

**CHALLENGES AND COPING MECHANISMS OF CAREGIVERS OF CHILDREN BETWEEN 3  
AND 8 YEARS WITH AUTISM SPECTRUM DISORDERS IN SELECTED KAMPALA SCHOOLS  
OFFERING SPECIAL NEEDS AND INCLUSIVE EDUCATION SERVICES**

**NYANJURA SIMPLE BYARUHANGA**


**REG NO: RJ22M21/012**

**A RESEARCH THESIS SUBMITTED TO THE FACULTY OF PUBLIC HEALTH, NURSING,  
MID-WIFELY IN PARTIAL FULFILLMENT OF THE REQUIREMENTS FOR THE AWARD OF  
A MASTERS OF PUBLIC HEALTH OF UGANDA CHRISTIAN UNIVERSITY**

**April 2025**

### Declaration

I declare that "Challenges and coping mechanisms of caregivers of children between 3 and 8 years with autism spectrum disorders in selected Kampala schools offering special needs and inclusive education services." is my own work. It has submitted to any University or Institution for any degree or examination.

Sign:  ..... Date: 7<sup>th</sup> / 05 / 2024 .....

Student: Nyanjura Simple Byaruhanga

Reg No: RJ22M21/012

**Approval**

"I approve that I have supervised Nyanjura Simple, and hereby forward this for review and examination."

Approved for internal and external examination

Dr. EK. Mukooza, supervisor

A handwritten signature in black ink, appearing to read 'Dr. EK. Mukooza', written in a cursive style.

7<sup>th</sup> August 2024

## **Acknowledgments and Dedication**

First and foremost, I would like to express my deepest gratitude to my supervisor, Dr Mukooza Edward, for his invaluable guidance, support, and encouragement throughout the course of this research. Your expertise, patience, and insightful feedback were crucial to the completion of this thesis.

I am also profoundly grateful to the faculty and staff of the faculty of nursing and public health at UCU for their assistance and support. Special thanks go to my colleagues and fellow students for their camaraderie and the stimulating discussions we shared, which greatly enriched my research experience.

I extend my heartfelt thanks to my family and friends for their unwavering support, understanding, and encouragement during this challenging journey. Your belief in me kept me motivated and determined to achieve this goal.

## List of Abbreviations

ASD	Autism Spectrum Disorder
APA	American Psychiatric Association
WHO	World Health Organization
ADDM	Autism and Developmental Disabilities Monitoring
UBOS,	Uganda Bureau of Statistics
ADDM	Autism and Developmental Disabilities Monitoring
CDC	Center for Disease Control
USA	United States of America
ACPF	The Africa Child Policy Forum

## Table of Contents

Declaration .....	ii
Approval.....	iii
List of Abbreviations- are these the only abbreviations? .....	iv
Abstract .....	xi
Chapter One: Introduction .....	1
1.0 Background .....	1
1.1 Statement of the Problem.....	5
1.2 Main Objective .....	6
1.2.1 <i>Specific Objectives</i> .....	6
1.2.2 <i>Research Questions</i> .....	6
1.3 Significance of the study .....	7
1.4 Scope of the study.....	8
1.4.1 <i>Geographical scope</i> .....	8
1.4.2 <i>Time Scope</i> .....	8
1.4.3 <i>Content Scope</i> .....	9
1.5 Theoretical Framework .....	9
1.6 Definition of Key Concepts .....	12

Chapter Two: Literature Review .....	13
2.0 Introduction .....	13
2.1 Autism Spectrum Disorder among Children .....	13
2.2 Challenges faced by Caregivers of Children with ASD .....	16
2.3 Coping mechanisms among Caregivers of Children with ASD.....	20
2.3.1 Problem Focused strategies .....	20
2.3.2 Emotion focused strategies.....	21
2.4 Summary of Literature Reviewed and Gaps Identified .....	23
Chapter Three: Methodology .....	24
3.0 Introduction .....	24
3.1 Study Design .....	24
3.2 Study Population .....	24
3.3 Study Setting .....	25
3.4 Sampling Procedure .....	27
3.5 Sampling Technique .....	28
3.6 Inclusion and Exclusion Criteria .....	28
3.7 Instruments.....	29

3.8 Quality Control.....	30
3.9 Data collection.....	31
3.10 Risk Management.....	32
3.11 Data Analysis.....	32
3.12 Data Management.....	35
3.13 Ensuring rigor.....	35
3.13 Ethical Considerations.....	37
3.14 Limitations of the Study.....	38
Chapter Four: Results.....	39
4.1 Introduction.....	39
Thematic Presentation.....	41
Analysis of Qualitative Data.....	41
Thematic Presentation of Results.....	42
4.3 Identifying that the child is on the Autism Spectrum.....	42
Delayed speech Milestones.....	43
Social-Psychological Delays.....	45
Cognitive Delays.....	47

Aggressive Behavior .....	48
Emotional Delays.....	50
Repetitive Behavior.....	50
Confirmation of Diagnosis by a Pediatrician .....	51
4.4 Challenges experienced by Caregivers of Children with ASD.....	51
Financial hardships.....	52
4.5.1 Problem-Focused Coping Styles of Caregivers of Children with ASD .....	60
Life Style Changes .....	69
4.5.2 Emotion-Focused Coping Experiences of Caregivers of Children with ASD ..	71
Chapter Five .....	81
Discussion, Conclusion and Recommendations .....	81
5.1 Introduction .....	81
5.2 Suspicions and Diagnosis.....	81
5.4 Coping Mechanisms of Caregivers of Children with ASD in Kampala .....	87
5.4.1 Problem-Focused Coping Styles of Caregivers of Children with ASD in Kampala .....	87
5.4.2 Emotion-Focused Coping Experiences of Caregivers of Children with ASD in Kampala .....	91

Conclusion .....	95
Recommendations.....	97
References.....	100
Appendix II: Consent Form .....	116
Appendix B: Socio-Demographics Questionnaire .....	119
Appendix C: Interview Guide.....	121

## Abstract

*Introduction:* Autism spectrum disorder [ASD] can be hard on both the child and the parents, but especially the parents. ASD manifests in a variety of ways, including the inability to maintain eye contact and respond with appropriate facial expressions; the inability to respond to peers in a manner that fosters healthy social and emotional relationships and communication; delayed speech; and repetitive behavioral patterns.

*Methods:* The study employed an interpretative phenomenological study design so that the researcher can get an in-depth understanding of the participants' experiences as they shared them extensively. A sample of ten caregivers selected using purposive sampling participated in the study. A semi-structured interview guide was used in data collection, and thematic-reflexive approach to analyze the data.

*Results:* The study revealed that motor delays, social-psychological delays, cognitive delays, and aggressive behavior were behaviors that triggered suspicion and later led caregivers to visit a health professional. Furthermore, the study featured a major theme, "Challenges experienced," which focused on the challenges faced by caregivers, including financial constraints, stigma, depression, and marital issues. Finally, the study focused on coping mechanisms, specifically emotional coping, and found that caregivers employed denial-based, pain-based, hopeful, and problem-focused responses. The data showed that caregivers employ various coping mechanisms such as faith in God, financial coping, social coping, and social support, particularly after participants disclosed their struggles to secure affordable and high-quality education for their children. Despite these ongoing challenges, the collective

efforts and support networks have significantly improved the caregivers' ability to provide for their children's needs.

*Discussion:* Caregivers faced significant challenges in accepting that their child is on the autism spectrum. Many experienced a delay in seeking help, initially noticing potential indicators but struggling to confront the hard reality of the diagnosis. This period of denial often led to emotional pain, isolation, and stigma. The support of family members, friends, and other parents of children on the spectrum played a crucial role in helping them come to terms with the diagnosis

## Chapter One: Introduction

### 1.0 Background

Autism spectrum disorder [ASD], can be hard on both the child and the parents, but especially the parents (DePape & Lindsay, 2015). ASD is a neurodevelopmental condition that primarily impacts an individual's ability to communicate, engage socially, and exhibit typical behavioral patterns (American Psychiatric Association, 2013). Although its precise causes remain unclear, research suggests that both genetic predispositions and environmental influences play a role (WHO, 2023). In many cases, ASD is also diagnosed alongside intellectual disabilities (Gao & Drani, 2024). Currently, there is no known cure for ASD (WHO, 2023). The widely accepted management strategy involves long-term intervention and training, which is typically carried out across various settings, including homes, mainstream and special education schools, specialized intervention centers, and hospitals (Gao et al., 2023).

Globally, about 1 in 100 children has autism. This estimate is an average number, and the stated prevalence varies a lot from one study to the next (World Health Organization [WHO], 2023). Different countries have very different rates of ASD. One in 36, 8-year-old children in the United States of America (USA) was thought to have ASD. This was about 4% of boys and 1% of girls (Maenner et al., 2023). These figures are higher than the ones made by the Autism and Developmental Disabilities Monitoring [ADDM] Network of 2018 which stood at one in 44 children under the age of five (Maenner et al., 2021). Narzisi et al., (2020), found that 1.15 percent of 7-9-year-

olds in Italy had ASD. Al-Shaigi et al. (2020) say that ASD is found in 3.9% of children in Asia and between 0.14 and 2.9% of children in Arab countries around the Persian Gulf. Lotter (1978) found that about 1 in 145 children with intellectual difficulties in sub-Saharan African countries had ASD. Autism is not well known in many low- and middle-income countries, resulting in a significant lack of representation in the field of autism research within these countries (Durkin et al., 2015).

The Uganda Autism Relief reveals that both children and parents have completely been ignored, they are suffering due to lack of support, love and care for the children with autism (The Africa Child Policy Forum [ACPF], 2011). However, there's no doubt that the main signs of ASD are behavioral problems and a lack of social and communication skills, which cause a lot of stress in the families of these kids (Goedeke et al., 2018). Gordon-Lipkin et al. (2018) say that ASD puts a big financial strain on society and the families of people with the disorder. These people are very sick and need a lot of care, which costs a lot of money. In 2015, the direct and indirect costs of caring for children and people with autism spectrum disorder (ASD) in the United States were estimated to be \$268.3 billion. This is more than the costs of stroke and high blood pressure. Overall, a person with autism will spend between \$1.4 million and \$2.4 million per year on schooling, health care, and other services that will last their whole lives (Leigh & Du, 2015).

When caring for a child with ASD, parents and caregivers face a lot of stress and challenges (Hayes and Watson 2012). Behavior problems or comorbidities related to ASD, like an adaptive functioning level, anxiety, hyperactivity, and obsessive-

compulsive rituals, can be stressful for parents and caregivers, especially for low-functioning children who need the most help with daily tasks (Peters-Scheffer et al. 2012). Chronic stress from caring for a child with a disability has been shown to affect parents and caregivers in a number of ways, including poor health and mental health (Johnson et al., 2011), problems with family functioning, and social isolation (Peters-Scheffer et al., 2012).

Autism spectrum disorder (ASD) makes it hard for mothers to raise a child because they worry about the child's behavior, it's hard to get specialized care, and the community doesn't accept them (Joseph et al., 2021). Society often doesn't understand mothers of children on the spectrum and treats them badly. Nakareyah and El-Zakazik (2018) talked to mothers with autistic children in Egypt about their experiences with discrimination. They talked about how these children are left out by their peers, who seem normal at school and other public places. Parents, and especially mothers, who have children on the spectrum are likely to have a hard time taking care of them (Goedeke et al., 2018). To cope, they have to make changes in their social, emotional, and financial lives. For mothers to have more time to care for their kids, they may have to change their careers or quit their formal jobs. This cuts the family's income, which must cover costs like medicine and testing (Jabrink et al., 2003). Because of the child's strange, unruly, and unpredictable behavior, regular social activities with the family are likely to be cut short or skipped (Fox et al., 2002). Numerous studies have highlighted a growing prevalence of Autism Spectrum Disorder (ASD) in Sub-Saharan Africa. For instance, a study conducted in North Africa found

that among children with developmental challenges, 11.5% in Tunisia and 33.6% in Egypt were diagnosed with ASD (Seif Eldin et al., 2008). In Nigeria, Bakare, Ebigbo, and Ubochi (2012) reported that 11.4% of 40 children assessed met the diagnostic criteria for childhood autism, with a male-to-female ratio of 4:1. Similarly, Lagunju, Bella-Awusah, and Omigbodun (2014) identified ASD in 54 out of 2,320 pediatric patients, reflecting a prevalence rate of 2.3%. In Uganda, Kakooza-Mwesige et al. (2017) diagnosed 68 children with moderate to severe neurodevelopmental disorders, including cerebral palsy and epilepsy, with eight cases specifically identified as ASD. Additional diagnoses included impairments in cognition, speech and language, hearing, and vision (Kakooza-Mwesige et al., 2014).

Research conducted in Uganda by Namuli et al (2020) identified notable deficiencies in the expertise of child health care providers, leading to a negative impact on the quality of treatment provided to children with autism. The research emphasizes that several experts, despite possessing a certain level of expertise in handling autism cases, have significant difficulties in diagnosing and treating the condition. Moreover, the scarcity of human resources for mental health in Uganda intensifies these problems, emphasizing the necessity for enhanced training and education for healthcare professionals (Namuli et al., 2020). It is therefore important to know how different types of parents, particularly mothers, deal with the stress of caregiving. Also, because there is scarce information on autism in Uganda, the goal of this study was to find out what problems child caregivers face and how they dealt with them thus contributing to the knowledge gap. If service providers had access to this information,

they would be able to give parents of children on the autism spectrum more specialized and useful help.

### **1.1 Statement of the Problem**

According to UBOS, there are an estimated 88 people with autism for every 10,000 people in Uganda. The most autistic people live in the central region, which has about 106,749 cases followed by those in the eastern area, 101,334 cases (Mawanda, 2022). In Uganda, persons with autism do not fit into any known category of disability, and in most cases, they are often classified by people as victims of mental sickness, witchcraft and bad omen to the family. Further, this group is confined to mental hospitals and others are treated with traditional remedies which may result into brain damage (Nduhura, 2016). Moreover, autism is not yet seen as a separate condition by our government from other mental health challenges (Nduhura, 2016). This means that parents have to pay for everything related to autism. Also, doctors, teachers, and therapists do not have enough training and knowledge about ASD as a whole. So, parents of children with ASD in Uganda are faced with numerous challenges and have to rely on less organized ways to get help (Nalukenge, 2016). This has an effect on the lives of the children, their caregivers, the therapies that are offered, and any home-based interventions that could help the children.

Parents of children on the ASD face challenges of stress and anxiety as a result of the difficulty of managing their children's behavioral issues, which has a negative effect on the parenting process (Benson, 2017). Although there have been several studies conducted in Europe, the United States of America, and Asia about autism and the

effects it has on carers, very little is known about the condition in the context of Africa and Uganda in particular (Franz et al., 2017). In Uganda, some people continue to hold the belief that autism spectrum disorder (ASD) is caused by witchcraft, which could further add on the challenges that parents of children with ASD are faced with (Mthimunye et al., 2014). Moreover, there is an urgent need to understand the difficulties and coping strategies of Ugandan parents who have children diagnosed with ASD. Hence, this will inform different stakeholders, thus contributing to better decision-making that aligns with the construction of effective support systems, health services, and improved livelihoods for families with ASD, which remains a formidable obstacle (Falk et al., 2014).

## **1.2 Main Objective**

To explore the challenges and coping mechanisms of caregivers of children from 3 to 8 years with autism spectrum disorders in schools in Kampala, Uganda.

### **1.2.1 Specific Objectives**

- I. To examine the challenges of caregivers of children with autism spectrum disorders in Kampala.
- II. To identify the coping mechanisms of caregivers of children with autism spectrum disorders in Kampala.

### **1.2.2 Research Questions**

- I. What challenges do caregivers of children with autism spectrum disorders experience in Kampala?

- II. What are the coping mechanisms of caregivers of children with autism spectrum disorders in Kampala?

### **1.3 Significance of the study**

By looking into this important but often overlooked part of caregiving, the study hoped to provide useful information that can be used in both academic and real-world settings and could even have policy effects in the following ways.

*The Importance of Conducting Research:* Caring for children with ASD poses unique obstacles that can greatly affect caregivers. This study was important because it illuminated these obstacles and caregivers' coping techniques in Kampala. Targeted interventions, support networks, and resources to help caregivers manage their jobs need to understand these challenges. The study also contributed towards improving caregivers' and ASD children's well-being by revealing these distinctions.

*Addressing the Knowledge Gap:* The literature on caregivers of children with ASD in Kampala is lacking in addressing their experiences. This research investigated the obstacles these caregivers faced and their coping techniques to close this gap. The study thoroughly examined these caregivers' specific conditions, adding to ASD caregiving knowledge and perhaps making it applicable to comparable contexts worldwide.

*Contribution to Literature and Practice:* This study's Kampala-specific perspective greatly enhanced the ASD care giving literature. The insights collected informed scholarly discourse, enabling cross-cultural comparisons and highlighting the global

character of ASD care giving difficulties. The research findings can be used to create Kampala caregivers' specific support programs, interventions, and resources. This study improved caregiving and the well-being of caregivers and their children by fostering healthier coping mechanisms and providing assistance.

The findings of this study informed evidence-based policy suggestions. They could be used by government, non-governmental, and healthcare bodies to create ASD caregiver policies. By recognizing the challenges and coping mechanisms identified in the study, policymakers can create initiatives that provide caregivers with practical assistance, respite services, and psychological support, improving the lives of Kampala's ASD families.

#### **1.4 Scope of the study**

##### ***1.4.1 Geographical scope***

The Nakawa and Kawempe division, which is a sub-county in the Kampala district, served as the focus of the study. These are among the five administrative divisions that make up the city of Kampala, which is both the capital of Uganda and the country's largest city. Kampala has established institutions that are extending support to children with autism spectrum disorders. It is comprised of 23 parishes, some of which are named Banda, Kyambogo, Bugolobi, Luzira, and Kyanja, amongst others.

##### ***1.4.2 Time Scope***

The investigator anticipated that the study would be finished sometime between June 2023 and August 2024.

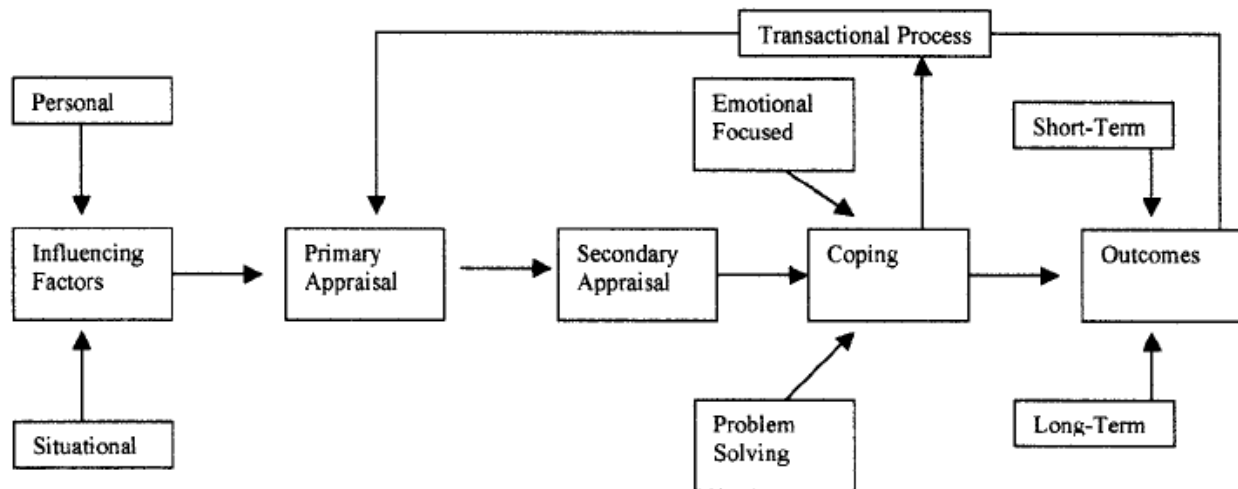
### **1.4.3 Content Scope**

The Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition (2013) (DSM-5) defined autism spectrum disorders as a neuro-developmental condition characterized by pervasive and severe impairments in social interaction, including difficulties with social emotional reciprocity and deficits in nonverbal communicative behavior for social relationships.

