PARENTAL EXPERIENCES OF PARENT SUPPORT GROUPS FOR CHILDREN WITH DEVELOPMENTAL DISABILITIES IN THE ACCRA AND CAPE COAST METROPOLIS, GHANA

BY

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THIS THESIS IS SUBMITTED TO THE UNIVERSITY OF GHANA – LEGON, IN PARTIAL FULFILMENT OF THE REQUIREMENT FOR THE AWARD OF THE MASTER OF PHILOSOPHY IN CLINICAL PSYCHOLOGY.

NOVEMBER 2024

DECLARATION

I Stanislaus Nyaku, declare at this moment that this thesis, titled "Parental experiences of parent support groups for children with developmental disabilities in the Accra and Cape coast metropolis" is an item of research generated by myself, conducted under the guidance of my supervisors, at the psychology Department of Psychology, University of Ghana. I have conducted all research present in this document and all sources of information, including written and verbal additions from others, have been properly acknowledged and cited. In furtherance, I declare that, no part of this thesis has been submitted to any academic qualification, and it has not been previously published in any form. Any similarities in content with other works have been properly cited and referenced. I take full responsibility for the accuracy and authenticity of the data presented in this thesis and the interpretations and conclusions drawn from it. I acknowledge that any errors or omissions are my own. I am aware of the consequences of academic misconduct, including plagiarism, and I affirm that this thesis is an honest and genuine representation of my academic work and intellectual contributions.

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DEDICATION

Proverbs 16:3 “Commit your work to the Lord and He will establish your plans.”

This thesis is above all else dedicated to God Almighty for making it possible for me to pursue this course and coming this far.

This thesis is also dedicated to the brave families enduring their children’s conditions and are continuing the fight of developmental disabilities in the light of limited resources and societal pressures, you are a great encouragement to all of us.

Lastly, I dedicate this thesis to the hunt of knowledge especially among the population of study; for only through research partnerships between researchers and participants can insight be developed to change the harsh realities that some persons managing such conditions face.

ACKNOWLEDGEMENT

I want to extend my heartfelt gratitude to everyone who helped me finish this thesis, "Parental experiences of parent support groups for children with developmental disabilities". This beautiful adventure would not have been possible without the presence and assistance of some particular individuals and organizations. First and foremost, I will like to give thanks to God Almighty for my faith admonishes me to be thankful to God in all situations, how much more a great occasion as this. I acknowledge the Divine hand of God before, during and after the submission of this thesis. May all the praise and glory be His.

I am particularly grateful to my supervisors Prof. Mabel Oti – Boadi and Prof. Joana Salifu Yendork for their essential assistance and mentorship throughout the research process. Your knowledge and expertise have been invaluable to putting this research work together.

To my family and well-wishers (Mrs. Perpetua Kplomedo, Rev. Fr. Nimorious Domanzing SMA, Mrs. Nana Yaa Obeng, Aseye Jiagge-Fiayornu, Phyllis Frances Dorgbedo to name a few) thank you for the encouragement and material support in the course of this work. To my brothers Jean and Joel, I see you!

To "The Special Mother's project" and "The challenged children's foundation", this work would not have been possible without you. Your trust in me for this project encourages me to probe deeper into the realities of families sharing your plight. Thank you for the confidence and your presence in this work. Lastly to all authors, whose writings and intellectual arguments contributed significantly to this study and greatly helped this research work. The success of this project is in fact a collective effort from the dedication and instrumentality of many people and all of you are duly acknowledged from the depth of my heart.

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LIST OF ABBREVIATIONS AND ACRONYMS

APA – American Psychiatric Association

COR – Conservation of Resources theory

CDC – Center for Disease Control and Prevention

DD – Developmental disabilities

GSS – Ghana Statistical service

JHS – Junior High School

LMICs – Low-and Middle-Income Countries

PSG – Parent support groups

PT – Participant

SHS – Senior High School

WHO – World Health Organization

ABSTRACT

This study explored the experiences of parents who participate in support groups for children with developmental disabilities. Using a descriptive qualitative design guided by a phenomenological approach, eleven parents were interviewed through semi-structured discussions to understand their perspectives on the role of parent support groups. The data were analyzed thematically, revealing five major themes: caregiving experiences, coping strategies, awareness of support groups, perceived benefits, and challenges encountered. Findings showed that parent support groups provided participants with holistic education, access to useful information, and both emotional and material support. The groups also offered opportunities for psychological well-being and social connectedness. Parents emphasized that interacting with others facing similar circumstances fostered understanding, resilience, and a sense of belonging.

Overall, parent support groups were found to play a vital role in enhancing the caregiving experiences and well-being of parents of children with developmental disabilities. The study highlights the importance of strengthening and expanding such groups to promote family resilience and psychological health. Implications for clinical practice and recommendations for future research are discussed.

CHAPTER ONE

INTRODUCTION

1.1 Background of study

Developmental disabilities (DD) are a group of conditions occurring due to impairment in physical, learning, language, or behavioral areas (Center for Disease Control and Prevention [CDC], 2022). The American Psychiatric Association (APA, 2022) classifies these conditions under neurodevelopmental disorders which are a group of conditions with onset in the early developmental period. The disorders typically manifest early in development, often before the child enters school, and are characterized by developmental deficits or differences in brain processes that produce impairments of personal, social, academic, or occupational functioning (APA, 2022). An estimated 1.3 billion people experience significant disabilities and this represents 16% of the world's population, or 1 in 6 persons (World Health Organization [WHO], 2022). The CDC (2022) reports that recent estimates in the United States show that about one in six, or about 17%, of children aged 3 through 17 years have one or more developmental disabilities. Data from the 2021 housing and population census in Ghana revealed that about 8% of the Ghanaian population (2,090,138 persons) experience some form of disability with a higher prevalence in females (8.8%) than males (6.7%) (Ghana Statistical Services [GSS], 2021).

Early childhood is a vulnerable time where there are many opportunities for the best possible brain development. In these early years, language, cognition, motor, and socioemotional domains all develop quickly (Meriem et al., 2020). As the child gains independence, these areas of development interact and support one another rather than operating or developing independently (Smythe et al., 2021). The risk factors of developmental disabilities include genetics; health of the parents and behaviors such as drinking and smoking

during pregnancy; birth complications; infections from the mother at birth or from the baby in early life; and exposure of mother or child to environmental toxins like lead (CDC, 2024). According to Johnson et al. (2018), about 53 million children under five are thought to live with DD worldwide, making it the most common cause of childhood disability. Most of these people are found in Low- and Middle-income countries, including Ghana (Johnson et al., 2018).

Research shows that caregivers of children with DD have higher levels of depressive symptoms (31% vs 7%, respectively) and anxiety symptoms (31% vs 14%, respectively) than caregivers of children without DD (Scherer et al., 2019). The literature also reveals that parents of children with DD undergo a substantial number of difficulties in the management of their children; especially in a society where there is still discrimination against children with disabilities and their parents (Ifeoma, 2019; Oti-Boadi 2020).

According to research conducted in Low-and Middle-Income Countries (LMICs), parents of children with disabilities commonly face a variety of challenges, including extreme stress, worry, despair, and physical exhaustion, as well as stigma and prejudice frequently influenced by conventional beliefs and poverty (Bunning et al., 2017; Lamptey, 2018; Oti-Boadi, 2017, Oti-Boadi et al., 2022). Families caring for such children are often stigmatized due to the perceived cause of the condition and some are isolated to care for and support themselves (Ifeoma, 2019; Oti-Boadi, 2017; Oti-Boadi et al, 2020). These families are also faced with the need for information about the condition of their wards, emotional needs, financial needs, and formalized support which includes parents' support groups to help them attend to the needs of their wards (Oti-Boadi et al., 2022).

Families of children with DD also face a challenge with the health needs of their children (Ifeoma, 2019; Oti-Boadi, 2017; Oti Boadi et al., 2020). Lamptey (2022) discovered

that, due to the condition of such children, they are relegated to the background when it comes to provision of health care and are not covered under the National Health Insurance. Parents of children with DD face unmet needs in healthcare such as information and advice as well as direct therapy and specialist mental health support for their children (Milosevic et al., 2022; Oti-Boadi et al., 2022). Moreover, studies have shown that individuals with DD are a vulnerable health population that do not receive adequate attention and support from the health system, society, and the family (Krahn et al., 2015).

Support from family and society is important to the well-being of parents of children with DD (Baker et al., 2021; Oti-Boadi et al., 2022). Parents expect to receive help in two main ways, formal and informal support systems. Formal support systems involve support from governments, non-governmental agencies, and community support groups and are provided in the form of financial, training, and information sharing (Geuijen et al., 2021). These have been found to be limited in LMICs including Ghana (Oti-Boadi et al., 2019). On the other hand, the informal support systems refer to support from family and friends which make parents feel more accepted (Jackson et al., 2018; Oti-Boadi, 2017; Papageorgiou & Kalyva, 2010).

In Ghana and other African countries, the extended family system provides support to members of the family in difficult times (Belgrave & Allison, 2006; Dzramedo et al, 2018; Gyekye, 2004). This is consistent with the Afrocentric worldview discussed by Belgrave and Allison (2006), where collectivism amongst other values is stated as a fundamental African value. According to Mugisha (2023), the typical African extended family catered for all the needs and worries of every family member, be it bereavement, childbirth, or any significant need. Thus, the family has been instrumental in supporting parents to address their challenges of caregiving (Ifeoma 2019; Neece et al., 2020; Oti- Boadi, 2017). This is reflected in the provision of support from grandmothers, aunts and uncles, and older siblings who volunteer to help care for children with DD as the caregiving process imposes an immense burden on

parents (Berg et al., 2019; Masulani-Mwale et al., 2018). Ghanaian parents have reported receiving help and encouragement from families and other interpersonal networks to invest in the care of their children (Amo - Adjei, 2023).

Current trends in modernization and urbanization, however, have contributed to a massive decline in some of these core cultural values of people of African descent especially collectivism (Adou, 2022; Nortey et al., 2017; Oladipupo, 2022). Modernization has led to the growth of urbanization which has seen the emigration of family members from their traditional settings into these urban areas, causing a break in the extended family system (Layefa et al., 2022). The nuclearization of the family system due to modernization has resulted in the further decline of family support for several families especially those with children with special needs (Gyekye, 2004; Mugisha 2018; Nortey et al., 2017). This has necessitated the involvement of governments stepping in and creating residential care facilities, and special homes amongst other amenities to house very needy people, which was not the case when the extended family existed fully in its time (Layefa et al., 2022).

Moreover, in most African countries, the beliefs associated with DD is in the form of a curse from the supernatural due to a sin that the parents might have committed against the gods making it difficult for parents to receive support from family and society (Amo - Adjei et al., 2023; Avoke, 2002; Oti-Boadi, 2017). This understanding is mostly due to limited general literacy among the population (Baffoe 2013). Consequently, such children, and their families are shunned by society because of the still prevailing myths and superstitions about children with DD in Ghanaian society as being children of evil deities and gods (Baffoe, 2013**).** Opoku (2017) discovered that some families deliberately neglected the plight of their relatives either with or nurturing some form of disability to their fate and others hid these people from the community giving them no assistance at all. The challenges experienced by parents have led to the emergence of Parent Support Groups to ease the burden of care and provide support to

parents of children with DD in several areas of their lives (Jackson et al., 2018; Solomon et al., 2001; Zuurmond et al. 2018).

Understanding the unique experiences of raising children with DD can make sense in the context of people who are facing similar challenges. Parents and caregivers have lamented on how they are often misunderstood by society and even medical experts in their attempt to seek help for their children (Arky, 2023; Zuurmond et al., 2018). Parents of children with DD in Ghana often experience stigma and social isolation within their communities and have limited information on the cause of their children's conditions (Mwinbam et al., 2023). The opportunity for parents raising children with DD to share experiences with others facing similar challenges has become increasingly significant. They can share experiences more freely and without fear of judgement and being misunderstood (Sadiki, 2023; Zeutenhorst, 2017). Parents also enjoy empathy from other parents which facilitates the sharing and understanding of experiences since they all face the same or a similar challenge.

Parent support groups (PSG) provide informal mutual support and opportunities to discuss parenting challenges and strategies (Zeutenhorst, 2017). Parent support groups offer a place to find resources, a safe place to vent, a place to share victories along with disappointments and a place to form deep friendships (Arky, 2023; Zeutenhorst, 2017). According to Jackson et al. (2018) support groups added beneficial value to all members and greatly helped them. Parents feel a sense of belonging in their condition during support group sessions, this greatly improves their self-confidence and self-esteem (Solomin, 2001). Support groups also helped participants demonstrate higher degrees of coping and greatly reduced stress levels of parents in relation to the condition of their children (Ifeoma, 2019). Parent support groups also help to provide emotional support to families (Jackson et al., 2018; Solomon et al., 2001).

