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SCHOOL OF NURSING

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UNIVERSITY OF GHANA, LEGON

QUALITY OF LIFE OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY IN THE ACCRA METROPOLIS

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THIS THESIS IS SUBMITTED TO UNIVERSITY OF GHANA, LEGON, IN PARTIAL FULFILLMENT OF THE REQUIREMENT FOR THE AWARD OF MASTER OF PHILOSOPHY DEGREE IN NURSING.

INTEGRI PROCEDAMUS

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DECLARATION

I, Kokui Dziedzom Klutse hereby declare that this thesis is the product of my original work, except for cited articles which were duly referenced. This study was undertaken under the direction and tutelage of Dr. Florence Naab and Mrs. Adzo Kwashie, both at the School of Nursing, University of Ghana. This work has never been submitted to any other institution or by anyone for any accolade.

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DEDICATION

All glory to God for his inestimable favour and mercies. This thesis is dedicated to the Almighty God who continuously endowed me with the fortitude and strength to undertake this study. I also dedicate this work to my family for their love and support throughout this course. Finally, this work is dedicated to all children with Cerebral Palsy and their Caregivers.

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LIST OF ABBREVIATIONS

E.g	For example
CP	Cerebral Palsy
CB	Caregivers Burden
QoL	Quality of Life
DAS	Depression, Anxiety and Stress
MoH	Ministry of Health
MGCSP	Ministry of Gender, Children and Social Protection
LEAP	Livelihood Empowerment Against Poverty
APA	American Psychological Association
AMA	Accra Metropolitan Assembly
GHS	Ghana Health Service
NGO	Non- Governmental Agency
SPM	Stress Process Model
NMIMR	Noguchi Memorial Institute for Medical Research
WHO	World Health Organization

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ABSTRACT

The consequences of living with a chronic condition such as Cerebral Palsy (CP) do not only affect the child but other members of the family. Using the Stress Process Model by Pearlin et al. (1990) as an organising framework, this study investigated the factors influencing the quality of life (QoL) of caregivers of children with CP. The role of social support in ameliorating the negative consequences of the stressors on QoL of caregivers of children with CP was also assessed. The study employed a cross-sectional survey design. Data was collected from 130 caregivers at 37 Military Hospital, Princess Marie-Louis Hospital and two Non-governmental agencies; Givers Never Lack Foundation and Sharecare Ghana. Statistical Package for Social Sciences (SPSS) version 20.0 was used for data analysis. Descriptive statistics, correlation and regression were the statistical tools used for data analysis. The findings revealed that caregivers of children with CP had a lower QoL. They also experienced higher amount of burden and moderate levels of depression, anxiety and stress. The primary and secondary stressors were found to negatively correlate with QoL of caregivers. Secondary Stressors were found to partially mediate the relationship between caregivers' burden and QoL. There was also a moderating effect of social support on the relationship between the primary stressor and QoL with social support accounting for 44.6% of the variance in QoL. Demographic characteristics of the caregivers collectively explained an insignificant 3.7% of the variance in caregivers' QoL. These findings have implications for nursing practice and informal caregiving.

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CHAPTER ONE

INTRODUCTION

1.1Background of the Study

The cry of a baby often signifies a successful birthing process which brings joy to the mother and the family at large. Besides this joy is the inner most desire coupled with uncertainties especially on the part of the mother for the child to grow and attain the required developmental milestones. However, some children encounter difficulties in the early and late stages of development which require substantial health care and resources (Davis, Shelly, Waters & Davern, 2009). One of such difficulties is chronic disability. Research has demonstrated that one of the commonest causes of chronic disability in children is cerebral palsy (CP) (White-Koning et al., 2007; Rosenbaum, Leviton, Goldstein, Bax, Damiano, Dan & Jacobsson 2007; Snider, Majnemer, & Darsaklis, 2010). This is supported by statistical evidence that the prevalence of CP is 1.5–2.5 per 1000 live births globally (Blair, 2010; Oskoui, Coutinho, Dykeman, Jette & Pringsheim, 2013). According to Cerebral Palsy International Foundation (2015), 1 in 500 babies globally is diagnosed with CP. In the United States of America, the Center for Disease Control (CDC) report indicates that CP affects 1 in every 303 children (CDC, 2011). In Nigeria, CP accounts for 36.0% and 42.4% of cases treated at the paediatric neurology clinics in Ibadan and in Kano respectively (Benlonwu, Gwarzo & Adeleke, 2009; Lagunju & Okafor, 2009). Reports indicate that about 4 to 5 children out of every 1000 births suffer from CP in Ghana (Ghana Business News, 2011).

The term CP refers to a group of permanent disorders associated with the development of movement and posture which has been attributed to non-progressive disturbances that occur during the development of the fetal or infant brain (Rosenbaum et al., 2007). CP is a chronic condition defined as a set of functional limitations due to alterations in the development of the central nervous system (Rethlefsen, Ryan & Kay, 2010). Shelly and

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colleagues (2008) asserted that CP results from mutilation to the fetal or developing brain which leads to partial loss of motor and cognitive functioning (Shelly et al., 2008). Reported characteristics of CP include impaired motor function, sensory and intellectual impairment, as well as complex limitations in self-care functions (Rosenbaum et al. 2007). The disturbing fact in this scenario is that there is no definite cure/treatment for the brain injury that leads to CP and its subsequent motor dysfunction (Centres for Disease Control and Prevention, 2015). What research has succeeded in doing thus far is to provide a variety of therapies which enhance a patient's overall QoL by mitigating musculoskeletal damages and pain (Waters, Maher, Salmon, Reddihough & Boyd, 2005). This implies that a child with CP would most probably need the assistance of a caregiver to help with activities such as trips to the hospital for routine visits and assisting with the child's daily routine. In view of this, some previous studies have given particular attention to caregivers of individuals with CP, especially, the informal caregivers (Pousada, Guillamón, Hernández-Encuentra, Muñoz, Redolar, Boixadós & Gómez-Zúñiga, 2013; Wippermann, 2013).

The enormous effects of living with a chronic condition such as CP affects both the child and especially the caregiver, who often spends much time with the CP patient (Bruns, Moe, Jennings, Ca & Natour, 2008). A caregiver in relation to CP is one with the primary responsibility of encouraging a child with CP to become independent in his or her daily activities (Mancini, Coster, Trombly & Heeren, 2002). This responsibility is in line with Mancini et al, (2002) assertion that children with the most severe motor impairment require the greatest level of assistance to perform tasks. Eker and Tuzun (2004) described the work of caregivers of CP as sacrificial. According to Eker and Tuzun (2004), it is a requirement for caregivers of children with CP to often sacrifice facets of their own well-being so that they can have enough time to care for their children.

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Caring for any child entails huge amount of resources, however the strain for these resources is often augmented when caring for a child with CP (Erdoganoglu & Gunel, 2007). Previous studies have shown that caregivers of children with CP do compromise their physical health and psychological well-being because they continually have to juggle between the needs of their children and their own needs (Brehaut et al., 2004; Raina et al., 2005). A child who requires special care such as children with CP may also influence the emotional, environmental, and physical aspects of others, especially the main person responsible for that child (Greenberg, Seltzer, Krauss, Chou & Hong, 2004). In fact, caregivers need ample time because children with CP require continuous special care, frequent medical checkups, and physiotherapy management (Erdoganoglu & Gunel, 2007). Studies have indicated that mothers are the main caregivers of children with this disability and that the disabled child's reliance on others in their everyday activities has a substantial effect on the psychological state of the caregiver (Yilmaz, Erkin, & Ezke, 2013). For this reason, the provision of a high level of care required by a child with CP can affect and impact the QoL of the caregiver. Other studies indicate that caregivers of children with chronic conditions such as CP are faced with physical, social and psychological health problems (Al-Gamal, 2013; Dellve, Samuelsson, Tallborn, Fasth & Hallberg, 2005; Turnbull, Turnbull, Brown & Turnbull, 2004).

The caring responsibility of caregivers in combination with their daily activities can be demanding (Prudente, Barbosa & Porto, 2010). The demands associated with caring for the CP patient have implications for the psychological and physical health and the QoL of the caregiver (Al-Gamal, 2013). The effectiveness of caregivers of children with CP is determined by their quality of life (Erdoganoglu & Gunel, 2007). This is because the adverse health status of the primary caregiver could interfere with the ability to meet the needs of the patient and might thereby affect the patient’s rehabilitation (Burkhard, 2011).

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According to the World Health Organization (2005), "health is not only the absence of disease and infirmity, but also the presence of physical, mental, and social well-being" (Terra, Cysneiros, Schwartzman, Arida, Cavalheiro, Seorza and Albuquerque, 2011). "QoL is an individual's view of his/her place in life, in the context of the customs and value systems in which he/she lives, and also in relation to his goals, potential, standards and concerns" (The WHOQOL Group, 1995). Research indicates that caregivers (such as parents) of children with CP report with poorer physical, mental, and social well-being than parents of children with no CP (Murphy, Christian, Caplin, & Young, 2006; Parkes, Caravale, Marcelli, Franco & Colver, 2011; Yilmaz et al., 2013). Taking care of a child with CP is connected with different physical, psychological and social changes for the caregivers. One of the most affected physical, psychological and social changes is the social network of the caregiver which results in lower QoL. This is due to the lack of opportunities for leisure activities, impossibility to go out and associate with friends and changes in family routines, (Amendola, Oliveira, & Alvarenga, 2011).

The QoL of the caregiver of a CP patient may be dependent on certain conditions, experiences, and activities that threaten the effort of the caregivers in achieving their purpose (Dezot, Alexandre, Freire, Mercês & Mazza, 2014). These factors are called stressors in caregiving. There are two categories of stressors, mainly primary and secondary stressors (Davis, Shelly, Waters, & Davern, 2009). Primary stressors are the magnitude and nature of care arising directly from the needs of the patient. Secondary stressors are the problems and hardships that stem from the impact of the primary stressor on the caregiver (Tessier, Hefner & Newmeyer, 2014).

One significant primary stressor that influences the QoL of caregivers is the unique difficulties that caregivers of children with CP encounter. These unique difficulties are called caregiver's burden. Caregiver's burden is defined as the extent to which the caregiver

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perceives that the different aspects of his/her life have been affected by the task of giving care (Segui, Ortiz-Talo, & de Diego, 2008). A number of factors contribute to the stressors of caregivers of CP. Among these factors include the characteristics of the patient, the responsibilities performed, time spent in caregiving and the characteristics of the caregivers themselves (Erdoganoglu & Gunel, 2007). The limitations of CP patients lead to long-term care, which can be overwhelming although the care provided is part of parenting. This extreme demand may affect the physical and psychological health of the caregiver negatively and also reduce the QoL of the caregiver (Tucker, Butler, Loyuk, Desmond, & Surrency, 2009).

To meet the child's medical, physical and social needs due to CP, caregivers sacrifice aspects of their own well-being in order to dedicate unlimited time to care for the child (Klassen, Klassen, Dix, Pritchard, Yanofsky, O'donnell, Scott & Sung, 2008). The commitment to long-term care and the significant amount of time devoted to the care of the child with CP can negatively affect the QoL of the caregiver (Klassen, Klassen, Dix, Pritchard, Yanofsky, O'donnell, Scott & Sung, 2008). Additionally, caregivers of children with CP run the risk of experiencing higher secondary stressors such as emotional distress and poor adjustment which are generated by the high level of the primary stressors such as caregiver's burden (Anjos, Boery, Pereira, Pedreira, Vilela, Santos & Rosa-Dde, 2015; Segui, Ortiz-Talo, & de Diego, 2008).

Caregivers of children with CP find it hard to cope when there is higher amount of primary and secondary stressors associated with the process of caregiving. Nevertheless, not all caregivers of children with CP have difficulty adapting even in the face of highly stressful life situations associated with the caregiving (Manuel, Naughton, Balkrishnan, Smith, & Koman, 2012; Thompson & Gustafson, 1996). It is therefore important to discern factors that buffer the relationship between the stressors and QoL of the caregiver. Researchers have

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indicated that perceived social support buffers the impact of the stressors on the quality of life of the caregivers (Anjos, Boery, Pereira, Pedreira, Vilela, Santos & Rosa-Dde, 2015; Burnette, Duci & Dhembo (2016).

Social support is a mutual process regarding any aid offered by people whom the caregivers usually have contact with. It deals with having someone to count on in difficult situations in order to receive material, emotional or affective help (Burnette, Duci & Dhembo, 2016; Sit, Wong, Clinton, Li & Fong, 2004). When caregivers do not have people to depend on for their material, emotional or sentimental help, it increases their level of psychological distress and thus affects their quality of life. Studies have indicated that in order for the caregivers to cope with the high demands associated with the caregiving, there is the need to get high support from networks comprising of relatives and friends(Yilmaz, Erkin, & Izki, 2013; Zanon and Batista ,2012). On the contrary, in most cases the caregivers do not receive the support from any of the networks and they have few people to count on (Burnette, Duci & Dhembo, 2016).

On the basis of the above, the present study used the stress process model by Pearlin et al (1990) to examine the QoL of caregivers of children with CP.

1.2 Problem statement

Globally, Cerebral Palsy (CP) is the most common physical disability in children characterized by motor impairments and other functional limitations (Aesha, 2012). The special needs of such children add to the emotional, physical and financial strain inherent in raising them. CP requires long term management. Considering the long period of management for children with CP, the presence of caregivers is immensely crucial to these children. Some studies (Kakooza-Mwesige, Forssberg, Eliasson & Tumwine, 2015; Tessier, Hefner & Newmeyer, 2014) on CP have focused on patients with CP instead of caregivers

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because of the conviction that the patients are the primary target. However, other studies have indicated that the long-term care-giving may affect the physical, social and emotional health of the caregivers, as well as their financial status and over all well-being (Grootenhuis & Bronner, 2009; Olawale, Deih & Yaadar, 2013; Pfeifer, Silva, Lopes, Matsukura, Santos & Pinto, 2013). It is therefore necessary to the benefit of the child that the psychological and emotional strain among the caregivers be given the needed priority and the appropriate support since the strain affects the quality of care rendered (Oh & Lee, 2009).

Earlier research has demonstrated that excessive responsibility on the part of caregivers may adversely affect their physical and psychological health (Brehaut et al., 2009; Tucker et al., 2009). According to Grootenhuis and Bronner (2009), the responsibility of caregivers may affect their social, cultural and professional lives consequently decreasing their QoL. Caring for a child with CP is associated with high financial demands that can adversely impact the financial resources which in turn can contribute to the level of stress among the caregivers. Studies have indicated that lack of social support due to superstition associated with CP, limited financial resources and everyday experiences of caregivers of children with CP could possibly impact the QoL of caregivers (Rentinck et al., 2006; Mobarak et al., 2000).

The psychosocial health and physical effects associated with caring for children with CP have attracted a lot of attention with a large body of studies indicating that psychological, social, economic, and physical factors affect the QoL of caregivers of children with CP (Brehaut et al., 2009; Chen et al., 2014; Fatudimu et al., 2013; Olawale et al., 2013; Wippermann, 2013). Though numerous studies have been carried out on the quality of life of caregivers of children with CP in the European countries, very little has been conducted in other jurisdictions specifically, Ghana (Olawale et al., 2013). In Ghana, because of the belief associated with the cause of the disorder, the children and their caregivers do not get the

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needed support to improve the QoL of the caregiver which invariably influences the patient with CP as well (Olawale et al., 2013).

CP has also always been poorly understood by some societies and has frequently been associated with numerous myths and beliefs as a result of incorrect information regarding the etiology of the disorder (Austin, Dunn, Johnson & Perkins, 2004). Cultural beliefs and misconceptions about CP influence the attitude towards the caregivers and the patients as well. Children with CP and their families are even socially discriminated against on the grounds of widespread negative public misconceptions and beliefs (Martiniuk, Speechley, Secco, & Campbell, 2007). This phenomenon thus highlights the importance of improvement in knowledge of CP in order to improve the care the patients receive. The present study examined the QoL of caregivers of children with CP in the Accra Metropolis.

1.3 Purpose

The purpose of this study was to examine the QoL of caregivers of children with CP in the Accra Metropolis.

1.4 Specific objectives:

The specific objectives are to:

1. Describe the quality of life and stressors of caregivers of children with CP.
2. Examine the relationship between the stressors (primary and secondary) and QoL of caregivers of children with CP.
3. Assess the impact of the stressors (primary or secondary) on the quality of life of the caregivers of children with CP.

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4. Investigate the mediating role of secondary stressors on the relationship between the primary stressors (caregiver's burden) and QoL of caregivers of children with CP.
5. Assess the moderating role of social support on the relationship between the primary stressors and the QoL of caregivers of children with CP.

1.5 Research Questions

1. What are the levels of stressors and quality of life of caregivers of children with CP?
2. What is the relationship between stressors (primary and secondary) and QoL of caregivers of children with CP?
3. How does secondary stressor (stress, depression and anxiety) mediate the relationship between the primary stressors (caregiver's burden) and QoL of caregivers of children with CP?
4. How does social support moderate the relationship between the primary stressors and the QoL of caregivers of children with CP?

1.6 Statement of Hypotheses

Based on the aims and specific objectives, the study sought to test the following hypotheses:

1. There will be a significant negative relationship between primary stressors and QoL of caregivers of children with CP.
2. There will be a significant negative relationship between secondary stressors and QoL of caregivers of children with CP.

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3. The relationship between primary stressors (caregiver's burden) and quality of life will be mediated by secondary stressors (depression, anxiety and stress).
4. Social support will moderate the relationship between the primary stressor (burden) and the QoL of caregivers of children with CP.

1.7 Significance of the Study

The significance of the study can be viewed basically in two facets: research and practice. Family centred care is paramount in paediatric practice and the caregiver by extension forms part of the family. The paediatric team cannot manage these children without the caregiver. This study therefore seeks to enable practitioners to have extensive knowledge in their area of practice. One of the key ways to tackle the management of children with CP is to focus on the QoL of caregivers. Caregivers' role in this respect cannot be overlooked since they are involved in the day- to -day care of the child. Thus, this study highlights the need to provide adequate information on caregivers' QoL as a significant part of management in the life of a child with CP. In view of this, the findings from this study will bring to the attention of the health team and society at large the need to focus on the QoL of caregivers of children with CP.

Additionally, assessing the QoL of caregivers could lead to better identification of the burden in care giving, the psychological and socio-economic stressors that affect them as well as the family unit in order to promote a productive working relationship. Furthermore, findings from this study can guide stakeholders and policy makers to create or shape policies through collaborative efforts to positively improve on the QoL of caregivers and children with CP in a wider context. Furthermore, assessing the QoL of these caregivers will reveal their challenges which when mitigated can positively impact the children with CP. Finally, the outcome of the study would augment the existing store of knowledge on the subject and

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to serve as a catalyst for future research due to the noticeable lack of research on the QoL of caregivers of children with CP in Ghana.

1.8 Definition of Terms

Caregiver: Anyone who spends most of his/her time on daily basis with the child. Such a person ensures the wellbeing of the child. The person performs activities of daily living of the child, sends the child for medical reviews and takes care of the child when he/she goes on admission.

Caregiver in the context of this study refers to the informal caregiver.

QoL: How the caregiver perceives his/herself psychologically, physically, economically, and socially with the duty of taking care of a child with CP and his or her total perspective on life.

Caregiver burden: The difficulties and responsibilities associated with taking care of a child with CP by the caregiver.

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CHAPTER TWO

THEORETICAL MODEL/LITERATURE REVIEW

This chapter presents the theoretical model guiding this study and also reviews relevant empirical literature on caregivers of children with CP

2.1 The Stress Process Model

The stress process model by Pearlin et al. (1990) was initially used for caregivers of Alzheimer's disease and has been applied to caregivers of schizophrenia, caregivers of persons with cancer and other conditions but not for caregivers of children with CP.

Pearlin and colleagues (1990) approached the study of caregivers from the viewpoint of what has been referred to as the stress process. According to Pearlin, et al, (1990), there are processes that force attention on the relationships among many conditions leading to personal stress. The relationships leading to stress develop and change over time. The model does not simply identify the conditions that are associated with stress but emphasizes how these factors are related to each other and the effects on caregivers' psychological wellbeing. Four main domains make up the model with each having subcomponents. These domains are: the background and context of stress; the stressors (primary and secondary); the mediators of stress; and the outcomes which in this study is the QoL of caregivers of children with CP. The relationship between these domains results in outcomes as presented in Figure 1.

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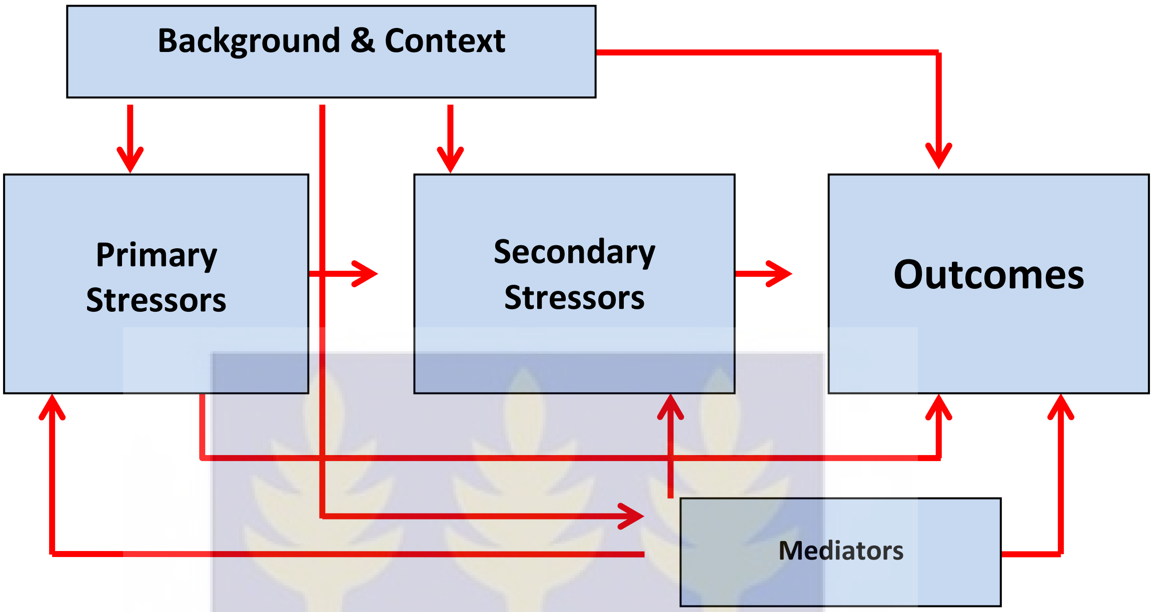
Figure 1: Stress Process Model for Caregivers (Pearlin et al, 1990)



2.1.1 The Background and Context of the Stress Process Model (SPM)

The background refers to the key characteristics such as age, gender, educational level, occupation among others which signify where people fall within stratified orders. This is relevant because care giving and its consequences are potentially affected by these characteristics (Pearlin, et al, 1990). According to the model, the kinds and magnitude of stressors people are exposed to and the ability to deal with them are subject to the effects of these key characteristics. For example, highly educated people will have higher knowledge on the disorder which will guide them in the extent to which they will deal with the stressor. This has the propensity of reducing the intensity of stress they encounter and how they deal with it. The association between the social and economic characteristics of caregivers with other components of the stress process model is of utmost importance. Caregivers may come to feel cut off from the larger society although these kinds of linkages have had some analytic

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attention in studies of caregiver stress, particularly with regard to gender (Tessier, Hefner & Newmeyer 2014).

