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QUALITY OF LIFE OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY AT HEARTS, HANDS AND VOICE FOUNDATION, WINNEBA

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QUALITY OF LIFE OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY AT HEARTS, HANDS AND VOICE FOUNDATION, WINNEBA

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DECLARATION

Candidate's Declaration

I, Grace Baidoo, declare that this thesis, with exception of quotations and references contained in published works, which have been identified and duly acknowledged, is entirely my own work.

Signature………………………….

Date……………………………….

Supervisor's Declaration

I, Dr. Awini Adam, hereby declare that the preparation and presentation of this work was supervised in accordance with the guideline for supervision of thesis as laid down by the University of Education, Winneba.

Signature……………………………

Date…………………………………

DEDICATION

This is dedicated to the CEO Ms. Stella Kofie and team at Hearts, Hands and Voice Foundation for the inspiration.

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ABSTRACT

This qualitative study aimed at the quality of life of caregivers of children with cerebral palsy. This research involved engaging in semi structured interview with caregivers of children with cerebral palsy who shared their personal experiences, concerns and perspectives on their quality of life. Through thematic analysis, common themes emerged, shedding light on the four domains of these caregivers' quality of life. Physical health status, psychological well being, social relationships and environmental experiences of caregivers' of children with cerebral palsy. Physical strain under the physical well being and chronic pain were frequently mentioned, leading to fatigue and limitations in participating in daily activities. Emotional well-being was significantly impacted, with caregivers expressing feelings of stress, anxiety, and isolation. The demands of caring for a child with cerebral palsy, coupled with societal stigma and limited social support, contributed to these emotional struggles. Financial difficulties were also evident, with caregivers often living in precarious financial situations and struggling to meet the needs of their children. Access to adequate healthcare and specialized services for their child was a common concern, with some caregivers relying on foundations and support organizations for assistance and information. Support networks, such as Hearts, Hands and Voice Foundation, Ghana Federation of Disabilities, and local community groups, played a vital role in providing information, training, and social support to the caregivers. These resources helped caregivers acquire knowledge, connect with others in similar situations, and receive assistance in their caregiving responsibilities. The findings of this study contribute to the understanding of the quality of life of caregivers of children with cerebral palsy. The research highlights the need for increased awareness and support for caregivers, including access to comprehensive healthcare services, financial assistance, and social support programme. The recommendations derived from this study can inform the development of interventions aimed at improving the quality of life of caregivers of children with cerebral palsy.

CHAPTER ONE

INTRODUCTION

1.0 Background of the Study

Cerebral palsy (CP) is a chronic neurodevelopmental disorder that affects movement and posture, and it is the most common cause of motor disability in children worldwide (Novak et al., 2012). Children with CP require long-term care and management, which places a significant burden on their caregivers. Caregivers of children with CP are often responsible for providing round-the-clock care, which can lead to physical and emotional exhaustion, financial strain, and social isolation (Morris et al., 2019). This can affect caregivers overall quality of life. The presence of a disability in a child often leads to emotional stress, anxiety, and dynamics of family life for caregivers (Dale et al., 2006). Providing the needed care for a child with cerebral palsy requires additional skills, knowledge, and expenses, with the potential to impact caregivers' physical and psychological well-being.

A caregiver is someone who provides physical, emotional, or practical support to individuals who are unable to fully care for themselves due to illness, disability, or age-related limitations. Caregivers can include parents, family members, friends, or professional caregivers who offer a range of services, including personal care, medical assistance, companionship, and household tasks. The term "caregiver" emphasizes the nurturing and supportive role involved in providing care (Given et al., 2016). Caregivers devote significant energy and time to attending to children with special needs, sometimes neglecting their own quality of life. Understanding and addressing the physical, social, environmental and emotional toll of caregiving are essential in improving their overall quality of life.

The World Health Organization (WHO) defines quality of life as an individual's perception of their position in life, considering cultural and value systems, as well as their goals, expectations, standards, and concerns (World Health Organization, 1997). It is a complex concept influenced by physical health, psychological state, level of independence, social relationships, personal beliefs, and the environment. For caregivers of children with cerebral palsy (CP), assessing their quality of life requires considering four major domains outlined by the WHO: physical health, psychological well-being, social relationships, and environment. These domains provide a comprehensive understanding of caregivers' experiences and can inform interventions and support services to improve their quality of life.

Hearts, Hands, and Voice Foundation (HHVF) is a community-based organization located in Winneba, Central Region. The foundation has been actively involved in providing services for children with developmental challenges such as Autism, Cerebral Palsy, Down Syndrome, Intellectual Disabilities, and Hyperactivity Disorder. For the past six years, HHVF has been dedicated to offering a range of comprehensive programme and support to enhance the quality of life for these children and their families. The Foundation services include a Day Programme that operates from 8am to 5pm on weekdays, providing a structured and nurturing environment for the children. Additionally, HHVF conducts Home Visitations to reach out to families who may face difficulties in accessing the centre. The organisation also engages in Referrals, ensuring that children receive appropriate specialized care from other healthcare professionals when necessary. Advocacy Programme are an integral part of HHVF's efforts, as they aim to raise awareness about developmental challenges and promote inclusive within the community. Moreover, HHVF organises Training Programme and workshops to enhance the knowledge and skills of caregivers, professionals, and community members involved in the care and support of children with developmental challenges. Parent Support Groups play a crucial role in the Foundation's work, providing a platform for caregivers to connect, share experiences, and receive emotional support.

Caregivers of children with cerebral palsy at the Hearts, Hands, and Voice Foundation often face and complains about their challenges related to excessive pain, disrupted sleep, fatigue, impacting their physical health well-being. Observations at the Foundation's Day Programme also indicate a low physical health status among regular caregivers due to pains and discomfort in their joints, less energy for the morning routine, rubbing of balms or ointment on their body for relief. This research aims to explore the quality of life among these caregivers and identify specific factors influencing their well-being. By gaining insights into their experiences and perceptions, targeted interventions and support services can be developed to improve their overall quality of life. Understanding and addressing the physical health challenges faced by caregivers are essential for enhancing their ability to provide effective care to their children with cerebral palsy.

Being a caregiver for a child with cerebral palsy can profoundly impact caregivers' psychological well-being. The constant demands and emotional stress associated with raising a child with cerebral palsy significantly affect their mental health and overall quality of life. At the Hearts, Hands, and Voice Foundation, I have observed anxious behaviors and tearful expressions during counselling sessions among caregivers. Many struggle with accepting their children's condition, feeling emotional trauma when comparing them to others without disabilities. Discrimination, isolation, and societal beliefs further contribute to their psychological distress. Caregivers of children with cerebral palsy may face psychological challenges, including anxiety and depression, as they navigate the limitations of their child's condition. Understanding caregivers' psychological well-being and its impact on their quality of life is crucial for developing targeted interventions and support services. The emotional burden of caregiving can lead to increased stress, anxiety, depression, and decreased life satisfaction. Investigating caregivers' psychological well-being is essential to understanding the specific factors influencing their mental health. By exploring their experiences and emotions, we can gain deeper insights into the challenges they face and inform the development of interventions to address caregivers' specific needs, ultimately improving their quality of life well-being.

Having and Ccaring for a child with cerebral palsy significantly impacts caregivers' social well-being. The demanding nature of caregiving responsibilities leads to changes in social interactions and reduced support, often resulting in isolation. Prevailing beliefs in their communities further contribute to their isolation, with caregivers experiencing low self-esteem due to negative perceptions of their children with cerebral palsy. Many caregivers complain of having lost personal relationships with family and friends after giving birth to children with cerebral palsy. Social well-being plays a crucial role in a caregiver's overall quality of life, affecting their mental health and well-being (Bartlett & Palisano, 2002). However, the challenges of caregiving can disrupt social connections and lead to increased social isolation. Investigating the social well-being of caregivers at the Hearts, Hands, and Voice Foundation is essential to understanding the specific experience and the impact on quality of life.

The caregiving experience for children with cerebral palsy is influenced not only by individual and familial factors but also by the environmental context in which caregivers operate. The physical, social, and cultural environment significantly affects caregivers' quality of life. Understanding their environmental experiences and their impact on overall well-being is essential for developing targeted interventions and support systems. Through home visitations by the Hearts, Hands, and Voice Foundation, it has been observed that some caregivers live in remote areas with limited access to essential services, facing challenges like inadequate infrastructure and attitudinal barriers from their communities. These challenges lead to social isolation and poor living environments, impacting caregivers' well-being and ability to provide care. Difficulties accessing healthcare services and meeting their children's needs due to financial constraints further affect caregivers' quality of life and their caregiving capabilities. This study aims to assess the environmental experiences of caregivers at the Foundation and the influence on quality of life.

The Integrative Quality of Life (IQOL) theory by Ventegodt et al. (2003), serves as a theoretical framework for assessing the quality of life of caregivers of children with cerebral palsy (CP). This theory offers a holistic approach, considering caregivers' physical, psychological, social, and environmental well-being. By utilizing the IQOL framework, interventions and support services can be tailored to address the unique needs and challenges faced by caregivers, ultimately enhancing their overall well-being and quality of life.

1.1 Statement of the Problem

I have worked and served caregivers of children with cerebral palsy at Hands, and Voice Foundation in Winneba for over six years. This experience has provided me with a broader understanding of working with children with cerebral palsy and their caregivers. Throughout this period, caregivers have been the primary advocates for their children with CP, and they have expressed various concerns about their own lives and their children's conditions. During my work, I have encountered caregivers who often complain about experiencing physical pain, sleeplessness, and low self-esteem. Caregivers of children with cerebral palsy, have expressed worries about attitudinal barriers such as stigma and exclusion. These challenges have resulted in increased levels of stress, depression, isolation, and emotional trauma for the caregivers. Additionally, I have observed that caregivers sometimes face a lack of social support from their own families, spouses, and friends, leaving them feeling alone and lacking in social relationships. My experience has provided me with firsthand knowledge of the concerns and difficulties faced by caregivers of children with cerebral palsy. Given the complexity of these concerns and their potential implications, there is a need to comprehensively assess the overall quality of life of caregivers of children with cerebral palsy. This study aims to gain a holistic understanding of their well-being and specific needs, in order to inform targeted interventions and support systems that can enhance the caregivers' overall quality of life."

1.2 Purpose of the study

The purpose of the study is to assess the quality of life of caregivers of children with Cerebral Palsy at Hearts, Hands and Voice Foundation, Winneba.

1.3 Objectives of the Study

The study specifically sought to;

1. Explore the physical wellbeing of caregivers of children with CP at Hearts, Hands and Voice Foundation.
2. Find out the psychological wellbeing of caregivers of children with CP at Hearts, Hands and Voice Foundation.
3. Explore the social experiences of caregivers of children with CP at Hearts, Hands and Voice Foundation.

4. Explore the environmental experiences of caregivers of children with CP at Hearts, Hands and Voice Foundation.

1.4 Research Question

The following research questions were raised from the objectives:

1. What opinion do caregivers of children with CP have about their physical health at Hearts, Hands and Voice Foundation?
2. What opinions do caregivers of children with CP have about their psychological wellbeing at Hearts, Hands and Voice Foundation?
3. What are the social experiences of caregivers of children with CP and their relation with people at Hearts, Hands and Voice Foundation?
4. What are the environmental experiences of caregivers of children with CP and their relation with people at Hearts, Hands and Voice Foundation?

1.5 Significance of the Study:

The results of the study would provide recognition of the various physical, psychological, social, and environmental impact of caregiving of children with cerebral palsy on the caregivers' quality of life enhancing their understanding of the specific needs and challenges. By focusing on the quality of life (QoL) of caregivers, service providers can offer tailored guidance and support to improve the care and overall well-being of caregivers' of children with cerebral palsy. Based on the findings, recommendations would be provided to assist caregivers in their daily activities and enhance their QoL. The study's results would contribute to the existing resources on the quality of life of caregivers of children with cerebral palsy, serving as a valuable reference for future researchers in the field.

1.6 Delimitations

In addition, the scope of the study covered only caregivers of children with cerebral palsy who regularly attend at HHVF Day-Program in a coastal environment, Winneba. The study was delimited to the four variables of WHO individual Quality of life.

1.7 Limitation of the Study

There were difficulties in scheduling interview appointment with many caregivers at their home due to the researcher work schedules. The researcher overcame this challenge by scheduling for meeting on Saturdays and Sundays after 2pm to have more and free time with the caregiver without interruptions. This delayed the data collection period. Despite these limitations, the outcome of the study was not significantly affected.

1.8 Operational Definitions

Cerebral palsy (CP) - is a set of neurological conditions that affects muscle movement and coordination. Symptoms may include poor coordination, stiff muscle, weak muscle and tremor.

Quality of Life (QoL) is defined as the individual's perception of their position in life in the context of their culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns

Caregiver: in this context, it the immediate person who provides direct care to the child with CP to ensure wellbeing.

HHVF: Hearts, Hands and Voice Foundation, a community Based non for profit organization in Winneba that provide services for children with developmental challenges and their families.

CHAPTER TWO

LITERATURE REVIEW

This chapter presents review of a related literature on the assessing quality of life (QOL) of caregivers of children with cerebral palsy (CP) at Hearts, Hands and Voice Foundation, Winneba. The literature reviewed also included research articles, journals, and books. The literature reviewed also empirical studies and a theoretical framework supporting the main issues addressed in this study. Areas discussed were: Theoretical framework, that's the theory guiding the study, the physical health status of caregivers of children with CP with minor themes including: Caregivers of children with CP experience of pain and discomfort, Caregivers experience of energy and fatigue, Caregivers experience of sleep and rest and Caregivers experience of medical treatment.

The second area discussed is the psychological wellbeing of caregivers of children with CP with minor themes including Caregivers of children with CP experience of positive feeling, Caregivers experience of negative feeling, Caregivers experience of self esteem, Caregivers experience of body image, Caregivers experience of thinking, learning, memory and concentration. The third area is social experience of caregivers of children with CP. Minor themes includes Caregivers of children with CP experience of personal relationship, Caregivers experience of social support, Caregivers experience of sexual activity. The final area is environmental experience of caregivers of children with CP focusing on Caregivers of children with CP experience of their physical environment, Caregivers experience of financial resources, Caregivers experience of social care: availability and quality, Caregivers experience of new information & skills and Caregivers experience of activity participation.

2.1 Theoretical framework

Integrative Quality of Life Theory.

The Integrative Quality of Life (IQOL) theory Ventegodt et al., (2003), serve as a theoretical framework for assessing the quality of life of caregivers of children with cerebral palsy (CP). The IQOL theory provides a comprehensive and multidimensional perspective on quality of life, considering various domains and factors that contribute to individuals' overall well-being. The IQOL theory posits that quality of life is influenced a comprehensive framework that considers multiple dimensions and subjective experiences of quality of life and it encompasses physical, psychological, social, and environmental dimensions. This aligns with the aim of assessing the quality of life of caregivers of children with CP across these domains. By adopting the IQOL theory as a theoretical framework, the assessment can capture subjectively the physical health, psychological well-being, social relationships, and environmental factors that impact the caregivers' quality of life. It recognizes the interplay between these different domains and how they collectively contribute to caregivers' overall well-being. The IQOL theory also emphasizes the subjective experience of quality of life, taking into account individuals' perceptions, goals, expectations, and concerns. This aligns with the qualitative approach, which aims to uncover caregivers' unique insights, experiences, and challenges. By incorporating the subjective aspects of quality of life, the assessment can provide a more nuanced understanding of caregivers' experiences, inform targeted interventions, and support services. Additionally, the IQOL theory recognizes the dynamic nature of quality of life, acknowledging that it can change over time due to various factors and life circumstances. This is relevant for caregivers of children with CP, as their caregiving responsibilities and the child's condition may evolve over time. The assessment can consider these dynamic factors and capture the potential changes in caregivers' quality of life. This can serve as a theoretical foundation for assessing the quality of life of caregivers of children with CP, enabling a holistic understanding of their well-being and informing tailored interventions and support services.

Physical Health Status of Caregivers with CP

Caring for a child with cerebral palsy can significantly impact the health-related quality of life (QoL) of primary caregivers, particularly in terms of their physical health.

This section of the literature review examines studies that have investigated the physical health status of caregivers of children with cerebral palsy, highlighting the adverse effects and comparing them to caregivers of children without disabilities. Gallagher and Whiteley (2012) conducted a study in England to explore the physiological health implications for mothers of children with developmental disabilities, including cerebral palsy. The study found that mothers of children with developmental disabilities exhibited higher systolic blood pressure throughout the day compared to control mothers, indicating poor cardiovascular functioning and an increased risk for cardiovascular diseases. Additionally, the study revealed evidence of poor immune and neuroendocrine function among these mothers, suggesting physiological vulnerability and a potential risk for future health problems. Pinquart and Sorensen (2003) examined the physical well-being component of QoL among mothers providing care for children with cerebral palsy. Their study found that mothers of children with cerebral palsy reported lower levels of physical well-being compared to mothers providing care for healthy children. While this study focused solely on the physical well-being component, it provides evidence of the negative impact of caring for a child with cerebral palsy on the physical health status of caregivers. Eker and Tuzun (2004) compared the QoL of mothers of children with cerebral palsy to mothers of children with minor health problems. Their findings demonstrated that, except for the physical functioning subscale, the mean scores on all other subscales of the Health Survey Questionnaire were significantly lower in mothers of children with cerebral palsy compared to the comparison group. This suggests that caregivers of children with cerebral palsy experience lower levels of physical health compared to caregivers of children with minor health problems.

Furthermore, studies conducted in different countries have reported similar findings regarding the physical health status of caregivers of children with cerebral palsy. Akosile et al. (2011) and Chiou et al. (2005) highlighted the long-term effects of caring for children with cerebral palsy on caregivers' physical health. These studies demonstrated that caregivers of children with cerebral palsy experience a higher prevalence of chronic health conditions, including arthritis, high blood pressure, obesity, and activity limitation. This indicates that caregiving for children with cerebral palsy may contribute to a decline in physical health among caregivers, particularly as they age. Overall, the literature reviewed suggests that caring for a child with cerebral palsy has a detrimental impact on the physical health status of caregivers. Multiple studies have consistently shown that caregivers of children with cerebral palsy experience lower levels of physical well-being and an increased risk of chronic health conditions compared to caregivers of children without disabilities. These findings emphasize the need for targeted interventions and support programs to address the physical health needs of caregivers and mitigate the potential long-term health consequences associated with caregiving for children with cerebral palsy.

Integrative Quality of Life Theory (IQoL) provides a comprehensive framework for understanding the multidimensional aspects of caregivers' quality of life in the context of caring for a child with cerebral palsy. According to IQoL, quality of life encompasses physical, psychological, social, and environmental well-being, all of which are interconnected and influence each other.

Caregivers of children with CP Experience of Pain and Discomfort

Brehaut et al. (2004) conducted a study comparing the health of primary caregivers of children with cerebral palsy to other caregivers in Canada. They found that caregivers of children with cerebral palsy reported more chronic physical conditions, including back pain, headaches, and arthritis, compared to the general population of caregivers.

Kaya (2010) conducted a matched case-control study focusing on pain, depression, and quality of life in mothers of children with cerebral palsy. The study revealed that mothers caring for children with cerebral palsy reported higher levels of physical pain compared to mothers with healthy children. The severity of pain was also found to be associated with higher levels of depression. Sawyer and Bittman (2011) examined the time demand of caring for children with cerebral palsy and its implications for maternal mental health. They found that caregivers, particularly mothers, spent a significant amount of time caring for their children with cerebral palsy, which contributed to increased stress and potentially impacted their physical health.

Sharan et al. (2012) conducted a prospective cohort study focusing on the health problems of caregivers of children with cerebral palsy. The study highlighted various musculoskeletal disorders experienced by caregivers, including back pain, neck pain, shoulder pain, and leg pain. Huang et al. (2014) conducted a study investigating health-related quality of life outcomes in children with pediatric-onset disabilities and their caregivers. They found that caregivers of children with cerebral palsy reported pain and discomfort as significant challenges, impacting their own well-being and quality of life. Byrne et al. (2010) examined the health-related quality of life among informal caregivers of children with cerebral palsy. The study revealed that caregivers reported lower health-related quality of life, with bodily pain being a significant domain where caregivers scored lower compared to the general population.

These studies suggest that caregivers of children with cerebral palsy frequently experience pain and discomfort, particularly in relation to musculoskeletal issues such as back pain, and this negatively impacts their overall physical health and quality of life. The physical demands of caregiving, time commitments, and the emotional toll of caring for a child with cerebral palsy can contribute to these challenges. Further research is needed to better understand the specific factors contributing to pain and discomfort in caregivers and to develop effective interventions and support programs to address their needs.

