PSYCHOSOCIAL EXPERIENCES INFLUENCING COPING MECHANISMS AMONG CAREGIVERS OF CHILDREN WITH SEVERE INTELLECTUAL DISABILITIES IN SPECIAL SCHOOLS OF JINJA DISTRICT, UGANDA

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STUDENT'S DECLARATION

I, the undersigned, declare that this thesis is a product of my own work and is not the result of anything done in collaboration. It has not been previously presented to any other institution. All sources have been appropriately cited and duly acknowledged in full.

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DEDICATION

I dedicate this research to all my beloved family members and members of the institute of the Sisters of Mary whose continued encouragement and support have enabled me to complete this study.

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TABLE OF CONTENTS

LIST OF TABLES

LIST OF FIGURES

LIST OF ACRONYMS

A' LEVEL	Advanced level
CRC	Convention of Rights of the Children
DIP	Diploma
ESRC	Economic and Social Research Council
FGD	Focus group discussion
FP	Female participant
ID	Intellectual disabilities
MP	Male participant
MRRH-REC	Mbale Regional Referral Hospital- Research Ethics Committee
NGO	Non-Governmental Organization
NPHC	National Population and Housing Census -
O' LEVEL	Ordinary level
SCT	Stress-coping theory
SDT	Self-determination theory
UNCST	Uganda National Council for Sciences and Technology
UNICEF	United Nations Children's Fund
US	United States
WB	World Bank
WHO	World Health Organization

ABSTRACT

With about seven billion total world population, there are almost one billion people having disabilities. Children constitute 200 million of those with disabilities. Of the 200 million children with disabilities, 80% live in developing countries most of which are in Sub-Saharan Africa. Taking care of children with severe intellectual disabilities is a very taxing experience for caregivers in Uganda. However, insight into caregivers' individual experiences is scarce to guide effective responses to their care needs. This study therefore explored the psychosocial experiences influencing coping mechanisms among caregivers of children with severe intellectual disabilities in Jinja district, Uganda. The study aimed at examining the psychosocial experiences, establishing the coping mechanisms and assessing the psychosocial support for caregivers. Although from the literature there are numerous studies conducted on psychosocial experiences and coping mechanisms among caregivers, most of them have been conducted in America, Europe and Asia. Uganda, one of the African countries south of the Sahara, with the greater percentage of children living with disabilities, has had sparse studies exploring psychosocial experiences influencing coping mechanisms among caregivers. The study was informed by two theories: the stress-coping theory by Lazarus and Folkman, and the self-determination theory by Deci and Ryan. A qualitative phenomenological research design was employed. The study used purposive sampling to select the participants. The target population of this study was 170. A sample of 20 participants was recruited for the study. The research instruments used were interview and focus group discussion schedules. The study employed thematic data analysis. The researcher conducted a pilot study with 2 participants who were not part of the study to guarantee the reliability of the instruments. The findings of this study indicated that caring for children with severe intellectual disabilities is beset with many negative psychosocial experiences and a general lack of psychosocial support for caregivers by the community or government. Therefore, this study recommends that caregivers of children with severe intellectual disabilities be supported socially, psychologically and emotionally for their better nurturing of such children. This study offers significant information for policy and research, and works as a guide in developing intervention programs for caregivers of children with severe intellectual disabilities by various stakeholders.

OPERATIONAL DEFINITIONS OF KEY TERMS

Psychosocial experiences in the current study refers to the individual feelings and perception toward something.

Influencing in this study refers to the ability to attract towards a certain behavior.

Coping mechanisms in this study refers to different ways by which caregivers act to manage stressful situation posed by a child with an intellectual disability.

Caregiver in the present study is defined as any person in the family above 18 years who gives unpaid care and support to a child with severe intellectual disability.

A child in this study refers to any human being from the age of 5 – 17 years.

Severe in this study refers to the worsened condition of children with intellectual disabilities.

Intellectual disability in this refers to a condition where a child is not able to function well in learning life skills.

Special school in the present study refers to an institution providing for children with special educational needs.

CHAPTER ONE

INTRODUCTION

1.0 Introduction

This chapter introduces the current study and presents the background to the study as well as the research problem statement. The chapter also presents the objectives of the study and the research questions, followed by a brief description of the location of the study, significance, and lastly the scope and delimitations of the study.

1.1 Background to the problem

Wilson (2012) points out that, with a world population of about seven billion, estimates suggest that there are nearly one billion people living with disabilities worldwide today. Moreover, children constitute 200 million of those with disabilities. According to the United Nations Children's Fund (UNICEF) (2013), of the 200 million children living with disability under five years of age worldwide, 80% live in poor developing countries and most of them are in Sub-Saharan Africa (United Nations General Assembly, 2011). Children experience different kinds of disabilities which include; physical, sensory and intellectual among others (Wilson, 2012). Accordingly, World Health Organization-World Bank (WHO-WB) (2011), observes that 93 million children aged 0-14 in the world have moderate to severe disabilities.

Although it is generally considered that disabilities are more in developing countries, Nadege and Anyimuzala (2014) report that developed countries have children with disabilities as well. For instance, the American Community Survey sample of 2006 projected that intellectual disabilities affected nearly 11.5 million Americans of age 5 years and above. This embodied about 43% of the total 26.6 million individuals with disabilities of the same age (U.S

Census Bureau, 2006). This made it difficult for children to learn, remember, or concentrate on different activities of life.

According to the report by Harris (2006), the global prevalence of intellectual disabilities (ID) is between 1% and 3% and rates for children range from 3–14 per 1000. Furthermore, a review report by Maulik, Mascarenhas, Mathers, Dua and Saxena (2011) suggested the whole population with intellectual disabilities to be at 1% for developed countries and 2% in developing countries. It is worth to note that the prevalence of disabilities among children in Africa is very difficult to gauge accurately. This is not only because of difficulties relating to unvarying definitions of disabilities, but because of incomplete data collection and incorrect statistical results as well (Maulik, et al., 2011).

In South Africa, a study on the incidence of intellectual disabilities among children reported 3.3% (Kromberg, Christianson, Manga, Zwane, Rosen, Venter & Homer, 1997). Another study reported occurrence at 0.64 per 1000 of severe intellectual disabilities and 29.1 per 1000 of mild intellectual (Christianson, Zwane, Manga, Rosen, Venter, Downs & Kromberg, 2002). Similarly, according to Ugandan Bureau of Statistics (UBOS) (2005), there were 43,306 children aged between 0 -17 years with one or more disabilities in the country.

Children with disabilities live in families and depend on other people (caregivers) who provide care and support to them. A family is an integrative system which comprises a collection of individuals and where one member affects and is affected by the other. Al Ali (2016) argues that having a child with any kind of disability in the family, can be the origin of conflict among members of that whole family. Hence, nurturing a child with a disability in the family directly upsets other members' social, economic, behavioural and emotional way of life.

Accordingly, for caregivers to raise a child with a severe intellectual disability, it requires a lot of effort on the part of family members. Wilson (2012) asserts that many times a dependent child becomes a dependent adult, making a short-term care giving a lifelong responsibility which can hinder the ability of caregivers to find employment. Other studies too concur that having a child with some kind of disability in the family does not only bring distress to parents but to other members of the family as well (Hindangmayum & Khadi, 2012; Isesolo, Kajula, & Yahya-Malima, 2016; Cramm, & Nieboer, 2011).

Therefore, begetting a child with any kind of disability is a surprising stressful affair which can disturb the entire family structure. Furthermore, the disability of the child and the problems associated with it, may touch a number of ways the family functions as well as the way individuals adjust. Caregivers go through intense emotional and psychological stress and may have less means of emotional pleasure (Hindangmayum & Khadi, 2012). They are likely to consider a child with intellectual disabilities as a threat to their self-esteem and view themselves as a source of the child's disability.

Taderera and Hall (2017) stress that besides being primary caregivers of children with disabilities, mothers still play their other roles such as nurturing other children, caring for the home, and finding income for the family. In addition, many caregivers face stigma, myths and stereotypes that accompany disability in many developing countries and one can see that indeed such women lead challenging lives (Edwardraj, Mumtaj, Prasad, Kuruvilla, & Jacob, 2010). As Ha, Greenberg and Seltzer (2011) claim, caregivers of such children face some challenges but not limited to added financial constraints, the child's problematic behavior, and social stigma related to disabilities.

Accordingly, people caring for children with major disabilities over and over again experience more physical health symptoms, negative effects, and poorer psychological well-being when compared to parents with children without any disability (Ha, Greenberg & Seltzer, 2011). Reynolds (2012) in agreement states that primary caregivers of children with severe intellectual problems encounter a variety of emotions and problems. This is because caring for children having this kind of disabilities, is usually a difficult experience for caregivers to face due to its varied problems which may include, problems of speech, reading, writing, memory and physical coordination (Ha, et al., 2011).

Lima, Cardoso and Silva (2016) too support that having a child with any disability imposes a burden which can lead to negative consequences on caregivers' health. Some studies have showed that generally, caregivers of children with disabilities look at their health as unsatisfying, indicated by signs of depression, stress, muscle pain and reduced quality of life (Freitas, Rocha, & Haase, 2014; Guyard, Fauconnier, Mermet, & Cans, 2011).

With changes in social expectations and a recent determination to deinstitutionalize children with disabilities, there has been a high impact on families (Browne, 2010). Several international studies regarding psychosocial experiences and coping mechanism among caregivers confirm similar results despite differences in concepts used. For instance, such studies were carried out by (Browne, 2010; Pompeo, Carvalho, Olive, Souza, & Galera, 2016 and Atienza, Aspacio, Gonzaga, & Sahiri, 2016). Despite the difference in the constructs used, they all have some indispensable similarity in the degree of emotional, physical and social costs encountered by the caregiver to raise a child with intellectual disability.

A study carried out in India by Kaur and Arora (2010) noted that the detection of intellectual disabilities in a child may lead to denial by family members. Family members find

it difficult to discuss problems of their child with other people due to fear of social stigma. This makes the family with such a child to become more and more withdrawn. Similarly, a study done in the Philippines, revealed that caregivers of children with intellectual disabilities faced countless challenges (Atienza, et.al, 2016). A child with intellectual disabilities exhibit disruptive and restrictive effects on the family which can take emotional, economic and social forms.

A study conducted in Sweden by Bostrom (2012) maintained that children who were severely intellectually disabled had common significant limitations in reasoning as well as in adaptive behavior. This affects the children's everyday social and practical skills, which increases care demands on their caregivers (Bostrom, 2012). The responsibility related to bringing up a child with intellectual disability generally affects the entire aspects of family life including routines, emotional and financial aspects (Kaur & Arora, 2010). Consequently, the provision of high quality care necessary for a child with severe intellectual disability can become psychologically as well as physically taxing to caregivers.

In Africa, people who look after children with severe intellectual disabilities face a lot of challenges which include; emotional stress, coping with the child's disability and financial inadequacies (Thwala, Ntinda & Hlanze, 2015; Boyd, 2010). A study conducted in Nigeria by Ajibade, Ajao, Fabiyi, Olabisi and Akinpelu (2016) revealed that the presence of a child with intellectual disabilities in the family brings doubts, confusion and disorder in that family. These studies confirm the difficulties associated with children having severe intellectual disabilities on family caregivers.

Accordingly, Zegwaard, Aartsen, Grypdonck and Cuijpers (2013) in their research further established that most often caregivers of children with intellectual problems get involved

in permanent caregiving. This can in turn impede the bountiful aspects of the caregivers' daily life and may lead to going beyond the limits of typical informal care. Consequently, the caregivers devote an extensive amount of time and energy in long-term caregiving, including at times jobs that might be unpleasant to them.

From East Africa, a study conducted in Tanzania by McNally and Mannan, (2013) indicated both objective and subjective challenges experienced by family caregivers. Resch, Mireles, Benz, Grenwelge, Peterson, and Zhang (2010) in their study also noted that it is physically demanding and psychologically distressing to care for children with disabilities. It does not only affect social and family relationships, but affects employment as well. Therefore, Mitra, Posarac and Vick (2011) found out that stigma can lead to social isolation and limited involvement in other activities by caregivers. The study further revealed that in households of disabled children, the higher percentage of the total expenditure is spent on health care in countries like Kenya and Malawi (Mitra, et al., 2011).

Equally important, a study conducted in Kilifi, Kenya showed some elements of stress as caregivers struggle to meet the requirements for a child with a disability (Gona, Mung'ala-Odera, Newton & Hartley, 2011). While caregivers (especially mothers) need time to attend to family and community obligations, most of their time is taken up by attending to the child with special needs. The ability for caregivers to look for resources for the family is significantly affected by the pressures of care, especially if the child has a severe or profound disability.

Consequently, this can lead to lack of basic needs for other members of the family causing more stress on the caregivers. Hartley, Ojwang, Baguwemu, Ddamulira and Chavuta (2005) maintain that although a number of families are able to cope with the disabilities in Uganda, they still face difficulties that include: the caring burden, poor conditions of living,

social stigma, and communication skills problem. Another research by Tusiime (2013) found out that caregivers experienced both positive and negative challenges while taking care of children with cerebral palsy. The current study therefore, is going to build upon the previous research by exploring caregivers' psychosocial experiences and coping mechanisms in Jinja, Uganda.

1.2 Statement of the problem

Taking care of children with severe intellectual disabilities is a very taxing experience for caregivers in Uganda. Yet, insight into their individual experience is rare. This is attributed to the fact that a lot of attention is given to children with disabilities but little or no consideration to caregivers. Although from the literature there are numerous studies conducted on psychosocial experiences influencing coping mechanisms among caregivers, several of them have been conducted in America, Europe, Asia and some few in South and West Africa. Uganda is one of the African countries south of the Sahara, found to be having a greater percentage of children living with disabilities. However, data on the psychosocial experiences among caregivers of children with severe intellectual disability needed to inform policy making is scarce. The few studies that are available only paid attention to caregivers of children with general physical disabilities and left out the challenges posed by severe intellectual disabilities. Therefore, this study found a research gap to explore the psychosocial experiences influencing coping strategies among caregivers of children with severe intellectual disabilities attending special education in Jinja district, Uganda.

1.3 Purpose of the study

The purpose of this study was to examine the psychological and social experiences of caregivers of children aged 5 – 17 years with severe intellectual disabilities attending special education and how these experiences influence the caregivers' coping mechanisms.

1.4 Objectives of the study

The present study was guided by one general objective and three specific objectives. The general objective of the study was to explore the psychosocial experiences influencing coping mechanism among the caregivers of children with severe intellectual disabilities in special schools of Jinja district, Uganda. In order to achieve the general objective, the following specific objectives guided the study:

1. To examine the psychosocial experiences among caregivers of children with severe intellectual disabilities in Jinja district, Uganda
2. To identify the coping mechanism among caregivers of children with severe intellectual disability in Jinja district, Uganda
3. To assess the existing psychosocial support system for caregivers of children with severe intellectual disabilities in Jinja district, Uganda.

1.5 Research questions

The study was guided by the following research questions:

1. What psychosocial experiences do caregivers of children with severe intellectual disabilities have in Jinja district?
2. What coping strategies do caregivers of children with severe intellectual disabilities in Jinja district apply?

