

KWAME NKRUMAH UNIVERSITY OF SCIENCE AND TECHNOLOGY,
KUMASI, GHANA

ANALYZING THE LIVED EXPERIENCES OF PRIMARY CAREGIVERS OF
CHILDREN WITH CEREBRAL PALSY ATTENDING THE KORLE-BU
TEACHING HOSPITAL IN THE GREATER ACCRA REGION, GHANA

By

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Master of Science

(Disability, Rehabilitation and Development)

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DECLARATION

I hereby declare that this thesis is my own work towards the fulfilment of the requirements for the award of the Master of Science in Disability, Rehabilitation and Development and that, to the best of my knowledge, it contains no material which has been accepted for the award of any other degree of the University, except where due acknowledgement has been made in the text.

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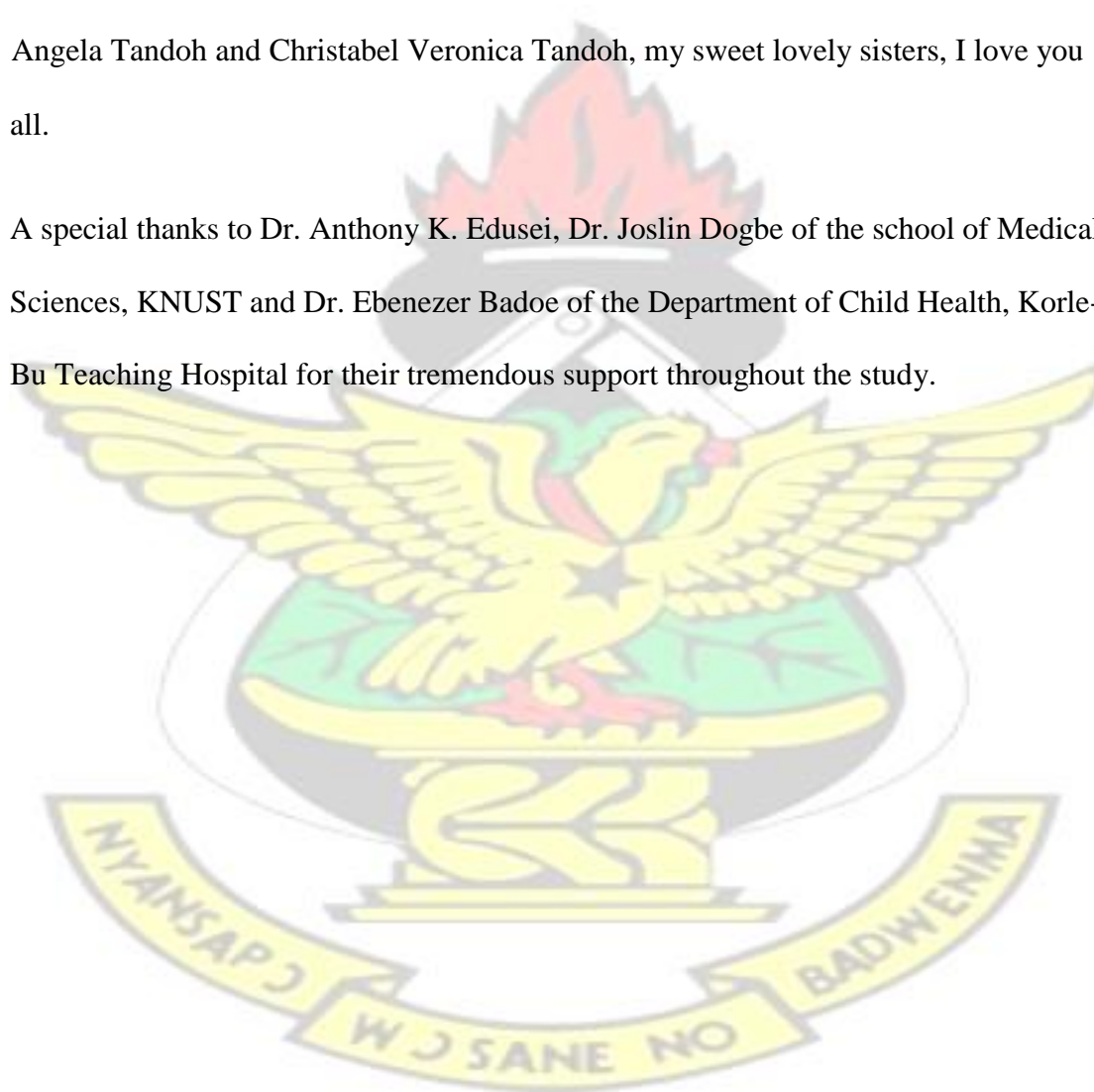
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DEDICATION

I dedicate this work to the almighty god, to Mr. Kofi Anane Kyeremateng, my lovely husband, Mr. John Kofi Tandoh and Mrs Veronica Celattia Tandoh, my lovely and dedicated parents, Benedicta Edna Amoah, Elizabeth Frances Aba Tandoh, Marian Angela Tandoh and Christabel Veronica Tandoh, my sweet lovely sisters, I love you all.

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ABSTRACT

Cerebral palsy presents in early childhood as a set of functional limitations that stem from disorders of the developing central nervous system. It is a non-progressive disorder that results from an anoxic brain injury to the foetal or new born brain. Because this disorder can cause disability ranging from mild to severe effects on motor and cognitive functioning, the diagnosis can vary from one child to another, causing family stress due to vague and unknown predicted outcomes of the disorder. The diagnosis of cerebral palsy affects families in different ways depending on coping mechanisms, support systems, and age and level of functioning of the child among other factors, it is therefore important to assess the experiences of their caregivers. This study reports on the lived experiences of primary caregivers of children with cerebral palsy attending the Korle Bu Teaching Hospital in the Greater Accra Region of Ghana. The study utilized a phenomenological approach to look at primary caregivers as the best-informed authority to explore and describe their lived experiences of caring for their child with cerebral palsy. In this qualitative study, forty (40) primary caregivers of children with cerebral palsy were interviewed regarding their experiences before the diagnosis of the condition, during the diagnostic process and post diagnostic experiences. Semi-structured, in-depth, face to face interviews and participant observation were the methods used for data collection. Narratives of 40 participants were transcribed and analysed using thematic coding. The themes and categories that resulted from the content analysis were under three broad fields of experiences namely: Experiences before the diagnosis of the condition, experiences during the diagnosis of the condition and experiences after the diagnosis of the condition. In terms of experiences before the diagnosis, two themes emerged: (1) Confronted with a situation of a child with an abnormality as a new mother, (2) Breaking out of the superstitious beliefs. Regarding experiences during the diagnostic process, three themes emerged: (1) Issues of blame and responsibility (2) Confusion and mistrust with helping professionals (3) mixed feelings about the diagnosis. Four themes emanated from the experiences after the diagnosis of the condition namely: (1) strained family relations (2) Experience of poverty (3) Experience of loss of social life (4) The challenge with finding educational resources and day-care. It is recommended that future research should expand beyond the scope of this work and include caregivers of children with different types of disability.

TABLE OF CONTENTS

DECLARATION.....	iv
ii DEDICATION.....	
iii ABSTRACT	
.....	iv
TABLE OF CONTENTS	v
LIST OF TABLES	viii
CHAPTER ONE	
1	
INTRODUCTION.....	
1	
1.1 BACKGROUND OF THE STUDY	
1	
1.2 STATEMENT OF THE PROBLEM	
4	
1.3 RESEARCH QUESTIONS	
5	
1.4 RESEARCH OBJECTIVES	
6	
1.5 RATIONALE/ SIGNIFICANCE OF THE STUDY	
6	
CHAPTER TWO	
8 LITERATURE REVIEW	8
.....	
2.1 INTRODUCTION	
8	
2.2 DEFINITION OF CEREBRAL PALSY.....	
8	
2.3 CURRENT AREAS OF RESEARCH IN CEREBRAL PALSY AND IMPLICATIONS FOR CAREGIVING	11
2.4 THE EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY BEFORE THE DIAGNOSIS OF THE CONDITION	18
2.5 THE EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY DURING THE DIAGNOSIS OF THE CONDITION	18
2.6 THE EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY AFTER THE DIAGNOSIS OF THE CONDITION	21

CHAPTER THREE	
25 METHODOLOGY	25
3.1 INTRODUCTION	25
3.2 STUDY TYPE AND DESIGN	25
3.3 PROFILE OF THE STUDY AREA	26
3.4 STUDY PARTICIPANTS	26
3.5 DATA COLLECTION TECHNIQUES AND TOOLS	27
3.6 SAMPLING TECHNIQUE AND SAMPLE SIZE	28
3.7 PRE-TESTING.....	29
3.8 DATA HANDLING AND STORAGE.....	29
3.9 DATA MANAGEMENT AND ANALYSIS	29
3.10 ETHICAL CONSIDERATIONS	30
3.11 DISSEMINATION.....	31
3.12 LIMITATION OF THE STUDY	31
3.13 ASSUMPTIONS	31
CHAPTER FOUR	
32 RESULTS	32
4.1 INTRODUCTION	32
4.2 SOCIODEMOGRAPHIC CHARACTERISTICS OF PRIMARY CAREGIVERS	33
4.3 EXPERIENCES OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY BEFORE THE DIAGNOSIS OF THE CONDITION OF THEIR CHILD	35

4.3.1 Confronted with a situation of a child with an abnormality as a new mother.	35
4.3.2 Breaking out of the superstitious beliefs	37
4.4 EXPERIENCES OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY DURING THE DIAGNOSTIC PROCESS OF THE CONDITION OF THEIR CHILD	40
4.4.1 Issues of blame and responsibility	40
4.4.2 Confusion and mistrust with helping professionals	41
4.4.3 Mixed feelings about the diagnosis	42
4.5 EXPERIENCES OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY AFTER THE DIAGNOSIS OF THE CONDITION OF THEIR CHILD.....	46
4.5.1 Strained family relations	46
4.5.2 Experiences of poverty	51
4.5.3 Experience of the loss of social life	55
4.5.4 The challenge with finding educational resource and day-care	56
CHAPTER FIVE	58
58 DISCUSSION	58
5.1. SOCIO-DEMOGRAPHIC CHARACTERISTICS OF PRIMARY CAREGIVERS	58
5.2 EXPERIENCES OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY BEFORE THE DIAGNOSIS OF THE CONDITION OF THEIR CHILD	59
5.2.1 Confronted with a situation of a child with an abnormality as a new mother	59
5.2.2 Breaking out of the superstitious beliefs	60
5.3 EXPERIENCES OF PRIMARY CAREGIVERS OF CHILDREN WITH	

CEREBRAL PALSY DURING THE DIAGNOSTIC PROCESS OF THE CONDITION OF THEIR CHILD	61
5.3.1 Issue of blame and responsibility	61
5.3.2 Confusion and mistrust with helping professionals	62
5.3.3 Mixed feelings about the diagnosis	63
5.4 EXPERIENCES OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY AFTER THE DIAGNOSIS OF THE CONDITION OF THEIR CHILD.....	64
5.4.1 Strained family relations	64
5.4.2 Experience of Poverty	66
5.4.3 Experience of loss of social life	67
5.4.4 The challenge with finding educational resource and day-care	67
CHAPTER SIX	
69 CONCLUSION AND RECOMMENDATIONS	69
6.1 CONCLUSION	69
6.2 RECOMMENDATION	72
REFERENCES	
74 APPENDICES	86
LIST OF TABLES	
Table 4.1: Distribution of Socio-demographic characteristics of respondents	33

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CHAPTER ONE

INTRODUCTION

1.1 BACKGROUND OF THE STUDY

Good health is a prerequisite for participation in a wide range of activities including education and employment. Article 25 of the United Nations Convention on the Rights of Persons with Disabilities (CRPD) reinforces the rights of persons with disabilities to attain the highest standard of health care, without discrimination.

A wide range of factors determine health status, including individual factors, living and working conditions, general socioeconomic, cultural and environmental conditions, and access to healthcare services (WHO, 2008). The world disability report (2011) shows that many people with disabilities experience worse socioeconomic outcomes than people living without disabilities; they experience higher rates of poverty, lower employment rates, and have less education. They also have unequal access to health care services and therefore have unmet health care needs compared with the general population. This situation becomes worsened with children with disabilities because they depend on their parents and family totally for care (ibid).

Current systems of care for children with disabilities depend on parents being willing and able to adopt unexpected „informal caregiving careers“, roles that typically span the course of a child’s life (Raina et al. 2004). As informal caregivers, parents provide long-term care that often requires extraordinary physical, emotional, social and financial resources. In addition to being responsible for physical care of their child, they must co-ordinate their child’s numerous and multifaceted medical, education and developmental interventions while balancing competing family needs (Silver et al.

1998).

Parent caregivers of children with disabilities struggle to meet the needs of their entire family by balancing the needs of their child, other family members, and themselves. They may face challenges such as financial burden, sibling rivalry, stigma, self-doubt and blame, marital stress, and difficulty accessing services, in addition to dealing with the symptoms their child is experiencing (Commonwealth Institute, 1999). Family caregivers have been described as stressed, with the potential of having more problems than the persons for whom they care (Lefley, 1997). If parents are not healthy and supported, they may not be able to provide themselves, their child, and the rest of their family with the best possible care.

Cerebral palsy, the most common cause of physical childhood disability, is a nonprogressive disorder that results from an anoxic brain injury to the foetal or new born brain (Shelly et al., 2008; Varni et al., 2005). Because this disorder can cause disability, ranging from mild to severe effects on motor and cognitive functioning, the diagnosis can vary from one child to another, causing family stress due to vague and unknown predicted outcomes of the disorder. Because the diagnosis of cerebral palsy affects families in different ways depending on coping mechanisms, support systems, and the age and level of functioning of the child, among other factors, it is important to assess the experiences of their caregivers.