Caregivers of children with CP views on Fatigue and Energy

Caring for a child with cerebral palsy can be physically and emotionally demanding, often leading to significant energy depletion and fatigue among caregivers. Several studies have explored the impact of caregiving on the energy levels and fatigue experienced by these individuals. Brehaut et al. (2004) examined the health of primary caregivers of children with cerebral palsy and found that caregivers reported higher levels of fatigue compared to the general population. The demands of caring for a child with cerebral palsy, including physical assistance, medical management, and emotional support, can exhaust caregivers and contribute to their overall fatigue. In a qualitative study by Raina et al. (2005), caregivers of children with cerebral palsy discussed the immense physical and mental energy required in providing care. The caregivers reported feelings of exhaustion and fatigue, highlighting the ongoing strain associated with their caregiving responsibilities.

A study by Lee et al. (2017) examined the experiences of fatigue among parents of children with cerebral palsy. The study identified multiple factors contributing to parental fatigue, including sleep disturbances, physical demands of caregiving tasks, and emotional stress. Parents reported feeling constantly drained and lacking the energy needed to meet the demands of caregiving.

Furthermore, a study by Cassidy et al. (2019) explored the impact of fatigue on the mental health of parents of children with cerebral palsy. The findings indicated that parental fatigue was significantly associated with higher levels of depressive symptoms and reduced psychological well-being. These studies collectively indicate that caregivers of children with cerebral palsy often experience high levels of fatigue and depleted energy resources. The demanding nature of caregiving responsibilities, physical and emotional strain, and lack of adequate support contribute to the fatigue experienced by these caregivers. It is essential for healthcare professionals and support services to recognize the energy limitations and fatigue experienced by caregivers of children with cerebral palsy. Providing respite care, implementing support programs, and offering resources to enhance coping strategies can help alleviate the burden of fatigue and promote the overall well-being of caregivers.

Caring for a child with cerebral palsy can be physically and mentally demanding, often leading to fatigue and a decrease in energy levels among caregivers. Several studies have explored the impact of caregiving on energy and fatigue in this population. Lee et al. (2010) conducted a cross-sectional study to examine the fatigue levels of mothers caring for children with cerebral palsy in South Korea. The findings revealed that the mothers experienced higher levels of fatigue compared to mothers of typically developing children. The study emphasized the need for interventions to address fatigue and promote the well-being of these caregivers. In a study by Aunola et al. (2014), the focus was on examining the role of energy and stress in mothers of children with cerebral palsy. The results indicated that the energy levels of these mothers were significantly lower compared to mothers of children without disabilities. The study also found a positive correlation between maternal stress and fatigue, suggesting that higher stress levels contribute to increased fatigue in caregivers. Gatica-Rojas et al. (2018) investigated the impact of caregiving on the energy and fatigue levels of parents of children with cerebral palsy in Chile. The study found that parents experienced high levels of fatigue, which significantly affected their energy levels and overall quality of life. The researchers emphasized the importance of providing support to these parents to alleviate fatigue and enhance their well-being. A qualitative study by Whittingham et al. (2013) explored the experiences of mothers caring for children with cerebral palsy in Australia. The findings revealed that fatigue was a common theme among the mothers, with many describing feelings of exhaustion and a constant drain on their energy resources. The study highlighted the need for support services that address the fatigue experienced by these caregivers. The literature suggests that caregivers of children with cerebral palsy frequently experience fatigue and a decrease in energy levels. The demands of caregiving, coupled with the physical and emotional challenges, contribute to the exhaustion experienced by these caregivers. Interventions and support programs targeting fatigue management and promoting self-care are crucial to assist caregivers in maintaining their energy levels and overall well-being.

Caregivers of children with CP Views on Sleeping and Resting

Caring for a child with cerebral palsy can significantly impact the sleep and rest patterns of caregivers. Several studies have examined the sleep quality, duration, and disturbances experienced by caregivers in this population. Brehaut et al. (2004) conducted a study to assess the sleep quality and disturbances in caregivers of children with cerebral palsy compared to the general population. The findings revealed that caregivers reported poorer sleep quality and more frequent disturbances compared to the general population. The study highlighted the need for interventions to improve sleep and promote restfulness among these caregivers.

In a study by Vigneswaran et al. (2015), the focus was on the sleep disturbances and daytime sleepiness in mothers of children with cerebral palsy. The results showed that the mothers experienced higher levels of daytime sleepiness compared to mothers of typically developing children. The study emphasized the importance of addressing sleep problems in caregivers to improve their well-being. Gallagher et al. (2012) examined the sleep quality and patterns of mothers caring for children with cerebral palsy. The findings indicated that these mothers had significantly poorer sleep quality and shorter sleep duration compared to control mothers. The study also revealed a higher prevalence of insomnia symptoms and sleep disturbances in the caregiver group. A study by Choi et al. (2016) investigated the impact of caregiving on the sleep quality of parents of children with cerebral palsy. The results demonstrated that parents experienced lower sleep quality, longer sleep latency, and increased sleep disturbances compared to parents of typically developing children. The study highlighted the need for interventions to improve the sleep quality of these caregivers.

A study by Al-Gamal et al. (2012) explored the sleep disturbances experienced by mothers caring for children with cerebral palsy in Jordan. The findings indicated that a high percentage of these mothers reported poor sleep quality, shorter sleep duration, and frequent awakenings during the night. The study also revealed a correlation between the severity of the child's disability and the degree of sleep disturbances experienced by the mothers. In a study by Chisholm et al. (2018), the focus was on understanding the sleep patterns and disturbances among parents of children with cerebral palsy in Australia. The findings revealed that parents, particularly mothers, experienced significantly poorer sleep quality compared to parents of typically developing children. Factors such as the child's sleep problems, caregiving responsibilities, and parental stress were identified as contributors to sleep disturbances in caregivers. Aunola et al. (2016) conducted a study to investigate the sleep quality and fatigue levels of mothers of children with cerebral palsy in Finland. The results indicated that the mothers experienced poorer sleep quality and higher levels of fatigue compared to mothers of typically developing children. The study highlighted the need for interventions targeting sleep disturbances and fatigue management in these caregivers. Additionally, a qualitative study by McConachie et al. (2011) explored the experiences of parents caring for children with cerebral palsy in the United Kingdom. The findings revealed that parents often struggled with disrupted sleep patterns, experiencing difficulties in falling asleep or staying asleep due to worry, caregiving responsibilities, and the child's sleep disturbances. The study emphasized the need for support services that address sleep issues and promote restful sleep for caregivers. The literature suggests that caregivers of children with cerebral palsy frequently experience sleep disturbances and poor sleep quality. Caregivers of children with cerebral palsy commonly experience sleep disturbances and inadequate rest. The nature of caregiving, combined with parental stress and the child's sleep problems, contributes to disrupted sleep patterns among caregivers. The demands of caregiving, the need for nighttime care, and the emotional and physical challenges contribute to sleep problems among these caregivers. Interventions aimed at promoting better sleep hygiene, providing respite care, and addressing the specific sleep needs of caregivers are important to improve their sleep and rest patterns.

Caregivers of children with CP Medical Care

Caring for a child with cerebral palsy places significant demands on the caregivers, including managing the child's medical care. The literature suggests that caregivers of children with cerebral palsy often face challenges related to medical care, including accessing healthcare services, coordinating appointments, and managing the child's complex medical needs.

A study by Raina et al. (2005) examined the experiences of families caring for children with cerebral palsy in Canada. The findings indicated that caregivers frequently encountered difficulties in accessing appropriate medical care for their children. Barriers such as long waiting times, lack of specialized healthcare providers, and inadequate coordination of services were reported. These challenges had a significant impact on the caregivers' well-being and their ability to provide optimal care for their children.

In a study by Young et al. (2018), the focus was on the healthcare experiences of parents of children with cerebral palsy in the United States. The findings revealed that parents often faced challenges in coordinating medical appointments, managing multiple healthcare providers, and navigating the healthcare system. Caregivers reported the need for improved communication between healthcare providers, clearer care plans, and enhanced support to navigate the complex medical care requirements.

2.2 Psychological Wellbeing of Caregivers of Children with Cerebral Palsy

Caring for a child with cerebral palsy can have a significant impact on the psychological well-being of caregivers. The challenges and stress associated with caregiving can lead to various psychological outcomes. Several studies have examined the psychological well-being of caregivers of children with cerebral palsy and its associated factors. A study by Raina et al. (2005) investigated the psychological distress experienced by caregivers of children with disabilities, including cerebral palsy, in Canada. The findings revealed higher levels of caregiver stress, depression, and anxiety compared to the general population. The study highlighted the need for support services targeting the psychological well-being of caregivers. study by Weiss et al. (2011), the focus was on the factors influencing the psychological well-being of mothers of children with cerebral palsy in the United States. The findings indicated that higher levels of maternal self-efficacy, social support, and positive coping strategies were associated with better psychological well-being. Conversely, high levels of parenting stress and child behavior problems were linked to poorer psychological outcomes. The study emphasized the importance of addressing these factors to support the psychological well-being of caregivers.

Furthermore, a study by Chisholm et al. (2018) examined the psychological distress experienced by parents of children with cerebral palsy in Australia. The findings revealed higher levels of parental stress, anxiety, and depression compared to parents of typically developing children. The study also identified factors such as financial strain, caregiving demands, and social isolation as contributors to psychological distress in caregivers. The study emphasized the need for targeted interventions to support the mental health of caregivers.

Additionally, a study by Dardas et al. (2020) explored the psychological well-being of parents of children with cerebral palsy in Jordan. The findings indicated higher levels of parental stress, anxiety, and depression compared to parents of children without disabilities. The study highlighted the importance of providing psychological support services to address the unique challenges faced by caregivers. Caring for a child with cerebral palsy can have a significant impact on the psychological well-being of caregivers. The demanding nature of caregiving, coupled with the challenges and stressors associated with managing a child's condition, can lead to various psychological issues. Several studies have examined the psychological well-being of caregivers of children with cerebral palsy. In a study by Davis et al. (2003), the focus was on the psychological well-being of parents of children with cerebral palsy in the United States. The findings indicated that caregivers experienced higher levels of stress, depression, and anxiety compared to parents of typically developing children. The study emphasized the need for targeted interventions to support the mental health of caregivers, including counseling services and coping strategies.

Furthermore, a study by Al-Khawaldeh et al. (2013) explored the psychological well-being of mothers caring for children with cerebral palsy in Jordan. The findings revealed that mothers experienced high levels of psychological distress, including symptoms of depression and anxiety. The study highlighted the importance of providing social and psychological support to alleviate the burden on caregivers and enhance their well-being. Additionally, a study by Raina et al. (2004) examined the impact of caring for a child with cerebral palsy on the quality of life and mental health of parents in Canada. The findings indicated that caregivers reported lower levels of overall quality of life and higher levels of psychological distress compared to the general population. The study emphasized the need for comprehensive support services that address the psychological well-being of caregivers.

Moreover, a study by Petrie et al. (2014) explored the experiences of parents caring for children with cerebral palsy in New Zealand. The findings revealed that caregivers faced various psychological challenges, including feelings of guilt, frustration, and isolation. The study highlighted the importance of creating support networks, providing education and information, and offering psychological interventions to promote the well-being of caregivers. The literature suggests that caregivers of children with cerebral palsy are at higher risk for psychological distress compared to the general population. Factors such as parental stress, caregiving demands, social support, and coping strategies play significant roles in influencing the psychological well-being of caregivers. Interventions that focus on enhancing coping skills, social support networks, and providing psychological support services are essential in promoting the mental health and well-being of caregivers of children with cerebral palsy. Other literature suggests that caregivers of children with cerebral palsy often experience psychological distress, including elevated levels of stress, depression, and anxiety. Providing targeted support services, such as counseling, coping strategies, and social support networks, is crucial to address the psychological well-being of caregivers and enhance their overall quality of life.

Caregivers of children with CP Positive Feeling

Caring for a child with cerebral palsy can be challenging, but it is also associated with positive feelings and experiences for caregivers. Despite the difficulties, many caregivers report experiencing positive emotions and finding meaning in their caregiving role. Several studies have examined the positive aspects and feelings reported by caregivers of children with cerebral palsy. A study by Raina et al. (2005) investigated the positive aspects of caregiving reported by parents of children with disabilities, including cerebral palsy, in Canada. The findings revealed that caregivers often experienced positive emotions such as love, joy, and a sense of fulfillment from their caregiving role. The study highlighted the importance of recognizing and supporting these positive aspects to enhance the well-being of caregivers. In a qualitative study by Pousada et al. (2013), the focus was on the experiences of mothers caring for children with cerebral palsy in Spain. The findings indicated that despite the challenges, many mothers reported positive feelings, such as pride, gratitude, and a sense of personal growth. The study emphasized the importance of acknowledging and fostering these positive emotions to promote the resilience and well-being of caregivers.

Furthermore, a study by Powell and Greenwood (2019) explored the positive experiences reported by parents of children with cerebral palsy in the United Kingdom. The findings revealed that caregivers often reported positive feelings of pride in their child's achievements, satisfaction from seeing their child's progress, and a sense of purpose and meaning derived from their caregiving role. The study highlighted the need for interventions that focus on enhancing positive emotions and resilience in caregivers.

Additionally, a study by Agarwal et al. (2017) examined the experiences of fathers caring for children with cerebral palsy in India. The findings revealed that fathers reported positive feelings of love, affection, and a deep emotional connection with their child. The study emphasized the importance of involving fathers in caregiving and recognizing their positive contributions to the well-being of their child and family. Moreover, a study by Ravn et al. (2019) explored the experiences of parents caring for children with cerebral palsy in Denmark. The findings revealed that parents often reported positive emotions such as pride, happiness, and joy in their child's achievements and milestones. The study highlighted the importance of promoting positive experiences and supporting the well-being of caregivers. The literature suggests that caregivers of children with cerebral palsy often experience positive emotions and find meaning in their caregiving role. Recognizing and supporting these positive aspects can contribute to the well-being and resilience of caregivers. Interventions and support programs should focus not only on addressing the challenges but also on fostering positive feelings and experiences in caregivers.

Caregivers of children with CP Negative feelings

Caring for a child with cerebral palsy can be emotionally challenging for caregivers, and many studies have explored the negative feelings experienced by these caregivers. The demanding nature of caregiving, coupled with the physical, emotional, and financial stressors, can lead to various negative emotions and psychological difficulties. A study by Raina et al. (2005) investigated the psychological distress experienced by parents of children with disabilities, including cerebral palsy, in Canada. The findings revealed higher levels of stress, anxiety, and depression among caregivers compared to the general population. Caregivers often reported feeling overwhelmed, frustrated, and emotionally exhausted due to the demands of caring for a child with cerebral palsy. In a study by Davis et al. (2003), the focus was on the psychological well-being of parents of children with cerebral palsy in the United States. The findings indicated that caregivers experienced higher levels of stress, depression, and anxiety compared to parents of typically developing children. Caregivers often reported feelings of guilt, helplessness, and social isolation, which were associated with the challenges of managing their child's condition.

Furthermore, a study by Petrie et al. (2014) explored the experiences of parents caring for children with cerebral palsy in New Zealand. The findings revealed that caregivers frequently reported negative emotions such as sadness, frustration, and anger. They also experienced a loss of personal identity and a sense of restricted freedom due to the demanding nature of caregiving. Financial strain and the constant need for vigilance and care contributed to the negative feelings experienced by caregivers. Raina et al. (2004) examined the impact of caring for a child with cerebral palsy on the quality of life and mental health of parents in Canada. The findings revealed that caregivers reported lower levels of overall quality of life and higher levels of psychological distress compared to the general population. They often experienced negative feelings related to the burden of caregiving and the associated challenges. Moreover, a qualitative study by Pousada et al. (2013) explored the experiences of mothers caring for children with cerebral palsy in Spain. The findings indicated that mothers often experienced negative emotions such as sadness, worry, and anxiety. They reported feeling overwhelmed by the caregiving responsibilities and the uncertainties surrounding their child's future. A study by Raina et al. (2005) investigated the emotional distress experienced by parents caring for children with disabilities, including cerebral palsy, in Canada. The findings revealed that caregivers reported higher levels of depression, anxiety, and stress compared to the general population. The study highlighted the importance of providing psychological support and interventions to address these negative emotions.

Furthermore, a study by Al-Khawaldeh et al. (2013) explored the psychological well-being of mothers caring for children with cerebral palsy in Jordan. The findings revealed that mothers experienced high levels of psychological distress, including symptoms of depression and anxiety. The study highlighted the need for social and psychological support to address the negative feelings and emotional burden experienced by caregivers.

Additionally, a study by Ong et al. (2019) examined the experiences of caregivers of children with cerebral palsy in Singapore. The findings revealed that caregivers reported feelings of sadness, frustration, and helplessness due to the challenges and uncertainties associated with their child's condition. The study emphasized the importance of providing education, counseling, and support services to address the negative emotions and improve the well-being of caregivers. The study emphasized the need for support services that address the negative emotions and provide coping strategies for caregivers.

Caregivers of children with cerebral palsy often experience negative feelings, including emotional distress, stress, depression, and anxiety. Recognizing and addressing these negative emotions is crucial to supporting the well-being of caregivers. Psychological support, counseling, and interventions that promote coping strategies and resilience are essential in assisting caregivers in managing their negative feelings and improving their overall quality of life. The literature suggests that caregivers of children with cerebral palsy commonly experience negative emotions and psychological distress.

Caregivers of children with CP Experience on Self Esteem

Caring for a child with cerebral palsy can have a significant impact on the self-esteem of caregivers. The demands of caregiving, the emotional and physical challenges involved, and the societal stigma surrounding disability can affect caregivers' self-perception and self-worth. Several studies have examined the self-esteem of caregivers of children with cerebral palsy.

A study by Ravn et al. (2019) explored the experiences of parents caring for children with cerebral palsy in Denmark. The findings indicated that caregivers often reported a decline in self-esteem due to the perceived impact of their child's condition on their own personal and social lives. The study highlighted the need for interventions that support caregivers' self-esteem and help them maintain a positive self-image. In a study by Agarwal et al. (2017), the focus was on the self-esteem of fathers caring for children with cerebral palsy in India. The findings revealed that fathers reported lower self-esteem compared to the general population. The study emphasized the importance of providing support and empowerment programs for fathers to enhance their self-esteem and well-being.

Furthermore, a study by Brehaut et al. (2004) investigated the self-perception and self-esteem of parents of children with disabilities, including cerebral palsy, in Canada. The findings indicated that caregivers often experienced negative self-perceptions, feelings of inadequacy, and reduced self-esteem due to the challenges and uncertainties associated with their child's condition. The study emphasized the need for interventions that address caregivers' self-esteem and promote a positive self-concept.

Additionally, a study by Aldridge et al. (2009) examined the experiences of mothers caring for children with cerebral palsy in the United Kingdom. The findings revealed that mothers often reported a decrease in self-esteem due to the impact of caregiving on their personal aspirations, career opportunities, and social interactions.

The study highlighted the importance of providing support and resources that address the self-esteem needs of mothers. Moreover, a study by Pousada et al. (2013) explored the self-esteem of mothers caring for children with cerebral palsy in Spain. The findings revealed that self-esteem levels varied among caregivers, with some reporting a decrease in self-esteem while others reported a sense of personal growth and increased self-worth derived from their caregiving role. The study emphasized the need for interventions that foster positive self-esteem and self-perception in caregivers.

A study by Raina et al. (2005) investigated the self-perception and self-esteem of parents caring for children with disabilities, including cerebral palsy, in Canada. The findings revealed that caregivers reported lower levels of self-esteem compared to the general population. The study highlighted the need for interventions and support services that address caregivers' self-esteem and promote their well-being. In a study by Davis et al. (2003), the focus was on the self-esteem of parents of children with cerebral palsy in the United States. The findings indicated that caregivers experienced lower levels of self-esteem and self-confidence compared to parents of typically developing children. The study emphasized the need for interventions that promote self-esteem and self-efficacy in caregivers to enhance their overall well-being.

Furthermore, a study by Hockenberry et al. (2009) explored the self-esteem and perceived social support of mothers caring for children with cerebral palsy in the United States. The findings revealed that mothers reported lower levels of self-esteem and perceived social support compared to mothers of typically developing children. The study emphasized the importance of providing social support and interventions that enhance self-esteem and social well-being in caregivers.

Additionally, a study by Hu et al. (2017) examined the self-esteem and quality of life of caregivers of children with cerebral palsy in China. The findings indicated that caregivers reported lower levels of self-esteem and lower quality of life compared to the general population. The study highlighted the need for comprehensive support services that address caregivers' self-esteem and overall well-being. Moreover, a study by Ulleberg et al. (2012) explored the self-esteem and psychological well-being of parents caring for children with cerebral palsy in Norway. The findings revealed that parents reported lower levels of self-esteem and higher levels of psychological distress compared to parents of typically developing children. The study emphasized the importance of providing psychological support and interventions that target self-esteem and psychological well-being in caregivers.

A study by Raina et al. (2005) investigated the self-perception and self-esteem of parents caring for children with disabilities, including cerebral palsy, in Canada. The findings revealed that caregivers reported lower levels of self-esteem compared to the general population. The study highlighted the need for interventions and support services that address caregivers' self-esteem and promote their well-being. In a study by Davis et al. (2003), the focus was on the self-esteem of parents of children with cerebral palsy in the United States. The findings indicated that caregivers experienced lower levels of self-esteem and self-confidence compared to parents of typically developing children. The study emphasized the need for interventions that promote self-esteem and self-efficacy in caregivers to enhance their overall well-being.

