FAMILY ADAPTATION PATTERNS OF CARING FOR A CHILD WITH AUTISM SPECTRUM DISORDER IN SELECTED HOUSEHOLDS IN LUSAKA, ZAMBIA

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DECLARATION

I declare that this Dissertation represents my own work and that all the sources I have quoted have been indicated and acknowledged by means of complete references. I further declare that this Dissertation has not previously been submitted for a Degree, Diploma or other qualifications to this or another University. It has been prepared in accordance with the guidelines for Master of Science in Mental Health and Psychiatric Nursing Dissertation of the University of Zambia.

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DEDICATION

I dedicate this study to my daughter Patricia Nkhosi.

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ABSTRACT

Autism Spectrum Disorder (ASD) is a disorder of development characterised by marked impairments in social interaction, communication, and restricted repetitive and stereotyped patterns of behavior. It is considered to be a severe disability because of its persistent lifelong effects on the affected individual and his or her family. A number of researches report that parents of children with ASD show higher levels of stress, anxiety, and depression than those of normally developing children. Therefore, families' coping mechanisms need to be explored so that health care workers can tap from them in order to help other parents. Nevertheless there is very little understanding of how families adapt and support each other in such situations.

The general objective of this study was to explore adaptation patterns of family members caring for a child with ASDat UTH and Bauleni Special schools in Lusaka according to Virginia Henderson's Activities of Daily Living (ADL).

Qualitative methodology utilising an interpretive phenomenological approach was used on a sample of eighteen family members who were selected using purposive sampling. Data were collected through individual in-depth interviews and a single focus group discussion (FGD). van Manen'ssix steps of analysis were used to analyse data.

Three major themes, namely: Perceived sources of parental distress; Experiences and beliefs; and Accommodating the needs of a child with ASD, emerged from the data. The major themes were supported by several subthemes. The implications of the findings on practice are that most parents were greatly distressed by their children's behavioural disorders and made significant adaptation changes in order to cope with the situation. Delays in diagnosis occurred due to lack of knowledge of ASD amongst health care workers and negative cultural beliefs resulting into late school placement. It was also noted that the ability for families to accommodate their child with ASD affected their adaptation.

It is therefore recommended that health workers utilise successful adaptation patterns to help parents and families with a child with ASD.

Key words: ***Adaptation, Autism Spectrum Disorder, Families, Child***

LIST OF ABBREVIATIONS

ADHD:	Attention Deficit Hyperactive Disorder
APA:	American Psychiatric Association
ASD:	Autism Spectrum Disorder
CDC:	Centre for Disease Control:
DEBS:	District Education Board Secretary
DSM-5:	Diagnostic Statistical Manual of Mental Disorders 5TH Revision
ICD – 10	International Classifications of Diseases in the 10th Revision
ID:	Intellectual Disability
MoCD:	Ministry of Community Development
MoGE:	Ministry of General Education
MoH:	Ministry of Health
NHRS:	National Health Research Authority
PDD:	Pervasive Developmental Disorders
UN:	United Nations
UNZA:	University of Zambia
UTH:	University Teaching Hospital
WHO:	World Health Organisation

DEFINITIONS

Conceptual definitions

ASD: ASD is a disorder of development first occurring before the age of three; which affect the brain leading to marked impairments in social interaction, communication, and restricted repetitive and stereotyped patterns of behaviour (APA, 2013).

Adaptation: Adaptation is a change that is made or intentionally not made to the family's daily routine of activities to accommodate the needs of the child with ASD (Skinner & Weisner, 2007).

Child: A child is every human being below the age of 19 years (UN, 1989).

Operational definitions

Family: A family includes members of the household of the child with ASD who have lived with the child for most of his/her life.

Child: A child is an offspring with ASD who has lived with the study participant for most of his/her life.

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CHAPTER ONE: INTRODUCTION

1.1 Introduction

This qualitative interpretive phenomenological study set out to explore the adaptation patterns of families caring for a child with ASD in selected households in Lusaka, Zambia. ASD is a disorder of development that affects the brain and first occurs before the age of three (World Health Organization [WHO], 2016). Chapter one presents an introduction to the dissertation, and provides background information of what the study is about. The Chapter gives an overview of ASD and its effect upon families. It specifies the purpose of conducting the study, explains the statement of the problem, and stipulates the significance of the study. The study rationale, research question, and specific objectives are also outlined. It also includes sections for definition of terms.

1.2 Background of the Study

ASD is a disorder which begins in childhood and continues into adolescence and adulthood (WHO, 2016; American Psychiatric Association [APA], 2013). Individuals with Autistic disorder, Asperger's disorder or pervasive developmental disorder-not otherwise specified (PDD-NOS) are diagnosed as having ASD (Bashir *et al.,* 2014). Asperger's disorder is a mild form of ASD in which there is a deficit in the social use of language but without the restrictive interests or repetitive behaviours (Aspergers, 2019).Individuals with ASD are affected in three basic domains of development, namely; reciprocal social interactions, verbal and non-verbal communication and stereotype, repetitive and injurious behaviours (WHO, 2016). ASD is considered to be a severe disability because of the intense lifelong effects it has on the individual and his or her family (Bashir *et al.,* 2014). The male female ratio of ASD is 4:1 (Mulenga, 2018). Children with ASD often present with behaviour problems that are severe and persistent and which in turn impact adversely upon the psychological wellbeing of caregivers (APA, 2013; Karst & Hecke, 2012). This results into an overwhelming experience that affects how parents and families adapt to the disability of their child.

Symptoms of ASD range from mild to severe, contributing to variations in behaviour from one child to another. The self-injurious or aggressive conduct that characterizes ASD may persist for a long time, thereby affecting the well-being and adaptation of parents and other family members. Significant disturbances may occur in family functioning, relationships and roles contributing to new needs in the physical, social, emotional and psychological areas of a family's life (Karst & Hecke, 2012; Hong *et al.,* 2010). Increased parental stress may result into mental and physical health problems. This has been proved by various studies that have investigated the psychological adjustment of parents and families of children with ASD, and found that they have higher levels of stress, anxiety, and depression than parents of typically developing children (Roberts *et al.,* 2017; Hayes & Watson, 2012; Johnson *et al.,* 2011). According to the Folkman& Lazarus's (1985) General Model of Stress, stress results when an individual is faced with a stressor from the environment in which they put into place various coping mechanisms to restore normal functioning. If the ability to deal with the stressor or solve the problem is ineffective to meet the new demand (stressor), the outcome is stress. Effects of stress include physical and psychological symptoms such as increased risk of developing ulcers, heart diseases, depression and fatigue (Folkman & Lazarus, 1985). Family members of children with ASD experience stress when normal family functioning is disrupted due to the severity of the condition and behavioural problems of the child (Mohammadi, 2011).

The global rate of ASD is 1%, and studies to determine the total number of cases in sub-Saharan Africa are lacking (Jeynes *et al.,* 2018). The prevalence and identification of ASD across cultures has been affected by lack of culturally sensitive diagnostic criteria (Matson *et al.,* 2011). Nevertheless, WHO, (2017) reports that the prevalence of ASD in children is 1 in 160 worldwide; while in many low and middle income countries, it remains unknown. In the United States of America(USA)prevalence of ASD is 1 in 59 children (1 in 37 boys and 1 in 151 girls) (Centres for Disease Control and Prevention [CDC], 2018). In Africa the prevalence rate of ASD was 11.5% and 33.6% amongst children with developmental disorders in Tunisia and Egypt respectively in 2008 (Bakare, 2014). According to Harrison *et al.,* (2014) there are no prevalence studies of ASD in South Africa (SA), or indeed in sub-Saharan Africa as a whole, due in part to a lack of standardized screening and diagnostic tools validated for African populations. However, in Nigeria, a hospital based population study showed prevalence of 0.8% (Bakare *et al.,* 2011) and 11.4% among children with Intellectual Disability (ID) (Bakare *et al.,* 2012). In Zambia there is no statistical data about the number of children with ASD (Mulenga, 2018). However, a hospital based prevalence of 1.4 % was reported at UTH by Nkole & Ciccone (2018).

Children with ASD and their families are vulnerable to discrimination and to protect their human and civil rights the United Nations (UN) Convention on the Rights of Children with Disabilities has put in place measures which ensure governments promote their human rights and fundamental freedoms (UN, 1985). In Zambia the rights of persons with disabilities are covered by "The Persons with Disability Act No. six (6) of 2012," and implemented through the National Policy on Disability, the Zambia Agency for Persons with Disabilities, and parent led associations (Ministry of Community Development, Mother and Child Health, 2015; Human Rights Commission, 2012).

A number of researches on families of children with ASD have identified factors that are significantly involved in the adaptation of parents. These can be summarized into child, parental and environmental characteristics (Mohammadi, 2011). Child characteristics include challenging behaviours, severity of disability and comorbid conditions and are reported to increase parental stress leading to poor mental health outcomes, such as anxiety disorders and depression (Guyard *et al.*, 2017). Parental characteristics are factors that influence adaptation to a child's disability and consist of a variety of coping strategies. One example is readily available mental coping strategies at one's disposal such as remaining optimistic despite challenges being faced (Machalicek *et al.,* 2015). Environmental characteristics that impact negatively on the wellbeing of primary caregivers of children with ASD include none availability of adequate health care and psychosocial support. Other factors include difficulties in the marriage relationship, and expensive specialized child care for working mothers (Machalicek *et al.,* 2015). Increased financial costs required for early intervention services and medical bills add to the difficulties that families of children with ASD experience. Other social cultural environmental factors which impact negatively on the adaptation of families include stigma, discrimination and social exclusion, which are known to be worldwide (Malungo *et al.,* 2018; McKenzie, 2013; SIRG, 2012).

It has been noted that families affect other members' thoughts, feelings, and actions, and seek attention, approval, and support as well as react to others' distress (Brown, 2012).As a result, when one member becomes anxious, it spreads to other members of the family causing more stress, feelings of being isolated and being out of control. Therefore, family focused ASD research is vital in increasing understanding of the impact of ASDs thus informing interventions for supporting families (Brown, 2012). Hence, adaptation of the family is best understood by talking to and involving all family members – parents, siblings and anyone else currently living with the family at the time of the study and for most of the ASD child's life. In this way individual family members are best understood in relationship to each other as part of an emotional unit (Cridland *et al.,* 2014). The overall purpose of this research was to understand the adaptation patterns of families caring for a child with ASD. Since caring for a child with ASD significantly impacts on the psychological wellbeing of parents and other family members there is need to explore further how affected families adapt to the situation (Sharmac, 2017).

The aim of the study was to explore family adaptation patterns of caring for a child with ASD using Virginia Henderson's ADLs. Henderson who was a nurse theorist discovered fourteen Fundamental Needs which demarcate specific needs that have to be sustained for a human being to maintain health and these areas are known as Activities of Daily Living (Pokorny, 2010). An individual maintains physical, mental, spiritual and social wellbeing by having these fundamental needs sustained. When their fundamental needs are sustained families will in turn make much needed adaptations to caring for their ASD child. Successful Adaptation will be shown through parents' descriptions and interpretations of their lived experiences in five of the selected fourteen activities of daily living, which represent the psychological, spiritual and social components of Virginia Henderson's Fundamental Needs Theory. Interpretations that illustrate parental stress will be taken to be an indication that family members are having difficulties adapting to their child, which in turn means that their quality of life is probably compromised. Hence this study used five out of the fourteen ADLs to explore the daily routines of how families adapt to their child with ASD during the in-depth interviews and focus group discussion. The five selected psychological, social and spiritual areas are as follows: Communicate with others in expressing emotions, needs, fears, or opinions; Worship according to one's faith; Work in such a way that there is a sense of accomplishment; Play or participate in various forms of recreation; Learn, discover, or satisfy the curiosity that leads to normal development and health, and use the available health facilities (Waller-Wise, 2013).With regard to communicating with others in expressing emotions, needs, fears, or opinions families need to learn to communicate with their child, spouse, other family members and community members within the home environment. Worship according to one's faith: Religion, a topic seldom studied in developmental research, is a powerful tool for many individuals as they make sense of disability and their lives in relation to it. Worshiping according to one's faith may take many forms, including praying or reciting scripture (Fuller, 2012). The National Institute of Health data indicates that praying is the most commonly used form of complementary and alternative medicine used today in healthcare, and is one of the oldest and most commonly used techniques. Work in such a way that there is a sense of accomplishment: Research by Mas, et al, (2016) found that parents, especially mothers, made accommodations in their jobs to meet their child's needs. Accommodations were required in order to maintain a schedule of activities for the child at home and in order to participate in different services such as coordinating the child's multifaceted medical, educational, and developmental interventions while balancing competing family needs. Such needs can cause parental stress and lower caregivers' psychological well-being. Accommodations also involve fewer working hours, changes in work shifts, failure to search for work, or not stopping work at all. Utilizing findings from Mas *et al.,* (2016) this study will explore how family members still manage to work both on an informal and formal basis and yet succeed in their work while at the same time adapting to the needs of their child. Play or participate in various forms of recreation: Sajjad (2010) states that mothers of children with a developmental disability do not have enough time for any entertainment as they are busy caring for their child most of the time. Responsibility of caring for an ASD child can be shared by some family members, neighbours, or volunteers. It has been found that offering prayers, watching television and chatting with friends on the telephone are the most common therapies used by mothers to cope with stress: Use the available health facilities: The study explored whether families of children with developmental delays used available health facilities for both their child and for their own psychological difficulties: Determining whether PCGs have successfully adapted to their Disabled child or not: The study explored how parents adapt by first identifying presence of parental stress from participants' descriptions and interpretations and how it impacted on family quality of life (FQOL) by using probes from Henderson's Activities of Daily Living during the in-depth interviews. The probes were used during in-depth interviews to ask parents to explain what changes they had made or intentionally not made in their daily routines in the areas of work, recreation, worshiping, use of available health facilities and communication in order to accommodate their child's disability. When parents interpreted their difficulties as being stressful to the point of disrupting their daily routine in such a way that they were no longer able to effectively work, participate in recreation, worship, communicate and use available health facilities it was an indication that they had not successfully adapted to their child's disability. In other words, stress lowered their family quality of life FQOL.

