

**PREDICTORS OF CAREGIVER STRESS AMONG FAMILY MEMBERS OF
SCHOOL GOING CHILDREN WITH INTELLECTUAL DISABILITIES IN
LUSAKA URBAN**

By

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**A research dissertation submitted to the University of Zambia in partial
fulfilment of the requirements for the award of Master of Arts degree in
child and adolescent psychology**

THE UNIVERSITY OF ZAMBIA

LUSAKA

2015

Declaration

I Kanyata Kanyata declare that this dissertation

- a) Represents my own work;
- b) Has not previously been submitted for a degree at this or any other University; and
- c) Does not incorporate any published work or material from another dissertation

Signed.....

Date.....

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Approval

This dissertation of Mr Kanyata Kanyata has **BEEN APPROVED** as partial fulfilment of the requirements for the award of the degree of Master of Child and Adolescent Psychology.

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Abstract

Caring for a child who has an intellectual disability can be stressful on the part of caregivers within the family context. A limited number of studies conducted elsewhere on this subject have not focused on the entire family, but on parents of children with intellectual disabilities and results have shown that having a child with intellectual disability often places parents in a stressful condition. Greater knowledge of caregiver's well-being and their needs may allow for the improvement of existing services and the development of new strategies to sustain caregivers in their important roles. This study was aimed at determining specific features that impact on caregiver stress among family members of school-going children with intellectual disabilities. One hundred and thirty five (135) caregivers of school-going children with intellectual disabilities residing within Lusaka Urban area completed a questionnaire and checklists on a number of aspects surrounding their day to day care for their children with an intellectual disability. The majority of participants in this study were females (56%) and average age of participants was 35 years. Scores for the Psychological Stress Measure (PSM-9), suggested a slight increase in caregiver stress levels on average. Correlation analysis showed some moderate and significant relationships between caregiver's stress and independent variables of: respondent's relationship with the child ($p < .001$); respondent's marital status ($p < .001$); and coping mechanism of thinking very hard about resolving the problem ($p < .01$). Above all, this study shows that caregiver's stress in families of school-going children with intellectual disability in Lusaka urban seems to be predicted more by increased amount of time caregivers spent on acquiring information about the child's disability, followed by the number of people earning an income within the household, and use of coping mechanism of focusing all efforts to resolve a problem ($F(9, 125) = 6.389, p < 0.001$). Coping mechanism of thinking hard about steps to take mediated the relationship between predictor variable of time involved in acquisition of information about the child's disability and caregiver's level of stress. Similarly, number of people earning income in the household had a mediation effect on the relationship between predictor variable age and caregiver's level of stress.

Dedications

I dedicate this work to my children, Christian Buseko, Chantal Subilo, Fabrice Mwepu Kanyata and my dear wife Ethel for their support and encouragement towards the completion of my taught class work and eventually this research dissertation.

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CHAPTER ONE

INTRODUCTION

1.1. Introduction

This chapter gives background information to the current study. The chapter further presents the statement of the research problem, research objectives, research questions, justification of the study, theoretical and conceptual framework for the study and the study operational definition of concepts and terms.

1.2. Background information

It is generally assumed that the birth of a child in the family is a source of joy to most parents across all cultures. However, available literature reveals that parenting is a highly stressful duty which may bring about mixed experiences of stress and despair among caregivers (Barnett, Clements, Kaplan-Estrin and Fialka, 2003). As such becoming a parent of a child with intellectual disability is one of the most stressful life events that can occur.

According to the Persons with Disabilities Act No. 06 of 2012 of the laws of Zambia, a person with disability means “a person with a permanent physical, mental, intellectual or sensory impairment which, in interaction with various barriers may hinder that person to fully and effectively participate in society on equal basis with others” (Government of Republic of Zambia, 2012, p. 73). In the same vein, the Diagnostic and Statistical Manual for Mental Disorders – Fifth edition (DSM-5™) defines intellectual disability as “a disorder with onset during the developmental period that includes both intellectual and adaptive functioning deficits in conceptual, social, and practical domains” (American Psychiatric Association, 2013, p. 33). This disability originates before the age of 18 years.

Incidence and prevalence estimates from studies conducted after 1980 are said to have varied. Generally, there are many factors that can affect the estimates of intellectual disability, such as diagnostic criteria, severity of disability, gender, age, study population, and socio-economic status. Nevertheless, it has been estimated that 1-3 percent of the world’s population has intellectual disabilities; with higher prevalence rates reported in higher income countries (Maulik, Mascarenhas, Mathers and Saxena, 2011). For example,

Maulik et al. (2011) report that according to a 2010 study by the Centers for Disease Control (CDC), intellectual disability is common and was reported in approximately 1 in 6 children in the United States (about 16 percent) in 2006-2008. While in Australia the prevalence rate was 14.3 percent in 2006 as compared to 3.9 percent in Ethiopia in the same year.

The World Health Organization (WHO) [2007] estimates that overall, in Africa, there are between 10 and 15 million people with intellectual disabilities. Based on a general projection of 10 percent provided by the WHO, Zambia has an estimated one to two million people with a disability (including intellectual disability) [Miller and Ziegler, 2006]. More recently, a survey on living conditions among people with disabilities (Loeb, Eide, and Mont, 2008) found the prevalence of disability in Zambia to be 13.3 percent. The magnitude of childhood disability in Zambia is not clearly known and there is limited information about available services for disabled children.

A needs assessment of the current situation of persons with a disability conducted in 2002-2003 by the Zambia Federation of the Disabled (ZAFOD) found that there is little awareness of the rights, needs and aspirations of persons with disabilities including intellectual disabilities, who are still victims of stigma by the larger society in Zambia.

Apart from care received within the family set up, children with intellectual disabilities in Zambia benefit to some extent from special education provided at some selected schools. According to the International Labour organization (2010), several projects have been carried out in the recent past to create opportunities for this group of people in Zambia with support from cooperating partners. These projects include creation of employment using a model for persons with intellectual disabilities, suitable for Zambia, and another that aims to increase opportunities for women and girls with intellectual disabilities to participate in social life, to improve their employment opportunities through peer support, co-operative society activities, material in simple language and public awareness campaigns.

However, little is known about projects that aim at promoting the welfare of family caregivers who play an important role in the care of such children, usually under very difficult life circumstances. It is from such a background that behavioural practitioners and health care providers may need to consider stepping up efforts towards improving the general welfare of caregivers who are at risk for heightened stress.

In terms of safeguarding the welfare and rights of the disabled, the Government of Zambia ratified the UN Convention on the Rights of Persons with Disabilities (UNCRPD) in 2010 and has signed but not yet ratified the optional protocol to the convention, which establishes an individual complaint mechanism. So far, Zambia has adopted a number of laws and policies on persons with disabilities, including the Persons with Disabilities Act No. 06 of 2012, which was enacted by parliament on the 31st of July, 2012 in line with the Convention on the rights of Persons with Disabilities (Southern Africa Federation of the disabled [SAFOD], 2014).

In addition, the current 2012 draft Zambian constitution includes specific provisions for persons with disabilities under the bill of rights. The Zambian vision 2030 also recognizes streamlining of service delivery for persons with disabilities as key to achieving the goals and objectives of the Vision. The Technical Education, Vocational and Entrepreneurship Training (TEVET) Act, 1998, states that the “special needs of people with disabilities will be taken into consideration” (SAFOD, 2014).

With regard to meeting the training needs of children with intellectual disabilities in Zambia, the National Policy on Education, 1996, recognizes the right to education for each individual, regardless of personal circumstances or capacity. The Ministry of Education in Zambia has overall responsibility for education, including special education. On the other hand, the Ministry of Community Development Mother and Child Health has been mandated to lead on disability issues in Zambia and is entrusted with formulating policy for persons with disabilities (Mitra, Posarac and Vick, 2011).

International human rights conventions recognize the right of children to family life in the community (United Nations, 1989, 2006). United Nations further write that in the vast majority of instances, children with intellectual disability are cared for by their parents who (along with other family members) serve as their most constant and life-long caregivers. They play a critical role in shaping the development and life experiences of their children with intellectual and/or developmental disability. In many contexts family involvement may extend over the life span of parents, with siblings and extended family members taking on caring roles, especially when parents are no longer able to.

Having a child with disability often places parents in a stressful condition. According to Holroyd and Lazarus (1982) as cited in Fiedler, Simpson and Clark (2007), stress exists

when environmental and/or internal demands tax or exceed the individual's resources for managing them. Anthony *et al.*, (2005) as cited in Margalit and Kleitman (2006) discussed parenting stress as the difficulty emerging from the demands of being a parent, affecting behaviour, well-being and children's adjustment. Parental stress therefore demands extra effort from parents in dealing with the demands of everyday living in raising their children.

A number of studies have demonstrated that parents of children with developmental disabilities experience higher levels of stress than parents of normally developing children (Hodapp *et al.*, 2003; Johnston *et al.*, 2003). Webster *et al.* (2008) found that the scores in the Parenting Stress Index were above 85th percentile in over forty percent of parents of children with developmental delay, indicating significant parenting stress.

Historically, research has led to an assumption that outcomes for parents of children with intellectual disability who experience additional stressors such as unmet daily needs and financial difficulties would without any doubt lead to pathology and maladaptation (Dykens, 2000).

In contrast, emerging research findings have demonstrated that although some families are at risk for having numerous difficulties many families positively cope and adapt to this stress (Konstantareas, 1991; Scorgie *et al.*, 1998 cited in Jones and Passey, 2005). Further, Jones and Passey assert that vast amount of research has shown that family outcomes can vary from healthy adaptation to maladaptation as a result of changing family responses over time. Current literature has therefore moved away from the single cause and effect relationship between parental stress and pathology and has emphasized the successful adaptation and normality of families.

1.3. **Statement of the problem:**

The intention of the United Nations is for most member countries to provide the necessary supportive services to individuals with a disability and their families. Zambia has to some extent worked to highlight issues related to disability and promote awareness by having in place the *Persons with Disabilities Act* No. 06 of 2012, and with the signing of The United Nations Convention on the Rights of People with Disabilities (2006).

With all these efforts put in place, results have not favoured caregivers of people with disabilities. Formal support systems in Zambia continue to be weak and as such, the responsibility of caring for people with disabilities has continued to largely fall on the family alone (Miller and Ziegler, 2006). Apart from special schools, the family in Zambia is often observed to be the only provider of care under very challenging circumstances which include poverty, limited resources for coping with the child's disability, coupled with a weakened extended family support system.

The national disability policy has not helped in supporting caregivers within the family set up to continue functioning effectively in their important role. It is generally accepted that caring for a child who has an intellectual disability can be stressful and involve significant and prolonged periods of time and energy, completion of physically demanding and unpleasant tasks, and frequent disruption to family routines and activities.

Further, given that some previous similar studies conducted elsewhere have not focussed on identifying specific variables that account for the proportion of stress among family members of children with intellectual disabilities, predictor variables for caregiver's stress remain obscure. It is therefore, reasonable to assume that the scarcity or lack of documented evidence on this particular topic and failure to consider identifying the features that predict heightened levels of stress among family members of children with intellectual disability in previous research work had created a significant gap in the current knowledge base on this particular topic area.

In closing this gap, this study addressed research questions on predictor variables associated with family care-giving stress. These questions were of great relevance when considering the potential impact this could have on the developing child. If parents experienced chronic heightened stress that affected negatively their own physical and/or psychological health, then their ability to provide prompting care and direction to their child was also likely to suffer. Bridging this knowledge gap could also prove vital in working with caregivers to bolster their ability to effectively manage stress and enhance their personal resources that are necessary for directing and leading their children toward improved quality of life.

1.4. Objectives

1.4.1 *The Study Aim*

The study was aimed at determining predictor variables of caregiver stress among family members of school-going children with intellectual disabilities.

1.4.2. *Specific objectives*

The specific objectives of this study were to:

1. Assess caregivers' stress levels.
2. Identify family demographic factors that are associated with care giving stress.
3. Determine the relationship between care giving demands on time and caregiver stress.
4. Determine the influence of coping strategies on caregiver stress.
5. establish the impact of social support on caregiver stress

1.5. Research Questions

1. Are family caregivers experiencing heightened stress?
1. What demographic characteristics are associated with giver stress?
2. What is the relationship between care giving demand on time and caregiver stress?
3. What is the influence of coping strategies on caregiver stress
4. What is the impact of social support on caregiver stress?

1.6. Justification of the study

Although some studies have been conducted to determine caregiver stress among parents of children with intellectual disability, few studies have attempted to identify some features of caregiving which predict heightened levels of stress among family members. Further, there were no readily available publications on studies conducted in Zambia on this topic. A review of literature showed that most of the previous similar studies were conducted in developed countries where variations exists when compared with a developing country such as Zambia in terms of support systems for families of children with intellectual disabilities and cultural variations in child care roles within the family.

The aim of this study was to determine factors that predict caregiver stress among family members of school going children with intellectual disabilities in the Zambian context. The findings of this study will contribute to the professional body of knowledge in the field of child and adolescent psychology by bridging part of the knowledge gap that exists with regard to caregiver stress in families of children with intellectual disabilities. Further, this study has drawn implications that will guide the provision of needed psychosocial, educational, and health services that can strengthen family coping and positive adjustment. It has also highlighted the need for further research on this particular subject. This in turn may foster positive parenting strategies for children with intellectual disabilities.

1.7. Theoretical and Conceptual framework

1.7.1 *Double ABCX Model of Family Stress.*

The Double ABCX Model of Family Stress (McCubbin and Patterson, 1983) is adapted from Hill's original ABCX family crisis model (1958) which attempts to provide an understanding of how families manage or cope within stressful situations. The model also explains how families struggle with change and illustrates how families approach and manage life demands.

This model applies well to the situation of family members of children with intellectual disabilities as it offers a theoretical framework on how the care needs of an intellectually disabled child may be approached by the family. It also offers an explanation on how some families are able to manage the challenges posed by such a child with ease and resilience, while others become overwhelmed and stressed.

Following Hill's original ABCX family crisis model (1958), McCubbin and Patterson (1983) summarized Hill's theory in the following general schematic: "A (the stress causing event such as care-giving demands) ---interacting with B (the family's crisis meeting resources such as coping strategies and social support) --- interacting with C (the definition the family gives to the event) --- produce X (the stress or crisis)."

The "A" component of the conceptual framework refers to what McCubbin and Patterson (1983) refer to as "stressors" and "hardships". The authors define a stressor as a "life event or transition impacting upon the family unit which produced, or has the potential of

producing, change in the family social system” (McCubbin and Patterson, 1983, p. 8). A hardship is defined as “those demands on the family unit specifically associated with the stressor event” (McCubbin and Patterson, 1983, p. 8). It is postulated that both the stressor and the resulting hardship place demands and strain upon the family. This strain requires action by the family to be managed. In relation to the current study, the day to day care giving for the child with an intellectual disability becomes a stressor for the family with its accompanying hardships such as increased time involved in caring for the child with disability which the family must deal with.

Using this model, the stressor which in this case, is care-giving demands of a child with intellectual disability and accompanying hardships interacting with the “B” factor, or the family’s resources for meeting these demands. These resources are thought of in terms of the ability for them to prevent a disruption in functioning caused by heightened stress within the family system (for example, coping strategies and social support). According to McCubbin and Patterson (1983), family adaptability or the family’s ability to meet the stressful demands and adjust accordingly is a basic example of a family resource.

The “C” factor within Hill’s original ABCX model is the family’s subjective value and meaning given to the stressor which reflects the values of the family and also involves previous experience in crises management. Varying meaning can be attributed to the stressor ranging from a welcomed challenge to overcome to an uncontrollable and overwhelming situation that is impossible to manage (McCubbin and Patterson, 1983).

The final variable within Hill’s model is the “X” factor. Hill theorizes that the interplay between the “A”, “B”, and “C” variables cause stress for the family. Family stress, according to Hill, is defined as “a state which arises from an actual or perceived demand-capability imbalance in the family’s functioning and which is characterized by a multidimensional demand for adjustment or adaptive behavior” (McCubbin and Patterson, 1983, p. 9). Family distress is thought to arise when stress is subjectively defined as unpleasant or undesirable by the family. Further, McCubbin and Patterson, assert that the “X” factor, or crisis, is the amount of disruption and disorganization that results from the level of family perception of the stress being undesirable. In this case, it is noted that crisis

will not result if the family manages to deal with a stressor using available resources and redefines the situation as not requiring change and/or adjustment.

McCubbin and Patterson (1983) built on Hill's original ideas to provide the foundation for their Double ABCX Model of Family Stress. In addition to the original model, the Double ABCX model adds post-crisis variables in order to describe:

- i. Additional life stressors that shape the course of family adaptability,
- ii. The vital social, psychological, and intra-familial factors families possess and utilize to manage crises,
- iii. The changes in how families redefine and attach meaning over time in an attempt to make sense of their situation,
- iv. The types of coping strategies used by families, and
- v. The results of all the above mentioned efforts.

The additional factors are integrated into the "A", "B", "C", and "X" variables of the original model as it is suggested that families rarely deal with stressors in isolation, but rather several stressors may impact the family at the same time. For example, socio-economic hardships, old age, and major role change within the family and other calamity. McCubbin and Patterson (1983) refer to the build-up nature of stressors as the "Aa" factor in the Double ABCX Model. According to these authors, five different types of stressors contribute to the build-up effect within the family system during a time of crisis. The first of these include the hardships caused by the initial source of stress. In this case, the stressor can result in increased burden of care for the caregiver which could lead to a hardship for the caregiver and family if not effectively managed.

As this applies to families of children with intellectual disabilities in the present study, parents and other family caregivers in addition to their other roles took on additional responsibility as the disability prevented the child from gaining and maintaining independence in day to day functioning. Usually, the increased responsibility was not readily resolved and may have been a source of strain on the family members.

Secondly, the normal transitions that occur within the family can place additional stress on the family. In addition to the initial event, changes such as caregiver's old age, marital status, socio-economic hardships or job change for the parent can place additional demand

on the family as the change requires adjustment. Next, any residual stress from prior strain placed upon the family seems to be exacerbated by new stress and can contribute to the build-up of demands families must manage within a crisis. A fourth variable that impacts the pile up of demands are the family's efforts to cope with the situation. Ineffective coping efforts can contribute to increased tension, thus resulting in more strain on the family. Lastly, ambiguity within the family may have had an impact on the family during a crisis. The uncertainty of roles within the family and confusion about family structure can paralyze a family in a crisis situation, leading to more stress.

In McCubbin and Patterson (1983) Double ABCX Model, the "Bb" factor represents the family's adaptive resources. In a time of crisis the family is thought to have two general types of resources: existing resources and expanded family resources. Existing resources are those that are already embedded within the family structure. These resources act to minimize the impact of the initial stressor and decrease the probability that the family will enter into a crisis. Expanded family resources, or the "b" in the "Bb" factor, are the new resources families generate in response to the demands that develop through the crisis period. According to McCubbin and Patterson (1983) these resources serve to stabilize the family and can come via individual, family, or community means. The two authors also note that a very important resource making up the "Bb" factor is social support. Families who are able to develop social resources are more resistant to major crises and are more apt to recover from crisis and regain stability within the family system (McCubbin and Patterson, 1983).

The "Cc" factor within the Double ABCX Model refers to the meaning the family attaches to the entire crisis situation. What differentiates this from the "C" factor in Hill's model is the family's ability to redefine and give new meaning to the crisis situation, which involves clarifying the crisis issues in order to make them more manageable. This lowers the emotional intensity of the situation and encourages social and emotional development of family members thereby facilitating a healthy family coping and adaptation.

