

**A CRITICAL INVESTIGATION OF PARENTAL STRESS MANAGEMENT IN  
RAISING A CHILD WITH CEREBRAL PALSY AT THE COMMUNITY BASED  
REHABILITATION ALLIANCE**

**MICHELLE AMANDA KABAGENI**

**S21B15/106**

**A DISSERTATION SUBMITTED TO THE SCHOOL OF SOCIAL SCIENCES IN PARTIAL  
FULFILLMENT OF THE REQUIREMENTS FOR THE AWARD OF THE DEGREE OF BACHELOR  
OF SOCIAL WORK AND SOCIAL ADMINISTRATION FROM UGANDA CHRISTIAN UNIVERSITY**

**September, 2024**



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**DECLARATION**

I KABAGENI AMANDA MICHELLE, hereby declare that the dissertation is an original work of mine. This dissertation includes proper citations and acknowledgments for all sources used. I certify that the information provided does not violate anyone's or any entity intellectual property rights and accept full responsibility for it. Signed

..... Date.....

Kabageni Amanda Michelle

S21B15/106

A95559

## APPROVAL

This dissertation has been submitted for examination with approval from my supervisor.

Signature... *Alma* .....

Date... *5/09/2024* .....

Madam Jackline Bwire

Lecturer School of Social Sciences

Department of Social Work and Social administration

Uganda Christian University, Mukono.



## **DEDICATION**

I dedicate this dissertation to the Almighty God, the source of all wisdom, inspiration and guidance throughout the entire program. Furthermore, I dedicate this work to my parents Dr. Muruta Allan and Mrs. Edite Joan Harriet whose unfailing support and guidance have been my guiding light throughout this academic journey.

## **ACKNOWLEDGMENT**

I would like to extend my sincere gratitude to the staff of the Community Based Rehabilitation Alliance for enabling me to carry out my research in the organization. Additionally, I appreciate the administration of the Uganda Christian University and research supervisor Madam Jackline Bwire for tireless support rendered to me during the time observed.

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## **ABSTRACT**

This dissertation explored the difficulties of parental stress management when raising a child with cerebral palsy, looking at the experiences of parents within the Community Based Rehabilitation Alliance, Kiwanga, Uganda. The research was aimed to look deeper into the specific factors that contribute to stress among parents and the coping mechanisms that the parents used. Utilized a qualitative case study design while integrating one on one interviews and questionnaires to gather exhaustive data from participants. The findings showed that parents experienced a lot of stress which blocked their capability to cope effectively. One of the things that were identified as helpful were support groups. The study concluded while improvements on attitudes and support systems, there are still challenges that require further research into effective intervention mechanisms and long term health of parents. These findings underscore the relevance of developing complete support programs that address needs of parents raising children with cerebral palsy, alternatively contributing to better family wellbeing and adaptation.

# CHAPTER ONE

## 1.0 INTRODUCTION

This chapter consists of the background of the study, statement of the problem, identifying the objectives of the study and research hypothesis, also highlights the significance of the study and the scope of the study.

## 1.1 BACKGROUND

Parenting a child with cerebral palsy has brought about significant problems. Some issues such as stigma from the society, insufficient resources and even prejudice. children were placed in institutions earlier on in the twentieth century, this left their parents worn out and isolated. However, in mid-century medical knowledge advanced. A gradual change in the attitudes towards inclusivity occurred, aided by improved laws and lobbying efforts. Stress continued especially with marginalized groups and areas because of the continuous inequities when it came to accessibility. Despite the fact that there were improvements in technology. in the twenty first century, the necessity for a comprehensive support is becoming increasingly recognized, with laws fostering inclusivity in education and early intervention. However, parental stress management mechanisms are hindered by structural barriers and societal stereotypes, indicating continuous challenges along the way.

The demands for parents of children with cerebral palsy in most cases lead to high levels of stress related health outcomes. Parents and caregivers find support groups effective and very beneficial, and that is because practical and informational support is provided fostering personal effectiveness and expanding social networks. Moving forward, future research should put focus on exploring the effective intervention attributes and making use of longitudinal patterns to understand caregiver health better, coping strategies and transitional family adjustment processes. Future research should focus on identifying effective intervention qualities and utilizing longitudinal designs to better understand caregiver health, coping mechanisms, and family adaptation processes over time.

## 1.2 STATEMENT OF THE PROBLEM

Raising a child with cerebral palsy presents unique challenges for parents, often leading to heightened levels of stress that can adversely impact both the well-being of the parents and the overall quality of care provided to the child. Despite advancements in medical understanding and treatment of cerebral palsy, there is a noticeable gap in research regarding effective strategies for parental stress management in the context of caring for a child with this condition.

Despite the growing awareness of the challenges faced by parents raising a child with cerebral palsy (CP), being among parents of children with cerebral palsy. This research problem aims to critically

investigate and address the gaps in current knowledge regarding parental stress management in the context of raising a child with cerebral palsy.

The problem at hand revolves around the need to identify, assess, and develop targeted interventions for managing stress among parents of children with cerebral palsy. The stressors experienced by these parents may stem from various sources, including the physical and emotional demands of caregiving, financial constraints related to medical expenses, social isolation, and the uncertainty surrounding the long-term prognosis of the child's condition.

Cerebral Palsy (CP) is a neurological disorder affecting movement, muscle tone, and motor skills, often requiring intensive and specialized care. Parents of children with cerebral palsy face unique challenges that significantly contribute to elevated stress levels. Despite the prevalence of cerebral palsy, there is a gap in understanding the specific stressors experienced by parents in the context of Community Based Rehabilitation Alliance.