One of the basic functions of a family is to ensure essential care and protection is given to children and so, when disability strikes, parents, siblings and other kin take part in supporting the affected member. At least 80% of caregivers for individuals with disability are family members (Pisani & McDaniel, 2012). While there has been research interest focusing on the best types of support for families living with ASD, there still remains very little understanding of the ways different family members adapt to and provide support for each other (Reinke *et al.,* 2014). For instance preliminary research suggests mothers and fathers differ in the type of support they provide for their families (emotional versus practical support respectively). Furthermore, studies on siblings of children with ASD have reported mixed results such as negative responses like anger, embarrassment and behavioural problems; and positive findings such as self-concept, self-efficacy and locus of control (Ward *et al.,* 2016). However, the findings could have been more sufficiently reported using a family-focused approach that takes into consideration factors not accounted for in research designs such as age, sex, birth order, family size, parental relationships, social economic status and other demographic characteristics (Cridland *et al.,* 2014). Many studies which have identified challenges of living with children with ASD have been limited by basic research designs and have in the process examined “stress” in a fragmented manner, leaving out other contributing factors such as allocation of responsibilities, boundaries between family members and personal meanings of having a family member with ASD (Sim *et al.,* 2018). Another important limitation is that there is reliance on maternal perspectives as representative of the whole family. Maternal perspectives may be important but do not necessarily represent the whole family (Cridland *et al.,* 2014). Many studies that have been done are of mothers, and findings are generalized to the rest of the family without interviewing other family members, such as siblings who live in the same household (Cridland *et al.,* 2014). One way of addressing this shortfall is by adopting a family-focused approach in which all members of a household who are living with the child with ASD are included in the study. According to Cridland *et al.,* (2014), research using the family-focused approach that has been conducted to investigate the adaptation and needs of families of children with ASD is considered to be recent, and is derived from the Family Systems (FS) theory that was introduced by Murray Bowen (1913 – 1990). The theory suggests that individuals cannot be understood in isolation, but are emotionally connected as part of their family, and that patterns exist amongst families in the way they respond to anxiety and stress (Edwards, 2011). Applications of systems approaches to families are referred to as FS approaches and are derived from General Systems Theory, which is seen as a ‘unique worldview’ Cridland *et al.,* 2014:17).

1.3 Statement of the Problem

ASD is a lifelong disability. Irrespective of its consequences and impact on family members of a child with the condition, there is paucity of information that addresses the needs and adaptation patterns of families (fathers, siblings and others). This paucity of information hinders the improvement of services especially in developing countries like Zambia (Silibello, 2016; Mandleco *et al.,* 2015).The current number of children diagnosed with ASD at Bauleni School is(18) and UTH Special School (9)(Ministry of General Education, [MOGE, 2018]). Therefore little is known about how the families of these children make adaptations, and how best to support each family. It is this gap that this study sought to fill. Research focused within families is critical for developing an understanding of how to best support families living with ASD.

1.4 Significance of the study

The importance of this study cannot be over emphasised. Families of children with ASD undergo a lot of stress (Roberts *et al.,* 2017; Hayes and Watson, 2012; Johnson *et al.,* 2011).Findings of this study illustrate how families who participated in the study adapted. Therefore programmes to support families can be put in place using these findings. Health care workers can tap from the findings as a basis for provision of care to affected families. In addition, findings of this study on family adaptation will increase nurses' understanding of the impact of ASD on families. Furthermore, the significance of such findings is that they can guide the development of family-centred interventions that can be implemented in low-resource settings by non-specialists such as nurses, community-based workers or peer caregivers (WHO, 2018).

1.5 Research Question

The research question was "How do families adapt to caring for a child with ASD?"

1.6 General Objective

The general objective of this study was to explore adaptation patterns of families living with children with ASD according to Virginia Henderson's Activities of Daily Living (Waller-Wise, 2013).

1.7 Specific Objectives

The specific objectives were to:

1.7.1 Explore the experiences of families living with a child with ASD at Bauleni and UTH Special Schools.

1.7.2 Identify the adaptation patterns of families living with a child with ASD at Bauleni and UTH Special Schools.

1.8 Organization of Report

The dissertation consists of six (6) Chapters altogether. Chapter one includes introduction, and background to the study. Chapter two (2) is the literature review. Chapter three (3) consists of the research methodology that was used to conduct the study, Chapter four (4) includes study findings. Chapter five (5) consists of the discussion of findings while chapter six (6) is composed of study conclusions and recommendations.

CHAPTER TWO: LITERATURE REVIEW

2.1 Introduction

This Chapter outlines literature that relates to ASD which is the phenomenon under investigation. The literature has been reviewed in line with the research objectives. The search engines that were used to search for literature were: Google Scholar and HINARI. Studies were sourced from the following electronic journals: PubMed, Medline, Science Direct, and Sage. Literature (qualitative, quantitative and mixed-method) included in this review was conducted locally, nationally, regionally and globally. The Chapter has been organized under the following headings: Defining ASD; diagnosing ASD across cultures; the effect of ASD upon the family; family centred interventions; factors influencing adaptation of families; child characteristics; parental characteristics; and environmental factors.

2.2 Defining ASD

Criterion that helps health professionals identify ASD universally is derived from both the International Statistical Classification of Diseases in its tenth revision (ICD-10) and Diagnostic Statistical Manual (DSM) guidelines, and is similar (WHO, 2016; APA, 2013). How ASD is defined is of utmost importance because it determines correct and timely detection of the condition, ensuring appropriate and prompt treatment and management. Early interventions in turn modify some of the pervasive behavioural disturbances, which characterise the condition. Criteria for identifying ASD was arrived at after conducting epidemiological research to ensure that it could be used by many cultures worldwide. However, Bakare *et al.*, (2015) has observed that since most of the research on ASDs is from Western countries, this has resulted into a criterion which easily identifies the condition in Western cultures. As a result while it is possible to identify ASD during infancy in developed countries this is not the case in Africa. Early identification and diagnosis necessitates early interventions during early childhood to promote the optimal development and well-being of individuals with ASD. It is therefore important that once identified children and their families with ASDs are offered relevant information, services, referrals and practical support, according to their needs, bearing in mind the fact that a cure for ASD is not available (Chambers *et al.*, 2016; Bakare *et al.*, 2015).

Evidence based interventions such as behavioural treatment and skills training for parents and other caregivers can reduce difficulties in communication and social behaviour, with a positive impact on the person’s wellbeing and quality of life (WHO, 2017). Since caring for these children can be demanding especially where access to services and support is inadequate, empowerment of caregivers is increasingly being recognized as a critical component of interventions for children with ASD (WHO, 2017). Late identification and diagnosis among African children occur for various reasons, which include poor knowledge/awareness about ASD and cultural beliefs and practices. In addition, poor health seeking behaviour, inadequate number of trained staff, and inadequate healthcare also contribute to delays in identification of the disorder (Chambers *et al.,* 2016; Bakare, 2015).

The following is a summary of the DSM-5 criteria that professionals in the health, educational and community development sectors utilize in order to make a diagnosis of ASD:

A. A diagnosis of ASD is made when a total of six or more items from 1, 2, and 3 are present with at least two from 1, and one each from 2 and 3:

1. Qualitative impairment in social interaction, as manifested by at least two of the following: A marked impairment in the use of multiple nonverbal behaviours such as eye-to-eye gaze, facial expression, body postures, and gestures to regulate social interaction; failure to develop peer relationships appropriate to developmental level; a lack of spontaneous seeking to share enjoyment, or achievements with other people such as a lack of showing, bringing, or pointing out objects of interest; and lack of social or emotional reciprocity.

2. Qualitative impairments in communication as manifested by at least one of the following: A delay in or total lack of the development of spoken language and not accompanied by alternative attempts to communicate such as gestures; in individuals with adequate speech, marked impairment in the ability to initiate or sustain a conversation with others; stereotyped and repetitive use of language; lack of varied, spontaneous, make-believe play or social imitative play appropriate to developmental level.

3. Restricted, repetitive and stereotyped patterns of behaviour, interests and activities, as manifested by at least one of the following: Encompassing preoccupation with one or more stereotyped and restricted patterns of interest that is abnormal either in intensity or focus; inflexible adherence to specific non-functional routines or rituals; stereotype and repetitive motor mannerisms (for example hand or finger flapping or twisting, or complex whole body movements); Persistent preoccupation with parts of objects.

B. Delays or abnormal functioning in at least one of the following areas, with onset prior to age three years: Social interaction, language as used in social communication, or symbolic or imaginative play.

C. The disorder is not better accounted for by Rett's or Childhood Disintegrative Disorder (WHO, 1992: 147-149 and APA, 2000:75).

2.3 Challenges in Early Detection of ASD

Research was conducted in South Africa on early detection of ASD among young Zulu-speaking children in order to adapt and translate the Zulu language into tools for detecting early signs of ASD. The results showed that existing tools for detecting ASD can be used to diagnose the condition following appropriate translation and adaptation procedures. It was concluded that similar methods could be replicated by other researchers in different cultural settings for early detection of ASD especially in low income countries Chambers *et al.,* (2016).

In Zambia a study currently taking place is seeking to establish ASD knowledge by different stakeholders such as medical professionals, teachers, policy makers and parents. It has made preliminary findings indicating that some of the professionals, including doctors and medical students, do not know about ASD (Mulenga, 2018). To remedy this anomaly, a Non-Governmental Organisation (NGO), the Mulenga Autism Foundation (MAF), has embarked on a sensitization and awareness raising and advocacy campaign for children with ASD targeting different stakeholders, among them parents of children with ASD (Mulenga, 2018).

2.4 The effect of ASD upon the family

ASD consists of a range of life-long enduring developmental disorders that affect individuals and their families in a number of ways. As a result, families with members who have ASD can be referred to as families living with ASD (Neely-Barnes *et al.,* 2011). Having a child with ASD causes a variety of clear difficulties on family members. Such difficulties include inflexible daily routines, management of unique intolerances, sudden mood changes, and being mediators in social interactions (Cridland *et al.,* 2014). Further, about a third of individuals with ASD require assistance with the following activities of daily living on a daily basis; self-care, mobility, communication, and cognitive or emotional tasks. Most of this care is provided by family members (Australian Bureau of Statistics, 2011). Due to these outlined issues as well as other problems, families living with a child with ASD experience more stress than families of typically developing children and children with other disabilities (Johnson *et al.,* 2011).

Few resources exist to help families accept and adjust to the diagnosis of ASD and deal with the impact of ASD on the family (Oberle, 2017). To address this shortfall, parent training can be undertaken to decrease problem behaviours in children with ASD. However, because it generally does not address family functioning, additional family-based work may be needed and can be done simultaneously with other ASD interventions. Sometimes the presence of problems in the family need to be addressed before parent training so that parents can have the emotional resources necessary to successfully implement behavioural interventions (Oberle, 2017). At a global level, the WHO, (2018) has recognized the need for early interventions in children with ASD by developing a parent skills training program which is currently undergoing field testing. This occurred following the Sixty-seventh World Health Assembly (WHA) resolution which took place in May 2014, entitled "Comprehensive and coordinated efforts for the management of ASD (WHO, 2018).

2.5 Family-centred interventions

When supports are expanded lives of families of children with ASD are improved. In order to reduce family stress caused by a child's behavioural problems, it is suggested that interventions that are family-centred be directed at some of the basic needs such as, access to quality information and services, parent skills training, coordinated services, and transitional supports (Russa *et al.*,2014). To meet these needs, models and strategies from the best practice literature that address family needs include Positive Behavioural Interventions and Supports, Parent–educator Partnership Models, Parent to Parent (PTP), the Medical Home Model, and the Family Navigator Model. An example of a PTP model is the WHO Care Skills Training Program for families of children with ASD, which can be implemented in low-resource settings by non-specialists such as nurses, community-based workers or peer caregivers. The program is family-centred, which means it focuses on training the caregiver on how to use every day play and home activities and routine and consists of nine group sessions and three individual home visits (WHO, 2018).

2.6 Factors influencing adaptation of families

The presence of a child with ASD in a family has adverse effects on marital adjustments, sibling relationships and daily family routines (Ward *et al.*, 2016). Besides the parenting stress accompanying the disorder, it has huge financial implications (Sim *et al.*, 2018). In addition, parents having ASD children experience periods of disbelief, deep sadness and depression and self-blame and guilt whereas others experience helplessness, feelings of inadequacy, anger, shock and guilt (Bashir *et al.,* 2014; Skinner & Weisner, 2007). Research exploring impact of ASD on family adaptation has shown various aspects that contribute to parental coping (Sim *et al.,* 2018; Ward *et al.,* 2016). The following studies highlight child, parental and environmental characteristics that are involved.

2.7 Child Characteristics

Research by Roberts *et al.,* (2017) explored the impact of sleep problems on families' resilience. Results indicated that parents of children with ASD and sleep problems had lower levels of resilience than those who slept well (Roberts *et al.,* 2017). A study by Tomeny, (2016) found that symptom severity was positively related to both parenting stress and maternal psychopathology symptoms. Research that investigated family adaptation in a European multicentre study found that taking care of an adolescent with abnormal behaviour, such as hyperactivity had an aggravating effect on parental distress (Guyard *et al.,* 2017). Results of a population-based investigation of behavioural and emotional problems, and maternal mental health in association with ASD showed that the presence of ASD and ID significantly and independently increased the odds for hyperactivity symptoms, conduct, and emotional problems. Consequently, emotional disorder was more prevalent in mothers of children with ASD (Totsika, 2010).

2.8 Parental characteristics

An investigation of mind-mindedness in mothers of children with ASD showed that mental descriptions of the ASD child were more negative compared to non-ASD siblings, and mothers reported high stress in relation to parenting a child with ASD. Being mind-minded did not protect against parenting stress (Sharmac, 2017).In Pakistan, Batool & Khurshid (2015) found that significant correlations were found between severity of impairment and parenting stress ($r = .53$, $p < .01$), and it was concluded that parents' ability and confidence in their competence of parenting a child in challenging situations may reduce their stress (Batool and Khurshid, 2015). In Zambia Nyoni and Serpell (2011) found that parents of children with ASD experienced pain, confusion, shock and denial and having a feeling like that of having lost a normal child through death. Research by Jones *et al.,* (2014) showed that lack of psychological acceptance was found to contribute to maternal anxiety, depression and stress, while fathers showed depression. It was concluded that parental psychological acceptance and mindfulness were important psychological processes that could be used to inform parental support interventions.

2.9 Environmental (contextual) factors

The presence of family members such as siblings and other kin in the household contribute to a supportive family environment because assistance in care giving is rendered, thereby reducing stress in parents (Cridland, *et al.*, 2014). Acknowledgement of the presence of such supports in the family can inform family-centred interventions, which in turn contribute to ameliorating stress in parents and other family members of children with ASD (Oberle, 2017). Environmental factors may therefore have both an adverse effect as well as a therapeutic benefit to the family as outlined in the following studies (Oberle, 2017; Cridland *et al.*, 2014).

Research investigating sibling experiences discovered that participants recognized difficulties such as decreased parental attention, extra responsibility, bothersome behaviours, and communication difficulties (Ward *et al.*, 2016). In another study by Sim *et al.*, (2018) on factors associated with stress in families of children with ASD it was found that forty-four percent (n = 241) of the caregivers reported severe family stress related to raising a child with ASD. Severe family stress occurred because of not being able to socialize; not having accessed individual therapy; negative co-parent relationships; and high out of pocket costs due to the child's ASD. Research conducted by Timmons *et al.*, (2016) examined daily affect in association with daily relationship factors (partner conflict, support from partner, and relationship happiness). Findings found that the quality of parents' relationships contributed to maternal mental health, family functioning, and daily affect (Timmons *et al.*, 2016). Results of research on “Families of Children with ASD: The Role of Family-Centred Care in Perceived Family Challenges” showed that families receiving family-centred care perceive fewer challenges and felt less unmet need for child health services (Reinke *et al.*, 2014).