Cerebral palsy presents in early childhood as a set of functional limitations that stem from disorders of the developing central nervous system (Bax, 1964). It is estimated that the worldwide population of cerebral palsy patients has exceeded 15,000,000

(Capute et al, 2008, Winster, 2002). Cerebral Palsy Africa (CPA), a non- governmental organization estimates that 1 per 300 births have cerebral palsy in Ghana. The main feature of cerebral palsy is impaired motor function. In addition, many children with cerebral palsy experience sensory and intellectual impairments, and sometimes have complex limitations in self- care functions such as feeding, dressing, bathing and mobility. These limitations can result in the need for long-term care far exceeding the usual needs of developing children (Breslau, 1982; Blacher, 1984).

Being a developmental disability, Cerebral palsy is likely to continue indefinitely in the life of the growing child. This means that, caregivers of children with cerebral palsy also acquire an informal work with indefinite ending. In effect, cerebral palsy does not only affect the children alone but rather have a daunting impact on their primary caregivers too.

In Ghana, disability is found to be a seriously stigmatizing condition due to the cultural beliefs attached (Tinney, Chiodo, Haig, & Wiredu, 2007; Avoke, 2002). In this regard, disability by birth or in the course of life is usually interpreted as punishment from God or the gods for one's wrong doing, that of a family member or by the community (Avoke, 2002; Kassah, 1998). In some cases, people with disabilities are hidden by family members from the wider community (Kassah, 1998). Even in extreme cases, children with disabilities are killed to avoid the shame it brings to the family (Avoke, 2002). Disability is also seen as a result of witchcraft, socery, „juju“ and magic (Avoke, 1997; Agbenyaga, 2003). Some Ghanaians believe that people with epilepsy are filled with demons that sometimes torment and throw them on the ground, when they so wish

(Agbenyaga, 2002), also persons with Down's syndrome and Cerebral Palsy in Ghana are believed to be children given by the river god, and hence called „Nsuoba“, meaning „water children“ (Avoke, 1997). These beliefs have impact on the lives of those with disabilities as well as their families. The issue of care for people with severe disability is emotion - laden because of the consequences attached in doing so. Amidst the superstitious interpretations of disability in the Ghanaian culture, primary caregivers of children with cerebral palsy also face the same amount of stigmatization, discrimination and abandonment in the society as their children with disabilities.

1.2 STATEMENT OF THE PROBLEM

Over the past two decades, issues on disability have received so much attention around the globe and every developing country in one way or the other is trying to understand this paradigm shift. The United Nations and its related agencies in their bit to make this confusion easier to deal with, has introduced laws and conventions to protect the rights of Persons with Disabilities (PWDs) around the world.

The increasing population of children with disabilities (cerebral palsy) indirectly indicates an increasing population of caregivers for these children but very little attention in the form of research has been given to these caregivers in the history of disability. Literature search shows that research on children with cerebral palsy and their primary caregivers in Ghana is barely existent. This was confirmed by search conducted using key international database such as the Cumulative Index to Nursing and Allied Health Literature (CINAHL), Education Resources Information Center (ERIC) and psychINFO. The big question this study eventually seeks to answer is:

“Who is caring for the Caregiver?” Thus, this study seeks to explore the issue of caregiving by investigating the lived experiences of primary caregivers of children with cerebral palsy, focusing on caregivers’ own perspective. It thus seeks to increase the knowledge about what it means to have and live with a child with Cerebral Palsy in the Ghanaian Context.

It is therefore, worth investigating the experiences of caregivers of children with different types of disabilities to understand the differences and similarities of their experiences. However, due to logistic and time constraints, partly due to the fact that this work is part of the requirement to meet for award of Masters in Disability, Rehabilitation and Development, the researcher has decided to focus on the lived experiences of primary caregivers of children with cerebral palsy attending the neurodevelopmental clinic in the Korle Bu Teaching Hospital in the Greater Accra Region of Ghana. This is also because these participants can be readily available to her. However, it will be recommended that future research should expand beyond this work and include caregivers of children with different types of disability and address this limitation of this work.

1.3 RESEARCH QUESTIONS

- a) What experiences do primary caregivers of children with cerebral palsy have before the diagnosis of the condition of their child?
- b) How do primary caregivers of children with cerebral palsy experience the diagnostic process?
- c) What experiences do primary caregivers of children with cerebral palsy have after the diagnosis of the condition of the child?

1.4 RESEARCH OBJECTIVES

Principal Objective:

The study aims to explore and describe the experiences of the primary caregivers of children with cerebral palsy attending the Korle Bu Teaching Hospital in the Greater Accra region of Ghana, before diagnosis, analyze their experiences during the diagnostic process, and how they adjust in different areas of family life after the diagnosis has been made.

Specific Objectives:

- a) To describe the lived experiences of the primary caregivers of children with Cerebral Palsy before the diagnosis.
- b) To analyze the experiences primary caregivers of children with Cerebral Palsy go through during the diagnosis
- c) To examine the experiences of primary caregivers of children with Cerebral Palsy after the diagnostic process

1.5 RATIONALE/ SIGNIFICANCE OF THE STUDY

The increasing number of children diagnosed with cerebral palsy indirectly is increasing the number of primary caregivers for these children, yet very little research has been done in this area; creating a big research gap in Ghana. Many career mothers are gradually being drawn from their careers to assume these „informal career“ roles with the acquisition of these neurodevelopmental problems in their homes. To a greater extent in the development arena, the nation’s economy is indirectly affected with this change in roles as productive man-hours at workplaces are gradually being switched to

this unrecognised role of caregiving. However, this situation has received very little attention in Ghana. In order to avert these and other unidentified consequences, it is very important to carry out this study to contribute in minimizing the gap created in and add on to the general body of knowledge of research in the experiences of primary caregivers of children with cerebral palsy in Ghana. Secondly, the study will inform policy makers on appropriate policies that would include the wellbeing of caregivers and identify them as informal service providers. Finally, the research will inform the academia about the need for further evidence based research on experiences of caregivers and subsequently lead to the development of appropriate training programmes for them.



CHAPTER TWO

LITERATURE REVIEW

2.1 INTRODUCTION

This chapter explores available literature on the lived experiences of primary caregivers of children with cerebral palsy. This involves reading and gathering information from other published works that closely support the current study. The review of literature looked at some relevant works on cerebral palsy and caregiving. The reviewed literature is categorized on various thematic areas based on the objective of the study.

2.2 DEFINITION OF CEREBRAL PALSY

Cerebral palsy is the term used to describe a range of non-progressive syndromes of posture and motor impairment that results from an insult to the developing central nervous system (Koman, Smith, and Shilt, 2004).

The first documented history of cerebral palsy dates back to 1843, when an English surgeon named Dr. William John Little came across a puzzling condition that affected young children. Cerebral palsy has been described as one of the most common causes of severe physical disabilities in children. Cerebral palsy is caused by irreversible brain lesions occurring before, during or shortly after birth (Mecham, 1996). In the literature, cerebral palsy is defined as „an umbrella term covering a group of nonprogressive, but often changing, motor impairment syndromes secondary to lesions or anomalies of the brain arising in the early stages of its development“ (Mutch, Alberman, Hagberg, Kodama, Perat, 1992, p.9). It may range from mild to severe, with 50-75% of affected individuals suffering from mental impairment (Mecham, 1996). Cerebral palsy may be characterized by spasticity, movement disorders, muscle weakness, ataxia, and/or

rigidity (Koman et al, 2004); however, the peripheral manifestations of cerebral palsy depend on the magnitude, extent and location of the insult to the brain, brainstem or spinal cord (Kuban and Leviton, 1994). Damage to the immature central nervous system may occur during the following phases of development (Bax and Brown, 2004):

- Prenatally (due to brain haemorrhage, maternal infection, or environmental factors such as maternal exposure to radiation),
- Perinatally (due to birth asphyxia), or
- Postnatally (due to head injury, infection, or anoxia).

Other factors associated with cerebral palsy include rhesus incompatibility, chorioamnionitis, maternal infection, antepartum vaginal bleeding, second stage labour lasting more than four hours, untreated hyperbilirubinaemia, fetal anoxic events, and fetal infection, such as meningitis (Nelson and Grether, 1999).

The cerebral palsies have been variously classified but for the purpose of this study, classifications as described by Love and Webb (2001) will be used:

- Spastic cerebral palsy as a result of damage to the pyramidal tracts, and may present as paraplegia, diplegia, quadriplegia, hemiparesis or monoplegia.
- Athetoid cerebral palsy as a result of damage to the basal ganglia and may affect the arms, legs, neck and/or trunk
- Ataxic cerebral palsy as a result of damage to the cerebellum and may affect the arms, legs and/or trunk.

Although these classification systems exist, the presentation of cerebral palsy is not always clear-cut, and thus children with cerebral palsy frequently have mixed

presentation and may present with associated impairments (Bax and Brown, 2004). Pimm (1996) states that cerebral palsy affects the motor system, and often other systems controlled by the brain. The associated impairments may include speech, language, feeding, oro-dental, visual, cognitive, hearing or behavioural impairments. Koman et al (2004) state that more than 50% of persons affected by cerebral palsy are able to walk without assistance, while 25% require assistance and a further 25% are immobile and rely on others to move them. Neurological problems are common with 50-75% of persons affected by cerebral palsy presenting with mental retardation, the condition being accompanied by seizures in 35% of cases, sensory impairment in 97% of cases, hydrocephalus in 9% of cases, visual impairment in 20-40% of cases, and urinary incompetence in 23% of cases (Hutton and Pharoah, 2002). Patterns of spasticity with resultant muscle imbalance can result in muscle shortening, joint contractures, bony deformities and/or joint dislocation. Secondary impairments, such as drooling and facial grimacing associated with effortful movement may also develop (Mecham, 1996). Additionally, the individual with cerebral palsy may suffer from functional abnormalities as a result of impaired muscle tone. These may include breathing impairments as a result of deviations in the position, size, and shape of the larynx; and/or an abuse of contractures in the tongue, lip and jaw, which may affect language in terms of expressive output, and speech in terms of dysprosody (Hardy, 1994).

Diagnosis of cerebral palsy is made by taking a complete case history, physical examination and ancillary examinations. According to Feldman, Haley and Coryell (1990) assessment of children with cerebral palsy should include a detailed case history including an account of gestation and peri-natal events, as well as an account of

developmental milestones. In addition to the physical examination, assessment should be made of muscle tone, static balance, spinal alignment, range of motion of joints, and the presence of limb deformity. In addition, MRI scans, CT scans and cranial ultrasonography can be used to assess the extent of CNS damage.

While there is no cure available for cerebral palsy, if appropriate healthcare is available, children affected by cerebral palsy without significant co-morbidities have normal-to-near-normal life expectancies (Koman et al, 2004). However, mortality is higher and lifespan is shorter in children with severe physical impairment, hydrocephalus, lack of basic functional skills, seizures and profound mental retardation.

2.3 CURRENT AREAS OF RESEARCH IN CEREBRAL PALSY AND IMPLICATIONS FOR CAREGIVING

Having reviewed the current literature regarding cerebral palsy, a number of themes have emerged in terms of areas of research. One common area of research is the area of assessment of quality of life and functional abilities of persons with cerebral palsy (Schneider *et. al.*, 2001). In the past, research into the developmental framework of assessment dominated (Haley, 1994). This framework was based on the belief that interventions should be directed at helping children attain sequential developmental positions and move normally within them (Nelson, 1995). These assessments were abundant in their descriptive nature and their explanations of abnormality decidedly shaped therapeutic practice (Haley, 1994). Clinicians, however, realised that assessment needed to be tied more closely to function, rather than evaluating the child's ability to attain motor milestones. Thus the focus of research moved towards measuring function and the ability to complete activities of daily living at home and in the community (Haley, 1994; Nelson, 1995). More recently, studies have moved towards researching

the condition not only in terms of physical functioning, but also in terms of the condition in relation to the body, the psyche and the way in which the person relates to society (Mweshi and Mpofu, 2001). This is in line with research conducted by medical anthropologist, Leavitt (1992) who notes that medical approach to the management of cerebral palsy lacks a framework for understanding the dimensions of disablement and functioning at the level of the body, the person, and the whole society as a whole.

Recently, several initiatives have focused attention on caregivers' health as an area requiring further research. A recent revision of the World Health Organisation International Classification of Functioning, Disability, and Health framework stresses the environment as critical to health and well-being (WHO, 2005). This framework highlights the important relationship between the health of the caregiver and the health of the child. Additionally, there has been a shift in healthcare delivery away from child-centered models that focus primarily on treating the disability, to family-centered models (Rosenbaum *et. al.*, 1998; Viscardis, 1998). This shift recognises the primary role of the family in child development, but may also serve to increase the demands on family members by requiring them to be more active participants in the care of the child. This shift has also been recognised in studies conducted by Lambat (2004); Levin (2005); Potterton (1996); Mweshi and Mpofu (2001); Meyer and Moagi (2000); and Green (2003) who provide evidence that the management of cerebral palsy requires a family-centered approach.

A study conducted by Roberts and Lawton (2001) researched the care requirements of caregivers caring for severely disabled children under the age of 16 years in the United Kingdom. The authors reviewed 40000 records of the Family Fund Trust where the

children were registered so that they could obtain disability grants. These records were analysed quantitatively according to five activities of daily living (washing, dressing, feeding, nightly routine and ability to be self-occupied). While these findings confirmed that children with severe disabilities have considerable extra care needs and revealed that caregivers appreciate it when healthcare providers acknowledge the extra care they provide to disabled children, the quantitative nature of study fails to recognise the personal experience of caring for a child with the disability. The personal experience significantly affects the outcomes of intervention as with most chronic conditions therapy extends beyond the therapy setting and into the natural environment of the patient.

