well as assistive devices. This is an indication of gendered inaccessibility to financial resources by mothers of children with CP.

Overall conclusion

Mothers of children with CP experienced psychological, social and financial challenges. The caregiving responsibility for children with CP disproportionately affects mothers of children thereby imposing upon them multiple challenges.

5.4 Recommendations

Based on the research findings, the researcher made the following recommendations:

• It is recommended that the Ministry of Social Welfare and other NGOs involved in welfare programmes introduce support groups. The groups may offer a platform for sharing of ideas by mothers of children with CP on their experiences, challenges, successes and solutions as well as supporting each other.

- Rights-based disability awareness raising by both government and non-governmental
 organisations may go a long way in reducing exclusion, discriminatory and prejudicial
 tendencies against mothers of children with CP and their children.
- It is also recommended that the Government and NGOs unveil sustainable capital or projects to the mothers of children with CP. The intended outcome is to ensure that mothers of children with CP have stable and sustainable sources of income to meet the special needs of their children.
- As a recommendation, future researchers may need to focus on the coping strategies
 adopted by mothers of children with CP to cushion themselves of the CP caregiving
 challenges. Also, future research needs to take a different geographical dimension and
 focus on the challenges faced by rural mothers of children with CP as these may
 present different experiences.

5.5 Conclusion

This chapter has discussed research findings, drawn conclusions and proposed recommendations on the basis of research findings.

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APPENDICES

APPENDIX 1

JAIROS JIRI ASSOCIATION

0 5 MAR 2018

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Telephone: (263) 54 260404 ext 2156

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FACULTY OF SOCIAL SCIENCES DEPARTMENT OF PSYCHOLOGY

To whom it may concern

Dear Sir/Madam

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recognicated granted

A. TOMBORI

JAIROS JIRI ASSOCIATION IMMUNITY BASED INCLUSIVE EVELOPMENT DEPARTMENT 0 5 MAR 2018 P.O. BOX 7018 MZIUKAZ! BULAWAYO, TEL: 09 888

RE: REQUEST FOR ASSISTANCE WITH DISSERTATION INFORMATION FOR CHIBNONGODZE TALENT

BACHELOR OF PSYCHOLOGY HONOURS DEGREE

This letter serves to introduce to you the above-named student, who is studying for a Psychology Honours Degree and is in his/her 4th year. All Midlands State University students are required to do research in their 4th year of study. We therefore, kindly request your organisation to assist him/her with any information that s/he requires.

Topic: CHALLENGES EXPERIENCED BY MOTHERS OF CHILDREN WITH CEREBRAL PALGY (CP) ATTENDING THE FIRST STEP PRE-SCHOOL IN BULAWAJO

For more information regarding the above, feel free to contact the undersigned.

Yours faithfully

Moube N. Ncube A/Chairperson

APPENDIX 2

INTERVIEW GUIDE FOR MOTHERS OF CHILDREN WITH CEREBRAL PALSY

Section A: Demographic data

- Marital status
- Age of child cared for
- Employment status

Section B: Challenges faced by mothers of children with CP.

Psychological challenges

- 1. What are your worries pertaining to the future of your child?
- 2. How would you describe changes in your sleep patterns since having a child with CP?
- 3. Describe your interest in daily activities since the birth of your child.
- 4. Explain how successful you think you are in your motherhood role.

Social challenges

- 5. Explain your relationship with friends and family since the birth of your child
- 6. Describe your participation in social activities since having your child.
- 7. How has been your intimate relationship since having your child?
- 8. Describe your home living experiences with your child's condition.

Financial challenges

- 9. May you explain your sources of income in caring for your child
- 10. How well have you managed to provide for your child's special needs?
- 11. What are your experiences in efforts to generate income to support your child with CP?
- 12. Explain any other challenges you face in caring for your child with CP.

APPENDIX 3

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