The context also refers to the networks (including family) to which caregivers have attachments and access to and use of resources and programmes available. There are many programmes that are designed to provide specialized services for patients or caregivers. However, the availability of such programmes varies considerably from one community to another. The extent to which the caregivers have access to these resources indicates the extent to which they can escape some of the hardships and stresses of caregiving.

2.1.2 The Stressors (Primary and Secondary Stressors)

The stressors are the conditions, experiences, and activities that threaten the effort of the caregivers in achieving their purpose. Giving care to the seriously impaired patient such as a child with CP can produce a variety of stressors. Stressors can be divided into primary and secondary stressors. Primary stressors arise from the direct needs of the patient and the quantum of the care given. It is the primary stressors that lead to other problems and hardships called the secondary stressor. An example of the primary stressor assessed in this study is the caregiver's burden. The caregiver's burden can lead to secondary stressors such as depression and anxiety.

The role of both primary and secondary stressors in determining the QoL of caregivers has been found in previous studies. A study by Davis et al. (2009) revealed that the wellbeing of caregivers was determined by the role they played. The study indicated that caregivers who performed roles above their limits experienced lower psychological wellbeing compared to those whose roles were not above their limit. Burkhard (2011) also found that the psychological wellbeing of caregivers is determined by secondary stressors such as depression and anxiety.

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2.1.3 Mediating and Moderating Factors

People exposed to seemingly similar stressors are not similarly affected by them in the same ways. The variability in outcome when exposed to the same stressors is explained by mediators and moderators. Secondary stressors (depression, anxiety and stress) and social support are the mediating and moderating variables respectively in this study that explain the different variability in outcomes when exposed to the same primary stressors (caregivers' burden).

In the model, the secondary stressor (depression, anxiety and stress) serves as the mediator of the relationship between caregivers' burden and QoL of caregivers of children with CP. This means that the primary stressors (burden) may first lead to the secondary stressors (stress, anxiety and depression). The level of secondary stressors (stress, anxiety and depression) produced by the primary stressor (caregivers burden) will determine the caregivers QoL. Kato, Jaarsma, Okada, Kagami, Endo, Ono, and Kinugawa (2015) revealed that caregivers' burden produces higher level of stress, depression and anxiety that negatively affect the quality of life of caregivers of children with CP.

Social support is the moderator of the present study. It explains the different variability in outcomes when exposed to the same stressors. The differences in the amount and quality of social support caregivers obtain account for the fact that caregivers confronting equivalent life problems are unequally affected by the problems. A moderator limits the impact of the stressor on the outcome. For example, social support prevents or inhibits the development of secondary stressors which in turn decreases the consequences of the primary stressors on the QoL of caregivers.

Stressors have the propensity to lead to lower QoL among caregivers; however, the impact of the stressors on the quality of life of the caregivers may be determined by the availability of social support that will help in coping with the stressors. The intensity of the

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impact of the primary stressors on the quality of life will be reduced if the caregiver has a high level of social support as means of coping mechanisms. A study by Cheshire, Barlow and Powell (2010) supported the moderating role of social support in the relationship between caregiver's stressors and quality of life.

2.1.4 Outcomes

Outcomes refer to the consequences of the stressors on the lives of the caregivers. The outcome of the present study is the QoL of caregivers of children with CP. Emotional distress associated with caregiving always surfaces first and if they persist for a long time results in lower QoL.

This model has found evidence from past researchers. There are many factors influencing the QoL of both children with CP and their families. Notable among the QoL determinants include psychological, socio-economic, social support and demographics. For instance, in the study by Wanamaker and Glenwick (2008), it was realized that socioeconomic status associated positively with quality of life. The relationship between socioeconomic status and quality of life was also moderated by social support.

2.2 Literature Review

Apart from the model elaborated above, this section discusses various studies and findings that best aid the researcher in explaining the possible predictors of QoL of caregivers of children with CP and helps to answer the hypothesis formulated for the study. It further reviewed studies on the QoL of caregivers of children with CP, socio-demographic characteristics of caregivers of children with CP and the stressors associated with the care giving process as well as the role social support plays in determining the QoL of caregivers of children with CP. The data sources include CINHL, Google scholar, HINARI, Wiley online

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library, SAGE, EBSCOS host, Science Direct, Taylor and Francis among others. The key words used in the search were; ‘caregiver of children with cerebral palsy’, ‘Quality of life of caregivers’, ‘psychological outcomes of care giving’, ‘social support in care giving’, and ‘Caregiver burden’.

2.2.1 Quality of Life of caregivers of children with CP

One of the complex clinical entities with high severity and complications often needing special care is CP (MacDonald & Callery, 2007). Caring for an individual with cerebral palsy has a possible direct impact on caregivers’ lives; generates overload and changes the caregiver’s normal routines. This has the predisposition to influence the QoL of the caregivers with researchers indicating negative impact of caregiving on the quality of life of the caregiver (MacDonald & Callery, 2007).

There is evidence to support the fact that the QoL of caregivers of children with CP influence the health outcome of the children with CP themselves and thus it is imperative to assess the QoL of the caregivers (Ones, Yilmaz, Cetinkaya & Caglar, 2005; Prudente, Barbosa & Porto, 2010).

Studies have found enormous support for both short and long- term impact of caregiving on the QoL of caregivers of children with cerebral palsy and other neurological diseases. Pavalko and Woodbury (2003) indicated that caregivers consistently experience higher rates of depression than non-caregivers. A study was conducted by Al-Gamal (2013) with the aim of assessing the QoL of caregivers of children with CP. The study recruited 204 parents providing comprehensive care to children with cerebral palsy. The findings indicated that majority of the parents experienced emotional strain. Most of the caregivers also experienced significantly lower level of quality of life.

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Some studies have also indicated lower QoL among caregivers of children with CP compared to those caring for healthy children. The studies also assessed the various components of QoL. For example, a study was conducted by Pinquart and Sorensen (2003) on the impact of caregiving on the QoL of caregivers of children with CP and those providing care for healthy children. The physical well-being component of quality of life was assessed. The results of the study revealed higher level of quality of life (physical well-being component) among mothers providing care for healthy children compared to mothers providing care for children with CP. The study by Pinquart and Sorensen (2003) assessed only the physical well-being component of QoL.

Similarly, Eker and Tuzun (2004) compared the QoL of mothers with children suffering from CP to the mothers of children with minor health problems. A total of eighty four (84) mothers consisting of 40 mothers with a child suffering from cerebral palsy and 44 mothers with a child suffering from minor health problems participated in the study. Data was collected using the Medical Outcomes Health Survey. Findings of the study indicated that with the exception of the physical functioning subscale, the mean scores on all the subscales of the Health Survey Questionnaire were significantly lower in mothers of children with CP than those of the comparison group. The study also indicated that most participants were informal caregivers and females. Eker and Tuzun (2004) explained that the inability to get competent people and the high cost of employing formal caregivers are the reasons for the mothers providing care for their children.

Long-term effects of caring for children with CP have also been well reported in earlier studies (Akosile et al, 2011; Chiou et al, 2005). These studies showed that long-term caring for children with CP had negative effects on the quality of life of caregivers' wellbeing. According to Romeo, Cioni and Distefano (2010), caregivers of children with CP show lower scores on physical and psychological domains on the QoL scale.

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A similar study conducted by Guillamon, Nieto, Pousada, Redolar, Munoz, Hernandex, Boixados and Gomez-Zuniga (2013) examined the QoL of caregivers of children with CP. Sixty two parents of children with cerebral palsy completed measures to assess the physical, environmental and social relationships as components of QoL. The results of the study indicated that parents of children with CP had low levels of all the three components of quality of life. These studies conducted in different countries (Eker & Tuzun, 2004; Guillamon, Nieto, Pousada, Redolar, Munoz, Hernandex, Boixados & Gomez-Zuniga, 2013; Romeo, Cioni & Distefano 2010) undeniably reported lower QoL among caregivers of children with CP. The studies however, considered aspects of QoL instead of the entire QoL domains.

Some studies have also employed descriptive statistics to investigate the QoL among caregivers of children with CP. A descriptive study was conducted by Deepthi and Krishnamurthy (2011) with the aim of assessing the mental health status and QoL of caregivers of persons with disabilities. The participants of the study consisted of caregivers of 23 children with cerebral palsy and intellectual disability. Findings of the study revealed that 56.52% of the primary caregivers had lower QoL.

Brehaut, Kohen, Garner, Miller, Lach, Klassen and Rosenbaum (2009) conducted a population based study which assessed the implications of caregiving on the health of the caregiver. Factors such as parenting status, income level, sex and educational background were controlled. The study employed 9401 caregivers of children with CP. The findings of the study revealed that the chronic conditions of caregivers of children with other health related problems were higher than the chronic conditions of caregivers of healthy children.

A study by Neves, Pietrovski and Claudino (2015) assessed the QoL of caregivers of children with CP. The study employed descriptive analysis and the results indicated that caregivers of children with CP had a lower level of QoL. Tessier, Hefner and Newmeyer

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(2014) also evaluated whether the severity of physical symptoms correlates with psychosocial QoL among caregivers of children with CP. A sample of 53 caregivers of children with CP took part in the descriptive study. Results indicated lower level of QoL and its sub-components among caregivers of children with CP.

Despite the fact that the results from the studies by Deepthi and Krishnamurthy (2011), Brehaut, Kohen, Garner, Miller, Lach, Klassen and Rosenbaum (2009), Tessier, Hefner and Newmeyer (2014) and Neves, Pietrovski and Claudino (2015) were consistent with the Stress Process Model for Caregivers (Pearlin, et al, 1990), the descriptive statistical design employed by the previous researchers did not help draw any conclusion as to whether the findings were significant and as such does not completely rule out alternative explanations.

Longitudinal studies have also been conducted to assess the QoL of caregivers of children with CP. For example, Prudente, Barbosa and Porto (2010) investigated the level of QoL of mothers of children with CP. The study was carried out in Brazil among 100 participants using the Medical Outcomes Health Survey. The results of the study indicated that the general health QoL of the participants were low. The QoL of the mothers giving care to the CP patients was significantly lower than the QoL of the general population.

Another longitudinal study was conducted by Strom, Kreuter, and Rosberg (2012) to investigate the QoL of caretakers of children with CP in Cambodia. Results indicated that the quality of life of the caretakers were significantly low in terms of their health, material and emotional well-being. The studies by Prudente, Barbosa and Porto (2010) as well as Strom, Kreuter, and Rosberg (2012) were not without limitations. Prudente, Barbosa and Porto (2010) as well as Strom, Kreuter, and Rosberg (2012) adopted the longitudinal survey design that made way for other confounding variables to influence the results. It could also possible that environmental factors influenced the results. The use of a cross-sectional survey could possibly have helped overcome this error.

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Nimbalkar, Raithatha, Shah and Panchal (2014) adopted the qualitative research design, using focus group discussions to illuminate the quality of life of parents taking care of children with cerebral palsy (CP). Two focus group discussions comprising one at a rural tertiary level care hospital and the other at an urban tertiary level care hospital were conducted. Thirteen parents participated in the two focus group discussions. The findings indicated that the caregiver experienced problems in their social relationships, health problems, financial problems, moments of happiness, worries about the future of the child, need for more support services, and lack of adequate number of trained physiotherapists which determined their lower level of QoL. The researchers concluded that parents of children with CP experienced significantly lower QoL. The study of Nimbalkar, Raithatha, Shah and Panchal (2014) was qualitatively conducted thus generalizability could be questioned.

In a meta-analytical study, Hamzat and Mordi (2007) found out in Nigeria that the general QoL of caregivers of children with CP was low compared with the general population using the General Health Questionnaire. The study by Hamzat and Mordi (2007) employed the meta-analytical approach which is associated with a lot of criticisms. According to Walker, Kattan and Hernandez (2008), several conditions are critical to a sound meta-analysis and small violations of those conditions can lead to misleading results. This renders meta-analytical studies as controversial. Summarizing large amounts of varied information using a single number is another controversial aspect of meta-analysis. Under scrutiny, some meta-analyses have been inappropriate, and their conclusions not fully justified. There is some form of publication bias which affects the reliability of meta-analyses (Walker, Kattan & Hernandez, 2008).

Basaran, Karadavut, Uneri, Balbaloglu and Atasoy (2013) compared the QoL, mental health and burnout of caregivers of patients with CP with caregivers of healthy children. Two

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hundred and three (203) participants consisting of 143 caregivers of children with CP and 60 caregivers of healthy children were selected for the study. The results of the study indicated that caregivers of children with CP had poorer QoL than caregivers of the healthy children. Caregivers of children with CP were also found to have poorer mental health and higher burnout compared to the caregivers of the healthy controlled children. Though the findings of the study being discussed cannot be questioned, the disparity in sample size between the caregivers of the children with CP and the healthy control group was too large thus affecting the extent to which the two groups can be compared. The caregivers of the healthy children (n=60) were not even half the number of the caregivers of the CP patients (n=143).

A comparative study was conducted by Cheshire, Barlow and Powell (2010) to assess the QoL of caregivers of children with CP and caregivers of children without a long-term health condition (LTHC) in the UK. The study involved seventy parents of children with CP and 70 parents of children without a LTHC. Findings of the study indicated that parents whose children have CP had considerably poorer psychosocial wellbeing compared with parents of children without a LTHC. Parents of children with CP had lower satisfaction with life and higher levels of anxious and depressed mood.

It is not all the available studies which have revealed lower QoL among caregivers; others have indicated higher quality of life among caregivers of children with different disorders. A study by Murphy et al. (2006) indicated that there are some positive aspects of caring for a child with a disability. According to the researchers, caregivers develop a sense of compassion and also feel more confident in their caregiving skills. Similarly, Tarlow, Wisniewski, Belle, Rubert, Ory and Gallagher-Thompson (2004) asserted that the role of caregiver makes them feel valuable and needed, increasing their appreciation of life in general.

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2.2.2 Demographic Characteristics of Caregivers of children with CP

Generally, females have been found to provide care for patients with different disorders compared to males. According to the Bureau of Labour Statistics (2014), although men also provide assistance, female caregivers may spend as much as 50 % more time providing care than male caregivers. Estimates of the percentage of family or informal caregivers who are women range from 59% to 75% compared to 25% to 40% by men (Prudente, Barbosa & Porto, 2010). The Ghana Statistical Annual Report indicated that caregiving is normally provided by reproductive mothers within the age of 25 to 45 years.

Studies on socio-demographic characteristics of caregivers of children with CP have largely reflected similar differences in the general population across different countries. A study by Williams and Wilson (2001) assessing the socio-demographic characteristics of caregivers also indicated that the majority of caregivers of children with CP were females who were also unemployed. The age range of the caregivers was largely teenagers and mothers. Among Americans, women were found to take the responsibilities of caregiving among people suffering from CP (Correa, Merhi, Fogaca and de Oliveira, 2009). Among Africans, a significantly higher number of caregivers of children with cerebral palsy are people with lower education and lower income (Family Caregiver Alliance, 2008).

Pinquart and Sorensen (2005) conducted a study with the aim of assessing the differences in caregiver background variables using the meta-analysis to integrate the results of 116 empirical studies. The results indicated that the majority of caregivers had a lower socioeconomic status, were younger, were less likely to be a spouse, and more likely to receive informal support. The study also indicated that the educational status of the caregivers were generally low. Similarly in a longitudinal study by Fatudimu, Hannzat and Akinyinka (2013) most of the caregivers of children with CP (82.3%) were mothers of the children. These caregivers also had lower economic status and lower level of education.

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Brehaut, Kohen, Raina, Walter, Russell, Swinton, O'Donnell and Rosenbaum (2004) also compared the physical and psychological health of caregivers of children with CP with that of the general population of caregivers. Data on the physical and psychological health of 468 caregivers of children with CP were collected using interviews. Demographic characteristics such as the sex, age, income, and educational background of the caregiver were investigated on QoL. Results of the study indicated that the income level of caregivers of children with CP was lower than did the general population of caregivers. Measures of psychological health showed greater reported distress, emotional problems, and cognitive problems among caregivers of children with CP.

All the studies reviewed on socio-demographic characteristics (Brehaut, Kohen, Raina, Walter, Russell, Swinton, O'Donnell & Rosenbaum, 2004; Pinquart & Sorensen, 2005; Williams & Wilson, 2001) only employed descriptive statistics making it difficult to draw any conclusion on the significance of the results.

Adegoke, Adenuga and Akosile (2015) compared the QoL of mothers of children with CP and mothers of typically developing children of similar age. Eighty mothers participated in this cross-sectional survey. Participants in both groups had their QoL assessed using the World Health Organization Quality of Life BREF (WHOQoL-BREF). The results of the study revealed that the caregivers were mostly teenagers. Religion, educational status and occupational status were found to have no significant influence on the QoL of the caregivers of children with CP. The study only employed 40 caregivers of children with CP which is relatively small and may affect the external validity of the findings.

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2.2.3 Impact of stressors (Caregivers burden, Depression, Anxiety and Stress) on QoL among caregivers of children with CP

Giving care to children with CP has been found to be associated with different stressors. According to the single-jeopardy hypothesis (Phillips, Ajrouch & Hillcoat-Nallétamby, 2012), there are higher levels of stressors among caregivers of CP because they are at a greater risk for poor health as a result of the cumulative effects of economic disadvantage and discrimination. The economic demands and discrimination paves the way for two major types of stressors affecting caregivers of children with CP. These are the primary (caregiver's burden) and the secondary stressors (stress, depression and anxiety) (Raina, O'Donnell, Rosenbaum, Brehaut, Walter, Russell, Swinton, Zhu & Wood, 2005).

Owing to the paucity of published research on the relationship between stressors and QoL of caregivers of children with CP, this review of relevant literature was drawn from general caregiving with different disabilities. Most studies have either assessed the primary stressors (caregiver's burden) or the secondary stressors (stress, depression and anxiety).

A significant number of studies have shown that the QoL of caregivers is partly influenced by their level of burden. A study was conducted by Westphal-Guitti, Alonso, Migliorini, da Silva, Azevedo, Caboclo, Sakamoto, and Yacubian (2007) to assess the QoL and burden in 100 caregivers of adolescent and adult patients with epilepsy. Among the caregivers, 50 were taking care of patients with temporal lobe epilepsy (TLE) whilst the remaining 50 were taking care of juvenile myoclonic epilepsy patients (JME). The results of the study indicated a mild to moderate burden on caregivers in both groups. The results also indicated that caregivers of patients with both epileptic syndromes experience interference in their lives. QoL was negatively affected by the burden associated with caregiving.

Similarly, Morimoto, Schreiner and Asano (2003) conducted a study with the aim of examining the characteristics of the caregiving duty which significantly increase their burden

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and to also examine the relationship between caregiver burden and health-related QoL among caregivers of stroke patients. One hundred (N=100) caregivers were sampled from seven randomly selected neurological hospitals in Japan and interviewed using the Zarit Burden Interview, the Modified Barthel Index, the Geriatric Depression Scale and the SF-12 Health Survey for health-related quality of life. The results of the study revealed that increased caregiver burden was significantly related to lower health-related QoL. Findings indicate that about 52% of caregivers had higher levels of depression. There was also a significantly negative relationship between caregiver's burden and health-related quality of life, thus increased burden significantly relates to decreased health-related QoL among stroke caregivers.

Despite the fact that the findings and recommendation of the study by Westphal-Guitti, Alonso, Migliorini, da Silva, Azevedo, Caboclo, Sakamoto, and Yacubian (2007) as well as Morimoto, Schreiner and Asano (2003) are unquestionable, they employed the descriptive design which makes it difficult to draw any conclusion from their studies. There is the need to go further and analyze the data with more inferential statistical techniques such as regression analysis and Pearson Product Moment Correlation Coefficient.

Deniz and Inci (2015) conducted a study to identify the burden of care and quality of life of caregivers of leukemia and lymphoma patients. Using a survey method, the researchers selected 123 caregivers who completed the caregiver's burden interview, and the caregiver Quality of Life Index. Data was analyzed using non-parametric test such as the Kruskall Wallis, and Mann-Whitney U tests. Results of the study indicated that the stressors associated with caregiving negatively predicted the quality of life of the caregivers. The study employed the non-parametric statistical test in data analysis which has low power. Perhaps using a parametric test which has higher statistical power may reveal different results.

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Krug, Miksch, Peters-Klimm, Engeser and Szecsenyi (2016) conducted a longitudinal study to examine the correlations between QoL and burden of family caregivers. Caregivers of Palliative patients with cancer took part in the study. The participants were assessed monthly for an interval of 6 months or until death of the patient. One hundred participants consisting of 63 males and 37 females took part in the study. The results indicated that caregiver burden was moderate and on average did not change over time. Caregiver’s burden was negatively correlated with quality of life explaining 19.3% variance. In addition, feelings of depression and anxiety among caregivers were found to increase the perceived burden of family caregivers. This study, being longitudinal in design could have been influenced by environmental factors and maturation could possibly have prejudiced the findings.

Though the studies reviewed so far assessed the caregivers of patients with different disorders, a significant number of studies have also indicated that quality of life of caregivers of children with CP is partly influenced by their level of burden. Raina, O'Donnell, Rosenbaum, Brehaut, Walter, Russell, Swinton, Zhu and Wood (2005) conducted a study with the aim of determining the factors influencing the physical and psychological health of adult caregivers of children with CP. The study was based on the stress process model. Four hundred and sixty eight (N = 468) caregivers of children with CP took part in the study. Data on demographic variables and caregivers' physical and psychological health were assessed using standardized questionnaires. The results of the study revealed that child behaviour, caregiving demands or burden, and family function were the significant predictors of quality of life among caregivers of children with CP. Less caregiving demands were associated with better physical and psychological well-being of caregivers. Gross income and social support moderated the relationship between the caregiver’s demands and quality of life of the caregivers of children with CP.

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Kato, Jaarsma, Okada, Kagami, Endo, Ono, and Kinugawa (2015) also examined the quality of life (QoL) of caregivers of children with CP and identified factors associated with caregivers' QoL. Only the physical and mental components of quality of life subscales were assessed. Fifty six patients and their caregivers were recruited from a university hospital in Japan. Caregiver burden was evaluated using the 8-item Zarit Caregiver Burden Scale. Results of the study indicated a negative relationship between caregiver's burden as measured with the 8-item Zarit Caregiver Burden Scale and quality of life. The researchers indicated that support and counseling were measures that decreased the impact of caregivers' burden on the QoL. The study assessed only the physical and mental components of quality of life.