There is growing evidence that support groups for people with mental health issues are beneficial for both the person with the mental health condition and their caregiver in low-resource settings (Cohen et al., 2012; Puschner et al., 2019). Literature on parent support groups has shown that families can overcome emotional and psychological distress, build self-confidence, and manage their children's condition better through sharing of ideas and experiences (Jackson et al., 2018; Solomon et al., 2001; Zuurmond et al., 2018).

According to extant literature (e.g., Zuurmond et al. 2018), parents in support groups were better at managing emotions of guilt and self-stigma and a change in attitude toward their child, all of which were reflected in improved care and support. Additionally, support groups helped families become more resilient in their caregiving for their children. It is crucial to implement programs that specifically assist families in empowering them to better care for their children, such as group-based psychological interventions that address difficulties primarily affecting families in their caregiving (Masulani-Mwale et al., 2018). The provision and availability of these support groups greatly improve the mental health of caregivers of children with DD (Zuurmond et al., 2018). Loop (2017) argues that parent support groups exist to help families to manage their children's condition in the best possible way.

1.2 Problem statement

Families of children living with DD are often strained and require a lot of support (Estes et al., 2009; Oti-Boadi et al., 2022). Some of the challenges they face are financial, lack of information condition of their children (Oti-Boadi, 2022), stigma, perceived cause of condition, and isolation. (Ifeoma, 2019; Oti-Boadi, 2017; Oti Boadi et al, 2020) and healthcare issues (Lamptey, 2020; Milosevic et al., 2022; Neece et al., 2020). These challenges make the management of these children very difficult. The burden on the primary caregivers of children with DD has become increasingly unbearable through increased stress levels, and physical ill

health among other negative consequences associated with caregiving (Burke & Hodapp, 2014; Nurullah, 2013). This has necessitated the development of parent support groups to complement the effort of the family as a primary caregiver and help reduce the distress they experience.

The breakdown of the African extended family system due to modernization has affected family support as an African cultural value (Layefa et al., 2022). The extended families felt responsible for orphans, widows, sick and people with disability if the need arose. This depletion of the extended family system through modernization and the high cost of living in urban states has made it very difficult for family members to assist the needy ones in their extended families (Gyekye, 2004; Layefa et al., 2022; Mugisha 2018; Nortey et al., 2017).

Inability of families to take care of their relatives has invited governments to carry the burden of building residential care facilities and special homes amongst other amenities to house very needy people, which was not the case when the extended family existed fully in its time (Layefa et al, 2022). This effort by the government has in no way fully helped parents, especially those with the burden of caring for children with special needs.

Extant literature has shown that PSG provides tremendous support to parents in the form of information sharing to gain more insight into the condition of their children as well as gain some form of empowerment to continue the caregiving roles (Ifeoma, 2019). These groups also provide parents with the support needed to cope with the stress and share ideas on how to better manage the special needs of their children (Jackson et al., 2018).

Many studies done in Ghana among the caregivers of children with DD focused a lot on the needs of caregivers with some emphasis on their physical and psychosocial well-being (Appah 2024; Oti-Boadi et al., 2022). Other studies have looked at the lack of information about the condition of children (Oti-Boadi 2017; Ori-Boadi 2022) and difficulty accessing

healthcare (Lamptey 2022; Oti-Boadi 2017). Based on these studies, it can be deduced that caregivers of children with DD in Ghana face many challenges. There is limited literature concerning how parents are supported especially through parent support groups. This study is designed to explore parental experiences PSG's in supporting them cope with raising their children.

1.3 Aims and objectives of the study

- To explore the challenges and rewards of parents caring for children with DD.
- To explore how parents of children with DD cope with the stresses associated with caring for their children with DD.
- To explore the knowledge of parents on PSG.
- To explore the benefits obtained from joining a PSG for parents of children with DD.
- To explore barriers to participation of parents of children with DD in PSG.

1.4 Relevance of the study

This study when conducted will be relevant in research, in families living with children with DD and the society at large. In research, this study will bridge the gap in literature on the importance of parent support groups and provoke further research into this area of study. In family life, this study seeks to explore the impact of parent support groups and how they help manage the new reality of families as they care for their children. Findings from this study will help remedy the distress families go through in their attempt to tackle this new reality of managing children with developmental disabilities. In society, it will influence policy direction for managing mental health conditions. Where applicable, parent support groups can be constituted for major mental health conditions such as schizophrenia, bipolar disorder, and other conditions.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter of the research work describes the theoretical foundation of the study and a review of related literature backing the work. It also states the rationale of the study and operational definition of terms.

2.1 Theoretical framework

The conservation of resources theory by Hobfoll (1989) and the social comparison theory by Festinger (1954) were used in this study.

2.1.1 Conservation of Resources Theory (Halbesleben et al., 2014; Hobfoll 1989)

Conservation of resources theory explains the motivation that energizes human beings to maintain the resources available to them and pursue other ones (Hobfoll, 1989). A resource can be defined as anything that an individual values such as objects, states, and conditions (Halbesleben et al., 2014) and an absence of these can cause significant distress (Hobfoll 1989). A general assumption of Hobfoll's theory is that an individual has some resources at his/her disposal which he/she greatly appreciates and is inclined to protect and never lose (Dudek et al., 2007). Stress is predicted to occur because of circumstances that represent: (1) a threat of resource loss, (2) an actual loss of the resources required to sustain the individual, and (3) the lack of reasonable gain following resource investments (Dudek et al., 2007).

Families of children with DD are prone to extinguishing all available resources at their disposal (money, peace of mind, friendships, and social networks) in a bid to take care for their

children. Where support from families, religious bodies and other organizations is lacking, the rate at which these resources run out is even faster than usual leading to distress. This is consistent with Dudek et al. (2007), predictors of stress because a child with a DD fit in all three criteria stated above and the parents do not really have much to do about it.

Halbesleben et al. (2014) explored two important principles of the conversation of resources theory namely, the primacy of resource loss and resource investment. The primacy of resource loss proposes that it is more harmful to people to lose resources as opposed to gaining resources. Resource investment states that people will be inclined to invest resources to guard against resource loss, recover from losses, and gain resources (Halbesleben et al., 2014). Support groups help combat this resulting distress by providing some resources such as education about caregiving, and material support among other resources that are lost to parents during these periods of raising children with DD.

According to Hobfoll (2002) self-efficacy, optimism, self-esteem, sense of control, social support, and active goal pursuit, are key resources that increase the resilience of individuals. Support groups leverage on the above sentiments to create a welcoming atmosphere for their members thereby strengthening them and giving them a sense of hope to continue taking care of their children.

2.1.2 Social Comparison Theory (Festinger, 1954)

Social comparison theory proposes that people have a certain internal tendency to evaluate themselves, especially by comparing themselves to other people (Festinger, 1954). It also explains the reasons, as well as the processes, behind the idea that people evaluate their own opinions, values, achievements, and abilities by comparison respectively with the opinions, values, achievements, and abilities of others (Powdthavee, 2014). Social cognitions spring forth a series of behavioural, cognitive, and affective reactions. These may depend on

the level of the individual's self-monitoring and might change over time when social comparison information changes (Miller, 2015).

Parents of children with DD undergo significant distress. Comparing their plight to parents of typically developing children is a very painful experience. However, in a situation where these parents encounter parents with similar needs, they are less likely to feel distressed. Upward social comparisons occur because of comparing a person's plight to people who are better than them to achieve similar results (Kesici & Erdogan, 2010). For example, when a parent raises a child with DD comparing their plight to a normal parent. Downward social comparisons occur when people compare their situation to people who are worse off than them. This happens so they may feel about their abilities and situation (Kesici & Erdogan, 2010). People compare themselves to others who are higher than them when they aspire to improve their situation and they compare themselves to those who are worse off when they want to feel better about their situation or abilities (Kendra, 2022). The concept of parent support groups aligns with this noting of comparison, as such, groups provide a context where can relate their experiences to the others facing a similar challenge. When parents feel their struggles are not theirs alone, they are better able to build resilience and mutual understanding, which helps them to manage their situation more effectively. This theory supports and explains why parents in specific support groups can coexist in mutual hope and understanding as they strive to seek a way to manage their situation.

2.2 Review of related literature

2.2.1 Caregivers experience of raising children with developmental disabilities

Parents of children with DD are burdened with numerous burdens of care. A study conducted by Oti-Boadi et al. (2022) on the challenges and support needs of parents of children with DD in Accra, Ghana, sought to capture the experiences of parents. This study employed

the qualitative research design and featured nine participants. The study discovered that Ghanaian parents struggled with emotional needs, which included stigma and distress, informational needs which included parental training and availability of counselling services, financial needs which covered little or no money to manage the condition of their children, information support which included access to caregivers and supportive assistance and lastly formalized support which included parent support groups and donor support groups to help them manage their burden of care. A limitation to this study was that only one father was interviewed on his caregiving experience.

In a similar study by Appah et al. (2024) on a qualitative enquiry into the challenging role of caregivers caring for children with autism spectrum disorders in Ghana was reviewed. This study employed a qualitative phenomenological study with an exploratory descriptive research design. Ten participants were sampled using the purposive sampling technique. Findings from the study revealed that, caregivers in this study also battled with social challenges, financial challenges and emotional challenges. They also struggled with accessing health care, education and training of their children to gain admission into the normal schools. The new detail this study presents is the struggle with health care and education for children battling with developmental disabilities. A limitation from the study was the fact that only females had their experiences captured in the study. Researchers hypothesized that male caregivers may have reported different challenges.

Studies by Opoku et al. (2020) supported the fact that parents had struggles with schooling children with Autism. The study also appreciated the role the special school played in easing caregiver burden for parents to be able to work and gain some income to continue caring for their children. The downsides reported in this study were that parents were hindered financially when it came to sustaining their children in the special schools and were also skeptical about the effects of the teaching their wards were receiving. Concerning the health of

caregivers of children with DD, it was observed by Barnett et al. (2020) that there was an adverse effect on the health of caregivers. In the domains considered, caregivers were found to have declined general health, physical health and mental health days. Comparing caregivers of Mental illness and Developmental disabilities, it was noted by the study that, Mental illness caregivers reported poorer overall health.

Burke and Hadapp (2014) also discovered that the behavioral problems of the children strongly correlated with maternal stress. The quality of family-school partnerships is significantly related to maternal stress. Where parents enjoyed positive family-school partnerships, they experienced significantly less stress. Mothers were not so comfortable advocating for their children. According to the study, this contributed significantly to their distress.

Nurullah (2013) also conducted a study titled "it's a roller coaster": experience of parenting children with DD. The qualitative approach was employed and four participants were interviewed in Alberta Canada. Findings from this study adds that, parents significantly battled with five major problems in the care for their children with DD namely; (1) negotiating between joys and sorrows, that is feeling of a sense of unfairness towards themselves, their child and God. (2) Physical and mental exhaustion where parents' health was greatly affected by their children's situation, (3) negotiating with family matters which highlights plan they needed to put in to accommodate the child with a DD. (4) social stigma was examined in relation to the stereotypes parent had to endure because of their children's conditions and (5) hope and despair; where parents expressed skepticism about the future of their children but others were hopeful that things will get better going forward. Parents of children with cerebral palsy revealed struggles with inadequate facilities and services, parents' social lives were limited and social seclusion of parents and children. A few parents believed that their experiences of care became great source of personal growth and had made them stronger. Some

parents identified religion as an important tool in managing the challenge of taking care of their children. Other parents also believed they were being punished by God for a misdeed done either by them or a family member to be given a child with DD. A limitation of this study is participants of this study were mostly married and the did not account for the experiences of single parents which would be rather complex considering the factors necessary for the care of children with DD.

Taking together the studies above, the struggles parents go through in their experience of care cannot be overemphasized. The struggles with finances and education for their children were very profound. This study will also explore the role parent support groups play to address the challenges outlined - especially on the education of children with DD. Financial constraints, and psychosocial challenges like loneliness, being worried, battling with stigma, seclusion and isolation are also realities that befalls such parents. This study explored how parents can be helped with these challenges through parent support groups. This study encouraged the participation of more males to help understand their worldview relating to the experience of care for their children with DD.

2.2.2 Knowledge and experience with support groups

Parent support groups have been shown to provide some relief to parents in the bid to care for their children. The following studies highlight some of their advantages and disadvantages as far as providing care is concerned.

Ifeoma (2019), conducted a study on the impact of parent support groups on parents of children with disabilities in Enugu Metropolis – Nigeria. The study employed a descriptive survey design with twenty participants who were women. Findings from the study discovered that, parents who belonged to parent support groups had significantly less stress in dealing with the day-to-day affairs of their children. They also demonstrated better coping to stress than

parents who were not in support groups. The study concluded that parents of children living with disabilities can share experiences to better manage the condition of their children. A limitation of this study was the fact that only women were used in the study and that the views of men would have added the additional meaning to the study.