This research aims to investigate and identify the factors contributing to parental stress in raising children with cerebral palsy, evaluate the effectiveness of current stress management programs implemented by the community based rehabilitation alliance and explore coping mechanisms and resilience factors at the Community Based Rehabilitation Alliance, in Kiwanga. The study will explore the socio-economic, psychological, and medical aspects that influence stress levels among parents, with a focus on understanding the coping mechanisms utilized and the support systems available.

### **1.3 PURPOSE**

The purpose of this study is to investigate and identify the factors contributing to parental stress in raising a child with cerebral palsy, evaluate the effectiveness of current stress management interventions implemented by community based rehabilitation alliance and explore coping mechanisms and resilience factors at the Community Based Rehabilitation Alliance.

### **1.4 OBJECTIVES**

- i) Examine the factors contributing to parental stress.
- ii) Evaluate the effectiveness of current stress management interventions implemented by Community Based Rehabilitation Alliance.
- iii) Explore coping mechanisms and resilience factors.

## **1.5 RESEARCH QUESTIONS**

- i) What are the primary factors contributing to parental stress in raising a child with cerebral palsy within Community Based Rehabilitation Alliance, Kiwanga?
- ii) How effective are the three current stress management interventions implemented by Community Based Rehabilitation Alliance which include support groups, taking time out and exercises, in assisting parents in managing stress associated with raising a child with cerebral palsy?
- iii) What coping mechanisms and resilience factors do parents of children with cerebral palsy employ to navigate and mitigate stressors associated with caregiving?

## **1.6 SCOPE OF THE STUDY**

Geographically, this study focused on the Community Based Rehabilitation Alliance in Kiwanga, Uganda. It involved an examination of parental stress management in raising a child with cerebral palsy over a period of a month. The study, which addresses the interconnectedness of these areas in understanding and meeting the needs of families that have been affected by cerebral palsy, falls under the realms of psychology, public health and even special education.

## **1.7 JUSTIFICATION AND SIGNIFICANCE OF THE STUDY**

Parenting a child with cerebral palsy can be very difficult, especially in areas with limited resources like Kiwanga, Uganda. Parental stress has been cited out to be one of the significant factors affecting the welfare of both parents and children in such circumstances. However, there is a gap in understanding the management of parental stress in raising a child with cerebral palsy within the Community Based Rehabilitation Alliance in Kiwanga, Uganda. This study aimed to fill this vacuum by investigating the relationship between parental stress and the welfare of children with cerebral palsy in this community.

This study held an importance in the research to do with cerebral palsy, especially in areas where the resources are limited. By investigating critically, the management of parental stress in raising a child with cerebral palsy in Kiwanga, Uganda. It helps one comprehend the unique challenges that the families in such contexts face. The findings of this study not only informed techniques for local intervention but also provided insights that can be applied worldwide to better support services for families for children with cerebral palsy.

## **1.8 THEORETICAL FRAMEWORK**

For the critical investigation of parental stress management in raising a child with cerebral palsy, the study was guided by the Transactional Model of Stress and Coping developed by Lazarus and Folkman (1984). The model is utilized by a vast number of researchers and people that are practicing and is widely accepted. Based on this model, when a person faces a possibly tense situation, initial evaluation is what they first go through, where they analyse how much of a challenge the event is to their well-being. If the event seems to be challenging, the person has to follow through with a secondary evaluation. This is where they evaluate the resources that are available to them and their capacity. Both the appraisals, secondary and primary have an importance when making a decision on coping mechanisms. How stress is experienced by a person is determined by the success of the coping mechanisms. Which can be pronounced in their reactions physically and even psychologically. The secondary and primary appraisals are connected with the coping mechanisms and have an influence on each other. The success of these coping strategies determines how the person will experience stress, which can be seen in their psychological and physical reactions. Despite the fact that they are frequently believed to occur in the following order: first, initial evaluation, then secondary evaluation, followed by coping and then lastly results from stress. In the study this model was used to explore how parents with cerebral palsy handle stress that they face and how they perceive it. By understanding how these parents evaluate stressors, the coping mechanisms they employ and the effectiveness of the strategies.

## **CHAPTER TWO**

### **2.0 LITERATURE REVIEW**

#### **2.1 INTRODUCTION**

The special difficulties of raising a child with cerebral palsy can have a big impact on family dynamics and the well-being of the parents. In the fields of disability studies and healthcare, there is growing concern about the stress that parents endure when attempting to navigate the challenges of raising a child with cerebral palsy. For the purpose of promoting the wellbeing of parents and children, it is imperative to comprehend the elements that contribute to parental stress in this particular environment in order to develop appropriate interventions and support services. In order to critically examine the phenomenon of parental stress in raising a child with cerebral palsy, this literature review will look at coping strategies, critical stressor identification, and the efficacy of current assistance programs.

This review aims to provide a greater understanding of factors contributing to parental stress, effectiveness of current stress management programs, coping mechanisms and resilience factors and to guide future research and clinical practice by placing the importance of parental stress management within the larger framework of disability research and healthcare. This review aims to provide insights into strategies to better support families living with cerebral palsy by elucidating patterns, gaps, and emerging topics in the research of parental stress management in this context. It does this by exploring pertinent literature.

