UNIVERSITY OF CAPE COAST

PSYCHOLOGICAL DISTRESS AND COPING MECHANISMS AMONG CAREGIVERS OF CHILDREN LIVING WITH CEREBRAL PALSY

DESMOND JOE KYEREMEH

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BY

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Thesis submitted to the Department of Education and Psychology of the Faculty of Educational Foundations, College of Education Studies, University of Cape Coast, in partial fulfilment of the requirements for the award of Master of Philosophy Degree in Clinical Health Psychology

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DECLARATION

Candidate's Declaration

I hereby declare that this thesis is the result of my own original research and that no part of it has been presented for another degree in this university or elsewhere.

Signature: ……………………… Date………………

Candidate's Name:

Supervisor's Declaration

I hereby declare that the preparation and presentation of the thesis were supervised in accordance with the guidelines on supervision laid down by the University of Cape Coast.

Signature: ……………….…. Date………………

Supervisors' Name:

ABSTRACT

Caregivers of children living with cerebral palsy often face significant psychological distress in their daily routines. Cerebral palsy, a nonprogressive but incurable condition, leads to lifelong functional disabilities and is prevalent among children in developing countries. This study aimed to uncover the psychological distress that Ghanaian caregivers of children with cerebral palsy experience. Employing a convergent parallel mixed method design, the study utilised a purposive and snowballing sampling approaches, involving a total of 65 caregivers. Qualitative interviews were conducted with 10 respondents, while 55 respondents participated in the quantitative aspect. The findings revealed that caregivers experienced various forms of psychological distress, including disorientation, worry, sadness, fear, rejection, and anger. Coping mechanisms employed by caregivers included humour, avoidance, acceptance, faith or religion, seeking support from professional advice or support groups, and relying on family support. The study found that avoidant coping and problem-focused coping significantly predicted anxiety among caregivers (B= .619, t=3.414, p=.001; B= .331, t=2.308, p=.025, respectively). Avoidant coping also emerged as a significant predictor of depression (B= .477, t=2.382, p=.021) among caregivers. In conclusion, this study highlights that, caregivers of children with cerebral palsy experience psychological distress in the form of depression, stress, and anxiety. Caregivers employ coping strategies, but these strategies may inadvertently increase their distress levels.

KEYWORDS

Cerebral palsy

Caregivers

Psychological distress

Coping mechanisms

Avoidant coping

Problem-focused coping

Emotion-focused coping

Depression

Stress

Anxiety

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DEDICATION

My lovely wife Hannah Kumiwaa Kyeremeh and my three children Aseda Saah, Knox Ekow and Jachine Akyeabea Kyeremeh are honored by this work.

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CHAPTER ONE

INTRODUCTION

Background to the Study

Cerebral palsy (CP) results from an insult to the developing brain, causing a non-progressive disorder of posture or mobility (Bulekbayeva *et al.*, 2017; Oskoui *et al.*, 2013). The most prevalent cause of childhood disability in various parts of the world is cerebral palsy (Vadivelan et al., 2020). In 1862, orthopaedic surgeon William James Little was the first to report this condition, it is a kind of neurodevelopmental disorder that affects the development of motor abilities such as movement, coordination, and posture before, during and after birth. It is a nonprogressive but incurable condition mainly caused by impairment due to an injury to the prenatal or neonatal brain (Al-Gamal & Long, 2013; Patel *et al.*, 2020; Vadivelan *et al.*, 2020). The prevalence of CP has been documented to happen in about 2 to 2.5 per 1000 live births in developed countries o and can be adequately diagnosed between ages 3 and 5 (Gulati & Sondhi, 2018). Although the damage to the brain is nonprogressive, the individual suffers secondary conditions or impairments due to the motor damage. Children with this disorder usually present with some developmental delays and motor deficits such as lower physical fitness, lower muscular endurance of limbs, cognitive impairments, speech impairments, behavioural impairments, impairments in visuo-spatial abilities, epilepsy, sensory impairments, perception impairments, ophthalmic impairments, gastrointestinal impairments, as well as urogenital impairments (Odding *et al.*, 2006; Patel *et al.*, 2020).

In middle and low-income countries, such as Ghana, UNICEF (2020) reports that there is a lack of data with regard to the actual prevalence of neurodevelopmental disorders such as cerebral palsy and as such its incidence cannot be adequately established. This is the case mostly because such children who are invisible in society, are not represented politically, and as such are not captured in censuses and surveys. Unfortunately, according to UNICEF, these low and middle-income countries have been documented to have a rather high number of risk factors that are associated with these disorders; such as nutritional deficiencies, poor prenatal care, poor neonatal care, and neonatal infections and as such, these neurodevelopmental disorders may be more common than reported and may be more common in females as compared to males. For example, in Ghana, a study by Polack *et al.* (2018), showed that among low resource populations, there exist problems as far as feeding children with cerebral palsy is concern, which contribute to the extremely prevalent issue of malnutrition.

As stated earlier, CP is an incurable condition, therefore it is a condition that requires management. A team of professionals is typically involved in caring for children with CP to address various aspects of the condition such as medical, social, psychological, and educational. The major objective of treating this illness is to maximize independence by stimulating growth., for the individual to be able to engage in tasks of everyday living independently. Managing CP medically, first of all, requires that the primary physician gives some form of education to the primary caregivers and ensures that the child receives all routine immunisations. Additionally, a thorough assessment should be conducted to find out the severity of the disorder. This should include an assessment of the heart to check for any pulmonary damage, the lungs for any respiratory damage, the brain for signs of epilepsy, and susceptibility to infections. Added therapies, usually based on specific needs include physical therapy which focuses on gross motor skills like sitting, standing, walking, use of a wheelchair, and general mobility and transfers (for example from a bed to a wheelchair) at home, with their peers and within the environment to promote independence (Patel *et al.*, 2020). Also, there is speech therapy to help with correcting and improving speech, and occupational therapy, which focuses on fine motor skills and visual skills to help individuals with tasks such as eating, dressing, writing, and bathing (Jan, 2006). Additionally, Jan (2006) states that orthopaedic interventions are also made available to help prevent or correct deformities, provide support and improve posture and gait. In order for the child's family to better comprehend the condition and be able to care for the child, the assistance of a psychologist is also required. The psychologist would also help fortify the supportive system around the family of the child by providing therapy sessions for the immediate caregivers, to protect their self-esteem, provide psycho-education and reduce or eliminate possible instances of anxiety and depression. In addition to these, other specialists may step in to address various needs of individuals as may be needed in each specific situation and these may require the services of social workers, educationists, and dieticians.

As previously said, the main objectives of this interdisciplinary team are to enable and enhance normal growth and functioning, to stop additional harm and problems, and to enhance the quality of life of the families, as well as the individuals. Helping the family and community adapt to the child's requirements is one of therapy's other objectives (Horn, 1997).

According to Dogbe, Kyeremanteng, Opoku, Nketia and Hammond (2022), in a typical Ghanaian family setting of a child living with cerebral palsy, even though there is an effort to create a helpful and comfortable environment for the child, it is impossible to ignore the financial difficulties, family conflicts (both immediate and extended), and often hostile attitudes from spouses that develop when trying to meet the requirements of the child. These difficulties and constraints could introduce psychological distress to the caregiver and even the child.

Psychological distress

Psychological distress is a state of emotional suffering characterized by a range of negative feelings and experiences that can significantly impact a person's daily life. It usually arises from situations that put an individual in a position that demands the use of resources they do not have or possess very little of. One such circumstance might be providing care for a child who has cerebral palsy. CP when first experienced or diagnosed, introduces the family of the child to a whole new world of a special kind of care required to sustain the child. This condition comes with numerous impairments which make use of the special care available. These numerous impairments associated with cerebral palsy require some form of specialised care, meaning that children with cerebral palsy are highly dependent on their caregivers. By nature, the birth of a child brings about major changes in the lifestyle of every home, and with this comes major demands and numerous challenges (Krstić, Mihić & Oros, 2017). These challenges further heighten when the child has special needs that require special care (Raina *et al.*, 2005). This is so because there is an excessive demand involved in managing the child's health condition, in addition to the demands of everyday living, which puts a very intimidating task in the hands of caregivers. Psychological distress associated with CP is known to be one of the most depressing conditions for families. In African cultures like Ghanaian culture, it is mostly the family of the individual with the condition who are responsible for caring for them (DeLaune & Brown, 2001). In most cases, the primary caregivers are the parents of the child who may be supported by the immediate family of the child. The primary caregivers are forced to assume their roles immediately, without much time for consideration or adequate preparation for the many responsibilities, and financial, physical, and emotional burdens that the caregiving role comes with (Cieza & Stucki, 2005; Dowswell et al., 1997). As a result, the burden associated with caring for children with neurodevelopmental disorders has largely been documented as having a lot of implications for caregivers (Dowswell *et al.*, 1997). In addition to the challenges discussed above, caring for a child with cerebral palsy can have significant impacts on the physical and mental health of caregivers (Brehaut *et al.*, 2004; Raina *et al.*, 2005), and also because the caregiving for these children is long term and with restricted social activity for the caregiver, it predicts more psychological conditions such as anxiety, depression and distress in the caregivers (Bareto *et al.*, 2020).

According to Dowswell *et al.* (1997) in many cases, the plans of primary caregivers become distorted and the current income sources suffer some form of neglect. Additionally, leisure time is lost and health status is negatively impacted. This happens mainly because, in the process of caregiving, many caregivers have to sacrifice caring for themselves, their interests and their emotions (Eker & Tüzün, 2004). These affect the mental health of caregivers which present in various ways such as; increased or chronic depression, stress, anxiety, low self-efficacy, grief, loss of motivation, and insomnia when compared to caregivers of children who do not require special care. According to Vilaseca *et al.* (2014), research has shown that these adverse physical and mental health outcomes are more prevalent among mothers of children with cerebral palsy compared to fathers. This is primarily because mothers are often the primary caregivers in the majority of cases. The increased caregiving responsibilities and associated stressors place mothers at a higher risk of experiencing negative health outcomes. According to Vilaseca et al. (2014), the gender gap in caregiving responsibilities adds to the varied effects on mothers' physical and mental health compared to fathers in this situation. Additionally, the difficulty of raising a child with a neurodevelopmental disability is made worse in middle- or low-income countries by economic difficulties, lack of amenities, little or no governmental support, and generally a lack of a supportive environment (Carnevale et al., 2008). Through these challenges, certain strategies must be adopted to successfully cope and to manage the condition of the child properly.

Based on physiological differences, cerebral palsy can be classified into two types: extrapyramidal, which affects other areas of the growing brain, and spastic, which affects the cortex or corticospinal (pyramidal) pathways. The extrapyramidal subtypes include athetoid, choreiform, ataxia, stiff, and hypotonia (Agarwa & Verma, 2012).

The spastic type which is characterized by spasticity, hyperreflexia, clonus and up going Babinski reflex is the most common type and accounts for about 80% of cases. The extrapyramidal also known as the dyskinetic cerebral palsy, characterized by more abnormal involuntary movements accounts for about 10-15%, with the ataxic type comprising of less than 5% (Stanley et al., 2000). Many patients however exhibit a mixture of both the spastic and extrapyramidal types. Hence the typical types include:

Spastic Quadriplegia: All four limbs are affected, and there is often involvement of the face and mouth. This is the most severe form of spastic CP.

Spastic Diplegia: Primarily affects the legs, with minimal or no arm involvement.

Spastic Hemiplegia: Only one side of the body is affected, either the right or left, and both the arm and leg on that side may be involved

Athetoid Dyskinetic CP: Characterized by uncontrolled, involuntary movements. Individuals may experience writhing, twisting, or repetitive movements.

Dystonic Dyskinetic CP: Involves sustained muscle contractions, leading to abnormal postures.

Ataxic CP: Affects balance and coordination, causing problems with depth perception and coordination of movements. Individuals may have shaky or unsteady movements.

The severity of cerebral palsy significantly impacts the distress experienced by caregivers. Previous research has consistently demonstrated a strong correlation between the severity of the disability and the amount of stress faced by parents or caregivers (Leonard *et al.*, 1993; Saddler *et al.*, 1993; Sjøbu, 1994). When a child with cerebral palsy has more severe impairments, such as limited mobility, severe motor difficulties, or significant cognitive impairments, caregivers often face additional challenges in providing care and support. These challenges may include assisting with daily activities, such as feeding, bathing, and dressing, managing medical needs like administering medication or attending doctor's appointments, coordinating therapies such as physical or occupational therapy, and attending to the child's social and academic needs. The increased demands and complexities associated with caring for a child with more severe cerebral palsy can lead to higher levels of emotional and psychological distress for caregivers. They may experience feelings of anxiety, depression, helplessness, frustration, and a sense of being overwhelmed by the responsibilities they face. Furthermore, research has demonstrated that caregivers of children with impairments are more susceptible to emotional, cognitive, and stress issues (Brehaut et al., 2009). For instance, Brehaut *et al.* (2009) found that caregivers experience significant stress and face challenges in coping with the demands of caregiving. Another study by Deepthi and Krishanmurthy (2011) stated that the continual demands of impaired children result in carer stress because of their limits in communication, execution of everyday tasks, and self-care activities. Additionally, Alzahrani *et al.* (2015) conducted a study in Saudi Arabia investigating the psychological effects of caring for others in a community with a larger variety of people. Their findings revealed a prevalence of depression in caregivers of hospitalised patients, with 72.8% experiencing depressive symptoms. In a comprehensive analysis by Liu et al. (2023) on the factors related to caregiver burden in family caregivers of children with cerebral palsy, it was discovered that the severity of the illness was named as a factor supporting caregiver burden that was only moderately supported.

Coping mechanisms

In many of these situations, the family or caregivers of children with cerebral palsy eventually adjust to the demanding task of having to cater to the child with special needs and thus adopt mechanisms to cope with their difficulties. These coping strategies are usually strategies adopted by caregivers to decrease or moderate the levels of impact of stress and negative emotions involved with caring for a child with CP and also to manage resources as well as maintain a well-functioning home (Maridal *et al.*, 2021). According to Lazarus & Folkman, (1984), coping strategies may function in two ways, first, being emotion-focused, where they serve to reduce the negative emotions or tension that is aroused by a stressful situation, secondly, they can be problem-focused, where they aim at addressing the stressful situation directly and solving it. However, there have been differences in the outcome of coping for caregivers with children living with CP. Some have been found to cope well whilst others do not (Raina *et al.*, 2005). According to Raina *et al.*, some factors that have been found to influence how well caregivers adapt to their situation or cope are; perceived levels of stress, which in other words, is the external environmental demands and the individual's seeming capacity to respond favourably to it, the caregivers' characteristics such as age, marital status, and coping levels, the characteristics of the child receiving care such as the degree of the disability and age, social factors such as access to social networks and social support, socioeconomic status of the caregiver, access to health care, cultural context and the shared history between the caregiver and the recipient of the care. According to Lin (2000), because coping strategies can either hinder or facilitate positive adaptation to events, it is necessary to investigate the coping behaviours of caregivers to better understand the strategies and how best they work. According to a study conducted by Klutse in 2016, research has demonstrated that social support can be an effective coping resource for caregivers, contributing to their overall well-being and health outcomes. For instance, Barakat and Linney (1992) found that carers' quality of life is increased and stress, anxiety, and depression are reduced when family, friends, and significant others are available to support them. Also, Wang and Zhao (2011) observed that social support plays a beneficial role in mitigating the negative effects of caregiver burden. Additionally, greater interpersonal encouragement is linked to carers' increased overall health (King et al., 1999; Zuurmond et al.,2015). When it comes to the causes of and treatments for cerebral palsy, there are a lot of myths and misconceptions that have persisted throughout the years (Austin, Dunn, Johnson & Perkins, 2004). This current study, as part of its broad aim, seeks to understand the coping strategies or methods that caregivers use and how best these strategies help them to adequately adapt to their situation and lessen their feelings of stress as well as investigate the prevalence and severity of psychological distress among the caregivers of children with cerebral palsy.

Age is an important factor that can help people cope. As a result, the age of caregivers can influence their coping strategies. Caregiving can be a demanding and stressful role, and different age groups may employ various coping mechanisms based on their life experiences, psychological development, and personal resources. Some studies have reported that age could influence how people cope. For instance, in their study of 161 older individuals and 75 younger couples' coping strategies, Folkman, Lazarus, Pimley, and Novacek (1987) discovered that younger persons were generally more likely to utilise problem-focused coping whereas older adults were more likely to use emotion-focused coping. Chen, Peng, Xu & O'Brien (2018) revealed that older persons utilised both positive and negative emotion-focused tactics similarly to younger adults. Age was discovered in the study to be unfavourably connected to problem-focused coping. This indicates that as people aged, they became less likely to use problem-focused coping mechanisms under stressful situations. Religious practices and beliefs have been shown in studies to assist people cope with challenging circumstances (Aflakseir & Mahdiyar, 2016), and as such Spiritual-Religious Coping has been described as the strategies individuals employ within their own spiritual and religious framework to alleviate emotional distress resulting from challenging life events. By incorporating beliefs, attitudes, or practices related to spirituality and religion, individuals can find meaning in their suffering, making it more manageable. This approach can help individuals regulate stress when faced with circumstances beyond their control. In recognising the positive impact of spiritual-religious coping, physicians should actively support and encourage its use as a valuable source of strength and hope for clients (Saad & de Medeiros, 2012).

Statement of the problem

Cerebral palsy is a long-term condition. This means that the care it requires for the patients who suffer it must also be long term. The particular requirements of children increase the psychological, physical, and financial strain that comes with parenting them, in addition to the time-intensive type of care required to manage such children. Given these requirements, it is obvious that having the support of caregivers is of utmost importance to these children. (Kakooza-Mwesige et al., 2015). Previous studies have researched cerebral palsy in detail but mainly focus on the psychological well-being, the coping mechanisms and the quality of life of the individuals. These studies have hardly given enough attention to the caregivers, as their role in managing the condition is also very crucial, being that their well-being in caring for such individuals goes a long way to affect the individuals themselves (Makris, Dorstyn & Crettenden, 2021; Olawale, Deih & Yaadar, 2013).

Secondly, it has been established that cerebral palsy is a nonprogressive disability that leaves permanent damage to children who suffer from it (Al-Gamal, 2013). It is reported that many more children than recorded in middle- and low-income countries such as Ghana suffer from permanently damaging neurodevelopmental disorders such as cerebral palsy (UNICEF, 2020) because there is a lack of adequate data or statistics about the prevalence of the condition. Due to this, many risk factors of the disorders exist. According to Kyeremateng et al. (2019), Cerebral Palsy Africa (CPA) estimates that 1 child in every 300 births in Ghana has cerebral palsy (CP), despite the fact that official statistics on the number of children with CP are unavailable. And there is no clear strategy in place to help those kids. The challenges facing people with CP are not specified in the Ghana Disability Bill, which was passed more than ten years ago. (Persons with Disability Act, 2006) (Adei- Atiemo, Rodrigues & Badoe, 2015; Polack *et al.*, 2018). Caring for children with neurodevelopmental disorders such as cerebral palsy has been shown to have detrimental effects on the physical and mental health of caregivers such as an increase in depression, stress, and anxiety (Eker & Tüzün, 2004; Vilaseca *et al.*, 2014). Most of the research conducted so far on the effects of caregiving on the life of caregivers has been in high-income countries, leaving a research gap with regard to knowledge about the situation in countries with low and moderate incomes, like Ghana. This according to Maridal *et al.* (2021) creates the impression that caregivers in this part of the world can adequately cater for these children, which may not be the case. The lack of data on middle- and low-income countries also does not give a holistic view of the prevalence of the condition in the world and therefore cannot move to generalise the results of those findings to such areas.

Again, the few studies done in the African sub-region on caregivers have not looked at psychological distress and the various coping mechanisms that the caregivers adopt. In Zimbabwe, Dambi, Mlambo and Jelsma (2015) assessed caregiver strain among caregivers of children with cerebral palsy, however, their focus was on caregiver burdens such as economic, physical and psychosocial burdens. Another study in Kenya by Geere *et al.* (2013) assessed the physical health challenges of caregivers of children with motor impairments like cerebral palsy. Again, other studies have also sought to address the quality of life of caregivers of children with cerebral palsy. A study done in Malawi by Namanja and Phiri (2022) looked at the quality of life of primary caregivers of children living with cerebral palsy and concluded that the majority of the caregivers have poor quality of life. In Ghana, Klutse (2016) also evaluated the caregivers' quality of life and found comparable results of low quality of life of caregivers. Nevertheless, most of the other studies in Ghana focused more on perceptions and experiences, for instance, Menlah *et al.* (2020) investigated the perceptions and experiences of caregivers of children with cerebral palsy in a suburban district of Ghana and reported that caregivers perceive the causes of cerebral palsy as mainly of spiritual origin and faced physical, marital, emotional, financial and social challenges. Kyeremanteng *et al.* (2019) in qualitative research in Korle Bu also explored the experiences of caregivers of children with cerebral palsy and indicated that participants experienced emotional distress, financial issues and doubts and confusion about the health problems associated with the disability of their child.

