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CAREGIVERS’ BURDEN OF CARING FOR CHILDREN WITH CEREBRALPALSY IN LAGOS, NIGERIA

Research proposal for the degree Masters in Physiotherapy

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DECLARATION

I hereby declare that: *Caregivers' burden of caring for children with cerebral palsy in Lagos, Nigeria,* is my work, and all the sources quoted have been indicated and acknowledged throughreferences. This dissertation has not been previously submitted for any other qualification at another institution.

Signature …..

2/23/2022

Date …..

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LIST OF ABBREVIATIONS / ACRONYMS

Abbreviation / acronym	**Meaning**
CP	Cerebral Palsy
FGD	Focus Group Discussion
ZBI	Zarit Burden Interview
ADL	Activities of Daily Living

ABSTRACT

Introduction

Cerebral Palsy is a disorder that affects the development of movement and posture causing limitation of activity and participation restriction. Due to the physical challenges faced by children with cerebral palsy, they depend on their caregivers (which include parents, grandparents) and other relatives of the family for their activities of daily living and care. Caring for a child with activity limitation increases the burden of care on the caregivers. Investigations on caregivers' quality of life (QoL), socio-economic and psychosocial factors of caring for CP children had been done; however, there is a dearth of literature on the burden of care on caregivers of children with CP.

Aim: This research sought to establish caregivers' burden of caring for children with cerebral palsy in Lagos, Nigeria.

Methods: A sequential mixed method design was used. This involved collecting quantitative data first, followed by qualitative data from the same population sample. A purposive sampling method was used to select the participants. The ZaritBurdenInterview questionnaire was used to collect the quantitative data andfocus group discussions were used to collect the qualitative data. The ZaritBurdenInterview questionnaire was handed to 120 participants who are caregivers of children with cerebral palsy on the day of their appointment to the clinic. All participants were required to complete the questionnaire; thereafter the same participant joined the focus group discussion (FGD), for qualitative data collection. There were six (6) FGDs comprisingoften (10) participants in each group,adding to a total of sixty (60) participants. Data from the ZaritBurdenInterview questionnaire were analysed using descriptive statistics and chi-square tests, whilst data from FGD were transcribed verbatim and analysed using open coding.

Conclusion: The findings of the study show that caregivers of children with CP face challenges that make caring for their children burdensome. The study showed that the caregivers faced challenges in the following areas; accessibility to healthcare and education, mode of transporting their children, financial, and social support. It was recommended that policymakers and the government intervene by making policies and setting up structures that will help alleviate the burden of the caregivers. The introduction of community awareness programs and support groups was recommended.

Key terms: Burden of caring, Caregivers, Caregiving, Cerebral Palsy, Children,Physiotherapy

CHAPTER 1

INTRODUCTION TO THE STUDY

1.1 BACKGROUND

Cerebral Palsy refers to a group of wide-ranging non-progressive neurological, physical, cognitive, communicative, and behavioural disorders that are caused by injury to a developing foetal or infant brain (Oskoui, Coutinho, Dykeman, Jette andPringsheim,2013). Care for children with cerebral palsy with its associated disability is usually carried out by informal caregivers (parents, siblings, and other relatives). Informal caregivers are mostly not paid for caring for thedisabled family member. Caring for children living with disabilities can be financially, physically, and emotionally taxing for the caregivers and may lead to physical and emotional burnout (Pierre and Emmanuel, 2018). The physical care of a child with cerebral palsy may be very difficult if the caregiver is not specifically trained on how to dress, position, and feed the child (Fatudimu, Hamzat andAkinyinka, 2013).

Health care for children with disability, such as CP,require frequent visits to the hospital or clinic resulting in spending finances on medication/hospital bills and may contribute to the family living in poverty (Mathye and Eksteen, 2016). Socially, caring for a disabled child may affect the interpersonal relationships in a family, and often the stigmatization they face by raising a disabled child can result in caregivers withdrawing from any social interaction and social support groups (Mathye and Eksteen, 2016). The different aspects of the burden of caring often lead to depression (Mathye and Eksteen (2016). The negative effect of the burden of caring on these caregivers may result in neglect of the children they care for. In the light of the sustainable development goals, (United Nations, 2015), governments should aim to, amongst other goals, ensure healthy lives and well-being for all ages, and end poverty in all its forms by 2030. To render an acquiescent physiotherapy service for caregivers of children living with CP, in Lagos Nigeria, the researcher engaged in this study to identify the caregiver’s burden of caring for children with CP. The study may contribute to the body of knowledge because caregivers may possiblygive recommendations on different ways on how to relieve their burden during the FGD.

1.2 OVERVIEW OF THE LITERATURE

Cerebral Palsy is common in childhood (Anderson, Irgens, Haagas, Skraned, Meberg and Viks, 2008) and affects children throughout their lives. CP affects the child's body movement due to impaired coordination, muscle tone, posture, and balance, (Anderson et. al., 2008).

This also affects their communication (ability to speak), intellectual abilities, as well as their social interaction and participation in community activities (Haak, Madeleine, Mary and Paneth, 2009; Bottcher, 2010). Affected children and their families often face the added burden of stigmatization, which leads to social isolation and inaccessibility to community support structures for children with cerebral palsy (Mathye and Eksteen, 2016). Geographical location and distance from health care facilities together with inaccessible transport for children and their wheelchair or other assistive devices may contribute to the inability of the children and their families not to have access to healthcare facilities for rehabilitative care (Mathye and Eksteen, 2016). Even when these services are available, the caregivers (parents/relatives) cannot afford the services (Lagunju, Adedokun and Fatunde, 2016).

Studies on caregivers' burden of care of children with cerebral palsy carried out in different parts of the world have identified different factors contributing to the burden of care. A report by Marron, Merce, Redpolar-Ripoll, and Nieto (2013) stated that anxiety was not a predictor of caregivers' burden of care, but rather that it is a response to acute life crises that they experience during the care of the child.Other factors which are linked to a greater burden of caregiving, including being a female caregiver (Ahanotu, Hammed and Peter. 2018), the age of the child, employment status, and the financial burden related to direct costs for managing the care of the child's disability and premorbid conditions (Wang, Xiao, He, Ullah and De,2014). Several studies have beendone to determine the factors associated with the burden of caregiving for children with disabilities, mentioned that most of their respondents were caring for children with cerebral palsy and less for children or other persons with disabilities (Marron et al., 2013; Wang et al., 2014 and Ahanotu et al., 2018).

The factors mentioned in the published research already, cannot be generalized to the Nigerian population of caregivers for children with CP because of differences in socio-demographical and geographical environment. The magnitude and nature of the burden faced by a caregiver of children with disability are content-specific and as such findings from another milieu may at best be informative and cannot be extrapolated to another clinical setting because of the unique combination of factors that influence caregiving. Hence identifying the specific combination of factors that play a role in the burden of care in Nigeria is necessary to ease the caregivers' burden, as well as improve the children's quality of life.

1.3 PATHOGENESIS OF CP

CP is a diagnosis as a result of the damage to the parts of a developing brain (Bottcher, 2010). The damage is non-progressive and affects the control of movement, balance, and posture, (Mohammed, 2006). According to Bottcher (2010), motor disability which includes gross motor (affecting the ability to roll, sit, stand, and walk independently) and fine motor (affecting the ability to grasp objects, feed self, and write) is the most visible limitation or challenges faced by children with cerebral palsy, the severity of the disability is determined by the presence of sensory, cognitive and communicative andsocial impairments, (Bottcher, 2010). The symptoms of cerebral palsy may range from mild to severe and vary from person to person based on the extent of injury or damage to the brain (Bottcher, 2010). The symptoms usually appear shortly after birth in the form of abnormal postures and movement. Children with CP also experience other challenges such as intellectual impairments, seizures, feeding challenges, and visual and hearing impairment, (Mohammed, 2006). The combination of impairments results in developmental problems.The extent of care that will be given during childhood, even into adulthood will be determined by the damage caused in the brain, (Mohammed, 2006). The symptoms of CP include; poor neck control, which may affect the ability to swallow, eye contact during communication, and focus on a learning task in an educational setting, (American Academy of Paediatrics, 2013). There are also delays in attaining gross motor skills such as rolling, pulling to sit, crawling, sitting, pulling to stand, standing, climbing furniture, walking, jumping, and hopping; attaining fine motor skills, such as grasping of objects, holding and releasing or manipulating objects. The delays do not exclude speech and communication abilities, (American Academy of Paediatrics, 2013).

1.3.1 Causes and classification of cerebral palsy

According to MacLean, Thompson, andGecz, (2015), the causes of CP include; birth asphyxia (lack of oxygen to the child's brain during labor); severe neonatal jaundice, (appears within the first three (3) days after delivery); brain infections (such as encephalitis and meningitis); head injuries as a result of a traumatic delivery) and seizures.CP is often classified based on the level of severity which could be mild, moderate, and severe. CP can also be classified based on topographical distribution which is based on the affected part of the body (hemiplegia, monoplegia, diplegia, and quadriplegia) and also on the tone of the muscle which could be hypertonic (increased muscle tone which presents with stiff limbs) and hypotonia (decreased muscle tone resulting in loose, floppy limbs).The World Health Organization (2001) and Surveillance of Cerebral Palsy (2002) in Europe developed a scale called the Gross Motor Functional System (GMFCS) as a standard scale that would be used universally for determining the physical capabilities of children with cerebral palsy. The scale focuses on the ability to sit, the capability to stand and walk, charting independence, the use of adaptive equipment, (Surveillance in Europe, 2002).

1.3.2 Risk factors of Cerebral Palsy

Risk factors associated with a high prevalence of CP include; acute hypoxia beginning in labor and neonatal encephalopathy, preterm birth, bacterial and viral intrauterine infections, intrauterine growth restrictions, antepartumhaemorrhage, tight nuchal cord and threatened miscarriage, also conditions such as rubella and HIV if it affects the mother can also cause cerebral palsy in the child (MacLennan et al., 2015). (Ross and Deverell, 2008). The high rate of poverty in most developing countries plays a major role in placing neonates at significant biological risks that may lead to conditions that may result in CP, (CDC, 2013). Somecaregivers living in rural areas of developing countries cannot access and afford specialized prenatal and postnatal care; this is due to inaccessibility to health care facilities for various reasons ranging from poor transportation systems to cultural beliefs, (Levin,2006). These sociological variables however are not well defined or recognized in developing countries due to underdeveloped healthcare systems and are overlooked as contributing introduction and background.

1.4 CHARACTERISTICS OF CAREGIVERS OF CHILDREN DIAGNOSED WITH CEREBRAL PALSY

In a study conducted in Kenya, aimed at identifying potential physical health effects of caring for a child with moderate to severe motor impairments, a caregiver was identified as one spending more time with a particular person, (Geere, Gona, Omondi, Kifalu, Newton and Hartley, 2012).Caregivers were discovered to be predominantly the mothers and grandmothers of the children with cerebral palsy (Dambi, Chivambo, Chiwarido and Matere, 2015). Other characteristics of caregivers wereidentified by looking at the duration of looking after a care recipient, which ranged from six months to five years, (Wijosinghe,Cunningham, Fonseka, Hewage and Ostbye,(2015); Dambi, Jelsma and Mlambo, 2015). In developed countries, the caregivers stay instructured care facilities while the average caregiver in developing countries stays in the home of the care recipient with the extended family even in the most discomforting environment, (Barlindhaug, Umar, Wazakalili and Emaus, 2016).

1.4.1 Caring for Children with Cerebral Palsy

According to Oskoui et al. (2013), caregivers an important role in the management and care of children with CP. Caregivers from developing countries experience physical, emotional, psychological, and financial strain while providing support and care(Oskoui et al., 2013). The experiences are attributed to because children with CP are dependent on their caregivers for their activities of daily living and mobility. There is alsoa financial burden resulting from the cost of transportation to health care facilities, as well as access to care from the facility. Children with CP require regular medical and rehabilitation services. Irrespective of the economic status of a country; caregivers experience a high level of burden of care (Dada, Okewole and Bello-Mojeed, 2011).The physical and psychological health of caregivers may be adversely affected, (Brehaut, Kohen, Raina, Walker,Russell, Swinton, O'Donnell and Rosenbaum.2009), thus affecting their social, cultural and professional lives and resulting in reduced their quality of life, (Davis, Shelly, Waters and Boyd, 2009). Poor insights or lack of knowledge of the child's condition usually leaves the caregivers vulnerable to depression and susceptible to societal cultural attacks (Olawale, Deih and Yadaar. 2013).

1.5 PROBLEM STATEMENT

The researcher is a physiotherapist at the Child and Adolescent Centre of the Federal Neuropsychiatric Hospital, Oshodi Annex, Lagos, Nigeria. This centrerenders rehabilitation service to children and adolescents with depression, schizophrenia, Autism Spectrum Disorder (ASD), Down syndrome, Intellectual disability, Attention Deficit Disorder (ADD), and Cerebral Palsy. Out of 40 children treated by the physiotherapist in a week, 20 children present with CP. Most of these children are wheelchair-bound, some can play in supported positions and few could walk with assistance. The observed varying disabilities in children with CP prompted the researcher to conduct a study and explore the burden of caring for children with CP. Previous studies conducted on caregivers of children with CP in Nigeria had only taken into consideration the psychosocial (Adegoke *et al.*, 2014) and socio-economic factors (Komono, Emmanuel, and Asindi, 2017) while other studies were focused on the quality of life of the caregiver (Adegoke *et al.*, 2014;Ahanotu*et al.*, 2018). No study investigated caregivers' burden of caring for children with CP. This has created a knowledge gap, especially since a study by Languju etal., (2016) reported that CP is a leading cause of childhood disability in Nigeria.

1.6 RESEARCH QUESTION,AIM, AND OBJECTIVES

1.6.1 Research question

What is the caregivers’ burden of caring for children with Cerebral palsy in Lagos, Nigeria?

1.6.2 Aimof the study

To explore caregiver’s burden of caring for children with Cerebral palsy in Lagos, Nigeria.

1.6.3 Objectives of the study

1. To determine the socio-demographic characteristics of caregivers of children with Cerebral Palsy.
2. To identify and describe theemotional burden of caring for children with Cerebral Palsy.
3. To explore and identify the factors that influence the burden of caring of caregivers of children with CerebralPalsy in Lagos, Nigeria.
4. To explore the magnitude of influence on the burden of care to physically and emotionally manage a child with cerebral palsy at home and the social and financial factors that influence the burden of care.

1.7 DEFINITIONS OF KEY TERMS

- **Cerebral Palsy**

Cerebral Palsy (CP) is a non-progressive disorder that primarily affects movement as a result of damage to the developing motor cortex of the brain and it may vary in severity also accompanied by a variety of other impairments including cognitive impairments, visual impairment, hearing impairment, impaired bladder control, impaired bowel control, speech and language impairments (Koman, Smith and Shilt 2004).

- **Operational definition:**

A child diagnosed with CPis someone aged between 0-17 years, who attend physiotherapy as an outpatient at the Child and Adolescent Centre of the Federal Neuropsychiatric Hospital, Oshodi Annex, Lagos, Nigeria.

- **Caregiver**

A caregiver is anyone who provides care and support at home, community, or in care facilities to an individual or family member who is living with a disability, who is ill, frail or elderly (Pelchat and Lefebvre, 2004). Parents, grandparents, nannies, and close relatives of children with CP who attend physiotherapy together with the child as an outpatient at the Child and Adolescent Centre of the Federal Neuropsychiatric Hospital, Oshodi Annex, Lagos, Nigeria.

- **Caregiver Burden**

The caregiver burden or burden of care is defined as the physical, emotional, psychological, financial, social, and/or other forms of strain load experienced by a person who cares for someone with severe functional impairments and limitations (Giovannetti, Pagani, Sattin, Castelli, Trabacca, Martinuzzi and Leonardi, 2012). In the context of this study, caregiver burden includes the physical, emotional, financial, and all other forms of challenges experienced by caregivers of children with cerebral palsy in Lagos, Nigeria.

1.8 CONTEXT / SETTING

The research was conducted on caregivers of children with CP who attend physiotherapy as outpatients at the Child and Adolescent Centre of the Federal Neuropsychiatric Hospital, Oshodi Annex, Lagos, Nigeria. The centrerenders a service to children and adolescents with different psychiatric and neurodevelopmental conditions such as; Depression, Schizophrenia, Autism Spectrum Disorder (ASD), Down syndrome, Intellectual disability, Attention Deficit Disorder (ADD), and Cerebral Palsy (CP). There are two outpatient clinic days per week, which are Tuesdays and Thursdays where an average of 16 – 20 children with CP are treated during each of those days. At least a total of 32 children with cerebral palsy attend the clinic with their caregivers weekly.

1.9 ASSUMPTIONS

A. Quantitative data:

1. The researcher assumes that there are factors that influence the caregivers' burden of caring for children with CP.
2. It is also assumed that patients will give truthful information when answering questionnaires.

3. The answers from FGDs will not be influenced by the previous answers given when answering the questionnaire.

B. Assumptions for Qualitative data:

Ontological assumption refers to a figured set of presumptions about reality (Brink, Van der Walt, and Van Rensburg et al., 2018). The researcher assumes that there is a burden of caring for children with CP that is experienced by caregivers.