It is not only the caregiver's burden (primary stressors) which influences caregiver's level of quality of life. Researchers have indicated a significant impact of secondary stressors such as stress, depression and anxiety on the quality of life of caregivers of children diagnosed with different disorders. Hooley, Butler and Howlett (2005) assessed the relationship between caregiver burden, depression and quality of life among caregivers of congestive heart failure. Fifty participants took part in the study. Findings indicated that caregivers of patients with congestive heart failure experience high caregiver burden and prevalence of depressive symptoms, which are related to the patient disease burden. There was a significant negative relationship between caregiver's burden and quality of life. There was also a negative relationship between depression and quality of life among the caregivers. Caregiver burden score correlated with both caregiver's depression and patient depression. The study by Hooley, Butler and Howlett (2005) assessed both primary and psychological (secondary) stressors. Though there are many components of psychological stressors, only depression was assessed. The role of stress and anxiety were ignored.

Grov, Dah, Moum and Fossa (2005) examined the impact of anxiety and depression on quality of life of caregivers of patients with cancer. The sample consisted of 49 female

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caregivers and 47 male caregivers. The Medical Outcome Short Form Scale (SF-36) and the Hospital Anxiety and Depression Scale were used to measure quality of life and anxiety and depression respectively. Findings of the study indicated that physical and mental QOL were significantly higher for female caregivers than male caregivers. There was no significant difference between males and female caregivers in level of depression. Lower quality of life was found to be associated with higher depression and anxiety.

Gotze, Brahler, Gansera, Polze and Kohler (2014) conducted a study to assess the role of psychological distress in predicting quality of life among caregivers of Palliative patients. The study also assessed the role of social support in moderating the impact of psychological distress on quality of life. The psychological distress was assessed using the Hospital Anxiety and Depression Scale. Data were solicited from 106 participants consisting of 28 palliative patients and 78 family caregivers who were all females. The results indicated that 33% of caregivers suffered from high anxiety and the remaining 67% exhibited higher level of depression. There was a significant positive relationship between patients and caregivers' anxiety and depression scores. Psychological distress was found to be predicted by high financial burden and low social support. Psychological distress was also found to account for higher significant variance in quality of life. However, the prediction was minimal with higher social support. This study involved only female caregivers which cannot be generalized to all caregivers because caregiving is not only the task of females.

Middleton, Simpson, De Wolf, Quirk, Descallar and Cameron (2014) examined the relationship between psychological distress, caregivers’ burden and quality of life (HR-QOL) among caregivers of people with traumatic spinal cord injury (SCI). The study adopted the longitudinal survey method. Forty four participants took part in the study. Psychological distress, HR-QOL, and caregiver’s burden were assessed using the General Health Questionnaire, Medical Outcomes Health Survey and Caregiver Strain Index respectively.

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Findings of the study indicated a positive relationship between psychological distress and caregiver burden. Both caregiver's burden and psychological distress were negatively associated with health related quality of life. There is a problem with generalization of findings of the study by Middleton, Simpson, De Wolf, Quirk, Descallar and Cameron (2014). This is because the sample size of 44 caregivers was relatively small to generalize the findings.

Similarly, Yilmaz, Erkin, and Ezke (2013) conducted a study to assess the psychological stressors associated with caregiving of children with CP and also determined the impact of these stressors on the health-related quality of life (HRQoL) of mothers giving care to children with cerebral palsy. Two hundred and seventy seven (277) participants took part in the study. The quality of life of the participants was assessed using the Short-Form Health Survey (SF-36) and the psychological stressors were assessed using the Beck Depression Inventory (BDI) and the Stigmatization inventory. Results of the study revealed caregivers burden, depression and stigmatization as significant stressors associated with caregiving of children with CP. There was also a significant negative relationship between psychological stressors and quality of life of caregivers of children with CP.

A study by Bemister, Brooks, Dyck and Kirton (2015) found that caregivers of children with cerebral palsy have increased risk for psychosocial concerns including depressive symptoms and poor family functioning. They conducted a study to assess the impact of the psychosocial concerns on quality of life of caregivers of cerebral palsy. Data was analyzed using the bivariate analyses. A total of 103 caregivers took part in the study. The results of the study indicated a significantly negative relationship between psychosocial concerns such as depression and quality of life. Condition severity, anxiety and blame were all found to predict lower quality of life among caregivers of children with cerebral palsy.

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Zanon and Batista (2012) assessed the level of anxiety and depression and the quality of life of caregivers of children with cerebral palsy. A cross-sectional and descriptive design was adopted. A total of 82 caregivers were selected for the study. Findings of the study revealed that anxiety was detected in 49% of the caregivers, and depression in 31%. Depression and anxiety of caregivers of children with CP was found to mostly affect emotional state and quality of life of the caregivers. Zanon and Batista (2012) explained that depression and anxiety are risk factors and their presence exposes caregivers to have lower wellbeing and quality of life. Based on the descriptive statistical design adopted of Zanon and Batista (2012), conclusion could not be drawn there is the need to use inferential statistics so that conclusions can be drawn on the influence of anxiety and depression on quality of life of caregivers of children with CP.

Marron, Redolar-Ripoll, Boixados, Nieto, Guillamon, Hernande and Gomez (2012) assessed the impact of the burden of care-giving on the physical and psychological health of primary caregivers of children with cerebral palsy. Sixty two caregivers (89% women and 11% men) aged between 30 and 54 years took part in the study. Regression analysis indicated that the degree of disability, depression and self-efficacy explained 40.9% of the total variance of physical and psychological health of caregivers. Caregivers' burden alone explained a significant 23% of the variance of physical and psychological health of caregivers. It was found that self-efficacy had a negative linear association with the burden of care-giving, while the degree of disability and depression showed a positive linear association. The most important predictors of caregiver burden were the degree of disability, depression and self-efficacy.

Furthermore, Dambi, Jelsma and Mlambo (2015) assessed the quality of life of caregivers of children with CP in Zimbabwe. A pre-test post-test design was adopted where forty six caregivers of children with CP were assessed twice, at baseline, and after three

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months, for perceived burden of care and health-related quality of life. Findings of the study revealed that caregivers reported a significantly higher level of burden with half (50%) of the caregivers reporting a higher level of burden scores. The high level of burden was associated with some form of pain, stress and depression. The higher level of burden associated with caregiving was found to be negatively associated with lower health-related quality of life.

2.2.4 Role of Social support on the relationship between the stressors and QoL

Studies have shown that social support may serve as a coping resource in optimizing the wellbeing and health outcomes of caregivers. The level of available support from family, friends and significant others has consistently been shown to be associated with fewer reports of stress, anxiety, depression and better quality of life of caregivers (Barakat & Linney, 1992; Kato, et al., 2015). A study conducted by Wang and Zhao (2012) revealed that social support ameliorates the negative consequences associated with caregivers' burden.

A high level of social support has been associated with improved personal wellbeing of caregivers (King et al., 1999; Zuurmond, Mahmud, Polack & Evans, 2015). A study was conducted by Frey, Greenberg, and Fewell (2009) using 96 caregivers of patients with different disabilities to assess the impact of social support on psychological distress. Results of the study revealed that higher support was associated with lower psychological distress among the caregivers. Zuurmond, Mahmud, Polack and Evans (2015) reported that quality social support aids caregivers in coping with their child's needs and reduced disability-related problems. The study also indicated that perceived social support moderated the relationship between the caregiving stressors and psychological wellbeing.

Phillips, Ajrouch & Hillcoat-Nalletamby (2012) assessed social support and its relation to quality of life among caregivers of children with cerebral palsy (CP). Sixty four (64) caregivers consisting of 59 Caucasian and 5 African American caregivers of children with

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mild or severe CP took part in the study. No relation was found between maternal stress and partner support. However, social support was found to improve the quality of life among the caregivers. Similarly, a study by Rose *et a*l. (2004) indicated that social support decreased the negative consequences of caregiving burden on the wellbeing of caregivers. Religion and family were some of the sources of social support found to boost the wellbeing of caregivers.

Anjos, Boery, Pereira. Pedreira, Vilela, Santos and Roda Dde (2015) conducted a study to examine the association between social support and quality of life of relative caregivers of dependent elderly at home. The study involved 58 relative caregivers of elderly dependent people. Data were collected using the Katz social support instrument, Zarit Burden Interview and WHOQOL-bref scale. Findings of the study revealed that the majority of caregivers were women, who were full-time caregivers and experienced moderate to severe burden. Burden and the time of care correlated negatively with quality of life of the caregivers. The correlation between caregiver's burden and quality of life was found to be insignificant when social support was fed into the model. This means that social support decreased the negative association between caregiver's burden and quality of life of the caregivers.

Another study was conducted by Burnette, Duci and Dhembo (2016) to examine the relationship between caregivers' stressors and quality of life. The study also assessed the role of social support in the relationship between the stressors and quality of life. A sample of 377 caregivers of parents with children who had CP took part in the study. Findings of the study indicated that participants reported high levels of psychological distress, moderate social support, and poor quality of life. Compared with men, women had higher levels of distress, worse quality of life, and comparable levels of support. Social support moderated a strong negative relationship between psychological distress and QoL

Contrary to the above findings, Oh and Lee (2009) found no significant impact of caregivers' burden on quality of life. Oh and Lee (2009) examined caregiver burden and

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social support perceived by mothers raising children with developmental disabilities in South Korea. One hundred and eighty one (181) mothers took part in the study. The results of the study indicated that caregivers experience high level of burden. However, there was no significant relationship between caregivers' burden and quality of life. Social support also increased the level of quality of life among the caregivers.

Summary of the Review

In summary, a number of studies focused on stressors and how they influence the QoL of caregivers of children with CP, some flaws however were identified. To begin with, most existing studies are western oriented where people are perceived to be individualistic. Ghanaians on the other hand are seen to be collective in nature (Bemister, Brooks, Dyck and Kirton, 2015; Gotze, Brahler, Gansera, Polze & Kohler, 2014; Hooley, Butler and Howlett (2005). This difference in cultural orientation does not make it appropriate to generalize the findings from the western countries to Ghana. There is therefore the need to conduct the study among Ghanaians to find out if there are variations.

Also, there has not been any valid conclusion as to the influence of demographic characteristics on QoL of caregivers. Additionally, the previous studies also assessed some components of QoL excluding others. Finally, researchers assessed the QoL of patients with different disorders with relatively few studies focusing on patients with CP. Those focusing on CP used the patients as participants. Assessing QoL however does not only involve the patients but those who provide care as well. Based on this, the study attempts to fill the gap by investigating the quality of life as a single entity and throwing light on the different dimensions of QoL among caregivers of children with CP in the Accra Metropolis of Ghana.

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CHAPTER THREE

METHODOLOGY

This chapter presents the research methodology that was used to investigate the QoL of caregivers of children with CP in Accra Metropolis. The section describes the appropriate methods employed to achieve the research objectives. The chapter entails the design, study setting, population, sample and sampling technique, the data collection tools, data collection procedure and ethical considerations.

3.1 Study Design

This study employed a quantitative approach using a survey. A cross sectional survey was adopted which sought participants' views using structured questionnaires to assess the QoL of caregivers of children with CP. A cross-sectional survey is a type of design which collects data to make inferences about a population of interest at one point in time (Dillman, 2007). The cross-sectional design was appropriate because data was collected at one point in time.

3.2 Research Setting

3.2.1 Accra Metropolis

The Accra Metropolitan Area is the biggest, most diverse and the second largest industrial centre in Ghana. It is made up of 11 sub-metros with an estimated land area of 173 square kilometres. The southern boundary of the Metropolis is the Gulf of Guinea from Gbegbeese to La. It shares boundary with the Ledzokuku-Krowor assembly on the east. On the northern and western frontiers there are Ga East, Ga West and the Ga South Districts (AMA, 2015).

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From the 2000 national census, the city had a population of 1,658,937 with a growth rate of 3.4 %and currently the most populated and fast growing Metropolis in Africa. Accra is expected to grow beyond 4 million by the year 2020. The city of Accra has encountered different economic fortunes since the 1970s. Also, in the 1987 industrial census, Accra had 32 % of Ghana's manufacturing industries situated in the metropolitan Area (Yankson, Kofie & Moller-Jensen, 2006). Furthermore, key financial institutions, multinational corporations, government ministries and other facilities including hospitals are all concentrated in Accra. In terms of employment, the 1984 national census indicated that 26 % of its workforce is in the service sector, 24 % in the wholesale/retail trade, 19 % in manufacturing, and only 3 % in agriculture (GSS, 2005).

3.3 Study Sites

The study sites were the 37 Military Hospital, Princess Marie-Louis Hospital (PML), Givers Never Lack Foundation and Sharecare Ghana. The 37 Military Hospital is a tertiary level referral hospital while Princess Marie-Louis Hospital on the other hand is the only children's hospital in Ghana. It serves as a referral facility and also runs clinics for children with CP though not a tertiary facility. Commissioned in 1926, PML is a 74 bed, Ghana Health Service facility located in Accra within Ashiedu Keteke sub-metro. Within the last decade out-patients attendance has increased from 4500 to 7300. PML provides medical care services for children, nutrition services and disease control among others. Clinics run in the facility include child development, asthma and sickle cell clinics.

The largest Military hospital in the republic of Ghana is the 37 military hospital established in 1941 and located in the Accra metropolis. It was conventionally built to provide treatment for troops injured in the Second World War but now provides health care for both military and civilians. The hospital has 400 beds with a paediatric department.

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Services provided at the paediatric department include asthma clinic, sickle cell clinic, neuro clinic and daily out-patient clinic just to mention a few.

Givers Never Lack Foundation is a Non-Governmental Organization (NGO) in Ga south District. It was established in 2014 to provide support and cater for children with CP and Autism.

Sharecare Ghana, another NGO was established in 2006 and lunched in 2008. Sharecare Ghana is located at Osu – Anorhor within the Korle Klottey constituency. It provides support for children suffering and living with autoimmune diseases and CP, including their families, caregivers and friends.

The support provided by the NGO include physiotherapy services for children with CP. Currently, the organization has enrolled 25 children with CP and their caregivers.

3.4 Target Population

The population for this study was all caregivers (parents, relatives, and other associates) of children with CP being managed at the neuro-developmental Clinics (NDC) of the 37 Military Hospital and the Princess Marie-Louis Hospital as well as some non-governmental organizations within Greater Accra that support children with CP. These people were used as target population because they served the purpose of the study.

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3.5 Sample size and sampling technique

Quality sampling is characterized by the number of participants and the technique used in the study. To avoid wasteful results from undersized sample size, the study employed the approaches proposed by Cohen (1992) as well as Cohen (1998) statistical power in selecting the sample for the study. According to Cohen (1998) statistical power, the minimum sample size for testing a model is 104+M (where M is the number of predictors). In this study there

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were eight predictors (i.e. caregiver's burden, stress, depression, anxiety, age, marital status, level of education and religion). Drawing from the above, the minimum sample size required to meet the requirement for testing a model of an analysis was 112.

As emphasized by Cohen (1992), the sample size that is required for correlational and multiple regression analyses are 85 and 116 respectively. This indicates that the sampling size can range from a minimum of 85 for performing correlation and regression analyses to a maximum of 116 as recommended by Cohen (1992). To cater for attrition rate or non-responses, 10% of the sample size of 112 was calculated. A total of one hundred and thirty (130) participants were recruited for the study. All one hundred and thirty participants (130) recruited completed and returned the questionnaires indicating a 100% response rate.

Probability sampling technique could not be used in selecting the participants because of how dispersed the caregivers were and the inability to obtain the sample frame. Participants for the study were therefore selected using purposive sampling. In using the purposive sampling, participation in the study was based on those who met the principle of the present study; that is only caregivers of children with CP who have been caregivers to the children for at least one year. This sampling technique was used for the study because it was very easy to carry out with few rules governing how the sample was selected.

3.5.1 Inclusion Criteria

The participants (caregivers) had spent one year or more in the care of the children. The caregiver was either a blood relation or not. The children being taken care of by the caregivers were at least 2 years of age with a confirmed diagnosis of CP by a paediatrician. Participants (caregivers) were 18 years and above in age.

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3.5.2 Exclusion Criteria

Caregivers who had obvious mental problems were not included in the study. A group of caregivers whose children had other neurological conditions as well as any caregiver who was a first time attendant in the facility was not included. Caregivers employed and paid to render care to a child with CP were also excluded.

3.6 Measures/Data Collection Tools

All variables were measured using a Likert scale questionnaires. The questionnaire for this study had four sections. Section A entailed questions about basic demographic characteristics. Section B consisted of measures of the caregiver burden (primary stressor). Section C contained items that measured Depression, anxiety and stress (secondary stressors). Section D measured the dependent variable (QoL). The scales are comprehensively described below:

3.7 Demographic Variables

A self designed questionnaire was used to assess the demographic characteristics. This included the caregiver's sex and age, marital status of the caregiver, employment status, educational level and religion.

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3.8 Care Giver Burden Scale (Lee & Wu, 1998)

Caregiver's burden was the primary stressor assessed in this study. Caregiver's burden was measured using the Caregivers Burden Inventory developed by Lee and Wu (1998). The scale measures the burden of caregivers of patients with different disorders. The scale consists of 20-items assessed on a four point Likert scale with a range from never (0) to often

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(3). The scale covers the problems most frequently mentioned with five dimensions including physical, emotional, family relationships, financial, and individual time and freedom areas.

The scale is scored from 0 (never) to 3 (often). Scores ranged from 0–60 with a higher score indicating higher level of perceived caregiver's burden. The degree of burden can be divided into three categories: 0 to 20 (little or no burden), 21 to 40 (mild to moderate burden), 41 to 60 (severe burden). Lee and Wu (1998) found the Cronbach alpha for internal consistency of the total scale to be .91 and the subscales ranged from 0.75 to 0.93. The Cronbach alpha for the caregivers burden scale in the present study was 0.82.

3.9 Depression, Anxiety, Stress Scale (DASS-21; Antony, Bieling, Cox, Enns & Swinson, 1998)

Depression, anxiety and stress were the secondary stressors assessed in the present study. The modified version of the Depression Anxiety Stress Scale (DASS-21; Antony, Bieling, Cox, Enns & Swinson, 1998) originally developed by Lovibond and Lovibond (1995) was used to measure the secondary stressors (Depression, Stress and Anxiety). DASS-21 is a short form of DASS which is a self-report 4-point Likert scale and composed of three subscales: Depression (DASS-D), Anxiety (DASS-A), and Stress (DASS-S). The DASS-21 measures each of the three mental health conditions, over the past week with each subscale having seven items.

Responses to each item ranged from 0 (did not apply to me at all) to 3 (applied to me very much). Each item was also scored based on the 4-point Likert scale (0 = did not apply to me at all, to 3 = Applied to me very much or most of the time). The intensity of any of the three conditions forming the subscales of the DASS is determined by the sum scores of responses on the four point likert scale to the 7-items. The total score for the DAS-21 ranged from 0 – 63 with a score ranging from 0- 21 for each component of the DAS-21. Higher

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scores depict higher psychological distress of the participant. The total scores of the DAS are interpreted based on five categories for each component: 0 to 4 (normal), 5 to 6 (mild), 7 to 10 (moderate), 11 to 13 (severe) and 14 and above (extremely severe) for the depression sub component. The scores of the anxiety component was interpreted as follows: 0 to 3 (normal), 4 to 5 (mild), 6 to 7 (moderate), 8 to 9 (severe) and 10 and above (extremely severe). The stress scores were interpreted as follows: 0 to 7 (normal), 8 to 9 (mild), 10 to 12 (moderate), 13 to 16 (severe) and 17 and above (extremely severe) for the stress components of the DAS (Antony, Bieling, Cox, Enns & Swinson, 1998).

The alpha reliability coefficients for the DASS–21 subscales have been examined in clinical and nonclinical samples and reported as 0 .94 for DASS-D, 0.87 for DASS-A, and 0.91 for DASS –S (Antony, Bieling, Cox, Enns & Swinson, 1998). The Cronbach alpha of the DAS in the present study was 0.89.

3.10 Multidimensional Scale of Perceived Social Support (Zimet, Dahlem, Zimet & Farley, 1988)

The Multidimensional Scale of Perceived Support (MSPS) designed by Zimet, Dahlem, Zimet and Farley (1988) was used to measure the level of perceived parental support by the adolescents. The Multidimensional Scale of Perceived Support (PSSS) is a validated 12-item instrument designed to assess perceptions about support from family, friends and others. Participants responded to the items using a five point Likert scale that ranged from strongly agree to strongly disagree. Zimet, Dahlem, Zimet and Farley (1988) reported a Cronbach alpha of .79 for the scale. Cronbach's alpha for the scale's score was .93 for the present study. High scores will indicate high levels of perceived parental support. The social support scale was scored on a five point Likert scale that ranged from 0 – 4. Since there are 12 items

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on the scale, scores ranged from 0 – 48. A score of 0-25 was considered as low parental support and a score of 26 – 48 was considered as high parental support.

3.11 WHO Quality of Life-BREF (WHOQOL-BREF, 1991*)*

Quality of life was measured using the WHO Quality of Life-BREF (WHOQOL-BREF, 1991). The WHOQOL assesses the individual's perceptions in the context of their culture and value systems, and their personal goals, standards and concerns. The WHOQOL instruments were developed collaboratively in a number of centres worldwide, and have been widely field-tested. The WHOQOL-BREF instrument is a shorter version of the original instrument and comprises of 26 items, which measure four broad domains including the physical health, psychological health, social relationships, and environment.

The scale is measured on a five point Likert scale ranging from strongly disagree (1) to strongly agree (5). Scores ranging from 26 - 130 were awarded with a higher score indicating higher QoL. The World Health Quality of Life Scale does not have universal cut off point for determining whether individuals experience high, moderate or low quality of life but the determination is based on the disorder or group of study. An average score around 70 is termed as moderate universally for the total quality of life scale (Gulbrandsen, Hjermstad & Wisloff, 2004). The mean moderate score of physical health components is around 20, 18 for psychological health, 9 for social relationships and 24 for environmental health. Gulbrandsen, Hjermstad and Wisloff (2004) found internal consistency of the scale to range from 0.76-0.90 across domains. The present study found a cronbach’s alpha value of 0.88 for the WHOQOL-BREF.

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3.12 Pre-testing the Measures

Although it is difficult to assess the quality of the data that one collects, it is possible to assess the accuracy of the survey tools used to collect data in any investigation and that can serve as means of assessing the quality of the data collected (Litwin, 1995). An assessment of the data relies upon determining the reliability and validity of the survey instruments. According to Churchill (1992), the pretest is the most inexpensive insurance for assessing the reliability and validity of the instrument. The scales for this study were pretested with 10 caregivers of children with CP at Tema General Hospital.