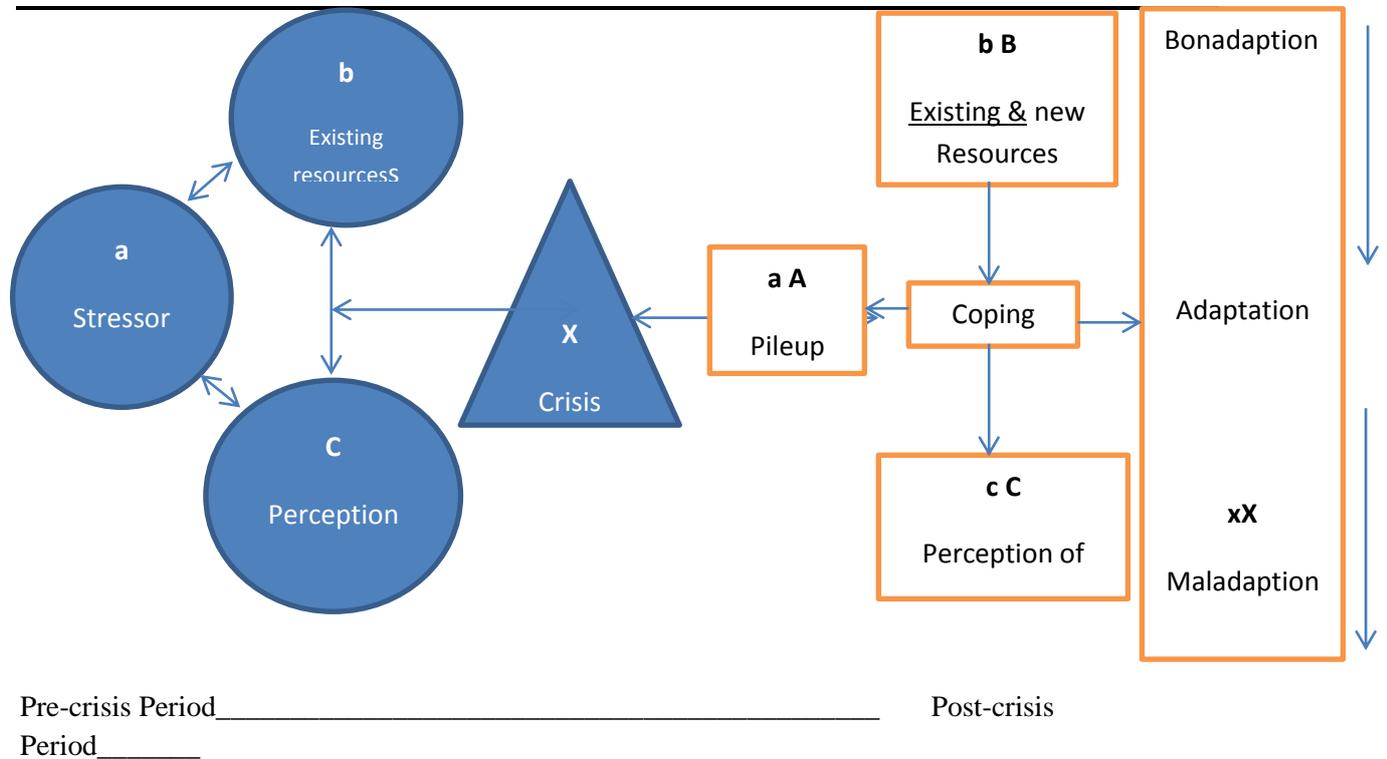
The last factor, or "Xx", within the Double ABCX Model refers to the family adaptation balancing. Whereas Hill's "X" factor signified the amount of crisis within the family system, the "Xx" variable within McCubbin and Patterson's model refers to the family's

ability to achieve balance between reciprocal relationships amongst individual members, the whole family system, and the community that result from the crisis situation.

At the initial level, it is theorized that balance is sought between individual family members and the family system. According to the model, stress results from a demand-capability imbalance at this level. In particular, an imbalance is thought to result when the demands placed upon the larger family system by the individual member exceed the capabilities of the family system. In relation to families of children with intellectual disabilities, an example of this imbalance would be where the care demands placed upon the family by the child exceeds the family unit's resources to meet the demands of care-giving for the child. At this point the family must negotiate a new balance between their child and others within the family.

At the next level of adaptation a balance between family and community is sought. According to McCubbin and Patterson (1983) important factors within the community that cause an imbalance for the family are demands placed on the family by work responsibility. Responsibilities at home and those at work typically compete for parental time and often result in stress and demand-capability imbalance. This can be particularly difficult for the parent of a child with a disability. The parent must find balance between the care needs of the child while ensuring that work responsibilities are met. Within the Double ABCX Model, adaptation is said to be the critical concept in describing the family efforts to achieve balance and to restore and improve functioning that was disrupted through crisis

Figure 1: The Double ABCX Model



Source: McCubbin & Patterson (1983).

1.8. Operational definition of terms

i. School-going child with intellectual disability:

A person under the age of 18 years who is currently enrolled in one of the special schools in Lusaka urban and has a disability characterised by significant limitations in both intellectual functioning and adaptive behaviour, which covers many everyday social and practical skills.

ii. Caregiver:

This refers to any adult family member and/or sibling who take part in the day to day care of the child with intellectual disability.

- iii. ***Care giving stress:***
This refers to negative personal psychological outcomes as a result of caring for a child with intellectual disability.
- iv. ***Family socioeconomic status:***
The measure which incorporates family members' wellbeing in terms of income, family assets and possessions
- v. ***Coping Strategies:***
Ways by which families of children with intellectual disabilities attempt to deal with the stress which results from caring for children with intellectual disabilities.
- vi. ***Support system:***
A network of available aid agencies for caregivers of children with intellectual disability such as extended families system, government and Non-governmental organisations

CHAPTER TWO

LITERATURE REVIEW

2.1. Introduction

The Persons with disabilities Act No. 06 of 2012 of the laws of Zambia describes disability including intellectual disability as a permanent impairment in an individual characterised by failure to interact in societal activities on an equal basis. Similarly, the Americans with Disabilities Act (1990), states that intellectual disabilities are marked by a series of adaptive functioning deficits. Disabilities are generally observed to inhibit an individual's ability to meet personal care needs as well as other activities of daily living. It is noted that in most cases, these individuals rely upon others to have their daily needs met. These tasks typically become the responsibility of parents and other family members and this is especially true for children with intellectual disabilities. Wayne (2011) observes that the amount of responsibilities placed upon parents and other caregivers is unique and potentially stressful. As the limitations resulting from the disability are usually predicted to continue throughout the individuals' life time, the responsibilities placed upon the family may be enduring without a predictable end. This could potentially threaten a parent's or family well-being both in the present and future. Wayne (2011) further notes, in the present, the child's care needs may disrupt family daily routines, potentially preventing family members from attending to their own needs. The author also asserts that over time, this can lead to mental and/or physical exhaustion for the caregiver. Exhaustion could lead to the caregiver being unable to meet the child's needs. Through this exchange, stress can have a detrimental impact on the caregiver and subsequently the child if it is uncontrolled.

Although the key focus of this study was to identify predictors of caregiver's stress in families of intellectually disabled children in Zambia, the literature on family perceptions of and experiences with caregiving of children with intellectual disabilities globally also adds useful context to the discussion of family responses to the disability, family strengths, and family support needs. It should be noted however, that most of the literature on caregiving of children with intellectual disabilities comes from the minority (Western) world contexts and may not be completely relevant to the Zambian situation.

In spite of this fact, this literature can still provide background into the caregiving experience of families of children with intellectual disabilities in general. This section will therefore highlight relevant literature and theoretical frameworks based on previous and contemporary studies related to the research problem under study.

2.2. Parental care giving and stress

The view that children with an intellectual disability are to a greater extent the source of parental or caregiver stress than children without disability has been the focus of most research and professional practice over the recent years (Byrne and Cunningham, 1985; Donovan, 1988, Baxter, 1989, as cited in Baxter, Cummins and Yiolitis, 2000). However, it is important to note that the specific influence the child with disability has on family stress is not clearly understood.

According to Baxter, Cummins and Yiolitis (2000), while a child with a disability is known to have a negative effect on the daily activities and wellbeing of families, some are more negatively affected than others and the stress-inducing conditions may differ between families with variations based on a range of family, child and community characteristics.

Research suggests that parental stress is a complex dynamic process which changes over time (Baxter, Cummins and Yiolitis, 2000). The three authors also observe that evidence from research further suggests that currently, children with intellectual disabilities are less likely to be cared for in an institution and less likely to be separated from their non-disabled peers during their schooling, and are more likely to live at home with their siblings.

In general, mothers of children with intellectual disabilities report greater parenting demands (such as difficulties in carrying out activities of daily life, and greater amount of time spent with such a child to ensure safety), increased stress levels and poorer physical and psychological wellbeing than parents of non-disabled children (Miodrag and Hodapp, 2010). Predictors of mothers' stress related to child care have been highlighted in a study conducted in a geographical catchment area of South-east Queensland, Australia on one hundred and five (105) mothers of preschool-aged children with intellectual disability and other developmental disability (Plant and Sanders, 2007). In the Australian study, mothers completed assessment measures addressing some key variables on caregiving related stress.

Results of the regression analyses demonstrated that the difficulty parents experienced in completing specific care- giving tasks, behaviour problems during these care-giving tasks, and level of child disability, respectively, were significant predictors of level of parent stress. In addition, parents' cognitive appraisal of caregiving responsibilities had a mediating effect on the relationship between the child's level of disability and parent stress. Mother's level of social support had a moderating effect on the relationship between key independent variables and level of parent stress.

Parents' experience of stress related to caring for a child with intellectual disability has also been demonstrated in a study by Gupta and Kuar (2010) which involved hundred and two (102) subjects from three schools meant for children with intellectual disability in India. In this study, parents of children with intellectual disability were chosen randomly. At the same time, three other schools for regular children were taken on convenient sampling basis for comparison purpose. The study included thirty (30) parents who had children with no disability (17 fathers and 13 mothers). In addition, sixty five (65) parents had children with intellectual disability (30 mothers and 35 fathers). A Quick Stress Assessment Test (QSAT) [Vaz, 1995] was used to collect data in two stages. Firstly, parents of children with no disability and an equal number of parents of children with intellectual disability were administered the QSAT individually. Secondly, additional parents of children with intellectual disability were included in order to establish differences based on gender. After scoring all the responses, data of the mental and physical health aspects were analyzed separately.

Results indicated that most subjects reported higher mental stress than physical stress (68 %). When the two groups of parents were compared, it was found that the mean stress score and variability of the group with disabled children was higher than the other group. The mean difference, when subjected to a t-test for independent means yielded a significant t ratio ($t= 2.46$; $p < .01$). This shows that Parents of children with intellectual disability group experienced far greater stress than the group for parents of children without intellectual disability.

Research suggests that mothers and fathers may experience different impacts of childhood disability and have appeared to cope with the disability differently. In comparison to fathers,

mothers of children with childhood disabilities have been found to present with heightened symptoms of depression (Hastings et al., 2005; Olsson and Hwang, 2001), increased caregiver burden and stress (Heller et al., 1997).

In comparing the experiences of mothers and father in families with and without children with developmental disabilities, Oelofsen and Richardson (2006) found that mothers of children with developmental disabilities experienced increased stress, had a weaker sense of coherence, and poorer health than their husbands. On the other hand, the comparison group (with children without developmental disabilities) did not exhibit any differences between mothers and fathers. Conversely, one study reported that mothers have more positive perceptions of care giving than fathers (Hastings, et al., 2005).

However, studies with smaller sample sizes did not find significant differences on measures of stress (Keller and Honig, 2004; McCarthy, Cuskelly, van Kraayenord and Cohen, 2006), and did not also find any significant differences on the variable of family support (Dyson, 1997). This is also reflected in a study involving forty (40) Australian families who had at least one child with fragile-X syndrome aged between 4 and 18 years, sixty-seven parents (39 mothers and 28 fathers) were interviewed (McCarthy, et.al., 2006). Thirty-two of the families had both mothers and fathers present; however, only in 27 of these families did both the mother and father agree to participate. In the Australian study, a repeated measure ANOVA was used to test for significant differences between mothers and fathers on all dependent and independent variables while correlations were used to determine associations between measures. In addition, a series of hierarchical regression analyses were carried out for each parent group separately, to examine the contributions of child behaviour (BASC-PRS subscales of Internalizing, Externalizing and Adaptive Skills), child attributes (Child Characteristics and Physical Limitations subscales of the QRS-F), family support (FSS Number of Supports and Satisfaction) and marital satisfaction (DAS) to caregiver's stress.

In this particular study, results of ANOVA for significant differences between mothers and fathers on all dependent and independent variables did not show any significant differences between parent groups on any of the measures used. No differences in levels of stress were found when mothers' and fathers' reports were compared. This was true for all three measures used in this study to assess stress.

The lack of significant findings in studies with smaller sample sizes suggests that differences between mothers and fathers may be small. In addition, mothers and fathers may also differ in what contributes to their stress. Keller and Honig (2004) found that for fathers, acceptance of the child with the disability and family harmony reduced stress. While mothers were also affected by family harmony, lower socioeconomic status and greater care demands which predicted stress. These differences may represent important differences in the way practitioners should intervene when helping mothers and fathers.

It should be noted, however, that in most studies conducted elsewhere, the majority of mothers of children with intellectual disabilities report normative levels of well-being (Baker, Blacher, and Olsson, 2005; Glidden and Jobe, 2006; Olsson, Larsman and Hwang, 2008). Studies have also demonstrated that mothers report positive aspects of parenting their child with intellectual disabilities (Blacher and Baker, 2007; Green, 2007).

On the other hand, a review of literature shows that there has not been great focus toward the well-being of fathers in caring for children with intellectual disabilities. The available evidence suggests that the association between caring for a child with intellectual disability and lower well-being is much less pronounced among fathers and that they typically report lower levels of psychological distress in comparison to their spouses (Emerson and Hatton, 2010; MacDonald and Hastings, 2010).

In other studies, researchers have shown that, in addition to the challenges, there can be many positive and rewarding aspects of providing care for family members with intellectual disabilities, such as an increased sense of psychological wellbeing (Hong and Seltzer 1995). Moreover, when trying to understand the circumstances or meaning behind having a child with a disability, studies report that many parents take comfort in their spirituality, which helps them view their child as a blessing or a test of their faith, rather than as a burden (Blacher, Neece, and Paczkowski 2005).

Many discussions of caring for people with intellectual disabilities combine ideas of either the 'burden' or stress entailed as well as its positive aspects. For example, although Kenny and McGilloway (2007) found evidence of caregiver stress, they also found that most participants were satisfied with their lives, used positive coping strategies, and had realistic

expectations for their children's future. In addition to studying the effects on families (both positive and negative) of caring for a disabled family member, studies have also highlighted certain family traits that may affect the outcome of their experiences. For example, in a study of hope as a psychological resilience factor in parents of children with disabilities, Lloyd and Hastings (2009) found that hope predicted increased positive wellbeing of families and decreased their psychological distress.

2.3. Grandparent caregivers and stress

Grandparents are also being called upon to serve as caregivers for children with intellectual disabilities in Zambia especially with the advent of HIV/AIDS which has claimed the lives of some younger parents leaving behind children who are now being cared for by their grandparents. One study conducted in the Western world indicates that these grandparent caregivers provide daily care for their disabled grandchild for an average of seven years (Janicki et al., 2000). The study further notes that most of the grandchildren have multiple problems or disabilities. The most common problems are learning disabilities, developmental delays, attention deficit hyperactivity disorder and intellectual disability.

Similar to the findings concerning depression in mothers, grandmothers, who make up ninety percent (90%) of grandparent caregivers, are also susceptible to depression when they are the primary care taker of a disabled grandchild, due to the additional stress of caring for the child (Dellmann-Jenkins, Blankemeyer, and Olesh, 2002; Kelley, Yorker, Whitley, and Sipe, 2001). Other predictors of stress and burden included having lower family income, having lower levels of social support, and not receiving welfare support (Burnette, 2000; Mills et al., 2005).

However, studies have not established clearly whether caring for a grandchild with a disability exacts a greater burden for the grandparent than caring for a grandchild without a disability. A comparative study of grandparents who were raising a grandchild with a disability and those raising a child without a disability showed fewer differences between perception of health status, stress and depression (Force et al., 2000). One difference found was that grandparents of children with a disability were more likely to need help with school. In addition, both groups of grandparents experienced low access to potentially useful services and low levels of financial supports.

This finding contradicts another study conducted by Burnette (2000), which compared Latino grandparents caring for a child with special needs to Latino grandparents who were caring for a grandchild without special needs. Those who were caring for a child with special needs reported greater levels of stress and depression and more unmet service needs than the grandparents who were not caregivers of special needs children. Considering these studies together suggest that caring for a grandchild is stressful, but the results are mixed regarding the level of distress experienced if the child has a disability.

Research has typically focused on the negative aspects or burden to the grandparents and its effects on their psychosocial functioning or health. An equally important area of focus is the positive benefits to raising a grandchild with a disability. Positive benefits include greater love and intimacy, finding meaning in the experience of care giving, personal growth, and improved relationships (Gardner, Scherman, Efthimiadis, & Shultz, 2004). However, it is still unclear whether a grandparent caring for a child with a disability experiences more stress and burden than a grandparent caring for a grandchild without a disability. Coping mechanisms used by grandparents when caring for a child with a disability may be pivotal to alleviating stress. Thus grandparents who are able to reframe the situation in a positive way and are more accepting of the disability could experience reduced stress related to care giving.

2.4. Sibling caregivers and stress

Apart from focusing on parental care giving stress, previous studies involving siblings of children with disabilities have also produced interesting findings regarding whether the impact of caring for their intellectually disabled sibling heighten stress or not. For example, contrary to most expectations, a few previously conducted studies have shown elements of positive benefits to siblings living with a child with intellectual disabilities (Crossman, 1972; Hannah and Midlarsky, 1985 as cited in Baxter, Cummins and Yiolitis, 2000).

However, to a larger extent, other studies indicate that siblings in these families are more often expected to take on additional responsibilities in relation to the physical care and socialization of their sibling with a disability and are therefore, more likely to have psychological or emotional difficulties (Baxter, Cummins and Yiolitis, 2000).

This scenario may not be different from what is generally observed in some Zambian family set-up where older children are also expected to participate actively in the care of their younger siblings. In these circumstances, while parents may benefit from siblings assisting with the care of the child with a disability, any difficulties experienced by the non-disabled siblings are likely to result in them being distressed and may spill over to predict stress in their parents.

Available evidence show that as parents grow older, siblings may become caregivers themselves (Heller and Arnold, 2010; Hodapp, Glidden, and Kaiser, 2005). Both benefits and disadvantages to siblings of children with intellectual disabilities have been reported in the literature.

Overall, it appears, though not conclusive that siblings of children with intellectual and/or developmental disability are at minimal (if any) risk for psychosocial problems (Heller and Arnold, 2010). In view of this, this study attempted to highlight the Zambian context of siblings' stress in relation to caring for children with intellectual disabilities within the family set up.

2.5. Economic factors and caregiver stress

Overall, it is suggested that families supporting a child with intellectual disability are more likely than other families to be exposed to poverty and a range of associated environmental adversities, though the strength of this relationship will vary with the severity of intellectual disability (Hastings, 2012). In this vein, a number of recent large-scale population-based studies have suggested that the poor well-being of families supporting a child with intellectual disability may be attributable in large part to their increased rates of exposure to poverty associated environmental adversities (Emerson, 2012; Emerson and Hatton, 2010; Olsson, Larsman and Hwang, 2008).

