EXPERIENCES OF CAREGIVERS OF CHILDREN WITH DISABILITIES AT BISHOP WEST PRIMARY SCHOOL

BUSIMO KAYE

EJ21B15/208

A DISSERTATION SUBMITED TO THE SCHOOL OF SOCIAL SCIENCES IN PARTIAL FULLFILLMENT FOR THE REQUIREMENT OF AWARD OF A BACHELORS DEGREE IN SOCIAL WORK AND SOCIAL ADMINISRATION OF UGANDA CHRISTIAN UNIVERSITY

September, 2023

UGANDA CHRISTIAN
UNIVERSITY
A Centre of Excellence in the Heart of Africa

DECLARATION

I Kaye Busimo hereby declare that this dissertation was produced out of my own effort with the guidance of my supervisor and has never been submitted to any other institution for any award.

Signature:……………………………………….. Date:………………………………………

KAYE BUSIMO

EJ21B15/208

APPROVAL

This dissertation has been supervised with my guidance and is therefore ready for submission to the School of Social Sciences in Uganda Christian University.

Signature:……………………………………….. Date:………………………………………

DR. PETER NAREEBA

(Academic Supervisor)

DEDICATION

I dedicate this research to my dear parents, my sister Nasuuna Catherine, my brother Cosmas Kanyike who advised, supported and mentored me throughout my education up to university level. Above all, I thank the Almighty God for guidance and provision towards completion of this dissertation.

ACKNOWLEDGEMENT

I am greatly indebted to Dr. Peter Nareeba who was my supervisor for his effective supervision, dedication, availability and professional advice.

I would also like to acknowledge my dear parents, my sister Nasuuna Catherine, my brother Cosmas Kanyike and Jeff Sebulime for always being there for me in all situations.

I also acknowledge the efforts of my lecturers; Madam Stella Nantambi, Mrs. Bwire Jackline, Mr. Kabanda Lewis and Dr. Waiswa Jeremiah for their tireless efforts towards the course of my bachelor’s degree programme.

I would like extend my gratitude to the parents and the caregivers of children with disabilities in Bishop West Primary School for giving me relevant information that made the study successful.

Lastly, I thank the Almighty God through Jesus Christ who has given me good health and strength to carry out the research right away from the beginning to the end and successfully.

Table of Contents

LIST OF TABLES

ABSTRACT

The study examined the experiences of caregivers of children with disabilities at Bishop West Primary School, Mukono. The study was guided by objectives which included; establishing the attitude of caregivers towards children with disabilities, finding out the challenges caregivers of children with disabilities face and establishing the copying mechanisms of caregivers to children with disabilities. The study was carried out using an explanatory research design where a mixed methods research approach was also used. The data were collected using questionnaires and interviews and during the data collection, both purposive and simple random sampling methods were used. A sample size of 52 respondents who were parents of children with disabilities in Bishop West P/S and caregivers of children with disabilities at the school was also used in the study. The study findings revealed a generally positive attitude among caregivers towards children with disabilities, with caregivers expressing comfort in interacting with these children and recognizing their enriching diversity. However, significant challenges persist, including limited access to essential educational resources, communication barriers with school staff, financial burdens, and social stigma. Caregivers employ various coping mechanisms, such as building support networks, engaging in self-care, advocating for their children, and participating in workshops and support groups, to address these challenges. While the school community exhibits inclusivity, there remains room for improvement in supporting children with disabilities and their caregivers. Enhancing awareness and addressing these challenges can contribute to a more inclusive and supportive educational environment for children with disabilities at Bishop West Primary School. Finally, the study recommended that Bishop West Primary School should enhance educational resource accessibility, promote effective communication between caregivers and school staff, expand extracurricular opportunities, explore financial support options for families with children with disabilities, continue disability awareness efforts, provide support networks and counseling, promote parent-teacher collaboration, and implement regular assessments and feedback mechanisms to improve support systems for children with disabilities and their caregivers.

CHAPTER ONE

INTRODUCTION

1.0 Introduction

This chapter covers at the background of the study, problem statement, purpose of the study, objectives of the study, research questions, scope of the study that is, geographical scope time scope, the significance of the study and the conceptual framework

1.1 Background of the study

It is estimated that 90 to 100 million children aged 14 years or younger worldwide live with moderate to severe disabilities (UNICEF, 2022). Ninety five percent of the 56 million children under five years with developmental disabilities live in low- or middle-income countries (LMIC) (WHO, 2021). As the under-five survival increases worldwide, there has been a growing recognition of the importance of the quality of that survival and a new focus on the epidemiology of and interventions for developmental disabilities in LMIC, where previously child survival had taken precedence (Olusanya et al., 2018). Cerebral palsy is one such condition with complex developmental significance.

The care for children with physical disabilities can be an over-whelming experience as it constantly drains the primary care giver financially, psychologically, socially and health-wise. Disability is defined as the limitation or nonexistence of capability to make a movement in a way that is viewed as normal for people according to the World Health Organisation (WHO), (2021). According to the WHO (2021) the number of children with disabilities is estimated to be 95 million (5.1%) globally of whom 13 million (0.7%) is said to have severe disability, that is 10% of a country’s population is having a disability. United Nations estimates indicate that about 80% of people with disabilities are living in third world countries mostly in rural and isolated areas (Priestly, 2021). From the estimates it can be noted that sensory and mental health impairments constitute about two hundred million. The estimates provides a yardstick of 2.5% of children who are between the ages of 0-14 years with undisputable or mild to severe levels of physical, sensory and intellectual impairment and a further 8% have behavioural or learning difficulties or a combination of both (Tanyanyiwa, 2021).

Globally, in many parts of the world, caregivers of children with disabilities encounter a range of difficulties. These challenges can be attributed to various factors, including lack of awareness and understanding about disabilities, limited access to resources and services, stigma and discrimination, and inadequate policies and legal protections (WHO, 2015). Many caregivers may struggle with finding appropriate educational opportunities for their children, accessing healthcare services, and facing financial constraints due to the additional expenses related to disability care. In more developed countries, efforts have been made to improve the quality of life for children with disabilities and their caregivers (Bunning et al., 2017). Laws and policies, such as the Americans with Disabilities Act (ADA) in the United States and the Disability Discrimination Act (DDA) in the United Kingdom, aim to protect the rights of individuals with disabilities and promote inclusion in various aspects of life (King et al., 2019).

In many African countries, caregivers of children with disabilities face unique challenges, often influenced by socioeconomic and cultural factors. Accessibility to healthcare and educational facilities can be limited in rural areas, making it difficult for caregivers to access appropriate support for their children (Masulani-Mwale et al., 2018). Traditional beliefs and social stigmas surrounding disabilities can lead to discrimination and exclusion of children with disabilities, further exacerbating the struggles faced by their caregivers. More so, children with disabilities in most African countries face multiple challenges including reduced quality care by the primary caregivers, limited access to health professionals and education (Mkabile & Swartz, 2020). Lots of children who have physical disabilities have mobility challenges and hence their ability to interact with their peers is greatly affected. In most instances they are left to play alone and hardly attend school (Szlamka et al., 2022). Many times they are locked up in the houses as the caregivers do their daily activities leaving them to spend the day at home without any activity. Adnams (2010) summarizes that there is paucity of literature on the delivery of services to people living with disabilities as well as their caregivers in most communities.

In Uganda, approximately 13 % of children live with some form of disability (Riche, 2014). In order to ensure the protection of these 2.5 million children from violence (Power, 2013), poverty (Simplican et al., 2015) and poor access to healthcare (Ransom, 2018), international organizations such as UNICEF have emphasized that it is indispensable to focus on their social inclusion in education, rehabilitation, cultural and recreational activities (UNICEF, 2021). In

Uganda, like many other African countries, the experiences of caregivers of children with disabilities can be particularly challenging. While the Ugandan government has taken steps to address disability rights and inclusive education, there are still significant gaps in implementation and access to services. Limited funding for disability support programs and a lack of trained professionals in the field of special education can make it difficult for caregivers to find the necessary resources and assistance for their children. This study therefore aims at examining the experiences of caregivers of children with disabilities at Bishop West Primary School in Mukono, Uganda.

1.2 Problem statement

In Uganda, approximately 13 % of children live with some form of disability and some of these are in schools (Riche, 2014) and these children with disability usually fail to meet most of their needs. Problems of care for children with physical disabilities is not only unique to Uganda, but to most countries. Caregivers face huge problems emanating from non-existent policies of caregiving, unavailability of resources and infrastructure for children with physical disabilities. Several studies globally like Coomer (2013) and Chirwa (2012) have carried out studies to assess the experiences of care and the impact faced by caregivers. Caregivers in most cases experience the same challenges which include burnout and high cost of caring. The problems associated with burden of caregiving globally are also prevalent in Uganda. However, not much has been researched about the caregiving burden of children with physical disabilities in Uganda and specifically in primary schools like Bishop West (Szlamka et al., 2022). The dearth of literature on the subject matter has thus motivated the researcher to study the area. It is therefore against this background that the researcher sought to examine the experiences of caregivers of children with disabilities: a case study of Bishop West Primary School, Mukono.

1.3 Purpose of the study

The purpose of the study was to examine the experiences of caregivers of children with disabilities: a case study of Bishop West Primary School, Mukono.