Solomon et al. (2001), conducted a descriptive study on the benefits parents of children with disability obtain from mutual support groups. Findings from the classical study revealed that parents who formed part of a mutual group experienced three important benefits (1) Due to the experiential knowledge shared during sessions, parents in mutual groups experienced a significant change in their relationships with the outside world, gaining a deeper sense of autonomy and control. (2) Parents experienced changes in the interpersonal domain, such as belonging to a community, being understood, and accepted, and having friendships and social networks where they could share their emotions and feel more "normal.". Parents reported intraindividual changes such as increased self-esteem and confidence, less guilt and self-blame, and greater acceptance of their child's disability. The study had some limitations. Firstly, the study featured only a few males with many women. Also, social acceptability bias may have come to play as participants may seek to appear socially desirable in the eyes of other participants thereby concealing some of the unpleasant information concerning their experience of care.

Lancaster et al. (2024) explored the efficacy of a peer support group intervention for parents of children with disability in Australia. This study used the quantitative research approach with a sample size of (n = 242). The study discovered that, improvements in parents' well-being and empowerment were maintained over a 6- to 30-month period after completing the intervention program. The study also affirms that peer support interventions were very important in the caregiving experience of parents of children with DD. This study, however, demonstrated that the gains that parents made in empowerment and well-being during the peer

support program were sustained over the medium to longer time frame and thus remained strengthened after 6 -30 months of intervention. The limitation of this study is that due to the small sample size the study needs to be replicated in larger samples.

In a study by Jackson et al. (2018) the perceived outcomes of parent support groups were looked at. Results from the study yielded two sets of responses: negative and positive perceptions. Some participants perceived support groups as valuable because they felt understood, helped each other, had positive experiences such as feeling better than when they came in, created connections where they related with each other with a common goal and lastly support groups offer a certain value that was beneficial. Some of the negative perceptions about parent support groups were that they brought people negative experiences, they were a poor fit, they do not help, and were unnecessary. The study's limitations include; participants were all residents of the state of Utah. Also, most participants were Caucasian, married and identified a Mormon significantly affecting the generalizability of the study.

On the disadvantages of parent support groups, the study by Shilling et al. (2015) noted that even though parents felt a nonjudgmental environment to discuss their issues and receive support and encouragement, it was also observed that befrienders felt emotionally drained and burdened in the role they were playing.

The above studies bring out the value of parent support groups especially to families of children with disabilities. Patrons of support group interventions enjoy several benefits from attending meetings. A sense of belongingness, personal growth and appreciation of child condition are among the many benefits parents gain from support group interventions as captured by the studies above. Future research can explore the participation of men in support groups. Access the challenges and barriers limiting the actions of support groups. Also, an

independent study can be designed to look into the constitution of parent support groups in Ghana.

This study will examine the challenges and barriers for participating in support group interventions. It will also explore challenges of parent support groups. Gathering data on all these aspects will effectively improve the functions of support groups and increase their efficacy.

2.2.3 Coping strategies of families of children with DD

Coping is defined broadly as an effort used to minimize distress associated with negative life experiences. Coping is a very important area in the care of children with special needs. Parents and caregivers who decide to continue the process of care may become worn out, stressed and overburdened. During these moments, they may need some strategies to keep them going again. Literature on coping suggests that caregivers are able to navigate their challenges of care when the right coping strategy is applied.

Juczyński and Ogińska-Bulik (2009) adopted the Brief Coping Orientation to Problems Experienced inventory (Brief – COPE) by Carver (1997) and validated it among the polish population and has been used in a number of studies (Bujnowska et al., 2021; Rzeszutek 2017; Szrajda 2019). This 28 – item scale is divided into three divisions problem focused coping (active coping, planning, use of informational support and planning) emotion focused coping (religious coping, acceptance, social support, venting, humor and self-blame), and avoidant coping (denial, substance use and behavioral disengagement). These divisions will guide the deliberations in this study pertaining to problem focused coping and emotion focused coping.

Gusrianti et al. (2018) conducted a study on factors affecting parents' acceptance towards children with familial intellectual disability. The quantitative approach was used and twenty mothers living with children of familial intellectual disability took part in the study.

The Parental Rejection Questionnaire (PARQ), Brief Arab Religious Coping Scale (BARCS), Social Support Questionnaire Short Form (SSQSR) and Supporting Facilities Questionnaires were used to assess parents and a multivariate logistic regression was used to analyze the data collected. The study discovered that social support significantly contributed to parents accepting the condition of their children. The other study variables yielded a non-significant relationship and they include (religious coping, family income, education and supporting facilities). The study underscores the importance of social support in the parental acceptance of the disability of their children. The limitation of the study was that, it was conducted in central Java province in Indonesia hence finding should be interpreted carefully across different cultures.

Another study was conducted by Kang et al. (2019) on comparison of acceptance of disability, stress, coping methods, and wellness between mothers of physically dysfunctional or developmental disabilities. The quantitative approach was employed. Data was collected from two groups of mothers (1) mothers with physical functional disordered children and (2) mothers of children with developmental disabilities. Finding from the study revealed mothers of physically dysfunctional children displayed a significant positive correlation in disability acceptance and coping, and disability acceptance and wellness and a negative correlation between disability acceptance and stress. Mothers of children with DD also displayed a significant positive correlation between disability acceptance and wellness and a negative correlation between disability acceptance and stress. The results from the study indicates that, for both population of study, disability acceptance either improved wellness, or coping methods or both and had a significant negative impact on stress. This means that, with the acceptance of the disability of their children, mothers had improved wellness and decreased stress to take care of their children.

Ludlow et al. (2012) conducted a study to examine the challenges faced by parents of children diagnosed with autism spectrum disorder. The qualitative approach was used with the snowball and convenient sampling techniques. Twenty participants were interviewed of with 14 were mothers and 6 were fathers. Findings from the study revealed that in the heat of the challenges faced by the condition of their children, parents turned to social support and social comparison as coping strategies. Social support has been proven to be a major coping strategy for families caring for sick children. The study reported that only a few parents were able to access help from family and friends during their period of caring for their sick relatives. Parents complemented this loss of support from family by joining parent support group where they met other parents in a similar predicament and shared their experiences. In those groups and gatherings, they were able to compare the plight of their children with other children and learnt to better appreciate their situation significantly reducing their stress. A limitation of the study was the limited generalizability of findings, though it provides us with a rich subjective experience of how parents cope with the condition of their children living with disability.

Antwi (2023), conducted a study on the unplanned journey: challenges of parents of children living with disabilities in Ghana. The phenomenological design was used with the qualitative approach. The study featured six participants who were parents of children with disability. The findings from the study revealed that parents of children with disabilities employed three coping strategies, namely; support from family, children's menta fortitude and spirituality or religious coping. Parents who had relatives helping them to take care of their sick children. Families that had relatives helping parents take care of their children allowed parents to work and do other things and parents greatly appreciated this support from relatives. Parents whose sick children had learnt to perform some of their duties like eating on their own and have become potty trained allowed their parents to use the extra time take care

of their other siblings and other responsibilities that demanded their attention. Religious coping or spirituality was also employed by parents, where parents constantly turned their eyes to God for help and sustenance to manage the condition of their children. The study emphasized that participants turning to God helped them to curtail their stress.

Bujnowska et al. (2021) conducted a study on coping with stress in parents of children with developmental disabilities. The quantitative approach was used and the COPE inventory and the CISS were used to assess participants. 167 parents of children with DD and 103 parents of typical development children (TD) voluntarily participated in this study. Findings from the study discovered that younger parents of children with DD were more geared towards using problem focused coping (task-oriented styles) than older parents in the care and upbringing of their children (planning and use of instrumental support). They were also less likely to engage in emotion focused practices (emotional support, seek support, sympathy). The study also discovered parents of children with DD did not use any religious coping which occurred in TD parents. Also, parents of DD children were found to have a personal resource; that was constructive coping which they employed to battle general stress and the stress from the caregiving experience of their children. A limitation of this study sample size and sample's characteristics affects the generalizability of the study.

Miranda et al. (2019) conducted a study on parenting stress in mothers of children with autism without intellectual disability – mediation of behavioral problems and coping strategies. The quantitative research approach was utilized and 52 families of children with autism diagnosis took part in the study. Findings from the study discovered parenting stress had a significant positive correlation with behavioral problems. This implies that parenting stress increases when the behavioral tendencies of children due to autism begin to manifest or manifest out of control. The study also discovered a significant negative relationship between parenting stress with engagement and confidant support. This implies that social support

greatly reduced parenting stress affirming emotion focused coping strategies as helpful in curtailing parental stress. It was also discovered that engagement (instrumental support, active coping, planning and emotional support) all mediated maternal stress that accompanied their caregiving process. This means that both emotion and problem focused coping strategies help in improving maternal stress. According to researchers, this study is the first to be conducted and is limited because of the small number of participants for generalization.

Panicker and Ramesh (2018) found that caregivers of autism significantly reduced their symptoms of stress and depression when they used problem focused interventions. On the other hand, arguments have also been made to support the efficacy of emotion focused interventions.

Junaidi and Dewantoro (2020) make a case for emotion focused coping as they explored parents' perceptions to understanding the disability of their children and coping as well. In their study, 86.7% of participants reasoned that the disability of the child was caused by the will of God. With this thinking, relying on God to relive their stress was the next line of action and this brought participant peace to continue caring for their wards.

The studies above highlight the significant impacts of coping strategies on the plights f parents caring for children with special needs. Social support, religious coping/spirituality, acceptance, planning among others were the dominant strategies captured in these studies above. Future research can probe into the efficacy of individual coping strategies and their roles in curtailing stress of parents with children with special needs. Another study can look at how many coping strategies are enough to deal with stress from this population of people. Most, if not all the studies above were conducted outside the African continent (USA, UK and India).

This study explored the coping strategies available to parents with children DD here in Ghana.

2.3 Research questions

- What are the challenges and rewards of parents caring for children with DD?
- How do parents cope with the stress associated with caring for their children with DD?
- What knowledge do parents have about PSGs?
- What are the benefits of joining a PSG to parents with a child with DD?
- What are the barriers affecting participation of parents with children with DD in PSG?

2.4 Rationale for the study

The breakdown of the extended family system in Africa due to modernization and urbanization has widened the burden of care that families face (Adou, 2022; Layefa, 2022). This has placed massive burdens on parents and their children. The rationale of this study is to investigate how parent support groups mitigate this gap of care for such families. This study will also add to the growing literature in this area of research helping the whole world understand and appreciate what such parents are going through. This study seeks to explain what parent support groups are about and the interventions they offer to help in the care of families burdened with a child with DD.

This study looks into the benefits that parents derive from support groups and also notes the challenges support groups go through in trying to mitigate the struggles of parents. By bringing these findings to the fore, relevant stakeholders can be engaged to begin a conversation around this delicate plight of parents caring for their children with a DD.

2.5 Operational definition of terms

- **Developmental disabilities (DD:** Developmental disabilities will comprise intellectual disability, Autism Spectrum Disorder, Attention-Deficit/Hyperactivity Disorder, Communication Disorders, and Neurodevelopmental Motor Disorders (CDC, 2022).
- **Parent Support Group:** A group of people who come together to help manage the condition of their children through the sharing of learning and sharing of experiences about the specific condition of their children. (Ifeoma, 2019; Solomon et al., 2001)
- **Family:** Includes parents or guardians who help to cater for a child with developmental disabilities
- **Parents:** Birth parents or guardians who take care of the day-to-day living of a child with DD.

CHAPTER THREE

METHODOLOGY

3.0 Introduction

This section presents the methodology of the study. It highlights the research design, study setting, population and sample size and sampling technique. It also presents the sources of data, data collection instrument, procedure, ethical considerations, and data analysis.

3.1 Research design

This study employed the qualitative approach to explore parental experiences of parent support groups (PSG's) for their children with DD. Cresswell (2007) asserts that the qualitative approach is considered the appropriate design for this study since it provides an in-depth understanding and a rich description of the experiences of participants. Lindlof and Taylor (2002) also describe the qualitative approach as one which helps a researcher attempt to retain and analyze the contextual form, substance, and experience of social activity.

The research method for this study was based on the phenomenological design which provides a vivid description of the phenomenon under study exploring the lived experiences of participants (Smith & Osborn, 2015). Smith (2011) argues that the purpose of phenomenological study is to investigate in detail how participants are making meaning of both the personal and social worlds in which they exist. This brings out a detailed examination of the participants' lifeworld by questioning personal experiences to unravel the individual's subjective account, as opposed to producing an objective account of the person's predicament, giving more meaning to the individual's subjective experience (Smith, 2011).

3.2 Research Setting

This research was conducted in the Accra and Cape Coast Metropolis. Both cities are the capital of their respective regions, that is Greater Accra and Central Region. Both cities due to their cosmopolitan nature, allow the inhabitance of a variety of people living in the towns and cities. The Accra metropolis will have about 284,124 people in 2024, and the Cape Coast metropolis has an amount of 189,925 people resident there according to the 2021 population census (GSS, 2021). The abundance of people in these metropolitan areas provides a rich diversity of experience that can be tapped for research purposes making them appropriate for research.