Caregiver challenges are significant occurrences that they encounter when caring for their children who have autism spectrum disorder. It could be anything from how they feel and think to how they act in response to certain situations their children face.

### **1.5 Theoretical Framework**

The Transactional Model of Stress and Coping (Lazarus & Folkman, 1984) guided this study. This model says that "psychological stress is a particular relationship between a person and his or her environment that the person judges as taxing or exceeding his or her resources and putting his or her health at risk." In this relationship, there are two important steps: (1) cognitive appraisals and (2) coping.



Source: Lazarus and Folkman (1984)

Cognitive appraisal is "the process of putting an experience and all of its parts into groups based on how important they are to well-being" (Lazarus and Folkman, 1984). In fact, someone has to think that a situation could be stressful before anything can be done about it. This evaluation looks at "primary" and "secondary" ways of thinking. First, you need to know what's at stake: How does a mom feel about taking care of a kid with autism spectrum disorder? "Am I in trouble, or will I get something good out of this, now or in the future, and how?" (Park & Folkman, 1997). During the first appraisal, the caregiver will do a threat and challenge assessment. Threat means that someone's health or sense of self-worth could be in danger, while challenge means that someone should focus on the success, social rewards, and personal growth that the situation could bring. Threat and challenge assessments are not at opposite ends of the same continuum, according to Lazarus and Folkman (1984). Even though threat and challenge assessments are negatively linked, they can happen at the same time (Skinner and Brewer, 2002). Folkman and Lazarus (1985).

On the other hand, secondary appraisal is an evaluation of coping resources and answers to the question, "Can I handle this situation?" It means that someone is sure they can handle the situation because they have the tools to do so. Resources can be physical (like health and energy), social (like help from family, friends, and a social network), psychological (like beliefs, self-esteem, perceived control, and morale), or material (e.g., financial resources, tools) (Billings & Moos, 1981). Coping means making "cognitive and behavioral efforts to master, reduce, or tolerate the internal and/or external demands that caring for a child with autism spectrum disorder brings" (Folkman and Lazarus, 1980). There are two main reasons why coping is so important. One is in charge of the emotions or worries that come with taking care of someone (emotion-focused coping). The other way to deal with stress is to fix the problem that is causing it by changing the things that are causing it (problem-focused coping). Even though both ways of dealing with stress are used in most stressful situations, which one is used depends on how the stressful event is perceived (as a threat or a challenge) and what happened before it (Fletcher & Sarkar, 2013).

Lazarus and Folkman (1984) found at least two broad groups of antecedents that directly affect how people see and deal with a situation: those that have to do with the person and those that have to do with the situation. For example, a person's commitment to caring for others shows what is important to them and what is at stake in a given situation. The first group also includes beliefs, like those about personal control, and personal traits, like self-esteem (Folkman, 2020). Situational factors include how new or predictable the situation is, how uncertain the event is,

how long it will last, and how clear the situation is. For example, time usually makes a threat worse, but it can also give you time to think (Lazarus and Folkman, 1984).

Lastly, the use of transactional models of stress is a real step forward because it helps explain and predict the different ways people react to discrimination and prejudice, as well as the effect of discrimination and prejudice on self-esteem and other variables related to adjustment (Major et al., 2003).

## **1.6 Definition of Key Concepts**

*Autism Spectrum Disorders:* Autism spectrum disorder (ASD) is a developmental disability caused by differences in the brain. People with ASD may behave, communicate, interact, and learn in ways that are different from most other people (Center for Disease Control [CDC], 2023)

*Coping Mechanisms:* These are thoughts and behaviors mobilized to manage internal and external stressful situations (Folkman & Moskowitz, 2004).

## **Chapter Two: Literature Review**

### **2.0 Introduction**

This literature demonstrated how a variety of experiences influenced the caregivers of children with ASD and how they coped. There were three main sections: the first described; the type of stress that autism caregivers experience, the second described the challenges that autism caregivers experienced, and the third described their coping mechanisms.

### **2.1 Autism Spectrum Disorder among Children**

Autism spectrum disorder (ASD) is a developmental disability characterized by problems with social interaction and communication, as well as limited hobbies and repetitive actions (1). In the 1960s and 1970s, the first studies on how common autism is were released. At that time, autism was thought to be a very serious condition that was often paired with intellectual disability (2). In 1980, the American Psychiatric Association published the third edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-III), which included diagnostic criteria for infantile autism and pervasive developmental disorder. This was the first time that autism was recognized as a separate clinical diagnosis. In 1994, the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition (DSM-IV) added new diagnostic criteria and five sub-types of autism, including autistic disorder, Asperger disorder, pervasive developmental disorder—not otherwise specified (PDD-NOS), childhood dis-integrative disorder, and Rett's disorder. The first three sub-types make up autism spectrum disorder (ASD). The fifth version of the DSM, which came out in 2013, reclassified ASD

as a single disorder and made some other changes to how it is diagnosed (Christensen, 2016).

It can be hard to tell if someone has ASD because there is no medical test, like a blood test, that can tell. To draw a conclusion, doctors look at the child's behavior and how it has grown and changed over time. According to CDC, there are three steps to identifying ASD. 1) Developmental Monitoring, which is an active, ongoing way to watch a child grow and encourage parents and teachers to talk about the child's skills and abilities. It means keeping an eye on how your child grows and seeing if he or she meets the normal developmental milestones, or skills, that most children reach by a certain age in playing, learning, speaking, acting, and moving. 2). For developmental screening, well-child checks are done even if there are no known problems. Researchers use screening surveys and checklists to compare a child to other children of the same age. There may be questions about speaking, movement, and thinking skills, as well as feelings and behaviors. 3) At this point, the developmental diagnosis, A screening tool is a quick test that doesn't give a diagnosis, but it can show if a child is on the right track for growth or if a specialist needs to take a closer look. If the screening tool shows a problem area, a formal evaluation of the child's growth may be needed. A trained specialist, like a developmental pediatrician, child psychologist, speech-language pathologist, occupational therapist, or other specialist, does this formal review, which is a more in-depth look at a child's development.

The prevalence of ASD in Africa is believed to be on par with other regions, although there is a lack of standardized evaluation methods across different African countries.

This discrepancy in assessment tools and diagnostic criteria poses a significant challenge in accurately estimating the prevalence of ASD in Africa (Aderinto et al., 2023). The limited data on the condition in the continent is attributed to factors such as low awareness, inadequate diagnostic tools, stigma, and the absence of culturally appropriate assessment tools for diverse African communities. Moreover, the challenges in diagnosing and treating autism in Africa are multifaceted. Issues such as limited access to specialized healthcare professionals, cultural beliefs impacting diagnosis and treatment, and the use of alternative therapies with uncertain efficacy are prevalent (Young et al., 2020). Families and caregivers of individuals with autism face substantial hurdles in accessing support services, combating stigma, and dealing with the lack of awareness among healthcare providers. Efforts are being made to increase awareness and reduce stigma surrounding ASD in African communities, but more research is essential to develop effective interventions and culturally sensitive treatments (Young et al., 2020).

Autism in Uganda presents a complex situation where autistic children face significant challenges due to stigma, discrimination, and limited access to healthcare services. The lack of awareness and understanding of autism in Ugandan society contributes to the stigmatization of autistic individuals (Marlow, 2019). This stigma leads to autistic children being hidden away from the community, resulting in social isolation and exclusion. Additionally, misconceptions about autism being attributed to superstitious causes such as demons or parental infidelity further exacerbate the discrimination faced by autistic children (Namuli et al., 2020). Further, there is a lack of knowledge and awareness about the condition (Marlow, 2019). This lack of awareness hinders

efforts to provide appropriate support and services to autistic children. The limited availability of healthcare services in Uganda, including the lack of properly functioning medical centers and basic medical equipment in some districts, further compounds the challenges faced by autistic children in accessing necessary medical care (Namuli et al., 2020).

## **2.2 Challenges faced by Caregivers of Children with ASD**

Folkman and Lazarus (1985) proposed that general stress coping is a transitional process in which coping methods change over time and across contexts to meet the shifting demands of stressful events. In addition, previous research on general stress coping has shown that adaptive and maladaptive mental health outcomes are associated with positive and negative general coping strategies, respectively (Skinner and Zimmer-Gembeck 2007). Adaptive strategies address stress causes and assist people in managing their emotions, thoughts, and behaviors for mental health (Holton et al., 2016). Seeking social support, regulating emotions, and setting limits are adaptive coping techniques. They improve problem-solving, emotional management, and personal growth. They help sustain mental health and resilience in difficult situations (Gloria & Steinhardt, 2016). Maladaptive, on the other hand, involves damaging or unproductive ways of managing stress, obstacles, and challenging emotions. These coping methods may help temporarily, but they often lead to bad results, distress, and personal growth and well-being (Holton et al., 2016). Maladaptive coping mechanisms can worsen mental health concerns and perpetuate negative feelings and behaviors. Maladaptive coping methods include ignoring or

avoiding stressful circumstances, responsibilities, or emotions and abusing drugs, alcohol, or other substances to numb emotional pain, which can lead to addiction and mental illness. Maladaptive coping mechanisms provide short-term respite but don't address the root causes of stress or emotional suffering (Cole et al., 2008).

As the primary guardians of children with disabilities, parents shoulder difficult caregiving responsibilities. Not only must they assist with the children's daily activities, but they must also closely monitor their changing health conditions, which leads to a decline in the caregivers' quality of life and changes in their lifestyle (Terathongkum et al., 2020). ASD children need help bathing, clothing, feeding, and toileting. Further they may also demonstrate violence, self-harm, meltdowns, or repetitive behaviors among others. Managing these behaviors can be emotionally draining and require specialized solutions (Benson, 2017). Many family members and caregivers, particularly mothers, report experiencing a great deal of tension as a result of their children's behavioral difficulties while caring for them (Jankowska et al., 2015). They experience a range of emotions, including grief, guilt, worry, and anxiety about their child's future especially mothers (Sivaratnam et al., 2021). Trends have been observed among caregivers of children with ASD. It has been reported that child age and symptom severity, parent personality, and family functioning influence parental stress (Ingersoll & Hambrick, 2011).

Gona et al. (2016) discovered associations between maternal stress and the level of social skills in autistic children, but nothing comparable was found for fathers of autistic individuals. Further, a high level of caregiving burden for children with

cerebral palsy negatively impacts the mental and physical health, family functions, and social interactions of caregivers, resulting in poor care quality and unmet patient needs (Dababneh & Al-Zboon, 2018). Moreover, a study by Durán-Pacheco et al. (2022) observed a positive correlation between depressive feelings and caregiver burden. In addition, ASD-related major adversities such as child elopement, other mental comorbidities, children seen in the ER due to mental health issues, or children suspended or expelled from school were noticeably related to greater caregiver strain. Mothers felt socially isolated and embarrassed about their ASD child's behavior in public. Half the mothers made proactive choices, preferring to keep the child at home by making schedules for others to care for the child at home in case of a social event, based on anticipating recurrences of previous negative experiences. One mother was quoted as saying, ""Of course, there is a profound impact. For example, if we are going to attend a wedding or a party, we usually think hundreds of times before we decide to go and plan for when he [the son] gets bored. Who will help? I mean dad, grandma, and I; we call us the triangle." (Gobrial, 2018). Societal stigma creates an additional burden of guilt and dread for mothers of children with autism spectrum disorder (ASD) because other mothers with apparently normal children despise them, thereby complicating their social interactions (Monika et al., 2017).

The unpredictability of behavioral changes in children with ASD causes parents' uncertainty and dread, which may lead to stress. A significant portion of the stress associated with raising a child with ASD stems from factors directly associated with the child's disability (Durán-Pacheco et al., 2022). Children with ASD frequently exhibit a wide range of challenging and socially deviant characteristics and behaviors.

According to Sivaratnam et al. (2021), coping with such severe deficits and behavioral issues on a daily basis causes significant chronic stress for many parents and families. Caregivers of children with ASD must continuously deal with their children's fluctuating behavior, which frequently deviates from societal norms, resulting in exhaustion and stress (Monika et al., 2017). Families of autistic children frequently revolve around coping with the child's atypical behaviors. These behaviors may have a negative effect on family functioning, resulting in stigma, which is one of the most difficult obstacles faced by parents of disabled children. It is a social construct that is defined as a sign of embarrassment or disgrace, marked by regret or humiliation. Stigma consists of labeling, stereotyping, separation, loss of status, and discrimination. One mother was quoted as saying, "People end up blaming me, saying that I am raising my child in a bad way. I'm seen as an irresponsible mother. I feel ashamed of myself." (Gona et al., 2016).

According to Gobrial (2018), mothers had to quit their employment to care for their children but struggled to pay for their expensive care. Parents agonize about the future and well-being of their children. One mother was quoted as saying, "I am a physician; however, I had to resign. I have not left my house for over 10 years since my son was born. This is because I am really busy looking after him, going to doctors, going to speech therapy, and traveling to Cairo." (Gobrial, 2018). Mothers' relationships with their spouses are also harmed because they are frequently stressed. Many mothers reported having to reorganize their lives and relationships in order to devote more time to their autistic child. In addition, they reported receiving limited assistance from their spouses. Additionally, parents reported that they did not receive

adequate support from their extended families because they lacked knowledge about their children's condition and were uninterested (Monika et al., 2017).

### **2.3 Coping mechanisms among Caregivers of Children with ASD**

When dealing with the challenges of being a caregiver for a child with ASD, mothers may look for different ways to deal with stress and tools to help them. Lazarus and Folkman (1984) talked about the two main types of coping strategies: those that focus on the problem and those that focus on the feelings. The goal of problem-focused coping is to change or handle stressful situations, while the goal of emotion-focused coping is to control one's emotional reactions to stressful situations. Coping strategies are important for well-being (Benson, 2014). Coping strategies may also moderate the relationship between stressors and caregiver stress in parents of children with ASD (Dabrowska & Pisula, 2010).

#### **2.3.1 Problem Focused strategies**

Collins et al.'s seminal study in 1983 illuminated the nuanced nature of coping mechanisms, underscoring their effectiveness as contingent upon situational context. Specifically, parents grappling with the stressors of planning for their adult child's future demonstrated the utility of problem-focused coping strategies by actively seeking professional advice, thereby mitigating the stress associated with such endeavors. Dabrowska and Pisula (2010) delved into the distinct coping patterns of parents with children diagnosed with autism, revealing a noteworthy variance in social diversion coping strategies compared to parents of typically developing children. Caregivers adopting pro-active, problem-focused coping strategies, including

the suppression of competing activities and benefit finding, reported lower levels of depressive symptomology, as evidenced by their study. The use of proactive, problem-focused coping mechanisms not only shields caregivers from depressive symptoms but also correlates with an enhancement in the quality of life of the care recipient.

Pourmohamadreza-Tajrishi et al. (2015) demonstrated that caregivers participating in a 12-week program aimed at improving problem-solving skills reported heightened caring skills and reduced interpersonal sensitivity and heightened caring skills. Moreover, caregivers who strategically employ proactive, problem-focused coping mechanisms appear to positively influence the quality of life of the care recipient. Similarly, Vernhet et al. (2019) observed that parents of children with autism spectrum disorder (ASD) tended to utilize more avoidance strategies and fewer social support-seeking strategies compared to parents of typically developing children. Furthermore, the adoption of problem-focused coping acted as a protective factor for parental stress and overall quality of life. Bourke-Taylor et al. (2021) supported this notion, asserting that problem-oriented coping emerged as a robust predictor of various care recipient outcomes, including mental discomfort and worry.

### **2.3.2 Emotion focused strategies**

Emotion-focused coping strategies play a pivotal role in the caregiving experiences of parents with children on the autism spectrum. Monat and Lazarus (1985) underscored that these strategies, which aim to manage and regulate emotional responses to stressors, don't necessarily tackle the root problem but are geared towards reducing

emotional distress and promoting psychological well-being. Parents utilizing emotion-focused coping techniques may engage in processes such as reevaluation, denial, or alternative thought patterns to mitigate the impact of stressors. Intriguingly, Monat and Lazarus found that emotion-oriented coping emerged as a predictor of parental stress among parents of children with autism and Down syndrome, while task-oriented coping played a similar role among parents of typically developing children.

Disengaged coping, involving the diversion of attention from stressful experiences, has significant implications for the psychological outcomes of caregivers, as revealed by Li et al. (2012). Caregivers employing disengaged strategies, including problem avoidance, denial, behavioral disengagement, and social withdrawal, reported higher levels of anxiety and depression. Denial or avoidance coping, a prevalent technique among caregivers struggling to accept their child's autism diagnosis, is associated with adaptive coping styles. However, Obeid and Daou (2015) demonstrated that distraction and disengagement coping predicted poorer well-being among mothers of children with autism.

The popularity of denial or avoidance coping persists, as highlighted by Shepherd et al. (2018). The degree of disorder seems to influence parents' successful adaptation and modification, reinforcing the link between coping styles and the acceptance of the child's autism spectrum status. Notably, Luong et al. (2009) found that despite gender differences in coping strategies, both fathers and mothers commonly adopt avoidance coping mechanisms, aligning this approach with the highest levels of stress experienced by parents.

Sheehan et al. (2014) delved into the repercussions of disengaged coping, finding that children with developmental disabilities, particularly those with behavior problems during and after treatment, often had caregivers who used disengaged coping. This suggests that when parents redirect their attention away from the stress of caring for an autistic child, it may impact their ability to manage the child's challenging behaviors effectively. Gudmundson and Leerkes (2012) added another layer by demonstrating that mothers' reactions to their children's negative emotions worsened when disengaged coping was more prevalent, indicating that caregivers' coping choices may intricately influence the quality of life of those they care for. These findings collectively emphasize the nuanced relationship between coping strategies, parental well-being, and the behavioral outcomes of children with autism.

#### **2.4 Summary of Literature Reviewed and Gaps Identified**

Most of the literature examined on autism is in countries other than Uganda. This suggests that conventional ASD control and living solutions may not apply to Uganda. This necessitated studying autism and related experiences in Uganda. The literature examined above implied that Uganda lacks autism information. Despite the fact that this information is crucial for improving services for children on the spectrum, there was little research and statistics on the occurrence and impact of ASD on families. There was limited information on experiences that care givers of children on ASD go through, in Uganda and Kampala in particular; this suggested that there is a research gap in literature regarding caregiver's stories in coping with ASD hence the need for this study.