2.10 Conclusion

This Chapter has covered literature review based on family adaptation, children with ASD and challenges families experience caring for a child with ASD. The literature review covered the following subtopics: Defining ASD, challenges of early diagnosis of ASD, the effect of ASD upon the family, family centred interventions; and factors influencing adaptation of families such as child and parental characteristics and environmental factors. Studies have found that these factors do not exist in isolation but interact with each other, thereby influencing the degree to which parents may or may not resolve their grief and successfully adapt to their child’s disability (Families Special Interest Research Group, 2012). A lot of studies have been conducted on family adaptation. However, most of these studies have used descriptive, ethnographic and not interpretive phenomenology. With interpretive phenomenology participants share pertinent issues that affect their lives thereby making a study very rich and informative. Interpretive phenomenology enables people to express themselves freely. The next Chapter will describe the methodology that was used to conduct the study.

CHAPTER THREE: METHODOLOGY

3.1 Introduction

This chapter presents the methodology and methods that were used to conduct this study. Selection of the methodology was directed by the research question: “How do families adapt to caring for a child with ASD and give meaning to the lived experience of caring?” The interpretive phenomenological research design was utilised to answer the research question because it is exploratory in nature. Also included in the chapter is information on participants’ demographic characteristics, how participants were recruited to the study, the study setting, data collection techniques, ethics issues, and how data was analysed.

3.2 Research design

This qualitative study utilised interpretive phenomenology to provide an understanding of the adaptation patterns of families caring for a child with ASD through eighteen (18) family members from October to December, 2018. The interpretive phenomenological strategy was used to conduct the study because it was found to be more appropriate for the study. This is because it had a greater perspective that could lead to a better understanding of the phenomenon being studied. According to Morris (2013), phenomenology is a rich textual interpretation of life as it is lived. Heidegger developed interpretive phenomenology in which a researcher moves beyond the description of the experience and seeks meanings that are embedded in everyday occurrences by exploring participant’s reflections with regard to their feelings, thoughts and actions (Reiners, 2012). In using the phenomenological research design the study attempted to understand and explore participants’ lived experiences with regard to their adaptation patterns. In this study, participants living the phenomenon under study – caring for a child with ASD, enrolled at Bauleni and UTH Special schools were interviewed, through individual in-depth and a FGD.

3.3 Study Settings

The study setting was Bauleni School and UTH Special School in Lusaka, Zambia. The sites were purposively selected because children who had been diagnosed with ASD were enrolled at these schools. The two schools are educational institutions under the Ministry of General Education. UTH Special School is situated at the UTH behind the Children’s Hospital. UTH Special School only carters for pupils with special educational needs and has a total of two hundred (200) children with various disabilities (MGE, 2018). Of these children, nine (9) had been diagnosed with ASD; six (6) being boys and three (3) girls. Bauleni School is an inclusive school, which means that it carters for both children with and without developmental disabilities. It is situated at Bauleni Special Needs Project near Bauleni residential area along Leopards Hill Road at Plot 473A, and opposite the Co-operative College. There are eighteen children who have been diagnosed with ASD; fourteen (14) of them boys and four (4) girls (MGE, 2018).

3.4 Study population

The study population was families of children with ASD in Lusaka who met eligibility criteria. The target population was families whose children had ASD and were enrolled at Bauleni School and UTH Special School.

3.5 Sampling

3.5.1 Sampling and recruitment of participants

Purposive sampling was used to select participants, in order to include diverse characteristics. The researcher informed families of the purpose of the study. From among those who were willing to participate in the study, participants were identified and selected with the help and guidance of the head and teachers of the two schools. Participants who were selected were those who were available to participate in the study. Attempts were made to include all members of selected families, such as mothers, fathers, siblings and other relatives living or giving care to the child with ASD. Participants were mostly mothers, grandmothers and some male siblings. It was difficult to get fathers because they were at work. The sample consisted of diverse participants' demographic characteristics such as occupation, religion, place of residence, marital status; and in children co-occurring conditions, and severity of disability and behavioural problems.

3.5.1.1 Inclusion Criteria

In phenomenology an individual who has experienced the phenomenon under study is the one who can be included in the study (Patton, 2015), and thus the inclusion criteria were as follows:

- Biological and foster parents who were living with the child with ASD.
- Any family member who had lived with the child for most of that child's life.
- Those whose children were currently enrolled at either Bauleni or UTH Special School.

3.5.1.2 Exclusion Criteria

Participants were excluded from the study if:

- They were diagnosed with mental health problems by a Clinician.

3.5.2 Sample size

Total number of family members interviewed individually and from a single focus group discussion (FGD) were eighteen from 13 families. The 18 family members interviewed included: 9 mothers, 2 grandmothers, 4 brothers, 1 father, 1 sister and 1 paid helper. The siblings were not primary caregivers, but the mothers, 1 paid helper and 2 grandmothers were primary caregivers. Since in phenomenology, each participant comes with their own individual story due to their diverse experiences (Hein and Austin, 2001), the sample size was not guided by data saturation. The interest was in comparing the different and unique meanings that participants made of their lived experiences. Furthermore, in phenomenology, the number of participants to be interviewed depends on the time available to conduct the study. This is because it takes longer to interview participants because of the exploratory and interpretive nature of in-depth interviews (Smythe, 2011). The researcher also collected data from six participants in a single FGD. The participants were not the same ones that had been involved in the individual in-depth interviews. The purpose of this FGD was to explore further the adaptation patterns of family members from the perspective of a group exchanging information, taking into consideration group dynamics. The members of the FGD were from six different families. They were composed of one older brother, one domestic worker who is a primary caregiver, and four biological mothers.

3.6 Data collection

Data was collected in between 9th and 19th October 2018 by the researcher. The place where data was collected was chosen by each participant in order to minimise the Hawthorne effect (McCambridge *et al.*, 2014).

3.6.1 Data collection methods

Data was collected using individual in-depth interviews and a single FGD. Participants were only interviewed once because in interpretive phenomenology the frame of mind of participants at a given time changes (Hein & Austin, 2001). So there was no need to go back to participants. Demographic details were obtained before each individual in-depth interview and after the FGD. Two voice recorders were utilised to ensure that no data was lost or forgotten, and in case one developed a fault or switched off during recording. The investigator interviewed more than one member of at least 5 families: The first interview involved a mother and sister of a 22 year old adult male ASD child and to access the family home where the interview took place, the researcher got permission from the mother. The second interview was with a mother with a child at UTH special school. The interview, which also involved a sibling to the epileptic child, took place at their home in Kalingalinga. The third interview took place in Zambia Air Force (ZAF) Twin Palms area. The interview was with the child's brother and mother. The fourth interview was with two members of the same family (grandmother and mother of the child). The interview took place in New Chilenje. The last interview was with a father and brother of a female 22 year old adult child with co-occurring severe ID, who was in pre-school at Bauleni School. The child had been disserted by her mother when she was four years old and was left behind to be raised by her father. The interviews took place in their home in Kalingalinga compound. Length of interviews ranged from 30 minutes to more than one hour, while the FGD took one hour.

3.6.1.1 Individual in-depth interview technique

Members of a household who met inclusion criteria were interviewed. Participants were asked to choose the place of interview and the researcher ensured it was a place which was safe for her to conduct an interview in, as well as a place which offered privacy to the participant during the interview. Unstructured in-depth interviews were used in order for participants to express themselves freely without being limited in whatever they wanted to say. However whenever a participant digressed from the topic the interviewer gently steered him or her back to the discussion topic. With regard to the interview technique, the researcher ensured the interviewee was at ease by first building rapport and showing respect to him/her. When the participants showed signs of being at ease, the researcher began the interview with an introductory question: "Tell me your experience of looking after your child with ASD including adaptation you have made in order to adjust to living with your child?" Or if it was an interview with a sibling the question would be: "Tell me your experience of living with your brother/sister with ASD and adaptations you have made in order to adjust to living with your sister/brother?" As each participant started talking, probes and prompts that were in line with the participant's response were included in the interview. Interviews that were conducted in vernacular and translated into English were proof read to ensure original meanings had not changed. This was done by randomly picking two to three translated interviews and giving them to someone else to proof read to ensure that the translation was accurate.

3.6.1.2 Focus group discussion technique

A FGD was conducted by the investigator in Bauleni Resource Room, which provided privacy and confidentiality. The purpose of the FGD was to explore further the adaptation patterns of families caring for a child with ASD by allowing multiple voices to be heard at one sitting; drawing a larger and more varied sample. It also enabled the researcher to engage with a naturally occurring group, in this case, six family members (four mothers, a paid helper and a brother) from different households who had not been previously interviewed. The affected children had ASD and attended the same school. Palmer *et al.,* (2010) indicates that FGDs may provide rich experiential data that may be integrated into interpretive phenomenological analysis. In addition a FGD may elicit more experiences than a one to one interview. During the FGD the researcher took note of group dynamics, and interactions and recorded her observations in her diary as field notes. The FGD was audio recorded with two recorders in case one of them malfunctioned.

3.7 Data management and storage

During the FGD and in-depth interviews, some field notes were written down to record information that could not be recorded such as body language, and the atmosphere around where data was collected. Audio recorded information was safely kept in a password protected computer. Names that were mentioned by participants were not disclosed during transcribing, analysis or report writing, and the participants were assured of this. At the end of each interview and the FGD the investigator transcribed each conversation while it was still vivid. The interviews and FGD were coded and numbers as well as pseudonyms were used so as not to identify any participant. Paper transcripts were locked in a secure cupboard. The voice recorders with the interviews were kept secure, and all information gathered during the interviews and FGD were kept confidential and participants were assured of this.

3.8 Data analysis

Although written in this manner, data analysis was not a distinctive step. It began as early as the choosing of the study topic in accordance with van Manen's (2001) six steps of analysis that were used in this study. The steps are as follows:

1. Turning to a phenomenon of interest

The investigator started by choosing a topic of interest. In this case 'Family adaptation patterns of caring for a child with ASD' was the phenomenon of interest.

2. Investigating experience as we live it

Data from participants who have the experience of living through this phenomenon were obtained by conducting individual in-depth interviews and a FGD.

3. Reflecting on the essential themes, which characterize the phenomenon

After transcribing the audio recorded interviews and FGD, themes were arrived at by reading sentence by sentence, and phrase by phrase. Key statements were chosen from the transcripts. Reflections of participants' feelings, thoughts and actions were arrived at from the key statements and were used to identify and outline meanings derived from their experiences. The meanings that the researcher identified were summarised into themes.

4. Describing the phenomenon (The art of writing and re-writing)

Themes were used to summarize each participant's story and then the stories were compared against each other for similarities and differences.

5. Maintaining a strong and oriented relation to the phenomenon

Participants' stories and their interpretation and not the investigator's preconceptions were obtained.

6. Balancing the research context by considering the parts and the whole

The investigator ensured that the themes were answering the research question and within the title of the topic by comparing individual stories (the part) with the research topic (the whole) repeatedly.

3.9 Rigour of the study

According to Yardley, (2008) rigour refers to the thoroughness of the study. Yardley's (2008) four broad principles were chosen to establish the quality of this qualitative research. The four broad principles are:

1. Sensitivity to context.
2. Commitment and rigour.
3. Transparency and coherence.
4. Impact and Importance.

3.9.1 Sensitivity to context

Interpretive phenomenology researchers start demonstrating sensitivity to context in the very early stages of the research process (Yardley, 2008). In this study sensitivity to context was demonstrated by showing the socio-cultural context. A literature review on the topic and how data were obtained from the participants has been outlined to introduce the reader to the topic. Selecting interpretive phenomenology as a methodology and the rationale for utilising it was based on sensitivity to context (Kwaleyela, 2016). Sensitivity to context was also ensured by rapport, empathy and respect during interviews so as to ensure participants freely voiced out their experiences. Moreover the investigator introduced herself as a student and did not reveal that she was a nurse. Sensitivity to context was also demonstrated by outlining a number of verbatim extracts from the participants' transcripts to support statements being reported on. These allowed the voices of participants to be heard by readers. The findings were later related to relevant existing literature in the discussion chapter.

3.9.2 Commitment and rigour

Commitment to probing so as to pick out important cues of meanings from the participants' narratives was undertaken. During interviews the investigator consistently sought to probe the meanings behind simple descriptions into interpretations. In line with Kwaleyela (2016) PhD's dissertation, commitment and rigour were also followed by repeatedly reading through the field notes written after each interview. Field notes were composed of participants' emotional responses, including body posture, and the atmosphere in the interview environment.

3.9.3 Transparency and coherence

Transparency refers to how clearly the stages of the research process are described in the write-up of the study (Yardley, 2008). This was achieved by describing selection of research participants, conduction of interviews, and data analysis steps as well as updating the supervisors with whatever was going on during the entire research process.

3.9.4 Impact and Importance

Yardley (2008) makes the point that however well a piece of research is conducted, a test of its real quality lies in its impact and importance. To provide the impact and importance of this study the investigator outlined the significance of conducting this study, the background information and the literature illustrating the phenomenon. Koch (2006) recommends the inclusion of a decision trail as an essential part of a study in order to confront the problem of establishing rigour in interpretive phenomenological research.

3.9.4.1 The Decision Trail

The decision trail of this study consisted of filling all the data in such a way that supervisors could follow the chain of events that led from the initial documentation through to the final report. According to Cridland *et al.,* (2014) an array of statistical techniques is available to researchers applying Family Systems (FS) approaches to individuals with ASD and their families. It is important to note that FS data naturally depends on each other. For instance, in this study the investigator was interested in how a child's characteristics influenced his or her parents, siblings or significant others' behaviour. So data from this FS research had certain characteristics that needed to be considered during analysis because data are usually nested or hierarchical in nature (Cridland *et al.,* 2014).ASD children are members of families and thus, they are nested within families.

Furthermore, in this study, when interviewing a parent the researcher had in mind the severity of the child's condition as well as any co-occurring conditions by taking note of the child at either the school or during the interviews in the home environment, as well as noting the quality of interactions between him/her and his or her parent(s). It was also important to consider the ways in which family dynamics could influence the analysis and interpretation of findings. Such considerations included family size (e.g. number of siblings), sibling ages and genders, and blended families. This was done by taking note of any history of previous separations and re-marriages and connecting this background to the participant's stories during the interviews. A constant record of field notes during individual interviews and the FGD was regularly referred to and considered during data analysis and meaning making.

3.9.4.2 Reflexivity

In the process of reflexivity, the investigator reflected continuously on her background and experience as a mental health nurse so that her professional experiences would not influence the interpretation of data.

3.10 Limitations of the Study

The researcher's intention was to conduct individual interviews with at least three to four members of each family, and to include, if possible both parents. However, this was constrained by difficulties in accessing fathers of children with ASD because they were at work during day time when it was possible to collect data; except for one father who made time, and waited to be interviewed together with an older sibling at their Kalingalinga home. This was despite efforts to get in touch with fathers through the school and other family members.

Since this study was contextual, the focus was on families living the phenomenon whose children with ASD were currently enrolled at Bauleni School and UTH Special School, and hence the findings should be generalized with caution.