3.3 Population

The population of this study was Parents of children living with a DD and belonging to a Parent's Support Group (PSG). The Special Mother's Project and the Challenged Children's Foundation provided participants for this study. The Special Mother's Project is an awareness and advocacy group on cerebral palsy and other DD and helps parents manage their wards better. Currently based online, it has participants from all over the country. Other support groups tap from the knowledge and experience shared on this platform and apply them to their various groups. Their platform currently has over three hundred participants including some stakeholders and resource persons intentionally stationed to assist them in any emergency or assistance.

The Challenged Children's Foundation is a group based in the Cape Coast metropolis. They are primarily interested in special needs children taking care of their education, empowerment and advocacy. They also have a parent support group for parents of special needs children to facilitate the care of these young ones. There are about 50 parents in their support

group. They have their support group meeting on Tuesdays and also call for emergency meetings when the need arises.

3.4 Sample and sampling technique

The study adopted purposive sampling and snowball techniques. The purposive sampling technique is based on the premise that seeking out the best cases for a study produces the best data and this translates into the result of the study (Mweshi & Sakyi, 2020). This approach makes room for rich information to be gathered so that they best address the objectives and outcomes of the study (Mweshi & Sakyi, 2020). This type of sampling involves the researcher using their judgement to select a sample that is most useful for the research (Mweshi & Sakyi, 2020) in this case, parents of children with DD who belong to parent support groups. Parent support groups of parents with DD were targeted by the researcher from which parents who were taking care of children with DD were selected to participate in the study.

The snowball sampling technique has also been identified as a method that yields rich information through the context in which the persons live and interact with one another (Noy, 2008). Both sampling methods were crucial to this study because children living with a DD are relatively rare compared to the general population. Also, finding parents who are actively in support groups due to their children's condition was a difficult task. From the purposive sampling method, parents from support groups helped the researcher with the address of participants who were also part of the support group but were absent. This information helped the researcher to visit these participants in their homes and interviewed them as well.

Eleven (11) participants were sampled for the qualitative study. Krueger (2014) suggests that 10 participants are large enough to get a variety of perspectives on a phenomenon and small enough not to become fragmented. According to Hennink and Kaiser (2022), saturation refers to the point in data collection when no additional issues or insights are

identified and data begin to repeat so that further data collection is redundant, signifying that an adequate sample size is reached.

The age of participants ranged between 21 to 64 years. The participants consisted of two males and nine females of which one was a guardian. Nine of the participants were Christians and two were Muslims. Three participants reached the tertiary level of education, one reached Senior High School, and the rest of the participants completed at the Junior High School level. Concerning the conditions of their children, six children had cerebral palsy either as the only condition or cooccurring with another condition. Three children were living with autism and all of them had a comorbid condition. ADHD, cerebral malaria, down syndrome, epilepsy and spinal bifida were the other conditions of the children in this study. Table 2 presents the full details of the demographic of participants and the condition of their children.

Table 2

Demographic characteristics of participants

Participant	Gender	Age	Education	Job	Religion	Marital status	Child's disability	Age	Gender
PT 1	Female	40	Primary	Trader	Islam	Married	Cerebral palsy	15	Male
PT 2	Female	40	JHS	Seamstress	Christian	Not married	Cerebral palsy	8	Male
PT 3	Female	37	Primary	Unemployed	Christian	Married	Epilepsy	16	Female
PT 4	Female	45	JHS	Housewife	Islam	Married	Cerebral palsy/autism	8	Male
PT 5	Female	31	JHS	Trader	Christian	Married	Autism/ ADHD	6	Female
PT 6	Male	37	JHS	Welder	Christian	Married	Cerebral Malaria	8	Female
PT 7	Female	27	JHS	Unemployed	Christian	Not married	Cerebral Palsy/Autism	12	Female
PT 8	Female	21	SHS	Unemployed	Christian	Not married	Down syndrome	9	Female
PT 9	Female	38	Tertiary	Nurse	Christian	Married	Spinal bifida	9	Male
PT 10	Male	64	Tertiary	Retired	Christian	Married	Cerebral palsy	9	Male

PT 11	Female	46	Tertiary	Employed	Christian	Married	Cerebral Palsy	11	Male

*PT= Participant *JHS= Junior High School *SHS= Senior High School

3.4.1 Inclusion Criteria and Exclusion criteria

The study's inclusion and exclusion criteria for participants were as follows.

Inclusion criteria

(i) Parent or guardian caring for a child with a DD.

(ii) The child should be older than five years but not more than seventeen years of age.

(ii) Parent or guardian belonging to a Parent Support Group for a child with DD.

Exclusion criteria

(i) Parent or guardian without a child living with conditions other than a DD.

(ii) A child of less than five years or more than seventeen years

(ii) Parent or guardian who does not belong to parent support group for DD.

3.5 Measures

3.5.1 Semi-structured Interview schedule

A semi-structured interview guide was developed by the researcher purposely for the current study. Developing a semi-structured interview guide essentially contributes to the trustworthiness of the interview as a qualitative research method (Kallio et al., 2016). The interview guide was developed from a broader set of research questions that needed to be answered in the study. It consisted of 10 questions each with probing questions. The interview guide asked questions about parents' burden of care, coping strategies available to them and the knowledge they have about support groups and the experiences they have had with them thus far. It also explored the availability

of parent support groups and what barriers are interfering with their participation in support group activities. The challenges of the support groups were also assessed. Below are sample questions from the interview guide. The complete interview guide can be located in appendix A of the research work.

1. How long have you cared for your child with developmental disability?

Probe: When did you get a diagnosis? At which age of the child?

- Where did you get the diagnosis for your child?
- How many children do you have with DD.

2. What support have you received since the birth of your child?

Probe: What types of supports are available to you? E.g., family, parent groups, religious group, social media networks?

- How reliable are these support systems and what is the impact on you and your child?

3.6 Data collection procedure

Letters of introduction were sent to the study sites including the Special Mother's Project and The Challenged Children's foundation by the researcher to sensitize the leaders about the study and solicit the participation of Parents/ Guardians for the study. Participants were assessed with the semi-structured interview guide designed for the study. The interview guide explored the demographics of parents and their children asking questions like employment of parent, disorder of child, support from families and other bodies as well as support obtained from the support group to summarize. A copy of the interview guide is added to the appendix's session of the study. The researcher had to travel to meet up with participants to have a face-to-face meeting with them and a record interview session with them. Seven out of the eleven participants preferred to have their interviews in the Twi dialect with the remaining four recording their interview in English. A parent

with tertiary level education and well versed in the Twi language helped to translate the interview questions to the participants. Participants asked several questions to understand the questions before attempting to answer any of the questions asked. A few participants who could have the face-to-face meeting arranged opted for over-the-phone interviews. These calls were recorded and safely stored with the remaining audio recordings. The files were encrypted and kept in a zip file. The interview sessions lasted between 30-45 minutes per participant. A set of stationery was given as compensation to participants in the study; a refreshment package was added to the stationery provided after participants successfully completed their interviews.

3.7 Ethical Considerations

Ethical approval was sought from the Ethics Committee for Humanities (ECH 226 22-23) of the University of Ghana. An introductory letter was obtained from the Department of Psychology stating the goal of the study. The letter was submitted to both research sites, namely; The Special Mother's Project and The Challenged Children's Foundation and their participation in the study was approved. Informed consent was sought using the face-to-face approach for consistency and effectiveness. Verbal informed consent was obtained from participants before each interview. To ensure confidentiality and anonymity, pseudo names were created for participants and assigned to their respective responses. In furtherance, permission of participants was sought for their interviews to be audiotaped for better analysis and accuracy of responses. Participants were also made aware of the fact that participation was strictly voluntary and that they were at liberty to withdraw if they felt the need to.

3.8 Trustworthiness

To guarantee the trustworthiness of the qualitative results, the procedure by Shenton (2004) was implemented. This includes credibility, transferability, dependability and confirmability.

3.8.1 Credibility

To ensure credibility, frequent sessions were held between the researcher and the supervisor to generate ideas for the research prior to the conducting of the study. Several deliberation sessions were done between researcher and supervisor and the adoption of a well-recognized research method was accepted and approved for the study. During data collection, participants were encouraged to be as frank as they could be in narrating their experiences with the questions that were asked during the interviews. The independence of response was also controlled to allow everyone to freely express their lived experiences. Again, back-and-forth engagement was made between the researcher and the supervisor until the data was completely analyzed to ensure credibility of the study.

3.8.2 Reflexivity statement

As a researcher with a background in clinical psychology, I acknowledge that my disciplinary training and professional experiences have inevitably influenced my approach to this study and the interpretation of data. My understanding of psychological distress, coping, and family adjustment is grounded in clinical frameworks that emphasize mental health, emotional regulation, and resilience. These perspectives have shaped how I attended to and engaged with the experiences of parents raising children with developmental disabilities.

In adopting a reflexive thematic analysis, I recognize that knowledge production is an interpretative process shaped by my subjectivity rather than an objective discovery of pre-existing themes. My clinical orientation allows me to approach participants' accounts with empathy and psychological insight; however, it also poses the risk of framing their experiences through diagnostic or therapeutic lenses. To address this, I have actively engaged in reflexive practice—continually questioning how my assumptions and expectations may influence data interpretation.

Reflexivity was integrated throughout all stages of the research process. During data collection, I remained attentive to the power dynamics inherent in my dual role as a clinician-researcher,

striving to create a safe, non-judgmental environment that privileged participants' voices. During

coding and theme development, I maintained an iterative process of revisiting transcripts, research notes, and preliminary themes, ensuring that the analytic process remained grounded in participants' meanings rather than my preconceptions. Reflexive journaling, peer debriefing, and supervision further supported transparency and critical self-awareness.

Ultimately, I view my positionality not as a source of bias but as a valuable interpretative resource that enriches the analytic process. My clinical background provided a nuanced understanding of emotional complexity, while reflexivity ensured that participants' lived experiences—rather than professional interpretations—remained central to theme development. This ongoing reflexive engagement aimed to enhance both the analytic depth and credibility of the findings.

3.8.3 Transferability

For transferability, findings from the study were discussed according to existing research in DD to allow for comparisons to be made. This study unearthed practical experience of the struggles parents of DD go through in the Accra and Cape Coast metropolis, and the experiences discussed in this study as very similar to findings discussed in literature from other parts of the world. This goes a long way to say that insights from this study could inform or be relevant to the situation of people in similar

3.8.4 Dependability

Participants' thoughts and ideas during the interview process were reechoed or reflected upon to ensure that their precise accounts about the events were well captured to ensure dependability of findings.

3.8.5 Confirmability

Also, probes were used in the data collection process to gain comprehensive information from participants. The shortcomings and limitations of the study were noted and the use of tables to illustrate some research findings helped to promote confirmability. Williams and Morrow (2009) also suggest that trustworthiness can be ensured through three ways: integrity of data, balance between reflexivity, and clear communication of results. The study employed all these strategies to enhance integrity. The drafts that were generated ensured the analysis was grounded in the data. To bracket the biases of the researcher from affecting the outcome of the study, utmost honesty was ensured while coding.

3.9 Data Analysis

All audiotaped interviews were transcribed using Microsoft Word's processing program. The seven interviews recorded in the Twi dialect, were first translated into the English language before they were transcribed. The transcribed data was then inspected to see if it had been accurately captured. Thematic analysis was used to analyze the data according to the Braun and Clarke (2006) model. This model suggests six stages of thematic analysis to identify recurrent themes within the responses. These stages involve data familiarization, generation of initial codes, searching of themes based on initial codes, reviewing of themes, defining, and naming themes and writing a report after a thorough process. The first step involved a familiarization process where the researcher carefully focused on the data by listening attentively to the audiotaped interviews to find meaning and patterns. After thoroughly listening to the audio, transcription was done, and initial codes were generated. This was done by writing notes and highlighting texts to identify patterns within the data.

After the identification of codes, a theme search based on initial codes was conducted and this organized all codes into potential themes. Thus, codes were sorted into potential themes and all

relevant codes were collated. The codes were analyzed to determine which could become a main theme. The fourth stage involved the review of themes where codes were reviewed to find out if they formed a coherent pattern. For example, “name calling”, “avoidance by others” and “mockery of child’s situation” were themed “Stigmatization”. Again, the various themes were checked to find out how relevant they were in relation to the codes and the entire data. As part of this stage, a thematic map of the analysis is generated and checked to ascertain whether it represents the meaning provided in the data.

The next stage involved the definition and naming of themes which implied explaining what each theme was about and directing each theme to the aspect of data it captured. For example, stigmatization was put under experience of care because that is the aspect of the data it represented. The aim was to identify the essence of what each theme is talking about. Finally, after themes were fully identified, a report was done when there was a full set of well-established themes. This report captured the findings of the study in relation to the research questions the study sought to answer.

Five main themes were generated in this study. These themes were the experience of caring for children, coping strategies, awareness of parent support groups, benefits of parent support groups and challenges facing parent support groups. The main themes were supported by sub-themes to help derive meaning from the experiences of participants.