For the above reasons, this study is essential, to ascertain the psychological distress that Ghanaian Caregivers of children with cerebral Palsy experience and also throw light on the appropriate coping mechanisms through the recommendations and implications, that are best for the caregivers and subsequently, the children.

Purpose of the study

The purpose of this study is to investigate the psychological distress levels among caregivers of children with cerebral palsy as well as the coping mechanisms that they employ. The specific objectives include;

1. To determine the various forms of psychological distress among Ghanaian caregivers of children living with cerebral palsy
2. To explore the various coping mechanisms (avoidant, problem focused and emotion focused) employed by Ghanaian caregivers of children living with cerebral palsy

3. To explore the effect of coping mechanisms on psychological distress levels of caregivers of children living with cerebral palsy
4. To examine the relationship between coping mechanisms and psychological distress
5. To determine whether the severity of disability of a child living with cerebral palsy influences the psychological distress levels of caregivers
6. To determine whether the age of caregivers of children living with cerebral palsy influences coping mechanisms.

Research Questions

1. What are the various forms of psychological distress among caregivers of children living with CP in Ghana?
2. What coping mechanisms do caregivers of children living with CP adopt to handle their psychological distress?
3. What is the effect of the coping mechanisms adopted on the psychological distress of caregivers of children living with CP?

Research Hypotheses

- H_1– The various dimensions of coping (avoidant, problem focused and emotion focused) will significantly predict the psychological distress levels among caregivers of children living with CP in Ghana
- H_2- The severity of disability of a child living with cerebral Palsy will influence the psychological distress levels of caregivers
- H_3 - The age of caregivers of children living with cerebral palsy will influence coping.

Significance of the Study

The purpose of the current study is to provide information to psychologists and other mental health professionals for use in therapy, counselling, and other related activities to help improve their practice, especially when dealing with caregivers of children with cerebral palsy. Additionally, this study seeks to provide data for advocacy and policy formation purposes concerning cerebral Palsy by providing data that does not only focus on the child suffering from cerebral palsy but on caregivers who equally bear a huge burden of the disorder. Also, this study is important because it will broaden knowledge in the area of CP as it will provide a Ghanaian perspective and understanding of the varying levels of psychological distress caregivers face when caring for children with cerebral palsy and the various ways they cope with their situation. This will allow for the identification of the most efficient coping techniques and the extent to which they relieve the burden of caregiving for children with cerebral palsy.

Delimitation

Only caregivers of children with cerebral palsy who go to the Holy Family Hospital in the Techiman Municipality were the subjects of the study, and the study only concentrated on their psychological distress and coping mechanisms. Holy Family Hospital is the largest secondary-level hospital that provides specialist care to children with cerebral palsy in the Bono East Region. Most Caregivers visiting the hospital with their children for specialist made participants available for the study, making data collection easily facilitated and cost-effective. It is also important to note that some cases of cerebral palsy required the researcher to visit the homes of the caregivers, which was arranged. Techiman is a Cosmopolitan city, with great cultural diversity and this is helpful with the generalisation of the study.

Limitations

The study's results were produced in a comprehensive manner by taking all necessary steps. To maintain the study's integrity in research and to provide guidance for future investigations, some limitations were encountered and they must be discussed. Firstly, this study relied on self-report measures in the form of questionnaires. Such survey findings could have socially desirable repercussions. Additionally, a perceptual bias could exist because the data are perceptual in nature. Anonymity of the participants is one way to reduce socially desirable responses and the study explored that. Unfortunately, that was unable to account for the perceptual bias as well. The reason for this could be that a significant number of the participants had distant review dates due to the specialised nature of cerebral palsy, which meant they were not easily accessible at the hospital during data collection. Consequently, they were provided compensation for their involvement in the study as they resided far away from the designated study location.

Purposive sampling and snowballing strategies were employed by the researcher. As a result, not every caregiver for a child with cerebral palsy was given the same chance to participate in the study. However, the lack of an updated and current sample frame from which to randomly select respondents made the purposive sampling and snowballing procedures appropriate. The participants were also not an easy group to gather, considering the condition of their children and the financial and mobility problems in getting to the research setting.

Definitions of Terms

Children living with cerebral palsy: Children with CP whose ages are from 3 to 18 years.

Caregiver: Parent, relative or an employed person who provides primary care for the child living with CP

Psychological distress in this study refers to a measurable and observable state characterised by emotional and cognitive symptoms such as anxiety, depression, irritability, and impaired functioning in daily life.

Coping mechanism: How the caregiver balances the caregiving role for children with CP while managing his or her own psychological, physical, financial, and social well-being. It encompasses emotion focused, problem focused and avoidant coping.

Social support: The availability of assistance or comfort while caring for a child living with cerebral palsy.

Organisation of the Study

This research has been distinctly managed into five chapters. Chapter one gives a broad overview of the psychological distress and coping mechanisms among caregivers of children living with cerebral palsy and justifies the need for the study in its significance. Chapter two deals with the theoretical framework, conceptual review and empirical research that have been carried out in the field of study. The goal is to discover what experts from different fields have written on the variables this study examined, as well as to offer new perspectives on the subject as it is presented in the current study. The research technique for the study and the procedures it underwent are presented in Chapter three (3). This includes the population, sample, sampling method, data gathering tools, data collection method, and data analysis. It also addresses issues of reflexivity and trustworthiness as far as qualitative research is concerned. Chapter four (4) covers the results and discussions derived from conducting the study and Chapter five (5), the last chapter, offers a summary, conclusions and recommendations, as well as some suggestions for additional research and stakeholders based on the research findings.

CHAPTER TWO

LITERATURE REVIEW

Theoretical framework

The theoretical underpinnings of the study are explained in this section. The Model of Carer Stress and Burden (Sörensen *et al.*, 2006), was the main model used to help explain and understand the process of caregiving stress, its effects on the caregiver, and coping. This model is an integrative model that addresses caregiving and the stress associated with it in the case of neurodegenerative disorders. The model of carer stress and burden, according to Sörensen *et al.* (2006) comprises six different but integrating factors that affect or influence caregiver burnout or stress (see Figure 1).

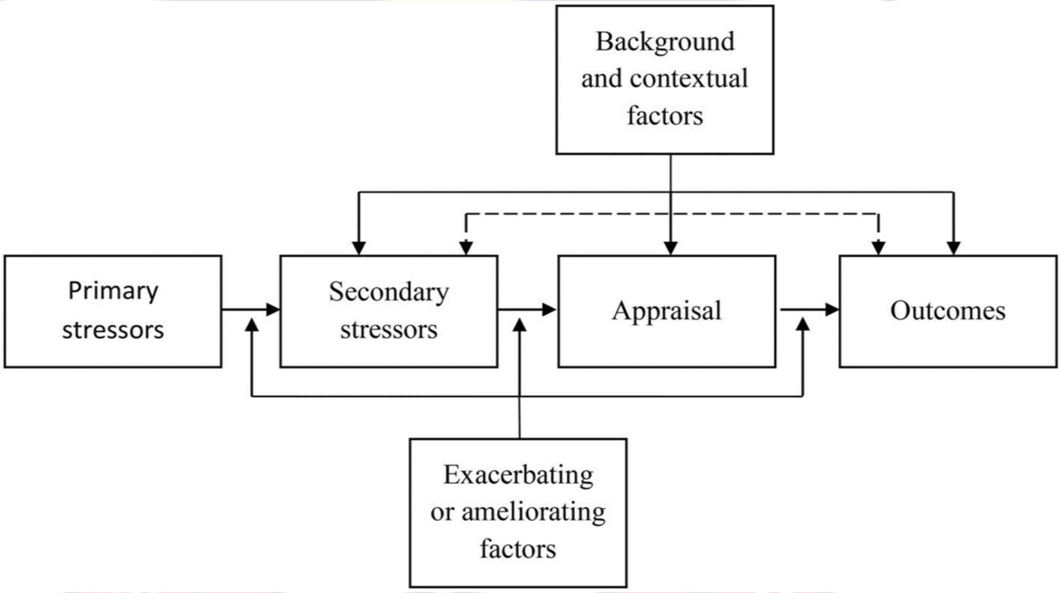

Figure 1: The Model of Carer Stress and Burden (Sörensen *et al.*, 2006)

The first elements of this model are the primary stressors. These stressors refer to elements in the caregiving setting that determine the nature and intensity of the caregiver's experience. Examples of these factors are the severity of the patient's illness, the intensity of functional or cognitive impairments, difficult behaviours and the amount of time spent giving care.

The primary stressors however cause another group of stressors known as the secondary stressors, which are the second factors of this model.

Secondary stressors can be described as the opportunity costs of the caregiver's burden or consequences that arise as a result of caregiving. These include little to no time for leisure, financial strain, less time for health-promoting activities like exercising and healthy eating, family conflicts, and little time for work. These secondary stressors act as mediators between the primary stressors and how the individual appraises the situation. For example, when there is a lot of time spent giving care, there might be little time for leisure which may result in increased distress and negative effects on psychological wellbeing. The third factor of this model is the appraisal. An appraisal is explained as how the caregiver subjectively assesses their situation or role, based on situational or contextual factors. In other words, an evaluation of demands and available resources. Such that given the same caregiving situation, no two caregivers may have an exact or equal assessment of the burden associated with it, based on different coping styles and capacities to meet the demands of the tasks. These appraisals then lead to the fourth factor which is the outcomes. These outcomes are the results of the assessments of the demands and resources to meet the demands. These outcomes may be psychosocial (depression, stress or an effect on wellbeing), physiological (increased health issues), or behavioural (substance abuse) When caregivers assess that their available resources are not enough to meet the demands of the situation, psychological distress and morbidity rates are higher. On the other hand, when the caregiver assesses that their resources are enough, psychological distress and morbidity rates are lower. However, these effects can be influenced by the fifth group of factors called the mitigating or exacerbating factors. These exacerbating or mitigating factors play modifying roles among all the above-mentioned factors such as modifying the relationships between the primary and secondary factors as well as the appraisal and outcome of the situation or the extent to which the primary situation may lead to a negative outcome.

Mitigating factors may comprise the availability of resources, positive coping skills, positive personality traits, good social networks, and frequent social contact. Exacerbating factors may include negative coping styles, dysfunctional family, emotional detachment and negativity and personal vulnerabilities such as neuroticism. Finally, the sixth factor that plays a role is the high-risk subgroups. In this case, the background and contextual factors like gender, sociodemographic, cultural, and ethnic factors affect the outcome of the caregiving burden. More women have been reported to experience depressive symptoms as a result of the caregiving burden most likely because they provide more hours of care in most cases and also because they report feelings or symptoms of depression much more than the male population. For example, Vilaseca *et al.* (2014) observed that mothers of children with cerebral palsy tend to have worse mental and physical health conditions compared to fathers.

Caregiving Stress Process Model

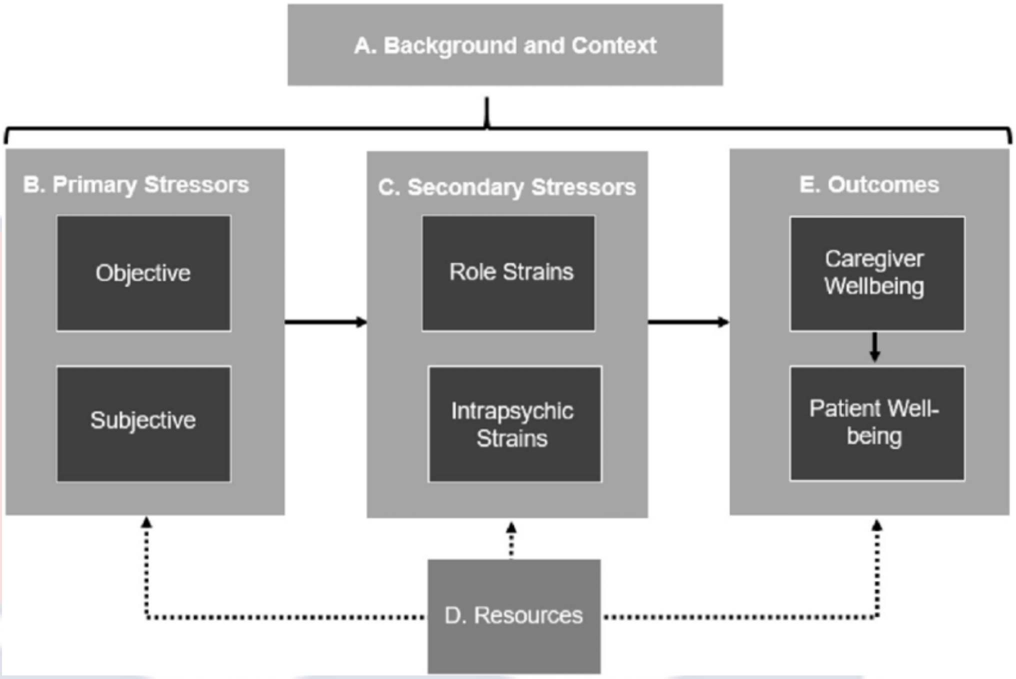

Figure 2: Caregiving Stress Process Model

The caregiving stress process model, developed by Pearlin, Mullan, Semple, and Skaff (1990), is a theoretical model that aims to assess the impact of caregiving on the health and well-being of informal caregivers. This model recognises that providing care for older adults, particularly those with dementia, can be a demanding and stressful experience for family members or friends who take on the caregiver role. The model focuses on the changes that occur when an older adult transitions from being independent to requiring substantial care from a caregiver. This transition represents a significant shift in the dynamics of the relationship, as the caregiver becomes responsible for meeting all the needs of the older adult with dementia. The model acknowledges that this change in responsibilities can have profound effects on the caregiver's physical, psychological, and social well-being. While originally developed for adult caregiving, it has been adapted and applied to various caregiving contexts, including caregiving for children with disabilities. This is explained by the fact that the primary difference between these frameworks is the relative focus on informal and formal care. Additionally, the model utilises all the five constructs proposed by Raina et al. (2004) in developing a multidimensional model that incorporates the advantages of existing frameworks from the geriatric as well as paediatric literature. These factors include background and context, child characteristics, caregiver strain; intrapsychic factors, coping/support and health outcomes.

According to the caregiving stress process model, Stress experienced by the carer is influenced by a number of important aspects. These include background and contextual factors, primary and secondary stressors, appraisal and coping strategies, and outcomes.

Background and Contextual Factors: This explores the caregivers' demographic characteristics, such as age, gender, and socioeconomic status, as well as any cultural or societal factors that may influence their caregiving experience. Additionally, assess the availability and accessibility of support systems, including healthcare services, respite care, and social support networks specific to caregivers of children with cerebral palsy.

Primary Stressors: This focuses on the primary stressors faced by caregivers, the disability, and the physical demands of caring for a child with cerebral palsy, such as assisting with mobility, daily activities, and medical care. Psychological stressors can include dealing with emotional challenges, witnessing their child's limitations, and managing the uncertainty of the condition's progression.

Secondary Stressors: This investigates stressors that may arise due to caregiving, such as financial strain due to medical expenses, time demands that interfere with work or personal life, and the potential impact on the caregiver's social relationships and social activities.

Appraisal and Coping: This examines how caregivers appraise and cope with the stressors they encounter, and assess their perceptions of the demands of caregiving, available resources, and their self-efficacy in handling these challenges. Explore coping mechanisms employed by caregivers, such as seeking social support, utilising respite care, engaging in self-care practices, and utilising professional psychological support.

Outcomes: This looks at psychological distress experienced by caregivers, including symptoms of depression, anxiety, and overall psychological well-being, as well as assessing how caregivers' coping mechanisms influence these outcomes and explore the potential impact on their quality of life and overall functioning.

The Biopsychosocial (spiritual) model

The biopsychosocial (spiritual) model is a holistic approach to understanding and addressing human health and well-being. It recognises that an individual's health is influenced by multiple interconnected factors, including biological, psychological, social, and spiritual dimensions. It offers a comprehensive framework for understanding caregiver burden. The burden experienced by caregivers is often linked to adverse consequences in terms of an imbalance in the biopsychosocial and spiritual perspective, resulting in heightened levels of anxiety and depression (Leurs et al., 2018). Hence, this model recognises that caregiver burden is influenced by a combination of biological, psychological, social, and spiritual factors and emphasises the importance of addressing all these dimensions to effectively support and alleviate caregiver burden.

Biological factors refer to the physical aspects of caregiving, such as the demands of providing assistance with daily activities, managing medical treatments, and coping with the health conditions of the care recipient. These physical demands can lead to physical exhaustion and increased stress for the caregiver.

Psychological factors involve the emotional and cognitive aspects of caregiving. Caregivers may experience feelings of guilt, sadness, or frustration due to the challenges they face in meeting the needs of their loved ones. They may also have to cope with the emotional strain of witnessing the decline in the care recipient's health.

Social factors encompass the interpersonal and societal dimensions of caregiving. Caregivers may face social isolation, as their caregiving responsibilities limit their ability to engage in social activities or maintain relationships. They may also encounter financial difficulties or experience changes in their roles and identities within their social networks.

Spiritual factors pertain to the existential and meaning-making aspects of caregiving. Caregivers may draw on their spiritual or religious beliefs to find solace, hope, and purpose in their caregiving role. Spirituality can provide a source of strength, resilience, and coping strategies for caregivers, helping them find meaning in their experiences.

Conceptual Review

Cerebral palsy

Cerebral palsy (CP) is a collection of lifelong mobility and posture abnormalities that limit activities and are thought to be caused by non-progressive defects in the developing foetus or infant brain (Sadowska, Sarecka-Hujar & Kopyta, 2020). This is the most frequent cause for childhood impairment. Depending on the aetiology, there are different levels and types of motor impairment and functional capacities. It is mostly diagnosed based on motor function and postural issues that start in early childhood and last all the way to the end of life; these issues are non-progressive but do alter with age. The primary symptoms of cerebral palsy are motor function problems, which are commonly accompanied by additional dysfunctions such as musculoskeletal disorders, epilepsy, sensory, perceptual, cognitive, communication, and behaviour problems. (Cans, 2000; Cans *et al.*, 2007; Rosenbaum *et al.*, 2007).

Aetiology

Cerebral palsy is brought on by abnormal fetal or neonatal brain development or brain injury. The non-progressive ("static") brain injury that results in CP can happen during pregnancy, during labor, or after delivery. An individual patient's aetiology is frequently complex. MacLennan *et al.* (2015) and Nelson (2008) opined that the aetiology of CP stems from prenatal causes, perinatal causes and postnatal causes. According to Nelson (2008) and MacLennan et al. (2015), chromosomal abnormalities, intrauterine infections, intrauterine stroke, and congenital brain anomalies are all causes of CP. MacLennan *et al.* (2015) and Nelson (2008) also reported that perinatal causes are a result of hypoxic-ischemic insults, central nervous system (CNS) infections, stroke and kernicterus. With respect to postnatal causes accidental and non-accidental trauma, CNS infections, stroke and anoxic insults were indicated as factors for CP (MacLennan *et al.*, 2015; Nelson, 2008). A substantial risk factor for cerebral palsy is prematurity. According to MacLennan et al. (2015) and Nelson (2008), cerebral palsy can result from prematurity-related complications such periventricular leukomalacia, intraventricular hemorrhage, and periventricular infarcts. Multiple pregnancies, intrauterine growth restriction, substance abuse by the mother, preeclampsia, chorioamnionitis, abnormal placental pathology, meconium aspiration, perinatal hypoglycemia, and genetic susceptibility are additional risk factors for cerebral palsy (McMichael et al., 2015; van Eyk, Corbett & Maclennan, 2018).

Epidemiology

The most frequent cause of childhood impairment is cerebral palsy. In 1000 live births, it happens in 1.5 to 2.5 cases (Oskoui et al., 2013). Infants born preterm have a much higher prevalence than those born at term. Infants born at fewer than 28 weeks gestational age had the highest chance of having cerebral palsy, with the risk increasing with decreasing gestational age (Oskoui et al., 2013). Additionally, the prevalence is higher in low-birth-weight babies. newborns born weighing less than 1500 grams are most at risk; 5% to 15% of these newborns go on to suffer cerebral palsy (Oskoui et al., 2013). About 80% of cerebral palsy cases are caused by prenatal events, while 10% are caused by postnatal events. However, in 2017, the average worldwide incidence of CP was reported to be 1 in 500 births (Stavsky *et al.*,2017), but in

Ghana cases of cerebral palsy are particularly high, affecting 1 in every 300 new-borns (Graham *et al.*, 2016).