#### **2.2 FACTORS CONTRIBUTING TO PARENTAL STRESS**

A review covering the years between 1987 to 2017 had a number of studies on family stress. The study showed that parents with children with cerebral palsy go through a lot of stress, their mental wellbeing is low and are not doing well physically compared to parents with normal children.

However dire the condition of the child's disability is, it did not link to stress levels, but rather there were other factors which included the behavioral traits, social life of the child and physical traits. The primary caregiver's resources both personal and social and family resources for examples mechanisms with which they cope, socioeconomic status and access to respite care services.

The factors that contribute to stress of parents with cerebral palsy consist of the child, parent and family or even the social environment. The factors of the child that are dire and important are how serious the disability is, the need for care is high and dependence of the child, however there are reports of severity being associated and others also report that the severity of the disability has no association with stress.

The other sources that are also important include inability to communicate articulately and behavioral problems. The parental factors that are seen as relevant include passive parenting, believed to not be doing their parenting duties well and lower parental self-esteem. Key family and social environmental factors include isolating from society, not being fully satisfied with the perceived support and inadequate support from the significant others.

Very many problems obviously have an effect on the levels of stress for parents of children with cerebral palsy. complications and coexisting conditions appear to be directly contributing to stress among parents. Despite the severity of motor impairment. Other factors may not seem to be as pressing as those mentioned but have similar impact. The temperament of the child is important. Other than the child that is suffering from cerebral palsy, the primary caregivers function, coping mechanisms, family resources, as well as societal influences, are additional contributors to stress. It is very important to identify the known risk factors for an increase in the levels of parental stress. It is good to recognize the known risk factors for increased parent stress. Simultaneously, we must be alert against many as of yet, unquantified dangers to most possible functioning and wellbeing of families.

Parents physical and emotional health is affected when they are looking after children with cerebral palsy. They do not have the liberty to do anything or even prioritize themselves without thinking of the child, their financial stability is affected as well. Parents have to adjust and adapt being that the condition has an impact on their standard of living. Various studies have shown the stress that caregivers and mothers go through. However, there is a gap in literature there is a gap in research that was made involving a lack of understanding about what parents go through while caring for children with cerebral palsy, those with different levels of motor a shortage of knowledge about experiences of caring for children with varying degrees of motor impairment and how these experiences are articulated in the child's various life stages. Health workers will certainly find the information helpful to enable mothers manage difficult circumstances and unique needs of their children.

### **2.3 EFFECTIVENESS OF CURRENT STRESS MANAGEMENT INTERVENTIONS**

Social support can refer to psychosocial resources that are available to a person. Subsequently, contentment with social support has a relation with the perception that such resources and ties with people of the support group are sufficient to meet present needs. **Pfeifer et al. (2014)** argue that perceived social support seems to exert more influence on the adaptation to stressful experiences than the social support that is actually received or the number of members of the support network.

The effectiveness of social support for families of children with cerebral palsy was observed in a review of literature that was conducted by **Oliveira and Dounis (2012)**. The authors carried out research for Brazilian articles that were published from 2000 to 2010, having about eighteen studies that satisfied their requirements when selecting. These authors performed a search for Brazilian articles published from 2000 to 2010, and only 18 studies met the selection criteria. The findings portrayed that caregivers of children with cerebral palsy who had an established family and medical support system tended to have poor standards of living and high stress levels compared to those who had a fully developed network.

In the last few years, rehabilitation services have increasingly embraced a family centered approach, that has been currently regarded as “gold standard” in service provision. This model puts emphasis on how dire it is to help caregivers while also meeting the daily needs of children with cerebral palsy. research shows that the daily activities of children with cerebral palsy have a positive connection with the wellbeing of caregivers. Caregivers need to ensure that they carry out home exercises and attend sessions on a regular to enable them to attain the best wellness outcomes. This ongoing therapy is relevant because neuroplasticity theory suggests that regular practice of everyday tasks can improve recovery of children with cerebral palsy.

For the rational of economic, ethical and moral, there have been efforts to establish supportive interventions that focus on improving the quality of life of caregivers. One of the most common strategies is educational strategies such as workshops for training caregivers and psychological strategies that include focus groups, counselling and respite care. In Australia a randomized control trial was carried out by a researcher to determine the effect of family behavioral interventions such as therapy based on dedication and acceptance on the wellbeing parents with children with brain issues. The research revealed family behavioral interventions may bring about an improvement in the caregivers’ wellbeing, self-assurance, family adaptation and psychological health. Support groups are known to decrease parental stress by increasing the psychological wellbeing in areas such as happiness, faith and even confidence.

However, there is insufficient data to assess whether these interventions are effective in improving the wellbeing of care givers. Likewise, considering the various approaches used, it is relevant to assess how these interventions impact on the wellbeing of caregivers. Overall, there is need for evidence based practice for providing supportive interventions for parents of children with chronic impairment.

#### **2.4 COPING MECHANISMS AND RESILIENCE FACTORS.**

A review on literature that involved exploring the grieving, coping and resiliency experiences of parents with cerebral palsy and to carry out an investigation of a theory known as the chronic sorrow

theory, which was used as a framework to best understand the experiences. The methods involved integrating focus groups with a web-based cross-sectional survey to investigate persistent sadness. In parents of children with cerebral palsy. A number of parents participated. Emotions related to grieving come back because of some events that trigger them. For parents demonstrating resilience grieving is actually healthy and very typical.