The pre-testing of the draft questionnaires took place in January, 2015. This was to determine whether participants could easily understand and respond to the questionnaire and whether the scales measured what they were supposed to measure. The pre-testing was aimed at; identifying possible gaps in the questionnaire, determining practical issues in their usage and recommend possible changes. The analysis of the pre-tested questionnaires using SPSS version 20.0 indicated a good reliability of cronbach's alpha of .86 for the whole scale. Reliability coefficients of the subscales ranged from 0.78 to 0.94. However, based on comments from participants of the pilot study, some minor changes were made to arrive at the final questionnaire used for the study. Changes to the draft questionnaire comprised rewording some of the questions for clarity and comprehension and correcting a few typographical errors.

3.13 Procedure for Data Collection

Ethical approval was sought from the Noguchi Memorial Institute for Medical Research and clearance from the Ghana Health Service Regional Health Directorate (Greater Accra) before the commencement of the research. Consent forms were signed by participants who expressed the willingness to partake in the study. To gain access to the facilities, two letters

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were written; an introductory letter from the School of Nursing, University of Ghana and a cover letter by the researcher explaining the purpose of the study and assuring the hospitals, Non-Governmental Organizations(NGO) and the participants of absolute confidentiality. These letters were sent to the institutions targeted for the study. Questionnaires were then sent to the hospitals and NGOs and administered face-to-face to caregivers who were present and willing to participate in the study.

3.14 Ethical Considerations

The Noguchi Memorial Institute for Medical Research at the University of Ghana and Ghana Health Service (GHS) were the institutions that ethical standards compliance was sought from. Preceding the study, introductory letters were secured from the School of Nursing and the Regional Health Directorate of GHS to grant access to the study sites in order to recruit participants for the study. Informed, written consent was obtained from the participants. This explained the benefits and possible risks if any, to the participants. Furthermore, participant's respect, privacy and information confidentiality were upheld. Participants were told about their right to withdraw from the study at any time on their own volition without suffering any consequence. Secrecy and confidentiality were also ensured in that names and identifying information were not sought for. Also, data provided by the participants were handled and used by only the researcher and the supervisor. The completed questionnaires were locked up in a cabinet accessible only to the researcher, supervisor and the School of Nursing.

3.15 Data Management and Analysis

Statistical Package for Social Sciences (SPSS), version 20.0 was used for statistical analysis. To ensure accuracy of the data entered, data cleaning was conducted by

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computing the frequencies of all variables. Descriptive statistics such as means, frequencies and standard deviations were used to summarize the data collected. Correlation analysis was conducted to determine the relationship between the QoL and other variables included in the study while multiple regression analysis was used to determine predictors of QoL. Data analysis was conducted at a significance level (Alpha) of 0.05 and a power of 95%.

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CHAPTER FOUR

FINDINGS

This chapter presents the findings of the study. The findings are presented in six sections. The first section reports the demographic characteristics of participants and other sections present results according to the objectives of the study.

4.1 Demographic Characteristics of the Participants

The mean age of the participants was 35.85 years (SD=8.14) with a modal age of 35 years. The age of the participants ranged from 19 to 65 years.

Among the caregivers who participated in the study, approximately 91% (N=118) were females forming the majority whilst the remaining (9.2%) were males. Approximately 78% (N=130) of participants were married, 10.8% were single, 3.1% were divorced and 5.4% were separated.

Most of the participants (90.8%) were Christians, whilst only 9.2% were Muslims. With regard to the employment status of the participants, the majority (62.3%) were unemployed whilst 37.7% (n=49) were employed. Participants' educational status ranged from Junior High School to PhD with most of them (31.5%) being Junior High School graduates. Details of the demographic characteristics are reported in Table 4.1

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Table 4.1: Demographic Characteristics of the Respondents

Variable	Frequency	Percent
Sex		
• Female	118	**90.8**
• Male	12	9.2
Age		
Mean age **35.85** (SD=8.14) years Modal age of 35 years		
Marital Status		
• Married	101	**77.7**
• Single	14	10.8
• Divorced	4	3.1
• Separated	7	5.4
• Others	4	3.1
Religion		
• Christianity	118	**90.8**
• Islamic	12	9.2
Employment Status		
• Yes	49	37.7
• No	81	**62.3**
Education		
• JHS	41	**31.5**
• SHS	35	26.9
• Degree	10	7.7
• Masters	3	2.3
• PhD	1	.8
• Others	40	30.8

4.2 Quality of Life of Caregivers of Children with CP

One fundamental objective was to describe the QoL of the caregivers of children with CP. Assessing the QoL based on the four dimensions (Physical, Psychological, Environmental and Social Relationships), the results showed that the mean score for physical QoL was 18.84 (SD=3.55) which is moderate and indicate moderate physical health of caregivers of children with CP. The mean of psychological health component of QoL was 16.84 (SD=3.15) which indicates moderate psychological health among caregivers. Similarly,

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the mean score for social relationship QoL was 8.08 (SD=2.54) which also indicates moderate social relationship QoL. In addition, the mean score of environmental components of QoL was 21.39 (SD=5.04) which indicates moderate environmental health QoL among caregivers of children with CP. These indicate moderate scores recorded for all the dimensions of QoL. In general, the results suggest that the mean total quality of life of caregivers of children with CP was 70.72 (SD=12.70) which indicates moderate level of quality of life of caregivers of children with CP. Results on the dimensional quality of life suggested that the psychological component of QoL was the most affected by caregiving followed by physical component of QoL. Next in line was the environmental component followed by the social relationship component of QoL. When the individual items of the physical component of QoL were examined, the results suggested that the mean score for satisfaction with sleep was high (mean = 3.17, SD = 1.13), indicating that the caregivers were not satisfied with their sleep. With the psychological component of QoL, the mean scores of the individual items suggested that the caregivers did not enjoy life as they were supposed to and they felt that their lives were not meaningful and they could not concentrate. With regard to the social component, the caregivers were neither satisfied with their personal relationships nor their sexual life. Details of the QoL of the caregivers of children with CP are presented in Table 4.2

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Table 4.2: Quality of Life of Caregivers of children with CP

DIMENSION OF QUALITY OF LIFE	Min	Max	Mean	SD	Standard Mean
PHYSICAL	**8**	**28**	**18.84**	**3.55**	**2.57**
I feel that physical pain prevents me from doing t I need to do	1	5	2.58	1.20	
I function well in my daily life	1	5	2.53	1.12	
I have enough energy for everyday life	1	5	2.98	1.08	
I am able to get around well with others	1	4	2.08	1.01	
I am not satisfied with my sleep*	1	5	**3.17**	1.13	
I am satisfied with my ability to perform my daily g activities	1	5	2.83	1.07	
I am satisfied with my capacity for work	1	5	2.68	1.07	
PSYCHOLOGICAL	**9**	**27**	**16.84**	**3.15**	**2.50**
I do not enjoy life as I am supposed to*	1	5	3.50	1.09	
I feel that my life is meaningful	1	5	3.26	1.24	
I am able to concentrate	1	5	3.16	1.07	
I am able to accept my bodily appearance	1	5	2.55	1.12	
I am satisfied with myself	1	4	2.39	.98	
I often have negative feelings, such as blue mood, air, anxiety, depression*	1	4	1.98	1.10	
SOCIAL RELATIONSHIP	**3**	**15**	**8.08**	**2.54**	**2.69**
I am satisfied with my personal relationships	1	5	3.12	1.05	
I am satisfied with my sex life	1	5	2.72	1.13	
I am satisfied with the support I get from my friends	1	5	2.25	1.18	
ENVIRONMENTAL	**9**	**36**	**21.39**	**5.04**	**2.67**
I feel safe in my daily life	1	5	3.44	.95	
I am healthy in my physical environment	1	5	3.30	.99	
I have enough money to meet my needs	1	5	2.42	1.10	
Information that I need in my day-to-day life are ily available	1	5	2.70	1.11	
I have the opportunity for leisure activities	1	5	2.48	.99	
I am satisfied with the conditions of my living place	1	5	2.68	1.11	
I am satisfied with my access to health services	1	4	2.08	1.00	
I am satisfied with my mode of transportation	1	4	2.30	.86	
GENERAL QUALITY OF LIFE	**2**	**10**	**5.55**	**2.15**	**2.77**
I rate my quality of life as very good	1	5	2.59	1.18	
I am satisfied with my health	1	5	2.96	1.20	
TOTAL QUALITY OF LIFE	**31**	**98**	**70.72**	**12.70**	**2.72**

* Reversed code Items

Findings of the components of QoL of participants revealed that, 63.8% (n = 83) of the caregivers of children with CP scored below moderate physical quality of life, 71.5% (n = 93)

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scored below moderate psychological QoL, 70.0% (n = 91) scored below moderate social QoL and 73.8% (n = 96) scored below moderate environmental QoL. These findings indicate that a higher number of participants had below moderate scores on all the four components of QoL.

Furthermore, the majority of the caregivers 51.5% (n=67) scored below moderate for their total QoL. These findings suggest that the QoL of the caregivers of these children regardless of the components is below satisfactory. Table 4.3 below shows the details of the components of QoL among these caregivers.

Table 4.3: Components of Quality of Life among Caregivers of children with CP

Dimension of Quality of Life	Range Score	Frequency	Percentage
PHYSICAL			
Below Moderate (Low QoL)	7 – 20	**83**	**63.8**
Above Moderate (High QoL)	21 – 35	47	36.2
PSYCHOLOGICAL			
Below Moderate	6 – 18	**93**	**71.5**
Above Moderate	19 – 30	37	28.5
SOCIAL RELATIONSHIPS			
Below Moderate	3 – 9	**91**	**70.0**
Above Moderate	10 – 15	39	30.0
ENVIRONMENTAL			
Below Moderate	8 – 24	**96**	**73.8**
Above Moderate	25 – 40	34	26.2
GENERAL			
Below Moderate	2 – 6	**86**	**66.2**
Above Moderate	7 – 10	44	33.8
TOTAL QUALITY OF LIFE			
Below Moderate	26 – 69	**67**	**51.5**
Above Moderate	70 – 130	63	48.5

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4.3 The Stressors of Caregivers of children with CP

Another primary objective of the study was to give a vivid description of the stressors caregivers of children with CP encounter. Two main stressors were described; primary and secondary stressors.

4.3.1 The Primary Stressor (Caregivers Burden) of Caregivers of children with CP

The primary stressor examined was the caregiver burden. The mean score for total burden among the caregivers was 42.11 (SD = 12.46) which is high and indicates that the caregivers experienced high level of burden.

Results on the dimensional caregivers burden indicated that 44.6% (n = 58) had severe physical,

43.8% (n = 57) had moderate family caregivers burden and as much as 56.2% (n = 73) had severe caregivers burden at the individual level. In terms of financial burden, approximately 54% (n= 70) had severe financial caregivers burden. These findings suggest that the caregivers were very much stressed by all the dimensions of caregiver's burden. In general, 53.8% (n = 70) of the caregivers reported severe total primary caregivers burden.

Furthermore, these findings revealed that with the exception of family burden in which the majority of caregivers exhibited a moderate score, higher numbers of the participants experienced severe burden in the other components of caregivers' burden.

Comparing the mean scores of the five components of caregivers burden in ascending order, caregivers recorded higher score on emotional burden (Mean = 2.53) compared to the other components. Table 4.4 presents the descriptive statistics of the caregiver burden.

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Table 4.4: Level of Primary Stressors (Caregivers Burden) among Caregivers of children with CP

Dimension of Caregivers len	Range Score	Frequency	Percentage	Min	Max	Mean
Physical				0	4	**2.31**
Little or No Burden	0-4	17	13.1			
Moderate	5-6	55	42.3			
Severe	7-10	**58**	**44.6**			
Emotional				1	4	**2.53**
Little or No Burden	0-3	9	6.9			
Moderate	4-5	42	32.3			
Severe	6-7	**79**	**60.8**			
Family				0	3	**1.90**
Little or No Burden	0-7	43	33.1			
Moderate	8-9	**57**	**43.8**			
Severe	10-12	30	23.1			
Individual				1	4	**2.37**
Little or No Burden	0-7	24	18.4			
Moderate	8-9	33	25.4			
Severe	10-12	**73**	**56.2**			
Financial				0	4	**2.34**
Little or No Burden	0-7	25	19.3			
Moderate	8-9	35	26.9			
Severe	10-12	**70**	**53.8**			
Total Caregivers den				16	67	**42.11**
Little or No Burden	0-20	3	2.4			
Moderate	21-40	57	43.8			
Severe	41-60	**70**	**53.8**			

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4.3.2 Secondary Stressors of Caregivers of children with CP

Three components of secondary stressors (depression, anxiety and stress) were examined.

Depression

Considering depression among the participants, none of them had normal level of depression. The level of depression among the caregivers of children with CP ranged from

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mild (2.3%, n = 3) to extremely severe depression (47.7%, n = 62). The majority of the participants 47.7 %(n = 62) had extremely severe depression.

Anxiety

The caregivers' levels of anxiety also ranged from normal (0.08%, n = 1) to extremely severe anxiety (63.1%, n = 82). Most of the participants (63.1%, n = 82) reported extremely severe anxiety levels.

Stress

The level of stress among the caregivers of children with CP ranged from normal (16.9%, n = 22) to extremely severe stress (11.5%, n = 15).The Majority (39.2%, n = 51) of the participants reported severe stress.

These descriptions mean that with the exception of stress, most of the participants experienced extremely severe levels of depression and anxiety.

Table 4.5 shows the different levels of stress, depression and anxiety as secondary stressors.

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Table 4.5: Description of Individual level of Secondary Stressors

Dimension of Quality of Life	Range Score	Frequency	Percentage
Depression			
Normal	0-4	0	0
Mild	5-6	3	2.3
Moderate	7-10	33	25.4
Severe	11-13	32	24.6
Extremely severe	14+	**62**	**47.7**
Anxiety			
Normal	0-3	1	.08
Mild	4-5	8	6.2
Moderate	6-7	15	11.5
Severe	8-9	24	18.5
Extremely severe	10+	**82**	**63.1**
Stress			
Normal	0-7	22	16.9
Mild	8-9	18	13.8
Moderate	10-12	24	18.5
Severe	13-16	**51**	**39.2**
Extremely severe	17+	15	11.5

In assessing the mean scores of the three components of the secondary stressors (stress, depression and anxiety), the results show that the mean score for depression was 13.07 (SD=3.28) which indicates severe level of depression among the caregivers of children with CP. The mean score of anxiety among the caregivers of CP was 11.24 (SD=3.98) which indicate extremely severe level. Furthermore, the mean score of stress among the caregivers of children with CP was 11.78 (SD=3.95) which also indicates moderate stress.

Comparing the mean scores, depression (M=13.07) was the highest. This was followed by the mean score of stress (M=11.78) with the scores of anxiety (M=11.24) being the least. This therefore implies that caregivers of children with CP encounter high levels of depression, followed by stress and anxiety in that order. Table 4.6 presents the details of these secondary stressors.

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Table 4.6: Mean Scores of Secondary Stressors of Caregivers of children with CP

COMPONENT OF SECONDARY STRESSOR	MIN	MAX	MEAN	SD
DEPRESSION	**5**	**21**	**13.07**	**3.28**
I felt that life was meaningless	0	4	1.06	1.14
I felt I wasn't worth much as a person	0	4	1.87	1.14
I was unable to become enthusiastic about anything	1	4	2.15	.89
I felt that I had nothing to look forward to	0	4	2.26	1.11
I felt down-hearted and blue	0	4	1.46	1.03
I found it difficult to work up the initiative to do things	0	4	1.48	.97
I couldn't seem to experience any positive feeling at all	0	4	1.42	.98
ANXIETY	**2**	**20**	**11.24**	**3.98**
I felt I was close to panic	0	4	1.76	1.06
I was worried about situations in which I might panic and e a fool of myself	0	4	2.08	1.19
I was aware of dryness of my mouth	0	4	1.59	1.17
I was aware of the action of my heart in the absence of ical exertion	0	4	1.42	.85
I felt scared without any good reason	1	4	1.62	.90
I experienced breathing difficulty	0	4	.35	.84
I experienced trembling	0	4	2.72	1.19
STRESS	**3**	**20**	**11.78**	**3.95**
I felt that I was rather touchy	0	4	1.47	1.02
I was intolerant of anything that kept me from getting on what I was doing	0	4	1.58	1.19
I found it hard to unwind	0	4	2.44	1.00
I found it difficult to relax	0	4	2.62	.97
I found myself getting agitated	0	4	1.60	1.01
I felt that I was using a lot of nervous energy	0	4	1.36	1.17
I tended to over-react to situations	0	4	1.78	.93

4.4 Relationship between Stressors and Quality of Life

Another primary objective was to find out the relationship between the stressors and the quality of life of caregivers of children with CP. There were two categories of stressors (primary and secondary) and the relationship between each of them on the quality of life was assessed.

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4.4.1 Relationship between Primary Stressor (Caregivers Burden) and Quality of Life

Results of the Pearson Product Moment Correlation Coefficient showed that there was a moderate and negative significant relationship between physical burden and QoL of caregivers ($r = -.398$, $p < .05$). A significant negative relationship was also found between emotional burden and QoL ($r = -.308$, $p < .05$). Similarly, a negative significant relationship was found between family burden and QoL ($r = -.477$, $p < .05$). In addition, individual burden also correlated negatively and significantly with QoL caregivers ($r = -.477$, $p < .05$). Financial burden was also found to correlate negatively and significantly with QoL ($r = -.486$, $p < .05$). The total caregivers' burden was also found to correlate negatively and significantly with QoL of caregivers ($r = -.504$, $p < .05$). Thus the first hypothesis that there will be a significant negative relationship between primary stressors and QoL of caregivers of children with CP was supported. This means the higher the level of burden in any of the components of caregiver's burden, the lower the QoL among caregivers.

Table 4.7 provides details of the correlation between caregivers' burden and quality of life.

Table 4.7: Relationship between Primary Stressors and Quality of Life

VARIABLES	QUALITY OF LIFE OF CAREGIVERS	
	r	P-value (one-tailed)
Physical Burden	-.398	.001
Emotional Burden	-.308	.001
Family Burden	-.477	.001
Individual Burden	-.447	.001
Financial Burden	-.486	.001
Total Caregivers Burden	-.504	.001

Criterion level: .05

A multiple linear regression analysis was performed to determine if demographic characteristics (model 1) and caregivers' burden (model 2) significantly account for the level of quality of life among the caregivers.

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In the first model, the demographic characteristics of the caregivers (age, education, marital status and religion) jointly accounted for an insignificant 3.7% of the variance in caregivers QoL ($R^2 = .037$, $F_{(4, 125)} = 1.197$). When the predictors (family, physical, emotional, individual and financial burden) were evaluated for their contributions to the model, none of the demographic characteristics were significant predictors of QoL in the model.

However, caregivers burden in general (physical, emotional, family, individual and family burden) collectively explained significant variance in caregivers QoL accounting for 38.4% of the variance in caregivers QoL ($R^2 = .384$, $F_{(4, 234)} = 6.487$, $p<.05$). The amount of variance accounted for caregivers quality of life by financial, physical, emotional, family and individual burden were 35.6%, 4.5%, 9.2%, 23.2% and 15.9% respectively. However, only financial ($p<.05$) and family burden ($p<.05$) were significant predictors of the caregivers QoL. Details of these predictors are shown in Table 4.8

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Table 4.8: Relationship between Caregivers Burden and Quality of Life of Caregivers of children with CP

		Unstandardized Coefficients		Standardized Coefficients			Correlation
Model	PREDICTORS	B	Std. Error	Beta	t	p-value	(r)
Model 1	(Constant)	78.594	6.832		11.504	.000	
	Age	-.017	.139	-.011	-.119	.906	-.030
	Marital	-1.750	1.114	-.138	-1.570	.119	-.108
	Education	-.621	.544	-.102	-1.142	.255	-.119
	Religion	-2.593	3.849	-.059	-.674	.502	-.066
Model 1 summary: R^2=.037, $F_{(4, 125)}$ = 1.197, p=.316							
Model 2	(Constant)	100.816	6.743		14.952	000	
	Age	.133	.117	.085	1.137	.258	-.030
	Marital	-.982	.940	-.078	-1.045	.298	-.108
	Education	-.386	.447	-.064	-.865	.389	-.119
	Religion	-1.910	3.173	-.044	-.602	.548	-.066
	Financial	-1.987	.447	-.356	-4.445	**.000**	-.486
	Physical	.219	.538	.045	.407	.685	-.398
	Emotional	-.459	.444	-.092	-1.033	.304	-.308
	Family	-.562	.261	-.232	-2.157	**.033**	-.477
	Individual	-.506	.311	-.159	-1.627	.106	-.447
Model 2 summary: R^2=.384, $F_{(9, 120)}$ = 8.328, p<.001							

Dependent variable: Quality of Life   Criterion Level: .05

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4.4.2 Relationship between Secondary Stressors (DAS) and QoL

The results of the Pearson Correlation indicated there was a significant negative relationship between depression and quality of life among caregivers of children with CP (r =-.390, $p < .05$). The relationship between anxiety and quality of life among caregivers of children with CP was also negative and significant (r =-.425, $p < .05$). Stress was also found to correlate negatively and significantly with quality of life of caregivers of children with CP (r =-.413, $p < .05$). The second hypothesis which also stated that there will be a significant negative relationship between secondary stressors and QoL of caregivers of children with CP was supported. This implies that when secondary stressors (depression, anxiety and stress) increase, the quality of life among caregivers of children with CP decreases. Table 4.9 provides details of the correlation between caregivers' secondary stressors and quality of life.

Table 4.9: Relationship between Secondary Stressors and Quality of Life

VARIABLES	**QUALITY OF LIFE OF CAREGIVERS**	
	r	P-value (one-tailed)
Depression	-.390	**.001**
Anxiety	-.425	**.001**
Stress	-.413	**.001**

Criterion level: alpha = .05

Multiple linear regression analysis was again performed to determine if demographic characteristics (model 1) and secondary stressors (model 2) significantly accounted for higher variance in quality of life among the caregivers.

In the first model, the demographic characteristics were fed into the model. The regression results indicated that the demographic characteristics of the caregivers (age, education, marital status and religion) collectively explained an insignificant 3.7% variance

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in caregivers QoL ($R^2 = .037$, $F_{(4, 125)} = 1.197$). When the predictors (depression, anxiety and stress) were evaluated for their contributions to the model, none of the demographic characteristics were found to significantly predict QoL of caregivers of children with CP.