Another study was conducted by Brehaut *et al* (2004) on the health of primary caregivers of children with cerebral palsy in Canada, which analysed the physical and psychological health of caregivers of children with cerebral palsy by issuing questionnaires and conducting face-to-face interviews. This study acknowledged that families are key participants in the process of establishing priorities and specific forms of care for their children with cerebral palsy. The results revealed that caregivers of children with cerebral palsy had lower incomes than that of the general population and listed „caring for their family“ as their primary activity. In South Africa, a similar study was conducted by Amosun, Ikeuesan, and Oloyede (1996) assessed using the General Health Questionnaire. The results revealed that caregivers of children with disability were more predisposed to the stressful impact of caregiving which may contribute to psychiatric morbidity. Thus the recommendation was made that caregivers of disabled children should be psychologically assessed on a regular basis.

Analysis of psychological health shows that caregivers of children with cerebral palsy were more predisposed to stress, emotional problems and cognitive problems, while they also showed a greater prevalence of physical ailments including back pain, asthma, headaches and gastro-intestinal problems than the average population. These results imply that healthcare professionals need to be aware of the relationship between childhood disability and caregiver's health and recommend that future research should be conducted on caregiver's perceptions of family-centered therapy. However, neither of the studies mentioned above undertook to delve into the nature of the psychological difficulties experienced by the caregivers and thus the recommendations failed to provide concrete ways of improving the quality of life of persons caring for a child with cerebral palsy.

A study conducted by Paine (1999) analysed fifteen semi-structured interviews conducted with primary caregivers of children with disabilities in the United Kingdom. The study explored the type of information that caregivers had received regarding the child's condition, whom they had received this information from, and whether or not they found this information valuable. Results indicated that most information was received from professionals and caregivers reported that the information had assisted them in emotionally adjusting to the child's disability, accessing services and in managing difficult behaviours. Numerous studies have highlighted that information is vital to the empowerment of persons affected both directly and indirectly by disability. However, there is scarcity of information on the manner in which healthcare information is disseminated in Ghana and the way in which this information is interpreted by customers of the healthcare service, particularly amongst the rural and illiterate populations of Ghana. Additionally, the nature of semi-structured interviews,

as employed by Paine (1999) has limitations in that they frequently make use of closed ended questions which prevent participants from voicing their opinions, concerns and experiences in their own words.

A number of studies have been conducted which have studied the survival of very low birth weight infants in South Africa (Cooper, Saloojee, Bolton, and Mockhachane, 1997; Hussey, et al, 1997; and Cooper, 2002). These studies employed quantitative methods and focused on the medical system and the resultant survival rate of very low birth weight infants. The result show a significant decrease in mortality rates with the improvement of medical technology. This is consistent with the international findings (Koman *et al*, 2004). However, these studies have not acknowledged the neurological outcomes of these very low birth weight infants or the parental experiences of the healthcare system, the number of patients who default from the medical system post discharge and the reasons for this. Studies related to the nature in which conditionspecific information is disseminated cross-culturally (Evans, 2000; Fisch, 2001; and Cilliers, 2005 as cited in Penn, 2007) revealed a wide variety of institutional language practices, with significant linguistic diversity and attitudes among clinicians, patients and persons brought into the clinical encounter to act as interpreters (for example, nurses, family members, cleaning staff and other patients). These studies revealed a wide variety of understandings in terms of the nature of a condition and the management thereof, which ultimately affects the effectiveness of the clinical encounter.

Based on the above, two major weakness were identified in current research on caring for a child with a disability. Firstly most studies draw conclusions from relatively small

potentially biased clinic-based samples, and secondly the methodologies used in these studies is frequently quantitative, relying mostly on questionnaires or closed-ended questions and therefore does not explicitly represent the experience of caring for a child with a disability. This highlights the fact that the nature in which research is conducted is the pivotal point such that one obtains a true reflection on the nature of the impairment and the effect that this has on the individual, the caregiver, the community, the society as a whole remains a contentious issue. This raises the issue of *how do we hear the client's voice?*

A study conducted by Glasscock (2002) in Orlando, in the United States of America used a convenience sample of fifteen mothers of children with spastic cerebral palsy between the ages of one and five years in order to describe the lived experience of caring for a child with cerebral palsy. The study employed phenomenological techniques and analysis of the transcripts revealed the following recurrent themes:

caregiver burden, social/family support, woman's/mother's roles, and socio-economic difficulties. The study revealed the importance of family relationships, an interest in learning about cerebral palsy and improving their child's quality of life, the need for therapy and social services to assist them and their children.

A study conducted by Irochu-Omare (2004) researched caregivers' experiences of physiotherapy services at a hospital in Uganda. The study utilised focus group interviews with caregivers at the hospital, and results indicated that most caregivers were satisfied with the services they received at the hospital. However, they were dissatisfied with the information they were provided with regarding the child's diagnosis and prognosis, as well as nature of interactions they had with the therapists.

Additionally, caregivers were dissatisfied with transport services to and from the hospital.

A study conducted by Olawale *et al* (2013) researched the psychological impact of cerebral palsy on families; the African perspective. The cross-sectional descriptive survey was conducted in the physiotherapy department of a tertiary hospital in Ghana. The study utilised questionnaires to determine the degree of psychological stress on the families and strategies adopted to cope with the stress. Results showed that respondents agreed that having adequate knowledge of CP would help them cope well with the demands of taking care of the children with CP.

The studies conducted by Glasscock (2002), Irochu-Omare (2004) and Olawale *et al* (2013) highlight the significance of researching disability by means of allowing the participants to tell their story as they have experienced it. Having reviewed the literature, there is a lack of such information obtained locally in Ghana within the disability sector, particularly related to childhood neurodevelopmental disability in rural areas. This raises concerns related to the nature of intervention that is provided to these populations since if healthcare professionals do not understand the cultural norms and practices of a given community, nor the experience of caring for a child with a disability it is difficult to provide an appropriate and equitable service.

2.4 THE EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY BEFORE THE DIAGNOSIS OF THE CONDITION

Parenthood poses a developmental crises and a challenging transitional stage for caregivers (Gerdes, *et. al.*, (1988). New parents may feel overpowered by the demands

of caring for a helpless infant. Confusion and doubt expressed by caregivers is even more pronounced as they struggle to understand and integrate exhausting health issues or developmental abnormalities in their children who appear to be perfectly normal (Nelson *et al.*, 2015). Locker, 1991, demonstrates that many chronic conditions are surrounded by uncertainty. This uncertainty may begin at the time when an individual notices that something is wrong and may continue throughout the course of the condition. Many chronic conditions have a slow and insidious onset, first emerging in the form of vague symptoms, and diagnosis may only be made years later. In addition to the issues of doubts, culture shapes people's attitudes and behaviours, and as a result affects the way in which people respond to challenges to their health. The decision to consult with a healthcare professional, particularly in rural areas is affected by, among other factors, access, education, age, prior experience, individual values, beliefs and judgement (Tollman and Kahn, 1999).

2.5 THE EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY DURING THE DIAGNOSIS OF THE CONDITION

Brody (1985) states that whether the primary caregiver assumes the responsibility of caring voluntarily or is assigned this role by the family members, he or she is more vulnerable to burden by virtue of the responsibilities assumed. According to Brody's research (1985) most caregivers will assume the responsibilities not by choice but because there is no alternative. Several research studies have identified that the primary responsibility as caregiver of a child with a chronic condition or neurological diagnosis falls most often to the mother (Glasscock, 2000; Hirose & Ueda, 1990;

Gibson, 1995; Seideman & Kleine, 1995; Gravelle, 1997; Hentinen & Kyngas, 1998).

Glasscock identified that mothers caring for their child with cerebral palsy have multiple roles which included initiating the diagnostic process.

According to Locker (1991), many chronic conditions have a slow and insidious onset, first emerging in the form of vague symptoms, and diagnosis may only be made years later. During this time, the affected person may consult with healthcare professionals but often find that their complaints are dismissed as trivial or evidence of hypochondria (Kendall and Buys, 1998). Stanton (2002) reports that many parents felt that their reactions to being told that their child had a disability were influenced by the negative attitudes of healthcare professionals. Parents are usually overwhelmed at the prospect of providing special care for a child who is physically handicapped. They often feel at a loss in terms of how to cope and find that their immediate family and friends do not fully understand the problems and difficulties involved with raising a disabled child (Stanton, 2002).

Hirose and Ueda (1990) identified that mothers of children with cerebral palsy were more emotional in their reactions to the child's diagnosis than fathers, who were more objective and realistic. Several authors have identified the experience of coping with parenting a child with a chronic condition, developmental disability or neurological problem as an experience of sorrow and/or chronic sorrow (Kearney & Griffin, 2001; Mallow & Bechtel, 1999; Hentinen & Kyngas, 1998; Gravelle, 1997; Seideman & Kleine, 1995). In contrast to the findings of sorrow was the joy that has been identified as an unanticipated consequence of the sorrow (Kearney & Griffen). Kearney and Griffin (2001) conducted a phenomenological study of six parents caring for their child

with developmental disability, and developed a model between joy and sorrow to describe the parenting experience. The model identified undercurrents of confusion, doubt, ambiguity, and dynamic interactions of joy and sorrow, hope and no hope, defiance and despair. A number of parents identified that sorrow originated from their dealings with other people's frequent messages of negativity and hopelessness (Kearney & Griffen, 2001). Other factors associated with sorrow included the anticipated possibility of the child dying, learning of the child's changed potential, being treated by others as if there were a death in the family, being left on their own by health system and feeling powerless (Kearney & Griffen). Chronic sorrow was an emotional response identified by all parents of children with developmental disabilities and those with a chronic illness (Seideman and Kleine, 1995; Gravelle, 1997; Mallow & Bechtel, 1999). Similarly, mothers and fathers exhibited initial patterns of sadness and grief at the time of diagnosis of their child with developmental disability; mothers' emotional response most often progressed to chronic sorrow, whereas the fathers' emotional response most often progressed to resignation (Mallow & Bechtel).

In contrast to sorrow was the identification of joy and an identified positive parenting experience. Themes that contributed to joy included the child not dying, the little things the child could do, and becoming stronger in the face of adversity (Kearney & Griffen, 2001).

Parents clearly identified the child as a source of joy; these parents tried to keep hope alive despite the child's identified limitations (Kearney & Griffen). They also kept hope and optimism alive through defiance of the child's prognoses (Kearney & Griffen). These findings are similar to the findings of Seideman & Kleine (1995), that guarding

hope represented the attempt to be hopeful for the best outcome while remaining cautious in parenting a child with developmental delay or mental retardation.

Mallow and Bechtel, (1999) found that mothers and fathers who experienced recurring chronic sorrow related to the care of their medically fragile child identified different triggers for the recurrence of these feelings. Mothers identified healthcare crisis as a trigger as compared to fathers who identified the crisis of the comparison of social norms between the medically fragile child and a normal child as a trigger of chronic sorrow (Mallow & Bechtel). Sorrow and fear in the adaptation of parents of a child with a chronic condition was identified in families experiencing parental conflicts (Hentinen & Kyngas, 1998).

2.6 THE EXPERIENCES OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY AFTER THE DIAGNOSIS OF THE CONDITION

Loss of identity and perceived lost goals and expectations for the future were identified themes by mothers of children with disabilities (Helitzer, CunninghamSabo, VanLeit, & Crowe, 2002). Many of the mothers described themselves as independent and pursuing dreams before their children were born, and that their identity was lost after the birth of their disabled child (Helitzer, et al., 2002).

Dickman and Gordon, 1985, illustrates the difficulties in raising a child as a parent and describes the attempt in providing a safe environment to foster physical, social and emotional growth as a complex task. He further states that, in many instances, as a result of poor coping skills, lack of support structures, or in response to money struggles, addictions, abuse, health impairments, or plain unhappiness families fall apart. It is therefore no surprise then that having a child with a disability can also drive

a parent into a state of chronic stress or crises. Disabling conditions tend to evoke strong emotional reactions in the affected individual, as well as in significant others in his or her environment. Lewis and Rosenlum (1974), demonstrate that these reactions are applicable across a broad range of disabilities and illnesses and are mostly believed to be cross-cultural.

Family relationships have been identified as an important factor in the adaptation of families of children with chronic disease or neurological disorders (Glasscock, 2000; Seideman & Kleine, 1995; Hentinen & Kingas, 1998; Knafl Breitmayer, Gallo, & Zoeller, 1996; Youngblut, Brernnan & Swegert, 1994; Hirose & Ueda, 1990). Glasscock examined the lived experience of 15 mothers of a child with spastic cerebral palsy, which included moderate and severe forms of the disorder. The participants were recruited from a high-risk clinic for children with chronic illness and a neurology clinic in the United States. All of the mothers identified that strong family relationships were an important factor in caring for their child with cerebral palsy.

Hirose and Ueda (1990) in qualitative study conducted in Japan found that the marital relationship was an important support for coping behavior in mothers of children with cerebral palsy. In a theory of transformed parenting that emerged from a grounded theory study of 29 mothers and 13 fathers of developmentally disabled children, limited time and energy due to the complex care demands was shown to increase marital stress and contributed to divorce in nine couples (Seideman & Kleine, 1995). In addition mothers expressed concern about making time for the other children in the family (Seideman & Kleine).