Coping

One of the major challenges in life is coping with stressful situations (Dardas & Ahmad, 2015). Coping, according to Lazarus and Folkman (1984), is the process of adjusting one's behavior and cognition in order to manage or endure a state that is deemed to be beyond one's control or available resources. Coping techniques are well-considered as the intermediary steps between stressors and health outcomes; as a result, they are the guidelines for the psychological well-being of those who care for children with chronic diseases. Most parents view having a child as a blessing even though providing for them is thought to be stressful and time-consuming. However, providing care for children who have chronic conditions places an even greater strain on caregivers and can disrupt the functioning of the entire family, necessitating a variety of coping mechanisms (Gray, 2006). The choice of coping techniques will determine the good or negative route we take in dealing with challenges. A mental step precedes action in the process of coping. (Salem & Ahmad, 2016).

According to Blount et al. (2008), coping is seen as a dynamic process that can alter depending on the qualities of the stressor. In order to respond to stress, some people have added to this definition by defining coping as conscious, intentional attempts to control emotion, cognition, behavior, physiology, and surroundings. There are various sorts of coping styles as a result of the numerous dimensions of coping that have been found. According to Lazarus and Folkman (1984), coping involves both problem-focused (i.e., making an effort to modify a situation's one component by removing or altering it) and emotion-focused (i.e., tactics used to regulate the unpleasant feelings connected to a scenario) coping strategies. Approach and avoidance are two other popular coping strategies (Compas et al., 2001). Approach coping, such as using ways to lessen pain during a vaso-occlusive crisis in Sickle cell disease, refers to attempts to concentrate on or confront a distressing occurrence, whereas avoidance coping refers to attempts to avoid or ignore a stressful event (Bernard, Cohen, McClellan & MacLaren, 2004; Rudolph, Dennig & Weisz, 1995). In general, problem-focused and approach coping are linked to better results for health and adjustment, while emotion-focused and avoidance coping are linked to worse outcomes (Lim et al., 2019). In children with recurrent pain, emotion-focused avoidance coping has been linked to feelings of sadness and anxiety. It has also been linked to increased pain intensity, distress, and functional impairment in healthy pediatric populations (Varni, Seid & Kurtin, 2001).

Psychological distress

According to Ridner (2004), "psychological distress" is a disorder characterised by pain and unpleasant feelings including irritation and dysphoria, that is brought on by specific situations or occurrences. Psychological distress, according to Abeoff, Armitage, Lichter, and Niederhuber (2000), is the notion that, in the face of stressful life circumstances, inappropriate behavioural changes occur. Caregiving distress is brought on by demands and broad bio-psychosocial impacts on carers, such as reduced time for working and earning money, fewer opportunities for socialising and relaxation, and psychological fallacies (Abeloff et al., 2000; Bussing et al., 2003).

Chew-Graham, Bashir, Chantler, Burman, and Batsleer's (2002) study of some multiracial women defined psychological distress as the culmination of stress and emotional symptoms that adversely develop after a negative event. Women are typically the most burdened caregivers in most families during crises, which results in psychological discomfort that manifests as anxiety and depression. Psychological distress, as described by Mehra, Berkowitz, and Sanft (2018), is characterized as a multifaceted adverse emotional experience of a psychological (cognitive, behavioral, emotional), social, and/or spiritual nature that impairs one's capacity to deal with a situation, an event which is stressful, or illness and its requirements and treatments. According to Mehra et al. (2018), when faced with enough difficulties and threats, people enter a state of being where coping mechanisms are either missing or difficult to use, which worsens their mood and overall performance.

Literature on psychological distress has attempted to understand the relationship between psychological distress to certain demographic characteristics such as socioeconomic and educational status, age, gender and social institutions providing roles and the severity of stressors (L'Abate, 2012).

In a study by Byles *et al.* (2012), 236,508 individuals, who were at least 45 years, old were randomly sampled from a medical database. The main aim of the study was to find how age and gender, in association with other sociodemographic variables impacted psychological distress in comorbid conditions. Findings from the study revealed that those with Higher educational levels and incomes, those who were married had significantly lower levels or risks of psychological distress as compared to those who had lower educational levels, lower income and were not married. This was so because lower educational levels were related to lower income levels, the unmarried status was also related to lower income levels since there was only one source of income in the household and this in relation to a comorbid disorder was found to result in higher levels of psychological distress. In other instances, education in terms of psychoeducation about the specific disorder, not just a general educational level, was found to have a significant impact on the general well-being of caregivers. In a study by Hudson *et al.* (2013), 298 caregivers were sampled for a randomised control trial. The study aimed to prepare them for the role of supporting family members who had been diagnosed with advanced cancer. Their psychological well-being levels were measured before and after the experiment and they were divided into the various experimental and control groups. Results from the study showed that the groups that received psychoeducation demonstrated increased preparedness and competence to handle their family member, which resulted in improved psychological well-being.

Concerning the effects of time, Sawyer *et al.* (2010) in his investigation explored the link between mental health problems, caregiving time and time pressure among 216 mothers of children with autism. After adjusting for age, social support and degree of the child's disorder, the researchers found that time on its own did not significantly correlate to psychological distress levels. However, time pressure had a significant positive relationship with the mothers' psychological distress levels.

Furthermore, the research revealed that women faced greater risks of experiencing psychological distress in such situations. This can be attributed to the fact that in many instances, women assumed the role of primary caregivers and were burdened with additional responsibilities, leading to an escalation in stress factors (Byles *et al.*, 2012). In another study by Perz (2011), the author sought to understand the factors that contributed to gender differences in caregiving. For the study, 329 informal cancer caregivers were sampled and women reported significantly higher levels of psychological distress as compared to the men. Reasons for these differences were further explored and the findings revealed that whilst men mainly cared for their sick spouses, women cared for not only their sick spouses but also were primary caregivers for their sick children, parents and any other dependent who may need care. In addition to this, they were burdened with other responsibilities such as caring for children and household chores. The study further linked women's high levels of psychological distress to high societal expectations placed upon them as compared to men and receiving less acknowledgement for the caregiving role. Additionally, the gender difference was attributed to women's self-internalised notion of regarding themselves as a failure if they are unable to adequately provide care for their dependents.

In the area of access to health care, the literature reveals that caregivers whose dependents had challenges accessing health care reported significantly higher levels of distress. Cross *et al.* (2021) in their study investigated caregivers and professional care service providers' psychological distress levels in relation to access to healthcare during the peak of the COVID-19 pandemic. These caregivers were mainly carers of persons living with epilepsy. The investigation's results showed that the restricted access to healthcare services greatly impacted caregivers' psychological distress levels due to an increase in relapses and difficulty in accessing medication and other forms of therapy. Similarly, according to Kalb *et al.* (2021), a study where the researcher looked into the degrees of psychological distress experienced by carers of children living with Autism, in relation to access to health care during the COVID-19 pandemic period revealed that caregivers reported an increase in psychological distress levels especially feeling of panic. This mainly was reported to be a result of a lack of educational, medicinal and therapeutic resources to support care. This study was conducted among 3556 parents raising children with Autism in the United States. These results, when applied to the context of the current investigation, indicate that parents of children with cerebral palsy who have poor access to healthcare facilities may have higher levels of psychological distress.

In a study conducted by Abreu *et al.* (2020), 102 persons with dementia and their caregivers were sampled. The study aimed to investigate how levels of frailty and functional dependency impacted on levels of psychological distress of the caregivers. Results from the study showed that those who had moderate to severe forms of dementia showed severe forms of frailty and functional dependency. The caregivers of these participants, as a result, reported higher levels of care burden as well as high levels of psychological distress. Moretta et al. (2014) found that a sample of 24 caregivers of patients with protracted disorders of consciousness who completed self-report measures of psychological distress had higher levels of distress. These findings show that the severity of a disorder increases the levels of psychological distress that caregivers may experience. Thus, drawing from these findings, severe forms of cerebral palsy that require higher forms of care could increase the care burden of caregivers, thus increasing their psychological distress levels.

Empirical Review

Thrush and Hyder (2014) opine that better evidence would provide incentive for governments of low- and middle-income countries to put the needs of caregivers higher on their agenda, and the lack of information about the situation of caregivers and their burden in low- and middle-income countries allows the perpetuation of the false belief that families in these countries can provide care without public or private institutional support. This is crucial in Ghana because caregivers of children with neurodevelopmental problems do not receive enough attention, which raises worries about their quality of life. This section of the literature review offers a pool of studies that portray the link between psychological distress and caregiving, caregivers and the coping mechanisms that they employ and coping and psychological distress of the caregivers.

Caregiving and Psychological distress

In an observational study, Power et al. (2019) intended to learn more about the psychological distress experienced by carers of adolescents with cerebral palsy and those without impairments in rural Bangladesh. A total of 173 carers of adolescents without impairments and 154 caregivers of adolescents with cerebral palsy were included in the study. Results from the study showed that caregivers of children with cerebral palsy were at a higher risk of being psychologically distressed as compared to caregivers of children without disabilities. Findings also showed that most caregivers of children with cerebral palsy did not have access to wheelchairs walking frames and other devices to aid movement. Additionally, mothers were discovered to be more engaged in raising the child and moving them around as compared to the fathers and in most cases, these mothers did not have enough information about cerebral palsy. Variables that further influenced psychological distress included being female, old age, lack of education, low income, housing impermanence, household crowding, and lack of access to running water and sanitation systems.

Another consideration is the child's illness' severity that affects the psychological distress. According to Werner (1987), psychological distress was significantly correlated with both perceived caregiver influence and the degree of the child's motor impairment as determined by the Gross Motor Function Classification System. A portion of this may be brought on by the added workload that comes with raising a child who is severely impaired. The stress of the caregiver may be reduced through interventions that lessen workload. Lack of mobility assistance, which is frequently compounded by impassable roads, can be a problem that causes both the impaired child and the caregiver to become very distressed. Eker and Tuzun (2004) also contrasted mothers of children with minor health issues with mothers of children with CP in order to determine how psychological distress influenced each group's quality of life. Eighty-four (84) mothers in all, including 40 mothers of children with cerebral palsy and 44 mothers of children with minor health issues, took part in the study. The study's findings revealed that mothers of children with CP had considerably lower mean scores on all of the Health

Survey Questionnaire's subscales than did mothers in the comparison group, with the exception of the physical functioning subscale. The survey also revealed that the majority of participants were female and informal carers. According to Eker and Tuzun (2004), mothers care for their children since it is difficult to find qualified individuals and paying formal caregivers is expensive.

Additionally, Pathak and Matthew (2017) conducted a cross sectional study to compare the psychological distress and its correlates among caregivers of children with mental illnesses to that experienced by caregivers of children without mental illnesses. In the study, the authors sampled 240 caregivers of children with mental illness and 240 caregivers from the general population. Findings from the study revealed that caregivers of children with mental illness reported significantly higher levels of psychological distress as compared to the sample of the general population of caregivers recruited for the study. Additionally, there were notable negative connections between education, occupation, and annual income and large positive correlations between psychological distress and gender, age, and married status.

Middleton et al. (2014) investigated the connection between caregivers' quality of life, caregiver load, and psychological distress among those who care for those who have suffered severe spinal cord injuries. The longitudinal survey method was used in the study. The study has forty-four participants. According to the study's findings, psychological distress and caregiver strain are strongly correlated. Psychological distress and caregiver load had an adverse relationship with health-related quality of life. Middleton et al.'s

(2014) extrapolation of the study's results has a problem. This is as a result of the sample size being too small to be generalized (44 caregivers).

Also, another qualitative study which was sought to explore psychological distress and its correlates among caregivers of children with neurodevelopmental disorders in Nepal, (Maridal *et al.*, 2021). Between the ages of two and twelve, children with cerebral palsy were among the 63 children with neurodegenerative disorders whose caregivers the authors sampled. The authors discovered that, in general, carers of children with neurodevelopmental disorders had high levels of psychological suffering. Largely, carers who are females, caregivers of children with higher degrees of disabilities, low governmental support, and low socioeconomic statuses were found to be high predictors of psychological distress. The socially supported however were found to have lower psychological distress in many cases.

Elkins, van Kraayenoord, and Jobling (2003) carried out research to look at parents' attitudes and perspectives regarding special needs children enrolled in a mainstream school. The survey method was used to get responses from 354 parents in total. Analysis revealed that carers had a favorable attitude toward integrating their children into mainstream. They were delighted that those in their care received the same treatment as other wards. Another study (Mbwilo, Smide, & Aarts, 2010) examined the variables that influence caregivers' perceptions of caring for loved ones who have mental disabilities such as cerebral palsy, mental retardation, autism, hyperactivity, microcephaly, and learning difficulty. Thematic analysis was employed in the study. The study discovered that the quality of care given to children and adolescents with mental disabilities is contingent upon a number of variables, such as family dynamics, healthcare accessibility, and awareness of mental illnesses. There were issues with discrimination and interpersonal interactions as a result of the family member's mental disorders. The study's conclusions were summed up by stating that a lack of social support and a lack of awareness of the disability led to divergent perceptions of family members of individuals with disabilities.

In a cross-sectional survey carried out by Zanon and Batista (2012), the researchers sought to assess the carers of children with cerebral palsy in terms of their levels of anxiety, depression, and quality of life. Eighty-two caregivers were recruited and data collection instruments were administered. Out of the total, 49% of the caregivers recorded high values of psychological distress and 39% recorded high values of low quality of life. Those who reported decreased levels of depression and anxiety attributed this to surrender. citing religion and religious beliefs as the reasons for resignation. Caregivers who knew about their children’s condition as well as those whose children received allowances and support from institutions also reported lower levels of psychological distress compared to those who did not. In the area of well-being, the level of impairment, caregiving demand, and family structure were impactful. Higher impairments, higher caregiving demands and poor family structures, negatively influenced the caregiver’s stress levels and well-being as a whole.

Also, on anxiety in caregivers, 101 patient-caregiver dyads participated in Hodges and Humphris's (2009) longitudinal study on head and neck cancer (3 and 6 months after patient diagnosis). In contrast to 18.8% of patients, 30.7% of carers presented withs symptoms of anxiety after three months, according to the study's findings. Symptoms associated with clinical anxiety were reported by carers 36.6% of the time, compared to patients' 20.8%, at six months. Additionally, caregivers were more concerned about recurrence than patients. At each time point, it was also discovered that fear of recurrence was associated to emotional suffering. The anxiety levels of carers and their patients were also compared in this study. The findings show a link between clinical anxiety and the amount of time spent providing care.

According to Berg's longitudinal research (2009) on depression as a type of psychological distress, the study's overall sample of caregivers for stroke patients reported depressed symptoms at a rate of 30–33%. The primary factors that predicted depression among caregivers during the acute phase were the advanced age of patients and the severity of the stroke. Additionally, it was discovered that the strongest indicator of depression at a later follow-up was acute caregiver depression. According to the study's findings, there is a strong correlation between the distress of the carer and the age of the patient.

Anum (2011) conducted a subjective investigation of groups of disabled people in Ghana. The contacts of Ghanaian families with a disabled child were the subject of this inquiry. Using subjective methods including member perception, account investigation and semi-organized meetings, and the specialist examined interactions between four households in the Dangme West District with children with disability. The study's findings showed that groups of children and teenagers with disabilities face shame, put stress on their family relationships, and probably need institutional support as a result. One argument given for why families, particularly mothers who serve as the primary leaders of their families, experienced shame in the Ghanaian environment was the societal justifications for ineptitude. Further investigation revealed that one of the elements causing conflicts within and across families was this sense of shame.

Caregiving has been discovered to have negative consequences on those providing care in general, but it has been shown that caring for children with disabilities, particularly those with cerebral palsy, has substantial detrimental repercussions on the caregivers' health (Power *et al.*, 2019; Vadivelan 2020). Also, according to Vadivelan, enough attention is not paid to the burdens that these caregivers carry. As such, there is the need to explore the challenges, especially the psychological challenges that these caregivers face in the performance of their caregiving roles in order to come up with tailored interventions to meet their needs. These needs could be in a way, met by adjusting and coping positively by the caregivers.

Caregiving and Coping mechanisms

Tilahun *et al.* (2016) as part of their study, investigated the perspectives of caregivers living in low-income countries with children with developmental disorders. The researchers explored the experiences in terms of stigma, needs and coping mechanisms of these caregivers. Quantitative data was collected from 102 carers whose children have various neurodegenerative disorders. Findings of the study revealed that carers experienced stigma, were concerned about being treated differently, and felt embarrassed of their child's condition. The unmet needs reported by the caregivers included the educational needs of their children not met, inadequate finances, lack of trained qualified professionals to manage their child’s condition and access to expert information about their child’s condition. These challenges were reported to be managed with coping mechanisms. The coping mechanisms reported by caregivers included prayer and social interactions such as talking with health professionals, friends and family. These widely reported coping mechanisms were reported to significantly impact the effects of the challenges they reported.

Dekawaty et al. (2019) also looked into the perspectives of caretakers of Parkinson's disease patients in another study. Data from five caregivers were acquired for this qualitative study. The study's conclusions showed that carers felt overburdened by their caregiving responsibilities. In the event that family and societal assistance was available to satisfy the requirements of both the disabled individuals and the caregivers, these caregivers would have been able to cope with their circumstances.

Again, Guillamon et al. (2013) explored coping methods and their effects on carers of children with cerebral palsy, as well as quality of life and mental health. 62 caregivers provided quantitative information, which was then analyzed. The study of the data revealed that, relative to the overall populace, these caregivers had a lower quality of life and poorer mental health.

In Africa, Obembe et al. (2019) conducted a study on coping methods and depression in parents of children with cerebral palsy in Nigeria, and aimed to determine the relationship between different coping strategies and the occurrence of depression in these parents. 132 people in all were selected to take part in the study. The Brief COPE inventory was used to assess their coping methods, while the Mini International Neuropsychiatric Interview was utilized to assess depression. Their research revealed a substantial positive association between depression and the use of instrumental support, self-blame, denial, and behavioral disengagement but a large negative correlation between depression and active coping, planning, positive reframing, and humor. Depression had a negative correlation with both problem- and emotion-focused coping methods. While depression and dysfunctional coping were strongly positively correlated. Emotional and problem-focused coping strategies have been proven to be more effective at preventing depression in carers of children with cerebral palsy than dysfunctional coping strategies.

The association between family adaptation and coping with cerebral palsy was examined in Lin's (2000) study. 274 families of people with cerebral palsy from the north central region of the United States were recruited as participants through 12 United Cerebral Palsy associations. Component analysis revealed that the following factor variables, including positive family evaluation, assistance from concerned third parties, spiritual support, personal development and lobbying, and positive social contact, explained 64.7% of the variance in family coping. Family adaptability was found to be substantially correlated with favourable family evaluation and spiritual support by stepwise multiple regression (p .000 and p =.013, respectively) of these variables. Family coping with cerebral palsy varied depending on the stage of the family life cycle, according to a multivariate analysis of variance with Pillai's criterion (p =.002). According to the analysis of variance, family adaptability varied according to the stages of the family life cycle (p =.004).

Krstić and Oros (2012) state that effective and ineffective coping mechanisms adopted by caregivers of children with special needs have not been fully explored. A number of studies have been done to highlight and explore the challenges of caregiving especially with children with disabilities such as cerebral palsy. Due to increased predisposing variables and a lack of facilities and services to help care for the child with the impairment, the majority of these studies were regrettably conducted in developed nations, with only a handful conducted in Africa. (Masulani-Mwale *et al.*, 2018). Therefore, in order to close the information gap and serve as a foundation for effective interventions and support plans for these caregivers in Ghana, it is necessary to investigate the coping mechanisms of caregivers.

Psychological distress and Coping mechanisms

According to Snyder (1999), coping is a strategy used to lessen the physical, emotional, and psychological strain brought on by stressful life events and inconveniences on a regular basis. According to studies (Folkman & Moskowitz, 2004; Lazarus & Folkman, 1984; Noh & Kaspar, 2003; Tuncay et al., 2008), effective coping strategies can lessen psychological distress. Previous research has also shown that caregiver-focused interventions and prevention measures may improve the wellbeing and circumstances of the caregivers by enabling them to be more responsive to the needs of the child and less affected by their disability. In a situation of limited income, it is realistic to anticipate similar outcomes. The status of the entire family, not just the challenged child, must therefore be addressed. Therefore, holistic interventions that address both the caregiver's psychological well-being and the overall family burden seem crucial. Also, to access the psychological distress and how they are managed by the coping mechanisms, the quality of life is examined to clearly report on the effect each one has on the other.