3.11 Ethical considerations

To start with, the research proposal was submitted to the University of Zambia Biomedical Research Ethical Committee (UNZABREC) for review and ethical approval. After obtaining ethics clearance (Appendix XV) from UNZABREC, permission to conduct the study was sought from the National Health Research Authority (NHRA) (Appendix XVI: a, b, and c), and District Education Board Secretary (DEBS) (Appendix XVI: d and e). After letters authorizing data collection were received from NHRA and the DEBS office, the investigator approached the school head teachers for permission to collect data. With assistance from the head teachers of the two schools, meetings with families were arranged. On prearranged dates and times, the researcher explained all the details of the study to the prospective participants with the use of information sheets. Queries were clarified, and those who wished to participate in the study were recruited in accordance with the inclusion criteria.

Participants were recruited into the study on a voluntary basis after being provided with an information sheet (Appendix IV, X) which explained what the study was all about. Those who agreed to participate were asked to sign a consent form (Appendix V, XI) based on the information that was given to them. Participation of all family members was based on voluntary and informed consent. To carter for family members who were below 18 years an assent form (Appendix VI, XII) was filled in and signed by the head of the family or parent if they agreed to their child (sibling of child with ASD) to participate in the study.

If a participant encountered psychological distress during the interview or FGD, they were referred to an identified trained counsellor. Participants' privacy and confidentiality was maintained throughout the study process. Participants were assured that if they wanted to withdraw from the study they would not be victimised or punished in any way neither would their child's education at the school be negatively affected.

CHAPTER FOUR: FINDINGS

4.1 Introduction

This phenomenological study focused on understanding the phenomenon of family adaptation experiences of caring for a child with ASD from interviews and a FGD with participants. This chapter presents socio-demographic characteristics of participants and their children with ASD and the themes derived from the study findings. Themes are regularly occurring meanings in form of actions, thoughts and feelings derived from reading the transcribed text, and repeatedly listening to participants' voice recorded interviews (Gill, 2014). Three major findings were arrived at during data analysis. The key findings emerged through three themes namely: Perceived sources of parental distress; Experiences and beliefs; and Accommodating the needs of a child with ASD, emerged from the data. The major themes were supported by several subthemes. The implications of the findings on practice are that most parents were greatly distressed by their children's behavioural disorders and made significant adaptation changes in order to cope with the situation. Delays in diagnosis occurred due to lack of knowledge of ASD amongst health care workers and negative cultural beliefs resulting into late school placement. It was also noted that the ability for families to accommodate their child with ASD affected their adaptation. The presentation of findings in this chapter will start by showing the narratives of the socio-demographic characteristics before the table.

4.2 Socio-demographic characteristics of participants

The socio-demographic features (Table 1) of the participants were as follows: The age range of participants interviewed was 14 to 61years. Out of 18participants who were interviewed 13were female. Of the 13female participants, nine were biological mothers, two were maternal grandmothers, one was a sibling and one was a paid helper who was also a primary caregiver. Five males were interviewed, and of these, four were siblings, while one was a biological father. The lowest educational level of participants was primary school level (five participants) and the highest educational level was a Degree. Participants who had Degrees were two mothers. Participants' areas of residence included Chawama, Kalingalinga, Bauleni, New Chilenje, Kamwala South, Libala, ZAF Twin Palms and Nyumba Yanga. Nine participants (all biological mothers) were married, while the siblings (5)were single. Two participants were divorced and two were widowed. The following were participants' occupations: Micro business dealers (3), domestic workers (3), housewives (2), junior secondary pupils (2), University student (1), professional footballer (1), shop assistant (1), laundry assistant (1), retiree (1), and teachers (2). Half of the participants were from traditional churches such as Catholic, New Apostolic, Seventh Day Adventist and Church of Christ, while the other half congregated with various Pentecostal Churches.

4.3 Socio-demographic characteristics of children with ASD

The socio-demographic characteristics (Table 1) of children with ASD were as follows: The age range was six to twenty-two years of age. The gender of the children was ten males and three females; and all the children had varying degrees of co-occurring IDs ranging from moderate (4) to severe (9).Four of the children had Attention Deficit Hyperactive Disorder (ADHD), two were poor sighted and two had seizure disorders. All were in special classes as follows: Six in preschool, two in grade two, two in grade one, one in grade six, one in grade seven and one was on individualised learning plan. Table 1 illustrates the socio-demographic characteristics of participants and their children:

TABLE 1. Biographical Data

Participants' Characteristics										**Child's Characteristics**				
Code	**Age**	**Sex**	**Educational level**	**Occupation**	**Marital Status**	**Religion**	**Relationship to child**	**Length of caring for child**	**Residential Area**	**Age of child**	**Sex**	**Educational level**	**Co-occurring conditions**	**Degree of intellectual disability**
1	45	F	Junior Secondary	Small scale business	Married	New Apostolic Church	Grandmother	8 years	Chawama	8 years	M	Pre-school	Seizures Low vision Weak left limbs	Severe I.D.
2	40	F	Senior Secondary	House wife	Married	Pentecostal	Mother	12 years	Kamwala South	12 years	F	Grade 2	ADHD	Severe I.D.
3	34	F	Primary School	Small scale vendor	Married	Pentecostal	Mother	11 years	Kalingalinga	11 years	M	Grade 2	Epilepsy ADHD	Severe I.D.
4	16	M	Junior Secondary	Pupil	Single	Pentecost	Brother	5 years	Kalingalinga	-	-	-	-	-
5	21	M	Degree Food & Nutrition	Student	Single	Church of Christ	Brother	9	ZAF Twinpalms	9	M	Grade 1	ADHD	Moderate I.D.
6	41	F	Degree Teaching	Teacher	Married	Church of Christ	Mother	9	ZAF Twinpalms	-	-	-	-	-
7	60	F	Primary	Retiree	Widowed	Catholic	Grandmother	10	New Chilenje	13	M	Grade 6	Squinted eyes	Moderate ID.
8	38	F	Senior Secondary	Works at UTH Laundry	Widowed	Catholic	Mother	4 years	New Chilenje	-	-	-	-	-
9	42	F	Primary School	Maid / Primary Caregiver	Divorced	Pentecostal	Not related	5 years 5 months	Kalingalinga	7 years 5 months	M	Lowani	-	Severe I.D.
10	36	F	Degree	Teacher	Married	SDA	Mother	9 years	Libala	9 years	F	One-on-one	-	Severe I.D.
11	37	F	Junior Secondary	Maid	Married	Pentecostal	Mother	16 years	Bauleni	16 years	M	Pre school	-	Severe I.D.
12	25	M	Degree	Brother	Single	Christian Baptist Church	Brother	12 years	Nyumba Yanga	12 years	M	Grade 1 Special School	-	Moderate I.D.

13	43	F	Primary Level	Trader / Salaula	Married	Presbyterian Church	Mother	6 years	Bauleni	6 years 11 months	M	Pre school	ADHD	Severe I.D.
14	43	F	Primary School	Maid	Married	International Church of God	Mother	10 years	Bauleni	10 years	M	Pre school	ADHD	Severe I.D.
15	61	M	Junior Secondary	Shoprite meat Section	Divorced	Pentecostal	Father	22 years	Kalingalinga	22 years	F	Lowani	-	Severe I.D.
16	26	M	Junior Secondary	Footballer	Single	Pentecost	Brother	22 years	Kalingalinga	-	-	-	-	-
17		F	Certificate	Housewife	Married	Pentecost	Mother		Nyumba Yanga	22	M	Grade 7	Disalcula	Moderate I.D.
18		F	Junior Secondary	Student	Single	Pentecost	Sister		Nyumba Yanga	-	-	-	-	-
Number of Participants interviewed 18														

4.4 Themes and sub-themes

Summary of Sub-themes and Themes

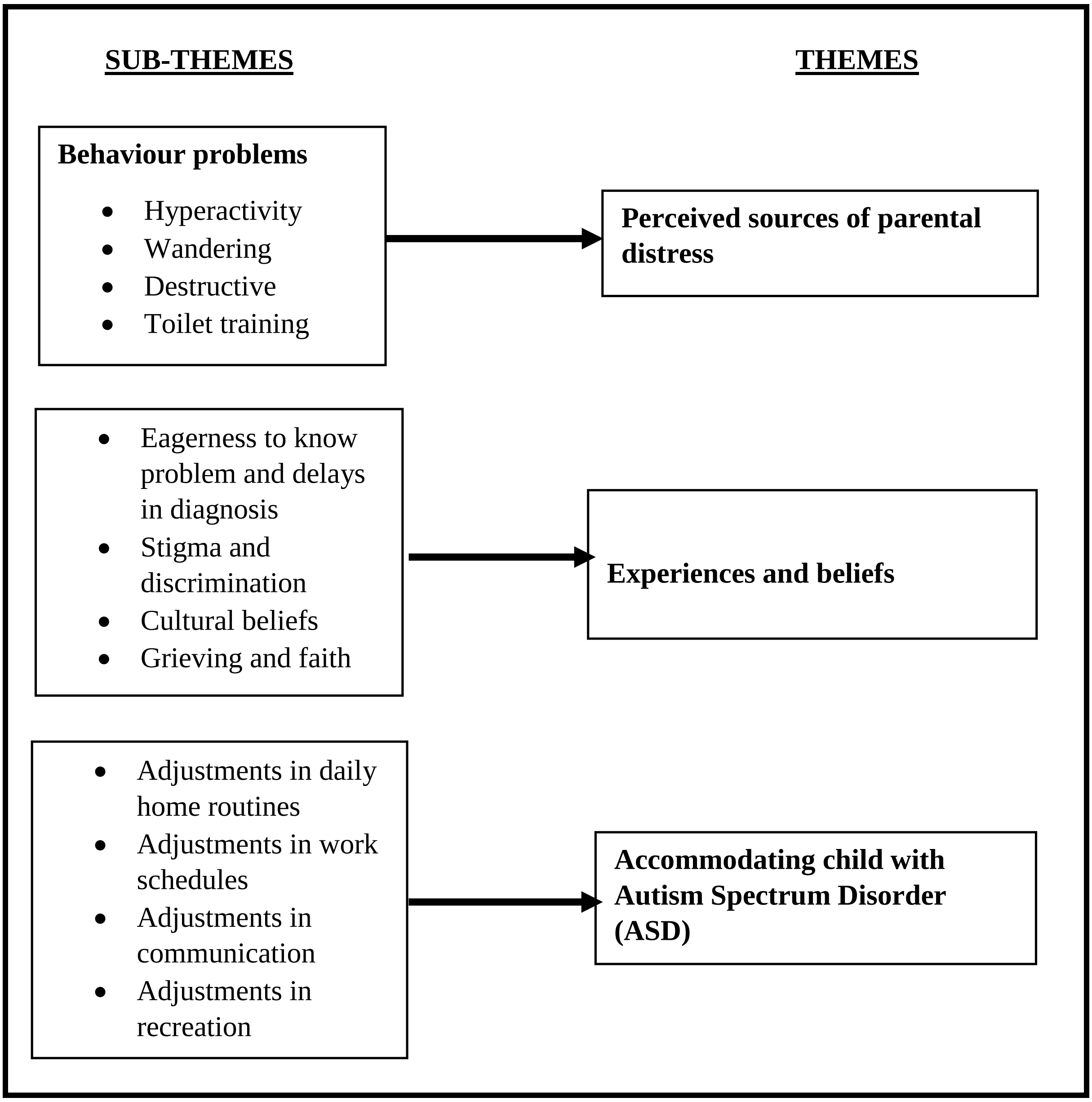

Figure 1

4.4.1 First theme: Perceived sources of parental distress

The theme "Perceived sources of parental distress" describes participants' distress due to their children's behavioural problems that were difficult to manage. Such behaviours were challenging and sometimes posed a danger for the affected child because of their life threatening nature. Behaviours that were a challenge included hyperactivity, which led to wandering and getting lost on numerous occasions. Many of the participants also reported difficulties with toilet training. Some participants reported violence, which involved pushing and fighting. Other behaviours included destruction to property, and antisocial behaviour which occurred both at home and in public. Most participants narrated that their children's abnormal behaviours made them realise that something was wrong. In addition, the unpredictable and dangerous nature of their children's behaviours caused anxiety and made it very difficult for family members to manage and cope. This is how Respondent 3 put it:

> *"...when she was young 3, 4, 5, 8 years was very crucial for me because I mean...even just at home when you are washing, the moment you just for a minute...you just...you are not seeing her...you are even scared...where is she...and the time...the difficult time is when we drilled a borehole at home...she used to climb on a tank high up there. What she would be doing up there is something else..."* (Respondent 3, p, 3)

The subthemes that informed this theme were:

4.4.1.1 Hyperactivity

Many participants reported that their children with ASD were constantly moving and would not keep still or sit in one place for long. They were always involved in types of behaviour such as continuous talking. A mother of 43 years old with a 7 year old child with co-occurring ADHD and severe ID related how her son developed an abnormal behaviour in which he was talking and singing continuously both day and night. Medical intervention had to be sought for the problem to be resolved.

> *"When he turned 4 years one Friday the whole day he spent the whole day and night making noises… and singing and the whole of Saturday…. So I took him to the clinic, and he was just busy talking continuously. ... When I would give him some food he would eat only a little bit."* (Respondent 14, p, 16)

Several parents with children who had ASD and co-occurring ADHD and severe ID related how their children were unable to be in one place but were always moving continuously. For instance one of them had this to say:

> *"What caused me to know that this child was not well because as he continued to grow towards two years of age he would be just a child who would move round and round…. He would not sit in one place…. He would move around the whole day… If you get hold of him and make him sit in one place he would then cry, stand up and continue going round and round the whole day.*" (Respondent 15, p, 18)

Many parents expressed anxiety at some of the serious behaviours which they found life threatening. For instance two families explained how their children had been hit by vehicles as a result of being hyperactive. Luckily, they were not seriously injured. A 16 year old elder brother to an 11 year old male child with co-occurring epilepsy, ADHD and severe ID had this to say:

> *"….he is naughty, we are just strong because when he is at home he doesn't sit in one place, he moves around a lot and you will hear that he has done this and that…. Recently we heard that he was bashed by a car ..."* (Respondent 5, p, 3)

Some family members related how their children often wandered away and got lost. For instance a 41 year old mother recounted how her 9 year old son with ASD and moderate ID often went missing because he was not able to sit in one place for long.

> *"I think he got lost about four times..."* (Respondent 7, p, 10)

4.4.1.2 Difficulty with toilet training

Most family members of children with ASD reported that toilet training was a challenging experience. For instance respondent 10 outlined the challenges that she experienced when caring for her child.

> *"... if its poop* (defaecating) *he would do it wherever he is sitting, ... when he would go into the toilet it was as if he would see something, he would run out of the toilet. So we let him be and he would defaecate behind the house"* (Respondent 10, p, 2)

4.4.1.3 Violence

Three participants reported that when playing with friends, fights often occurred in which the child with ASD hits or pushes his play mates.