3. How are the caregivers supported in their efforts to care for children with severe intellectual disabilities?

1.6 Significance of the study

It was hoped that the findings of the current study would be beneficial to society considering that there are increasing numbers of children with intellectual disabilities who require caregiving and support. The study identified five significant areas of positive contributions. Primarily, the present study provides knowledge and shared experiences for parents of children with severe intellectual disabilities. The study further provided the parents the opportunity to learn that they were not alone but other people share similar burden of caring for children with such disabilities. Second, the study is significant to teachers in special schools. The information of the current study is expected to guide teachers in understanding the attitude people have towards children with severe intellectual disabilities and the struggles parents of their pupils go through.

Third, the results of the present study may provide information for organizations and individuals who support children with disabilities to start focusing on caregivers as well, especially in terms of psychological support. Forth, the results of this study may provide information for policy makers. The government policies that are formulated for the children with disabilities might include the children's caregivers so that they are supported socially, psychologically and emotionally. Fifth, the study is significant to future researchers. The ideas presented in this study might be used as reference data in conducting new researches or in testing the validity of other findings.

1.7 Scope and delimitations of the study

Simon and Goes (2013) define the scope of the study as the parameters under which the study operates. Hence, the scope for this study covered collecting data on the psychosocial experiences influencing coping mechanisms among caregivers of children with severe intellectual disabilities whose children attend special education in two schools only. Delimitation on the other hand according to Simon (2011), are those characteristics that limit the scope and define the boundaries of the study. It is the level to which the researcher wishes to stretch the study. Therefore, this study focused on caregivers of children with severe intellectual disabilities and not mild or any other disability except for those with multiple disabilities, for example, those with severe intellectual disabilities as well as physical disability.

The study covered caregivers of children attending special education in two selected schools. The research sample comprised of caregivers with children of ages between 5 – 17 years residing in Jinja district. Caregivers of children with intellectual disabilities within the age bracket but not attending special education were excluded. The study was also delimited to informal caregivers, that is, parents, grandparents, siblings and other guardians related to the child and not formal caregivers such as teachers, health workers, to mention a few. In the next chapter, the study focuses on the theoretical review of the literature.

CHAPTER TWO

LITERATURE REVIEW

2.0 Introduction

This chapter presents the review of related literature, a theoretical review which provided the basis for proper discussion of the current research. The chapter describes briefly the theoretical review of Self-determination theory and Stress-coping theory on which the current study has been anchored. It also presents the empirical review of literature on psychosocial experiences, coping mechanisms as well as psychosocial support systems, and lastly a diagrammatic conceptual framework of the study.

2.1 Theoretical review

Theories provide a foundation for the research, they therefore help the researcher to gain clarity as well as understanding of the theoretical practicalities related to the current study (Kombo & Tromp, 2006). The researcher in the current study has thus studied the relationship between psychosocial experience influencing coping mechanisms on the basis of particular theories. While there are several psychosocial theories that could relate to the current study, the researcher has limited the study to two theories. The theories identified for this study were: the Self-determination Theory (SDT) by Deci and Ryan (1985), and the Stress-Coping Theory (SCT) by Lazarus and Folkman (1984). The reason for the choice of these two theories was because of their focus on motivation, stress and coping. The three concepts were important for the current study because the caregivers meet a number of challenges in their caring activities. A brief discussion of these therefore is fundamental.

2.1.1 Self-determination theory (SDT)

Deci (1980) defined self-determination as the process of exploiting one's will. He believed that self-determination activated certain gifts like people accepting their boundaries, identifying forces that operate on them, using their ability to choose, and enlisting support. This suggests that when individuals are determined to achieve something, complete a task or satisfy a need, they will certainly be aware of their difficulties, exercise choice and find help as needed. The term was later redefined as a quality of human functioning that includes the experience of choice (Deci & Ryan, 1985).

According Deci and Ryan (2008), SDT's central idea is autonomous motivation and controlled motivation. With autonomous motivation people are both intrinsically and extrinsically motivated. On the one hand, people who are autonomously motivated identify with the value of an activity and preferably integrate it into their sense of self. When people are autonomously motivated, their actions are willed or authenticated. On the other hand, people whose motivation is controlled act with a sense of pressure to engage in the action. A person's behavior is a function of external eventualities of reward or punishment, and the regulation of action is partially internalized and energized by factors like the motive of being approved, avoiding shame, contingent self-esteem, and ego-involvements (Deci & Ryan, 2008).

Ryan, Deci, Grolnick and LaGuardia (2006) posit that basic to SDT are three psychological needs. They are autonomy, relatedness and competence needs (Riley, 2016). Wulf, Schmidt and Randall (2015) argue that once these three basic needs are maintained and fulfilled within a social framework, people experience more vitality, become self-motivated, and function well. On the contrary, when they are frustrated it can lead to diminished self-motivation and greater ill-being (Ryan et al. 2006). Autonomy as put forward by Ryan, (1993),

refers to the experience of behaving in agreement with one's own interests or values and is maintained by non-controlling, supportive relationships. Relatedness is the inclination toward connectedness or belongingness with others, and is fostered when others treat one in warm and caring ways. Lastly, a sense of competence is derived from success experiences and overall positive feelings about an activity (Deci & Ryan 2008; Riley, 2016).Rosenshine and Russell (2014) as well as international body of research, agree that Deci and Ryan's work support the findings that when people feel a sense of autonomy and personal agency; when supported by close, trusting relationships; and experience competence in facing challenges, they develop intrinsic motivation to succeed and persevere through adversity.

Self-Determination Theory helped the researcher in the current study to establish how caregivers are motivated to care for children with intellectual disabilities. There are a lot of challenges faced by caregivers in their attempt to give care, yet they continue to care for the child with intellectual challenges. Basing on this theory, the current study established the kind of support the caregivers enlist in their efforts to care for their children with severe intellectual disabilities. It was critical to understand how caregivers cope with stress,

2.1.2 Stress-Coping Theory (SCT)

Stress-coping theory can be traced back in the late 1960s. It was originally developed by Richard Lazarus (1966). The Lazarus theory has undergone numerous significant revisions for instance, (Lazarus & Folkman, 1984; Lazarus, 1991; 1993). Lazarus and Folkman's (1984) transactional model, explains the process people go through in their effort to deal with stressful situations. The model suggests that there is an interface between the person and the stressful situation, which is predominantly obvious in the person's evaluation of the problem being faced. According to this model, individual persons cognitively evaluate an incident to decide

the degree to which it has the possibility to exhaust their resources (Mitrousi, Travlos, Koukia & Zyga, 2013). Stress-coping theory has two models that are fundamental to it, that is, appraisal and coping.

There are two main forms of appraisal in the review work of Lazarus, and are categorized as primary and secondary appraisals (Lazarus, 1993). In the primary appraisal, the main concern is whether something of importance to the person's well-being occurs, while the secondary appraisal is concerned with choices for coping. Zaumseil and Schwarz (2014) added that primary appraisal on the one hand, is making a judgement by an individual whether there is any challenge, threat, harm, loss or not in respect to duties, values, or goals in line with the environment. Secondary appraisal on the other hand, is where the person assesses what can be done to relieve, prevent harm, or to improve the likelihoods for a positive outcome.

Goh, Sawang, and Oei, (2010) further pointed out that central to transactional model is that, a potentially stressful event will trigger the primary appraisal process in which an individual assesses the degree of the threat in relation to his or her wellbeing. When an event is perceived as threatening or challenging, the secondary appraisal process provides a universal assessment of the individual's coping resources and ability to manage the threat/challenge. Hence, the way people react to stress as observed by Bagutayan (2015), depends on a number of reasons, which include among others; how much control they feel over the situation, how predictable and intense the stressor is, and their individual perspective. Bagutayan (2015) further explains that Lazarus and Folkman used the method that had the basis on specific efforts, both behavioral and psychological, which people employ to master, tolerate, reduce, or minimize stressful events.

Primary caregivers as Olson (2010) reports, are affected with the care demands of the child with the disability. Hence, coping can take long because the caregivers have many other responsibilities in the family. Stress coping theory informed the present study since it states that people giving care to children with severe intellectual disabilities experience some kind of stress. In developing country like Uganda, caring for even a 'normal' child is very stressful. Consequently, the stressful situation is made worse when there is a child with severe intellectual disabilities in the family. The presence of a child with severe intellectual disabilities exposes a caregiver to different kinds of stress and coping may take time for the primary caregivers who might view the disability as some sort of punishment. Due to the heavy burden, the child may pose to caregivers, sometimes it may be abandoned to the care of grandparents or in school. This may raise some psychological issues. In the next section the study presents the empirical review of the literature.

2.2 Psychosocial experiences among caregivers

The term psychosocial was first proposed by Erick Erickson; psyche means mind and social means relationship. According to Oxford English Dictionary (2004), the word psychosocial means the influence of social factors on an individual's mind or behavior, hence, the relationship between behavioural and social factors. It shows the close link between caregivers' psychological experiences, for instance, thoughts, emotions and behavior, and their wider social experiences such as relationships, traditions and cultures.

A study conducted by Oshodi, Adeyemi, Aina, Suleiman, Erinfolami and Umeh (2012), in Nigeria articulated that caregivers of children with intellectual disabilities experience two kinds of burdens, that is, subjective and objective. Bayen, Papeix, Pradat-Diehl, Lubetzki and Joel (2015) define subjective burden to mean psychological consequences on the way a

caregiver personally evaluates the situation, and its apparent severity. Objective burden on the other hand, means an outward determinate stresses placed on the caregivers.

Some forms of burdens experienced by caregivers while they care for children with severe intellectual disabilities can include among others, financial constraints, pressure on interpersonal relationships, inadequate social support, physical violence, disruption of family routines as well as altering leisure time. In addition, McCubbin and Patterson (1982) suggested some ways caregivers experience stress while caring for children having intellectual disabilities. These include; restricted social life, time restrictions caused by care demands, family contact with professionals which can cause frustration, disappointment and anger, mourning and depression. Caregivers of children with severe intellectual disabilities experience great psychological stress.

2.2.1 Psychological experiences

Ambikile and Outwater (2012) in their study established that people who give care to children with intellectual disabilities experience psychological and emotional challenges. These can be grouped as disturbing thoughts, emotional disturbance, unavoidable situation, and communication problems. Caregivers feel stressed by explicit behavior of the child because the child does not only cause problems to family members but also to other people in the neighborhood. For example, some children with intellectual disabilities have aggressive behavior, they are destructive, hyperactive, make noise and may not have proper eating skills.

A study by AI Ali (2016) further established that psychological stress is the most remarkable challenge families with a child having intellectual disabilities face. Mash and Johnston (1990) conceptualized parental stress as involving behavioural, affective and cognitive components. In the relationship with a child, the level of stress experienced depends

on the difference between the situational demands and the individual's resources and goals. In addition, it has been noted by Thwala, et al. (2015) that caring for children with intellectual problems can lead to greater stress and many caregiving challenges. For instance, stress can lead to health problems as well as higher levels of parental depression.

The caregivers also suffer from exhaustion and stress due to the degree of the amount of care needed by the child with intellectual disabilities. A study conducted in Kenya by Gona, et al. (2010), also revealed that one of the psychological experiences caregivers of children with intellectual disability face is stress. Stress is experienced in form of insufficient time for caregivers to do other chores and responsibilities, as well as isolation from community activities due to time spent on attending to the child's needs.

From the literature, some studies have suggested that primary caregivers especially mothers are much more likely to experience higher levels of anxiety and depression than mothers of children without the problem (Bostrom, 2012; Mekki, 2012 and Taderera & Hall, 2017). For instance, a study conducted in Ireland reported that parents of children with intellectual disability experienced more psychological distress as well as physical health problems (Lee, 2013).

Stress, depression, sleep disturbances, headaches, gastrointestinal problems and respiratory infections are some of the problems experiences by primary caregivers (Lafferty, O'Sullivan, O'Mahoney, & Taggart, 2016). These problems in turn influence the effective care for a child with a disability in the family which can possibly result into the child being neglected by family members. As Trollope (2014) argues, there is more draining on caregivers with the presence of a child with intellectual disability in the family. Due to extra tasks that need to be done to take care of the child, it makes caregivers sometimes feel overworked, stressed out and

unhappy. Therefore, the psychological wellbeing of caregivers is important because it may affect how they cope and support their children with intellectual disabilities. Missing out on social moments can be crucial to such caregivers.

2.2.2 Social experiences

Some earlier research findings established that caring for children with severe intellectual disabilities is connected with several social challenges (Ambikile & Outwater, 2012). The caregivers' experience in the social world may include; how to get social services, stigma and caring responsibilities. Children with intellectual disabilities are not able to acquire education because of insufficient number of special schools. Secondly, getting to see a doctor with such a child, caregivers may wait for long without being attended to, and in most cases there may be no medicine for the child. There could be lack of facilities such as toilets in hospitals and other public places. Due to stigma and the disturbing behavior of the child, caregivers sometimes avoid going to social gatherings for example, church, meetings just to mention a few. Having a child with an intellectual disability depending on the type, can create tension and lack of peace especially with the neighbors.

The presence of a child with a disability in the family impacts a lot on the social life of that particular family. Caregivers are restricted in social and leisure activities due to the presence of a child with intellectual disability (Alejandra, et al. 2011; Mukherjee & Shignapure, 2016). Therefore, caregivers' social networks are halted which leads to their remaining isolated in their homes. These restrictions are made worse if the child has multiple disabilities for instance, severely intellectually disabled with behavior problems. Due to constant monitoring of the child so that he/she is not harmed, the primary caregiver (mother) does not work outside the home.

In agreement, Thwala, et al. (2015) in their study revealed that caregivers of children with any kind of disability experience social isolation; from the community, friends and relatives. Owing to the presence of a child with a disability, some relatives and friends avoid visiting or being supportive to caregivers. Similarly, social isolation increases especially when the caregivers want to avoid feeling uncomfortable or hurt when asked questions about their child's disability. This makes caregivers stay away from social functions such as parties, family holidays among others.

Besides, some studies have shown that with the existence of a child with an intellectual problem in the family, caregivers' social relationship is disadvantaged. For example, a study conducted in Nigeria by Lawal, Anyebe, Obiako and Garba (2014) revealed that 55% of caregivers reported that with a disabled child, they were unable to move out of the home and still 40% missed their social interactions because of the health conditions of their children. Some caregivers experience poor family relationship which is characterized by constant quarrels and abandonment especially by one spouse. Consequently, the existence of a child with an intellectual problem in the family can be the basis of pressure for family members.

Another study carried out in India, Darsana and Suresh (2017) further revealed that the burden of the caregivers and their emotional condition are made worse by the negative attitudes and criticism from the community. For example, the caregivers become disappointed and easily exhausted when they hear criticism about their child. Many times this subsequently leads to the child with the disability not receiving adequate care and assistance from the caregivers. In addition, stress heightens when finances are also needed.