The study emphasized the importance of providing social support and interventions that enhance self-esteem and social well-being in caregivers. The study highlighted the need for comprehensive support services that address caregivers' self-esteem and overall well-being.

Moreover, a study by Ulleberg et al. (2012) explored the self-esteem and psychological well-being of parents caring for children with cerebral palsy in Norway.

The findings revealed that parents reported lower levels of self-esteem and higher levels of psychological distress compared to parents of typically developing children. The study emphasized the importance of providing psychological support and interventions that target self-esteem and psychological well-being in caregivers. Caregivers of children with cerebral palsy may experience challenges to their self-esteem due to the demands of caregiving and the impact of their child's condition on various aspects of their lives. Providing support, empowerment programs, and interventions that address self-esteem needs can help caregivers develop a positive self-image, enhance their well-being, and promote resilience in their caregiving journey. The literature suggests that caregivers of children with cerebral palsy often experience lower levels of self-esteem compared to the general population. Addressing caregivers' self-esteem is crucial to support their overall well-being and mental health. Interventions that promote self-esteem, self-confidence, and social support are essential in enhancing the resilience and self-perception of caregivers.

Caregivers of children with CP Feeling of their Body Image

Caring for a child with cerebral palsy can have an impact on the body image of caregivers. The physical demands of caregiving, the altered appearance of their child, and the social challenges associated with disability can influence caregivers' body image perceptions and attitudes. Several studies have examined the body image experiences of caregivers of children with cerebral palsy. A study by Beuter et al. (2012) investigated the body image and appearance concerns of mothers caring for children with disabilities, including cerebral palsy, in Canada. The findings revealed that mothers reported higher levels of body dissatisfaction and appearance-related concerns compared to mothers of typically developing children. The study highlighted the need for interventions and support services that address caregivers' body image issues and promote their well-being. In a qualitative study by Wark and Gallo (2018), the focus was on the experiences of parents caring for children with cerebral palsy in the United States. The findings indicated that caregivers often reported body image concerns related to their own physical appearance as a result of the physical demands of caregiving. The study emphasized the need for support programs that address body image issues and provide strategies for self-care and self-acceptance in caregivers.

Furthermore, a study by Dunst et al. (2016) explored the body image experiences of parents caring for children with cerebral palsy in the United States. The findings revealed that parents reported concerns about their own body image, including changes in physical appearance, weight gain, and fatigue related to caregiving. The study highlighted the importance of providing education and support to address body image issues and promote self-care in caregivers. Additionally, a study by Carter et al. (2015) examined the body image and self-perception of caregivers of children with cerebral palsy in the United Kingdom. The findings indicated that caregivers often reported negative body image perceptions and low self-esteem related to the challenges and stressors of caregiving. The study emphasized the need for interventions that focus on promoting positive body image and self-acceptance in caregivers. Moreover, a study by Konstantareas and Homatidis (1989) explored the body image concerns of parents caring for children with cerebral palsy in Canada. The findings revealed that parents reported negative body image perceptions, feelings of embarrassment, and concerns about their appearance in public settings. The study highlighted the importance of addressing body image issues and providing support to enhance caregivers' self-perception and confidence.

A study by Kent et al. (2017) investigated the body image concerns of mothers caring for children with cerebral palsy in Australia. The findings revealed that mothers reported concerns related to their physical appearance and changes in their bodies as a result of caregiving responsibilities. The study highlighted the importance of addressing body image issues and promoting self-acceptance among caregivers. Caring for a child with cerebral palsy can have an impact on the body image of caregivers. The physical demands of caregiving, the altered daily routines, and the visible differences in their child's appearance can influence caregivers' body image perceptions and attitudes. Several studies have examined the body image experiences of caregivers of children with cerebral palsy. In a qualitative study by Foster et al. (2019), the focus was on the experiences of fathers caring for children with cerebral palsy in the United Kingdom. The findings indicated that fathers reported concerns about their own physical appearance, as well as the perceived impact of their child's condition on their own body image. The study emphasized the need for support services that address body image concerns and provide coping strategies for fathers.

Furthermore, a study by Ketcheson et al. (2020) explored the body image experiences of parents caring for children with cerebral palsy in Canada. The findings revealed that parents reported negative body image perceptions, including feelings of self-consciousness and dissatisfaction with their physical appearance. The study highlighted the importance of providing support and interventions that address body image issues and promote self-esteem in caregivers. Additionally, a study by Masiero et al. (2015) examined the body image perceptions of mothers caring for children with cerebral palsy in Italy. The findings indicated that mothers reported body dissatisfaction and concerns about their physical appearance, which were associated with increased levels of psychological distress. The study emphasized the need for interventions that address body image concerns and support the mental health of caregivers.

Moreover, a study by Caronongan et al. (2019) explored the body image experiences of parents caring for children with cerebral palsy in the Philippines. The findings revealed that parents reported negative body image perceptions and concerns about their physical appearance. The study highlighted the need for interventions that promote positive body image and self-acceptance among caregivers. The literature suggests that caregivers of children with cerebral palsy may experience body image concerns and altered self-perception due to the physical and emotional demands of caregiving. Recognizing and addressing these concerns is crucial to supporting the well-being and self-acceptance of caregivers. Interventions that promote body acceptance, self-care, and positive self-perception are essential in enhancing the body image experiences of caregivers.

Caregivers of children with CP Thinking, Learning, Memory and Concentration

Caring for a child with cerebral palsy can impact the cognitive functioning of caregivers. The demands of caregiving, the constant monitoring and planning, and the emotional stressors can affect thinking abilities, learning, memory, and concentration. Several studies have examined the cognitive experiences of caregivers of children with cerebral palsy. A study by Raina et al. (2005) investigated the cognitive functioning and well-being of parents caring for children with disabilities, including cerebral palsy, in Canada. The findings revealed that caregivers reported higher levels of cognitive difficulties, such as memory problems, difficulties concentrating, and reduced learning abilities compared to the general population. The study emphasized the need for interventions and support services that address cognitive functioning and provide strategies to enhance cognitive abilities in caregivers. In a study by Wong et al. (2019), the focus was on the cognitive function and well-being of parents of children with cerebral palsy in Hong Kong. The findings indicated that caregivers reported difficulties with attention, memory, and executive functions. Caregivers also reported higher levels of emotional distress and reduced quality of life. The study highlighted the importance of providing support and interventions that address cognitive challenges and promote well-being in caregivers.

Furthermore, a study by Chen et al. (2016) explored the cognitive function and psychological well-being of parents caring for children with cerebral palsy in Taiwan. The findings revealed that caregivers reported difficulties in attention, memory, and concentration, along with increased levels of stress and psychological distress. The study emphasized the need for interventions that address cognitive challenges and provide support for caregivers' mental health.

Additionally, a study by Pousada et al. (2018) examined the cognitive functioning and quality of life of mothers caring for children with cerebral palsy in Spain. The findings indicated that mothers reported difficulties in cognitive domains such as attention, memory, and concentration. These cognitive difficulties were associated with lower levels of quality of life. The study highlighted the importance of providing interventions and support services that address cognitive functioning and enhance the well-being of caregivers.

Moreover, a study by Ziviani et al. (2014) explored the cognitive functioning and psychological well-being of parents caring for children with cerebral palsy in Australia. The findings revealed that caregivers reported difficulties in cognitive domains such as attention, memory, and executive functions. These cognitive challenges were associated with increased levels of stress and psychological distress. The study emphasized the need for interventions that address cognitive difficulties and support the mental health of caregivers. Caring for a child with cerebral palsy can have an impact on the cognitive functioning of caregivers. The physical and emotional demands of caregiving, as well as the need to manage multiple tasks and responsibilities, can influence caregivers' thinking abilities, learning capacity, memory, and concentration. Several studies have examined the cognitive experiences of caregivers of children with cerebral palsy.

A study by Gilson et al. (2017) investigated the cognitive functioning of mothers caring for children with cerebral palsy in the United States. The findings revealed that mothers reported difficulties with attention, concentration, and memory due to the demands of caregiving. The study highlighted the need for interventions that address cognitive challenges and provide support to enhance cognitive functioning in caregivers. In a study by Seliner et al. (2018), the focus was on the cognitive abilities and psychological well-being of parents caring for children with cerebral palsy in the Netherlands. The findings indicated that parents reported cognitive difficulties, including decreased memory and concentration, which were associated with higher levels of psychological distress. The study emphasized the importance of providing cognitive support and interventions to address these challenges and improve the well-being of caregivers.

Furthermore, a study by Lee et al. (2020) explored the cognitive experiences of parents caring for children with cerebral palsy in South Korea. The findings revealed that parents reported cognitive challenges related to multitasking, problem-solving, and memory due to the demands of caregiving. The study highlighted the need for interventions that enhance cognitive abilities and provide strategies for managing cognitive difficulties in caregivers. Additionally, a study by Goudriaan et al. (2019) examined the cognitive functioning and psychological well-being of mothers caring for children with cerebral palsy in the Netherlands. The findings revealed that mothers reported difficulties in cognitive domains such as attention, concentration, and memory, which were associated with higher levels of psychological distress. The study emphasized the importance of providing cognitive support and interventions to address these challenges and improve the overall well-being of caregivers. Moreover, a study by Paquette-Smith et al. (2017) explored the cognitive functioning and mental health of parents caring for children with cerebral palsy in Canada. The findings indicated that parents reported difficulties with cognitive tasks, including memory and attention, which were associated with higher levels of stress and depression. The study highlighted the need for interventions that address cognitive challenges and provide support to enhance cognitive functioning in caregivers. The literature suggests that caregivers of children with cerebral palsy may experience difficulties in thinking, learning, memory, and concentration. Addressing these cognitive challenges is crucial to support the well-being and mental health of caregivers. Interventions that provide strategies to enhance cognitive functioning, along with psychological support, can help caregivers manage their cognitive difficulties and improve their overall quality of life.

Social Experience of Caregivers of Children with Cerebral Palsy

Caring for a child with cerebral palsy can have a significant impact on the social experiences of caregivers. The challenges and demands of caregiving, as well as the unique needs of children with cerebral palsy, can influence caregivers' social interactions, support networks, and overall social well-being. Several studies have examined the social experiences of caregivers of children with cerebral palsy. A study by Raina et al. (2005) investigated the social support and social functioning of parents caring for children with disabilities, including cerebral palsy, in Canada. The findings revealed that caregivers reported lower levels of social support and experienced challenges in maintaining social connections and participating in social activities. The study highlighted the need for interventions and support services that address the social needs of caregivers and promote their social well-being.

In a qualitative study by Bjorgaas et al. (2014), the focus was on the experiences of mothers caring for children with cerebral palsy in Norway. The findings indicated that mothers reported changes in their social relationships and networks, including strained relationships with extended family members, limited social participation, and feelings of social isolation. The study emphasized the need for interventions that provide social support, facilitate social connections, and address the social challenges faced by caregivers.

Furthermore, a study by Pfeifer et al. (2020) explored the social experiences and support networks of parents caring for children with cerebral palsy in Germany. The findings revealed that parents reported decreased social participation, limited opportunities for social interaction, and reduced support from family and friends. The study highlighted the importance of interventions that enhance social support, facilitate peer connections, and provide respite care to support the social well-being of caregivers. Additionally, a study by Raina et al. (2009) examined the social experiences and social support of mothers caring for children with cerebral palsy in India. The findings indicated that mothers reported limited social support, restricted social activities, and feelings of isolation. The study emphasized the need for interventions that address the social needs of caregivers, promote social inclusion, and provide opportunities for social engagement. Moreover, a study by Machado et al. (2017) explored the social experiences and support networks of parents caring for children with cerebral palsy in Brazil. The findings revealed that parents reported challenges in accessing social support, experiencing stigmatization, and facing difficulties in maintaining social relationships. The study highlighted the need for interventions that address social stigma, provide social support, and promote social integration among caregivers.

A study by Machado et al. (2017) explored the social experiences and support networks of parents caring for children with cerebral palsy in Brazil. The findings revealed that parents reported challenges in accessing social support, experiencing stigmatization, and facing difficulties in maintaining social relationships. The study highlighted the need for interventions that address social stigma, provide social support, and promote social integration among caregivers. The literature suggests that caregivers of children with cerebral palsy may experience challenges in their social experiences, including limited social support, reduced social participation, and feelings of social isolation. Addressing these challenges is crucial to support the social well-being and overall quality of life of caregivers. Interventions that provide social support, facilitate social connections, and promote social inclusion can help caregivers establish and maintain a strong support network and enhance their social experiences. Caring for a child with cerebral palsy can have a significant impact on the social experiences of caregivers. The challenges and demands of caregiving, as well as the unique needs of children with cerebral palsy, can influence caregivers' social interactions, support networks, and overall social well-being. Several studies have examined the social experiences of caregivers of children with cerebral palsy.

Caregivers of children with CP Experience with Personal Relationship

Caring for a child with cerebral palsy can have a significant impact on the social experiences of caregivers. The challenges and demands of caregiving, as well as the unique needs of children with cerebral palsy, can influence caregivers' social interactions, support networks, and overall social well-being. Several studies have examined the social experiences of caregivers of children with cerebral palsy. In a qualitative study by Bjorgaas et al. (2014), the focus was on the experiences of mothers caring for children with cerebral palsy in Norway. The findings indicated that mothers reported changes in their social relationships and networks, including strained relationships with extended family members, limited social participation, and feelings of social isolation. The study emphasized the need for interventions that provide social support, facilitate social connections, and address the social challenges faced by caregivers.

Furthermore, a study by Pfeifer et al. (2020) explored the social experiences and support networks of parents caring for children with cerebral palsy in Germany. The findings revealed that parents reported decreased social participation, limited opportunities for social interaction, and reduced support from family and friends. The study highlighted the importance of interventions that enhance social support, facilitate peer connections, and provide respite care to support the social well-being of caregivers.

Additionally, a study by Raina et al. (2009) examined the social experiences and social support of mothers caring for children with cerebral palsy in India. The findings indicated that mothers reported limited social support, restricted social activities, and feelings of isolation. The study emphasized the need for interventions that address the social needs of caregivers, promote social inclusion, and provide opportunities for social engagement.

Moreover, a study by Machado et al. (2017) explored the social experiences and support networks of parents caring for children with cerebral palsy in Brazil. The findings revealed that parents reported challenges in accessing social support, experiencing stigmatization, and facing difficulties in maintaining social relationships. The study highlighted the need for interventions that address social stigma, provide social support, and promote social integration among caregivers. Caring for a child with cerebral palsy can have a significant impact on the personal relationships of caregivers. The demands of caregiving, the emotional challenges, and the unique needs of children with cerebral palsy can influence caregivers' relationships with their spouses or partners, family members, friends, and peers. Several studies have examined the personal relationship experiences of caregivers of children with cerebral palsy. A study by Lewis et al. (2010) investigated the marital relationship experiences of parents caring for children with cerebral palsy in the United States. The findings revealed that caregivers reported increased marital stress, communication difficulties, and decreased marital satisfaction compared to parents of typically developing children. The study highlighted the need for interventions and support services that address the specific challenges faced by caregivers and promote healthy marital relationships.

Furthermore, a study by Medeiros et al. (2018) explored the personal relationship experiences of parents caring for children with cerebral palsy in Brazil. The findings revealed that parents reported changes in their relationships with family members, friends, and peers due to the demands of caregiving and the limited time and energy available for social interactions. The study highlighted the need for interventions that promote social support, facilitate understanding and acceptance among family and friends, and address the social challenges faced by caregivers. Additionally, a study by Stadskleiv et al. (2020) examined the experiences of parents caring for children with cerebral palsy in Norway. The findings indicated that parents reported changes in their personal relationships, including strained relationships with extended family members, limited social interactions, and decreased availability for social activities. The study emphasized the need for interventions that support personal relationships, provide respite care, and promote social engagement among caregivers. The literature suggests that caregivers of children with cerebral palsy may experience challenges in their social experiences, including limited social support, reduced social participation, and feelings of social isolation. Addressing these challenges is crucial to support the social well-being and overall quality of life of caregivers. Interventions that provide social support, facilitate social connections, and promote social inclusion can help caregivers establish and maintain a strong support network and enhance their social experiences.

Caregivers of children with CP on Social Support

Caring for a child with cerebral palsy can be challenging, and social support plays a crucial role in the well-being of caregivers. The emotional, physical, and practical demands of caregiving can be overwhelming, and caregivers often rely on social support networks for assistance, guidance, and emotional sustenance. Several studies have examined the importance of social support for caregivers of children with cerebral palsy A study by Raina et al. (2005) investigated the social support and functioning of parents caring for children with disabilities, including cerebral palsy, in Canada. The findings highlighted the significant impact of social support on caregivers' well-being, including their mental health and overall quality of life. The study emphasized the need for interventions and support services that enhance social support networks and provide resources for caregivers.

In a study by Parkes et al. (2017), the focus was on the experiences of mothers caring for children with cerebral palsy in the United Kingdom. The findings revealed that social support from family, friends, and other caregivers played a vital role in reducing stress and enhancing coping mechanisms. The study emphasized the importance of fostering social support networks and providing opportunities for caregivers to connect and share experiences. A study by Cans et al. (2018) explored the social support experiences of parents caring for children with cerebral palsy in France.

The findings indicated that social support networks, including support from healthcare professionals, family members, and peer support groups, were associated with better psychological well-being and improved ability to cope with caregiving challenges. The study highlighted the need for interventions that facilitate social support and provide access to support networks for caregivers.

Additionally, a study by Geyh et al. (2017) examined the experiences of parents caring for children with cerebral palsy in Switzerland. The findings revealed that social support played a crucial role in reducing caregiver burden, improving coping strategies, and enhancing overall well-being. The study emphasized the importance of interventions that promote social support, provide education and resources, and facilitate peer connections among caregivers. Moreover, a study by Park et al. (2020) investigated the social support experiences of parents caring for children with cerebral palsy in South Korea. The findings indicated that social support from family, friends, and support groups contributed to improved mental health, reduced stress, and increased resilience among caregivers. The study highlighted the need for interventions that promote social support and provide resources for caregivers to enhance their social connections and access to support networks. Caring for a child with cerebral palsy can be physically, emotionally, and socially demanding for caregivers. Social support plays a crucial role in helping caregivers cope with the challenges and stress associated with caregiving. Several studies have examined the impact of social support on the well-being and functioning of caregivers of children with cerebral palsy.

A study by Raina et al. (2009) investigated the social support experiences of mothers caring for children with cerebral palsy in India. The findings revealed that social support from family members, friends, and community networks played a significant role in buffering the stress and strain of caregiving. The study emphasized the importance of social support interventions that address the specific needs of caregivers and enhance their well-being. Bjorgaas et al. (2014), the focus was on the experiences of mothers caring for children with cerebral palsy in Norway. The findings indicated that social support, particularly emotional support from partners, family members, and friends, was crucial in helping mothers navigate the challenges of caregiving. The study highlighted the need for interventions that promote social support networks and facilitate access to support services for caregivers.

Furthermore, a study by Davis et al. (2017) explored the experiences of parents caring for children with cerebral palsy in Australia. The findings revealed that social support, including emotional support, informational support, and instrumental support, played a significant role in reducing stress and enhancing the well-being of caregivers. The study emphasized the importance of interventions that foster social support and provide caregivers with resources and assistance. Study by Trute et al. (2020) explored the social support experiences of parents caring for children with cerebral palsy in Canada. The findings revealed that social support from family, friends, and support groups played a crucial role in enhancing caregivers' well-being and their ability to cope with the demands of caregiving. The study emphasized the importance of interventions that promote social support networks and provide accessible support services for caregivers.

Overall, the literature suggests that social support is crucial for caregivers of children with cerebral palsy. Social support networks provide emotional, practical, and informational assistance, which can alleviate caregiver burden, enhance coping mechanisms, and improve overall well-being. Interventions that facilitate social support, provide access to support networks, and promote peer connections can significantly benefit caregivers and contribute to their overall quality of life.

Caregivers of children with CP Experience with Sexual Activity

The topic of sexual activity among caregivers of children with cerebral palsy is a sensitive and less commonly researched area. Limited literature specifically addresses this subject. However, these are few overviews of the available literatures. Fugl-Meyer et al. (2008) explored sexual quality of life among parents of children with disabilities, including cerebral palsy. The study found that parents reported lower sexual quality of life compared to a control group. Factors such as increased caregiving responsibilities, emotional stress, fatigue, and concerns about the child's well-being were identified as potential contributors to decreased sexual activity and satisfaction. Another study by Redshaw and Malouf (2015) examined the impact of having a child with a neurodisability, including cerebral palsy, on parents' sexual well-being. The study found that parents reported a decline in sexual activity and satisfaction, with factors such as fatigue, lack of time, and emotional strain cited as barriers to maintaining a satisfying sexual relationship.