> *"He plays with friends but if they disturb him he would get a stone or beat the friend with hands ... Sometimes he would beat you up ... hurls food around and go away ... he stoned someone's child ... they were playing my child stoned that child and blood started coming out."*(Respondent 4, p, 11)

4.4.1.4 Destruction to property

Some participants narrated how their children destroyed property within their homes and in other people's homes. For instance one participant related how her son had broken a window at a certain house and how she was asked to replace it. Another participant recounted how her child unknown to her, entered a neighbour's house and broke some household items. The following quotation highlighted destructive behaviours of one ASD child as narrated by a mother.

> "*She reached a stage whereby she would destroy things in the house ... she would spill water in the mealie meal ... she would get a container of milk maybe it's even full sealed we haven't even used it she would just open it and then throw the milk in the sink and even the juice she used to do that.*" (Respondent 3, p, 2)

4.4.1.5 Parents expressed need for respite and desire for other supports

Almost all the parents with children who had behaviour problems expressed their need to have some kind of rest or relief through provision of a school bus, boarding facilities, and longer school hours. Two mothers and a father stated their desire to have their children in boarding while many of the mothers suggested that the schools should keep children at school for the whole day. This is what one mother said:

> *"We are requesting for help whether the school could keep our children the whole day from morning till 16 hours to make our burden light."* (Respondent 14, p, 20)

Her husband who was not the child's biological father was not involved in supporting her care for her son, and they often had conflicts because of his destructive behaviour – to the extent of having gone on separation at least three times in the recent past, after fighting. She expressed her desire to have her son enrolled in a boarding school:

> *"I just go round looking for him ... Anyway what I am thinking on such a child is that if maybe he can go to a boarding school ... like those for sisters where at least they are well kept so that unnecessary movements are reduced... I am just in pressure because there is no one to relieve me."* (Respondent 4, p, 2, 4)

4.4.2 Second theme: Experiences and beliefs

The theme *"*Experiences and beliefs*"* consisted of four sub-themes: Parents' eagerness to learn about their child's condition and Delays in diagnosis and intervention; Stigma and discrimination against children with ASD; Grieving and faith; and Cultural beliefs about the causes of ASD. Most of the parents and guardians related experiences they had been going through due to lack of information and knowledge of ASD, and how the some private schools were very unsupportive and ignorant of the condition. In addition parents stated how some clinics and hospitals took long to assess their children. One mother made the following remarks:

> "*...it took time for her to be admitted at ...* (A named special school)*, others I hear they give up and me I never gave up ... I went to the hospital I had to negotiate with them to do all the tests within that month because I cannot stop working with her what is she going to be eating ....."* (Respondent 11, p, 4)

4.4.2.1 Eagerness to know problem and delays in diagnosis

The sub-themes "Eagerness to know problem and delays in diagnosis" is a reflection of what parents in the study experienced in order to learn about their child's condition and how they had to become assertive in order to have their child assessed and treated. Most of the study participants, narrated that it took time to know what was wrong with their child, partly because some of the health personnel in the clinics and hospitals did not seem to know about ASD. They related how their children had to undergo a long assessment process, which involved taking their children to several Departments located in different parts of the city of Lusaka. One participant travelled all the way with her ASD child to the UTH in Lusaka from Livingstone, but he still was not diagnosed. Here is what she said:

> "*... we made an effort and visited the UTH. ……. travelled to Lusaka, they tried to screen although the procedure was not well completed. We were told that you just wait he will be able to communicate..."* (Respondent 7, p 1)

Parents who were in employment worked hard to explain to their employers why they had to make frequent reviews to the hospital, while at the same time negotiating with the hospital to conduct all the required tests in good time. Three parents, a grandmother and two mothers explained how when they realized their children had problems in their development made efforts to take them to private pre-schools in the hope that they would catch up, but to no avail. They also indicated how visits to hospitals to seek for answers to their children's problems was a slow process, that left them seeking for help from other sources such as relatives and private mainstream pre-schools. A grandmother had to consult a relative who lived in Kabwata for help, as can be seen from the following statement:

> *".... I .... and the mother ………took him to the hospital where he was examined, ... I was not told the results so ... a sister in law who lives in Kabwata ... ... assessed him and confirmed that he needed to be in a special school and to be checked by a doctor."*(Respondent 8, p 2)

4.4.2.2 Stigma and discrimination against children with ASD

The sub-theme "Discrimination against children with ASD" expressed most participants' experiences of having their disabled children discriminated against in almost every area of life. These included some traditional churches, normal stream schools, public transport, residential neighbourhoods, and even in their own families. Respondent 3, for instance, narrated her experience with strong emotional undertones which have been highlighted in bold italics:

> *"The first day she went to school I went there during lunch…the head mistress was so upset she told me, 'we can't handle your child here this child is abnormal there is something wrong with her brain...take her, and come for your refund.'…**Just like that**…**I felt bad.** I felt* (strongly emphasized) *bad…**I didn't do anything just tears coming out of my eyes**. I got my child I got on a bus and went home"* (Respondent 3, p, 4)

In addition, some participants confessed that many people they knew keep their children hidden children at home and did not take them for assessment or available interventions because they feared stigmatization. This practice of hiding children was confirmed by Respondent 9, a 38 year old widow and mother of two who confessed that when her child was younger she attempted to hide him at home but was encouraged by her mother to expose him and take him to a special school. She said:

> *"At first I never took him to the special school I just said I'll keep my child at home. I won't let anyone know about this problem…There are some women out there who do not expose their children, like mine…"* (Respondent 9, p, 7)

4.4.2.3 Helplessness and powerlessness

The experience of helplessness and powerlessness reflected many of the participants' experiences of having a child with ASD discriminated against and explained the phenomena further. For instance the sentiment,

> "*I didn't do anything just tears coming out of my eyes,"*

was Respondent's 3's expression of how she felt at the discrimination that she experienced at the private school.

4.4.2.4 Grieving and Faith

Almost all participants testified of spiritual growth as a result of having a child with ASD. However, from their narratives it was evident that it had been a process of grieving that began with denial, and was followed by anger and questioning God's sovereignty, and ended with accepting the child's condition as God's purpose. Respondent 11 for instance, had many feelings to battle with. These included feelings of what she perceived to be betrayal by God, unfairness, and the thought that maybe she was more sinful than other people. However, she narrated how she later came to accept her child's condition and shared how she had become strong in her faith in God. She shared during the FGD how she sings in three choirs at church, reads the Bible when feeling troubled about her daughter's condition, and how she takes her child to church for various activities. Highlighted italicized words illustrate strong emphasis as the participant expressed herself.

> "*So I was like aah… but* **this is not fair God, why?...***Because I had a miscarriage between her and the other one. So I started thinking Uum… But this what is this?* ***I began to go through in my mind, Does it mean that I am full of sins****, why God all these things, But when I reached home I just said God I go to church I am a Christian, if this is permanent, let it be but* ***help me to accept and to live within this thing that you have given me.****"*(Respondent 11, p, 12)

4.4.2.5 Cultural beliefs about ASD

Most participants narrated how they believed their children were bewitched at first, and even sought the assistance of witch doctors and prayers for a cure. However, after realizing that the advice and treatments they were receiving was not helping their children, they sought medical attention from clinics and hospitals. They related how the witch doctors informed them of various causes of the condition. One sibling, a 16 year old participant, indicated that his mother was told that it was the child's paternal grandmother who had bewitched his brother. This is how he put it:

> *"Yes, when the granny died he became well…..What they did to him made me feel very bad. What I heard is that … granny is the one who did this to him… The problem was that she wanted JJ to die so that she can be well. Instead JJ became well, and she is the one who died and that was the problem."* (Respondent 5, p, 2, 3)

4.4.3 Third theme: Accommodating the needs of a child with ASD

The theme "Accommodating the needs of a child with ASD" is a picture of the various and numerous changes that all participants in the study made while caring for their ASD child. It was informed by the sub-themes: Adjustments in daily home routines; adjustments in communicating with ASD child; adjusting work schedules to meet the needs of a child with ASD and adjustments in lifestyle to accommodate child with ASD.

4.4.3.1 Adjustments in daily home routines

Different family members such as mothers, grandmothers, brothers and a father reported how changes in the family's daily routine enabled them meet their children's unique needs and at the same time enabled them to adjust successfully to life with a child with ASD. However many participants highlighted how they were still experiencing challenges as they sought to make adaptations as illustrated by Respondent 14.

> *"Some time ago we used to live a comfortable life, waking up at whatever time we wanted but this time I wake up early in the morning, and see how I am going to transport this child to school, and he needs a bath, and needs to be cared for, not to scold him, and you should make sure that he has eaten, and talking to him very gently."* (Respondent 14, p,1)

Participants who were siblings supported their parents by picking up their ASD brother or sister from school and supervising him or her at home. For instance, Respondent 13, the older brother of an eleven year old ASD child explained how he and other family members participated in supporting his mother by taking over various tasks which included taking his brother to and from school:

> *"Adjustments are there ... mother has grown older so I am the one who supports taking him to and from school with other family members.."* (Respondent 13, p, 9)

4.4.3.2 Adjustments in communication

Most participants gave examples of how the made "Adjustments in communication". They related how they talked patiently and calmly to their children, avoiding harshness because this precipitated angry outbursts. A 45 years old grandmother of an 8 year old ASD child with co-occurring seizures, low vision, weak left limbs and severe I.D. related her grandson's emotional expressions when upset:

> *"If you express harshness when talking with him, he tends to easily get into a temper tantrum. When you tell him that you will not take him to school because he is misbehaving he will become very quiet…but when you tell him that you have changed your mind and that you will take him to school he will be very happy and even go out to play."* (Respondent 2, p, 2)

4.4.3.3 Adjustments in parents' jobs

"Adjustments in parents' jobs" reflected changes that parents in employment made in order to meet their children's unique needs. All participants reported an adjustment in their daily home routines, work and business ventures. This ranged from stopping work and finding alternative means of income, to negotiating with employers on re-scheduling of work, or having certain days off in order to meet the needs of their child. Participants with low educational attainments, such as primary school education supplemented their financial needs by getting involved in micro business ventures or working as domestic workers. Respondent 11, a secondary school teacher, had to tell her supervisor about her situation so that her work schedule would be in synchrony with her child who was on an individualised learning plan. Here is what she had to say:

> "*… the head teacher they just said no,' you should be teaching all your periods up to 10 hours.' So with me at work I knock off at 10hours for now. So that I bring my child here I wait one hour and then again go back with her but there are times that I can't manage, my young sister brings her so now she is the one who is with her there."* (Respondent 11, p, 8)

However this was not the case for Respondent 3 who had hoped to improve her educational level, and after that go for teacher training, whilst at the same time carrying out her business. Instead, she had to forgo thoughts of advancing her studies and getting a good job, and she could not continue with her business due to caring demands required for her daughter. The following remarks outline how she expressed herself with regard to this issue:

> *"I wanted to rewrite certain subjects to make a certificate improvement on that and then I wanted to do teaching. And then of which it never happened... And then with the business I couldn't continue …"* (Respondent 3, p, 9)

This mother's adjustment to her life's plans seemed to be fraught with regrets of what could have been had her dreams, wishes and plans come to pass.

4.4.3.4 Adjustments in lifestyle to accommodate child

The sub-theme “Adjustments in lifestyle to accommodate child,” reflected how most families made various life style changes to enable them adapt to their child’s ASD. Nevertheless, they still expressed feelings of being burdened and desired respite, relief and support. Involving siblings in caring for their brother or sister was one of the ways of adapting. For instance, one father, Respondent 16, aged 61 years and the only father in the study had raised his daughter with severe ID, now 22 years, from the time she was 4 years old after separating from his wife. He explained that he had to deliberately delay remarrying for the sake of his daughter because he did not want her to be mistreated by a stepmother. He reported that his daughter’s siblings were boys and stated that when it came to self-care during times she was having her periods or when she opened her bowels - that is when they faced extreme challenges because the domestic workers he employed were not live-ins. He related how there were times when after defecating the daughter forgot to put back her trousers on, and so he would have to pick them up for her and hand them back. He also indicated that he ensured she did not leave the house because they lived in a small flat within a complex and used communal toilets. So whenever she needed to use the toilet, they allowed her to open her bowels in the house after which they would clean up. This is how he expressed this difficulty that he faces,

> *“At such a time that is when it becomes very difficult.”*

Her elder brother confirmed that he was responsible for keeping his sister company and cooking for her whenever their father was at work. However, with regard to having a sister who is disabled he expresses these feelings:

> *“I do not feel good in this situation in which my sister is because she also needs to talk and to help with house work.”* (Respondent 17 p, 1)

4.4.3.5 Recreation for families and their children

Most participants reported how that they attended functions such as weddings leaving their children with ASD behind because of their hyperactive and destructive behaviour. In addition, some of the mothers indicated that their children were very sensitive to the noise that characterises these functions. For instance Respondent 15 a 43 year old mother to a 10 year old child with ASD and co-occurring ADHD and severe ID said:

> *"Most of the time I do not go with him I leave him because when I go with him in a noisy place he doesn't want. He closes his ears; he does this (she demonstrates by holding both ears with both her hands)."*(Respondent 15, p, 10)

However, one participant, indicated that she takes her child along to weddings and encourages him to participate in whatever is going on during the function in orderto make him happy:

> *"With me when there are wedding programs I take him along with me… I encourage him to go and join the dancing ... I just want him to be going so that he also rejoices at such occasions. Yes ... I take him along I don't want to leave him behind."* (Respondent 12, p, 10)

On the other hand, two mothers explained that their husbands take their other normally developing children for outings but leave the ASD children with them at home. Respondent 3 narrated how it affects her when her husband leaves her daughter behind, more specially that the girl shows that she would love to join her brother, when their father is taking him and her smaller sister on family outings:

> *"…there were instances whereby ... He would take the young brother and leave Blessings crying ... yes."*(Respondent 3, p, 13)

The other mother; a 41 year old primary school teacher stated that her husband takes her other two children out on family outings but leaves their child with ASD behind with her at home. She did not seem to mind and explained that in fact her son, aged 9 years liked to remain with her at home.

> *"At first, what used to happen is when the other two girls goes for parties, birthday party or just an adventure to go out, we used to leave him because what he used to do is, when you are with him, just a few moments you find that he is not with you. running up and down, ... hyperactive.* …. (Respondent 7, p, 9)

CHAPTER FIVE: DISCUSSION

5.1 Introduction

This chapter discusses the findings of this interpretive phenomenological study, which was focused on providing an understanding of the lived experience of how families adapt to caring for a child with ASD. Data was collected using in-depth interviews and a single FGD with family members from different households. Participants included biological mothers, grandmothers, one father, and siblings. The study was conducted from October to December in the year 2018. The general objective of this study was to explore family adaptation patterns of caring for a child with ASD at Bauleni and UTH Special Schools utilizing Virginia Henderson's Activities of Daily Living. The study addressed the question: How do families adapt to caring for and living with a child with ASD? In line with the principles of interpretive phenomenology, participants were asked to reflect upon the meaning of the phenomenon they were experiencing and what their feelings, thoughts and actions were in response to the phenomenon under study. Their voices have been highlighted in the form of quotations as reflected in the previous chapter. The themes and sub-themes that emerged therefore inform the basis for discussion in this chapter and they are as follows: Perceived sources of parental distress; Experiences and beliefs, and Accommodating the needs of a child with ASD.