In the second model, the secondary stressors (stress, depression and anxiety) jointly explained significant variance in caregivers quality of life predicting 25.5% of the variance in caregivers quality of life (R^2=.255, $F_{(7, 122)} = 5.978$, $p<.05$). Depression, anxiety and stress accounted for 28.1%, 22.3% and 16.0% respectively in caregivers' quality of life. However, only depression ($p<.05$) and anxiety ($p<.05$) were significant secondary predictors of QoL of caregivers of children with CP. Details of the regression analysis are presented in Table 4.10

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Table 4.10: Relationship between Secondary Stressors and Quality of Life Caregivers of children with CP

Model		Unstandardized Coefficients		Standardized Coefficients	T	p=value	r
		B	Std. Error	Beta			
Model 1	(Constant)	78.594	6.832		11.504	.000	
	Age	-.017	.139	-.011	-.119	.906	-.030
	Education	-.621	.544	-.102	-1.142	.255	-.108
	Marital	-1.750	1.114	-.138	-1.570	.119	-.119
	RELIGION	-2.593	3.849	-.059	-.674	.502	-.066
Model 1 summary: R^2=.037, $F_{(4, 125)}$ = 1.197, p=.316							
Model 2	(Constant)	102.553	7.460		13.747	.000	
	Age	-.042	.125	-.027	-.337	.737	-.030
	Education	-.437	.487	-.072	-.897	.371	-.108
	Marital	-1.596	1.002	-.126	-1.593	.114	-.119
	RELIGION	-3.356	3.436	-.077	-.977	.331	-.066
	Depression	-.853	.386	-.281	-2.212	**.000**	-.390
	Anxiety	-.649	.378	-.223	-1.718	**.038**	-.425
	Stress	-.385	.393	-.160	-.980	.079	-.413
Model 2 summary: R^2=.255, $F_{(7, 122)}$ = 5.978, p<.001							

Dependent variable: Quality of Life   Criterion Level: .05

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4.5 Mediating Role of Secondary Stressors (Depression, Anxiety and Stress) on Caregiver Burden-QoL Relationship

The study was also aimed at assessing whether depression, anxiety and stress mediate the relationship between caregivers burden and quality of life among caregivers of children with CP. Each of the secondary stressors was evaluated to examine the mediating role on the relationship between caregiver's burden and quality of life.

The mediating role was tested using Baron and Kenny's (1986) four (4) step approach in which several regression analyses were conducted and significance of the coefficients examined at each step. The steps are as follows:

Step 1: Simple regression analysis of primary stressor (caregiver's burden) predicting quality of life (Path c)

Step 2: Simple regression analysis of primary stressor (caregiver's burden) predicting secondary stressors (depression, anxiety and stress) (i.e. Path a)

Step 3: Simple regression of secondary stressors (depression, anxiety and stress) predicting quality of life (i.e. Path b).

Step 4: Multiple regression analysis of primary stressor (caregiver's burden) and secondary stressors (depression, anxiety and stress) predicting quality of life.

This can be illustrated diagrammatically as shown in figure 4.1 below

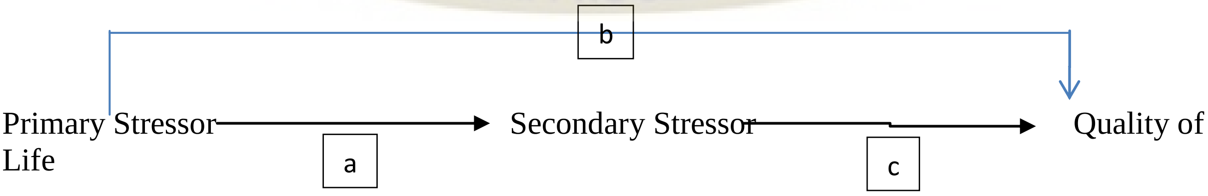

Figure 4.1: Mediating Relationship Diagram

Steps 1, 2 and 3 are to establish that relationships exist among the variables and so are not reported as part of findings of the study. In step 4, according to Baron and Kenny (1986)

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some form of mediation is supported if the effect of primary stressor (caregiver's burden) remains significant after controlling for secondary stressor (path b). When primary stressor (predictor) is not significant in predicting quality of life after controlling for secondary stressors (mediator), then the finding supports full mediation. If primary stressor (caregiver's burden) is still significant (i.e. both primary and secondary stressors significantly predict quality of life), the finding supports partial mediation.

4.5.1 Mediation Role of Depression on the Relationship between Caregiver Burden and QoL

The regression coefficients of the mediation analysis reveal that, there was an initial significant relationship between caregivers' burden and quality of life ($\beta = .504$, $p < .05$) in the first model with caregivers' burden accounting for 25.4% ($R^2=.254$, $F_{(1,\ 128)} = 43.672$, $p<.05$) of the variance in quality of life. When depression was controlled in the second model, caregivers' burden was still significant (i.e. both caregivers burden and the depression significantly predicted quality of life) ($R^2=.341$, $F_{(7,\ 127)} = 32.799$, $p<.05$). This finding suggests that depression partially mediates the relationship between caregivers' burden and QoL. These findings also indicate that depression ($p<.05$) is a significant partial mediator of these caregivers QoL. Details of the mediating effects of depression is shown in Table 4.11

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Table 4.11: Mediating Effect of Depression on the Ccaregivers' Burden – QoL Relationship

		Unstandardized Coefficients		Standardized Coefficients			
Model		B	Std. Error	Beta	T	Sig.	R
Model 1	(Constant)	92.375	3.416		27.043	.000	
	Caregivers Burden	-.514	.078	-.504	-6.609	**.000**	-.504
Model 1 summary: R^2=.254, $F_{(1, 128)}$ = 43.672, p<.001							
Model 2	(Constant)	104.912	4.457		23.537	.000	
	Caregivers Burden	-.452	.075	-.443	-6.609	**.000**	-.504
	Depression	-1.160	.285	-.300	-4.075	**.000**	-.390
Model 2 summary: R^2=.341, $F_{(7, 127)}$ = 32.799, p<.001							

Dependent variable: Quality of Life   Criterion Level: .05

4.5.2 Mediation Role of Anxiety on the Relationship between Caregivers Burden and Quality of Life

The regression coefficients of the mediation analysis of anxiety on the relationship between caregivers' burden and quality of life indicated an initial significant relationship between caregivers' burden and quality of life ($\beta = .504$, $p < .05$) in the first model with caregivers' burden accounting for 25.4% (R^2=.254, $F_{(1, 128)}$ = 43.672, p<.05) of the variance in quality of life. When anxiety was controlled in the second model, caregivers' burden was still significant (i.e. both caregivers burden and anxiety significantly predicted quality of life) (R^2=.336, $F_{(2, 127)}$ = 32.092, p<.05). This means that anxiety partially mediates the relationship between caregivers' burden and quality of life. Results of the analysis are presented in Table 4.12.

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Table 4.12: Mediating role of Anxiety on the Caregivers' Burden – Quality of Life Relationship

Model		Unstandardized Coefficients B	Std. Error	Standardized Coefficients Beta	t	Sig.	r
Model 1	(Constant)	92.375	3.416		27.043	.000	
	Caregivers Burden	-.514	.078	-.504	-6.609	.000	-.504
Model 1 summary: R^2=.254, $F_{(1, 128)}$ = 43.672, p<.05							
Model 2	(Constant)	99.197	3.670		27.027	.000	
	Caregivers Burden	-.421	.077	-.413	-5.441	.000	-.504
	Anxiety	-.955	.242	-.299	-3.943	**.000**	-.425
Model 2 summary: R^2=.336, $F_{(2, 127)}$ = 32.092, p<.05							

Dependent variable: Quality of Life Criterion Level: .05

4.5.3 Mediating Role of Stress on the Relationship between Caregivers' Burden and Quality of Life

Assessing the regression coefficients of the mediation role of stress on the relationship between caregivers' burden and quality of life, the first model indicated a significant relationship between caregivers' burden and quality of life (β = .504, *p* < .05). When caregivers' burden was entered first, it accounted for 25.4% (R^2=.254, $F_{(1, 128)}$ = 43.672, p<.05) of the variance in quality of life. When stress was controlled in the second model, caregivers' burden was still significant (i.e. both caregivers' burden and stress significantly predicted quality of life) (R^2=.313, $F_{(2, 127)}$ = 28.936, p<.05). This means that stress partially mediated the relationship between caregivers' burden and quality of life. Results of the analysis are presented in Table 4.13

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Table 4.13: Mediating role of Stress on the Caregivers' Burden – Quality of Life Relationship

		Unstandardized Coefficients		Standardized Coefficients			
Model		B	Std. Error	Beta	t	Sig.	r
Model 1	(Constant)	92.375	3.416		27.043	.000	
	Caregivers Burden	-.514	.078	-.504	-6.609	.000	-.504
Model 2 summary: R^2=.254, $F_{(1, 128)}$ = 43.672, p<.05							
Model 2	(Constant)	98.076	3.719		26.370	.000	
	Caregivers Burden	-.415	.081	-.407	-5.126	.000	-.504
	Stress	-.840	.255	-.261	-3.293	**.001**	-.413
Model 2 summary: R^2=.313, $F_{(2, 127)}$ = 28.936, p<.05							

Dependent variable: Quality of Life   Criterion Level: .05

4.6 Moderating Role of Social Support on the relationship between Caregivers' Burden and Quality of Life

A moderator is a variable that alters the direction or strength of the relationship between a predictor and an outcome (Holmbeck, 1997), thus, a moderator effect is nothing more than an interaction whereby the effect of one variable depends on the level of another. To test this hypothesis, the hierarchical regression in which three distinct steps are stipulated was conducted.

To assess the moderation role of social support on the relationship between caregivers burden and quality of life of caregivers, the procedures proposed by Baron and Kenny (1986) for testing moderation effect using hierarchical multiple regression was used. Baron and Kenny (1986) hierarchical multiple regression for testing moderating effect is called the causal path analysis. The three causal paths proposed by Baron and Kenny (1986) is illustrated in figure 4.2 below (a, b, and c). These involved entering into the dependent variable (DV), quality of life: the effect of the IV (primary stressor) on the DV (quality of life) (path a, model 1), the effect of the moderation variable (social support) on the DV

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(quality of life) (path b, model 2), and the interaction or product of these two paths on the DV (path c, model 3). The moderator hypothesis is supported if the interaction term (path c, model 3) is significant (Baron & Kenny, 1986). Details of the regression analysis are presented in Table 4.14 on page 74

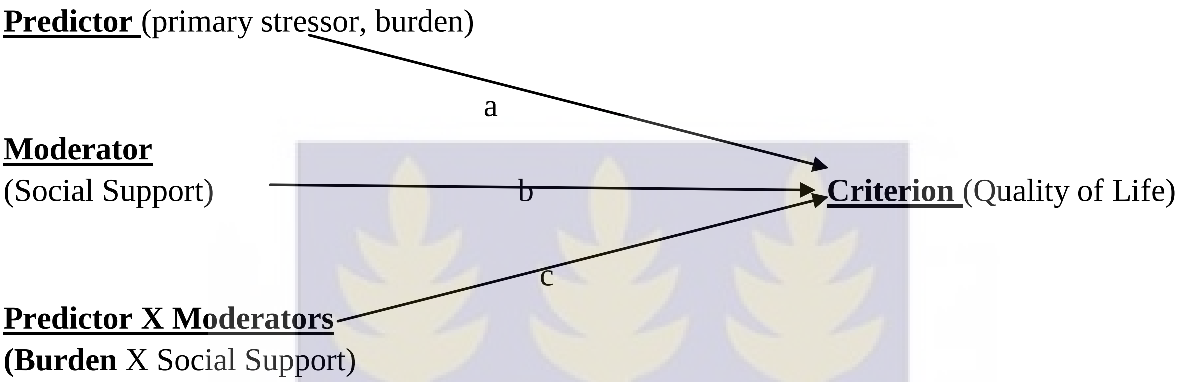

Figure 4.2: Path diagram of moderation model (Baron & Kenny, 1986)

Hierarchical linear regression analysis was performed to determine if social support moderates the relationship between caregiver's burden and quality of life of caregivers of children with CP.

In the first model, caregivers' burden was fed into the model. The regression results indicated that caregivers' burden explained a significant 25.4% variance in caregivers' quality of life. Model 1 summary (R^2=.254, $F_{(1, 128)}$ = 43.672, p=.000).

When the moderator (social support) was fed into the model in the second step, the two variables (social support and caregivers burden) jointly explained a significant variance in caregivers' quality of life; Model 2 summary (R^2=.330, $F_{(2, 127)}$ = 31.275, p=.000) with social support adding 7.6% of the variance in caregivers' quality of life.

In the third step of the regression analysis indicating whether moderation effect exists, the interaction term between caregivers' burden (primary stressor) and social support

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(moderator) was fed into the model. The results indicated that the interaction term between caregivers' burden (primary stressor) and social support (moderator) explained a significant increase in variance in quality of life; Model 3 summary: R^2=.446, $F_{(3, 126)}$ = 22.192, p=.000). Thus, social support is a significant moderator of the relationship between primary stressor (caregiver's burden) and quality of life. Results are demonstrated on Table 4.14

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Table 4.14: Results of Hierarchical Multiple Regression Analyses for the moderation effect of Social Support on the relationship between Primary Stressor and Quality of Life

		Unstandardized Coefficients		Standardized Coefficients			
Model		B	Std. Error	Beta	T	r	p-value
Model 1	(Constant)	92.375	3.416		27.043		
	Caregivers Burden	-.514	.078	-.504	-6.609	-.482	.000
Model 1 summary: R^2=.254, $F_{(1, 128)}$ = 43.672, p=.000							
Model 2	(Constant)	78.378	4.923		15.919		
	Caregivers Burden	-.362	.084	-.355	-4.298	-.482	**.000**
	Social Support	.383	.101	.313	3.785	-.502	**.000**
Model 2 summary: R^2=.330, $F_{(2, 127)}$ = 31.275, p=.000							
Model 3	(Constant)	91.480	8.975		10.193		.000
	Caregivers Burden CB)	-.647	.184	-.634	-3.521	-.482	.001
	Social Support (SS)	-.161	.328	-.132	-.492	-.504	.624
	Interaction (CB X SS)	.938	.539	.416	1.740	-.215	**.024**
Model 3 summary: R^2=.446, $F_{(3, 126)}$ = 22.192, p=.000							

Dependent variable: Quality of Life   Criterion Level: .05

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4.7 Summary of Results

In summary, the mean age of the caregivers was approximately 36 and a modal age of 35 years. Most of the caregivers were females (90.8%) and the remaining 9.2% were males. Approximately 38% (n=49) of the participants were employed whilst the majority of 62.3% (n = 81) were not employed due to provision of care to the children with CP.

The results also showed that caregivers were affected negatively in all the four components of QoL (physical health components, psychological health, social relationships and environmental health). A higher number of caregivers had below moderate scores on all the four components of QoL. However, caregiving severely affected their psychological health (Mean = 2.50) and physical health (M=2.57) than their environmental health (M = 2.67) and social relationships (Mean = 2.69).

Caregivers of children with CP also perceived higher levels of burden (M=42.1, SD = 12.46). More than half (53.8%) of the caregivers of children with CP experienced severe burden in caregiving. Among the components of burden, most of the caregivers (43.8%) experienced moderate level of family burden. Aside family burden that most obtained moderate level, higher numbers of caregivers experienced severe burden in physical (44.6%), emotional, (60.8%), individual (56.2%) and financial (53.8%) aspects of the burden. Among the five components of caregivers' burden, emotional burden was found to be the highest affecting the caregivers. This was followed by the individual, financial, physical and the family burdens respectively. In addition, the caregivers were found to experience severe level of depression (M=13.07, SD=3.28), extremely severe level of anxiety (M=11.24, SD=3.98) but moderate stress (M=11.78, SD=3.95) However, the caregivers of children with CP encountered highest level of depression, followed by stress and anxiety.

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The primary and secondary stressors were found to moderately correlate with QoL of caregivers. Caregivers' burden in general (physical, emotional, family, individual and family burden) collectively explained 38.4% of the variance in caregivers' QoL. The amount of variance accounted for caregivers quality of life by financial, physical, emotional, family and individual burden were 35.6%, 4.5%, 9.2%, 23.2% and 15.9% respectively. The three components of secondary stressors (stress, depression and anxiety) collectively explained 25.5% of the variance in caregivers' QoL

The findings also indicated a partial mediation of stress, anxiety and depression on the relationship between caregiver's burden and quality of life. When depression, anxiety and stress were controlled, caregivers' burden accounted for 34.1%, 33.6% and 33.0% respectively indicating partial mediation. There was also a moderating effect of social support on the relationship between caregiver's burden and quality of life with social support accounting for 44.6% of the variance in QoL. Meanwhile, demographic characteristics were not significant predictors of quality of life of caregivers of CP.

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CHAPTER FIVE

DISCUSSION OF FINDINGS

This chapter presents the discussion of the findings of the study. The demographic characteristics of the participants are discussed first followed by other findings.

5.1 Demographic characteristics

The study assessed the demographic characteristics of the caregivers of children with CP which included their age, gender, marital status and educational attainment. The mean age of the participants was 35.85 years which is consistent with the average age of reproductive mothers in Ghana which has been found to range between 20 to 45 years (GHS annual report, 2013). The finding also revealed that a significant majority of the participants (78%) were married. Caregiving is mostly provided by the mothers of the patients due to lack of competent people and high cost of professional caregivers. The ages of the caregivers in this study tallies with the ages of the mothers in other related studies (Eker & Tuzun, 2004).

The findings also indicated that among the caregivers who participated in the study, approximately 91% (N=130) forming the majority were females whilst the remaining (9.2%) were males. Also, the majority (62.3%) of the caregivers were unemployed whilst 37.7% (n=49) were employed. This finding is in consonance with the widely held view that caregiving is normally provided by mothers. According to the Bureau of Labour Statistics (2014), although men also provide assistance, female caregivers may spend as much as 50 % more time providing care than male caregivers. Estimates of the percentage of family or informal caregivers who are women range from 59 % to 75 % compared to 25 % to 40% by men (Prudente, Barbosa & Porto, 2010).

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The findings also suggest that the high burden associated with caregiving does not allow the caregivers to engage in any productive work. The finding of the present study is in line with the findings of the study by Anjos, Boery, Pedreira, Vilela, Santos and Roda Dde (2015) which indicated that the majority of caregivers are women, who were full-time caregivers and have limited time to engage in income productive activities. A longitudinal study by Fatudimu, Hannzat and Akinyinka (2013) also indicated that most of the caregivers of children with CP (82.3%) were mothers of the children. The caregivers were also having lower economic status and lower level of education due to the cost of providing care to the child and the lack of time to be engage in gainful employment. Even though this finding is not conclusive about the distribution pattern of caregivers in Ghana, it further fuels concerns that caregivers of children with CP may be experiencing financial problems since most of them are not working.

The current study again found that participants' educational status ranged from Junior High School to Tertiary level with most of them (31.5%) being Junior High School graduates. This affirms the assertion that among Africans, a significantly higher number of caregivers of children with CP are people with lower education and lower income (Family Caregiver Alliance, 2008). Pinquart and Sorensen's (2005) study also indicated that the educational status of the caregivers were generally low which the present study's finding supports.

The findings indicated that demographic characteristics were not significant predictors of quality of life of caregivers of children with CP. Demographic characteristics of the caregivers (age, education, marital status and religion) collectively explained an insignificant 3.7% of variance in caregivers' quality of life. This means that in determining quality of life of caregivers of children with CP, demographic characteristics such as age, education, marital status and religion do not perform any major role.

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The current study discovered that the caregivers' Christian or Muslim affiliation did not influence QoL. Being a Christian or Muslim was found to lead to equal level of QoL of the caregivers. This finding may be due to the fact that both Muslims and Christians alike derive satisfaction in their worship as such one may not have an advantage over the other. Both Christianity and Islam are associated with some positive effect. These positive effects contribute equally to the sense of psychological wellbeing and serve as coping strategy for the Christian and Muslim caregiver equally. Rose et al. (2004) reported that both Islam and Christianity serve as social support and coping mechanisms and as a result, may have contributed to boost the wellbeing among caregivers. Both religions perform sacred religious practices and these acts could encourage them to view themselves positively no matter the condition of their children. This could be the reason why Christian and Muslim caregivers did not differ in their in their QoL.

The QoL of the caregivers of children with CP was also not significantly influenced by the marital status, age and level of education of the caregivers in the present study. This suggests that marital status, age and level of education of the caregiver have no significant impact on their ability to cope with the demands of their roles as caregivers. This is similar to earlier findings of no association between the level of education of the caregiver of children with CP and the QoL of the caregiver (Correa, et al., 2009). Among Africans, a significantly higher number of caregivers of children with CP are people with lower education and lower income (Family Caregiver Alliance, 2008).

5.2 Quality of Life of Caregivers of Children with CP

The caregivers assessed in this study reported very low quality of life. The results showed that caregivers were negatively affected in all the four components of quality of life (physical health, psychological health, social relationships and environmental health). In

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addition, caregiving severely affected the psychological health (Mean = 2.50) and physical health (M=2.57) than their environmental health (M = 2.67) and social relationships (Mean = 2.69).

The lower QoL of caregivers of children with cerebral palsy found in the present study is similar to findings of earlier studies among caregivers of individuals with different disorders such as epilepsy, multiple sclerosis, and juvenile idiopathic arthritis (Brehaut, Kohen, Garner, Miller, Lach, Klassen & Rosenbaum, 2009; Deepthi & Krishnamurthy, 2011; Ones, Yilmaz, Cetinkaya & Caglar, 2005; Prudente, Barbosa & Porto, 2010) which have all indicated that the higher burden and emotional torture associated with providing care for children with various disorders affect the quality of life of the caregivers both objectively and subjectively. To juxtapose the findings of the present study with those for epilepsy, multiple sclerosis, and juvenile idiopathic arthritis, it is probably due to the reality that all those conditions such as CP require constant care from caregivers, leading to a cumulative daily burden that often makes them lose their own self-care perception and wellbeing.

The lower level of QoL among caregivers of children with CP can be attributed to a lot of factors. The undue stress associated with caregiving, the financial difficulties, the high level of depression associated with caregiving and the stereotypic attitudes from the community collectively contribute to lower level of quality of life among the caregivers of children with CP (MacDonald & Callery, 2007). Similarly, caring for an individual with CP generates high work overload and changes the caregiver's normal routines which have the propensity to decrease the QoL of the caregiver (MacDonald & Callery, 2007).

Caregivers of children with CP dedicate most of their time to the care of these children. Due to this, they do not have time to satisfy their own social needs, leading to a feeling of overload and tension. Besides having an impact on their physical and emotional health, it also has a ripple effect on their, marital relations, employment, financial situation

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and their general well-being (Davis, Shelly, Waters, Boyd, Cook & Davern, 2010; Rocha, Afonso & Morais, 2008). Such overloads might have direct influence over the quality of life (QoL) of these caregivers, as the World Health Organization (WHO) defines quality of life as the perception of the individual's, position in life, in the context of cultural values in which he/she lives. This is related to their goals, objectives, and expectations in life (Rocha, Afonso & Morais, 2008).