For instance, 167 children with their caregivers were sampled for Chen et al.'s (2014) study, which sought to thoroughly investigate the factors that affect the quality of life of caregivers of children with cerebral palsy based on the International Classification of Functioning, Disability, and Health for Children and Youth. The potential influencers of quality of life, such as child traits, caregiver characteristics, and environmental factors in all their forms, were gathered. Four multiple regression models showed that factors including the child's age, type of cerebral palsy, fine motor impairment, other illnesses, behavior and emotions, visual impairment, and hearing impairment were significant predictors of caregivers' quality of life. General mental health, parenting stress, marital status, family coping styles, socioeconomic status, and environmental factors like the child's medication, school environment, and current rehabilitation service, the caregiver's spouse's age, effects on the family life, and the presence of a domestic helper were among the caregiver characteristics. The study revealed that caregivers of children with cerebral palsy had lower quality of life, except the environment quality of life. The quality-of-life issues that affect carers of children with cerebral palsy are multifaceted and include aspects of the child, the caregiver, and the surroundings. Additionally, caregiver characteristics of general mental health, parenting stress, and coping mechanisms, caregiver characteristics of severity of fine motor impairments and emotional and behavioral problems, environmental factors of family life impacts, and school environment all showed significant relationships with quality of life of carers.

Additionally, Polack et al. (2018) evaluated the connection between feeding difficulties and nutritional condition of children with cerebral palsy in Ghana and found that caregiver QoL levels were low. In comparison to a maximum score of 100 (highest QoL), the median summary total score was

12.5 (SD 18.7). Physical functioning had a median summary score of 16.7, while daily activities had a median summary score of 0 (SD 24.9). Even after controlling for potential confounders, quality of life scores were significantly worse for caregivers of children who had the most feeding issues (median score 11.5 Standard Deviation (SD) 24.3) than for those who had the least difficulties (30.2 SD 10.2, p=0.01). When compared to caregivers of children without cerebral palsy who were not underweight (11.1 SD 16.2), QoL was comparable (11.8 SD 16.2), with a p-value of 0.14. The results of Polack et al. (2018) show a significant association between feeding issues and underweight status in children with cerebral palsy. This implies that, compared to children without such challenges, cerebral palsy patients who encounter feeding difficulties are more likely to be underweight. The study also discovered a link between reduced quality of life (QoL) for carers and eating issues in children with cerebral palsy. This suggests that carers of cerebral palsy children who have feeding difficulties confront difficulties that may have a negative influence on their general quality of life. However, the study did not discover a connection between caregiver quality of life and a child's nutritional health. The child's nutritional status alone did not have a substantial impact on the caregiver's quality of life, even while feeding issues and underweight status were associated to caregiver QoL.

Initial information on family quality of life in Bosnia and Herzegovina is provided by the paper Family quality of life: adult school children with intellectual disabilities in Bosnia and Herzegovina, by Awaad et al. (2014). Additionally, it offers recommendations for enhancing the standard of living for families with one or more members who have an intellectual disability

(ID). The primary carers of individuals with intellectual or developmental impairments were the target audience for the Family Quality of Life Survey (Brown et al., 2006). The sample was made up of the primary caregivers of 35 families with ID-affected adult children ages 18 and older who attended lessons in a specifically modified program at the B&H Vocational Secondary School (n = 19) and the Center for Children with ID, Autism, and Cerebral Palsy (n = 16). 15 boys or daughters were diagnosed with ID of unknown etiology, eight had cerebral palsy, four had Down syndrome, four had epilepsy, and another three had epilepsy as a co-morbidity, two had autism, and two had Prader-Willi syndrome, according to the primary caretakers. One person was diagnosed with both ID and a mental condition. Three people rated their family's overall quality of life as "excellent," eight as "very good," 16 as "good," seven as "fair," and one as "poor." In addition, 13 respondents indicated that they were neither content nor unsatisfied with their family's quality of life, while two others indicated that they were "neither very satisfied nor dissatisfied."

According to Lefley (1997), the capacity of a carer to control stress changes with time. At different stages of caring, various coping techniques are employed. (Nolan et al.,1996). The most efficient stress-management strategy is probably a mixture of problem or emotion-focused coping (Folkman & Lazarus, 1980). For instance, a caregiver for a burns patient can decide to ignore their anxiety or sadness while purposefully implementing healthy adjustments to lifestyle including learning to relax and cope with negative emotions.

Garca-Alberca et al. (2012) investigated the role of disengagement coping in carers of Alzheimer's disease patients' relationships with caregiver burden, anxiety, and depression. The analyses' findings revealed that anxiety and depression scores were significantly predicted by more disengagement and less participation in coping strategies. However, the study's cross-sectional design can hide contextual elements that might have an impact on how anxious and depressed the caregivers are.

In regard to the post-onset personality and physical changes in patients with neurological illnesses, Kausar and Powell (2005) investigated the coping levels and psychological distress experienced by parents or caregivers. 112 parents or carers of patients, who were either a close relative or a friend, took part in the study. According to the theory, the degree of personality changes would be correlated with the level of discomfort felt by parents or carers, and psychological distress in parents or caregivers would be anticipated by the coping mechanisms used to manage post-onset alterations in the patient. Four to eight months after the patients' neurological impairments first manifested, the parents or caregivers were evaluated. The "Ways of Coping Questionnaire" was used to evaluate coping. The subjective burden, anxiety, and depressive symptoms experienced by parents and other carers were used to gauge their psychological discomfort. A 10-point rating scale and the Leeds' measures for anxiety and depression were used to gauge the subjective strain on parents or other carers. Regression, correlation, and t-test analyses were used to analyze the data. It was discovered that parents or other carers went through a lot of psychological pain. Parents or caregivers who relied more on emotion-focused coping mechanisms than those who relied more on problem-focused ones expressed greater suffering.

Van den Borne et al. (1999) investigated the psychosocial issues, coping mechanisms, and information needs of parents of children with Prader-Willi syndrome and Angelman syndrome. The findings of the study indicate that a significant number of parents are particularly anxious about the potential disappointment that their child may experience in the future. the parent's child's isolation and the child's difficulties getting worse. There is a substantial difference in these kinds of worries between the two parent groups, according to a comparison (t = -24430; p = 0.02). The Prader-Willi parent group is more concerned than the Angelman parent group about potential negative effects on the child. This was also discovered in a study that used data from just two parent families (t = -2581; p = 0.01). When compared to worry of adverse events happening to the child, both groups are less afraid of negative occurrences happening to them as parents. In addition to the fear of losing their patience with their child, several parents also mentioned the fear of not being taken seriously when discussing their child with others, the fear of becoming dependent on others due to their child's condition, and the anxiety of traveling to other people's homes while carrying their child. With these fears, the study showed that information on the disorder their child is facing will serve the purpose of helping the parents to cope.

In an article on psychological support for families of autistic children by Ashum and Singhal (21005). The stress levels and coping mechanisms in the families of autistic children were discussed in the paper. The need of giving psychological assistance to the families of autistic children as well as its lack were both emphasized in the research. The study found that children with such medical conditions often have dispersed intellectual abilities or isolated capabilities, as well as chronic behavior problems including self-stimulatory behavior. These traits have been linked to parenting stress. It also made note of the relationship between stress in parents and the behavioral, social, and cognitive aspects of the disease.

From an African perspective, to recognise and describe the psychosocial effects of CP on families and to ascertain the coping mechanisms used by families, Olawale et al. (2013) undertook a study. A cross-sectional descriptive survey was conducted for the study in the physiotherapy department of a tertiary hospital. Participants included 52 parents of CP children. They answered a questionnaire meant to gauge the level of psychological stress experienced by the families and the coping mechanisms used. Responses were displayed graphically using descriptive statistics. The respondents concurred that being adequately informed about CP would enable them to handle the responsibilities of caring for children with CP. 38.5% of respondents reported that they have been blamed by members of the community of doing something improper that caused their children to be born with CP. Loss of employment, inability to focus at work, a lack of joy in the family, and financial mismanagement are examples of personal troubles people have encountered. Of these, 26 (or 50%) turn to religious or spiritual involvement as an additional or alternative form of care for their children, while 28% rely on their extended families for assistance. Families who take care of children with CP typically have a positive outlook on their kids. To help the parents cope better, it is necessary to educate the public about the causes of CP and the treatment choices available to families.

Yilmaz, Erkin, and İZKİ (2013) in Turkey investigated the psychological stressors connected to caregiving for children with cerebral palsy and to ascertain the effect of these stressors on mothers caring for children with cerebral palsy's health-related quality of life. The study included 277 participants, or 200 people in total. The Short-Form Health Survey (SF-36) was used to gauge participants' quality of life, while the Beck Depression Inventory (BDI) and Stigmatization Inventory were used to gauge psychological stresses. According to the study's findings, major stresses related to the care of children with CP include carers' burden, depression and stigmatization. Additionally, there was a strong negative correlation between psychological stressors and caregivers' quality of life for children with CP.

Conceptual Model

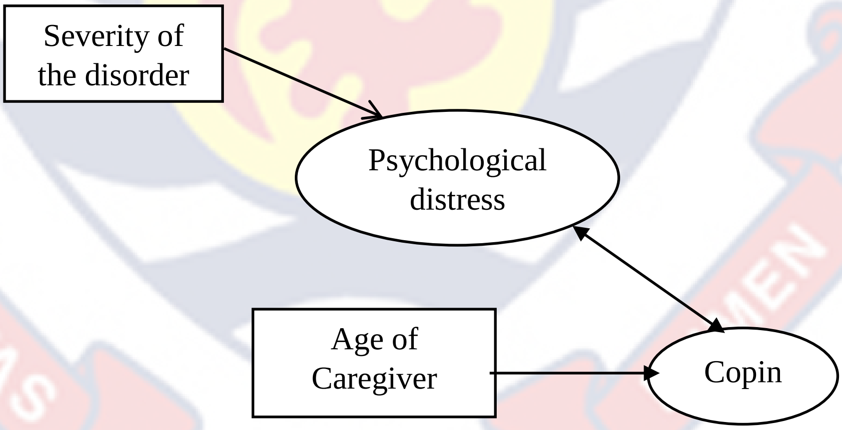

Figure 3: Conceptual Model

Based on the available literature, it is hypothesised that age of caregivers could influence their coping strategies. It was also observed that the severity of disability could influence the level of psychological distress among caregivers. Again, it was found that coping and psychological distress are related. Figure 3 illustrates the hypothesised model.

CHAPTER THREE

RESEARCH METHODS

Introduction

The type of research methodology utilised to examine the psychological distress and coping mechanisms of caregivers of children with cerebral palsy in Techiman, Bono East Region, Ghana, is described in this chapter. The section explains the suitable strategies used to accomplish the study's goals. The design, research setting, population, sample, and sampling strategy, as well as the data collection tools and procedure that was employed.

Research Design

This research employed a convergent parallel mixed design as it possesses characteristics of both the quantitative and qualitative methods of research (Teddlie & Tashakkori, 2006). Convergent mixed method designs are useful when a researcher is interested in using multiple data sources to examine similar issues at the same time points (Tashakkori & Teddlie, 2009). In a convergent parallel mixed methods design, both qualitative and quantitative processes are carried out concurrently, producing research questions, data collection methodologies, and analytic methods that are mostly independent of one another (Creswell, Klassen, Plano-Clark & Smith, 2011; Tashakkori & Teddlie, 2009). The two data streams are then combined and used to produce meta-inferences (Creswell et al., 2011). Meta-inferences combine and integrate information from both data strands to form inferences that lead to analytical conclusions (Tashakkori &Teddlie, 2009).

A method of exploratory research was employed for this investigation's qualitative aspect in order to extract information from the participants to uncover new information in the said area (Creswell, 1998). Semi-structured interviews were used to collect the data, as they provide a structure to guide the researcher as well as give room for follow up questions, to ensure that information from the area of study was well exhausted. In order to learn more about the experiences and different coping strategies used by the carers of children with CP in Ghana, a well-developed semi-structured interview guide was used. Utilising clinical diagnostic questionnaires was part of the research's quantitative component to attain descriptive details of the participants as well as clinically investigate the presence of distress and coping among the participants, the influence of the severity of disability of child on psychological distress and the influence of age of caregiver on coping.

Convergent parallel mixed methods design follows a four standard processes (Creswell & Plano-Clark, 2017). Gathering concurrent but distinct strands of qualitative and quantitative data that are pertinent to the study objectives constitutes the first step. Analysing the two separate data strands makes up the second stage. The results from the two strands of data are combined at a point of inference in the third phase to produce meta-inferences (Tashakkori & Teddlie, 2009). The fourth phase entails evaluating the combined results and examines how the two data strands converge, diverge, or otherwise help us understand the phenomenon better (Creswell & Plano-Clark, 2017). This is basically how the analysis of both strands of data in this study was done.

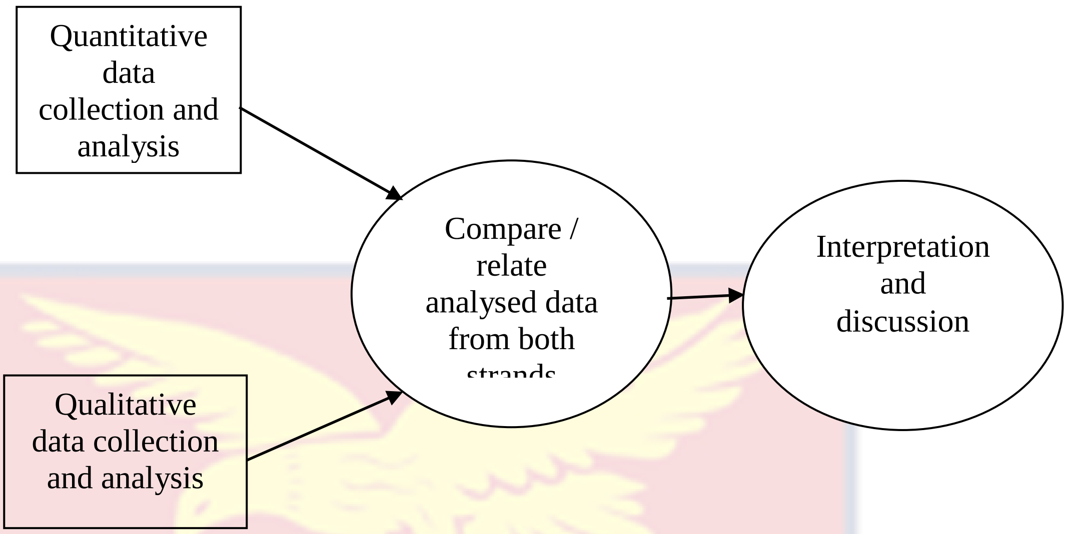

Figure 4: Four standard processes

Research Setting

The study was conducted in Techiman, in Ghana's Bono East Region. The Techiman Municipal is one of Ghana's 260 Metropolitan, Municipal and District Assemblies (MMDAs). It is a component of the Bono East Region's 11 Municipalities and Districts, which has Techiman as its capital. The Municipality is located in the middle of Bono East Region, between latitude 80 00' north and 70 35' south and longitude 10 49' east and 20 30' west. The land surface area of the Municipal Assembly is 649.0714 square kilometers, and it was founded by Legislative Instrument (L.I) 2096. It shares borders with the Techiman North District, the Bono East Region's Wenchi and Nkronza South Municipalities, and the Ashanti Region's Offinso North District.

Data was specifically collected at the Holy Family Hospital. This hospital was chosen because it has been identified as a hospital that offers many specialised services including a clinic for children with neurodevelopmental disorders, and that includes children with cerebral palsy.

Population/ Sample

The population of Techiman as of the 2010 census was 147,788 with about 2.2% of its population suffering from various disabilities, the majority of which are speech, intellectual, hearing, sight, physical and emotional. (Ghana Statistical Service [GSS], 2014). There are an estimated 300 children living with the various forms of Intellectual and Developmental Disabilities, with approximately 100 of them suffering specifically from Cerebral Palsy (Hospital's Database, 2022). The sample used for the qualitative aspect of this study was 10 caregivers of children living with cerebral palsy recruited from Holy family Hospital, Techiman municipal. This sample size has been cited by Sandelowski, 1995 as adequate for sampling among homogenous populations, and by Boddy (2016), as an appropriate number for qualitative research. For the quantitative aspect, based on the population of children with cerebral palsy who accessed Holy Family Hospital in Techiman, 73 caregivers were projected to be used from a population of 90 caregivers, after 10 caregivers out of the 100 were used for the qualitative aspect. This number is in accordance with the Krejcie and Morgan table, which determines sample size (Krejcie & Morgan, 1970). However, after applying the inclusion and exclusion criteria, a sample size of 55 was used for the quantitative aspect, hence a total sample size of 65 was used altogether for this study. The data from the hospital database could not establish how many caregivers were in the primary caregivers, however all the respondents who took part in the study were known to be the primary caregivers of the children. The number of children who fell into the age category of 3-18 were about 71.

Inclusion Criteria

Participants were included in this study if

i. They are primary caregivers for children who have cerebral palsy

ii. If their children were from the ages of 3-18 years

Exclusion Criteria

Participants were excluded from this study if

i. They are not primary caregivers of children with cerebral palsy

ii. If the children are below 3 years and above 18 years of age

The sampling techniques that were employed for this study were the purposive and snowballing sampling techniques. The purposive sampling techniques were used to help the researcher find a specifically targeted population that possesses the characteristics or experiences needed for the research (Etikan *et al.*, 2016). Caregivers who came to the cerebral Palsy clinic as well as the physiotherapy on Mondays, Wednesdays and Fridays were purposefully sampled for both the quantitative and qualitative data. The snowballing technique was also used as some caregivers helped to reach other caregivers who did not have an appointment or whose appointment dates were not due to come to the hospital during the period of data collection, as well as caregivers who were also not seeking care due to unknown circumstances.

A total of 65 participants were used for this study using the purposive and snowballing techniques. For the quantitative research, 55 caregivers of children with Cerebral palsy were sampled for the study, and 10 respondents selected to participate in the qualitative aspect of the study.

Data Collection Instruments

Demographic questionnaires

The tools used to obtain the data included a demographic questionnaire. This made it easier to compile pertinent data on the carers' sex, age, level of education, and other relevant characteristics. Additionally, this instrument helped gather relevant information about the age and gender of the child, severity of CP diagnosis, and previous or current access to therapy.

There are various instruments used in assessing the severity of disability in children with Cerebral palsy. These instruments include the Manual Ability Classification System (MACS) by Eliasson (2006) and the Gross Motor Function Classification System (GMFCS) by Palisano *et al.* (2006). The MACS assesses an individual's manual dexterity and upper limb function and classifies individuals into five levels based on their ability to handle objects and perform manual tasks whilst the GMFCS focuses on the evaluation of gross motor function and also classifies individuals into five levels based on their mobility limitations. However, in this study's context, the shortened two-item questionnaire by Mung ala-Odera *et al.* (2004) was favoured because it tends to combine both functions of gross motor and manual dexterity. This two-item questionnaire has been shown to be valid and reliable for identifying moderate to severe motor impairment (Geere *et al.*, 2013; Mung ala-Odera *et al.*, 2004). These questions were used to assess the degree of disability of a child with cerebral palsy. A yes or no response to the question “Does your child have difficulty in holding implements, dressing and sitting upright or need help to move around?” suggests moderate impairment (yes) or no impairment (no). Also, a yes or no response to the question, “Is your child unable to walk and/or without functional use of the hands?" suggests severe impairment (yes) or no severe impairment (no).

Qualitative Interview Guide

A semi-structured interview guide was developed by the researcher to purposely explore caregivers' various forms of psychological distress and how they cope with taking care of children with cerebral palsy. In developing the interview guide, the related studies that were reviewed helped to identify specific questions needed to fill the research gap. Additionally, the researcher adhered strictly to Boyce and Neale's (2016) process for developing an interview guide. The purpose of this interview guide was to collect information on caregivers' individual experiences, narratives of how they manage caregiving, and the types of assistance that are accessible to them during the caregiving process.

Quantitative Instruments

Depression, Anxiety and Stress Scale -21 Items (DASS-21, Lovibond &Lovibond 1995)

The DASS-21, a 21-item questionnaire, assesses the levels of emotional of an individual. This version is a shortened version of a 42-item self-report measure developed by Lovibond and Lovibond (1995). This scale is made up of three subscales which assess depression, anxiety, and stress. Each subscale is made up of seven items and each of these items is measured on a 4-point Likert scale, ranging from 0 (did not apply to me at all) to 3 (applied to me most of the time).

Items on the depression scale assess an individual's state of self-condemnation, hopelessness, anhedonia, lack of interest/involvement, states of dysphoria devaluation of life, and inertia. The anxiety subscale is also made up of measures of situational anxiety, skeletal muscle effects, autonomic arousal, and subjective experiences of anxious response. Finally, items on the stress subscale measure an individual’s nervous arousal, difficulty relaxing, agitation levels, irritable levels, and impatience (Lovibond & Lovibond, 1995).