5.2 Perceived sources of parental distress

The first theme, "Perceived sources of parental stress" was informed by participants' descriptions of challenges they faced caring for their children with ASD. Different family members reported serious behaviour problems such as hyperactivity which often led to wandering, being destructive, anti-social behaviour, and difficulties in toilet training. Parents in particular indicated that their children's abnormal behaviours filled them with a lot of anxiety about safety issues and feelings of experiencing a difficult time in their lives. In addition, most of the participants seemed physically exhausted as well, and verbalized that they would appreciate some kind of relief. Behavioural disorders have been cited as child characteristics that have a negative impact upon a parent's psychological wellbeing (Guyard *et al.,* 2017). This finding is supported by Guyard *et al.,* (2017) who found that taking care of an adolescent with abnormal behaviour such as hyperactivity resulted into significant parental distress. Wandering and getting lost among children with ASD is relatively common and is a safety issue that must be considered when planning interventions (Rice *et al.,*2017). Families experience distress due to hyperactivity because they have to be alert all the time which can lead to exhaustion (Totsika, 2010). Exhaustion can in turn complicate into physical and psychological health problems.This is because symptom severity of children was tends to be positively related to parenting stress (Tomeny, 2016). When parents are thus stressed, it affects their care giving of their child thereby impacting upon any interventions that benefit the child. It is therefore important to ensure parents are cared for psychologically through counselling services, while making interventions on their children.

5.3 Experiences and beliefs

The experiences of parents included eagerness to learn about their children's conditions that were often met with prolonged assessment procedures and delays in diagnosis and intervention. Cultural beliefs also influenced participants' health seeking behaviours contributing to delays in diagnosis and subsequent interventions. An example of how cultural beliefs influenced health seeking behaviours is the hiding away of disabled children in which parents were blamed of being Satanists and witchcraft. Such beliefs have continued to contribute to children with ASD being discriminated against at various levels. Cultural beliefs of ASD show that society and families of children with ASD are not aware about the causes and treatment of ASD. On the other hand religious beliefs have helped families especially primary caregivers like mothers and grandmothers have hope and comfort in their pain. This enabled them cope with the process of grieving, through applying their faith. Experiences families underwent show that many health professionals are lacking in knowledge about ASD, contributing to delays in diagnosis and interventions. However, religious beliefs to a great extent enabled most mothers and grandmothers to finally accept their child's condition, and to make necessary adjustments to their daily routines and lifestyles. Nevertheless, a right application of religious beliefs must be observed to ensure mothers, in particular realize that they must diligently work and utilise recommended interventions instead of expecting and waiting for a 'miracle healing'.

In seeking to answer the many questions about their children's developmental delays and behavioural disorders that often accompany ASD, almost all participants sought help. Help was sought from different sources other than health facilities, However, even when they finally got to health facilities, they indicated that it still took a long time for diagnosis and interventions to be instituted. These findings are similar to those of Nyoni and Serpell, (2011) who conducted a qualitative study on the impact on parents of raising a young child with autism in Lusaka, Zambia. The researchers found that there were bureaucratic tendencies in hospitals. In addition, Bakare *et al.,* (2015) has observed that since most of the research on ASDs is from Western countries, this has resulted into criteria, which easily identify the condition based on Western cultures. As a result, while it is possible to identify ASD during infancy in developed countries, this is not always the case in Africa. It is important that once identified, affected children and their families are offered relevant information, services, referrals and practical support according to their needs bearing in mind the fact that a cure is not available (Chambers *et al.,* 2016; Bakare *et al.,* 2015).

Caring for ASD children can be demanding, and yet services in place for families are inadequate and hence empowerment of caregivers is increasingly being recognized as a critical component of interventions for affected children, (WHO, 2017; Frederickson & Cline, (2010). This is despite researchers in the USA recommending that within 6 weeks of diagnosis, pre-school children should have access to a trained professional skilled in ASD, followed by a 15 hours per week for 2 weeks programme (Frederickson and Cline, 2010). There continues to be delays in the enrolment of children with ASD into a special school due to delays in diagnosis and the long and complicated assessment process. Late enrolment further results into disruption in optimal development for these children. Timely interventions such as special school placement and other developmental interventions are most effective when made as early as possible (Chambers *et al.,* 2016; Bakare *et al.,* 2015).

Interestingly, Chambers *et al.,* (2016) found that the existing tools for detecting ASD had potential for describing symptoms of ASD in young Zulu-speaking children following appropriate translation and adaptation procedures. Hence, it was concluded that similar methods could be replicated in different cultural settings for early detection of ASD, especially in low income countries such as Zambia. Nevertheless, Nkole & Ciccone, (2018) successfully used DSM – 5 Criteria to identify ASD at age 36 – 48 months after first screening with autism Red Flag Symptom Checklist in a hospital based prevalence study at the outpatient paediatric section of the UTH Children's Hospital in Lusaka, Zambia. The remaining concern is the need for diagnostic criteria that can be used to identify ASD in infancy. Such a tool would promote the optimal development and well-being of children with ASD (Chambers *et al.,* 2016).

Discrimination of children with ASD and stigmatization of their parents is a cultural environmental characteristic that has continued to affect the adaptation of families. Children and their families experience exclusion, and discrimination from all angles including (McKenzie, 2013; SIRG, 2012). In addition, negative cultural beliefs have an adverse effect on the timely diagnosis and early interventions of children with ASD (Oberle, 2017; Cridland *et al.*, 2014). Disability is perceived as a curse from God in some African circles or due to witchcraftand this results into families seeking help from sources that are not so helpful such as certain traditional healers and sometimes even self-acclaimed religious leaders (Malungo *et al.*, 2018; Carvalho & Nsemukila, 2014). This results into further delays in diagnosing the condition and making much needed early interventions.

In this study some participants reported spending their time, money and energy seeking out witch doctors and treating their children with various concoctions without any success. This in turn led to delays in seeking out health assessments and interventions. All nurses need to use culture to understand behaviours of families and communities at large through negotiation while at the same time respecting their cultural beliefs and values. They can do this by helping families modify their ways of life for more beneficial health outcomes through giving them information about their child's condition, and available resources and supports. Children with ASD and their families are vulnerable to discrimination and their human and civil rights have been addressed by the United Nations (UN) Convention on the Rights of Children with Disabilities. Besides, measures have been put in place to ensure governments promote all fundamental freedoms (UN, 1989).

Coming down to the Zambian context the rights of persons with disabilities are advocated for by The Persons with Disability Act No. six (6) of 2012, and implemented through the National Policy on Disability, the Zambia Agency for Persons with Disabilities, and parent led associations, which include the newly formed Mulenga Autism Foundation (MAF), (MAF, 2018; Ministry of Community Development, 2015; Human Rights Commission, 2012).The MAF, (2018)vision is to create an equal society in Zambia, where barriers to those living with ASD are removed and equal access to rights and opportunities are enforced.

Family members tend to be at different stages of the grieving process with many of them having reached acceptance. However, some keep moving between feelings of anger, sadness and denial. Nurses who come into contact with these families must recognize any distress that is present and help parents and other caregivers work through their feelings (Gabbard, 2014). It has been noted that when individuals are going through a challenging moment they respond to stress by turning to religion (Carver *et al.*, 1989). Religion helps people with emotional-focused coping, which includes acceptance. Acceptance involves getting used to the idea that something has happened and that it cannot be changed, while denial is refusing to believe that something has happened and acting as though it has not happened. Turning to religion in this case involves seeking God’s help, putting one’s trust in God, and trying to find comfort in God through praying more often as a way of coping with stress. Findings of this study are also in agreement with research by Sajjad (2011) who found that offering prayers is among other therapies that mothers of children with ASD use to cope with stress. Participants encountering distress employed various means of coping in order to control their emotions. Pearlin & Schooler, (1978) have defined coping as any response to external life strains that serves to prevent, avoid or control emotional distress. Many parents derive their strength and encouragement from going to church, singing hymns, and reciting favourite Bible verses. Religion is a powerful tool for many individuals as they make sense of disability and their lives in relation to it (Fuller, 2012). Having a child with a disability leads to spiritual growth in many families. Praying or reciting scripture are techniques that enable families cope effectively with their children’s ASD (Schaefer *et al.*, 2012). Furthermore, reciting scripture is also a commonly used form of religious expression, and may be used as declarations, to change negative feelings into more positive ones, and is therefore a coping strategy (Perez, 2006). Nurses must help patients retain and preserve relevant care values so that they can maintain wellbeing, and face the disability of their child by adopting a non-judgemental attitude.

5.4 Accommodating the needs of a child with ASD

The third and last theme, “To accommodate the needs of a child with ASD” was informed by several sub-themes; Adjustments in daily home routines, adjustments in communicating, and “adjusting work schedules in order to meet the needs of their child with ASD”. These findings are similar to research which found that participants changed their daily routines significantly to support and accommodate their child with ASD (Hartman, 2012). A child with ASD requires close supervision and care depending on the severity of the condition. To be able to effectively care for their children, families make necessary changes that in turn reduce stress and difficulties resulting from the disability. The changes that participants in this study made were according to Henderson’s ADLs and included: Changes in participants’ occupation, health seeking behaviours, communication, daily routines, recreation and faith in God. Such changes enable families to overcome stress and successfully adapt (Mohammadi, 2011; Folknam and Lazarus’s, 1985).

However, while changes in ADLs can be successful, enabling families adapt, having a child with ASD can cause difficulties which include inflexible daily routines, impacting negatively upon their psychological wellbeing. Due to comorbid conditions individuals with ASD require daily assistance with the various activities of daily living such as self-care, mobility, communication, and cognitive or emotional tasks, and most of this care is provided by family members (Australian Bureau of Statistics, 2011). When families are unable to make adjustments successfully the result may be marital disharmony such as misunderstandings, blaming each other, fighting, breakups, separations; leaving the bulk of the responsibility of raising the child, and financial burdens with one spouse and sometimes grandmother (Mohammadi, 2011).

Participants in this study outlined how they had to make adjustments on effective ways of communicating with their children. They stated how they had to learn to talk gently, reason with their child and avoid scolding and harsh treatment. They also explained that talking to their child using concrete statements and sign language was better understood by their ASD children. Such positive findings can be combined with negative ones to help inform family centred interventions as indicated by Bradford, (2010). This could be due to difficulties individuals with ASD have in communication and reciprocal social relationships necessitating assistance with communication on a daily basis (Australian Bureau of Statistics, 2011). The presence of a child with ASD can lead to conflicts in a home, which in turn affects adaptation negatively. However, presence of family members such as siblings and other kin in the household can contribute to a supportive family environment because assistance in care giving is rendered, thereby reducing stress in parents (Cridland *et al.,* 2014). The extended family system found in Zambia and Africa at large serves as a strong support system for parents caring for a child with ASD. It is a cultural value that greatly enables physical, social, psychological and spiritual supports for affected families.

Most families change their work schedules in order to attend to the needs of their children more effectively, while at the same time keeping their jobs and being able to use the income for improving their families' quality of life (Mas *et al.,* 2016). Stopping work to be at home on a full time basis for the purpose of being available for a child with ASD and co-occurring conditions such as ADHD that necessitate close supervision is desirable if another source of income is available. Most parents are very innovative and conduct small business ventures that keep them near their child. Parents who decide to continue in formal employment find alternative means of being available when their child needs them. They negotiate working hours with their employers so that they are able to take their child to school or pick them after class. Making work adjustments enable parents and other family members accommodate their child’s needs thereby enabling successful adaptation. Knowledge of such practices can be used to help inform interventions for family members.

Cridland *et al.,* (2014) has observed that most studies that have been done on mothers are generalized to the rest of the family without interviewing other family members, such as siblings who live in the same household. The investigator in this study managed to interview five siblings, each from a different family. From participants’ reports, an observation was made that mothers perform most of the basic routine caregiving but assign siblings responsibilities to play with their brother or sister with ASD, or supervise him or her when they are away from home. It was also observed that while mothers prepared their child with ASD for school in the mornings, siblings, especially brothers were given the responsibility to take the child and pick him or her from school. This is because each different member plays a specific and unique but important role in the care of a child with ASD, and is therefore involved in the adaptation of the family unit as whole. These findings are supported by Shaffer & Kipp, (2010) who have asserted that older siblings provide caretaking services for younger brothers and sisters, as teachers, playmates, advocates and important sources of emotional support within Vygotsky’s Sociocultural Perspective Zone of Proximal Development and Scaffolding. It is also common practice for grandmothers to assist their daughters who have children with disabilities by helping out with routine care and emotional support. This finding is supported by Brown (2012), who has observed that families affect each member’s feelings, and actions, and seek support from and react to each other’s needs and distress. An example of family members’ feelings affecting other members was highlighted when a grandmother to a child with ASD was being interviewed and she began to sob, narrating the challenges they were facing as a family raising a child with ASD. Her daughter, the mother of the child also joined in crying. When one member becomes anxious, it spreads to other members of the family causing more stress and feelings of being isolated, and out of control (Brown, 2012).

5.5 Implications on practice

Findings of this study have implications for service development, policy formulation, nursing professionals’ education, and advanced mental health psychiatric nursing practice, and research. Further, results will also be used to develop theories to help inform clinical support services and interventions for affected families (Woods & Brown, 2011). Since families of children with ASD tend to be exposed to unhelpful traditional beliefs about ASD, nurses have an important role to play in imparting correct information to individuals, families, and communities, to enable them quickly recognize the condition and seek early medical attention and subsequent interventions. Correct knowledge of ASD by families, such as its causes and treatment, will in turn change unhelpful beliefs. When wrong cultural beliefs are changed the family will accept their child's condition in time to access much needed early interventions.

CHAPTER SIX: CONCLUSION AND RECOMMENDATIONS

6.1 Conclusion

This study set out to explore family adaptation patterns of caring for a child with ASD using an interpretive phenomenological qualitative design in which in-depth interviews were conducted on twelve participants and one FGD. The findings of this study were answered according to the research objectives. Findings revealed three major themes namely: 1. Perceived sources of parental distress; 2. Experiences and beliefs; and 3. Accommodating the needs of a child with ASD. The implications of the findings on practice are that most parents were greatly distressed by their children's behavioural disorders and made significant adaptation changes in order to cope with the situation. Delays in diagnosis occurred due to lack of knowledge of ASD amongst health care workers and negative cultural beliefs resulting into late school placement. It was also noted that the ability for families to accommodate their child with ASD affected their adaptation.

The study has revealed that children with ASD had abnormal behaviours which distressed caregivers. Experiences that parents passed through included stigmatization, the grieving process, and searching for ways to cope by putting their faith in God. When parents and families were able to cope it affected the way they adapted to their child's condition. Coping in a positive way, such as, acceptance, enabled families to accommodate the needs of their child.

Families sought help and advice from different sources such as traditional doctors, and this resulted in delays in seeking medical attention. Cultural beliefs in turn influenced ways in which families understood ASD. After realising that this did not help they sought help from health facilities, and eventually made changes to accommodate the affected child. Making changes in activities of daily living according to Virginia Henderson's ADLs influenced how families adapted to their children's condition (Waller-Wise, 2013).