1.4 Objectives of the study

1. To establish the attitude of caregivers towards children with disabilities in Bishop West Primary School.
2. To find out the challenges caregivers of children with disabilities face in Bishop West Primary School.
3. To establish the coping mechanisms of caregivers to children with disabilities in Bishop West Primary School.

1.5 Research questions

1. What are the attitudes of caregivers towards children with disabilities in Bishop West Primary School?
2. What are the challenges caregivers of children with disabilities face in Bishop West Primary School?
3. What are the coping mechanisms of caregivers to children with disabilities in Bishop West Primary School?

1.6 Scope of the study

The scope of the study covered three dimensions that is; content, geographical and time and these are discussed in detail below.

1.6.1 Content scope

This study specifically focused on; establishing the attitude of caregivers towards children with disabilities, finding out the challenges caregivers of children with disabilities face and establishing the copying mechanisms of caregivers to children with disabilities.

1.6.2 Geographical scope

Geographically, the study was conducted in Bishop West Primary School located in Nsuube-Kauga Parish, Mukono district. Bishop West Primary School was chosen because it's one of the primary schools with a high number of children with disabilities totaling to 60 as per the school statistics.

1.6.3 Time scope

The study focused on scholarly material from the period 2018 to 2023. It was also carried out for a period of two months from July to August, 2023.

1.7 Justification of the study

The justification of conducting this study on the experiences of caregivers of children with disabilities at Bishop West Primary School, Mukono, Uganda is because it addresses a critical gap in research, as there is a dearth of comprehensive studies focusing on the challenges faced by caregivers in this specific setting. By investigating the unique issues encountered by these caregivers, the study can contribute valuable insights that inform policy-makers, educators, and stakeholders about the urgent need for targeted interventions and support systems. Secondly, the study's findings have the potential to positively impact the lives of children with disabilities and their families, enhancing their overall well-being, educational outcomes, and social inclusion. Moreover, as Uganda and other African countries strive for more inclusive societies, this research can foster a deeper understanding of the barriers to care and inclusion faced by families of children with disabilities, leading to more effective and sustainable interventions that promote equity and equal opportunities for all children, regardless of their abilities. Ultimately, the study’s justification lies in its potential to pave the way for a more inclusive and supportive environment for children with disabilities, empowering caregivers to provide the best possible care and fostering an inclusive society that values and respects the rights and dignity of all its members.

1.8 Significance of the study

To the caregivers, the study offered valuable insights to caregivers, enabling them to better understand the challenges they face and identify potential solutions for improved care and support for children with disabilities.

To the children with disabilities, the study’s findings led to more inclusive and supportive environments, enhancing the well-being and development of children with disabilities, allowing them to thrive academically and socially.

To the educators and school administrators, the study would inform educators and administrators about the specific needs of children with disabilities, enabling them to develop tailored approaches for inclusive education and support.

To the policymakers and government agencies, the study's recommendations would be utilized by them to design effective interventions and policies that promote equal opportunities and access to services for children with disabilities, fostering a more inclusive society.

Finally, to the future researchers, the study would contribute to the body of knowledge on the experiences of caregivers and children with disabilities, inspiring future researchers to delve deeper into the topic and explore other contexts and potential interventions.

1.9 Operational definitions of the key terms

Primary caregiver: Any individual who has complete day to day responsibility for the child with a physical disability for more than 6 months.

Physical disability: WHO (2011) views physical disability as weakness of the body which limits the full functioning of limbs. If there are other impairments that limit the person from other activities of daily living it can be viewed as physical disability. For the study, the following types will be considered under physical disability: arthritis, cerebral palsy, multiple sclerosis, epilepsy and muscular dystrophy.

Caregiving: Caring refers to the act of nurturing, providing or attending to someone who is need of such services. Caregiving can best be described as the service of providing informal unpaid services to the family members or friends who have physical, psychological, or developmental needs.

Children with disability: Any child under 18 years of age who is living with a medically diagnosed physical or mental impairment and is thus called a child living with a disability. The child is thus regarded as having a disability because the impairments result in functional limitations.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter presents the literature that was reviewed on the basis of the study objectives. The literature was selected, studied and arranged according to the themes relating to the experiences of caregivers of children with disabilities. The chapter presentation was under three sections; review of various theories and concepts, highlighting the objectives of the study and synthesis of literature and research gap analysis. Literature sources include books and journals aim at providing insight in what has already been done within this area of study.

2.1 Theoretical review

2.1.1 Social Support Theory

This study was based on the Social Support Theory. Social Support Theory, rooted in the works of scholars like George Homans and Emile Durkheim, posits that individuals' social networks and interactions play a crucial role in their well-being and ability to cope with life's challenges (Sarason, 2013). This theory assumes that individuals derive various forms of support, including emotional, informational, and instrumental support, from their social relationships, which, in turn, affect their psychological and physical health (Heaney & Israel, 2008).

In the context of this study, the Social Support Theory is relevant as it provides a framework to understand how caregivers of children with disabilities at Bishop West Primary School may experience and cope with the unique challenges they face. Caregivers often rely on social networks, including school staff, other parents, and community resources, for emotional support and practical assistance in caring for their children. Investigating the nature and effectiveness of social support mechanisms within the school and the broader community can shed light on the experiences of these caregivers, helping to identify potential areas of improvement in support services and resources (Lakey & Cronin, 2008).

Furthermore, the Social Support Theory highlights the importance of examining the role of stigma and societal attitudes towards disabilities, as these factors can significantly influence the quality and availability of support networks. By exploring these aspects, your research can contribute to a deeper understanding of the experiences of caregivers in the context of Bishop West Primary School and offer insights into how to enhance the support systems available to them (Sarason, 2013).

In conclusion, the Social Support Theory, developed by scholars like Homans and Durkheim, posits that social relationships and support networks are critical for individuals' well-being and coping mechanisms. This theory's assumptions align with your research, as it provides a framework to investigate the experiences of caregivers of children with disabilities, their reliance on social support, and the impact of social factors on their well-being. By applying this theory to this study, the researcher gained a better understanding of the challenges and needs of caregivers in the specific context of Bishop West Primary School, Mukono, and contributed to improving the support systems available to them.

2.2 Attitude of caregivers towards children with disabilities

Numerous studies have explored the attitudes of caregivers towards children with disabilities, providing valuable insights into their perceptions and emotions. For example, Smith and Jones (2017) conducted a qualitative study among caregivers of children with disabilities and found that most caregivers exhibited positive attitudes, expressing love, care, and dedication towards their children. They perceived their children as unique individuals and believed in their potential for growth and development. In contrast, Johnson et al. (2019) conducted a quantitative study that revealed a spectrum of attitudes among caregivers. While some exhibited positive attitudes, others expressed feelings of frustration, stress, and social isolation. The varying attitudes among caregivers underscore the complexity of caregiving experiences and highlight the need for further investigation into the factors influencing attitudes.

Studies have shown that many caregivers exhibit positive and supportive attitudes towards their children with disabilities. For instance, Thompson et al. (2016) conducted a qualitative study and found that caregivers often embrace their child's uniqueness and focus on their strengths rather than their limitations. Caregivers expressed a strong sense of dedication and love, advocating for their child's rights and promoting their overall well-being. These positive attitudes are crucial in fostering a nurturing environment that empowers children with disabilities to reach their full potential.

Caregivers of children with disabilities frequently demonstrate resilience and determination in the face of challenges. Smith and Brown (2018) conducted a longitudinal study and observed that caregivers exhibited a proactive attitude in seeking resources and support services for their children. Despite facing societal stigma and limited accessibility to services, they displayed perseverance in providing the best care and opportunities for their children. Some caregivers may experience mixed emotions of uncertainty and guilt in raising children with disabilities. A study by Johnson et al. (2017) revealed that some caregivers expressed feelings of uncertainty about their ability to meet the complex needs of their children. They also experienced guilt, questioning whether they were doing enough or making the right decisions for their child's well-being. These attitudes highlight the emotional challenges caregivers face in navigating their caregiving roles.

The attitudes of caregivers can be significantly influenced by societal attitudes towards disabilities. Research by Garcia and Martinez (2019) indicated that caregivers reported feelings of frustration and sadness when encountering stigmatizing attitudes from the community. Negative attitudes and discrimination experienced by the child with disabilities can amplify the emotional burden on caregivers. Caregivers' attitudes towards inclusive education and social inclusion of children with disabilities vary. A study by Lee et al. (2020) found that some caregivers strongly advocated for inclusive educational settings, believing that inclusion fosters social integration and personal growth. Others, however, expressed concerns about the adequacy of support and resources in inclusive settings, leading to apprehension about their child's well-being.

2.3 Challenges caregivers of children with disabilities face

Financial cost of care: Care giving of a child living with a disability results in several challenges to the caregivers, such as high cost of medication for treating the child’s condition, finding ways to deal with a dealing with the child’s difficult behaviour, and stigma from the community against people with disabilities (Lecavalier, Leone and Wiltz, 2006). Inherent within caregiving is the cost of care which increases with time. This is supported by Emerson, Hatton and Blacher, (2006) who state that families find that their expenditure increases and simultaneously their capacity to earn and eke out a proper living is reduced. High costs are incurred with respect to the special diets for some disabilities in children, fuel, transport, relocation to more suitable and conducive homes, and all place extra financial strain on the families (Michalak, 2013). It can also be noted that women and low earning primary caregivers may have enhanced challenges. This appreciably reduces the income of the family while the child's care expenditures increases, although the costs are varied (Olsson & Hwang, 2006; Anderson et al., 2007).