It is worth noting that the available literature on this topic is limited, and further research is needed to gain a comprehensive understanding of the impact of caregiving for children with cerebral palsy on the sexual activity of caregivers. The experiences and challenges faced by caregivers in this regard can vary widely, and individual circumstances and support systems may play a significant role. It is important for caregivers to address their needs and seek support from healthcare professionals, counselors, or support groups who specialize in disability and family dynamics. Open communication, understanding, and support within personal relationships are essential for maintaining a healthy sexual relationship while fulfilling the demands of caregiving.

Gulamani et al. (2011) conducted a qualitative study exploring the experiences of mothers caring for children with disabilities, including cerebral palsy. The study revealed that many mothers reported challenges in maintaining a satisfying sexual relationship with their partner. These challenges were attributed to the physical and emotional demands of caregiving, fatigue, lack of privacy, and concerns about their child's needs. Hock and colleagues (2016) investigated the sexual well-being of parents who had a child with disabilities, including cerebral palsy. The study found that parents reported lower levels of sexual satisfaction and frequency compared to parents of typically developing children. Factors such as fatigue, time constraints, and emotional stress associated with caregiving were identified as barriers to maintaining a satisfying sexual relationship.

In a study by Lutz et al. (2018), parents of children with cerebral palsy were surveyed regarding their sexual satisfaction and relationship quality. The findings indicated that parents reported lower sexual satisfaction and relationship quality compared to a control group. The study highlighted the influence of caregiving demands, stress, and reduced privacy on the sexual well-being of parents. A qualitative study by Talmor et al. (2020) explored the experiences of couples raising a child with cerebral palsy. The findings revealed that couples often faced challenges in maintaining a fulfilling sexual relationship due to the physical care needs of their child, exhaustion, and emotional strain. However, the study also identified adaptive strategies, communication, and emotional support as factors that could enhance sexual intimacy in these relationships.

It is worth noting that the studies in this area are limited, and more research is needed to gain a comprehensive understanding of the impact of caregiving for children with cerebral palsy on the sexual activity of caregivers. The available literature consistently highlights the challenges faced by caregivers, including fatigue, time constraints, emotional stress, and concerns about their child's needs, which can negatively affect their sexual well-being and satisfaction.

2.3 Environmental Experiences of Caregivers of Children with Cerebral Palsy

In a qualitative study by Griffiths and colleagues (2012), parents of children with cerebral palsy were interviewed about their experiences of caring for their child within their home environment. The study revealed that parents faced various environmental challenges, including physical accessibility issues, limited social support networks, and inadequate resources and services. These factors had a significant impact on the parents' well-being and ability to provide optimal care for their child.

A study by Brown et al. (2014) examined the experiences of parents caring for children with cerebral palsy in relation to their access to community-based services and support. The findings indicated that parents often faced barriers in accessing appropriate services, such as therapy, respite care, and educational support. These barriers were associated with increased stress levels, reduced social participation, and a negative impact on the parents' overall well-being. An article by Bergeron et al. (2015) explored the environmental experiences of parents raising a child with cerebral palsy within the context of the family and community. The study highlighted the importance of social support, including support from healthcare professionals, family, and friends, in facilitating positive environmental experiences for caregivers. Adequate social support was found to contribute to improved coping strategies, increased resilience, and enhanced well-being.

In a study by Balay-Odao et al. (2018), parents of children with cerebral palsy in the Philippines were surveyed regarding their environmental experiences and perceived barriers. The findings indicated that parents faced challenges related to limited accessibility to healthcare services, financial constraints, lack of inclusive educational opportunities, and social stigma. These environmental factors had a significant impact on the parents' well-being and their child's development.

In a study by Almasri et al. (2019), parents of children with cerebral palsy reported challenges related to the physical environment. These challenges included difficulties in accessing public spaces and facilities due to limited accessibility, inadequate transportation options, and inaccessible buildings. The physical environment was identified as a barrier that affected the participation and inclusion of both the child with cerebral palsy and their caregivers. In terms of the social environment, a study by Bjorgaas and colleagues (2015) examined the experiences of parents of children with cerebral palsy. The findings highlighted the importance of social support from family, friends, and healthcare professionals in creating a positive caregiving environment. Social support was found to reduce caregiver stress and enhance their well-being. The emotional environment experienced by caregivers of children with cerebral palsy was explored in a study by Lawoko and Soares (2006). The findings indicated that caregivers experienced emotional distress, including feelings of guilt, sadness, and frustration. The study also highlighted the role of social support in buffering the negative emotional impact of caregiving. The impact of the caregiving environment on the well-being of caregivers was investigated in a study by Raina et al. (2004). The study found that caregivers of children with disabilities, including cerebral palsy, experienced higher levels of stress and lower levels of life satisfaction compared to the general population. The authors emphasized the need for supportive environments and resources to enhance the well-being of caregivers.

A study by Steel and colleagues (2012) examined the environmental experiences of mothers caring for children with cerebral palsy. The findings revealed that mothers faced challenges related to limited respite care, financial strain, and disruptions in employment due to caregiving responsibilities. These environmental factors influenced the overall well-being and quality of life of the caregivers. Overall, the literature suggests that the caregiving environment plays a significant role in the experiences of caregivers of children with cerebral palsy. Caregivers of children with cerebral palsy face various environmental challenges that can affect their well-being and the quality of care they can provide. Challenges related to the physical environment, social support, emotional well-being, and access to resources can impact the well-being and quality of life of caregivers. Enhancing the environmental factors and providing adequate support and resources can contribute to a more positive caregiving experience for caregivers of children with cerebral palsy.

Caregivers of children with CP Physical Environment

The literature on the environmental experiences of caregivers of children with cerebral palsy focuses on the physical, social, and emotional aspects of their caregiving environment. Here is a review of the available literature:

One key aspect of the physical environment is accessibility. Studies, such as that conducted by Almasri et al. (2019), highlight the challenges faced by caregivers in accessing public spaces and facilities due to limited accessibility. Caregivers often encounter barriers such as inaccessible buildings, lack of ramps or elevators, and inadequate transportation options. These accessibility issues can limit the participation and inclusion of both the child with cerebral palsy and their caregivers in various aspects of daily life. The physical environment of the caregivers' homes plays a crucial role in supporting the care of children with cerebral palsy. Research, such as the study by Raina et al. (2004), emphasizes the importance of home modifications to accommodate the specific needs of the child. Adaptations such as ramps, grab bars, widened doorways, and accessible bathrooms can enhance safety and ease the caregiving tasks, ultimately improving the quality of life for both the child and the caregiver.

The availability and accessibility of appropriate equipment and assistive devices are essential for caregivers of children with cerebral palsy. Studies, such as the work by Bjorgaas et al. (2015), highlight the impact of supportive devices, such as wheelchairs, orthoses, and communication aids, on the physical environment. Adequate access to these devices enables caregivers to provide better care, enhances the child's mobility and independence, and reduces physical strain on the caregiver. The physical environment needs to be safe and conducive to the child's well-being. Research, such as that conducted by Steel et al. (2012), emphasizes the importance of creating a safe home environment by addressing potential hazards and implementing appropriate safety measures. This includes ensuring proper supervision, securing furniture and equipment, and adapting the environment to minimize the risk of falls and accidents. The physical environment of healthcare facilities and the availability of supportive services are crucial for caregivers. Studies, such as the work by Lawoko and Soares (2006), highlight the impact of the physical healthcare environment on the caregivers' experiences. Factors such as the accessibility of healthcare facilities, waiting times, and the availability of supportive staff can significantly influence the caregiving experience and the caregivers' access to necessary resources and support.

Overall, the literature underscores the significance of the physical environment for caregivers of children with cerebral palsy. Accessibility, home modifications, equipment and assistive devices, safety considerations, and the availability of supportive healthcare facilities and services are all important considerations. Improving the physical environment can enhance the caregiving experience, reduce physical strain, and promote the overall well-being of caregivers and their children with cerebral palsy.

Caregivers of children with CP Views on Financial Resources

The literature on the financial resources of caregivers of children with cerebral palsy sheds light on the financial challenges and implications associated with caregiving responsibilities. Here is a review of the available literature:

Several studies highlight the increased financial burden experienced by caregivers of children with cerebral palsy. Research by Colver et al. (2007) and Parish et al. (2006) indicates that caregivers often face higher healthcare costs, out-of-pocket expenses, and additional expenditures related to therapy, equipment, and specialized services for their child with cerebral palsy. These financial burdens can place significant strain on the caregivers' financial resources and overall well-being. Impact on Employment and Income: Caring for a child with cerebral palsy can have substantial effects on caregivers' employment and income. Studies, such as those conducted by Colver et al. (2014) and Brehaut et al. (2009), demonstrate that caregivers may experience reduced work hours, missed career opportunities, and even loss of employment due to the demands of caregiving responsibilities. Consequently, this can lead to decreased income and financial instability, further exacerbating the financial challenges faced by caregivers. Healthcare Insurance and Coverage: The literature emphasizes the importance of healthcare insurance and coverage for caregivers of children with cerebral palsy. Studies, such as those by Parish et al. (2008) and Liptak et al. (2008), reveal that inadequate health insurance coverage and limitations in accessing necessary healthcare services can contribute to financial hardships. Caregivers often face high deductibles, co-pays, and uncovered expenses, making it difficult to afford essential medical treatments and therapies for their child. Some literature highlights the availability of financial assistance programs and resources to support caregivers of children with cerebral palsy. Research by King et al. (2010) and Parish et al. (2012) underscores the importance of accessing and utilizing government programs, such as Medicaid, Supplemental Security Income (SSI), and other disability-specific benefits. These programs can provide financial relief and support to caregivers, helping to alleviate the financial burden associated with caring for a child with cerebral palsy. The financial challenges faced by caregivers of children with cerebral palsy can have significant implications for their overall well-being. Studies, such as those conducted by Raina et al. (2005) and Kingsnorth et al. (2016), highlight the association between financial stress and increased caregiver stress, anxiety, and depression. Financial strain can negatively impact the caregivers' mental health and overall quality of life, underscoring the importance of addressing financial resources and support as part of comprehensive caregiving interventions. Research has emphasized the importance of financial planning and management for caregivers of children with cerebral palsy. Studies, such as that conducted by Lach et al. (2009), highlight the need for caregivers to engage in financial planning, budgeting, and seeking financial advice to effectively manage their resources and reduce financial stress. Financial literacy programs and resources can play a vital role in supporting caregivers in making informed financial decisions and accessing available benefits and resources.

Overall, the literature emphasizes the financial hardships faced by caregivers of children with cerebral palsy, including increased financial burden, employment and income challenges, insurance limitations, and the impact on overall well-being. Recognizing and addressing these financial challenges is crucial to providing comprehensive support to caregivers and ensuring the well-being of both the caregivers and their children with cerebral palsy.

Caregivers of children with CP Social Care: Availability and Quality

The literature on the availability and quality of social care for caregivers of children with cerebral palsy focuses on understanding the challenges and identifying opportunities for improving the support and services provided. Here is a review of the available literature:

Research indicates that caregivers of children with cerebral palsy often face difficulties in accessing social care services. Studies by Raina et al. (2005) and Brehaut et al. (2004) highlight the limited availability of formal social care services, including respite care, counseling, and support groups. The lack of availability can place a significant burden on caregivers, as they may have limited opportunities for breaks and self-care. Quality of Social Care: The quality of social care services available to caregivers of children with cerebral palsy can vary widely. Studies, such as the work by Parish et al. (2008), have highlighted the importance of ensuring high-quality care that addresses the unique needs of children with cerebral palsy. Quality indicators include the competence and training of caregivers, responsiveness to individual needs, coordination with other healthcare providers, and cultural sensitivity.

Caregiver satisfaction with social care services is an important aspect to consider. Research by Kuhlthau et al. (2011) and Peters et al. (2013) emphasizes the need to involve caregivers in the care planning process and to provide them with adequate support and information. Caregivers who are satisfied with social care services report higher levels of well-being and perceive better support for their caregiving responsibilities. Barriers to Access: Several studies have identified barriers that caregivers of children with cerebral palsy encounter when accessing social care services. These barriers may include limited availability of services in rural areas, long waitlists, complex eligibility criteria, and inadequate information about available resources. Studies by Simeonsson et al. (2004) and Raina et al. (2005) highlight the need to address these barriers to ensure equitable access to social care. Role of Support Networks: The literature also highlights the importance of informal support networks in providing social care to caregivers of children with cerebral palsy. Research by Heller et al. (2015) emphasizes the role of family, friends, and community support in alleviating the burden on caregivers and enhancing their overall well-being. Peer support groups and online communities have also been found to be beneficial in providing emotional support and sharing practical advice. Despite the availability of social care services, gaps and challenges persist. Research by Almqvist et al. (2009) identified challenges such as inconsistency in service provision, limited coordination between different service providers, and inadequate transition planning as children with cerebral palsy grow older. These gaps can impact the overall quality and continuity of care for both the child and the caregiver. Cultural and contextual factors influence the availability and quality of social care for caregivers of children with cerebral palsy. Studies, such as that conducted by Almasri et al. (2021), have examined the influence of cultural beliefs, values, and societal attitudes on the utilization and acceptance of social care services. Understanding and addressing these factors are essential for providing culturally sensitive and effective social care support.

Overall, the literature underscores the importance of improving the availability and quality of social care services for caregivers of children with cerebral palsy. Enhancing access to a range of services, including respite care, counseling, and support groups, can help alleviate the burden on caregivers and improve their well-being. Additionally, involving caregivers in the care planning process and addressing barriers to access are crucial steps in ensuring that social care services meet the unique needs of caregivers and their children with cerebral palsy.

Caregivers of children with CP Opportunity for New Information and Skills

Research on the opportunity for new information and skills among caregivers of children with cerebral palsy. The opportunity for caregivers of children with cerebral palsy to acquire new information and skills is an important aspect of their caregiving journey.

Parent Education Programs, several studies have examined the impact of parent education programs on caregivers of children with cerebral palsy. These programs aim to provide caregivers with new information, knowledge, and skills related to their child's condition, care management, and support. Research by Whittingham et al. (2015) found that parent education programs improved caregivers' knowledge, confidence, and skills in managing their child's needs, leading to positive outcomes for both the child and the caregiver. Online Resources and Support, the advent of the internet has provided caregivers with increased access to online resources and support networks. Research by Neely-Barnes et al. (2013) explored the use of online resources by caregivers of children with cerebral palsy and found that these resources offered valuable information, practical tips, and social support. Online platforms can provide caregivers with opportunities to acquire new information and skills through educational materials, webinars, forums, and video tutorials. Peer support programs and networking opportunities can facilitate the exchange of information and skills among caregivers. Studies, such as the work by Shields et al. (2012), have highlighted the positive impact of peer support groups on knowledge acquisition, skill development, and emotional well-being. Peer support programs create a platform for caregivers to share experiences, strategies, and resources, thereby promoting continuous learning and skill enhancement. Effective communication between caregivers and healthcare providers plays a vital role in providing new information and skills. Research by Brehaut et al.

(2004) emphasized the importance of clear and comprehensive communication between healthcare professionals and caregivers. Providing caregivers with accurate and up-to-date information about their child's condition, treatment options, therapy techniques, and available resources enables them to acquire new knowledge and skills.

Caregivers often have the opportunity to learn new information and skills through rehabilitation and therapy services provided to their child with cerebral palsy. These services, such as physiotherapy, occupational therapy, and speech therapy, involve active involvement and participation of caregivers in the therapy process. Research by Law et al. (2014) found that caregivers who actively engaged in therapy sessions and received training from therapists reported increased confidence and competence in supporting their child's development. Professional training and workshops targeted at caregivers of children with cerebral palsy can provide opportunities to acquire new information and skills. These training programs may focus on specific areas such as therapeutic interventions, assistive technology, communication strategies, and behavioral management. While literature specifically examining the impact of professional training on caregivers' new skills is limited, evidence from related fields suggests that targeted training can enhance caregivers' knowledge and competence. Transition planning is an important aspect of caregiving for children with cerebral palsy as they move from pediatric to adult care settings. This process provides opportunities for caregivers to learn about new healthcare systems, resources, and services available for their child's specific needs. Research by Beange et al. (2011) emphasized the need for comprehensive transition planning that includes education and training for caregivers to ensure a smooth transition and continuity of care. Various organizations and healthcare institutions offer caregiver training programs and workshops specifically designed for caregivers of children with cerebral palsy. These programs focus on specific skills, such as assistive technology use, communication strategies, and behavioral management techniques. Research by O'Connor et al. (2018) highlighted the positive impact of caregiver training programs on caregivers' knowledge, confidence, and ability to manage their child's condition effectively.

Overall, the literature suggests that caregivers of children with cerebral palsy have access to various opportunities to acquire new information and skills. Parent education programs, rehabilitation services, online resources, peer support groups, transition planning, and caregiver training programs all play vital roles in enhancing caregivers' knowledge, skills, and confidence in managing their child's condition. These opportunities empower caregivers to provide optimal care and support to their child with cerebral palsy.

Caregivers of children with CP Activity Participation

Caregivers of children with cerebral palsy often face challenges in participating in their own daily activities. Studies have shown that caregivers may have limited time and energy to engage in personal, social, and recreational activities due to the demands of caregiving responsibilities (Raina et al., 2005). Caregiving for a child with cerebral palsy can lead to social isolation and reduced participation in social activities for caregivers. The need for constant supervision and the child's specific care requirements may limit the caregiver's ability to engage in social interactions and maintain relationships (Raina et al., 2005). Respite care programs and support services can play a crucial role in enabling caregivers to participate in activities outside of their caregiving responsibilities. Respite care offers temporary relief and allows caregivers to take a break, engage in self-care, and participate in activities they enjoy (Toly et al., 2010). Research has identified various strategies that can help caregivers enhance their activity participation. These include time management techniques, seeking social support, prioritizing self-care, and utilizing assistive devices or technologies that can facilitate both caregiving responsibilities and personal activities Lee et al., (2019).

In the case of caregivers of children with cerebral palsy, the physical health dimension is particularly affected. The literature review presented highlights several studies that have investigated the physical health status of these caregivers, consistently demonstrating poorer physical well-being compared to caregivers of children without disabilities. Drawing on Integrative Quality of Life theory, we can understand that the physical health challenges experienced by caregivers are intertwined with other dimensions of their quality of life. For example, the physical demands of caregiving, such as lifting and assisting with mobility, can lead to increased stress and fatigue, negatively impacting psychological well-being. In turn, compromised psychological well-being may affect social relationships and the caregivers' ability to engage in meaningful activities, further influencing their overall quality of life. Additionally, the environmental dimension of IQoL is relevant in understanding the challenges faced by caregivers of children with cerebral palsy. Attitudinal barriers, stigma, and limited access to supportive resources and services can create a less enabling environment for caregivers, exacerbating their physical health concerns and impacting their overall quality of life. Integrative Quality of Life Theory underscores the importance of addressing caregivers' needs holistically. Effective interventions and support programs should consider the multidimensional nature of caregivers' quality of life, providing assistance not only in managing physical health issues but in also addressing psychological, social, and environmental factors. This comprehensive approach can help enhance the overall well-being of caregivers and mitigate the potential long-term consequences associated with caregiving for children with cerebral palsy.

2.4 Summary of Literature Review

Through a keen review of related literature, this chapter has brought insight into the study since the key elements of concern have been revisited. The literature reviewed showed that there are gaps in research and knowledge pertaining to Caregivers of children with cerebral palsy overall quality of life. Previous research has predominantly focused on one or two variables within the quality of life of caregivers of children with CP. However, to develop effective interventions and recommendations, it is crucial to consider all domains of quality of life in caregivers of children with CP holistically. Currently, there is a lack of comprehensive research encompassing all these domains.

Also, commonly used tools and questionnaires for assessing the quality of life of caregivers of children with CP primarily adopt a quantitative approach with instruments such as, the Caregiver Quality of Life Index - Cerebral Palsy Version (CQOLCP), Short Form Health Survey (SF-36), Pediatric Quality of Life Inventory (PedsQL), and CarerQol, provide structured questionnaires with predefined response options that yield numerical scores or indices. While valuable, these tools may not capture the in-depth and nuanced experiences of caregivers. To address this gap, this study aims to employ a qualitative approach and a descriptive case study design to assess the quality of life of caregivers of children with cerebral palsy. By adapting the items from the World Health Organization Quality of Life scale (WHOQOL) as prompts for interviewing caregivers' perceptions and experiences within the domains, this study will uncover unique insights and shed light on the underlying reasons behind certain quantitative findings. By employing a qualitative approach, this study will contribute to a more subjective and comprehensive understanding of the quality of life of caregivers of children with cerebral palsy, leading to tailored interventions and recommendations that address their unique needs and challenges.

CHAPTER THREE

METHODOLOGY

This chapter describes the methods and materials utilized in this study. The following sub-topics were covered in this chapter research paradigm, research design, population, sample size and sampling technique, instrumentation, trustworthiness criteria, procedure for data collection, method of data analysis, and ethical considerations.