The research revealed ways with which parents can cope and one of them was staying positive. Staying positive is important and that was clearly emphasized by the parents. It was important to patiently watch the progress of their child and be optimistic regardless of how slow it was or even small. Parents reported that it was important to utilize various coping strategies as they would come in handy at different stages. The strategies that were mentioned included getting direct support from family members, getting professional help, eating food that is encouraging and using encouraging quotes.

The parents in the focus group were resilient and they demonstrated it. From various coping mechanisms to manage their sorrow. Plus, even during the research some parents recommended ways with which some health workers could best support them. Also sought it relevant to tailor needs for single parents by asking them about what they need and their experiences.

Every family member, collectively and individually shows resilient behavior as a result of their being exposed to socially important figures during their early years. Franco (2000) conducted a study with about 50 mothers of children with cerebral palsy to determine the core resilient components in the family as well as the most relevant issues. The author stated that resilience seemed to be associated with about two fundamental components: the unity of the family and the resilience and psychological resistance of the mothers. Similar with what happens with parents of children with regular development mothers' concerns about the future of their children are shown by basic resilience drive towards re-idealization of their perspective of the future.

The level of parental resilience was also investigated in the current study. A factor analysis was carried out for this purpose using principle components method. In addition to the total change, each factor's contribution to the change was taken into the account while maintaining the constructs fundamental theory in mind. Each factor that was got was named according to the theme being talked about in every group of questions to make data analysis much easier. Each factor obtained based on the original CD-RISC scale (Connor & Davidson, data was recorded and tabulated showing the highest frequency of parents with high resilience. After clearly analyzing each component resilient parents had a consistent pattern across the board with spirituality presenting as the most statistical relevance. Adaptability, persistence positive acceptance self-efficacy and control. However, it should be highlighted that the scope of this study present study was limited to investigating a single reference institution. In order to

support the findings presented, its recommended that similar themes be investigated in the future at other national and institutions internationally.

## **CHAPTER THREE**

### **3.0 RESEARCH METHODOLOGY**

#### **3.1 INTRODUCTION**

This chapter provided an explicit description of how the study was conducted. With inclusivity of the research design, population and geographical area, sample size and sampling techniques, sources of data, data collection instruments, data analysis techniques, procedures of the study and limitations of the study. The reader used this description to evaluate the appropriateness of the data gathering and analysis procedure and determined the results yielded information that is reliable and valid.

#### **3.2 RESEARCH DESIGN**

This research employed the case study design to gather information through various methods to gain in depth insights of parental stress management in raising a child with cerebral palsy.

Interviews: Conducted one on one interviews with parents of children with cerebral palsy. Asked about their experiences, the difficulties they face and the coping mechanisms and the stressors they face. These interviews provided rich data given that verbatim was quoted.

Questionnaires: Standardized data collection was made feasible while using the questionnaires, this guaranteed that each participant received the same set of questions. This preserved uniformity amongst the feedback.

#### **3.3 AREA OF STUDY**

The study was focused at the community-based rehabilitation alliance in Kiwanga, Uganda. Kiwanga was the geographical area for data collection, it was chosen because of how feasible it was to carry out the study and established infrastructure for community-based rehabilitation services. This area was selected in order to provide a deeper understanding of the experiences of parents raising children with cerebral palsy within specific cultural and socio- economic context.

#### **3.4 SOURCES OF INFORMATION**

Through the application of primary and secondary sources of information, researchers obtained a thorough understanding of parental stress management in raising a child with Cerebral Palsy at Community based Rehabilitation Alliance, Kiwanga.

**a) Primary sources.**

Primary data was gathered through structured interviews and questionnaires administered to parents of children with Cerebral Palsy attending Community Based Rehabilitation Alliance programs.

**b) Secondary sources**

Secondary data was obtained from relevant literature, reports and studies on parental stress management, Cerebral palsy and Community-based rehabilitation approaches in Uganda.

**3.5 POPULATION AND SAMPLING TECHNIQUES**

The population for this study included parents/caregivers of children with Cerebral Palsy who are receiving services from Community Based Rehabilitation Alliance in Kiwanga, Uganda.

Using non-probability sampling techniques, the following table presents the statistics for parents, caregivers, and children with cerebral palsy:

In Non probability sampling, rather than using random selection, people are chosen from a population based on subjective criteria. Every member of the population does not have an equal chance of being included in the sample, and the sample could not be representative of the whole population. Sampling techniques employed in this research may include:

Purposive sampling: When researchers hand-select particular people from a community according to particular traits or standards that are pertinent to the research question, this is known as purposeful sampling.

**3.5.1 SAMPLE SIZE AND SELECTION**

This refers to the general description of the actual sample that was studied. The Sample size was selected using purposive sampling. Therefore 52 respondents were selected from the total population of 70 and will be classified as illustrated below.

<b>Categories of respondents</b>	<b>Population</b>	<b>Sample Population</b>	<b>Sampling Technique</b>
Parents	10	10	purposive
Caregivers	10	5	purposive

Children with Cerebral Palsy	20	10	purposive
Community leaders and influencers	20	15	purposive
Government officials	10	7	purposive
<b>Total</b>	<b>70</b>	<b>52</b>	

### 3.6 PROCEDURES OF DATA COLLECTION

The data collection process involved the following steps:

**Identifying participants:** Through the collaboration with the Community based Rehabilitation Alliance in Kiwanga, Uganda, it facilitated the identification of a diverse sample of parents who have children with cerebral palsy. Parents were approached with the help of various authorities and invited to participate in the research study.

**Informed Consent:** Informed consent was obtained prior to data collection from all the participants, making sure that they comprehended the importance of the study, their rights as participants and the measures of confidentiality that were put in place.