Epistemological assumptions are defined as assumptions based on knowledge of reality (Brink et al 2018). The researchers assume that answers to the Zarit questionnaire, as well as FGDs will reveal the different factors that caregivers experience that contribute to the burden caregiversexperience from caring for children with CP.

Methodological assumption refers to methods or procedures that will be implemented to understand the problem that the researcher set out to investigate (Brink et al., 2018). The researcher conducted a mixed method approach to triangulatethe results of theZarit questionnaire with the results from conducting focus group discussions with a sample of the same group of participants who completed the ZBI.

1.10 DELINEATION

The study was conducted on caregivers whose children between the ages 0-17 years, whowere diagnosed with CP, and were receiving physiotherapy services as outpatients at the Child and Adolescent Centre of the Federal Neuropsychiatric Hospital, Oshodi Annex, Lagos, Nigeria.

1.11SIGNIFICANCE / CONTRIBUTION

The study will add new knowledge about the challenges associated with caring for children with CP.

- It will provide information to policymakers and stakeholders (such as the government, healthcare professionals, teachers, family members, religious leaders,relatives, and members of the community) that may enable the government to formulate policies that may bring about availability and accessibility to basic amenities to relieve the burden of care on the caregivers.

- Awareness may be created in the communities which may bring about better social support leading to increased productivity of the caregivers.
- The results of the study may contribute to physiotherapists' better understanding of the factors that affect the burden of care of the caregivers and as such may contribute to improving the rehabilitation service to the CP children and their caregivers.

1.12 OUTLINE OF STUDY

The dissertation will be outlined according to the following chapter structure:

- Chapter 1: Gives an introduction to the study, and presents the problem statement, aim, and objectives of the study. The significance of the study is described.
- Chapter 2: presents the literature review which explains the available knowledge on the topic of investigation
- Chapter 3: in Chapter 3 the methodology of the study is explained in detail.
- Chapter 4: in Chapter 4 the results of quantitative data analysis are presented
- Chapter 5:in Chapter 5 the results of qualitative data analysis are presented.
- Chapter 6:presents the discussion of the quantitative and qualitative results,based on the aim and objectives of the study stated in Chapter 1. The conclusion, limitations, and recommendationsfor clinical service rendering and research are also outlined in Chapter 6.

CHAPTER 2

LITERATURE REVIEW

2.1 INTRODUCTION

Cerebral Palsy (CP) is one of the common neurodevelopmental conditions in childhood (Anderson, Irgens, Haagas, Skraned, Meberg and Viks, 2008). Cerebral Palsy refers to a group of non-progressive neurological, cognitive, communicative, and behavioural disorders that are common during pregnancy, at birth, or after birth. It is caused by impairment to the brain of a developing foetus (Oskoui et al., 2013).The most visible limitation of CP is a motor disability and the severity is determined by sensory, cognitive, communicative, and behavioural impairments (Botcher, 2010).

The symptoms of CP vary from child to child based on the extent and location of the brain lesion. The functional classification of the child's disability and the symptoms may range from mild to severe (Reid, Carlin, Reddihough, 2011). The symptoms usually appear before the child reaches three or four years of age. Children with cerebral palsy also experience potential disabilities such as intellectual impairments, seizures, feeding difficulties, and ophthalmologic and hearing impairments. The combination, as well as the severity of the impairments in the children, will determine the extent of caregiving that the child needs and which may extend even into adulthood (Mohammed, 2006).

2.2 PREVALENCE OF CEREBRAL PALSY

The prevalence of CP is about 2.11 per 1000 live births globally (Oskoui et. al.2013). The ratio of CP in Europe is higher in males than in females with a ratio of 3:1 (Johnson, 2002). In Nigeria, CP is one of the leading causes of childhood disability with a prevalence rate of 10 per 1000; affected children face the added burden of social stigmatization, poverty, inadequate facilities for rehabilitative care, and limited educational opportunities (Lagunju et al., 2016). Studies carried out by Adegoke et al. (2014) and Ahanotu et al. (2018) in different parts of Nigeria, showed that caring for a child with cerebral palsy has a significant impact on informal caregivers' burden of caring, social support, and quality of life.

2.3 TYPES OF CEREBRAL PALSY

In the literature, CP is described by using different classifications which include four motor types as spastic CP, dyskinetic CP, ataxic CP, and mixed CP (Can, 2000; Australian cerebral palsy register report, 2018)

- ***Spastic CP***: Spasticity is defined as an increase in the physiological resistance of a muscle to passive motion. This is the most common type of CP representing about 80% of all cases (John, 2013). There are three (3) types of spastic CP;
    - *Hemiplegic spastic CP (unilateral)*: This affects one side of the body with the upper side generally more affected than the lower limb. Seizure disorders, visual field deficits, tactile agnosia, and proprioceptive loss are common amongst these children.
    - *Diplegia spastic CP (Bilateral)*: The lower extremities are severely involved and the arms are mildly involved, intelligence is usually normal and seizures are less common in these children.
    - *Quadriplegia spastic CP (Bilateral)*: This form of CP involves all four (4) limbs, the trunk, and muscles that control the mouth, tongue, and pharynx.

- ***Dyskinetic CP:*** This type is characterized by a mixture of hypotonic and hypertonic muscle tone which causes the muscle tone to fluctuate. There are two groups namely choreo-athetoid and dystonic CP (O'shea, 2008). The causes include damage to the brain's basal ganglia and cerebellum. The basal ganglia are responsible for regulating motor function and eye movements, while the cerebellum controls balance and coordination (Gerry, Orit and Robert, 2014). The upper extremities are more affected than the lower extremities. According to Rogers and Wong (2012), dyskinetic CP is mostly caused by birth asphyxia, kernicterus, and genetic disorders. Choreo-athetoid CP is characterized by involuntary movements which are predominantly found in the face and extremities while dystonic CP is characterized by slow, strong contractions which may occur locally or encompass the whole body (Bercher, 2002).

- ***Ataxic CP***: Ataxia is characterized by a loss of balance, coordination, and fine motor control. Children with ataxic CP can therefore not coordinate movements. Ataxia is associated with cerebellar lesions (McHale, Jackson, Campbell, Leveve, Corry, Woods, Lench, Muller and Markham, 2002). Ataxic CP is observed in approximately 5% of all cases of CP, making it the least frequent form of CP(McHale et al.,2002).

- ***MIXED CP***: This occurs when a child shows symptoms of more than one type of CP previously mentioned.

2.3.1 Classification of cerebralpalsy

Cerebral Palsy is classified based on the level of severity such as mild, moderate, and severe (Morris, 2007). The condition (CP) can also be classified based on topographical distribution. Topographical classification is based on the distribution of the affected part of the body (hemiplegia, monoplegia, diplegia, and quadriplegia) and thirdly the classification is based on the degree of the muscle tone which may entail hypertonia (increased tone often resulting in stiff limbs) and hypotonic (decreased muscle tone resulting in loose, floppy limbs) or fluctuating tone (the tone fluctuates between hyper and hypo tone). The severity of the CP affects the functional abilities of the child (Morris, 2007).

The World Health Organization (WHO) and Surveillance of Cerebral Palsy in Europe developed the GMFCS as a universal standard for determining the physical capabilities of children with CP between the ages of two and eighteen. The evaluation system gives parents, therapists, and teachers an indication of the child’s functional ability at the time of assessment (i.e. ability to sit, walk with or without assistive devices) and secondly it gives them an idea of the equipment and mobility devices the child would need. The assessment system also enables parents, teachers, and therapists to chart the child’s independence and the use of adaptive technology.

There are five (5) levels of the GMFCS and as the child’s score increases, it is an indication that his/her mobility decreases which would further indicate and that the child’s dependency on the caregiver increases (Morris, 2007; Reid et al., 2011). Table 2.1 below shows the level of CP as per GMFC score and their description.

Table 2.1: Description of the GMFC score levels 1- 5

LEVEL 1 CP:	This is characterized by the person's ability to walk without limitations.
LEVEL 2 CP	A person with level 2 CP can walk long distances without limitations but they can't run or jump. They may need assistive devices such as; leg and arm braces when learning to walk.
LEVEL 3 CP	A person with level 3 CP can sit and stand with little support. They need handheld assistive devices such as a walker or care while walking indoors.
LEVEL 4 CP	A person will level 4 CP can walk with the use of assistive devices. They can move independently in a wheelchair and they need some support when they are sitting
LEVEL 5 CP	A person level 5 CP needs support to maintain their head and neck position. They need support to sit and support

2.3.2 Causes of cerebral palsy

Factors that have been linked as causes of CP include factors before, during, and after birth; these factors may include; acute hypoxia starting during labor and neonatal encephalopathy (MacLennan et al., 2015).Risk factors associated with a high prevalence of CP include; preterm birth,bacterial and viral intrauterine infections, intrauterine growth restrictions, antepartum haemorrhage, and threatening miscarriage during pregnancy (MacLennan et al., 2015).Maternal conditions that can cause CP in the child (Ross and Deverell, 2008) may include such as rubella, AIDS, and multiple pregnancies.

Risk factors during the perinatal stage include breech delivery, placental abruption, prolapsed cord, and instrumental delivery. Postnatal risk factors include; some cerebral infections such as catastrophic infections and cerebrovascular accidents (Krigger, 2006).

The incidence of CP in developing countries is significantly higher in developed countries and is influenced by a variety of sociological variables which include access to healthcare resources, the effects of low socioeconomic conditions, the absence of public education programs, traditional and religious beliefs (Rosenbaum, 2004). According to Levin (2006) poverty contributes to the development of CP due to poor prenatal care and nutrition.

Levin (2006) also explains that rural communities usually don’t have access far away from health care facilities due to their geographical isolation; poor transportation systems and access to specialized care and intervention are not possible. These sociological variables however are not well defined or recognized in developing countries and are overlooked as contributing as a cause of CP (Rosenbaum, 2004). In developed countries the factors that cause CP is well defined and therefore more easily preventable; this results in proportionately fewer children diagnosed with CP. There is limited research on the causes of CP in Nigeria; however, asphyxia is recorded as a leading cause of CP (Belonwu, Adeleke and Gwarzo, 2009).

2.3.3 Impairments associated with cerebralpalsy

The impairments associated with CP could vary from person to person and range from mild to severe impairments; the impairments can become more or less severe over time and may also vary depending on the parts of the brain that is affected. According to Levitt (2006), some of the impairments include.

2.3.3.1 Gross Motor Impairments

Delay in attaining gross motor skills milestones such as rolling, pull to sitting, sitting, crawl, pull to standing, standing, walking, jumping, hopping and persistent infantile reflexes such as moro and asymmetrical tonic neck reflexes are some of the gross motor impairments associated with CP (Levitt,2006; Liptak and Murphy,2011).

2.3.3.2 Fine Motor Impairments

Fine motor skills are reflected in milestones such as grasping objects, holding, manipulating, and releasing objects (Ross and Deverell,2004), Poor muscle coordination results in fine motor impairments in children with CP (Levitt,2006).

2.3.3.3 Visual and Hearing Impairments

Visual and hearing Impairments may be caused by either neurological impairments or by secondary complications (Levitt, 2006). Eye movements in children with CP are affected by abnormal eye muscle control (Ross and Deverell, 2004). A significant percentage of individuals living with CP have some form of visual impairment which includes strabismus, cataracts, and refractive issues (Odding, Roebroeck and Stam, 2006), high-frequency deafness, and auditory agnosia (Levitt, 2006).

2.3.3.4 Speech and Language Impairments

Delay or difficulty in speech may be caused by the CP child’s inability to finely coordinate the muscles around the mouth and tongue that are responsible for articulation (Ross and Deverell, 2004). Recent population-based data from the United Kingdom suggest that 33-63% of children experience speech impairment (Parkes, Hill, Platt and Donnelly, 2010). Several studies have used various definitions to examine the occurrence of speech and articulation impairment (Cockerill, Elbourne, Allen, Scruton, Will and McNee, 2014).

2.3.3.5 Seizures

Seizures occur in about 35% of children with CP (Ross and Deverell, 2004) and may be an indication of the severity of the child’s neurological damage; the seizures may further influence the children’s degree of motor and intellectual disabilities (Odding et al., 2006).

2.3.3.6 Cognitive Impairments

According to Odding et al. (2009), a large proportion of children with cerebral palsy experience cognitive dysfunction, the prevalence varies with the type of CP and this can range from mild to severe. Some of the signs include; delayed language development, short attention span, issues with sensory stimulation, difficulty learning to read and count difficulty in speaking and responding to others (Odding et al., 2009).

2.4 MANAGEMENT OF CEREBRAL PALSY

Professionals and parents can by working together minimize the problems associated with CP to ensure that each child achieves as much of their potential as possible (Miller, 2005). There is no known cure for CP; however, children diagnosed with CP are managed by therapists who include; physiotherapists, occupational therapists, and speech therapists (Miller, 2005) in collaboration with the teaching staff in special schools. The major goal of the therapy process for children with cerebral palsy is to promote the child's participation in his/her significant life context (Brandao, Olivera and Mancini, 2014).

The therapists help in promoting children's functional ability by teaching them the acquisition of new skills and educating the caregivers assisting with the daily care needs and handling of the children, While the teachers help in educating the children (Jones et al., 2007).

The purpose of physiotherapy in the treatment of children with CP is to optimize their motor development and functional skills, Orthotic devices and braces are utilized to stretch spastic muscles which can improve balance, motor development and, general handling of the children (Jan,2006). Studies that have been conducted to determine the effectiveness of physiotherapy in children with CP reveal that physiotherapy promotes normal motor development and therefore prevents deformity and contractures following early intervention (Capjon and Bjork, 2010).

Occupational therapists aim to optimize the children's functional activities of daily living and the fine motor skills of the upper extremities (Miller, 2005). The management of CP by occupational therapists would aim to optimize activities such as picking-up of objects, self-feeding, removing clothes, fine motor skills such as using scissors and writing skills, and toilet training (Oien, Fallang and Ostensjo,2010; Reid, Brouwer, Clutton, Evans, Russel and Barlet,2011).

The development of speech and communication skills is optimized by speech therapists (Chen, Liu, Chung and Wu, 2010). Their treatment is focused on the integration of speech control using different techniques such as articulation therapy, oral motor therapy, or language intervention therapy depending on the need of the child(Chen et al.,2010), and optimizing the children's feeding and swallowing is evaluated by the speech therapist(Miller,2005).

Caregivers 'are primarily involved in the decision-making process about the therapeutic goals of their children and should never be omitted from the rehabilitation process (Oien et al., 2010). Dempsey and Keen (2009) believe that an unsupportive professional relationship between the caregivers and the health professionals exacerbates the difficulties faced by the caregivers of the children with disabilities, of which those with CP are part. Professional support is one of the strongest predictors of the quality of life of the family as well as the CP children. Training of the extended family to support the family is of utmost importance (Fereday, Oster and Derbyshire, 2010).

2.4.1Caring for a child with cerebralpalsy

Globally literature that focuses on the care of a child with CP is lacking. Most studies have rather focused on types of CP, aetiology, and prevalence (Ulrica, Meta, Katharina and Kate, 2019; Nigel, Ting and Steven, 2006). Following the birth of a child with a disability, many caregivers adopt the position that there is nothing they can do to change the situation and therefore have to accept it and make the most of it (Greef and Notling, 2013). Bayat (2007) suggests that positive perceptions about a situation act as a buffer for stresses associated with caring for a child with a disability such as CP.

Fraid (2009) mentioned that the key to successful caregiver/parental adaptation to caring for a child with CP lies in the capacity of the families to access appropriate resources and services that support them in coping with their child's needs and reduce the problems related to their child's disability. The success of family adaptation and coherence in caring for children with CP is influenced by access to the support of rehabilitation therapists and healthcare personnel. The development of effective support services for the care of children and their family members is of utmost importance, to assist the family in their care of the child resulting in reduced levels of caregiver stress (Udall, 2013).

Community awareness of the extent of disabilities amongst children such as CP is an important element to help families/caregivers of children with CP cope and adapt to the stressors caregiving (Ross and Deverell, 2004).Reports by researchers on the stigmatization of children with disabilities in a community may contribute to poor adaptation of caregivers or influence healthy family interaction (Levin, 2006 and Green, 2003).It is therefore of paramount importance to educate the populace/communities on the causes and clinical presentation of disabilities like CP to correct negative attitudes of people in the community and as such promote caregivers adaption to caring for their child (Ross and Deverell, 2004).

Results of studies showed that caregivers sustain musculoskeletal, psychological, financial, social, and emotional problems during the process of caring for their CP (disabled) child (Barlindhurg et al., 2016;Geere et al., 2012). In a study by Levin (2006), he agreed that the burden of care for children with CP in many families is affected women more; especially they are not empowered to be a caregiver of a child with CP. These women often become caregivers of disabled children because they are unemployed and illiterate. Many of these women have little or no knowledge about the available professional services for their children (Vijesh and Sukumaran, 2007). The caregiving outcomes can be predicted both negatively and positively based on the quality of life and caregiving expenses of the caregiver (Vellone, Fida, Cocchieri, Sili, Piras and Alvaro, 2011).