## **Chapter Three: Methodology**

### **3.0 Introduction**

This chapter presented the research methods that was used in the study. This included study design, sample size, population demography, the tools and techniques of data collection, and data management and analysis.

### **3.1 Study Design**

Research study design is a framework, or the set of methods and procedures used to collect and analyze data on variables specified in a particular research problem (Ranganathan & Aggarwal, 2018). This study was exploratory in nature, hence employed qualitative methods. The researcher employed an interpretative phenomenological study design so that the researcher can get an in-depth understanding of the participants' experiences as they shared them extensively. Through it, the researcher would describe the challenges of different caregivers of children with ASD within the Ugandan context.

### **3.2 Study Population**

A study population is a group considered for the purposes of research or statistical analysis. The study population is not restricted to human beings alone. It is a collection of aspects that have a common characteristic (Fabyio, 2020). They can be items, animals, measures, etc. that share numerous features. The study population included caregivers of children between the ages of three and eight years with ASD. Limiting a population study to caregivers of autistic children aged 3 to 8 years will allow the researcher to target a critical developmental period where ASD symptoms

are typically more pronounced and early intervention efforts are actively underway (Maksimović et al., 2023). This age range provided insights into caregivers' experiences with accessing and utilizing early intervention services, understanding the specific stressors and support needs during a period of heightened caregiver burden, and explored factors influencing caregiver quality of life.

For purposes of this study, "a care giver was a woman who had lived with and taken care of a child on the autism spectrum for at least one year." According to Aucliff and Thomas (2019), in many homes, mothers orchestrate and set up routines through which families are able to run and make room to care for children on the autism spectrum. Therefore, the researcher considered mothers as participants in this study. Consequently, mothers bear the greater burden of child care in many families and are often faced with difficult and unpleasant circumstances, yet they feel like it's necessary for them to stay close to their children nearly all the time. Hence, they are likely to often be the main caregivers of children with ASD (Monika et al., 2012).

### **3.3 Study Setting**

The study was qualitative with participants whose children attended schools that offer special needs and inclusive education. Participant children had to be attending one of the purposively selected schools. This approach ensured that the study captures a range of experiences and perspectives from caregivers whose children attended different schools offering special needs education in Kampala.

*Teens and Tots Development Center:* The study had three participants come from here. It was founded in 2020, The Centre is a therapeutic centre in Kampala for

children aged 3 to 18 years old. It promotes the education and development of children with autism and other neurological conditions such as cerebral palsy.

*Open Friends Center Ntinda:* The study had two participants come from here. It's a Center for children with special needs, focusing on supporting the care of children of ages 3 to 17 years and young adults up to 21 years with developmental, behavioral and emotional challenges that are brought about by disorders such as autism, childhood depression, bipolar, attention deficit disorder/ Attention Deficit Hyperactive Disorder and learning difficulties. Open Friends is a place of acceptance where children with the above challenges come to for support, received as they are, and given an experience of Love without conditions. The center believes every child can be nurtured holistically in character, growth and development to their full God intended potential.

*Hill Preparatory School:* The study had two participants come from here. Hill Preparatory School is an Education Institution Integrating Children with Special Needs, it is located in Naguru, a Kampala suburb. It was founded in 1988, and has a novel concept that defeats several conventional educational ideas and practices.

The study involved caregivers of children with ASD. For purposes of this study, caregivers of children refer to mothers of children with ASD in Kampala district who have been involved in a child's life for at least one year after their diagnosis has been confirmed.

### **3.4 Sample size**

The sample size was 10 caregivers of children on the autism spectrum who have been diagnosed by pediatricians or psychologists and are between the ages of three and eight years. The sample was influenced by data saturation.

### **3.5 Sampling Procedure**

This study included care takers of autistic children in Kampala, Uganda. The sample size was 10 caregivers of children on the autism spectrum who have been diagnosed by pediatricians or psychologists and are between the ages of three and eight years. The caregivers were able to read and speak the English and/or Luganda languages for accurate and easy transcription. The sample size of the study was 10 was determined to ensure in-depth exploration of individual experiences while managing available resources effectively. This sample size was also informed by data saturation; data saturation occurs when a researcher has collected enough data to draw necessary conclusions, and collecting further data won't produce value added insights. Qualitative research emphasizes depth over statistical representativeness, and with a smaller sample, the researcher can dedicate more time and resources to each participant, facilitating rich and detailed insights into the challenges, coping strategies, and support needs of caregivers within this specific context. Qualitative research often utilizes small samples to facilitate in-depth case-oriented analysis, which is integral to this approach (Vasileiou et al., 2018). Additionally, the chosen sample size allowed for the exploration of experiences within a manageable timeframe and budget, aligning with the study's objectives of understanding the

complexities of caregiving for autistic children in Kampala while ensuring feasibility and consistency in data collection and analysis. The selection process of children whose caregivers took part in the study was purposive, however the informed consent and the other ethical considerations were central to participation.

### **3.6 Sampling Technique**

This sample was obtained through purposive sampling. Purposive sampling involves selecting participants based on specific criteria relevant to the research questions and aims, such as caregivers of children with autism aged 3 to 8 years who had been diagnosed by pediatricians or psychologists and are English and/or Luganda-speaking. This sampling technique allowed the researcher to deliberately select participants who could provide valuable insights into the phenomenon under study, ensuring that the sample represented the population of interest in terms of relevant characteristics and experiences. Additionally, within purposive sampling, subtypes such as maximum variation sampling were considered to ensure diversity within the sample in terms of socio-demographic factors, severity of autism symptoms, and caregiving experiences, further enriching the depth and breadth of data collected.

### **3.7 Inclusion and Exclusion Criteria**

To be included in this study, the caregiver had to be a care giver of a child diagnosed as being on the autistic spectrum, attending one of the selected schools. The child had to be between three and eight years old. Further still, for purposes of easy transcription, caregivers had to be able to speak the English/or Luganda language.

### **3.8 Instruments**

#### *Demographic Information*

The researcher included the biodata of participants in a demographic questionnaire to reflect basic information that will would help define and clarify the experiences of participants. Some of the details of caregivers asked about included their occupations, ages, areas of residence, and the gender of their child.

#### *Semi-structured Interview*

Aucklife & Thomas (2019) suggest an interpretive phenomenological approach in their study about the experiences of mothers with autism. With this approach, semi-structured interviews were employed as an appropriate method to obtain participants views. Interviews were carried out and recorded with the participants consent. The semi-structured interview guide employed open-ended questions and probes that focus on allowing the participant to have control over the interview process. In addition, they enabled and empowered the interviewee to tell his or her own story, directly allowing their voice to be heard, unlike structured questions. Underneath this kind of interview was the notion that participants understood the world in a varying personal way; hence, issues were explored from a distinctive perspective (Coughlan, 2009). Five questions were considered to allow the participants to own and tell the stories of the challenges and how they coped with taking care of a child on the autism spectrum. The purpose of this interview was to explore the experiences of caregivers and find out the various ways in which they managed to care for their children on the autism spectrum.

### 3.9 Quality Control

The study put in place measures to ensure the accuracy, validity, and originality of the data that collected while writing the report. The researcher worked closely with a supervisor to ensure the study goes through all the necessary steps: obtaining consent, collecting bio-data, and carrying out the interview, which were recorded with the participants' permission. The researcher manually transcribed all the data collected during the interviews to stay connected to and honest about the participants' experiences. The researcher checked with participants to verify the accuracy of responses by sending them transcriptions and asking for feedback. Phone calls were be made to follow up.

The researcher ensured the credibility of the data collected by carefully and closely working with a peer to review her transcripts for this study. They reviewed the codes and the researcher's code book to reduce bias by the researcher and enhance the work by accessing the work to see if it fulfills the publication criteria. The peer reviewer checked to see if the following three factors are present: the novelty of the data, the truth of the data, and how significant or crucial the data collected is (Korstjens & Moser, 2018). The researcher used member checking as a method to improve trust between participants, allowing them to provide feedback where necessary and make additions or subtractions to the data where they perceive it to have been wrongly interpreted (Korstjens & Moser, 2018).

### **3.10 Data collection**

The researcher sought approval to carry out this study from the faculty of Public Health, Nursing and Midwifery of Uganda Christian University. The researcher further obtained an approval letter from the Research Ethics Committee of the university. After that, the researcher got administrative permission from the selected schools and engaged the selected participants from, informed them about the purpose of the study, and requested their participation. Participants were asked to agree to a face-to-face interview. Upon agreement, a date for the interview was set. Each participant was asked to sign a consent form prior to the interview. Prior to each interview, the researcher requested the participants that the interview be recorded for ease of transcription.

Transcribed copies of interviews were shared with the participants via email to inquire if they want to make any additions and check for an accurate representation of their experiences. Additional information was then included in the final copy of the transcription. This study consisted of as many interviews as it required to reach saturation. At the point of saturation, no supplementary data was found (Saunders, 2017). Data saturation is attained when there is sufficient information to duplicate a study and the ability to acquire supplementary new information has been reached, making further coding no longer practical. Failure to reach data saturation negatively impacts a study, compromising the validity of one's research (Fusch, 2015). Interviews were manually transcribed word for word. The audio recordings was securely transferred to a computer and kept in a folder with a password.

### **3.11 Risk Management**

The researcher carried out the interviews in a convenient location. The researcher stored all audio recordings from interviews on a computer with a password. In case any uncomfortable memories evoked for participants during the interview, the researcher encouraged the participant to contact a health worker they are familiar with or provided the contact information of a professional psychologist whom they can reach for assistance. Additionally, the researcher provided participants with a therapist's contact information. This was done for them to be able to contact her in case they experienced uncomfortable memories while narrating their experiences of caring for their children with ASD.

### **3.12 Data Analysis**

The researcher used a thematic-reflexive approach to analyze the data. In an exploratory and reflexive phenomenological approach, interviews entailed much more than collecting data. It is a relationship with the specific aim of eliciting a participant's experience and giving meaning to a certain subject. The interview was multi-faceted and multi-dimensional that involved an engagement between the interviewer and interviewee that resulted in the formation of ideas with new meanings. It is the deriving of these fresh meanings and perspectives that gave weight to this approach and enabled the researcher to create novel themes in relation to a study. Reflecting on the interview relationship (Binder Per-Einar, 2012).

The researcher went through the following steps while collecting data: transcribed each interview manually, type out all field notes, and arranged and grouped all data depending on its source to get a general picture of it. All interviews were audio recorded. Data was transcribed verbatim, and each transcript was carefully examined. The researcher conceptualized each participant's data within the Ugandan context. Transcribed copies of interviews were sent to participants to inquire if they wanted to make any additions and check if the information they shared is accurately presented. Additional information was included in the final copies of the transcription.

*Phenomenological bracketing:* The researcher obtained a detailed narrative of participants' experiences. Organized the data by categorizing it in chunks based on the meaning it conveys and writing a word or letter representing each chunk in brackets While doing this, the researcher was careful to do a critical self-search and reflection to check on how her relationship with the participants affected their answers to questions and to limit the interference of her own personal assumptions and biases with the data collected (Korstjens & Moser, 2018).

*Notes:* The researcher studied each line in the collected data, making sure to identify any words or phrases linked to the focus of the study. The researcher wrote notes about these in the margins of the transcripts. She considered the relationship between every phrase or statement obtained during bracketing and the phenomenon under investigation. The researcher took time to observe and interact with participants in the field, to become fully engaged with the context from which they

tell their stories, to remain open, and to look out for misinformation so as to get deeply informative data (Korstjens & Moser, 2018).

*Making a codebook:* The researcher made codebook that was used in the compilation of derived codes. The researcher read and scrutinized the data several times and analyzed it to select relevant themes. The researcher noted and relabeled the codes and categories to which they belonged. The researcher studied the data until it gave rise to new depths of insight. (Korstjens & Moser, 2018).

*Synthesizing:* The researcher clustered meaning units, or codes, into themes. These themes represented the interpretation of the phenomenon.

*Making Comparisons:* The researcher drew comparisons or findings contrasts with the codes in relation to the main themes. They combined similar themes and fused overlapping categories.

*Finalizing themes and developing the coding manual:* The researcher continued to merge themes and reformulate category titles.

*Final coding:* The researcher applied the final coding manual to each interview to ensure inter-coder agreement. Convergent themes were grouped together and assigned a new code. Themes irrelevant to the study will be omitted.

A table with the relevant themes and new codes was compiled. Relationships between the themes were cross-referenced back to the original scripts to reduce the chances of misinterpretation. Any additional information, including tone and non-verbal

information relevant to the study, were noted separately. A narrative analysis of the data was compiled.

### **3.13 Data Management**

Every interview was audio recorded with the consent of the participants and transcribed verbatim. Codes were assigned to each response, representing an experience the caregiver of the child on the ASD spectrum faced. Similar codes were grouped together. Data was analyzed and kept under lock and key while was being done.

### **3.14 Ensuring rigor.**

Rigor, in qualitative terms, is a way to establish trust or confidence in the findings of a research study. It allowed the researcher to establish consistency in the methods used over time. It also provided an accurate representation of the population studied. Rigor was established through the following Truth-value (credibility); applicability (transferability) Consistency (dependability) Neutrality (confirmability) (Johnson et al., 2020).

***Truth-Value (Credibility):*** This pertained to the believability and authenticity of the research findings. Achieving credibility involved employing various strategies such as member validation (member checking), triangulation (using multiple data sources or methods), and prolonged engagement to ensure a comprehensive and accurate portrayal of the studied phenomenon (Johnson et al., 2020).

**Applicability (Transferability):** Applicability was concerned with the extent to which the findings can be applied or transferred to other contexts or populations. To enhance transferability, the researcher provided rich, context-specific descriptions and details about the study setting, participants, and methods, allowing readers to assess the potential applicability of the findings to their own situations (Johnson et al., 2020).

**Consistency (Dependability):** It referred to the stability and reliability of the study's findings over time and across researchers. Establishing dependability involved maintaining a clear and comprehensive audit trail, employing consistent data analysis procedures, and ensuring transparency in the research process. Peer debriefing and external audits also contributed to ensuring dependability (Johnson et al., 2020).

**Neutrality (Confirmability):** This addressed the objectivity and neutrality of the research process. It involved minimizing the influence of the researcher's biases and perspectives. Techniques such as reflexivity, where researchers critically examined their own roles and potential biases, and an audit trail documenting decisions and interpretations, contributed to confirming the neutrality of the study (Johnson et al., 2020).

By attending to these four criteria—truth-value, applicability, consistency, and neutrality, the study enhanced its rigor, fostering confidence in the trustworthiness and relevance of its findings (Morse, 2015).

### **3.15 Ethical Considerations**

The researcher submitted the proposal to Uganda Christian University's Research Ethics Committee for ethical approval. Thereafter, administrative approval was sought from the selected ASD institutions in Kampala. After obtaining permission, the researcher sought the informed consent of the participants, and explained the goal of the study and the potential benefits of participation to the parents of these children. A pseudonym was issued for identification upon approval. The pseudonym intended to protect the caregivers' and children's identities. During data collection, unique identities were employed, and anonymized data was used for analysis and display. The participants were re-imbursed a token of appreciation between 20000 and 50000 Uganda shillings

In a secure place, face-to-face interviews were conducted. The researcher made efforts to preserve the confidentiality of participants information, and interviews were viewed by the researcher and a peer. In addition, the researcher requested the participants' consent to record their interview sessions for future reference. The right to withdraw from the study at any moment was regularly emphasized to the participants. The study anticipated a few dangers, most notably emotional distress. Hence, the participants were provided with a contact number for a Counsellor in the event that unsettling recollections caused emotional distress. To protect the information of respondents, completed surveys and recorded sessions were stored under lock and key. During the interview sessions, the researcher provided a snack

and a drink, further a transport refund was given to them. Further a play doll was given to each care giver for the children or children that they are looking after.

### **3.16 Limitations of the Study**

The emotional and mental weight of talking about sensitive problems and ways to deal with them brought back some troubling memories for the people taking part. This made it hard for the study to talk about autism spectrum disorders in a sensitive and in-depth way.

The study also included only caregivers who know to read and speak English. Because of this, a number of considerable number of caregivers were left out and the results were more useful to an elite group of people than to the average Ugandan caregiver of an autistic child.

This study looked at how things are. It told us in depth about the lives of people who take care of autistic children by describing their experiences and how they dealt with them. On the other hand, since this was a qualitative study, the results could not be applied to everyone.

## Chapter Four: Results

### 4.1 Introduction

In this chapter, the researcher presents the results under four main themes. These themes have been presented in line with the research objectives. Theme one is entitled “suspicion and diagnosis”. Theme two “challenges faced by caregivers” Theme three and four which are entitled “Problem focused” and “Emotional focused” coping.

### 4.2 Demographic Information

The researcher presents the demographics within the introduction section for purposes of contextualization, so that the reader may view and interpret the results within context. This demographic data was obtained by asking participants specific questions before carrying out the semi structured interview. The demographic information availed by the participants during the interview process enabled the researcher to get a more detailed understanding of the characteristics of her sample and to contextualize their responses. Ten participants were interviewed from Kampala district.

Table 1 shows the demographics of the respondents;

ID	Age	Profession	Most time with Child	Child's			Diagnosis
				Birth position	Age	Gender	

1	20-30	Banking	Other (care-taker)	First born	3yrs	M	Psychiatrist
2	31-40	House Wife	Both father and mother	First born	2yrs and 11months	M	Psychiatrist
3	31-40	Education	Mother	First born	7yrs	F	Psychologist and Psychiatrist
4	37-45	Education	Mother	Last born	2yrs	M	Psychiatrist
5	35-45	Public-health worker	Both parents	First born	5yrs	M	Psychiatrist
6	46-50	Economist	Mother and siblings	Last born	3yrs	M	Psychiatrist
7	20-29	House Wife	Mother	Firstborn	3yrs & 7months	M	Psychiatrist
8	30-39	House Wife	Mother	Middle child	2yrs	M	Psychiatrist
9	25-35	Statistician	Both parents	Last born	1yr 8mths	F	Psychiatrist
10	31-40	Education	Mother	First	4yrs	M	Psychiatrist

				born			t
--	--	--	--	------	--	--	---

### **Thematic Presentation**

These results are presented under four main themes. These themes align with the two specific research objectives. The presentation starts with the suspicion that caregivers had about their children, followed by the challenges caregivers face, and lastly the coping mechanism used by the caregivers. Major themes portray main ideas whereas minor themes are the secondary layers within the data collected in a study. In a thematic network, principles demonstrating the processes that were used to progress from analysis of text to its clarification are brought together (Akin ode & Khan 2018).

### **Analysis of Qualitative Data**

Analysis was carried out at the same time as the data was collected and interpreted. Having reviewed the transcripts', written data was broken down in four main ways as described herewith: -: 1) Line-by-line code - lines, phrases and words were systematically examined to select all those that were relevant to the research question. When found, that part of the data was used to form a code that was a representation of emergent perceptions. The words in the data were sufficient and remained unaltered lest the underlying meaning changed. 2) Paragraphs were then scanned to derive units of meaning significant to the research question and then used to extract descriptive codes. A paragraph contained several units that formed codes or none. Coding involved reviewing the paragraph, deducing what was significant in the paragraph in relation to the research question and stating a code for it. 3)

Following line-by-line coding and reviewing paragraphs, the extracted codes were grouped logically by a method known as categorization; labels were altered with time to create clarity (Harding & Whitehead, 2013). The researcher went through all the steps mentioned above while writing the results in this chapter.