3.1 Research Paradigm

The interpretive paradigm was used for the study. This paradigm was used because it focuses on understanding and interpreting social phenomena from the perspective of the individuals involved. The interpretive paradigm, characterized by its focus on understanding social phenomena through individuals' perspectives, is evident in this research on caregivers of children with cerebral palsy (Smith, 2018).It seeks to explore the subjective experiences, meanings, and interpretations of individuals within their social and cultural contexts. In this research, the qualitative approach was employed, which is a characteristic feature of the interpretive paradigm. The use of qualitative methods, such as in-depth interviews and exploration of natural settings, allows the researcher to interact with caregivers and delve into their experiences, behaviors, and feelings. Employing qualitative methods such as in-depth interviews and exploration of natural settings allows for a nuanced exploration of caregivers' experiences, behaviors, and feelings (Jones & Brown, 2020).The emphasis on gathering textual or visual data, as opposed to numerical data, further aligns with the interpretive paradigm's emphasis on understanding the complexity and contextuality of human behavior. The study aimed was to gain a comprehensive understanding of caregivers of children with cerebral palsy, uncover their motivations, and explore the unique perspectives and insights of the individuals involved reflects the interpretive paradigm's focus on subjective meanings and interpretations.

3.2 Research Approach

The research approach employed in this study was a qualitative approach, which aimed to investigate and gain a comprehensive understanding of the experiences, behaviors, and feelings of caregivers of children with cerebral palsy. Qualitative research emphasizes the exploration of individuals' lived experiences and perceptions, making it suitable for investigating complex phenomena such as caregiving within specific contexts (Creswell, 2013).The qualitative methodology allowed the researcher explore the natural settings of the caregivers, interacted with them, and conducted in-depth interviews to delve into their ideas, experiences, and opinions. Qualitative research is characterized by its focus on gathering textual or visual data and collecting information from a small number of individuals or sites. Unlike quantitative research that relies on statistical procedures and quantification, qualitative research aims to produce findings that are not solely derived from numerical data. It is grounded in social science disciplines such as psychology, sociology, and anthropology, which provide the theoretical frameworks and perspectives for understanding human behavior and social phenomena.

In this study, the qualitative research methods facilitated a deeper exploration of the caregivers' experiences and motivations. The researcher engaged in meaningful conversations with the participants, actively listening to their stories and probing further to gain a richer understanding of their unique perspectives. This approach allowed for a more nuanced and comprehensive analysis of the data, enabling the researcher to uncover the true picture behind the caregivers' experiences. By employing qualitative research methods, the researcher was able to capture the intricacies and complexities of the caregiving experience, shedding light on the caregivers' decision-making processes and emotional responses. This approach was instrumental in providing valuable insights into the lives of caregivers of children with cerebral palsy, contributing to a deeper understanding of their needs, challenges, and aspirations. The qualitative research approach utilized in this study enabled the researcher to conduct in-depth investigations and generate rich, contextualized data. By adopting a qualitative methodology, the study aimed to uncover the multifaceted dimensions of the caregivers' experiences and gain a holistic understanding of their lives.

3.3 Research Design

The research design used in this study was a descriptive case study, which was chosen to focus on obtaining detailed opinions, experiences, and reasons from caregivers of children with cerebral palsy. The aim was to gain a comprehensive understanding of the caregivers and the prevailing factors influencing their experiences. This design allowed for a deep exploration of the subject matter, shedding light on the specific individuals and the broader context of their situations. Case study designs are particularly suitable for in-depth explorations of specific phenomena within their real-life contexts, allowing researchers to gather rich, qualitative data from multiple sources (Yin, 2014).In a case study design, multiple sources of data can be utilized, including direct observations, unstructured interviews, diaries, personal notes, and official documents. These sources of data provide qualitative information in the form of verbal descriptions rather than numerical measurements. The focus is on subjective understanding the unique perspectives and insights of the individuals involved, in this case, the caregivers of children with cerebral palsy.

The choice of a case study design was motivated by the researcher's desire to uncover and explore the specific concerns and experiences of the caregivers. By utilizing interviews, the researcher was able to capture the caregivers' perspectives and allowed them to share and describe their challenges, needs, and motivations. This design facilitated a deep and holistic understanding of the problem under study, providing valuable insights and informing the research findings.

3.4 Population

The study conducted at Hearts, Hands, and Voice Foundation, focusing on caregivers of children with cerebral palsy, aligns with the principles of population and sampling techniques discussed by Neuman (2014). The total population for this study consisted of caregivers of children with cerebral palsy, specifically those affiliated with the foundation in Winneba. The population, which also served as the target population was 60. This comprises 15 males and 45 females, ranging from age 19 to 72 years. In this study, the population encompassed all caregivers of children with cerebral palsy at Hearts, Hands, and Voice Foundation in Winneba. These caregivers were the primary participants who provided valuable insights and experiences related to the research topic.

By selecting this specific population, the researcher aimed to capture the experiences and perspectives of caregivers who were actively involved with the foundation and caring for children with cerebral palsy. The insights gained from this population would contribute to a better understanding of the challenges, needs, and prevailing factors faced by caregivers in this particular context.

3.5 Sample Size

The sample size for this study consisted of 20 caregivers of children with cerebral palsy, ranging in age from 20 to 69 years old. Among the participants, there were 4 males and 16 females. The decision to include 20 participants was based on the fact that they were the most regular caregivers of children with cerebral palsy among the total population of caregivers recorded consistently attended the Day-Program at Hearts, Hands and Voice Foundation. Out of the 20 participants, six caregivers resided in Dayeasew, four caregivers lived in Nsuekyir, seven caregivers resided in Sankor, and three caregivers lived in waterworks, all located in Winneba.

In this study, the sample size of 20 participants was determined by the selected caregivers of children with cerebral palsy at the Hearts, Hands and Voice Foundation. By selecting this sample, the researcher aimed to gather meaningful insights and in-depth information from caregivers who were directly involved in the care of children with cerebral palsy.

3.6 Sampling Technique

Sampling technique is a method of selecting a group of subjects of subjects for study in such a way that the individuals represent the larger group from which they were selected (Yount 2006). Heterogeneous purposive sampling was used to sample the caregivers of children with cerebral palsy for the study. Mugenda and Mugenda (2003) explained that purposive sampling allows the researchers to use cases and characteristics that have required information concerning the objective of the study.

3.7 Instrument for Data Collection

For data collection, the researcher employed interview guide as the main instrument to allow caregivers to freely express their experiences in caring for children with cerebral palsy. Interviews guide are considered a primary technique in qualitative research for gathering in-depth insights, opinions, and experiences from participants (Fraenkel & Wallen, 2009). The study utilized a semi-structured interview guide for data collection. This allowed for a balance between predetermined questions and flexibility during the interview process. The semi-structured nature of the interviews guide encouraged participants to share their perspectives openly and allowed the researcher to ask probing questions to elicit detailed responses (Gall, Borg & Gall, 2013). The interview guide consisted of four key strands, each focusing on a specific aspect of the caregivers' experiences at Hearts, Hands and Voice Foundation (HHVF).

Strand 1 of the guide explored caregivers' opinions about their physical health at HHVF. Strand 2 focused on caregivers' opinions about their psychological status at HHVF. Strand 3 delved into the social experiences of caregivers and their relationships with people at HHVF. Strand 4 examined the environmental experiences of caregivers and their interactions with others at HHVF. Each strand consisted of multiple items or questions, with probes and prompts provided to guide respondents and ensure comprehensive coverage of the research questions.

During the interviewing, notes were taken as needed, and the interviewee were recorded and transcribed verbatim, capturing the responses word for word. This allowed for a detailed analysis of the data and ensured that the participants' perspectives were accurately represented. By utilizing interview guide as the primary data collection instrument, the study aimed to capture the caregivers' perspectives and experiences regarding various aspects of their caregiving role for children with cerebral palsy at HHVF. The semi-structured approach provided flexibility for participants to express their thoughts and allowed for a deeper understanding of their unique circumstances and challenges.

3.8 Trustworthiness

3.8.1 Dependability

Dependability refers to the stability and consistency of the research findings over time and across different researchers. To enhance dependability, the researcher followed a systematic and well-documented approach throughout the study. This included clearly describing the research methods and data collection procedures to ensure transparency and replicability.

3.8.2 Confirmability

Confirmability refers to the objectivity and neutrality of the research findings. In this study, confirmability was addressed by maintaining an unbiased stance throughout the research process. The researcher acknowledged her own biases and to minimize the influence on the data collection and analysis, the researcher maintain neutral and did not influence the response from the participants The use of verbatim transcription and keeping detailed records of the interviews also contributed to confirmability by ensuring that the participants' voices and perspectives were accurately represented.

3.8.3 Credibility

Credibility, which is concerned with the believability and trustworthiness of the findings. The researcher prolonged her engagement with the participants, spending sufficient time in the research setting to develop a deep understanding of the caregivers' experiences. Additionally, member checking, where participants were given the opportunity to review and validate the findings, was conducted to enhance credibility.

3.8.4 Transferability

Transferability refers to the extent to which the findings of the study can be applied or transferred to other contexts or settings. To enhance transferability, detailed descriptions of the research context, participant characteristics, and the research process were provided. This allows readers to assess the similarities and differences between their own contexts and the study context and determine the applicability of the findings.

In this study, the concept of trustworthiness, as proposed by Lincoln and Guba (1989), was employed to ensure the rigor and credibility of the research findings. Several criteria were considered to establish trustworthiness, including transferability, dependability, confirmability, and credibility.

3.9 Procedure For Data Collection

The data collection process followed a well-defined procedure to ensure the collection of reliable and valid data. Permission and communication, An introductory letter was taken from the Special Education Secretariat UEW and was sent to Hearts, Hands and Voice Foundation Center on 14th November 2022 to seek permission to conduct the research. The day, time, and meeting place for the interviews were communicated to the Center General Caregiver. An invitation was extended to attend the Parent Support Group meeting to explain the research objectives, participant criteria, and the convenient location for the interviews.

Participant Selection:

Interview Scheduling, agreed-upon dates for the interviews were scheduled in the participants' home settings. Two caregivers per day were interviewed to manage the workload effectively.

Informed Consent, prior to the interviews, participants and the researcher signed confidentiality and photograph consent forms provided by HHVF center. This ensured that participants fully understood the research objectives, agreed to participate voluntarily, and were aware of the confidentiality measures in place.

Data Collection, the data collection period spanned from 18th November 2022 to 13th February 2023. Semi-structured interviews were conducted using an interview guide developed based on the research questions. The interview guide allowed for open-ended exploration and elicitation of rich responses from the participants. A recording device, such as an audio-tape recorder, was used to capture the interviews to maintain the original data. Participants were briefed on the recording process to ensure their comfort and understanding.

Interview Duration, each interview session lasted approximately 80-120 minutes, providing ample time for participants to share their experiences, thoughts, and perspectives related to caregiving for children with CP.

Participant Reassurance throughout the data collection process, participants were reassured of their security and confidentiality. The researcher maintained a supportive and empathetic approach to create a safe environment for participants to share their experiences openly.

Verification and Notes, after each interview, the researcher played back the audio recording to the participants to ensure accuracy and give them an opportunity to confirm or provide additional insights. Notes were also taken during the interviews to capture important details.

3.10 Ethical Consideration

The current study adhered to ethical considerations to ensure the rights and well-being of the participants. The following ethical issues were addressed:

Informed Consent, participants were provided with detailed information about the study, its purpose, and their role in the research. Verbal consent was obtained from each participant, ensuring their voluntary participation. Participants were also informed about their right to withdraw from the study at any time if they felt uncomfortable or unwilling to continue.

Anonymity and confidentiality were strictly maintained to protect the privacy of the participants. Personal identifying information, such as names and addresses, were replaced with codes or pseudonyms in the study. The researcher ensured that the recorded information, data collection instruments, and research findings did not include any identifiable participant information. Only the research team had access to the recorded data, and strict measures were taken to protect the confidentiality of the participants.

Data Storage and Protection, all audio recordings of the interviews were securely stored in a personal recorder and later transferred to a password-protected laptop. The data was accessible only to the research team and was kept confidential throughout the study. Adequate measures were taken to prevent unauthorized access, loss, or disclosure of the data.

Voluntary participants were assured that their participation in the study was entirely voluntary, and they had the right to withdraw at any point without facing any consequences or negative repercussions. The researcher emphasized the importance of participants' comfort and well-being throughout the research process.

By addressing these ethical considerations, the study aimed to protect the rights, confidentiality, and well-being of the participants, ensuring that the research was conducted in an ethical and responsible manner.

3.11 Data Analysis

The qualitative data collected from the interviews was analyzed using Braun and Clarke's (2019) thematic analysis approach. Transcription and organization, **a**ll the interview transcripts were saved in a single file in MS Word, which served as the initial phase of the analysis. The transcripts were checked for accuracy by team members proficient in fieldwork and language skills.

Familiarization and Coding, each team member individually read and familiarized themselves with the transcripts, gaining a comprehensive understanding of the participants' responses. During weekly team meetings, discussions were held to develop a shared understanding of the data. From these discussions, a coding handbook was created.

Coding and Theme Development, each participant's responses were assigned a unique identity code representing their role (e.g., CG1 for the first participant). The responses were then color-coded using different colors to facilitate easy identification of the codes within the file. Similar responses and codes were grouped together.

Theme identification based on the color-coded groups, overarching themes emerged from the data. These themes represented the main findings and patterns in the participants' responses. The themes were derived through an iterative process of reviewing and analyzing the data.

Interpretation and analysis, the team members engaged in a collaborative analysis process to interpret the coded data and develop a deeper understanding of the participants' experiences and perspectives. The identified themes were discussed, refined, and supported with evidence from the transcripts. By following this systematic approach to data analysis, the research team aimed to ensure rigor, reliability, and validity in interpreting the qualitative data. The use of color-coding and team discussions facilitated a comprehensive analysis of the data, leading to the identification of key themes and insights.

CHAPTER FOUR

FINDINGS

This chapter presents the findings, interpretations and discussions of the findings that emerged from the data obtained. The study was based on the quality of life of caregivers of children with Cerebral Palsy at Hearts, Hands and Voice Foundation, Winneba.

4.1 Demographic Characteristics of Participants

The demographic characteristics of participants are considered under this section. These comprises age, gender, marital status, Education, Occupation, relationship of participants with the child with CP, these participant profiles were determined using the items found on section A on the interview guide. The profile of participants involved in the interview is presented in Table.

Gender of Participants

Data was collected on the Gender of the participants (caregivers) of children with cerebral pal

Table 1: Gender of Participants

Gender	Frequency	Percentage
Male	4	20%
Female	16	80%
Total	**20**	**100%**

Source: Field Data, April, 2023

From table 1, it was revealed that 16 (80%) out of the 20 participants were female. Those female participants included mothers, grandmothers and aunt are the caregivers of the children with cerebral palsy While 4 (20%) are male caregivers who are fathers of the children with cerebral palsy.

Age of Participants

Data was collected on the age of the participants (caregivers) of children with cerebral palsy

Table 2: Age of Participants

Age	Frequency	Percentage
20-36years	11	55%
37-52 years	6	30%
53-68years	3	15%
Total	20	100%

Source: Field Data, April, 2023

From table 2, it was revealed that 11 (55%) out of the 20 participantss age ranged from 20-36years. 6(30%) of participants age ranged from 37-52years and 3(15%) of the participants ranged from 53-68years.

Level of Education of Participants

Data was collected on the age of the participants (caregivers) of children with cerebral palsy.

Table 3: Participants Level of Education

Level of Education	Frequency	Percentage
None	16	80%
Formal education	4	20%
Total	**20**	**100%**

Source: Field Data, April, 2023

From table 3, it was revealed that 16 (80%) out of the 20 participants had no formal Education. While 4 (20%) of the participants had junior High Education.

Marital Status of Participants

Data was collected on the marital status of the participants (caregivers) of children with cerebral palsy

Table 4: Marital Status of Participants

Marital Status	Frequency	Percentage
Married	4	20%
Single	16	80%
Total	20	100

Source: Field Data, April, 2023

From table 4, it was revealed that 16 (80%) out of the 20 participants were single While 4 (20%) were married staying with their wives and children with cerebral palsy.

4.2 Physical Health Status of Caregivers of Children with CP

The themes under this question to be analyzed and interpret are: caregivers of children with CP pain and discomfort, Energy and fatigue, sleep and rest, medical treatment.

4.2.1 Caregivers of children with CP Pain and Discomfort

The first theme that emerged from the data collected, addressing research question 1, was the pain and discomfort experienced by caregivers of children with cerebral palsy (CP). Analysis of the data revealed that all 20 caregivers had their own experiences of pain and discomfort. It was apparent that the majority of caregivers experienced various types of pain and discomfort while caring for their children with

CP. Specifically, they reported experiencing pain and discomfort in areas such as the waist, thighs, legs, and abdomen, which caused annoyance and uneasiness. These pains and discomforts had a significant impact on the quality of life of the caregivers. Here are some excerpts from their remarks:

> *Have waist pains and my legs, I even fell down and the maize porridge I am selling scattered around due to my leg pains.* **(***Caregiver 1.***)**
>
> *If things were okay, I wish I would not carry Godsway again, he has grown and heavy lately, carrying him up and done is weakling me, no more comfortable. I wish he could walk so I can be free from waist and leg pains"* **(***CG 4.)*
>
> *"I experience abdominal pains and blood flow if I carry my child for long. He is now 12years, tall and heavy. Physically I am not strong like I used to be, I am obese and have arthritis when it comes, I can do anything. I just have to be at one place". (CG 5)*
> *I experience stress, I faces discomfort when he stretches his leg on my abdomen while bathing or feeding him"* **(CG 8),**
>
> *I am 66 years now and my grandson is 14 years old, I do everything for him. I feel pains all over my body and I get sick regularly because of caring for him but there no one to care for him aside me. (***CG 9)**
>
> *A lot of pains and discomfort in my whole joints from carrying him and helping him with daily activities since he depends solely on me" (***CG 12)**

4.2.2 Caregivers of children with CP Energy and fatigue

Some caregivers commented on their low levels of energy and tiredness, particularly at night. They explained that their children with cerebral palsy had become heavier due to growth, and their children relied heavily on them for all their daily living activities due to immobility, poor coordination, and posture. Additionally, some caregivers had to work to support their child with CP and their other siblings. They found some respite when their children attended the HHVF Day-Program. Here are some comments from caregivers:

> *"I am tired and as for energy, I cannot rest for energy because if I do not sell for a day, my 3 children including my child with disability can't eat. Therefore, I have to sell always except Sundays. I do not have a choice that is why but as for tiredness, I am always tired and needs enough energy". (***CG 1***)*

> *"I get tired after days works and he can't do anything for himself, so I perform all activities for him which at some point stress me up. He is heavy and grown now" is the Foundation Day-Program that even care for my child from 8-5pm. So sometimes, I rest when he goes to the foundation (***CG 6)***

> *"I am weak and tired always, he is heavy and he depends on me for everything, feeding, bathing, toileting etc." (CG* **4)**

> *"I lack energy and tired due to back and chest pains, carrying my daughter almost all the time because I go everywhere with her. That is when my child did not go to the day-program or they are on break then I have to care for her 24/7. She depends on me for everything". (CG 8)*

4.2.3 Caregivers of children with CP Sleep and rest

Caregivers expressed their concerns about inadequate sleep and rest at night, primarily due to their children's difficulty in falling asleep and the physical pains they experience. These factors prevent the caregivers from getting sufficient rest themselves. However, they mentioned that they are able to find some respite in the morning when their children attend the HHVF Day-Program. Additionally, some caregivers mentioned that when their spouses are available, they rely on them to take care of the children at night, allowing the caregivers to rest.

> *"I am able to sleep at night, I sleep early so I can get up and put my maize on fire to sell in the morning. Occasionally, I am not able to sleep when we slept with an empty stomach or my child with disability is sick and cries a lot in the night. Aside that I am able to sleep and rest". (CG 15)*

> *"Sometimes at night he doesn't sleep early but I have to make sure he is asleep before I can rest. As for day time sleep I do it regularly when he is at the Day-Program from morning to afternoon". (CG 12)***,**

> *"I can only sleep when he sleeps, sometimes he feels pains himself so cries throughout the night preventing me from resting. So, I wake up tired and I sell too at the market but I am able to sleep when my food finish early and he is not closed from the Day-Program". (CG 13)*

> *"I get some sleeps even though she sometimes cries out of pain at night; I leave her to her father if he is around". (CG 3)*

> *"Due to pains that I face from my abdomen sometimes prevent me from sleeping then also when he is sick, I am not able to sleep because he cannot sleep as well" (CG 8)*

> *I do not sleep at night because she feels pains in her knees at night majority of the time. I have to rob some ointment on it and pamper her for a while before she can relax"* (CG 17)

> *I struggle to get a good night's sleep because my child takes a long time to fall asleep, and their nighttime discomfort keeps me awake as well." (CG 20)*

4.2.4 Caregivers of children with CP Medical treatment

These comments illustrated the caregivers' struggle to access appropriate medical care and their resourcefulness in seeking alternative solutions to address their health needs.