In research focusing on parental mental health, the economic burden of raising a child with a developmental disability has also been examined. The economic burden has been noted to have a particular impact on mothers. Comparative studies of parents with and without disabilities have noted that mothers of children with disabilities work fewer hours and have lower earnings than mothers of typically developing children (Olsson and Hwang, 2006;

Parish, Seltzer, Greenberg, and Floyd, 2004). In addition, mothers have reported spending more time caring for the child with the disability than fathers (Heller, Hsieh, and Rowitz, 1997) and that the care giving demands associated with the child's disability lead to increased work absenteeism (Warfield, 2001).

Generally, it has been observed that people with intellectual disabilities frequently find themselves in the lower brackets of government priorities, planning and policy development. The World Health Organization and the World Bank, (2011) posit that governments may fail to provide essential services to people with intellectual disabilities and their families in such areas as education and employment thereby perpetuating the problems of persons with intellectual disabilities, as well as the stigma, exclusion, and shame associated with the disability. Less than 50 percent of low or middle income countries report providing any support to families of children with intellectual and/or developmental disability in such areas as institutional care, home based-support or advocacy (World Health Organization, 2007).

In the current study, respondents' socioeconomic status were measured based on reliable family income (such as employment or business earnings) and possessions in form of assets such as ownership of a house. The focus was to establish the relationship that existed between socioeconomic status of caregivers and their stress levels.

2.6. Caregiver's knowledge and skills of managing disability

In a study conducted on support needs of caregivers of children with learning disabilities in South Africa by Sandy, Kgole and Mavundla (2013), most caregivers reiterated on few occasions that having access to relevant information about care provision makes them feel empowered and gives them confidence in their caregiving role. However, it was apparent from the narratives that caregivers had limited skills and knowledge of learning disability and how to care for individuals with this diagnosis. In the South African study, lack of or limited knowledge of learning disabilities was the main cause identified by caregivers for their experiences of distress and anxiety when caring for children with this diagnosis. Understanding these issues and acquiring knowledge of learning disabilities and needs of children with this condition may alleviate stresses caregivers experience as well as lead to effective care provision (Marcellus, 2007).

It is known that stresses of caregivers of children with intellectual disabilities can arise from the behaviors presented by children in their care. For example, children with intellectual disabilities can display a range of challenging behaviors, which may include aggression and self-harm (Merrifield, 2011). Exposure to these behaviors can be overwhelming and threatening to caregivers (Sandy & Shaw, 2012). Caregivers may react to these experiences by distancing themselves or withdrawing their attention from the cared-for (Royal College of Nursing (RCN), 2006). These experiences may also have a negative impact on the quality of care caregivers offer to children. Such reactions can be attributed to lack of or limited knowledge and skills on how to respond to behavior related challenges, a view also acknowledged by (Sen & Yurtsever, 2007).

2.7. Religion and stress in families of children with disabilities

One important aspect of culture that is likely to shape values and experiences of families is spirituality and religion. Religious beliefs play a vital role in shaping cultural attitudes toward disabilities, individuals with disabilities, and how individuals generally perceive the world around them (Miles, 2002). In this regard, Poston and Turnbull (2004), assert that cultural attitudes have a strong impact on how families perceive their child with a disability. Christianity and most other religions provide both positive and negative influences on family perceptions.

An example of negative perceptions toward disabilities in Christian beliefs is the notion that people with disabilities cannot have a fulfilling relationship with God. Historically, these individuals have been alienated from religious practices or the Christian community (Bishop, 1995). Also, the connections between sin and suffering are viewed as pervasive themes in Christian texts, and illness or disability is depicted as sin and portrayed as something to be healed, not accepted (Miles, 2002; Schumm and Stoltzfus, 2007). These perceptions are likely to contribute negatively to attitudes of people. For example, Poston and Turnbull (2004) in their study on the influence of religion on caregiving reported that families of children with disabilities expressed their feelings that attending church was difficult. In this study, some families reported that their child with a disability was not accepted and welcomed, and were of the view that the church did not provide any support. The religious community can be a source of stress for families when other members of the community do not show their support and acceptance of children with disabilities (Bennett,

Deluca and Allen, 1995). The social stigma as the result of these negative perceptions to disability can cause isolation of the families.

Contrary to the negative view about religion, it is important to note that religious beliefs also have positive influences on family perceptions in both Christian and most other religious beliefs. Pearce (2005) reported in her comprehensive literature review that family care giving experiences could be positively associated with religious beliefs and practices (for example, a sense of feeling good as a result of care giving). Indeed, past studies have repeatedly reported that spiritual and religious beliefs contribute to parents' ability to gain positive perceptions toward their child with disabilities (Bennett et al., 1995; Blacher & Baker, 2007; Pearce, 2005; Poston & Turnbull, 2004; Schumm & Stoltzfus, 2007). In this regard, Christianity has contributed to guiding parents in gaining a positive perception toward their children with disabilities by providing views about how their child with a disability is a gift from God or a test of their faith (Bennett et al., 1995; Poston & Turnbull, 2004). In addition, Faith itself can be a strong source of support for families. Faith in a relationship with God has been observed to bring about family strength, patience, and a feeling of inner peace (Poston & Turnbull, 2004).

One widely shared view by many Christians is that God intends for this world to be good and everything will be all right if one has faith (Schumm & Stoltzfus, 2007). A sense of being spiritual and having a secure relationship with God enhances positive perceptions of families in areas such as higher self-esteem, more care giving satisfaction, perceived rewards, feeling well, and spiritual growth (Pearce, 2005).

In their study, Tway et al. (2007) found that Asian Americans showed more resilience in coping to the stressors of caring for their child with autism than European Americans. These Asian American parents were reported to perceive the stressor as a fact of life, in correspondence to Buddhist doctrine. Therefore, they could perceive the stressor in a more positive way based on their Buddhist values of harmony with nature.

2.8. Severity of disability and parenting Stress

The severity and complex nature of a child's intellectual disability can have negative consequences on stress levels experienced by family members of children with intellectual disability. In this regard a study conducted by Richman et.al., (2009) to investigate the

impact of specific childhood developmental disabilities on parenting stress levels, similarities and differences in self-report parental stress, patterns of challenging behaviours by the child, and characteristic of the disabilities were analysed. The findings from the study indicated that parents experienced significantly higher levels of stress and the amount of stress experienced was significantly related to the amount of challenging behaviour, pro-social behaviour, and self-injury/stereotypy related to the disorder exhibited by the child. Further, the researchers postulated that a reciprocal relationship may exist between parenting stress and severity of disability.

Wayne (2011) observes that propositions have been made to suggest that the child's disruptive behaviour and low levels of adaptive and independent functioning may worsen parent stress and the parent or caregiver, in turn, may act in a manner toward the child that further perpetuates the deficits that the child is already experiencing.

According to Glidden (2012), one of the most replicated findings in family research is that parental well-being is lower when children exhibit more maladaptive behavior. Results from different studies on this topic have demonstrated that it is child behavior problems, rather than intellectual disabilities *per se*, that are associated with lower levels of parental well-being (Nalavany, Glidden, and Ryan, 2009; Totsika et al., 2011 as cited in Hastings, 2012). Similarly, other studies have also demonstrated the same results for sibling well-being (Hastings, 2007; Neece, Baker, and Blacher, 2010).

According to Hastings (2012), most studies conducted on child behavioural characteristics (Dykens and Hodapp, 2001; Dykens, Hodapp, and Finucane, 2000) have focused on individual differences as a result of diagnosis of the disability. What is noted as the main outcome of these studies is the finding that demonstrates that the association between child disability and parental well-being being is much less pronounced among parents of children with Down syndrome than among parents of children with other diagnoses of developmental disorders. In this case, research relates this finding to the higher level of adaptive behavior exhibited by individuals with Down syndrome and widely documented higher prevalence of behavior problems among children with autism (Hartley, Sikora, and McCoy, 2008).

Though this study did not focus on the children's specific diagnoses as one of the variables tested, one of the objectives of this study was to determine a child's behavior characteristics (level of disability) that were likely to contribute to care giving stress in families of children with intellectual disabilities. Studies focussing on identifying the specific levels of child's disability that heighten care giving stress in families of children with intellectual disabilities in the *Zambian* context would be more valuable to the existing body of knowledge on this particular topic.

2.9. Caregiver coping strategies and stress

Though it was difficult to access documented literature on caregiver's personal characteristics, it can be stated that for both mothers and fathers, a variety of personality factors and coping strategies have been reported to be related to parental well-being (Baker et al., 2005; Glidden, Billings, and Jobe, 2006, Hastings, and Fitzsimons, 2010 as cited in Hastings, 2012). In this regard, Glidden and Natcher (2009) have indicated that there are various coping strategies that individual caregivers of children with intellectual disabilities employ to deal with increased demand of care.

Furthermore, there is some evidence suggesting that stress processing abilities (coping) may be linked to personality factors which in turn are related to levels of well-being in parents of children with intellectual disabilities (Baker et al., 2005; Glidden and Natcher, 2009). Personal characteristics seem to be a better predictor of adaptation for mothers, whereas coping strategies have been found to predict more variance for fathers (Glidden and Natcher, 2009).

Available literature on parents who adapt and cope effectively suggests that optimism; hope, positive reframing of thoughts and attitudes about their circumstances may be important for adaptive parental coping (Baker et al., 2005; Hastings and Brown, 2002; MacDonald et al., 2010). There is also some evidence of cultural variation in terms of personal characteristics and association with care giving stress. For example, in the United States of America, evidence suggests that Latino families are more positive toward their children with intellectual disability; an effect that has been demonstrated across ages, level of intellectual disability and over time (Blacher & Baker, 2007; Blacher & Begum, 2011, as cited in Hastings, 2012).

An individual's tendency toward optimism or pessimism has been found to have an impact on stress levels. Psychologists believe that optimism is an important factor that leads to a subjective positive life experience that in the long run improves quality of life and prevents development of psychopathology (Seligman & Csikszentmihalyi, 2000). It can be noted that positive psychology theorists believe that a tendency toward optimism for the future is a valued personal characteristic that may have a significant impact on the individual.

As Seligman and Csikszentmihalyi (2000) observe, people who are very optimistic are believed to have better moods, are more persevering and successful, are more effective in problem solving, and experience better physical health than people who are pessimistic. Previous studies have supported this ideas put forth by positive psychology theorists. For example, Kayfitz, Gragg, and Orr (2010) explored the impact that positive experiences had on mothers and fathers of children with autism. Specifically, the study examined the positive experiences that parents raising school-aged children with autism reported with a particular focus placed on these experiences in the context of parenting stress. The researchers sought to understand if parental focus on the positive aspects of raising a child with autism had a significant impact on the stress they experienced. Scores obtained from both mothers and fathers on positive experiences were found to be significantly negatively correlated with parental distress suggesting that parents who were able to view the contributions of their child more positively experienced relief from the parenting stress associated with caring for a child with a developmental disability.

Kayfitz, Gragg, and Orr (2010), speculate that having a more positive approach to viewing their child with a developmental disorder allows parents not to focus more on the child's limitations in turn protecting the parents against ill feelings. Similarly, Aspinwall and Grunhart (2000) conducted a study to establish the relationship between optimism and use of effective coping. The study concluded that higher levels of optimism facilitates the ability to process information related to health and that optimistic beliefs may play an especially important and beneficial role in earlier stages of the coping process. De Schipper et al. (2008) conducted a study comparing caregiver mood and observed quality of interaction between the caregiver and the children in their care. Results of that particular study demonstrated that optimism contributed significantly to both the quality of caregiver behaviour toward children and to the children's well-being. Parents who themselves have

intellectual disability (or borderline intellectual disability) are said to face their own special challenges in accessing the knowledge, resources and support that contribute to effective parenting of a child with intellectual disability (McConnell, et al., 2008).

While much literature has examined the risk of stress, burden, and depression in families of children with disabilities, less literature has examined interventions that are aimed at improving the caregiver's experience of stress. A review of literature has shown that there are some limited but promising interventions or approaches for caregiver's experience of stress (Hastings and Beck, 2004). Most of the studies of interventions for caregiver's experience of stress utilized some form of cognitive approaches (for example, enhancing problem solving, cognitive restructuring, setting goals) and behavioral techniques (for example, operant conditioning, reinforcement, punishment, extinction) which were delivered in both groups and individual formats. The aim was to improve child behavioral management techniques, which ultimately led to decreased parental stress. Other interventions including case management services and respite care also show some benefit (Chan & Sigafos, 2001).

Another area of research relevant to improving parent well-being involves an understanding of problem-focused coping. Problem-focused coping includes the use of cognitive and behavioral problem-solving in order to manage the source of stress. That is, with problem-focused coping the person takes some action to reduce their stress. For example, the person can develop a problem list and then prioritize the problem list starting with the most pressing issue. Conversely, emotional focused coping seeks to change a person's negative emotional state by focusing on moderating the negative emotion. These could include such techniques as using relaxation techniques, rethinking the problem in a more positive light, and denial. Essex, Seltzer, and Krauss (1999) found that mothers who coped with their child's disability using problem-focused coping experienced less stress and depression than those who employed emotion-focused coping, which simply seeks to manage the emotions surrounding the source of stress. However, Essex et al. (1999) found that fathers did not get the same benefits from problem-focused coping and only experienced decreases in stress when they refrained from emotion focused coping. Similarly, Ylven, Bjorck-Akesson and Ganlund (2006) point out that emotion-focused coping is only beneficial in situations that are beyond the caregiver's control. These findings suggest that clinicians may be able to

decrease caregiver stress by helping the caregiver to focus on aspects of the disability that are under his/her control (such as asking for assistance and advice when needed or advocating for the child's needs).

2.10. Social support and caregiver stress

A review of literature appears to suggest that social support is a strong predictor of stress for parents and primary caregivers of children with disabilities. Langford et al. (1997), in a conceptual analysis of social support, found that social support was linked to various positive health states that included effective coping behaviours, sense of stability, psychological well-being, and perceived control among others. Research shows that the linkages and assistance received by an individual from other agencies including family members may be factors that cushion the impact that stress can have on parental well-being. In their study to examine the impact that parenting stress and social support had on the course of behavioural problems for children with cerebral palsy, Sipal et al., (2010) observed that "situational stress vs. support" measure was significantly correlated with the "relational stress vs. support" implying that stress associated with environmental support correlated with stress experienced by parents in their relationships with their child and their significant other.

In addition, Beckman (1991), in a study comparing the perceptions of parents of children with and without disabilities, found that parents of children with disabilities reported more care giving demands and stress in all domains. Stress was also negatively correlated with informal support (friends, family) for both mothers and fathers and was positively associated with increased care giving requirements for mothers.

Spratt, Saylor, and Macias (2007) conducted a study that also investigated correlates of stress for parents of children with developmental disabilities. However, in this study, a broader range of disabilities were analysed. The sample included children experiencing a variety of health, developmental, behavioural and neurological problems. In this study, the results of multiple regression analysis showed that perceived inadequacy of family support and maternal support were related to parenting stress in the samples investigated. Similarly, Smith, Oliver, and Innocenti (2001) demonstrated in their study of parenting stress in

families of children with disabilities that the variable of social support predicted parenting stress more accurately than variables related to the child's level of functioning.

Conclusion

In conclusion, literature review has generally highlighted a number of studies indicating that though factors affecting caregiver stress may be varying, mothers, fathers, siblings and grand parents of children with intellectual disabilities report greater parenting demands and increased stress levels than parents of non-disabled children. Studies have also suggested that families supporting a child with an intellectual disability are more likely than other families to be exposed to poverty and a range of associated environmental challenges. Poor social economic status has been largely linked to the poor psychological well-being of families supporting a child with intellectual disability. In addition, studies conducted within Africa have demonstrated that caregivers of children with intellectual disabilities felt confident in their caregiving role when they had access to adequate information about their child's disability. On the other hand, it was apparent from the African studies that lack of or having limited knowledge of intellectual disabilities was the main cause identified by caregivers for their experiences of distress and anxiety. Literature review has further indicated that the severity and complex nature of a child's intellectual disability can have negative consequences on stress levels experienced by family members of children with intellectual disability. In terms of establishing the impact of coping mechanisms and social support on caregiver stress, studies have clearly shown that coping strategies may be linked to personality factors which influence levels of well-being in parents caring for children with intellectual disabilities. In the same vein, support has been shown to be a strong predictor of caregivers of children with intellectual disabilities. Lastly, the methodology used by a number of key studies on this particular topic has to a larger extent influenced the methodological approach in the current study.

CHAPTER THREE

METHODOLOGY

3.1. Introduction

In this section, the research design, study population, study setting, sample size, sampling technique, data collection instruments, study procedures, and data analysis methods which were used will be discussed.

3.2. Study design

A correlational-descriptive study design was used to quantitatively investigate the extent to which the variables of caregiver's demographic characteristics (age, sex, marital status, level of education attained, employment status, sources of income, religion, size of the family), time involved in care-giving tasks, caregiver's coping strategies, and availability of social support were able to predict level of caregiver stress in families of children with intellectual disabilities.

3.4. Study setting

This study was conducted at four schools operating within Lusaka urban namely: Chainama Special School; University Teaching Hospital (UTH) Special School; Bauleni Special School and George Central Special School. The four special schools were considered mainly because at the time of the study, they were the main institutions in Lusaka urban that provided formal education services to children with intellectual disabilities on a daily basis. Three of these special schools are entirely run by the Government of Zambia with the exception of Bauleni Special School which is mainly supported by the Catholic Church and to some extent by the Government of Zambia. All of the schools offer special education to children with various developmental disabilities, but segregated from the main stream classes from pre-grade to grade seven. In the case of Bauleni School, the education system goes up to secondary school level. All the pupils in the four schools attend school on a daily basis from their homes.

3.5. Study population and sample size

The study population included all parents/family members who lived with and provided care to an intellectually disabled child enrolled at any of the four special schools in Lusaka

urban. The sample size was 135 participants which included the child's Father (n = 31, mean age = 41yrs), mother (n = 41, mean age = 39yrs), grandparents (n = 12, mean age = 62yrs), uncles and aunts (n = 26, mean age = 26yrs), and siblings (n = 25, mean age = 22yrs). Majority of participants were those who had children with intellectual disabilities enrolled at Chainama special school (40%), followed by Bauleni special school (34%), UTH special school (20%) and George Central special school (6%).

3.6. Sampling method

Participants to this study were selected using purposive sampling method. The study targeted those caregivers who participated in the care of the child with intellectual disability on a day to day basis. According to Leary (2008), for a purposive sample, researchers use their judgment to decide which participants to include in the sample based on how typical they are to the study population. Leary further states that for non-probability sample, the ability to generalize results is limited, but this does not take away the ability to test hypotheses on how a particular variable relates to behavior. In this case, the purpose of the study was to determine predictor variables of caregiver stress among family members of school-going children with intellectual disabilities and therefore, selection of participants to this study focused on those family members who cared for the children on a daily basis. Invitation letters were sent to homes of children with intellectual disabilities to request family members who participated in the care of the child to participate in this study.

3.6.1 Selection criteria

Only family members who participated in the day to day care of a child with intellectual disability enrolled at any of the four special schools namely: Chainama Special School; University Teaching Hospital (UTH) Special School; Bauleni Special School and George Central Special School were allowed to participate in this study.

3.7. Data collection instruments

All the instruments used in this study were translated to chinyanja specifically for those participants who did not understand the English language. For participants who had good knowledge of English language, the original English versions of the instruments were used.

3.7.1. *Caregiver stress level*

Caregiver stress level was assessed using a Psychological Stress Measure (PSM-9) checklist adopted from (Lemyre and Tessier, 2003). The PSM-9 assessment tool is a brief measuring tool for psychological stress levels using an 8-point Likert scale based on the degree to which each statement applied to the respondent in the last 4 to 5 days. Ratings for each of the eight point scales were summed up and a total score calculated. The higher the score, the more stress being experienced by a caregiver.