### **Thematic Presentation of Results**

The themes, the subthemes and major themes obtained from the data have been presented in the tables below. These tables are in line with the research questions.

#### **4.3 Identifying that the child is on the Autism Spectrum**

The researcher in this study sought to understand how the caregivers got to know that their children were on the autism spectrum. After interviewing the participants and analyzing the interviews, several themes emerged. The major theme that emerged was “Suspicion and Diagnosis” and it comprised of six subthemes.

**Table 1**

#### **Themes and Sub Themes Response of Caregivers after Diagnosis**

---

Theme 1: Suspicion and Diagnosis
a) Motor delays
b) Social-psychological delays
c) Cognitive delays
d) Aggressive Behavior
e) Emotional Delays
f) Repetitive Behavior

---

During the study, many of the participants came to the conclusion that they suspected that something is wrong with their child; they, their friends, family or doctors noticed the child's unusual motor, cognitive, emotional and social-psychological behavior. This unusual behavior most cases manifested as (a) Speech (b) Cognitive, (c) Social and (d) Emotional (e) Social psychological delays.

### **Delayed speech Milestones**

Caregiver's worries about the development of their children increased when they realized they were not hitting their growth milestones. This is evidenced below through the different communications from participants.

. Participant 7 whose child took a long while to speak had this to say:

“He was coming to three years, I think like one year and eight months, around there... but even earlier on, I would see somethings that are off... but the time I really confirmed was about one and eight months when I and the father took him to a kid's clinic, so..., we were like... this by now at least he should be starting to say something... some few things...”

She further expressed their child's struggle to walk in the following words:

“Even when he tries to say something, you notice that many things he is off, the way he is, you talk to him and you see that he is off, like he is not understanding. He was well, but then something... he started forgetting somethings...like some words he used to call me mama, but had started forgetting, even singing, words started not to come out...”

Participant 8 had this to say:

My son is nearly 5 now, but we started Early Intervention with him around 2years and 7 month when he only had 3 words and wasn't pointing or making any effort to make any signs. We started therapy... though it is financially demanding...We didn't seem to have much progress for several months and then around when he was 3 and 2 months it was like a light-switch. Within weeks he went from a handful of words to 2-3 word sentences. And he had great pronunciation too.

Participant 10 said:

My son was 2years and 8months. I was worried because his friends and little cousins all speak very well and have been for months. This hit me so hard that I started to worry a lot about my child... I was worried because I had seen a child who wasn't able to speak at 4 years and I didn't like it.

Participant 5 said:

My daughter turns 3 in February... she hasn't really started forming full words... she has 3 words she keeps uttering... I am concerned as a mother, the father too but we are taking time. The psychologist told us it is autism... That's bad news but we believe in God and we are hoping for the best as we do what we can as parents.

"Delayed speech milestones" emerged as a significant theme from caregivers' experiences, causing considerable apprehension and concern. Caregivers reported that their children were not growing and developing at the same pace as their peers. They noticed delays in various areas such as speech and social interactions. These

observations led them to suspect that their children might be on the autism spectrum. The failure to hit expected developmental milestones, such as speaking their first words or engaging in typical social behaviors, intensified their worries and prompted them to seek professional evaluations and support. This theme underscores the profound impact that developmental delays have on caregivers' perceptions and the subsequent steps they take to address their children's needs.

### **Social-Psychological Delays**

All participants highlighted social-psychological delays as a typical distinguishing feature in their children. Often social-psychological delays emerged as a trait that created great difficulty in communication and development of social skills in their children. They appeared as lack of eye contact, hypersensitivity, hyperactivity and having a very quiet child.

Another participant 3 had this to say;

Initially, he was displaying some symptoms that I had seen before in people I had seen before, but these were adults with learning disabilities. When he started those symptoms such as not responding to their name, repetitive movement and some peak moments of aggressiveness... My son started avoiding eye contact, something I didn't know him for... I got concerned and was worried because I had seen these symptoms in people I had worked with.

To this effect, participant 7 started getting concerned about the child's social life, she said;

“He started playing in a strange way, He doesn't want to be with other children...He was strange.”

Another caregiver, Participant 1, shared a similar experience:

"It started with him not hitting his milestones. A friend of ours, who is a child psychologist, visited and observed him. They noticed he wasn't making eye contact."

Participant two said:

"So, around the age of a year and eight months, there wasn't much progress with my child. I was unsure and asked friends whose kids were around the same age and already talking, but mine wasn't saying anything."

Participant 4 said:

I noticed my daughter had a hard time adapting to new environments or changes in her routine. She would become very anxious and would insist on following the same rituals every day. Her intense reactions to minor disruptions, like a change in her mealtime routine, raised red flags for me. I started researching and found that these behaviors could be linked to anxiety disorders or even traits on the autism spectrum.

Participant 10 said

I began to suspect something was different with my son when he struggled to engage with other kids at playdates. He preferred lining up his toys exactly than joining in their games... If you interrupted that process...my son would cry. It struck me one day when he had a meltdown over a minor change in routine. His intense reactions reminded me of children I've read about with sensory processing disorders.

Social-psychological delays often emerged as a significant trait, creating substantial difficulties in communication and the development of social skills in children. These delays impeded their ability to interact effectively with others, further complicating their overall developmental progress.

### **Cognitive Delays**

Most participants reported that their children experienced cognitive delays. They explained these delays as failure to adjust and progress at school in comparison with other children. Cognitive delays further resulted in difficulty understanding verbal and non-verbal cues. The phenomenon of failure to adjust to school was voiced by participant 3 as:

“My child was dragonized with autism at 2years and 9months, He sang at about a year, we had heard a song baby Jesus, so now when he is two, he loses speech... so he like his not speeching anymore, its like he can’t hear but then he can hear certain noises like sneezes, coughs. He would not respondent to his name and that hit hard and I first denied was I was seeing”

Then Participant one, whose child struggled to understand verbal and non-verbal cues, had this to say:

Like any other parent, I kept expecting that he would start talking—at one year old, then at two years old, and then at three years old—but he never did. He couldn't write, understand, or express himself verbally. When he wanted to communicate, he would just come to us, hold our hand, and try to make gestures that were often unclear and difficult to understand.”

Participant 5 said:

From an early age, my daughter showed signs of struggling with memory and learning. She would often forget instructions or become easily confused when presented with new information. Her preschool teachers mentioned concerns about her inability to concentrate during lessons and her limited progress in acquiring new skills. I started to get worried, I would be in thoughts about my little baby.

Participant 6 said:

"I noticed from the age of 3, my son seemed to struggle with grasping basic concepts. While other children his age were starting to recognize letters and numbers, he showed little interest and couldn't seem to retain information.

The child's inability to communicate effectively with family and peers created significant doubt in the parents about their child's normal development. This lack of communication led caregivers to suspect developmental issues.

### **Aggressive Behavior**

Most caregivers reported that their children experienced aggressive behavior. The aggressive behavior children exhibited caused care givers to wonder about their full and normal development. They were overly involved with an object or activity and resisted anything that interfered with them.

Participant 1 who realized their child's aggressive behavior had this to say:

He wouldn't make any sounds at times; then, out of the blue, he would start shouting. He throws tantrums frequently, and if you ask him to do something, he becomes extremely annoyed. His frustration can escalate to the point where he even bites himself.

Participant 4 had this to say,

“It wasn’t easy, especially at the beginning, my wonder Janice (not her real name) had aaa tantrums if she woke up in the morning and the milk was not ready, she would just start right away no wasting time like you have to make sure the milk is in her normal...Not even place. It wasn’t that but it had to be it, not like she has to wake up and you go and start warming the milk, no. The moment she wakes up, she wants the milk done, ready.”

Participant 4 further narrated,

On several occasions, we have gone to church, that before I know that my daughter is on the spectrum, and on several accession while at church, she would start screaming, to me I didn’t know. I just thought that maybe she is having a bad day and friends started to tell me about the possibility of my child being sick.

Most caregivers reported that their children displayed some form of aggressive behavior, making it difficult for them to adjust to various social contexts. Their children struggled to express their emotions, which often led to frustration and anger outbursts. These behaviors included sudden shouting, frequent tantrums, and, in extreme cases, self-harm such as biting themselves. The unpredictability and intensity of these reactions further complicated their ability to interact socially and created significant challenges for both the children and their caregivers.

## **Emotional Delays**

All participants reported that their children experienced significant emotional delays. These delays manifested in various ways, including self-isolation, indifference towards their parents, and repetitive behaviors. Additionally, children exhibited aggressive and obsessive behaviors, coupled with limited affective responses. These emotional challenges were consistently observed across all interviewed participants, highlighting the complex and multifaceted nature of emotional development issues in children with autism spectrum disorders.

## **Repetitive Behavior**

Caregivers realized that their children had the habit of engaging in repetitive behavior. This kind of behavior created alarm for them, because of its impact on their children's overall emotional development.

Participant 3 had this to say:

“And then when I'd take her to school, she would run away from me immediately and go to a certain classroom, so one day I just out of curiosity I asked the teacher why does she, why she keeps going you know. So, the teacher told me she likes Legos or they are called legos or what. Yes, she likes playing with them, stuff like that. And she is always doing the same thing.”

Participant 2 said:

“My daughter developed a fascination with organizing objects by color from a very young age. She would spend hours arranging her toys or books in perfect rows, and if anyone disrupted her pattern, she would become visibly upset. It

became clear that this repetitive behavior was her way of finding order and predictability in her world."

### **Confirmation of Diagnosis by a Pediatrician**

Majority of caregivers consulted a pediatrician to confirm the suspicion of their child being on the autism spectrum. Most caregivers consulted the pediatrician when the child was 2-5 years old.

### **4.4 Challenges experienced by Caregivers of Children with ASD**

The researcher in this study aimed to identify the challenges experienced by caregivers of children with autism spectrum disorders. After interviewing the participants and analyzing their responses, several subthemes emerged under the main theme of acceptance and adjusting. These includes; Financial hardships, Stigma, Stress, Depression, Psychological distress and Physical health challenges.

### **Table 2 shows theme 2 and Sub-themes under Challenges faced by Caregivers**

---

*Theme 2: Challenges experienced by caregivers*

- a) Financial hardships
  - b) Stigma
  - c) Stress
  - d) Depression
  - e) Psychological distress
  - f) Physical health challenges
  - d) Marital challenges
-

## Financial hardships

Financial hardships among caregivers of children on the autism spectrum represent a significant and multifaceted challenge. These caregivers faced substantial economic burdens due to the high costs of medical treatments, therapies, and specialized educational services required for their children. Additionally, many caregivers experience a reduction in household income, as the demands of caregiving limited their ability to maintain full-time employment. This financial strain was compounded by the indirect costs, such as transportation expenses for medical appointments and the need for specialized activities or home modifications. The cumulative effect of these financial pressures not only impacted the caregivers' economic stability but also contributed to heightened stress and decreased quality of life, further complicating their ability to provide optimal care for their children.

Participant 3 for example had this to share

*I quite employment, because I returned home, I was living away at the time, I had travelled as a student, I didn't get to finish my course, I dropped that and then also I didn't seek employment.*

Participant 3 further added on saying

*Its an expensive journey as well, as it takes you on a financial drain, because the treatment plan you are given involves a lot of therapies and the exposure to other forms of activities that could be like therapies to stimulate their senses... you know, the tactile and all of that, so it's a lot... you need the*

*swimming pool, you need to involve him in sports and anything else that can work for him if they are not going to be academic*

This financial strain was compounded by the indirect costs, such as transportation expenses for medical appointments and the need for specialized activities or home modifications. Participant 5 shared;

*When we received our child's diagnosis, we knew it would bring challenges... It was really a time of testing for me and my husband. The financial burden was overwhelming. His therapy regimen include weekly sessions of different therapies... Each session requires specialized attention. We've had to prioritize their needs over other expenses.*

The cumulative effect of these financial pressures not only impacted the caregivers' economic stability but also contributed to heightened stress and decreased quality of life. Participant 7 had this to say:

*Feeding the baby is very expensive, they have a specific foods they are supposed to eat which are quite expensive. Actually I had to stop renting and go back to my mother's home to save up money to cover the child's meal. For example, the child drink this normal cow milk, I have to buy diary free milk which is more expensive.*

Similarly, caregivers were faced with financial burden resulting from care demand as Participant 9 put is saying:

*Every week, I have to take my child to hospital. It's expensive but I have to find a way to get money at least every week to take my baby to hospital. The father support by paying for the therapies... but I am a mother who left my work to look after the child. So getting money for these other expenses is still difficult.*

## **Stigma**

Stigma among caregivers of children on the autism spectrum is a pervasive and challenging issue that significantly impacts their daily lives and well-being. Caregivers often face societal misunderstandings and negative stereotypes about autism, which can lead to social isolation, discrimination, and judgment from others. This stigma not only affects their social interactions but also exacerbates feelings of guilt, shame, and helplessness. The fear of being judged or misunderstood can discourage caregivers from seeking necessary support and resources, further isolating them and their children.

Here is what participant 3 had to say

*Yes, he was self-harming and also aggressive, so when we would go out in the public, if he can not have his way, his melt downs were very aggressive. He is either harming himself or he is hurting you. So, I reached a point, I didn't want to take him anywhere any more because its embarrassing, people are thinking you have a spoilt child, or you are not raising your child well.*

Participant 1 said

*And of cause, its overwhelming for you, and you are also crying in public.*

Caregivers often face societal misunderstandings and negative stereotypes about autism. Participant 3 further said;

*So, I started business, I had a saloon, and my workers behind my back are talking about how I sacrificed my child for money. And you are wondering, where is the money? You know. So that whole talk of you sacrificed your child, and you're like did I choose...cries... so that the talk people have out there... about our children... but you think, would I choose to have this.*

This stigma not only affects their social interactions but also exacerbates feelings of guilt, shame, and helplessness as participant 4 shared:

*I had to first stop going to church, they would discriminate my child. Some parents had complained to the Sunday school teacher that my child is violent.*

Participant 6 said:

*My husband also, it was a blow in my face. He left me claiming that in their family, they don't have such children*

Moreover, due to stigma, caregivers' social interactions became minimal as participant 4 further said:

*I started avoiding public places apart from hospital. In public places... especially in the super market... you know because of some of the rare*

*behaviors of the child. People will keep asking “what is wrong with this child?  
But as a mother, I have learnt to live with it.*

### **Psychological distress**

Psychological distress among caregivers of children on the autism spectrum is a critical concern, as these individuals often grapple with significant emotional and mental health challenges. The constant demands of caregiving, coupled with the need to manage complex behavioral issues and coordinate various therapies, can lead to feelings of overwhelm, helplessness, and chronic fatigue. This distress is further compounded by the social isolation and lack of understanding from the broader community, which can exacerbate feelings of anxiety and depression. The cumulative effect of these stressors can severely impact caregivers' mental health, highlighting the urgent need for targeted psychological support and resources to help them cope effectively. Addressing psychological distress in caregivers is essential not only for their well-being but also for the sustained and effective care of their children.

Here is what participant 2 had to say

*Also just finding out where the necessary information is, where the people to work with are can be straining, because these are not readily available. It can be touch*

Further, participant 2 added;

*As a parent, my mental state was hit the most*

Participant 7 said;

*I dreaded him coming back home, like every time its clocking 3:00pm, anxiety kicks in, like, I wish he could stay away longer... but even he is away, you have failed to relax, you thought you could sleep and relax but you're still just meditating on him and worried all the time.*

The constant demands of caregiving, coupled with the need to manage complex behavioral issues were a great issued as shared by Participant 3;

*At some point I got addicted to sleeping pills... pain pill... pain pills sorry. You feel pain that you don't understand. It feels like... you know when people talk of heartache... but this is heartache that you actually feel like as though physically your heart is paining... it's not a heart attack or something but it pains. And when I would take them, I sleep and it's like the pain goes away.*

Similarly the stressors were many as shared by participant 4 said,

*Being able to tune out is hard, it's hard because it's not like just give a tab and everything... the condition goes away*

Moreover, the balance between work and being present in the childs life also a challenge as Participant 6 revealed that;

*The toughest was to have that presence of mine in the child's life, yet you have a lot that you dealing with inside you*

The cumulative effect of these stressors can severely impact caregivers' mental health as put by Participant 9 saying;

*Emotionally, sometimes you are overwhelmed and you don't know what to do*

## **Depression**

Depression among caregivers of children on the autism spectrum is a prevalent and serious issue that demands attention. These caregivers often face overwhelming responsibilities, including managing their child's special needs, navigating healthcare and educational systems, and dealing with social stigma. The relentless pressure and emotional toll of caregiving can lead to persistent feelings of sadness, hopelessness, and exhaustion, which are hallmark symptoms of depression. Additionally, the isolation and lack of support many caregivers experience can impair their depressive symptoms, making it difficult for them to function effectively in their caregiving role.

Some caregivers to isolating themselves from friends for some time. *Participant 2* had to say

*I did isolate myself for a while, Yaa for a while, you don't pick up phone calls. Because you're always thinking... that's what people ask, are you married? How old is your child? Where are you working? You know. So, you hide, and I did that*

Similarly *Participant 3* agreed to having insomnia tendencies saying;

*I wasn't sleeping, so sometime you think what is the point of sleeping, let me just stay awake because every two hours sort of, they are awake*

Moreover, *participant 3* acknowledged going through a cycle of depression, she said;

*I went through a cycle of depression, which took my hair away. As you can see, I lost my hair. So, depression is one of the toughest because every other day you are trying to figure out ways of helping this child, especially when the child cannot communicate...*

## **Marital Challenges**

Marital challenges among caregivers of children on the autism spectrum are a significant and often overlooked issue. The intense demands of caregiving, coupled with the emotional strain of managing a child's complex needs, can place considerable stress on relationships. Couples may struggle with differing coping mechanisms, feelings of isolation, and the redistribution of family roles, which can lead to misunderstandings and conflicts. The financial pressures associated with specialized care and therapies further compound these challenges, often resulting in reduced quality time and intimacy between partners. Consequently, maintaining a healthy marital relationship becomes increasingly difficult, emphasizing the need for targeted support and counseling services for these families.

Participant 2 acknowledged having marital challenges saying;

*The father walked away, saying in their clan, they don't have such children and supporting the child when you are a single mother is really hard.*

## 4.5 Coping mechanisms among Caregivers of Children with ASD

### 4.5.1 Problem-Focused Coping Styles of Caregivers of Children with ASD

The researcher in this study sought to identify the problem-focused coping styles of caregivers of children autism spectrum disorders. After interviewing the participants and analyzing the interviews, several subthemes emerged as follows.

**Table 3: Themes and Sub-themes of Problem-Focused Coping Styles of Caregivers**

---

Theme 3: Wholesome coping	
a) Faith in God	4
b) Need for special and inclusive education	
c) Need to adjust child's diet	4
d) Personal growth for caregivers	2
e) Support from other relatives or friends	9
f) Financial coping	10
Social coping	10
Emotional coping	10
l) Life style changes	7

---

Caregivers revealed that fully accepting their child's autism diagnosis was pivotal in their ability to cope effectively with the challenges it posed. Acceptance enabled

them to acknowledge and embrace the reality of their situation, facilitating the development of coping strategies. They recognized the necessity of making significant adjustments across various facets of their lives to better support their child. These coping strategies encompassed essential needs such as access to affordable special and inclusive education, dietary adjustments for their child, personal growth opportunities for themselves, support from family and friends, financial management, social engagement, emotional resilience, and lifestyle adaptations.