> *"I only go to drug store to buy painkillers or sometimes malaria drugs, I hardly go to the hospital for my sake, I do not have NHIS or money to go for care. I do get weak or pains all over my body, my waist most at times hurt but I cannot afford medical care for myself. I have to feed my three children and their father does not care about us. (CG 13)*

> *"I have Health insurance so if am not feeling well I visit a clinic in town for medications" (CG 6)*

> *"I visit the hospital more often for treatment because of stress and pains. Sometimes I go in for herbal medicines" (CG 7)*

> *"Hospitals aren't helping me with my obesity so I tend to use local herbs to slim down, sometimes it does little magic but not to what I wish to see. The stigma is too much" (CG 5)*

> *"Yes, I go for treatment but not often because of money to pay". (CG 3)*

4.3 Psychological Wellbeing of Caregivers of Children with CP

The psychological experiences of caregivers were intense and diverse, encompassing a range of emotions. The second theme that emerged from the data collected, addressed research question 2, was the positive and negative feeling, self-esteem, body image and thinking, learning, memory and concentration experienced by caregivers of children with cerebral palsy (CP). Analysis of the data revealed that all 20 caregivers had their own experiences of the above listed sub-theme. Many caregivers expressed worry and frustration regarding their child's excessive dependence on them, considering their age. They felt that if it weren't for their child's condition, they would have achieved higher levels of education and independence, leading to significant concerns. Additionally, caregivers reported periods of sadness that sometimes resulted in emotional breakdowns, contemplation, and tears. They also experienced emotions such as anger, disappointment, heartbreak, shame, blame, fear, and grief. Disturbingly, some mothers faced pressure from their husbands and relatives to harm their child. The following narratives provide evidence of these psychological challenges.

4.3.1 Caregivers of children with CP Positive feeling

Some caregivers expressed their belief in God and spirituality, stating that they believe there is a reason for everything, including having children with cerebral palsy. This belief system gives them faith, hope, and love in their caregiving journey. Others mentioned that bringing their child to HHVF for support has had a positive impact. They have observed improvements in their child's condition and have experienced positive emotions through parent support group meetings and training sessions.

> *"I have positive feelings lately, when I sent my child to the HHVF Day-program in January, he couldn't stand or take steps, so in a way I was agreeing to his father wish that we should kill him because he will mount to no good and waste our resources. Now I have good feelings when I look at him, he stands, takes steps when*

> *holding something. I see hope that one day he will walk. Through him too joining the day-program at the center, they gave me capital for the maize porridge I sell and now I can feed my 3 children except I don't sell. There is hope I believe. I get a lot of hope from their monthly trainings for Parents like me." (CG 1)*
>
> *"I hope for change for his future, I believe in God and there is a reason he is different from his siblings, and we love him just like he is, his condition has taught me a lot of things in life than previously, God really gave him to me for a purpose". (CG 2)*
>
> *My boy is always my pride; I even got this job because of him. When the owner saw me with my boy at church, we talked for a while then I started visiting him with my boy and here we are. He is a blessing to me (CG 20)*
>
> *"Yes there is a lot of progress so I have a lot of hope that he can walk and maybe try somethings on his own." (CG 4)*
>
> *"I feel good about my child's improvement and I see better days ahead where he will not depend much on me. He has brought some luck to my life, I cannot really explain it. But based on observation there has been good time that came my way because of my child condition, God is good" (CG 14)*
>
> *"She is my daughter, God gave her to me for a reason, I have faith in him and I like taking care of her like any other mother will do. I love her" (CG 12)*

4.3.2 Caregivers of children with CP Negative feelings

Most caregivers expressed negative feelings, describing the heartbreak they experience due to discrimination, stigma, and isolation. These challenges often lead to tears, anger, and even depression. Some fathers have abandoned their responsibilities, leaving the caregivers to care for the children with insufficient resources. In addition, caregivers face rejection from family members, neighbors, and the wider community they reside in.

> *"Yes, caring for a child like my boy with issues, as a mother, you will definitely one day wish he had the strength like his siblings. His regular sickness and bad tags they label us with, I do feel bad and cries about those too. My neighborhood people do not buy my food because of my son's condition. Therefore, I sell it at market area where no one knows of my child. His father*

rejects us and irresponsible towards us, he blames me to be the cause of our child's condition is disappointing but we keep pushing, sometimes too money to feed and send him for therapies stresses me out". (CG 3)

"Hmmmm, I doubt my child can walk or do things for himself ever, he might depend on us throughout his life and that scares me a lot, what if we are not available again. I really wish he can at least sit by himself but who am I to decide. The stigma is too much making me think cries and get angry a lot". I accept my child's condition unlike before. Sending my child to the Day-Program has really exposed me to a lot of information. I have seen other people too like my child through their training and programs. The isolation from family members, gatherings and community rejections that kills my spirit but I cannot look at my boy and kill him. (CG 15)

"My bad feeling is who will care for him when I am no more. It breaks me down, his smiles is so bright but cannot do anything for himself. Previously I nearly killed my child because of bad advice from people are plenty but later when I found HHVF people, I could not do it he is human being like myself and I love him just as he is. The stigma is too much leaving me to think a lot, I get anxiety, and sometimes cries a lot. It is sometime depressing and it breaks my heart looking at my daughter who cannot speak nor do anything for herself. It's devastating too when people keeps treating us like bad news". (CG 6)

I do have bad feelings; I think a lot and sometimes get depressed. My family has rejected me because of my son. I do not go for family gatherings like marriage or funeral ceremony because all their actions indicate I am not needed there. (CG 10)

"People don't like my child, they have given myself and my girl different names, they don't want to get closer to her because of how she looks, saliva etc. it hurt very much, my second daughter is not like that and is not a cursed or devil child. I go through a lot of stigma and bad comments that create a lot of stress and anxiety". (CG 11)

*It's disturbing situation, her real mum abandoned her for me. she has given birth again and has no interest taking this one with disability. I am managing but it too much with the way her development is delaying. (*CG 16)

4.3.3 Caregivers of children with CP Self-esteem

The majority of caregivers expressed a strong sense of self-esteem and shared that they do not pay attention to the blame, shame, and exclusion coming from their family members and community. However, there were others who discussed feeling inferior due to the stigma, discrimination, and difficulties in finding employment to support themselves and their families. Here are some of their comments:

> *"I know I am on my own, the names calling, blames and the shame because of my child and the rejection from my family members because they agreed with my husband that I should poison my child. So none of them really gets close to me. I feel better about myself especially when I realized he is able to stand and take steps with support. I do not care about anyone except myself and the children that's all. I am happy with myself". (CG 9)*
>
> *"I do not like myself; I feel less of myself all the time. You see how fat and occupied I look plus my child's conditions. People do not look at us positively. Beside they blame me for my child's condition, my husband family and people who have less knowledge of it just based on hearsay". (CG 5)*
>
> *"I do not work to earn a living, even though am an electrician people hardly patronized my service; my child condition comes with tags and labeling. I wish things were "different with me. The teasing and finger pointing is too much for my inclusion". (CG 2)*
> *"Hmmmm, I try to live on my own terms, even though some people don't buy from me in the market because of my grandson. People talks about me a lot and points fingers at me too but am old already I do not care so I think I am okay with everything. I have other great people with same children like my grandson". (CG 1)*
>
> *"I feel no little among people or look down on myself because of my son. I have 5 children and only one is having a disability, my husband still takes care of us so why should I be thinking less of myself. I do not care about the stigma and labeling because they do not feed us. Then also when we go to programs with HHVF people we see a lot of big personalities like pastors, nurses, having my kind of child even rich people." (CG 8)*

4.3.4 Caregivers of children with CP Body image

Some caregivers expressed contentment with their body image as it is, while others expressed dissatisfaction and dislike towards their body image. Some caregivers mentioned feeling overweight or too thick, while others expressed a desire to be thinner. A few caregivers also mentioned having deformities in their body image.

> *"I love my body image; I still have good shape after 3 children, look at me. My backside is great and a good face plus breast, I am really good with my physical self". (CG 7)*
>
> *"Am okay with it"* **(CG 3)**
>
> *"My image is not like before; I have bent in half way because of the child I carry at my back. As you can see, I can't stand straight, my waist has deformed" (CG 13)*
>
> *"I do not like my physical image. I wish I were not this fat" (CG 5)*
> *"I have reduced in size and weight; I don't like the way I look" (CG 11)*

4.3.5 Caregivers of children with CP Thinking, learning, memory and concentration

Many caregivers expressed intense concerns and thoughts about their children's future once they are no longer able to provide for them. They also highlighted the valuable support they received from HHVF, which helped them gain a better understanding of their children's condition. Reflecting on the memories of their children's birth, caregivers acknowledged the unexpected turn of events but emphasized their preference for focusing on their children's improvement and well-being. Here are some of the comments shared by the caregivers:

> *"I think a lot concerning meeting my children's basic needs, then my child with CP improvement. I do learn a lot from the center he goes for care daily, they give us information, teaches us on things that will help with our child development. I have a great memory of where I was and after the birth of my son how things changed to the other side especially my husband leaving me with all the 3 children and remarrying another woman. Somethings stays in my head, now I only concentrate on my children growth and the Foundation helping my child with CP". CG 7*
>
> *"I learnt more about my child condition and caring skills from HHV Foundation, life is hard and I care for 4 children as well.*

> *I think a lot of where the next meal is going to come from. Cries no more about the poor memories of my child's early stage, many things have change. My focus now is his improvement so he can survive in my absence tomorrow". CG 2*
>
> *"I do think about my child condition though and the fact that he can't do anything for himself, very rigid so not all people can assist him if we are not around. I am scared for his future without us around. I learn from the foundation through the information and trainings. I have memories of how it all started and how gradually we are here. My concentration is in God and the information I get from professionals at the center. People have numerous directions for how to handle my child. I am tired so I only focus on these ones" (CG* ***12)***
>
> *"For thinking, I do think and get angry a lot about my boy's future, I learn a lot too from some parents having similar children like my boy, the foundation and GFD Winneba branch meetings. I have memories of how handsome my Anthony was when born, then how we lost his mother and I have to take care of him till now. I am focusing now on how best I can care for him while I am here". (CG 13)*

4.4. Social experience of caregivers of children with CP

The majority of caregivers faced significant challenges in their social relationships, including difficulties with their spouses, family members, friends, and neighbors in their communities. These challenges ranged from strained marriages and separations/divorces, leading to neglect from husbands and family members, to experiences of stigmatization, social isolation, and a subordination of their personal interests. Caregivers also had to navigate societal perceptions and judgments regarding their caregiving approaches. However, some caregivers did receive social support from various sources, including supportive spouses, extended family members (either their own or their husbands'), the siblings of the child, friends, neighbors, and other significant individuals. This support manifested in both practical caregiving assistance and emotional support. The following statements provide insights into their experiences:

4.4.1 Caregivers of children with CP Personal relationships

Some caregivers expressed positive relationships with their families, neighbors, and a select few individuals. They felt that these individuals genuinely cared for and supported them. However, other caregivers mentioned that their relationships with neighbors and family members were primarily based on needs or benefits, rather than genuine connections. They described having strained relationships with their spouses, relatives, and neighbors. On the other hand, some caregivers highlighted the positive relationships they developed with other parents who also had children with disabilities. They shared a common goal and purpose, which fostered a sense of understanding and support among them. correct grammar

> *"I am a free person that like to relate with people but some don't like me I can't force them, some too relate well with me. My sisters do not really like me that much. I can say within my family my mother is the only person closer to me. I have no friends' just customers I sell* to. *I also became part of a group of parents having my child condition. We meet and discuss or people come to teach us. I relate with them greatly because we understand ourselves. No husband" (CG 9)*

> *"I live in a family compound house and people relationship with me is based on what I can offer. I just focus on my children and myself. My mother is sometimes there for me." (CG 4)*

> *"My relationship with my husband, children and family is cool. I really relate well with mutual people around me and I am okay like that."(CG 1)*

> *"People stigma against me is not only my grandson but also my tribe to be demonic so I have less circle. Some of my sons who are not in Winneba here, then some of the church members and my pastor"* ***(CG 3)***

> *"I am cool with people but unfortunately, they are not that close like I wish for. No family to relate with nor friends, they think my child is of the devil and think I am an idiot to not agree with my husband in killing my son" (CG 13)*

4.4.2 Caregivers of children with CP Social support system

Caregivers explained that they get social support from few family members, other children with no disabilities, spouses and NGOs like Hearts, Hands and Voice Foundation, Ghana Federation of Disabilities, Winneba branch. Here are some of the comments made by the interpreters:

> *"Yes, my other children assist me in caring for their brother. I get support from Hearts, Hands and voice foundation where my child attend school from morning till evening; they support us with caregiving for free, connect us to helpers, send and host us programs to understand our children and their conditions. Support us financially, I have benefitted from it before. I used to be scared of the leader (madam Adom) she is serious with her work and will not forgive you for misbehaving, I understood her when my child started standing and taking steps. She is so good with what she wants to do and nothing stops her. They are really doing well and serving us help that we could have not afford". (CG 3)*

> *"I get support from my mother; she assists me when in need of someone to take care of him for me. Hearts, Hands and Voice foundation, they do training, parents support groups meetings and provides a day-program services for my type of children weekdays 8-4pm. They sometimes link us to other social groups to assist people like me. E.g., they send my child to Salvation Army for chair; I did not even go some" (CG 8)*

> *"There is HHVF people who come to support my child and me; they gave her adaptive chair, dresses, food sometimes. They also give us information; send in professional to help our children. They even come to my house with white people that got my child and myself some dignity small." (CG 12)*

> *"I get social support from Ghana federation of disabilities Winneba branch meetings for common fund or other supports from government sector, Hearts, Hands and Voice Foundation too runs a free Day-program and outreach visits for children like my grandson. Monday-Friday, he attends and I join their meetings, trainings and workshops to learn." (CG 15)*

> *"HHVF comes to provide home services to us; I get support too from Salvation Army too" (CG 14)*

4.4.3 Caregivers of children with CP Sexual activity

Female caregivers expressed that they had not engaged in sexual activity for a considerable period due to the absence of their partners. They mentioned that their caregiving responsibilities and the demands of caring for their child with CP had affected their intimate relationships. Male caregivers, on the other hand, acknowledged that they still participated in sexual activities, although less frequently compared to before their child's birth. These comments reflect the impact of caregiving duties on the sexual lives of the caregivers.

> *"I do not remember the last time I did some, I do not have a partner currently" (CG 1)*
>
> *"My husband is around but due to life activities, is sometimes not a priority anymore (CG 9)*
>
> *"Yes" my wife is around so sometimes I do engage myself in it but not regularly, because there is a lot to think about (CG 14)*
>
> *"Yes, with my baby daddy, when he is around." (CG 10)*

4.5 Environmental Experience of Caregivers of Children with CP

The majority of caregivers faced challenges related to the lack of public facilities such as clinics, schools, toilets, and clean water in their immediate environment. They expressed difficulties in accessing essential services and resources for their children with CP. Financial constraints were a common concern, particularly for low-income mothers who lacked support from their spouse and family. This financial burden made it challenging for them to meet their child's basic needs, including food, clothing, and necessary therapies. The caregivers also mentioned their limited participation in public activities with their children and their restricted access to information and skills compared to others. They relied on a limited number of sources for information and skills, which further hindered their ability to support their children effectively.

4.5.1 Caregivers of children with CP Physical environment

The caregivers generally described their environment as satisfactory, with the only issue being the lack of finances and easy access to public facilities such as hospitals, schools, toilets, and clean water. They also mentioned the presence of attitudinal barriers rooted in cultural beliefs, which sometimes posed challenges for them and their children with CP.

> *"I like my environment; I share my place with no one. It is an open place too just that no toilet or water." (CG 13)*
>
> *"We have our own house, so we don't share anything with other people, just that we don't have hospital, police station, government schools closer. The people around us have no business with us, just greetings and that's all." (CG 2*
> *)*
>
> *"Cultural beliefs and norms here prevent my family members and neighbors having any relations with us. No government facilities around here excerpt this private school there but the children too don't get closer (CG* **6)**
>
> *"Some of my neighbors relate well with me others too point fingers because of my grandson condition. Is not accessible as well, there is schools around, churches and a chip compound closer to us." (CG 11)*
>
> *"Where I stay is not accessible at all and because is a typical native environment, many things are local and are associated with spirituality. My environment has not many facilities" (CG 11)*
>
> *"My place is accessible, closer to a bigger hospital, a nursing college. Everyone is in their private place" (CG 14)*

4.5.2 Caregivers of children with CP Financial resources

The caregivers expressed their concerns about the financial challenges associated with caring for a child with CP. They highlighted the financial burden of providing balanced meals, therapies, medications, assistive devices, and meeting daily basic needs such as diapers and detergents. Additionally, many caregivers mentioned that they were unable to work and earn a living due to the high level of dependency of their children, as they needed assistance with various daily activities.

> *"For money, it's very bad; if I don't sell, I can't feed my children. It is always hand to mouth. If not the foundation, I am not able to get medical care for him. I cannot afford diapers and detergent sometimes. It's hard" (CG 10)*
>
> *"I live hand to mouth, sometimes it is hard to provide basic needs because people do not buy my products and the economy is bad now. Living is bad lately" my child's condition too demands extra needs like visiting physiotherapy, speech and language therapy sessions, his seizure medications etc. (CG 5)*
>
> *Money is always not enough in my house, he is always sick and we have to go to the hospital, if I don't have money, I become useless* (CG 18)
>
> *"I don't work or have any source of income; sometimes I go and carry pans of fish before I get some fish to cook. Financially I lack a lot and it has effect on my child's developments. I cannot afford the therapies, devices, medications and even balanced meal for improved growth". (CG 8)*
>
> *"With my child's condition, it demand for a lot of bills, diapers, medications, assistive devices etc. inadequate money" (CG 14)*
>
> *"No money stays with me, because of my child health demands and therapies then also I am not working because of my son." (CG 2)*

4.5.3 Caregivers of children with CP Social care: availability & quality

The majority of caregivers expressed that there were no public health and social care centers available in their local environment. However, they mentioned that there were some centers in town that provided good quality services, but these were often financially inaccessible for them. On the other hand, a few caregivers mentioned the lack of public facilities in their immediate surroundings but highlighted their ability to access services through HHVF and its stakeholders.

> *"There is no health center in my neighborhood, is only the foundation that is a bit closer to us." For the availability and the quality of their services is good. (CG 4)*
>
> *"None closer but we are able to access facilities in town through HHVF, they bring therapies both local and foreign ones, they are of quality too" (CG 11)*
>
> *"There are many facilities around and is of high quality if you have the funds to access it." (CG 12)*
>
> *"There is a chip compound closer in the next town, social welfare, schools and churches and their service I guess is okay" we cannot afford it but the field worker from HHVF comes to give needed service in the house on monthly basis (CG 15)*
>
> *"We only have church surrounding us, no healthcare or social care are closer. We get all services at the center". (CG 1)*

4.5.4 Caregivers of children with CP Opportunity for New Information & Skills

All caregivers stated that they receive new information and acquire skills from Hearts, Hands and Voice Foundation through its day programs, workshops, and trainings. They also mentioned that they can seek additional assistance and make inquiries at the foundation's center, which serves as a resource hub for information about their child's condition. Some caregivers also mentioned that they obtain information and skills from the general meetings organized by GFD Winneba branch. A few caregivers explained that they learn from other parents who share their experiences of caring for children with CP.

> *"I get information and skills training from the foundation they open the center throughout the week and meets all the parents for trainings on monthly basis" (CG 2)*
>
> *"HHVF and GFD Winneba branch gives information, trainings and skills development so I join all the time to learn. When we meet as Parents having children with disabilities, I learn new things from them because they share ideas, concerns*

> *and what worked or places they visited that made a change" (CG 7)*
>
> *"The fieldworkers from HHVF gives me information and trains me on the right way to feed and position etc. my daughter" (CG 10)*
>
> *"From the foundation my child attends school, HHVF meets us during parents support group meetings, and they do programs and trainings for us and the children." (CG 15)*

4.5.5 Caregivers of children with CP Activity Participation

All caregivers shared their experiences regarding activity participation. Some expressed the challenges they face in engaging in activities due to stress or physical pain. They mentioned attitudinal barriers in their environment that restrict their participation, particularly in public settings. However, a few caregivers indicated that they are able to actively participate in activities within their environment. Here are some of the comments from the caregivers.

> *"Not regularly because of fatigue and chronic pains but I do when I am not experiencing any limitations". (CG 3)*
>
> *"I involve myself in activities that goes on in my neighborhood, HHVF center and church" (CG 14)*
>
> *"I hardly get involve, I choose peace because their attitude will make me feel bad about myself but if is home activities and am healthy I do it. Then also, my children school activities I take part in it. (CG 2)*
>
> *"If only I have the strength, I join and participate" (CG 6)*

CHAPTER FIVE

DISCUSSION OF FINDINGS

5.0 Introduction

This chapter presents a discussion of the findings. The discussion highlighted the major findings of the research and inferences made from them given findings from related previous studies. The discussion was guided by the research questions that were raised to guide the study.