This particular tool is originally in the English language and has been reported to have psychometric qualities of reliability, validity and internal consistency of (.89) [Lemyre and Tessier, 2003]. However, when piloted and reviewed for the purpose of the current study, the PSM-9 checklist was found to be relevant to the study objectives and as such deemed a valid tool. It was also consistent with the type of data it was meant to collect such that when tested for its reliability, the Cronback's alpha reliability test showed that it was reliable with a reliability coefficient (alpha = .75).

3.7.2. *Family socio-demographic characteristics*

A Family background questionnaire formulated by the researcher in line with variables of interest for this study was used to obtain demographic information. The first section of this checklist provides demographic information pertaining to the child with intellectual disability. The second section provides family details such as caregiver's relationship with the child, age, sex, marital status, educational level, employment status and family income, size of the family.

The English version of this questionnaire was translated to Chinyanja and in order to assess for its validity and reliability, the questionnaire was subjected to a pilot study on family members of children with intellectual disabilities at two special school units which are not part of the actual study setting. These special school units take in children of similar age ranges to the ones at the actual study setting, though they had limited number of children with intellectual disabilities learning together with children with other developmental disabilities within the same environment. The inclusion education set up was similar to the setting at the major special schools that were part of this study's setting.

3.7.3. *Child's level of disability*

Information on child's level of disability could not be obtained from the schools as official records on children's diagnoses were generally not available. This led the researcher to drop out this variable from the list of candidate variables.

3.7.4. *Time involved in completing care-giving tasks*

Time involved in completing care-giving tasks was assessed by respondents indicating whether they spend more or less time completing tasks with their intellectually disabled child than they would with a child without the disability. Care-giving tasks are grouped into eight day to day care-giving areas for children with intellectual disability as identified in the work of (Shearn and Todd, 1997). Respondents rated their time involved in the tasks on a 5-point Likert scale which ranged from 1 (extremely less time) to 5 (extremely more time). Ratings for each of the eight care-giving areas were analyzed individually in the regression analysis.

Equally, this check list was translated to Chinyanja and subjected to a pilot study in order to assess for its validity and reliability. The contents of this checklist were deemed to be relevant to the objectives of this study upon review and as a result of this process, the measure was perceived as a valid index of care-giving tasks undertaken on a daily basis by family caregivers of children with intellectual disability. Results of the piloted checklists also showed a reliability coefficient ($\alpha = .82$), indicating that the tool was reliable.

3.7.5. *Caregiver coping strategies*

Caregiver coping strategies were assessed using an adopted Brief Cope inventory checklist (Carver, Scheier and Weintraub, 1989) which is an abbreviated version of the original 60 item COPE Inventory checklist. The brief inventory checklist has 28 items where respondents had to rate themselves on a 4-point Likert scale in terms of their methods of coping when they experience a stressful event.

In terms of its psychometric properties, Cooper, Katona and Livingston (2008) indicate that when tested on one hundred twenty-five family caregivers of people with Alzheimer's disease, Internal consistencies for Brief cope were good for emotion-focused, problem-focused, and dysfunctional subscales ($\alpha = 0.72, 0.84, 0.75$). Test-retest reliability over a

year was demonstrated for emotion-focused, problem-focused, and dysfunctional subscales among caregivers in whom burden scores did not change significantly ($r = 0.58$, $r = 0.72$, $r = 0.68$; $p < 0.001$).

However, considering that this particular tool was originally in the English language and no information was available to suggest that it had been previously used in Africa; it was translated to Chinyanja and back translated for quality as well as tested for its validity and reliability through a pilot study on a smaller sample ($n = 30$). The tool demonstrated that it was relevant to the study objectives in terms of content suggesting that it was valid. In addition, the tool was deemed reliable ($\alpha = .71$).

3.7.6. Caregiver's social support

Caregiver's social support was assessed using a Multidimensional Scale of Perceived Social Support (MSPSS). The MSPSS is an adopted, brief, easy to administer self-report instrument containing twelve items rated on a five-point Likert-type scale. It is meant to measure an individual's perception of how much he or she receives outside social support and has been tested on people from different age groups and cultural backgrounds and found to be a reliable and valid instrument (Cox et al., 2003).

Most investigations have revealed MSPSS to be a three-factor construct which demonstrates good to excellent internal consistency and test-retest reliability (with a Cronbach's alpha of 0.81 to 0.98 in nonclinical samples, and 0.92 to 0.94 in clinical samples (Wongpakaran, Wongpakaran and Ruktrakul, 2011).

There was no evidence suggesting that this particular tool had been previously used in Africa. Therefore, it was translated to Chinyanja and piloted on a small sample. Analysis results showed that it had content that was relevant to this study objectives and had good internal consistence and test reliability ($\alpha = .80$).

3.8 Pilot study

A pilot study involving 30 family caregivers of children with intellectual disabilities enrolled at two special school units in Lusaka urban was conducted prior to carrying out this study.

The aim of the pilot study was:

- i. To become familiar with the use of data collection instruments and interactions with caregivers of children with intellectual disabilities.
- ii. To test the instruments for validity and reliability.

After conducting the pilot study, changes were made to the Brief COPE and Multidimensional Scale of Perceived Social Support (MSPSS) checklists by removing some items that respondents in the pilot study were not familiar with and re-phrasing questions that were deemed not to be clear by the respondents. The instruments' validity was checked by way of noting how consistent the responses were to checklist items. Lastly, responses to checklist items on four instruments (i.e. PSM-9, Time involved in completion of care tasks checklist, Brief copes inventory and (MSPSS) checklist) were subjected to a test for reliability using cronbach's alpha reliability test with results showing that the instruments had reliability coefficients above ($\alpha = .70$). This indicated that they were reliable for use in the current study and as such adopted.

3.9. Data collection procedure

After identification of potential participants, an initial contact letter was sent to the respective schools' management providing information about the study project and asking for permission to contact the families. The researcher explained the nature of the project and took time to answer questions that arose before consent was given by both the school management and the parents/family members. Participants were assured that they would not be penalized for refusing to participate or withdrawing from the project and that their participation in this project was on voluntary basis. Confidentiality was maintained by informing the participants not to include their names to the questionnaires, but numbers were assigned to participants in case need arose to revisit some responses given earlier in the process of the project. This information was only accessed by those directly involved in the study.

The researcher approached each prospective respondent in person and asked them to fill in the structured questionnaire and checklists or in certain cases where the respondents were not able to read and write, the researcher read out the questions to them and filled in the questionnaire and checklists on their behalf according to their responses using either

Chinyanja or English language. Each participant was expected to fill in all the four checklists and a structured questionnaire, all lasting between 10 to 15 minutes each. All the checklists and questionnaires were completed and collected by the examiner over a period of one month.

3.10. **Data processing and analysis:**

3.10.1. *Data coding and processing:*

The collected data was coded one at a time according to the variable of interest for the purpose of inclusion to the analysis. Nominal independent variables that were included to the analysis were assigned values in rank order based on common traditional practice observed among Zambian caregivers in terms of child care roles. Specifically, on the variable of respondent's relationship to child, status of being a mother, because of their significant care responsibility was assigned the highest value, followed by father, Grandparent, sibling, and others at the lowest end. On the variable of respondent's marital status, the status of being married was assigned the highest value because it is common practice in Zambia for married couples to take up the largest responsibility of caring for children within the family set-up, followed by those who had separated, divorced, and single on the other end.

Respondent's stress score was measured on an 8-point Likert scale and had codes with the highest value at seven and lowest value coded as one. At the end of it all, values for caregiver's stress scores were summed up using SPSS to arrive at a new variable with total stress scores for each individual caregiver. The remaining other variables were not totalled but had individual items from the checklists considered and coded for analysis. In this regard, time involved in acquisition of information about the child's disability was measured on a 5-point Likert scale and was therefore coded in that order. The variables of coping by concentrating efforts on to the problem and coping by thinking hard about steps to take when faced with a stressful situation were coded from one (rarely used) to four (frequently used) based on the 4-point Likert scale used to collect the data. Lastly, caregiver's perception of support was measured on a 7-point Likert scale and was coded with values in that rank order i.e. one for less support up to seven for more support.

Finally, data was entered onto the template created and processed electronically by means of the Statistical Package for Social Sciences (SPSS- version 16).

3.10.2. **Preliminary analysis**

The total sample in this study consisted of Mothers (n = 41), fathers (n = 31), aunts and uncles (n = 26), siblings (n = 25) and grandparents (n = 12). Data was conducted using a self-administered demographic questionnaire and checklists for caregiver stress, time involved in care of the child, coping mechanisms of respondents, and their perceived social support. Validity of the data collection instrument was determined by means of having a small number of experts (special education teachers and research supervisor) go through the content of the instruments and by way of piloting the data collection instrument on a smaller number of respondents at two special school units outside the study setting (n = 30). The Cronbach's alpha reliability test was used to establish the instruments' reliability. All checklists had shown reliability coefficients (alpha) of .70 or higher and as such were considered to be reliable.

Correlation analyses were then conducted to determine whether specific independent variables (demographic characteristics, time involved in the child's care, coping mechanisms, and perceived social support) correlated significantly to the outcome variable of caregiver stress. Further, candidate independent variables were visually assessed for multicollinearity by way of scatterplots and collinearity diagnosis. At the end of preliminary analysis, candidate Independent variables which did not correlate significantly with the outcome variable of caregiver stress and those that had shown a high level of Variable Inflation factor ($VIF > 10.00$) were declared redundant and excluded from the list of independent variables for the multiple regression analysis.

3.10.3. **Regression analysis:**

Regression analyses were undertaken to determine whether specific identified independent variables of caregiver's socio-demographic characteristics (relationship of respondent to child, age of Respondent, respondent's marital status, number of people earning an income within household), time involved in care-giving tasks, caregiver's coping strategies, and availability of social support contributed to the outcome variable of assessed caregivers' stress levels when measured individually or in combination with other variables at significant level of $p < .05$.

3.10.4. *Differences between high and low caregiver stress*

A median split was conducted to divide the sample into two groups according to level of caregiver stress (low vs. high). In this regard, an independent samples *t*-test was conducted to compare the groups across variables in order to establish the significance of the differences across variables between the two groups.

3.11. **Ethical considerations**

Ethical approval for this study was sought from the University of Zambia's Humanities and Social Sciences Research Ethics Committee, while permission to conduct this study was sought from the Permanent Secretary at the Ministry of Health as advised by the Research Ethics Committee (see appendix ii). In addition, permission to conduct this study was obtained from at least four schools in Lusaka, namely: Chainama Special School; University Teaching Hospital Special School; Bauleni Special School and George Central Special School.

Participants to this study were informed about what this study was all about, what procedures were involved and the approximate time that was demanded from them to fill in the questionnaires. They were also informed of their voluntary participation on this study while still retaining their right to withdraw from the study at any point during the course of the study if they decided to do so. Following the process of information giving, consents were obtained from each adult participant and in case of participants below the age of 16 years; written assent was obtained from individual participants.

Their confidentiality was assured such that names of participants did not appear anywhere on the study materials and were not revealed to anyone else apart from those directly involved in this study. Instead, numbers (codes) were assigned to each participant as a way of observing confidentiality and the participant's information kept locked at all times.

In this study, participants travelled to the schools covering long distances and made several trips to and from the schools in order to hand in filled-in questionnaires as such they incurred extra costs on their transportation. Therefore, in order to lessen their burden, refund of money specifically used towards transport was made to all caregivers who participated in this study. Similarly, as a result of the slightly long time that participants took to fill in the questionnaires, they were provided with refreshments during the process of data collection.

In addition, participants were given information on existing professional help regarding their psychosocial status resulting from the burden of care for their children with intellectual disabilities. They were also advised on how they could access information pertaining to their general wellbeing and findings of this study. Otherwise, participants generally did not encounter any risks by participating in this study.

CHAPTER FOUR

RESULTS

4.1. Introduction

This chapter presents the findings of the present study in line with the objectives and study questions of the study.

4.2. Demographic characteristics of participants

A descriptive analysis was conducted on demographic data for participants and their families using SPSS. Table 1 summarizes demographic information for respondents and their families in this study. This shows that the age range for children with intellectual disabilities being cared for by respondents in this study was 6 -17 years (Mean = 12.00, SD = 3.08) and that of respondents themselves was 16 – 76 (Mean = 35.00, SD = 13.40).

Summary of results in table 1 show that in terms of participants' relationship with the child, (31%) comprised mothers, (21%) fathers, (24%) aunties/uncles, (18%) siblings, and (6%) grandparents. The distribution of participants' gender was (56%) females and (44%) males. Participants' type of accommodation was (33%) lived in rented houses, (31%) parents' house, (27%) lived in their own houses, and (10%) lived in other type of accommodation. The respondents' main source of income was (66%) formal employment or small scale business, and (32%) family support. Further, in terms of participants' education attainment, (31%) attained tertiary education, (40%) secondary education, (21%) primary education and (5%) no formal education. Marital status of participants was (37%) married and the rest being single separated or divorced.

Table 1 Demographic Characteristics of participants and their families

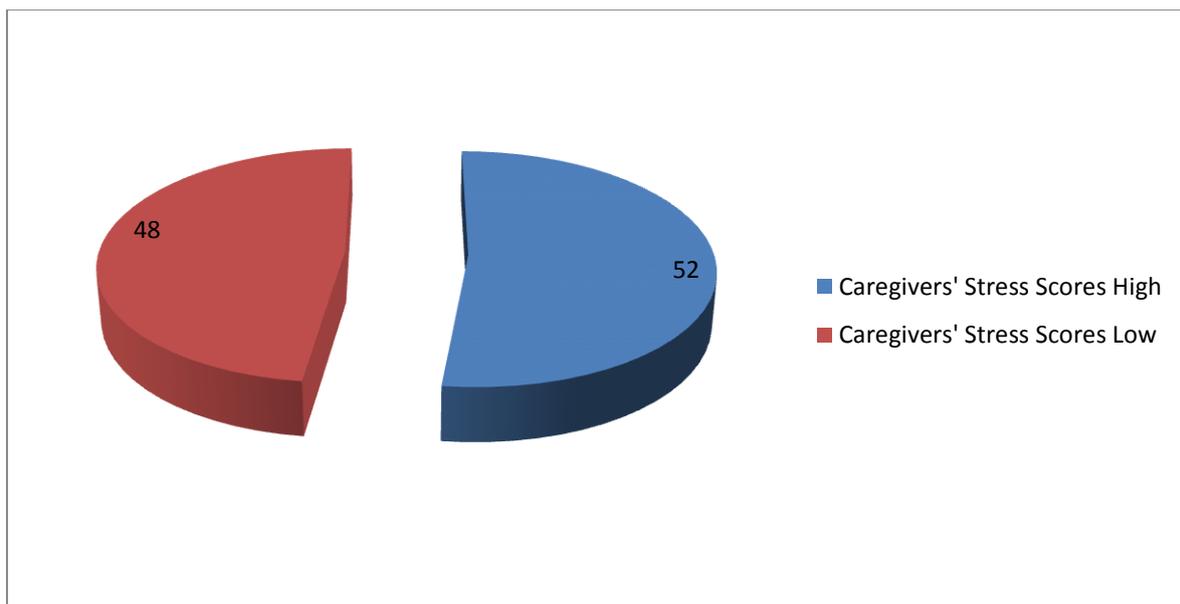
Variable	Mean	SD	Range		
Child's age (yrs.)	12	3.08	6 to 17		
Respondent's age (yrs.)	34.57	13.4	16 - 76		
Family Size	3	0.922	2 to 5		
Number of family members earning an income	1	0.753	1 to 2		
Relationship to child					
	% (n)				
Father	21.0 (31)				
Mother	31.0 (41)				
Sibling	18.0 (25)				
Aunt/uncle	24.0 (26)				
Grandparent	6.0 (12)				
Respondent's gender					
Male	44.0 (59)				
Female	56.0 (76)				
Respondent's Residence					
Own house	27.0 (36)				
Parents' house	31.0 (42)				
Rented house	33.0 (44)				
Other	10.0 (13)				
Family's source of income					
Wage/business	66.0 (89)				
Family support	34.0 (46)				
Variable	Father	Mother	Sibling	Aunt/Uncle	Grand parent
Education Level	% (n)	% (n)	% (n)	% (n)	% (n)
(p < 0.001)					
No education	1.0 (2)	2.0 (4)	2.0 (4)	0.0 (0)	0.0 (0)
Primary education	13.0 (17)	2.0 (4)	3.0 (3)	3.0 (5)	0.0 (0)
Secondary education	9.0 (12)	7.0 (9)	12.0 (15)	12.0 (15)	0.0 (0)
College education	5.0 (7)	6.0 (8)	3.0 (5)	9.0 (12)	1.0 (2)
University education	3.0 (5)	4.0 (7)	0.0 (0)	0.0 (0)	0.0 (0)
Employment status					
(p < 0.001)					
Unemployed	14.0 (24)	3.0 (3)	13.0 (17)	15.0 (20)	3.0 (3)
Retired	0.0 (0)	1.0 (1)	0.0 (0)	0.0 (0)	2.0 (2)
Self-employed	10.0 (20)	10.0 (15)	3.0 (3)	4.0 (4)	0.0 (0)
Part-time employed	0.0 (0)	0.0 (0)	1.0 (1)	4.0 (4)	0.0 (0)
Full-time employed	7.0 (7)	7.0 (7)	1.0 (1)	1.0 (1)	1.0 (1)
Marital status (p < 0.001)					
Single	4.0 (4)	1.0 (1)	13.0 (17)	19.0 (29)	1.0 (1)
Married	21.0 (31)	16.0 (26)	4.0 (4)	3.0 (3)	4.0 (4)
Separated	4.0 (4)	2.0 (2)	0.0 (0)	0.0 (0)	1.0 (1)
Divorced	2.0 (2)	2.0 (2)	0.0 (0)	1.0 (1)	0.0 (0)

4.3 Participants' stress scores

In terms of caregivers' stress levels, results of the Psychological Stress Measure (PSM-9): (*median = 12.00, Mean = 13.29, SD = 7.00*) suggested an average level of caregiver's stress falling within the medium to high range of total stress score. These stress scores have a possible range from 5 to 34 with higher scores indicating increased caregiver stress levels.

Figure 2 shows the distribution of participants in low and high stress groups. A slight majority (52%) of participants had scored higher on the Psychological Stress Measure (PSM-9) as compared to those who scored lowly (48%).

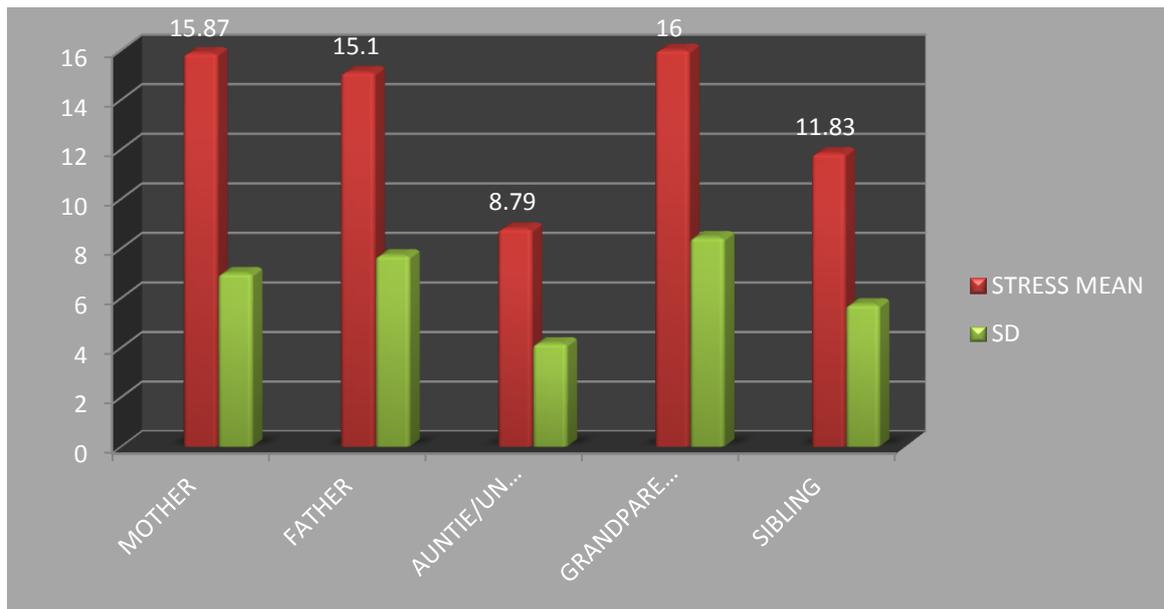
Figure 2 Distribution of participants in low and high stress groups in percentage



Source: Field data (2015)

Similarly, the findings in figure 3 highlight the type of relationship a caregiver had with the child and their mean stress scores on the Psychological Stress Measure (PSM-9). The results in figure 3 indicate that on average, stress scores for mothers, fathers and grandfathers were high and comparable. The others had scored lowly on the PSM-9 scale.