CHAPTER FOUR

RESULTS

4.0 Introduction

The objective of this study was to explore parental experiences with parent support groups for their children with DD. Also, the study explored the coping strategies of participants, the benefits of parent support groups in caring for their children and the challenges confronting parent support groups. Additionally, sub-themes were generated to derive meaning from the narratives of participants to support the objectives of the study.

4.1 Emerging Themes

The data obtained from the qualitative study of the impact of parent support groups on families of children with DD were analyzed using thematic analysis. Five main themes emerged from the data. These themes were the caregiving experience of children, coping strategies, awareness of parent support groups, benefits of parent support groups and challenges facing parent support groups. These major themes were accompanied by sub-themes which reflected their meaning. Table 3 below shows a summary of the themes and sub-themes generated from the qualitative data.

Table 2

Themes and sub - themes

Themes	Sub-themes
1. Caregiving experience	Stigmatization and discrimination
	Financial constraints
	Child dependency
	Joys amid the storm
2. Coping strategies	Acceptance
	Social comparison
	Religious coping
	Social support
	Planning
3. Awareness of parent support groups	Availability of PSGs
	Accessibility of PSGs
4. Benefits of parent support groups	Holistic education
	Access to valuable information
	Promotion of psychological wellbeing
	Material support
5. Challenges of parent support groups	Lack of financial assistance
	Lack of crucial infrastructure
	Lack of respite care

4.2. Theme 1: Caregiving experience

Families of children with DD undergo a lot of struggles and pains to care for their sick children. Most of them have no external help to ease their burden of care. Stigmatization and discrimination, financial constraints, child dependency and joy amidst the storm are the highlights of the caregiving experience from this study. The subsequent paragraphs highlight the caregiving experience that parents in this study recounted as they take care of their children with DD.

4.2.1 Stigmatization and Discrimination

Stigmatization generally refers to marking a person with disapproval, often underpinned by negative societal stereotypes. Participants recounted several episodes of abuse they have had to suffer because of the situation of their children. In this study, participants reported how people in their communities consciously or unconsciously leveraged on the condition of their children and made certain harsh pronouncements on either the parents or the children or both. This has been a bitter pill for the parents to swallow and a sad reality they have had to grow used to. Some participants narrate how people call their children "monsters" and "river children "because of their appearance. These voices echo their narrative.

> *"At first his father didn't mind the child. And sometimes he likes to exempt the child from some things. But now his attention towards the child is lukewarm. Some people even tag the child as a river child and my relationship with his father is lukewarm., he mostly listens to what people say."* (PT 4, female, 45 years, mother of child with cerebral palsy/autism)

> *"For the negative experiences there are a lot, there was stigmatization at work and everywhere. It even affected my marriage and career."* (PT 11, female 46 years, mother of child with cerebral palsy)

Discrimination refers to unfair treatments metered out to people or groups of people based on traits like race, gender, disability, religion among a number of other factors. With respect to this study, parents were discriminated against on the account of their children's disability. Participants were labelled misfits in society because of the condition of their children. This comes with several implications, one of such is that, those who go out to trade are refused sales at the sight of their sick children with them. Others are denied sales and working opportunities because of their affiliation to a child with DD. The account of some participants supports this point.

> "*They're not working, because of the child they lose their jobs, like if they're selling something with the child, people are not buying it"* (PT 8, female 21 years, guardian of child with down syndrome)

> *"I have great challenges raising the child, it is very stressful. Stigmatization and discrimination is one thing we go through a lot."* (PT 1, female 40 years, mother of child with cerebral palsy).

4.2.2 Financial constraints

Financial constraints refer to the difficulty to generate money to cater for pressing needs. Most participants were financially handicapped due to the condition of their children. Unemployment is a major contributing factor to this plight of parents. The problem of unemployment is a major challenge in sub-Sahara Africa and the issue is the same in Ghana. The dependency ratio is also very high especially amongst marginalized groups such as these parents and their children. This makes living very challenging for them as compared to normal or regular parents. The narrative highlights how parents have sold everything they own to be able to take care of their children and support their homes. A parent had this to say.

"Because of this child I've lost my job. You can't leave him in the care of anyone. All the money goes into hospital bills as we talk now, I have nothing. I've sold my container because of the child and my rent is also due. And it's because of this child that I'm going through all these sufferings but it's difficult". (PT 2, female 40 years, mother of child with cerebral palsy).

Narratives also highlighted the rate at which some parents are facing hardships because they have either given up their source of livelihood to stay home with their children or the fact that they have sold everything they once had so that they can take care of their children. Some participants shared that they had successfully exhausted all their savings and are relying on the grace of God to feed them as the days go by. The conditions of their children according to the narratives has placed most parents in adverse poverty. The following comments highlight the plight of some participants.

"Because of the situation we find ourselves in, we go through hardships. We sometimes find it difficult to afford food to eat." (PT 6, male 37 years, father of child with cerebral malaria)

4.2.3 Child Dependency

The nature of the condition according to the narrative leaves most children very dependent on their parents. Most are not able to eat, drink, bath and successfully use the toilet. Others don't even know when they empty their bowels therefore need to regularly get their dippers changed. The narrative highlights how participants have sacrificed their lives to accommodate this new reality.

"...when I met her, like if she want to urinate, she cannot say I want to urinate, like the speech... the speech is not coming, and she's not talking and if she want something she'll not talk, unless you give it to her, like you see her behavior, if she want to urinate, she cannot talk, she'll be running about, she cannot stand at one place so you help her urinate, if she's hungry she'll be hitting her stomach and be crying, you know

that she's hungry…the first thing, if you wake up you have to brush the teeth, she cannot brush her teeth herself, you brush the teeth after that we bath her and feed her, we give her breakfast, we have to give her, so we feed her and be monitoring her, if she urinate, you change the diaper, if she pupu, you change the diaper, afternoon time is she's hungry, you give her food evening time you'll be bathing her, like that" (PT 8, female 21years, guardian of child with down syndrome)

"After attending to his siblings, I attend to him and take him along with me everywhere I go. I bath him and do everything for him."

(PT 5, female 31 years, mother of child with autism/ADHD)

4.2.4 Joy amid the storm

Pain, suffering, and sorrow were dominant throughout the narrative participants shared. Having a child suffering from some form of DD is a very trying moment for families. Notwithstanding that, participants also shared some moments of joy and peace with their children. This solace and peace keep parents going in this trying time. Participants shared how their children make them laugh through their gestures and utterances, others also shared how their children served as a unifier in their families,

"…he manages to bring all of us together as a family and deepen our bond of love for each other." (PT 11, female 46 years, mother of child with cerebral palsy)

"…if you're with them they make you laugh. Like Beatrice like this if you're playing song she'll be dancing and you'll even laugh and forget all your problems…" (PT 8, female 21 years, guardian of child with down syndrome)

4.3 Theme: 2 Coping strategies for families

Coping strategies are methods that families employ to cope with the burden of care they endure in looking after their children. Coping strategies as the main theme was supported by sub-themes to add meaning to the experience of participants. The sub-themes were, acceptance, social comparison, religious coping, social support, and planning. These methods were employed by participants when they realized that the condition of their children may not change anytime soon therefore had to find ways to successfully live with them.

4.3.1 Acceptance

Participants shared that they had to accept their reality and tune their minds to the fact that this is what they will have to deal with for the rest of their lives. Some came to terms with the human nature of their children, hence the need to take care of them. Others also explained the day-to-day adventures they went through in caring for their children, knowing that this is going to be part of their life for some time to come. The voices below echo some of these thoughts.

> *"Being a parent of Cornelieus ermm I don't know it's a blessing because it's been like an adventure every day, we are exploring even though it's not easy sometimes we have to pass through the pain because he goes through some pains and we have to feel for him the temperature. he loves to have people around him so every day you have to be there for him".* (PT 9, female 38 years, mother of child with spinal bifida)

> *"Some people make me feel sad about the situation, but I remember that he is mine to I can't abandon him. At first, I used to be sad but I've been educated not to feel sad"* (PT 5, female 31 years, mother of child with Autism/ADHD)

4.3.2 Social Comparison

Some participants compared the plight of their children to others and realized that, though both situations were not the best, they had an advantage. The wards were doing better than other children with the same conditions. This generates some positivity amid the negative experience they were going through. Most of the participants drew consolation from this by reframing the general experience of their children's situation. The following are what some participants shared.

> *"We are trying our best. He is human like us so all we need to do is to manage the situation."* (PT 10, male 64 years, father of child with cerebral palsy).

> *"When I see the condition of another child, I get consoled with mine because some can't even stand, but mine can walk."* (PT 1, female 40 years, mother of child with cerebral palsy)

> *"I see my problem to be better than others and that help me cope. When we meet and I see the children of other parents, I get hope that it is well".* (PT 6, male 37)

4.3.3 Religious coping

The argument of a supreme deity taking care of us was not excluded from the narrative of the participants. The God factor was very profound in most of the narratives. Most of the study participants turned to God and hoped for a miracle someday as a coping mechanism. They had this to say;

> *"At the beginning, I had hope that we would be fine in no time. Also, when I look at the situation of others, I get hope that God can heal him"* (PT 3, female 37 years, mother of child with epilepsy)

"*We have nothing to do than to give thanks, because this situation in which we find ourselves it is the doing of the Lord."* (PT 7, female 27 years, mother of child with cerebral palsy/autism)

"The challenges are enormous; we even find it difficult to enrol him in school. I always tell myself that it is Christ who gave him to me, and he'll see me through it. I believe that a miracle will happen." (PT 10, male 64 years, father of child with cerebral palsy).

4.3.4 Social support

Social support has a way of significantly impacting the emotional states of people. The presence of help in such situations reduces stress levels drastically and the absence of help complicates situations of people. A few participants were fortunate to receive some help from their families and they had this to say;

"My family support us a lot especially my siblings, and my church also helps in prayers. They have been supportive a lot. Through them we've been able to get new wheelchairs for him." (PT 10, male 64 years, father of child with cerebral palsy)

"My family supports me a lot, one time when I was pregnant with my second child my sister came for him for almost a year, the same as my mum. My brother also brings wheelchairs and other equipment and items. They also support him, occasionally they come to him at home and sing for him" (PT 11, female 46 years, mother of child with cerebral palsy)

Most of the participants had no help from anyone and had to take care of their children with their own efforts. The words below capture their ordeal;

"I do not get any support from anyone. All people say is that the Lord will provide, some even tag him as a river child and admonish me to get rid of him." (PT 6, male 37 years, father of child with cerebral malaria).

"I've not received any support from anybody. I take care of him with my own effort." (PT 3, female 37 years, mother of child with Epilepsy).

"I do not get any support from anyone. It is not easy; I get tired a lot. But even when I feel pains, I'll take drugs and continue caring for him." (PT 5, female 31 years, mother of child with autism/ADHD).

4.3.5 Planning

Problem-focused coping methods were not very profound in the narratives generated. A participant, however, adopted the use of planning as a coping mechanism by reading some inspirational messages online to calm her nerves and taking notice of facts that can help them better. She engages in discussing challenging issues concerning her child with her husband for them to plan the solutions together.

The voice below captures her experience.

"*I pick inspirational messages from Facebook and other social media platforms to get me going. I sometimes watch motivational videos of families who are in my predicaments and take notice of what they have been doing to be at peace. I then plan with my husband to replicate this in our home and it has helped us to this day".* (PT 9, female 38 years, mother of child with spinal bifida)

4.4 Theme 3: Awareness of parent support groups.

Participants identify parent support groups as a place of solace for their relief. Participants described support groups as groups that are available to support disabled children.

Others also narrated that the essence of such groups is to help mothers provide better care for their children. Some of their narratives are captured below.

"I know that the PSG helps us to take good care of our children and provides help to us through gifts."

(PT 3, female 37 years, mother of child with epilepsy)

"I know that it is a group that brings awareness to parents and advises us to withstand all negativity from the community."

(PT 10, male 64 years, father of child with cerebral palsy)

On the availability of parent support groups in Ghana. Most participants narrated that there are many such groups in Ghana. 35% of the participants agreed with this assertion. The comments below capture their voices.

"... for parent support groups, I believed that there are a lot in our country..." (PT 3, female 37)

"Oh yes .... There are a lot of these groups, when we go for programs, we meet some of these groups..."

(PT 7 female 27 years, mother of child with cerebral palsy/ autism).

The remaining participants also narrated that, not many of these groups existed in the country. 65% of participants believed this assertion. The comments below highlight their voices.

"No, I don't think there are any such groups in the country, they are only a few"

(PT 4, female 45 years, mother of child with cerebral palsy/autism)

"I haven't heard of any of this groups apart from the one I belong to."

(PT 5, female 31 years, mother of child with Autism/ADHD)

Accessibility of parent support groups also appeared challenging to some participants. For some money to transport themselves and their children to the support group interventions is very challenging. To others, the condition of their children requires carrying them about all the time and as they grow, they are becoming heavier making moving them around very difficult. Some of the voices below capture the narrative of participants.