Aspects that influence caregiving positively are affection for the CP child, good family relationships, and the fact they do good to other human beings which may be rewarded in the future; this is often seen from a religious perspective (Gray, Hahn, Thongcharoenchupong and Thapsuwan, 2016).In Nigeria , healthcare provided by government facilities are subsidized and are few thus not within the reach of most of the populace, thus making it inaccessible to people especially people with disabilities such as CP.

To highlight the huge role played by family caregivers and to structure appropriate support programs, it is therefore important to conduct both quantitative and qualitative studies to understand caregivers’ challenges and experiences.

In a critical review discussion to analyse the definition of caregiver burden, it was suggested that future studies on caregiver burden need to adopt a mixed-method approach to explore the burden of caregiving from different perspectives.

2.4.1.1 Characteristics of the Caregiver Population

There are two types of caregivers; formal and informal caregivers. A formal caregiver has undergone formal training on how to take care of a child with CP and he/she is usually remunerated for their services while an informal caregiver is either remunerated or not remunerated and is without formal training in how to take care of a CP child and are members of the child’s social network who helps them to perform activities of daily living (Umaru, Omoyemi, Ade and Ekechukwu, 2017). Commonly the term’ caregiving is used to describe a person who takes care of people/children with impairments related to old age, disability, disease, or mental disorders.

From reviewed studies; it was found that the time a primary caregiver had looked after a care recipient varied from six (6) months to five (5) years with a common pattern of a minimum of one year (Wijesinghe, Cunningham, Fonseka, Hewage and Ostbye, 2015; Dambi, Jelsma and Mlambo,2015). Unlike in developed countries where the caregivers stay in care facilities, the average caregiver in developing countries stays with the care recipient with the extended family (Barlindhaug, Umar, Wazakalili and Emaus,2016). It was observed that most of the participants were an average age of thirty (30) years old, with 61% of them being unemployed, 30% being informally employed, and 9% formally employed. Of these caregivers, at least 65% had secondary education while 20% had tertiary education. Caregiving activities depend on the age and level of disability of the recipient of the care, this involves assisting with the personal care of the recipient (adult/child) such as bathing, dressing, toileting, and in some cases feeding. It was also a common characteristic that the caregivers were predominantly the mothers and grandmothers of the children (Dambi, Chivambo, ChiwaridoandMatere, 2015).

Other studies on caregivers' burden reported that their health was affected negatively since they started their caregiving duties and it was also observed that the majority of the caregivers were females (Ma, Lu, Xiong, Yao and Yong, 2014). Research by Cooper, Katona, Orell and Livingstone (2008) also shows that majority of caregivers are females.
Though there is no explanation why females are more likely to act as caregivers than males, In a review of an article by Sharma, Chakrabarti and Grover, (2016) culture and ethnicity were also indicated as an influence on gender disparities in caregiving.

2.4.1.2 Burden of Caring of the Caregiver

Caregiving can be a stressful experience as most caregivers are not prepared for the experience. This stressful experience could be physical, financial, and emotional and results in decreased quality of life of the caregiver. (Marron, Redola-Ripol, Boixados, Neito, Guillamon andHernandez, 2013).

Some factors have been identified to be associated with the burden of caregiving and include the factors mentioned below:

Physical/Musculoskeletal burden: This relates to chronic fatigue which results in the impairment of the caregiver's physical health (Wang, Xiao, He, Ullah and De Bellis, 2014). Carrying a small child on one's back is a common practice in Nigeria; this practice normally stops when children reach the age of three (3). However, for those families with children with physical disabilities that are non-ambulatory, this practice of carrying the child continues well into adolescence. This practice has been found to contribute to low backache in some caregivers (Barlindhurg et al., 2016). While it is a common cultural practice of carrying children on an adult's back, it should be noted that some caregivers regard this practice as necessary but not essential (Geere, Gona, Omondi, Kifalu, Newron and Hartley, 2012). The implication of the findings of Geere et al., (2012) is that strapping and carrying children with disabilities on one's back causes chronic spinal pain may not be true for everyone. Dambi, Mandzivizda, Chiwaridzo, Nhunvzi, and Tandyanemhandu (2016) in their study on the experiences of caregivers in caring for a child with CP in Zimbabwe, found that at the beginning of the study, caregivers reported physical strain and discomfort on the Caregiver Stress Index (CSI) and pain after the three months of the study period.

Low back pain is prevalent in caregivers of children who are non-ambulatory needing assistance with positioning, mobility, and transfers in either lying or sitting compared to those caregivers who are not required to perform any physical handling of a child (Geere et al., 2012). The results from the study by Geere et al., (2012) are comparative with findings from a qualitative study in Ndola, Zambia, which aimed to describe the challenges faced by caregivers of children with CP. The Zambian study by Singogo, Rhoda and Mweshi (2015) also revealed that caregivers continually perform physically demanding tasks of lifting, bathing, and transferring the child, resulting in some caregivers saying that the physical strain makes them suffer from headaches. Inaccessibility to assistive devices such as hoists or transfer boards results in a lot of manual handling and physical input from caregivers. The overall lack of assistive devices makes it almost impossible for the child with mobility impairments to attend school due to the unavailability of structures such as ramps to meet the needs of the child (Barlindhurg et al., 2016).

The outcome of a qualitative study done with primary caregivers of children with CP in Malawi showed that the care of a CP child with urinary/faecal incontinence often results in the caregiver having to do laundry manually throughout the day. Doing washing manually is usually done in a bent position (Barlindhurg et al., 2016).A mixed study method that was done in Kenya with the primary caregivers of children with motor impairments showed that the impact of this hard work leads to poor health, loss of weight, and being on medication for some non-specific physical ailments. The researchers in the study byGeere et al., (2012) ended up diagnosing most caregivers with a provisional musculoskeletal diagnosis. When caregivers were asked to prioritize problems encountered in the fulfilment of their caregiving role they listed spinal pain as their main concern (11 participants), shoulder pain(3 participants), lack of equipment (2 participants), and performing daily routine chores (1 participant) as the major challenges they experienced (Geere et al., 2012).The main cause of the participants' low back pain was found to be musculoskeletal pain due to carrying and transferring the child. The results by Geere et al., (2012) however, did not investigate whether there was an association between caring for a child with CP and the poor health and well-being reported by the caregiver. The caregivers who were experiencing musculoskeletal impairments may have been able to manage their child's medical, postural and functional needs if they got more appropriate training from the healthcare professionals (Olawale et al., 2013).

Developmental burden: The term 'developmental burden' can be defined as the time lost from doing what is appropriate for a person at a particular age (Wang et al.,2014) In a descriptive American study that partly aimed at describing the burden or psychological distress among family caregivers of clients with dementia; the authors found that unemployed caregivers who lived in the same house as a child with a disability experienced more developmental distress compared to other caregivers who were not staying with the care recipient (Razani, Kakos, Orieta-Barbalace, Wong,Casas, Lu, Alessi and Josephson, 2007).

Psychological burden: Psychological burden refers to the negative feelings experienced by the caregivers because they are not enjoying their caregiving role (Wang et al.,2014) Caregivers who reported higher psychological distress were those who had low social support, activity restrictions, were earning lower salaries and residing in rural areas (Yamaoka, Tamiya, Moriyama, Sandoval Garrido, Sumazaki and Noguchi, 2015; Wijesinghe et al., 2015). A limitation in the nationwide study done in Japan, however, was the failure to explore the type of social support mentioned in their study; another study found higher incidences of mental health problems among caregivers without paid employment compared with those with paid employments (Sawyer, Bittman, La Greca, Crettenden, Borojevic, Raghavendra and Russo, 2011). The result of the latter study explains the strong correlation between caregivers with a low income and psychological distress that has been found in the study done in Japan. The possible reason for this correlation is likely due to higher medical expenditure associated with the child with a physical disability, these medical expenses may include hospital admission, toiletries, and assistive devices, mental health diagnosis, and how those affected by the psychological distress due to caregiving utilized medical services (Yamaoka et al., 2015).

Emotional burden: The role of being a primary caregiver for an individual with a disability may be emotionally stressful resulting in feelings of despair, guilt, and resentment in some cases. Olawale et al., (2013) in their study in Ghana found that none of the caregivers in their study said that they felt hopeless with the child's condition or ever contemplated terminating the child's life. The constant thoughts of what went wrong with the child and the caregiver trying to cope with the hope that the child will receive a miracle and questions on whether he/she will walk affect the caregiver (Dambi et al., 2016; Barlindhurg et al., 2015). These inner emotional struggles may affect the caregiver's health and wellbeing which could be initiated or aggravated by emotional issues, psychosocial issues, and environmental factors.

The burden of time dependency: Having a child with a mobility challenge has been found to increase the time it took to care for such a child than the time it took to care for a child who could walk independently or with a walker (Sawyer et al., 2011). Caregivers who have a child which requires a high caregiving time usually have poor family support, are female, unemployed, and have financial problems related to the care for the recipient (Wang et al., 2014). This lack of support contributes to a lack of the caregiver's time. Other activities that the caregivers engage in with their children include being a playmate for the child with CP. A study on children with CP in Iran which aimed at describing the experiences of mothers of children with cerebral palsy showed that the children had little skills in toy manipulation and exploration since they spent more time with their adult mothers (Dalvand, Hosseini, Rassafaini, Samadi, Khankeh and Kelly, 2015).

Financial burden: Financial challenges arise from the direct cost related to the care recipient (Lai, 2012). A descriptive cross-sectional study that was done in Nigeria and aimed to investigate the socio-economic challenges faced by parents of children with neurological dysfunctions found that at least 20% of the parents were earning an average of US$60 per month; this amount is far below the US$360 average income of other families of children without CP. The low income of families caring for a CP child could be linked to the disruption of the family's business activities and the additional cost of care related to a disabled child with CP (Lawal, Anyiebe, Obiakor and Garba, 2014).A low income places the family in the lower socio-economic class in the community. A population-based study was done using the Taiwan National Health Insurance database in Taiwan that aimed at determining the prevalence of cerebral palsy in the population of children below the age of seven (7) years old and to establish the association between socioeconomic status and the prevalence of CP in Taiwan. The results from this study revealed that there was an association between low income and ahigher prevalence of CP. The study also found that CP was more prevalent among the rural dwellers compared to people living in urban areas (Tseng, Lee, Chou, Sheu and Lee, 2018). These reasons for these findings were ascribed to caregivers who have a lower level of education who had fewer job opportunities and poor maternal health (Brehault, Kohen, Raina, Walter, Russell, Swinton, O'Donnell and Rosenbaum, 2004). Fewer job opportunities can explain why some caregivers have suggested financial support for food and so that they may be better off financially to provide care for their child with CP (Geere et al., 2011).

The cost of living is higher for families with children with a disability than those who don't have children with a disability. These families needed additional income for transportation to get medical assistance at tertiary hospitals which are usually far from where the family and the child with CP resided to purchase assistive devices, medications and at times it became necessary to employ a domestic worker to look after the other children (Lawal et al., 2014). Furthermore, the continuous and unpredictable demands of caregiving were sometimes found to affect the source of livelihood of the caregivers thus leading to some of them being unemployed.Unfortunately, being unemployed further deepens the financial burden since healthcare costs and very important toiletries (soap, diapers) still need to be constantly bought. In a cross-sectional descriptive study in Nigeria on caregivers of children with CP, it has been observed that the other siblings were indirectly affected by the demands of the child with CP. Families had to do budget cuts to accommodate the increase in expenditure on expensive medication and medical investigations of the child with neurological deficits (Lawal et al., 2014).

Health care burden: The extent of healthcare of a CP child depends on the severity of the child's impairment.A study in India on about a hundred cases in which the clinical patterns, predisposing factors, and associated comorbidities among children with CP were studied showed that 55% of the CP children had mental retardation, 45% suffered from seizures, 26% had visual impairments, 19% had hearing impairments and 47% had delayed development. Spastic CP children which were the most common diagnosis (81%), 12% of the CP children were hypotonic, five percent (5%) were diagnosed with dystonia while two percent (2%) were diagnosed with mixed CP impairment. The researchers also noted that seizures contributed to the poor prognosis of medical intervention. The presence of co-morbidities will increase the burden of care on the caregiver because in this case, the care may include apart from medication, also rehabilitation, and management of assistive devices (Gowda, Kumar, Shivappa, Srikanteswara, Shivananda, Mahadeviah, Govindraji and Ramaswamy, 2015). From the findings in a nationwide survey in Japan on parents of children with disabilities mental health, the researchers found that the proportion of parents with children with disabilities who had been suffering from psychological distress and serious mental illness was higher than those for the overall Japanese population (Yamaoka et al., 2015). Barlindhurg et al., (2016) performed a qualitative study in Malawi which aimed at gaining a better understanding of how families coped in caring for a child with CP and how they perceived the rehabilitation services being offered. The results showed that when parents delay in taking their children with severe physical disabilities for continuous monitoring and treatment at the hospitals, it usually leads to defaulting with medication to the children for some days, this practice resulted in the children suffering from seizures even more.

Similarly, in a study performed by Geere et al., (2012) in Kenya and Barlindhurg (2016) in Malawi, the researchers observed that children with CP who presented with health problems such as; feeding and swallowing problems, verbal communication, mobility, spasms, and regurgitation require more attention and care and these problems add to the burden of care since the child will be heavily dependent on the caregiver for long-term rehabilitation home program and may need regular doctors'/rehabilitation follow-ups in a hospital. In the Malawi study researchers noted that caregivers placed a high value on rehabilitation, they felt that rehabilitation made a difference in the children's ability to do things. However, the most valued rehabilitation assistance may not be available (Barlindhurg et al., 2016).

In developing countries, a child with severe CP who lacks mobility devices such as postural support wheelchairs finds it difficult to attend school. The lack of mobile devices increases the risk of developing secondary complications such as fixed deformities and pressure sores from poor posture or due to prolonged lying and sitting (Barlindhurg et al., 2016; Dambi et al., 2015).

Social burden: The social burden entails the caregiver's inability to engage in social participation due to their caregiving role. Lack of social interaction results in a feeling of social isolation and loss of social relationships (Razani, Kakos, Oriela-Barbalace, Wong, Casas, Lu, Alessi and Josephson, 2007).In urban as well as rural areas poverty has been found to increase caregivers' perception of their caregiver burden; However, caregivers in the rural areas are affected more since they have less access to formal services such as psychologist's interventions or assistance within the community from the government. Other challenges that caregivers in rural areas face are frequent transportation, the cost of transportation to bigger cities to access rehabilitation services (Wijesinghe et al., 2015). The stigma towards disability, together with varying cultural beliefs that cerebral palsy iscaused by the promiscuity of the mother or witchcraft adds to the social burden of the caregiver (Singogo et al., 2015).

2.5 ASSESSMENT OF CAREGIVER BURDEN

In the previous section, the aspects that contribute to the burden of caring of the caregivers of children with disabilities were discussed, It is important to assess the caregiver and caregiving situation, this is particularly complex as it involves; understanding the demands which the disability impose on the family, assessing psychological symptoms of the caregivers often below clinically significant levels, determining the conditions which pre-disposes the caregivers to positive or negative experiences while carrying out their caregiving roles. The variables to be assessed are:

The Situation: The situation to be assessed in this context include; caregivers' immediate questions, challenges, and priorities, the caregiving stage of the family in response to the illness progression, the family's understanding of the illness/disability, and their approach to it.

The Context: The family system includes the structural and functional characteristics, the family's developmental stage (e.g., family with young children), family members' capacities, and willingness to take on new roles. Perceived fairness of the distribution of care responsibilities is included.

The Meaning: The previous experience of the family while providing care to an ill or disabled loved one. The various assessments instruments used to determine the burden experienced by caregivers are namely:Zarit Burden Interview (ZBI), Perceived Family

Burden Scale (PFBS), Experience of Caregiving Inventory (ECI), and Family Problems Questionnaire (FPQ).The assessment instrument used for this study was the Zarit Burden Interview (ZBI) and is discussed in the next section.

2.5.1 THE ZARIT BURDEN INTERVIEW (ZBI)

The Zarit Burden Interview (ZBI) is a screening instrument used to identify the emotional burden of the caregiver. It was designed by Stephen H. Zarit in 1980; its objective was to assess the level of burden experienced by principal caregivers of persons living with senile dementia and disabilities. Since the original description of the ZBI in 1980 as a 29-item instrument, other versions have subsequently been published (Herbert, Bravo and Preville, 2000). All versions feature statements that are ranked by respondents on a five-point descriptive scale occurring, never, rarely, sometimes, quite frequently, and nearly always, with these responses scoring 0-4 respectively; higher overall scores equate to greater caregiver burden. For this study, the full 22-item version of the ZBI will be used. The description of the various versions of the ZBI and the interpretation of the score is presented In Table 2 below;

Table 2.2: Zarit Burden Interview (ZBI) versions: number of items, score range, and suggested cut off scores

ZBI VERSION	Number of items	Score range	Suggested cut off Scores
Full	22	0-88	0-21 Little or no burden 21-40 mild to moderate 41-60 moderate to severe burden 61-88 severe burden [hence>40/88=high burden}

Short	12	0 – 48	>17/48severe /high burden
Screening	4	0-16	>8/16severe /high burden

2.6 SUMMARY OF CHAPTER2

In summary, this chapter has discussed the prevalence, types, causes, signs, and symptoms of cerebral palsy. The management of children with cerebral palsy requires a multidisciplinary approach with the involvement of the caregiver as this will determine the success of the treatment. The literature has also shown that caring for children with cerebral palsy is challenging for the caregiver and the challenges identified have been attributed to the nature of the disability. The burden of caring for a child with CP does not only put a strain on the health of the caregiver it also affects the emotional and psychological well-being of the caregivers, as well as the functioning of the family as a whole.