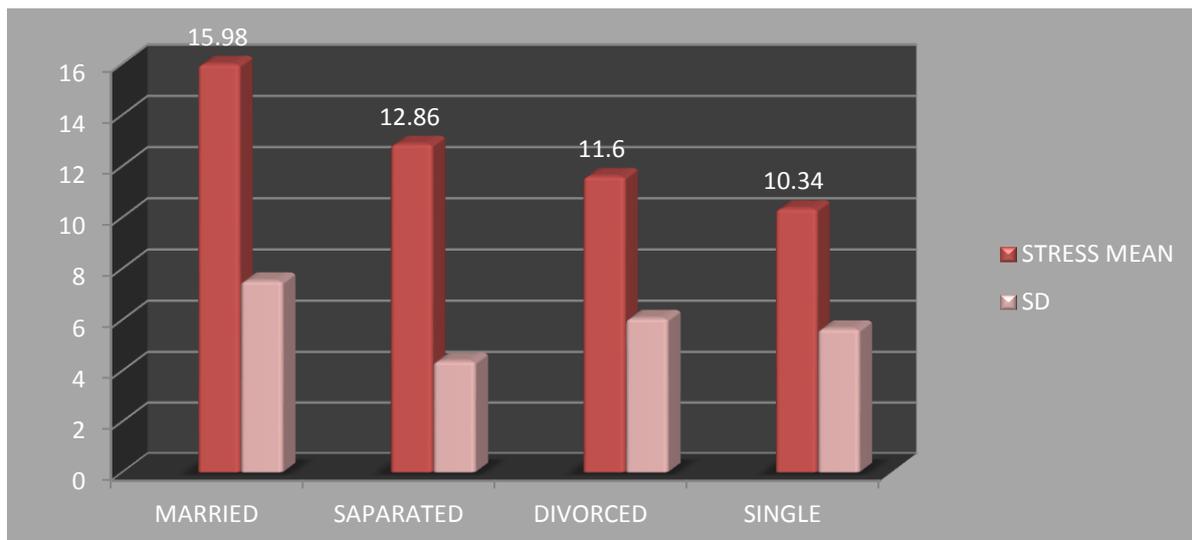
Figure 3 Caregiver's relationship to child and their mean stress scores



Source: Field data (2015)

Furthermore, when compared based on marital status, results in figure 4 indicate that married caregivers had the highest scores of stress level, while caregivers who were separated scored mild levels of stress with the rest scoring lower levels of stress related to the care of a child with an intellectual disability.

Figure 4 Caregiver's marital status and mean stress scores



Source: Field data (2015)

4.4. Correlations between participants' independent variables and stress score

Using Spearman's correlation analysis, relationships between variables used in the multiple regression analysis were investigated and these are summarized in Table 2. The dependent variable of caregiver's stress correlated significantly with all seven independent variables (relationship of respondent to child, age of Respondent, respondent's marital status, number of people earning an income within household, time involved in acquisition of information about child's disability, coping by concentrating efforts on to the problem and coping by thinking hard about steps to take). Results of the analysis show moderate positive correlations between caregiver stress and the variables of respondent's relationship with the child ($r_s = 0.41$, $n = 135$, $p < 0.001$), Respondent's marital status ($r_s = 0.38$, $n = 134$, $p < 0.001$), and coping mechanism of thinking very hard about a stressful situation ($r_s = 0.34$, $n = 132$, $p < 0.01$).

In addition, statistically significant correlations were observed between caregiver stress level and respondent's age ($r_s = 0.29$, $n = 133$, $p < 0.01$), caregiver stress level and time involved in acquisition of information about child's disability ($r_s = 0.26$, $n = 134$, $p < 0.01$), caregiver stress level and coping by concentrating efforts on to the problem ($r_s = 0.28$, $n = 135$, $p < 0.01$). However, these relationships were weak. Conversely, a weak inversely correlated relationship was found between caregiver's stress and number of people earning an income within the household ($r_s = -0.26$, $n = 135$, $p < 0.01$).

Furthermore, caregiver stress level and respondent's age correlated significantly ($r_s = 0.29$, $n = 133$, $p < 0.01$). Correlation analysis further revealed that respondent's age was also strongly and positively correlated with respondent's marital status ($r_s = 0.74$, $n = 135$, $p < 0.001$). This implies that married caregivers were more likely to be older in age than others. Likewise, the independent variable of respondent's age showed a statistically significant but inverse moderate correlation with number of people earning an income within the household ($r_s = -0.34$, $n = 134$, $p < 0.01$). Meaning that as caregiver's age increased; the smaller the number of people earning an income within the household was likely to be. Respondent's age did not show any statistically significant correlation with the other variable in the analysis.

Table two also shows that respondent's marital status which was positively correlated to the outcome variable of caregiver stress level ($r_s = 0.38$, $n = 134$, $p < 0.001$), was also inversely

correlated to number of people earning an income within the household ($r_s = -0.27$, $n = 135$, $p < 0.01$). Number of people earning an income within the household which was significant and inversely correlated with the outcome variable of caregiver stress level ($r_s = -0.32$, $n = 135$, $p < 0.01$) was found to be positively correlated with time involved in acquisition of information about the child's disability ($r_s = 0.19$, $n = 134$, $p < 0.05$), but this relationship was weak. Other variables did not significantly correlate with number of people earning an income within the household. Time involved in acquisition of information about the child's disability was significant and positively correlated with the independent variable of coping by way of thinking hard about steps to take ($r_s = 0.22$, $n = 135$, $p < 0.05$). This relationship though significant was weak.

Table 2 correlations of variables in the Analysis (n = 135)

	1	2	3	4	5	6	7	8
(Constant)	1							
Relationship to child	.411***	1						
Age of Respondent	.297**	.510***	1					
Respondent's marital status	.380***	.575***	.737***	1				
Number of other people earning an income within household	-.255*	-.317**	-.338**	-.277**	1			
Time involved in acquisition of information about child's disability	.262**	.130	.104	.110	.194*	1		
Copes by concentrating efforts on to the problem	.275**	.098	.221*	.123	-.034	.066	1	
Copes by thinking hard about steps to take	.338**	.188*	0.055	0.148	-0.022	.224*	.286**	1

* $p < .05$, ** $p < .01$, *** $p < .001$ (2-tailed)

4.5. Predictor variables of caregiver stress

A standard multiple regression analysis was conducted to determine if independent variables of respondent's relationship with the child, respondent's age, respondent's marital status, number of people earning an income within household, time involved in acquisition of information about child's disability, coping by concentrating efforts on to the problem, coping through help and advice from other people, and coping by thinking hard about steps to take predicted caregiver stress.

Using the enter method it was found that the prediction model was statistically significant, ($F(9, 125) = 6.389, p < 0.001$), and accounted for approximately 33% of the variance in the value of caregiver stress score ($R\text{-squared} = .39, R\text{-Adjusted} = .33$). R-squared indicates the proportion of the variance in the dependent variable that is explained by the combined impact of the independent variables.

Caregiver stress was primarily significantly correlated with type of relationship of respondent to child, respondent's age, respondent's marital status, number of people earning an income within household, time involved in acquisition of information about child's disability, coping by concentrating efforts on to the problem, coping through help and advice from other people, and coping by thinking hard about steps to take (see table 2). The raw and standardized regression coefficients of the predictors together with their squared semi partial correlations and their t values are shown in table 3.

Using the standard coefficients to compare the seven significant independent variables, the order of influence on caregiver stress is observed as: (.24), time involved in acquisition of information about child's disability received, (.21), number of people earning an income within household, (.17), mechanism of coping by concentrating efforts on to the problem and the rest having low weights which were not statistically significant.

With the sizeable correlations between predictor variables and dependent variable caregiver stress, the unique variance significantly explained by each of the variable indexed by the squared semi partial correlations in table 3 was relatively low and follow this order of effect on stress: (.05), time involved in acquisition of information about child's disability, (.03), coping by concentrating efforts on to the problem (.02), coping by thinking hard about steps to take. The unique variance accounted for by the other variables in caregiver stress level were not statistically significant.

Table 3 Standard Regression Analysis Results

Variable	b	SE-b	Beta	T	Sr Sq	Sig
(Constant)	9.089	3.898		2.332		0.022
Relationship to child	0.822	0.49	0.189	1.678	0.019	0.097
Age of Respondent	- 0.028	0.063	-0.054	-0.440	0.001	0.661
Respondent's marital status	0.557	0.643	0.115	0.865	0.005	0.389
Number of other people earning an income within household	-1.947	0.927	-0.21	-2.101*	0.029	0.038
Time involved in acquisition of information about child's disability	1.294	0.487	0.238	2.656**	0.048	0.009
Copes by concentrating efforts on to the problem	1.216	0.617	0.173	1.972*	0.026	0.050
Copies by thinking hard about steps to take	0.964	0.622	0.14	1.55	0.016	0.125

Note. The dependent variable was caregiver stress. R-squared = .39, R- Adjusted = .33. Sr-squared is the semi-partial correlation. *p < .05, **p < .01.

4.6. Differences between high and low caregiver stress scores

A median split was conducted to divide the sample into two groups according to level of caregiver stress (low vs high). The difference in the two groups' stress scores was compared across all independent variables using an independent samples t-test. Results of the analysis are summarized in table 4 where means of scores on the Likert scales and actual interval data for each individual independent variable in the group with low stress scores and those in the group with high stress scores are compared.

The findings in table 4 show significant differences between the two groups (high and low) for the variables of relationship of respondent to child, age of Respondent, respondent's marital status, number of people earning an income within household, and coping by concentrating efforts on to the problem. Though differences are also seen between the two groups for the rest of the other variables, the differences were not statistically significant.

The findings shown in table 4 indicate that for caregivers in the high stress group, their close relationship with the child appear to negatively affect stress. The same can be said for married caregivers as compared to those who were not married. In addition, caregivers from households with limited number of people contributing to family income seem to have experienced more stress. Lastly, adoption of coping strategy of concentrating efforts on to the problem appears to have led to negative effects of stress.

Table 4 Comparison of participants across independent variables in low and high stress groups

	Low Stress group		High stress group		t	Sig.
	Mean	SD	Mean	SD		
Relationship to child	2.75	1.64	3.69	1.43	-3.08**	0.003
Age of respondent	32.45	12.87	37.20	13.72	-1.78	0.760
Respondent's marital status	2.27	1.43	3.02	1.37	-2.66**	0.009
Number of other people earning an income within household	1.41	0.738	1.02	0.72	2.70**	0.008
Time involved in acquisition of information about child's disability	2.84	1.27	3.20	1.29	-1.41	0.161
Copes by concentrating efforts on the stressful situation	2.78	1.10	3.36	0.74	-3.10**	0.004
Copes by thinking hard about steps to take	2.64	1.01	3.13	0.97	0.37	0.014

*p < 0.05, **p < 0.01

4.7. Mediating factors of participants' independent variables and stress

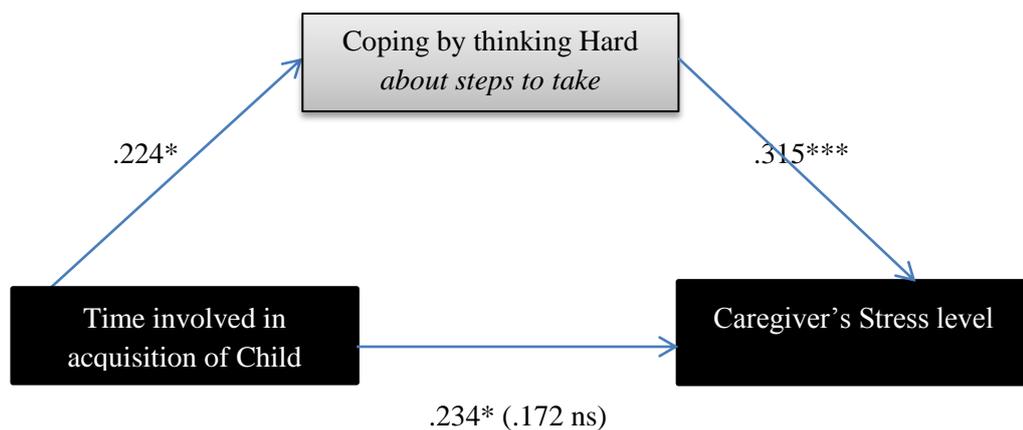
Hierarchical regression procedures were used to examine the mediating effect of coping mechanism of thinking hard about steps to take when faced with a difficulty situation on the relationship between caregiver's time involved in acquisition of information about the child's disability and the experience of stress. In line with procedures by Baron and Kenny (1986), for the first analysis, the score for time involved in acquisition of information about the child's disability was entered first into the regression as a predictor variable. In order to test for mediation effect, coping mechanism of thinking hard about steps to take when faced with a difficulty situation was entered as a second step into the regression.

Figure 5 shows that twenty three percent (23%) of the variance in level of caregiver stress is significantly predicated by time involved in acquisition of information about the child's disability. It also shows that time involved in acquisition of information about the child's disability significantly explains twenty two percent (22%) of the variance in coping mechanism of thinking hard about steps to take when faced with a difficulty situation. Further, results of the analysis show that the coping mechanism of thinking hard about steps

to take when faced with a difficulty situation make unique and statistically significant contribution of approximately thirty two percent (32%) towards the variance in caregiver’s level of stress.

The inclusion of a mediator variable (coping mechanism of thinking hard about steps to take when faced with a difficulty situation) to the analysis resulted in a non-statistically significant increment in the variance of around two percent (2%) in the regression model. The variance accounted for by the mediator variable of coping mechanism of thinking hard about steps to take when faced with a difficulty situation in caregiver’s level of stress significantly reduced to approximately twenty eight percent (28%) and the one accounted for by the predictor variable of time involved in acquisition of information about the child’s disability in the caregiver’s level of stress reduced to seventeen percent (17%) and was statistically non-significant. This indicates that there is evidence to suggest that coping mechanism of thinking hard about steps to take when faced with a difficulty situation had a mediating effect on the relationship between predictor variable of time involved in acquisition of information about the child’s disability and caregiver’s level of stress. The regression model as a whole was statistically significant ($F [2, 132] = 7.062, p < 0.001$).

Figure 5 mediation effect of coping mechanism of thinking hard about steps to take.



Source: Field data (2015)

Note: *= $p < .05$; **= $p < .01$; *** = $p < .001$

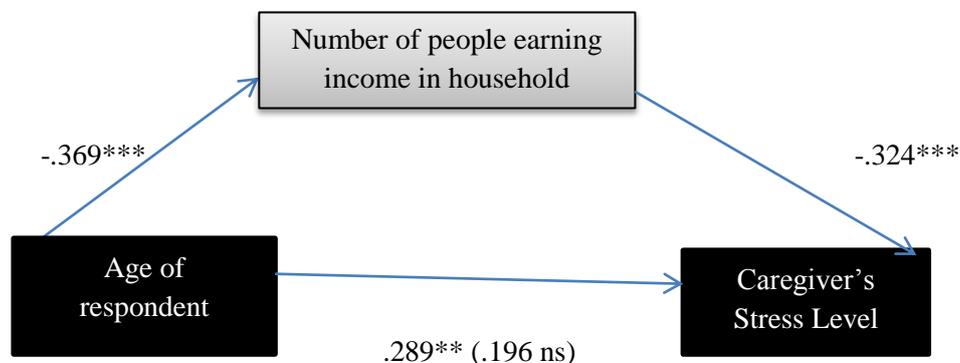
Figure 5 standardized regression coefficients for the relationship between Time involved in acquisition of information about the child’s disability and level of caregiver’s stress as mediated by coping by thinking hard about steps to take. The standardized regression coefficient between time involved in acquisition of information about the child’s disability and level of caregiver’s stress, controlling for coping by thinking hard about steps to take is in parentheses.

A separate hierarchical regression was also conducted to examine the mediating effect of number of people earning an income in a household on the relationship between respondent's age and the experience of stress. Respondent's age was entered first as a predictor variable while number of people earning an income in a household was entered as the second step.

Summarised regression analysis results in figure 6 show that age of respondent make a unique and statistically significant contribution to caregiver's stress level of around twenty nine percent (29%) and approximately thirty seven percent (37%) in the variable of number of people earning income in the household. Furthermore, results show that the variable of number of people earning income in the household explains thirty two percent (32%) of the variance in caregiver's level of stress.

Inclusion of a mediator variable (number of people earning income in the household) to the analysis showed that the whole model was statistically significant ($F [2, 133] = 7.787, p < .001$). The variance explained in the caregiver's level of stress by number of people earning income in the household significantly reduced to twenty five percent (25%) and that explained by age of respondent also reduced to around twenty percent (20%), but not statistically significant. This indicates that there was evidence to also suggest that number of people earning income in the household had a mediation effect on the relationship between predictor variable age and caregiver's level of stress.

Figure 6 mediation effect of number of people earning income in a household.



Source: Field data (2015)

Note: *= $p < .05$; **= $p < .01$; *** = $p < .001$

Figure 6 standardized regression coefficients for the relationship between respondent's age and level of caregiver's stress as mediated by number of people earning income in the household. The standardized regression coefficient between respondent's age and level of caregiver's stress controlling for number of people earning income in the household is in parentheses.

4.8 Moderating factors of participants' stress

Evidence of potentially moderating effects of coping by concentrating efforts on problem solving and coping by thinking hard about steps to take when faced with a problem on relationship between predictor variable time involved in acquisition of information about the child's disability and outcome variable caregiver's level of stress were examined. Confirmation of moderating effects occurred if the interaction term explained a significant amount of variance up and above that predicted by the main effects of the two contributing variables (Baron and Kenny, 1986). However, there was no evidence to suggest that any one of the potential moderator variables had significantly accounted for moderation effect between the relationship of predictor variable time involved in acquisition of information about the child's disability and outcome variable caregiver's level of stress.

Baron and Kenny (1986), define a moderator as a qualitative or quantitative variable that has influence on the direction and/or strength of the relationship between a predictor (independent) variable and criterion (dependent) variable. On the other hand, Baron and Kenny (1986) define a mediator as a variable that accounts for the relationship between the predictor and the criterion variables.

CHAPTER FIVE

DISCUSSION

5.1. Introduction

This chapter discusses the findings of the present study and how they relate to theory and other study findings. The findings are discussed according to the objectives and research questions of the study. In addition, the chapter discusses important findings as well as limitations of the study and the implications in relation to further research and interventions for behavioral and health care services.