### **Faith in God**

Faith in God was a central component to coping

A number of participants acknowledged the working of God in their dealing with the child, Participant 3 had this say about Faith

*My faith, many times I have noticed, we seek miracles because we have problems. I did love the lord, you know you go church and all of that, but getting my son sort of pushed me to search for that higher being even on a deeper level. It took though down parts of fraud stars as well, but it was the only way that I managed to cope. Because if science cannot explain it...no one can explain what's going on... you sort of turn to faith... Yaa to faith.*

Moreover, Participant 4 shared how only prayer and faith in God were her pillars of strength, she said:

*I withdrew from people and it was only prayer and my faith that carried me through. I would go to church every evening because it was my only hope.*

Similarly, Participant 7 echoed saying God has been her strength in this trying times. She said:

*My child, it's been God. I really don't know if I didn't have my faith firm in God. On several occasion, my night were full of tears because of the difficulties... but I cried my tears to God.*

### **Need to Adjust Child's Diet**

Caregivers realized that paying attention to and appropriately adjusting their child's diet. They thus purposed to make adjustments in the kind of food they feed their children with. *Participant 10* had this to say:

*"We saw a doctor who is a pediatrician and also a hormone doctor, she kept on telling us that one of his hormones was affected. So, he's very big, he's bigger, he's fat he's actually tending to obese because there are foods that he doesn't eat and yet the body needs it for instance he doesn't eat meat, he doesn't eat chicken, he doesn't eat fish, he doesn't eat potatoes, he doesn't eat cassava he will eat only rice, beans, posho, rice, beans and cabbage."*

Changes in diet were made by caregivers to improve the children's welfare. Majority of them noted that before the diagnosis was confirmed they had been unsure about how to feed their child. Having attained the diagnosis and clearer information about the disease meal choices for the child became much easier: Here is what *participant 3* had to say:

*"I wasn't comfortable and the mere fact that the child did not eat. I think to me, I think the child didn't eat because I tried to ask the teachers and then*

*they started asking, you know like I ask you did Rhona eat and then you're like, you also ask another party. Did she eat? So, I saw they were not serious. Yes, they didn't follow up, they're like trying to find out so I said of course her glucose levels were down. At some point I saw she could not stand; I just rushed her to hospital. And moreover, at that time I didn't even wait for the cue"*

Participant two who benefitted from assistance from Teens and Tots autism Children's center narrated:

*"The fact that we were so ignorant about the state of our child even the foods that we were feeding him on was another problem...when we got to know his issue about that its autism, they guided us on which kind of food to feed him. On how to handle him so when we changed his diet it also made a huge, huge difference by the way."*

### **Personal Growth for Caregivers**

Caregivers had to pay attention to their behavior. Accepting that their child is on the spectrum implied that caregivers make changes in their personal lives: Here is what *Participant 10* had this to say:

*"But you know one thing I like about this experience it has helped me mature because I always, I would cry and every day of my life I'm telling you the truth, I would cry, even at times I cry, I breakdown and cry and I say God why, so at the end of it all I say, how long will I cry something just tells me how long are you going to cry now me I would and say I wish my mother was here she would tell me how to go about with it but I said for*

*how long will I cry. Let me get out of this dream of this pity, start looking for action.”*

In the same breath another *participant 7* said:

*“For me it was, I more or less also became a therapist, if you can ask Pat, we would like go to, you know I’d ask her but what about this you know we hit this milestone, what about this it’s so.”*

After the acceptance phase, the caregivers tried to cope. This effort to cope resulted in effective changes in various spheres of the caregiver’s lives. Caregivers adopted a holistic mode of coping to manage their child’s treatment and wellbeing.

### **Financial Coping**

Parents had to accommodate their child’s dynamic needs financially. They would often have to pay for special education or therapists. Some had to leave formal work environments and take on informal work finding other gainful means of employment. *Participant 3* had this to say:

*“Out there people are, these facilities are free, everything is free. They even give you extra support besides the tuition and what they give you like extra money for you to take care of that child. Here its different people are using people as well; because now let me give you an example my daughter was in that nursery school right, we at that time I used to pay around nine hundred thousand per month not even a term and remember its open throughout the year.”*

Then *Participant 10* reiterated that:

*“When they told us the rates they told us that you know you have to pay 1 million per month and then aah.. you’re supposed to, you’re supposed to take him with a care taker, then we looked at it now every month you are paying 1 million, it wasn’t cost effective.”*

Caregivers work was affected and they changed occupations or spent less hours at work in order to care for their child. In relation to this participant six narrated;

*“His sleeping pattern was difficult, he could not speak, he could bang his head, so you didn’t even know what you are dealing with, you didn’t know what is hurting him, that had such a big toll on my work because then my commitment, work hours were irregular, especially those moments when it would be too much....”*

Caregivers realized that taking care of their children required more time. For some this meant that much of their personal time was devoted particularly to managing their child’s symptoms which made them exhausted or burnt out. To other caregiver’s child care meant greatly reducing the time spent socializing while spending it alone with their child. Participant one had this to say;

*“Aaa.... because of the hyperactivity. I will sss... most of the time was spent attending to him and you know of course it’s exhausting and you have to do other things, other things have to get done you know you have no ‘me time’ to yourself which you never get, you know and the only time you get is when they are asleep and they don’t sleep for long and he didn’t sleep for long, for a very short time.”*

## Accessibility to Affordable Special and Inclusive Education

Special education was central to the education component of coping. Holism in the education for the child on the spectrum can be seen in the caution the caregivers took to ensure the child has a wholesome education. To this end, some caregivers searched for special needs schools while others preferred to take them to “normal schools” which had a policy for inclusive education. Some caregivers with financial endowment contracted the expertise of therapists or special needs teachers to work with them, while in an inclusive school setting. This helped improve and ease the lives of caregivers and children.

*“But the beauty is that they give him more time at his school, because he stays more at school on weekends”*

and further I respect to the sacrificial offering of time by the child’s father commented:

*“Even the dad he ends up coming earlier so that they engage more he ends up like putting more effort than when he’s not around.”*

Participant six emphasized dedicated quality care to the child saying;

*“He came to School and we see miracles happen. Actually, the teacher who is helping him now is a special need...those who sit behind them and help them absorb faster.”*

Another caregiver, participant seven whose child attended a special needs school reiterated;

*“The intervention came in form of a special need’s school. That was established just a few blocks from my house. So that is ‘Silent Angel’s’ TR.*

*Pat's place. It made my life so... kind of easy actually. It demystified autism. It's not really, I'm not doing my wish for no... no... don't get me wrong, mine was value addition"*

The same caregiver further narrated about the sacrifice the caregiver was giving to ensure holistic child care saying;

*"As in after therapy, he would go to school, therapy school. From 8 to I think 1pm, so I managed to change my work hours, I'd be home at about 6. So, from 6 maybe when he goes back, he goes to bed at 8 or 10pm. I would be continuing with what he'd done at school, you understand."*

### **Support from Other Relatives and Friends**

In Kampala where this study was done, it was apparent that holistic care not only sucked in the child's family but the community was also engaged. The caregiver often called on friends and the wider family for social support; this meant that without the backing of family and friends, caring for children on the spectrum would be very difficult; or almost impossible. These friends and relatives also helped in taking the child to the hospital for monitoring and follow up. Participant one expressed their gratitude to this third-party support in this way:

*"We took him to my mother's home and he was at my mother's home for like a year. Yes, like for a year. Yes, we would visit but mainly he was with her because she was willing and able to take him through the therapy, some people around would help him. Yeah, which really helped him a great deal."*

Another caregiver, participant five appreciated the help from friends saying:

*“We share with our friends so at least our friends know. That for her she is like that, this is what’s up so. There’s not too much of explaining to do so I don’t know we’ve just gotten to live with it and maybe the fact that they are actually so many parents...Who actually have autistic kids so somehow you feel like... aa are we the only people but then when you get to therapy with your child and someone is also saying the same thing you are like ooo okay, we are not alone in this so everyone is trying to do the best they can.”*

### **Emotional Coping**

One of the caregivers, participant 10 who put in effort to develop empathy and build a stronger bond with their child had this to say:

*“They told me the moment you see something. If he doesn’t eat food because it would be hard for me to know that he’s sick cause remember he wasn’t talking. Then they tell you if he doesn’t eat know that that is the, he’s going to fall sick so when he’s ...You have to now study him properly, when he’s quiet you know there is something wrong because he is hyper.”*

*Participant 2 narrated*

*“So, you can easily attack a child with autism, you can easily beat him up, you can easily but when you understand his situation you you handle him with care and love and you know understanding because you know his issue. But without knowing his issue you can think its other issues like maybe I’ll manners or just he is just being stubborn.”*

As evidenced by some caregivers' communication between them and the child improved. *Participant 10* reiterated:

*“He’ll cry when you see him crying because he is this person who is short tempered something wrong has happened to him, he’ll cry, he’ll say crying, he’ll cry then he’ll say you ...beat me... Like that he’ll try to show you something that something went wrong. That is when you know that something went wrong.”*

The same caregiver noted that with the help her son was receiving from therapists, he was able to speak. This was a great achievement both for the child and his parents, who had longed to communicate with him;

*“Now at 8 years is when Jeremy spoke his first word in November. Jeremy spoke his first word. He said ‘Mummy’. I started crying, when he saw me crying actually we were in the room and then I told my husband did you hear, he came he was reading a book there was some homework they gave him they had written ‘mother- in-law’ so he first started saying ‘mom, mom’ then he said ‘mummy’ ee I told my husband did you hear.”*

### **Life Style Changes**

Caregivers reported that they benefitted from making a strict schedule for the children. They realized that children on the spectrum benefitted and thrived on having a predictable schedule. By so doing they were able to reduce stressful moments and manage their children's daily activities better: *Participant 10* says:

*“Every time even during weekends he is up at 5. Hihi. laughs from 5 he knows 5 by 6 I should have had breakfast, if you are late, it is 6 so if you're preparing*

*food if not, you're not yet up by 5 you're he's during weekends, he's already in the kitchen serving breakfast, lunch should be ready by 1, if not he will just keep moving, pacing in the kitchen."*

In the same breath participant seven whose child was able to learn structure and routine from a special needs school known as Silent Angels narrated:

*"He would go to school, therapy school. From 8 to I think 1pm, so I managed to change my work hours, I'd be home at about 6. So, from 6 maybe when he goes back, he goes to bed at 8 or 10pm. I would be continuing with what he'd done at school, you understand; absolutely, the routine."*

Participant 10 was grateful that despite the confirmation of the diagnosis she was able to see her child for what he is and appreciate his strong areas. She has learned through the process of acceptance that when caregivers ignore the child's abilities and focus more on the inabilities they miss out on a wholesome picture of the child. Upon realizing this, she decided to harness her child's abilities to:

*"We were surprised that Jeremy has a talent of swimming, we actually got to know that he is talented in swimming. He could swim, he can swim on his own, he learnt how to swim on his own. He even sings. He can listen to a song and he can sing... In his normal school where he was before we transferred him to a special school, they had given him a scholarship of swimming because he would swim almost the whole day so they actually advised us to take him for swimming lessons and he can even compete in future."*

All spheres of the caregiver's life including their orientation on the knowledge and understanding of the disease and its impact on the child, attitude towards the

child’s actions, psychological, financial, social and spiritual aspects had to undergo a paradigm shift so as to effectively cope with the child and its incapacity, albeit variations among different caregivers.

#### 4.5.2 Emotion-Focused Coping Experiences of Caregivers of Children with ASD

The researcher in this study aimed to identify the emotion-focused coping experiences of caregivers of children with autism spectrum disorders. After interviewing the participants and analyzing their responses, several subthemes emerged under the main theme of acceptance and adjusting.

**Table 4**

#### **Theme 2 and Sub-themes under Emotion-Focused Coping Experiences**

---

*Theme 2: Acceptance and adjusting*

a) Denial based reactions	8
b) Discomfort based reactions	9
c) Pain based reactions	19
d) Hopeful reactions	21

---

Caregivers reacted to the doctor’s diagnosis of autism in various ways. Initially, many experienced pain, discomfort, and denial upon hearing the news. However, as they embarked on a journey of understanding and support, their reactions evolved towards acceptance, hopefulness, and a generally positive attitude. The caregivers' responses to the diagnosis of autism were commonly expressed as (a) denial, (b) discomfort-

based reactions, (c) acceptance reactions, and (d) hopeful reactions, reflecting their emotional and psychological journey towards embracing and supporting their child's unique needs.

## **Denial**

Initially, denial characterized most caregivers' response to the diagnosis of autism. This phase was marked by a sense of helplessness, accompanied by episodes of confusion, anxiety, internal conflict, and stress. Some caregivers attempted to rationalize their situation through cultural interpretations, while others sought solace in spiritual explanations for their child's condition. Despite these efforts, many remained in a state of denial, grappling with the harsh reality and its implications.

Participant 1, for example, struggled profoundly upon receiving confirmation of the diagnosis that their child was on the autism spectrum. This intense struggle with acceptance and understanding is a common experience among caregivers facing such diagnoses.

*Participant 3's words in a quote:*

*“So, it was hard, it was denial, yes, so we kept going back to the Doctor until they chased me...you know, you have to accept it, your child may never talk, may never have compassion, empathy... all of that” In that denial, you sort of what to prove a point*

In the same light, *Participant 5* reiterated,

*“Aan intellectual disability in not like a physical one where, you know, you're probably going to get a walking aid, you're going to get a hearing aid... because*

*the things involved in getting a child a normal life are not that obvious... so denial is the first thing to step in. I knew something on autism but because I thought the Doctors had it wrong, I moved to about five different Doctors... I think I was desperate for a different diagnosis.”*

### **Shock**

Some caregivers imagined that at least this would not be real, wishing that perhaps this was another illness with a definite cause, treatment plan or cure but not autism. For many it was indeed a shocking reality to perceive: *Participant 9* recalled this painful journey in the words;

*“Yes, I was shocked because on Google it says. No cause, no cure, so that’s what shocked me first. I’m like now what should I do. What do I do? Of course I was ‘aaa’ I was a bit traumatized.”*

### **Disbelief**

Some caregivers struggled to believe the accuracy of the diagnosis. It took a lot of convincing and effort for them to come to terms with the fact that they have a child on the spectrum. *Participant 3* particularly expressed disbelief when the diagnosis was confirmed. *Participant 3* narrated to this effect:

*“I kept asking the same questions already I had read and known. Because you see it’s not, it’s like I went the following day, after reading the article, no, I took my time reading and reading so by the time I went to see that doctor, already like in my head.”*

## Confusion

Caregivers confess to have felt confused and perplexed when the diagnosis was confirmed. They did not know what autism meant, what help or treatment options were available and where to find much needed support. They felt stuck. One of the caregivers narrated, participant 10:

*“You don’t know what autism is you don’t know, we ask them what pro, what caused this. They now kept on telling me there are many causes as to why this child could have developed this syndrome, this disorder but now...”*

In the same breath another *Participant 9* said she was confused after seeing a doctor;

*“He told me to take the letter to a certain teacher, a special needs teacher. So aaa I, I went there but she wasn’t there, so I said let me read and see what he wrote. So, I went home and read. And aaa I saw ‘autism’ of course I didn’t know what it is so I just read myself. I started I went to Google and started reading about it, so as I read, I realized that t the signs are the same as my children, my child. So, I just got to know.”*

## Fear of the Unknown

Some caregivers became fearful of their child’s future upon confirmation of the diagnosis. They did not know what to expect, how to handle this disease without a cure, and what implications it could have on their child’s well-being. *Participant 10* had this to say to this effect:

*“Where will I go, where will I start from, who do I turn to, how will I, how will I face society, how will he face other children, how. How will he be with other*

*children, how will he be with his siblings, cause that is now my biggest challenge.”*

### **Anxiety**

Caregivers often became anxious when the diagnosis was confirmed. It evoked a lot of worry and concern. They became unsure of how to handle their children, and even fearful of the ways they could have mishandled their children making their condition worse. Participant six had this to say:

*“I got a little anxious wondering what are the implications of this diagnosis will he never be able to talk, will he never be able to go to school? I had quite many observations but ...Anahi mean many concerns.”*

To this effect another Participant 10 narrated:

*“We don’t know how to handle children who are like that those some of our worries, you see he is now developing pubic hair, where will you start from yet he is this person who will just remove off his cloth and go to the bathroom. For him he doesn’t know what is happening... you are imagining how will life be after because remember this Dawn stops at maybe P.4 from now P.4 where will I start from?”*

### **Pain based reactions**

Coming to terms with the autism diagnosis was a painful process for most caregivers. This included reactions which included self-blame, depression, trauma and devastation. They experienced psychological pain that remarkably impacted their lives. Prior to being able to accept that their child is on the spectrum, many

parents had to work through many uncomfortable and painful emotions. *Participant 10* whose first-born child on the spectrum with tears down her cheeks narrated:

*“At times I ask God why, why (cries)... why did it have to be me, why, why, why did it have to be my first child. Why and those are questions I, I every time when I think of. And you know someone says anything I ask God I say why, why him, why is it the first child.”*

### **Self-Blame**

In some cases, caregivers blamed themselves for the fate of their child. They wished they would have done something to keep their child from experiencing autism. Here is what a *Participant 1* had this to say:

*“You go into definitely, the phase of what did I do wrong, did I eat right, did I do so many scandals.”*

### **Feelings of Sadness**

Some Care givers often became depressed when the diagnosis was confirmed. It was quite overwhelming and emotional for them. *Participant 3* narrated:

*“There are so many things you think about life after... Of course, in most cases mothers are always on the front line. Okay, if I’m not on this earth what is going to happen? And for me unfortunately I was born like one child. So, I’m like now, I’d think maybe my parents would come in and like my mom, but even then, she is not growing younger so it gives you that depression, you are like what will my kid’s be.”*

Similarly, some caregivers admitted having experienced feelings trauma upon confirmation of the autism diagnosis. *Participant 10* had this to say:

*“It is hard, it is painful and every day you have to hear something. You have to hear something you have to hear someone say make a statement, you have to see react after seeing this child, you know there is a lot so when he was diagnosed with autism, it was painful, we actually burst into tears actually me I started crying from the minute Byarugaba told me that .. up to now I cry when I see my child.”*

### **Devastation**

Participant 10 expressed that the reactions of acquaintances and friends on discovering her child is on the spectrum caused her a lot of devastation. Participant 10 further recalled and narrates hearing their hurtful remarks in these words:

*“They demoralize you; they actually make you feel small. Yeah, they do so, there’s one who was, taking my child to school, he would drop my kid every morning and pick him up, so one time just threw it in my face and told me “ Oh my husband said, I think these people wake up in the morning and just feed this child, there’s nothing much this child does.”*

Participant 10 in other words narrates that the confirmation of the diagnosis left her quite discouraged:

*“The doctor kept on telling us you know, ‘why did you give birth to this child, you even see his head is too big.’ Yeah, that is what he told us, told me, I cried, I cried, I cried, I shed tears, my husband told me ‘Don’t cry we know what, God really knows, we don’t know what happened we are just new parents.”*

## Hopeful Reactions

Caregivers gradually progressed from denial to acceptance. Acceptance was expressed through a sense of relief, a determination to find a solution and believe that there was indeed a higher purpose for the suffering.