The factors associated with the burden of care were reviewed. The following chapter presents the research methodology utilized in this study as well as the findings of the study.

CHAPTER 3

METHODOLOGY

3.1 INTRODUCTION

In this chapter the research design and methodology that was followed to answer the research question, ‘what is the caregivers’ burden in caring for children with cerebral palsy in Lagos, Nigeria’ is discussed. A detailed description of the research methodology, study design, research setting, sampling process, pilot study, data collection tools, and ethical considerations applied in this study are addressed in this chapter.

3.2 RESEARCH DESIGN

A mixed method (QUANT+QUAL) design was used in this study. This research design entails collecting data using a quantitative research approach and exposing the sameparticipants to a qualitative approach in the same single study, (Creswell, 2013). In this design, the quantitative data was collected first followed by the qualitative data collection (Kemper, Springfield and Teddlie, 2003). Using the mixed method approach (quantitative and qualitative) increases the richness in the knowledge that is generated and results in a more meaningful understanding of the phenomena that is being investigated than would be the case when either a qualitative or quantitative data collection is used in isolation (Creswell and Plano, 2007). The purpose of a qualitative data collection method such as focus group discussions (FGDs) was to explain and elaborate on the quantitative results collected in the first phase. The FGD of the same participants who participated in the quantitative phase of the study served to triangulate the data and optimize the quality of evidence that results from the study. Quantitative and qualitative data were collected during a clinic visit where the caregivers brought their children for assessment and treatment at the same clinic. The quantitative data was collected first followed by a random selection of 10 participants to participate in the FGD to conduct the pilot study.

3.3 ETHICAL APPROVAL

Ethical approval to conduct the study was granted by the Research and Ethics Committee of the Faculty of Health Sciences of the University of Pretoria, (PN 615/2020 and Annexure J).Permission to conduct the study at the Federal Neuro-Psychiatric Hospital, Yaba, Lagos (Annexure K) was also granted.

3.4 RESEARCH SETTING

The participants of this study were the caregivers of children with CP who brought their children to attend the physiotherapy outpatient clinic at the Child and Adolescent Centre of the Federal Neuropsychiatric Hospital, Oshodi Annex, Lagos, Nigeria. The centre renders a service for children and adolescents with a variety of psychiatric and neurodevelopmental conditions such as; Depression, Schizophrenia, Autism Spectrum Disorder (ASD), Down syndrome, Intellectual disability, Attention Deficit Disorder (ADD), and Cerebral Palsy (CP). There are two outpatient clinic days per week, which on Tuesdays and Thursdays where an average of 16 – 20 children with CP are treated each of those days. At least a total of 32 children with cerebral palsy come to the clinic with their caregivers weekly.

3.5 DATA COLLECTION

The research question guided the method of data collection. The method of data collection for this study is described in the sections below.

3.5.1 Data collection Instruments

Socio-demographic data were collected using the data collection sheet (Annexure C), while also administering the ZBI questionnaire (Annexure D), The ZBI questionnaire was piloted after receiving permission from the author. The demographic data was used during the data analysis and writing up of the thesis without revealing the identity of the participants.

(1) **Zarit Burden Interview questionnaire:** The questions on the ZBI questionnaire have a 0-4 scoring. It strongly correlates with the Burden Assessment Scale (BAS), General Health Questionnaire (GHQ-28), Dementia Management Strategies Scale (DMSS), and the Revised Memory and Behaviour Problems Checklist (RMBPC) (Seng, Luo, Ng, Lim, Chionh, Goh, and Yap, 2010). The Pearson's correlation coefficient with these questionnaires ranged from: 0.53 to 0.73. The Cronbach's alpha value for the ZBI items was 0.93; the intra-class correlation coefficient for the test-retest reliability of the ZBI was 0.89 (n = 149) (Seng et al., 2010).

(2) Development of the question guide for the focus group discussions

The development of the question guide is as important as the pre-focus group planning and recruitment stages. The questions were structured based on the recommendations of Krueger and Morgan (1998). Three types of questions were used; the probe questions, the follow-up questions, and the exit questions. The questions were formulated based on the researcher’s observations of the factors that contribute to the burden of caregivers of children with CP during weekly communication with caregivers in the clinics. The question guide was put through a process of face validity by asking colleagues to complete the questionnaire and assess the questionnaire in terms of the clarity of the questions and whether the answers would result in the content that would render relevant answers to the research question. The question guide was adapted based on the feedback from the colleagues (Annexure A).

3.5.2 POPULATION

The study population is caregivers of children diagnosed with CP, between the ages 0-17 years, and who were receiving physiotherapy services as outpatients at the Child and Adolescent Centre of the Federal Neuropsychiatric Hospital, Oshodi Annex, Lagos, Nigeria.

3.5.2.1 Inclusion Criteria

- Caregivers of CP children who had a confirmed diagnosis by a medical team. The caregiver should have been caring for the child with CP for at least six (6) months. To avoid bias the researcher checked the information on the diagnosis and ages of the children for all the caregivers.
- The recipients of the care (CP children) had to be registered patients in the institutions where data was collected.
- Voluntary informed consent was given by the caregiver after being informed of the purpose and procedures of the study.

3.5.2.2 Exclusion Criteria

- This study excluded caregivers of children with cerebral palsy older than 17years of age.
- Caregivers of children with a disability due to any other diagnosis (including autism) will also be excluded.

3.5.2.3 Sampling Method and Sample Size

The purposive sampling method was used to select participants in the current study. Purposive sampling is a non-probability sampling method in which participants were selected because the participants had been identified to provide accurate and adequate information related to the phenomenon under investigation for the fact that they have lived through the experience (Palinkas, Green, Wisdom, Horwitz, Duan and Hoagwood, 2015).

The 22 item ZBI questionnaire was used to collect the quantitative data. The sample size of the study was calculated by a statistician. A sample of 120 participants were asked to answer the ZBI questionnaires which would estimate all the proportions to within 0.1 of the population proportions with a 0.95 probability. The sample size determined for this study refers to the estimation of multinomial proportions.A participant’s ZBI score can be categorized as experiencing a mild, moderate, or severeemotional burden of caring for her/his CP child.

For the FGDs, 60 participants were randomly selected from the total sample of 120 participants who completed the ZBI. The total number of participants that had to participate in the FGDs was calculated by a statistician who indicated a number of 60. The participants were then divided into six (6) focus groups consisting of ten (10) participants per group according to Creswell and Poth (2018). According to these authorsten (10) participants per focus group would be a valid and reliable sample size.

3.5.2.4 Recruitment of Participants

On the clinic days for the CP children at the Child and Adolescent Center of the Federal Neuropsychiatric Hospital, Lagos (which were Tuesdays and Thursdays), the researcher addressed the participants to inform them about the purpose of the study and invited them to participate in the study. All participants were assured that their identities will not be revealed to anybody and that the questionnaires they completed will only be available to the researcher. The questionnaires they completed will be coded so that their identities will be protected. They were informed that the results of the study will be printed as a research dissertation, published in an academic journal, and also shared with relevant stakeholders such as policymakers, healthcare professionals, and government officials. The participants had the opportunity to ask questions for clarity on their participation in the study. They were also made aware that participation in the study was voluntary and they could withdraw if they choose to withdraw, and their withdrawal will not change the quality services their children receive in the clinic. Caregivers who agreed to participate in the study received an informed consent form to sign in the presence of the researcher (Appendix F). All participants who signed a consent form on a particular day were taken to a separate room, where they were asked to complete the ZBI questionnaire without the influence of other participants.It took the participants about 15 minutes to complete the questionnaire.Ten of these participants were randomly selected to participate in the FGD using the simple randomization technique immediately (on the same day) after they completed the ZBI questionnaire. The consent of the participants to participate in the FGDs was included in the consent they gave they gave to participate in thecompletion of the ZBI questionnaire.

3.6 DATA COLLECTION PROCEDURE

Quantitative data was collected using a survey on the purposive sample. The English version of the ZBI questionnaire was used to collect the participants' demographic data and to determine the level of their emotional burden in caring for a child with CP. The participants were asked to sit down in a well-ventilated room, observing all covid-19 protocols after consenting to be part of the study. The socio-demographic and ZBI questionnaires were distributed, when the participants had completed the questionnaires the researcher collected the questionnaire from them and put it in an envelope. Ten of the participants were then randomly selected to participate in the FGD. Those selected for the FGD were then taken into a different room for the FGDs.

Qualitative data was collected by conducting six (6) FGDs with ten (10 participants in each group).

The participants were asked if they would give informed consent that the interview can be recorded. To ensure the good quality of the recording, a digital recorder was used. The same participants who completed the ZBI questionnaire participated in the focus group discussions. The duration of the FGD was about 30 minutes (Creswell, 2013). While the focus group discussions were ongoing the children of the participants were seated on their CP chairs in the therapy room. The data collected was then transcribed.

3.7 ETHICAL CONDUCT

On the day that the participants attended the clinic with their children, the participants were invited into a separate room from the children and were informed of the aim and objectives of the study by the researcher and voluntarily signed consent to participate in the study.The participants were assured that they could withdraw from the study if they wished to without penalty even if the consent form was signed.

Potential participants were told of the expected time duration of FGD and completion of the questionnaire. To adhere to the covid-19 precautions, the participants were required to wear a mask, wash their hands before they were ushered into a well-ventilated room in the Physiotherapy department where the questionnaires were completed and focus group discussions took place. There were not more than 10 participants in the room at a particular time and they sat 6 feet (2 meters) apart from each other in compliance with the Covid -19 precautions. The venue was sanitized after each FGD. The pens that were provided to them to complete the questionnaire were sanitized after each session. The recorder was sanitized after each FDG.

Consent forms (Annexure F) were given to all participants who agreed to participate in the study to read and sign before commencing the FGD, their consents were requested for voice recording during the focus group discussion. Participants were informed that there is no payment to be expected by participating in the study and no penalty for declining to be part of the study at any point in the process.The hospital managers and the caregivers were fully informed of the aims of the study and procedures to be followed in collecting data. It was clearly explained to the participants that information obtained is not going to be used against them or their children if they participate in the study.

The participants were not requested to write their names on the ZBI questionnaire when they completed it. The researcher allocated a number or a code to the questionnaire and data was transferred to an excel spreadsheet. Any information through which a participant could be identified such as; an address or phone number was not collected from the participants.

The participants were not required to mention their names during the FGD but rather to use the numbers that were allocated to them at the beginning of each FGD. Each FGD received a specific symbol to distinguish between the focus groups.

To maintain confidentiality, all completed questionnaires and informed consent forms were kept in a cabinet only accessible to the researcher throughout the data collection and data analysis process. Quantitative data was saved electronically using an Excel program, and it is protected using a password only known to the researcher. Participants were informed not to repeat what was said in the focus groups to others. After the FGD,the participants took their children from where they were seated for their session with the physiotherapists.

3.8 PILOT STUDY

Before the data collection described above, the pilot study was conducted that included all the processes described above section3.5. Six (6) participants, who were not part of the main study, were asked to complete the socio-demographic data form and ZBI; the same participants were asked to participate in aFGD. The data collected was analysed as described in section 3.6.The aim was to establish whether the data collection tools were valid and reliable.

For qualitative data, the aim was to establish if questions were clear, all participants were able to understand the questions, and whether the answers to the questions rendered the answers to the research questions. The researcher discovered during the pilot study of the FGD that a question to determine ‘whether the children were attending school’, needed to be added to the question guide. The procedure for the data collection analysis in the pilot study was adapted in the main study with an increase in the number of participants in the FGD reason for this was to allow more caregivers to participate; the researcher ensured all participants contributed to the discussions. The data of the pilot study was not included into the main study.

3.9 DATA ANALYSIS

The data extracted from the 22 ZBI items were analyzed using the Strata Release 16 statistical software which was then summarized using frequencies and cross-tabulations with demographic, physical, and financial factors, along with a univariate Fisher’s exact test. The multinomial proportions estimates were reported along with simultaneous 95% confidence intervals.

The results of the ZBI were discussed based on the results of the coded data from the FGD.

The audio recordings of the FGD were transcribed verbatim and coded. The participants' names were replaced by codes to maintain their anonymity, thereby protecting their privacy. The analysis of the FGD was done independently of the data obtained from the ZBI. The transcribed data from the focus groups was open and axially coded by the researcher and an independent researcher (coder) who is experienced in qualitative data analysis but who was not involved in the data collection. Coding by the researcher and independent coder was compared by the researcher and the independent coder, and the differences were resolved through discussion and consensus.

3.10 RIGOUR / QUALITY CONTROL

- **Quantitative data:**

A pilot study was conducted to determine the validity of the ZBI. The researcher administered the ZBI questionnaire to six (6) participants, whose data were not included in the main study. Also, pre-test and post-test reliability were established.

The Cronbachs alpha of the ZBI was tested and found to be 0.92 which was acceptable internal consistency. The item-total correlation was found to be consistent and varied between 0.40 and 0.76; the mean item-item correlation was 0.365.

The ZBI was therefore an instrument that would give reliable results in this study.

- **Qualitative data:**

Trustworthiness is the method of ensuring rigour in qualitative research without compromising relevance and it involves the following (Babbie and Mouton, 2015; Speziale and Carpenter, 2007).

3.10.1 TRUSTWORTHINESS

Because trustworthiness in a qualitative research investigation are influenced by the fact that the researcher is the instrument through which data, (participants' responses) are observed and interpreted, the researcher needs to adhere to the following criteria to ensure trustworthiness: credibility, member checking, transferability, dependability, conformability, and triangulation(Shenton, 2004; Babbie and Mouton, 2015).

- **Credibility:** To ensure credibility, in-depth information was gathered during the FGD with caregivers to explore and identify the burden they are experiencing in taking care of their disabled children. Measures that were taken to ensure credibility included;(1) the utilization of a recognized research method; (2) the use of qualitative and quantitative data collection strategies (3) detailed description of the procedures that were followed and (3) comparing the findings with existing literature(Shenton,2004).

- **Member checking:** This is to ensure that the interpretation and representation of the participants by the researcher match their understanding of their experiences (Braun and Clarke, 2013).During the FGD the researcher asked the participants to interpret and rephrase the researcher's documentation of their responses. This step ensured that the researcher understood the factors contributing to the caregiver's burden in the same way they verbalized it.

- **Transferability:** Transferability means that the researcher can apply the findings of the study to other communities in which children with CP live (Bowen, 2005). Based on this, the researcher collected sufficient information on the burden of care on the caregiver to understand the factors that influence the burden of care better and as such clinicians or researchers in other environments to interpret the outcome ofthe study relative to similar studies. Data will only be transferable to areas in the population of Nigeria that have a similar geographical and environmental compilation than the population in which the study was conducted based on the demographic characteristics that were collected (Anney, 2015).
- **Dependability:** The demographic characteristics, methodology, and results were presented in detail to grant other researchers the opportunity to replicate the study and to indicate that the results were based on the methodology (Shenton, 2004;Speziale and Carpenter, 2007).

- **Conformability:** Through a detailed description of data gathering and analysis researcher bias was limited. A co-coder that is familiar with qualitative data analysis was asked to code the data independently and the final concepts (factors) and themes were agreed upon through a process of discussion consensus between the co-coder and the researcher (Babbie and Mouton, 2015).
- **Triangulation:** In this study, six (6) FGDs were conducted to gain insight into the participants' views on their burden of caring for a disabled child. Triangulation was also obtained when the results showed that the views of the participants' responses in the FGDs were homogeneous.

3.11 SUMMARY OF CHAPTER3

This research utilized a mixed method design (quantitative and qualitative).A purposive sample of the target population was caregivers of CP children who attended the outpatient clinic of the Child and Adolescent Unit of the Federal Neuro-Psychiatric Hospital Yaba, Lagos. The proposal for the study was approved by the Faculty of Health Sciences Research Ethics Committee, University of Pretoria. Permission was granted for the use of the Zarit burden interview questionnaire by the author (Annexure K) The target population and sampling of the participants, data collection procedures, ethical conduct during the data collection, and the data analysis are described.Finally, the rigor and quality control exercised during the study is described A pilot study was implemented and the feedback resulted in a slight amendment to the focus guide questions. In Chapters 4 and 5, the results from the quantitative and qualitative data obtained during the data collection were presented.

CHAPTER 4

RESULTS OF QUANTITATIVE DATA ANALYSIS

4.1 INTRODUCTION

The previous chapter outlined the methodology followed in collecting data to answer the research questions in this study. In this chapter, the analysis of the quantitative data is presented and interpreted. The results of the data are presented in two main categories:

- Demographics of the caregivers of children with CP.
- Descriptive statistics of the ZB reflect the quantified results of the burden faced by the caregivers.