To obtain overall scores for this scale, the total scores for each subscale are summed up and multiplied by 2 to get a score ranging from 0 to 42. For specific scores on each subscale, total scores of the items under each category are summed. For the depression subscale, scores ranging from 0-9 indicate normal mood, scores ranging from 10-13 indicate mild depression, scores ranging from 14-20 indicate moderate depression, 21-27 indicate severe depression and scores 28 and above indicate extremely severe depression. For the anxiety subscale, scores 0-7 indicate normal anxiety levels, scores 8-9 indicate mild anxiety, scores 10-14 indicate moderate anxiety levels, scores 15-19 indicate severe anxiety levels, and scores 20 and above indicate extremely severe anxiety levels. On the stress subscale, scores 0-14 indicates normal stress states, mild stress is represented by scores 15-18, moderate stress is represented by scores 19-25, severe stress is represented by scores 26-33, and extremely severe stress is represented by scores 34 and above. Substantial scores on the scale, lower values, according to Lovibond & Lovibond (1995), suggest a lack of or very low levels of psychological distress, whereas higher values indicate high levels of psychological distress.

The various subscales' Cronbach's alpha has been reported to be high. According to reports, the scale's total Cronbach's alpha is.95. The reported values for the depression, anxiety, and stress subscales are.93,.85, and.90, respectively (Dahla, Wong, and Ponsford, 2013). Additionally, the scale has strong convergent and divergent validity as well as good criterion validity, according to Bottesi et al. (2015). The Depression scale is claimed to have an internal consistency of.82, the Anxiety scale to have an internal consistency of.74, and the Stress scale to have an internal consistency of.85, giving the entire scale an internal consistency of.90.

The Brief COPE Inventory (Carver, 1997)

The Brief COPE Inventory by Carver (1997) is a 28-item multidimensional measure of strategies used for coping or regulating cognitions in response to stressors. This abbreviated inventory based on the complete 60-item COPE Inventory is comprised of items that assess the frequency with which a person uses different coping strategies (e.g., “I've been turning to work or other activities to take my mind off things,” “I've been making fun of the situation,” “I’ve been criticising myself”) rated on a scale from 1, I haven't been doing this at all, to 4, I've been doing this a lot. There are 14 two-item subscales within the Brief COPE, and each is analysed separately on; self-distraction, active coping, denial, substance use, use of emotional support, use of instrumental support, behavioural disengagement, venting, positive reframing, planning, humour, acceptance, religion, and self-blame.

The Brief-Cope was developed as a short version of the original 60-item COPE scale (Carver *et al.*, 1989), which was theoretically derived based on various models of coping.

The Brief COPE has good internal consistency when grouped as emotion-focused, problem-focused, and dysfunctional coping strategies, with

Cronbach’s alpha ranging from 0.72–0.84 among caregivers of individuals with dementia and 0.55–0.75 among caregivers of individuals with acquired brain injury (DeDios-Stern, Lee & Nitsch, 2017).

The questionnaires were subjected to critical scrutiny to ensure its consistency and appropriateness. It was given to my supervisor for his perusal and comments with the view to establishing face and content validity.

The questionnaires were pilot-tested at the Sunyani Teaching hospital on a total of 13 Caregivers of Children with Cerebral palsy. These caregivers were regular service users at the Physiotherapy unit. The purpose of the pilot test was to help determine the extent to which the research questionnaires were effective in collecting data from respondents for the actual study.

For the DASS-21, the total Cronbach's alpha was .92. The values for the depression, anxiety, and stress subscales were .90, .85 and .90 respectively. With respect to the Brief Cope Inventory the Cronbach alpha for Problem Focused was .65, Emotional Focused was .70 and Avoidant coping was .75.

Ethical considerations

The University of Cape Coast's ethical review board for the college of education studies was consulted before data collection got started. The investigation's ethical reference number is CES/ERB/UCC/EDU/46/22-118. Afterwards, permission was sought from the Holy Family Hospital Research and Development team through the Hospital Management team. The researcher was given approval and a specialist Paediatrician was assigned as an on-site supervisor.

The researcher obtained participants' informed consent after receiving the permission before beginning data collection. Participants received guarantees of privacy and anonymity. Participants in the study were informed that they might opt out at any time during the research period and that their participation in the study was optional. Throughout data collection, the researcher was also present to answer any queries and questions that came up. Also, a separate room designated by the physiotherapy department was used for the administration of the questionnaires and interviews.

Data Collection Procedure

The study began after receiving ethical approval from the university of cape coast ethics committee and receiving an introduction letter from the psychology department. These letters were submitted to the hospital where data collection commenced. Participants were recruited using the purposeful and snowballing methods.

Participants who were recruited were briefed on the nature and purpose of the study. They were given details on the benefits and possible risks of the study and were assured of confidentiality. However, they were also made to understand participation was entirely voluntary. Afterwards, caregivers who agreed to participate in the study were asked to endorse a consent form. After this endorsement, those for the quantitative aspect were presented with the data collection instruments to complete with the aid of the researcher and his assistants who were available to clarify ambiguity and difficult to understand concepts. In-depth interviews which averaged about 30 minutes were also conducted at the same period individually in a private room in the physiotherapy unit with the 10 participants who were purposefully sampled. The demographic questionnaire and the semi-structured interview guide were used and their responses were recorded with an audio recorder.

Reflexivity

Qualitative research as we know, is subjective. Palaganas *et al.* (2017) share that it is influenced by the kind of responses the participants give and also the expertise and technical know-how of the researcher. This is one of the reasons why reflexivity is done, to acknowledge the shortfalls and give attention to the other ways to make it better. Thus, being reflective enables the researcher to identify specific potential influences on the research as well as the steps taken to overcome those influences.

This area of study has been of interest to me ever since I started working at the paediatric unit at the hospital. I encountered many caregivers who brought their children in for appointments. I noticed certain similar characteristics (i.e., irregular visits and apathy to the clinics, financial issues, expressions of exhaustion and traveling from long distances, etc.) in the calibre of the caregivers and wanted to know more, in terms of why they behaved in the ways they did, as well as to know and understand their experiences.

To satisfy my hunger to know all these things, I decided to conduct a casual literature search on the area. The results of my search fetched me a few papers and studies done on cerebral palsy. Most of these studies were not culturally specific to Ghana and the few which were, did not exactly have all the information that I was gathering from my time of service at the hospital. I thought to myself, if I could build rapport with the caregivers and get them to be willing to share their experiences in caring for such children, I would be contributing to filling the literature gap that I found in my search.

From my discussions with the caregivers when they came in to have their support group meetings and for their appointments, I realised there was so much they did not know and so much they were hiding from the healthcare professionals. To my understanding, if this gap was bridged, we would have more caregivers in the right frame of mind and better informed to care for such children. I began to ask myself some questions like why the caregivers of children living with cerebral palsy came in irregularly to see the doctor, especially because this condition was delicate. I also wondered what resources went into caring for the children and the caregivers as well.

I started reaching out to the caregivers immediately I was given the green light to begin collecting data. Initially I thought it would be easy since I had already seen some of the caregivers and spoken to them but it turned out not so easy as the caregivers were not regular in coming to the hospital. Some of them admitted that they had financial challenges or had resorted to other means of caring for their children. I had to re-strategise my approach to collecting data and either provide transportation assistance or visit them in their homes. Half way through data collection, I employed the assistance of a colleague who helped me gather more caregivers to take the interviews and fill the questionnaires. During the interviews I realised some of the caregivers held back some of the information because they had the impression that I was one of the doctors at the hospital who was making sure they were caring for the children properly. Information such as how they managed to feed the children and the use of funds given to them by NGOs for transportation to their appointments, was later revealed to me after I reassured them, I was not going to report or penalise them for their unrecommended ways of managing their children.

One challenging aspect was when the caregivers sometimes broke in tears as they recounted their experiences, especially with how their own families treated them. I had to serve a dual role as a psychologist providing therapy for them and researcher at the same time. Some interviews took more than a day as we had to break and continue another time due to how emotional some of them got.

After each day's session of data collection, I reflected on the positives and negatives of the process, in order to make the next one better and maintain validity as much as possible. This way I managed to keep the data true and reflective of the area of study.

Data Processing and Analysis

The qualitative data analysis was conducted thematically, utilising the revised steps for Reflexive thematic analysis by Braun and Clarke (2019). These steps are described as follows; after data was collected, there was first of all a familiarisation process where the transcribed data was read and reread. After this stage, there was systematic coding where coding labels were attached to the data. Then initial themes were generated from the codes that has been created. Themes were reviewed and similar subthemes developed and further grouped to form an overarching theme and then followed by a refining, defining and naming the various themes, then finally used these themes to write a report which reflected in the discussion section of this study.

The hypotheses to be tested in the quantitative aspect was done by a statistical software. The relationship between psychological distress and coping was investigated using multiple regression because this hypothesis has three predictors (emotion focused, problem focused and avoidant coping), and the hypothesis testing how the independent variables predicted the psychological distress levels of caregivers of children with cerebral palsy. A one-way Manova was used to investigate both the influence of the severity of disability of a child living with cerebral palsy on psychological distress as well the influence of the age of caregiver on the coping mechanism of caregivers.

Trustworthiness of the Study

According to Milton (2004), trustworthiness in qualitative research can be achieved through thorough inspection of interpretations of the ideas and submissions of the participants in a study. This is usually done by using methods of inter-rater validity. For example, in this study, more than one interviewer handled the qualitative data collection. Also, the data from the interviews were thoroughly examined by an external reviewer who is an expect and well experienced in thematic analysis to find out whether similar codes will be generated. Finally, after the interviews were done, the respondents were asked to take time to confirm their submissions by asking them literally to confirm what had been captured and transcribed.

Chapter Summary

In summary, the design of the study was a convergent parallel mixed design as it possesses characteristics of both the quantitative and qualitative methods of research (Teddlie & Tashakkori, 2006). The research was specifically done at the holy family hospital in Techiman in the Bono East Region of Ghana. Ethical considerations were satisfied before data collection began and reflexivity and trustworthiness of the data were achieved during the process. Multiple regression analysis and one-way Manova were used to test the quantitative hypotheses that were developed on the study. For the qualitative aspect, thematic analysis was used. The study's methodology carefully carried out, revealed interesting results which are worth noticing.

CHAPTER FOUR

RESULTS AND DISCUSSIONS

Introduction

This chapter presents the study's findings. The qualitative aspect and the quantitative aspect were each given their own part. Thematic analysis was used in analysing the qualitative aspect, and tables were used to demonstrate where necessary. The participants' and their children's demographic data makes up the first section of the qualitative findings. The experiences of caregivers of children with cerebral palsy are also covered in the second section.

Qualitative Results

Demographic Background of Respondents

Table 1: Demographic distribution of respondents

Participant	Age	Age of child	Gender	Education	Employment
C1	44 years	7 years	Female (mother)	Basic	Unemployed
C2	36 years	6years	Female (mother)	Secondary	Unskilled worker
C3	45 years	4 years	Female (mother)	Basic	Unskilled worker
C4	63 years	14 years	Female (mother)	None	Unemployed
C5	41 years	13 years	Female (mother)	Secondary	Unemployed
C6	39 years	15 years	Female (mother)	Secondary	Unskilled worker
C7	43 years	9 years	Female (mother)	Basic	Unskilled worker
C8	50 years	9 years	Female (mother)	None	Unskilled worker
C9	45 years	7 years	Female (mother)	Secondary	Unskilled worker
C10	42 years	17 years	Female (mother)	Basic	Unskilled worker

Source: Field Survey (2023) n (10)

The participants' ages, which were between 36 and 63 years old, are shown in the results in Table 1. The children's ages likewise ranged from 4 to 17 years. All 10 care givers were mothers of the children. 4 respondents had basic education, 4 had secondary education and 2 had no formal education. With regard to employment 7 out of the 10 respondents were unskilled workers and 3 were unemployed.

Table 2: Summary of emerging themes from qualitative interviews

Major themes	Sub themes
1. Factors influencing psychological distress in caregivers of children living with CP	a. Financial difficulties b. Time constrains in caring for a child with CP c. Time of detection and intervention d. Availability of information
2. Forms of psychological distress	a. Disorientation b. Worrying c. Sadness d. Fear e. Rejection f. Anger
3. Coping mechanisms employed by caregivers	a. Humour b. Avoidance c. Acceptance d. Faith or religion e. Coping with support groups / professional advice f. Family support as a means of coping
4. Caregivers’ experiences of children living with CP	a. Nurtured love b. Religious or spiritual confrontations c. Ridicule d. Discrimination e. Reduced social life f. Issues of mobility

Source: Field Survey (2023)

The table examines the psychological distress in caregivers of children with Cerebral Palsy (CP), covering factors like financial difficulties, time constraints, detection timing, and information availability. Psychological distress manifests in forms such as disorientation, worrying, sadness, fear, rejection, and anger. Caregivers employ coping mechanisms such as humour, avoidance, acceptance, faith, seeking professional advice, and relying on family support. Experiences of caregivers include nurtured love, religious conflicts, ridicule, discrimination, reduced social life, and mobility challenges. The comprehensive overview explores the multifaceted dimensions of caregiving for children with CP, shedding light on the intricate interplay of factors, emotions, and coping strategies.

Factors influencing psychological distress in caregivers of children living with CP

This theme discusses the various psychological distresses that the caregivers of children living with cerebral palsy have to deal with regularly. This is a main theme which has been broken down further to encompass the individual distresses that resonated throughout the study.

Financial difficulties

This theme was particularly common among the responses given by the participants. It explains the financial or money related concerns the participants continually encounter, in order to provide for and cater to the needs of themselves and their children living with CP.

One respondent narrated;

> *"When I got pregnant there was hardship, so every time I had to go hawking with pure water, so anytime I come home I feel tired, and it also gets me thinking because if I don't go hawking all the time, I wouldn't be able to survive, that is why it gets me*

> *thinking and worrying about what will happen to me if I deliver, so sometimes I sit quietly to think, and after giving birth too it turned out that the child had this sickness."* (Caregiver 1)

From this submission, it can be seen that finances posed the difficulty right from the period of pregnancy till the child was delivered and diagnosed of the disorder. However, the financial situation due to the condition, worsened.

The requirements to maintain a child with CP can be costly and the caregivers tell their experiences. One respondent also said;

> *"As for finances hmm….! This matter... Even right now they are saying he needs a special shoe that will help his walking. The doctors had initially informed me that they can't operate the child's leg but we can have some special shoes that will help him to walk even without assistance. And I was told I can get some at Wenchi for GHC 6000. After seeing the Doctor, he told me he will make the shoe which will cost GHC 5000. So, I went to solicit for funds from a lady who works at the Techiman North Assembly but she told me other people have come there already with their issues for help. So right now, what we are doing is to try and get some funds."* (Caregiver 6)

This respondent narrated how the child's condition has worsened her finances and health. She said;

> *"…because of the financial situation, am not able to pay my rent and it has left me worrying and anxious…and a doctor*

> *diagnosed me of hypertension after recording BP of 180/ 106mmhg."* (Caregiver 5)

Time constrains in caring for a child with CP

An issue of the amount of time it takes to handle simple tasks for a child living with CP was also a stressor for the caregivers, especially those who are employed or have business of their own. One respondent said;

> *"it is really difficult, it is difficult because at times you want to do something for your child, like maybe you want to bring him to the physio unit or maybe you are in the house and couldn't come to the physio and you want to perform exercises on him, but because you are alone you can't have time and do it as quick as you want, and you will also not get anyone that will do it, though they know your problem, they may not do it like how you want."* (Caregiver 2)

She added;

> *"…if you don't wake up early to do your own personal stuff, you will spend much time with him and the time will be far gone. If not because of his school we were coming to physio 3 times a week, on Mondays, Wednesdays and Fridays. But now because of school we come 2 times a week. Before he started attending school, I always had to be moving around with him every day…"*

Time of detection and intervention

The period in which the caregiver realises that there may be a developmental problem with the child is essential. With such a condition, detecting it early on and exploring medication and physiotherapy solutions may bring some kind of early relief or may help to salvage the situation.

One respondent mentioned;

> *"When I delivered and the child was 3-4 months, I wanted to make the child sit, but anytime I put her to sit on the ground, then she will fall on her face, then later I realised his head was becoming heavy, so someone told me that Holy Family Hospital attends to children who have such problems. So, I brought her to Holy family and they told me to start bringing the child for exercising (physiotherapy) So, when I started the exercising the child was 6 months. So, I continued for a long time, and the child was able to sit"* (Caregiver 1)

Another participant also added by sharing her experience on when she felt something was wrong with her child. She reported that it was immediately the child was born but she did not know specifically that the child would be living with cerebral palsy. She just knew something was wrong. Here is her quote;

> *"Okay, When I delivered, I never left the hospital, we were in the hospital for 3 weeks. As soon I gave birth to him his whole body was green, and his weight too was not up to 3 kg. I was operated so he was sent to the NICU before I even came out. I have left something out. When I came in labour, I was on admission for 4 days but I was not dilating for the child to come out. So, it was on the fourth day that they noticed that his breathing was not good, before they went to operate on me. So*

> *as soon as the child was removed his body looked green and he also looked small in size, so for 3 weeks we were on admission at the NICU. At first it was his head which looked big and they went to do a scan and saw there was water accumulated in his head. So as for a deformed body their mind wasn't there initially. It was later on they saw that his leg looked a bit tilted and rigid." (Caregiver2)*

According to Burhouse (2017), babies who are born preterm and babies who suffer long labour periods, usually beyond 24 hours to 2 days have a high risk of developing the cerebral palsy condition. This is due to the lack of oxygen, pressure and stress on the baby's delicate brain, as well as the chances of being exposed to infections. This particular participant's case could have been as a result of any of these instances, which brought about the condition in her child. This caused the respondent some distress because these where not her expectations before delivering her child. She further added;

> *"I didn't take it lightly at all, because it is not an easy thing to be told that your child has a condition like this. But they said exercising can help him and even with that it is not 100% that he will rise and walk, but then exercising will help him not to be too rigid. It was so painful, I thought that my child will grow after delivery but later on he was just lying down"* (Caregiver 2)

Availability of information

From the data, it was noticed that at points where the respondents got access to information about the condition of their children, they were able to use it to either get necessary help or simply be informed about how best to cater for such a child and saved themselves some distress.

In this respondent's case, she was able to use doctors' advice to plan and prepare meals for her child and eventually weaned him off the liquid foods' meal plan. This reduced the stress she faced concerning her child's meal preparation and feeding. She narrated;

> *"...another doctor told me to give him meals with soup, but I needed to apply okro on the food so the child can swallow. He said if I do this his throat will be open so he can eat well. And when I did this for some time, by God's grace he is able to eat every kind of food"* (Caregiver 1)

In other instances, the participants stated that caring for a child with this condition gives one the opportunity to learn about it to be informed. From the responses, having the right information makes it a bit easier to cater for the children with CP as the respondents get to understand that it is neither the children's fault nor theirs. One respondent mentioned;

> *"The little I have learnt is that, when a woman goes to labour and it's time for the child to come out, and the head is stuck in the pelvis, at the moment no air goes into the brain, so any of such part that needs to function for the body to work becomes dead, so this is what is able to make a child have CP So that is the little I know"* (Caregiver 2)

She added;

> *"The doctors themselves teach us about it, and there is a NGO also came to unite us and we formed an association, that is*

> *what made me have more knowledge about it, because I didn't actually know that if you are in labour and you delay (you know my own happened here) but most people stay home longer, and not knowing that air entering the brain of the child, that was what made me know that the moment no air goes into the brain of the child, it can result in such a problem. And now that I have this information, I educate others I see that in their labour they should not delay"* (Caregiver 2)

Another also said;

> *"…It broadens your knowledge, but to stay in the house and be crying or resort to traditional treatment will be wasting your finances and will not yield any gains."* (Caregiver 3)

This respondent also stated that some organisations also pitch in to help with sensitisation and providing support for the caregivers of the disorder. She said;

> *"There is an NGO who have been educating us a lot about accepting our children with CP and ignore the misconceptions people have about CP children."* (Caregiver 3)

Forms of psychological distress

The current study as part of its objectives, sought to find out some of the psychological distresses the caregivers go through. Some research from the reviewed literature cited anxiety, stress and depression as problems. The respondents to this study were able to provide information about additional distresses they had to deal with.