## Relief

*Participant 2* relieved after the diagnosis was confirmed had this to say:

*“We took it because remember we had spent most of the time grumbling in different areas trying to find you know. It was like a relief trying to find out what happened to our lovely son. Aaaa because just following the explanation as told we moved in different areas. We went to Mulago we went to some specialists in around Kamwokya you know but all in vain not until we Goggled and landed into an institution which is basically handling them, so by the time we landed here it was a relief. It was a very big achievement on our side.”*

## Determination to find solutions

Confirmation of the diagnosis results sparked off the caregiver’s determination to find solutions for the well-being of their child. Initially they felt stuck, but when they confirmed the child’s illness, they were capable of forging a way forward. Participant 3 narrated:

*My son talks, and it’s not the journey with most people... it’s not that even though they have had the speech therapy sessions and all of that... the self-harming went because when he started talking, I taught his scripture, since I was on the journey... I would be like “by His stripes you are healed” so am like you say this... so every time he would be in a moment of a meltdown... you*

*know, we call them sometimes tantrums... I would just tell him recite, recite, recite. So, for me, it is walking with God I must say that is carrying me through this Journey.*

Participant 10 sought spiritual help for their child that helped her accept his condition. The caregiver who had a supportive spiritual community around her attributes her ability to accept the diagnosis through seeking spiritual help; through prayer. Here is what she had to say:

*“I said God, thank you for this because I remember I told God, I just started now, actually I resorted to pray I said now you know what there is nothing now I can do. I just have to pray. One of my friends taught me how to pray.”*

### **Gratitude**

There was in some a sense of gratitude that at least, now they know what the child is suffering from. With time, they grew to accept their child and many of them were able to start finding help and ways of improving their children’s overall wellbeing. Many parents who came to this point were better equipped to deal with the challenges and adjustments that come with having a child on the spectrum. It is through acceptance that caregivers were able to make a positive shift in terms of caring for their children expressed in the words of participant 2:

*“But eventually with time we got to adjust because we realized the earlier you accept the faster you get help; you get him help.”*

And participant 3 as

*“Once we got to find out we were like now what should we do, that means we really had to get into that mode of what can we do to help her, yeah, yeah.*

*Cause we didn't know at first, we thought maybe she heard a hearing problem cause she didn't respond to her name."*

Acceptance often led to a hopeful and positive outlook to life through personal changes in the growth of the child. Some caregivers attempted to improve the welfare of the autistic child through diet adjustment, adopting a customized approach, seeking special education facilities and exploring all possible ways of managing the ailment. This meant deliberately resolving to treat the child individually with a customized approach. It meant that parents would stop comparing the child on the spectrum to their siblings. Participant three further narrated;

*"Somehow, I put so much pressure on my first born I was like this one I'm not putting pressure whenever she feels like it she will. She will talk she will but at least I see she is social she wants to play. Just now she just copies a lot of her sister so."*

## **Chapter Five**

### **Discussion**

#### **5.1 Introduction**

The objective of this study was to investigate the difficulties and strategies employed by caregivers of children diagnosed with autism spectrum disorder in Kampala. This chapter aims to provide interpretations for the findings reported in Chapter four and examine the two primary research topics, which are to investigate the difficulties faced by caregivers of children on the autism spectrum and their methods of managing these issues. Additionally, the study findings are connected to the research questions. Ultimately, the restrictions, findings, and suggestions are documented. The primary research inquiries for this study were: 1) What are the challenges faced by caregivers of children on the autistic spectrum in Kampala? 2) What coping strategies do caregivers of autistic children in Kampala employ?

#### **5.2 Suspicions and Diagnosis**

Caregivers faced several distinguishing qualities that set their children on the autism spectrum apart from typically developing youngsters. They were more determined to find solutions, seeking information from a variety of sources, including doctors and psychologists. Over time, they were able to reason that many of these traits were suggestive of autism spectrum disease. The onset of these signs and symptoms initiated their journeys towards acceptance, seeking appropriate assistance, and creating resources to effectively meet their children's needs. One sign that caregivers emphasized was delayed milestone, as seen by the parents, worried friends, and

physicians. Most parents characterized this as a gradual development that is slower than usual, manifested by delays in crawling, sitting, talking and walking when compared to other children of the same age. Scientists have discovered that children diagnosed with ASD show impairments in their motor skills.

A study by Posar & Visconti (2022) revealed that children with autism spectrum disorder have gross motor delays. These delays are evident as early as six months of age in newborns at high risk for autism. In this particular group of children, they are highly prevalent and tend to worsen in severity between the ages of 5 and 10. According to Hedgecock et al. (2018), parents can identify early indications of potential developmental difficulties in children with ASD by the age of 14 months. The severity of these delays is greater when parents recognize them at an earlier stage. These negative impacts hinder their capacity to do everyday tasks; hence, motor delays or delayed milestones might lead to more severe social difficulties for children on the autism spectrum than previously recognized.

Most caregivers reported experiencing social-psychological delays, leading to physical tiredness. These traits were predominantly marked by limited eye contact, heightened sensitivity, and excessive activity. Approximately 90% of the caregivers acknowledged that their children experienced difficulties with hyperactivity, resulting in negative impacts on their social relationships and causing anguish to their moms. A participant said that her child frequently exhibited restlessness and cried throughout the night, causing her to experience sleep deprivation on several occasions. This situation led to the accumulation of stress and physical fatigue for her. In their study,

Wijesekera and Madhavi (2017) observed and recorded the physical exertion and fatigue experienced by parents while caring for their children. They emphasized the negative impact of this strain on women's physical health and overall well-being. Researchers have verified that maternal stress can be attributed to the deficient social skills observed in autistic children, although no such correlation has been found for parents of persons on the autism spectrum (Gona et al., 2016).

Parents often saw cognitive delays in their offspring, including challenges in acquiring language, solving problems, and comprehending social signals. These results align with other research that emphasizes cognitive deficits as a prevalent initial indication of autism. Alrehaili et al. (2023) conducted research that frequently identifies cognitive impairments, particularly in language and executive functioning, as the initial signs of ASD. The caregivers' observations of their children's challenges in reaching cognitive developmental milestones are consistent with the diagnostic criteria for autism, which encompass deficiencies in intellectual functioning and adaptive behavior. Further, Caregivers also reported numerous instances of aggressive behavior. Physical aggression, such as striking or biting, as well as verbal hostility, frequently occurred. These actions frequently stem from communication challenges and feelings of frustration, which are common in children with autism. Research conducted by De Giacomo (2016) supports similar findings, suggesting that violent behavior is prevalent among children diagnosed with ASD. This behavior can cause anxiety for both the child and the caregiver, resulting in difficulties in handling everyday tasks and social interactions.

Caregivers also reported emotional delays, which include minimal affect, apathy towards caregivers, and challenges in comprehending and expressing feelings. These delays are a clear indication of the wider social and emotional impairments linked to autism. Tathgur and Kang's (2021) research demonstrates that children with autism spectrum disorder (ASD) often experience significant delays in their emotional development. These delays manifest in challenges related to empathy, emotional regulation, and establishing social bonds. Caregivers' accounts of their children's emotional deficits correspond with the fundamental diagnostic criteria of autism, which highlight deficiencies in social-emotional reciprocity. Caregivers frequently saw repetitive behaviors, such as hand-flapping, strict routines, and a strong fixation on certain hobbies. These behaviors are characteristic of autism and are part of the diagnostic criteria. Martínez-Pedraza et al. (2009) conducted research that highlights the high occurrence of repeated behaviors in children diagnosed with autism spectrum disorder (ASD). Researchers see these activities as self-soothing strategies or reactions to sensory stimulation. Observations made by caregivers on repeated activities frequently serve as a pivotal factor in raising initial concerns about autism and pursuing a formal diagnosis.

### **5.3 Challenges faced by caregivers of children on the Autism spectrum**

The study aimed to uncover the multifaceted challenges experienced by caregivers of children with autism spectrum disorders (ASD). Through in-depth interviews and careful analysis, several subthemes emerged under the main theme of acceptance and adjusting: financial hardships, stigma, stress, depression, psychological distress,

physical health challenges, and marital challenges. These findings align with and expand upon existing literature, providing a comprehensive understanding of the caregiver experience.

Financial difficulties are a prominent issue among caregivers of children with ASD, as evidenced by this study and corroborated by previous research. Studies by Lavelle et al. (2014) and Matin et al. (2022) also highlight the substantial economic burden associated with ASD, including costs for therapies, medical treatments, and specialized education. The reduction in household income, as caregivers often need to reduce work hours or leave their jobs entirely, exacerbates these financial pressures. This economic strain is further intensified by the high costs of private services, which are often necessary due to insufficient public resources. Further, the stigma associated with autism is another significant challenge reported by caregivers. This finding is consistent with studies by Turnock et al (2022) and Aderinto et al (2023), which illustrate the pervasive social stigma and discrimination faced by families of children with autism. Stigma can lead to social isolation and a reluctance to seek help, negatively impacting both the caregivers' and children's quality of life. The lack of public understanding and awareness about autism contributes to this issue, making it essential to promote educational campaigns and foster a more inclusive society.

Moreover, caregivers in this study reported high levels of stress due to the continuous and unpredictable demands of caregiving. This stress is well-documented in the literature, with studies by Nik Adib et al. (2019) and Fuld (2018) highlighting the

chronic stress experienced by caregivers of children with ASD. The need to manage behavioral interventions, medical appointments, and educational needs can be overwhelming, leading to significant emotional and psychological strain. The complexity and intensity of these caregiving tasks contribute to elevated stress levels. Further, the prevalence of depression among caregivers, as found in this study, aligns with findings from studies by van Niekerk et al. (2023) and Chen et al. (2024), which report high rates of depressive symptoms among caregivers of children with autism. The emotional burden, combined with social isolation and financial strain, can lead to persistent feelings of sadness, hopelessness, and exhaustion. The cumulative effect of these stressors can significantly impact caregivers' mental health and their ability to provide effective care.

Besides, Psychological distress, encompassing anxiety, emotional strain, and mental fatigue, was a common challenge identified in this study. Previous research, such as a study by Tathgur and Kang (2021) highlights the significant psychological impact on caregivers of children with ASD. The need for constant vigilance and the management of complex behavioral issues can lead to substantial emotional and psychological burdens, making it crucial to provide targeted psychological support and resources for caregivers. In addition, Caregivers' physical health challenges, as reported in this study, are supported by findings from a study by Kang et al (2020) which indicates that the physical demands of caregiving can lead to various health issues, including chronic fatigue, sleep disturbances, and other physical ailments. The relentless nature of caregiving tasks often leaves little time for self-care, exacerbating these health problems. Ensuring caregivers have access to health care and support is

essential for their well-being. Moreover, marital challenges emerged as an additional subtheme, highlighting the strain caregiving can place on relationships. This finding is consistent with research by Papadopoulos (2021) which discusses the increased risk of marital conflict and divorce among parents of children with ASD. The stress and demands of caregiving can lead to conflicts, reduced intimacy, and differing coping strategies between partners, affecting the overall family dynamic. Providing marital counseling and support can help mitigate these challenges.

## **5.4 Coping Mechanisms of Caregivers of Children with ASD in Kampala**

### **5.4.1 Problem-Focused Coping Styles of Caregivers of Children with ASD in Kampala**

A number of participants expressed Faith in God, or spiritual beliefs as a way they dealt with some of the challenges. Faith plays a significant role in the coping mechanisms of many caregivers of children with autism spectrum disorders (ASD); it offers emotional solace, a sense of purpose, and a supportive community, helping caregivers navigate the complex challenges associated with their caregiving role (Ekas et al., 2009). Faith in God provides caregivers with a source of emotional and psychological support. The belief in a higher power and the practices associated with faith, such as prayer and meditation, offer comfort and hope. This is in agreement with a study by Sen et al., (2022) highlights that spirituality can significantly reduce stress and anxiety among caregivers, fostering a sense of peace and resilience. Caregivers often find solace in their faith, believing that their challenges have a greater purpose and that they are not alone in their struggles. In addition, caregivers can share their experiences with others who understand their struggles, receive

emotional support, and access practical help from community members. This social network can provide respite care, financial assistance, and moral support, alleviating some of the caregiving burden (Ekas et al., 2009).

Also, many participants acknowledged that special education programs designed to meet the individual needs of children with autism were helpful. These programs offer customized teaching methods, specialized curricula, and appropriate accommodations to support the child's learning and development. This is in agreement with Ahlers et al. (2023) who highlight the benefits of inclusive education in enhancing social competence and peer relationships for children with ASD. Caregivers often advocate for inclusive settings to help their children develop essential social skills and build friendships, which are critical for their overall development. Moreover, children with autism often experience gastrointestinal (GI) issues such as constipation, diarrhea, and abdominal pain. Therefore, adjusting their diet helped manage these symptoms, improving the child's comfort and well-being. Research by Blennerhassett et al. (2023) indicates that GI problems are prevalent in children with ASD, and dietary interventions can be effective in alleviating these issues. Caregivers often implement changes such as increasing fiber intake, reducing dairy, and eliminating foods that trigger symptoms, which can result in significant improvements in the child's digestive health (Blennerhassett et al., 2023). One of the most popular dietary interventions for children with autism is the gluten-free and casein-free (GFCF) diet. This diet involves eliminating all sources of gluten (found in wheat, barley, and rye) and casein (found in dairy products) from the child's diet (Quan et al., 2022).

Participants also made time to improve themselves, caring for a child with autism often requires caregivers to become well-versed in a variety of skills and knowledge areas. This includes understanding the specifics of the disorder, learning effective communication strategies, and implementing behavioral interventions. Studies by Green et al. (2006) and Myers et al. (2007) highlight that caregivers who engage in educational programs and training courses feel more competent and confident in their caregiving roles (Aithal et al., 2023). By gaining expertise in these areas, caregivers can provide better support to their children and manage challenging behaviors more effectively. Personal growth involves developing resilience and effective coping mechanisms to handle the stress and demands of caregiving. Resilience enables caregivers to adapt to challenging situations and bounce back from setbacks. Bekhet et al., (2012) indicates that caregivers who focus on personal growth report higher levels of resilience, which helps them cope with the emotional and physical demands of their role. This includes practicing self-care, seeking social support, and engaging in stress-reducing activities.

Support from relatives and friends also emerged as a coping mechanism for caregivers. This support is essential for caregivers to prevent feelings of isolation and maintain a sense of normalcy in their lives. Support from relatives and friends can facilitate social activities and community involvement, helping caregivers stay connected to their social networks. Studies by Weiss et al. (2013) and McStay et al. (2014) indicate that caregivers who engage in regular social interactions report higher levels of life satisfaction and lower levels of depression. Social activities provide caregivers with opportunities to relax, share experiences, and gain new perspectives.

Support from relatives and friends can include financial assistance or help in accessing financial resources. A study by Parish et al. (2012) highlights the financial strain on families of children with autism and the benefits of financial support from extended family and friends. Financial assistance can ease the burden on caregivers, allowing them to focus more on their child's needs and well-being.

Caring for a child with autism often requires significant financial resources. Costs can include diagnostic evaluations, behavioral therapies, speech and occupational therapy, special education services, and assistive devices. According to a study by Lavelle et al. (2014), families of children with autism face average medical costs that are significantly higher than those for children without autism. These expenses can strain family finances and create a need for effective financial coping strategies. Effective financial planning and budgeting are essential for managing the costs associated with autism care. Caregivers who develop detailed budgets and track their expenses are better equipped to allocate resources efficiently. Parish et al. (2012) highlights the importance of financial planning in reducing financial stress and improving financial stability for families of children with autism. Creating a budget helps caregivers prioritize expenses, plan for future needs, and avoid unnecessary debt.

Caregivers of children with autism also use emotional coping as a mechanism of coping in the face of intense emotional challenges. The demands of caregiving, combined with the unique needs of their children, can lead to chronic stress and emotional exhaustion. A study by Pena-Shaff (2023) highlights the high levels of

emotional distress reported by caregivers. Common emotional challenges include anxiety about the child's future, frustration with behavioral issues, and feelings of isolation due to the demanding nature of caregiving. One effective emotional coping strategy is seeking professional support, such as therapy or counseling. Mental health professionals can provide caregivers with tools to manage stress, process their emotions, and develop healthy coping mechanisms. Weiss et al. (2013) suggests that caregivers who engage in therapy report improved emotional well-being and reduced symptoms of depression and anxiety. Therapy can offer a safe space for caregivers to express their feelings and receive guidance on managing their emotional challenges.

#### **5.4.2 Emotion-Focused Coping Experiences of Caregivers of Children with ASD in Kampala**

Denial-based behaviors are frequently observed as an initial coping strategy among caregivers when they are informed of their child's diagnosis of autism spectrum disorder (ASD). This coping method entails caregivers engaging in a deliberate refusal to acknowledge or accept the actuality of their child's illness. Individuals may demonstrate skepticism, downplay symptoms, or evade conversations pertaining to autism (Ismael et al., 2018). Denial functions as a defensive barrier against the intense emotions and consequences linked to autism, offering caregivers a brief respite from anguish. Nevertheless, an extended period of refusing to acknowledge the truth might result in harmful consequences for both the person providing care and the child. Caregivers may postpone obtaining necessary treatments and support services, which are vital for their child's developmental advancement. Kowal et al.

(2022) conducted research demonstrating that denial can lead to social isolation, as caregivers may struggle to publicly acknowledge and discuss their child's illness. Moreover, responses based on denial can intensify the stress experienced by caregivers and add to feelings of powerlessness and uncertainty. Caregivers who refuse to accept the diagnosis may hinder their ability to make well-informed decisions about their child's educational, therapeutic, and medical needs. This coping mechanism is prevalent in diverse cultural situations, as demonstrated by global studies. In research done in Sri Lanka (Wijesekara et al., 2017), mothers initially exhibited hesitation and skepticism upon getting the autism diagnosis for their children, which resulted in a delay in their involvement with essential treatment measures. Therefore, although denial may provide temporary emotional comfort, it is critical to confront and overcome denial through education, therapy, and peer support in order to facilitate successful caregiving and improve outcomes for children with ASD.

Caregivers of children with autism spectrum disorder (ASD) commonly have discomfort-based emotions, which refer to emotional responses arising from the difficulty and unpredictability involved with caregiving. This coping approach involves experiencing emotions such as annoyance, uneasiness, and tension while dealing with the daily challenges of taking care of a child with autism spectrum disorder (ASD). Caregivers may encounter unease when faced with behavioral issues, sensory sensitivities, or communication difficulties that are inherent to autism. These reactions may appear to be emotional discomfort and may have an impact on caregivers' well-being and coping methods. Research has indicated that experiencing

discomfort is a notable component of providing care for children with autism spectrum disorder (ASD). Hastings and Brown's (2002) research reveal that caregivers frequently encounter stress and emotional strain when addressing their child's behavioral challenges. These emotions can result in increased levels of worry and fatigue among caregivers, impacting their capacity to deliver consistent and efficient care. Efficient coping mechanisms for reactions based on discomfort frequently entail utilizing support networks, practicing self-care, and participating in training programs that equip caregivers with practical skills to handle stress and improve their resilience. To enhance their capacity to handle the difficulties of caring for a child with ASD and encourage the child's growth and welfare, caregivers can proactively manage reactions stemming from discomfort.