4.2 DATA MANAGEMENT AND ANALYSIS

A total of 120 ZBI questionnaires were completed by the participants. The data captured on the questionnaire were transferred to a Microsoft Excel spreadsheet,the data checked to ensure it was complete, the data was cleaned and inconsistencies were corrected.A total of 120 Zarit questionnaires were handed out to participants of children with CP for a month, to gather their demographic information. Data wereanalysed using Strata Release 16 statistical software. Demographic data and burden characteristics were analysed using descriptive statistics

4.2.1Demographic data

The demographic characteristics of the sample group who participated in the study include; sex (gender), age group, religion, ethnic group, education, occupation, and income. The results from the data collected are presented in frequencies and percentages.

4.2.1.1 Sex of Participants

Eleven (11) males and 109 females completed the ZBI questionnaire. Figure 4.1 represents the sex of all participants. The females were 90.8% and the males 9.2% of the sample group.

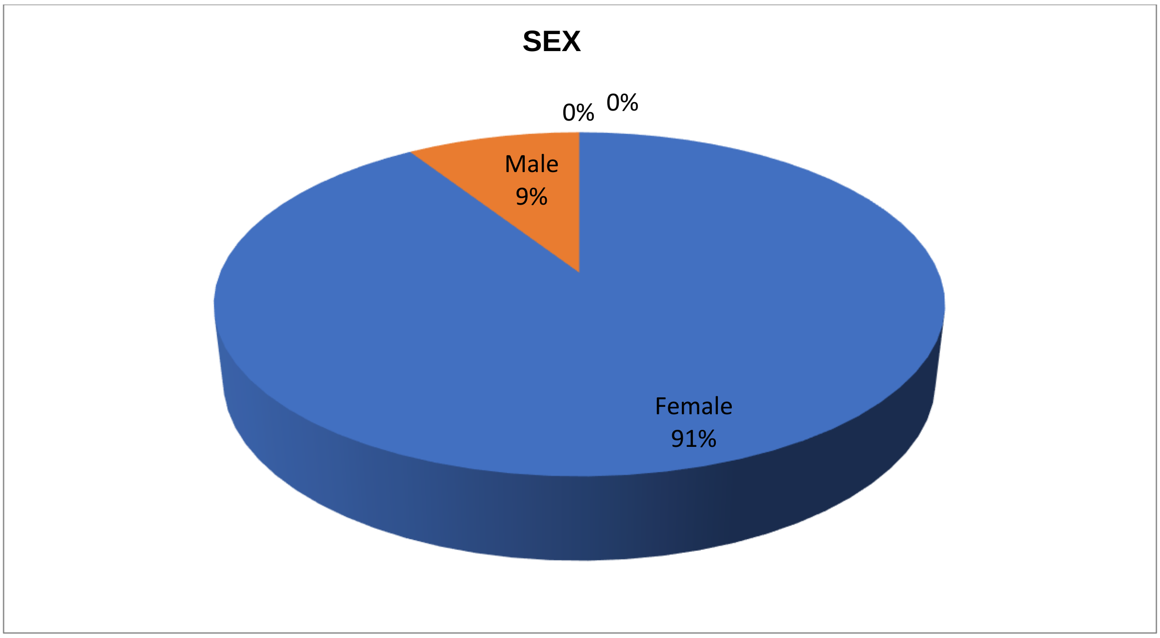

Figure 4.1: Sex of the Participants

4.2.1.2 Age of Participants

The ages of participants range from young adults to middle age. The age range of the participants is presented in intervals of ten years. Table 4.2 below illustrates the age ranges for all participants.

Table 4.1: Age of Participants

Variable: Age(Years)	Frequency(n=120)	Percentage (%)
20-29	16	13.3
30-39	86	71.7
40-49	16	13.3
≥ 50	2	1.7
Total	120	100

The majority of participants were between 30-39 years.There were a few participants in the middle age group 50 years and above.

4.2.1.3 Religion of Participants

Figure 4.2 depicts the religion of the participants. It was observed that most participants belonged to the Christian faith (n=83, 69.2%).

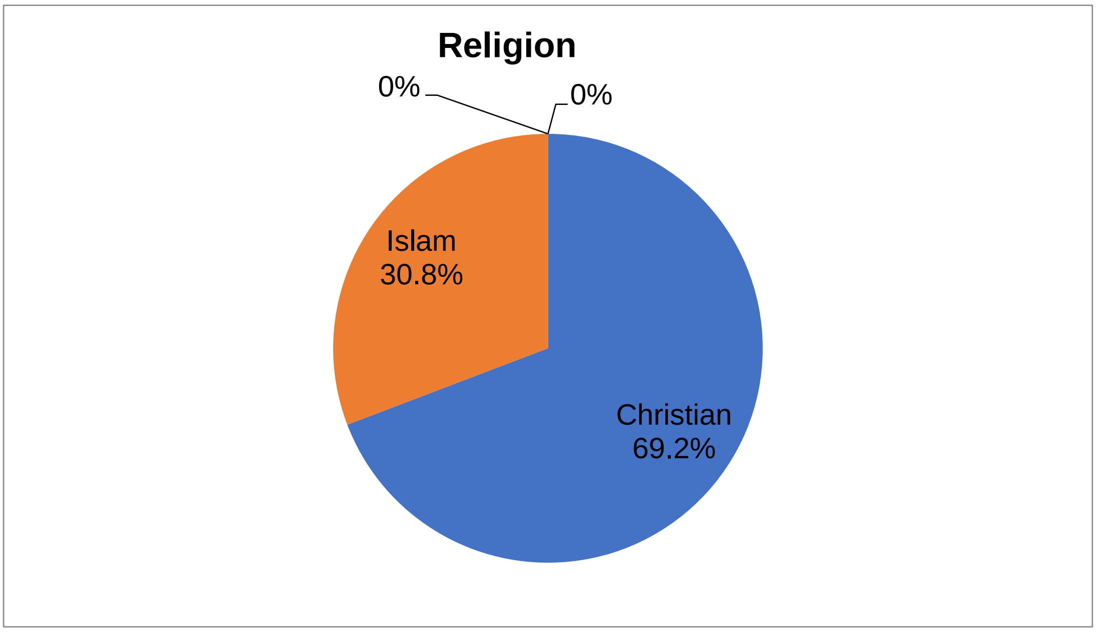

Figure 4.2: Religion of the Participants

4.2.1.4 Ethnicity

The participants belonged to the three major ethnic groups in the country the minority ethnic groups were a group as others. In table 4.2 the ethnic groups of the participants are presented.

Table 4.2: Participants' Ethnicity

Variable: Ethnicity	Frequency(n=120)	Percentage (%)
Hausa	4	3.3
Yoruba	75	62.5
Igbo	27	22.5
Others	14	11.7
Total	120	100

The possible reason why the majority of the participants were from the Yoruba ethnic group (75%) is that the study was carried out in the South Western part of the country where the Yoruba ethnic group is dominant.

4.2.1.5 Education of Participants

The participant level of education is presented in table 4.3 below illustrates the level of education attained by the participant.

Table 4.3: Education of Participants

Variable: Education	Frequency(n=120)	Percentage (%)
Primary	3	2.5
Secondary	49	40.8
Tertiary	68	56.7
Total	100	100

Table 4.3 shows that majority of the participants had completed their secondary (40.8%) and tertiary education (56.7%).This confirms that most of the participants were well educated and were able to understand the condition of their children.

4.2.1.6 Occupation of Participants

The categories of the participants' occupations are presented in Table 4.4.Occupations such as doctors, lawyers, engineers, nurses, and teachers were categorized as professional occupations; occupations such as technicians, computer operators, and administrative assistants were categorized as skilled workers; and jobs such as traders, cleaners, and gardeners were categorized as unskilled workers a final category are those who are unemployed.

Table 4.4: Occupation of Participants

Variable: Occupation	Frequency(n=120)	Percentage (%)
Professional	18	15.0
Skilled	71	59.2
Unskilled	13	10.8
Unemployed	18	15.0
Total	120	100

Table 4.4 shows that most (74%.2), of the participants wereprofessionals or skilled workers.

4.2.1.7 Income of the Participants

Participants' income was categorized into five categories presented in Table 4.5.

Table 4.5: Income of Participants in Nigeria Naira

Variable: Income(Naira)	Frequency(n=120)	Percentage (%)
<7.5k	15	12.5
7.5k – 15k	44	36.7
15k – 50k	43	35.8

50k – 100k	16	13.3
100k – 150k	2	1.7
Total	100	100

*1 Naira is equivalent to Twenty-nine Rand (R29)

Table 4.5 depicts that majority of the participants(36.7%) were earning below the national minimum wage which is 30k Naira per month. Eighty five percent (85%) of the participants earned below to just above the minimum wage.Due to the high unemployment rate in the country the majority of the participants though having professional and skilled occupations are paid low wages.

4.3 ZARIT BURDEN INTERVIEW QUESTIONNAIRE

The ZBI questionnaire contains 22 questions that have to be answered on a four-point Likert scale (0 – 4).The final score can therefore range from is 0 – 88, the final score is interpreted as follows; 0 – 20 indicates little or no burden;21 – 40 indicates mild to moderate burden; 41 – 60 indicates moderate to severe burden; 61-88 indicates severe burden.

Table 4.6: Zarit Burden Interview (ZBI) results

Variable: Zarit category	Frequency(n=120)	Percentage (%)
0 – 20	21	17.5
21 – 40	65	54.2
41 – 60	32	26.7
61 – 88	2	1.7

Total	120	100

From Table 4.6 it is observed that all participants experienced some level of burden. The results showed that the majority of the participants (54.2%) experienced a mild to moderate burden in caring for their CP child; at least a quarter (n=32) of the participants experienced moderate to severe burden and two participants carried the severe emotional burden.

Table 4.7 Comparison of participant variables with participant Zarit score

Variables	Little/no	Mild/moderate	Moderate/severe	Severe	P-Value
Age					0.386
20-29	9.52 %	13.85%	12.50 %	50.0%	
30-39	80.96%	67.69 %	78.13 %	0.0%	
40-49	9.52 %	15.38 %	9.37%	50.0%	
≥ 50	0.00 %	3.08 %	0.00%	0.0%	
Total	100	100	100	100	
Sex					
Male	14.29	6.15	12.50	0.0	0.495
Female	85.71	93.85	87.50	100.0	
Total	100	100	100	100	
Religion					
Islam	23.81	32.31	34.38	0.0	

Christianity	76.19	67.29	65.63	100.0	0.802
Total	100	100	100	100	
Education					
Primary	4.76	1.54	3.13	0.0	0.660
Secondary	28.57	41.54	46.88	50.0	
Tertiary	66.7	56.92	50.00	50.0	
Total	100	100	100	100	
Occupation					
Professional	4.76	23.08	6.25	0.0%	0.007
Skilled	47.62	60.00	68.75	0.0%	
Unskilled	19.05	6.15	15.63	0.0%	
Unemployed	0.00	0.00	0.00	100.0	
Total	100	100	100	100	
Ethnicity					
Igbo	33.38	10.76	37.50	50.0	0.030
Yoruba	47.62	72.31	53.13	50.0	
Hausa	9.50	3.08	0.00	0.0	
Other	9.50	13.85	9.37	0.0	
Total	100	100	100	100	

Personal income					
<7.5k	23.81	4.62	15.63	100.0	
7.5k – 15k	42.86	36.92	34.38	0.0	0.077
15k – 50k	28.57	38.46	37.50	0.0	
50k – 100k	4.76	16.92	12.50	0,0	
100k – 150k	0.0	3.08	0.0	0.0	
Total	100	100	100	100	

Table 4.7 shows that most participants in the 20-29 and 40-49 age groups experienced a mild/moderate burden with a percentage of 14.5% and 16.1% respectively, while those in the 30-39 age groups experienced a moderate to severe burden in caring for their CP child– their answers fell in the moderate/severe category. Most female participants experienced mild/moderate burden while 12.5% of the male caregivers experienced a moderate to severe burden in caring for their CP children.

Socio-demographic variables of the caregivers werealso compared with the burden categories.It is also observed that there was a significant association between the occupation of the participants and the zarit score (P=0.030) — 75% of the skilled and professional workers experience a moderate to severe burden in caring for the CP children. As far as ethnicityis concerned the Yorubaand Igbo ethnic groups of people, especially the Yoruba group of people experience a moderate to severe burden in caring for their CP children; although the Yoruba group were by far the majority of the ethnic groups who participated in the study (P=0.007).

Participants within the lower income groups experienced a moderate to severe burden of care for their CP children compared to the participants in the higher income groups although the strength of the association was within a 10% level of significance.

4.4 SUMMARY OF CHAPTER 4

In summary,in this chapter, the results of the analysis of the quantitative data were presented. The statistical analysis was done by a statistician the data. The results of the demographic data analysis include;the sex, age, religion, education, and ethnicity of the caregivers. The analysed results of the ZBI were presented to describe the burden faced by the caregivers of children with CP. In the next chapter, the results of the analysed qualitative data will be presented.

CHAPTER 5

QUALITATIVE DATA ANALYSIS RESULTS

5.1 INTRODUCTION

In this chapter the findings of the qualitative phase of the study are presented. Data was collected using FGDs. A total of sixty (n=60) caregivers who completed the ZBI questionnaires in the first part of the study participated in the FGD. A total of six (6) FGD with ten (10) participants each was conducted in the second part of the study. Participants were selected randomly from the total sample group of 120 participants who completed the ZBI.

5.2 SOCIO-DEMOGRAPHIC DATA OF THE PARTICIPANTS

The results presented in this chapter address the research question: to identify the factors that contribute to the burden of care of the caregivers of children with CP in Lagos, Nigeria. The qualitative results add meaning and more depth to understanding the quantitative results of the burden of care based on the results of the ZBI presented in Chapter 4 as it explains the factors or reasons why the caregivers experienced the care of their disabled CP child as a burden. The experiences of the caregivers were verbally transcribed, checked by the researcher, and open and axially coded.The profile of the participants was collected from the information on the socio-demographic data form (Annexure A).The socio-demographic characteristics of the participants are presented in Table 5.1 below:

Table 5.1: Socio-demographic details of the caregivers

Socio-demographic details	**Number(n)**
Age (in years)	
20-29	10
30-39	46
40-49	4
<=50	0
Sex	

Female	55
Male	5
Religion	
Christianity	44
Islam	16
Ethnicity	
Hausa	2
Igbo	18
Yoruba	37
Others	3
Education	
Primary	0
Secondary	23
Tertiary	37
Occupation	
Professional	5
Skilled	45
Unskilled	6
Unemployed	4
Income of caregivers (Naira)	
<7.5K	
7.5K – 15K	4
15K – 50K	32
50K -100K	16
100K – 150K	8
	0
*1Naira is equivalent to 29 Rands	

There were six (6) focus groups with ten (10) participants in each focus group.The majority (55) of the participants in the FGDs were female and five (5) were male. Sixty-two percent (62%; n=37) of the caregivers had obtaineda tertiary level of education, while 45% (n=27)27)obtained a secondary level of education.This fact showed that the caregivers were all literate. The income of the majority (60%; n=36) of the participants fell in the low-income level (7.5K -15K); though most (75%; n=45) of them were engaged in skilled jobs.

The trustworthiness of the FGD is discussed in the following section in addition to the setting in which the FGDs wereconducted; the participant selection process, the data gatheringprocess, the analysis of the transcribed FGDs andfinally the format the results in which are reported (Tong, Sainsbury and Craig,2007).

5.3 CODING OF DATA

The audio recordings of all FGDs were transcribed verbatim by an independent typist and checked by the researcher. The researcher read the transcribed data repeatedly to get an understanding of the content of the data and identify similarities and patterns in the concepts and categories as they emerged from the data (Bless, 2013).The process of coding involved grouping the concepts in the text into small categories and assisted the researcher to understand the perspectives of the participants and analysing their responses. A computer-assisted qualitative data analysis software, Nvivo 10 was used to aid the process of data management and analysis. The software was not used as the primary instrument of data analysis but to assist the researcher to solidify data analysis.A total of sixty (60) participants were involved in the FGDs out of which fifty-five (55) were females and five (5) were males. Three of the groups had only female participants (Groups 1, 3, and 6) while the five (5) male participants were in groups 2, 4, and 5. The data isanalysed using thematic analysis (Braun and Clarke, 2006), and six (6) main themes and their related sub-themes emerged that were common to all the FGDs.

5.3.1 Themes and sub-themes

A theme is a pattern found in the information that describes the possible observations or interprets certain aspects of a research problem. The use of the question guide assisted in the identification of themes. An overview of the themes and sub-themes that emerged from the FGDs was presentedin Table 5.1. Each concept on which a theme was based is then discussed and substantiated with translated direct quotes by the participants. Six (6) themes were identified from specific patterns that emerged from the issue discussed.

Table 5.2: Overview of the themes and sub-themes

THEMES	SUB-THEMES
Access to healthcare	Distance and time it takes to access healthcare facilities Unavailability of public transport to transport the children Private transport
Access to education	2.1) Lack of awareness about the need to educate the child 2.2) No access to affordable education 2.3) Child too disabled to be admitted to the school system
Mode of transporting the child	3.1) Carrying the child on the back 3.2) Impact of carrying of the child on the back on the health of the caregiver 3.3) Transporting the child in a taxi/public transport. 3.4) Transport child in private car
Financial support	4.1) High cost of caring for a child with CP 4.2) Financial support from spouse/family /siblings /friends 4.3) Self-support

Social support	5.1) Social support from spouse/family/friends 5.2) Caregiver's care of the child and other children/family members 5.3) No support from community/public 5.4) No support from family

5.3.2 Theme 1: Access to healthcare

Children with CP need regular healthcare such as rehabilitation services, access to healthcare has been indicated as a burden experienced by the majority of the caregivers.There are however those few caregivers who did not experience limited access to healthcare Reasons why participants experienced difficulty or not accessing healthcare are discussed in the following paragraphs.