2.2.3 Financial difficulties

To raise a child with severe intellectual disabilities bears a lot on the primary caregivers (mothers especially). According to Reichman, Corman and Noonan (2008), part of this stress results from the economic burden. The economic burden is experienced by caregivers because they work less paid hours due to care demands. This therefore affects the amount of income earned by the primary caregivers (Kelly, Craig, McConkey & Mannan, 2009). Furthermore, Thwala, Ntinda and Hlanze (2015) argue that nurturing a child with severe intellectual disability can be very expensive than raising a typical child. Expenses may come as a result of medical equipment and supplies such as wheel chairs. Other expenses could be for medical care, hiring someone to support with the care, private education, learning equipment, tutoring or specialized transportation (Thwala, Ntinda & Hlanze, 2015).

From the literature, it seems like caregivers of children with disabilities only have negative experiences which make caregiving for children a real burden. There is hardly any positive experience noted. This present study therefore may identify some positive experience the caregivers have encountered as a result of caring for children with severe intellectual disabilities. In order to manage the caregiving stress, caregivers device various coping strategies to deal with the care stress.

2.3 Coping mechanisms among caregivers

According to Zaumseil and Schwarz(2014), coping is where people make continuous cognitive and behavioural efforts to deal with specific external or internal stresses they assesses as persistent or exceeds their means. Folkman and Lazarus (1980) proposed that coping is all about cognitive and behavioural efforts to master, reduce, or tolerate demands. In addition, Matheny, Aycok, Pugh, Curlette, and Silva-Cannella (1986) defined coping as any effort,

conscious or unconscious, to avert, remove, or weaken stressors, or to bear their effects in the least upsetting manner.

In the natural sense, nobody wishes to persistently live in tension and emotional strain. Accordingly, people will always assume some kind of strategy to avoid the conflicting situation to help themselves. As already mentioned, stress is a common factor when giving care to children with intellectual disabilities. Baqutayan (2015) observes that stress can be psychologically positive or negative, and that the ways of coping can be effective or ineffective in meeting the challenge presented by the stressful situation. In Africa, Ae-Ngibise, Doku, Asante and Owusu-Agyei (2015) mentioned that caregivers embrace various coping mechanisms to deal with problems of caring for children with severe intellectual disabilities. However, the current study focuses on two forms of coping strategies advanced by Lazarus and Folkman (1984). They are problem-focused and emotion-focused strategies, and these strategies can be either helpful or detrimental to the person applying them.

2.3.1 Problem-focused coping

Bagutayan (2015) proposes that problem-focused coping is where efforts are made to do something active to alleviate stressful circumstances. Accordingly, problem-focused coping pays attention to the causes of stress in practical ways by tackling the stressful situation causing stress. It emphasizes managing the stressor in one's environment. Problem-focused strategies may also include among others; cognitive reframing such as acceptance, changing expectations and shifting priorities and goals in life. It also involves appreciation of a child's qualities and humor, seeking resources, empowerment, setting up treatment plans, active engagement with child, mobilizing support from others, maintaining cooperation within family, and family integration with the child (Lai & Oei, 2014).

Lai and Oei (2014) in their study established that several other studies on caregiver's coping with children with autism, had derived many coping strategies. For instance, seeking treatment or intervention, and information (Glazzard & Overall, 2012); seeking social support (Marshall & Long, 2010); reappraisal and reframing (Marshall & Long, 2010); adjusting and accommodating to child's needs (Glazzard & Overall, 2012); spirituality (Marshall & Long, 2010); and seeking respite (Glazzard & Overall, 2012). According to Tajrish, Azadfallah, Garakani and Bakhshi (2015), problem-focused coping aims at reducing environmental demands or increasing personal resources to deal with the stressful situation. Lewis and Frydenberg, (2002) suggest that problem-focused or active coping strategies are related to wellbeing and health.

2.3.2 Emotion-focused coping

Emotion-focused coping involves efforts to regulate the emotional consequences of stressful events (Bagutayan, 2015). Emotion-focused coping as McLeod (2009) proposes, helps caregivers to lessen the negative emotional reactions associated with stress of embarrassment, fear, anxiety, depression, excitement and frustration. Examples of emotion-focused strategy include; isolation, escape, avoidance and wishful thinking.

With emotion-focused coping the concentration is on controlling emotional responses to stressful situation (Lazarus & Folkman, 1984). People may decide to fight the realities of experienced stress by struggling so as to achieve what they want. Secondly, they may run away from what makes them feel stressed. They are able to regulate their emotional responses to a stressful situation through behavioral and cognitive approaches. For instance, they may adopt to behaviors such as taking alcohol or using drugs or cognitively they may change the meaning of a situation or deny unpleasant facts about the situation (Baqutayan, 2015).

Additionally, people using emotion-focused coping may apply active avoidance for example, behavioural disengagement, distraction, social withdrawal, distancing, escaping, denial, ignoring child, and passive appraisal (Lai & Oei, 2014). Some studies have shown that emotion-focused coping is ineffective and is associated with more psychological problems (Braun-Lewensohn, Celestin-Westreich, Verleye, Verte& Poncaert-Kristoffersen, 2009). The current study will find out the strategies particularly used by the caregivers of children with intellectual disabilities in Jinja, Uganda.

2.4 Psychosocial support systems for caregivers

Psychosocial support means paying attention to the emotional, psychological, social and spiritual needs of caregivers in the framework of their family, friends and community (Fraser & Health, 2008). In many African societies social support was taken care of by the extended family system in the past. However, today social network has been destroyed by modernity.

Lima, Cardoso and Silva (2016) argue that models seeking to understand the way members of the family adapt to disability in childhood a number of things must be considered. These may include among others family functioning, social support, and caring stress; within the perspective of the child's care. This is important for the course of coping with the child's intellectual disability (Mekki, 2012) and (Bostrom, 2012). Al-Gamal and Long, (2013) in their study suggest that primary caregivers identify levels of stress that are high with diminished mental health, reduced quality of life, as well as being disappointed with the social support. Therefore, social support is important for preventing as well as weakening situations that are stressful. When social support is lacking then, it may lead to feelings of rejection, sadness, and anger, which can have undesirable outcomes for the caregivers' experience in the presence of a child's disability (Polita, & Tacla, 2014).

According to Polita and Tacla (2014), social support is important for health and stress relief because it increases resilience, multiplies joy, and softens sorrow. Social support provides resource for coping with stress, due to the presence of other people in whom the caregivers can confide and from whom they can expect help and concern. Lahey (2002) is in agreement when he said that the magnitude of reaction to stress is considerably less for caregivers with good social support from close friends and family members than for caregivers with inadequate social support. Hence, psychosocial support gives hope and also encourages caregivers to pay attention to the child with a mental disability. Psychosocial support is vital, therefore, the researcher in the current study intends to find out the existing social support accessed by caregivers, and how they benefit from such support.

2.5 Conceptual framework

A conceptual framework according to VandenBos (2007), is a diagram used to represent in visual form the relationship between concepts or between concepts and their attributes. Miles and Huberman (1994) also define a conceptual framework as a written form of visual presentation that explains the main ideas to be studied either graphically or in a narrative form, that is, the variables and the apparent relationship between them. Figure 2.1 is the pictorial presentation of how variables in this study relate.

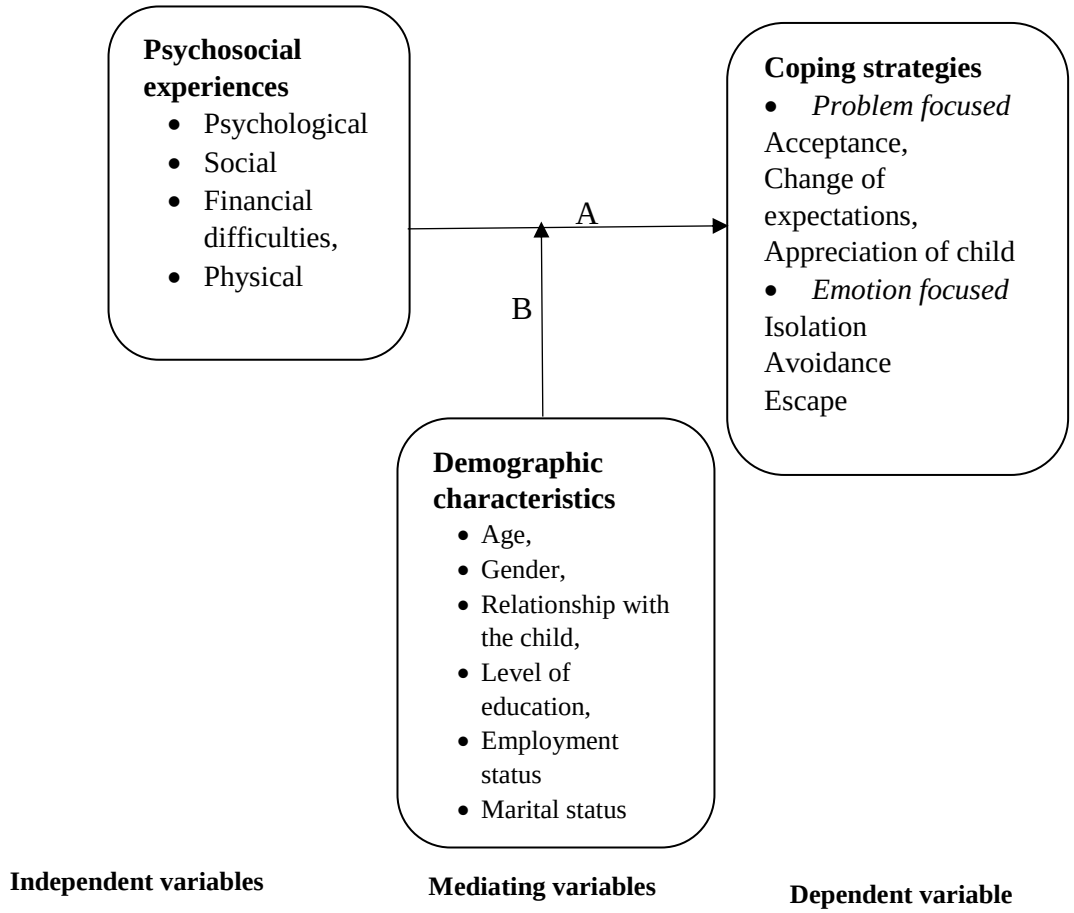

Figure 2.1: Conceptual framework

In the current study, the conceptual framework shows the relationship between psychosocial experiences and the coping strategies. Hence, it is assumed that direction A the independent variables (psychosocial experiences) such as psychological and social experiences, financial difficulties as well as physical exhaustion affect coping mechanisms, which make up the dependent variables. The psychosocial experiences determined whether the caregivers applied problem-focused or emotion-focused coping or both. With direction B, it is assumed that demographic characteristics such as age, gender, relationship with the child, level of education, employment status and marital status has effect on both independent and dependent variables. In the next chapter, the study focuses on research methodology this study engaged.

CHAPTER THREE

METHODOLOGY

3.0 Introduction

This chapter presents the methodology used in the study and details of how the study was conducted. This includes the research design, the study population and sampling procedures, sampling techniques, research instruments, reliability and validity, data collection procedures, data analysis, and ethical considerations.

3.1 Research design

According to Oladipo, Ikamari, Kiplang'at and Barasa (2015), a research design gives the organization of the research and joins the whole research together. Furthermore, a research design is an overall framework that forms the scope of the study (Selvam, 2017). Therefore, the current study will employ a qualitative phenomenological research design. A qualitative methodology is proposed for this study because it operates under the principle that social reality is mediated by interpretation, therefore, this fits the topic under investigation. According to Creswell (2014), a qualitative research is a methodology where a person conducting the research, explores and understands the meaning persons or groups attribute to a social or human problem. In addition, a qualitative research involves developing questions and procedures that naturally collect data within the participant's setting. Then data is analyzed inductively that is, constructing from particulars to general themes.

Lastly, the researcher makes interpretations of the meaning of the data (Creswell, 2014). Moreover, it provides the means by which data on multiple realities can be examined, because the purpose of this current research is to explore, a deep understanding of people's knowledge on the given situation (Patton, 1990).Furthermore, a qualitative research as Denzin

and Lincoln (2004) observe, is a multi-method in focus. It involves an explanatory and realistic approach to its subject matter, therefore researchers study things in their natural settings, and attempt to interpret the phenomena in terms of meanings people attach to them. Giorgi (2009) also emphasizes that a phenomenological research is one in which the researcher describes the lived experiences of individuals about a phenomenon as described by participants. This research design was preferred because the researcher collected data in the field at the site where participants experience the problem under study (Creswell, 2013; Marshall, & Rossman, 2011). Thus, in a qualitative research design, the information is gathered by talking directly to participants in their natural setting.

3.2 Location of the study

The present study was conducted in two schools in Jinja district. Jinja district is found in the Southeastern part of Uganda. It is east of the Nile River and along the northern shores of Lake Victoria. According to UBOS (2017), Jinja has a population of about 471,242 persons. The district is subdivided into 3 counties namely, Butembe, Kagoma and Jinja Municipality. There are 6 sub-counties and these include, Budondo, Mafubira, Busede, Butagaya, Buyengo and Buwenge. Jinja municipality is divided into 3 divisions; Central division, Masese/Walukuba division and Mpumudde division. The current study was conducted among caregivers of children with severe intellectual disabilities learning in a special educational needs unit attached to Walukuba West primary school found in Masese/Walukuba division and St. Ursula special school found in Mafubira sub-county.

The rationale for carrying out the study in Jinja district was because no meaningful study had been conducted in Uganda to explore the psychosocial experiences influencing coping mechanisms among caregivers of children with severe intellectual disabilities. Jinja district

was targeted because according to the National Population and Housing Census (NPHC) conducted in 2014, Jinja has more (about 10,019) children between 2 – 17 years having different kinds of disabilities compared to other districts (UBOS, 2017).

3.3 Target population

A population is a group of people or items from which samples are drawn for measurements (Kombo, & Tromp, 2006). The study population as Oladipo, et al. (2015) observed is the whole of units from the population that the researcher has access to. Therefore, the population target for the current study were parents or guardians of children with severe intellectual disabilities enrolled in 10 schools with special educational needs in Jinja district. Of the total 10 schools with special education needs, eight were public primary schools with special education needs units and two were privately owned special schools. The total population of caregivers having children with severe intellectual disabilities registered in all the schools was 250.

3.4 Sampling techniques and sample size

Sampling is the method used by the researcher to select the sample population for the study (Kombo, & Tromp, 2006). It is a process as noted by Orodho and Kombo (2002) of picking a number of participants from a given population such that the sampled group has elements representative of the characteristics found in the entire group. Hence, a sample is a group of participants chosen from a bigger population for the purpose of the study. The sample for this study is illustrated in table 3.1.

3.4.1 Sampling techniques

In the present study, the researcher employed non-probability sampling technique to select schools and participants. This was because the items for the sample were selected

deliberately by the researcher (Singh, 2016). As Mugenda and Mugenda (2009) observe, non-probability sampling is used when the focus is on in-depth information. Purposive sampling was used because as stated by Babbie (2010) and Isesolo, Kajula, and Yahya-Malima (2016), purposive sampling is applied when the researcher is knowledgeable about the given population, and the type of research objectives, that is, the researcher has the ability to judge and knows the purpose of the study.