Disorientation

Disorientation was one of the emotions that the respondents reported to have felt, considering their child's condition. As narrated by a respondent;

> *"At the time it was difficult, even when I'm walking and someone talks to me, I couldn't hear. And they also said at the time that I needed to have an operation at KATH…"* (Caregiver 1)

Worrying

Worrying was also another way with which the respondents showed their distress while caring for their children with CP. One respondent submitted;

> *"When I wake up every morning, I pray for God to give me strength to be able to carry him, however what really saddens me and it's the biggest problem for me is who takes care of this child when I sleep today and don't wake up." (Caregiver 4)*

Another respondent added;

> *"…it has left me worrying and anxious. I started having symptoms like palpitations, general malaise and numbness in my fingers and I took a lot of herbal medications but I wasn't relieved. I therefore went to Abrafi Hospital and a doctor diagnosed me of hypertension after recording BP of 180/ 106mmhg."* (Caregiver 5)

Sadness

Some respondents report that they experience sadness as a result of their child's condition, especially after they are diagnosed for the first time. This respondent said;

> *"I felt very sad, it was so painful, I felt sad, because I thought that with all the numerous troubles that I have been through I would have had my child and be happy, but with this kind of condition called CP, they are explaining to me that everything of his will be delayed, from his walking, talking and everything will be delayed, because the part of the brain that will help him walk and talk have been affected. So, I was really sad…some of the things people say make me sad, because if my child has not gotten this problem, I wouldn't have heard such things"* (Caregiver 7)

Another respondent added;

> *"Oh, I was sad, and shed tears. I cried a lot. I was looking forward to have a daughter and finally that dream came through and the child ending up in this situation made me cry a lot. Mhmm… hmm"* (Caregiver 10)

Fear

Most of the respondents had not seen or experienced such a condition before. Fear was one of the reactions they showed while being educated about CP for the first time. One participant said;

> *"I got scared. I did get scared. As I got the information of the child's condition, I said eei God what is this? If this is how the*

> *child's condition will be, not being able to walk, what do I do to help the situation?"* (Caregiver 8)

Rejection

Society responds in a particular way to caregivers of children with conditions like CP. Sometimes the responses are unfavourable, in the form of rejection which elicits some amount of stress in the caregiver. One respondent shared her experience with rejection from her family. She said;

> *"My husband's father suggested we go and kill the baby because the child will be a burden to us. Many people kill their children with such condition. But I told them I couldn't do that and I had no say in that if they would want to do that to their kin. My in-law then told me since I couldn't kill the child, then I must leave the house since it was their family house."* (Caregiver 8)

Anger

Another response to distress was anger. According to the respondent, she felt angry at the sight of the child because she felt she had caused her trouble. She quoted;

> *"At first, I used to get angry anytime I see her because I felt she is the reason for all that I am going through. There were times she would speak to me and I would get unnecessarily angry and beat her for no reason but afterwards, I feel remorse and apologise for doing that because I did it out of anger."* (Caregiver 10)

Coping mechanisms employed by caregivers

As discussed in the literature review, coping mechanisms are employed by individuals who are facing some kind of distress and this aids them to manage their situations. Coping mechanisms may be emotion based or humour based or be positive or negative. This main theme draws attention to what kind of coping mechanisms the respondents employed in managing their situations of caring for children with CP.

Humour

Humour as a method of coping involves finding the funny aspects of the problem one is facing to help lighten up the severity of the distress that comes with it. It is usually a way that temporarily relives stress. One respondent reported that she used humour to relieve some of her distress as she was tending to her child living with CP. She reported;

> *"…So now I don't go through a lot of sorrow like before, because the child himself is able to make me happy at home. sometimes he laughs over funny situations to the point that makes me laugh as well. Even today when we came, we sat at this side, and as soon as he saw me he screamed "maa" and I started laughing and he also busted into laughter, so now even myself he makes me happy when I'm with him."* (Caregiver 1)

Avoidance

According to Allen and Myers, (2019), avoidance which involves victims or patients actively deprive themselves of experiencing emotions or feelings mainly because they cannot help the situation, is one maladaptive way of coping with stress. In this study, the respondent mentioned that if she entertains thoughts which suggests she's tired or stressed, she will be unable to care for the child. She stated;

> *"There is nothing to do, because its something which has become a part of me. The moment you entertain the thoughts of being tired, then you can't be able to take care of him…I know I have to do these responsibilities everyday so as soon as I wake up, I begin to do everything I need to do. I don't give myself the chance to say I cannot, I don't entertain those thoughts, else I cannot do anything."* (Caregiver 2)

Acceptance

Some caregivers come to the realisation that the condition of their child is for a life time. This helps them to accept and manage the situation in the best way possible. One participant said;

> *"At times I go into a lot of thinking and worrying and crying, but nothing can be done because this problem has happened already and I can't throw the child away, so we take it like that."* (Caregiver 3)

Faith or religion

Also, religion or a person's faith influences a greater part of their lives and influences the decisions and actions. In this case, it helps the respondents cope with their situation as caregivers of children living CP.

One respondent submitted;

> *"…All what I say is that God is my helper, so in everything I leave it to God's hands, that He should come to my aid in every situation, and I can't fight this battle except Him the sovereign*

> *lord who will fight for me, so I don't really mind what people were saying…"* (Caregiver 1)

According to this statement, the respondent externalised her problem as beyond her strength. Therefore, leaving it to an external force to help or fight for her brought her some relief.

Another respondent added;

> *"…so I always ask God to give me strength so I don't say I'm tired…this is what I strengthen myself with, that God should always be with me so that every day I will get the strength to do everything I need to do for him."* (Caregiver 2)

In agreement to the others, this respondent said;

> *"…Eeeh Hmm for now my hope is in God, and God is our comforter because it's not easy for us…"* (Caregiver 3)

Coping with support groups / professional advice

In some cases, the respondents sought help and solace in the support groups that they attended. Seeing another person who shares in their problem brings some kind of assurance and relief that encourages them to keep fighting as the problems come and go.

Respondent one mentioned;

> *"The union we have formed really helps me, anytime we meet, we receive teachings and instructions concerning the feeding of the children, that we always have to devote a lot of time towards these children. Some people also come very sorrowful and I'm also able to share my experiences with them, to let them know I also had similar challenges from the beginning but*

> *now by the grace of God I have hope and faith in God that in future the child will also do well."* (Caregiver 1)

Another respondent added;

> *"…And with the association too it has led to increase in my knowledge, and even how to talk to others to know that the problem they are in is not peculiar them alone. For some people when they were not part of the association, they feel so recoiled and think they are the only one going through such a problem. But when we came together there are times, we all come together with the children and doctors and they educate us and other things. This has made all the worries we had at first to disappear. Though I think of it occasionally as person but I don't become overwhelmed to the point that will not make me unable to do what I'm supposed to do. We meet on the last Sunday of every month at 1 pm at the disabled centre, old council behind the fire service station near the immigration…"* (Caregiver 2)

She added;

> *"Things are difficult but I'm not overwhelmed like before where my thoughts were flooded by the problems. It has given me a lot of hope. The more we help the children the more we see improvement in the children"* (Caregiver 2)

Just as some respondents received support from the help and education in support groups of other caregivers with similar conditions, some received their support from the professional advice from their doctors or healthcare providers. One such respondent said;

> *"Some of my help comes from the doctors through the advice they give me about the anticipated problems associated with the condition, so it made me know what is ahead of me. So, this always strengthened me"* (Caregiver 2)

Apart from the professional help the support group provides to the caregivers of the children living with CP, they also help in terms of finances. One respondent mentioned that sometimes the caregivers in her support group are given an amount of money to supplement their transportation to the hospital. She said;

> *"…and for the association too when we go for our meetings, at times they give us our transportation fares, because at times I leave home not having even GHC10 on me. But after trying little by little to walk to the place, they give us some TNT, and take some amount out to buy her food. …"* (Caregiver 3)

Family support as a means of coping

Support from family is always very important when one is faced with a stressful situation. The thought of having people around who will selflessly help out with their time and finances is heart-warming. This respondent shared her experience of how helpful her family has been and that us helped her cope till now. She submitted;

> *"…also in my family, my siblings, my mother, and my father. I am especially thankful to my father, as a pensioner he used his salary to a loan of Ghc 5,200 in 2016 from Abosmankotere*

> *credit union so I can be able to pay for the shunt for my child's surgery at KATH. He didn't make me go through pain, or shed any tear. He was always encouraging me and telling me that with God all things are possible. So, he was with me in my 2 years up and down trips to KATH, and because of that people even thought he was the father of my child. So, the things my mother and my father has done for me are things I cannot even paid them."* (Caregiver 2)

Another respondent added;

> *"…I used to stay more indoors and it was my mum who was helping me in taking care of the child. "(Caregiver 6)*

Caregivers' experiences of children living with CP

Nurtured love

CP is a disorder in which most patients do not have mobility or find it very difficult to achieve, sometimes do not have control over their bowel movement and are highly dependent on their caregivers for support and care. According to respondent 1, this has made her develop a kind of love for attending to her child with CP, understanding that he is helpless and totally dependent on her. She quoted;

> *"because of way the child is I have developed a certain love for the child so he wouldn't be worried, because he calls me for everything, he can call "maa" but cannot say other words, so I have developed love for the child, I do my best to take care of this particular child the most."(caregiver 1)*

Religious or spiritual confrontations

Africa and Ghana for that matter refer to religious or spiritual meanings to occurrences. That being so, lifelong illnesses like CP which sometimes come with the child from birth are given spiritual connotations. In this case, the participants family and friends believe that the participant's child had the disorder because of spiritual or religious reasons. She mentioned;

> *"It brings a lot of problems in my relationships. People tell me that my child was gotten from the river so I should go and leave it for the 'gods' but I don't listen to them and I tell them that God will not create an animal and put it in the womb of a human being, and I tell them that this is just due to illness."* (Caregiver 1)

Another respondent said;

> *"…when the illness started, we heard that people were saying that we have used him for money rituals because my husband had just built a house and roofed it prior to the onset of the child's illness…"*(Caregiver 4)

Respondent 10 also shared her experience by saying;

> *"Some told me she wasn't human; she was a snake and that I should go throw her away. Others told me to go see ritualists who could give me concoctions to bath her for her to die so I can be relived I but I told them I couldn't do that."* (Caregiver 10)

Ridicule

According to a respondent, ridicule is one of the stressful experiences one goes through while caring for a child with cerebral palsy. She reported that even though it is uncomfortable to hear the comments of ridicule, she is able to stay strong and keep caring for the child with CP. She quotes;

> *"People say a lot things, when I got pregnant after this particular child, people made fun of me and said I'm carrying a baby at my back and in my womb, but in all this I didn't give up and I'm still taking care of the child."(Caregiver 1)*

This respondent also faced some ridicule from people. She said;

> *"...there are times I hear people abusing my child and referring to him with words like "hey sick boy get out of here" and other words and I normally respond to them by saying 'So if someone is sick does that not make him a human'?'. Others also make mockery of me by comparing their children with my child."* (Caregiver 6)

Discrimination

Discrimination is an unfortunate experience which persons of marginalised groups go through. Normally because one may be different from the others in a population, they turn to be looked down on and side-lined. The caregivers of children living with CP have experienced it and report on it in the study. One respondent narrated;

> *"Because of the child I used to sell water, but because of the child people don't buy from me except the person is a visitor, but those who live in my vicinity do not buy me because I have*

> *given birth to 'sick' child. So, when I set up visitors are the ones who show me mercy and buy from me."* (Caregiver 1)

Another respondent's situation was quite the opposite. She mentioned that she did not experience any form of discrimination to the best of her knowledge. She said;

> *"…in my vicinity I don't have problem with my work, people by water from me, anyone who wants to buy buys from me, and I have good relationships with them, I have no problem on that…"*(Caregiver 3)

Reduced social life

For some people, one way to escape the distress of their problems is to have a good social life. With some caregivers of children living with CP, their social connections were reduced due to their relationship with their CP child. One participant said;

> *"Hmm... it's really a problem, apart from we meeting in the hospital for our meetings or going to church I don't really have any leisure. Even with church I was unable to go until the doctor Maier gave me a wheel chair which helps me send him to church. But at first, I arranged with my husband for one of us to stay home and take care of him because he is very heavy, so when he goes to church for two weeks, then I also go for two weeks."* (Caregiver 1)

Another respondent's concern was her social relationships regarding having a partner to live with. She reported;

> *"…So, to get time for child, or even for your own self you don't get time for yourself, for say an outing, like by this time I should have been living with a man, but no one comes. As soon as anyone sees you with this child, they begin to have a double mind about you, and they will be questioning themselves whether if they marry you, they will also give birth to such a child…Apart from that even if you meet someone (a man), the person may want you to visit, because once you begin to date someone you will have to go his house, but who will you leave this child for so you can go? So, all your time is for the child. So, to get time for yourself to just say you are going for an outing to have fun, you wouldn't get any time like that because even his feeding is a problem, brushing of his teeth and every other thing has to be done for him. Even if you want to teach him to do anything by himself is also difficult. So, you can't have time for yourself"* (Caregiver 2)

She added;

> *"So now my relationship is a problem, because if you don't make enough time for the person he leaves you, and even if you explain your situation to him, because he is human, once he requests that you do something for him and you cannot make time then he concludes that you are not serious then the relationship collapses."* (Caregiver 2)

Issues of mobility

Mobility of the CP child is an issue of concern for the caregiver because they are the ones who have to manage the child's movements to eat, bath, change clothes and go for doctors' appointments. Respondent 1 reported;

> *"…If he has to visit the toilet, I have to carry him onto a chamber pot every day. He sleeps well at night but cannot wake up to go and urinate so I have to buy pampers morning, afternoon and evening daily…* (Caregiver 1)

The respondent continued by pointing out that mobility is a main problem but she was relieved after getting some equipment. She narrated;

> *for now, what relieves my challenge is the wheel given to me by* Dr U.M *so I don't have to carry the child at my back. But now one thing that also worries me is that I'm unable to drive him in the wheel along the road so today I picked a car and came with him. I should have push the wheel along the road, but I'm unable to that due to the numerous cars passing through. I really like the wheel but it has somehow become a problem for me. It would have been easier if I was using the route through the Holy Family Nursing Training school, but when I began to use that route, they also said they wouldn't allow me to pass there again, so because of that I'm unable to put him in the wheel and bring him unless I board a car."(Caregiver 1)*

Another respondent also commented on mobility to the hospital. She said;

> *"In coming to the hospital, we have a wheel chair as a gift from a certain white man that I could have put him in, but with where I live you need to count about 10 houses before you get to the road side, and from the house to the road side is a rough road, so before you can be able to push the wheel to the road side and also get a taxi, is something I cannot do. So, I carry him at my back from the house to the road side, then I will hire a tricycle to bring him to the hospital. There was a time I fell ill, I had pneumonia and was admitted, and lost weight so I couldn't carry this child…So, for all the 6 months I was ill the child never came to the physiotherapy, he never visited the hospital, the father never brought him and the grandfather too cannot carry him because he is very heavy" (Caregiver 2)*

Summary of qualitative results

The qualitative findings explored the factors influencing psychological distress in caregivers of children living with cerebral palsy (CP). Financial difficulties emerged as a prevalent theme, with caregivers facing ongoing challenges related to the costs of meeting the needs of both themselves and their children with CP. Financial strain extended to healthcare expenses, such as special shoes and physiotherapy, leading to increased distress and, in some cases, adverse health effects for the caregivers.

Time constraints added another layer of stress, especially for those juggling caregiving responsibilities with employment or personal businesses. The amount of time required for daily tasks, coupled with the need for regular physiotherapy sessions, posed challenges for caregivers.

Early detection and intervention were highlighted as crucial factors in managing CP-related distress. Caregivers emphasized the importance of recognizing developmental issues early, seeking medical attention, and engaging in physiotherapy to mitigate the impact of the condition.

Access to information played a significant role in alleviating distress for caregivers. Those who received guidance from doctors, support groups, and NGOs reported feeling better equipped to handle the challenges associated with caring for a child with CP. The dissemination of accurate information also contributed to reducing societal misconceptions about CP.

The study identified various forms of psychological distress experienced by caregivers, including disorientation, worrying, sadness, fear, rejection, anger, and coping mechanisms. Coping mechanisms ranged from humour and avoidance to acceptance, faith or religion, and seeking support from professional advice, support groups, and family.

Caregivers reported nurtured love for their children with CP, but they also faced religious or spiritual confrontations, ridicule, discrimination, and a reduction in social life. Issues of mobility were a significant concern, with caregivers struggling to manage their children's movements, especially in challenging environments.

Overall, the findings underscore the multifaceted nature of psychological distress experienced by caregivers of children with CP and emphasize the importance of support networks, accurate information, and coping mechanisms in mitigating these challenges.

Quantitative Results

Table 3: Demographic information of Caregivers

	Frequency	Percent
Age of caregiver		
19-30	32	58.2
31-45	12	21.8
46-64	11	20.0
Educational background		
None	8	14.5
Basic school	26	47.3
Secondary School	18	32.7
Tertiary	3	5.5
What is your most recent occupation?		
Professional	1	1.8
Skilled worker	34	61.8
Unskilled worker	14	25.5
Unemployed	6	10.9
What is the size of your family?		
2 members	6	10.9
3-4 members	23	41.8
5-6 members	9	16.4
above 6 members	17	30.9
Age of child		
3-6	13	23.6
7-10	11	20.0
11-14	31	56.4
Do you have anyone who assist you all the time when caring for your child?		
Yes	14	25.5
No	41	74.5

Source: Field Survey (2023)

The findings, as shown in Table 3, demonstrate that 58.2% of caregivers are of ages ranging from 19-30, 47.3% of them have basic education, 61.8% are skilled workers, 41.8% have family size of 3-4, 56.4% of them have children of ages ranging from 11-14 and 74.5% of them do not have anyone assisting them in caring for their children.

H_1– The various dimensions of coping (avoidant, problem focused and emotion focused) will significantly predict the psychological distress levels among caregivers of children living with CP in Ghana.

Table 4: Multivariate regression analysis for relationship between the dimensions of coping and psychological distress

Dependent Variable	**Parameter**	***B***	***SE***	***t***	***p***	**η^2**
	Intercept	6.033	4.687	1.287	.204	.031
Stress	Avoidant coping	.275	.188	1.461	.150	.040
	Problem focused coping	-.051	.149	-.339	.736	.002
	Emotion focused coping	.001	.125	.012	.991	.000
	Intercept	-6.134	4.511	-1.360	.180	.035
Anxiety	Avoidant coping	.619	.181	3.414	.001	.186
	Problem focused coping	.331	.144	2.308	.025	.095
	Emotion focused coping	-.171	.121	-1.420	.162	.038
	Intercept	5.483	4.978	1.102	.276	.023
Depression	Avoidant coping	.477	.200	2.382	.021	.100
	Problem focused coping	-.317	.158	-1.999	.051	.073
	Emotion focused coping	.118	.133	.888	.379	.015

Source: Field Survey (2023)

The table above presents a multivariate regression analysis for relationship between the dimensions of coping and psychological distress. The analysis revealed that Avoidant coping (*B*=.275, *t*=1.461, *p*=.150), Problem focused coping (*B* =-.051, *t*= -.339, *p*= 736) and Emotion focused coping (*B*= .001, *t*=.012, *p*=.991) were not significant predictors of Stress. With respect to

Anxiety, Avoidant coping (*B*= .619, *t*=3.414, *p*=.001) and Problem focused coping (*B*= .331, *t*=2.308, *p*=.025) were significant predictors except Emotion focused coping (*B*= -.171, *t*=-1.420, *p*=.162). with regard to Depression, Avoidant coping (*B*= .477, *t*=2.382, *p*=.021) was a significant predictor, and Problem focused coping (*B*=-.317, *t*=-1.999, *p*=.051) was also a nearly significant predictor. However, Emotion focused coping **(***B*=.118, *t*=.888, *p*=.379) was not a significant predictor.

In summarising the results, it was discovered that anxiety was significantly predicted by both avoidant coping and problem-focused. However, only avoidant coping was found to predict depression. Consequently, the various aspects of psychological distress could not be predicted by all the dimensions.

H_2- The severity of disability of a child living with cerebral Palsy will influence the psychological distress levels of caregivers

Table 5: One-way Manova for influence of the severity of disability of child living with cerebral palsy on the psychological distress of caregivers

	A1	M	SD	N
Stress	No moderate impairment	5.50	4.03	12
	Moderate impairment	9.32	3.20	43
	Total	8.49	3.72	55
Anxiety	No moderate impairment	2.16	2.88	12
	Moderate impairment	4.97	4.06	43
	Total	4.36	3.98	55
Depression	No moderate impairment	5.08	3.82	12
	Moderate impairment	8.84	4.08	43
	Total	8.02	4.28	55

Source	Dependent Variable(DV)	SS	df	MS	F	Sig.	η^2
A1	Stress	137.304	1	137.304	11.921	.001	.184
	Anxiety	74.084	1	74.084	5.004	.030	.086
	Depression	132.205	1	132.205	8.140	.006	.133
Error	Stress	610.442	53	11.518			
	Anxiety	784.643	53	14.805			
	Depression	860.777	53	16.241			
Total	Stress	4713.000	55				
	Anxiety	1906.000	55				
	Depression	4529.000	55				
Corrected Total	Stress	747.745	54				
	Anxiety	858.727	54				
	Depression	992.982	54				

Source: Field Survey (2023) **A1=Does your child have difficulty in holding implements, dressing and sitting upright or need help to move around?**

The table above presents the results of One-way Manova which examined the influence of the severity of disability of child living with cerebral palsy on the psychological distress of caregivers. The results indicate that children with cerebral palsy who have moderate impairment (i.e., difficulty in holding implements, dressing and sitting upright or need help to move around) significantly influence the Stress levels (p=.001, η^2=.184), Anxiety levels (p=.030, η^2=.086) and Depression levels (p=.006, η^2=.133).