- **Sub –Theme 1.1**: **Distance and time it takes to access healthcare facilities**

The majority of the participants reported that they experienced difficulties accessing healthcare services, especially rehabilitation services such as physiotherapy, occupational therapy, and speech therapy because the clinic is located in the city centre and most caregivers are living in the outskirts of the city. The hospitals where rehabilitation services are offered are highly recommended for children with CP. The following quotations are from the participants:

It is very difficult to access healthcare services especially this physiotherapy service, it takes me 4 hours to get to the hospital and I spend about 3 hours in the hospital for my child to have her session before I start heading home.(FG 2;P 2).

I wake up as early as 3 am any day my daughter has her hospital appointment for me to get to the hospital before 7 am.(FG1;P 8).

- **Sub-Theme 1.2: Unavailability of public transport to transport the children**

Transportation to and from the hospital is quite challenging for themajority of the caregivers this is described by some of the comments made by them below;

I usually move around with my child in public transport which is not always convenient as the buses are always packed full and I have to carry my child on my lap. To get to the hospital I usually take about 2 buses, When it rains or heavy traffic I can stand at the bus stop for 15 minutes before I get a bus, If the hospital was closer to my place it would be easier(FG2;P1).

Another participant who also uses public transport to get to the hospital added:

Transporting my daughter to the hospital is not always easy since I don't have a car and only bikes run from my house to the closest bus stop where I will then board a bus. Another major challenge is that no bus or bike that runs from the closest bus stop to the hospital, we now have to walk for about 10 minutes with her strapped to my back(FG;P7).

The responses of the caregivers indicated that they experience major difficulty accessing healthcare services. This shows that there are little or no provisions by the healthcare management system for the rehabilitation of children with CP at the primary healthcare level.

- **Sub – Theme 1.3: Use of private transport**

Though some caregivers revealed that transporting their children in their private cars is more convenient they still have complaints about the bad roads and travel time from their places of residence to the hospital, as this affects them as caregivers according to the direct quotes highlighted in their responses:

I move around with my child in our private car which makes it easier but it takes about 3 hours to get to the hospital on the day she has appointments(FG4;P9).

My husband takes us to the hospital which is more convenient as he is big but that would mean he won't go for his business that day the access road from my house is full of potholes and it takes us 4 hours(FG6; P10).

Transport to the nearest hospital for medical care or rehabilitation services contributes in a different way to the caregivers' burden in caring for the child with CP. Transport to the hospital/rehabilitation service of caregivers who lived near the hospital did not contribute as much to their burden in caring for their child.

5.3.3 Theme 2: Access to education

One of the themes identified from the responses of the caregivers in the burden of caring for children with CP is access to education. Aspects that contribute to this theme are; lack of awareness of educational services, no access to affordable education,and child too disabled to be admitted into the school system. These issues are discussed as sub-themes hereafter.

- **Sub-Theme 2.1:Lack of awareness of the need to educate the child**

The Nigerian national policy on education (2004) stipulates that persons with disabilities should be educated in regular schools along with their non-disabled peers. The policy further stipulates that persons with disabilities will receive free education from primary school up to higher institutions. From the responses of the caregivers, it is observed that they were not aware of the governmental policy for persons with disabilities of which CP is one of them. This is expressed in the following quotations;

My child is not in school because I don't think he can be educated as he can't sit, stand, walk and talk (FG4; P2).

I am not aware that a child with CP can be educated so my child is not in school (FG5; P7)

My child is not in school because I am not aware that he will benefit from going to school education (FG3; P3).

- **Sub –Theme 2.2:No access to affordable education**

The educational policy that stipulates that persons with disabilities would receive free education from primary school up to higher institution seems not to be enforced by schools as reflected in the statements of the caregivers quoted;

Educating a child with CP is very expensive that is if you get a school that will accept your child, I pay the regular fees for the school and also pay the facilitator that assists her with her schoolwork while in school(*FG4;P10).*

The few schools that run inclusive units are too expensive, I had to stop him from going to school because I couldn't afford it any longer(FG 1;P6).

These responses illustrate that the caregivers were not aware of the provision of the law of free education for persons living with disabilities from primary school to tertiary level and the policy is not being implemented as the caregivers were spending so much to get their children educated.

- **Sub-Theme 2.3: Child too disabled to be admitted into the school system**

In some cases, the caregivers were aware of the importance of education for their children and they also had access to schools or educational programs for their children but refuse to enrol their children because they feel their children are too disabled or dependent to be enrolled in the school system. This is highlighted in their responses:

My child cannot sit on his own, how can he go to school?(FG 4; P7).

A child that cannot walk on his own will not be able to cope in school, I don't think the teachers will be willing to carry the child about in school,such as when there are having outdoor activities or going to the toilet(FG6;P8).

5.3.4 THEME 3: MODE OF TRANSPORTING OF THE CHILD

From the theme above four sub-themes emerged and they include; carrying the child on the back of the caregiver, the impact of carrying the child on the back on the health of the caregiver, transporting the child in a taxi/bus,and transporting the child in a private car. These sub-themes are discussed below:

- **Sub-theme 3.1: Carrying the child on the back of the caregiver**

The mode of carrying the children by most of the caregivers was on theirbacks. This is a common practice of carrying young children in this part of the world until they can start walking independently because most of the children with CP are non-ambulatory the caregivers carry on with this practice even throughout the child's life.

I carry my child on my back as he can't walk on his own (FG1; P4).

I carry my child on my back (FG5; P10).

I carry my child though she is big and heavy she can't walk on her own (FG3; P8).

- **Sub-Theme 3.2: Impact of carrying of the child on the back on the health of the caregiver**

The majority of the caregivers complained that they were having back pain which they feel is a result of the constant carrying of their child on their back. Some caregivers complained of chest pain which they stated started when the challenge with their child started. This is further illustrated in the quotes below;

My child is 9 years old and he is not walking, Ihave been carrying him on my back since he was born and have back pain that I have been treated for 6 years now, there was a time I couldn't walk for 3 months because of the pain (FG1;P2).

Every day I suffer from chest pains especially after carrying my child on my back, I am always taking painkillers. It is affecting my blood pressure.

- **Sub-Theme 3.3: Transporting the child in a taxi/bus**

Most caregivers transport their children in either taxisif they can afford it or buses. These are the more common means of transportation, though it has their challenges as it concerns the CP child. A further illustration of this is seen in the quotes below;

I carry my child on the back whenever we need to go out and we use to move around with public buses (FG3; P7).

I move around with my child in a public bus and I carry him on my back while in the bus (FG2, P9).

We move around in taxis if we need to go out (FG6; P6).

- **Sub- Theme 3.4: Transporting the child in a private car**

Few participants reported that they transport their children in their private cars which is much more convenient for the caregivers and the children.

I transport my child with our personal car(FG1;P1).

We move around with my child in our private car as I don't need to carry him while in the car he sits in his car seat (FG6; P3).

5.3.5 THEME 4: FINANCIAL SUPPORT

The theme of financial support was found to be a common factor contributing to caregivers' burden in the care of their CP child. The sub-themes that emerged from the transcriptions were: the high cost of caring for a child with CP**,** financial support from spouse/family/friends**,**and self-support.

- **Sub-theme 4.1: High cost of caring for a child with CP**

The participants have indicated that taking care of their CP children has impacted their finances. This is reflected in the following comments made by participants.

It has not been easy in terms of finance I spend a lot of money on medications and therapy(FG2; P10).

It is expensive taking care of this child, as it has affected our finances(FG2;P6).

The money I spend on this child alone monthly is affecting our finances(FG5;P4).

I had to stop working as a banker to take care of my child and this has affected our finances asa household (FG 3;P 9).

Other than the monetary expenses, the cost of caring for the child with time spent caring for the child with CP is reflected in the following responses of the participants;

All my activities are centredon this child, taking care of him takes my time (FG4; P9).

My day starts and ends with my child apart from taking care of my other children who go to school (FG6;P10).

- **Sub-Theme 4.2: Financial support from spouse/family/friends**

My wife and I support each other and our child. Some relatives support us financially(FG4;P1).

I get money for taking care of my child from my elder sister as she lives and works abroad so she is the only one around me who understands that taking of a child with CP costs a lot, so she supports me to buy his drugs and every other bill for him(FG 5;P8).

Family members and friends give me money from time to time, without them, I don't know what would have happened to me (FG2; P4).

- **Sub-Theme 4.3: Self-support**

Some caregivers stated they don't get any form of support; they carry the burden of caring for their child alone. This is illustrated in the following quotes;

I don't get any form of support from anyone,not even my spouse as he talks down on me and my child(FG6;P6).

I don't get support from anyone and it makes this journey cumbersome (FG6;P10).

I am a single mother and I have no form of physical, social, or financial support (FG4; P10).

5.3.6 Theme 5: Social support

The theme of social support is common in the responses of the majority of the caregivers that participated in the FGDs. The sub-themes are: support from spouse, family, and friends, care for the CP child and other children/members of the family, and no support from the community

- **Sub-theme 5.1:Support from spouse/family/friends**

The majority of the caregivers revealed the supportive roles played by their spouses and family members following the birth and diagnosis of their child with CP. Some caregivers said they were not receiving any form of support from anybody. The caregivers' response of whether support is received or not received is illustrated in the quotes below:

My parents and siblings support me emotionally and financially (FG4;P3).

My husband supports me in this journey, if not I don't know what would have happened to me(FG6;P6).

No support from anybody, instead they blame me for still taking care of my child as some had advised me earlier to abandon the child in the bush(FG5;P3).

Some participants stated that the support they received from family helped them deal with the emotions of caring for a child with CP.

- **Sub –Theme 5.2: Caregiver has to care for the child and other children/members of the family**

The caregivers aside from taking care of the child with CP also have the responsibility of taking care of other children and family members. This is illustrated in their response below;

My daily activities are centredon taking care of my child with CP and my other children(FG2;P10).

My daily activities involve preparing food and washing the clothes of my husband and children alongside taking care of my child with CP(FG5;P4).

I take care of everyone in the house, I do all the house chores in addition to taking care of my child with CP(FG3;P5).

- **Sub –Theme 5.3: No support from the community**

Support from the community is lacking because there are no structures in the communities that would help alleviate their burden, this is illustrated in the quotes below;

I have to take my child everywhere as there is nowhere in the community to keep the child (FG5; P5).

There is nowhere to keep my child, if I need to go somewhere quickly I lock her in the house and go (FG1; P2).

I can't work because of my child as employers won't employ me when they hear I have a child with special needs, so I take care of my child alone(FG3;P7).

5.4 SUMMARY OF CHAPTER 5

This chapter presented the analysis of the qualitative data (focus group discussions).The themes and sub-themes that emerged from the focus group discussions were presented. Chapter 6 will provide a detailed discussion of the findings, conclusion, limitations, as well as recommendations for further study.

CHAPTER 6

DISCUSSIONS, CONCLUSIONS, LIMITATIONS, AND RECOMMENDATIONS

6.1 INTRODUCTION

In this chapter, the findings of the quantitative and qualitative data collection sections of the study are discussed followed by the conclusion, limitations, and recommendations. The results from the quantitative section (using the ZBI questionnaire) and the qualitative (FGD) section are combined to answer the objectives of the study.

6.2 DISCUSSION OF THE RESEARCH RESULTS

The research question that this study aimed to answer was “What is the caregivers’ burdenof caring for children with Cerebral palsy in Lagos,Nigeria”. The answer to this question may help stakeholders such as policymakers, physiotherapists, and members of the community to understand and alleviate caregivers’ burden in caring for their CP children. The study aims to explore caregivers’ burden of caring for their children with cerebral palsy in Lagos, Nigeria. The researcher was interested in achieving the objectives of the study, which include;

6.2.1 THE SOCIO-DEMOGRAPHIC CHARACTERISTICS OF THE CAREGIVERS OF THE CHILDREN WITH CP

The findings of this study show that the caregivers of CP children who participated in this study area predominantly a group of young people between the ages 30-39 years which is about 71.1% of the participants,13.3% of the participants were in the groups of 20-29 and 40-49 while 1.7% were 50 years and above (Table 4.1).This involvement of the youth has strong implications for young caregivers as they are in the productive age group in society. It is worthy to note that 90.8% (n=109) of the caregiverswho completed the questionnaires were females(refer to Figure 1) while 9.2% were males. These participating numbers of caregivers correlate with the study conducted by Wijesinghe et al., (2015) who determinedthe factors linked to caregivers’ burden for caring for children with CP in Sri Lanka. In an article by Sharma et al (2016),the authors indicated that culture and ethnicity could be the reason for the gender disparities of caregivers of children with CP.

6.2.2 The emotional burden of caring for children with CPmeasured on the ZBI

The results of the ZBI showed that 54.2% of the caregivers experienced their burden in caring for the CP children to bemild to moderate and 26.7% of the caregiversexperienced the burden of their CP children as moderate to severe. Yilmaz et al., (2013) found that the emotional status of caregivers(who were predominantly mothers) of children with CP is worse than those of mothers with healthy children. Previous studies on the caregivers' burden of care using the ZBI questionnaire showed

6.2.3 The factors that influence the burden of caringaccording to the FGD

The caregivers' burden is a multifaceted issue that can be influenced by various factors. Based on the results of the qualitative dataanalysis in this study, themes and subthemes of burden were identified that allude to physical, social, and financial challenges that were experienced by the caregivers.

It is not expensive taking of this child, as it has affected our finances (FG2; P6).

No support from anybody, instead they blame me for still taking care of my child as some had advised me earlier to abandon the child in the bush (FG5; P3).

I can't work because of my child as employers won't employ me when they hear I have a child with special needs, so I take care of my child alone(FG3; P7).

My child is 9 years old and he is not walking, I have been carrying him on my back since he was born and have back pain that I have been treated for 6 years now, there was a time I couldn't walk for 3 months because of the pain (FG1; P2).

6.2.3.1 Social Isolation

Many of the caregivers in the current study reported that their experience of social isolation (their inability to attend some functions) occurred because of the condition of their children who they could not leave at home alone or with their younger children.The stress of taking care of their children with CP sometimes in addition to other children in isolation affects the caregivers.This could be as a result of the non-acceptance of the children with CP by the community,this makes the caregiver worry about the future of their children.Most caregivers do not participate in social activities as their caregiving roles take a chunk of their time.These quotes indicate the social issues experienced by the participants;

All my activities arecentredon this child, taking care of him takes my time (FG4;P9).

My day starts and ends with my child, all I do apart from taking care of my other children who go to school is for this child (FG6; P10).

There is nowhere to keep my child, if I need to go somewhere quickly I lock her in the house and go (FG1; P2).

I can't work because of my child as employers won't employ me when they hear I have a child with special needs, so I take care of my child alone(FG3; P7).

No support from anybody, instead they blame me for still taking care of my child as some had advised me earlier to abandon the child in the bush (FG5; P3).

Nimbalker, Raithatha and Shah (2014) also found that the fear of what the future holds for the child keeps the caregivers anxious and worried and influences the caregivers negatively.Relaxation programs, counseling, and support should be provided to the caregivers in other to make their roles of taking care of the child with CP less exhaustive (Lima,Cardoso and Costa Silva, 2016).

6.2.3.2 Transportation of Children to Health Care Facilities

Lack of assistive devices such as wheelchairs for easytransport of the children left the caregivers with no other option than to carry the children on their backsto the nearest bus or taxi park.This practicein turn affected their health as some caregivers complained of chest and low back pains after carrying their children, especially when they are older and heavier.

Inadequate health care and rehabilitative facilities in the communitiesresulted in long traveling times to access the facilities which are located in the center of the city which added to the caregivers' burden of care. Moreoverfrequent transportation to the rehabilitation facility added to the financial challenges of the caregivers and as such contribute to theirincreasing experience of the burden of care (Wijesinghe, 2015). Frequent travels to the healthcare facility for other health procedures other than rehabilitation, became timeconsuming,especially if the primary caregiver was the mother who also has to care for other children and perform the house chores.An illustration of this is in the following quote:

All my activities are centredon this child, taking care of him takes my time (FG4; P9).

My day starts and ends with my child apart from taking care of my other children who go to school (FG6; P10).

I take care of everyone in the house, I do all the house chores in addition to taking care of my child with CP (FG3; P5).

6.2.3.3: Financial Burden in Caring For CP Children

From the comments of the caregivers in the current study, it was revealed that taking care of a child with CP affects the finances of the caregiver/family negatively. In this study, 85% were earning below the national minimum wage of thirty thousand naira per month (R1087/$73). The caring of a child with cerebral palsy incurs significant expenses related to ongoing medical care, rehabilitation services, and personal needs of the child such as diapers. Expenses on the transport of the children with CP to get medical assistance from the hospitals which are usually far from where they resided was indicated in this study as a contributory factor to their stress as also reported in a related study by Lawal et al. (2014). The quotes illustrate below this;

It has not been easy in terms of finance will spend a lot of money on medications and therapy (FG2; P10).