5.2. Caregivers' stress levels

This study investigated factors that impacted upon the levels of caregiver stress among family members of school-going children with intellectual disabilities. Results of this study confirmed that comparably, more caregivers of children with intellectual disabilities experienced increased stress levels related to the day to day care of such a child (see figure 2). This finding is consistent with a more recent study by Miodrag and Hodapp (2010) which reported that greater parenting demands and amount of time spent with a child with an intellectual disability increased stress levels and poorer physical and psychological wellbeing of their caregivers than those of non-disabled children.

In addition, the current study revealed that on average, it seems mothers; fathers and grandparents had experienced similar patterns of stress levels related to the day to day care for a child with an intellectual disability. This finding is in line with other recent studies which have shown that the level of stress reported by mothers and fathers of children who have intellectual disabilities is very similar (Cuskelly et al., 2004; Keller & Honig, 2004). This particular finding may be linked to similar patterns in amount of time involved by both mothers and fathers in the day to day care of the child and coping mechanisms used when faced with a problem situation. On the contrary, however, other studies have suggested that the association between caring for a child with intellectual disability and experience of stress is much less pronounced among fathers in comparison to their spouses (Emerson and Hatton, 2010; MacDonald and Hastings, 2010). This finding in the current study is an interesting one because it is generally expected that in an African context, more

responsibility of caring for children is taken up by mothers as compared to fathers and therefore the burden of care in the case of families of children with intellectual disability should be more on the part of mothers. It is therefore, possible to suggest that fathers of children with intellectual disabilities also played a major role in child care within the family setup. This contradiction in findings highlights the need for further research to compare contextual factors related to child care and stress level across gender.

Furthermore, very limited information is available regarding grandparents as caregivers and their experience of stress related to caring for a child with an intellectual disability. In this study, it came out that though on average the stress scores for grandparents, mothers and fathers were comparable, grandparents scored the highest on the PSM-9 scale. Results of the present study have also demonstrated that the older a caregiver was, the smaller the base of their household income was likely to be. Economic challenges coupled with the increased burden of caring for a child with an intellectual disability may have led to the higher stress scores observed among grandparents who participated in this study. The results of this study are similar to findings of a study concerning grandparents as caregivers, where among other predictors of stress, having a lower family income, having lower levels of social support, and not receiving welfare support were noted (Burnette, 2000; Mills et al., 2005).

Nevertheless, interpretation of results on grandparents in this study should be considered with caution due to the smaller number of grandparents represented in the sample. Future research should consider looking at a much larger sample size representing grandparents in order to further establish the impact of caring for a child with intellectual disability on their levels of stress.

In addition and contrary to expectations, results of this study have demonstrated that family size was not significantly associated with caregiver stress. It is generally assumed that family size may influence caregiver stress either positively or negatively. In this case, common expectations are that a large number of children being cared for within the family set up could be a factor contributing to increased stress on the part of the caregiver. On the other hand, it is also common to expect reduced caregiver stress in families which have a bigger number of caregivers each contributing towards the day to day care of a child with intellectual disability. However, this was not the case in the current study.

5.3. Caregiver's social economic status

The current study has confirmed that caregiver's socio-economic status was linked to stress level. Caregivers who lived in households with limited number of people contributing to family income were associated with a moderate amount of increased stress levels. Number of people contributing to household income was also inversely related to age of caregivers, indicating that older caregivers were more likely to have experienced limited amount of income which when coupled with the burden of caring for the disabled child increased the experience of stress. This finding is in line with other recent studies that have suggested that caregivers' experience of stress may be largely linked to severe poverty conditions in which they live (Emerson, 2012; Emerson and Hatton, 2010; Olsson, Larsman and Hwang, 2008).

In the present study, it appears that though the relationship that existed between caregiving task of acquiring information about the child's disability and number of people earning an income within the household was weak, the relationship was significant to indicate that the stress experienced by caregivers through this particular task could also have been compounded by limited financial resources at household level taking into account the age of the caregiver. Moreover, there was evidence in this study to suggest that number of people earning income in the household had a mediation effect on the relationship between predictor variable age and output variable of caregiver's stress. In Zambia, it is common to find older family members (grandparents and others) taking over the responsibility of caring for orphaned children amidst socio-economic hardships which when combined with the burden of caring for a child with an intellectual disability may result in increased experience of stress.

5.4. Marital status and caregiver's stress

Results of this study have also shown that married caregivers were more stressed than those who were single and divorced. In addition, marriage was inversely associated with the number of people contributing to the household income. This entails that married caregivers were more likely to have lived in families with limited financial resources and as such faced with a huge challenge of caring for their children with intellectual disabilities. Another study conducted in Kenya reported similar results on stress levels indicating that married caregivers had a statistically significant higher risk for depression related to caregiving stress (Mbugua, Kuria and Ndeti, 2011).

In an African setting, it is believed that having a child with a disability may be associated with superstition and accusation of a spouse as having been responsible for such a disability which in turn increases the risk for stigma and increased stress among married caregivers (Mbugua, Kuria and Ndeti, 2011). Similarly, studies conducted in Uganda and Kenya show a perception that disability is the work of evil spirits or a curse or God's punishment resulting in children with disabilities being hidden (Gona et al., 2011). Thus, stigma could also have contributed to increased stress among married caregivers.

Though the aspect of quality of relationship in marriage was not examined in this study, increased stress levels among married caregivers could also be explained by examining the quality of relationship in marriage which may be moderating the relationship of being married and experience of stress. Recent research has found that having a good relationship with an intimate partner is associated with decreases in parenting stress and that married parents in a chaotic and poor quality relationship are likely to experience increased levels of stress associated with parenting (Mulsow et al., 2002).

5.5. Caregiver's relationship with the child and stress

Caregiver's relationship with the intellectually disabled child was significantly correlated to caregiver's level of stress. In addition, a statistically significant difference existed between caregivers who experienced increased stress and those with low stress levels when compared across the variable of caregiver's relationship to the child. How close the relationship is between caregiver and care recipient appears to be important also. This was also demonstrated in another study conducted on Victorian Caregivers, where parents and spouses tended to be more positively involved in caregiving than did other family members (Schofield et al., 1998 as cited in Savage and Bailey, 2004). Intimacy and love in the relationship between caregiver and care recipient have been associated with lower levels of minor psychiatric symptoms and caregiving stress (Braithwaite, 2000). Further research on relatedness of caregivers to children with intellectual disability needs to be conducted to explore more on factors involved.

5.6. Care giving tasks and stress

One of the questions answered by this study is the extent to which caregiving tasks were associated with the outcome variable of caregiver's stress. Results of this study confirmed that caregiving demand on time involved in acquisition of information about the child's

disability was the most significant predictor of caregiver's stress level. This accounted for the largest percentage of the variance in caregiver's stress and was positively correlated to stress. Indicating that the more time spent by caregivers in the caregiving task of acquisition of information about the child's disability, the more stress they experienced. It is therefore, important for practitioners in health and behavioural sciences to consider supporting caregivers of children with intellectual disabilities with easy access to information about the child's disability as a way of empowering them in their continued role of caregiving.

This finding in the current study contradicts theory which suggests that seeking out information on causal attribution for situations of stress or for aversive experiences may help individuals to gain or re-establish a sense of control (Taylor, Lichtman and Wood, 1984). Furthermore, it is noted that searching to understand more about the child with an intellectual disability and seeking help from numerous sources has been shown to be an aspect of positive coping and adaptation skills (Summers, Behr, and Turnbull 1989).

Nevertheless, caregivers in this study may not have attained yet the ability to cope with stress and crisis which comes about when families eventually re-establish balance and accept their family member's disability, while still promoting that member's positive development. In a study conducted in Tanzania on family perceptions of intellectual disability, caregivers who coped well had come to accept their family member's disability and continued to provide support towards the development of the disabled family member (Aldersey, 2012).

On the other hand, the finding in the present study concerning time involved in acquisition of information about the child's disability and stress is in agreement with research on parental stress that has noted that providing care for a family member with an intellectual disability often requires additional time and resources while trying to coordinate the family member's unique needs at the same time attempting to balance competing family needs (Murphy, Caplin, and Young 2006; Silver, Westbrook, and Stein 1998). Caregiving and the time involved in carrying out related tasks among families of children with intellectual disability, then, has been seen to contribute to caregiver's stress and to lower caregivers' sense of psychological wellbeing (Cramm and Nieboer, 2011).

In any case, knowledge of the ways in which families experience stress (in this case through increased amount of time involved in acquisition of information about the child's disability)

can inform interventions that utilize identified needs and family strengths to create appropriate support. For example, studies have shown that formal and informal support can act as a buffer, with parents reporting lower stress, anxiety and depression when they perceived greater support (Blacher, Neece, and Paczkowski 2005).

5.7. Mechanisms of coping and caregiver's stress

Coping mechanism of concentrating efforts on to the problem though on a minimal scale has been established in this study as a significant predictor of increased caregiver's stress. The present study also presented evidence to suggest that coping mechanism of thinking hard about steps to take when faced with a difficulty situation had a mediating effect on the predictor variable of time involved in acquisition of information about the child's disability and its association with caregiver's level of stress. This means that the use of coping mechanism of thinking hard about steps to take explains part of the increase in stress level for caregivers who spent most of their time trying to acquire valuable information about their child's disability.

However, these two findings are contrary to expectations in that going by Carver (1997)'s description, coping by concentrating efforts onto the problem is theoretically associated with active coping, while thinking hard about steps to take is categorized under planning which should have made the caregivers' efforts more effective accompanied with lowered stress levels. Other factors not investigated in this case could have played a role in increasing caregiver's stress levels when the two types of coping mechanisms were frequently utilized. For example, studies have shown that caregivers who adapt and cope effectively are those who are optimistic, and use positive reframing of thoughts and attitudes about their disabled children and their own circumstances (Baker et al., 2005; Hastings and Brown, 2002; MacDonald et al., 2010). This means that despite the use of active coping mechanisms and planning, caregivers of children with intellectual disabilities in this study may not have possessed certain personal characteristics that make it more effective to cope with the burden of caring for the disabled child in the family set up hence the experience of increased stress.

5.8. Theoretical significance

The double ABC-X family crisis model which attempts to provide an explanation on how some families are faced with a crisis while others manage to cope well when faced with

stressful situations fits in well with some of the findings of this study. In line with McCubbin and Patterson (1983) Double ABC-X model, a number of stressors (“Aa” factor) may contribute to the build-up effect within the family when faced with a crisis.

In this regard, the present study has demonstrated that in comparison, more caregivers of children with intellectual disabilities experienced increased stress levels related to the day to day care of such a child than those with low stress levels. This implies that having a child with intellectual disability itself may be an initial stressor which when compounded by other challenges within the family set-up increases the burden of caring for such a child and may lead to a crisis if not well managed. Such challenges could be in the form of economic hardships within the family set-up or difficulties related to old age as observed from the results of this study.

Using the double ABC-X family crisis model, having a child with an intellectual disability accompanied with old age and economic hardships as indicated in the results of this study will interact with the family coping resources (“Bb” factor) such as existing and new coping mechanisms and support from others in order to meet the care demands on a daily basis. Contrary to expectations however, the results of this study indicated that mechanisms of coping used by caregivers that are categorized under active coping and planning appeared to be associated with increased caregiver stress levels. This means that despite the use of active coping mechanisms and coping by planning, other factors such as personal and family characteristics (“Cc” factor)), that make it more likely to view the stressful situation from a positive perspective may have been lacking or ineffective hence the increase in stress levels.

The implication of this theory is that having a clear understanding of how factors interact within the family set-up and the outside environment can aid behavioural and health practitioners to come up with interventions that will strengthen coping abilities of caregivers of children with intellectual disabilities even when faced with a multitude of challenges which may easily lead to stress.

5.9. Limitations of the study

Overall, this study has brought out very important findings regarding caregivers’ experience of stress among family members of children with intellectual disabilities. However, it is also

necessary to note that the study did not go without some limitations. Initially, one of the study objectives was to determine the extent to which child's level of disability predicted caregiver's stress. However, that particular aspect could not be taken into account because some official records for individual children (including records on their levels of disability) at the schools were not complete and in some cases not available. Given more time to carry out this research, other standardized tools could have been used to carry out assessments of the children's disability levels during the process of data collection. Furthermore, this study was primarily limited by its sample size involving only caregivers of school-going children with intellectual disabilities in Lusaka urban. As such, caution should be exercised when generalizing the findings. A larger sample size with more diversity would have benefitted the results of this study. Inclusion of caregivers of children with intellectual disabilities not enrolled at any school could have diversified experiences represented in the sample.

CHAPTER SIX

CONCLUSION AND RECOMMENDATIONS

6.1. Conclusion

From the discussion of the findings in this study, it can be concluded that slightly more caregivers of school-going children with intellectual disabilities experienced increased stress as compared to those with low levels of stress. In addition, the current study revealed interesting results that seem to differ from what other studies have reported on in terms of variations between mothers and fathers. This study was able to demonstrate that similarities in terms of experience of increased stress may have existed among grandmothers, mothers and fathers. Furthermore, previous studies had not focused much on the experience of grandparents, but this study did bring out some interesting results showing that grandparents, though limited in sample size had experienced increased stress similar to mothers and fathers of children with intellectual disabilities. Age, marital status and relationship of the caregiver to the child with an intellectual disability were positively associated with stress. Conversely, number of people contributing to family income was inversely associated with stress. In general, this study was also able to confirm that caregiver's experience of increased stress was predicted to a larger extent by increased amount of time caregivers spent on acquiring information pertaining to their child's disability, followed by a limitation in the number of people contributing to family or household income and lastly by the frequent use of active coping mechanism of concentrating efforts to resolve a problem situation. Finally, while this study examined several important variables which impact upon caregiver's stress among family members of children with intellectual disabilities, there are likely other variables which have the potential to contribute to caregiver's stress within such families in Zambia. These may include cultural factors, child's level of disability and parenting knowledge which are beyond the scope of this current study. This study has added to existing body of knowledge in research on this topic in that it has systematically addressed a number of key variables related to caregiver's stress among family members of school-going children with intellectual disabilities.

6.2. Recommendations

Based upon the above discussion of caregivers in families of school-going children with intellectual disabilities, three immediate implications for future practice and research are apparent.

1. Firstly, healthcare providers and other practitioners should support and encourage families to have easy access to information about their child's disability. Supporting this search for meaning may build upon and advance family strengths in coping with stress and crisis.
2. Current psychosocial, educational and health services need to incorporate training strategies that aim at reducing caregiver's stress by enhancing social support and use of coping strategies that promote positive appraisal of the caregiving role.
3. Experiences of families with children spending part of their time at school and those with children spending much of their time with family members at home may not be similar. As such, further research on this topic should consider a more diverse larger sample which should include caregivers of children with intellectual disabilities both enrolled in school and those not enrolled in any school.

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Appendix A: Ethical clearance



THE UNIVERSITY OF ZAMBIA
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E-mail: drgs@unza.zm

IRB 00006464

IORG: 000376

P O BOX 32379

LUSAKA, ZAMBIA

16th January 2015

Mr. Kanyanta Kanyanta
C/O School of Humanities and Social Sciences
Department of Psychology
University of Zambia
P.O Box 32379
Lusaka
ZAMBIA

Dear Mr. Kanyanta,

Re: EXEMPTION FROM FULL ETHICAL CLEARANCE

With reference to your research proposal entitled:

Predictors of caregiver's stress among family members of school-going children with intellectual disabilities in Lusaka urban.

As your research project does not contain any ethical concerns, you are hereby given an exemption from full clearance to proceed with your research.

ACTION:	APPROVED
DECISION DATE:	16 th January, 2015
EXPIRATION DATE:	15 th January, 2016

Please note that you are expected to submit to the Secretariat a Progress Report and a copy of the full report on completion of the project.

Finally, and more importantly, take note that notwithstanding ethical clearance given by the HSSREC, you must also obtain authority from the Permanent Secretary Ministry of Health, before conducting your research. The address is: Permanent Secretary, Ministry of Health, Ndeke House, P.O Box 30205, Lusaka. [Tel:260-211-253040/5](tel:260-211-253040/5); Fax +260-211-253344.


Dr. Augustus Kapungwe
CHAIRPERSON, HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE

cc: Director, Directorate of Research and Graduate Studies
Assistant Director, Directorate of Research and Graduate Studies
Assistant Registrar (Research), Directorate of Research and Graduate Studies

All Correspondence should be addressed to the
Permanent Secretary
Telephone: +260 211 253040/5
Fax: +260 211 253344



REPUBLIC OF ZAMBIA
MINISTRY OF HEALTH

In reply please quote:

MH/101/17/6

No.....

NDEKE HOUSE
P. O. BOX 30205
LUSAKA

9th February, 2015

Kanyata Kanyata
C/O School of Humanities and Social Sciences
Department of Psychology
P.O. Box 32379
LUSAKA

Dear Kanyata Kanyata,

Re: Request for Authority to Conduct Research

The Ministry of Health is in receipt of your request for authority to conduct research titled "Predictors of caregiver's stress among family members of school-going children with intellectual disabilities in Lusaka Urban." I wish to inform you that following submission of your request to my Ministry, our review of the same and in view of the ethical clearance, my Ministry has granted you authority to carry out the above mentioned exercise on condition that:

1. The relevant Provincial and District Medical Officers where the study is being conducted are fully appraised;
2. Progress updates are provided to MoH quarterly from the date of commencement of the study;
3. The final study report is cleared by the MoH before any publication or dissemination within or outside the country;
4. After clearance for publication or dissemination by the MoH, the final study report is shared with all relevant Provincial and District Directors of Health where the study was being conducted, and all key respondents.

Yours sincerely,

Dr. D. M. Chikamata
Permanent Secretary

Appendix C1: PARTICIPANT

INFORMATION SHEET (English version)



THE UNIVERSITY OF ZAMBIA

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HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE

PARTICIPANT INFORMATION SHEET

TITLE OF RESEARCH:

PREDICTORS OF CAREGIVER'S STRESS AMONG FAMILY MEMBERS OF SCHOOL-GOING CHILDREN WITH INTELLECTUAL DISABILITIES IN LUSAKA URBAN.

PURPOSE OF THE STUDY:

You are being asked to participate in a research study examining factors that predict care giving stress among family members of children with intellectual disabilities. You are being asked to participate because you have been identified as a caregiver of a child with an Intellectual disability. This study is being conducted as partial fulfillment of the requirements for the award of a Master's degree in Child and adolescent psychology.

DESCRIPTION OF THE STUDY AND YOUR INVOLVEMENT:

If you decide to participate in this study you will be asked to complete a total of five questionnaires. Each questionnaire measures a different variable associated with the study. The estimated total time to complete all the questionnaires provided is 90 minutes.

CONFIDENTIALITY:

All information collected about you during the course of this study will be kept without your names or identity, except for a code that will only be known by you. Information collected from you will only be used for the purpose of this study as such will only be accessed by those directly involved in this

study. Such information will be kept under lock and key in a special file with the code on it and no names will appear anywhere

VOLUNTARY PARTICIPATION AND WITHDRAWAL:

Taking part in this study is voluntary. You are free to not answer any questions or withdraw at any time even after data has been collected. Your decision will not change any present or future relationships with the researcher

RISKS AND BENEFITS:

There are no known risks at this stage for participation in this study, but just in case some of the questions trigger some emotional disturbance, the researcher will assure the respondent and give them information on available professional help to this effect.

There are no direct benefits from participating in this study at this stage, but information from this study may benefit you and other people now or in the future.

CONTACTS FOR QUESTIONS (Names, addresses and phone numbers of the following):

1. **Principal Investigator: Kanyata Kanyata**
2. **Chairperson, Humanities and Social Sciences, Research Ethics Committee, University of Zambia.**
3. **The Director, Directorate of Research and Graduate Studies.**

Appendix C2: PARTICIPANT INFORMATION SHEET

(CHINYANJA VERSION)

UNZAREC FORM 1a



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HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE

PARTICIPANT INFORMATION SHEET

(CHINYANJA VERSION)

MUTU WA KAFUKU-FUKU:

Predictors of caregiver's stress among family members of school-going children with intellectual disabilities in Lusaka urban.