	A2	M	SD	N
Stress	No severe impairment	4.9091	3.96118	11
	Severe impairment	9.3864	3.10450	44
	Total	8.4909	3.72117	55
Anxiety	No severe impairment	1.0000	1.41421	11
	Severe impairment	5.2045	3.98590	44
	Total	4.3636	3.98778	55
Depression	No severe impairment	4.6364	3.38446	11
	Severe impairment	8.8636	4.09532	44
	Total	8.0182	4.28819	55

Source	DV	SS	df	MS	F	Sig.	η^2
A2	Stress	176.405	1	176.405	16.364	.000	.236
	Anxiety	155.568	1	155.568	11.726	.001	.181
	Depression	157.255	1	157.255	9.973	.003	.158
Error	Stress	571.341	53	10.780			
	Anxiety	703.159	53	13.267			
	Depression	835.727	53	15.768			
Total	Stress	4713.000	55				
	Anxiety	1906.000	55				
	Depression	4529.000	55				
Corrected Total	Stress	747.745	54				
	Anxiety	858.727	54				
	Depression	992.982	54				

Source: Field Survey (2023) **A2= Is your child unable to walk and/or without functional use of the hands?**

The table above presents the results of One-way Manova which examined the influence of the severity of disability of child with cerebral palsy on the psychological distress of caregivers. The results indicate that children living with cerebral palsy who have severe impairment (i.e., being unable to walk and/or without functional use of the hands) significantly influence the Stress levels (p<.001, η^2=.236), Anxiety levels (p=.001, η^2=.181) and Depression levels (p=.003, η^2=.158).

Overall, the analysis of the results indicates that the severity of disability of children living with cerebral palsy has a significant influence on the psychological distress levels of caregivers. In this instance those with moderate to severe disability influence psychological distress.

H_3 - The age of caregivers of children living with cerebral palsy will influence coping

Table 6: One-way Manova which examined the influence of the age of caregivers on their coping strategies

Measure	**Age of caregivers**								
	19-30		31-45		46-64				
	M	S.D	M	S.D	M	S.D	F	*P*	η^2
Avoidant Coping	13.59	2.68	12.58	3.37	12.45	2.62	.964	.388	.036
Problem Focused Coping	24.59	3.44	22.83	4.06	23.00	3.49	1.470	.239	.054
Emotion Focused Coping	31.62	5.06	34.17	3.51	32.81	3.12	1.483	.236	.054

Source: Field Survey (2023) **df=2,52**

The table above presents the results of the One-way Manova which examined the influence of the age of caregivers on their coping strategies. The findings showed that caregivers' ages did not significantly influence Avoidant coping. [*F* (2,52) =.964, *p*=.388], Problem Focused Coping [*F* (2,52) =.1.470, *p*=.239] and Emotion Focused Coping [*F* (2,52) =.1.483, *p*=.236]. Based on the results, there is evidence to suggest that the age of caregivers does not have a significant influence on their coping strategies.

Summary of quantitative results

In the first hypothesis, a multivariate regression analysis explored the relationship between coping dimensions and psychological distress. Avoidant coping and problem-focused coping were significant predictors of anxiety, while only avoidant coping predicted depression. However, emotion-focused coping did not significantly predict stress, anxiety, or depression. Overall, the dimensions of coping did not consistently predict psychological distress.

The second hypothesis utilised One-way Manova to investigate the impact of the severity of disability in children with cerebral palsy on caregiver distress. Children with moderate impairment significantly influenced stress, anxiety, and depression levels in caregivers. Similarly, those with severe impairment had a significant impact on psychological distress. The results collectively suggest that the severity of disability in children with cerebral palsy significantly influences the psychological distress of their caregivers.

Lastly, the third hypothesis also employed a One-way Manova to analyse the influence of caregiver age on coping strategies. The findings revealed that caregiver age did not significantly affect avoidant coping, problem-focused coping, or emotion-focused coping. In conclusion, caregiver age does not seem to have a notable impact on the coping strategies they employ.

Discussion of Results

This chapter presents the discussion of the results obtained from the study. The qualitative and quantitative findings have been simultaneously discussed in areas where they coincide. Other unique findings have also been explained in detail.

Demographic characteristics

This section of the results focused on the age of the caregivers, the age of the children living with Cerebral Palsy (CP), employment status, gender and educational level of the caregivers. These demographics are seen in other studies, to have influenced the lifestyle and coping styles of the caregivers of the children living with CP. In this study it was no different. The caregivers employed coping strategies to their various difficulties which suited their demographic distribution.

The findings of the study on this section revealed that all the participants who were interviewed were women, specifically mothers of the children living with cerebral palsy. This data supports the generally held belief that mothers often offer caregiving. Male caregivers also provide support, although the Bureau of Labour Statistics (2014) estimates that female caregivers may devote up to 50% more time to caregiving than male caregivers.

Also, the caregivers were either unemployed or engaged in menial jobs such as hawking to make a living to cater for themselves and their children. As expected, these female caregivers had very low educational backgrounds, with four of them attaining secondary school education and six of them having basic education or no education at all. Anjos et al. (2015) noted that the majority of caregivers in families with children who have such challenges are women. These caregivers are full-time and have little time for activities that would generate revenue. A longitudinal study by Fatudimu, Hannzat, and Akinyinka (2013) found that mothers accounted for 82.3% of the carers with caregiving roles for children with CP. The burden of child upbringing and the inability to find meaningful work because of time constraints are the main reasons why the carers also had poorer socioeconomic status and educational attainment, and this conclusion is similar with the findings of the aforementioned studies. However, Ghana has made progress in improving access to education and employment opportunities for empowerment in various sectors. The specific number of employed and educated Ghanaian women may vary over time due to factors such as population growth, economic conditions, and government policies. Regarding education, Ghana has made significant strides in achieving gender parity in primary and secondary education. According to data from the World Bank, in 2018, the gross enrolment rate for girls in primary education in Ghana was around 98%, indicating high levels of access to education for Ghanaian girls. However, it's important to note that educational attainment beyond primary and secondary levels may vary. Regarding employment, Ghanaian women are active in various sectors of the economy, including agriculture, industry, and services. However, women's participation in the formal labour force tends to be lower compared to men. According to the International Labour Organisation (ILO) data from 2019, the female labour force participation rate in Ghana was approximately 47.2%, while the male participation rate was around 70.7%.

Factors influencing psychological distress in caregivers of children living with CP

Aside the contribution of the demographic characteristics to the quality of life of the caregivers of children living with cerebral palsy, there were some main factors which were identified to have influenced the psychological distress of the caregivers. First, psychological distress for the caregivers is as a result of the fact that their children have a disability. According to Power *et al.* (2019), caregivers of children with cerebral palsy were at a higher risk of being psychologically distressed as compared to caregivers of children without disability. Likewise in this study, all the caregivers reported to have some amount of distress due to their child's condition. Other factors also contributed to the psychological distress of the caregivers. Among these factors was the problem of financial difficulty. Majority of the caregivers of the children submitted in their interviews that they had encountered financial problems in the process to take care of their children with cerebral palsy and themselves. This occurrence seemed to have stemmed from the low income or no income of the caregivers who were all mothers of the children living with cerebral palsy. Due to the responsibility of catering for their children, they are not able to find gainful employment to generate income and even if they do, they are not able to sustain it due to how much time goes into catering for their children. Financial assistance in the form of purchasing medication, house supplies and generally any tool or equipment that would make the caregiving process easier would go a long way to ease their distress but was unavailable. This assertion is supported by the study reviewed by Power *et al.* (2019). According to the authors, variables that further influenced psychological distress included being female, old age, lack of education, low income, housing impermanence, household crowding, lack of access to running water and sanitation systems. Simultaneously considering the results from the quantitative study which speaks to the influence of particularly the age of caregivers on their coping strategies, proved to have no influence on the psychological distress of the caregivers. The study arrived at this by conducting a one-way Manova test to examine the influence of the age of caregivers on their coping strategies. The findings showed that the age of carers had no discernible impact on problem-solving, emotion-focused, or avoidant coping strategies. The results of the present study indicate that the ages of the caregivers did not have a significant influence on the level of psychological distress they experienced. However, it is worth noting that these findings are not consistent with those of Power *et al.* (2019) and Pathak and Matthew (2017). The discrepancies in the results can potentially be attributed to the differences in the study populations. While the present study focused on caregivers, Power *et al.* (2019) examined children living with cerebral palsy. The age range of the carers engaged may be one explanation for the discrepancy in the results. The age range of the carers in the current investigation was over 11 years, whereas Pathak and Matthew (2017) used a 10-year age range. The discrepancy in age ranges might have contributed to the differing outcomes observed across the studies.

A correlating study by Pathak and Matthew (2017) which sought to investigate psychological distress and its correlates among caregivers of children with special needs such as mental illnesses in comparison with caregivers of children without special needs, found similar results as the qualitative aspect of the current study. Their study revealed that caregivers of children with special needs reported significantly higher levels of psychological distress as compared to the sample of general population of caregivers recruited for the study. Additionally, high positive correlations were also found between psychological distress and gender and marital status. Maridal *et al.* (2021) in their research on psychological distress and it's correlates among caregivers of children with neurodevelopmental disorders also revealed similar results, in that female caregivers, caregivers of children with higher degrees of disabilities, low governmental support, and low socioeconomic statuses were found to be high predictors of psychological distress. Their study however went ahead to investigate the distress levels of the socially supported and found that they had lower psychological distress in many cases. Zanon and Batista (2012), as reviewed in the literature found in their study that higher impairments, higher care giving demands and poor family structures, negatively influenced the caregiver’s stress levels and wellbeing as a whole. The quantitative results of this study indicated same as it showed that caregivers who had to deal with situations in which the children with cerebral palsy had moderate to severe symptoms, experience high psychological distress. To test this hypothesis in the quantitative section, a one-way Manova analysis was used to examine the influence of the severity of disability of children living with cerebral palsy on the psychological distress of caregivers. The results indicated that children living with cerebral palsy who have moderate impairment (i.e., difficulty in holding implements, dressing and sitting upright or need help to move around) significantly influence the Stress levels, Anxiety levels and Depression levels. Likewise severe impairment (i.e., being unable to walk and/or without functional use of the hands), it significantly influenced the Stress levels, Anxiety levels and Depression levels. Analysis of the results indicated that the severity of disability of children living with cerebral palsy has a significant influence on the psychological distress levels of caregivers. In explaining these results, it should be acknowledged that catering for children in general is stressful and therefore children with any form of disability such as cerebral palsy can come as a major challenge for the caregivers. The effort, time, financial support and emotional energy that is required of the caregivers is huge. If the effort from the caregivers falls short of the demands of the child's needs, psychological distress will set in. This therefore accounts for the high psychological distress levels in catering for children living with cerebral palsy with moderate to severe symptoms. Some of the research we looked at corroborate this claim. For instance, Werner (1987) discovered in his study that perceived caregiver influence and psychological distress were both significantly correlated with the degree of the child's motor handicap as determined by the Gross Motor Function Classification System. Some of this might be brought on by the added workload that comes with raising a child who is seriously disabled. Reduced workload interventions may be helpful in easing caregiver stress. Lack of mobility assistance and difficult roads can be a problem, which can cause both the impaired child and the caregiver to get very upset. Similarly, in the reviewed study by Maridal *et al.* (2021), there were high levels of psychological distress among caregivers of children with neurodevelopmental disorders. Largely, female caregivers of children with higher degrees of disabilities, low governmental support, and low socioeconomic statuses were found to be high predictors of psychological distress.

Focusing on the poor family structure of the caregivers, in this study, all the caregivers were the mothers of the children living with cerebral palsy and most of them did not have partners who lived with them to help with the children. Most of them lived in broken homes or failed marriages due to the condition of their children. This contributed to their high distress levels as seen in Zanon and Batista (2012).

Vadivelan (2020) made an assertion that enough attention is not paid to the burdens that these caregivers carry and thus in a way, accounts for a portion of their psychological distress. In the current study, the qualitative submissions of some participants indicated same. Going through the interviews with the caregivers and having them discuss their burdens and insecurities even without outright solutions, offered some form of relief to some of them, as their facial expressions depicted.

Another factor which influenced the level of psychological distress for the caregiver was the time of detection of the condition in the children and access to information on the condition. The caregivers who noticed changes in their children early enough and took them for diagnosis and treatment, reported that they were worried a little less and had help with managing their children than the caregivers who detected the condition much later. Early detection gave the caregivers access to information and help from the healthcare facilities. Information such as how to feed such children, the medications they needed and general psychological support from other caregivers and healthcare personnel reduced their psychological distress.

The forms of psychological distress of the caregivers included disorientation, fear, sadness, anger, worry and rejection. These emotional categorisations of the psychological distress the caregivers reported took different forms. With disorientation, the caregivers had no idea about what to do or how to manage their children. Those who experienced fear were afraid of what the future holds for them and their children and this fear built up as they got more information on the condition. Hodges and Humphris (2009) discovered in their study that clinical anxiety which is closely associated with fear was measured in a group of carers of patients with cancer. It was realised that the period of caregiving was positively correlated with higher levels of clinical anxiety. As seen in the current study, the caregivers entertained fear and a result of caring for their children with cerebral palsy. Also, in Berg's study (2009), similar results were seen. Among caregivers of stroke patients, depressive symptoms were reported. One emotional symptom which was not directly reported in the current study was the emotion of shame, disgrace or embarrassment. It was however reported in a Ghanaian study by Anum (2011). The results of the investigation into his work showed that groups of disabled children and adolescents, together with their caregivers, experience shame, put a strain on family ties, and likely require institutional assistance because of their experience with shame. Additionally, it was shown that this feeling of shame was one of the factors contributing to tensions inside and between families.

The model of carer stress and burden, according to Sörensen *et al.* (2006), which was one of the frameworks of this study, made mention of six different but integrating factors that affect or influence caregiver burnout or stress. The first elements of this model are the primary stressors. These stressors refer to elements in the caregiving setting that determines the nature and intensity of the caregiver's experience. Examples of these factors are the severity of the patient's illness, the intensity of functional or cognitive impairments, difficult behaviours and amount of time spent giving care. The results of this study depict the primary stressors in the theory. The time spent in caregiving and the intensity of the condition of the children living with cerebral palsy accounted for them. The theory however supports the submissions of the caregivers, identifying these stressors as primary. These primary stressors are termed as such because they are the initial source of the caregivers' psychological distress. Once they set in, they are bound to give rise to other stressors known as secondary stressors.

The secondary stressors which the theory refers to are described as the opportunity costs of the caregiver's burden or consequences that arise as a result of caregiving. These include little to no time for leisure, financial strain, less time for health-promoting activities like exercising and healthy eating, family conflicts, and little time for work. These secondary stressors act as mediators between the primary stressors and how the individual appraises the situation, such that, for example, when there is a lot of time spent giving care, there might be little time for leisure which may result in increased distress and negative effects on psychological wellbeing. The findings of this study support this, since several carers complained of being excluded from social events and having to put up with arguments over family and religion. Engaging in social activities such as dating, attending programs or church activities could be relaxing and psychologically positive for people. Once they are deprived of it due to situations like having to care for a sick or disabled person, psychological distress may set in. The results of this study proved it just as other reviewed studies.

Coping mechanisms

The coping strategies used by carers of children with cerebral palsy took different forms. According to the qualitative study, some caregivers used humour, avoidance or acceptance while others used religion, professional advice or professional support groups and family support as means to cope with the stress. The quantitative study also threw more light on coping strategies like avoidance and revealed other coping styles including problem-focused coping and emotion-focused coping. Some of the coping styles were maladaptive because they helped the caregivers escape their feelings of stress but prevented them from actually dealing and overcoming the psychological distress. One such coping style was avoidance. According to Allen and Myers (2019), avoidance which involves victims or patients actively deprive themselves of experiencing emotions or feelings mainly because they cannot help the situation. This is how the caregivers in this study explained their experience of avoidance.

Under the quantitative results of the study, the link between the various coping dimensions and psychological distress was looked at. Multivariate regression analysis was done to study this relationship between the dimensions of coping and psychological distress, in order to find out which coping strategies predicted psychological distress more in the caregivers. From the study, the dimensions of coping; problem focused, emotion focused and avoidant focused coping were observed. The analysis revealed that Avoidant coping, Problem focused coping and Emotion focused coping were not significant in predicting stress. With respect to Anxiety, Avoidant coping and Problem focused coping were significant predictors except Emotion focused coping**)**. With regards to Depression, Avoidant coping was a significant predictor, however, Problem focused coping and Emotion focused coping were not significant predictors. In summary, the findings of the study indicate that avoidant coping, which caregivers commonly engage in, strongly predicts both anxiety and depression. Additionally, problem-focused coping was found to be a significant predictor of anxiety. These results suggest that when caregivers adopt avoidant coping strategies, their levels of anxiety and depression tend to increase. Similarly, when caregivers employ problem-focused coping strategies, their anxiety levels also show an upward trend. Literal anxieties could be seen in how caregivers struggle with meeting the financial needs of themselves and the children and the fear of their children's condition worsening. Depression could be seen in how the caregivers hope for better recovery outcomes for their children yet are disappointed by how slow the recovery and treatment process are. In a concurring longitudinal study by Berg (2009) on depression as a form of psychological distress, found that among caregivers of stroke patients, caregiver depression at the acute phase was at a high level.

The other forms of coping styles such as religious beliefs, family support, professional advice or support groups and acceptance which showed a more positive outlook were used by some of the caregivers according to the qualitative study and were synonymous to some coping mechanisms discussed in other studies. For example, Tilahun *et al.* (2016) as reviewed, investigated the perspectives of caregivers living in low-income countries with children with developmental disorders. The coping mechanisms reported by caregivers included prayer and social interactions such as talking with health professionals, friends and family. These widely reported coping mechanisms were said to significantly impact the effects of their challenges. Caregivers relying on their religious beliefs such as prayer as a coping mechanism further agrees with Aflakseir and Mahdiyar (2016) who discovered that religious practises and beliefs can assist people deal with challenging circumstances, and again, Saad and de Medeiros (2012) also assert that individuals incorporating beliefs, attitudes, or practices related to spirituality and religion, can find meaning in their suffering, making it more manageable. The biopsychosocial (spiritual) model also used in this study, which takes a more holistic approach to human health and wellbeing aligns with the finding of religious beliefs as a coping mechanism from this study. The spiritual aspect of the model emphasises the existential and meaning-making aspects of caregiving where caregivers' spirituality can provide a source of strength, resilience, and coping strategies, and also help them find meaning in their experiences. Dekawaty *et al.* (2019) also revealed that family and social support, especially in meeting the needs of both the persons with disability and the caregivers, were reported to be available in which case, these caregivers were able to cope with their situation. According to Olawale (2013), there is need to educate the public on the causes of cerebral palsy and treatment options available to families to help the parents cope better. In this study, caregivers who had the opportunity to attend support group sessions and visit the hospital regularly for review sessions with health professionals reported that they were coping better. These meetings provided some sort of reassurance and encouragement for the caregivers and made them feel supported in a way. Some also mentioned that seeing another caregiver managing their child in a worse situation or sometimes a better situation than theirs, made them feel like they were not alone in their situation.

Personal Experiences of caregivers

The personal experiences in caring for children living with cerebral palsy were captured in the qualitative study as it afforded the opportunity, unlike the quantitative study. Their responses were analysed and presented as well. According to Hamzat and Mordi (2007), caring for a child with CP comes with a load that is more than three times as great as caring for a healthy child. Caregiver load refers to the ongoing maintenance tasks for children with CP. This involves the time and effort mothers devote to caring for their children physically and emotionally. Given that a child with CP becomes incapacitated and needs all the support possible, it is understandable that caring for these children entails a heavy responsibility. Carers are burdened more because of the social disregard, money constraints, psychological trauma and physical health problems that are associated with it.