Good family relationships have been found to be part of quality adaptation; freedom to express feelings in the family was also identified as a part of good adaptation (Hentinen & Kyngas, 1998). Poor adaptation was associated with increased family conflicts in families of children with chronic illness (Hentinen & Kyngas). Knafl, Breitmayer, Gallo and Zoeller (1996) identified various family responses to chronic illness, and their findings suggest that parental conflict over how to manage the child's condition, and differing expectations of one another contributed to a negative family response to chronic illness. Conversely, parents who were found to be positively adapting to the chronic illness expressed mutuality in their definition and management of the situation (Knafl et al., 1996). The parents who were coping positively with the child's chronic illness identified the added emotional closeness among family members as a positive consequence to the child's chronic illness (Knafl et al.). Similarly, in an exploratory study of medically fragile children, family strengths were assessed using the family strengths scale; the findings indicated that these families identified a moderate amount of family strengths (Youngblut, Brennan, & Swegert, 1994). The strengths identified included trust in each other, shared values and beliefs, limited conflicts, ability to express themselves within the family, family pride, family loyalty and the belief that things will work out well (Youngblut, et al., 1994).

In addition to the emotional aspects, the challenge of caring for a disabled child requires considerable resources including time and money. Studies have shown that caring for a child with a disability requires more time from the caregiver than when caring for an able-bodied child (Starmuch and Mortimer, 1982; Gowen *et.al.*, 1989; and Kendall and Buys, 1998), and costs of medical treatment have been estimated to be 2.5 to 20 times higher than the average costs of caring for nondisabled children (Ireys *et.al.*, 1993). Potterton (1996) found that many parents of children with cerebral palsy in Giyani,

South Africa, expressed regret that the traditional extended family was breaking down as they felt that this would have provided them with more support. This is significant particularly in the light of HIV/AIDS infection where a significant breakdown in the nuclear family and the traditional extended family has been noticed.

Ingstad (1999) points out that when families are unable to cope with the care of a disabled relative, it is usually the result of poverty and a lack of knowledge about what can be done to improve the situation, rather than the result of a lack of love or negative attitudes. This concurs with Kilonzo's (2004) findings which showed that most caregivers displayed a lack of understanding of the permanence of their child's condition. Another study done by Rumano (1994) in Zimbabwe found that lack of understanding and negative attitudes within the community coupled with the other roles that the family member has besides caring for the disabled person as being barriers to effective caregiving. This is common in Ghana where many people still hold the belief that if a child is born disabled it means that his/her mother did something „evil“ during her pregnancy (Potterton, 1996).

CHAPTER THREE

METHODOLOGY

3.1 INTRODUCTION

This chapter presents the various methods that were used effectively to achieve the study objectives. It includes the study type and design, profile of the study area, study population, sampling technique, data collection, data analysis and data storage and safety.

3.2 STUDY TYPE AND DESIGN

The current study employed a qualitative design using a phenomenological approach to describe what the primary caregivers of children with cerebral palsy experience in caring for them.

'Phenomenology' refers to a person's perception of the meaning of an event, as opposed to the event as it exists externally to (outside of) that person. The focus of phenomenological inquiry is what people experience in regard to some phenomenon or other and how they interpret those experiences. Thus, a phenomenological research study tries to answer the question *'What is it like to experience such and such?'* The researcher's primary mandate in phenomenological research is to listen to what the incidents/phenomena tell him/her and to remain faithful to the concrete dimensions of the phenomenon as it appears (Kruger, 1988).

The information above points toward the following criteria that was expressed by Kruger (1988) that researchers should follow:

1. The research interview situation should involve a description of experience on the phenomenon in its lived-world context;
2. Explication of the protocols should be concerned with the meaning of the data from the participant's perspective;
3. Essential themes should be extracted in their varying manifestations; and
4. The dialectic between approach, method and content should be maintained.

3.3 PROFILE OF THE STUDY AREA

The study was conducted at the Korle Bu Teaching Hospital, Accra, Ghana. Established on 9 October 1923, the hospital has grown from an initial 200-bed capacity to over

2,000. It is currently the third largest hospital in Africa and the leading national referral centre in Ghana. The facility receives referrals from both local and international health facilities. As at 2013, the hospital had over 2000 beds,

21 clinical and diagnostic departments/units and three „Centers of excellence“. Currently, it has over 4000 medical and paramedical staff with an average daily attendance of 1500 patients, about 250 of which are admitted.

The Child Health Department runs many special clinics some of which are Neurology Clinic from which this study was done, HIV clinic, Down syndrome clinic, etc. The paediatric neurology clinic is run every Monday of the week mostly in the mid mornings after their morning ward rounds. The clinic has a monthly attendance of about 160 clients. One senior doctor is the in charge, assisted by two house officers and two residents to manage the clinic.

3.4 STUDY PARTICIPANTS

That participants were selected based on the following criteria: (1) have had experiences relating to the phenomenon being researched; (2) are verbally fluent and are able to communicate their feelings, thoughts and perceptions in relation to the phenomenon being researched; (3) have the same home-language as the researcher; and (4) express a willingness to be open to the researcher.

With due consideration of the aforementioned criteria, research participants in this study were included based on the following criteria: (1) S/he is the primary caregiver of a child with cerebral palsy between the ages of 1 and 15 years; (2) His/her child has been formally assessed by a multidisciplinary team and has been given a diagnosis of cerebral palsy, (3) S/he is willing to give consent to being interviewed and to the

interviews being audio-taped; and (4) S/he is able to confidently converse in either English and/or Ga/Twi/Fante.

3.5 DATA COLLECTION TECHNIQUES AND TOOLS

Primary caregivers were recruited from the Out-Patient Department of the Department of Child Health at the Korle-Bu Teaching Hospital during the Neurological clinic on Mondays. The researcher confirmed their inclusion by reviewing the hospital records of the children with the help of a nurse to know if they had been duly diagnosed as children with cerebral palsy by a paediatrician. They were invited to a nearby private room to discuss the study and their possible participation. The rationale for adopting this method was to get to know each potential participant, discuss the purpose, research process, potential risks and benefits of the study, and to be aware of how both the researcher and each participant were responding to and defining the situation. Following such discussion, participants signed a consent.

The researcher used a semi-structured, in-depth, face-to-face interviews as method of data collection. The semi-structured interview guide developed for the interview, covered the three broad objectives of the current study. A great advantage of the semistructured interview, according to Kruger (1988), is its flexibility, which allows the researcher to grasp more fully the participant's experience than would be possible through the implementation of a more rigid methodological technique. De Vos (1998), suggests that face-to-face interview assists researchers to understand the closed worlds of individuals, families, organizations, institutions and communities. Kruger (1988) further asserts that interviews allow participants to be as near as possible to their lived experience, does not preclude the possibility of dialogue during this early phase of research. The advantages of in-depth interviews as method of data collection outlined

above directly relates the envisaged aim of this study, which is to explore and describe primary caregivers' experiences of raising children with cerebral palsy in Ghana. Audio-recordings of the interviews were made with the informed consent of participants. Each participant was interviewed for about one to two hours. The researcher kept a fieldwork journal also to document observations made during the interviews and to reflect on personal experiences during the data collection process that may affect the validity of the data obtained. Data was collected from November, 2013 to April, 2014.

3.6 SAMPLING TECHNIQUE AND SAMPLE SIZE

A purposive sampling method was adopted to recruit the participants for the current study.

Forty (40) participants between the ages of 27 and 58 years were interviewed. These participants were made up of five (5) males, all biological fathers, thirty-five (35) females, made up of two (2) grandmothers, one (1) caregiver at an orphanage and thirty-two (32) biological mothers. Participants came from varied socio-economic strata and the biological data of these participants are presented in Table 4.1.

3.7 PRE-TESTING

In order to ensure that the semi-structured interview guide is clear and well understood by the participants, it was pretested with ten (10) primary caregivers of children with cerebral palsy at Sharecare Ghana, an association of persons, including several children, with autoimmune and neurological conditions, their families and care-givers to ensure that the tools generate the data. The needed modification and identified flaws were rectified.

3.8 DATA HANDLING AND STORAGE

The recorded interviews were saved on a computer and secured using a password protected computerized system after double entry and then backup created on an external hard drive.

3.9 DATA MANAGEMENT AND ANALYSIS

Recorded audio files obtained from the research interviews were transcribed by the researcher. These transcripts were coded so that the respondents' names did not appear for the protection of the anonymity of the participant. The transcribing followed the broad categories and order of questions used in the semi-structured interview schedules.

The initial form of data analysis was mainly content analysis. The researcher further reduced the text by highlighting individual interesting passages, which were then coded and grouped into categories (Seidman, 1991). The categories were systematically selected, related to other categories, and connections were identified between these categories. These were then studied for thematic connections within and among them, in order to produce a set of interview excerpts that were thematically organized.

Kruger (1988) supports the notion that, in phenomenological research, the researcher cannot be viewed as an independent observer, but must be seen as a participant observer. As such, phenomenological methods of research must thus be "reflexive in nature and intent" in order to remain faithful to their purpose (Kruger, 1988, p.150).

The researcher further considered her reflective learning and the thematically organized summary of responses against the research question in order to:

1. Describe the nature of primary caregivers' pre – diagnostic experiences
2. Produce an understanding of the experiences of primary caregivers during the diagnostic process and
3. Analyze their post-diagnostic experiences.

3.10 ETHICAL CONSIDERATIONS

The study received a written permission from the Head of Department of the Department of Child Health, Korle Bu Teaching Hospital and the Committee on Human Research, Publication and Ethics (CHRPE) of the School of Medical Sciences, Kwame Nkrumah University of Science and Technology (KNUST)/ Komfo Anokye Teaching Hospital (KATH) Institutional Review Board. Written or verbal consent was sought from participants with an assurance of maintenance of confidentiality and privacy.

3.11 DISSEMINATION

The outcome of this study will be presented in an academic defense, a technical report will be stored at the Centre for Disability and Rehabilitation Studies for both reference and academic purposes, published in the African Journal on Disability (AJOD) and other journals if possible and also presented at scientific conferences and seminars. The findings of this study will bring to the fore the lived experiences of primary caregivers of children with cerebral palsy attending the Korle Bu Teaching Hospital in the Greater Accra Region.

3.12 LIMITATION OF THE STUDY

The number of primary caregivers recruited for the study were few

3.13 ASSUMPTIONS

It was assumed that the respondents gave correct responses.

CHAPTER FOUR

RESULTS

4.1 INTRODUCTION

This chapter outlines the results from the data interpretation process. Three broad fields of experience that correlate with the specific objectives of the study emanated from the interpretation process are described in this section. They are: (1) Experiences before the diagnostic processes, (2) Experiences during the diagnostic process and (3) Experiences after the diagnostic process.

4.2 SOCIODEMOGRAPHIC CHARACTERISTICS OF PRIMARY CAREGIVERS

Table 4.1: Distribution of Socio-demographic characteristics of respondents

No.	CHARACTERISTICS		NUMBER	PERCENTAGE (%)
1	Gender	a. Male	5	12.5
		b. Female	35	87.5
2	Age (years)	a. 20 – 30	5	12.5
		b. 30 – 40	24	60.0
		c. 40 – 50	8	20.0
		d. 50 – 60	3	7.5
3	Medium of communication	a. Twi	32	80.0
		b. Fante	2	5.0
		c. English	6	15.0
4	Highest level of education	a. Tertiary	7	17.5
		b. Training college	1	2.5
		c. Vocational training	8	20.0
		d. Senior high	8	20.0
		e. Junior high	16	40.0
5	Occupation	a. Teacher	6	15.0
		b. Accountant	1	2.5
		c. Accounts clerk	1	2.5
		d. Nurse	1	2.5
		e. Retired Naval officer	1	2.5
		f. Trader	12	30.0
		g. Petty trader	2	5.0
		h. Baker	1	2.5
		i. Taxi driver	1	2.5
		j. Seamstress	2	5.0
		k. Hairdresser	1	2.5
		l. Not working	11	27.5
		m. farmer	1	2.5
6	Marital status	a. Married	30	75.0
		b. Divorced	1	2.5
		c. Separated	3	7.5

		d.	Widow	1	2.5	
		e.	Single	5	12.5	
7	Relationship of caregiver to child	a.	Mother	32	5	80.0
		b.	Father			12.5
		c.	Grandmother	3		7.5
8	No. of Children with CP in the family	a.	One	39	1	97.5
		b.	Two			2.5
9	No. of other children without CP in the family	a.	zero	20		50.0
		b.	One	8		20.0
		c.	Two	9		22.5
		d.	Three	2		5.0
		e.	Four	1		2.5

The researcher interviewed forty (40) primary caregivers in the study. Of these participants, 87.5% were females and 12.5% were made up of males. The results further showed that majority of them (60%) were aged between 30 to 40 years of age; followed by those aged between 40 to 50 years, making up 20%. The medium of communication mostly used by the caregivers to the researcher's understanding was Twi. Majority (80%) spoke Twi fluently, followed by 15% in English.

The results again showed the highest level of education attained by the caregivers was the Junior High School, making up 40%. This was followed by 20% each that had attained Senior High and Vocational training respectively. Few (17.5%) of the caregivers interviewed however, had education level up to the tertiary level and only 2.5% had had education up to the training college.

When asked of their occupations, the results showed that 30% of the caregivers interviewed were traders, and 27.5% were not working at the time of the interview. Of these, 22.5% were working parents who had lost their jobs due to the condition of their children. The researcher further probed the marital status of the caregivers and the

results showed that, 75% were married at the time of the interview whilst 12.5 % were single. Of the remaining 12.5%, 7.5% were separated and the 2.5% each were divorced and separated.