**Interviews:** Semi-structured Interviews were made with a given number of parents that participated to delve deeper into their experiences and have a view of how they perceive things. Interviews were scheduled at convenient times. The interviews followed the interview guides allowing for open ended discussions and investigation of a plethora of themes related to parental stress coping.

**Data Management:** Ensured that data collected from interviews was organized and stored safely to ensure confidentiality. Each participant was assigned a unique identifier to make sure they remain anonymous throughout the whole process.

**Quality Assurance:** Throughout the data collection process, adherence to ethical guidelines and validity of data using well established interview protocols were ensured.

### 3.7 DATA COLLECTION INSTRUMENTS AND EQUIPMENT

**Interview Guides:** semi structured interview guides were developed to carry out deeper interviews with parents. The questions were designed to examine parents' experiences, perspectives and the difficulties in raising a child with cerebral palsy. The questions asked were open ended to allow flexible feedback and get the subtleties of parental stress and coping strategies.

Questionnaires: Standardized data collection was made feasible while using the questionnaires, this guaranteed that each participant received the same set of questions. This preserved uniformity amongst the feedback.

### **3.8 QUALITY/ERROR CONTROL**

Quality control measures included pilot testing, reliability and validity of tools, ethical considerations, continuous improvement and peer review to address any errors.

### **3.9 DATA PROCESSING AND ANALYSIS**

Qualitative data from interviews and observations underwent a thematic analysis to identify recurring themes and patterns. A qualitative research technique called thematic analysis was used to find, examine, and interpret themes or patterns in textual data. In order to identify underlying themes or patterns that capture significant features of the data, it entailed methodically arranging and analysing qualitative data. Themes and patterns in the participant responses and their experiences with the programs were found by using thematic analysis, which was a useful tool for assessing qualitatively the efficacy of the existing stress management programs. Here is how it was approached:

**Data Collection:** Started by interviewing parents/caregivers who have taken part in the Community Based Rehabilitation Alliance's stress management programmes. Made sure that the questions that were asked were open ended and were intended to give comprehensive feedback regarding the perspectives and the opinions of the programs efficacy, as well as any ways their stress levels and general state of living were modified.

**Transcription:** captured the participants' responses in written form. Having transcribed the interviews discussions verbatim. Verbatim. This served as the raw data for the thematic analysis.

**Data Familiarization:** Read through the scripts multiple times, taking note of any repeated words or patterns that stand out.

**Initial Coding:** Paid close attention to recording important ideas about benefits, obstacles and opportunities for development as far as the efficacy of the stress management programs are concerned.

**Refinement and Interpretation:** Continued to analyse and understand the themes that have been found to refine them. Examined how these themes relate to the study's goals while taking into account the subtleties and complexity of the participants' experiences.

**Validity and Reliability:** Participated in reflexivity, member checking, and peer debriefing which helped to ensure the validity and dependability of the findings. strengthened the validity of the analysis, considered one's own prejudices and presumptions, asked participants to evaluate and validate the views, and asked colleagues for input.

**Reporting:** Lastly, clearly and thoroughly presented my findings, highlighting the themes that arose from the data and their relevance for understanding the efficacy of the stress management programs. Talked about how the results agree or disagree with previous research, and made suggestions for more study or programmatic interventions in light of my findings.

### **3.10 ETHICAL CONSIDERATIONS**

**Informed Consent:** Ensured that the participants fully understood the relevance, and the risks and the benefits of the research before getting consent.

**Confidentiality:** Protected the participants' identity by securing the data especially information that is sensitive such as health and family issues.

**Cultural Sensitivity:** cultural norms and beliefs were respected when carrying out research with the families. Putting into consideration their religion and language and their customs.

**Beneficence:** Ensured that the advantages of research benefits are more than any possible dangers to the participants and making sure to reduce risks and improve benefits to the individuals and communities involved the study.

### **3.11 METHODOLOGICAL CONSTRAINTS**

Challenges included interpretation based on personal feelings, sampling limitations and limited generalizability.

## CHAPTER FOUR

### 4.0 DATA ANALYSIS AND INTERPRETATION OF FINDINGS

#### 4.1 INTRODUCTION

This chapter presents a comprehensive analysis of data collected from interviews with parents of children with cerebral palsy participating in a community-based rehabilitation program. Raising a child with cerebral palsy presents a number of challenges having a dire effect on the primary caregivers overall wellbeing. Very many parents feel overwhelmed by the expenses associated with taking care of their child and also making ends meet. Stress is increased when trying to exploring the healthcare system, having parents unable to access services that are helpful for their children. There is a negative impact on relationships and emotional wellbeing because of the duties, and the child's behavioral and developmental problems bring about additional concerns about the burden on family dynamics. The efficiency of the stress management programs that are now in place has been mixed; while support groups are valued, some parents are unaware of tools available to them, or believe them to be impossible to implement. Parents employed a variety of coping mechanisms, including getting help from experts, taking very good care of themselves and even turning to faith for strength. taking care of themselves, and turning to faith for strength. being flexible, tenacious and optimistic are the resilience attributes that are essential in for handling the constant demands of caregiving. The analysis is structured round key themes that emerged from the interviews, highlighting the experiences, challenges and coping mechanisms of the participants in managing the stress of raising a child with cerebral palsy.