The lower physical health found among the caregivers of children with CP in the present study supports the study by Pavalko and Woodbury (2003) which indicated lower physical health among the caregivers. As explained by Pavalko and Woodbury (2003), caregivers of children with cerebral palsy experience reduced physical well-being, with backache, migraine, intestinal and stomach ulcers, rheumatism, as well as a higher number of chronic physical diseases because of the high demands and burden in caregiving (Pavalko & Woodbury, 2003). Furthermore, caregivers of children with CP participate less in social activities, have more problems at work if employed, and show higher frequency of family conflicts which all do not allow them to enjoy better quality of life.

Additionally, the present study revealed that although quality of life of caregivers is low, its cascading effect manifested in the psychological health and physical components. This means that caregivers of children with CP encountered significant levels of psychological problems. This finding is similar to a survey conducted by Romeo, Cioni and Distefano (2010) to assess the quality of life of caregivers of children with CP using the same WHO Quality of Life-BREF (WHOQOL-BREF, 1991) used in the present study. The study by Romeo, et al., (2010) found that the domains with worse scores were psychological health, with 19.2 points and physical problems with 20.15 points. It is worth noting that the scores obtained by the caregivers of children with cerebral palsy in the current study were even lower, with 16.84 and 18.84 points respectively for psychological and physical health.

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5.3 The Stressors of Caregivers of children with CP

Another objective of the study was to give a vivid description of the stressors caregivers of children with CP encounter. Two main stressors were described; primary and secondary stressors. The findings of the study suggested that caregivers of children with CP had higher burden. This is comparable to the results of the study conducted by Hamzat and Mordi (2007). Hamzat and Mordi (2007) found that the magnitude of the burden associated with caring for a child with CP is more than thrice that associated with caring for a healthy child. Caregiver burden deals with the day-to-day task associated with the upkeep of children with CP. This includes mothers' time and energies channeled to the emotional and physical care of the children. It is not surprising that the burden associated with caregiving of children with CP was very high because a child with CP is incapacitated and so the caregiver provides all the needed assistance. The psychological trauma, physical problems, financial difficulties and social neglect in the life of the person who is giving care culminates in the higher burden of the caregivers.

According to Williamson and Shaffer (2001), the vast majority of caregivers (87%) of children with CP are usually informal caregivers who do not receive any pay and their knowledge level with regard to CP is very low. The caregiver's lack of knowledge about CP, and the financial difficulties contribute to the high level of burden for the caregiver of the child with CP. Coupled with this, the person giving care experiences social isolation, and feels guilty over the decision to institutionalize the child with CP which all add to the high burden among the caregivers.

Again, the results of the study indicated that the caregivers experienced severe levels of depression (M=13.07, SD=3.28), and moderate level of stress (M=11.78, SD=3.95) but extremely severe levels of anxiety (M=11.24, SD=3.98). These levels of stress, depression and anxiety observed among the caregivers of children CP warrant the need for a greater

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attention to the health of these people. The caregiving routine is exhausting for the caregiver, causing different levels of stress, depression, anxiety, insomnia, and physical symptoms like muscular pain.

The stressful routine of the caregiver contributes to the moderate level of anxiety and depression in the process. The poor knowledge in caregiving, transportation problems for those not having their personal cars and the difficulties in accessibility and affordability of wheelchairs contribute to the high level of stress among the caregivers.

Another important factor for the increase in anxiety is the fact that caregivers usually compare the treatment response shown by their children with that of other children. This comparison can be a triggering factor for depression, if the caregiver concludes that the progress of his/her child was not the same as that shown by the other children who they met during the routine management (Family Caregiver Alliance, 2008). The uncertainties experienced by caregivers when it comes to not knowing what will happen to the child at any moment in time elevates their anxiety levels. The agitations, stress and depression worsen when the caregiver notices the poor knowledge exhibited about their children's disease and the management they require, especially considering the variability of CP, which presents uniquely in each patient (Williams & Wilson, 2001).

The high level of stressors (caregiver’s burden, stress, depression and anxiety) among caregivers of children with CP was highlighted by the single-jeopardy hypothesis (Phillips, Ajrouch & Hillcoat-Nalletamby, 2012). As explained by the single-jeopardy hypothesis, there are higher levels of stressors among caregivers of CP because of the cumulative effects of economic disadvantage and discrimination. The economic demands and discrimination put a high toll of burden, depression, anxiety and stress among the caregivers of children with CP.

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5.4 Relationship between Stressors and Quality of Life

The two categories of stressors (primary and secondary) and the relationship between each of them and the quality of life were assessed. The primary and secondary stressors were found to moderately correlate with quality of life of caregivers. Primary stressor (caregiver's burden) explained 38.4% of the variance in caregiver's quality of life. The amount of variance accounted for caregivers' quality of life by financial, physical, emotional, family and individual burden were 35.6%, 4.5%, 9.2%, 23.2% and 15.9% respectively. In other words, as perceived level of caregiving burden increased, perceived quality of life decreased among the caregivers of children with CP.

The negative relationship between caregiver's burden and quality of life of caregivers of children with CP is consistent with previous studies. In a study conducted by Kato, Jaarsma, Okada, Kagami, Endo, Ono, and Kinugawa (2015) on the relationship between caregiver's burden and quality of life, it was found that higher caregiver's burden was associated with lower quality of life among caregivers of children with epilepsy. Similarly, in a study of caregivers of children with CP, Westphal-Guitti, Alonso, Migliorini, da Silva, Azevedo, Caboclo, Sakamoto, and Yacubian (2007) found that caregivers' burden was negatively associated with quality of life among the caregivers of children with CP. These studies all underscore the importance of perceived caregiver burden as a factor in lowering quality of life.

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Caregiver burden can culminate in acute and chronic physical disorders, resulting in isolation and depression, as well as financial disequilibrium, reduction in libido and self-accusation which all affect the quality of life of the caregiver. In addition to domestic responsibilities, the caregivers undertake complex activities which are not part of their routine, arising from the care of their children with CP which serves as a burden for them and decrease the quality of their life.

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The negative relationship between caregivers' burden and quality of life is based on the fact that caregivers' burden imposes a high level of stress among the caregivers. However, every individual has some amount of stress he or she can endure at every point in time. When the level of burden imposes higher amount of stress than the individual can cope with it affects the psychological functioning and wellbeing of the person and thus leads to lower quality of life.

The negative relationship between caregiver's burden and quality of life contradicts the findings of the study conducted by Oh and Lee (2009) which indicated no significant impact of caregiver's burden on quality of life. The inconsistencies in the findings between the present study and that of Oh and Lee (2009) can be due to two main factors; participants and cultural differences. Oh and Lee (2009) recruited caregivers of children with developmental disabilities whilst the present study used caregivers of children with CP. The two disabilities are not the same and so the level of burden perceived by the two caregivers may not be the same. Also, Oh and Lee (2009) conducted their study in South Korea whilst the present study was conducted in Ghana. South Koreans are individualistic whilst Ghanaians are collective culture. It is worth noting that cultural differences shape people's perception of quality of life and wellbeing (Macedo, da Silva, Paiva & Ramos, 2015).

The study also predicted a negative relationship between secondary stressors and quality of life. The findings supported the prediction with the three components of secondary stressors (stress, depression and anxiety), which collectively explained 25.5% of the variance in caregivers' quality of life. This means that when the levels of secondary stressors (stress, depression and anxiety) increase, it decreases the quality of life of the caregivers.

The negative relationship between depression and quality of life is in agreement with the study by Hooley, Butler and Howlett (2005) which assessed the relationship between depression and quality of life among caregivers of congestive heart failure patients. Findings

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indicated a negative relationship between depression and quality of life among the caregivers. Similarly, a study by Zanon and Batista (2012) found that stress decreases the quality of life of caregivers and negatively affect their psychological functioning.

5.5 Mediating Role of Secondary Stressors (Depression, Anxiety and Stress) on Caregivers' Burden – QoL Relationship

The study assessed whether secondary stressors (depression, anxiety and stress) mediate the relationship between caregivers' burden and quality of life of caregivers of children with CP. The findings indicated a partial mediation of stress, anxiety and depression on the relationship between caregivers' burden and quality of life. These findings mean that the extent to which the primary stressor (caregivers' burden) can be responsible for lower quality of life will depend on the extent of depression, anxiety and stress associated with the burden.

The finding is in agreement with the findings of the study by Marron, Redolar-Ripoll, Boixados, Nieto, Guillamon, Hernande and Gomez (2012) which was aimed at assessing the role of depression and stress on the relationship between burden and quality of life. Stress and depression were found to mediate the relationship between caregiver's burden and quality of life. The finding also supports the study by Dambi, Jelsma and Mlambo (2015) which found a partial mediation role of depression on the relationship between caregiver burden and quality of life among caregivers of CP.

The partial mediation of secondary stressors on the relationship between primary stressors and quality of life can be explained using the stress process model by Pearlin et al. (1990) which was the guiding framework for the study. According to the stress process model, secondary stressors (depression, stress and anxiety) explain the relationship between the caregivers' burden and quality of life. According to the model, the variability in quality of

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life predicted by caregivers' burden depends on the amount of stress depression and anxiety associated with that burden. The burden may first lead to higher levels of depression, anxiety and stress and the level of stress, anxiety and depression produced by the caregivers' burden will determine the quality of life of the caregivers. As found by Walter, et al. (2005), caregiver's burden produces a higher level of stress, depression and anxiety that negatively affect the quality of life of caregivers of children with CP.

5.6 Moderating Role of Social Support on the relationship between Caregiver Burden – QoL

The present study also predicted that social support will moderate the relationship between caregiver's burden and quality of life. The findings indicated a moderating effect of social support on the relationship between caregiver's burden and quality of life with social support accounting for 44.6% of the variance in QoL. This means that a caregiver with higher caregiving burden when exposed to social support will exhibit a better quality of life compared to a caregiver without social support. Thus, social support contributes to alleviating the negative consequences of stress and burden of the caregiver in caring for a child with CP.

This finding supports the results from the study conducted by Anjos, Boery, Pereira. Pedreira, Vilela, Santos and Roda Dde (2015) which indicated that social support played a partial role as a moderator in the relationship between burden and quality of life. Social support for caregivers is important to prevent health complications such as bio-psychosocial stress, and provides favourable conditions for quality of life, by allowing greater freedom to develop in daily activities. Based on this, the negative consequences associated with higher burden may not be felt much when there is a higher level of social support from family members and other significant others.

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This finding is in line with the study conducted by Zuurmond, Mahmud, Polack and Evans (2015) which reported that social support moderates the relationship between caregiver's burden and quality of life. The result also agrees with the explanation given by Burnette, Duci and Dhembo (2016) that the extent to which the burden associated with caregiving can affect the wellbeing of an individual will depend on the quality of support they receive from the family and significant others. Invariably, social support serves as a coping tool in optimizing the wellbeing and health outcomes of caregivers.

The moderating role of social support on the relationship between caregivers' burden and quality of life can be due to the fact that the level of available support from family, friends and significant others lowers the stress, anxiety and depression associated with caregivers' burden. This can in turn lower the negative consequences of the stress, depression and anxiety on quality of life (Wang & Zhao, 2012). The overall QoL and domain scores for the quality of life may be boosted by the support caregivers receive and thus the negative consequences of caregivers burden may not be felt much (Burnette, Duci & Dhembo, 2016).

In summary, the quality of life of caregivers of children with CP was found to be influenced by the primary stressor (caregiver's burden) and secondary stressors (stress, depression and anxiety). This is in line with the stress process model which approached the caregivers' stress as a process. This process results from interactions or relationships between conditions that develop and generate over time. The stressors are the heart of the process. Juxtaposing it to the current study, negative relationships were established between the variables (primary stressor, secondary stressors and quality of life) such that as caregivers' burden increases, quality of life of the caregiver decreases. Similarly, as depression, anxiety and stress of the caregivers of children with CP increase, quality of life decreases.

Thus if the desired outcome is to increase quality of life, then measures must be instituted to decrease caregivers' burden, depression, stress and anxiety. Consistent with the

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model used (stress process model), the current study has demonstrated that the lower level of quality of life of caregivers is due to high levels of caregiver burden. It is the caregivers' burden that results in the secondary stressors which also influence the quality of life of the caregivers. The model predicts that caregiving and its consequence is potentially influenced by key demographic characteristics such as age, gender and educational level. Differing from the model, the present study revealed that demographic characteristics did not have any significant influence on the quality of life of the caregivers of the children with cerebral palsy. Adding up to the stress process model, the findings revealed that social support moderate the relationship between the primary stressors and quality of life of the caregivers of children with CP.

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CHAPTER SIX

SUMMARY, IMPLICATIONS, LIMITATIONS CONCLUSIONS AND RECOMMENDATIONS

6.1 Summary

The study examined the QoL of caregivers of children with CP and the factors influencing the QoL of caregivers of children with CP. Caregivers (parents, relatives, and other associates) of children with cerebral palsy being managed at the Neuro-developmental Clinics (NDC) of the 37 Military Hospital and the Princess Marie-Louis Hospital as well as some Non-Governmental Organizations within Greater Accra that support children with CP were recruited as the participants.

The stress process model by Pearlin et al., (1990) was the guiding framework for the research. A quantitative approach was engaged for the study in order to gather data from respondents. In selecting respondents, only caregivers of children with CP who had spent one year or more in the care of the child were purposively sampled to participate in the study. A total of one hundred and thirty respondents, made up of 12 males and 118 females participated in the study. Questionnaires were answered by respondents anonymously. The stated objectives were analyzed using descriptive statistics, Pearson Product Moment Correlation Coefficients and the hierarchical regression for moderating and mediating effects.

The results of the study showed that caregivers had lower QoL and were affected negatively in all the four components of QoL (physical, psychological, social relationships and environmental). A higher number of caregivers had below moderate scores on all the four components of QoL. Caregiving severely affected their psychological and physical health than their environmental health and social relationships.

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Caregivers of children with CP also expressed higher amount of burden with a larger number of the caregivers (53.8%) experiencing severe burden in caregiving. With the exception of family burden in which most of the caregivers (43.8%) experienced moderate level, higher number of caregivers experienced severe burden in physical (44.6%), emotional, (60.8%), individual (56.2%) and financial (53.8%) aspects of the burden. Among the five components of caregiver burden, emotional burden was found to be the most severe. This was followed by the individual, financial, physical and the family burdens respectively. The caregivers also experienced moderate levels of depression followed by stress and anxiety in the given order.

The primary stressor (caregiver's burden) and secondary stressors (stress, depression and anxiety) were found to moderately correlate with quality of life of caregivers. Caregiver's burden in general collectively explained 38.4% of the variance in caregiver's quality of life. The three components of secondary stressors (stress, depression and anxiety) also collectively explained 25.5% of the variance in caregiver's quality of life.

Stress, anxiety and depression were found to partially mediate the relationship between caregiver burden and quality of life. There was also a moderating effect of social support on the relationship between caregiver burden and quality of life with social support accounting for 44.6% of the variance in QoL. However, demographic characteristics of the caregivers (age, education, marital status and religion) collectively explained an insignificant 3.7% of the variance in caregiver's quality of life.

6.2 Implications

The findings of this study have implications for nursing practice, informal caregiving and policy formulation.

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6.2.1 For Nursing Practice

Findings of this study showed that a majority of caregivers of children with CP in the Accra Metropolis were at risk of developing lower quality of life. Thus there is the need to provide adequate support and educate the caregivers of children with CP on how to cope with caregiving to increase their quality of life. Healthcare providers and the society at large need to be mindful about issues of stigma associated with CP since the consequences of this do not affect only the children with CP but the caregivers as well. Nurses need to create awareness on CP and intensify education on the causes and management. Healthcare providers and other stakeholders involved in providing support for the children with CP need to create a safe space for caregivers to acknowledge the negative impact that their lower quality of life have on the health of the children.

Health care workers who have considerable knowledge on the disability must also provide individual counseling, parenting therapy, and programmes to assist the family members of the caregiver and siblings of the child with cerebral palsy. There is also the need for the nurses to be enlightened on the enormous burden that caregivers of children with CP encounter and its consequences of high levels of stress, anxiety and depression in order for them to provide the caregivers the needed support

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6.2.2 For Informal Caregiving

Caregivers need the knowledge and skills pertinent to the care they are providing for the children with cerebral palsy. To this end, health institutions and other facilities that deal with disabilities in Ghana can develop educational programmes in which children with cerebral palsy and their families, especially caregivers can participate in order to learn new independent living and coping skills. Informal caregivers need to educate themselves about

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the disability (cerebral palsy), managing stress, coping with depression and anxiety and developing proper caregiving techniques.

The findings of the study revealed that caregivers of children with CP experience higher amount of primary stressors (caregiver's burden) and secondary stressors (stress, depression and anxiety). These findings imply that there is the need for informal caregivers to seek financial, social and psychological support to ease the burden, stress, depression and anxiety they encounter.

This study particularly demonstrated that social support helps to ameliorate the negative impact of caregiver's burden on quality of life among caregivers of children with CP. Intervention aimed at maximizing the social support networks of caregivers can be of great assistance to caregivers of children with CP and caregivers of other similar disabilities. Self-help groups for these caregivers can be a culturally-appropriate intervention in the world and Ghana to be specific.

6.3 Limitations of the Study

Though the present study took all possible steps to provide the findings in a holistic way, the study had some limitations. The findings of this study should be interpreted in light of its limitations.

First and foremost, this study relied on self-report measures which are subject to social desirable effects. Due to the perceptual nature of the data, there is the possibility of a perceptual bias. Nevertheless, the researcher made sure the respondents remained anonymous which reduced the socially desirable responses but could not control for the perceptual bias. However, the data collected on quality of life and stressors might not provide a true reflection of the actual feelings of the caregivers due to the perceptual nature of the study.

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Secondly, this empirical study confines itself to a correlational survey method, which leaves room for speculation with regard to causality among the variables. The researcher used purposive sampling technique instead of random sampling. By that, not all the caregivers of children with cerebral palsy had an equal chance of participating in the study. The purposive sampling however became appropriate because there was no up-dated and current sample frame from which respondents could be randomly selected. The length of the questionnaires (79 items) could cause lack of concentration and boredom, which in turn, can impact on the results of the study.

6.4 Recommendations

The following recommendations were made to the Ministry of Health, Ministry of Gender, Children and Social Protection and Researchers.

6.4.1 To Ministry of Health (MOH)

The Ministry of Health should:

- Collaborate with the national health insurance scheme to have a policy that allows for free physiotherapy sessions for children with CP for as long as required without a limit so as to ease the financial burden of paying for physiotherapy sessions by the caregiver.
- Have a policy for mandatory annual health assessment for any caregiver of a child with CP. This health assessment must be accessible for any caregiver attending any government facility to mitigate the effect of caregiving on their health.
- Mandate all health facilities managing children with CP to have social support groups for the caregivers. The social support group should have a psychologist who will

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provide free counselling to the caregivers of children with CP to reduce their level of stress, depression and anxiety.

6.4.2 To Ministry of Gender, Children and Social Protection (MGCSP)

The MGCSP should;

- Include all caregivers of children with CP in the Livelihood Empowerment Against Poverty (LEAP) programme so as to benefit from the allowances to reduce the financial burden on the caregiver.
- Waive transportation cost of children with CP and their caregivers as it is being rolled out for the elderly (in the EBAN project) to reduce the financial burden of the caregiver.
- Have an avenue to provide wheelchairs and other assistive devices at a subsidized rate to the children in order to facilitate their movement and ameliorate the physical burden associated with providing care for these children.
- Provide respite services or facilities where children with CP can be taken care of. This could be in the form of a day care where the caregivers or parents can send these children during the day so they in turn can secure employment.

6.4.3 To Researchers

Future research should:

- Investigate the needs of the caregivers, their satisfaction with their therapy, difficulties encountered in accessing the specialized services, and support networks.
- Compare the burden and quality of life of caregivers of children with cerebral palsy and caregivers of other chronic ailments.

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- Establish the relationship between the quality of life of caregivers and the wellbeing of the child so as to enlighten the caregiver and the society at large on the need to support the caregiver.
- Employ either qualitative research approach or mixed methods for a better understanding of the interaction effects of all the variables in the study.

6.5 Conclusion

Over the years, researchers and practitioners have been emphasizing on the wellbeing and health of the children with disabilities. The health of the caregiver however is both a cause and a consequence of the health of the child. The study in its entirety has revealed that caregivers of children with CP in the Accra Metropolis expressed higher caregiver burden leading to higher levels of anxiety, depression and stress.

Most of the findings of the study were consistent with the stress process model. For instance, primary (caregiver's burden) and secondary (stress, depression and anxiety) stressors had negative impact on the quality of life of the caregivers of children with CP.

Secondary stressors (stress, depression and anxiety) were also found to mediate the relationship between caregiver's burden and QoL. However, demographic characteristics did not have any significant impact on QoL of caregivers of children with CP. Social support moderated the relationship between caregiver's burden and QoL of the caregivers of children with CP. Therefore, there is the need to provide adequate support to caregivers to boost their quality of life.