With regards to the relationship between the caregiver and the child, 80% responded they were the biological mothers of the children, 12.5% were the biological fathers and the remaining 7.5% were their grandmothers. When asked the number of children with cerebral palsy the caregivers had, 97.5% responded they had just one, while the remaining 2.5% had two children with cerebral palsy. The researcher further probed if they had other children without cerebral palsy, 50% of the caregivers interviewed had none, 22.5% had two additional children, 20% had just one child in addition, 5% had three and 2.5% had four other children.

4.3 EXPERIENCES OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY BEFORE THE DIAGNOSIS OF THE CONDITION OF THEIR CHILD

This section describes the themes identified with regards to the experiences the primary caregivers had before the diagnosis of the condition of their child.

4.3.1 Confronted with a situation of a child with an abnormality as a new mother

This section presents early recollections of female caregivers on their pregnancies and important activities surrounding the births of their children who were later diagnosed with cerebral palsy. Developmental delays and early warning signs alerted these caregivers to potential abnormalities in their children's development.

All forty participants (100%), of which thirty-two (80%) mothers and five (12.5%) fathers reported uncomplicated pregnancies. However, eight parents experienced complications during the birth process. Two of them had induced labour and were allegedly left unattended to by the health professional on duty, this made the infants sustain birth asphyxia during the unassisted births. One participant allegedly experienced nuchal cord during pregnancy, but her condition was neglected and asked to undergo natural vaginal delivery. This resulted in birth asphyxia during the birth process. Another participant, a health worker asked to be injected with a drug (pethidine) to ease the labour pains but this made her so weak that she could not push the baby out by herself and had to be assisted by colleague health workers. This delayed labour caused a brain injury in the infant. The last three participants reported their children convulsed later after birth before their first birthday.

Throughout account of their pregnancies and delivery, 40% reported their infants had jaundice at birth, the following are vivid experiences of two of the participants:

“When I gave birth to him, after three days he become yellow and we sent him to hospital and they told us to expose him in the sun but still he become more yellow and we sent him back and they admitted him and put him in incubator after four days they told us they need to refer us to Koforidua or Korle Bu and we went to Koforidua, the doctor told us there that his blood is turned yellow and they had to change it which they did. He cries always and we noticed that he cried because of the problem he is going through. After three months he still cries always.”

“Her mother was a student when she got pregnant with baby P, when she gave birth to her, she became very sick after 5 days. The doctor said jaundice, so they took her blood and replaced it with another and since then we have been coming to the hospital always. We virtually live in the hospital.”

Out of the 40 participants, 20% also reported their babies did not cry at birth, two participants reported:

“At birth, she didn’t cry. The nurses took her away for about three (3) hours and later told me she had to be kept in the incubator. Upon my enquiry, the nurses told me she didn’t have the energy to breathe. I could only pray for her survival then. I heard her first cry when she was a week old, but it didn’t sound like the way other children cry”

“Baby J, was very adorable at birth. She didn’t cry, the nurse pinched her feet several times to stimulate her to cry but didn’t happen. Eventually, she made some sounds as if she was in pain. I wasn’t sure what was wrong, during weighing, I complained to the nurse, but she asked me to give her some time as the children can be a bit different sometimes. This went on till she was 4 months, she would make some crying sounds but not so loud, then I sent her to the general hospital to see the doctor, then we were referred to Korle Bu to the Neuro clinic. Here the doctor explained that the brain didn’t develop well, thus causing such behaviour”

Caregivers also employed psychological defences to understand and integrate their child’s atypical development.

4.3.2 Breaking out of the superstitious beliefs

This section explores the contribution of some culture and its interpretations of disability. Caregivers share the ordeal they had to go through to either succumb to the pressures of these superstitious beliefs or flee for help from professional medical practitioners.

Superstitious beliefs are common attributes in the African culture. Of the forty participants (100%) interviewed, twenty (50%) commented they had experienced some of these superstitious attributes that existed within their culture. Five participants (12.5%) reported they had been accused for bringing forth spirit children, some referred to the children as “nsuoba” (river child) whereas others were blamed for bringing taboos to the families of their husbands. One participant recounted how she was thrown out of her husband’s family house after realizing her child could not sit at 6 months, could not keep his head straight after eight months and kept drooling at age one. Another mother reported that her husband left their house after their child was born majorly due to pressure from his family. Two mothers gave a vivid account on how they escaped the consequences of the strong superstitious beliefs rooted within their families.

“My husband works with the Ghana Fire Service and I am a seamstress. When I gave birth to baby V, my father called me and informed me that there was some kind of ritual that had to be done for me. He gave me time to discuss with my husband. I did not consider what he said because I had witnessed what they did to children with abnormalities in our community. After some time, my father called me again, this time with my husband and insisted that the ritual be done and that it was a taboo to keep such a child in the family; the ritual was long overdue. Two nights after that meeting,

my husband helped me pack my belongings and sneaked me to the station to pick a bus to Accra with our two children. “After settling in Accra, I came to Korle Bu children hospital. I was then referred to the neurological clinic and since then, we have been attending the clinic. I have not set foot in my community in Tamale since then. My husband visits when he can.”

“Baby K is the third of my children, we were living in Cape Coast when I gave birth to him. I was living in my husband’s family house with my husband. Six months after giving birth to Baby K, I realised he was not sitting and still did not have a straight neck. My mother in-law also realised this. It was after this event that her attitude towards me changed. She had been helpful with the two other children I had but after realising Baby K had some abnormality, she distanced herself and informed other family members about the condition. One day, she commented that the way Baby K was behaving, it could happen that I had given birth to an “nsumba” (river child in fante). Days after that comment was made, she told me that it was an embarrassment to have such a child in the family. She advised that we consulted the elders of the town to “escort the child” and that it was best we returned him to where he came from. This would prevent any calamities that would befall the family in later life she explained. My husband is a sea man and sometimes he goes away for days. Before I could inform him of what his mother thought of our child, his mother had already conscientized him to do away with our last baby. He never made a comment on what his mother and other family members were doing to me with respect to Baby K’s condition. I advised myself when I could not bear the pressure anymore to relocate. I came to Accra with my three children. It was difficult in finding a place but by God’s grace we found an uncompleted building to put up. I started selling charcoal then later started cooking to sell. After

seven months, I was able to put the two elderly children in a public school. They have been helpful in taking care of Baby K. they love him and treat him as their brother.”

4.4 EXPERIENCES OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY DURING THE DIAGNOSTIC PROCESS OF THE CONDITION OF THEIR CHILD

4.4.1 Issues of blame and responsibility

This section describes the assignment of blame for the child’s difficulties and responsibility for overseeing the diagnostic process, which were typically apportioned to one member of the parental unit.

Throughout the accounts of the forty (100%) participants interviewed, about 40%, mostly mothers indicated that they were fully responsible in taking care of their child. A mother reported that though she was staying with the husband and still married, the husband showed very little concern in the condition of their child. Another mother reported that, the husband felt too embarrassed to show their child in public and had ordered her not to send the child out in the public. If she did, she could consider herself solely responsible for the child. This made it very difficult for her to seek any form of help. A mother who happened to be a health professional shared her ordeal and the guilt that had filled her up for bringing forth a child with an abnormality. She reported:

“As a nurse, having witnessed several times the pains women go through during labour, I wanted the easiest way out. I ordered my other colleague nurse on duty to inject me with pethidine to calm the pains down, they warned me about it but the pains could not make me think. I fought them for the injection and I finally got it, it was such a relief. That was the last memory of the labour pains, I fell asleep afterwards and slept

throughout the labour. This hindered the process, I could not push when I was asked to because I was asleep, and this caused a delay in the child's delivery. Anytime I see my child, the voice of my colleague nurse echoes in my head, then I begin to cry. I do not think I can ever forget that moment so far as my son is alive and I must admit that it is a huge torture. To add to my misery, the father of my son does not even care what I go through to take care of his son, he just provides money periodically and it ends there."

4.4.2 Confusion and mistrust with helping professionals

This section recounts caregivers' early experiences with helping professionals during the diagnostic process. Caregivers found helping professionals to be generally unsupportive and insensitive to their vulnerabilities, fears and confusion regarding their children's condition, prognosis and treatment options.

About ninety percent (90%) of the participants in the present study first visited the hospital for an understanding of their children's condition. This action marked the beginning of a long and difficult journey for caregivers as they began to interact with multiple professionals in order to obtain a clinical diagnosis for their child's condition. Participants felt strongly that helping professionals initially negated their concerns and did not take their reports of delayed development in their children seriously. For example:

"At four months I realised my child wasn't sitting, I was very worried as his siblings at that age would be sitting with some support and playing on their own. I knew there was something wrong but when I complained at the hospital, all they told me was that it was normal for some children. I made the same complain the following month when

I went for a review but nothing convincing came from the doctors.”

“I had my first child with this kind of condition, I have been visiting the Neuro clinic since then, coming for reviews upon reviews but my two year child is still at my back, not walking. Unfortunately, the second child came with the same condition and nobody is willing to tell me the cause of this condition. All I do is to carry these two kids to the hospital every time. When I ask the doctors, none can tell me what the actual cause is. It is very a difficult situation for me because I thought this is where I could get the answers to my questions. It is very difficult working with these people sometimes.”

4.4.3 Mixed feelings about the diagnosis

This section explores caregivers’ reactions to receiving the diagnosis of their child’s condition. Reactions ranged from initial relief that they finally know what is wrong with the child, to a continuous complex process of grief over the loss of a “normal” child.

Relief

Participants reported that their concerns and anxiety lessened somewhat once the children were diagnosed, since they were now in a position to seek appropriate treatment and educational programmes suitable to their children’s unique needs.

Participants’ sense of relief was reflected in the following statements:

“She was very well, talking, and schooling until she had malaria at age 6. She could not talk nor walk again. As a teacher, I got confused because I had not seen such condition before. After the doctors confirmed that a part of the brain had been damaged

resulting in her loss of speech and movement, I took it upon myself to research about the condition and ask parents with children of similar condition.... Now, I know, this is the turn my life has taken, I am willing to help her go through life with the help of God; and ready to join any supporting group that would help me understand my daughter better as well as educate others mothers on the condition”.

“With „D”, my wife and I got some sense of relief when the professionals finally explained the repercussion of the condition. I am able to help with „D” in the house since I”m on retirement. My wife”s hands are already full with the two other children. „D” is growing and becoming difficult to carry her, she now needs a wheelchair”.

Grieving the loss of a normal child

Participants in the present study confirmed that they felt like they had lost a valuable thing and they sometimes grieved as if their children did not exist. They expressed varying emotions that are associated with stages in the grief cycle illustrated by (Tommasone & Tommasone, 2000), namely: initial shock and denial; anger and resentment; depression; and eventual acceptance. **Initial shock and denial** were expressed in the following ways:

“I accepted it with much ease than my husband did, I think it was because I had more frequent contact with baby K on a daily basis than he did. He almost pretended as if it wasn”t happening.... He thought baby K would grow out of it or that something would change.”

“I woke up every day hoping to see a change... that she (cerebral palsy child) would get on her feet again and play with her siblings as she used to. I had a strong believe it was something temporal; she was probably just feeling very weak, making her unable to walk until the doctor advised us to get her a wheelchair and start physiotherapy”

Participants also expressed **angry and resented** the difficulties that they experienced in caring for their children with cerebral palsy. For example:

“I don’t know whether to call it anger, these are innocent children. It is difficult to explain... I just get so frustrated and bitter sometimes. I have to halt my life and take care of him (cerebral palsy child) from dawn to dusk. If only his dad would show a little concern; his understanding of caring for a child is just his upkeep monies, that’s all.”

“There is no point crying over spilt milk; if only the lazy nurse had paid attention to a woman in labour after inducing labour, I wouldn’t be walking around here while I should be at work to earn something to take care of the family. I have sold every asset I own; no amount of money is enough to care for my daughter. It is just so difficult.”

Depression emerged in various forms in combinations of guilt, sorrow and tearfulness. For example:

“My eyes are always filled with tears when I remember that day. I somehow believe I’m being punished for my sins. To think of the fact that if I had not taken that injection and went through the normal labour pains, this might not have happened.”

“I have grown to love him (child with cerebral palsy) dearly, but sometimes it is difficult to comprehend his gestures. I mean, I can hardly tell if he loves what I do.

May be with time I will learn his gestures better.”

“Sister (referring to the interviewer), I am a Christian, but now I doubt my faith; I doubt if there is any God. One child with this condition is already a headache, I have two! What did I do wrong to merit this? I don’t believe in any God because he is not there to see my plight. I walk around always questioning myself, what I did wrong.

Now, I’m scared to even think of having any more kids”.

“I was a pupil teacher in a basic school, I started teaching right after training college. I was young then and life was very lovely with very little to care about; my condition changed right after having baby J, it’s a different world all together”

Respondents reported that, they were able to attain some level of **acceptance** once they adjusted their expectations regarding their children’s capabilities and what the future held for them. The adjustments was in both directions as caregivers also adjusted their expectations of themselves by accepting the reality of their situations and allowed themselves to learn to make mistakes in the difficult task of raising children with cerebral palsy. The following account reflects the above:

“For me, it’s a life lesson I’m learning from taking care of this child. She has taught me patience and love. She has taught me to be humble because there is nothing like a perfect world. I asked for a child and this is what God gave me, though not very easy in the beginning, the whole family has grown to love her. Her siblings take turns in playing with her sometimes; you can hardly feel her „absence” in the family, she fully participates in everything we do.”

“I used to compare him a lot with other children, questioning when he would reach his milestones in sitting, crawling and eventually walking. This puts a lot of stress on me and very anxious inside. Eventually he started walking when his colleagues were already running (giggling). Then came issues with speech. Eventually, I taught myself to stop comparing him with other children and concentrate on him as a special case, after all, all the fingers are not the same.”