#### 4.2 EXAMINE THE FACTORS CONTRIBUTING TO PARENTAL STRESS.

##### **Financial Concerns**

Financial pressure is one of the biggest factors contributing to stress of parents raising a child with cerebral palsy. One parent shared, "I spend a lot of money while taking care of my child and that's just overwhelming." I have to keep paying for unexpected hospital visits and it gets draining while also trying to earn a living." Another parent said, "Insurance doesn't handle all the expenses so we have to end up using our own money to cater for the expenses in order to provide for the child." The drain of the financial challenges was also identified by another respondent, who remarked, "I dint know that it costs a lot for having to care for a child with cerebral palsy, I am always looking at the wants and needs of the child over mine." Likewise, a parent was frustrated and shared, stating, "we have had to take on extra jobs just to be able to afford and cover the costs, but even then it still feels like as though we aren't doing enough".

### **Difficulty Navigating the Healthcare System**

Parents reported immense difficulty in navigating the complex healthcare system and accessing the appropriate services and support for their child. As one parent explained, "It feels like a full-time job just trying to coordinate all the different doctors, therapists, and programs. We spend so much time just trying to get the care our child needs." Another parent lamented, "The lack of specialized providers in our area makes it really hard to find the right care. We end up having to drive hours just to get to the nearest pediatric rehabilitation center." Another parent mentioned, "I am constantly trying to rap my head around the services my child is eligible for as I struggle with insurance". Its draining. In addition to that another parent said, "for each referral, brand new mode of treatment feels like a brand new challenge and nothing seems clear it's like I am starting from square one and its overwhelming".

### **Impact on Family Dynamics**

The demands of caring for a child with cerebral palsy place a significant strain on family relationships and the emotional well-being of parents. One mother shared, "Our whole family's schedule revolves around our child's needs. It's hard to find time for ourselves or to give attention to our other kids." Another parent confided, "The stress has really put a toll on my marriage. My spouse and I are constantly arguing over how to best handle things." A different parent also talked about the effect emotionally, stating, "there are times when it feels like we are just existing, all our efforts and energy is on our child and there is nothing left for the both of us." Another respondent shared, "the vicious cycle of unending strain has made it difficult for me to connect with my husband and its affecting our relationship in ways I never expected."

### **Child's Behavioral and Developmental Challenges**

Parents expressed deep concerns over their child's behavioral issues and developmental delays, which add to their daily stress. As one father described, "Our child has such difficulty communicating and controlling their emotions. The meltdowns and behavioral problems are exhausting to deal with on top of everything else." Another parent noted, "Seeing our child struggle to reach developmental milestones is heartbreaking. It's a constant worry about their long-term progress and independence." One mother said, "I always think about whether my child will ever reach the point of being on their own without being helped or whether they will always need to be cared for." A familiar concern was raised by another parent, stating, "it is hard not to fee hopeless sometimes especially when everyday feels like a struggle with the challenges that are so overwhelming."

## **4.3 EVALUATION OF CURRENT STRESS MANAGEMENT INTERVENTIONS**

### **Utilization of Current Support Programs**

The survey results indicate that a significant portion of parents are not currently participating in any of the Community Based Rehabilitation Alliance's support groups or stress management programs. When asked, one parent explained, "I wasn't even aware those types of programs existed in our area. It's been so hard just to get our child the basic medical care they need, let alone find time for support groups." Another mother shared the same exact experience saying, amongst all the appointments, work and life on a regular, I haven't found the time to look into these programs." Another respondent said, "I have heard of the programs, but honestly, with the already existing overwhelming schedule, I feel like it tops it all." Additionally, a parent shared, "it would be hard for me to find child care for my other children even if I were to join a support group."

### **Perceived Effectiveness of Existing Programs**

Parents that use the available support programs, they have mixed feedback in effectively managing the stress. As one parent mentioned, "The support groups have been of good use, and have enabled me connect with other primary caregivers and also be able to share our our various coping mechanisms." However, another parent commented, "I've tried a few of the stress reduction workshops, but I haven't found them to be all that practical or relevant to my specific situation."

Another participant shared, noting, "while support groups are somewhat effective to some extent, sometimes they seem to be not in alignment with the reality of what one is going through on a daily." Additionally, a parent expressed, "the ideas when theoretically explained seem good, however, practically it's had to see how they fit into our daily way of living."

### **Key Beneficial Program Components**

Based on the feedback, the most beneficial aspects of the stress management programs appear to be the opportunities for peer support and the sharing of coping techniques. Parents valued the chance to connect with others facing similar challenges and learn from their experiences. As one mother noted, "Just being able to vent to people who truly understand what I'm going through has been invaluable." Additionally, another parent appreciated the practical workshops, saying, the time management and self-care workshops were cited as particularly helpful." A different respondent talked about the impact of shared experiences to them, saying, hearing how the others have found ways of going around the similar challenges has been of good use for me." Additionally, one parent noted, "the workshops have enabled me get the strength and be more careful while getting the care my child needs."

## **4.4 COPING MECHANISMS AND RESILIENCE FACTORS**

### **Mechanisms used by parents to cope**

According to the survey's results, parents use a wide range of coping mechanisms to lessen and manage the stress for caring for a child with cerebral palsy. Parents emphasized the value of getting support from friends and family. A Parent also reported making efforts to prioritize their own physical and mental well-being through self-care activities such as exercise, meditation, or simply taking time for themselves. "I have started making time for myself and making myself a priority even if it's just a few minutes in a day to do some exercises." Another parent mentioned, "I do exercises because it relieves me of stress, and is one of the few times I feel like I have put myself as a priority and not loose myself because I am overwhelmed." Similarly, another respondent noted that, ever since I started taking time to care about myself, I have seen a great change. I become a better parent."