Purposive sampling targets people who meet a certain predetermined criteria (Oladipo, et al., 2015). With this sampling technique, the researcher aimed at deliberately choosing only those participants who had relevant view on the issue at hand. The technique provided enriched data from the participants about their own experiences concerning caring for children with intellectual disabilities (Sa'id & Madugu, 2015). This technique helped the researcher to avoid wasting time and resources on items that might have been of very little use to the present study.

3.4.2 Sample size and sample frame

In order to determine the sample size, Mugenda and Mugenda (2009) suggest that a sample size of between 10% and 30 % is an adequate representation of the target population, thus, 10% is suitable for analysis. Table 3.1 shows samples distribution for both schools and participants and their percentage. The total population for schools was 10 and sample size was 2 which is 20%. Two schools sampled were; Walukuba West primary school (special education unit) found in Masese/Walukuba division Jinja Municipality and St. Ursula private special school in Mafubira sub-county, Jinja district. The researcher used purposive sampling to select two schools because they had a bigger number of children with intellectual disabilities enrolled. St. Ursula Special School for instance, handles children with intellectual disabilities purely. While the special education unit in Walukuba West Primary School though had children with

mixed disabilities, the school had more children with intellectual disabilities compared to other schools with special education units. The second special school in the district of Jinja enrolls children with mainly physical disabilities which was not the focus of this present study.

Whereas the total population of caregivers of children with intellectual disabilities was 170 and sample was 20 which is 23%. Hence, from the 10 schools in Jinja district, 2 schools were sampled for the current study. The sample size of 20 participants out of the 170 caregivers corresponding to the number of children enrolled in the two schools was recruited to participate in the study. The next section exemplifies the sample frame for this study.

Table 3.1: Sample Size distribution

Population Characteristics	**Population target**	**Sample size**	**Sample technique**
No. of schools with special education	10	2 (20%)	Purposive sampling
St. Ursula special school caregivers	90	11(12%)	Purposive sampling
Walukuba special school caregivers	80	9 (11%)	Purposive sampling
Total	**170**		

Due to the small sample size, the formula below by Krejcie and Morgan (1970) was used by the researcher to calculate the sample size of the participants from the total population.

$$S = \frac{X^2 NP(1-P)}{d^2(N-1) + X^2 P(1-P)}$$

Where:

S= the desired sample size

X^2 = 3.841 this is table value of chi-square for 1degree of freedom at the desired confidence level (Krejcie & Morgan, 1970; Ittiravivongs, 2012; Chege, Wachira, & Mwenda, 2015)

N = the population size

P = the population proportion (0.5)

d = the degree of accuracy expressed as a proportion (.05)

The caregivers who participated in this study were recruited using the following criteria:

They were were adults of 18 years and above, he/she was either a parent, grandparent or any family guardian, was caring for a child having among others any of these conditions; down syndrome, autism, ADHD, or a combination of them. The child being given care had been assessed by psychiatric personnel for any of the conditions above. The caregiver's child must have been attending special education in any of the two schools. A period of caregiving was not less than two years, the caregiver was residing within Jinja district and spoke English or Lusoga (local language). In addition, for the researcher to be certain that participants were giving care to children with intellectual disabilities, assement forms in the special schools were examined. From the assessment forms, the researcher determined which caregiver qualified to participate in the study by recruiting only caregivers of children with any of the conditions mention above.

3.5 Research instruments

A research instrument is what the researcher uses to collect information (data) to answer the research questions. In the present study, the researcher used an interview schedule and focus group discussions (FGD) schedule as instruments for data collection. The interviews were administered to 6 participants while focus group discussion collected data from 14 participants in two groups of 7 participants each.

3.5.1 Interview schedule

With an interview schedule, the researcher ensured that none of the important issues to be discussed was left out. The interview schedule was developed by the researcher based on the research objectives as shown in (*appendix 1).* Using an interview schedule with semi-structured questions was of an advantage because it allowed the participants speak out in their own words. However, the researcher guaranteed that data was systematically examined for patterns in the nature and sequence of the experience (Bernard & Ryan, 2010). The interviews lasted approximately 30-40 minutes as it depended on the responsiveness of the participant. For the few interviewees who were semi-illiterate, the interviews were conducted in the local language translated by the research assistants.

3.5.2 Focus group discussion schedule (FGD)

Focus group discussion schedule was employed for gathering information from the participants *(please see appendix 1).* FGD as Nyumba, Wilson, Derrick and Nibedila (2018) point out, is a qualitative approach for gaining an in-depth understanding of a social issue at hand. It provides a rich and detailed set of data about people's insights, thoughts, feelings and impressions using their own words (Stewart & Shamdasani, 1990). Secondly, because the researcher aimed at finding out the caregivers' understanding and experiences about caring for children with intellectual disabilities. Finally, FGD was used because the method is usually appropriate for examining sensitive issues, where the people have to give their own experiences of caring for children with intellectual disabilities (Dilshad, 2013).

3.6 Reliability and validity of the instruments

According to Creswell (2013), reliability of an instrument is the consistency with which a measuring instrument yields certain results when the unit being measured does not change. In

order to enhance reliability, the researcher carried out a pilot study with two caregivers who were not part of the study to determine if the instrument would give the correct responses to the objectives of the study. Kim (2010) describes a pilot study as a mini-study methodological test usually carried out to prepare for the main study. Its main aim is to ensure that the methods or ideas can work in practice. The researcher contacted two caregivers who had children with intellectual disabilities but learning in a school different from the two target schools. Next, the researcher ensured that the same interview questions used for the pilot study were administered to all participants in the main study for further enhancement of reliability. With the pilot study, it was found out that caregivers needed more time to talk about their experiences of taking care of children with severe intellectual problems. Thus, the proposed time of 20 – 30 minutes was short to cover all the questions. Subsequently, the researcher changed the interview duration to 30 – 40 minutes per interviewee.

The validity of a measurement instrument on the other hand, refers to "the extent to which the measurement measures what it is supposed to measure" (Mugenda & Mugenda, 2013). It is that which determines whether the study truly measures that which it was intended to measure or how truthful the research results are. As Creswell (2013) observes, validity is one of the strength of a qualitative research and it dissuades the accuracy of the findings from the view-point of the researcher, participant or the reader of account. Therefore, the instruments of data collection were scrutinized by the researcher's supervisors to judge the appropriateness and determine whether both the interview and focus group discussion schedules represented all the areas that needed to be investigated.

The participants were people who had been giving care to children with severe intellectual disabilities for not less than two years. The researcher also ensured that the

information was recorded and transcribed without any bias. In addition, the researcher compared the field notes written by research assistants during the interviews with the transcribed scripts to ensure all data were included. Lastly, participant validation was done, that is, the initial results were tested with participants to see if they were the true record of what they had given.

3.7 Data collection procedures

As Mugenda and Mugenda (2013) notes, data collection is a technique used for gathering data systematically from various sources for a particular purpose using a data collection instrument. According to McQueen and Namey (2011), data may be in any form ranging from transcription of interview, field notes, videos or even documents. To undertake this study, the researcher commenced on the process, by first of all getting the approval from the Institute of Youth Studies and from the Tangaza University College Research Ethics Committee to proceed to the field.

Secondly, before applying for the research permit from the Uganda National Council for Science and Technology (UNCST), the researcher sought the approval and clearance from Mbale Regional Referral Hospital Research Ethics Committee (MRRH-REC) as required by UNCST for all students studying outside the country. With a clearance letter from MRRH-REC the researcher then proceeded to apply for the research permit from UNCST to carry out the study in the site. The researcher also sought clearance and permission from the head teachers of the two target schools to collect data from the caregivers of their pupils.

Thereafter, the researcher engaged two research assistants who were good at both English and Lusoga (local language) for easier translation and taking notes. These were recruited and trained by the researcher before pilot testing of the research instruments and actual

data collection commenced. Upon agreement with the schools administration, 20 participants were contacted, by phone and invited to the schools where they were informed about the study. Those who consented to participate in the study, the researcher made appointments for the interviews and focus group discussions. The interviews lasted between 30 – 40 minutes. The appointment for interviews or focus group discussions was made depending on the availability of the participants. The voices of the participants were audio recorded for purposes of not missing out any given information.

3.8 Data analysis

The present study employed thematic analysis to analyze the collected data. Thematic analysis is a process by which the researcher identifies, analyses and reports the patterns (themes) of data (Selvam & Mwangi, 2014). The method involves coding the data systematically and eventually reporting patterns that are identified in the data (Selvam & Mwangi, 2014). In the current study the researcher used thematic analysis to organize the data through three stages namely; open coding, axial coding and thematic identification.

Step 1. *Open Coding:* This refers to the procedure of getting a better understanding of the data without benefit of a specific theoretical orientation.

Step 2. *Axial Coding:* At this level of coding, the researcher grouped the open codes basing on the nature of their perceived relationship to form higher level of categories.

Step 3. *Thematic Identification:* The themes that provided answers to the research questions were carefully chosen for reporting in the results section.

3.9 Ethical Considerations

Research ethics as defined by Economic and Social Research Council (ESRC, 2005) are the moral principles that guide research from its inception to its completion. Therefore, before

embarking on the data collection process, the researcher sought approval, clearance and permission to collect data from the Institute of Youth Studies and from the Tangaza University College Research Ethics Committee. In addition, the researcher sought the approval of Mbale Regional Referral Hospital Research Ethics Committee (MRRH-REC) and a permit from the Uganda National Council for Science and Technology (UNCST) to carry out the study in the suggested site. The researcher also sought clearance and permission from the head teachers of the two special schools to collect data from the caregivers of their pupils.

Furthermore, ethical issues such as confidentiality, consent of participants, anonymity and voluntary participation were considered. The researcher assured the participants that their identity would not be disclosed. Hence, the researcher kept confidential personal data of the participants. The researcher presented an information sheet and a consent form to the participants who read through. The participants who had problems of reading for themselves, were assisted by research assistants who translated for them in the local language to understand before they signed the consent form. The researcher asked for permission from the participants to record their voices for the purpose of not missing out the important information they were to give. The researcher ensured that both data from literature and the field was written in conformity with adherence to ethical issues of plagiarism when writing the literature and the report of the findings. The researcher ensured as well that no plagiarism was done by appropriately citing the literature used. Representation of the participants was done through codes and not by use of their real names. The researcher promised both the schools and participants a copies of the final work once compiled. The next chapter presents the findings and discussion of the study.

CHAPTER FOUR

PRESENTATION AND DISCUSSION OF THE FINDINGS

4.0 Introduction

This chapter presents the findings of the study on exploration of psychosocial experiences influencing coping mechanisms among caregivers of children with severe intellectual disabilities attending special education in two schools of Jinja district, Uganda. Firstly, it presents personal demographic details of participants, then, the emerging themes from the transcribed interviews and focus group discussions. The themes are presented and discussed in three major groups, based on the research objectives: (a) Psychosocial experiences of caregivers of children with severe intellectual disabilities; (b) Coping mechanisms applied by caregivers of children with severe intellectual disabilities; (c) Psychosocial support systems among caregivers of children with severe intellectual disabilities. The major themes were described and supported by verbatim quotes from the participants. The next section presents participants' demographic information.

4.1 Demographic details of participants

The characteristics of personal demographics of each participant include age, gender, relationship with the child, level of education, employment status, marital status, child's age, child's gender and lastly total number of children under the care of the participant. A total number of 20 caregivers (female & male) participated in the study. Six participants were interviewed and 14 participants in two groups of seven people participated in focus group discussion.

In order to safeguard the anonymity of participants, names were not used and instead letter "p" and numbers were used to represent the participants as shown in tables 4.1, 4.2 and

4.3. Therefore, when structuring the quotes obtained during the interviews, the letter "m" for male or "f" for female followed by letter "p" and a number and the age of the participant were used in brackets. For focus group discussions, the quotes also included the acronym FGD and the number of the group the participant was in.

4.1.1 Interview participants

The demographic results of the interview participants are presented in Table 4.1.

Table 4.1. Description of interview participants

Code	Age	Gender	R/with child	Educ.	Employment	Marital status	Child's age	Child's gender	No. of children
P1	45	Male	Father	Dip	Self-employed	Married	14years	Female	05
P2	35	Female	Mother	Degree	Employed	Single	14years	Male	02
P3	33	Female	Mother	A' level	Employed	Single	6years	Male	02
P4	38	Female	Mother	Degree	Employed	Married	11years	Male	04
P5	33	Female	Mother	Dip	Self-employed	Single	9years	Female	01
P6	42	Female	Mother	Degree	Employed	Widow	16years	Male	01

Key*:*

R/with child = Relationship with child *Educ. = Education*

Table 4.1 shows the demographic profiles of six participants who participated in face-to-face interviews. They were all primary caregivers of children with intellectual disabilities. The age of the participants ranged from 33 years to 45 years. By gender, 5 of the participants were female with 1 male making it 6 participants. Educational level of the participants, the findings revealed that 3 participants had a bachelor's degree, 1 had a diploma and one had an A-level certificate, 4 of the participants were employed, and 2 were self-employed. Also, the marital status showed that, 3 participants were single mothers, 2 were married and the other 1

was a widow. The age of the children given care ranged from 2 to 16 years old. Gender-wise, the children were 4 male and 2 female. Lastly, the number of children by the participants ranged from 1 child to 5 children.

4.1.2 Focus group discussions (group one)

The demographic results of the focus group discussion participants of group one are presented in Table 4.2

Table 4.2. Description of FGD participants group 1

Code	Age	Gender	R/with child	Educ.	Employment status	Marital status	Age of child	Child's gender	No. of children
P1	58	Female	Mother	Primary	Unemployed	Divorced	13years	Male	10
P2	41	Male	Father	Degree	Employed	Married	5years	Female	03
P3	36	Female	Mother	Primary	Unemployed	Married	9years	Male	07
P4	28	Female	Mother	O' level	Self-employed	Married	5years	Female	01
P5	39	Female	Mother	Primary	Self-employed	Widow	12years	Female	09
P6	46	Female	Mother	Dip	Employed	Separated	8years	Female	04
P7	60	Male	Father	Primary	Self-employed	Divorced	16years	Female	06

Table 4.2 gives the demographic profiles of seven participants of focus group discussion group one. The age of the participants ranged from 28 years to 60 years. By gender, 5 of the participants were female and 2 were male making 7 participants. All the participants were biological parents to children with intellectual impairment. Regarding educational level, 4 participants had attained primary level, 2 had diploma certificates and 1 had a bachelor's degree. 2 of the participants were employed, 2 were un-employed, and 3 were self-employed. Marital status showed that, 3 participants were married, 2 divorced, 1 widowed and 1 separated. The age of the children ranged from 5 years to 16 years. According to gender, there were 5 female and 2 male. Lastly, the number of children by the participants ranged from 1 child to 10.

4.1.3 Focus group discussion (group two)

The demographic results of the focus group discussion participants of group two are presented in Table 4.3.