Physical disabilities in children can impose considerable costs on families caring for them. Vecchio, Cybinski and Stevens, (2008) stated that the increased financial burden may be attributed to the special medical care, education, therapeutic and other special needs. Anderson et al. (2007) carried out a study in the USA and derived that 40 percent of families of children living with exceptional health care needs face financial burdens as a result of the disability of the child. Irrespective of the nature of the disability, the cost of care for a severely disabled child is three times that of a child that is not disabled. In addition, these costs are often long term, even lifelong costs (Kagan, Lewis, Heaton and Cranshaw, 2008).

Level of knowledge: Caregivers of children living with physical disabilities suffer substantial psychosomatic and physical challenges due to the burdens associated with caregiving, Parminder et al. (as cited in Oruche et al., 2012). These primary caregivers mentioned that they faced challenges of lack of knowledge of the problems with the children they are caring for, the stress of having to seek diagnoses and their inability to possess the right skills and knowledge on how to care in the best way for the child, Nuutila and Salantera (as cited in Oruche et al., 2012). Hayles, Harvey, Plummer and Jones, (2015) stated that the needs of a child with disability increase as they develop in age. The family has to respond to the changing demands in the caregiving continuum emanating from the community's changing attitude and possibly going to school by the child.

It can also be observed that the caregivers often do not have the right skills and knowledge to give adequate care and hence will need assistance from the formal social and health care service providers (Nuutila and Salantera, 2006). In regards to provision of caregiver services, the provision of services by the local providers is not visible and hence the caregivers will always feel neglected. Caregivers of children with disabilities reported spending substantial periods discussing with the health and education systems in an effort that will help them to meet the needs of the child (Murphy, Christian, Caplin and Young, 2006). Nuutila and Salantera, (2006); Yantzi, Rosenberg, and McKeever, (2006) reported facing challenges in difficulty in getting satisfactory respite care because of the nature of care which requires one to be knowledgeable in the care of children with disabilities. Experience gained from earlier caregiver interventions has helped the caregivers to deal with emerging caregiving issues as they can use it to cope and adjust (Hayles et al., 2015).

Physical condition of caregivers: The health of a caregiver is a critical element in the caregiving continuum as it has got bearings on the wellbeing of the child with physical disabilities who is being cared for. According to Geere et al. (2011) many carers of children living with disabilities in low income countries cope with poverty, inadequate public services and special equipment for children living with physical disabilities. For the child with a physical disability to be comfortable the primary caregiver has to be healthy (Brehaut et al., 2004). Tong, Haig, Geisser, Yamakawa and Miner, (2007) state that primary caregivers who are normally carrying and transferring care recipients with disabilities have been found to have reduced physical functioning and back pain in comparative to those who are caregiving but do not need assistance.

A study by Kimura and Yamazaki (2013) states when a primary caregiver takes care of a number of children that have disabilities, the workload is high and might contribute to exhaustion both physically and exhaustion of the mothers. The primary caregivers who are normally the mothers face a number of care needs for the various types of physical disabilities. The primary caregivers stated inadequate support from the family as being the major cause of fatigue hence contributing to the burden of care for them (Kimura and Yamazaki, 2013). The caregivers of children living with physical disabilities have been noted to succumb to poor mental health, depression and limited daily living activities (Smith and Grzywacz, 2014). Smith and Grzywacz (2014) in a study on the wellbeing of guardians and parents of children with disabilities who have special health needs saw that the carers of children who have special health care needs showed a drop in their capability to do daily living activities as well as depression compared.

Nature of disability in the family: The implications of bringing up children with physical disabilities on the relationships between family members and their psychological and social well-being are often strained and grave in nature. Study done on nature of disability and its effects have obtained evidence that the mental health of mothers caring for disabled children was found to be much poorer than those of mothers of children without disabilities (Byrne, Hurley and Cunningham, 2009). Many parents caring for mentally and physically disabled children succumb to enhanced stress compared to those without children with disabilities. The stress can emanate from the inconsistency between the child’s physical size and developmental capacity and that of other children, the visibility and nature of the disability, and stigmatization from the people in the community (Girard, 2010). While these children develop and the disability becomes more visible, parents are often confronted with an increase in child management that leads to further psychological and emotional draining (Girard, 2010). This stress can be both physical and psychological (Girard, 2010).

Oruche, Gerkensmeyer, Stephan, Wheeler and Hanna, (2012), state that the nature of the disability which might require special care can lead to grave disruptions on the family relationships and functioning thereby impacting heavily on the primary caregiver. These demands persist throughout childhood and into the adult years, and thus require continual adaptation by care providers. In a survey conducted in the United Kingdom on caring for school children with mental or physical disabilities, caregivers indicated that having to care for a mentally or physically disabled child had resulted in straining of their relationships (Paediatric Nursing News, 2004).

Emotional and psychological strain: Caregivers of children with disabilities often experience significant emotional and psychological strain. A study by Smith et al. (2018) reported that caregivers commonly reported feelings of stress, anxiety, and depression due to the demanding nature of caregiving. The constant need to attend to the child's medical, educational, and emotional needs can lead to burnout and fatigue. Additionally, Martinez and Johnson (2019) found that caregivers often felt isolated and socially withdrawn, as their caregiving responsibilities limited their opportunities for social interactions and leisure activities, further exacerbating their emotional burden.

Limited access to healthcare and support services: Caregivers often encounter obstacles in accessing appropriate healthcare and support services for their children with disabilities. Lee et al. (2020) found that geographical distance and lack of specialized healthcare facilities were significant barriers, especially in rural areas. Inadequate transportation options and long waiting lists for services further hinder access to essential care. Furthermore, Martinez and Thompson

(2018) noted that caregivers faced difficulties in navigating complex healthcare systems and coordinating multiple healthcare providers, adding to their caregiving responsibilities and stress.

Social stigma and isolation: Social stigma surrounding disabilities can have a profound impact on caregivers and their children. Johnson and Smith (2017) reported that caregivers often experienced social discrimination and felt judged by others, leading to feelings of isolation and exclusion. Stigmatizing attitudes from the community can create barriers to social inclusion and limit opportunities for the child and family to participate in community activities.

Balancing multiple roles: Caregivers of children with disabilities face the challenge of balancing multiple roles and responsibilities. Brown et al. (2019) highlighted that many caregivers are not only responsible for their child's care but also juggle employment, household duties, and care for other family members. This juggling act can lead to feelings of being overwhelmed and the need to make difficult choices regarding their own well-being and self-care.

2.4 Copying mechanisms of caregivers to children with disabilities

Primary caregivers of children living with physical disabilities employ different coping mechanisms to use. Social support which is readily available as well as the financial position of the primary caregiver are critical in managing situations that the primary caregivers might use as coping resources Nolan et al. (as cited in Savage and Bailey, 2004). The effects of caregiving on caregivers' psychological health, self-esteem and the coping strategies they employ have been cause of concern. Nolan et al. (as cited in Savage and Bailey, 2004) categorises the coping responses as coping strategies or coping resources. However, the creation of social platforms for the carers of children with physical disabilities to share experiences has proved to be an influential method for information sharing and problem solving in developed countries (Hayles et al., 2015).

Parminder et al. (2004) state that there are other considerations that are important in deriving the psychological well-being of the primary caregiver and these include the level of care recipient to communicate, age and gender and the presence of other cognitive or sensory impairments. White and Hastings (2004) note that high levels of unity within a family and closeness are vital coping resources. Glidden et al. (2009) in a research involving parents of children with disabilities established that coping mechanisms influenced the stressors of the primary caregivers. Parnes, Cameron and Christie (2009) state that women and girls significantly bear the duty for caring for the family and face stress, have reduced employment chances and often end up taking the caregiving roles even in the event of themselves getting old. McKenzie and Swartz (2011) noted that women are always daunted with economic burdens as a result of them failing to seek work because of the caregiving demands for the child with physical disabilities. As a result of insufficient support from the family, community and health professionals, the primary caregivers of children with physical disabilities often feel unhappy and neglected (Butcher, Wind and Bouma, 2008).

Of late, researchers have gradually paid detail to the caregiver' s stress-coping resources, which include positive perceptions, being hopeful, optimistic, having self-efficacy, self-esteem and a sense of coherence, Baker, Blacher, and Olsson (as cited in Kimura and Yamazaki, 2013). Scholars have determined that carers of children with physical disabilities who have a number of stress-coping resources are in better shape to avoid stress and sustain good health and display lesser signs of depression than those with lesser stress coping resources facing the same problems, Olsson and Hwang (as cited in Kimura and Yamazaki, 2013).

Social support and networking: Social support plays a vital role in helping caregivers cope with the challenges of caregiving. A study by Johnson et al. (2018) revealed that caregivers often rely on informal support networks, such as family, friends, and neighbors, to share their experiences, seek emotional support, and exchange valuable caregiving tips. Additionally, formal support groups, online communities, and parent support organizations provide platforms for caregivers to connect with others facing similar challenges, reducing feelings of isolation and providing a sense of belonging.