Some parents however, had difficulties making these changes and this subsequently affected family adaptation. Areas involved in making changes were work, communication, recreation, daily home routines, worship and faith, and learning more about the child's condition through engaging with available health resources, such as clinics and hospitals. Difficulties adapting may also occur when there is lack of acceptance, as well as denial of one's child's condition. Denial and lack of acceptance can increase the parental distress that already exists due to challenging behaviours by ASD children, negatively influencing adaptation of the family.

The study also found out that care givers found it difficult to adjust when wrong information was imparted.

Furthermore, the researcher also found out that many studies on ASD were on mothers and findings are often generalised to the rest of the family. Thus one way to address this shortfall is adopt a family-focused approach in which all members of a household who are living with the child with ASD are included. This study included different family members, such as, siblings, a father and grandmothers. The researcher suggests that interventions should utilise all family members as supports to provide great relief for challenges such as behaviour problems and the grief that mothers often experience. Such relief in turn results into successful adaptation of parents, siblings and the family as a whole. Lastly, the researcher also found out that mothers do bear the greater part of the caring burden for children with ASD, and therefore agrees with Cridland *et al.,* (2014) that mothers' experiences cannot be taken as being representative of the rest of the family's experiences.

6.2 Recommendations

Based on the findings, the following recommendations are made:

MoH

All families with children with ASD undergo stress. Therefore the MoH must come up with a policy to deal with this problem, thereby enabling families adapt successfully to their ASD children. Such a policy should include early diagnosis of ASD, especially in infancy.

Policies and strategic plans must be put in place on early diagnosis of ASD and development of services for children and their families by the MoH, partnering with the MoGE and the MoCD. There should be specific plans for supporting families of children with ASD, because if they are not supported interventions for ASD will be negatively affected. The MoCD must sensitize families and communities about their rights as outlined in the Zambia Disability Act of 2012. The Zambia Policy on Disability and Disability Act stipulates that screening exercises shall be periodically undertaken for early identification and intervention of ASD. Further, it also has been outlined that all health facilities shall have resource centres to offer support, and interventions to families and their children with ASD. Lack of knowledge as outlined in the Act by persons with disabilities and their families is perhaps the greatest hindrance in securing the rights of persons with disabilities in Zambia. Without knowledge, they are not able to demand the rights outlined in this Act (Malungo *et al.*, 2018).

Nurse education

Nursing education institutions and partners such as GNC must implement MoH policies and guidelines on how to include ASD in the curriculum.

Service development

Procedures must be put in place from MoH policies and guidelines for a smooth, quick process of assessing for ASD, such as having all specialists under one roof, or place where parents can easily access them. Simple to use tools must be availed for early identification of ASD to all frontline health workers and teachers, social workers, and psychologists in the form of wall charts and clinical guide manuals. Nurses and other professionals (teachers, doctors, physiotherapists, psychologists, social workers, and clinical officers) who come into contact with children need to be knowledgeable about ASD so that they can recognise the condition during service provision, and hence take necessary measures to refer affected children for further assessment and subsequent interventions without any delays. Early identification and diagnosis necessitates early interventions during early childhood to promote the optimal development and well-being of individuals with ASD (Chambers *et al.*, 2016; Bakare *et al.*, 2015). Screening exercises for ASD must be undertaken whenever health professionals come into contact with all children; In outpatients departments, during ward rounds, children's clinics, post-delivery, and during postnatal visits.

Further research

Further research targeting nurses should be conducted on importance of early knowledge of ASD.

6.3 Dissemination of findings

Findings of this study will be disseminated to professionals who are in contact with children such as teachers, nurses, midwives, doctors, clinical officers, physiotherapists, psychologists and social workers. The findings of this study have been submitted to the Journal of Research in Nursing, Midwifery and Health Sciences at the Department of Research, Monitoring and Evaluation, School of Nursing Sciences, UNZA. When opportunities arise findings will be presented at research conferences and work place presentations. In addition, copies of the research report will be placed in the Medical Library of UNZA, and at NHRA.

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APPENDICES

APPENDIX I Participant Information Sheet

THE UNIVERSITY OF ZAMBIA
DIRECTORATE OF RESEARCH AND GRADUATE STUDIES
UNIVERSITY OF ZAMBIA BIOMEDICAL RESEARCH ETHICS COMMITTEE

Participant Information Sheet

Title of Research

Family Adaptation Patterns of Caring for a Child with Autism Spectrum Disorder in Selected Households in Lusaka, Zambia.

Purpose of Study

The overall purpose of the research is to describe the adaptation patterns of families of selected households living with a child with ASD who attend school at Bauleni School and UTH Special School in Lusaka, Zambia by interviewing several members of selected households as a family unit.

Description of the study and your involvement

You are being invited to take part in this study which will involve having discussions with family members from a number of households with children who attend school at Bauleni and UTH Special schools. The discussions will take place between the chief investigator and individual family members and between the chief investigator and two households as group discussions. Family members that will participate in this study are parents, siblings as well as any kin or other people living in the same household with the child with ASD. Interviews with individuals as well as family group discussions will take place at any place of your choice where privacy is assured, such as a room in your house or a room at your child’s school at Bauleni/UTH Special Schools. Both the individual interviews and family group discussions will be held on days and timings of your choice and will involve sharing what adaptations you have made raising your child, as well as experiences you have undergone while caring and living with your child/sibling/family member with ASD. The individual interviews and group discussions will be led by the investigator and will both be tape recorded. I

Confidentiality

Names of those who will participate will be withheld and instead, pseudonyms will be used. In case a name is accidentally mentioned during an interview or group discussion it will not be shown when transcribed, instead a pseudonym will be used. Information collected from group discussions and home observations will be kept private, that is, in a computer and audio recorder with a password which only the Chief Investigator has, except for use in professional circles to further your welfare.

Voluntary participation and withdrawal

It is not mandatory to take part in the study if you do not wish to do so. However, if you participate in the study you are free to withdraw at any time you so wish. If you decide to withdraw you will not be penalized in any way neither will your child's education.

Risks and benefits

You may feel tired during group discussions. To reduce on this you are free to ask for a short break whenever you require it.

You will have to allow the researcher into your home for interviews and group discussions depending on whether you choose to have interviews and discussions in your home. You may feel distress when you recollect your experiences with your child during the group discussions. To remedy this the researcher will be able to refer you to a counsellor for support.

You might find the group discussions time consuming. You might also need transport to come to the schools for interviews or group discussions. You may feel hungry during the group discussions. To compensate on your time and transport money you shall each be compensated fifty kwacha. Furthermore, snacks shall be provided during group discussions.

We cannot guarantee that you will receive direct benefit from this study though you will have an opportunity to contribute to how professionals like nurses, teachers, and physiotherapists can support you in various ways in successfully adapting to your child.

Contacts for questions:

The Chairperson
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APPENDIX II Consent Form

UNIVERSITY OF ZAMBIA BIOMEDICAL RESEARCH ETHICS COMMITTEE

UNZABREC FORM 1b THE UNIVERSITY OF ZAMBIA

DIRECTORATE OF RESEARCH AND GRADUATE STUDIES

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P. O. Box 32379
Fax: +260-211-290258/293937
Lusaka, Zambia
E-mail drgs@unza.zm
(Translated into vernacular if necessary)

Title of Research:

Family Adaptation Patterns of Caring for a Child with Autistic Spectrum Disorder in Selected Households in Lusaka, Zambia.

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. Your permission is required if tape or audio recording is being 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: ....
Participant's thumbprint:..Consent Date: ....
Name of Researcher Conducting Informed Consent (Printed):
…………………………………………………………………………................................
Signature of Researcher:
……………………………..…………...Date:……………
Signature of parent/guardian:
…………………………………………………………………………………………
Thumbprint of parent/guardian:
………………………………………...Date:...………

APPENDIX III Informed Assent Form

For children under the age of 18 years:

The purpose of this study has been explained to the child and I understand the purpose, the benefits, risks and discomforts and confidentiality of the study.I further understand that if I agree to my child taking part in this study, she/he can withdraw any time without having to give an explanation and that taking part in this study is purely voluntary.

I …………………………………………………………………………………(Names)

Agree for my child to take part in this study.

Signed: ……………………………………………………………………………………

Thumbprint: ………………………………………………………………………………….

Date:……………………………...

Signed: ……………………………………………………………………………………….
Date:………………………………………………………………………………………….

(Witness)

Signed: …………………………………… Date: ……………………………………………

(Researcher)

Person to contact for Questions:

1. The Dean
   School of Nursing Sciences
   P. O. Box 50110
   Ridgeway Campus
   UNZA
2. The Chairperson
   UNZABREC
   P. O. Box 50110
   Ridgeway Campus
   UNZA

APPENDIX IV Family Members Demographic Details

Family members' details

1. Code:____

2. Age

a. Below 17 Years

b. 17 – 35

c. 36 – 45

d. 45 – 65

e. 65 and above

3. Sex:

a. Male

b. Female

4. Educational level:

a. Non-literate

b. Primary level

c. Junior secondary

d. Senior secondary

e. Certificate

f. Diploma

g. Degree

h. Above degree

5. Marital status:

a. Married

b. Separated

c. Divorced

d. Widowed

e. Single

6. Occupation:

7. Religion / Church:

8. Relationship with child:

  a. Mother

  b. Father

  c. Sibling

  d. Aunty

  e. Uncle

  f. Grandparent

  g. Other

9. Length of time caring / living with child:

  a. Less than 2 years

  b. 3 – 5 years

  c. 6 – 9 years

  d. 10 – 19 years

  e. 20 – and above

CHILD'S DETAILS

10. Age of child:

a. Less than 2 years

b. 3 – 5 years

c. 6 – 9 years

d. 10 – 19 years

e. 20 – and above

11. Sex of child:

a. Male

b. Female

12. Educational level of child:

a. Level 1

b. Level 2

Grade

13. Co-occurring conditions:

a. Epilepsy

b. Cerebral palsy

c. Deaf

d. Deaf Blind

e. Blind

f. Down’s syndrome

g. Other

14. Degree of Intellectual Disability:

a. Borderline

b. Mild

c. Moderate

c. Severe

APPENDIX V Individual Interview Guide

Date of interview:……..………………………………………...

Place:…………………………Date:…………………………Time:……………………........

Participant's code:……..…………………………………………........................... ....

Introduction

This interview is for the purpose of you as a family member / mother / father living / caring for your child to share your experiences about your adaptation patterns while caring for your child with Autism Spectrum Disorder (ASD).

1. Could you describe to me what you have experienced during caring for your child with ASD?

APPENDIX VI Focus Group Discussion Guide

1. What changes have you made as a family in order to care for your child who has ASD and to live with him/her more effectively?

APPENDIX X Nyanja Participant Information Sheet

THE UNIVERSITY OF ZAMBIA
DIRECTORATE OF RESEARCH AND GRADUATE STUDIES
UNIVERSITY OF ZAMBIA BIOMEDICAL RESEARCH ETHICS COMMITTEE

(Participant Information Sheet)
Pepala Yaotengakombali Mbiri ya Chifufuzo

Muthu Wa Chifufuzo

Family Adaptation Patterns of Caring for a Child with Autistic Spectrum Disorder in Selected Households in Lusaka, Zambia.

Kusintha Machitidwe kwa Banja Posamalira Mwana Amene Santha Kulankhula Bwino, Kapena kulepera kugwilizana na kusakwanisa kuchezeka ndiena anthu, kapena mwana uyu alinso ndi khalidwe yoletsedwa ndi yobwerezabwereza; m’mabanja yosankidwa mu m’zinda wa Lusaka, m’ziko la Zambia.

Cholinga cha Fufuzo

Cholinga chakufufuza nikufotokoza mwamwene mabanja a ana amene santha Kulankhula Bwino, Kapena kulepera kugwilizana na kusakwanisa kuchezeka, kapena mwana uyu alinso ndi khalidwe yoletsedwa ndi yobwerezabwereza akwanisa kusintha machitidwe posamalira ana awo. Chifufuzo ichi chizankhala mu ma banja ozankidwa amene ali ndi ana otero amene apunzila ku ma special sukulu aku Bauleni na UTH, m’mzinda wa Lusaka m’dziko la Zambia. Wo fufuza wam’kulu azayamba kufunsa mamembala anai kapena asanu yama banja osankidwa o siyana siyana.

Kufotokoza kwa kafukofuko ndi kutengako mbali kwa inu

Ma itanidwa kutengako mbali kufufuzo yamene kuzankala ku kambilana ndi a membala a mabanja amene azasankidwa, amene ana awo apunzila kuma sukulu aBauleni na UTH Special sukulu. Kukambilana kuzankala pakati pa Wofufuza wam’kulu ndi amembala amabanja yosiyana siyana.Mafunso nakukambilana kuzankala pakati pa Wofufuza wa’mkulu ndi umozi ndi umozi w.mumabanja yosiyansiyana.Mafunso ndikukambilana kuzakalanso pakati pa wofufuza wa’mkulu ndi tumabungwe tuwiri twama banja yosankidwa.

Ndichifukwa chani mwaitanidwa kutengako mbali pali iyi nkhani?

Ndifuna anthu onitandizila mu nkhani iyi.

Mungatandizile chifukwa ndinu anthu omwe tikuyanganilapo.

Ndimwe mudziwa mnakhalidwe yanu.

Mudziwa bwino zimene anthu ena sadziwa.

Ma membala amabanja amene azatengako mbali mu fufuzo iyi nimakolo ndi abale kapena ena achibululu amena ankhala mubanjamo; mwa mwana asantha kulankula, kapena kulepera kugwilizana na kusakwanisa kuchezeka, kapena mwana uyu alinso ndi khalidwe yoletsedwa ndi yobwerezabwereza.

Mafunso na kukambilana ndi ma membala yamabanja umozi umozi ndi mutugulu yazankhala kumalo kosankidwa na otengako mbali mufufuzo iyi. Tero kukambilana kuzankala kunyumba kwanu kapena kusukulu kwa mwana wanu kulingana na kufuna kwanu.

Kukambilana umozi ndiumozi na kukambilana mutugulu twama banja kuzankala pamasikhu napamantawi yamene otengako mbali azasanka. Ku zankhala kukambilana mwamene makolo (atate ndi amai), asisita, ndi abulatha, ambuya ndi ena amene ankhala pamodzi ndi mwana uyu asintha makalidwe awoposamalira, kapena ponkhala pamodzi, ndi mwana uyu.

Kukambilana mu tumagulu ndi kukambilana umozi ndiumozi kuza chitidwa ndi wofufuza wam’kulu ndipo ziza jambulidwa.

Pokambilana khuzankala kugawilana mwamwne mabanja asintha machitidwe posamalira mwana wamene santha Kulankhula Bwino, Kapena kulepera kugwilizana na kusakwanisa kuchezeka, kapena mwana uyu alinso ndi khalidwe yoletsedwa ndi yobwerezabwereza.