A large proportion of individuals playing the caregiving role for children with cerebral palsy (87%) are often unpaid, informal caregivers with very little to no expertise. The high amount of responsibility placed on the caregiver of the child with CP is exacerbated by the caregiver's lack of understanding of cerebral palsy and their financial challenges (Williamson & Shaffer, 2001). Additionally, the person providing care feels guilty for placing the child with CP in an institution and suffers from social isolation, all of which contribute to the high load on caregivers. Similar assertions are seen in this study as the caregivers’ reported feelings of being burdened and stressed over their children living with CP. Aside the challenges they reported financial problems, severity of their children’s condition and so on, some of the caregivers reported their experiences at random, which the study took note of.

Among these experiences were that of some caregivers feeling discriminated against because of their children’s condition. Discrimination is an unfortunate experience which persons of marginalised groups go through, because they may be different from the others in a population. According to Mbamba, Yeboah and Ndemole (2022), Due to stigmatization, social exclusion, discrimination, and financial stress, single moms in Ghana who care for children with autism spectrum disorder (ASD) face emotional and material problems. Their ability to effectively care for and protect the welfare of the autistic children is hampered as a result.

Another experience worth reporting on was the issue of mobility for the children with cerebral palsy. Results showed that it was a major concern for the caregivers as ease in that area, reduced their concern for how to go for hospital visits, how to attend social gatherings like church and how to generally manage their children at home. Power *et al.* (2019) in their study's findings showed that most caregivers of children with cerebral palsy did not have access to wheel chairs and walking frames and other devices to aid movement. Mothers who were mostly caregivers, were also found to be more involved in caring for the child and moving them around. Werner (1987) also adds on by saying that lack of mobility aids, often combined with inaccessible roads, can be a challenge resulting in both the disabled child and the caregiver becoming significantly distressed. Likewise, the caregivers interviewed in this study reported lack of accessible roads and movement equipment, made it difficult to manage the children with cerebral palsy.

Final Conceptual Model based on the findings of this study

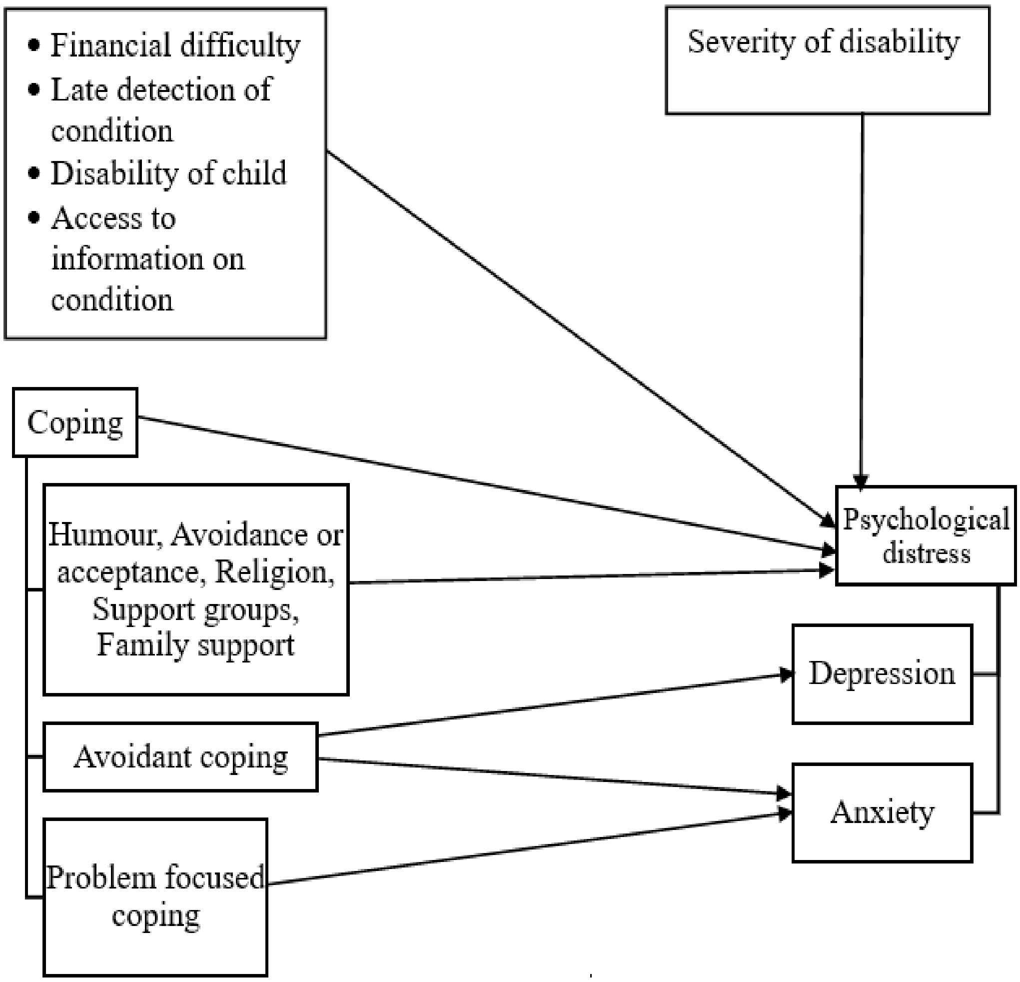

Figure 5: Final Conceptual Model

Figure 5 illustrates the key factors that contribute to psychological distress among caregivers. The qualitative findings reveal that financial difficulties, late detection of the condition, disability of the child, and access to information on the condition are significant issues leading to psychological distress among caregivers. In contrast, coping mechanisms, such as humour, avoidance or acceptance, religious beliefs, support groups, and family support, play a crucial role in alleviating psychological distress among these caregivers.

On the other hand, the quantitative findings indicate that coping strategies, including avoidant coping and problem-focused coping, have a direct impact on psychological distress. Additionally, psychological distress that carers face is influenced by the severity of the disability.

CHAPTER FIVE

SUMMARY, CONCLUSIONS AND RECOMMENDATIONS

This chapter discusses the summary of the study, along with the implications, limitations and recommendations for further research and practice.

Summary of Major Findings

From the results of the study, it was established that psychological distress for these caregivers stems from the fact that they cater for children living with the challenge of cerebral palsy. Also, the unavailability of certain systems in both the homes and institutions which are supposed to provide help for these caregivers add up to some of the psychological distress. The children's disability from cerebral palsy was the primary influence on the relationship, however other elements including money, education, and social support may have also had a role. In many such situations, the family or caregivers of children with cerebral palsy eventually adjust to the demanding task of having to cater to the children with cerebral palsy and thus adopt mechanisms to cope with their difficulties. These coping strategies are usually strategies adopted by caregivers to decrease or moderate the levels of impact of stress and negative emotions involved with caring for a child with cerebral palsy.

Conclusions

Many studies in this area generally focus on the health of the children living with cerebral palsy and the implications on their psychological wellbeing. Little attention is given to the caregivers and how they cope with the psychological distress that arise from catering for such children. It is an important area because the psychological wellbeing of the caregivers serves implications to the wellbeing of the children living with cerebral palsy. The study basically showed that the caregivers experience some amount of psychological distress in the form of depression, stress and anxiety and as a result, employ some coping strategies to manage the distress. The coping strategies could be positive or negative which then calls for professional help from health care services as well as clinical health psychologists. Recommendations have been suggested as well as guidelines for further studies.

Implications of the study

Numerous areas of concern were raised by the study's findings. The information gathered have implications for different stakeholders, including the caregivers, the government of Ghana and Health facilities.

Caregivers

The skills and information needed to care for children with cerebral palsy must be available to caregivers. Health organizations and other disability-focused groups in Ghana can develop educational programs that allow caregivers and children with cerebral palsy to participate and learn new coping and independent living skills in order to realize this goal. Informal carers must become knowledgeable about cerebral palsy, managing stress, coping with depression and anxiety and developing proper caregiving techniques. They also have to commit themselves to a support group and attend meetings and check-ups regularly to support themselves.

Government of Ghana

The government of every country has the responsibility of being concerned with the welfare of its citizens, especially the marginalised groups. Caregivers of conditions like cerebral palsy count as part of the marginalised groups in Ghana and must therefore be given some special attention. Even though resources may be limited, effort such as providing free space for the caregivers to meet regularly, providing subsidy on some health services and supporting health facilities to serve the children living with cerebral palsy and the caregivers better, should be made possible.

Recommendations

Based on the findings and conclusions drawn from the study, the following recommendations are made:

- The Ministry of Health and healthcare facilities should collaborate with healthcare providers and state insurances to establish clear guidelines enabling ongoing physiotherapy sessions for children with cerebral palsy, ensuring that caregivers are not financially burdened. Additionally, they should mandate annual health evaluations for caregivers of children with cerebral palsy, accessible through government institutions. It is essential to incorporate professionals like psychologists into social support groups within medical facilities to effectively address caregiver psychological distress.
- Health professionals need to provide tailored individual counseling, parenting therapy, and supportive programs for families and caregivers of children with cerebral palsy. They should be well-informed about the significant stress, anxiety, and depression experienced by

caregivers in order to offer empathetic support during hospital visits. Furthermore, support groups at healthcare facilities should be strengthened by involving clinical psychologists and social services to provide comprehensive assistance.

- Researchers should evaluate the implementation and effectiveness of these recommended changes. They should also investigate caregivers' needs, satisfaction with therapy, barriers to accessing specialist services, and support networks. Further research should explore the relationship between coping mechanisms and psychological distress in caregivers of children with cerebral palsy to better inform future interventions and support strategies.

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APPENDICES

APPENDIX A: QUESTIONNAIRE FOR CAREGIVERS

UNIVERSITY OF CAPE COAST

COLLEGE OF EDUCATION STUDIES

FACULTY OF EDUCATIONAL FOUNDATIONS

DEPARTMENT OF EDUCATION AND PSYHCOLOGY

DATA COLLECTION INSTRUMENT

Dear Participant,

I'm Desmond Joe Kyeremeh, from the above-mentioned Institution, offering M.Phil. Clinical Health Psychology. This questionnaire seeks to collect data on the psychological distress levels among caregivers of children living with cerebral palsy as well as the coping mechanisms that they employ. Please, the questionnaire is comprised of three sections: Sections A, B and C. Kindly respond to all the questions. Taking part in this study is however voluntary. Please tick (√) the space or circle the number that corresponds to your answer.

Thank you

SECTION A

DEMOGRAPHIC INFORMATION

Please respond to all the following questions by either ticking or filling in the spaces provided

1. Age ….
2. What is the age of your child?
3. Educational background

   None [ ] Basic School [ ] Secondary School [ ] Tertiary [ ]
4. What is your most recent occupation?

   Professional [ ] skilled worker[ ] unskilled worker[ ] Unemployed[ ]

5. What is the size of your family?

   Above 6 members [ ] 5 – 6 members[ ] 4 – 3members[ ] 2 members [ ]

6. How long have you performed this role as a caregiver for a child with C.P? ……………………………

7. Does your child have difficulty in holding implements, dressing and sitting upright or need help to move around? Yes [ ] No [ ]

8. Is your child unable to walk and/or without functional use of the hands? Yes [ ] No [ ]

9. Do you have anyone who assist you all the time when caring for your child?

   Yes [ ] No [ ]

SECTION B: DASS 21

Please read each statement and circle a number 0, 1, 2 or 3 which indicates how much the 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 is as follows:

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 time
3 Applied to me very much or most of the time

	Rating			
	0	1	2	3
I found it hard to wind down				
I was aware of dryness of my mouth				
I couldn’t seem to experience any positive feeling at all				
I experienced breathing difficulty				
I found it difficult to work up the initiative to do things				
I tended to over-react to situations				
I experienced trembling				
I felt that I was using a lot of nervous energy				
I was worried about situations in which I might panic and make a fool of myself				

I felt that I had nothing to look forward to				
I found myself getting agitated				
I found it difficult to relax				
I felt down-hearted and blue				
I was intolerant of anything that kept me from getting on with what I was doing				
I felt I was close to panic				
I was unable to become enthusiastic about anything				
I felt I wasn't worth much as a person				
I felt that I was rather touchy				
I was aware of the action of my heart in the absence of physical exertion				
I felt scared without any good reason				
I felt that life was meaningless				

SECTION C: Brief-COPE

Instructions:

The following questions ask how you have sought to cope with a hardship in your life. Read the statements and indicate how much you have been using each coping style

Note: 1= I haven't been doing this at all, 2= A little bit, 3= A medium amount and 4= I've been doing this a lot

Statements	Rating			
	1	2	3	4
I've been turning to work or other activities to take my mind off things.				
I've been concentrating my efforts on doing something about the situation I'm in				
I've been saying to myself "this isn't real".				
I've been using alcohol or other drugs to make myself feel better				
I've been getting emotional support from others.				
I've been giving up trying to deal with it.				
I've been taking action to try to make the situation better.				
I've been refusing to believe that it has happened.				
I've been saying things to let my unpleasant feelings escape.				
I've been getting help and advice from other people.				
I've been using alcohol or other drugs to help me get through it.				
I've been trying to see it in a different light, to make it seem more positive.				
I've been criticizing myself.				
I've been trying to come up with a strategy about what to do.				
I've been getting comfort and understanding from someone.				
I've been giving up the attempt to cope.				

I've been looking for something good in what is happening.				
I've been making jokes about it.				
I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.				
I've been accepting the reality of the fact that it has happened.				
I've been expressing my negative feelings.				
I've been trying to find comfort in my religion or spiritual beliefs.				
I’ve been trying to get advice or help from other people about what				
I've been learning to live with it.				
I've been thinking hard about what steps to take.				
I’ve been blaming myself for things that happened				
I've been praying or meditating				
I've been making fun of the situation.				

APPENDIX B: INTERVIEW GUIDE FOR CAREGIVERS

SECTION ONE

DEMOGRAPHIC INFORMATION

Please respond to all the following questions by either ticking or filling in the spaces provided

1. Age ..…
2. What is the age of your child?
3. Educational background

   None [ ] Basic School [ ] Secondary School [ ] Tertiary [ ]
4. What is your most recent occupation?

   Professional [ ] skilled worker[ ] unskilled worker[ ] Unemployed[ ]
5. What is the size of your family?

   Above 6 members [ ] 5 – 6 members[ ] 4 – 3 members[ ] 2 members [ ]
6. How long have you performed this role as a caregiver for a child with C.P? ……………………………
7. Does your child have difficulty in holding implements, dressing and sitting upright or need help to move around? Yes [ ] No [ ]
8. Is your child unable to walk and/or without functional use of the hands? Yes [ ] No [ ]
9. Do you have anyone who assist you all the time when caring for your child?

   Yes [ ] No [ ]

SECTION TWO

INTERVIEW QUESTIONS ON CAREGIVING OF CHILDREN LIVING WITH C.P

10. How did you feel when you were pregnant with your child?

a. what were your expectations towards delivery and child’s growth?

11. What did you notice that made you bring your child to the hospital?
12. How did you feel when the doctors diagnose your child with C.P (Anger, sad, fear. Disappointed, denial)?
13. What do you personally know about CP? (General information, perception)
14. How do you get information about CP (health worker, media, social support groups)?
15. Please describe your experiences as a caregiver for a child with CP regarding

a. daily activities

b. relationship with others

c. work

d. leisure

e. during hospital visits

f. finances

i. Please describe a typical day of caregiving for a child with CP

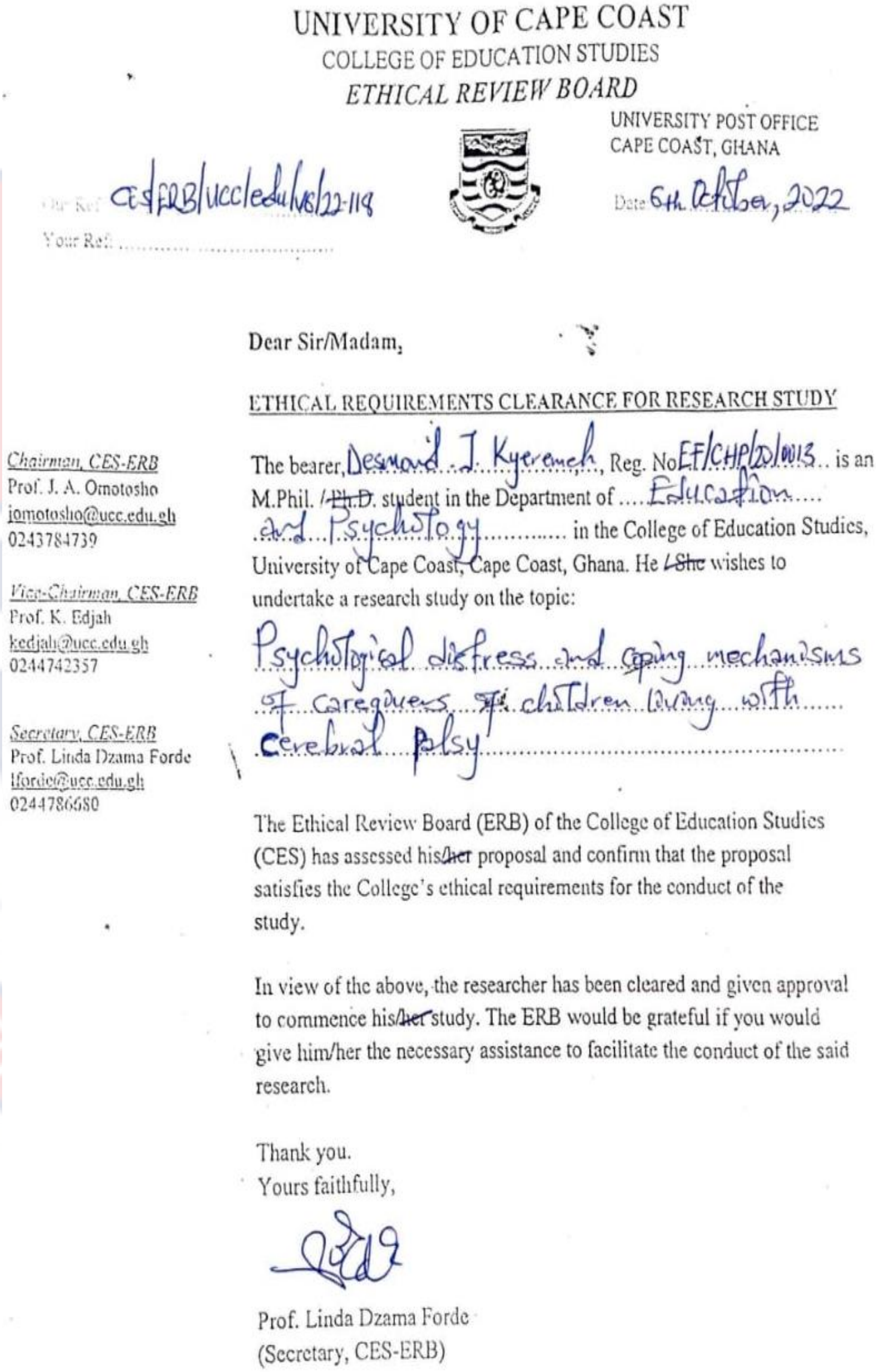
ii. How do you manage?

16. What are your challenges as a caregiver of a child with C.P, in managing your

- Daily activities
- Relationship with others (stigma)
- work,
- social life
- movement

17. How do you deal with the challenges? (Spiritually, family, social support, resilience, network group support)
18. How does those activities make you feel about your situation now?

APPENDIX C: ETHICAL CLEARANCE



UNIVERSITY OF CAPE COAST
COLLEGE OF EDUCATION STUDIES
ETHICAL REVIEW BOARD

UNIVERSITY POST OFFICE
CAPE COAST, GHANA

Our Ref: CES/ERB/ucc.edu/v6/22-118

Your Ref: ....

Date: 6th October, 2022

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Dear Sir/Madam,

ETHICAL REQUIREMENTS CLEARANCE FOR RESEARCH STUDY

The bearer, Desmond J. Kyeremeh, Reg. No EF/CHP/20/0013 is an M.Phil. /~~Ph.D.~~ student in the Department of Education and Psychology in the College of Education Studies, University of Cape Coast, Cape Coast, Ghana. He ~~/She~~ wishes to undertake a research study on the topic:

Psychological distress and coping mechanisms of caregivers of children living with cerebral palsy

The Ethical Review Board (ERB) of the College of Education Studies (CES) has assessed his~~/her~~ proposal and confirm that the proposal satisfies the College's ethical requirements for the conduct of the study.

In view of the above, the researcher has been cleared and given approval to commence his~~/her~~ study. The ERB would be grateful if you would give him/her the necessary assistance to facilitate the conduct of the said research.

Thank you.
Yours faithfully,

Prof. Linda Dzama Forde
(Secretary, CES-ERB)