Table 4.3. Description of FGD participants group two

Code	Age	Gender	R/with child	Educ.	Employment status	Marital status	Age of child	Child's gender	No. of children
P1	45	Female	Mother	Dip	Employed	Married	8years	Female	07
P2	43	Female	Aunt	O'level	Employed	Married	10years	Female	09
P3	30	Female	Mother	Degree	Employed	Married	5years	Male	01
P4	60	Female	Mother	O'level	Unemployed	Widow	15years	Male	07
P5	49	Female	Aunt	O'level	Self-employed	Single	17years	Male	04
P6	37	Famale	Mother	Degree	Employed	Married	11years	Male	03
P7	33	Male	Father	Degree	Employed	Married	6years	Male	01

Table 4.3 illustrates the demographic characteristics of seven people who participated in focus group discussions in group two. The participants' age ranged from 30 years to 60 years. By gender, there were 6 female and 1 male making 7 participants. Four participants were biological parents while 2 were aunties; guardians to the children. Considering educational level of the participants, 3 had bachelor's degrees, 3 ordinary level certificates and 1 had a diploma certificate. Five participants were employed, 1 was un-employed, and 1 was self-employed making the number 7. On marital status, the results showed that 5 participants were married, 1 was single, and 1 widowed. The age of the children ranged from 5 years to 17 years. In line with gender, the children with severe intellectual problems were 5 males and 2 female. Lastly, the number of children by the participants ranged from 1 child to 9.

4.2 Findings from the study

Having presented and discussed the demographic data of the participants, the next section focused on the presentation of the findings of the 3 objectives of the study. The data was presented in form of themes that emerged to answer the research questions. Each theme had a number of sub-themes derived from the participants' verbatim expressions. After analyzing the data, three super-ordinate themes emerged based on the four research questions of the study. These themes included: psychosocial experiences, coping mechanisms and psychosocial support for caregivers.

4.3 Psychosocial experiences

The first research question of this study was to examine the psychosocial experiences among caregivers of children with severe intellectual disabilities in Jinja district. Evidence from the interview data indicated that both female and male caregivers of children with severe intellectual disabilities in Jinja district had challenging experiences. This was expressed in the shared responses about their experiences as; caregiving challenges, lack of acceptance from the immediate and extended family members, societal reactions towards such children, and attribution of the disability to malignant spirit of the dead.

4.3.1 Caregiving challenges

Several participants acknowledged that caring for children with intellectual disabilities was indeed a challenge. Caregiving challenges were expressed as time consuming, a child being totally dependent, and problems with neighbors among others. These caregiving challenges lead to a stressful situation for most caregivers. It also affects their daily family activities especially employment. Six of the responses expressing the challenges involved in caregiving for such

children in the family given by the participants are presented. A male participant captured these challenges of caring for a child with intellectual disabilities in the family, he said:

> "The experience of the child with a disability is not the best because the child requires carrying her, bathing her and feeding her. The experience is not the best…Having a child with a disability really affects our life because you need to go to work but you might fail to do so. You cannot leave her with a maid, they torture her you know she does not talk sometimes you want to go to village but then you have to carry her, she does not walk and she does not even wheel herself so it really affects us" (MP1, 45years).

Another participant during the interview also said,

> "At times my boy gives a lot of stress because he is the type you cannot leave in the house alone. When you leave him alone in the house you will find that he has turned everything upside down, ooh….he can disorganize everything…..you will find all the water cans emptied on the floor and things like; flour, sugar and salt all mixed in it. So you become so angry when you get home to find a house in a mess, yet you cannot leave him out because he will be mistreated by other people in the neighborhood" (FP6, 42 years).

It is overwhelming experience for caregivers of children with intellectual disabilities. One participant also shared her experience thus, *"The experience is overwhelming I tell you, with a child like mine, you have to program yourself in such a way that your activities fit in his….if his grandmother is not at home and he is being brought from school I have to abandon whatever I am doing to be with him. It is difficult to stay at work beyond a certain period" (FP2, 35years).*

A female participant from the focus group discussion also brought out another dimension of these challenges which comes from the nature of the intellectual disability of her two children. She said:

> "I have challenge with my boy, he is very restless and makes a lot of noise and also he is aggressive. He destroys things and so he is not liked by people. In school he does not concentrate he keeps moving and so understands nothing. The girl instead is quiet, her brain does not work so keeps repeating….repeating one thing. You do almost everything for her……these children are a real problem. You cannot leave them alone at home and nobody wants to live with them" (FP1, 58years FGD1).

Still on caregiving challenges one participant lamented, *"One thing I know about these children is the fact that they stress you as a parent. It is a real burden which nobody can help you out with. … Not even a maid will understand the child. Even their fathers don't like taking care of them. They can provide for the child but not to take care" (FP6, 46 years FGD1).* Lastly, the burden may even be worse if the family members are not God fearing. One female participant aptly expressed this burden as well, thus: *"With the presence of a child with disability in the family if members of that family are not religious, then the mother bears it all" (FP3, 30 years FGD2).*

4.3.2 Lack of knowledge about the condition by family members

Another major theme that emerged from the data given by the participants on psychosocial experiences was lack of knowledge about the condition by family members. This response was mostly reported by the focus group discussion participants. Lack of knowledge by members of the family leads to one parent especially the mother being blamed for the condition of the child. These participants shared that, children with intellectual disabilities are more often rejected or neglected by their fathers who think that such a child is not theirs. Mothers are blamed for bringing a wrong gene into the family and the she may be abandoned with the child. These negative comments by members of their families affective the quality of caregiving to children with disabilities. Five responses on this as narrated by the participants are shown below.

According to one male participant, *"It took long for the family members to understand and accept the child's condition. Even her fellow children it took long for them to understand that she has a problem and to accept her. Even as parents it took us time to learn and understand how to deal with our child" (MP2, 41years FGD1).* Similarly, another participant

shared her own experience hence: *"The biggest problem we mothers face is; when you give birth to this kind of child, the husband may abandon you with the child… But I want to tell you that with such children the father of the child can tell you that we don't give birth to this kind of children in our family" (FP3, 36 years FGD1).*

In the same way, a female participant shared her painful experience of having been blamed for giving birth to a picture by her mother in-law saying: *"My mother-in-law used to call her just a picture because she is not able to do anything. She would complain,* w*hy did they produce for us a picture in the family? This hurt me a lot and at times I would feel depressed because of the words of the people about my child" (FP6, 46 years FGD1).* Still on rejection by family members, one participant expressed her painful situation saying: *"The mother can be abandoned by the husband and it is worse if the child is the first born. The family of the husband tends to blame it all on the mother of the child. If the husband has no God in his heart he may resort to taking another wife" (FP3, 30 years FGD2).*

Lastly, on lack of knowledge about the condition by the family, one female participant expressed her experience in terms of outright rejection of the child by her mother saying:

> "From experience, a child with this problem is not accepted by the family first of all, this kind of children suffer a lot, some of them are denied food, and some are locked away from the public. If he is to eat then he is served alone. From my experience of caring for my niece, these type of children are usually disliked by one parent; either the mother or the father. For my niece, the mother did not like her and so I had to take the responsibility to care for her" (FP2, 43 years FGD2).

4.3.3 Societal reaction towards intellectual disabilities

Another salient feature brought out by the participants interviewed and also those in focus group discussions was societal reaction towards children with intellectual disabilities. The participants especially reported that having a child with intellectual disabilities was often a transition into a new and most likely undesirable identity in society. They demonstrated their

awareness of societal attitudes which made them many times feel stigmatized and isolated. From their narratives, it became obvious that much of the reaction resulted from lack of understanding of the cause of intellectual disabilities. This led to fear on the part of community members and in some cases hostility towards the children.

Five of the responses from participants are presented here to support this point. A participant felt the pain as a result of the habit of mockery by members of the society towards her son because of his condition saying: *"It is very disturbing the way our children are treated by other members of the community, for example, my son is always regarded as a useless thing and you know with that kind of attitude even keeping a maid becomes tricky. You know what it means to keep a useless thing in your house and you are spending on it and the mockery around" (FP6, 42 years).*

Likewise, one male respondent shared his experience on how his children are treated by other children and members of the community on account of their epileptic condition. This he expressed thus:

> "My children have a problem of epilepsy…..you know epilepsy destroyed their brains and so they are not able to learn well in school. To tell you the truth, my children are abused, segregated and imitated because of their condition. Other children don't want to play with them in the village for fear that they will also be affected. One of my girls is 16 years a big girl now but when she gets attacks they have to call me because no one wants to go near her…it is sometimes hard for me as an old man" (MP7, 60years FGD1).

Again, on societal reaction, one female participant had this to say about her experience: *"The public or community…. they treat her as a misfit, as cursed and they think we parents are also cursed, very few relatives come to our house…..oh yaah they call her the cursed one, so as a parent you don't feel happy when your child is being mistreated" (FP1, 45 years FGD2).* Furthermore, another participant voiced her experience of being laughed at and mocked by community members saying: *"Many times we are laughed at that we have a lot of money to*

waste on such children. People ask sarcastically, how can you waste your money to pay school fees for such a child? Sometimes we are mocked by some people from the community like; where were you looking to conceive such a child? It is really frustrating and discouraging" (MP2, 43 years FGD2).

Lastly, on the societal reactions towards intellectual disabilities, two participants in FGD group2 touched on the physical abuse suffered by their children from society,

> "The community members do not understand that these children have a problem so many times they beat them and chase them should they exhibit a bad behavior. They are beaten, abused and chased by adults who have normal children. So as a parent you feel very bad that what they do to your child they are directly doing it to you" (FP5, 49 years FGD2).

Similarly, another participant said: *"Sometimes in the beginning we used to tie him so as to avoid quarrels with neighbors because he was spoiling this or that and the neighbors abused and even beat him. My nephew is called all kinds of names for example the "Mulalu" (the mad one, the possessed), "Kasiru" (the stupid one, one with no brains) and so on" (FP6, 37 years FGD2).*

4.3.4 Perceived cause of intellectual disabilities.

Last, on the psychosocial experiences among caregivers is the perceived cause of intellectual disabilities. The way people try to explain the cause of intellectual disabilities in these children was another form of experience (theme) that came up from the data. Most participants expressed their pain and frustrations suffered from people within and outside the family who wrongly attributed the cause of their children's intellectual disabilities to one thing or the other. There was evidence from the interview data indicating that many people in the community attributed intellectual disabilities to spirit possession and witchcraft, genetics transmission from mothers, and use of contraceptives by mothers of such children. Six of the

responses on the attribution of the disabilities from family and members of the society are given next.

One participant said that community and family members explained the intellectual disabilities of his child as a possession by a malignant spirit. This he expressed saying: *"Ok like those people in the village they attribute the child's problem to "Lubales" (small gods) you know tradition so we needed to do some rituals so that the child would be ok, which I did not agree with. My relatives and even some neighbors feel that our child is like that because the spirits are not happy with us. So they keep pestering us to do some rituals so that the child recovers"* (*MP1, 45years).*

Another participant, her experience was similar as she said *"Many people told me that it was my co-wife who had gone to the witchdoctor so that my child would be that way. I really had a lot of fear and wondered why she could do that to my child because when I got married, she had already divorced*" *(FP3, 36years FGD1).* Similarly, one participant said: *"Family members and other people attribute the disability to the dead. They say the child is possessed with a spirit of a dead person who is not happy with the family Sooo….besides the stress caused by caring for the child, other family members also stress you with all sorts of talk about your child. With this kind of child in the family not many people will come to your home" (MP2, 41years FGD1).*

Moving away from spirit possession and witchcraft, three participants shared their experience of having been accused as the cause of their children's intellectual disabilities. One participant said, *"When his condition was diagnosed his grandmother (mother to his father) said… We don't have people with such disabilities in our family it must be from your side. I am kind of blamed for the disability of my child. But, my son had severe brain damage due to cerebral*

malaria" (FP6, 42years). Further still, another participant showed her confusion about what to exactly believe concerning her child saying:

> "Actually, like most of them used to say that it was because of family planning pills that affected the child, others say there is something I did which was not right, still others attribute the problem to curses so everyone has a lot of stuff sometimes you just don't listen to what they are saying" (FP5, 33years).

Lastly, one participant expressed her double agony as a result of the interpretations given to the intellectual disability of her child. This she captured thus:

> "There is a way the community perceives it because people are not comfortable with this situation, some of the things they say are very disturbing. They say, they have some money therefore, they must have sacrificed the child for money. I really don't know what caused my child's disability, although people out there think I was taking contraceptives, yet by that time I did not know much about contraceptives the child being my first born. Sometimes they say it is in the family but I know nobody in the family with a similar condition" (FP2, 35years).

These psychosocial experiences influence the way the caregivers cope with the situation of caring for a child with severe intellectual disabilities. The next section presents some of the coping mechanisms applied by the participants of the current study.

4.4 Coping mechanisms used by caregivers

The second research question of this study was to establish the coping mechanisms employed by caregivers of children with intellectual disabilities. There was evidence from the interview data indicating that most participants employed some psycho-spiritual coping strategies. Some examples of the themes on coping mechanisms included accepting the situation and living with it, belief in and praying to God for strength, and ignoring negative comments from both the family and the community.

4.4.1 Acceptance of the situation

When people are faced with difficult situations, through resilience, they come up with different coping strategies. A very important coping strategy used by caregiver of children with

intellectual disabilities reported in this study was acceptance of the situation. Most of the participants reported having no control over the situation of their children but had to accept it. They also expressed that accepting the condition of their child eased their frustrations. Five coping strategies were given by the participants.

First of all it comes in the form of acceptance of the uniqueness of the child: *"We accept what God has given us, she is a child like the rest of the children I have, although she is more special" (MP1, 45years).* Another participant said, *"I am able to cope with my son's situation because I now understand him and I also know that his situation is permanent. So, I decided to love him the way he is and live with him as my child"* (FP2, 35years). Still on acceptance of the child's condition one participant acknowledged, *"It takes time for people in the family to accept the condition….it is the only way because you cannot deny the child. So the only way is to accept the condition of the child. We need to love our child so that other people can see and also accept the child" (MP2, 41years FGD 1).*

In the same vein, one other participant said: *"For me the only way to cope with a child like ours is to accept the child and support each other with the mother to raise our child. Mmm…we have to show love to this child who is with a disability because when you love him or her you will not feel burdened, he/she will be like any other child. We need to treat the child like any other child in the family" (MP7, 33years FGD 2).*

Lastly, the acceptance comes from the awareness that the child is God's gift to them. A participant thus expressed:

> "Because of people's negative attitude towards me and my child in the family, I learned to accept and appreciate the child. If a parent does not to like the child, what will other people do? We just need to accept the situation because it has happened. My husband and I accepted our child as God given and treat him just like any other child and in that way I stopped pitying myself and regretting for the gift God has given us" (FP4, 60years FGD 2).

4.4.2 Belief in God

Belief in God was another important theme reported by the participants both during interviews and focus group discussions. Nearly all participants expressed the belief in God by praying for the strength to carry on with the challenges of caring for their children. The discourse of coping through prayers by the participants is summarized into praying for strength to carry on, and praying for healing from God for their children. Four of the responses on this coping mechanism given by the participants are as follows:

A female participant during the interview stated how prayers have been really a pillar of strength for her when caring for her son with autism;

> "Without prayer we wouldn't have managed. But I know God answers our prayer when we pray to him. I also know that God takes his time in answering but I also know that his time is the best. So I always lean on prayer because when His time comes he can do for you what you want. Above all, God is the overall doctor, overall healer so I have hope, faith and trust in him that anything can happen because He is a God of signs and wonders plus miracles" (FP4, 38years).