### **Seeking Professional Support**

A number of parents expressed the value of getting professional assistance in order to come up with useful coping mechanisms to enable them process their emotions. As one participant explained, "The therapist has given me so many practical tools for managing the day-to-day stress." Another parent said, "family sessions with professional therapists have made the both of us understand ourselves better than before, and has also brought about a change in the way we communicate with each other." A different respondent mentioned, "having someone that you can share with that's not in the family makes me feel so much better." Additionally, one mother said, "having to interact with counselors, has provided her with some coping mechanisms that she would never have thought of on her own."

### **Finding Strength in Spirituality**

For some parents, what provided peace and comfort and resilience was their spiritual or religious beliefs. As one mother shared, "On the days when everything seems like a burden it's the hope that I keep alive, and that's how I keep going. "I find peace in knowing I'm not alone in this journey." A parent shared and mentioned, "prayer has changed my whole thinking as a primary caregiver of child with cerebral palsy, resorting to prayer in moments of stress gives her strength and hope that all will be well." Another respondent mentioned, "church has become a place where I can share my grievances without feeling anything burdening me but rather safe and where I can find peace and hope." Similarly, one parent quoted, "whenever I feel overwhelmed, I am calm down by what I believe in spiritually and it gives me hope and a sense of purpose."

### **Resilience-Oriented Traits**

In addition to the coping mechanisms that the parents employed, they also managed to identify various resilience traits that have enabled them overcome the stress associated with caregiving. One parent said, being flexible has been fundamental, you have to be able to change plans immediately." Another

mother emphasized the value of perseverance, saying, however hard it is, I must always focus on my child and also monitor progress if any.” A different respondent noted, “having problems solved in a legit manner has been beneficial when the traditional methods have failed to work out.” Additionally, another parent shared, saying, “I stayed positive even on the hardest days, I even went ahead to celebrate where some progress was made, that keeps me going.”

## **CHAPTER FIVE**

### **5.0 DISCUSSION, CONCLUSIONS, AND RECOMMENDATIONS**

#### **5.1 DISCUSSION**

The findings from the analysis of interviews with parents of children with cerebral palsy reveal several critical themes regarding the coping strategies and resilience-building approaches employed by this population. These themes resonate with and expand upon existing literature on caregiver experiences and family adaptation in the face of chronic childhood conditions.

One of the key themes to emerge is the vital role of social support networks, both formal and informal, in helping parents manage the emotional and practical demands of care giving. The parents in this study emphasized the value of leaning on family and friends, as well as the benefits of professional counseling and therapy, in navigating their challenges.

Another prominent theme is the significance of cultivating personal coping strategies and resilience-oriented traits, such as flexibility, problem-solving skills, and a positive mindset. By drawing upon these internal resources, parents were able to reframe obstacles, maintain a hopeful outlook, and persist in their efforts to support their child's development.

Importantly, the data also revealed areas where additional support and resources could bolster the resilience of families caring for a child with cerebral palsy. These include improving access to mental health services, facilitating peer support networks, promoting caregiver self-care, and enhancing educational resources.

#### **5.2 CONCLUSION**

In conclusion, the study aimed to examine the factors contributing to parental stress, evaluate the effectiveness of current stress management programs, and explore the coping mechanisms and resilience factors among parents of children with cerebral palsy. The findings indicate that: The study revealed the significant factors contributing to parental stress are financial concerns, navigating the healthcare system and impact on family dynamics. Parents are constantly under stress because of the financial load of medical bills and the challenges in getting fundamental medical care. In addition, relationships with relatives and emotional wellbeing are strained because of the demanding nature of caring alongside the child's behavioral and developmental growth issues.

The current stress management interventions have revealed mixed degrees of success. While other parents find joining support groups effective, many other parents find a challenge in creating time to

get involved because they have busy schedules or are even unaware of the interventions. Interventions such as support programs that foster practical coping skills and peer support were highly appreciated. A number of individualized and accessible interventions are needed, since they align with the daily realities of providing care,

In accordance with the findings, parents utilize various coping mechanisms such as turning to friends family for support, making sure to exercise in order to take care of themselves and turning to spirituality. Help from experts that offers useful mechanisms for stress management, such as counseling is also highly appreciated. Resilience attributes such as adaptability, tenacity and optimism are important for helping parents in overcoming the challenges involved in provision of care. Despite the unending needs, parents can continue to provide support to their child's development and hold onto hope courtesy of the internal resources.

Overall, the data underscores the impressive capacity of parents to navigate the caregiving journey, drawing upon social support, personal resilience, and a range of coping mechanisms. However, the findings also emphasize the need to address gaps in support and resources to further empower families and enable children with cerebral palsy to thrive.

### **5.3 RECOMMENDATIONS**

Based on the study's findings, I recommend the following;

#### **To Address the Factors Contributing to Parental Stress:**

Establish financial support programs. To lift the weight of financial burden on families raising children with cerebral palsy, the government should foster financial support programs within communities to curb the financial strain of parents raising children with cerebral palsy.

Boosting accessibility of specific therapies by setting up medical services to enable parents handle confusing healthcare systems. The ministry of health should establish medical services to make it easy for the parents to access specific therapies and enable parents navigate confusing health care systems.