It is not expensive taking of this child, as it has affected our finances (FG2; P6).

The effect of the covid -19 pandemic on the economy of the country has increased the financial burden on the caregivers with resultant rising inflation rates which has caused a rise in the price of goods and services.These circumstances increased the financial burden on the caregivers.

6.2.3.4 Lack of Educational Opportunities

Although they were a few caregivers who did not know about the educational facilities that were available for CP children for other caregivers these facilities were too expensive to afford for their children.Some caregivers expressed their concern about the fact that their child will not be able to receive any education(Lagunju et al., 2016;Levin, 2006).This challenge is illustrated in the following quotes:

My child is not in school because I don't think he can be educated as he can't sit, stand, walk and talk (FG4; P2).

I am not aware that a child with CP can be educated so my child is not in school (FG5; P7).

*Educating a child with CP is very expensive that is if you get a school that will accept your child, I pay the regular fees for the school and also pay the facilitator that assists her with her schoolwork while in schoo*l(*FG4;P10).*

The few schools that run inclusive units are too expensive, I had to stop him from going to school because I couldn't afford it any longer(FG 1;P6).

Jeong,Jeong and Bang (2013) found out that there is a negative correlation between caregivers' burden and stress experienced in caring for children with CP.These authors recommend that support from the government and other relevant stakeholders is warranted to provide good, accessible,and affordable health, educational facilities way to ease the burden of the caregivers.

6.2.4 The magnitude of influence on the burden of care due to emotional, social, physical, and financial factors on caregivers of children with CP

This study showed that about 81% of the caregivers who participatedin this study were experiencing a high level of burden of carewhile carrying out their caregiving roles.Such a high level of burden of carecould be associated with thechildren's high dependency on the caregivers for their ADL. It is thus evident from the findings of this study that the burden of care of the caregivers of children with CPaffected the caregiversphysically, emotionally, socially, and financially. The negative effect of these factors on the caregivers makes the caregiving roles burdensome and affects them socio-economically, psychologically, emotionally as well as physically. These would in turn affect the community they belong to and the country at large because the community and the nation would be denied the input of these caregivers as their time and resources are channeled to taking of their children.

6.3 CONCLUSION

The researcher carried this study to answer the research question;” what is the caregivers’ burden of caring for children with cerebral palsy in Lagos, Nigeria? The aim was to explore the caregivers of caring for children with cerebral palsy in Lagos, Nigeria. Based on the literature review and the findings showed that raising a child with CP affects the general well-being of the caregiver, they have to deal with challenges and problems associated with their care. The caregivers of children with CP are affected emotionally and financially as a result of the condition of their childrenthis was revealed in the quantitative analyses and verified in the qualitative analyses.Recommendations that could contribute to alleviating the burden of caring for children with CP and indirectly affect the well-being of the children.

6.4 LIMITATIONS

The limited sample size of this study, the act that it was conducted in one site and one region of the country does not permit generalization of the findings to the larger population of caregivers of children with CP.

6.5 RECOMMENDATIONS

Based on the findings and the conclusions of the study, the following recommendations are proposed;

- Support groups for caregivers of children with CP should be encouraged to provide a platform to better equip the caregivers with ideas on how to carry out their caregiving roles to alleviate thecaregivers’ burden of care.
- Physiotherapists should educate the caregivers on evidence-based home care programs which would include proper positioning strategies and available social support services that will assist them in their caregiving tasks. The physiotherapists should also prescribe assistive devices that will give the child with CP independence in other to decrease the physical burden associated with carrying and manual lifting of the child.
- Community-based programsshould be established in communities nearer to where many of the caregivers live. Furthermore,community awareness programs on the challenges that caregivers of CP children experience should be created in the communities so that support structures such as schools,daycare centers, and other initiatives can be established that will assist these children and their caregivers. An awareness program

could impact positively the caregivers by reducing the stigma of having a child with disability/CP and, encouraging social support at the community level.

- Policymakers should establish affordable and well-equipped ensure more primary healthcare centersto provide rehabilitation and other medical services for children with CP to limit caregivers' traveling for long distances to access appropriate healthcare services.
- Family-centered care should be embedded in the national health care policy and must be embraced by healthcare and social service providers who provide services for children with CP and their family members. The caregivers should also be madepartners in the formulation of health policy to influence the nature and of the care thattheir childrenneeds
- The government should provide a well-structured school system both in the public and private sector with trained professionals to educate children living with CP and other developmental disabilities. The government could provide incentives to the private schools that provide educational services for children with CP.
- Adequate transportation services should be provided for caregivers to transport their children to essential services.
- Financial support from the government throughdisability grants and subsidies on the services required for children with CPshould be initiated. From the literature reviewed financial support has proven to reduce the burden of care of caregivers of children with developmental disabilities like CP(Olawale et al.,2013). The provision of assistive devices such as;wheelchairs will alleviate the burden of carrying childrenon the backof the caregiverwhich in turn would be a preventive measureto improve the health of the caregiver.
- Similar research projectsshould be conducted throughout the country to determine the influence or role of the environment on caregivers' burden of care for children with CP.The results of studies from different regionsshould be compared to the results of this study.Researchin a variety of regions throughout the country may reveal other factors that contribute to the burden of caring for children with CP than what was revealed in this study.

6.6 SUMMARY

The findings from the study show that caregivers of children with CP are faced with several challenges with the care of their child. The study highlighted the challengesthey experienced which contributed burden that thesecaregivers live with of children with CP in caring for them; the inputs needed to address these challenges were also highlighted. Financial constraints, inaccessibility to healthcare and educational services are some of the challenges that were highlighted and their effect on the burden of caring for the child with CP; the caregivers also experience physical and emotional stress. Based on the findings recommendations were proposed by the researcher to ease the burden of care.

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ANNEXURE A

Focus group interview guide

1) Describe your daily activities currently.
   Follow-up prompt: How did caring for a child with cerebral palsy change your daily activities now as compared to before? What are the major problems you face in your day-to-day upbringing of this child?
2) How do you move around with your child? (i.e. carry on your back, using a pram, personal car, bus, taxi,etc)
3) If there is a government or private health facility (i.e. clinic or hospital) how long does it take you to access the facility?
4) How difficult do you find it to access the health facility, using your car, a taxi, or a bus?
5) What type of school system is available to your child? (i.e. Montessori, public government schools, special education schools, home school)
   Follow-up: How does your child access the available school system?
6) Describe any form of support that you have in caring for your child?

ANNEXURE B

Focus group interview guide (Revised)

1) Describe your daily activities currently.
   Follow-up prompt: How did caring for a child with cerebral palsy change your daily activities now as compared to before?What are the major problemsyou face in your day-to-day upbringing of this child?
2) How do you move around with your child? (I.e. carry on your back, using a pram, personal car, bus, taxi,etc.)
3) If there is a government or private health facility(i.e. clinic or hospital) how long does it take you to access the facility?
4) How difficult do you find it to access the health facility, using your car, a taxi, or a bus?
5) Does your child attend school?
   Follow-up:What type of school system is available to your child? (I.e.Montessori, public government schools, special education schools, home school)
   Follow-up: How does your child access the available school system?
6) Describe any form of support that you have in caring for your child?

ANNEXURE C

SOCIO-DEMOGRAPHIC DATA

1. What is your sex? (a) Female [ ] (b) Male [ ]
2. What age range do you belong? (a) 20-29 [ ] (b) 30-39 [ ] (c) 40-49 [ ] (d) 50 and older[ ]
3. What is your religion? (a) Christianity [ ] (b) Islam [ ] (c) Traditional [ ] (d) Others [ ]
4. What is your ethnicity? (a) Hausa [ ] (b) Igbo [ ] (c) Yoruba [ ] (d) Others (Please specify) _______
5. What is your highest educational level? (a) Primary [ ] (b) Secondary [ ] (c) Tertiary [ ]
6. What is your occupation? (a) Professional [ ] (b) Skilled [ ] (c) Unskilled [ ]
   (d) Unemployed []
7. What is your personal monthly income (N)? (a) <7,500[ ] (b) 7,500 – 15,000 [ ] (c) 15,000 – 50,000 [ ] (d) 50,000 – 100,000 [ ] (e) 100,000 – 150,000[ ] (f) >150,000

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ANNEXURE D

THE ZARIT BURDEN INTERVIEW

0: NEVER
1: RARELY
2: SOMETIMES
3: QUITE FREQUENTLY
4: NEARLY ALWAYS

Please circle the response that best describes how you feel.

Question	**Score**
1 Do you feel that your relative asks for more help than he/she needs?	0 1 2 3 4
2 Do you feel that because of the time you spend with your relative that you don’t have enough time for yourself?	0 1 2 3 4
3 Do you feel stressed between caring for your relative and trying to meet other responsibilities for your family or work?	0 1 2 3 4

4 Do you feel embarrassed over your relative’s behavior?	0 1 2 3 4
5 Do you feel angry when you are around your relative?	0 1 2 3 4
6 Do you feel that your relative currently affects our relationships with other family members or friends in a negative way?	0 1 2 3 4
7 Are you afraid what the future holds for your relative?	0 1 2 3 4
8 Do you feel your relative is dependent on you?	0 1 2 3 4
9 Do you feel strained when you are around your relative?	0 1 2 3 4
10 Do you feel your health has suffered because of your involvement with your relative?	0 1 2 3 4
11 Do you feel that you don’t have as much privacy as you would like because of your relative?	0 1 2 3 4
12 Do you feel that your social life has suffered because you are caring for your relative?	0 1 2 3 4
13 Do you feel uncomfortable about	

having friends over because of your 0 1 2 3 4
relative?

14 Do you feel that your relative
seems to expect you to take care of
him/her as if you were the only one
he/she could depend on? 0 1 2 3 4

15 Do you feel that you don't
have enough money to take care of your
relative in addition to the rest of your
expenses? 0 1 2 3 4

16 Do you feel that you will be unable
to take care of your relative much
longer? 0 1 2 3 4

17 Do you feel you have lost control
of your life since your relative's
illness? 0 1 2 3 4

18 Do you wish you could leave the
care of your relative to someone 0 1 2 3 4
else?

19 Do you feel uncertain about what
to do about your relative? 0 1 2 3 4

20 Do you feel you should be doing 0 1 2 3 4
More for your relative?

21 Do you feel you could do a better 0 1 2 3 4
Job in caring for your relative?

22 Overall, how burdened do you feel 0 1 2 3 4
In caring for your relative?
Interpretation of Score: 0 - 21 little or no burden
21 - 40 mild to moderate burden
41 - 60 moderate to severe burden
61 - 88 severe burden

Caregiver’s initial:

ANNEXURE E

DEPARTMENT OF PHYSIOTHERAPY

REQUEST TO THE RESEARCH AND ETHICS COMMITTEE OF THE FEDERAL NEUROPSYCHIATRC HOSPITAL YABA, LAGOS,NIGERIA

Dear Sir/Madam

RE: REQUEST FOR PERMISSION TO DO RESEARCH IN THE CHILD AND ADOLESCENT CENTRE OF THE HOSPITAL

I hereby wish to apply for permission to conduct research in the physiotherapy department of the child and adolescent centre of the hospital. My research work will involve caregivers of children with cerebral palsy whose children are between ages 0 – 17 years, My research topic is **Caregivers’ burden of caring for children with cerebral palsy in Lagos,Nigeria**

The research project will involve semi-structured interviews that will be audio recorded and the filling of a questionnaire, the consent of the caregivers will be sought before they participate in the study. The information obtained will be treated with the utmost confidentiality and used solely for this study.

I presume that the research findings will make a remarkable impact in alleviating/easing the burden of care of caregivers of children with cerebral palsy.

For more information you may contact me (lilychinweakuma@gmail.com) or my supervisor, Dr .N. Mshunqane, a senior lecturer of the Faculty of Health Sciences at the University of Pretoria, South Africa (nombeko.mshuquane@up.ac.za).

Yours Sincerely

....

Akuma , Lilian

(2348035780119)

ANNEXURE F

PARTICIPANT'S INFORMATION AND INFORMED CONSENT DOCUMENT

Title of the Study: CAREGIVERS' BURDEN OF CARE FOR CHILDREN WITH CEREBRAL PALSY IN LAGOS, NIGERIA.
Researcher: AKUMA, LILIAN.C.
Address: P.O BOX 70991, Victoria Island, Lagos-Nigeria
Cell: +2348035780119
E-mail: lilychinweakuma@gmail.com

Date and time of informed consent discussion:

Day	Month	Year	Time

Dear prospective participant

1. Introduction

You are cordially invited to volunteer for a research study. I am doing the research for a fulfilment of the requirements for a Masters degree at the University of Pretoria. This information in this document is to help you to decide if you would like to participate. Before you agree to take part in this study you should fully understand what is involved. If you have any questions, which are not fully explained in this document, do not hesitate to ask the researcher. You should not agree to take part unless you are completely happy about all the procedures involved.

2. The nature and purpose of this study:

The aim/purpose of this study is to establish the factors that affect the caregivers' burden of care of children with cerebral palsy (CP).

3. Explanation of procedures and what will be expected from participant

The participants will be informed and recruited by the researcher. For this study, each participant would be required to put on a face mask, wash his/her hands before being ushered into a well-ventilated and spacious room in the physiotherapy department of the hospital where the data will be collected, each participant will sit 6 feet apart from the other. This study will involve each participant being in a group (Focus group discussion) of eight (8) participants who will be asked questions in the group and there will be an audio recording of the discussions with the consent of the participants,the FDG will be more or less 45 minutes, Also each of the participants will be required to fill out a 22 item questionnaire simultaneously, this will be completed by the participants and will be more or less 15 minutes.

4. Possible risks and discomforts involved

There are no possible risks and discomforts involved in this study.

5. Possible benefits of this study

The study will inform policymakers, healthcare professionals (Physiotherapists) on the challenges faced by caregivers of children with cerebral palsy and also raise awareness thereby creating strategies that will improve the lives of children with cerebral palsy and their caregivers.

6. Compensation

You will not be paid to take part in the study. There are no costs involved for you to be part of the study.

7. Your rights as a research participant

Your participation in this study is entirely voluntary and you can refuse to participate or stop participating at any time without stating any reasons. Your withdrawal will not affect your access to medical care. You, as a participant, may contact the researcher at any time to clarify any issues pertaining to this research. The respondent as well as the researcher must each keep a copy of this signed document.

8. Ethics approval

This protocol will be submitted to the Faculty of Health Sciences Research Ethics Committee, the University of Pretoria, telephone numbers 012 356 3084 / 012 356 3085, and written approval will be granted by that committee. The study has been structured in accordance with the Declaration of Helsinki (last update: October 2013), which deals with the recommendations guiding researchers in biomedical research involving human subjects. A copy of the Declaration may be obtained from the investigator should you wish to review it.

9. Information

If I have any questions concerning this study, I should contact: The researcher at +2348035780119 or lilychinweakuma@gmail.com.

10. Confidentiality

All information obtained during this study will be regarded as confidential. Each participant that is taking part will be provided with codes as identification. This will ensure the confidentiality of the information so collected. Your identity as a participant will not be disclosed to unauthorized people, only the researcher will be able to identify you as a participant. Results will be published or presented in such a fashion that participants remain unidentifiable. The hard copies of all your records will be kept in a locked facility at the Physiotherapy department of the University of Pretoria.

11. Consent to participate in this study

- I confirm that the person requesting my consent to take part in this study has told me about the nature and process, any risks or discomforts, and the benefits of the study.
- I have also received, read, and understood the above-written information about the study.
- I have had adequate time to ask questions and I have no objections to participating in this study.
- I also consent to the audio recording of the focus group discussions.
- I am aware that the information obtained in the study, including personal details, will be anonymously processed and presented in the reporting of results.
- I understand that I will not be penalized in any way should I wish to discontinue the study and that withdrawal will not affect my further treatments.
- I am participating willingly.
- I have received a signed copy of this informed consent agreement.

WRITTEN INFORMED CONSENT

__________________________________	_____________________
Participant’s name (Please print)	Date
__________________________________	_____________________
Participant’s signature	Date
__________________________________	_____________________
Researcher’s name (Please print)	Date
__________________________________	_____________________
Researcher’s signature	Date

VERBAL INFORMED CONSENT *(Only applicable if the respondent cannot write)*

I, the undersigned, _____________________________have read and have explained fully to the participant, named ______________________________ and his/her relatives, the informed consent document, which describes the nature and purpose of the study in which I have asked him/her to participate. The explanation I have given has mentioned both the possible risks and benefits of the study. The participant indicated that he/she understands that he/she will be free to withdraw from the study at any time for any reason and without jeopardizing his/her standard care.

I hereby certify that the participant has agreed to participate in this study.

________________________________	____________________
Participant’s name (Please print)	Date
________________________________	____________________
Participant’s signature	Date
________________________________	____________________
Researcher’s name (Please print)	Date
________________________________	____________________
Researcher’s signature	Date
________________________________	____________________
Witness’s name (Please print)	Date

Witness’s signature Date

ANNEXURE G

DECLARATION OF ORIGINALITY

UNIVERSITY OF PRETORIA

The Department of Physiotherapy places great emphasis upon integrity and ethical conduct in the preparation of all written work submitted for academic evaluation.