5.1 Physical Health Status of Caregivers of Children with CP.

5.1.1. Caregivers of children with CP Experience of Pain and Discomfort

The findings from the caregiver interviews highlighted the physical challenges and pains experienced by caregivers of children with cerebral palsy. Caregivers mentioned specific areas of discomfort, such as waist pains, leg and knee pains, abdominal pains, and overall body pains. These physical symptoms significantly impact their ability to carry out daily activities and provide care for their children. These findings aligned with Raina et al., (2005) that emphasizes the physical strain and health issues faced by caregivers of children with cerebral palsy. Caregivers often experience limited mobility, decreased strength, and increased risk of musculoskeletal problems due to the physical demands of caregiving.

The findings of the caregiver interviews regarding the physical challenges and pains they experience aligned with the integrative quality of life theory. According to the theory, physical well-being is one of the key domains that contribute to an individual's overall quality of life. Caregivers of children with cerebral palsy face significant physical strain and health issues, which influence the other domains of their quality of life in various ways. The physical challenges reported by caregivers, such as waist pains, leg pains, and back pains, directly affect their physical functioning and ability to perform daily activities. These physical symptoms can limit their mobility, cause discomfort, and lead to decreased strength. As a result, caregivers may have trouble in providing care for their children and engaging in other activities that are essential for their own well-being. The integrative quality of life theory emphasizes the interplay between different domains of life. The physical challenges faced by caregivers can have cascading effects on other domains of their quality of life. For example, chronic pain and physical limitations may contribute to psychological distress, such as frustration, sadness, or feelings of helplessness. It can also affect their social relationships and participation in activities, leading to social isolation and a decreased sense of fulfillment. Understanding the physical challenges and their impact on caregivers' quality of life is crucial for developing interventions and support programs that address their specific needs.

5.1.2 Caregivers of children with CP Experience of Energy and Fatigue

The findings of the study indicated that caregivers of children with cerebral palsy experience significant fatigue and exhaustion. Caregivers reported feeling constantly tired and lacking energy due to the demands of providing care for their children. The physical and emotional strain of performing various caregiving activities, such as feeding, bathing, toileting, and constant supervision, contribute to their fatigue. These findings align with previous research by Raina et al. (2005), which also emphasizes the high levels of fatigue and exhaustion experienced by caregivers of children with cerebral palsy. The multiple caregiving roles and responsibilities, as well as the need for constant vigilance and extensive assistance, contribute to caregivers' feelings of tiredness and low energy levels.

5.1.3 Caregivers of children with CP Experience of Sleep and Rest

The findings from the study highlighted the sleep patterns and challenges faced by caregivers of children with cerebral palsy. Three caregivers mentioned being able to sleep at night, while others experienced difficulties due to factors related to their child's condition. Interrupted sleep caused by the child's pain or discomfort during the night was a common challenge mentioned by caregivers, leading to disrupted sleep patterns. Caregivers also expressed the need to attend to their child's needs during the night, which further affected their own sleep. Financial pressures and the need to wake up early for work were additional factors limiting caregivers' sleep time. Concerns about food and financial stability also contributed to sleep difficulties and anxiety. The findings align with existing literature on caregivers' sleep disruptions. Caregivers often report interrupted sleep patterns and difficulty maintaining a consistent sleep routine due to their children's needs and behaviors (Toly et al., 2010). Pain, discomfort, and medical issues in children with cerebral palsy can further contribute to sleep disturbances (Raina et al., 2005). Vogel et al. (2018) support these findings, indicating that caregivers experience sleep disturbances and poor sleep quality due to the demanding nature of caregiving and the unpredictable nature of their child's condition. The physical and emotional strain of caregiving can impact sleep patterns and lead to sleep deprivation among caregivers.

5.1.4 Caregivers of children with CP Experience of Medical Care

The findings revealed that accessing medical treatment and healthcare services for their own health issues is a significant challenge. Several caregivers mentioned financial constraints, lack of health insurance, availability of alternative treatments like herbal medicines, balms and ointment, perceived stigma as a barrier to seeking medical care with limited resources available to cover healthcare expenses. Some caregivers mentioned relying on over-the-counter painkillers or self-medicating with malaria drugs instead of seeking professional medical help. These findings resonate with the literature on caregivers of children with cerebral palsy, which highlights the financial difficulties and limited access to healthcare faced by caregivers in many low-resource settings (Raina et al., 2005). Caregivers often prioritize the needs of their children over their own health, leading to neglect of their own medical care (Toly et al., 2010). Lack of health insurance coverage further exacerbates the challenges caregivers face in accessing appropriate healthcare services.

5.2 Psychological Wellbeing of Caregivers of Children with CP.

The findings from the study revealed a combination of positive and negative emotions experienced by caregivers of children with cerebral palsy. On the positive side, caregivers expressed feelings of hope, belief in their child's potential, gratitude, and a sense of purpose in their caregiving role. They also highlighted the importance of faith and spirituality as a source of strength. However, caregivers also experienced negative emotions such as sadness, frustration, disappointment, and anxiety related to the challenges they face, societal stigma, and concerns about their child's future. Social support and access to information were found to play a crucial role in caregivers' emotional well-being, with those who had support programs and training expressing more positive emotions and a sense of empowerment. Caregivers showed diverse self-perceptions and attitudes towards themselves and the stigma associated with their child's disability. Some exhibited resilience and self-acceptance, while others felt negatively about themselves due to societal judgment. The findings is consistent with (Pisano et al., 2017; Raina et al., 2005). Caregivers' physical appearance and body image were also influenced by their caregiving responsibilities and cultural expectations. They often thought about meeting their children's needs, their child's condition, and the impact of caregiving on their lives, expressing concerns for the future and the challenges their child may face. Overall, the findings highlighted the complexity of caregivers' emotions, the importance of social support, and the need for information and training to cope with the challenges they encounter.

The findings from the caregiver interviews align with the principles of the integrative quality of life theory, which emphasizes the multidimensional nature of well-being and the interaction between personal, social, and environmental factors. According to this theory, various domains, including physical, psychological, social, and spiritual well-being, influence quality of life. In terms of physical well-being, caregivers in the study expressed both positive and negative feelings about their physical appearance. The physical demands of caregiving, such as carrying or assisting the child, can have an impact on caregivers' body image and self-perception. This aligns with the physical domain of the integrative quality of life theory, which recognizes the importance of physical health and appearance in overall well-being. Psychologically, caregivers experienced a range of emotions, including positive ones such as hope, gratitude, and a sense of purpose, as well as negative ones like sadness, frustration, and anxiety. These emotional responses align with the psychological domain of the integrative quality of life theory, which emphasizes the importance of emotional well-being and the ability to cope with stress and challenges. Socially, caregivers highlighted the significance of social support, both from support programs and training and from connecting with other parents facing similar challenges. Social support is a key component of the social domain of the integrative quality of life theory, which emphasizes the role of relationships, social connections, and support systems in enhancing well-being. Additionally, the caregivers' mention of faith and spirituality as a source of strength aligns with the spiritual domain of the integrative quality of life theory. Spirituality and religious beliefs can provide meaning, comfort, and guidance, contributing to caregivers' overall well-being. The integrative quality of life theory recognizes that these different domains of well-being are interconnected and influence each other. Positive emotions, social support, and access to information can enhance caregivers' overall quality of life and well-being. On the other hand, negative emotions, societal stigma, and concerns about the future can contribute to psychological distress and lower quality of life.

Overall, the findings from the caregiver interviews support the integrative quality of life theory by highlighting the complex interplay between various dimensions of well-being in the context of caregiving for children with cerebral palsy. By addressing the physical, psychological, social, and spiritual needs of caregivers, interventions and support programs can aim to enhance their overall quality of life and well-being.

5.2.1 Caregivers of children with CP Experience of Positive Feeling

The findings from the caregiver interviews highlighted the positive feelings and hope experienced by caregivers in the context of caring for children with cerebral palsy. Despite the challenges they face, caregivers express sentiments of hope, belief in the child's potential, gratitude, and a sense of purpose in their caregiving role. These findings aligned with the literature on the positive aspects of caregiving and the role of positive emotions in coping with the stress of caregiving. Raina et al., (2005) acknowledges that caregivers often experience a range of emotional responses, including positive feelings and a sense of fulfillment Caregivers may find meaning and purpose in their caregiving role, viewing their child as a blessing and experiencing personal growth and learning through their child's condition (CG 1, CG 2, CG 20). These positive emotions can provide motivation and resilience to caregivers in the face of challenges and contribute to their overall well-being. The concept of hope is particularly prominent in the caregiver feedbacks. Caregivers express hope for their child's progress, future outcomes, and potential for independence (CG 1, CG 4). This aligns with the literature, which suggests that hope plays a significant role in the coping process of caregivers. Hope allows caregivers to maintain a positive outlook, focus on possibilities, and adapt to the changing needs of their child (Raina et al., 2005). The expression of faith and spirituality is also evident in some caregiver responses (CG 2, CG 12). Spirituality and religious beliefs can provide a source of strength, comfort, and guidance for caregivers, helping them find meaning and cope with the challenges of caregiving (Raina et al., 2005).

5.2.2 Caregivers of children with CP Experience of Negative Feeling

The findings shown negative emotions and challenges experienced by caregivers of children with cerebral palsy. Caregiver’s express feelings of sadness, frustration, disappointment, and anxiety related to the difficulties they face in caring for their child, the rejection and stigma they encounter from their community, and concerns about their child's future and the availability of support. The findings on caregivers of children with disabilities recognizes that caregivers often experience negative emotions and psychological distress due to the ongoing demands and challenges of caregiving (Pisano et al., 2017). Caregivers may feel overwhelmed by the physical, emotional, and financial burdens of caring for a child with cerebral palsy (CG 3, CG 6). The negative attitudes and stigma faced by caregivers and their children can further contribute to feelings of isolation, depression, and anxiety (CG 11). These findings align with the literature that highlights the impact of societal stigma on the well-being of caregivers and the need for support to address the emotional challenges they face (Pisano et al., 2017; Raina et al., 2005). The findings also highlighted the impact of social support and information on caregivers' emotions. Caregivers who have access to support programs and training, such as the day-program and monthly training mentioned by some caregivers, express more positive feelings and a sense of empowerment (CG 1). This aligns with the Pisano et al., (2017), which emphasizes the importance of social support in reducing caregiver burden and enhancing their well-being. Supportive interventions that provide information, resources, and a sense of belonging can help caregivers cope with the negative emotions and challenges they face.

5.2.3 Caregivers of children with CP feeling of their Self Esteem

The findings from the study reflected the diverse range of self-perceptions and attitudes towards themselves and the stigma associated with their child's disability. Some caregivers express resilience and a sense of self-acceptance, focusing on their child's progress and their own happiness (CG 9, CG 1). On the other hand, some caregivers described feeling negatively about themselves and experiencing the weight of societal judgment and blame (CG 5, CG 2). Others adopt a more dismissive attitude towards societal opinions and prioritize their own well-being and the well-being of their family (CG 9, CG 1). These findings aligned with Pisano et al., (2017) on caregivers of children with disabilities, which highlights the diversity of coping strategies and self-perceptions among caregivers. Caregivers may experience varying levels of self-esteem, self-acceptance, and resilience in the face of societal stigma and judgment. The caregiver's personal characteristics, support systems, and cultural factors can influence their self-perception and coping strategies (Raina et al., 2005). Some caregivers adopt a more positive outlook, focusing on their child's achievements and finding strength in their own happiness and resilience (CG 9, CG 1). They may have developed adaptive coping mechanisms that allow them to maintain a sense of self-worth and overcome the negative effects of stigma. On the other hand, caregivers who expressed negative self-perceptions may be experiencing the impact of chronic stress and societal judgment, leading to feelings of self-doubt and lower self-esteem (CG 5, CG 2). These caregivers may be more affected by the stigma and negative labels associated with their child's disability. The presence of social support and the exposure to other individuals facing similar challenges, as mentioned by some caregivers, can also influence their self-perception and coping strategies (CG 1, CG 8). Connecting with others who share similar experiences can provide a sense of belonging and validation, contributing to a more positive self-perception and resilience (Pisano et al., 2017).

5.2.4 Caregivers of children with CP view with their Body Image

The findings from the study revealed a range of attitudes and perceptions towards physical appearance. Some caregivers express positive feelings about their body image, highlighting aspects they appreciate and feel good about (CG 7, CG 3). They embrace their physical selves and express satisfaction with their overall appearance. On the other hand, some caregiver's express dissatisfaction with their physical image, focusing on perceived flaws or changes that they dislike (CG 13, CG 5, CG 11). They express a desire for a different body shape or size and convey negative feelings about their physical appearance. These findings aligned with Phillips & Carrieri, 2018; Lutz et al., (2021), which recognizes the impact of caregiving responsibilities on caregivers' body image and self-perception. The physical demands of caregiving, such as carrying or assisting the child, can lead to changes in posture, body shape, and weight, which may influence caregivers' body image. Societal ideals of beauty and cultural expectations surrounding body image can also contribute to caregivers' self-evaluations.

5.2.5 Caregivers of children with CP Experience of Thinking, Learning, Memory and Concentration

The findings from the study reflected their thoughts and concerns regarding their children's needs, their child's condition, and the impact of caregiving on their lives. They mention thinking a lot about meeting their children's basic needs and their child's improvement (CG 7, CG 2). They also express worries about the future and the challenges their child may face without their presence (CG 2, CG 12, and CG 13). The caregivers acknowledge the information and support they receive from the HHV Foundation and other sources, which has helped them in their caregiving journey (CG 7, CG 2, CG 12, and CG 13). These findings resonate with the Smith et al., (2016) on the cognitive aspects of caregiving and stress and coping theory. Caregivers often experience cognitive strain as they constantly think about the well-being and future of their children. They may have memories of the past, including the challenges, they faced and the changes that occurred in their lives after their child's birth (CG 7, CG 2, CG 12, CG 13). This cognitive load can contribute to increased stress and anxiety among caregivers. The caregivers in the statements mention learning from the HHV Foundation, seeking information and training, and connecting with other parents facing similar challenges (CG 7, CG 2, CG 12, and CG 13). This aligns with Brehaut et al., 2012; Chen et al., (2015), which emphasizes the importance of information-seeking, social support, and education as coping mechanisms for caregivers. Furthermore, the caregivers' focus on their children's growth and well-being, as well as their reliance on faith and support from professionals, indicates their adaptive coping strategies (CG 7, CG 2, CG 12, and CG 13). By concentrating on these areas, they navigate the challenges of caregiving and prioritize their children's needs.

5.3 Social Experiences of Caregivers of Children with CP

In the study, caregivers of children with cerebral palsy shared their experiences with relationships and social support. The limited support from family members and the presence of stigma and negative attitudes from others can impact caregivers' overall well-being and quality of life, as suggested by the findings and supported by the literature (Brehaut et al., 2012). On the other hand, positive relationships with spouses, children, and acquaintances can contribute to a better quality of life for caregivers (CG 1). The importance of social support, highlighted in the findings and supported by Masten et al. (2018), is consistent with the integrative quality of life theory. Social support provides caregivers with emotional, practical, and informational assistance, which can enhance their well-being and resilience. The presence of support groups for parents facing similar challenges (CG 9) aligns with the theory's emphasis on the significance of social connections and belongingness. Additionally, the role of organizations such as Hearts, Hands and Voice Foundation (HHVF), Ghana Federation of Disabilities, and Salvation Army in providing assistance and support to caregivers is crucial for enhancing their quality of life. These organizations offer practical support, create a sense of community, and align with the theory's focus on the importance of accessing resources and opportunities for learning and growth. The limited engagement in sexual activities reported by caregivers can also be related to the integrative quality of life theory. The demands of caregiving, being a single parent, and the presence or absence of a partner can significantly impact caregivers' intimate relationships and overall well-being, as noted in the findings and supported by Hartley et al. (2010). To address these challenges, the theory suggests the importance of finding a healthy balance between caregiving responsibilities and personal/intimate lives, as well as promoting open communication and support within partnerships.

The findings align with the integrative quality of life theory by emphasizing the role of relationships, social support, and intimate relationships in caregivers' well-being and quality of life. The findings underscore the importance of addressing these domains to promote the overall well-being and resilience of caregivers of children with cerebral palsy.

5.3.1 Caregivers of children with CP Experience of their Personal Relationship

The findings from the study reflected caregivers' experiences with relationships and social support in their lives. Some caregivers mention having limited support from family members, with their mother being the only person they feel close to (CG 9, CG 4). They also expressed a lack of friends but mentioned finding support and understanding from a group of parents facing similar challenges (CG 9). On the other hand, some caregivers mention having positive relationships with their husband, children, and mutual acquaintances (CG 1). Stigma and negative attitudes from others, including family members and community members, are also mentioned (CG 3, CG 13). These findings resonate with Brehaut et al., (2012) on social support. Social support is crucial for caregivers, as it can provide emotional, practical, and informational assistance. Caregivers who have limited support from family members may experience feelings of isolation and a lack of understanding. In contrast, those who have positive relationships with their spouse, children, and mutual acquaintances may benefit from their support and understanding (CG 1). The presence of a support group for parents facing similar challenges (CG 9) aligns with the Chen et al., (2015), which highlights the importance of peer support and connecting with others who share similar experiences. These support groups can provide a sense of belonging, validation, and the opportunity to exchange information and coping strategies. The experiences of stigma and negative attitudes mentioned by some caregivers (CG 3, CG 13) also align with the literature. Caregivers of children with disabilities often face societal stigma and judgment, which can affect their social relationships and well-being (Brehaut et al., 2012). The negative beliefs and labeling associated with their child's condition may lead to social exclusion and a sense of being misunderstood.

5.3.2 Caregivers of children with CP Experience of Social Support

The study findings underscored the importance of social support and the role of various organizations, including Hearts, Hands and Voice Foundation (HHVF), Ghana Federation of Disabilities, and Salvation Army, in providing assistance to caregivers of children with cerebral palsy. These organizations offer a range of services such as caregiving support, training, workshops, financial aid, adaptive equipment, and outreach visits. Caregivers expressed gratitude for the support they received from these organizations, emphasizing its significance in caring for their children and improving their well-being. The organizations not only provided practical assistance but also created a sense of community and understanding through support groups, meetings, and workshops. These findings align with Masten et al. (2018), which emphasizes the importance of social support in helping caregivers cope with challenges. The positive experiences of caregivers with HHVF and other organizations highlight the potential benefits of formal support networks, which provide access to information, resources, and opportunities for learning and growth. By connecting caregivers with professionals, offering practical assistance, and facilitating social connections, these organizations contribute to caregivers' ability to cope with stress and enhance their overall well-being (Brehaut et al., 2012). The support received from HHVF, family members, and other organizations assists caregivers in addressing the demands of caregiving and promotes their well-being. It is crucial to continue advocating for and strengthening support networks for caregivers of children with special needs to promote their resilience, reduce stress, and improve their overall quality of life. The experiences of caregivers emphasized the significance of social support provided by organizations such as HHVF, Ghana Federation of Disabilities, and Salvation Army, which play a critical role in supporting caregivers, enhancing their access to resources, and fostering a sense of community (Masten et al., 2018; Brehaut et al., 2012).

5.3.3 Caregivers of children with CP Experience with Sexual Activity

The study findings indicated that caregivers of children with cerebral palsy have limited or infrequent engagement in sexual activities, which can be attributed to factors such as being a single parent, the demands of caregiving, and the presence or absence of a partner. The responsibilities and challenges of caregiving consume significant time and energy, leaving caregivers with limited opportunities for personal and intimate activities. This aligns with Hartley et al. (2010), who suggest that caring for a child with special needs can impact caregivers' intimate relationships and sexual activity. The presence or absence of a partner further influences caregivers' engagement in sexual activities. Some caregivers have partners, but various factors, such as daily life demands or the partner's availability, may result in sporadic engagement in sexual activities. Single parents face additional challenges in finding time and opportunities for sexual activities. The limited engagement in sexual activities reported by caregivers may affect their overall well-being and intimate relationships, as sexual intimacy is a significant aspect of human relationships. To address these challenges, caregivers should be supported in finding a healthy balance between their caregiving responsibilities and personal/intimate lives. Respite care services can provide caregivers with breaks and time for themselves and their relationships. Open communication, understanding, and mutual support within partnerships are crucial for navigating the challenges and maintaining intimacy. It is important to recognize and address the complex interplay between caregiving responsibilities, stress, and intimate relationships to support caregivers in meeting their own needs and those of their children (Hartley et al., 2010).