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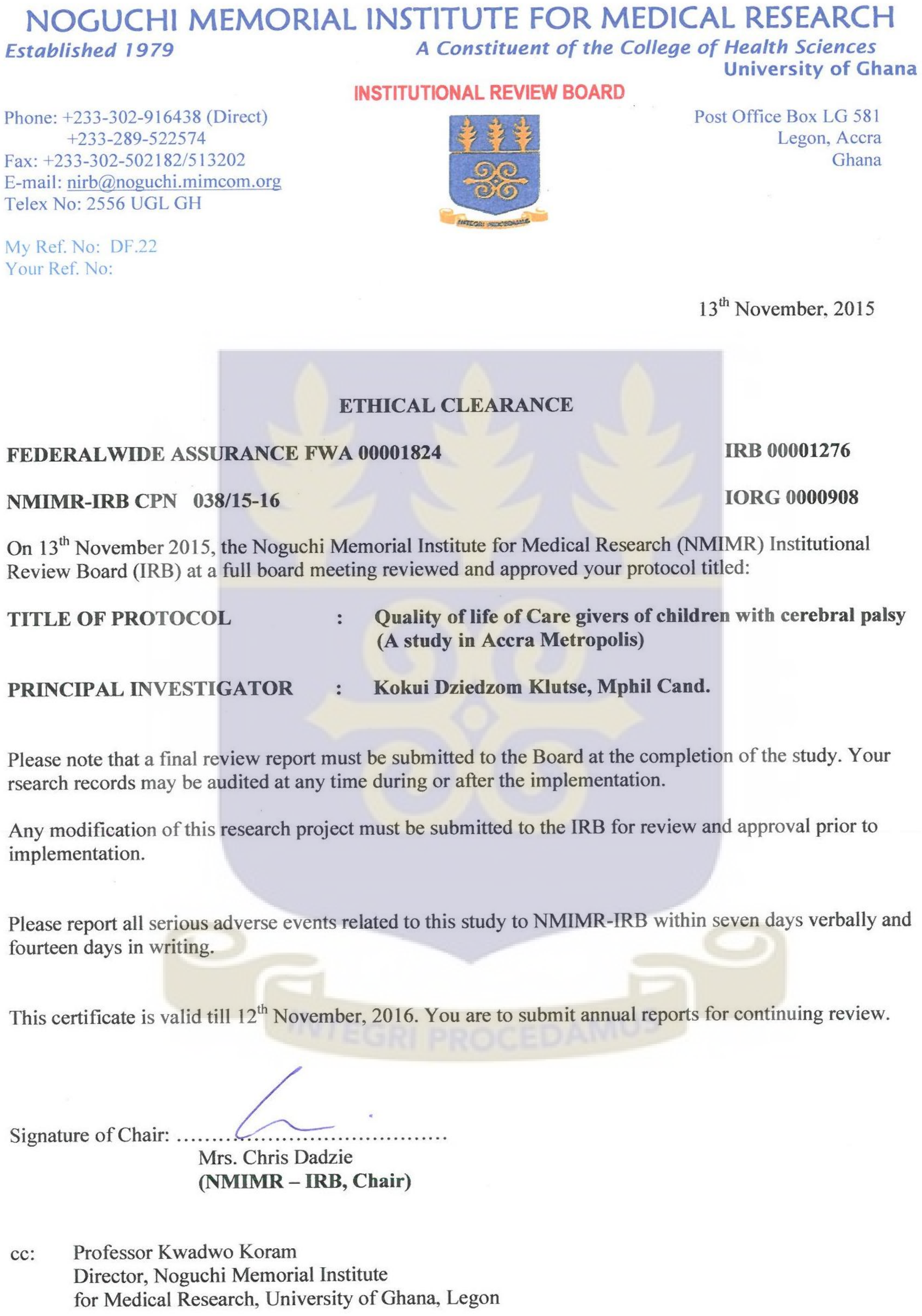
APPENDICES

APPENDIX A: ETHICAL CLEARANCE



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Post Office Box LG 581
Legon, Accra
Ghana

My Ref. No: DF.22
Your Ref. No:

13th November, 2015

ETHICAL CLEARANCE

FEDERALWIDE ASSURANCE FWA 00001824 **IRB 00001276**

NMIMR-IRB CPN 038/15-16 **IORG 0000908**

On 13th November 2015, the Noguchi Memorial Institute for Medical Research (NMIMR) Institutional Review Board (IRB) at a full board meeting reviewed and approved your protocol titled:

TITLE OF PROTOCOL : **Quality of life of Care givers of children with cerebral palsy (A study in Accra Metropolis)**

PRINCIPAL INVESTIGATOR : **Kokui Dziedzom Klutse, Mphil Cand.**

Please note that a final review report must be submitted to the Board at the completion of the study. Your rsearch records may be audited at any time during or after the implementation.

Any modification of this research project must be submitted to the IRB for review and approval prior to implementation.

Please report all serious adverse events related to this study to NMIMR-IRB within seven days verbally and fourteen days in writing.

This certificate is valid till 12th November, 2016. You are to submit annual reports for continuing review.

Signature of Chair: ....
Mrs. Chris Dadzie
(NMIMR – IRB, Chair)

cc: Professor Kwadwo Koram
Director, Noguchi Memorial Institute
for Medical Research, University of Ghana, Legon

APPENDIX B: INTRODUCTORY LETTER- GHS

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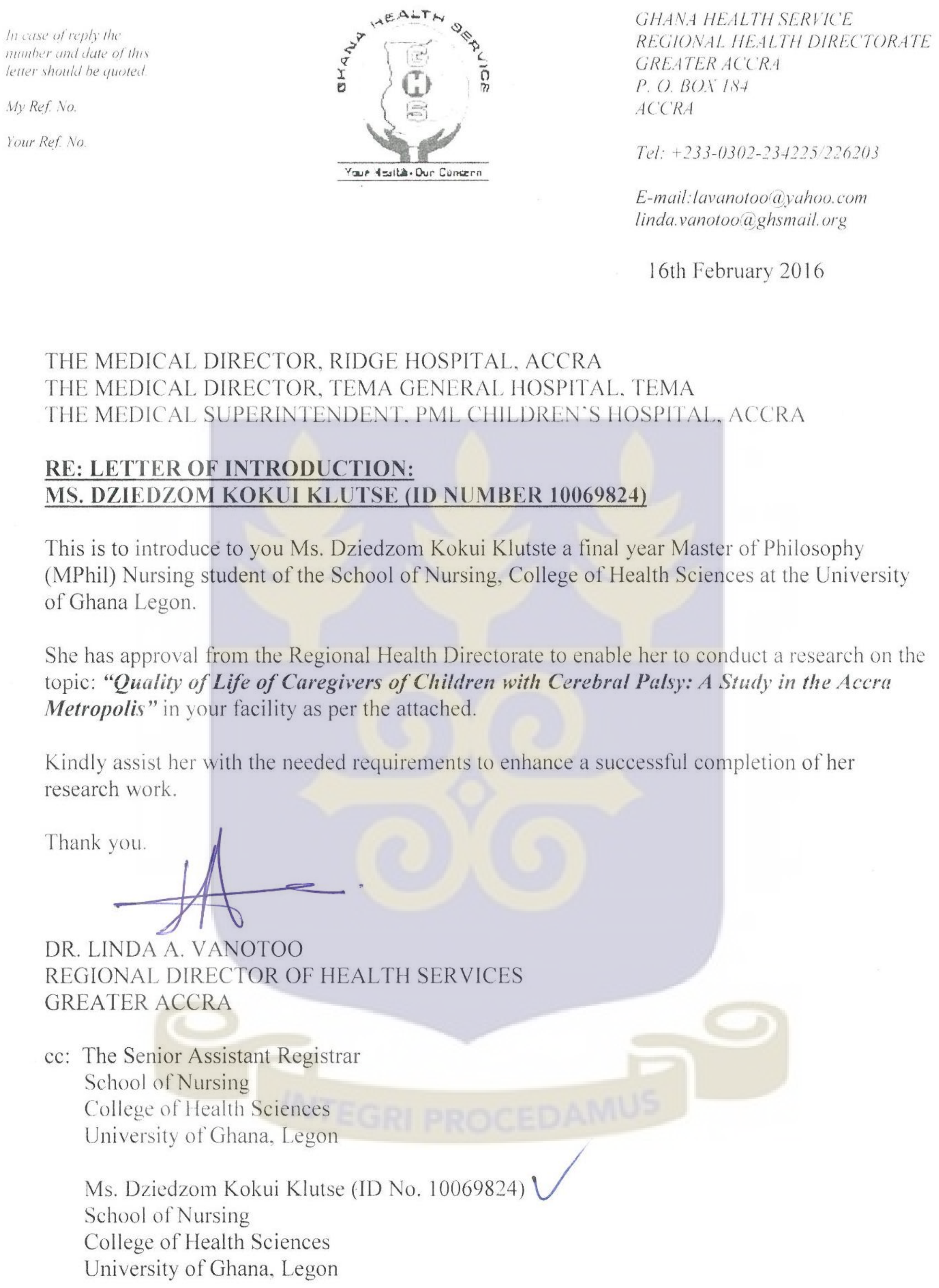


In case of reply the number and date of this letter should be quoted.

My Ref. No.

Your Ref. No.

GHANA HEALTH SERVICE
REGIONAL HEALTH DIRECTORATE
GREATER ACCRA
P. O. BOX 184
ACCRA

Tel: +233-0302-234225/226203

E-mail:lavanotoo@yahoo.com
linda.vanotoo@ghsmail.org

16th February 2016

THE MEDICAL DIRECTOR, RIDGE HOSPITAL, ACCRA
THE MEDICAL DIRECTOR, TEMA GENERAL HOSPITAL, TEMA
THE MEDICAL SUPERINTENDENT, PML CHILDREN'S HOSPITAL, ACCRA

RE: LETTER OF INTRODUCTION:
MS. DZIEDZOM KOKUI KLUTSE (ID NUMBER 10069824)

This is to introduce to you Ms. Dziedzom Kokui Klutste a final year Master of Philosophy (MPhil) Nursing student of the School of Nursing, College of Health Sciences at the University of Ghana Legon.

She has approval from the Regional Health Directorate to enable her to conduct a research on the topic: ***"Quality of Life of Caregivers of Children with Cerebral Palsy: A Study in the Accra Metropolis"*** in your facility as per the attached.

Kindly assist her with the needed requirements to enhance a successful completion of her research work.

Thank you.

DR. LINDA A. VANOTOO
REGIONAL DIRECTOR OF HEALTH SERVICES
GREATER ACCRA

cc: The Senior Assistant Registrar
School of Nursing
College of Health Sciences
University of Ghana, Legon

Ms. Dziedzom Kokui Klutse (ID No. 10069824) ✓
School of Nursing
College of Health Sciences
University of Ghana, Legon

INTEGRI PROCEDAMUS

University of Ghana http://ugspace.ug.edu.gh

APPENDIX C: INTRODUCTORY LETTER – SCHOOL OF NURSING

SCHOOL OF NURSING
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA
LEGON

Telephone: 0302-513255 (Dean)
Ext. 6206
0302-513250 } Secretary
028 9531213
Fax: 513255
E-mail: nursing@ug.edu.gh

P. O. Box LG 43
LEGON, GHANA

Our Ref:.........SON/F.11..........
Your Ref:..

December 16, 2015

The Head
Dept. of Paediatric
37 Military Hospital
Accra.

Dear Sir/Madam,

INTRODUCTORY LETTER

I write to introduce to you Ms. Kokui Dziedzom Klutse, an M'Phil student of the University of Ghana, School of Nursing. She is seeking your permission to collect data for her research on the topic **"Quality of Life of Caregivers of Children with Cerebral Palsy: A Study in Accra Metropolis."**

I would be grateful if you could kindly assist her with the information that she may require for her thesis.

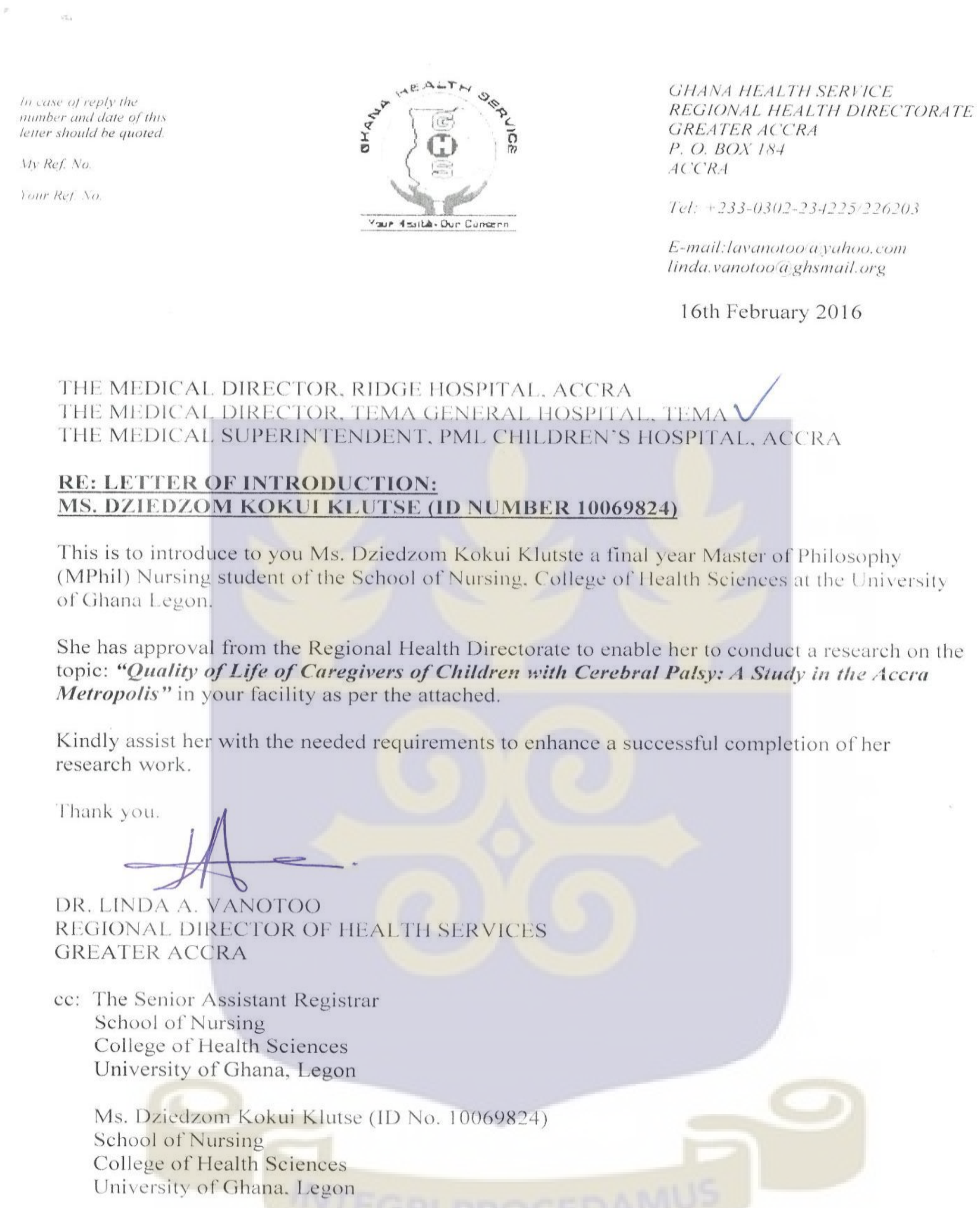
Thank you.

Yours faithfully,

Dr. Florence Naab
LECTURER

University of Ghana http://ugspace.ug.edu.gh

APPENDIX D: INTRODUCTORY LETTER – GHS



In case of reply the number and date of this letter should be quoted.

My Ref. No.

Your Ref. No.

GHANA HEALTH SERVICE

Your Health - Our Concern

GHANA HEALTH SERVICE
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16th February 2016

THE MEDICAL DIRECTOR, RIDGE HOSPITAL, ACCRA
THE MEDICAL DIRECTOR, TEMA GENERAL HOSPITAL, TEMA ✓
THE MEDICAL SUPERINTENDENT, PML CHILDREN'S HOSPITAL, ACCRA

RE: LETTER OF INTRODUCTION:
MS. DZIEDZOM KOKUI KLUTSE (ID NUMBER 10069824)

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Kindly assist her with the needed requirements to enhance a successful completion of her research work.

Thank you.

DR. LINDA A. VANOTOO
REGIONAL DIRECTOR OF HEALTH SERVICES
GREATER ACCRA

cc: The Senior Assistant Registrar
School of Nursing
College of Health Sciences
University of Ghana, Legon

Ms. Dziedzom Kokui Klutse (ID No. 10069824)
School of Nursing
College of Health Sciences
University of Ghana, Legon

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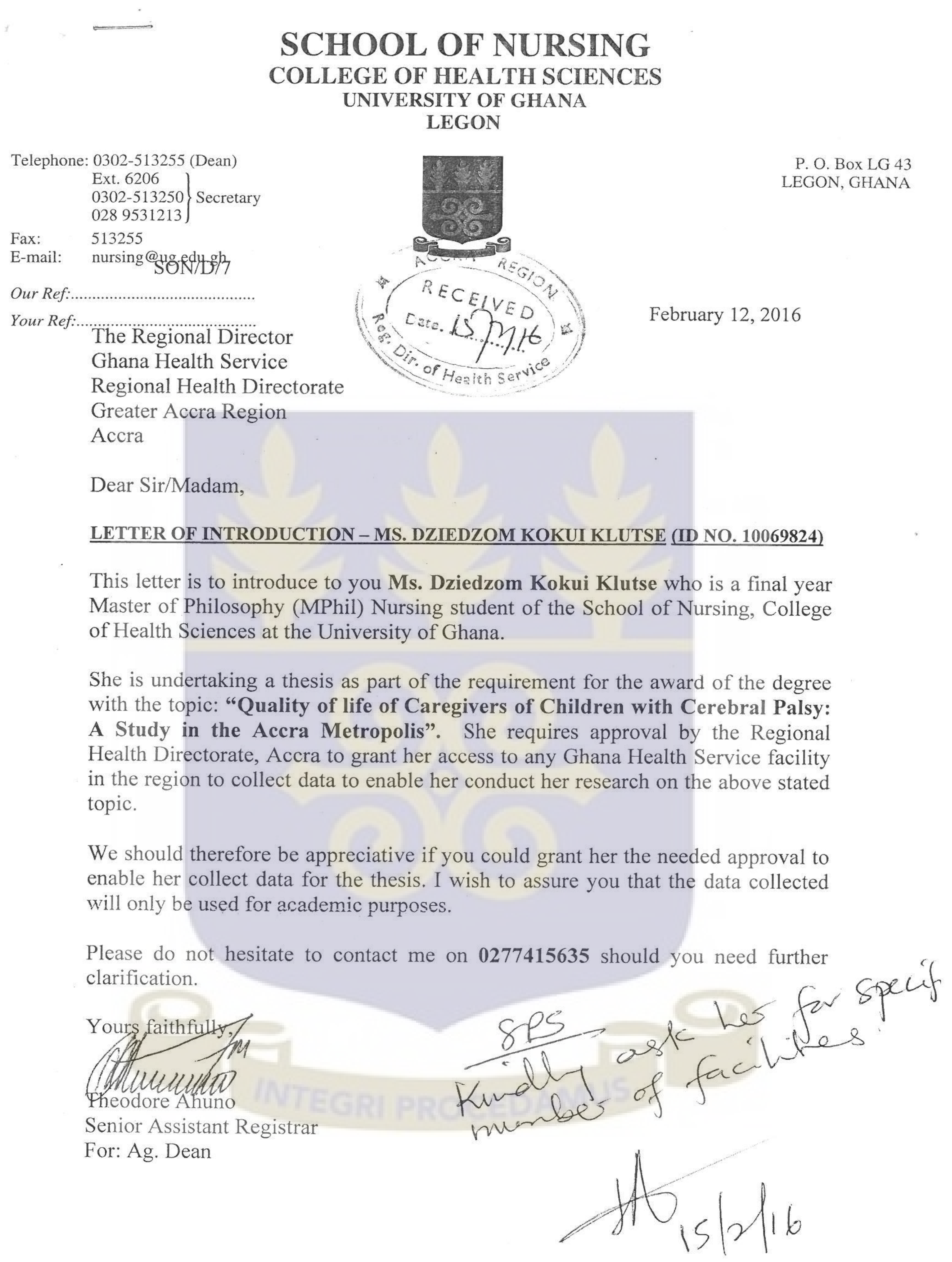

SCHOOL OF NURSING
COLLEGE OF HEALTH SCIENCES
UNIVERSITY OF GHANA
LEGON

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LEGON, GHANA

Our Ref: SON/D/7
Your Ref:

ACCRA REGION
RECEIVED
Date. 15/2/16
Reg. Dir. of Health Service

February 12, 2016

The Regional Director
Ghana Health Service
Regional Health Directorate
Greater Accra Region
Accra

Dear Sir/Madam,

LETTER OF INTRODUCTION – MS. DZIEDZOM KOKUI KLUTSE (ID NO. 10069824)

This letter is to introduce to you **Ms. Dziedzom Kokui Klutse** who is a final year Master of Philosophy (MPhil) Nursing student of the School of Nursing, College of Health Sciences at the University of Ghana.

She is undertaking a thesis as part of the requirement for the award of the degree with the topic: **"Quality of life of Caregivers of Children with Cerebral Palsy: A Study in the Accra Metropolis".** She requires approval by the Regional Health Directorate, Accra to grant her access to any Ghana Health Service facility in the region to collect data to enable her conduct her research on the above stated topic.

We should therefore be appreciative if you could grant her the needed approval to enable her collect data for the thesis. I wish to assure you that the data collected will only be used for academic purposes.

Please do not hesitate to contact me on **0277415635** should you need further clarification.

Yours faithfully,

Theodore Ahuno
Senior Assistant Registrar
For: Ag. Dean

SPS →
Kindly ask her for specif
numbers of facilities.

15/2/16

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APPENDIX E – NMIMR-IRB CONSENT FORM

NMIMR-IRB CONSENT FORM

Title: Quality of life of care givers of children with cerebral palsy (A study in Accra Metropolis)

Principal Investigator: Kokui Dziedzom Klutse.

General Information about Research

You are being requested to voluntarily participate in a research study that seeks to understand the wellbeing of people taking care of children with brain paralysis. The purpose of this study is to determine how you see your life in general due to taking care of a child with cerebral palsy. The study also seeks to find out whether there are difficulties or strain associated in giving care to the child. You qualify to take part in this research because you have spent at least one year or more in this care giving duties. Before you decide whether or not to take part, ask questions about anything you do not understand. If you choose not to participate in this study, you will not be penalized or lose any benefits to which you or your child would otherwise be entitled.

If you agree to participate, you will be requested to fill out a questionnaire that will take up about 40 minutes of your time. The questionnaire is made up of five sections. The first part of the questionnaire seeks some information about you (such as age, educational level, marital status). The second part elicits information on the burden of taking care of a child with cerebral palsy. Some mental strains associated with care giving such as depression and anxiety are assessed in the third section of the questionnaire ,the fourth section seeks information on social support whilst the final section addresses issues related to your quality of Life as far your care giving role is concerned. You are kindly informed that, the questions you will be asked are for academic purposes only and you are free to withdraw from the study at any point in time.

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Possible Risks and Discomforts

No risks are expected to arise from this study. You may decline to respond to any question you find uncomfortable. You may also contact the principal investigator if you require additional clarifications about the study.

Possible Benefits

There is no direct benefit to you as a result of your participation in the study. However, in the future, your responses will be used to educate people who take care of children with cerebral palsy .

Confidentiality

To maintain your confidentiality, your name will not be included in any questionnaire or reports about this project. Instead, every enrolled participant shall be assigned a unique study identity number. Information collected on paper forms will be stored in a locked filing cabinet while electronic copies shall be stored on a computer with password security. Only the principal investigator (Kokui Dziedzom Klutse) and the research supervisors will have access to data collected.

Compensation

There will be no financial compensation for your participation in this study. However, fruit juice and pie will be offered as refreshment.

Voluntary Participation and Right to Leave the Research

Your participation in this study is voluntary. You are free to withdraw your participation at any time without any penalty. If you decide to withdraw for any reasons kindly inform the investigator.

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Contacts for Additional Information

Further information can be obtained from the principal investigator; Kokui Dziedzom Klutse, an MPhil Nursing candidate of the University of Ghana, School of Nursing.