*"The activities are helping, sometimes we don't get enough funds to take our children to meetings. Most of the mothers don't work because of their children so they don't get to participate in contributions and gifts that may be shared on such days***."**

(PT 11, female 46 years, mother of child with cerebral palsy)

"I would very much love to go for meetings because of what I gain from them, but my child is now stronger and stronger and carrying him around is become so hard for me. I am beginning to feel pains in my waist and lower back when I carry him. This makes it difficult now for me to go for meetings regularly.

(PT 1, female 40 years, mother of child with cerebral palsy)

The majority however, were able to attend meetings and access whatever the support groups offered. They shared their experience below.

"They organize pastors, nurses and health care professionals to come and talk to us. There are topics for parents and the children as well and we enjoy them so much."

(PT 4, female 45 years, cerebral palsy/ autism)

"I joined because of the experiences I've gotten when people share their experiences. These experiences make me stronger."

(PT 10, male 64 years, father of child with cerebral palsy)

4.5. Theme 4: Benefits of support groups.

Parent support groups offer a number of benefits to participants. The narrative captures some of the benefits that participants have enjoyed by virtue of belonging to this group. They include education, psychological well-being promotion, material support and access to valuable information.

4.5.1 Holistic Education

Education as a tool for empowerment has been very instrumental in transforming some aspects of the lives of participants. This sub-theme stresses the attempts made by support groups not only to educate the minds of parents but also to provide some practical working and lifestyle training for them to help themselves and their children. The narrative tells that participants are now more actively able to advocate for their children and correct wrong perceptions of their children's condition thanks to the role of the education they receive during support group interventions. Some comments are as follows.

> *"Yes, I would inform the person. Because when we come here the education helps reduce overthinking and we also get gifts from people."*
>
> (PT 6, male 37 years, father of child with cerebral malaria)
>
> *We are encouraged to have the voice to always defend our children.*
>
> (PT 10, male 64 years, father of child with cerebral palsy)

Education in self-care and healthy lifestyle has also been very important to participants. They narrate that, personal hygiene and daily bathing of their children are some tips they have gathered so far. The narrative also captured the fact since most of them are single parents, the need

to prioritize self-care to be able to remain strong enough to take care of their children. The

following comments add more context to participants' narrative.

> "People *come from outside to teach us, some also talk to us and we are educated on how to take care of our children and also advised on how to live a healthy life"* (PT 3, female 37 years, epilepsy)

> *"We've been educated that we are single parents, so if we don't take good care of ourselves who will take care of our children? So, we need to take care of ourselves so that the child won't be sad or worried."*

> (PT 2, female 40 years, mother of child with cerebral palsy)

The target of education was not limited to parents and lifestyle tips. Provision was made for their children to also go to school of some sort. The narrative captures a running initiative where parents had their children taken to school and returned. Leveraging on educating these young ones, seeks to provide them a stable future. This participant reflects on this provision below.

> *"They help with the education of the children, there is also a car to convey them to the school and back with all expenses on the support group."*

> (PT 7, female 27 years, mother of child with cerebral palsy/ Autism)

Skills training and vocational training have become a growing channel for entrepreneurs in our country today. Support groups have also invested in entrepreneurial education to help make participants self-reliant and able to do something small as a side job to help cater for the needs of their respective homes. A participant shares some light on this below.

> *"We are taught how to bake pastries like cake, meat pie and other skills like beads and ribbons to help us get work to do. The activities help us very much."*

(PT 7, female 27 years, mother of child with cerebral palsy/ autism)

Other participants shared that they indulged in farming practices spearheaded by the support group and they are able to cultivate a number of products which benefited them massively. This gradually cuts down the cost of food and reduces their burden on what to eat.

> *"We do some farming sometimes when we meet, we go into the farm and cultivate plantain, cassava, garden eggs tomato and others. These foodstuffs help us in times of need and helps us to save some money to use on our children.*"
>
> (PT 4, female 45 years, mother of child with cerebral palsy/autism)

4.5.2 Access to valuable information

It also includes directing someone to a resource that can help them. In parent support groups, varying experiences exist concerning care for children and knowledge of where to find useful resources for children's conditions among parents. Participants' narratives highlight how this great pool of experience has helped in the better management of their health and that of their children. Through support groups, information on how to get access to wheelchairs, physiotherapy, and medication among others has been very easy according to participants. The comments below highlight these assertions.

> *"I was a mother struggling with the care of my child, it wasn't an easy task at. But when I joined the support group, the shared experiences have informed me on what to do to make my life way easier and less stressful. I must admit I am much better now and, on my part, I try to direct every young person I encounter with the same situation as mine to come and also have access to this great source of information…"* (PT 1, female 40 years, mother of child with cerebral palsy)

"Through my support group I was linked to an NGO that supports needy parents with wheel chairs and I have been able to get one for my son. I have also been directed to a place that teaches massages for children like mine, learning this has significantly helped my finances since going for physiotherapy was become a challenge for me. My boy is responding well to the massages and that gives me so much joy."

(PT 10, male 64 years, father of child with cerebral palsy)

4.5.3 Promotion of psychological wellbeing

Psychological well-being promotion refers to an improvement in an individual's overall happiness, satisfaction with life and mental and emotional health, it can also be referred to as the presence of positive feelings and the absence of negative feelings. Participants narrate varied ways of attaining some form of psychological well-being. According to their narrative one way was through resilience and acceptance of their situation. Participants narrate how troubled they were before joining the support group about how they struggled to relate with the community when issues arose concerning their sick children. They add that after the experiences they have shared in these groups, they have realized a deeper sense of acceptance of their situation and are working with their current reality. Some participants had this to say.

"*…People tag me as the sick child's mother, but I always tell them I am happy with my child because he is a gift from God…"*

(PT 5, female 31 years mother of child with Autism/ADHD)

"...when we went for a training in Accra, they told us that we should be talking to the parents. like we should be talking to the parents that the children that they are having they are not witches, there are gift of God so we should be encouraging them not to

commit suicide or to throw them away or to be giving them medicine so they will die…"

(PT 8, female 21 years, guardian of child with down syndrome)

Resilience is the body's way of coping in times of adversity and trauma. Participants narrate that, through their interactions with one another in the support groups, they have been able to grow in resilience as well. That which triggered them in the past about the condition of their children does not worry them so much now. They have outgrown the insults and derogatory remarks they used to feel sad about. They acknowledge that life is so much better psychologically now compared to before the sessions with their support groups. Some of the responses here throw more light on these assertions.

"We motivate and encourage ourselves to be strong in our individual situations. We are taught to reduce overthinking and be happy. I listen to the word of God a lot for hope and encouragement to raise the child."

(PT 1, female 40 years, mother of child with cerebral palsy)

"When we meet and advice each other, we leave with hope that the situation can change but until it changes, we have what it takes to deal with it."

(PT 6, male 37 years, father of child with cerebral malaria)

Socialization and belongingness have also contributed massively to the psychological well-being experience of participants from the support groups. Participants narrate that when their children are able to come outside their confines and interact with other children in their bracket (with similar conditions), it gives the children so much joy and the parents themselves rejoice to see their children very happy and excited. They were very grateful for the opportunities provided

for socialization and other parties that were organized to bring them and their children together to meet other people in the same situation and have fun together. Below are some comments from the participants on this matter.

> *"When we come out like this the children become happy that we have taken them out to public. We the parents also become happy. Also, we are taught how to treat the children well and what is good for the children."*
>
> (PT 1, female 40 years, mother of child with cerebral palsy)
>
> *"We come for meeting because we want our children to be happy. When they go out and see people, they get happy and interact with people because when they are indoors, they are quiet. We also come so we may get a helper who can support us - what makes me happy is that the children get to go out so they don't miss out on chances to make them happy."*
>
> (PT 2, female 40 years, mother of child with cerebral palsy)

Aside socialization, participants narrate that there is a deeper bond which they share which makes everybody's child their child. The bond of love and affection they share in their group makes this possible as well. That way everyone feels loved and belonged. The belongingness encourages participants to continue this difficult task of caring for their children knowing that they are not all alone by themselves.

> *"When we come here, we do not only care for our child, but also all the other children here because we see all of them to be our children. The experience has been good so far"* (PT 6, male 37 years, father of child with cerebral malaria)

"The group helps the parents …it helps them to get the need's sometimes… sometimes they'll help them to provide their needs and to let them know that they're not alone and they should not feel lonely."

(PT 8, female 21 years, guardian of child with down syndrome)

4.5.4 Material support

The nature of the plight of families caring for children with DD predisposes them to a lot of material needs. Material needs are very crucial to these families. This is the famous kind of support that most participants know and appreciate so much. The narrative from participants shows that they are in dire need of toiletries, funds, and other accessories that will make their lives easier. The support groups have to some extent helped participants with some of these necessities. The most notable among these needs is diapers. The subsequent remarks express some comments from participants.

"The group has helped a lot. Because sometimes when we come, we get goodies like pampers, t roll so we use for our children."

(PT 2, female 40 years, mother of child with cerebral palsy)

"We get pampers, rice, t roll, dresses and education for our children and also a car to convey them to school".

(PT 6, male 37 years, father of child of cerebral malaria).

4.6 Theme 5: Challenges facing parent support groups.

Challenges are hindrances that prevent an intervention from running smoothly. In relation to challenges facing parents support groups in this study, a two-way approach was used. Firstly, the individual challenges parents faced as members of support group and secondly, the challenges the group faces in their effort to coordinate their activities. According to the narrative, support groups have done very well to assist parents during this difficult face they are going through. However, parents also shared some challenges they are facing. Some people struggle to get transportation to meeting grounds. A participant had this to say.

> *"The activities are helping, sometimes we don't get enough funds to take our children to meetings. Most of the mothers don't work because of their children so they don't get to participate in contributions and gifts that may be shared on such days***."** (PT 11, female 46 years mother of child with cerebral palsy)

A participant lamented on the lack of the presence of other caregivers in her situation. She wished she could leave her child in the care of another and also benefit from support group interventions. Her *voice is captured below.*

> *"I don't have anybody in the house to leave my son with and go for meetings. This is very difficult for me. When he was younger, I could carry him to meetings but now he is bigger and quite heavy…. this has made attending meetings a big problem for me."*
>
> (PT 1, female 40 years, mother of child with cerebral palsy).

Some participants cried for sponsorship packages and avenues to augment their plight. They asked for financial support from stakeholders and well-wishers. With these funds they

argued that the support group can run many interventions in addition to that which they are benefitting from. Some also called for some amenities and interventions that would make their life easier. Some also called for facilities that can house their children temporarily so they can go to work an earn a living to cater for their children The voices below echo these thoughts.

> *"We need sponsorship and financial aid to be able to take care of the children."* (PT 5, female 31 years, mother of child with Autism/ADHD)

> *"We need financial support and also a school building and instruments for physiotherapy."* (PT 6, male 37 years, father of child with cerebral malaria)

> *There should be a substantial financial support system and more organizations should come on board to help with support items as well.*

> (PT 10, male 64 years, father of child with cerebral palsy)

Other participants called for social amenities like schools to be able to accommodate their children the way they are so that they do not miss out on the opportunity to be educated.

> *We wish to have someone to build a school here for us so we can cut down cost on transportation since we have a large piece of land here. So that when our children are in school, we can also go and work to support our homes.*

> (PT 2, female 40 years mother of child with cerebral palsy)

> *"We need a car to transport the children to school and also a school building"* (PT 4, female 45years, mother of child with cerebral palsy/autism)

4.7 Summary of findings

In all, the qualitative study revealed five main themes. The first theme discussed the Caring experiences of parents of children with DD. Four sub-themes generated from this main theme were stigmatization and discrimination, financial constraints, child dependency, and joys amidst the storm. The second main theme generated from the data were coping strategies. This brought out five sub-themes namely, acceptance, religious coping, social comparison, social support and planning. The third main theme was on awareness of parent support groups. This came with two sub-themes, availability and accessibility of parent support groups. The fourth theme was the benefits of parent support groups. This generated four sub-themes which are, holistic education, access to valuable information, material support, and promotion of psychological wellbeing. The last theme focused on the challenges facing support groups. The sub-themes include lack of financial assistance, lack of crucial infrastructure and lack of respite care.

CHAPTER FIVE

DISCUSSION

5.0 Introduction

The present study was conducted to explore the parental experiences of parent support groups (PSG's) for their children with DD. The study explored the caregiving experiences of parents, the coping strategies available to them, their awareness of parent support groups as well as benefits and challenges of their parent support groups. This chapter provides a discussion of the findings of this study.

5.1 Discussion

Caring for children with DD poses several challenges to parents, families and the social network of the children. This study highlighted some of these challenges. Stigmatization and discrimination of children and their parents was very profound, especially among mothers. From giving names like "river children" or children of god's, to public refusal to patronize goods and services of parents because of their children's condition, worsen the plight of these families. According to the conservation of resources theory (COR) by Hobfoll (1989), parents in such circumstances require resources to support them to function well. Provision of financial resources to parents to support their children is key to their survival as many of them lose their jobs and are also unable to secure jobs because of their children's condition, predisposing them to poverty and hardships (Oti-Boadi 2017). These findings reflect the Ghanaian and African understanding and interpretation of developmental disabilities as related to curses from the supernatural or a sin that a parent might have committed against a deity (Avoke, 2002; Oti-Boadi, 2017).