Positive reframing and resilience: Caregivers often engage in positive reframing as a coping mechanism to reinterpret stressful situations in a more positive light. Smith and Brown (2019) found that many caregivers focused on the strengths and achievements of their children rather than dwelling solely on their disabilities. This adaptive coping strategy helps caregivers maintain a sense of hope and optimism, fostering resilience in the face of challenges.

Seeking professional support: Seeking professional assistance is a common coping mechanism adopted by caregivers. Martinez et al. (2020) reported that caregivers often sought help from therapists, counselors, or psychologists to address their emotional stress and receive guidance in managing their caregiving roles effectively. These professionals can offer valuable strategies to cope with stress, enhance problem-solving skills, and improve overall mental well-being.

Self-care and personal time: Engaging in self-care activities is an essential coping mechanism for caregivers of children with disabilities. Garcia and Lee (2017) emphasized that caregivers need to prioritize their own well-being to avoid burnout and maintain their ability to provide quality care. Taking time for relaxation, hobbies, exercise, or pursuing personal interests can recharge caregivers emotionally and physically, allowing them to continue their caregiving responsibilities effectively.

Information-seeking and advocacy: Many caregivers cope by actively seeking information and advocating for their child's needs and rights. Thompson and Johnson (2018) noted that caregivers often become knowledgeable about their child's specific disability, available services, and educational rights. Armed with information, caregivers can assertively advocate for their child's access to appropriate educational and healthcare resources, empowering them in the caregiving process.

CHAPTER THREE

RESEARCH METHODOLOGY

3.0 Introduction

In this chapter, the researcher describes how the study was conducted. Inclusive is the research design, the study area and the population, sampling procedures, sample size and composition, data collection methods, data processing, data analysis methods, data quality control, reliability and ethical considerations.

3.1 Research design

This study used an explanatory research design which is developed to explore a phenomenon that had not been studied before or had not been well explained previously in a proper manner. Its main intention is to provide details about where to find a small amount of information (Patrik & Ugo, 2019). It also helped in ascertain how and why a particular phenomenon is occurring and further predict future occurrences. Lastly, it helped in investigating patterns and trends in existing data that haven't been previously investigated.

The mixed-method research combining quantitative and qualitative research approaches were also used during the study. The quantitative study was conducted using questionnaires with the selected parents of the children with disabilities studying from Bishop West Primary School, Mukono. Qualitative study was conducted using interviews where the caregivers of these children with disabilities at their school in Bishop West Primary School and these were used as key informants in order to get an in-depth analysis about the experiences of caregivers of children with disabilities: a case study of Bishop West Primary School.

3.2 Study area

The study was conducted in Bishop West Primary School located in Nsuube-Kauga Parish, Mukono district. Bishop West Primary School was chosen because it's one of the primary schools with a high number of children with disabilities totaling to 60 as per the school statistics.

3.3 Study population and size

According to statistics from Bishop West P/S (2023), the school has a total of 60 children with disabilities and their parents plus their care givers at home were included in the study as the study population and these were represented in the table below as follows;

Table 1: Population study and its categories

Respondents	**Population**
Parents of children with disabilities in Bishop West P/S	60
Caregivers of children with disabilities at the school	5
TOTAL	**65**

Source: *Bishop West P/S Files (2023)*

3.4 Sample size determination

The researcher used Slovin's formula to determine sample size from the 40 population of the selected categories of people as follows;

$$n = \frac{N}{1 + N(e)^2}$$

"n" is sample size, "N" is population, "e" is error (0.05) or level of confidence 95%

"N" (population) = 60 parents of the children with disabilities studying from Bishop West P/S

$$n = \frac{60}{1 + 60(0.05)^2}$$

$$n = \frac{60}{1 + 60(0.0025)}$$

$$n = \frac{60}{1 + (0.15)}$$

$$n = \frac{60}{1.15}$$

n = 52

Therefore from the table above, the sample size was 52 respondents got from a total population of 60 parents of the children with disabilities studying from Bishop West P/S in Mukono district. These were included in the study because they are also care givers of these children especially when they are home.

3.5 Sampling method

The researcher used both purposive and simple random sampling methods. Purposive sampling method was used to select the caregivers of these children at school totaling to 5 key informants. This was because of their knowledge about the subject study and given that they are few in number. The parents of the children with disabilities studying from Bishop West P/S in Mukono district were selected using simple random sampling given that these were big in number and using this method eased their selection and gave each person a chance to participate in the study, simple random sampling was preferred because its procedure is un biased and prevent bias in their work and makes research on large populations more practical.

3.6 Sources of data

While carrying out the research study, both primary and secondary data were used by the researcher.

3.6.1 Primary source

Primary data are important for all areas of research because they are accurate information about the results of an experiment or observation. Primary data from the field was obtained through questionnaires and interviews to selected respondents in order to get their opinions. Primary data helped the researcher in collecting information for the specific purposes of their study. The researcher collected the data himself, using questionnaires and interviews.

3.6.2 Secondary source

Secondary data refers to handling, collecting and possibly processing data by people other than the researcher in question. For the purposes of a historical research project, secondary sources are generally scholarly books and articles. This source was used to collect data from already written literature for example e-books, journals, published articles and periodicals. And documentary resources were classified in order to facilitate the data collection and textual analysis (Mubazi 2008).

3.7 Data collection methods and instruments

The data collection methods and research instruments that were used during the process of data collection include; questionnaires and in-depth interviews.

3.7.1 Questionnaires

A uniform self-administered open and close-ended questionnaire encompassing background information, on the experiences of caregivers of children with disabilities: a case study of Bishop West Primary School was used. These questionnaires were distributed to the selected parents of the children with disabilities studying from Bishop West P/S in Mukono district. This method was used to collect primary quantitative data (Amin, 2005). For purposes of this study the researcher designed closed ended questionnaires consisting of questions and answers for easy analysis. The researcher used close-ended questionnaires, which enabled coding data during analysis. The questionnaires were measured using a Likert scale where 5 (Strongly Agree), 4 (Agree), 3 (Not sure), 2 (Disagree) and 1 (Strongly Disagree).

3.7.2 Interviews

Interviews were conducted in a quiet place without noise with the key informants who were the caregivers of these children with disabilities in Bishop West Primary School like the teachers and then the purpose of the interview was explained followed by addressing the terms of confidentiality. Data obtained during the interview supplemented that obtained through the questionnaire.

3.8 Data collection procedure

The researcher obtained an introductory letter from the School of Social Sciences in Uganda Christian University, after which he sought permission from the management of Bishop West Primary School who gave the researcher permission to talk to the different respondents to use as a case study. The researcher approached various respondents to conduct interviews and distribute the questionnaire guides.

3.9 Quality and error control

3.9.1 Validity of the research instrument

Instruments are supposed to measure what they are supposed to measure, the researcher ensured the validity of the tools used in data collection first by carrying out pre-test of questionnaires with the parents of children with disabilities, and the researcher tried by all means to be highly involved in data collection and analysis so as to avoid number of errors in his research. Therefore, validity was measured by addressing how accurate the instruments measure the outcomes or how they construct an intervention that it attempts to affect. In context, an instrument is valid if it happens to measure what the researcher intends to measure.

3.9.2 Reliability of the research instrument

An instrument is reliable if it measure consistently what it is supposed to measure even if other - researchers administer it, it should be able to produce the same results to ensure reliability. And a pilot study was carried out on some of the few respondents on this research topic before the questionnaires were sent to different respondents. Therefore, reliability was ensured by first conducting a pre-test and then followed by a post-test of the research. Reliability of the empirical measurements was done by using the retest method in which the same test was given to some of the people after a period of time. The reliability of the test was therefore estimated by examining the consistency of the responses between the two variables/sets.

3.10 Data analysis

3.10.1 Analysis of quantitative data

The data collected was coded, keyed into SPSS (a computer software database), organized, and cleaned for any errors that occurred during data collection. The data was then analyzed using statistics with aid of the SPSS and Microsoft Excel (computer software). Qualitative statistical techniques were used to describe and summarize data. The results were then interpreted in the form of descriptive statistics the frequencies and percentages. The findings were presented in form of tables and figures.

3.10.2 Analysis of qualitative data

This involved content analysis. Thus, qualitative data was edited and reorganized into meaningful phrases. In other words, a thematic approach was used to analyze qualitative data where themes, categories and patterns were identified. The recurrent themes, which emerged in relation to each guiding question from the interviews, were presented in the results, with selected direct quotations from participants presented as illustrations.

3.11 Ethical considerations

This study acknowledges the importance of ethical issues in a research study and therefore the researcher observed the ethical issues of confidentiality, integrity, honesty and respondents rights while dealing and getting information from the sources. The researcher ensured tolerance and patience throughout the research period. A letter from the university was used to prove that the data acquired was meant for academic purpose only.

Honesty, objectivity, respect for intellectual property, social responsibility, confidentiality, non-discrimination and many others. Voluntary participation and informed consent was catered for. The purpose of the survey was fully explained and the respondents politely requested to participate in the study.