Research has demonstrated the significant influence of pain-induced responses on the emotional welfare and psychological state of caregivers. Neely-Barnes et al. (2011) conducted a study that explored how caregivers of children with ASD feel emotions similar to loss and mourning while facing the difficulties of parenting their kids. If not addressed through efficient support networks and therapies, these emotions can lead to enduring states of sadness, anxiety, and long-term stress. It is essential to acknowledge and affirm the emotional distress experienced by caregivers in order to provide them with the requisite tools, including therapy, peer support groups, and educational courses, to properly manage their situation. Caregivers may strengthen their ability to bounce back, create plans to assist their child's distinct needs, and optimize their capacity for a satisfying existence in spite of the difficulties associated with autism spectrum disorder by recognizing and dealing with responses to suffering.

Caregivers of children with autism spectrum disorder (ASD) utilize hopeful responses as an essential coping mechanism to overcome the difficulties and uncertainties linked to their child's diagnosis. The ability to maintain a positive outlook, actively seek opportunities for personal growth and advancement, and actively participate in treatments and therapies that enhance their child's development distinguishes this coping style. Caregivers who adopt optimistic responses frequently prioritize the identification and utilization of resources that enhance their child's distinct skills and capabilities, cultivating a favorable perspective on their child's future despite the obstacles presented by ASD.

Studies have emphasized the important impact of optimistic responses on improving the ability of caregivers to bounce back from challenges and maintain their mental and emotional health. In their study, Cejalvo et al. (2021) discovered that caregivers who possess an optimistic perspective tend to have reduced levels of stress and anxiety in comparison to those who lack this attitude. This coping approach enables parents to assertively champion their child's needs, actively engage in the process of treatment planning, and proactively seek out support networks that offer emotional validation and practical help. In addition, optimistic responses contribute to a supportive atmosphere that promotes the child's social, emotional, and cognitive growth (Bhattacharyya et al., 2021). Efficient methods for fostering optimistic responses involve utilizing educational materials, engaging in support communities, and commemorating minor milestones and accomplishments in the child's development. Caregivers may have a significant impact on their child's well-being and

the possibility of a successful life despite the obstacles of the autism spectrum condition by encouraging optimism and proactive involvement.

## **CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS**

### **6.1 Introduction**

This chapter presents the conclusions drawn from the study findings and offers practical recommendations based on the evidence gathered. The study explored the experiences of caregivers raising children on the autism spectrum, highlighting the different challenges they encounter and the various coping strategies they adopt.

### **6.2 Conclusion**

Caregivers of children on the autism spectrum face a multitude of interrelated challenges that affect their emotional, psychological, social, and physical well-being. Financial hardships are among the most commonly reported issues, often stemming from the high costs of therapies, specialized care, and reduced income due to caregiving responsibilities. Stigma from the community further exacerbates their burden, leading to social isolation and reluctance to seek support. As a result, many caregivers experience chronic stress, which if unaddressed, can evolve into depression and persistent psychological distress. The emotional toll of caregiving is also reflected in physical health challenges, including fatigue, sleep disturbances, and other stress-related illnesses. Moreover, the strain of caring for a child with autism can impact family dynamics, leading to marital challenges such as communication breakdown, tension, or separation. These overlapping difficulties highlight the urgent need for

holistic support systems that address not only the needs of the child but also the well-being of the caregiver.

In response to the numerous challenges they face, caregivers of children on the autism spectrum often adopt a range of problem-focused coping strategies to navigate their complex realities. Many caregivers draw faith in God as a foundational source of strength, helping them maintain hope and resilience through spiritual belief. A significant number also emphasize the need for special and inclusive education, advocating for appropriate learning environments that cater to their child's developmental needs. Adjusting the child's diet was also cited as a crucial strategy, particularly for managing sensory issues or behavioral challenges. Over time, caregivers reported experiencing personal growth, gaining patience, resilience, and advocacy skills. Support from other relatives or friends provided practical help and emotional encouragement, while financial coping strategies, such as budgeting, income-generating activities, or seeking external aid, helped them meet care-related expenses. Caregivers also leaned on social coping mechanisms, including community groups and peer support networks, and engaged in emotional coping practices like journaling or counseling. Finally, many made broader lifestyle changes, restructuring their routines and priorities to better align with their child's unique needs. These coping mechanisms collectively enabled caregivers to manage the stressors of their caregiving roles while fostering a supportive and adaptive environment for their children.

Moreover, in coping with the emotional burden of raising a child on the autism spectrum, caregivers often experience a variety of emotion-focused coping reactions.

Many initially exhibit denial-based reactions, struggling to accept the diagnosis and holding onto hope that their child may "grow out of it" or that there was a mistake in the assessment. This stage of denial often leads to discomfort-based reactions, including feelings of confusion, helplessness, or frustration, especially when comparing their child's development to that of typically developing peers. Over time, these reactions may evolve into pain-based responses, such as deep emotional sorrow, grief, or a sense of loss for the expectations they once held for their child's future. Despite these challenges, many caregivers ultimately adopt hopeful reactions, finding comfort in small milestones, celebrating their child's unique progress, and focusing on their strengths rather than deficits. This emotional shift plays a crucial role in building resilience and maintaining mental well-being amidst the long-term demands of caregiving.

### **6.3 Recommendations**

Many caregivers struggled to locate an inclusive special needs school where their children could thrive. Following their children's expulsion, these caregivers relocated to multiple schools before settling on one. Several schools denied admission to children on the spectrum. We should assess each child's autism special needs to determine their severity and the type of education they require. The school system should adjust and integrate this into its curriculum. Medical practitioners encouraged some caregivers of children with moderate autism to consider enrolling their children in regular and inclusive schools. Many schools hesitated to include them, fearing they

would present challenges. Prior testing may enable youngsters to study in regular schools.

Doctors and nurses were reluctant to provide parents with the information they needed to grasp their child's condition, according to many caregivers. Others avoided dealing with kids out of fear and shame. They had to undertake most of the background investigations and service searches alone. Health service professionals added that working, interacting, and communicating with their children was difficult. When caring for autistic children, many caregivers seek advice from family and friends. Health personnel need to participate in ASD awareness programs. Awareness and education might minimize stigma and ignorance about autistic children

Caregivers said that officials and instructors knew nothing about ASD. School personnel and administration should advocate for and raise awareness for ASD youngsters. ASD awareness may lessen stigma and unfavorable attitudes toward children on the spectrum since teachers, support workers, and administration may recognize their traits and problems and discover better methods to address them. Caregivers and school personnel (teachers, support workers, and administrators) may also work well together. An informed perspective will guide child rearing.

#### **6.4 Areas for Future Research**

Further research is required to investigate the correlation between autism and frequent seizures in children who are on the autism spectrum. In this study, we observed that recurring seizures negatively impacted the physical and mental health

of one autistic child until the age of seven. Due to the lack of information about this condition at the time, his caregivers mistakenly attributed the seizures to epilepsy, leading to confusion. The child's caregivers first believed that he did not have autism but instead had epilepsy. We should provide parents with explicit information on autism, its associated diseases, and their impact on children.

Additional research is necessary to improve the delivery of educational services for children diagnosed with autism spectrum disorder. Participants encountered significant difficulties in school. To help children on the autism spectrum achieve the highest standards of education, research should identify methods of creating more conducive learning settings.

## References

Aderinto, N., Olatunji, D., & Idowu, O. (2023). Autism in Africa: prevalence, diagnosis, treatment and the impact of social and cultural factors on families and caregivers: a review. *Annals of medicine and surgery (2012)*, 85(9), 4410-4416.

<https://doi.org/10.1097/MS9.0000000000001107>

Ahlers, K., Hugh, M. L., Tagavi, D., Eayrs, C., Hernandez, A. M., Ho, T., & Locke, J. (2023). "On an island by myself": implications for the inclusion of autistic students in self-contained classrooms in public elementary schools. *Frontiers in psychiatry*, 14,

1241892. <https://doi.org/10.3389/fpsyt.2023.1241892>

Aithal, S., Karkou, V., Makris, S., Karaminis, T., & Powell, J. (2023). Supporting the wellbeing of caregivers of children on the autism spectrum: A qualitative report on experiences of attending group dance movement psychotherapy. *PloS one*, 18(8),

e0288626. <https://doi.org/10.1371/journal.pone.0288626>

Al-Dababneh, K. A., & Al-Zboon, E. K. (2018). Parents' attitudes towards their children with cerebral palsy. *Early Child Development and Care*, 188(6), 731-747.

<https://doi.org/10.1080/03004430.2016.1230737>

Al-Oran, H., Khuan, L., Ying, L. P., & Hassouneh, O. (2022). Coping Mechanism among Parents of Children with Autism Spectrum Disorder: A Review. *Iranian journal of child neurology*, 16(1), 9-17. <https://doi.org/10.22037/ijcn.v16i2.31518>

Alrehaili, R. A., ElKady, R. M., Alrehaili, J. A., & Alreefi, R. M. (2023). Exploring Early Childhood Autism Spectrum Disorders: A Comprehensive Review of Diagnostic Approaches in Young Children. *Cureus*, 15(12), e50111. <https://doi.org/10.7759/cureus.50111>

Alshaigi, K., Albraheem, R., Alsaleem, K., Zakaria, M., Jobeir, A., & Aldhalaan, H. (2020). Stigmatization among parents of autism spectrum disorder children in Riyadh, Saudi Arabia. *International Journal of Pediatrics and Adolescent Medicine*, 7(3), 140-146. <https://doi.org/10.1016/j.ijpam.2019.06.003>

American Psychiatric Association, D., & American Psychiatric Association. (2013). *Diagnostic and statistical manual of mental disorders: DSM-5* (Vol. 5, No. 5). Washington, DC: American psychiatric association. <https://www.psychiatry.org/psychiatrists/practice/dsm>

Bekhet, A. K., Johnson, N. L., & Zauszniewski, J. A. (2012). Effects on resilience of caregivers of persons with autism spectrum disorder: the role of positive cognitions. *Journal of the American Psychiatric Nurses Association*, 18(6), 337-344. <https://doi.org/10.1177/1078390312467056>

Benson, P. R. (2014). Coping and psychological adjustment among mothers of children with ASD: An accelerated longitudinal study. *Journal of autism and developmental disorders*, 44, 1793-1807. <https://doi.org/10.1007/s10803-014-2079-9>

Bhattacharyya, K. K., Liu, Y., Das Gupta, D., Molinari, V., & Fauth, E. B. (2023). The Healthy Caregiver? A Positive Impact of Informal Caregiving Status on Cognitive

Functions Over Time From the Midlife in the United States Study. *Journal of Aging and Health*, 0(0). <https://doi.org/10.1177/08982643231209482>

Billings, A. G., & Moos, R. H. (1981). The role of coping responses and social resources in attenuating the stress of life events. *Journal of behavioral medicine*, 4(2), 139-157. [10.1007/BF00844267](https://doi.org/10.1007/BF00844267)

Blennerhassett, C., Richards, M., & Clayton, S. (2023). Caregiver-Implemented Feeding Interventions for Autistic Children with Food Selectivity: a Systematic Review. *Review Journal of Autism and Developmental Disorders*, 1-19. <https://doi.org/10.1007/s40489-023-00378-2>

Bourke-Taylor, H. M., Lee, D. C. A., Tirlea, L., Joyce, K., Morgan, P., & Haines, T. P. (2021). Interventions to improve the mental health of mothers of children with a disability: systematic review, meta-analysis and description of interventions. *Journal of autism and developmental disorders*, 51, 3690-3706. [10.1007/s10803-020-04826-4](https://doi.org/10.1007/s10803-020-04826-4)

Brand, C., Barry, L., & Gallagher, S. (2016). Social support mediates the association between benefit finding and quality of life in caregivers. *Journal of health psychology*, 21(6), 1126-1136. [10.1177/1359105314547244](https://doi.org/10.1177/1359105314547244)

Broom, D. M. (2001). Coping, stress and welfare. *Coping with challenge: Welfare in animals including humans*, 1-9.

Carver, C. S., & Connor-Smith, J. (2010). Personality and coping. *Annual review of psychology*, 61, 679-704. <https://doi.org/10.1146/annurev.psych.093008.100352>

Cejalvo, E., Martí-Vilar, M., Merino-Soto, C., & Aguirre-Morales, M. T. (2021). Caregiving Role and Psychosocial and Individual Factors: A Systematic Review. *Healthcare (Basel, Switzerland)*, 9(12), 1690. <https://doi.org/10.3390/healthcare9121690>

Centers for Disease Control and Prevention (CDC. (2009). Prevalence of autism spectrum disorders-autism and developmental disabilities monitoring network, United States, 2006. *Morbidity and mortality weekly report. Surveillance summaries (Washington, DC: 2002)*, 58(10), 1-20. <https://www.cdc.gov/mmwr/preview/mmwrhtml/ss6103a1.htm>

Chen, X., Tong, J., Zhang, W., Wang, X., Ma, S., Shi, D., Yan, D., & Liu, Y. (2024). Factors predicting depressive symptoms in parents of children with autism spectrum disorder in eastern China. *BMC public health*, 24(1), 226. <https://doi.org/10.1186/s12889-024-17731-7>

Collins, D. L., Baum, A., & Singer, J. E. (1983). Coping with chronic stress at Three Mile Island: Psychological and biochemical evidence. *Health Psychology*, 2(2), 149. <https://doi.org/10.1037/0278-6133.2.2.149>

Dabrowska, A., & Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of intellectual disability research*, 54(3), 266-280. <https://doi.org/10.1111/j.1365-2788.2010.01258.x>

De Giacomo, A., Craig, F., Terenzio, V., Coppola, A., Campa, M. G., & Passeri, G. (2016). Aggressive Behaviors and Verbal Communication Skills in Autism Spectrum

Disorders. *Global pediatric health*, 3, 2333794X16644360.  
<https://doi.org/10.1177/2333794X16644360>

DePape, A. M., & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative health research*, 25(4), 569-583.  
<https://doi.org/10.1177/1049732314552455>

Durán-Pacheco, G., Silkey, M., Johnson, M., Liu, C., Clinch, S., Law, K., & Loss, G. (2022). Effect of children's autism spectrum disorder severity on family strain and sleep quality: A cross-sectional online survey in the US. *Journal of Autism and Developmental Disorders*, 1-14. <https://doi.org/10.1007/s10803-022-05457-7>

Ekas, N. V., Whitman, T. L., & Shivers, C. (2009). Religiosity, spirituality, and socioemotional functioning in mothers of children with autism spectrum disorder. *Journal of autism and developmental disorders*, 39, 706-719.  
<https://doi.org/10.1007/s10803-008-0673-4>

Fabyio Villegas (2020) Study Population: Characteristics & Sampling Techniques.  
<https://www.questionpro.com/blog/study-population/> Accessed on 21/March 2023

Fletcher, D., & Sarkar, M. (2013). Psychological resilience. *European psychologist*.  
<https://psycnet.apa.org/doi/10.1027/1016-9040/a000124>

Folkman, S. (2020). Stress: appraisal and coping. In *Encyclopedia of behavioral medicine* (pp. 2177-2179). Cham: Springer International Publishing.

Folkman, S., & Lazarus, R. S. (1985). If it changes it must be a process: study of emotion and coping during three stages of a college examination. *Journal of*

*personality and social psychology*, 48(1), 150. <https://doi.org/10.1037//0022-3514.48.1.150>

Fuld S. (2018). Autism Spectrum Disorder: The Impact of Stressful and Traumatic Life Events and Implications for Clinical Practice. *Clinical social work journal*, 46(3), 210-219. <https://doi.org/10.1007/s10615-018-0649-6>

Gao, X., & Drani, S. (2024). Parent-implemented interventions in Chinese families of children with autism spectrum disorder. *Humanities and Social Sciences Communications*, 11(1), 1-8. <https://doi.org/10.1057/s41599-024-02710-5>

Gao, X., Lu, X., & Drani, S. (2023). Growing in adversity: A narrative study of resilience generation in Chinese families of children with ASD. *Behavioral Sciences*, 13(2), 136. <https://doi.org/10.3390/bs13020136>

Gobrial, E. (2018). The lived experiences of mothers of children with the autism spectrum disorders in Egypt. *Social sciences*, 7(8), 133. <https://doi.org/10.3390/socsci7080133>

Gona, J. K., Newton, C. R., Rimba, K. K., Mapenzi, R., Kihara, M., Vijver, F. V., & Abubakar, A. (2016). Challenges and coping strategies of parents of children with autism on the Kenyan coast. *Rural and remote health*, 16(2), 3517.

Gordon-Lipkin, E., Marvin, A. R., Law, J. K., & Lipkin, P. H. (2018). Anxiety and mood disorder in children with autism spectrum disorder and ADHD. *Pediatrics*, 141(4). <https://doi.org/10.1542/peds.2017-1377>

Gudmundson, J. A., & Leerkes, E. M. (2012). Links between mothers' coping styles, toddler reactivity, and sensitivity to toddler's negative emotions. *Infant Behavior and Development*, 35(1), 158-166. <https://doi.org/10.1016%2Fj.infbeh.2011.07.004>

Ingersoll, B., & Hambrick, D. Z. (2011). The relationship between the broader autism phenotype, child severity, and stress and depression in parents of children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 5(1), 337-344. <https://psycnet.apa.org/doi/10.1016/j.rasd.2010.04.017>

Ismael, N., Lawson, L. M., Moqbel, M., & Little, L. (2018). Coping strategies among caregivers of children with autism spectrum disorders: A cluster analysis. *International Journal Of Medical And Health Sciences*, 7(3).

Jankowska, A. M., Włodarczyk, A., Campbell, C., & Shaw, S. (2015). Parental attitudes and personality traits, self-efficacy, stress, and coping strategies among mothers of children with cerebral palsy. *Health Psychology Report*, 3(3), 246-259. <https://psycnet.apa.org/doi/10.5114/hpr.2015.51903>

Johnson, J. L., Adkins, D., & Chauvin, S. (2020). A review of the quality indicators of rigor in qualitative research. *American journal of pharmaceutical education*, 84(1).

Kang, S. G., Song, S. W., Kim, S. H., Kang, Y. J., Kim, Y. R., & Eun, Y. (2020). Fatigue and Mental Status of Caregivers of Severely Chronically Ill Patients. *Pain research & management*, 2020, 6372857. <https://doi.org/10.1155/2020/6372857>

Kasuya, R. T., Polgar-Bailey, M. P., & Takeuchi, M. R. (2000). Caregiver burden and burnout a guide for primary care physicians. *Postgraduate medicine*, 108(7), 119.

<https://doi.org/10.3810/pgm.2000.12.1324>

Kowal, K., Skrzypek, M., & Kocki, J. (2022). Experiencing illness as a crisis by the caregivers of individuals with Prader-Willi Syndrome. *PloS one*, 17(9), e0273295.

<https://doi.org/10.1371/journal.pone.0273295>

Lai, W. W., Goh, T. J., Oei, T. P., & Sung, M. (2015). Coping and well-being in parents of children with autism spectrum disorders (ASD). *Journal of autism and developmental disorders*, 45, 2582-2593. <https://doi.org/10.1007/s10803-015-2430-9>

Lavelle, T. A., Weinstein, M. C., Newhouse, J. P., Munir, K., Kuhlthau, K. A., & Prosser, L. A. (2014). Economic burden of childhood autism spectrum disorders. *Pediatrics*, 133(3), e520-e529. <https://doi.org/10.1542/peds.2013-0763>

Lazarus, R. S., & Folkman, S. (1984). *Stress, appraisal, and coping*. Springer publishing company.