Similarly, another female participant revealed that her mother sometimes assists her in taking the child for prayers. She also prays for the child but more so for strength to keep loving and caring for the child: *"I pray for him and a few times my mother takes him for prayers but most times I pray for strength from God to give me life to continue caring for him. He is not going to heal and I am aware that his condition is permanent and he will not heal so I pray that I am able to help him since he is my only child" (FP6, 42years).*

Still on prayers as a coping mechanism, another participant expressed her struggles and hope in the efficacy of prayer saying:

> "I do pray because for this kind of child it is only God who can support and give you strength to carry on. When I realized the condition of my child was not a normal one, I tried to take her for prayers, but you know, I just stopped this thing of moving here and there because at the end of the day you would see no change. I only pray always for strength to continue carrying for my child. I am hoping to try again to

take her to a prayer meeting in Lagos sometime in August because I still believe that God can do a miracle and my child can get better." (FP5, 33years).

Lastly, on praying for strength to cope with the burden of care for her child, one participant expressed her coping with prayers thus: *"For me I pray for God to give me strength to manage to care for my child. I don't blame God or anyone for my child but I love him and ask God to give me strength to care for him"* (FP3, 36years FGD1).

4.4.3 Ignoring negative comments from people

A third theme on coping mechanisms that emerged from the data was ignoring the negative comments from the family members and neighbors about their children. The participants mentioned that they pretend not hear what other people are saying about them and their children so as not to be frustrated and stressed. Some said that when a negative comment is directed towards them, they simply keep silent.

From their narratives, it came out that most participants use this mechanism in different contexts. Four responses from the participants to support this point are presented here. It involves pretending not to hear what people say. *"To manage not to get stressed, the only way is to pretend not to hear what people say because people can criticize and if you listen to everything you can become mad. When people abuse my child, I just ignore though it is painful to hear. What can I do? I have the child and he is mine" (FP5, 39years FGD1).*

Another participant in a focus group discussion stated thus: *"Mmm….I have learnt not to listen to what people say about my child. I ignore whatever people say and I continue loving my child and when they see that I care about him they also start coming closer to him" (FP1, 45years FGD2).* Another participant said this: *"You know my son does not talk and whatever bad thing other children in the neighborhood do, they always say it is my son. I just ignore*

because most cases he is not the one and because he doesn't talk he cannot defend himself so I just look at them and say nothing" (FP4, 38years).

Lastly, one female participant attested to the fact that she and her husband have both learned not to listen to what people say about their child. According to her, *"My husband and I ignore what other people say about our child and have accepted him as God given and treat him just like any other child and in that way I stopped pitying myself and regretting for the gift God has given us" (FP3, 30years FGD2).*

4.5 Psychosocial support for caregivers

The third research question of this study was to assess how caregivers were supported in their efforts to care for children with intellectual disabilities. Based on the research findings, it is evident that majority of the participants rely solely on their own resources to care for their children who have intellectual problems. Therefore, two themes that came up included; lack of psychological and financial support, and support from special schools as described in the next section.

4.5.1: Lack of psychological and financial support

The findings of the current study demonstrated that caregivers of children with severe intellectual disabilities entirely depend on themselves to care for their children. Apart from the support given by special schools which trains their children in daily living skills, there is hardly any support given from either the community or government in support of caregivers. Six responses to support this feeling are indicated below. It comes from the efforts of both parents, *"We are not supported by anybody or organization in anyway. For us to take care of this daughter of ours, we work had ourselves me and the mother and get money which supports the child, we pay school fees and it is very expensive and the money we get also provides for our*

child's feeding, medication and clothes. We don't share our problems with anybody" (MP1, 45years).

Participants in a focus group discussion 2 expressed how they are not supported but have to do it by themselves. One female participant expressed how society regards their children by saying:

> "We as parents of these kind of children are not supported. People most times think it is a waste of resources. Our children don't show tangible progress to improve in terms of academics. I support my child with the little I am able to get but how I wish we could be helped by the government to construct special schools for these kind of children. A child with a disability takes most of the resources and yet we have other children to take care of" (FP5, 49years FGD2).

A male participant expressed how a traditional family system has been affected by modernity saying; *"It is a pity…..even the family system that used to support families has been affected by modernity and so we don't have any support systems to help us take care of our children with disabilities. Even to ask a family member to support no one is willing to do so. So you have to work hard to care for your child. Children with especially intellectual disabilities can easily die because people are not interested in helping them" (MP7, 33years FGD2).*

For one female participant, expressed: *"I depend on my job for financial assistance to take care of him. The money is used in feeding, clothing and medication, school fees and so on. My child is an expensive child and if I had no good job, it would be very difficult for me to care for him single handedly" (FP2, 35years).* Still on lack of support in caring for the children with intellectual disabilities, another participant shared how she managed to take care of her child single handed. She expressed saying*: "I depend on the little income I get from my small business to buy for my child clothes, food because every day I have to pack for her some food to go with to school, school fees, toiletries and others things" (FP5, 33years).*

In addition, on the lack of financial support, a participant in a focus group discussion expressed saying:

> "Since I got this child, I work hard and get some money, we combine with his father to pay school fees. But I do not have any support from any Organization or people. In this country there is no free medication. When this kind of children are sick even if you go to government hospitals you will be asked to buy medicine from the pharmacies. So if your child is to survive, you must work hard and maintain the child" (FP3, 36years FGD1).

Lastly, a female participant expressed how she takes care of her son by saying: *"I am a government employee, so yaaah… depend on my salary for taking care of the boy. I work hard even if it means overtime to earn some money to take care of him. I also go to other schools or help weak students so long as their parents can pay some money to help me care for my boy. It is very scaring to care for a child like mine singly" (FP6, 42years).*

4.5.2 Support from special schools

Despite lack of support expressed by a number of participants, a sizable number of them felt that the only biggest support they had was the special schools or units in primary school that care for their children most of the time of the day. However, they expressed that the special schools in the district are private and expensive, yet, they can only do other activities when the children are at school.

Five responses were advanced to support this theme. In his words one male participant expressed saying:

> "The biggest support I feel we have is having special unit to have these children come to school. These schools help us to train our children to learn some daily living skills which makes a big difference in their lives and ours also. I have realized a very great change in her… I appreciate this school so much, the school has supported me very much because I can see a positive change in my child" (FP2, 43years FGD 1).

A female participant also said: *"There is no support I get from anyone except from the school where my child goes to learn some life skills. These skills have helped now I am able to*

understand my child when he makes signs" (FP4, 28years FGD1). One other participant appropriately expressed this saying: *"Yaaah… the only support I know of is the child being at school and the teachers support him to learn some life skills such that he can now respond when you call him and indicate what he wants. There is no support in terms of medical, finance, education. We pay for every services we require for the boy" (FP6, 37years FGD2).*

Another female participant said: *"In the beginning, I used to get some counselling sessions in the hospital and in special needs schools. So there is some support from the special schools especially teachers who ensure that the child is brought home and handed over to me. Besides that, I get no support from any organization or government" (FP2, 35years).* For another participant it is *"I get no support from anywhere except from the special school where they are training him in some daily living skills……yaah the teachers also come and talk to us on how to look after him when he is at home so that is the only support we get as parents of these children with disabilities"* (FP4, 38years). Table 4.4 shows the major themes and subthemes of the findings of this study.

Table 4.4. Summary of themes and subthemes that emerged from the data

Objectives	Sub-themes	Themes
Psychosocial experiences	• Burden • No time • No communication • Spoiling things • Isolation	➢ Caregiving challenges
	• Neglect • Attribution of blames to mothers • Negative comments • Abandonment	➢ Lack of knowledge of the condition and rejection by family members
	• Hostility • Name calling • Stigma • Blaming • Segregating	➢ Societal reactions towards ID
	• Spirit possession and witchcraft • Genetic transmission • Use of contraceptives by mothers • Desire for riches	➢ Perceived cause of ID
Coping mechanisms	• Love for the child • Seeing the child like other children • Treat a child as God's gift • Understanding the child's condition	➢ Acceptance of the situation
	• Praying to God for strength & solace • Praying to God for healing of the child • God's love and mercy • Taking the child for prayers	➢ Belief in God
	• Pretend not to hear • Learn not to listen to what others say • Not answering when they talk	➢ Ignoring negative comments
Psychosocial support systems for caregivers	• Hard work, poor attitude • Depend on salary • Income from self-owned businesses	➢ Lack of psychological financial support
	• Train in life skills • Counselling	➢ Support from special schools and units in primary schools

4.6 Discussion of results

The objective of the current study was to explore the psychosocial experiences influencing coping mechanisms among caregivers of children with severe intellectual disabilities in special schools of Jinja district, Uganda. More precisely, it aimed at examining the psychosocial experiences among caregivers, establishing the coping mechanisms and assessing the psychosocial support offered to caregivers of children with severe intellectual disabilities. All participants attested to having psychosocial experiences in their effort to care for children with severe intellectual disabilities in their families. These psychosocial experiences included; caregiving challenges, lack of knowledge about the condition by family members, societal reaction towards children with severe intellectual disabilities and the perceived cause of the condition.

The study revealed that having a child with severe intellectual disabilities forces the routine of the family change. The child with intellectual disabilities requires constant monitoring and this makes it difficult for the primary caregivers (especially mothers) to work away from home. Almost all participants interviewed expressed having to rent a house close to their work place for close monitoring on their children. What the participants in this study point to as the challenges of caregiving is similar to what Kaur and Arora (2010) revealed. They claimed that challenges related to nurturing children with intellectual disabilities typically affects the whole atmosphere of home as well as routine family life.

It is also consistent with a study conducted in Nigeria by Ajibade, et al. (2016). They mentioned that children with severe intellectual disabilities constituted a source of burden to their family members. Caregivers often report feeling overwhelmed, frustrated, lonely, and abandoned by people from whom they usually seek support.

The findings of the present study indicate that families with children with severe intellectual disabilities, lack knowledge about the condition and keep blaming it on the mothers as the cause. Such children are left to the care of their mothers with little or no support from other members of the family. Some caregivers have been abandoned by their spouses due to the presence of a child with intellectual disabilities. This has been supported by the findings of the study conducted in Namibia by Ntswane and Rhyn (2007) "examining the life-world of mothers who care for mentally retarded children", which stated that most fathers rejected the mother and her child with intellectual disabilities.

In addition, the current study has shown that the in-law relatives of caregivers do not want anything to do with the mothers and their children. Thus, the presence of a child with intellectual disabilities shakes the foundation of the family. Negative family attitudes especially a rejecting attitude towards children with intellectual disabilities has been reported also in a research by (Kaur & Arora, 2010).

Furthermore, the results of the present study on psychosocial experiences has demonstrated that caregivers of children with severe intellectual disabilities suffer stress and stigma due to reactions by the society towards their children. Many times the society is apprehensive to children with intellectual disabilities and judgmental to caregivers of such children. Primary caregivers especially mothers are blamed for not training their children to exhibit good behaviors in society.

The caregivers feel judged for delivering children with intellectual abnormalities by members of the community. The judgements people make against caregivers due to nurturing children with intellectual disabilities frustrate them and this in turn causes them distress. This assertion was supported by the findings of a study conducted in Namibia Ndadzungira (2016)

which stated that community members judged caregivers for giving birth to children with disabilities.

It is also consistent with a study conducted in India by Mukherjee and Shignapure (2016). They stated that society on the whole tends to view the existence of a child with a disability in the family as an unspeakable catastrophe which the family cannot recover from. From the findings of the present study, society seems to look at children with severe intellectual disabilities negatively and valueless. Furthermore, the findings of this study have shown too that normal people still have negative attitudes towards children with disabilities. These negative attitudes are probably because of the cultural beliefs associated with disabilities in Africa (Oti-Boadi, 2017). In most African cultures, children with disabilities and more so intellectual impairment are not only regarded as a curse from God but are also seen as a sign of bad omen to the family. Thwala et.al. (2015) in support of this idea stated that culturally people with disabilities are looked at as different from other normal beings and as such they are treated as weaker social beings. They are many times victimized, ridiculed and less considered as people in the community.

From the findings, it is also evident that the cause of intellectual disabilities as presented by participants was largely attributed to three factors; malignant evil spirits of the dead, the genes from the mother of the child as well as use of family planning pills. The interpretation of disabilities in the African context might have influenced the caregivers' interpretation about the cause of the condition of their children. The participants did not elucidate the likelihoods of spiritual implications even though they made an impression that they did not believe in evil interpretations of society linked to the situation of their children.

The findings are consistent with a study conducted in Ghana by (Otti-Boadi, 2017) who showed that caregivers' experiences were situated in the context of how they believe society views and treats their children. From the African perspective, when a person develops any kind of disability the cause for the disability has to be found among direct family members or the evil neighbors. So, with the presence of a child with intellectual challenges, the parents who are primary caregivers bear it all.

The findings of the present study attest to the fact that the greater number, if not all caregivers of children with severe intellectual disabilities experience social stigma, isolation as well as psychological distress due to nurturing children with such disabilities. Although the experiences seem to be all negative, the caregivers are still encouraged to take care of their children regarding them to be like any other child in the family. None of the participants expressed the desire or wish for the child to die so that he/she is burden free.

In the second objective that explored the coping mechanisms, one common strategy used by the participants in the current study was acceptance of the situation. The majority of the participants were mothers and expressed the need to accept the situation as it is and live with it. Once the caregivers realize that the situation cannot be reversed by any treatment, they accept it. This acceptance helped them to reduce on the stress levels they had at the beginning when the child had just been diagnosed with the problem.

This probably echoes a study by Kandel and Merrick (2017) which suggested features caregivers process to reach acceptance. For instance, the caregiver try to perceive the child's skills and capabilities as she also appreciates the limitedness of the child. The caregiver may genuinely visualize the child's complications created in the family with appreciation; this helps caregivers not to become overcome by feelings of self-pity and guilt. Lastly, when the caregiver

accepts the condition of the child, he/she is capable of offering love to the child with no feelings of rejection or over-protection. Thus, acceptance of the child's condition by the caregiver and other family members not only helps the caregivers to cope but helps the child to feel loved and valued as well.

Almost all the participants reported belief in God as one of the coping strategies they relied on to deal with the challenges posed by the presence of the child with severe intellectual disabilities under their care. The participants relied on God for strength because they realized that little or no support was given to them from the community or government. The participants exhibited a variety of strengths in the form of their spiritual beliefs, for example, a child is God's gift. This was in line with Aldersey (2012) and Durà-Vilà et al. (2010) who stated that many caregivers were strengthened by the faith when they reclined to God. Furthermore, a study by McNally and Mannan (2013) supported that participants underscored their belief in God and His power to carry them through their experiences of nurturing a child having disabilities. A research by Oti-Boadi (2017) also showed that caregivers might use the beliefs to infer their children's disability as a special gift from God and ease the distress related to caring for their children.