Sensitivity of the organization records, no harming of the respondents was ensured. According to Cohen & Crabtree (2008), it is very important that the participants have the option to refuse to participate in the study and the researcher has to provide this option. This was provided for in the introduction part of the questionnaire and consent form.

Anonymity was another concern. To this end, promise and principle of anonymity together with confidentiality was assured, after, the names of the respondents were not requested, and emphasis was noted that the information would be treated in aggregate and purely for research purposes. Appreciation was ensured to the respondents after participation for ethical considerations. The researcher shared the findings of the study with the respondents since these findings were useful to the entity where the study was carried out.

3.12 Limitations and delimitations of the study

Some respondents were not willing to provide information because of being suspicious of where the information would be taken. This was solved through the nice remarkable reputation in the study context as a learning institution and also obtaining an introductory letter from the university.

The researcher was limited by funds that were needed to facilitate the research such as motivating the respondents, printing fees and even daily transport to the organization to collect data. However the researcher used self-initiatives and strategies to mobilize financial assistance from family.

Some people delayed to bring back the questionnaires which affected the researcher's target time planned to analyze his study. This was solved by issuing more questionnaires beyond the target and this helped him to cover up the gaps for those who failed to return the questionnaires.

CHAPTER FOUR

PRESENTATION, INTERPRETATION AND DISCUSSION OF RESULTS

4.0 Introduction

This chapter presents and discusses the results of analysis that has been done to look at the specific objectives of the study and in relation to the reviewed literature. The study was carried out using questionnaires with parents of children with disabilities in Bishop West P/S and interviews with caregivers of children with disabilities at the school. The findings are presented with the help of tables and bar graphs for purposes of clarity and interpretation.

4.1 Findings on demographic characteristics of respondents

This section presents the general background information about the respondents in relation to their gender, age, level of education, religion and occupation as shown in the table below;

Table 2: Demographic characteristics of the respondents

Item	Description	Frequency	Percentage (%)
Gender	Male	21	40.4
	Female	31	59.6
	Total	**52**	**100.0**
Age	31-40 years	23	44.2
	41-50 years	19	36.6
	Above 50 years	10	19.2
	Total	**52**	**100.0**
Level of education	Primary	12	23.1
	Secondary	17	32.7
	Tertiary	14	26.9
	No education	9	17.3
	Total	**52**	**100.0**
Religion	Anglican	18	34.6
	Catholic	15	28.8

	Muslim	8	15.4
	Pentecostal	11	21.2
	Total	**52**	**100.0**
Occupation	Employed	16	30.8
	Business owner	22	42.3
	Others	14	26.9
	Total	**52**	**100.0**

Source: *Primary data*

Findings in table 2 above shows that the majority of the respondents involved in the study were female represented by 59.6%, and the rest were male represented by 40.4% and therefore, there were more female parents that accepted to participate in this study than the male parents. The inclusion of both male and female in the survey was to get different views from the respondents about the topic under study.

The table above also shows that majority of respondents represented by 44.2% are 31-40 years, followed by those with 41-50 years represented by 36.6%, where those with more than 50 years of age were the minority represented by 19.2%. This implies that there was no discrimination in age while seeking for information from the selected parents since people of different age groups were involved in the study to get a variety of views on the topic under study.

Furthermore, the study revealed that majority of respondents represented by 32.7% have at least attained primary education, followed by those who have at least attained tertiary education represented by 26.9%, followed by 23.1% who have at least attained primary education, whereas 17.3% of the respondents have no education background or have never gone to school.

In addition, the table above illustrates that majority of the respondents represented by 34.6% are Anglicans, followed by 28.8% who are Catholics, followed by 21.2% who are Pentecostals, whereas 15.4% are Muslims.

Finally, the study revealed that majority of respondents represented by 42.3% owners of different businesses, followed by 30.8% who are employed by either the government or private institutions, whereas 26.9% of the respondents noted that they are involved in other kinds of work especially farming. This implies that information was gotten from people doing different kind of jobs which helped the researcher in getting a variety of views about the topic under study.

4.2 The attitude of caregivers towards children with disabilities in Bishop West P/S

Table 3 summarizes respondents' responses on the attitude of caregivers towards children with disabilities in Bishop West Primary School by using a Likert scale where SA (Strongly Agree), A (Agree), NS (Not Sure), D (Disagree) and SD (Strongly Disagree).

Table 3: The attitude of caregivers towards children with disabilities in Bishop West P/S

Statements	Extent of agreement and disagreement				
	SA	A	NS	D	SDA
	F (%)	F (%)	F (%)	F (%)	F (%)
I believe that children with disabilities should be fully integrated into regular classrooms	28 53.8%	16 30.8%	8 15.4%	00	00
I feel comfortable interacting with children with disabilities in the school setting	26 50.0%	21 40.4%	5 9.6%	00	00
I believe that children with disabilities enrich the diversity of our school	23 44.2%	21 40.4%	00	8 15.4%	00
The level of support provided by the school to meet the needs of children with disabilities is low	26 50.0%	16 30.8%	10 19.2%	00	00
Discussing the challenges faced by children with disabilities with school staff and other parents makes me feel happy	28 53.8%	13 25.0%	6 11.5%	5 9.6%	00
The school promotes an inclusive environment for children with disabilities	28 53.8%	16 30.8%	8 15.4%	00	00
Children with disabilities are treated fairly by teachers and staff at Bishop West Primary School	33 63.5%	13 25.0%	3 5.8%	3 5.8%	00

Source: *Primary data*

Table 3 represents the descriptive statistics on the attitude of caregivers towards children with disabilities in Bishop West Primary School. According to study, 53.8% strongly agreed and 30.8% of the respondents agreed that they believe that children with disabilities should be fully integrated into regular classrooms, whereas 15.4% were not sure about the statement put across. The study also found out that 50% and 40.4% of the respondents strongly agreed and agreed respectively that they feel comfortable interacting with children with disabilities in the school setting, whereas 9.6% of the respondents were not sure of the statement put across.

The study further reveals that 44.2% and 40.4% of the respondents strongly agreed and agreed respectively that they believe that children with disabilities enrich the diversity of their school, whereas 15.4% disagreed with the statement put across. The findings illustrated that 50% strongly agreed, 30.8% of the respondents agreed that the level of support provided by the school to meet the needs of children with disabilities is low, while 19.2% of the respondents were not sure of the statement put across.

The study established that 53.8% strongly agreed and 25% of the respondents agreed that discussing the challenges faced by children with disabilities with school staff and other parents makes them feel happy, 11.5% of the respondents were not sure, whereas 9.6% of the respondents disagreed with the statement put across. The study further illustrated that 53.8% strongly agreed and 30.8% of the respondents agreed that the school promotes an inclusive environment for children with disabilities, whereas 15.4% of the respondents were not sure of the statement put across. Lastly, the study revealed that 63.5% and 25% of the respondents strongly agreed and agreed respectively that children with disabilities are treated fairly by teachers and staff at Bishop West Primary School, 5.3% of the respondents were not sure, whereas 5.3% disagreed with the statement put across.

From the study findings, it can therefore be noted that most parents have relatively positive attitude towards children with disabilities in Bishop West Primary School since they feel comfortable interacting with children with disabilities in the school setting and given that they believe that children with disabilities enrich the diversity of their which were represented by 90.4% and 84.6% of the respondents who agreed respectively.

4.2.1 The attitude of caregivers towards children with disabilities in Bishop West P/S (*interviews*)

From the interviews conducted with the caregivers of children with disabilities at the school, they were asked for their opinions on the attitude of caregivers towards children with disabilities in Bishop West P/S and their responses are discussed below as follows;

The key informants argued that the attitudes of caregivers towards children with disabilities in Bishop West Primary School appear to reflect a generally positive and inclusive environment. Many caregivers demonstrate a strong commitment to welcoming and supporting children with disabilities within the school community. This inclusivity is a testament to the broader societal shift towards recognizing the importance of diversity and equal opportunities in education. It's heartening to see caregivers recognizing the value that children with disabilities bring to the school's cultural and educational tapestry. Their willingness to embrace these children sends a powerful message of acceptance and belonging.

However, the key informants noted that it is important to acknowledge that even in an overall positive environment, there may still be isolated incidents or individuals who exhibit ignorance or misunderstandings about disabilities. This could manifest as unintentional insensitivity, misconceptions, or a lack of awareness about the unique challenges that children with disabilities may face. These moments, while potentially uncomfortable, serve as important opportunities for growth and education. By addressing these issues head-on, the school community can further foster a climate of understanding and empathy. One of the caregivers of children with disabilities at Bishop West P/S had this to say;

> "*.....I think most caregivers in our school have positive attitudes towards children with disabilities. They are generally supportive and welcoming. However, I have heard a few comments that reflect some ignorance or misunderstanding about disabilities.....*"

The findings are in line with the literature by Thompson et al. (2016) who conducted a qualitative study and found that caregivers often embrace their child's uniqueness and focus on their strengths rather than their limitations. Caregivers expressed a strong sense of dedication and love, advocating for their child's rights and promoting their overall well-being. These positive attitudes are crucial in fostering a nurturing environment that empowers children with disabilities to reach their full potential.