4.5 EXPERIENCES OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY AFTER THE DIAGNOSIS OF THE CONDITION OF THEIR CHILD

4.5.1 Strained family relations

This section explores primary caregivers’ experiences on how the presence of a child with cerebral palsy has influenced the spousal subsystem and the marriage relationships, as well as parent – child relationships with normal developing siblings.

Caregivers also give account of sibling relationships as influenced by the presence of a sister or brother with cerebral palsy.

About 50% of the research participants have other children apart from the child with cerebral palsy. Of this 50%, 20% of them had one other child, 22.5% had two other children, 5.0% had three other children and 2.5% had four other children. The report further showed that of the 20% that had one other child, 17.5% of them were married and the remaining 2.5% were single. Likewise, of the 22.5% that had two other children, 17.5% of them were married, 2.5% were separated and the remaining 2.5% were

divorced. Out of the 5% that had three other children, all of them were married and lastly, the 2.5% that had four other children were all married.

It is contended that the presence of a family member with disability definitely has an influence on the dynamics of all other family subsystems. Research participants were of the opinion that the presence of a child with cerebral palsy had influenced the spousal subsystem and the marriage relationship, as well as parent-child relationships with the other normal developing siblings. Based on caregivers' observations, sibling relationships also are not spared by the presence of a brother or sister with cerebral palsy.

Marital conflicts and Stress

About 30 out of the 40 (75%) participants in the current study reported that some conflict in their marriages arose after the birth of their child with cerebral palsy. They also referred to the extreme demand on their time, energy and finances made by the child as the most common cause of the conflict. They reported that this gave them little or no time to spend with themselves as couples. The following were expressed by participants:

"It is a very difficult situation when it comes to the relationship. There is virtually no „us“ anymore; because you don't have a normal life as you and your husband. Our routine conversations is now all about „P“. Sometimes I think about what he (husband) would be going through. As a mother, I have gotten used to the caregiver role, he helps

a lot but I take the lead and he just follows. I think in this situation, you either „jell“ or you fall apart as a couple”

“In the early months of „Baby K“, when the condition was diagnosed, of course hospital attendance became part of our lives which was very stressful. This put a toll on our marriage. The financial burden became too heavy for him (husband) to bear. We could hardly save a pesewa, let alone plan something special for ourselves. Every pesewa earned went into medication and physiotherapy, aside the routine baby budget. I realised later that, the communication between us was breaking up because of the demands. I had to stop working to care for “Baby K”. Our home is not lovely anymore because, each free minute we have on our hands, we have to be planning where next to get money to care for „Baby K”.

“He left us. He just left home and never returned. He abandoned his responsibilities and blamed the condition on me since I carried the baby. I moved to my parents” house so I could get a helping hand with „D”.”

“I lost my husband the moment I gave birth to him (child with cerebral palsy). He is now the financier of the child”s welfare but wants nothing to do with me anymore.”

The needs of the child with cerebral palsy versus the needs of other siblings in parenting

Participants of the current study who had other children apart from the child with cerebral palsy agreed that the birth of their child with cerebral palsy affected the relationships with their other children. Primary caregivers mentioned a tendency to

devote less parental attention to „normal“ developing siblings, as their child with cerebral palsy made extreme demands on their time and energy. Three participants shared their experiences, they made the following comments:

“Well, the routine had been that after school, I checked their homework, we do a little play time together; they would report all that happened in school and on their way home. After „J“ dropped, things changed. I think they appreciated my stress with „J“ and the fact that I always had to handle him. They rather asked to help me with „J“. I hardly had time and a good composure to play with them like before; I would be exhausted by the time they return from school. My husband suggested a home teacher and we thought it was a good idea. After their home studies, they play with their brother.”

“Baby K (child with cerebral palsy) is almost always with me, unfortunately, it makes the other two siblings feel neglected. My husband has been helping with them but in a way I have a feeling they are missing their motherly love. Now they call daddy more often when they need help. I’m missing out on their development”

“It was quite difficult for „P“ (normal developing sibling) as she grew. I cannot actually remember her learning to walk, talk, anything.... She taught herself. With „P“, I think she was ignored a lot. She copped with the situation, and I was barely coping with „N“ (child with cerebral palsy) and with the both of them.

Sibling Relationships: Living with a sister or brother with cerebral palsy

Caregivers shared their perceptions on how the presence of a brother or sister with cerebral palsy had impacted sibling relationships. Participants reported that their

„normal“ developing children demonstrated anger or resentment as a result of the condition of the child with cerebral palsy but on the contrary often showed love or respect and preparedness to help their brother or sister with cerebral palsy. Participants with other children agreed the presence of the child with cerebral palsy had resulted in greater responsibility of their other children. They confirmed signs of sadness or depression in their children as a result of the impact of the child with cerebral palsy on the family life. An example of anger or resentment in normal developing siblings is:

“I pick a lot of anger from the questions he (older brother) asks me about „J“ (child with cerebral palsy). He (older brother) is angry because he cannot play with „J“ the way he wants to. He expresses a lot of frustration when questioning about his movement and I try as much as possible to explain the condition to him.”

Siblings’ sense of responsibility for the brother or sister with cerebral palsy was expressed as follows:

“„T“ (younger brother) is very protective of „K“ (brother with cerebral palsy). There was a time when they were little, when they were on vacation, „T“ would join us to the hospital for physiotherapy sessions. When he meets the nurses, he would say, „this is my brother, we have come here to exercise because he cannot walk“. Whenever we had the chance to go out together, he was always the one to introduce the brother and help push his wheel chair as well. Whenever given a gift or something personal, the next question after thank you is always to ask for his brother“s.”

The description below is an expression of depression or sadness in normal developing siblings as accounted by one participant:

“As children and boys especially, most of their games involve running around the house, which is what „T” misses whenever he wants to play with his brother. Sometimes out of frustration, he would ask me repeatedly when his brother would be able to walk. I try to vary the answers I give him so he doesn’t lose hope in his brother... this sometimes brings tears to my eyes because I know how he feels.”

4.5.2 Experiences of poverty

This section describes the experiences caregivers shared on how caring for their children with cerebral palsy had made it impossible for them to work, how the expense of medication and equipment took a toll on their finances and how the inaccessibility of hospitals with specialist services for their children added to their financial challenges.

When asked how caring for their children affected them financially, all forty (100%) participants complained that it had a huge toll on them. About 45% of the respondents reported they had had to stop working or quit their jobs in order to take care of their children with cerebral palsy. All participants complained about the cost of medication for their children as they were not covered by the National Health Insurance Scheme; these were medication they took daily for almost their entire life so far as the condition existed. Participants with children above five years who could not walk, complained

about the non-availability and cost of equipment, especially wheel chair for their children. Some caregivers with toddlers also mentioned the non-availability and cost of standing frames for their children as a major challenge. The inaccessibility to specialist clinics was of unanimous concern among all participants as some had to travel from other regions of the country in chartered vehicles to access healthcare in the Greater Accra Region.

Inability to work

Eleven (27.5%) of the respondents, all mothers of children with cerebral palsy felt that they were unable to go out to work as their children required constant care and they felt they were unable to leave the child with anyone else while they went out to work. Two mothers reported:

“I have to take him everywhere I go. It is very difficult to get someone to help look after him, they complain that he cannot express himself and that makes it very difficult for them to understand when he wants to go to toilet or when he is hungry or unhappy about something.”

“I just had to quit my job to look after baby „J”. He had not gained neck control as at 6 months old. My mother who was helping me after his delivery was beginning to get tired of taking care of him, she said, she had assumed that by 3 months, she could return back to her house but it looked like, it was an unending task of caregiving. I had to carry him everywhere I went; he just could not be independent. It was at that point that I realized I had to make a decision to quit my job to take care of him; he is my first child.”

Expense of Medication and Equipment

About 95% respondents expressed difficulty in procuring the prescribed medication and equipment for their children which would help to improve their functioning. Two of the caregivers (one mother and the other a father) shared their experience:

“There are about three medicines the doctors always prescribe for him but none is covered by the health insurance. I have to buy these medicines every month. The hospitals do not also provide assistive devices to help them move, if I need it, I will have to go and get it myself but I cannot afford it. As I talk to you, I had to go to the roadside to find a taxi to come and pick him from the house to come to the hospital. He is grown now and I can no longer carry him; at least if he had a wheel chair, it would have helped with his movement a bit”

“I must admit it is a very difficult situation the family finds itself especially when it comes to finances. As the father, this major task is on me as the mother is unable to work because she has to take care of our sweet daughter. Her (child with cerebral palsy) condition is such that, she cannot eat and has to be fed through a tube; this tube has to be replaced every three days so you can imagine how frequent we come to the hospital. It comes at a cost too. This expense is aside the medications she has to take. I am only a young graduate who found a job and just got married a little over a year ago, I must say, I have spent all my savings on our daughter’s care, I have sold my car and now taking public transport just to be able to afford the care for her.”

Inaccessibility of Hospital

Of all the participants that took part in the current study, only three (7.5%) lived in close proximity (about 2km) to the Korle Bu Teaching Hospital. Three mothers who participated in the study said they felt that the hospital was inaccessible. One mother who lived 190 km reported:

“The district general hospitals do not have this kind of clinic so we have no option than to travel the distance to access it; and it becomes more costly when we have to charter a vehicle because most public vehicles will not let you board their vehicle when you have a child with such condition.”

Another mother who lived about 12km from the main tarred road where public transport could be accessed shared her experience:

“I have to pay people to carry him to the roadside before we can get a car to the hospital, I repeat the same when we return from the hospital.”

The third mother shared the frustrations she goes through when they finally get to the hospital saying:

“This is the only hospital in the capital that runs a neurodevelopment clinic. After hassling with transportation to get to the hospital, we have to queue and get numbers to stay in the queue waiting to see the doctor who comes at 2pm in the afternoon. Meanwhile, we have to get here early in the morning to get a better position in the queue in order to see the doctor early.”

4.5.3 Experience of the loss of social life

This section describes the experiences the caregivers shared on the effects of having and caring for a child with cerebral palsy on their social life. They gave account on society's perceptions about them and the stigmatisation they endure as carers of children with cerebral palsy.

All participants reported having a child with cerebral palsy had affected their social life in one way or the other. One mother shared her experience within the extended family after having her child:

"My husband's family do not visit anymore, I'm not invited to family gatherings anymore because they do not accept „K“ (child with cerebral palsy) as one of their own and if I could give birth to such a child, then I'm not worth joining the family; that was what my mother-in-law told me after having „K“."

Another mother shared her ordeal with her child when she stepped out. She reported that: *"Going out with „P“ is a whole mission now... the community in which we live shun children with such condition. The moment you step out with him and his clumsy movements, all eyes turn to look at you. We cannot attend functions anymore at church, it is quieter and easier caring for him at home than to experience the „rolling eyes“ when we go out."*

A third mum shared her story of how she had to stop joining all societies and groups after having her child:

“the Ghanaian society and for that matter Africans as we are, we depend on each other but now I cannot honour invitations to funerals and other important events in people’s lives after having my child. It got to a time, I realised I was no longer getting the invitations. I am unable to attend associations and society meetings anymore because I have to care for my child 24/7... the sad part is no one will actually check on you to know why and sympathize with whatever condition you may be going through; you simply get cut off the society.”

4.5.4 The challenge with finding educational resource and day-care

This section describes the difficulties that primary caregivers encountered as they searched for suitable day-care and education for their children with cerebral palsy. They reported that mainstream preschools and schools were unable to meet the special educational needs of these children and are often unwilling to accommodate them. Caregivers are faced with limited resources even in special schools because of the intensive care required for these children.

About 60% of the participants interviewed were still searching for an educational facility that could admit their children. Two mothers reported that they had been to mainstream schools and turned away because they did not have facilities and personnel to take care of such children.

One mother reported: *“when „P” finally started walking, my biggest joy was that he could finally attend school just as his peers but that dream was far-fetched as I was turned away by many public schools. They told me they did not have the personnel to*

take care of him. One principal told me „such children disturb the class when the children are learning“”.

Another mother reported: *“someone told me to try the special schools, I was very hopeful that at least, mingling with his kind was better than none but again I was turned away by two special schools, they said they were not in a position to give such intensive care for children with cerebral palsy; if only I could get him a personal assistant, then they could consider admitting him.”*

CHAPTER FIVE

DISCUSSION 5.1. SOCIO-DEMOGRAPHIC CHARACTERISTICS OF PRIMARY

CAREGIVERS

It was encouraging to note that in the Ghanaian culture, though the 87.5% caregivers being females is expected, 12.5% of males are taking care of children with cerebral palsy. Of much concern however, is the fact that about 80% of the caregivers are aged 30 -50 years. This is the productive years of a person's life, but for the 80% of the caregivers, much of their time would have to be devoted to care for the child with cerebral palsy at the expense of other productive activities to take care of the other members of the family. Perhaps, this explains why in the developed countries like the United Kingdom and the United States of America, the government provides a social intervention to fully cover the maintenance costs of persons with disabilities.

The revelation that majority (40%) of the caregivers had attained the highest educational level of Junior High School is to be expected since with that level of education, they are not likely to be employed with paid salaries.

More than half of the caregivers were either trading (30%) or not engaged in any income generation activity (27.5%). This is to be expected because the caregivers should not work under any strict regulation since that will limit their quality of care. Certainly, 80% of caregivers would be mothers since the mothers by nature show the motherly love for children they have borne from conception to delivery. However, the fact that 97.5% of the respondents had just one child seem to suggest that the mothers on giving birth to a child with cerebral palsy get scared and decide to end her reproductive life.