Still on belief in God, Thwala, et.al (2015) stated that caregivers were coping with their children's disabilities through the grace of God. They believed that the challenging situation they experienced required some spiritual attachment and that it was only God who could help them cope with the situation. It is also consistent with the study done in Kuwait, Raman, Mandoda, Hussain, Foley, Hamdan and Landry (2010) mentioned that mothers turned to Allah to try and explain their situation as a means of coping. In Iran too caregivers relied mostly on

spiritual/religious coping and believed that they were chosen by Allah for a certain reason to raise a child with disabilities (Wilson, 2011).

One other coping mechanism reported by nearly all the caregivers was that they ignored negative comments directed towards them and their children in order for them to continue caring for their children. Negative comments not only come from the community and neighbors but from the family and extended family members as well. These comments affect the caregivers and make them frustrated thus, affecting their care activities. This is consistent with Mwei (2015) whose study findings noted that when caregivers experience external challenges in their environment, it affects how much they continue to reach out for services. Some of the caregivers get overwhelmed and feel defeated. The caregivers reported that they have learnt not to listen to what people say about their children because they can change nothing about it. However, some caregivers also admitted that sometimes it is very discouraging when those comments are uttered especially by family members who should give support to them.

From the findings of this study, it is observed that several caregivers employ problem-focused coping. They recognize the challenges posed by their children and accept the situation as it presents itself. On the other hand, emotion-focused coping is not so much applied by the caregivers who participated in the study. The study findings have indicated none of the participants reporting avoiding or escaping their care responsibilities. Nevertheless, some small proportion has indicated fathers abandoning the mothers due to the presence of a child with intellectual disabilities in the family.

In the third and last objective that assessed the psychosocial support rendered to caregivers of children with severe intellectual disabilities, the participants revealed that caregivers of children with intellectual disabilities lacked both psychosocial and financial

support. Majority of the participants expressed depending on their own salary and other little incomes they get to support their children's condition. They lamented the expenses they incur in terms of medical, education and feeding their children with disabilities. Their responses were consistent with Thwala (2015) who stressed that a child with special needs can dig deeper into the pocket of the parent.

Again, raising a child with disabilities can be too expensive than raising a normal child. These expenses may arise from medical equipment and supplies such as wheelchairs, medical care, and care giving expenses, private education, learning equipment or specialized transport. Lack of support to caregivers of children with intellectual disabilities was in line with the African traditional setup that neglects children with disabilities (Bunning et al., 2014).

The participants noted that they only got support from special schools and units that enroll their children and train them daily living skills. They mentioned that having their children in these schools has helped them to ease their care burden. With their children spending sometime at school they were able to do some work either in the home or outside the home without worries. Although the participants acknowledged the presence of specials schools and units in public primary schools, they mentioned that they were very few in the region and also lacked trained personnel to cater for the special educational needs of their children with severe intellectual disabilities.

The participants also noted that special schools are privately owned, therefore they are pretty expensive for them and so they require to work very hard to maintain their children in schools. They voiced the need to be supported by the government or any other body so that their care burden can be eased and care for other members of the family. The next chapter presents the summary, conclusions, limitations, recommendations and reflexivity of the study.

CHAPTER FIVE

SUMMARY, CONCLUSION AND RECOMMENDATIONS OF THE STUDY

5.0 Introduction

This chapter provides the summary, conclusions, limitations as well as recommendations to improve the well-being through support of caregivers of children with intellectual disabilities in Jinja district, Uganda.

5.1 Summary of the study

This study explored the psychosocial experiences influencing coping mechanisms among caregivers of children with severe intellectual disabilities in Jinja district, Uganda. The study in chapter one looked at the background to the problem, the statement of the problem, the purpose and objectives of the study, research questions, significance, and the scope and delimitations of the study. Chapter two dealt with theoretical review of the literature. The study anchored on two theories; Self-determination theory and stress-coping theory. Chapter three presented the methodology used. These included; the research design, location of the study, target population, sampling techniques and sample size, research instruments, reliability and validity of the study, data collection procedures, data analysis and ethical considerations. Chapter four presented the findings and discussion of the study. In this chapter, demographic details of the participants, findings and discussion of the study were done. Lastly, chapter five presented the summary, conclusions, limitations, recommendations and reflexivity of the study.

The study revealed that the participants encountered different psychological and social challenges when caring for their children with severe intellectual disabilities. The participants showed a concrete awareness of it and were able to express it and offer meaningful examples of their personal experiences and perceptions of children with intellectual disabilities in Jinja

district. The themes that surfaced from psychosocial experiences were: the caregiving challenges, lack of knowledge about the condition by family members, societal reaction towards children with disabilities and perceived cause of intellectual disabilities.

The participants also presented some coping mechanisms employed by them to deal with the challenges posed by the presence of the child with intellectual disabilities in the family. Themes like acceptance of the situation, belief in God and ignoring negative comments from people came up from the participants. In the last objective, the support systems for caregivers, two themes were identified: lack of psychological and financial support and support from special schools. According to their expressed opinions in this study, there exists an awareness of the challenges confronting caregivers of children with intellectual disabilities in Jinja district, Uganda.

5.2 The Conclusions

The conclusions were drawn from the three specific objectives. These were: to examine the psychosocial experiences among caregivers of children with severe intellectual disabilities in Jinja district; to find out the coping mechanisms employed by caregivers of children with severe intellectual disabilities in Jinja district and lastly, to assess the psychosocial support given to caregivers of children with severe intellectual disabilities in Jinja district, Uganda. The results from this study highlighted that caregivers of children with severe intellectual disabilities experience a number of caregiving challenges. These challenges were made worse by the unsupportive attitude of some family members and the way society or people in the community treat children with intellectual disabilities. The study findings also indicated that family members as well as the society in which children with intellectual disabilities live have no knowledge about the causes of the condition. The results of this study further indicated that

people are still stuck in cultural beliefs about intellectual disabilities thus, such children are feared leading to stress, stigma and isolation for caregivers of such children.

From the findings, it is also clear that most caregivers having their first born children with intellectual disabilities are single mothers. This is due to the beliefs attached to disabilities in African cultures. Mothers having children with disabilities are resented by other members of the society. It is believed that a mother with one child having a disability may have another one. It is also because men fear the responsibilities of caring for children with especially severe intellectual disabilities.

Although, the study findings did not highlight any positive experiences from the participants, the findings presented some positive coping strategies used by the caregivers in their efforts to care for their children with intellectual disabilities. The most highlighted strategies were acceptance of the situation, belief in God and ignoring the negatives comments from people. These coping strategies help the caregivers feel motivated to carry on caring for their children despite the negativity towards them. The results of the current study conforms to the theories used namely the stress-coping theory and self-determination theory. The caregivers the present research apply mostly problem-focused coping when dealing with care demands.

Finally, the results have indicated that caregivers of children with intellectual disabilities in this study are not supported in all ways. The caregivers struggle on their own to maintain their children. Although they are supported by special schools, such schools are few and are privately owned, therefore very expensive for the caregivers who struggle with other family demands. The inclusive education proposed by the Ugandan government does not favor children with severe intellectual disabilities. The only support caregivers get is from immediate

family members particularly from grandmothers of the children. This means therefore, the care giving is entirely on the parents especially mothers of the children with intellectual disabilities.

5.3 The limitations of the study

Like other studies, this study was not without limitations. The results of this study may not be generalized to all caregivers in Uganda, the current study focused on caregivers in one district who also lived in urban or semi-urban areas of Jinja town, therefore it remains unknown if the psychosocial experiences that influence the coping is different for caregivers who live in rural areas of the district. Secondly, the participants of this study were somewhat homogenous for they were only parents of children attending special schools in the district. Consequently, the findings might not be generalized to caregivers with children who are not attending special schools. Next, the nature of the current study being a qualitative one, limits the generalization of the results to a wider population. A larger sample might have authenticated the findings further, nonetheless, thematic saturation was arrived at using the sample size, therefore, the results from this study might provide for future research into the psychosocial experiences of caregivers and may lead to an improvement in the caregivers' well-being.

5.4 The Recommendations

In this study, the findings have revealed the support offered by special schools to be significant to caregivers, yet, they are few and privately owned. This study recommends that special schools should be established to help to keep and train children so that the caregivers can have time to attend to other family and employment activities. In addition, special schools if well-established would also provide counselling services to cater for the mental health of caregivers.

Further still, there is need for family and community education programs. This may help to positively influence interactions within the family and family's interaction with others in the society. There are several welfare programs established by the government and other voluntary organizations for children with disabilities in Uganda. However, families (especially caregivers) of children with severe intellectual disabilities have been ignored. Therefore, the intervention measures should not only be directed towards children with disabilities but to caregivers as well who experience to a greater extent care stress. Then, there can be change of viewpoint about care for such children.

Another recommendation from the findings of the current study is the setting up of a peer support network for the caregivers of children with severe intellectual disabilities so that they can share their feelings in an open and supportive environment with people who have similar experiences to theirs. From the findings of this study, there is also a dire need for the government to put into place a system to support caregivers of children with severe intellectual disabilities not only in social matters but in psychological and financial issues as well. Findings revealed that many caregivers are worried about what will happen to their children when they are not able to work and earn money or if they die. In order to lessen the emotional stress experienced by caregivers especially mothers, there is need for them to be supported emotionally and financially by members of their families, friends, society, professionals, governments and nongovernmental organizations concerned with improving the lives of caregivers and their children with severe intellectual disabilities. It is recommended that future researchers could carry out research on the psychosocial experiences of caregivers of children with severe intellectual disabilities with a larger sample size using mixed methods.

5.5 The possible areas of future research

It is suggested that future researchers could consider looking at the psychosocial experiences of the formal caregivers of children with severe intellectual disabilities. These could include; teachers, day caregivers in institutions and medical personnel. Another possible area for future research could be exploring the perception of society about intellectual disabilities and culture. Future researchers could also consider researching on the psychosocial support for caregivers of children with severe intellectual disabilities. Another research could also focus on the positive experiences of caregivers of children with severe intellectual disabilities instead of the negative experiences.

5.6 The Reflexivity

The notion of doing a qualitative research was a new idea for the researcher, therefore, it required that the researcher engaged into background reading of the research area. The researcher had the interest in the topic due to her experience of working and interacting with parents who have children with intellectual disabilities. The researcher had thought that caregivers of children with disabilities were well supported by the government and NGO programs in Uganda and had wondered why in spite of the support, caregivers still felt overwhelmed with the responsibilities of care. The current study has shed light to what these caregivers experience. A qualitative research design was a better option for this research because through interviews and focus group discussions the participants were able to express their feelings and thoughts about what their experiences of caring for children having severe intellectual disabilities were.

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APPENDICES

Appendix 1: Interview and focus group discussion schedules

Participants' general information

1. Your age: ☐ **2.Gender:** Male ☐

Female ☐

3. Relationship with the child:

Mother……☐

Father……..☐

Grandparent……....☐

Uncle/aunt……☐

Sibling……☐

4. Level of Education:

O'level……☐

A'level……☐

Diploma…….. ☐

University……☐

5. Employment status:

Employed…….☐

Self-employed ……..☐

Unemployed…….....☐

6. **Marital status:**

Married……...☐

Single……..☐

Separated/divorced……☐

Widow/widower……☐

7. No. of children under your care ……

8. Child's age (years)…….. **9. Child's gender**…….

Interviews Questions

1. How does having a child with the problem of a disability affect your life?
2. What is the perception of your relatives, friends and neighbors about your child?
3. How do you cope with the challenges posed by your child?
4. What kind of support do you get from your family, community, teachers, government and health care providers?
5. What financial assistance is available for caregivers of children with intellectual disabilities in your area? From whom?

Focus group discussions Questions

1. What are your experiences of caring for your children with disabilities?
2. What is the perception of the relatives, friends and neighbors about your child?
3. How do you manage the challenges posed by your child?
4. What kind of support do you get from your family, the community, neighbors, teachers, and health care providers?
5. What financial assistance is available for caregivers of children with intellectual disabilities in your area? From whom?

Appendix 2: Tangaza University College - Participant's Consent Form

Title of the Research: Psychosocial Experiences and Coping Mechanisms among Caregivers of Children with Intellectual Disability in Jinja District, Uganda
This study will be conducted by a counselling psychology student from Tangaza University College. The study has been approved by the Tangaza Research Ethics committee; (contact: dir.pgsr@tangaza.ac.ke) The study involves no known risk to participants and contains no deception. It will take about 30 – 40 minutes to participate in the present of the study. The task entails participants' effort in answering a series of questions. All responses will be treated with confidentiality. Participant's results will not be presented individually but only in aggregate form. Participation in this study will be voluntary and devoid of monetary compensation. A participant is at liberty to decline participation without being penalized in any way. Participants have the right of participation and withdrawal if and when they choose to.
Name of the researcher: Matilda Gratia Nekesa
Position of the researcher: MA Student
Address and telephone number of the College: Tangaza University College, Langata, Nairobi, Kenya 15055-00509
Signed by researcher:…… Date:.....
Statement to be signed by the participant: I endorse that the organizer has explained fully the nature of the study and the variety of activities which I will be asked to embark on and that I have received an information sheet. I confirm that I have had adequate opportunity to ask questions about this project. I understand that my participation is voluntary and that I may withdraw at any time during the study, without having to give a preseason. I agree to take part in this study, by filling in the questionnaire.
Signed by participant……Date:

Appendix 3: Research permit-Tangaza University College REC

TANGAZA UNIVERSITY COLLEGE

The Catholic University of Eastern Africa

DIRECTORATE OF POSTGRADUATE STUDIES & RESEARCH

E-mail: dir.pgsr@tangaza.ac.ke **Website:** www.tangaza.ac.ke

OUR Ref: DPGSR/ERC/No.017/05/2018 **Date:** 24th May 2018

Nekesa Matilda Gratia,
Reg. No. 16/00233
Institute of Youth Studies
Tangaza University College

Dear Nekesa,

RE: Psychosocial experiences influencing coping mechanisms among caregivers of children with intellectual disabilities in special schools of Jinja, Uganda

Reference is made to your request dated *24th May 2018* for ethical approval of your thesis proposal research tools by Tangaza University Ethics Review Committee.

We are pleased to inform you that your proposal and the research tools have gone through the ethical review committee as requested and the approval has been granted. In line with Tangaza University College Research policy, you will be required to submit a copy of the final research findings to the Director of Research for records.

Before proceeding to the next stage, ensure that all the comments that were made regarding your research tool have been addressed to the satisfaction of your supervisors. Note that it is an offence to proceed without addressing the concerns of the Ethics Review Committee.

This approval is valid for one year from *25th May 2018.*

This approval does not exempt you from obtaining a research permit from the Uganda National Council for Science and Technology (UNCST).

Yours sincerely,

TANGAZA COLLEGE
Catholic University of Eastern Africa
P. O. Box 15055 - 00509
NAIROBI

Daniel M. Kitonga (Ph.D)
Director, Post-Graduate Studies & Research

CC:
Ms. Lucy Njiru –Programme Leader, MA in Counseling Psychology

P.O. Box, 15055 - 00509 Langata, Nairobi Kenya
Tel: 254 20 8067667/ 0732 897000/ 0733 685059/ 0722 204724/ 0714 610777
Email: inquiries@tangaza.org
Website: www.tangaza.org

Appendix 4: Research introductory letter to UNCST

TANGAZA UNIVERSITY COLLEGE

The Catholic University of Eastern Africa

DIRECTORATE OF POSTGRADUATE STUDIES & RESEARCH

E-mail: dir.pgsr@tangaza.ac.ke **Website:** www.tangaza.ac.ke

OUR Ref: DPGSR/ERC/No.016/05/2018 **Date:** 25th May 2018

To Executive Secretary,
National Council for Science and Technology
P.O. Box 6884
Kampala, Uganda.