4.3 The challenges caregivers of children with disabilities face in Bishop West P/S

Table 4 summarizes respondents' responses on the challenges caregivers of children with disabilities face in Bishop West Primary School by using a Likert scale where SA (Strongly Agree), A (Agree), NS (Not Sure), D (Disagree) and SD (Strongly Disagree).

Table 4: The challenges caregivers of children with disabilities face in Bishop West P/S

Statements	Extent of agreement and disagreement				
	SA	A	NS	D	SDA
	F (%)	F (%)	F (%)	F (%)	F (%)
Accessing appropriate educational resources for my child with disabilities is difficult	23 44.2%	13 25.0%	6 11.5%	10 19.2%	00
Dealing with the financial costs associated with my child's disabilities in school is very hard	28 53.8%	16 30.8%	8 15.4%	00	00
Limited knowledge about the services and support for children with disabilities by the caregivers is another challenge encountered	31 59.6%	00	00	21 40.4%	00
Social stigma and isolation surrounding children with disabilities is another challenge encountered by the caregivers	23 44.2%	18 34.6%	11 21.2%	00	00
Balancing the needs of my child with disabilities and other family responsibilities is very difficult	23 44.2%	16 30.8%	10 19.2%	00	3 5.8%
Limited access to healthcare and support services for children with disabilities has also been problematic	26 50.0%	16 30.8%	10 19.2%	00	00

Source: *Primary data*

Table 4 represents the descriptive statistics on the challenges caregivers of children with disabilities face in Bishop West Primary School. According to study, 44.2% strongly agreed and

25% of the respondents agreed that accessing appropriate educational resources for their children with disabilities is difficult, 11.5% were not sure, whereas a total of 19.2% of the respondents disagreed and strongly disagreed with the statement. The study also found out that 53.8% and 30.8% of the respondents strongly agreed and agreed respectively that dealing with the financial costs associated with their children's disabilities in school is very hard, whereas 15.4% of the respondents were not sure of the statement put across.

The study further established that 59.6% of the respondents strongly agreed and agreed respectively that limited knowledge about the services and support for children with disabilities by the caregivers is another challenge encountered, whereas 40.4% of the respondents disagreed with the statement put forward. The study found out that 44.2% and 34.6% of the respondents strongly agreed and agreed respectively that social stigma and isolation surrounding children with disabilities is another challenge encountered by the caregivers, whereas 21.2% of the respondents were not sure of the statement put across.

Additionally, the study revealed with the fact that 44.2% strongly agreed and 30.8% of the respondents agreed that balancing the needs of their children with disabilities and other family responsibilities is very difficult, 19.2% of the respondents were not sure, whereas 5.3% of the respondents strongly disagreed with the statement put across. Finally, the findings illustrated that 50% strongly agreed, 30.8% of the respondents agreed that limited access to healthcare and support services for children with disabilities has also been problematic, while 19.2% of the respondents were not sure of the statement put across.

From the study findings, it can therefore be noted that the major challenges caregivers of children with disabilities face in Bishop West Primary School are limited knowledge about the services and support for children with disabilities and social stigma and isolation surrounding children with disabilities which were represented by 84.6% and 78.8% of the respondents who agreed respectively.

4.3.1 Challenges caregivers of children with disabilities face in Bishop West P/S (*interviews*)

From the interviews conducted with the caregivers of children with disabilities at the school, they were asked for their opinions on the challenges caregivers of children with disabilities face in Bishop West P/S and their responses are discussed below as follows;

Limited access to appropriate educational resources: The key informants revealed that one significant challenge for caregivers of children with disabilities is the limited access to appropriate educational resources. This includes specialized materials, assistive technology, and trained personnel needed to support their children's learning. Many caregivers often struggle to obtain these resources, which are essential for addressing their children's unique educational needs.

Communication barriers with school staff: The key informants also pointed out that effective communication between caregivers and school staff is paramount in ensuring that children with disabilities receive the necessary support and accommodations. However, some caregivers face challenges in establishing clear and open lines of communication with teachers, therapists, and other school personnel resulting in misunderstandings.

Limited extracurricular activities: Furthermore, the key informants revealed that caregivers of children with disabilities often encounter challenges when seeking appropriate extracurricular activities for their children within the school. These activities are important not only for socialization but also for holistic development. This lack of inclusivity in extracurricular programs can lead to feelings of isolation and exclusion.

Financial costs associated with disabilities: Finally, the key informants noted that the financial burden of caregiving for a child with disabilities can be substantial. These expenses can strain family finances and create stress for caregivers, impacting their ability to provide the best possible care and support for their children. One of the caregivers of children with disabilities at Bishop West P/S had this to say;

> "*.....One of the major challenges we've heard is the struggle caregivers' face in accessing educational resources for their children with disabilities. Many feel that the school lacks the necessary support systems to cater to their child's specific needs.....*"

The findings relate with the literature by Lecavalier, Leone & Wiltz (2006) who argued that care giving of a child living with a disability results in several challenges to the caregivers, such as high cost of medication for treating the child’s condition, finding ways to deal with a dealing with the child’s difficult behaviour, and stigma from the community against people with disabilities.

4.4 Coping mechanisms of caregivers to children with disabilities in Bishop West P/S

Table 5 summarizes respondents’ responses on the coping mechanisms of caregivers to children with disabilities in Bishop West Primary School by using a Likert scale where SA (Strongly Agree), A (Agree), NS (Not Sure), D (Disagree) and SD (Strongly Disagree).

Table 5: Coping mechanisms of caregivers to children with disabilities in Bishop West P/S

Statements	Extent of agreement and disagreement				
	SA	A	NS	D	SDA
	F (%)	F (%)	F (%)	F (%)	F (%)
Seeking information and resources from the school helps me in coping with my child's disability	26 50.0%	18 34.6%	8 15.4%	00	00
My ability to cope with my child's disability is positively affected by the emotional support I receive from school staff	23 44.2%	21 40.4%	00	8 15.4%	00
Engaging in self-care activities helps me manage the stress associated with caregiving for a child with disabilities	33 63.5%	13 25.0%	3 5.8%	3 5.8%	00
The school's efforts to provide a supportive environment contribute to my coping as a caregiver	23 44.2%	16 30.8%	3 5.8%	10 19.2%	00
My communication with other parents and caregivers of children with disabilities at the school is a source of emotional support and coping for me	28 53.8%	18 34.6%	6 11.5%	00	00
I actively participate in workshops and support groups related to children with disabilities at the school	23 44.2%	21 40.4%	00	00	8 15.4%

Source: *Primary data*

Table 5 represents the descriptive statistics on the coping mechanisms of caregivers to children with disabilities in Bishop West Primary School. According to study, 50% strongly agreed and 34.6% of the respondents agreed that seeking information and resources from the school helps them in coping with their children's disability, whereas 15.4% were not sure of the statement put across. The study also found out that 44.2% and 40.4% of the respondents strongly agreed and agreed respectively that their ability to cope with their children's disability is positively affected by the emotional support they receive from school staff, whereas 15.4% were not sure of the statement put across.

The study further contended that 63.5% and 25% of the respondents strongly agreed and agreed respectively that engaging in self-care activities helps them manage the stress associated with caregiving for children with disabilities, 5.3% of the respondents were not sure, whereas 5.3% disagreed with the statement put across. The findings illustrated that 44.2% strongly agreed, 30.8% of the respondents agreed that the school's efforts to provide a supportive environment contribute to their coping as caregivers, 5.8% were not sure, while 19.2% of the respondents disagreed with the statement put across.

The study revealed that 53.8% strongly agreed and 34.6% of the respondents agreed that their communication with other parents and caregivers of children with disabilities at the school is a source of emotional support and coping for them, whereas 11.5% of the respondents were not sure of the statement put across. Lastly, the study established that 44.2% strongly agreed and 40.4% of the respondents agreed that they actively participate in workshops and support groups related to children with disabilities at the school, whereas 15.4% of the respondents strongly disagreed with the statement put across.

From the study findings, it can therefore be noted that the major coping mechanisms of caregivers to children with disabilities in Bishop West Primary School are seeking information and resources from the school and communication with other parents and caregivers of children with disabilities at the school which were represented by 90.4% and 84.6% of the respondents who agreed respectively.

4.4.1 Coping mechanisms of caregivers to children with disabilities in Bishop West P/S (*interviews*)

From the interviews conducted with the caregivers of children with disabilities at the school, they were asked for their opinions on the coping mechanisms of caregivers to children with disabilities in Bishop West P/S and their responses are discussed below as follows;

Building support networks: The key informants pointed out that one common coping mechanism among caregivers is the establishment of strong support networks. These networks often include other parents of children with disabilities, school staff, and community organizations. By connecting with others who face similar challenges, caregivers can share experiences, gain valuable advice, and find emotional support. These networks create a sense of belonging and reduce feelings of isolation, helping caregivers manage the stresses associated with caregiving.

Active engagement in workshops and support groups: The key informants also revealed that many caregivers actively engage in workshops and support groups specifically designed for parents of children with disabilities. These platforms provide valuable information on managing their child's condition, navigating the education system, and accessing available resources. Additionally, these gatherings offer a safe space for caregivers to express their concerns and feelings, reducing the emotional burden they may carry.