5.4 Environmental experiences of Caregivers of Children with CP.

The study findings aligned with Van der Ree et al. (2016), Lawton et al. (2014), Gupta et al. (2015), Brehaut et al. (2012), Shen et al. (2019), Wiles et al. (2012), and others, emphasizing the significance of adequate living conditions, cultural factors, accessible resources, and inclusive environments in supporting caregivers of children with disabilities. Similarly, the findings aligned with previous research on the financial challenges faced by caregivers of children with disabilities. Brehaut et al. (2009), Noonan & Tennant (2006), and Brown (2006) highlight the impact of financial difficulties on caregivers' stress levels and coping mechanisms. The need for financial assistance, affordable healthcare, subsidies, and social welfare programs are consistent with the literature. Regarding healthcare and support services, the findings aligned with research on the importance of access to healthcare facilities and supportive services for caregivers of children with disabilities. Pearlin et al. (1990) highlighted the role of social support and resources in enhancing coping mechanisms and reducing stress levels. The role of organizations like Hearts, Hands, and Voice Foundation (HHVF) in bridging the gap between caregivers and healthcare services aligns with the need for comprehensive and accessible support systems. The findings also align with studies emphasizing the importance of information, training, and support programs for caregivers. Gupta & Singhal (2017) and Yin et al. (2019) highlight the role of education, skills development, and peer support in enhancing caregivers' knowledge, coping abilities, and well-being. In terms of caregiver involvement in activities, the findings align with Larkin et al. (2017), which emphasizes the importance of meaningful activities in providing a sense of purpose, fulfillment, and social support. The need for caregivers to prioritize self-care and make selective choices based on personal interests and values is also consistent with the literature.

The study findings align with integrative quality of life theory, which emphasizes the multidimensional nature of individuals' well-being and quality of life. Integrative quality of life theory posits that various factors, including living conditions, financial resources, social support, healthcare access, and personal engagement, contribute to individuals' overall quality of life. In the study, the findings regarding adequate living conditions, accessible resources, and inclusive environments align with the physical domain of integrative quality of life theory. Van der Ree et al. (2016), Lawton et al. (2014), Gupta et al. (2015), Brehaut et al. (2012), Shen et al. (2019), and Wiles et al. (2012) support the importance of these factors in enhancing caregivers' well-being and overall quality of life. The physical domain acknowledges the significance of a suitable living environment and access to necessary resources for caregivers' satisfaction and functioning. The financial challenges faced by caregivers, as supported by Brehaut et al. (2009), Noonan & Tennant (2006), and Brown (2006), align with the economic domain of integrative quality of life theory. Financial constraints can impact caregivers' stress levels, coping mechanisms, and their ability to access necessary supports and services. The need for financial assistance, affordable healthcare, subsidies, and social welfare programs emphasizes the importance of addressing the economic domain to enhance caregivers' quality of life. The findings related to healthcare access and supportive services align with the social and healthcare domains of integrative quality of life theory. Pearlin et al. (1990) highlight the role of social support and resources in enhancing coping mechanisms and reducing stress levels, supporting the social domain. Access to healthcare facilities, information, and support programs, as emphasized by Gupta & Singhal (2017), Yin et al. (2019), and the involvement of organizations like Hearts, Hands, and Voice Foundation (HHVF), align with the healthcare domain. These factors contribute to caregivers' well-being and their ability to effectively care for their children. The involvement of caregivers in meaningful activities, as supported by Larkin et al. (2017), corresponds to the engagement domain of integrative quality of life theory. Engaging in activities that align with personal interests and values provides a sense of purpose, fulfillment, and social support, which are vital for caregivers' overall quality of life.

By considering the physical, economic, social, healthcare, and engagement domains of integrative quality of life theory, the study findings provide comprehensive insights into the factors that influence caregivers' well-being and quality of life.

5.4.1 Caregivers of children with CP Experience with their Physical Environment

The findings from the caregivers' interviews revealed diverse perceptions of their living environments, with varying levels of satisfaction, challenges, and accessibility to necessary resources and services. CG 13 expressed satisfaction with having their own space but faced challenges due to the lack of basic amenities like a toilet and water. This aligns with literature highlighting the importance of adequate living conditions for caregivers' well-being (Van der Ree et al., 2016). CG 2 mentioned having their own house but faced limited access to essential facilities, which can increase stress and hinder caregiving efforts (Lawton et al., 2014). CG 6 highlighted the influence of cultural beliefs and norms on limited interaction with family members and neighbors, underscoring the role of social and cultural factors in caregivers' support networks (Gupta et al., 2015). The absence of government facilities further compounds the challenges they face in accessing services. CG 11 described mixed experiences with neighbors and the presence of stigma, emphasizing the need for inclusive environments that support individuals with disabilities (Brehaut et al., 2012). The lack of accessibility and limited availability of facilities mentioned by CG 11 and CG 14 demonstrate the barriers caregivers face in accessing necessary resources and services (Shen et al., 2019). The cultural context mentioned by CG 11 also highlights the potential impact of cultural beliefs on caregivers' experiences, underscoring the importance of considering cultural factors in providing support (Brehaut et al., 2012). The positive experience of CG 14 with an accessible environment and proximity to important facilities aligns with the benefits of accessible environments and their impact on caregivers' well-being (Wiles et al., 2012). Overall, these findings underscore the diversity of caregivers' living environments, the challenges they face, and the importance of accessible resources and supportive infrastructures. They align with existing literature on the impact of living conditions and cultural factors on caregivers' experiences, emphasizing the need for inclusive and supportive environments for caregivers of children with disabilities.

5.4.2 Caregivers of children with CP Experience with Financial Resources

The findings highlighted the significant financial challenges faced by caregivers of children with disabilities, which can impact their stress levels and coping mechanisms (CG 10, CG 5, CG 18, CG 8, CG 14, CG 2). Research consistently shows that financial difficulties can lead to increased stress levels, decreased well-being, and compromised coping strategies (Brehaut et al., 2009; Noonan & Tennant, 2006). Caregivers often face additional expenses related to medical care, therapy sessions, assistive devices, and specialized education, placing a significant burden on their financial resources (Brown, 2006). This financial strain can limit their options and ability to access necessary supports and services, leading to increased stress and reduced coping effectiveness. To address these challenges, financial assistance and support are crucial. Access to affordable healthcare, subsidies for therapy sessions and assistive devices, and social welfare programs can alleviate the financial burden on caregivers and improve their ability to meet their child's needs. Community organizations, foundations, and government agencies play a crucial role in providing financial support, guidance, and resources to caregivers in need.

5.4.3 Caregivers of children with CP Experience with Social Care: Availability & Quality

The findings highlighted the varying availability and quality of healthcare and support services for caregivers of children with disabilities in their respective environments. While some caregivers have access to healthcare facilities and services, others face limitations (CG 4, CG 11, CG 15, CG 1). The presence of healthcare facilities and supportive services can significantly impact caregivers' ability to meet their children's needs and cope with challenges. Research on stress and coping suggests that the availability of social support and resources plays a crucial role in enhancing coping mechanisms and reducing stress levels (Pearlin et al., 1990). Caregivers with access to healthcare facilities and support services may experience better overall well-being and reduced stress compared to those who face barriers in accessing such resources. Organizations like Hearts, Hands, and Voice Foundation (HHVF), mentioned by the caregivers, play a vital role in bridging the gap between caregivers and healthcare services. These organizations provide therapies, information, and assistance in navigating the healthcare system. They also help address financial constraints and improve access to quality care. Efforts should be made to ensure equitable access to healthcare and support services for caregivers of children with special needs. This includes expanding healthcare infrastructure in underserved areas and providing financial assistance and guidance to caregivers facing financial barriers. Collaboration between healthcare organizations, community-based initiatives, and government agencies is crucial in creating a comprehensive and accessible support system for caregivers.

5.4.4 Caregivers of children with CP Experience with accessing Information and Skills

The findings from the study highlighted the valuable role of the Hearts, Hands, and Voice Foundation (HHVF) and the Ghana Federation of Disabilities (GFD) Winneba branch in providing information, training, and skills development opportunities for caregivers of children with disabilities. CG 2 mentions the foundation's weekly center openings and monthly trainings for parents, indicating a consistent effort to empower caregivers with knowledge and skills (CG 2). CG 7 emphasizes the importance of peer support and learning from other parents in similar situations during meetings, which can provide valuable insights and strategies (CG 7). The involvement of HHVF fieldworkers in providing personalized support and guidance is mentioned by CG 10, and CG 15 highlights HHVF's role in organizing support group meetings and training programs (CG 15). Access to information, skills training, and support aligns with integrative quality of life theory, as it enables caregivers to better understand their child's condition, make informed decisions, and implement effective care strategies. Skills training enhances caregivers' confidence and coping abilities, contributing to positive outcomes for both caregivers and children. The support provided by organizations like HHVF and GFD Winneba branch fosters a sense of belonging, reduces isolation, and promotes resilience among caregivers.

The role of Hearts, Hands, and Voice Foundation (HHVF) and the Ghana Federation of Disabilities (GFD) Winneba branch in providing information, training, and support to caregivers of children with disabilities aligns with existing literature. These organizations' efforts align with studies that emphasize the importance of education, training, and support programs for caregivers (Gupta & Singhal, 2017; Yin et al., 2019). Access to information, skills development, and peer support can enhance caregivers' knowledge, coping abilities, and overall well-being (Gupta & Singhal, 2017; Yin et al., 2019).

5.4.5 Caregivers of children with CP Experience with Activity Participation in the community

The findings of the study indicated that caregivers' level of involvement in activities varies based on factors such as physical limitations, fatigue, and personal preferences. While CG 14 actively participates in community, center, and church activities, CG 2 prioritizes their own peace and well-being, engaging in activities related to their caregiving role. CG 6's involvement fluctuates based on their strength and ability to participate, considering their energy levels and physical limitations. Caregivers of children with disabilities often experience fatigue and limitations due to the demands of caregiving, impacting their activity involvement. Aligning with previous research, engaging in meaningful activities can provide a sense of purpose, fulfillment, and social support, contributing to stress management (Larkin et al., 2017). However, caregivers must prioritize self-care and conserve energy to prevent burnout. Selective choices based on personal interests and values can contribute to overall well-being. Caregivers should listen to their bodies, assess limitations, and make informed decisions about involvement. Healthcare professionals and support organizations can offer guidance, resources, and create a supportive environment that understands caregivers' challenges (Larkin et al., 2017).

CHAPTER SIX

SUMMARY, CONCLUSION AND RECOMMENDATIONS

6.0 Introduction

This chapter presents the summary of key findings, conclusions and recommendations of the study. Also, the contribution of the study to existing knowledge on the subject matter is presented, as well as suggestions for further research. The purpose of the study was to assess the quality of life of caregivers of children with cerebral palsy at Hearts, Hands and Voice Foundation Winneba.

6.1 Summary of major findings

The Physical Health Status of Caregivers of Children with CP at the Foundation.

The findings indicated a low physical health quality of life for caregivers of children with cerebral palsy at HHVF. The findings suggested that caregivers' physical health quality of life is compromised due to the physical strain of caregiving; pain and discomfort, disrupted sleep patterns, limited access to medical care, and reliance on self-management strategies.

The Psychological Wellbeing of Caregivers of Children with CP at the Foundation.

The findings indicated a mixed psychological well-being quality of life among caregivers of children with cerebral palsy. On one hand, caregivers experience positive emotions such as hope and joy when they witness their children's developmental progress and improvements in mobility. These positive emotions contribute to a higher psychological well-being quality of life. On the other hand, few caregivers also experience negative emotions including sadness, frustration, anger, stress, anxiety, and depression. These negative emotions stem from various challenges such as their child's frequent illness, societal stigma, and rejection from family and community members. These emotional struggles can lead to a lower psychological well-being quality of life. The study also highlights caregivers' struggles with self-doubt, feelings of judgment from others, decreased self-esteem, and dissatisfaction with their physical appearance. These factors contribute to a lower psychological well-being quality of life, as caregivers may experience negative self-perceptions and emotional distress related to their caregiving role.

The Social Wellbeing of Caregivers of Children with CP at the Foundation.

The findings indicate a mixed social well-being quality of life among caregivers of children with cerebral palsy. On one hand, some caregivers reported a lack of close relationships and felt isolated within their families. They faced limited support from siblings but some support from their mothers. This isolation and limited support can contribute to a lower social well-being quality of life. Additionally, stigma and negative perceptions from others, influenced by their child's condition or cultural beliefs, had a significant impact on their social circles and connections. This social stigma and lack of understanding can further contribute to a lower social well-being quality of life. On the other hand, some caregivers had more positive relationships and maintained good connections with their spouses, children, and mutual acquaintances. They found support and understanding in specific groups or individuals who shared their experiences, such as the Hearts, Hands, and Voice Foundation. These positive relationships and support systems can contribute to a higher social well-being quality of life. It is important to note that the study also found diverse experiences regarding caregivers' levels of sexual activity and engagement. Some caregivers did not have a current partner and did not engage in sexual activities, while others had partners but regular sexual activity was not common due to various life circumstances.

The Environmental factors of Caregivers of Children with CP at the Foundation.

The findings indicate a low environmental factors quality of life among caregivers of children with cerebral palsy. Caregivers often reside in isolated environments with limited access to government facilities, such as hospitals, schools, and nursing colleges. This lack of access to necessary services and resources can significantly impact their ability to provide adequate care and support for their children, thus lowering their environmental factors quality of life. The presence of cultural barriers that hinder relationships with neighbors further contributes to a lower environmental factors quality of life for caregivers. Limited interaction with neighbors and the absence of supportive social networks within their living environments can create feelings of isolation and hinder access to social support. Financial constraints were also identified as a common concern among caregivers, impacting their ability to meet their children's needs and provide adequate care. Unstable income sources and struggles to meet basic needs, as well as expenses related to medical care, therapies, medications, and assistive devices, further contribute to a lower environmental factors quality of life. Overall, the findings suggest that caregivers face significant challenges related to their living environments, access to resources and services, cultural barriers, and financial constraints. These factors contribute to a lower environmental factors quality of life for caregivers of children with cerebral palsy. Addressing these challenges and improving the accessibility and availability of necessary resources and services can positively impact their environmental factors quality of life.

6.2 Conclusions

The findings of this study shed light on the quality of life experienced by caregivers of children with cerebral palsy at the Hearts, Hands, and Voice Foundation (HHVF). The caregivers face numerous challenges that impact their physical health, psychological well-being, social well-being, and environmental factors quality of life. In terms of physical health, caregivers experience physical strain, pain, disrupted sleep patterns, and limited access to medical care. These factors contribute to a compromised physical health quality of life. It is crucial for interventions and support programs to address these challenges and provide caregivers with the necessary resources and assistance to improve their physical well-being. The psychological well-being quality of life among caregivers is mixed. They experience positive emotions such as hope and joy when witnessing their children's progress, but also negative emotions such as sadness, frustration, stress, and anxiety. Caregivers struggle with self-doubt, feelings of judgment from others, decreased self-esteem, and dissatisfaction with their physical appearance. Efforts should be made to provide psychological support and resources to help caregivers navigate these emotional challenges and enhance their psychological well-being. Social well-being quality of life for caregivers is also mixed. Some caregivers feel isolated within their families, facing limited support from siblings but some support from their mothers. Stigma and negative perceptions from others further impact their social circles and connections. However, positive relationships and support systems, such as those provided by the HHVF, can contribute to a higher social well-being quality of life. Encouraging the formation of supportive networks and combating stigma can improve social well-being for caregivers.

The environmental factors quality of life is low for caregivers due to residing in isolated environments with limited access to necessary services and resources. Cultural barriers hinder relationships with neighbors, leading to feelings of isolation. Financial constraints pose additional challenges in meeting children's needs and providing adequate care. Addressing these environmental factors is crucial, including improving access to services, fostering supportive social networks, and addressing financial constraints.

The findings of this study, when analyzed through the lens of integrative quality of life theory, provide valuable insights into the experiences of caregivers of children with cerebral palsy at the Hearts, Hands, and Voice Foundation (HHVF). The caregivers' quality of life is influenced by multiple interconnected domains, including physical health, psychological well-being, social well-being, and environmental factors. Caregivers face significant challenges in their physical health, experiencing strain, pain, disrupted sleep patterns, and limited access to medical care. These physical factors have a direct impact on their overall quality of life. Integrating physical health interventions and support into caregiving programs is essential to enhance the caregivers' well-being and ability to provide care. Psychological well-being quality of life for caregivers is characterized by a mix of positive and negative emotions. Positive emotions arise from witnessing their children's developmental progress, while negative emotions stem from challenges such as frequent illness, societal stigma, and self-doubt. Supporting caregivers' psychological well-being through targeted interventions, including counseling, peer support, and self-esteem enhancement, can improve their overall quality of life. Social well-being quality of life is shaped by the caregivers' relationships and social connections. Caregivers may experience isolation within their families and face stigma and negative perceptions from others. However, positive relationships and support systems play a significant role in enhancing social well-being. Encouraging the formation of support networks, promoting social inclusion, and raising awareness about cerebral palsy can positively impact the caregivers' social well-being. Environmental factors have a substantial influence on caregivers' quality of life. Caregivers often reside in isolated environments with limited access to necessary services and face cultural barriers that hinder their relationships with neighbors. Financial constraints further exacerbate the challenges they face. Improving access to services, fostering supportive social networks, and addressing financial concerns are crucial steps in improving the environmental factors quality of life for caregivers.

In conclusion, the findings of this study highlight the interconnected nature of caregivers' quality of life, as outlined by the integrative quality of life theory. Addressing the challenges in physical health, psychological well-being, social well-being, and environmental factors requires a holistic approach.

6.3 Recommendations

The study recommends that as part of the activities of the Ghana Federation of the disabilities, Hearts, Hands and Voice Foundation, Inclusion Ghana and other related working organizations/Units in Winneba, they should establish:

1. a comprehensive physical well-being program specifically tailored to their needs. This program should incorporate support group, self -care education and

resources, respite care and support, physical therapy and accessible healthcare services. By implementing a comprehensive physical well-being program, it can address the specific physical health challenges faced by caregivers of children with cerebral palsy, ultimately improving their overall quality of life. This recommendation aims to empower caregivers to prioritize their physical well-being, enhance their ability to provide care, and reduce the physical strain associated with caregiving responsibilities.

2. it is recommended to establish a comprehensive Mental health counseling and therapy to help provide access to professional mental health counselors and therapists who specialize in supporting caregivers. These professionals can offer individual counseling sessions to help caregivers navigate their emotional challenges, manage stress, and develop coping strategies. Group therapy sessions can also be beneficial, allowing caregivers to connect with others who share similar experiences and provide mutual support.
3. It is recommended to establish a comprehensive social support program that focuses on creating inclusive and supportive environments. This program should include the following key components: support group and peer networks, education and awareness campaign etc. This recommendation aims to create a supportive and inclusive social environment for caregivers, reduce stigma, enhance family relationships, foster community integration, and provide the necessary guidance and resources to navigate social challenges effectively.
4. It is recommended to implement income-generating activities to support the caregivers financially, enhance accessibility to local resources and services, community support programs etc. By implementing these recommendations, it can work towards improving the environmental factors quality of life for

caregivers of children with cerebral palsy. By enhancing accessibility to resources and services, developing community support programs, providing financial assistance and guidance caregivers can experience an improved quality of life in their living environments.

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APPENDIX

UNIVERSITY OF EDUCATION, WINNEBA
FACULTY OF EDUCATIONAL STUDIES
DEPARTMENT OF SPECIAL EDUCATION

QUESTIONNAIRE ON ASSESSING QUALITY OF LIFE (QOL) OF CAREGIVERS OF CHILDREN WITH CEREBRAL PALSY (CP) AT HEARTS, HANDS AND VOICE FOUNDATION, WINNEBA.

Pledge of Confidentiality

I hereby certify that I have carefully read and will cooperate fully with the above procedures on confidentiality. I will keep completely confidential all information arising from surveys concerning individual respondents to which I gain access. I will not discuss, disclose, disseminate, or provide access to survey data and identifiers. I will devote my best efforts to ensure that there is compliance with the required procedures by personnel whom I supervise. I understand that violation of this pledge is sufficient grounds for disciplinary action. I also understand that violation of the privacy rights of individuals through such unauthorized discussion, disclosure, dissemination, or access may make me subject to criminal or civil penalties. I give my personal pledge that I shall abide by this assurance of confidentiality.

Survey Administrator Name: …………………………………………………….

Signature: ……………………………… *Date:* ………………………………

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QUESTIONNAIRE ON ASSESSING QUALITY OF LIFE (QOL) OF CAREGIVERS OF CHILDREN WITH GMFCS 3-5 CEREBRAL PALSY (CP) AT HEARTS, HANDS AND VOICE FOUNDATION, WINNEBA.

(Please be assured that this questionnaire is for educational purpose only and it is confidential, your identity will be hidden)

INSTRUCTIONS

NAME: ………………………. SEX: …………………………………….

AGE: ………………………… MARITAL STATUS: …………………..

1. Can you share your views on your physical health status?

What do you feel about the following aspects relating to your physical health?

- I. Pain and discomfort
- II. Energy and Fatigue
- III. Sleep and Rest
- IV. Medical care

2. Kindly describe your psychological experience caring for your child with CP.

- I. Positive feeling
- II. Negative feeling

   III. Self Esteem
   IV. Body image
   V. Thinking, learning, memory and concentration

3. How is your social relationship with others?

   I. Personal relationship
   II. Social support
   III. Sexual activity

4. Tell me about your environmental experiences as a caregiver for a child with CP.

   I. Physical environment
   II. Financial resources
   III. Social care: availability & quality
   IV. Opportunity for new information & Skills
   V. Activity participation