CHOLINGA CHAKE

cholinga chake chakafuku-fuku uno ndikufuna kudziwa zinthu zimene zisonyedza kuti anthu mumabanja omwe akupeleka chisamalilo ku mwana olemala kapena ochepela m'nzeli ali ndi bvuto mumaganizo awo. Kafuku-fuku uyu ukuchitidwa monga mbali imodzi yondiyeneretsa kuti ndi tenge Digiri (Degree) ya Master of Arts mu mapunzilo ya child and Adolescent psychology.

ZINTHU ZINA ZOYENERA KUDZIWA PA NKHANI YA KAFUKU- FUKU UYU

Ine ndine mukulu ochitisa kafuku-fuku uyu ndiponso mukafuku-fuku uno tizasewenzesa mafunso ena olembedwa pa pepala muzigawo zisanu kuti tinvele za anthu mumabanja omwe akupeleka chisamalilo ku mwana olemara kapena ochepela m'nzelu.

MBALI YA CHISINSI (CONFIDENTIALITY)

Dziwani kuti nkhani iliyonse imene muzatiuza kapena imene tizatenga kwa inu mukafuku-fuku uyu idzasungidwa kopanda kulemba dzina lanu, chithunzi chanu kapena chizindikilo china chili chonse cha inu kupatulapo nambala ya chinsinsi (Code) yomwe lizadziwidwa ndi inu chabe. Ndiponso nkhani imene iyi izasungidwa bwino bwino mu fayilo yanu kopanda kulora anthu ena amene sathengako mbali mukafuku-fuku

UFULU WOTENGAMO MBALI MU KAFUKU-FUKU UYU KAPENA KUSIYA KUTERO (VOLUNTARY PARTICIPATION AND WITHDRAWAL)

Kutengamo mbali mukafuku-fuku uyu ndi kwa ulele (ufulu) sitipatikiza. Ndinu omasuka kusayankha funso lililonse kapena kusiya kutengamo mbali panthawi iliyonse ngati mwafuna kutero. Chosankha chanu sichidza sintha m'gwirizano/ubale wanu ndi amene aku fufuza nthawi ino kapena mutsogolo.

MAPINDU NDI ZO-OPETSA (RISKS AND BENEFITS)

Monga otengamo mbali mukafuku-fuku uyu siuzapezamo pindu looneka kweni kweni pakali pano, koma uthenga uli mukafuku-fuku uyu uzapindulitsa inu komanso anzanu/anthu ena panopa kapena mutsogolo.

Pakali pano palibe zoopsya zili zonse kapena chodesa nkhwana ngati mwatenga mbali mukafuku-fuku uno, koma ngathi mafunso ena azaletsa bvuto lililolonse mumaganizo ya munthu akuthengamo mbali mukafuku-fuku uno, tizamudziwisa kumene angathe kupeza thandidzo bwino bwino.

MAYINA NDI MANAMBARA YA ANTHU OPELEKHAKO MAFUNSO

- 1. Principal Investigator: Kanyata Kanyata, P.O. Box 33991, Lusaka. Mobile#: 0979859288**
- 2. Chairperson, Humanities and Social Sciences, Research Ethics Committee, University of Zambia
P.O. Box 32379, Lusaka**
- 3. The Director, Directorate of Research and Graduate Studies, P.O. Box 32379, Lusaka
Phone #: +260-211-290 258**



UNZAREC FORM 1b

THE UNIVERSITY OF ZAMBIA

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HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE

CONSENT FORM

(Translated into vernacular if necessary)

TITLE OF RESEARCH: Predictors of caregiver stress among family members of school-going children with intellectual disabilities in Lusaka Urban

REFERENCE TO PARTICIPANT INFORMATION SHEET:

1. Make sure that you read the Information Sheet carefully, or that it has been explained to you to your satisfaction.
2. Take note of whether tape or 'audio' recording will be used.
3. Your participation in this research is entirely voluntary, i.e. you do not have to participate if you do not wish to.
4. Refusal to take part will involve no penalty or loss of services to which you are otherwise entitled.
5. If you decide to take part, you are still free to withdraw at any time without penalty or loss of services and without giving a reason for your withdrawal.
6. You may choose not to answer particular questions that are asked in the study. If there is anything that you would prefer not to discuss, please feel free to say so.
7. The information collected in this interview will be kept strictly confidential.

8. If you choose to participate in this research study, your signed consent is required below before I proceed with the interview with you.

VOLUNTARY CONSENT

I have read (or have had explained to me) the information about this research as contained in the Participant Information Sheet. I have had the opportunity to ask questions about it and any questions I have asked have been answered to my satisfaction.

I now consent voluntarily to be a participant in this project and understand that I have the right to end the interview at any time, and to choose not to answer particular questions that are asked in the study.

My signature below says that I am willing to participate in this research:

Participant's name (Printed):

Participant's signature: Consent Date:
.....

Researcher Conducting Informed Consent (Printed)
.....

Signature of Researcher: Date:

Signature of parent/guardian: Date:

FORM 1b



THE UNIVERSITY OF ZAMBIA

DIRECTORATE OF RESEARCH AND GRADUATE STUDIES

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HUMANITIES AND SOCIAL SCIENCES RESEARCH ETHICS COMMITTEE

FOMU YA CHILOLEZO (CONSENT FORM)

MUTU WA KAFUKU-FUKU (TITLE OF RESEARCH):

Predictors of caregiver's stress among family members of school-going children with intellectual disabilities in Lusaka Urban.

PEPALA LACHITSIMIKIZO CHACHIDZIWITSO CHA OTENGAMO MBALI:

1. Tsimikizani kuti mwawelenga pepala lachidziwitso iyo mosamala, kapena kuti pepali la masulidwa kwa inu ndipo mwa khutira kapena kunvesesa.
2. Chibvomerezo chanu ndi chofunika maka-maka ngati pakhala kujambulidwa (kukopewa) kwa chithunzi, kapena mau anu pa kufu-fuza za kafuku-fuku
3. Kutengamo kwano mbali mukafuku-fuku uyu kuzakhala kodalira pa ufulu wanu chabe, ndipo dziwani kuti simudzafunika kutengamo mbali ngati simukufuna kutero.
4. Kukana kutengamo mbali kwano, sikudzabweletsa chilango china chilichonse kapena kutaya mwayi wa zinthu ndi thandizo lowe mukhanagwiritsira nchito poyamba.
5. Ngati mwasankha kutengamo mbali, mukhale omasuka kusiyi kutengamo mbali pa nthawi ina iliyonse popanda kulandira chilango kapena kutaya mwayi Kamba kakuti simuna pereke zifukwa zosiyira kutengamo mbali.
6. Muli omasuka kusayankha mafunso ena afunsidwa mukafuku-fuku uno. Ngati pali chinthu china chomwe mufuna kuti mukambirane kapena kufotokoza, chonde, khalani omasuka kuti uza zimenezo.

7. Nkhani iliyonse ndiponso chidziwitso chilichonse chimene mudzatiuza, ndi zimene tidzatenga kwainu mukafuku-fuku uyu, iza sungidwa mwachisnsi kwambiri mumene tingathele.
8. Ngati mwasankha kutengamo mbali mukafuku-fuku uno, mufunika kusaina monga chitsimikizo cha chibvomerezo chanu. Mudzafunika kusaina pa kamzera kaikidwa pansu apa mukaribe kupitiriza makambirano athu awa.

CHIBVOMELEZO CHANGA CHAULELE

Ndawelenga (ndamasukilidwa) zonse ponena za kafuku-fuku uyu monga mumene ziliri mu pepala lachidwitso chakafuku-fuku uyu. Ndinali ndi mpata wofunsa mafunso onena za kafuku-fuku, ndipo funso lililonse, limene ndinafunsa layankhidwa mokhutilitsa.

Tsopano nabvomereza kwaufulu (mwaulele) kukhala m’modzi waotengamo mbali m’chochitika ichi ndamvetsa kuti ndili ndi ufulu wotsiliza kukambisana pa nthawi iliyonse, ndiponso womasuka kusankha kusayankha funso iliyonse ya funsidwa mukafuku-fuku uno.

Siginecha yanga munsu umu ukuonetsa kuti ndine wolelera kuthengamo mbali mukafuku-fuku uyu.

Dzina la otengam mbali.....

Siginecha la otengamo mbali.....Pasiku la.....

Wochitisa kafuku-fuku amene akutenga chibvomerezo choona.....

Siginecha ya ochitisa kafuku-fuku.....Pasiku la.....

Siginecha yakholo/wosunga mwana.....Pasiku la.....

Appendix E 1: INFORMATION AND ASSENT FORM FOR YOUNG PEOPLE (<16 YEARS)

What is the title of the research?

Predictors of caregiver's stress among family members of school-going children with intellectual disabilities in Lusaka Urban.

What is research?

Doing research helps us find out new things about the way the world and people work. Doing research also helps us find out factors that may contribute to a problem.

Some important things to know about research:

- You can say YES or NO about taking part in research
- Some people may need more time to make a choice about taking part in research.
- The researcher must go through this form with you to see if you want to take part in the research.
- This form helps you understand how your words will be used in the research.
- Then you can say if it's ok or not for us to use your words
- This is called giving your permission
- Another word for permission is consent.

Who is doing the research?

- I am the researcher. My name is Kanyata Kanyata. I am a Masters student in Child and Adolescent psychology at the University of Zambia.

Why have you been invited to take part in this research?

- I need people to help me with my research
- You can help me because you are a person who takes part in caring for a child with an intellectual disability in your home.

Can anything bad happen to you?

- I will try very hard to make sure nothing bad happens to you
- Some of the things you talk about could make you sad or angry, or remind you of sad things, or things you don't want to think about.
- I will try my best to listen about your sadness, or tell you about other people that can maybe help you.

Will anyone know you are in the study?

- I will not tell anyone your name
- I will not give information about you to anyone else
- I will only use your words for my information
- Your words will be kept safe in a special file with a number on it. Not your name.
- Your file will be locked away safely
- I will keep a copy of this form
- If you want to see your information, you can ask me

Who can you talk to about the study?

- You can talk to someone you trust about getting involved in the research
- This could be a friend, a care worker, another staff member, or a family member.
- This person should check that you understand what your words will be used for
- This person will be called your witness
- Your witness will sign to say that he or she has helped you understand about getting involved
- He or she will help you understand what you are giving consent for

What if you do not want to do this?

- You do not have to take part in the research if you do not want to
- Even if you said yes in the beginning, you can change your mind to no
- You will not be doing anything wrong if you want to stop

- You can tell me if you have any questions about your information
- Remember, you can say YES or No about taking part. It's up to you.

What if you have any questions or complaints?

- If you have any questions now or during the interview, you can ask me anything.
- If you have any questions after I have left, you can contact the lead researcher:

MR. Kanyata Kanyata

Address: Chainama College of Health Sciences
P.O. Box, Lusaka
Phone #: 0979 859288
Email: kkanyatta@yahoo.co.uk

- If you have any complaints about the researchers or the research, you can contact you can contact the Ethics Committee, or the Director of Research at University of Zambia:

Chairperson, Humanities and Social Sciences, Research Ethics Committee

Address: University of Zambia, Great East Road Campus, P.O. Box 32379, Lusaka

The Director, Directorate of Research and Graduate Studies

Address: University of Zambia, Great East Road Campus, P.O. Box 32379, Lusaka
Phone #: +260-211-290 258

ASSENT FORM

Young People (<16 years)

Title of Research:

Predictors of caregiver's stress among family members of school-going children with intellectual disabilities in Lusaka Urban.

Do you understand this research study and are you willing to take part in it?

YES or NO

Do you have any questions about the research?

YES or NO

Did the researcher answer all your questions?

YES or NO

Do you understand that you can stop being a part of the study at any time?

YES or NO

If you have answered YES to all the questions above, you can sign your name below:

Participant's name (Printed):

Participants Signature: Date:

Witness's name (Printed):

Witness's Signature: Date:

Researcher Conducting Informed Assent (Printed):

Signature of Researcher: Date:

Appendix E2: INFORMATION AND ASSENT FORM FOR YOUNG PEOPLE (<16 YEARS)

ANTHU OCHEPELA DZAKA 16 (<16)

Mutu wa kafuku-fuku

Predictors of caregiver stress among family members of school-going children with intellectual disabilities in Lusaka Urban.

Kodi kafuku-fuku ndi chiani?

Kafuku-fuku kamatithandiza kuti tidziwe mwamene zinthu zina zisewenzera pa dziko la pansi pano.

Zinthu zina zoyenera kudziwa pa nkhani ya kafuku-fuku uyu

- Ukala omasuka kuthengamo mbali mukafuku-fuku uyu kapena kukana kuthengamo mbali
- Anthu ena amakhala othenga nthawi yaikulu kuti abvomekedze kuthengamo mbali mukafuku-fuku.
- .munthu ochitisa kafuku-fuku uyu akhale okuthandiza kuwerenga fomu iyi ndipotso kusimikhiza kuti uli obvomekheza kuthengamo mbali mu kafuku-fuku uyu.
- Fomu iyi izakuthandiza kudziwa mumene mau ako azathandidzira mukafuku-fuku uyu.
- Ndiponso ungatiuze kapena wabvomeredza kuti mau ako tiasewenzetse mukafuku-fuku uyu.
- chimene ichi ndichochedwa lolezo
- .Pa chizungu ndiye imene yochedwa consent.

Ndani akuchita kafuku-fuku uyu?

- Ine ndine wamumukulu ochitisa kafuku-fuku uyu ndiponso dzina langa ndine **Kanyata Kanyata**.
- Ndine umodzi waopunzira mapunzira apamwamba ya Child and Adolescent psychology pa sukulu la University of Zambia.

Nichifukwa chani waithandidwa kudzathengako mbali mu kafuku-fuku uyu ?

- Ndifuna anthu onithandidza mukafuku-fuku uyu
- Unganithandidze chifukwa ndiwe umodzi wa anthu amene amasamalira mwana olemara kunzeru mubanja lanu.

kodi pali zinthu zina zoipa zimene zingachitike pa iwe?

- Zinthu zina zamene uzakambapo zingakunvetse kusakondwa kapena kukhala okwiya, kapena zingakukumbuse zinthu za chisoni, kapena zinthu zina zimene sumafuna kukambapo.
- Ndizakhala oyeselera kumva zaiwe zokuchitisa chisoni, kapena kukhala othandidzara kudziwisa thandizo limene lingapezeke kwaiwe.

Kodi pali ena amene azakhala oziwa kuti wathengamo mbali mukafuku-fuku uyu?

- Sindidzauza munthu wina aliense dzina lako
- Sindidzapasa munthu wina aliense zokhambilana zaiwe
- Mau ako kapena zokhambilana ndi iwe zizakhara zosungidwa bwino bwino ndi nambara yache yoka kopanda kuikapo zina lako.
- Fayilo yako idzakhala mumalo okhomedwa bwino bwino
- Ndizakhala osunga fomu imeneyi imodzi
- Ukafuna kuona makhambilano ako mukafuku-fuku uyu, ukhale omasuka kundiuza

Ndani wamene ungafune kuziwa za kafuku-fuku uyu?

- Ungauze munthu wina wache wamene ukuluphilira monga pakuthengamo mbali kwaiwe mukafuku-fuku uyu
- Munthu uyu angathe kukhala mzako, osamalira anthu, osewenzwa wina, kapena wina wabanja.
- Munthu azafunika kuyanganira kuti iwe wanvesesa mumene mau ako azasewenzesewa mukafuku-fuku uyu.
- Munthu uyu azakhala kamboni (witness)

- Kamboni uyu azafunika kuonesa siginecha lache kuti akhala okuthandidza pakuthengamo mbali mukafuku-fuku uyu.

Tsopano ngathi siufuna kuthengamo mbali mukafuku-fuku uyu ?

- Ukhale omasuka kusathengamo mbali mukafuku-fuku uyu ngati siufuna.
- Ngakhale unali wabvomelesa kuthengamo mbali mukafuku-fuku uyu poyamba, ukhale omasuka kulekheza pakhati.
- Sichidzakhala choipa khelekhedza pakhati pakafuku-fuku uyu.
- Ukhale omasuka kufunsa mafunso pamakambilo yako mukafuku-fuku uyu.
- Dziwa kuti ungakhale obvomeleza kapena osabvomeleza kuthengamo mbali mukafuku-fuku uyu. Chillli kwaiwe.

MAYINA NDI MANAMBARA YA ANTHU OPELEKHAKO MAFUNSO

MR. Kanyata Kanyata

Address: Chainama College of Health Sciences
 P.O. Box, Lusaka
 Phone #: 0979 859288
 Email: kkanyatta@yahoo.co.uk

Chairperson, Humanities and Social Sciences, Research Ethics Committee

Address: University of Zambia, Great East Road Campus, P.O. Box 32379, Lusaka

The Director, Directorate of Research and Graduate Studies

Address: University of Zambia, Great East Road Campus, P.O. Box 32379, Lusaka
 Phone #: +260-211-290 258

ASSENT FORM

Anthu ochepela dzaka 16 (<16 years)

Mutu wakafuku-fuku uyu

Predictors of caregiver stress among family members of school-going children with intellectual disabilities in Lusaka Urban.

Kodi wambvesesa za kafuku-fuku uyu, ndiponso ukufuna kuthengamo mbali?

Inde or ayi

Kodi uli ndimafuntso aliense pakafuku-fuku uyu?

Inde or ayi

Kodi ochitisa kafuku-fuku uyu ayankha mafuntso ako onse?

Inde or ayi

Kodi wanbvesesa kuti ndiwe omasuka kulekhedza pakhati kuthengamo mbali mukafuku-fuku uyu?

Inde or ayi

NGATI WAYANKHA MOBVOMELEZA PAMAFUNTSO ONSE PAMWABA APA, IKA SIGINECHA PANYANSI APA:

Siginecha lako: Date:

Siginecha la kamboni kapena witinesi: Date:

Researcher Conducting Informed Assent (Printed):

Signature of Researcher: Date:

Appendix F 1: SOCIO-DEMOGRAPHIC QUESTIONNAIRE

(All information in this questionnaire is confidential).

Respondent's Code: _____ **Interview Date:** _____

NB: The questionnaire must be answered by parents/other family caregivers, including older siblings.

1. Relationship to child:

- a. Mother _____
- b. Father _____
- c. Grandparent _____
- d. Sibling _____
- e. Aunt/Uncle Other _____

2. Child's age _____

3. Child's level of disability (to be filled in by the researcher based on official records):

- a. Borderline _____
- b. Mild _____
- c. Moderate _____
- d. Severe _____

4. Age of Respondent _____

5. Gender: Male _____ female _____

6. What is your marital status?

Single _____ Married _____ divorced _____ separated _____

7. What is your employment status?

Full time employed _____

Part time employed _____

Self-employed _____

Housewife/husband _____

Unemployed _____

Retired_____

8. **What is your highest level of education?**

Never been to school_____

Primary school_____

Secondary school_____

College_____

University_____

9. **Where do you live?**

In my own house_____

In my parents' house_____

In a rented house_____

Other_____

10. **How many family members live in the same house with you in addition to the child with intellectual disability?**

None_____

One_____

Two_____

More than two_____

11. **How many other people in the house earn an income?**

All_____

Only one

None_____

Other (specify) _____'

12. **What is your main source of financial support?**

My income (pay check or income from businesses) _____

Family support _____

Other (Specify)

Appendix F2: SOCIO-DEMOGRAPHIC QUESTIONNAIRE (chinyanja version)

(Nkhani ili yonse kapena chili chonse chalembedwa muchofunsila ichi ndi za chinsinsi)

Dziwani izi: Mafunso onse ali muchofunsila chakafuku-fuku uno afunika kuyankidwa ndi makolo amwana obvutikila kuikapo ali yense wa mubanja amene akuthengamo mbali/kuthandidzako kusamalila mana uyo.