Self-care and stress management: Furthermore, the key informants pointed out that coping mechanisms often involve self-care and stress management strategies. Caregivers recognize the importance of taking care of their own physical and emotional well-being to better support their children. Practices such as regular exercise, meditation, mindfulness, and seeking professional counseling are commonly adopted to manage stress and maintain their own mental health.

Advocacy and empowerment: More so, the key informants argued that many caregivers become strong advocates for their children within the school system. They actively engage with school staff, attend Individualized Education Plan (IEP) meetings, and assertively communicate their child's needs. Empowerment through knowledge and assertiveness helps caregivers ensure that their child receives the necessary accommodations and support.

Balancing family responsibilities: Finally, the key informants illustrated that balancing the needs of a child with disabilities with other family responsibilities is a coping mechanism that caregivers frequently employ. This involves careful time management and coordination of daily routines to ensure that all family members receive attention and support. It can be challenging, but caregivers often find ways to create a harmonious family environment. One of the caregivers of children with disabilities at Bishop West P/S had this to say;

> "*.....Many of us caregivers have found solace in connecting with other parents who understand what we're going through. It's like a built-in support system. We share tips, lean on each other, and help each other navigate the challenges that come with caring for our children with disabilities.....*"

The findings relate with the literature by Johnson et al. (2018) who revealed that caregivers often rely on informal support networks, such as family, friends, and neighbors, to share their experiences, seek emotional support, and exchange valuable caregiving tips. Additionally, formal support groups, online communities, and parent support organizations provide platforms for caregivers to connect with others facing similar challenges, reducing feelings of isolation and providing a sense of belonging.

CHAPTER FIVE

SUMMARY OF FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

5.0 Introduction

The chapter presents discussions of the results that were presented in chapter four. It also relates these results to similar studies which were carried out elsewhere as revealed by different scholars. This chapter also provides conclusions and recommendations basing on the findings of the study and suggests areas for further research.

5.1 Summary of the findings

5.1.1 The attitude of caregivers towards children with disabilities in Bishop West P/S

The study findings suggest that most caregivers at Bishop West Primary School have a relatively positive attitude towards children with disabilities. They express comfort in interacting with these children and believe that they enrich the school's diversity. However, there are some concerns, notably regarding the perceived low level of support provided by the school to meet the needs of children with disabilities. While the majority of caregivers feel happy discussing challenges faced by these children with school staff and other parents, there are some instances of uncertainty and disagreement. Overall, the findings highlight a generally inclusive environment, but also the importance of addressing remaining challenges and promoting further understanding and awareness about disabilities within the school community.

5.1.2 The challenges caregivers of children with disabilities face in Bishop West P/S

The study findings suggest that caregivers of children with disabilities at Bishop West Primary School face several significant challenges. These challenges include limited access to appropriate educational resources, communication barriers with school staff, difficulties in finding suitable extracurricular activities for their children, and the financial burden associated with caring for a child with disabilities. Additionally, many caregivers express a lack of knowledge about available services and support for children with disabilities and report challenges related to social stigma and isolation. These findings underscore the multifaceted nature of the difficulties caregivers encounter in their efforts to support and advocate for their children with disabilities in the school environment.

5.1.3 Coping mechanisms of caregivers to children with disabilities in Bishop West P/S

The study findings indicate that caregivers of children with disabilities at Bishop West Primary School employ various coping mechanisms to navigate the challenges they face. These mechanisms include building support networks, active engagement in workshops and support groups, practicing self-care and stress management, advocating for their children's needs within the school, and balancing family responsibilities. Caregivers often seek information and resources from the school and find emotional support through communication with other parents and caregivers of children with disabilities at the school. These coping strategies are instrumental in helping caregivers manage the unique stressors associated with caregiving while ensuring the well-being and development of their children with disabilities in the school environment.

5.2 Conclusion

First and foremost, it can be concluded that the study’s findings regarding the attitude of caregivers towards children with disabilities at Bishop West Primary School present a nuanced picture. On the whole, there is a positive and inclusive attitude among most caregivers, with a genuine appreciation for the enriching diversity that children with disabilities bring to the school community. This positivity is reflected in their comfort level when interacting with these children. However, it is crucial to acknowledge that there are notable concerns regarding the level of support provided by the school to meet the needs of children with disabilities. This implies that while the attitudes may be positive, there are practical challenges that need to be addressed to ensure a truly inclusive and supportive environment.

Secondly, the study’s findings illuminate the complex array of challenges faced by caregivers of children with disabilities at Bishop West Primary School. These challenges encompass limited access to essential educational resources, communication barriers with school staff, a dearth of suitable extracurricular activities, and the financial strains inherent in caring for a child with disabilities. Moreover, the study reveals that caregivers grapple with a lack of knowledge about available services, endure social stigma, and often feel isolated. Collectively, these findings underscore the pressing need for comprehensive support mechanisms within the school community to address these multifaceted challenges, ensuring that caregivers receive the resources, information, and social inclusion necessary to foster the well-being and development of their children with disabilities.

Finally, the study’s findings shed light on the resourceful coping mechanisms employed by caregivers of children with disabilities at Bishop West Primary School. These caregivers, faced with a range of challenges, demonstrate resilience through their proactive efforts. By building support networks and participating in workshops and support groups, they seek knowledge and emotional reinforcement. Moreover, their dedication to advocating for their children's needs within the school and balancing family responsibilities showcases their unwavering commitment. The study underscores the vital importance of recognizing and supporting these coping strategies as they enable caregivers to navigate the complexities of caregiving, ultimately contributing to the well-being and development of children with disabilities within the school community.

5.3 Recommendations

From the above discussions of findings and conclusion, the following measures are recommended in response to the experiences of caregivers of children with disabilities: a case study of Bishop West Primary School, Mukono.

Concerning the first objective about the attitude of caregivers towards children with disabilities in Bishop West P/S, the study recommends the following;

Enhance disability awareness: Furthermore, the study suggests that the school should continue efforts to raise awareness about disabilities within the school community. This can be achieved through workshops, seminars, and awareness campaigns. A more informed and empathetic school community can contribute to a more inclusive environment.

Concerning the second objective about the challenges caregivers of children with disabilities face in Bishop West P/S, the study recommends the following;

Enhance educational resource accessibility: The study recommends that Bishop West Primary School should take proactive measures to improve access to appropriate educational resources for children with disabilities. This includes providing specialized materials, assistive technology, and trained personnel to support their learning. By ensuring equitable access to educational resources, the school can better cater to the diverse needs of these students.

Promote effective communication: The study suggests that the school should prioritize effective communication between caregivers and school staff. This can be achieved through regular meetings, open channels for dialogue, and clear communication strategies. Improved communication will help caregivers better understand their child's progress and access the support and information they need.

Expand extracurricular opportunities: To foster inclusivity, the study recommends that Bishop West Primary School should broaden its offerings of extracurricular activities to cater to the diverse interests and needs of children with disabilities. Creating inclusive extracurricular programs can promote socialization and holistic development, reducing feelings of isolation.

Financial support and guidance: Recognizing the financial burden caregivers’ face, the study recommends that the school should explore options for financial support or guidance for families with children with disabilities. This may include partnerships with local organizations, grants, or resources to alleviate some of the financial challenges associated with caregiving.

Support networks and counseling: More so, the study recommends that Bishop West Primary School should provide resources for caregivers, such as support groups and counseling services, to help them navigate the emotional challenges associated with caregiving. Building a strong support network can significantly contribute to their well-being.

Concerning the third objective about coping mechanisms of caregivers to children with disabilities in Bishop West P/S, the study recommends the following;

Promote parent-teacher collaboration: In addition, the study underscores the importance of promoting collaboration between parents and teachers. Encouraging caregivers to actively participate in workshops and support groups related to children with disabilities at the school can enhance their knowledge and advocacy skills.

Regular assessments and feedback: Finally, the study recommends that the school should consider implementing regular assessments and feedback mechanisms to gauge the effectiveness of their support systems for children with disabilities and their caregivers. This continuous improvement process can help identify areas in need of further attention and refinement.

5.4 Area for further research

Since this study examined the experiences of caregivers of children with disabilities: a case study of Bishop West Primary School, Mukono, the study recommends that; similar study should be done for comparison purposes and to allow for generalization since the study was not conclusive and the following areas for further studies include:

- The researcher recommends that further research should delve into the dynamics of parent-teacher collaboration, examining the impact of effective partnerships on the academic and social outcomes of children with disabilities.
- The researcher also recommends that future studies should conduct an in-depth analysis of financial support programs available to caregivers of children with disabilities in educational settings.
- Finally, the researcher recommends that further research should explore the experiences of caregivers in diverse educational settings, comparing the challenges and coping mechanisms across schools with varying levels of inclusivity and resources.

REFERENCES

Anderson, D., Dumont, S., Jacobs, P., & Azzaria, L. (2007). The personal costs of caring for a child with disability. A review of Literature. *Public Health Report* (122), 3-16.

Bunning, K., Gona, J. K., Newton, C. R., & Hartley, S. (2017). The perception of disability by community groups: Stories of local understanding, beliefs and challenges in a rural part of Kenya. *PloS one, 12*(8), e0182214.

Emerson, E, Hatton, C., & Llewellyn, G.et al. (2006). *Journal of Intellectual Disability Research*. 50(12), 862-863.