5.2 EXPERIENCES OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY BEFORE THE DIAGNOSIS OF THE CONDITION OF THEIR CHILD

5.2.1 Confronted with a situation of a child with an abnormality as a new mother

Parenthood poses a developmental crises and a challenging transitional stage for caregivers (Gerdes, *et. al.*, (1988). New parents may feel overpowered by the demands of caring for a helpless infant. Confusion and doubt expressed by caregivers is even more pronounced as they struggle to understand and integrate exhausting health issues or developmental abnormalities in their children who appear to be perfectly normal. The participants in the current study confirmed the above as a vivid experience they went through. The researcher also observed the above as the primary caregivers mostly mothers, tried to recollect the events that surrounded their pregnancies and birthing processes, they expressed confusion and doubts in pointing at a particular event that led to the malformation of their child. This expression was understood as it was expected of mothers to look out for signals of abnormalities in their children right from birth. Perhaps, the difficult part would be picking up signals one probably could not compare

to that of other children's development. This was a daunting task for the primary caregivers.

Participants in the current study experienced internal conflict, vacillating between denial and acceptance when they first noticed developmental delays that alerted them to potential abnormalities in their children's development. Participants experienced emotional hardship prior to turning to medical professionals for an understanding of their children's development. Another phenomenon that emanates during the prediagnostic phase is a tendency for caregivers to vacillate between admitting that something is wrong with the child, and denial of reality is perhaps the simplest of selfdefense mechanisms and it is a way of distorting what the individual thinks, feels or perceives in a traumatic situation. It consists of defending against anxiety by "closing one's eye" to the existence of threatening reality (Corey, 1996).

It was disheartening to note that among the perinatal causes given by the mothers, birth asphyxia rated high whereas neonatal jaundice led in the postnatal causes. This confirms Badoe, a neurologist's report in 2011 which indicated that about 4 to 5 children out of 1000 birth suffer from CP in Ghana, asphyxia and neonatal jaundice are the main cause.

5.2.2 Breaking out of the superstitious beliefs

In Ghana, disability is found to be a seriously stigmatizing condition due to the cultural beliefs attached (Tinney *et.al.*, 2007; Avoke, 2002). In this regard, disability by birth or in the course of life is usually interpreted as punishment from God or the gods for one's wrong doing, that of a family member or by the community (Avoke, 2002; Kassah, 1998). In some cases, people with disabilities are hidden by family members from the

wider community (Kassah, 1998). Even in extreme cases, children with disabilities are killed to avoid the shame it brings to the family (Avoke, 2002).

Disability is also seen as a result of witchcraft, socery, „juju“ and magic (Avoke, 1997; Agbenyaga, 2002). Some Ghanaians believe that people with epilepsy are filled with demons that sometimes torment and throw them on the ground, when they so wish (Agbenyaga, 2002). Also persons with Down's syndrome and Cerebral Palsy in Ghana are believed to be children given by the river god, and hence called „Nsuoba“, meaning „water children“ (Avoke, 1997). These were confirmed by participants interviewed as they shared their experiences. The world is changing with the presence of varied technologies to help in detecting and diagnosing these conditions, it is unfortunate to note that the education on health related issues has not gone down well with the people in the communities. It was discouraging to note that with all the efforts the government had made in putting up health structures like the Community – based Health Planning and Services (CHPS) compound to render services within communities and educate community folks on public health related issues, children with developmental disorders were still stigmatized and either killed or sacrificed due to cultural beliefs. The caregivers in the current study who mastered courage to flee for help with professional practitioners in the big cities are rare cases in handling cultural issues in our country Ghana.

5.3 EXPERIENCES OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY DURING THE DIAGNOSTIC PROCESS OF THE CONDITION OF THEIR CHILD

5.3.1 Issue of blame and responsibility

Bringing forth children naturally comes with roles and responsibilities for both parents.

In the Ghanaian culture, it is typical for fathers to have the responsibilities of financing the daily upkeep of the children, especially being the head of the family into which the child has been born. Mothers on the other side are responsible for the daily upkeep of the child from nursing the baby from birth, bathing, eating, attending to medical needs and making sure the child gets whatever is required for a good growth.

It is typical in Ghanaian culture for the father to be congratulated when a new baby arrives in the family because he is seen as the creator of the new member of the family. In a home with „normal growing children“, this is usually the routine but the case is different when parents give birth to a child with a developmental disability.

Participants in the current study, especially mothers confirmed they were blamed for having a child with a disability. It was disheartening to note that the father was completely forgotten by other family members as part of the parents that brought forth the child. They begin this blame game right from birth and tend to shift responsibility of bringing up their child solely to the mothers. It was evident in the study that majority of the primary caregivers were the mothers who usually seek for medical attention for their child and continue this process throughout the journey of the diagnosis.

5.3.2 Confusion and mistrust with helping professionals

For some participants, diagnosis of their child's condition was delayed, either because in the mother's opinion healthcare professionals did not perform thorough and careful physical examinations or did not suggest seeking further opinions. Primary caregivers often felt that health professionals were careless or lacked sufficient knowledge about CP to ensure that their child received optimal medical assessment and diagnosis.

Some primary caregivers felt angry, overwhelmingly shocked and helpless when healthcare professionals did not take their suspicions seriously or gave them false hope that their child was healthy, which contributed to delays in diagnosis and lost opportunities for early treatment. Where children suffered from mistaken diagnosis and treatments, mothers reported they felt angry and powerless.

Primary caregivers felt there was a communication gap between themselves and the health professionals because they had a lot of unanswered questions which no one was available to report to. This mostly led to mistrust of the diagnosis in majority of the cases and subsequently led to delay of treatment and lost hope for most mothers. George *et al.* (2007) pointed out that disclosure without giving any positive information leads to dissatisfaction with a physician's insensitive attitude, caring and support. Hope is an important motivating factor for parents in seeking treatment for their child and helping them overcome their negative emotions (Graungaard & Skov, 2006). These findings echo previous research relating to a loss of trust in healthcare professionals and resulting in loss of hope for future treatment and possibilities for their child (Baired *et al.* 2000; Rannard *et al.* 2005; Graungaard & Skov 2006; Tattersall & Young 2006; Fitzpatrick *et al.*, 2007).

5.3.3 Mixed feelings about the diagnosis

Primary caregivers had paradoxical feelings about the diagnosis. They had feared that there was something wrong with their child, yet felt a sense of relief after learning the diagnosis of their child. The diagnosis confirmed long-held suspicions about their child's developmental delays. However, it was hard to accept the diagnosis at that moment, because it destroyed their hope of being a mother of a healthy normal child.

The relief felt by some mothers on learning about their child's diagnosis suggests that they needed some certainty, a possible picture of the future, and direction for starting treatments and subsequent management (Graungaad & Skov 2006; Fitzpatrick *et al.*, 2007; George *et al.*, 2007). Graungaad and Skov (2006) argued that knowing a diagnosis creates new images rather than uncertainty about the future and identifies possibilities for action.

5.4 EXPERIENCES OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY AFTER THE DIAGNOSIS OF THE CONDITION OF THEIR CHILD

5.4.1 Strained family relations

There is undoubtedly an inordinate amount of stress placed on a marriage when a child has a disability. Marriages unravel due to complications and stress that simply cannot be managed. When this happens, the consequences of divorce can be enormous and exponential: the financial pressures, stress of single-parent caregiving, impact on the child with a disability who has an even harder time managing change; as well as effects on the typically developing children who are already coping with having a sibling with special needs (Tzivy Reiter, 2012).

Tzivy, 2012 further states at the same time, there are couples who parent a child with a disability with marriages that are incredibly strong: couples who “have each other’s backs,” who understand the unique pressures they each face and provide support to one another as they meet them. Corman & Kaestner, 1992 argues that having an unhealthy child decreases the mother’s likelihood of being married. These differences were confirmed in the current study. Half (50%) of the participants interviewed had only one child that was the child with CP. Out of that, some mothers could not have another child with the fear of having another child with disability while others had had a broken home due to the stress of managing that child with CP. On the other hand, a unique finding in the current study was the fact that, caregivers that had two or three other children in addition to the child with CP had very strong marriages where both parents were involved in caring for the child with CP.

Unequal caregiving responsibilities: Often one parent, (usually the mother) carries a disproportionate amount of the caregiving responsibilities. These roles may be assumed by design or they may just evolve over time. This can occur even when financial responsibilities are shared. In these instances, the primary caregiver will often feel that her/ his spouse just doesn’t “get it”- the extent of the care they need to provide, the minutiae of their daily responsibilities, the stress from navigating the bureaucratic service delivery system and their personal need for some time away from caregiving. This divide can create emotional distance unless it is recognized and suitable attention is focused on the needs of both parents says Tzivy Reiter (2012).

The mixed emotional expressions experienced by the siblings of child with CP was expected as children who did not have a full picture of the condition. Sharpe and

Rositter's meta- analysis on siblings of children with chronic illness showed that psychological functioning (i.e., depression, anxiety), peer activities, and cognitive development scores were lower for siblings of children with a chronic illness compared to the normative. This was confirmed in the current study.

5.4.2 Experience of Poverty

The word „poverty“ means different things to different people, and it is one's value judgment that determines the kind of definition one is likely to give to this social phenomenon. While this study did not set out to study poverty per se, poverty emerged as an overriding factor.

It appears that although children with cerebral palsy do have very specific needs, the mothers of these children do not trust others to take care of them as they would a nondisabled child and thus isolate themselves further from society hence they find it difficult to go out to work. These reports are confirmed by Johnson and Deitz (1985) who found that mothers with physically handicapped children had difficulty getting away from home in order to participate in social activities.

The difficulty in procuring the prescribed medication and equipment to help improve the functioning of their children was unanimous among the participants of this study. This is confirmed in a study by Amanda Honeycutt *et al*, (2003), as she tries to estimate the direct medical costs, non-direct medical costs and productive losses resulting from increased morbidity and premature mortality for people with developmental disability. Her findings suggested that lifetime costs in excess of costs for individuals without

developmental disabilities was approximately US\$ 800,000 per person for cerebral palsy.

Transport remains a major barrier to health services for people living in rural areas (Anderson and Phohole, 2003). Kilonzo (2004) reported that caregivers identified lack of transport and lack of understanding on the behalf of taxi and bus drivers (regarding transporting disabled children and wheelchairs) as problems which made coping with caregiving roles difficult. These were confirmed in the current study as common complaints among caregivers of children with cerebral palsy included long distances which people have to travel, combined with expensive, unreliable transport, making regular follow-up visits difficult to achieve.

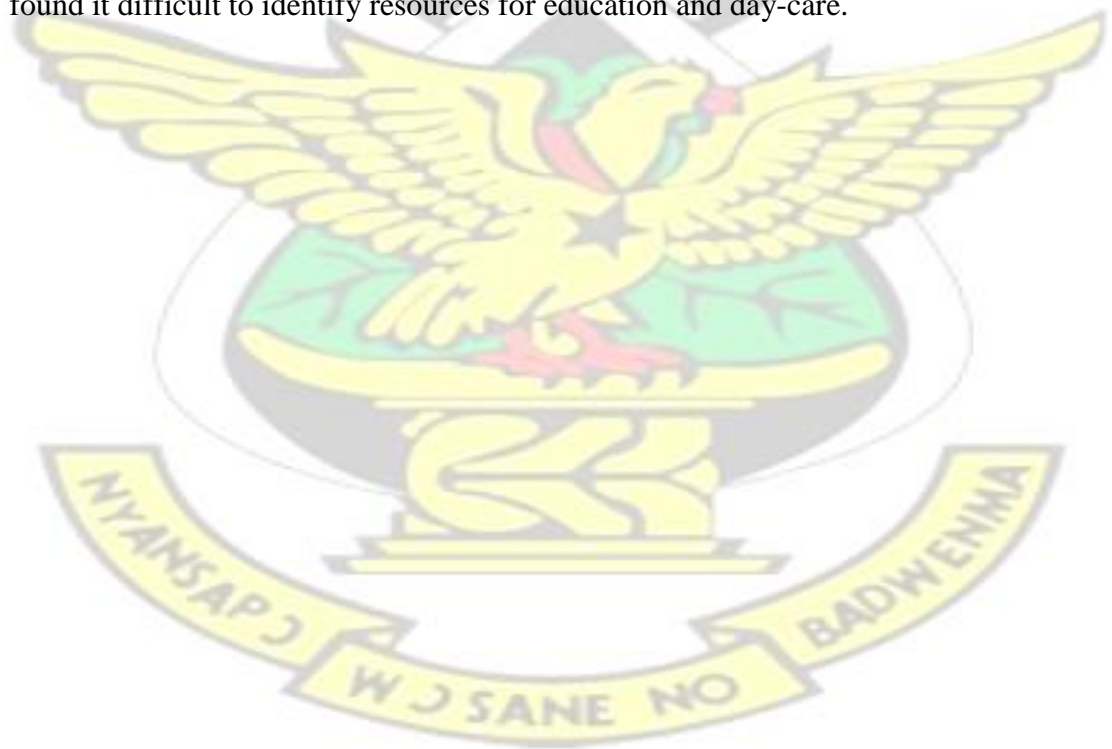
5.4.3 Experience of loss of social life

Due to the strong stigma attached to disability, in many instances, the family may become isolated from their communities and in these instances, it is not uncommon for marital breakdown to occur (McConachie, 1997). Often parents of new-borns with disabilities are advised to institutionalize their baby or risk social exclusion and marital distress (McConachie, 1997). In Ghana, disability is found to be a seriously stigmatizing condition due to cultural beliefs attached (Tinney et.al., 2007; Avoke, 2002). In this regard, primary caregivers in the current study found it more comfortable in staying indoors with their children or be among other caregivers of children with the same condition either as individuals or in support groups, rather than facing the society that inflicts emotional pain in addition to their already deplorable situation. The value of support groups is immeasurable as Kurtz (1997), states it. It has also been noted in

previous studies (Houton, Cooper and Ford, 2002) that it can be run in any setting without any specific expertise.