Address: Department of Maternal and Child Health, School of Nursing, University of Ghana, Legon

Email:kokuiklutse@gmail.com/kokuiklutse@yahoo.com

Mobile number, +233-244668579.

Your rights as a Participant

This research has been reviewed and approved by the Institutional Review Board of Noguchi Memorial Institute for Medical Research (NMIMR-IRB). If you have any questions about your rights as a research participant you can contact the IRB Office between the hours of 8am-5pm through the landline 0302916438 or email addresses: nirb@noguchi.mimcom.org

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VOLUNTEER AGREEMENT

The above document describing the benefits, risks and procedures for the research title **(Quality of life of care givers of children with cerebral palsy: A study in Accra Metropolis)** has been read and explained to me. I have been given an opportunity to have any questions about the research answered to my satisfaction. I agree to participate as a volunteer.

Date   Name and signature or mark of volunteer

If volunteers cannot read the form themselves, a witness must sign here:

I was present while the benefits, risks and procedures were read to the volunteer. All questions were answered and the volunteer has agreed to take part in the research.

Date   Name and signature of witness

I certify that the nature and purpose, the potential benefits, and possible risks associated with participating in this research have been explained to the above individual.

Date   Name Signature of Person Who Obtained Consent

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APPENDIX F: DATA COLLECTION INDTRUMENT

DATA COLLECTION INSTRUMENTS.

Quality of life of Care givers of Children with Cerebral Palsy (A study in the Accra Metropolis).

DEMOGRAPHIC QUESTIONNAIRE.

Instructions

Kindly answer the following questions.

Gender

1. Male
2. Female

How old are you? ______________________________

What is your educational level?

1. Junior Secondary School _________________________
2. Senior Secondary School _________________________
3. First degree ____________________________________
4. Masters degree __________________________________
5. PhD ___________________________
6. Other

Marital status

1. Married ____________________________
2. Single ____________________________
3. Divorced ___________________________
4. Separated __________________________
5. Other _____________________________

Religion

1. Christian __________________________
2. Muslim ___________________________

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3. Traditional believer ____________________

4. Other ____________________________

Are you currently employed?

1. Yes

2. No

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DATA COLLECTION INSTRUMENTS.

CARE GIVER BURDEN SCALE.

This questionnaire is to assess your perceived burden associated with taking care of your child with cerebral palsy. Kindly select the most appropriate option that best describes your burden.

ITEMS	SCORES			
	NEVER (0)	SOMETIMES (1)	MANY TIMES (2)	ALWAYS (3)
I. Physical burden	0	1	2	3
I use intense physical strength.	0	1	2	3
I am tired and exhausted.	0	1		
My health is failing	0	1	2	3
II. Emotional burden				
I feel upset to see the deterioration of his/her health.	0	1	2	3
I feel mentally drained.	0	1	2	3
I worry about being unable to handle things well.	0	1	2	3
I feel angry while taking care of him/her.	0	1	2	3
I feel frustrated.	0	1	2	3
I feel guilty that I am not doing enough for him/her.	0	1	2	3
III. Family relationship burden				
My contact with friends and relatives has diminished	0	1	2	3
The family must undergo a period of readjustment due to change in routine	0	1	2	3
I feel that I don't have anyone to help me, yet I feel that I should have.	0	1	2	3
I cannot take care of my immediate family and the elder at the same time.	0	1	2	3
The relationship between	0	1	2	3

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family members has worsened				
Other family members complain that I am not doing a good job of taking care of him/her	0	1	2	3
IV. Individual time and freedom burden				
I need to pay attention to him/her all the time.	0	1	2	3
I have no free time.	0	1	2	3
My outings and travel are restricted	0	1	2	3
V. Financial burden				
I need to scrimp and save on expenses	0	1	2	3
I cannot afford his/her expenses	0	1	2	3

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WHOQOL-BREF (1997)

This questionnaire asks how you feel about your quality of life, health, or other areas of your life. Please answer all the questions. If you are unsure about which response to give to a question, please choose the one that appears most appropriate.
Please read each question, assess your feelings, and circle the number on the scale that gives the best answer for you for each question.

1. Strongly Disagree 2. Disagree 3. Neutral 4. Agree 5. Strongly Agree

		1	2	3	4	5
1	I rate my quality of life as very good					
2	I am satisfied with my health					
3	I feel that physical pain prevents me from doing what I need to do					
4	I need medical treatment to function in my daily life					
5	I do not enjoy life as I am supposed to					
6	I feel that my life is meaningful					
7	I am able to concentrate					
8	I feel safe in my daily life					
9	I am healthy in my physical environment					
10	I have enough energy for everyday life					
11	I am able to accept my bodily appearance					
12	I have enough money to meet my needs					
13	Information that I need in my day-to-day life are readily available					
14	I have the opportunity for leisure activities					
15	I am able to get around well with others					
16	I am not satisfied with my sleep					
17	I am satisfied with my ability to perform my daily living activities					
18	I am satisfied with my capacity for work					
19	I am satisfied with myself					
20	I am satisfied with my personal relationships					
21	I am satisfied with my sex life					
22	I am satisfied with the support I get from my friends					
23	I am satisfied with the conditions of my living place					
24	I am satisfied with my access to health services					
25	I am satisfied with my mode of transportation					
26	I often have negative feelings, such as blue mood, despair, anxiety, depression					

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Depression Anxiety Stress Scale (DASS)
Please read each statement. Type 0, 1, 2 or 3 over the dotted lines to indicate how much each statement applied to you over the past week. There are no right or wrong answers. Do not spend too much time on any statement.

The rating scale:

0	Did not apply to me at all
1	Applied to me to some degree or some of the time
2	Applied to me to a considerable degree or a good part of the time
3	Applied to me very much or most of the time

		0	1	2	3
1	I felt that life was meaningless				
2	I felt I wasn't worth much as a person				
3	I was unable to become enthusiastic about anything				
4	I felt that I had nothing to look forward to				
5	I felt down-hearted and blue				
6	I felt that I was rather touchy				
7	I found it difficult to work up the initiative to do things				
8	I couldn't seem to experience any positive feeling at all				
9	I was intolerant of anything that kept me from getting on with what I was doing				
10	I felt I was close to panic				
11	I found it hard to unwind				
12	I found it difficult to relax				
13	I found myself getting agitated				
14	I felt that I was using a lot of nervous energy				
15	I was worried about situations in which I might panic and make a fool of myself				
16	I was aware of dryness of my mouth				
17	I tended to over-react to situations				
18	I was aware of the action of my heart in the				

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	absence of physical exertion				
19	I felt scared without any good reason				
20	I experienced breathing difficulty				
21	I experienced trembling				

Multidimensional Scale of Perceived Social Support

This questionnaire is to assess your perceived support from family members, friends, and "a special person" whilst taking care of your child with cerebral palsy. Kindly select the most appropriate option that best describes your social support.

Items	Scores				
	Strongly Disagree (0)	Disagree (1)	Neutural (2)	Agree (3)	Strongly Agree (3)
There is a special person who is around when I am in need					
There is a special person with whom I can share my joys and sorrows					
My family really tries to help me.					
I get the emotional help and support I need from my family.					
I have a special person who is a real source of comfort to me.					
My friends really try to help me.					
I can count on my friends when things go wrong					
I can talk about my					

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problems with my family					
I have friends with whom I can share my joys and sorrows.					
There is a special person in my life who cares about my feelings.					
My family is willing to help me make decisions.					
I can talk about my problems with my friends.					

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APPENDIX G – WORK PLAN

Activity	2015		2015/2016	2016				
	May-July	Aug-Nov	Dec-Feb	Mar	Apr	May	June	July
Proposal Writing	■							
Application for ethical clearance		■						
Piloting /Administering of Questionnaire			■					
Data analysis				■				
Report of findings					■			
Correction and writing of final draft						■		
Presentation of thesis and defense							■	
Correction and final submission								■
Studying, monitoring and evaluation	→ On going →							

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APPENDIX H: SPSS OUTPUT

Analysis

Normality of Data

	N	Minimum	Maximum	Mean	Std. Deviation	Skewness		Kurtosis	
	Statistic	Statistic	Statistic	Statistic	Statistic	Statistic	Std. Error	Statistic	Std. Error
Physical	130	.00	9.00	5.5385	2.59443	-.193	.212	-.127	.422
Emotional	130	3.00	16.00	8.8538	2.55516	.182	.212	-.254	.422
Family	130	.00	18.00	8.4538	5.23718	.208	.212	-.956	.422
Individual	130	1.00	15.00	11.3462	4.00525	-.781	.212	-.649	.422
Financial	130	2.00	13.00	7.9154	1.80883	.056	.212	.697	.422
CGB	130	16.00	67.00	42.1077	12.46468	-.111	.212	-.010	.422
DASS	130	11.00	54.00	34.0308	9.65926	-.047	.212	-.778	.422
PSS	130	1.00	46.00	19.8462	10.39041	.307	.212	-.615	.422
WHOQOL	130	6.00	87.00	46.2462	13.64276	-.043	.212	.098	.422
Valid N (listwise)	130								

Correlation Matrix

		TPhysical	TEmotional	TFamily	TIndividual	TFinancial	TCGB	TDASS	TPSS	TWHOQOL
Physical	Pearson Correlation	1	.537**	.660**	.594**	.191*	.814**	.327**	-.472**	-.435**
	Sig. (1-tailed)		.000	.000	.000	.015	.000	.000	.000	.000
	N	130	130	130	130	130	130	130	130	130
Emotional	Pearson Correlation	.537**	1	.514**	.325**	.145*	.658**	.329**	-.227**	-.348**
	Sig. (1-tailed)	.000		.000	.000	.050	.000	.000	.005	.000
	N	130	130	130	130	130	130	130	130	130
Family	Pearson Correlation	.660**	.514**	1	.614**	.316**	.906**	.396**	-.377**	-.511**
	Sig. (1-tailed)	.000	.000		.000	.000	.000	.000	.000	.000
	N	130	130	130	130	130	130	130	130	130
Individual	Pearson Correlation	.594**	.325**	.614**	1	.185*	.796**	.270**	-.500**	-.478**
	Sig. (1-tailed)	.000	.000	.000		.018	.000	.001	.000	.000
	N	130	130	130	130	130	130	130	130	130
Financial	Pearson Correlation	.191*	.145*	.316**	.185*	1	.407**	.140	-.091	-.096
	Sig. (1-tailed)	.015	.050	.000	.018		.000	.056	.152	.138
	N	130	130	130	130	130	130	130	130	130
CGB	Pearson Correlation	.814**	.658**	.906**	.796**	.407**	1	.409**	-.477**	-.544**
	Sig. (1-tailed)	.000	.000	.000	.000	.000		.000	.000	.000
	N	130	130	130	130	130	130	130	130	130
DASS	Pearson Correlation	.327**	.329**	.396**	.270**	.140	.409**	1	-.275**	-.465**

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	Sig. (1-tailed)	.000	.000	.000	.001	.056	.000		.001	.000
		130	130	130	130	130	130	130	130	130
PSS	Pearson Correlation	-.472**	-.227**	-.377**	-.500**	-.091	-.477**	-.275**	1	.507**
	Sig. (1-tailed)	.000	.005	.000	.000	.152	.000	.001		.000
	N	130	130	130	130	130	130	130	130	130
WHOQOL	Pearson Correlation	-.435**	-.348**	-.511**	-.478**	-.096	-.544**	-.465**	.507**	1
	Sig. (1-tailed)	.000	.000	.000	.000	.138	.000	.000	.000	
	N	130	130	130	130	130	130	130	130	130

**. Correlation is significant at the 0.01 level (1-tailed).

*. Correlation is significant at the 0.05 level (1-tailed).

Hypothesis 1

Depression

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Normal	0	0	0	0
	Mild	3	2.3	2.3	2.3
	Moderate	33	25.4	25.4	27.7
	Severe	32	24.6	24.6	52.3
	Extreme	62	47.7	47.7	100.0
	Total	130	100.0	100.0	

Anxiety

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Normal	1	.8	.8	.8
	Mild	8	6.2	6.2	6.9
	Moderate	15	11.5	11.5	18.5
	Severe	24	18.5	18.5	36.9
	Extreme Severe	82	63.1	63.1	100.0
	Total	130	100.0	100.0	

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Stress

		Frequency	Percent	Valid Percent	Cumulative Percent
Valid	Normal	22	16.9	16.9	16.9
	Mild	18	13.8	13.8	30.8
	Moderate	24	18.5	18.5	49.2
	Severe	51	39.2	39.2	88.5
	Extreme Severe	15	11.5	11.5	100.0
	Total	130	100.0	100.0	

One-Sample Statistics

	N	Mean	Std. Deviation	Std. Error Mean
DASS	130	34.0308	9.65926	.84717

One-Sample Test

	Test Value = 0					
					95% Confidence Interval of the Difference	
	T	df	Sig. (2-tailed)	Mean Difference	Lower	Upper
DASS	40.170	129	.000	34.03077	32.3546	35.7069

Hypotheses 2 and 3
Relationship between Burden, DASS and QoL

Correlations

		TCGB	TDASS	TWHOQOL
TCGB	Pearson Correlation	1	.409**	-.544**
	Sig. (1-tailed)		.000	.000
	N	130	130	130
TDASS	Pearson Correlation	.409**	1	-.465**
	Sig. (1-tailed)	.000		.000
	N	130	130	130
TWHOQOL	Pearson Correlation	-.544**	-.465**	1
	Sig. (1-tailed)	.000	.000	
	N	130	130	130

**. Correlation is significant at the 0.01 level (1-tailed).

Hypothesis 5
The relationship between primary stressors (caregiver's burden) and quality of life will be mediated by secondary stressors (depression, anxiety and stress).

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Step 1:

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.544[a]	.296	.290	11.49254

a. Predictors: (Constant), TCGB

ANOVA[b]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	7104.070	1	7104.070	53.787	.000[a]
	Residual	16906.053	128	132.079		
	Total	24010.123	129			

a. Predictors: (Constant), TCGB

b. Dependent Variable: TWHOQOL

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	T	Sig.
		B	Std. Error	Beta		
1	(Constant)	71.315	3.564		20.011	.000
	TCGB	-.595	.081	-.544	-7.334	.000

a. Dependent Variable: TWHOQOL

Step 2

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.409[a]	.167	.161	8.84789

a. Predictors: (Constant), TCGB

ANOVA[b]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	2015.381	1	2015.381	25.744	.000[a]
	Residual	10020.496	128	78.285		
	Total	12035.877	129			

a. Predictors: (Constant), TCGB

b. Dependent Variable: TDASS

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Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	T	Sig.
		B	Std. Error	Beta		
1	(Constant)	20.678	2.744		7.537	.000
	TCGB	.317	.062	.409	5.074	.000

a. Dependent Variable: TDASS

Step 3

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.465[a]	.216	.210	12.12677

a. Predictors: (Constant), TDASS

ANOVA[b]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	5186.623	1	5186.623	35.269	.000[a]
	Residual	18823.500	128	147.059		
	Total	24010.123	129			

a. Predictors: (Constant), TDASS

b. Dependent Variable: TWHOQOL

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	T	Sig.
		B	Std. Error	Beta		
1	(Constant)	68.586	3.909		17.545	.000
	TDASS	-.656	.111	-.465	-5.939	.000

a. Dependent Variable: TWHOQOL

Step 4

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.544[a]	.296	.290	11.49254
2	.605[b]	.366	.356	10.94526

a. Predictors: (Constant), TCGB

b. Predictors: (Constant), TCGB, TDASS

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ANOVA[c]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	7104.070	1	7104.070	53.787	.000[a]
	Residual	16906.053	128	132.079		
	Total	24010.123	129			
2	Regression	8795.695	2	4397.847	36.710	.000[b]
	Residual	15214.428	127	119.799		
	Total	24010.123	129			

a. Predictors: (Constant), TCGB

b. Predictors: (Constant), TCGB, TDASS

c. Dependent Variable: TWHOQOL

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	T	Sig.
		B	Std. Error	Beta		
1	(Constant)	71.315	3.564		20.011	.000
	TCGB	-.595	.081	-.544	-7.334	.000
2	(Constant)	79.811	4.078		19.570	.000
	TCGB	-.465	.085	-.425	-5.489	.000
	TDASS	-.411	.109	-.291	-3.758	.000

a. Dependent Variable: TWHOQOL

Excluded Variables[b]

Model		Beta In	t	Sig.	Partial Correlation	Collinearity Statistics
						Tolerance
1	TDASS	-.291[a]	-3.758	.000	-.316	.833

a. Predictors in the Model: (Constant), TCGB

b. Dependent Variable: TWHOQOL

Moderation

Model Summary

Model	R	R Square	Adjusted R Square	Std. Error of the Estimate
1	.544[a]	.296	.290	11.49254
2	.613[b]	.375	.365	10.86796
3	.618[c]	.491	.467	10.85667

a. Predictors: (Constant), TCGB

b. Predictors: (Constant), TCGB, TPSS

c. Predictors: (Constant), TCGB, TPSS, SS_CGB

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ANOVA[d]

Model		Sum of Squares	df	Mean Square	F	Sig.
1	Regression	7104.070	1	7104.070	53.787	.000[a]
	Residual	16906.053	128	132.079		
	Total	24010.123	129			
2	Regression	9009.827	2	4504.914	38.141	.000[b]
	Residual	15000.296	127	118.113		
	Total	24010.123	129			
3	Regression	9158.837	3	3052.946	25.902	.000[c]
	Residual	14851.286	126	117.867		
	Total	24010.123	129			

a. Predictors: (Constant), TCGB

b. Predictors: (Constant), TCGB, TPSS

c. Predictors: (Constant), TCGB, TPSS, SS_CGB

d. Dependent Variable: TWHOQOL

Coefficients[a]

Model		Unstandardized Coefficients		Standardized Coefficients	T	Sig.
		B	Std. Error	Beta		
1	(Constant)	71.315	3.564		20.011	.000
	TCGB	-.595	.081	-.544	-7.334	.000
2	(Constant)	55.918	5.104		10.956	.000
	TCGB	-.428	.087	-.391	-4.901	.000
	TPSS	.421	.105	.321	4.017	.000
3	(Constant)	64.754	9.368		6.912	.000
	TCGB	-.620	.192	-.567	-3.233	.002
	TPSS	.054	.343	.041	.158	.875
	SS_CGB	.308	.067	.361	4.124	.003

a. Dependent Variable: TWHOQOL

Marital Status, Level of Education and Religion on Quality of Life

Report

Education	RELIGION	marital	N	Mean	Std. Deviation
JHS	CHRISTIAN	MARRIED	29	47.3793	12.31264
		SINGLE	6	39.3333	18.15122
		DIVORCED	1	18.0000	.
		SEPARATED	2	41.5000	7.77817
		OTHER	1	57.0000	.
		Total	39	45.3333	13.76749
	MUSLIM	MARRIED	1	40.0000	.

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		SINGLE	1	47.0000	.
		Total	2	43.5000	4.94975
	Total	MARRIED	30	47.1333	12.17327
		SINGLE	7	40.4286	16.82119
		DIVORCED	1	18.0000	.
		SEPARATED	2	41.5000	7.77817
		OTHER	1	57.0000	.
		Total	41	45.2439	13.44764
SHS	CHRISTIAN	MARRIED	22	51.0000	11.73111
		SINGLE	6	46.8333	14.90526
		DIVORCED	2	40.0000	9.89949
		Total	30	49.4333	12.27749
	MUSLIM	MARRIED	4	45.5000	8.26640
		SINGLE	1	47.0000	.
		Total	5	45.8000	7.19027
	Total	MARRIED	26	50.1538	11.30908
		SINGLE	7	46.8571	13.60672
		DIVORCED	2	40.0000	9.89949
		Total	35	48.9143	11.67544
DEGREE	CHRISTIAN	MARRIED	9	52.8889	15.67198
		OTHER	1	50.0000	.
		Total	10	52.6000	14.80390
	Total	MARRIED	9	52.8889	15.67198
		OTHER	1	50.0000	.
		Total	10	52.6000	14.80390
MASTERS	CHRISTIAN	MARRIED	3	60.0000	9.84886
		Total	3	60.0000	9.84886
	Total	MARRIED	3	60.0000	9.84886
		Total	3	60.0000	9.84886
PHD	MUSLIM	MARRIED	1	39.0000	.
		Total	1	39.0000	.
	Total	MARRIED	1	39.0000	.
		Total	1	39.0000	.
OTHER	CHRISTIAN	MARRIED	29	43.4138	16.25581
		DIVORCED	1	46.0000	.
		SEPARATED	5	37.4000	10.43072
		OTHER	1	43.0000	.
		Total	36	42.6389	15.11887
	MUSLIM	MARRIED	3	43.0000	5.29150
		OTHER	1	36.0000	.
		Total	4	41.2500	5.56028
	Total	MARRIED	32	43.3750	15.50806
		DIVORCED	1	46.0000	.
		SEPARATED	5	37.4000	10.43072
		OTHER	2	39.5000	4.94975
		Total	40	42.5000	14.41153
Total	CHRISTIAN	MARRIED	92	47.9457	14.12609

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		SINGLE	12	43.0833	16.31206
		DIVORCED	4	36.0000	13.58921
		SEPARATED	7	38.5714	9.30694
		OTHER	3	50.0000	7.00000
		Total	118	46.5424	14.17452
	MUSLIM	MARRIED	9	43.3333	6.22495
		SINGLE	2	47.0000	.00000
		OTHER	1	36.0000	.
		Total	12	43.3333	5.95946
	Total	MARRIED	101	47.5347	13.65398
		SINGLE	14	43.6429	15.07217
		DIVORCED	4	36.0000	13.58921
		SEPARATED	7	38.5714	9.30694
		OTHER	4	46.5000	9.03696
		Total	130	46.2462	13.64276

Tests of Between-Subjects Effects

Dependent Variable:TWHOQOL

Source	Type III Sum of Squares	df	Mean Square	F	Sig.
Corrected Model	3704.505[a]	21	176.405	.938	.544
Intercept	36145.298	1	36145.298	192.247	.000
marital	546.075	4	136.519	.726	.576
Education	523.304	5	104.661	.557	.733
RELIGION	21.654	1	21.654	.115	.735
marital * Education	578.659	6	96.443	.513	.797
marital * RELIGION	135.432	2	67.716	.360	.698
Education * RELIGION	74.180	2	37.090	.197	.821
marital * Education * RELIGION	24.014	1	24.014	.128	.721
Error	20305.618	108	188.015		
Total	302042.000	130			
Corrected Total	24010.123	129			

a. R Squared = .154 (Adjusted R Squared = -.010)

Correlations

		Age	TWHOQOL
Age	Pearson Correlation	1	-.057
	Sig. (1-tailed)		.261
	N	130	130
TWHOQOL	Pearson Correlation	-.057	1
	Sig. (1-tailed)	.261	
	N	130	130