Dear Sir/Madam,

Re: Research Permit for Nekesa Matilda Gratia

This is to confirm to you that the person named above is a student at Tangaza University College (TUC). She is registered in the Institute of Youth Studies (Reg. No 16/00233) and she is pursuing a degree in Master of Art in Counseling Psychology.

Nekesa has met all our provisional academic requirements leading to data collection. However, she cannot proceed to the field before she gets a Research Permit from the Uganda National Council for Science and Technology (UNCST). Kindly assist her to process the permit for the same purpose.

Thanking you in advance for your cooperation

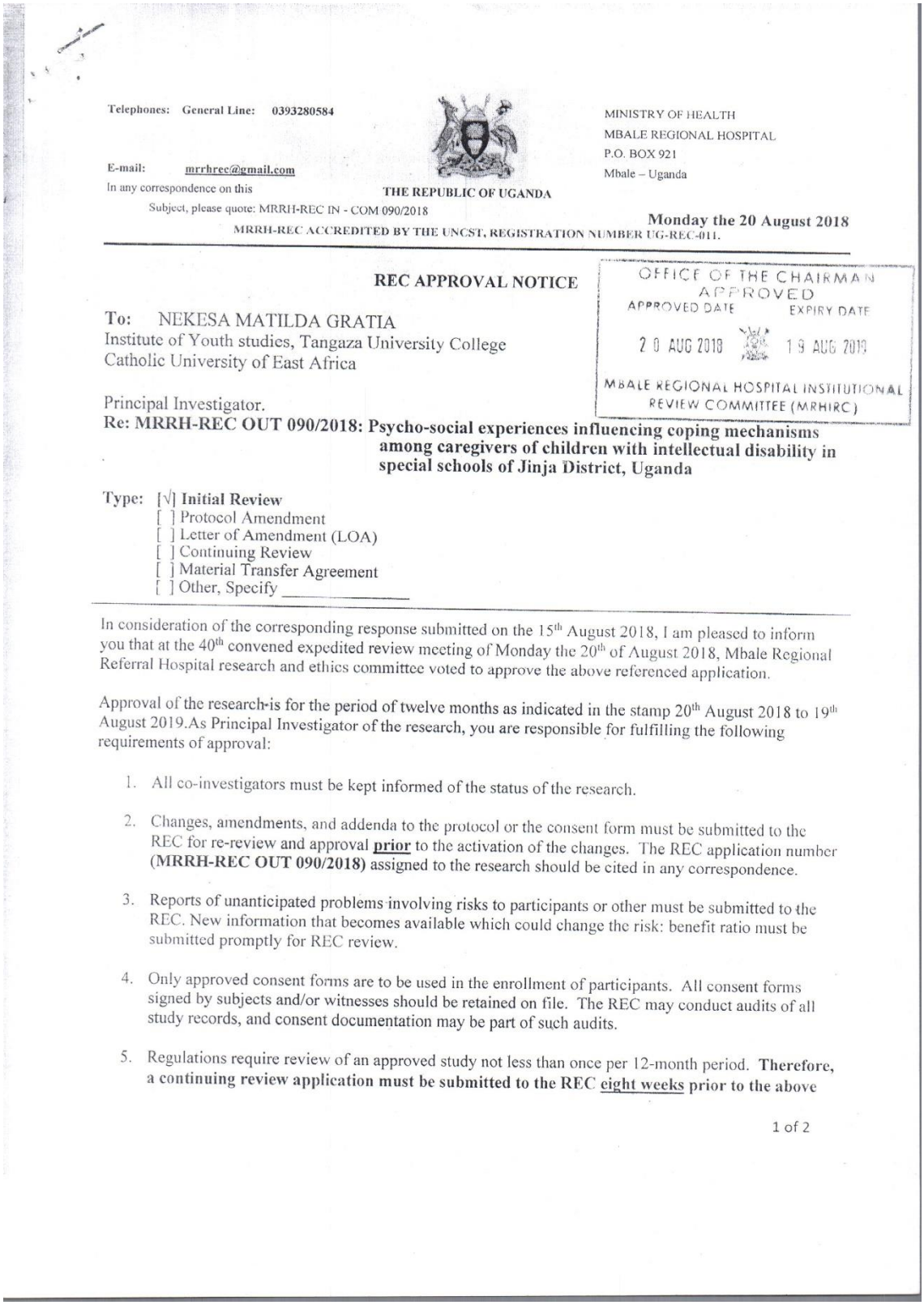
Yours sincerely,

TANGAZA COLLEGE
Catholic University of Eastern Africa
P. O. Box 15055 - 00509
NAIROBI

Daniel M. Kitonga (Ph.D)
Director, Post-Graduate Studies & Research

CC:
Ms. Lucy Njiru –Programme Leader, MA in Counseling Psychology

Appendix 5: Approval letter – MRRH-REC



Telephones: General Line: 0393280584

E-mail: mrrhrec@gmail.com

In any correspondence on this Subject, please quote: MRRH-REC IN - COM 090/2018

THE REPUBLIC OF UGANDA

MINISTRY OF HEALTH
MBALE REGIONAL HOSPITAL
P.O. BOX 921
Mbale – Uganda

Monday the 20 August 2018

MRRH-REC ACCREDITED BY THE UNCST, REGISTRATION NUMBER UG-REC-011.

REC APPROVAL NOTICE

OFFICE OF THE CHAIRMAN
APPROVED
APPROVED DATE 20 AUG 2018 EXPIRY DATE 19 AUG 2019
MBALE REGIONAL HOSPITAL INSTITUTIONAL REVIEW COMMITTEE (MRHIRC)

To: NEKESA MATILDA GRATIA
Institute of Youth studies, Tangaza University College
Catholic University of East Africa

Principal Investigator.

Re: MRRH-REC OUT 090/2018: Psycho-social experiences influencing coping mechanisms among caregivers of children with intellectual disability in special schools of Jinja District, Uganda

Type: [√] **Initial Review**
[ ] Protocol Amendment
[ ] Letter of Amendment (LOA)
[ ] Continuing Review
[ ] Material Transfer Agreement
[ ] Other, Specify _____

In consideration of the corresponding response submitted on the 15th August 2018, I am pleased to inform you that at the 40th convened expedited review meeting of Monday the 20th of August 2018, Mbale Regional Referral Hospital research and ethics committee voted to approve the above referenced application.

Approval of the research is for the period of twelve months as indicated in the stamp 20th August 2018 to 19th August 2019.As Principal Investigator of the research, you are responsible for fulfilling the following requirements of approval:

1. All co-investigators must be kept informed of the status of the research.
2. Changes, amendments, and addenda to the protocol or the consent form must be submitted to the REC for re-review and approval **prior** to the activation of the changes. The REC application number **(MRRH-REC OUT 090/2018)** assigned to the research should be cited in any correspondence.
3. Reports of unanticipated problems involving risks to participants or other must be submitted to the REC. New information that becomes available which could change the risk: benefit ratio must be submitted promptly for REC review.
4. Only approved consent forms are to be used in the enrollment of participants. All consent forms signed by subjects and/or witnesses should be retained on file. The REC may conduct audits of all study records, and consent documentation may be part of such audits.
5. Regulations require review of an approved study not less than once per 12-month period. **Therefore, a continuing review application must be submitted to the REC eight weeks prior to the above**

1 of 2

expiration date in order to continue the study beyond the approved period. Failure to submit a continuing review application in a timely fashion may result in suspension or termination of the study, at which point new participants may not be enrolled and currently enrolled participants must be taken off the study.

6. The following is the list of all documents approved in this application by Mbale regional referral Hospital research and ethics committee.

	Document Title	Language	Version	Version Date
1.	Letter of introduction: from the principal investigator Dated 10th April 2018	**English**	NA	NA
2.	**Study protocol** Psycho-social experiences influencing coping mechanisms among caregivers of children with intellectual disability in special schools of Jinja District, Uganda	English	August 2018	NA
3.	**Informed consent form** Appendix I page 44-45	In English	August 2018	NA
4	**Data Collection Tool. Appendix 2** page 46—48	In English	August 2018	NA

Signed,

OFFICE OF THE CHAIRMAN
APPROVED
APPROVED DATE EXPIRY DATE
20 AUG 2018 19 AUG 2019
MBALE REGIONAL HOSPITAL INSTITUTIONAL REVIEW COMMITTEE (MRHIRC)

Dr. J.S.O. OBBO MB.Ch.b, MMed, MRCP (UK), FCP (ECSA).
MRRH-REC CHAIRPERSON.

Appendix 6: Approval

ST. URSULA SPECIAL SCHOOL

P. O. Box 1869
Jinja - Uganda

Our Ref:.....

27th August, 2018

Your Ref.....

The Executive Secretary,
Uganda National Council for Science and Technology
P. O. 6884
Kampala, Uganda.

Dear Sir/Madam,

Re: Research Clearance for Nekesa Matilda Gratia

This is to confirm to you that Nekesa a student of Tangaza University College seeks to do research on the psychosocial experiences influencing coping mechanisms among caregivers of children with intellectual disabilities in Jinja district. The school administration and management are aware of the research. The research does not involve any risk to the parents, so we give our consent to involve the parents of our children in the study. We permit the researcher to use our assessment records to identify caregivers of children with intellectual disabilities to participate in the study. We also permit the researcher to use our school premises for focus group discussions on the scheduled date. Therefore, your assistance to her will be highly appreciated.

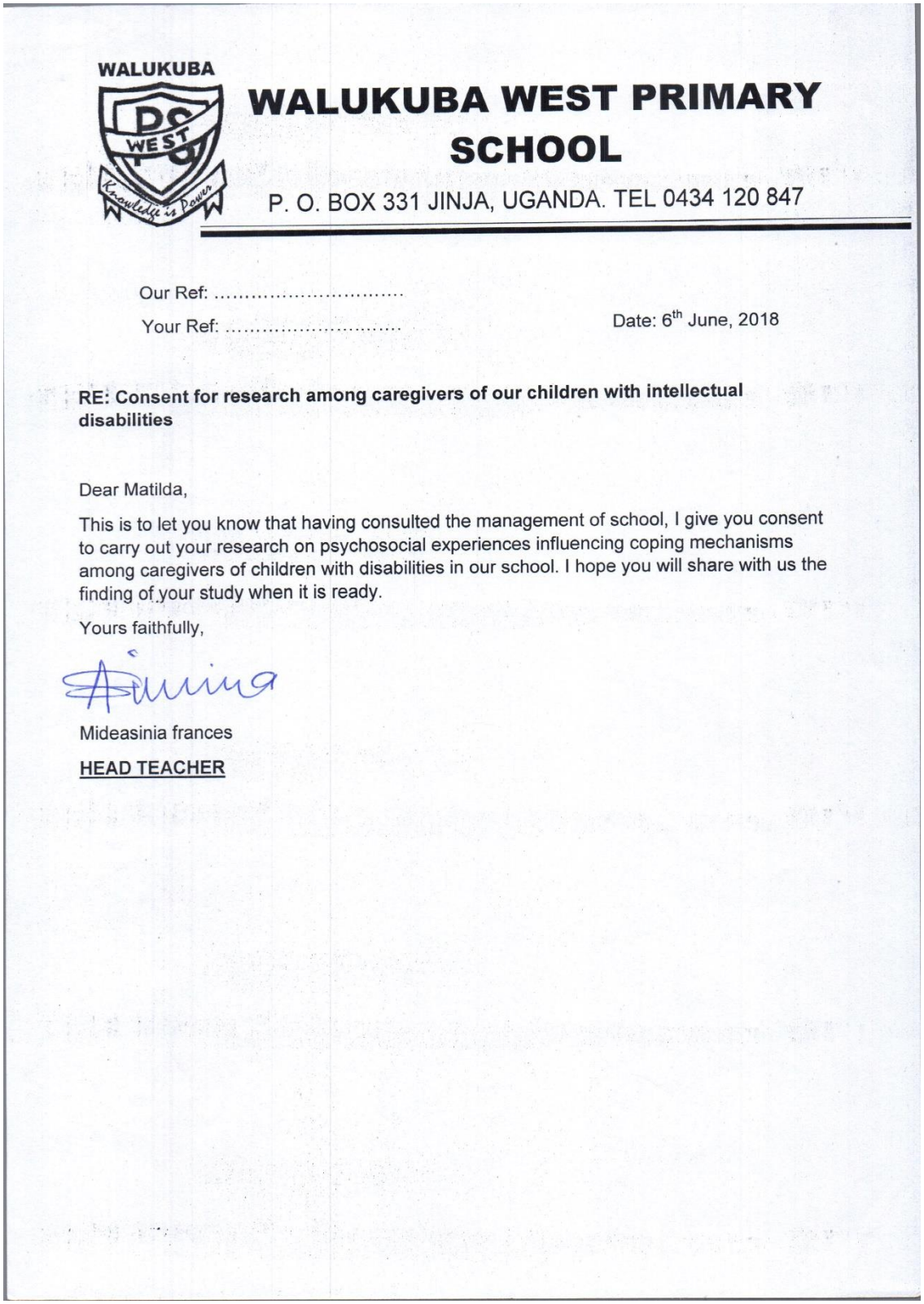
Yours Faithfully

Sr. Lucy Wakolli
HEAD TEACHER

ST. URSULA SPECIAL SCHOOL
P.O. BOX 1869 JINJA
DATE 27.8.2018

Sisters of Mary of Kakamega- Jinja- Wanyange- Musima

Appendix 7: Approval



WALUKUBA

WALUKUBA WEST PRIMARY SCHOOL

P. O. BOX 331 JINJA, UGANDA. TEL 0434 120 847

Our Ref: .....

Your Ref: .....

Date: 6th June, 2018

RE: Consent for research among caregivers of our children with intellectual disabilities

Dear Matilda,

This is to let you know that having consulted the management of school, I give you consent to carry out your research on psychosocial experiences influencing coping mechanisms among caregivers of children with disabilities in our school. I hope you will share with us the finding of your study when it is ready.

Yours faithfully,

Mideasinia frances

HEAD TEACHER

Appendix 8: Permit local council chairman

LC1 Musima village
Wanyange parish
Mafubira sub-county

28th /08/2018

The Executive Secretary,
Uganda National Council for Science and Technology
P. O. 6884
Kampala, Uganda.

Ref: NEKESA MATILDA GRATIA

This letter serves to introduce to you the above mentioned person who is a resident of the above mentioned village. I have known her a period of 10 years but during her stay with us, she has been a well behaved person and quite social in our community. Currently she is doing a course in Kenya. Therefore, any assistance rendered to her towards her research will be highly appreciated.

Yours in service

Kisira Andrew
Parish Chief

CHAIRMAN LC1
DATE 28/8/2018
MUSIMA VILLAGE