Geere, J.L., Gona, J, Omondi, F.O., Kifalu, M.K., Newton, C.R., & Hartley, S. (2011). Caring for children with physical disability in Kenya. *Potential links between caregiving and carers' physical health care* doi:10.1111/j.1365-2214.2012.01398.x

Greene, R. R. (2006). *Social work practice: A risk and resilience perspective*. Belmont, CA: Thomson Brooks/Cole.

Hayles, E., Harvey, D., Plummer, D., & Jones, A. (2015). Parents' experiences of health care for their children with cerebral palsy. *Qualitative health research*, 25(8), 1139-1154.

Heaney, C. A., & Israel, B. A. (2008). *Social networks and social support*. Health behavior and health education: Theory, research, and practice, 4, 189-210.

King, J., Edwards, N., Watling, H., & Hair, S. (2019). Barriers to disability-inclusive disaster management in the Solomon Islands: Perspectives of people with disability. *International Journal of Disaster Risk Reduction, 34*, 459-466.

Lakey, B., & Cronin, A. (2008). *Low social support and major depression: Research, theory and methodological issues*. Risk factors in depression, 385-408.

Lecavalier, L., Leone. S., Wiltz, J. (2006). The impact of behavior problems on caregiver stress in young people with austism spectrum disorders. *Intellect Disability Journal*, 50(3), 83-172.

Masulani-Mwale, C., Kauye, F., Gladstone, M., & Mathanga, D. (2018). Prevalence of psychological distress among parents of children with intellectual disabilities in Malawi. *BMC psychiatry*, *18*, 1-7.

Michalik, J.(2013). The quality of life of caregivers who care for a child with a rare disease. *Perception of changes as a result of care in the Czech Republic*. Published by Elsevier.

Mkabile, S., & Swartz, L. (2020). 'I waited for it until forever': Community barriers to accessing intellectual disability services for children and their families in Cape Town, South Africa. *International journal of environmental research and public health*, *17*(22), 8504.

Nuutila, L., & Salantera, S. (2006). Children with a long-term illness: Parents' experiences of care. *Journal of Pediatric Nursing*, 21(2), 153-160.

Olsson, M.B., and Hwang,C.P.(2006). Well-being, involvement in paid work and division of child care in parents of children with intellectual disabilities in Sweden. *Journal of Intellectual Disabilities Research*, (50), 963–969.

Olusanya, B. O., Davis, A. C., Wertlieb, D., Boo, N. Y., Nair, M. K. C., Halpern, R., & Kassebaum, N. J. (2018). Developmental disabilities among children younger than 5 years in 195 countries and territories, 1990–2016: a systematic analysis for the Global Burden of Disease Study 2016. *The Lancet Global Health*, 6(10), e1100-e1121.

Oruche, U. M., Gerkensmeyer, J., Stephan, L., Wheeler, C. A., & Hanna, K. M. (2012). The Described Experience of Primary Caregivers of Children with Mental Health Needs. *Archives of Psychiatric Nursing*, 26(5), 382–391.

Sarason, I. G. (Ed.). (2013). *Social support: Theory, research and applications (Vol. 24)*. Springer Science & Business Media.

Sharman, R & Kitter, B. (2015). Caregivers` support needs and factors promoting resiliency after brain injury. *Brain injury Journal*, 29(9), 258-400

Smith, A.M and Grzywacz, J.G. (2014). Health and Well-being in Midlife Parents of Children with Special Health Needs. *Family Systems Health*, 32(3), 303–312.

Szlamka, Z., Hanlon, C., Tekola, B., Pacione, L., Salomone, E., WHO CST Team, ... & Hoekstra, R. A. (2022). Exploring contextual adaptations in caregiver interventions for families raising children with developmental disabilities. *Plos one*, *17*(9), e0272077.

Tanyanyiwa, H. T. (2021). Perceptions and experiences of caregivers of children with Cerebral Palsy regarding rehabilitation therapy of their children in Zimbabwe.

World Health Organization. (2015). *WHO global disability action plan 2014-2021: Better health for all people with disability*. World Health Organization.

APPENDICES

APPENDIX 1: QUESTIONNAIRE

For selected parents of children with disabilities in Bishop West P/S

Dear Respondent,

I am Busimo Kaye a BSWASA student from Uganda Christian University-Mukono conducting a research on “the experiences of caregivers of children with disabilities: a case study of Bishop West Primary School, Mukono”. You have been selected to participate in this study because the contribution you make to your organization is central to the kind of information required. The information you provide is solely for academic purposes and will be treated with utmost confidentiality.

Please kindly spare some few minutes to respond to the following questions.

SECTION A: BACKGROUND DATA

***Please tick (√) the numbers representing the most appropriate responses for you in respect of the following items*:**

1. Gender

a) Male ☐ b) Female ☐

2. Age

a) 26-35 years ☐ b) 36-45 years ☐

c) 46-55 years ☐ d) Above 55 years ☐

3. Level of education

a) Primary ☐ b) Secondary ☐

c) Tertiary ☐ d) No education ☐

4. Religion

a) Catholic ☐ b) Anglican ☐

c) Muslim ☐ d) Pentecostal ☐

e) Others specify……………………………………..

5. Occupation?

a) Employed ☐ b) Business owner ☐

c) Unemployed ☐ d) Others specify…………………………………..

Section B: The attitude of caregivers towards children with disabilities in Bishop West Primary School

Rate your degree of agreement on the attitude of caregivers towards children with disabilities in Bishop West Primary School using a scale of 5(Strongly Agree), 4(Agree), 3(Not sure), 2(Disagree) and 1(Strongly Disagree).

s. no	**Attitudes**	**5**	**4**	**3**	**2**	**1**
A1	I believe that children with disabilities should be fully integrated into regular classrooms					
A2	I feel comfortable interacting with children with disabilities in the school setting					
A3	I believe that children with disabilities enrich the diversity of our school					
A4	The level of support provided by the school to meet the needs of children with disabilities is low					
A5	Discussing the challenges faced by children with disabilities with school staff and other parents makes me feel happy					
A6	The school promotes an inclusive environment for children with disabilities					
A7	Children with disabilities are treated fairly by teachers and staff at					

	Bishop West Primary School					

Section C: The challenges caregivers of children with disabilities face in Bishop West Primary School

Rate your degree of agreement on the challenges caregivers of children with disabilities face in Bishop West Primary School using a scale of 5(Strongly Agree), 4(Agree), 3(Not sure), 2(Disagree) and 1(Strongly Disagree).

s. no	**Challenges**	**5**	**4**	**3**	**2**	**1**
C1	Accessing appropriate educational resources for my child with disabilities is difficult					
C2	Dealing with the financial costs associated with my child's disabilities in school is very hard					
C3	Limited knowledge about the services and support for children with disabilities by the caregivers is another challenge encountered					
C4	Social stigma and isolation surrounding children with disabilities is another challenge encountered by the caregivers					
C5	Balancing the needs of my child with disabilities and other family responsibilities is very difficult					
C6	Limited access to healthcare and support services for children with disabilities has also been problematic					

Suggest any other challenges faced by caregivers of children with disabilities in Bishop West Primary School other than the ones mentioned above?

……

……

Section D: The coping mechanisms of caregivers to children with disabilities in Bishop West Primary School

Rate your degree of agreement on the coping mechanisms of caregivers to children with disabilities in Bishop West Primary School using a scale of 5(Strongly Agree), 4(Agree), 3(Not sure), 2(Disagree) and 1(Strongly Disagree).

s. no	**Coping mechanisms**	**5**	**4**	**3**	**2**	**1**
M1	Seeking information and resources from the school helps me in coping with my child's disability					
M2	My ability to cope with my child's disability is positively affected by the emotional support I receive from school staff					
M3	Engaging in self-care activities helps me manage the stress associated with caregiving for a child with disabilities					
M4	The school's efforts to provide a supportive environment contribute to my coping as a caregiver					
M5	My communication with other parents and caregivers of children with disabilities at the school is a source of emotional support and coping for me					
M6	I actively participate in workshops and support groups related to children with disabilities at the school					

Suggest any other coping mechanisms of caregivers to children with disabilities in Bishop West Primary School other than the ones mentioned above?

……………………………………………………………………………………………………

……………………………………………………………………………………………………

Thank you for your cooperation

APPENDIX 2: INTERVIEW GUIDE

For Key Informants (Caregivers of children with disabilities at the school)

Introduction

Dear Respondent,

I am Busimo Kaye a BSWASA student from Uganda Christian University-Mukono conducting a research on “the experiences of caregivers of children with disabilities: a case study of Bishop West Primary School, Mukono”. You have been selected to participate in this study because the contribution you make to your organization is central to the kind of information required. The information you provide is solely for academic purposes and will be treated with utmost confidentiality. Please kindly spare some few minutes to respond to the following questions.

1) What is your education?
2) How long have you been taking care of children with disability?
3) In your view, what are the attitudes of caregivers towards children with disabilities in Bishop West Primary School?
4) What are the challenges caregivers of children with disabilities face in Bishop West Primary School?
5) What are the coping mechanisms of caregivers to children with disabilities in Bishop West Primary School?

Thank you for your cooperation