Numbala ya otengamo mbali (Respondent's Code): _____ Tsiku la makambilano (Interview Date): _____

1. Ubale umene ulipo ndi mwana uyu:

- a. Amai ake _____
- b. Atate ake _____
- c. Ambuye ake _____
- d. Mukulu wake _____
- e. Amalume aka/alongo awo atate ake _____

2. Zaka za mwana _____

3. Kukula kwa bvuto (to be filled in by the researcher based on official records):

- a. Lili poambilira peni peni (borderline) _____
- b. Pang'ono (Mild) _____
- c. Pakati (Moderate) _____
- d. Lalikulu kwambiri (Severe) _____

4. Zaka za amene akuthengamo mbali _____

5. Kusiyansa (Gender)

Mwamuna _____ Mukazi _____

6. Kodi muli pachikwati?

Sindili pa chikwati _____ ndili pa chikwati _____ chikwati chnata _____ tinapatukana _____

7. Kodi mukugwira nchito yotani?

Ndili pa nchito yolembedwa nthawi zonse _____

Sindili panchito ya nthawi zonse _____

Ndigwila nchito yanga nekha _____

Sindili pa nchito ili yonse _____

Ndina tenga penshoni _____

8. **Pomwe munalekezela maphunziro?**

Primary school_____

Secondary school_____

College_____

University_____

9. **Kodi mukala kuti?**

Munyumba yanga-yanga_____

Munyumba yamakolo anga_____

Munyumba ya renti_____

10. **Kodi ndi angati antu amene mumakhala no panyumba panu?**

Palibe_____

Umodzi chabe_____

Awiri_____

Opitilira awiri_____

11. **Kodi ndi anthu ena angati panyumba panu amene amafola malipilo pamwedzi?**

Onse_____

M'modzi chabe_____

Palibe ngakhale m'modzi_____

Ena (fotokozani) _____

12. **Kodi ndi njira imene mupezelamo ndalama?**

Ndimafola ndalama kuchokela ku nchito/malonda anga _____

Thandizo kuchokela ku banja langa (achibululu) _____

Kwina(fotokozani)-----

Appendix GI: Psychological stress measure PSM-9 (English version)

This questionnaire asks you to indicate what you generally feel like in the last 4 to 5 days.

Then respond to each of the following items by **TICKING** one number on the Questionnaire for each, using the response choices listed just below. Please try to respond to each item by choosing your responses thoughtfully, and make your responses as true FOR YOU as you can. Please answer every item. There are no "right" or "wrong" responses, so choose the most accurate response for YOU

	DESCRIPTION OF MOOD	NOT AT ALL	NOT REALLY	VERY LITTLE	A BIT	SOMEWHAT	QUITE A BIT	VERY MUCH	EXTREMELY
		1	2	3	4	5	6	7	8
	I feel calm								
	I feel rushed, I do not seem to have enough time								
	I have physical aches and pains, sore back, headache, stiff neck, stomach								
	I feel preoccupied, tormented, or worried.								
	I feel confused; my thoughts are muddled (confused and unclear); I lack concentration; I cannot focus								
	I feel full of energy and keen to do something								
	I feel too much work on my shoulder								
	I have difficulty controlling my reactions, emotions, mood, or gestures.								
	I feel stressed								

Appendix H 1: Time involved in care-giving tasks check-list (English version)

This section of the questionnaire asks you to indicate HOW MUCH TIME it takes you to complete tasks for your child with intellectual disability.

Then respond to each of the following items by **TICKING** one number on the Questionnaire for each, using the response choices listed just below. Please try to respond to each item by choosing your responses thoughtfully, and make your responses as true FOR YOU as you can. Please answer every item. There are no "right" or "wrong" responses, so choose the most accurate response for YOU

Indicate HOW MUCH time it takes you to complete tasks for your child with intellectual disability.

Check and TICK the number that best indicates the degree to which each statement relates to you experience.						
	DESCRIPTION OF ACTIVITIES	Extremely less time	Less time	Moderate amount of time	More time	Extremely more time
		1	2	3	4	5
1	Direct care tasks such as bathing, feeding, dressing, toileting					
2	In-home therapy such as the completion of special activities recommended by medical practitioners, therapists and teachers					
3	Attendance at medical appointments, therapy sessions and/or educational programmes					
4	Supervision of the child's activities and whereabouts					
5	Involvement in leisure and play activities					
6	Acquiring education and information about your child's disability					
7	Advocating for your child's services					
8	Managing your child's behaviour					

Appendix I 1: Brief cope inventory (English version)

This questionnaire asks you to indicate what you generally do and feel when you experience stressful events. Obviously, different events bring out somewhat different responses, but think about what you usually do when you are under a lot of stress.

Then respond to each of the following items by **TICKING** one number on the Questionnaire for each, using the response choices listed just below. Please try to respond to each item by choosing your responses thoughtfully, and make your responses as true FOR YOU as you can. Please answer every item. There are no "right" or "wrong" responses, so choose the most accurate response for YOU

Indicate what YOU usually do when YOU experience a stressful event.

Check and TICK the number that best indicates the degree to which each statement relates to your experience.					
	DESCRIPTION OF ACTIVITIES WHEN EXPERIENCING STRESSFUL EVENT	I HAVE NOT BEEN DOING THIS AT ALL	I HAVE BEEN DOING THIS A LITTLE BIT	I HAVE BEEN DOING THIS A MEDIUM AMOUNT	I HAVE BEEN DOING THIS A LOT
		1	2	3	4
1	I've been turning to work or other activities to take my mind off things.				
2	I've been concentrating my efforts on doing something about the situation I'm in.				
3	I've been saying to myself "this isn't real."				
4	I've been using alcohol or other drugs to make myself feel better.				
5	I've been getting emotional support from others.				
6	I've been giving up trying to deal with it.				
7	I've been taking action to try to make the situation better.				
8	I've been refusing to believe that it has happened.				
9	I've been saying things to let my unpleasant feelings escape.				

10	I've been getting help and advice from other people.				
11	I've been using alcohol or other drugs to help me get through it.				
12	I've been trying to see it in a different light, to make it seem more positive.				
13	I've been criticizing myself.				
14	I've been trying to come up with a strategy about what to do.				
15	I've been getting comfort and understanding from someone.				
16	I've been giving up the attempt to cope.				
17	I've been looking for something good in what is happening.				
18	I've been making jokes about it.				
19	I've been doing something to think about it less, such as going to movies, watching TV, reading, daydreaming, sleeping, or shopping.				
20	I've been accepting the reality of the fact that it has happened.				
21	I've been expressing my negative feelings.				
22	I've been trying to find comfort in my religion or spiritual beliefs.				
23	I've been trying to get advice or help from other people about what to do.				
24	I've been learning to live with it.				
25	I've been thinking hard about what steps to take.				
26	I've been blaming myself for things that happened.				
27	I've been praying or meditating.				
28	I've been making fun of the situation.				

Appendix J 1: Multidimensional Scale of Perceived Social Support (English version)

This questionnaire asks you to indicate how generally feel about the following statement.

Then respond to each of the following items by **TICKING** one number on the Questionnaire for each, using the response choices listed just below. Please try to respond to each item by choosing your responses thoughtfully, and make your responses as true FOR YOU as you can. Please answer every item. There are no "right" or "wrong" responses, so choose the most accurate response for YOU

Check and tick the number that best indicates the degree to which each statement relates to you.								
	DESCRIPTION OF YOUR FEELING	Very Strongly Disagree	Strongly Disagree	Mildly Disagree	Neutral	Mildly Agree	Strongly Agree	Very Strongly Agree
		1	2	3	4	5	6	7
1	There is a special person who is around when I am in need.							
2	There is a special person with whom I can share my joys and sorrows.							
3	My family really tries to help me.							
4	I get the emotional help and support I need from my family.							
5	I have a special person who is a real source of comfort to me.							
6	My friends really try to help me							
7	I can count on my friends when things go wrong.							
8	I can talk about my problems with my family							
9	I have friends with whom I can share my joys and sorrows.							
10	There is a special person in my life that cares about my feelings.							
11	My family is willing to help me make decisions.							
12	I can talk about my problems with my friends.							

Appendix G 2: Psychological stress measure PSM-9 (Nyanja Version).

Chofusila mafunso akafuku-fuku ichi chikupempani kuti musonyeze mumene munali kuzinvelera matsiku anai kapena asanu apitawa.

Ndipo muyankhe mbali ili yonse yotsatila mwakuchonga panambala imodzi pa funtso lililonse, mwakugwilitisila nchito mundandada wa mayanko aikidwa munsu mwake. Chonde, yesetsani kuyankha funso iliyonse mwakusankha yankholo mutaganizila bwino bwino, ndipo tsimikilani kuti yankho lanu ndiloonadi kwainu, yankhani mbali ili yonse. Sipadzakhala lankho labwino kapena loipa, mayankho onse ndi oyenelera, motelo sankhani yankho limene lili logwilizana kweni kweni ndi momwe zilili kwa inu.

Fufuzani ndi kuchonga pa nambala imene ikusonyeza bwino bwino kupitilira yonse. Mulingo umene mauo alikulinganilana ndi zimene mumakumana nazo posachedwapa, pomwe ndi masiku 4 mpaka 5 mumbuyomu									
	KUFOTOKOZA KWA MUMENE MUMADZINVELERA M'MAGANIZO	OSATI NANGU PANG'ONO	OSATI KWENI KWENI	PANG'ONO KWENI KWENI	PANG'ONO CHABE	MOTERO	ZIMATERODI	ZIMATERO KWAMBIRI	ZIMATERO KWAMBIRI MBIRI
		1	2	3	4	5	6	7	8
1	Ndimadzimva odeka mtima								
2	Ndimadzimva kukhala ofulumizidwa, ndiponso sindiona kuti ndili ndi nthawi yokwanira.								
3	Ndidzimvera kuwawa muthupi, kuwawa kwamusana, khosi, ndi mumimba.								
4	Ndimadzimva kukhala olemesedwa, obvutisidwa ndi odela nkhwawa.								
5	Ndimadzimva kukhala osokonedzeka, maganizo anga sakhala pamodzi. Ndimalepela kuika maganizo pachinthu chimodzi.								
6	Ndimadzimva ozazidwa ndi mphambvu ndi ofunisisa kugwira nchito								
7	Ndimadzimva kukhala ndi zochita zambiri, nchito zonse zili pa phewa langa chabe.								
8	Ndimalephera kuziletsa mwamene ndimadzimvelera, maganizo anga ndi kasonthedwe kanga ka manja.								
9	Ndimadzimva kukhala olemesedwa ndi obvutika.								

Appendix H 2: **Time involved in care-giving tasks check-list (Nyanja Version)**

Nthawi yomwe imathela pakusamalira maudindo osamala za mwana amene uyu.

Ndipo muyankhe mbali ili yonse yotsatila mwakuchonga panambala imodzi pa funtso lililonse, mwakugwilitsila nchito mundandada wa mayanko aikidwa munsi mwake. Chonde, yesetsani kuyankha funso iliyonse mwakusankha yankholo mutaganizila bwino bwino, ndipo tsimikilani kuti yankho lanu ndiloonadi kwainu, yankhani mbali ili yonse. Sipadzakhala lankho labwino kapena loipa, mayankho onse ndi oyenelera, motelo sankhani yankho limene lili logwilizana kweni kweni ndi momwe zilili kwa inu.

Onesani kuti ndi nthawi yochulukira kotani imene mumathenga pa kusamalira mwana amene uyu.

Yanganani ndipo CHONGANI nambala yomwe ikusonyeza ndenede kulingana kwake kwa zochitika zolembedwa ndi zimene mukukumana nazo.						
	KUFOTOKOZA KWA ZOCHITIKA	Nthawi yaingono kwambiri	Nthawi yaingono	Nthawi yochulukilapo	Nthawi yochulukira	Nthawi yochulukira kwambiri
		1	2	3	4	5
1	Kusamalira monga kusambika, kudyetsa, ndi kupelekeza kuchimbudzi					
2	Thandizo la panyumba monga, kutsiliza zochitika za padera zo uzidwa ndi za umoyo (akuchipatala) ndi aziphunzitsi.					
3	Kupezeka pa nthawi youzidwa kuzaonana ndi azaumoyo, aphungu ndi azamaphunziro.					
4	Kuyanganira zichitidwe za mwana amene uyu ndi zina zotele.					
5	Ndimathengamo mbali pa zachiphale ndi za masewela					
6	Kuphunzira ndi kudziwa za bvuto la mwana amene uyu.					
7	Kumenyela ndi kulankhulira zo thandidzira mwana amene uyu.					
8	Kuyanganira ndi kulangiza ndiposo kuphunzitsa mwana amene uyu makalidwe					

Appendix I 2: Brief cope inventory (Nyanja version)

Muchofunsila kafuku fuku ichi, tikupemphani kuti muonetse zimene mumachita mukakumana ndi zotetsa nzeru ndiposo zochitika zolemetsa (Zowawitsa Mutima). Chochitika chilichonse chimabwera ndi mbali yake yake, koma ganizilani zimene zimakuchitikilani kawiri kawiri pamene muli mu mabvuto ndi zobvutitsa zambiri.

Ndipo muyankhe mbali ili yonse yotsatila mwakuchonga panambala imodzi pa funtso lililonse, mwakugwilitisila nchito mundandada wa mayanko ayikidwa munsi mwake. Chonde, yesetsani kuyankha funso iliyonse mwakusankha yankholo mutaganizila bwino bwino, ndipo tsimikilani kuti yankho lanu ndiloonadi kwainu, yankhani mbali ili yonse. Sipadzakhala lankho labwino kapena loipa, mayankho onse ndi oyenelera, motelo sankhani yankho limene lili logwilizana kweni kweni ndi momwe zilili kwa inu.

Onetsani mumene mumachitira pamene mwakumana ndi zowawitsa mutima pamene mukusamalira mwana wanu.

Yanganani ndipo CHONGANI nambala yomwe ikusonyeza ndedede kulingana kwake kwa zochitika zolembedwa ndi zimene mukukumana nazo.					
	KUFOTOKOZA KWA ZIMENE ZIMACHITIKA MUKAKUMANA NDI ZOBVUTA	Sindimachita izi ngakhale pang'ono	Ndimachita izi mwapang'ono chabe	Ndimachitadi zimenezi	Ndimachita zimene izi kawambiri mbiri
		1	2	3	4
1	Ndakhala ndi kugwira nchito kapene kuyika maganizo anga pa zinthu zina kuti ndiwaleko mabvuto				
2	Ndakala ndikuyika maganizo anga ndi mphambvu zanga zonse pamodzi kuti ndikwanise kulimbana ndi mabvuto awa.				
3	Ndakhala ndi kuziiza kuti zimenezi sizoona zeni zeni.				
4	Ndi mamwa mowa ndi kugwilisa nchito mankwala osokoneza bongo kuti ndizizimvetsako bwino.				
5	Ndakhala ndi kulimbisikidwa ndi kuthandizidwa ndi anthu ena.				
6	Ndakhala ndi kusiya kuchitapo zili zonse pamabvuto anga.				
7	Ndakhala ndi kuyesesa kuchita zili zonse zomwe ndi ngakwanise kuti zinthu zikhale bwino.				
8	Ndakhala ndi kukana kukhulupilira kuti zimene izi zakhala zikuchitikadi.				
9	Ndakhala ndi Kunene zinthu zosiana siana kufuna kusiliza zoipa zimene zikundichitikila.				
10	Ndakhala ndi kulandira thandizo ndi malangizo kuchokela kwa anthu ena.				
11	Ndakhala ndi kumwa mowa ndi kugwilisa nchito mankwala osokoneza bongo kuti ndikwanise kupilira mabvuto awa				
12	Ndakhala ndi kuganizira zabvuto ili munjira yoenelela ndi				

	kuipanga kukhala chinthu chosabvuta				
13	Ndimazimva kukhala olakwa				
14	Ndakhala ndikuyesa kupeza njira imene ingandithandize kusiliza mabvuto awa.				
15	Ndakhala ndi kupeza chilimbikiso ndi kumvela bwino pa zabvuto ili kupitila mu anthu ena				
16	Ndakhala ndikusiya kuyesa yesa kwanga kupeza njira imene ndinga pililire				
17	Ndakhala ndi kuyesa kupezapo chabwino pa zinthu zimene zi kundichitikira				
18	Ndakhala ndi Kunene zosekesa pa zimene zikundichitikira				
19	Ndakhala ndi kuchita zinthu zina kuti ndichepeseko maganizo, zinthu monga kuonelera T.V., kuwerenga, kulota muzuwa, kugona ndiponso kugula zinthu.				
20	Ndakhala ndikubvomeleza kuti zinthu zimene zikundichitikira ndi zoona zeni zeni				
21	Ndakala ndi kufotokoza maganizo anga oyipa ponena za zinthu zimene zikundichitikira.				
22	Ndakhala ndi kupheza ubwino kapena chilimbikiso kuchokera ku tchalichi change ndiponso pazimene ndi makhulupilira				
23	Ndakhala ndi kuyesa kufuna malangizo azinthu zimene ndifuna kuchita kuti mabvuto anga athe kuchokera kwa anthu ena				
24	Ndakhala ndi kupunzira kukhara molingana ndi mabvuto anga				
25	Ndakhala ndi kuganizira kwambiri pa zimene ndi zafunika kuchita				
26	Ndakhala ndi kunzimva kukhala olakwa, ndi maona kuti ndine ninalengesa mabvuto awa.				
27	Ndakhala ndiri kupemphera ndi kuganizilapo ngako pa bvuto ili.				
28	Ndakhara ndi kuona mabvuto awa monga masewera chabe				

Appendix J 2: Multidimensional Scale of Perceived Social Support (Nyanja version)

Yanganani ndipo CHONGANI nambala yomwe ikusonyeza ndedede kulingana kwake kwa zochitika zolembedwa ndi zimene mukukumana nazo.									
	KUFOTOKOZA KWA MUMENE MUMADZINVELERA	Ndi tsutsilatu zimenezi	Ndi tsutsa zimenezi	Ndi tsutsako pang'ono	Ndilibepo chonena	Ndivomerez a zimenezi pang'ono	Ndivomerezadi zimenezi	Ndivomereza zimenezi ngako	
		1	2	3	4	5	6	7	
1	Pali munthu wina wosiana ndi ena (wapadera) amene amakhala nane m'mabvuto anga								
2	Pali muthu wina wapadera amene timasangalira ndi kulilira pamodzi mumabvuto ndi mu m'tendere.								
3	Achibale anga amayetsesa kundithandiza								
4	Ndi ma peza chilimbikitso ndi mtendere wam'maganizo ndi zithu zimene ndikufunikira kuchokera kwa abale anga								
5	Ndili ndi muthu wapadera amene ndiye kumene kumachokela chilimbikitso ndi chithonhozo change								
6	Anzanga amayetsesa kundi thandiza								
7	Ndimadalira pa anzanga ngati zinthu zandibvuta								
8	Ndimakwanisa kukambilana ndi abale anga za mabvuto anga.								
9	Ndili ndi anzanga amene ngati alipo ndimasekera ndi kulilira nawo pamodzi								
10	Pali muthu wina wapadera muumoyo wanga amene amasamala zaine ndi m'mene ndimamvera								
11	Abale anga ndi okonzekera ndiposo wololera kundi thandiza kusankha zomwe ndingachite								
12	Ndimakwanitsa kukambirana ndi anzanga za mabvuto anga.								