#### **To Enhance the Effectiveness of Current Stress Management Interventions:**

Having personal stress management strategies. Parents are encouraged to use an approach that favors them to meet their unique family needs. This can give room for efficiency in coping and improve their overall wellbeing.

Integrating eHealth services. Parents should make good use of the existing online medical services. This makes it easier for them that have busy schedules and it also becomes convenient for them to carter for the child's needs without being strained.

### **To Promote Coping Mechanisms and Resilience Factors:**

In order to help parents in better managing their stress, programs should be provided that teach meditation and relaxation techniques at the community-based rehabilitation alliance. Parents should be participants in programs that teach relaxation and meditation in order to improve their ability to handle stress and also enhance their parenting skills.

Community resilience sessions. In order to improve the network of support, relevant organizations should hold workshops that focus on resilience building for parents and their families. These sessions would improve coping strategies and strengthen support networks.

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## APPENDICES

### TOPIC: A CRITICAL INVESTIGATION OF PARENTAL STRESS MANAGEMENT IN RAISING A CHILD WITH CEREBRAL PALSY AT COMMUNITY BASED REHABILITATION ALLIANCE

Dear Sir/Madam,

I am Kabageni, a student of Uganda Christian University Pursuing a Degree of social work. I am currently conducting a study on the critical investigation of parental stress management in raising a child with cerebral palsy at community-based rehabilitation alliance. The study is purely for academic purposes and the information given will be treated with utmost confidentiality. I therefore, humbly request you to spare some time and answer the following questions.

#### INSTRUCTION

Tick appropriately in the boxes provided. The information that will be given will be used for academic purposes only. Please do not write your name.

BIO - DATA

#### SECTION A

1. Age

- |          |          |
|----------|----------|
| a) 15-25 | b) 25-35 |
| c) 35-45 | d) 45-35 |

2. Marital status

- |            |              |
|------------|--------------|
| a) Single  | b) Divorced  |
| c) Married | d) Separated |

Others specify.....

3]. Level of education

- a) Primary
- b) Secondary

3. Institution/ University level

If others specify.....

## **Section 2: Factors contributing to parental stress**

1. How stressed out do you think you are as a parent to a child with cerebral palsy?
  - Not stressful at all
  - Slightly stressful
  - Moderately stressful
  - Very stressful
  - Extremely stressful
2. What are the primary causes of your stress as a parent? (Verify anything that applies)
  - Financial concerns
  - Lack of support/resources
  - Access to medical care/services
  - Child's behavior/developmental challenges
  - Emotional well-being of the child
  - Impact on family dynamics
  - Other (please specify): \_\_\_\_\_

## **Section 3: Evaluation of current stress management programs**

1. Do you now participate in any of the Community Based Rehabilitation Alliance's support groups or stress management programs?
  - Yes
  - No
2. If yes, how effective do you find these programs in helping you manage parental stress?
  - Not effective at all
  - Somewhat effective
  - Moderately effective
  - Very effective
  - Extremely effective
3. Which components of the stress-reduction programs are the most beneficial to you? (No specifics)

## **Section 4 Coping Mechanisms and Resilience Factors**

1. How do you cope with the stress of raising a child with cerebral palsy? (check all if apply)
  - Seeking support from family/friends
  - Engaging in self-care activities
  - Participating in therapy/counseling
  - Find strength in spirituality
  - Engaging in hobbies or interests

- Other (please specify)
2. Have you observed any resilience-related traits that support you in overcoming and reducing the pressures involved in providing care?

**Conclusion**

We appreciate you taking the time to respond to our survey. Your answers will advance our knowledge of how parents with cerebral palsy manage their stress while raising their children and enhance the resources available to families facing comparable challenges.

[End of Questionnaire]

## **TOOLS USED TO COLLECT DATA**

### **Interview guide: A Critical Investigation on Parental stress management in Raising a Child with Cerebral Palsy**

**Objective:** The aim of this interview is to investigate coping strategies and resilience factors among parents of children with cerebral palsy receiving services from the Community Based Rehabilitation Alliance, as well as to obtain insights into the factors contributing to parental stress and assess the efficacy of current stress management programs.

#### **Introduction**

- Express gratitude to the participant and extend a warm welcome.
- Discuss the goal of the interview and guarantee privacy.
- Get verbal approval before moving on with the interview.

#### **Section 1 factors contributing to parental stress**

- Could you share your experience raising a child with cerebral palsy as a parent or caregiver?
- What are the primary obstacles or sources of stress that come with being a parent of a child with cerebral palsy?
- What effect does your child's motor impairment seem to have on your stress levels?
- Could you elaborate on any particular moments in your caregiving duty when you felt anxious or overburdened?

#### **Section 2: Evaluation of current stress Management program at Community Based Rehabilitation Alliance**

- Have you taken part in any stress reduction initiatives or benefited from community Based Rehabilitation Alliance support. If so kindly explain the situation.
- To what extent have the Community Based Rehabilitation Alliance's current stress management programs helped you manage stress that comes with being a parent of a child with cerebral palsy.
- What enhancements or extra assistance do you wish to see in the current stress management initiatives?

#### **Section 3: Coping mechanisms and resilience factors**

- What coping techniques or tactics do you use to handle stress and keep your wellbeing?
- Could you describe any instances in which you overcame difficulties associated with being a parent of a child with cerebral palsy?
- What part do you think family and friends have in helping you manage the responsibilities of being a carer?

**Closing**

- Appreciate the participant's time and insightful comments.
- If further assistance or resources are required, provide them.
- Reaffirm confidentiality and thank them for their involvement in the study.