Leigh, J. P., & Du, J. (2015). Brief report: Forecasting the economic burden of autism in 2015 and 2025 in the United States. *Journal of autism and developmental disorders*, 45, 4135-4139. <https://doi.org/10.1007/s10803-015-2521-7>

Li, R., Cooper, C., Bradley, J., Shulman, A., & Livingston, G. (2012). Coping strategies and psychological morbidity in family carers of people with dementia: a systematic review and meta-analysis. *Journal of affective disorders*, 139(1), 1-11.

<https://doi.org/10.1016/j.jad.2011.05.055>

Liu, C., Fabius, C. D., Howard, V. J., Haley, W. E., & Roth, D. L. (2021). Change in Social Engagement among Incident Caregivers and Controls: Findings from the Caregiving Transitions Study. *Journal of Aging and Health*, 33(1-2), 114-124. <https://doi.org/10.1177/0898264320961946>

Liu, F., Shen, Q., Huang, M., & Zhou, H. (2023). Factors associated with caregiver burden among family caregivers of children with cerebral palsy: a systematic review. *BMJ open*, 13(4), e065215. <https://bmjopen.bmj.com/content/bmjopen/13/4/e065215.full.pdf>

Lotter, V. (1978). Childhood autism in africa. *Child Psychology & Psychiatry & Allied Disciplines*. <https://doi.org/10.1111/j.1469-7610.1978.tb00466.x>

Luong, J., Yoder, M. K., & Canham, D. (2009). Southeast Asian parents raising a child with autism: A qualitative investigation of coping styles. *The Journal of School Nursing*, 25(3), 222-229. <https://doi.org/10.1177/1059840509334365>

Maenner, M. J., Warren, Z., Williams, A. R., Amoakohene, E., Bakian, A. V., Bilder, D. A., ... & Shaw, K. A. (2023). Prevalence and characteristics of autism spectrum disorder among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 sites, United States, 2020. *MMWR Surveillance Summaries*, 72(2). <https://doi.org/10.15585/mmwr.ss7202a1>

Make Children Better (2022). Uganda's Unkown Emergency. <https://www.makechildrenbetter.org/> Accessed on 11<sup>th</sup> June 2023.

Maksimović, S., Marisavljević, M., Stanojević, N., Ćirović, M., Punišić, S., Adamović, T., Đorđević, J., Krgović, I., & Subotić, M. (2023). Importance of Early Intervention in Reducing Autistic Symptoms and Speech-Language Deficits in Children with Autism Spectrum Disorder. *Children (Basel, Switzerland)*, *10*(1), 122. <https://doi.org/10.3390/children10010122>

Marlow, M., Servili, C., & Tomlinson, M. (2019). A review of screening tools for the identification of autism spectrum disorders and developmental delay in infants and young children: recommendations for use in low-and middle-income countries. *Autism Research*, *12*(2), 176-199.

Martínez-Pedraza, F.deL., & Carter, A. S. (2009). Autism spectrum disorders in young children. *Child and adolescent psychiatric clinics of North America*, *18*(3), 645-663. <https://doi.org/10.1016/j.chc.2009.02.002>

Matin, B. K., Byford, S., Soltani, S., Kazemi-Karyani, A., Atafar, Z., Zereshki, E., Soofi, M., Rezaei, S., Rakhshan, S. T., & Jahangiri, P. (2022). Contributing factors to healthcare costs in individuals with autism spectrum disorder: a systematic review. *BMC health services research*, *22*(1), 604. <https://doi.org/10.1186/s12913-022-07932-4>

McCoy, S. K., & Major, B. (2003). Group identification moderates emotional responses to perceived prejudice. *Personality and Social Psychology Bulletin*, *29*(8), 1005-1017. <https://doi.org/10.1177/0146167203253466>

Monat, A., & Lazarus, R. S. (Eds.). (1991). *Stress and coping: An anthology*.

Monika, K., Wijayarathne, H. G. I., Gunarathna, G. A. M. I. L., Wijesekara, G. G. W. C., & Madhavi, A. P. (2017). Mothers' experiences of having a child with autism spectrum disorder in a Tertiary. <http://www.ou.ac.lk/ours/wp-content/uploads/2018/01/OURS2017-all-part-3-New-55-58.pdf>

Morse, J. M. (2015). Critical analysis of strategies for determining rigor in qualitative inquiry. *Qualitative health research*, 25(9), 1212-1222.

Mthimunya, B. S. (2014). The knowledge and experiences of single mothers raising an autistic child in a low-income community in the Western Cape. <http://hdl.handle.net/11394/4182>

Mukiibi Everest (2022) Central and Eastern Uganda have highest numbers of autistic cases-UBOS survey. <https://www.watchdoguganda.com/news/20220402/133476/central-and-eastern-uganda-have-highest-numbers-of-autistic-cases-ubos-survey.html> Accessed on 14th June 2023.

Nalukenge Rose (2016). Entebbe Action on Autism Organization. <https://www.autismaroundtheglobe.org/story/entebbe-action-on-autism-organization/> Accessed on 14<sup>th</sup> June 2023.

Namuli, J. D., Nakimuli-Mpungu, E., Mwesiga, E. K., & Joyce, N. S. (2020). Knowledge gaps about autism spectrum disorders and its clinical management among child and adolescent health care workers in Uganda: a cross-sectional study. *EC psychology and psychiatry*, 9(9), 112.

Narzisi, A., Posada, M., Barbieri, F., Chericoni, N., Ciuffolini, D., Pinzino, M., . . . Muratori, F. (2020). Prevalence of Autism Spectrum Disorder in a large Italian catchment area: A school-based population study within the ASDEU project. *Epidemiology and Psychiatric Sciences*, 29, E5. <https://doi.org/10.1017/s2045796018000483>

Nik Adib, N. A., Ibrahim, M. I., Ab Rahman, A., Bakar, R. S., Yahaya, N. A., Hussin, S., & Wan Mansor, W. N. A. (2019). Perceived Stress among Caregivers of Children with Autism Spectrum Disorder: A State-Wide Study. *International journal of environmental research and public health*, 16(8), 1468. <https://doi.org/10.3390/ijerph16081468>

Obeid, R., & Daou, N. (2015). The effects of coping style, social support, and behavioral problems on the well-being of mothers of children with autism spectrum disorders in Lebanon. *Research in Autism Spectrum Disorders*, 10, 59-70. <https://psycnet.apa.org/doi/10.1016/j.rasd.2014.11.003>

Papadopoulos D. (2021). Mothers' Experiences and Challenges Raising a Child with Autism Spectrum Disorder: A Qualitative Study. *Brain sciences*, 11(3), 309. <https://doi.org/10.3390/brainsci11030309>

Park, C. L., & Folkman, S. (1997). Meaning in the Context of Stress and Coping. *Review of General Psychology*, 1(2), 115-144. <https://doi.org/10.1037/1089-2680.1.2.115>

Pena-Shaff, J., Heckart, A., Mannion, C., & Barry, K. (2023). Caregivers' anxiety and perception of their children's wellbeing: a year into the COVID-19 pandemic. *Frontiers in psychology, 14*, 1115322. <https://doi.org/10.3389/fpsyg.2023.1115322>

Posar, A., & Visconti, P. (2022). Early Motor Signs in Autism Spectrum Disorder. *Children (Basel, Switzerland), 9*(2), 294. <https://doi.org/10.3390/children9020294>

Pourmohamadreza-Tajrishi, M., Azadfallah, P., Garakani, S. H., & Bakhshi, E. (2015). The effect of problem-focused coping strategy training on psychological symptoms of mothers of children with down syndrome. *Iranian journal of public health, 44*(2), 254.

Quan, L., Xu, X., Cui, Y., Han, H., Hendren, R. L., Zhao, L., & You, X. (2022). A systematic review and meta-analysis of the benefits of a gluten-free diet and/or casein-free diet for children with autism spectrum disorder. *Nutrition reviews, 80*(5), 1237-1246. <https://doi.org/10.1093/nutrit/nuab073>

Ranganathan, P., & Aggarwal, R. (2018). Study designs: Part 1 - An overview and classification. *Perspectives in clinical research, 9*(4), 184-186. [https://doi.org/10.4103/picr.PICR\\_124\\_18](https://doi.org/10.4103/picr.PICR_124_18)

Sen, H. E., Colucci, L., & Browne, D. T. (2022). Keeping the Faith: Religion, Positive Coping, and Mental Health of Caregivers During COVID-19. *Frontiers in psychology, 12*, 805019. <https://doi.org/10.3389/fpsyg.2021.805019>

Shattnawi, K. K., Bani, Saeed, W. A. M., Al-Natour, A., Al-Hammouri, M. M., Al-Azzam, M., & Joseph, R. A. (2021). Parenting a child with autism spectrum disorder:

perspective of Jordanian mothers. *Journal of Transcultural Nursing*, 32(5), 474-483.  
[https://digitalcommons.liberty.edu/cgi/viewcontent.cgi?article=1035&context=nurse\\_grad\\_fac\\_pubs](https://digitalcommons.liberty.edu/cgi/viewcontent.cgi?article=1035&context=nurse_grad_fac_pubs)

Sheehan, J., Hiscock, H., Massie, J., Jaffe, A., & Hay, M. (2014). Caregiver coping, mental health and child problem behaviours in cystic fibrosis: a cross-sectional study. *International Journal of Behavioral Medicine*, 21, 211-220.  
<https://doi.org/10.1007/s12529-013-9289-y>

Shepherd, D., Landon, J., Taylor, S., & Goedeke, S. (2018). Coping and care-related stress in parents of a child with autism spectrum disorder. *Anxiety, Stress, & Coping*, 31(3), 277-290. <https://doi.org/10.1080/10615806.2018.1442614>

Sivaratnam, C., Devenish, B., Howells, K., Chellew, T., Reynolds, K., & Rinehart, N. (2021). Risk factors for mental health difficulties in parents of children with cerebral palsy: a systematic review and meta-analysis. *Clinical Psychologist*, 25(1), 1-18.  
<https://doi.org/10.1080/13284207.2020.1829945>

Skinner, E. A., & Zimmer-Gembeck, M. J. (2007). The development of coping. *Annu. Rev. Psychol.*, 58, 119-144. <https://doi.org/10.1146/annurev.psych.58.110405.085705>

Tathgur, M. K., & Kang, H. K. (2021). Challenges of the Caregivers in Managing a Child with Autism Spectrum Disorder- A Qualitative Analysis. *Indian journal of psychological medicine*, 43(5), 416-421. <https://doi.org/10.1177/02537176211000769>

Terathongkum, S., Panyatanakun, N., & Vallibhakara, S. A. O. (2020). Factors Associated with Well-Being of Family Caregivers of Children with Cerebral Palsy in

Bangkok. *JOURNAL OF THE MEDICAL ASSOCIATION OF THAILAND*, 103(11), 1214-9.  
[doi.org/10.35755/jmedassocthai.2020.11.12256](https://doi.org/10.35755/jmedassocthai.2020.11.12256)

Turnock, A., Langley, K., & Jones, C. R. G. (2022). Understanding Stigma in Autism: A Narrative Review and Theoretical Model. *Autism in adulthood : challenges and management*, 4(1), 76-91. <https://doi.org/10.1089/aut.2021.0005>

van Niekerk, K., Stancheva, V., & Smith, C. (2023). Caregiver burden among caregivers of children with autism spectrum disorder. *The South African journal of psychiatry : SAJP : the journal of the Society of Psychiatrists of South Africa*, 29, 2079. <https://doi.org/10.4102/sajpsychiatry.v29i0.2079>

Vasileiou, K., Barnett, J., Thorpe, S., & Young, T. (2018). Characterising and justifying sample size sufficiency in interview-based studies: systematic analysis of qualitative health research over a 15-year period. *BMC medical research methodology*, 18, 1-18. <https://doi.org/10.1186/s12874-018-0594-7>

Vernhet, C., Dellapiazza, F., Blanc, N., Cousson-Gélie, F., Miot, S., Roeyers, H., & Baghdadli, A. (2019). Coping strategies of parents of children with autism spectrum disorder: A systematic review. *European child & adolescent psychiatry*, 28, 747-758. <https://doi.org/10.1007/s00787-018-1183-3>

WHO (2023). Autism, Key facts. <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders#:~:text=It%20is%20estimated%20that%20worldwide,figures%20that%20are%20substantially%20higher>. Accessed on 11<sup>th</sup> June 2023.

WHO. (2023, November 15). *Autism*. Available online: [https://www.who.int/news-room/factsheets/detail/autism-spectrum-disorders?gad\\_source=1&gclid=Cj0KCQjwmOm3BhC8ARIsAOSbapVIGbP5Qh-UU8YTDaDHBkd7hfb9W2jTeKFoXRWNN-YIAEk9GyjronYaAoxkEALw\\_wcB](https://www.who.int/news-room/factsheets/detail/autism-spectrum-disorders?gad_source=1&gclid=Cj0KCQjwmOm3BhC8ARIsAOSbapVIGbP5Qh-UU8YTDaDHBkd7hfb9W2jTeKFoXRWNN-YIAEk9GyjronYaAoxkEALw_wcB) (accessed on 228 November 2024).

Wong, M. G., & Heriot, S. A. (2008). Parents of children with cystic fibrosis: How they hope, cope and despair. *Child: care, health and development*, 34(3), 344-354. <https://doi.org/10.1111/j.1365-2214.2007.00804.x>

Ying, K., Rostenberghe, H. V., Kuan, G., Mohd Yusoff, M. H. A., Ali, S. H., & Yaacob, N. S. (2021). Health-related quality of life and family functioning of primary caregivers of children with cerebral palsy in Malaysia. *International Journal of Environmental Research and Public Health*, 18(5), 2351. <https://doi.org/10.3390/ijerph18052351>

Young, S., Hollingdale, J., Absoud, M., Bolton, P., Branney, P., Colley, W., ... & Woodhouse, E. (2020). Guidance for identification and treatment of individuals with attention deficit/hyperactivity disorder and autism spectrum disorder based upon expert consensus. *BMC medicine*, 18(1), 1-29

## Appendix II: Consent Form

My name is Nyanjura Simple, I am pursuing a master's degree of Public Health from Uganda Christian University (UCU). I am requesting you to take part in my academic research study called: ***“Challenges and coping mechanisms of caregivers of children between 3 and 8 years with autism spectrum disorders in selected Kampala schools offering special needs and inclusive education services”***

***The purpose of this study is to:***

- III. To examine the challenges of caregivers of children with autism spectrum disorders in Kampala.
- IV. To identify the coping mechanisms of caregivers of children with autism spectrum disorders in Kampala.

***Study Procedures:***

You are being asked to participate in this study, as a care giver to a child on the Autism Spectrum Disorder, you can help us understand the challenges care givers go through, and the coping mechanisms used.

- If you take part in this study, you will be asked to:
- Take part in a one-time, one-on-one, using an interview guide
- The interview will take approximately 45minutes;
- The interview will take place at a location most convenient to you.

***Benefits:***

There may be no direct benefits associated with your participation in the study, but the information you will provide will be useful in planning and organizing health awareness campaigns on adolescent health services.

***Risks or Discomfort:***

This research is considered to be minimal risk. That means that the risks associated with this study are the same as what you face every day. There are no known additional risks to those who take part in this study.

***Compensation:***

No research participants will be compensated, however, there will be transport reimbursement and an appreciation token between 20,000 and 50,000 Uganda shillings.

***Privacy and Confidentiality:***

We will keep your study records private and confidential. Certain people may need to see your study records. By law, anyone who looks at your records must keep them completely confidential. The only people who will be allowed to see these records are:

The research team, including the Principal Investigator and those involved with the study. I may publish what I have learnt from this study. If I do, I will not include your name. I will not publish anything that would let people know who you are.

***Voluntary Participation / Withdrawal:***

You should only take part in this study if you want to volunteer. You should not feel that there is any pressure to take part in the study. You are free to participate in this research or withdraw at any time. There will be no penalty or loss of benefits you are entitled to receive if you stop taking part in this study.

You can get the answers to your questions, concerns, or complaints

If you have any questions, concerns or complaints about this study, or experience an adverse event or unanticipated problem, contact the principal investigator on +256772645456.

If you have questions about your rights as a participant in this study, general questions, or have complaints, concerns or issues you want to discuss with someone outside the research, call the Chairperson of Research Ethics Review committee UCU Dr. Edward Mukooza on (0772957345).

***Assessment of understanding:***

Please check which box best describes your assessment of understanding of the above informed consent document:

- I have read the above informed consent document and understand the information provided to me regarding participation in the study and benefits and risks. I give consent to take part in the study and will sign the following page.

\_\_\_\_\_  
Signature of Person Taking Part in Study

\_\_\_\_\_  
Date

**Appendix B: Socio-Demographics Questionnaire**

Given pseudonym ..... Time: .....

(To be filled by the researcher)

Date: .....

/...../.....

Please check only what applies to you.

1. Age

2. What is your marital status?

Single:

Separated

Married:

Divorced:

3. Education level?

Primary

Secondary

Uni/Tertiar

No education

4. Which birth position is the autistic child?

First born

Middle child

Only child:

Lastborn

5. What gender is your child?

Male:

Female

6. Was the pregnancy that resulted in the birth of this child?

Planned       Unplanned

7. Who spends the greatest amount of time with the child?

Mother:       Father:       Other:

8. Employment status of Father?


Employed       Unemployed       Housewife

## **Appendix C: Interview Guide**

### Experiences of Care givers of children on the Autism spectrum

1. Tell me about how you found out that your child is on the autism spectrum?
2. By whom was the diagnosis of autism spectrum disorder done?
3. When was the diagnosis done?
4. Tell me about how you reacted when the diagnosis was confirmed?
5. How has your life changed after this?
6. Tell me about challenges you have faced as caregivers of autistic child?
7. How have you managed to cope with those challenges?

## Appendix D Compliance Report



# UGANDA CHRISTIAN UNIVERSITY

A Centre of Excellence in the Heart of Africa

UGANDA CHRISTIAN UNIVERSITY  
SCHOOL OF RESEARCH & POSTGRADUATE STUDIES

**DISSERTATION CORRECTION COMPLIANCE REPORT BY THE CANDIDATE (POST VIVA FORM)**

Date: 22nd/04/2025

Name of Candidate: Nyanira Simpe Byambanga Reg. No: 212201012

Title of Dissertation: CHALLENGES AND COPING MECHANISMS OF CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDERS IN SELECTED KAMPALA SCHOOLS OFFERING SPECIAL NEEDS AND INCLUSIVE EDUCATION SERVICES

SN	COMMENTS BY EXTERNAL EXAMINER	ACTION TAKEN	INDICATOR
1	Typographic and grammatic errors were many	paid more attention to grammar during thesis revision	Done
2	Need to elaborate on the study procedure	study procedure was revised and elaborated on	Done
3	Conclusion needs to be bulletted	This was clearly worked on	Done
4	Discussion should be deleted from abstract	Deleted from abstract as advised	Done
5	Look at marked dissertation for minor corrections	reviewed the <sup>marked</sup> dissertation and minor corrections were made	Done

RCEK