Moreover, these findings are consistent with Zuurmond et al. (2018) who discovered an intersectionality of gender and caregiving in the experience of stigma noting that mothers were mostly blamed in the event of birthing a child with a DD. Other studies (Mwinbam et al., 2023; Tekola et al., 2020) have also discovered that parents of children with a DD in African countries experience high levels of stigma and isolation.

Participants of this study faced the problem of child dependency. Most of their children's condition required them to be available around the clock to cater for them. This restricted parents a lot and made them very tired. This finding resonates with the work of Antwi (2023) who discovered that parents spent a considerable amount of time caring for their children with special needs. They had to bathe them, provide special meals for them and attend to the hygiene needs of their children. This left parents very exhausted because of the many responsibilities they had to play in the care of their dependent children. Nurullah (2013) supports that, the time demands that the dependent children take from their parents rob them of spending time with another sibling, their spouses and even some alone time for themselves. According to the COR theory (1989), the amount of time and energy that parents and guardians invest in the care of their children with DD are threatened when parents become overwhelmed by the demands of care.

Financial constraints were another existential crisis that participants complained bitterly about. Due to the condition of their children, participants had to quit their jobs to take care of children rendering them unemployable. Others had to sell their belongings to cater for the feeding and medical expenses of their children. This has rendered many parents extremely poor and facing a lot of hardships because of their situation. Ghana as a country has a significant dependency ratio and a high rate of unemployment. This further complicates any efforts parents can make to help

themselves. These findings are consistent with the works of (Mwinbam et al., 2023; Oti-Boadi, 2017; Oti-Boadi et al., 2022), who also discovered that the financial constraints faced by such families mainly due to unemployment.

These findings from the caring experiences of participants are corroborated by Hobfoll's (1989) conservation of resources theory. The parental lack of necessary resources like money to cater for their basic needs and their children condition, energy to carry their very dependent children and the lack of time to relax and recuperate from all these experiences of care predisposes parents to excessive stress and the inability to gain these resources leaves them very vulnerable.

The experience of care has not always been negative, painful and excruciating as often reported, but also entailed an aspect of joy and happiness (Beighton & Wills 2017; Nurullah, 2013). Participants in this study also reported several moments of joy and happiness with their children. Participants also reported that having such children has taught them to be resilient and this has opened a different worldview for them. This finding is consistent with a recent study Oti-Boadi et al. (2024) who discovered that resilience had a direct impact on the quality of life of participants. Beighton and Wills (2017), found that caring for children with disabilities greatly improved parents' faith and spirituality, improved their appreciation of life, made them active sharers in their children's accomplishments and helped them to build more meaningful relationships. Similar findings were reported by participants of this study. Participants were happy to celebrate the gains of their children in all aspects, they reported a deeper connection to God especially because of their children and a better appreciation for life in general.

According to COR theory (1989), resource losses need to be compensated for to reduce stress. Coping strategies are important to help participants make some gains against stress especially for people predisposed to a lot of stress like parents with children with DD. Most participants in the current study resorted to the use of emotion-focused coping strategies. Emotion-focused coping is a strategy to stress reduction where the emotional response to the stressor is changed rather than the stressor itself (Lazarus & Folkman, 1984). Emotion focused coping was evident in strategies such as acceptance of the situation, social comparison, religious coping, and social support as a coping mechanism.

Most parents perceived that they could not change their situation by any means hence their acceptance of the stressful situation as part of their reality. Although, emotion focused coping has often been linked to poor psychological outcomes for parents (Miranda et al., 2019; Vernet et al., 2018), recent findings have indicated that there is a positive relationship between emotion focused coping by parents of children with DD and quality of life (Ganjiwale et al., 2017; Oti-Boadi et al., 2024). While some participants acknowledged denial of their children's diagnosis initially, their decision to accept despite all the odds against them to face their new reality was helpful to their functioning. This finding is corroborated by the findings of Antwi (2023) which highlights parents' struggle with accepting the diagnosis of their child and consequently accepted their situation in order to provide optimal care for their children and themselves.

The social comparison theory by Festinger (1954) explains how people cope with stress by drawing parallels from their experience and that of other people. In essence, people compare their experience with that of other people usually in the same situation. Participants in this study adopted social comparison as a coping mechanism by looking at the plight of their colleagues and drawing inspiration to continue their caregiving responsibilities. Where there was an upward

comparison, participants resolved to learn more to adjust to the caregiving needs of their children. Where there was a downward comparison, they felt rather fortunate and were encouraged to continue the process of care. These findings are corroborated in the works of Ludlow et al. (2012).

Furthermore, in the current study, most of the participants had recourse to their objects of worship for coping. Many participants in this study saw their situation as the will of God. They also held the faith that if all things are possible for God, then one day, a miracle might happen and take away all their distress. Ghana as an African country is known to be a very religious country with about 94% of the population considered religious and interpret almost every situation in religious terms (Ghana Statistical Services, 2021). The coping experiences shared by parents in the current study resonates the findings of existing literature Antwi (2023) and Oti-Boadi et al. (2017), where most parents in adopted spiritual beliefs in the form of prayer and organized religious activities as a means of coping. Parents believed that their children's disability was caused by the will of God, therefore, channeled all their stress to God.

With reference to social support, some participants reported that they received some form from their families in the form of words of encouragement and consolation during difficult moments, provision of items to ease the burden of care that parents struggle with. This finding is consistent with the works of Ludlow et al. (2012) which found that parents who were assisted by their extended families had a better experience of care for their children with disability. Ganjiwale et al. (2016), also reported that providing social support to parents of children with DD improves their quality of life.

Most participants in the current study did not receive any form of social support from their families. This finding, however, does not reflect the African cultural value of collectivism where

family members looked out for one another in times to trouble (Belgrave & Allison, 2006; Gyekye, 2003). This can be related to the trends in modernization and urbanization which are gradually depleting the fabric of the African extended family structure (Adou, 2022; Nortey et al., 2017; Oladipupo, 2022). Traditionally, African families cared for each other, especially in moments where there was ill health, bereavement and other misfortunes (Mugisha, 2023).

Emotion focused coping is usually the most common coping strategy adopted by parents of children with DD (Benson, 2010; Smith et al., 2008; Twoy et al., 2007; Zablotsky et al., 2013). Problem focused interventions are also beneficial (Kaimi and Goodgold 2017; Pepperell et al., 2018). Problem focused coping as a stress reduction strategy attempts to undo the stressor from their root causes. In other words, they attempt to alter, actively manage or eliminate the stressor. (Lazarus and Folkman 1984). In this study, these strategies were evident in the use of planning as a coping strategy. Only one participant employed a problem focused coping strategy. Vernhet et al. (2018) and Miranda et al. (2019), discovered in their study that problem focused interventions greatly improved psychological distress when compared to emotion focused coping. Al – Oral et al. (2022), also reported that men were more likely to resort to problem focused coping while women preferred emotion focused coping interventions. The findings from this study reported contrasting findings to the above study. Both men in this study only resorted to emotion focused coping. A study by Cauda - Laufa (2017) reported that both problems focus coping and emotion focused coping had no significant impact on parental distress. The study however discovered that, with the adequate social support available to families, dealing with stress was easier as opposed to coping behavior. Participants in this study reported tangible evidences of how their coping strategies benefited them.

Participants demonstrated varied views in their knowledge and awareness of what support groups do and why they are in existence. Most participants demonstrated significant understanding regarding the mission and vision of parent support groups. This could directly be linked to the first-hand experience of what their respective support groups have offered them, especially in the care of their children with a DD. Almost all participants benefited from their support groups in one way or the other.

Regarding the availability of parent support groups and their accessibility, more than half of the participants shared that they had no idea about the existence of these groups. Awareness creation campaigns around mental health conditions in Ghana are shooting up gradually but not everyone has received this information yet especially people based in rural areas (WHO, 2023). In the same spirit, some traditional leaders have called on the initiators of these mental health campaigns to collaborate with traditional leaders so that people living in remote areas of the country can also benefit from the care they bring. (WHO, 2023). Some participants also disclosed that they changed on the availability of support groups during their visits to the hospitals with their children. Members of Parent support groups shared their experiences and encouraged others to join. This finding is corroborated in the works of Mandell and Salzer (2007), who noticed that referrals from hospital settings were one of the ways that make support groups known to parents.

Accessibility to parent support groups was very easy for most participants. This was due to the proximity to meeting grounds and the lack of substantive resources like food and toiletries for both parents and their children. A sad discovery from the study was that some participants had no support with regards to feeding and depended solely on other members of the support group for their daily bread. Some participants also lacked the means of getting items such as toilet rolls, pampers, soap and detergents for the care of their children. These items were shared occasionally in support

groups by members or external sources. Häggman-Laitila & Pietilä (2009) confirmed that parents in support groups aided each other where they could and were happy to assist each other.

To acquire, maintain, and protect resources as proposed by the conservation of resources theory (1989), parents support groups have done a lot to complement the needs of parents in their care for their children with DD. Gains in informational needs, material needs, self-esteem needs among others to help parents in the better management of their children were made. Parent support groups also provided the avenue for parents to compare experiences and situations of their children which promoted gratitude and resilience consistent with the social comparison theory (Festinger, 1954; Häggman-Laitila & Pietilä 2009; Zeutenhorst 2017). Moreover, the provision of education to parents and their children was a major benefit participant mentioned. Parents are educated through seminars and support group meetings on how to care for their children and themselves. They are educated on the kind of meal to give their children, how to respond to their needs among others. This education received by parents has greatly improved how they relate with their children and has significantly improved their lives (Shilling et al., 2013; Ujianti 2018). Parents have also enjoyed an intervention by a parent support group in this study to bus their children to school and back. The idea behind this is that children who suffer from DD can also grow and contribute to society therefore investing in their education at the early stages of their life will help them later in life. Ujianti, (2018), corroborates that parent support groups provide a medium for discussing the educational needs of children with special needs.

This study also revealed parent support groups as a place where valuable information necessary for the holistic care of participants and their children is shared. Informational support provides individuals with advice and guidance or useful information that helps individuals meet a need, resolve a difficult challenge or acquire insight into complex situations (Sadiki, 2023). Participants significantly benefited from the informational resources available through support groups. Information about lifestyle tips, medical help, and valuable materials like wheelchairs and

toiletries were obtained through directions from members within the support groups. The experience

was also a resource experience that was dispensed during parent support group gatherings. The very experienced parents in the care of their children helped their younger counterparts with the necessary information they needed to thrive well in this challenging situation (Sadiki, 2023; Solomon et al., 2001; Ujianti, 2018).

Additionally, participants boasted of improved psychological well-being through participation in support group activities. The sharing of experiences helped many parents to gain a deeper insight into their situation and an appreciation of their reality. This improved their overall happiness in life and stress management. This also complimented their resilience and improved their advocacy. Parents who attend support group meetings, did not only gain more information about educational services, but also gained a stronger sense of empowerment, advocacy, and contentment (Sadiki, 2023; Zeutenhorst 2017). Ifoema (2019), reported a similar finding that parents in support groups having a high-level advocacy rate with 60% of participants showing significant improvements in stress management. Jackson et al., (2018) and Sadiki (2023) found that parent support groups helped parents to come to an acceptance of their children's condition and this greatly improved their ability to speak and defend their children where necessary.

Furthermore, the socialization and belongingness which the support group offered also contributed to their emotional well-being. This finding elucidates the assertion by (Sadiki 2023; Zeutenhorst, 2017) that parents who join support groups feel like they belong. This group provides much-needed emotional support by giving people a safe place to voice their worries, anxieties, and disappointments without fear of being judged (Sadiki,2023; Zeutenhorst, 2017). Sadiki (2023) adds that there is much empathy among parents since they are all in the same situation, which is caring for a child with a disability, therefore understanding each other is relatively easier. Overall, parent support groups advancing the psychological well-being of participants is corroborated by the work of Zeutenhorst, (2017), that participants in parent support groups experienced changes in the

interpersonal domain: belonging to a community, being understood and accepted, and having friendships and social networks where they could share emotions and feel more "normal." Parents' accounts echoed the importance of "therapeutic" factors (e.g., catharsis, empathy, acceptance, universality, and a psychological sense of community). The groups provided parents with a space in which they felt relaxed and "normal," as opposed to feeling isolated from society and stigmatized (Shilling et al., 2015; Solomon et al., 2001).

The avenue of collectivism and familial interactions which has diminished in contemporary society due to the disintegration of the extended family system, appears to be compensated for through the emergence of mutual interdependence among individuals. Though not blood relations, the relationship exhibited in support groups in this study is one where each participant views the child of another as his/her own and does anything to help them where necessary. This finding is confirmed by (Lancaster et al., 2024; Zeutenhorst 2017) who reported that participants of parent support groups developed closer friendships and a deeper connection to other families in their group. Many of them no longer felt isolated from people in their communities since they belonged to a support group.