5.4.4 The challenge with finding educational resource and day-care

A recent systematic review on participation in leisure activities in children and adolescents with CP has highlighted that very few studies have described this domain in this particular population (Shikako-Thomas *et al*, 2008). However, Majnemer (2006) identifies participation in leisure activities emerging as an important „outcome“ for children with disabilities, with benefits that include fostering friendships, enhancing skill competencies, and developing personal interests and identity. Unfortunately, the case for the children of the primary caregivers in the current study is different as they found it difficult to identify resources for education and day-care.



CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.1 CONCLUSION

The aim of the current study was to explore and describe the experiences of primary caregivers of children with cerebral palsy before the condition is diagnosed, analyze their experiences during the diagnostic process and to examine their experiences after the diagnostic process. The following conclusions were made from the research findings:

1. The emotional turbulence of primary caregivers of children with cerebral palsy already begins shortly after giving birth to the child. Caregivers are confronted with doubts and confusion in trying to understand the emerging health problems and or developmental abnormalities in their children. Some primary caregivers may vacillate between denial and acceptance when they find out about the developmental delays and the early warning signs in their children.
2. Primary caregivers with staunch cultural backgrounds in Ghana may be confronted with repercussions of superstitious beliefs and are compelled to act as directed by the heads of their families and/or community leaders in the communities in which they live. Their actions may lead to sacrificing or abandoning the child with cerebral palsy.
3. Primary caregivers, mostly mothers experience greater stress and

responsibility in caring for a child with cerebral palsy than their husbands or partners. Their position of increased responsibilities exposes mothers to blame and criticism by their partners, and other family members which intensify their

perceived stress, self-blame and guilt regarding the child with cerebral palsy's condition.

4. The relationship between helping professionals and primary caregivers is one of the most important relationships that intercedes primary caregivers' experiences of the diagnostic process. Caregivers of children with cerebral palsy often feel disempowered by the tendency of helping professionals to negate their concerns and do not take their reports of delayed development in their children into serious consideration. Opinions expressed by helping professionals during the diagnostic process are sometimes, confusing, vague and non-definitive. Most caregivers have many professional contacts either by referral or on their own because the diagnosis of the children are usually varied. As a result of these difficulties, there is the possibility that primary caregivers of children with cerebral palsy could become disappointed and lose their trust in the medical professionals.
5. Primary caregivers of children with cerebral palsy get a sense of relief once the diagnosis is finally made because their anxiety and fear that something may be wrong with their child becomes confirmed. The grief process of primary caregivers of children with cerebral palsy relates to the loss of a normal child.
6. Almost all family subsystems are affected by the presence of a child with cerebral palsy. It is not uncommon that conflict in the parental subsystem could spill over into the spousal subsystem or the sibling subsystem and viceversa. A common cause of conflict in marital relationships relates to extreme demands on time and energy that children with cerebral palsy make on caregivers. This give them little or no time to spend with their partners; at

the same time, this affects parenting for other normal growing children. Primary caregivers may be left with guilt and regret that they had missed out on special moments during their other children's development. Normal developing

siblings are not left out as they demonstrate contradicting emotions of anger or resentment and at the same time love towards their sibling with cerebral palsy. It has been noted that they show a sense of responsibility towards their sibling with CP too.

7. The linkage between disability and poverty emanated from this study as most primary caregivers of children with cerebral palsy were unable to leave their care duties to go out to work. The expense of medication and equipment deepened the financial burden on caregivers and the inaccessibility of hospitals aggravated the already deplorable condition.
8. Primary caregivers of children with cerebral palsy tend to lose their social lives due to the stigma society puts on disability. Though they may not be disabled themselves, the pervasive influence of disability does not leave them out. This situation eventually leaves them more comfortable within the company of other caregivers of children with the same or similar conditions than the normal society.
9. Primary caregivers of children with cerebral palsy face further challenges as they search for suitable day-care and education for their children. Mainstream preschools and schools are unable to meet the special education needs of these children, and are often unwilling to accommodate them because of their intensive care demands. Caregivers are faced with limited resources for

learners with special education needs in Ghana and the financial burden associated with such education further increases the stress on these families.

6.2 RECOMMENDATION

The following recommendation are provided to improve services rendered to primary caregivers of children with cerebral palsy:

1. Multidisciplinary approach by helping professionals

Health professionals are encouraged to empower primary caregivers with information and resources, and to adopt a greater collaboration and partnerships between multidisciplinary professionals during the diagnostic process. Research participants called for the involvement of a psychologist and a social worker to cater for the needs of the caregivers, in addition to the neurologist, physiotherapist and dieticians that only cater for the child with cerebral palsy.

2. Educating the community

The social model of disability says that disability is caused by the way society is organised, rather than by a person's impairment or difference. It looks at ways of removing barriers that restrict life choices for disabled people. Barriers are not just physical. Attitudes found in society based on prejudice or stereotype, also disable people from having equal opportunities to be part of society. However, the changing of attitudes is not something that happens automatically or spontaneously. The process of educating the community, thus initiating the attitude change can be targeted through a number of processes. To start with, one needs to raise awareness in terms of disability, human rights and development. It is hoped that doing this would decrease the discrimination

experienced by persons with disabilities and their families. In the context of primary healthcare, community nurses in conjunction with Community

Based Rehabilitation (CBR) workers can run workshops in clinics and hospitals.

Likewise, CBR workers together with social workers can address community durbars and use other communication channels like posters and banners in public places. This would include introducing new ideas and concepts through community leaders and engaging them as first point of access to attitude change.

3. Setting up Support groups

Establishment of support groups in the community and hospital will help caregivers engage better and learn from each other. In the hospital, it will benefit caregivers attending the neurological clinic from diverse backgrounds to engage and share experiences.

4. Developing Public policies to include caregivers of children with disabilities

In drafting policies, issues of Persons with disabilities and their caregivers must be dealt with independent of each other. The needs and rights of the informal caregiver should be separated from the needs and rights of the person with disability. A balance must be found, so that each person has independence, dignity, and quality of life.

5. Research

Subsequent studies should explore the influence of the community, gender dynamics in caring and religion on the experiences of the caregiver in depth as the current study could not include these due to the limited time for the research. .

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APPENDICES

Appendix A – Semi-Structured Interview guide

SEMI-STRUCTURED INTERVIEW GUIDE EXPERIENCES UP TO THE DIAGNOSTIC PROCESS

□ Researcher introduces self and summarizes the aim of the study.

Main areas of inquiry:

[Start questions with: *how have you experienced....; what is your understanding of....; please tell me more about....; what was it like....; what do you remember most....; what was most helpful....; what made it difficult....; what (if anything) would you have done differently....; what sense did you make of...*]

1. Biological data (Name, age employment, highest level of education, home language, marital status).
2. Family size and focused family history (Employment of caregivers, birth order of children, basic characteristics/ personalities of family members).
3. How did you experience [name of child with cerebral palsy] as an infant and baby? What do you remember most as you think back to that time?

EXPERIENCES DURING THE DIAGNOSTIC PROCESS

1. How did it come about that you decided to seek help for [child's name]? Tell me about this time in your family's life.
2. Who first mentioned cerebral palsy? What sense did you make out of such diagnosis/ what did that diagnosis mean to you?
3. What was particularly difficult during this time?
4. What was helpful?
5. How did you feel during this stage?
6. What did you do/felt like doing after you were told? What thoughts and concerns ran through your mind as you tried to understand your child's condition?

POST DIAGNOSTIC EXPERIENCES

Main areas of inquiry:

1. Tell me about the general running of the household after [child's name] was diagnosed with cerebral palsy. How is this different now, than it was when he/she was first diagnosed? How did you manage daily tasks such as feeding, meals, bath time, using the toilet, bedtime, fun activities, etc.?
 2. What difficulties did you encounter? What helped?
 3. How did you cope with all the demands on your time and energy? What or who was the most helpful in coping with the demands of raising a child with cerebral palsy? Who did you turn to for help?
 4. Tell me about your experiences, struggles and eventual adjustment in terms of the impact of [child's name] on other siblings and family members.
 5. What formal support systems and helpful organizations are available to you? What informal support networks have helped you through tough times? How did you experience the efficacy of these resources?
 6. What do you still need? How can the services available to caregivers of children with cerebral palsy be improved?
 7. What are your thoughts about [child's name] future? What are your main concerns about him/her? What gives you hope?
- *Summarize main areas covered in the interview. Ask participants to share anything else that they regard as important or that the researcher did not ask about.*
 - *Thank participants for their willingness to share their experiences. Obtain postal address or telephone number to provide summarized details of the major findings and recommendations of the study at the completion of the research to participants who want this information.*

Appendix B – Participant Information Leaflet and Consent form

Participant Information Leaflet and Consent Form

This leaflet must be given to all prospective participants to enable them know enough about the research before deciding to or not to participate

Title of Research:

INVESTIGATING THE LIVED EXPERIENCES OF PRIMARY CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY IN THE ACCRA METROPOLIS

Name(s) and affiliation(s) of researcher(s):

This study is being conducted by JOANA DOROTHY TANDOH, a student of Community Health, Kwame Nkrumah University of Science and Technology, Kumasi.

Background (Please explain simply and briefly what the study is about): There is a gradual increase in the population of children with cerebral palsy globally and this is indirectly increasing the population of caregivers for these children, but these caregivers have received very little attention in any kind of intervention. The big question his study seeks to answer is: who is caring for the caregiver? The study thus seeks to explore and understand the lived experiences of primary caregivers of children with cerebral palsy attending the KorleBu Teaching Hospital in the Greater Accra Region.

Purpose(s) of research: The study seeks to explore and describe how the primary caregivers of children with Cerebral Palsy experience the diagnostic process and how they adjust in the different areas of family life after the diagnosis has been made in Ghana.

Procedure of the research, what shall be required of each participant and approximate total number of participants that would be involved in the research: After purposively recruiting the participants, each participant will be asked to sign the consent form after carefully reading, understanding and agreeing to the consequences of engaging in the study. Each participant will then be interviewed for approximately, 30 minutes. The interviews will be audio taped for subsequent analysis. Anonymity and confidentiality of the participants will be ensured since there will no inclusion of any identifiers and or any incriminating information on participants.

Risk(s):

This study will pose no risk of harm, embarrassment or offence to participants, to third parties, or to the community at large

Benefit(s):

The findings of my study will contribute to the general body of knowledge of research in the experiences of primary caregivers of children with cerebral palsy in Ghana. Secondly, the study will inform policy makers on appropriate policies that would include the wellbeing of caregivers and identifying them as informal service providers and finally inform the academia about the need for appropriate training programmes for caregivers at the grass root level.

Confidentiality:

All information collected in this study will be given code numbers. No name will be recorded. Data collected cannot be linked to you in anyway. No name or identifier will be used in any publication or reports from this study. Audio tapes will be destroyed right after transcription and coding to protect the confidentiality of the research participants

Voluntariness:

Taking part in this study should be out of your own free will. You are not under obligation to. Research is entirely voluntary.

Alternatives to participation:

If you choose not to participate, this will not affect your treatment in this hospital/institution in any way.

Withdrawal from the research:

You may choose to withdraw from the research at any time without having to explain yourself. You may also choose not to answer any question you find uncomfortable or private.

Consequence of Withdrawal: There will be no consequence, loss of benefit or care to you if you choose to withdraw from the study. Please note however, that some of the information that may have been obtained from you without identifiers (name etc), before you chose to withdraw, may have been modified or used in analysis reports and publications. These cannot be removed anymore. We do promise to make good faith effort to comply with your wishes as much as practicable.

Costs/Compensation: For your time/inconvenience/transport to the hospital, we will compensate you with a play item for your child to show our appreciation for your participation.

Contacts: If you have any question concerning this study, please do not hesitate to contact Joana Dorothy Tandoh (Name of Researcher or PI) on 0203739633

Further, if you have any concern about the conduct of this study, your welfare or your rights as a research participant, you may contact:

**The Office of the Chairman
Committee on Human Research and Publication Ethics
Kumasi
Tel: 03220 63248 or 020 5453785**

CONSENT FORM

Statement of person obtaining informed consent:

I have fully explained this research to _____ and have given sufficient information about the study, including that on procedures, risks and benefits, to enable the prospective participant make an informed decision to or not to participate.

DATE: _____ NAME: _____

Statement of person giving consent:

I have read the information on this study/research or have had it translated into a language I understand. I have also talked it over with the interviewer to my satisfaction.

I understand that my participation is voluntary (not compulsory).

I know enough about the purpose, methods, risks and benefits of the research study to decide that I want to take part in it.

I understand that I may freely stop being part of this study at any time without having to explain myself.

I have received a copy of this information leaflet and consent form to keep for myself.

NAME: _____

DATE: _____ SIGNATURE/THUMB PRINT: _____

Statement of person witnessing consent (Process for Non-Literate Participants):

I _____ (Name of Witness) certify that information given to _____ (Name of Participant), in the local language, is a true reflection of what I have read from the study Participant Information Leaflet, attached.

WITNESS' SIGNATURE (maintain if participant is non-literate): _____

MOTHER'S SIGNATURE (maintain if participant is under 18 years): _____

MOTHER'S NAME: _____

FATHER'S SIGNATURE (maintain if participant is under 18 years): _____

FATHER'S NAME: _____