While academic staff teaches you about referencing techniques and how to avoid plagiarism, you too have a responsibility in this regard. If you are at any stage uncertain as to what is required, you should speak to your lecturer before any written work is submitted.

You are guilty of plagiarism if you copy something from another author's work (e.g. a book, an article, or a website) without acknowledging the source and passing it off as your own. In effect, you are stealing something that belongs to someone else. This is not only the case when you copy work word-for-word (verbatim), but also when you submit someone else's work in a slightly altered form (paraphrase) or use a line of argument without acknowledging it. You are not allowed to use work previously produced by another student. You are also not allowed to let anybody copy your work to pass it off as his/her work.

Students who commit plagiarism will not be given any credit for plagiarised work. The matter may also be referred to the Disciplinary Committee (Students) for a ruling. Plagiarism is regarded as a serious contravention of the University's rules and can lead to expulsion from the University.

The declaration which follows must accompany all written work submitted while you are a student of the Department of physiotherapy. No written work will be accepted unless the declaration has beencompleted and attached.

Full names of students: Akuma Lilian

Student number: u20803789

Declaration

1. IunderstandwhatplagiarismisandamawareoftheUniversity'spolicyinthisregard.
2. I declare that this dissertation titled: Caregivers' burden of caring for children with cerebral palsy in Lagos,Nigeriais myoriginal work. Where other people's work has been used (either from a printed source, Internet or any other source), this has been properly acknowledged and referenced in accordance with departmental

requirements.

3. I have not used work previously produced by another student or any other person to hand in as my own.
4. I have not allowed, and will not allowanyone to copy my work with the intention of passing it off as his or he work.

SIGNATUREOF STUDENT ....

SIGNATUREOFSUPERVISOR………………………………………………………………………

ANNEXURE H

Declaration for the storage of research data and/or documents

I/ We, the principal researcher(s) AkumaLilian ______________________.and supervisor(s) ____

of the following study, titled Caregivers' burden of caring for children with cerebral palsy in Lagos,Nigeria ____________________________will be storing all the research data and/or documents referring to the above-mentioned study in the following

Department / Centre: ____

We understand that the storage of the mentioned data and/or documents must be maintained for a minimum of 10 years from the commencement of this study.

Start date of study: ____

Anticipated end date of study:____

Yearuntil which data will be stored: ____

Name of Principal Researcher(s)	Signature	Date

Name of Supervisor(s)	Signature	Date

Name of Head of Department	Signature	Date

ANNEXURE I

HELSINKI DECLARATION

All Researchers

Please note that all researchers must from today, sign the attached declaration, when handing in a protocol at the Faculty of Health Sciences Research Ethics Committee - University of Pretoria.

WORLD ASSOCIATION DECLARATION OF HELSINKI
Ethical Principles
For
Medical Research Involving Human Subjects

Adopted by the 18th WMA General Assembly

Helsinki, Finland, June 1964

And amended by the

29th WMA General Assembly, Tokyo, Japan, October 1975

35th WMA General Assembly, Venice, Italy, October 1983

41st WMA General Assembly, Hong Kong, September 1989

48th WMA General Assembly, Somerset West, Republic of South Africa, October 1996

and the

52nd WMA General Assembly, Edinburgh, Scotland, October 2000

A. INTRODUCTION

1. The World Medical Association has developed the Declaration of Helsinki as a statement of ethical principle to provide guidance to physicians and other participantsin medical research involving human subjects. Medical research involving human subjects includes research on identifiable human material or identifiable data.

2. It is the duty of the physician to promote and safeguard the health of the people. The physician's knowledge and conscience are dedicated to the fulfilment of this duty.

3. The Declaration of the Geneva of the World Medical Association binds the physician with the words, "The health of my patient will be my first consideration," and the International Code Medical Ethics declares that, "A physician shall act only in the patient's interest when providing medical care which might have the effect of weakening the physical and mental condition of the patient."

4. Medical progress is based on research which ultimately must rest in part on experimentation involving human subjects.

5. In medical research on human subjects, considerations related to the wellbeing of the human subject should take precedence over the interests of science and society.

6. The primary purpose of medical research involving human subjects is to improve prophylactic, diagnostic, and therapeutic procedures and the understanding of the etiology and pathogenesis of the disease. Even the best proven prophylactic, diagnostic, and therapeutic methods must continuously be challenged through research for their effectiveness, efficiency, accessibility, and quality.

7. In the current medical practice and medical research, most prophylactic, diagnostic, and therapeutic procedures involve risks and burdens.

8. Medical research is subject to ethical standards that promote respect for all human beings and protect their health and rights. Some research population is vulnerable and need special protection. The particular needs of the economically and medically advantaged must be recognized. Special attention is also required for those who cannot give us or refuse consent for themselves, for those who may be subject to giving consent under duress, for those who will not benefit personally from the research, and for those for whom the research is combined with care.

9. Research investigators should be aware of the ethical, legal, and regulatory requirements for research on human subjects in their own countries as well as applicable international requirements. No national ethical, legal or regulatory requirements should be allowed to reduce or eliminate any of the protections for human subjects set forth in this Declaration.

B. BASIC PRINCIPLES FOR ALL MEDICAL RESEARCH

10. It is the duty of the physician in medical research to protect the life, health, privacy, and dignity of the human subject.

11. Medical research involving human subjects must conform to the generally accepted scientific principles, be based on the thorough knowledge of the scientific literature, other relevant sources of information, and on adequate laboratory and, where appropriate, animal experimentation.

12. Appropriate caution must be exercised in the conduct of research that may affect the environment, and the welfare of animals used for research must be respected.

13. The design and performance of each experimental procedure involving human subjects should be clearly formulated in an experimental protocol. This protocol should be submitted for consideration, comment, guidance, and where appropriate, approval to a specially appointed ethical review committee, which must be independent of the investigator, the sponsor or any other kind of undue influence. This independent committee should be in conformity with the laws and regulations of the country in which the research experiment is performed. The committee has the right to monitor ongoing trials. The researcher has t obligation to provide monitoring information to the committee, especially any serious adverse events. The researcher should also submit

to the committee, for review, information regarding funding, sponsors, institutional affiliations, other potential conflicts of interest, and incentives for subjects.

14. The research protocol should always contain a statement of the ethical considerations involved and should indicate that there is compliance with the principles enunciated in this Declaration.

15. Medical human research involving subjects should be conducted only by scientifically qualified persons and under the supervision of a clinically competent medical person. The responsibility for the human subject must always rest with a medically qualified person and never rest on the subject of the research, even though the subject has given consent.

16. Every medical research project involving a human subject should be preceded by careful assessment of predictable risk and burdens in comparison with foreseeable benefits of the subject or to others. This does not preclude the participation of healthy volunteers in medical research. The design of all studies should be publicly available.

17. Physicians should abstain from engaging in a research project involving human subjects unless they are confident that the risk involved has been adequately assessed and can be satisfactorily managed. Physicians should cease any investigations if the risks are found to outweigh the potential benefits or if there is conclusive proof of positive and beneficial results.

18. Medical research involving human subjects should only be conducted if the importance of the objective outweighs the inherent risks and burdens of the subject. This is especially important when the human subjects are healthy volunteers.

C. ICH GUIDELINE FOR GOOD CLINICAL PRACTICE

1. Clinical trials should be conducted in accordance with the ethical principles that have their origin in the Declaration of Helsinki, and that are consistent with GCP and the applicable regulatory requirement(s).

2. Before a trial is initiated, foreseeable risk and inconvenience should be outweighed against the anticipated benefit for the individual trial subject and society. A trial should be initiated and continued if the anticipated benefits justify the risk.

3. The rights, safety, and wellbeing of the trial subjects are the most important considerations and should prevail over the interest of science and society.
4. The available non-clinical and clinical information on an investigational product should be adequate to support the proposed clinical trials.
5. Clinical trials should be scientifically sound and described in a clear, detailed protocol.A trial should be conducted in compliance with the protocol that was received prior Institutional review board (IRB)/independent ethics committee (IEC) approval/ favourable opinion.
6. The medical care given to, and medical decisions made on behalf of, subjects should always be the responsibility of the qualified physician or, when appropriate, of a qualified dentist.
7. Each individual involved in conducting a trial should be qualified by education, training, and experience to perform his or her respective task(s).
8. Freely given informed consent should be obtained from every subject prior to clinical trial participant.
9. All clinical trial information should be recorded, handled, and stored in a way that allows accurate reporting, interpretation, and verification.
10. The confidentiality of records that could identify subjects should be protected, respecting the privacy and confidentiality rules in accordance with the applicable regulatory requirement(s).
11. Investigational products should be manufactured, handled, and stored in accordance with applicable good manufacturing practices (GMP).They should be used in accordance with the approved protocol.
12. Systems with procedures that assure the quality of every aspect of the trial should be implemented.

Full names of student: Lilian Akuma-u20803789

The topic: Caregivers' Burden of Care of Children with Cerebral Palsy in Lagos, Nigeria

Declaration

I declare that the study will follow all ethical guidelines and standards set by theethics committee. All participants will be given informed consent to sign and all the records will be kept confidential. No participant will be subjected to any harm and they will be informed that they can withdraw from the study at any point with no implications.

Signature………………………………………………………………………………………

ANNEXURE J

23 October 2020

Approval Certificate

New Application

Ethics Reference No.: 615/2020
Title: Caregivers' burden of caring for children with cerebral palsy in Lagos,Nigeria

Dear Mrs LC Akuma

UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA

Faculty of Health Sciences

Institution: The Research Ethics Committee, Faculty Health Sciences, University of Pretoria complies with ICH-GCP guidelines and has US Federal wide Assurance.

- FWA 00002567, Approved dd 22 May 2002 and Expires 03/20/2022.
- IORG #: IORG0001762 OMB No. 0990-0279 Approved for use through February 28, 2022 and Expires: 03/04/2023.

The **New Application** as supported by documents received between 2020-09-23 and 2020-10-21 for your research, was approved by the Faculty of Health Sciences Research Ethics Committee on 2020-10-21 as resolved by its quorate meeting.

Please note the following about your ethics approval:

- Ethics Approval is valid for 1 year and needs to be renewed annually by 2021-10-23.
- Please remember to use your protocol number (615/2020) on any documents or correspondence with the Research Ethics Committee regarding your research.
- Please note that the Research Ethics Committee may ask further questions, seek additional information, require further modification, monitor the conduct of your research, or suspend or withdraw ethics approval.

Ethics approval is subject to the following:

- The ethics approval is conditional on the research being conducted as stipulated by the details of all documents submitted to the Committee. In the event that a further need arises to change who the investigators are, the methods or any other aspect, such changes must be submitted as an Amendment for approval by the Committee.

Additional Conditions:

- Approval is conditional upon the Research Ethics Committee receiving permission from the Nigerian Health

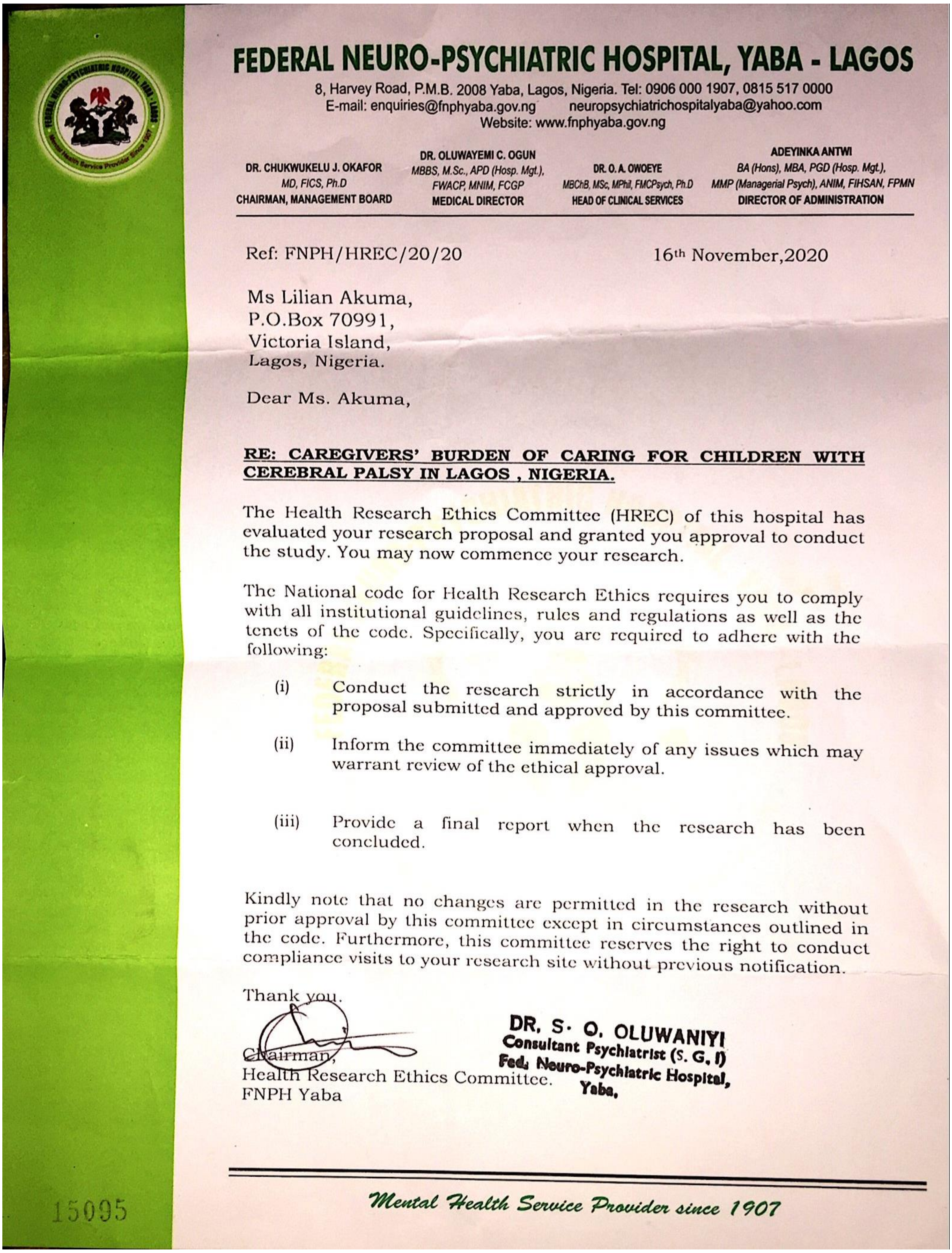
Institute. We wish you the best with your research.

Yours sincerely

Dr R Sommers
MBChB MMed (Int) MPharmMed PhD
Deputy Chairperson of the Faculty of Health Sciences Research Ethics Committee, University of Pretoria

The Faculty of Health Sciences Research Ethics Committee complies with the SA National Act 61 of 2003 as it pertains to health research and the United States Code of Federal Regulations Title 45 and 46. This committee abides by the ethical norms and principles for research, established by the Declaration of Helsinki, the South African Medical Research Council Guidelines as well as the Guidelines for Ethical Research: Principles Structures and Processes, Second Edition 2015 (Department of Health).

ANNEXURE K



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DR. CHUKWUKELU J. OKAFOR *MD, FICS, Ph.D* **CHAIRMAN, MANAGEMENT BOARD**	**DR. OLUWAYEMI C. OGUN** *MBBS, M.Sc., APD (Hosp. Mgt.), FWACP, MNIM, FCGP* **MEDICAL DIRECTOR**	**DR. O. A. OWOEYE** *MBChB, MSc, MPhil, FMCPsych, Ph.D* **HEAD OF CLINICAL SERVICES**	**ADEYINKA ANTWI** *BA (Hons), MBA, PGD (Hosp. Mgt.), MMP (Managerial Psych), ANIM, FIHSAN, FPMN* **DIRECTOR OF ADMINISTRATION**

Ref: FNPH/HREC/20/20 16th November,2020

Ms Lilian Akuma,
P.O.Box 70991,
Victoria Island,
Lagos, Nigeria.

Dear Ms. Akuma,

RE: CAREGIVERS' BURDEN OF CARING FOR CHILDREN WITH CEREBRAL PALSY IN LAGOS , NIGERIA.

The Health Research Ethics Committee (HREC) of this hospital has evaluated your research proposal and granted you approval to conduct the study. You may now commence your research.

The National code for Health Research Ethics requires you to comply with all institutional guidelines, rules and regulations as well as the tenets of the code. Specifically, you are required to adhere with the following:

(i) Conduct the research strictly in accordance with the proposal submitted and approved by this committee.

(ii) Inform the committee immediately of any issues which may warrant review of the ethical approval.

(iii) Provide a final report when the research has been concluded.

Kindly note that no changes are permitted in the research without prior approval by this committee except in circumstances outlined in the code. Furthermore, this committee reserves the right to conduct compliance visits to your research site without previous notification.

Thank you.

DR. S. O. OLUWANIYI
Consultant Psychiatrist (S. G. I)
Fed. Neuro-Psychiatric Hospital,
Yaba.

Chairman,
Health Research Ethics Committee.
FNPH Yaba

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