The present study also revealed that parent support groups managed to secure packages of valuable items that participants needed to ensure their continuous survival and ease the burden of care that participants faced. Occasionally, cash donations, food items, and toiletries among other essential items were donated and shared with participants in the parent support groups. Participants of this study appreciated goods like diapers and toilet rolls so much because of the condition of most of their children.

Parent support groups of parents of children with DD have several challenges they endure in their line of duty. Parents in these groups are also burdened with several challenges. These challenges reecho the assertion made by the COR theory (1989), that the absence of certain resources (money, wheelchairs, recreation) negatively influences the wellbeing of parents caring for children with DD. Participants shared some of the challenges facing parent support groups.

Parent support groups are burdened with the lack of financial assistance. This lack of finances affects the general running and coordination of interventions to help parents. Participants of PSGs who lack the financial capability to attend meetings usually miss out on productive deliberations that will help in the continuous care for their children. On other occasions, PSGs are not able to bring in resource persons of their choosing due to their financial commitments and have to rely on the services of volunteers and other already funded interventions that helps their course. The lack of ready financial backing for these PSGs generates a lot of heat from their members and their inability to assist needy members in times of emergencies was also stated as a very big challenge to them.

These findings are consistent with the works of (Antwi 2023; Ifeoma 2019; Oti-Boadi 2017; Oti-Boadi et al., 2022) who noted parents of children with disability struggled a lot with only a few of them able to pay for medical expenses and buy other assistive gadgets for the care of their children with disability. This point is strongly linked to the inability of parents to secure stable employment because of the situation of their children (Mwinbam et al., 2023; Oti-Boadi, 2017; Oti-Boadi et al., 2020) hence they were hopeful they could get more financial assistance from the parent support group intervention to help their plight. Parents who are well to do sometimes contribute some money to the group to support each other a keep their respective support groups running (Sadiki, 2023).

Participants also requested for amenities like schools and a place for physiotherapy which would be affordable and accessible to ease some of their struggles. Participants shared that if parent support groups can acquire these amenities, it would take away a significant amount of stress from them. This finding is confirmed by My Joy Online (2023), highlighting the call for the government to provide facilities for children with special needs. In an interview with the founder of Special Mothers Project, a parent support group for children with special needs, the founder reiterated this concern and called on the government to provide classrooms and other facilities where children with special needs can be housed and cared for as parents go out to make a living in a bid to gather sufficient resources to take of the needs of their families. This intervention will help the plight of parents.

Some participants are over burdened with the condition of their heavily dependent children. The unavailability of people to help them take care of their children disrupts their engagements with support groups. Those of them who manage to go for meetings have to contend with their conscience to ascertain whether it was a good parenting decision or not. This finding is consistent with the findings of Häggman-Laitila & Pietilä (2009) who noted that parents and caregivers in general struggle to find substitutes for themselves during the caregiving roles thereby missing out on other important activities.

5.2 Limitations of the study

The current study is beset with some limitations. Firstly, results cannot be generalized to all parents and guardians caring for children with DD and belonging to parent support groups in Ghana. The dynamics of this study restricts the study to the Accra and Cape Coast metropolis which are

both urban areas. These findings may not be applicable to parents caring for their children with DD in rural areas in Ghana. They will require an independent inquiry to ascertain their experience.

Secondly, this study interviewed some participants within their support group settings, acknowledging that the independence of thought and experience was essential to the credibility of the findings. The researcher, however, recognizes that the experiences shared by one participant (participant A) may have influenced or generated a similar line of thought in another participant (participant B).

Thirdly, the experience of care for various participants will differ as their children aged. This study did not make provision for this and investigated that on a general tangent. A future study may further divide the experiences of parents in multiples of five years to further appreciate the dynamics in the experience of care among parents caring for children with DD.

5.3 Implications for policy and practice

The findings of this study have several implications. Firstly, the increased burden of care for parents nursing children with DD predisposes them to a lot of stress and anxiety. The complexities in care such as child dependency, medical emergencies on the part of children, financial constraints on the part of parents and stigmatization and discrimination on the parts of both children and parents lead to a situation of hopelessness making life very difficult for families. This study revealed that putting together parents with similar needs into support groups greatly reduces their stress and anxiety and offers them a better experience of care for their children (Sadiki, 2023; Zeutenhorst 2017). Knowledge from this study can be leveraged on by the health sector to better manage the psychological distress among people in this population. It will be of massive help if every major hospital in the country can intentionally constitute and manage parent support groups as this. It will go a long way to serve the needs of this population of people. This idea does not only serve people caring for DD patients, it can be extended to encompass other health conditions.

Secondly, most parents of children with DD lack the adequate knowledge and experience to take care of their children. Sometimes, knowing where to go to find the right interventions for their children's condition becomes very difficult. Coming together in a parent support group allows room for sharing practical experiences that lead to better management of children's conditions, sharing ideas about where to receive aid specific to a child's condition among a lot of valuable information to benefit from.

Stigma and discrimination from society tend to make parents feel lonely and isolated. This study showed that the constitution of parent support groups for such parents has improved their insight into their children's disability and has renewed their psychological sense of community (Sadiki, 2023). This has boosted their mental health and most importantly improved their ability to defend and advocate for their children (Ifeoma, 2019; Zeutenhorst 2017). Policy makers and advocacy groups can put this information to good use by establishing community support groups across the country especial in the rural areas. This will help to dispel the doubts of conditions such as DD and allow room for parents and caregivers to develop their self-esteem and self-worth so as to constantly advocate for their children with the knowledge and expertise they gain from such gatherings.

In addition, the financial burden that parents suffer due to unemployment and discrimination because of the condition of their children needs careful attention (Antwi, 2023; Oti-Boadi, 2017). The government and its stakeholders can constitute a trust fund targeted towards children suffering from developmental disabilities. This fund will be made available to all parents caring for such children through allowances to support their living experience.

Also, a nationwide campaign must be started to advertise the importance and benefits of parent support groups, not only for parents of developmental disabilities, but for other conditions like child stroke, and organ failure, among others. These campaigns will provide some resources

that are lost in the burden of care (self-esteem, loneliness, informational help) according to the conservation of resources theory by Hobfoll (1989). This will greatly feed parents with the needed experience and knowledge to have a better experience of care through the pool of rich information that will be available to them through support group deliberations and other interventions.

Lastly, the mental health regulatory bodies in the country should invest in these parent support groups, especially for the cases that are mental health-related. This investment must include training leaders for these support groups, drawing a comprehensive program that will meet the psychosocial needs of the support groups, and occasionally facilitating some of the discussions in the various groups. Implementing the above will considerably benefit parents whose children are suffering from these conditions and ease their burden of care.

5.4 Recommendations for future studies

Future research can expand the scope of the study in terms of number of participants and conducted region by region. It should also examine the dynamics in the burden of care of parents of children with DD between urban areas and rural areas. The increased number of participants will allow for the generalizability of results and the comparison between rural and urban data will better inform the public on the unique challenges that families go through as they cater for their sick children.

Another research can be conducted to study the funding avenues and opportunities available to parent support groups and how they can how these opportunities can be made available to them to ease their psychological distress of members.

5.5 Conclusion

This study explored the role of parent support groups in mitigating parental distress in their care for children with DD. As previously discussed, parents are confronted with several challenges as they cater for the needs of their children with DD (Estes et al., 2009; Ifeoma, 2019; Oti-Boadi, 2017; Oti-Boadi, 2022). They face a lot of resource loss such as (time, energy, money, information about children's condition) and this is consistent with the conservation of resources theory by Hobfoll (1989). This predisposes parents to chronic stress and further complicates their burden of care. With reference to coping strategies available to participants, most participants drew inspiration from their faith. A few participants experienced some form of social support which eased their burden of care (Ludlow et al., 2012). Comparing the plight of participants among parents in support groups also helped in the development of resilience and better appreciation of the condition

of their children and the need to continue the process of caring for them (Festinger 1954). Parent support groups contributed greatly to the plight of the participants of this study. They enjoyed a sense of belongingness, greatly improved their advocacy roles especially for their children and have learnt a lot about the condition of their children and how to better manage them (Häggman-Laitila & Pietilä, 2009; Ifeoma 2019; Sadiki, 2023).

The present findings lend additional support to previous studies showing that parent support groups ease the burden of care of people caring for their sick relatives. Many parents gained their self-esteem, confidence, valuable experience in dealing with their children and improved psychological wellbeing (Häggman-Laitila & Pietilä, 2009; Ifeoma 2019; Sadiki, 2023). This study underscores the urgent need for medical, psychological and social workers to constitute several of such groups for the care of children with DD. The key suggestions to stakeholders from this study are (a) the necessity of creating and managing parent support groups for various conditions (DD, Child stroke, other child disabilities) across the country, (b) the necessity of adopting and managing

struggling parent support groups in the country especially DD parent support groups, and (c) generating and allocating funds for the successful running of the to be constituted parent support groups.

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APPENDICES

Appendix A (Semi structured questionnaire)

INTERVIEW SCHEDULE

Section A: Demographic Information

Age:

Child's disability:

Age of child:

Gender of child:

Gender of parent whether male or female;

Parent educational level

Employment status:

Religious affiliation:

Marital status**:**

Section B: Experience of caring for a child with DD

1. How long have you cared for your child with developmental disability?

   Probe: When did you get a diagnosis? At which age of the child?

   - Where did you get the diagnosis for your child?
   - How many children do you have with DD.

2. Tell me about your experience caring for your child with DD.

   Probe: What has been the challenge in caring for your child?
   How has your child with DD impacted on your life and your family's life?

- Describe to me what a typical day is like caring for a child with developmental disability?
- What does it feel like being a parent of a child with developmental delay?
- What has been some of the positive/ negative experiences of being a parent to a child with developmental disability?

Section C: Coping strategies available to families

3. What support have you received since the birth of your child?
   Probe: What types of supports are available to you? E.g., family, parent groups, religious group, social media networks?
   - How reliable are these support systems and what is the impact on you and your child?

4. How do you cope with the challenges of being a parent of a child with DD?

   Probe: Do you get support from family, friends, religious organization?

   How do you cope on your own?

Section D: Knowledge and Experience with Support group.

5. What do you know about Parent support groups (PSG)?

   Probe: How available are Parent Support Groups in Ghana?

   - How long have you been a member of a PSG?
   - What has your experience with a PSG been?
   - Which activities do the PSG have? Which activity did you like the most?
   - What is the importance of having a network of parents of children with DD?

6. Why did you join a Parent Support Group?

   Probe: What are your reasons for attending meetings/being attached to their platform?

   - What do you think of these activities of PSGs? Are they beneficial? Explain

7. What has been the role of PSG in caring for your child with DD?

   Probe: What do the parent support groups offer you? Have they provided information on how to care for yourself?

- What does this group offer your child?
- Do they organize seminars on specific topics for you and your child?
- Have they provided information on your child's diagnosis and how to care for your child?
- How has PSG impacted your ability to advocate for your child?

8. What supports, and coping strategies do they provide for you?

   Probe: How has this group contributed to your network of parents with children with DD?

   - Do they provide information regarding healthy lifestyles during the meetings?
   - Which activity was most informative and/or useful and why?
   - Which aspects have you adopted and practiced at home?

9. What are the challenges or barriers in joining PSG groups?

   Probe: Which challenges have you noticed since you joined?

   - How have they affected your care for your child?
   - How have these challenges affected your network or connections with other parents?
   - How can these challenges be resolved?

10. Would you recommend Parent Support Groups to other parents, and why?

    Probe: What else should be offered in Parents Support Groups?

    - What could be improved, or have you found missing from the group?

Is there any other information that you think would be important for me to know to better understand the things that are important to you?

Thanks

Appendix (B). Research budget

Research Budget and Budget Justification

	Material/Service	Activity	Estimated Cost (GHC)
1.	Compensation of participants	Provision of stationary worth Ghc 20	220
2.	Subsistence	Food and water for student researcher during interviews	200
3.	Transportation	Transportation for researcher to research sites	500
4.	Editing of final work	Standard cost for editing thesis	800
5.	Stationary	Photocopies, audio recorder, diary, printing, binding etc.	400
6.	Miscellaneous		300
TOTAL			2420

Appendix C (Work plan)

Work Plan

	Activity	Period	Duration
1.	Visiting the research centers to meet the leaders.	08/08/2023 – 12/08/2023	One week
2.	Identification and recruitment of participants.	14/08/2023 – 26/08/2023	Two weeks
3.	Data collection	29/08/2023 – 3/10/2023	Six weeks
4.	Data entry and analysis	04/10/2023 – 18/10/2023	Two weeks
5.	Thesis report	19/10/2023 – 31/10/2023	Two weeks
6.	Preparation and submission of thesis	01/11/2023 – 31/11/2023	Four weeks
7	Extension	31/11/2023 – 15/11/2024	51 weeks