Chinsinsi

Mazina yaotengakombali aza sungidwa muchinsinsi (aza lesedwa m’malo mwake, manambala azasewenzesedwa).

Nkhani yamene azasonkha munthu aliyense pamanfunso izasungidwa muchisinsi yapadera.

Kupatulapo a katswiri a magulu pupereka chitandizo patsogolo kwainu.

Kudzipereka kutengambali ndi kuzichosapo pakutengako mbali

Simufunika kutenga mbali muli nkani iyi ngati simufuna.

Ichi sichizaleta choipa chili chonse paumoyo wanu munjila ili yonse.

Mungani funse panthawi yonse pamene munga funile kuti nileke kusebenzetsa mau anu.

Ngati mwani funsa sinizalemba kapena kuika mau anu pakalimba.

Kapena muenavomera poyamba, munga chinje (kusintha) nzelu zanu nakukana.

Simuza lakwa chili chonse mukafuna kusiya.

Simuzangena mubvuto ili yonse.

Munganiuze ngati mulinamafunso alionse pamau mwanipatsa (mukumbakire).

Mungabvomele kapena kukana kutenga mbali.Chili kuli imwe.

Kodi kuliko zoipa zimene zingathe kuchitika kuli imwe?

Nizayesese kwambili kuona kuti kulibe choipa chili chonse chizachitika kweimwe.

Vintu vina muzakambapo vingamu kumu dwiseni.Kapena kumikwiyisani, kamene vinga mu kumbukiseni vinti vamene vinga mupaseni chisoni.Kapena vintu vamene simungafune kukambapo.

Nizayeyesa kumvela nkhani yanu yachisoni, kapena ku uza anthu ena kuti amitandizeni.

Pokambilana umozi ndiumozi napokambilana mu tumagulu kapena muza mvela kulema. Mukamvela kulema mungapempe ka ntha wi kangono kuti mupumule, kapena kuti mumwe mwanzi kapena chakudya.

Kulingana nakufuna kwanu, kukambilana nkhani yachifufuzo kuzankhala mumanyumba yanu, kapena kuli konse kosankidwa ndi imwe ngati masankhidwa kutengakombali.

Kuligana nakwamene muzasanka kuti tikambilane nkhani yachifufuzo, mungapezeke kuti kufunika ndalama yo kwelwla galimoto yomubewlesani.Ofufuza wam'kulu azamupatsani ndalama yo mutandizani ku kwelera galimoto.Kapena muzakhala ndi njala pokambilana nkani.Muzapasidwa ndalama kapena chakudya pokabilana nkhani.

Kodi Kulizabwino zamene zingachitike kwaime?

Kufufuza uku sikungate kumutandizani mwamusanga ayi. Koma zamene muzaniuza pamakalidwe anu ndi mwana wanu zizapasa nzeru omitandizani osiyana siyana amene ayangana zaumoyo wa ana anu kuti amitandizenu ndithu. Awa amene ayanganila zaumoyo wanu ni apunzisi, anasi, akayondolola, adotolo, ndiena.

Nanga ngati muli namafunso kapena madandaulo?

Ngati muli namafunso manje kapena tikayama kukambisana nkani mungani funse.

Ngati mankala nama funso pambuyo yaine na, mungatumile akulu ankhani iyi pamanambala aya:

Ms. Jane Kumalinga Nkhosi
Contact number 0978608581
Ngati mulinamadandaulo, mungatumile:
Chairperson, Biomedical Research Ethics Committee
University of Zambia
P.O. Box 32379,
Ridgeway Campus
Telephone: +260-211-290258/293937
Fax: +260-211-290258/293937 Lusaka, Zambia
E-mail drgs@unza.zm

APPENDIX VII Nyanja Consent Form

PEPALA YACIVOMEREZO

MUTU WOFUFUZA:

UMBONI WA ANTHU OTENGAKO MBALI

1. Onetsetsani kuti mwawerenga pepala modekha mtima kapena kuti zamatsulilidwa kwa inu mokhutilitsidwa.

2. Onani kuti ngati zojambula kapena zomvela mukusambula zizagwiritsidwa nchinto. Zizatsewenzetsedwa.

3. Kutengako mbali kwa kufufuza ndi kosakamizidwa uku ndi kunena kuti musatengeko mbali ngati simufuna.

4. Kukana kutengako mbali simupatsidwa milandu kapena kulandidwa zafunikira zomwe milandu zinthu zofunika ndi lanu.

5. Ngati mwafuna kutengako mbali muli omasuka kuleka kutengako mbali pa nthawi ili yonse kopanda kupatsidwa kapena kusowa kwanchinto ndi kosapatsa lingo yolekera.

6. Mungasankhe kusayankha mafunso ena amene afunsidwa muphunziro iyi. Ngati kuli zinthu zomwe mungafune kukambitsana, conde nkhalani omasuka.

7. Nkhani imene izatengedwa pa kukambirana izo zosungidwa mu cisinsi.

8. Ngati mwasankha kutengako mbali muzo fufudza izi citsimikiro canu muku lemba munsimu ndilofuna ndikalibe kupitiliza kukambitsana ndi inu.

BVOMEREDZO YOSAKAKAMIDZIDWA

Ndawerenga (kapena andimatsulira) Zomwe zili kufufusidwa monga zalembedwa mucipepala cili ndikhani ya otengako mbali ndinali ndi danga yofunsa mafunso pali ici ndiponso funso liri lonse lomwe ndinafunsa ndinapatsidwa yankho yondikutilitsa. Tsopano ndibvomera motsakakamidziwa kunkala otengako mbali muli fufuzo ili ndili nao ufulu otetsa kukambirana pa nthawi lililonse ndikusankha kosayankha mafuso ena amene afunsidwa mu fufudzo ili.

Cibvomeredzo canga mukulemba munsimu cikuti ndifuna kutengako mbali mu kufufudza.

Dzina la otenga mbali………………………………………………………………

Otengako mbali mukulemba …………………… Tsiku lobvomerera……......................

Ofufudza amene acititsa za mabvomeredzedwe………………………………………

Cibvomeredzo mukulemba caofufudza…………………..Tsiku…………………………

Cibvomeredzo mukulemba ca kholo kapena oimirira…........................Tsiku............……

Person to contact for Questions:

1. The Dean
School of Nursing Sciences
P. O. Box 50110
Ridgeway Campus
UNZA
2. The Chairperson
UNZABREC
P. O. Box 50110
Ridgeway Campus
UNZA

APPENDIX VIII Nyanja Assent Form

For children in between the age of 10-18 years:

PEPALA YOBVOMALA

Ya bana bangono na achinyamata ndi achitsikana (<18 years) azaka zochepa kumi zisanu nazitahi ndi anthu siakwanisa ku vomekeza

Mwamvetsetsa nkani iyi ndipo mufuna kutengako mbali?

INDE kapena AYI

Muli ndimanfunso pankani iyi?

INDE kapena AYI

Kodi ofunsa nkani aya mafunso anu onse?

INDE kapena AYI

Mwa mvetsetsa kuti mungasiye kutenga mbali munkani iyi pathawi ili yonse?

INDE kapena AYI

Ngati mwayanka INDE pamafunso onse pamwamba munga saine panyansi apa:

Dzina la otenga mbali

Otengako mbali mukulemba Tsiku lobvomerera

Ofufudza amene acititsa za mabvomeredzedwe

Cibvomeredzo mukulemba ca ofufudza Tsiku …………..

Person to contact for Questions:

1. The Dean
School of Nursing Sciences
P. O. Box 50110
Ridgeway Campus
UNZA

2. The Chairperson
UNZABREC
P. O. Box 50110
Ridgeway Campus
UNZA

APPENDIX IX Nyanja Individual Interview Guide

Date of interview:……..…………………………………………..

Place:…………………………Date:…………………………Time:……………………........

Participant's code:….…………………………………………...

Kuyambira

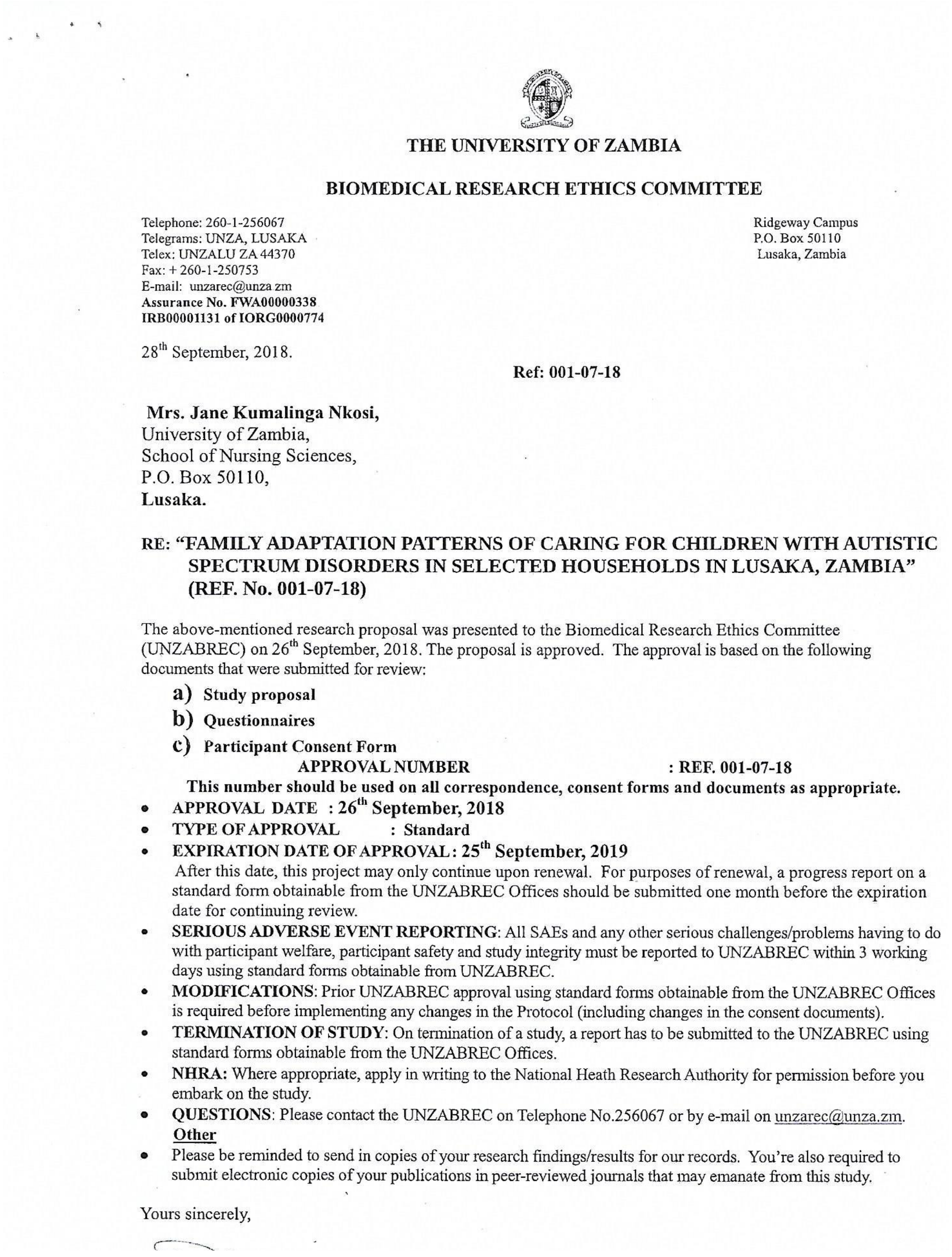
Cholinga chokambilana naimwe amembala a banja iyi inu amai, atate amene mu samalira mwana wanu kuti mugave zamene mumapitamo na mwana wanu amene santha kulankhula; Kapena kulepera kugwilizana na kusakwanisa kuchezeka ndiena anthu, kapena mwana uyu alinso ndi khalidwe yoletsedwa ndi yobwerezabwereza.

Kodi mungani fotokozele vamene mapitamo po samalira mwana wanu na vamene masintha kapena vamene simuna sinthile dala mumakhalidwe yanu yasiku ndisiku, kuti mukwanise kusamalira mwana wanu**Amene Santha Kulankhula Bwino, Kapena kulepera kugwilizana na kusakwanisa kuchezeka ndiena anthu, kapena mwana uyu alinso ndi khalidwe yoletsedwa ndi yobwerezabwereza;**

APPENDIX X Nyanja Focus Group Discussion Guide

1. Fotokozani / nigawileni mwamwne muchinjila makalidwe yanu yamasiku onse kuti mukwanise kusamalira nakunkala bwino namwana wanu amene ali ndi Autism.

APPENDIX XI LETTER FOR ETHICS CLEARENCE



THE UNIVERSITY OF ZAMBIA

BIOMEDICAL RESEARCH ETHICS COMMITTEE

Telephone: 260-1-256067
Telegrams: UNZA, LUSAKA
Telex: UNZALU ZA 44370
Fax: + 260-1-250753
E-mail: unzarec@unza zm
Assurance No. FWA00000338
IRB00001131 of IORG0000774

Ridgeway Campus
P.O. Box 50110
Lusaka, Zambia

28th September, 2018.

Ref: 001-07-18

Mrs. Jane Kumalinga Nkosi,
University of Zambia,
School of Nursing Sciences,
P.O. Box 50110,
Lusaka.

RE: "FAMILY ADAPTATION PATTERNS OF CARING FOR CHILDREN WITH AUTISTIC SPECTRUM DISORDERS IN SELECTED HOUSEHOLDS IN LUSAKA, ZAMBIA" (REF. No. 001-07-18)

The above-mentioned research proposal was presented to the Biomedical Research Ethics Committee (UNZABREC) on 26th September, 2018. The proposal is approved. The approval is based on the following documents that were submitted for review:

a) **Study proposal**
b) **Questionnaires**
c) **Participant Consent Form**

APPROVAL NUMBER : REF. 001-07-18

This number should be used on all correspondence, consent forms and documents as appropriate.

- **APPROVAL DATE : 26th September, 2018**
- **TYPE OF APPROVAL : Standard**
- **EXPIRATION DATE OF APPROVAL : 25th September, 2019**
  After this date, this project may only continue upon renewal. For purposes of renewal, a progress report on a standard form obtainable from the UNZABREC Offices should be submitted one month before the expiration date for continuing review.
- **SERIOUS ADVERSE EVENT REPORTING**: All SAEs and any other serious challenges/problems having to do with participant welfare, participant safety and study integrity must be reported to UNZABREC within 3 working days using standard forms obtainable from UNZABREC.
- **MODIFICATIONS**: Prior UNZABREC approval using standard forms obtainable from the UNZABREC Offices is required before implementing any changes in the Protocol (including changes in the consent documents).
- **TERMINATION OF STUDY**: On termination of a study, a report has to be submitted to the UNZABREC using standard forms obtainable from the UNZABREC Offices.
- **NHRA:** Where appropriate, apply in writing to the National Heath Research Authority for permission before you embark on the study.
- **QUESTIONS**: Please contact the UNZABREC on Telephone No.256067 or by e-mail on unzarec@unza.zm.

Other

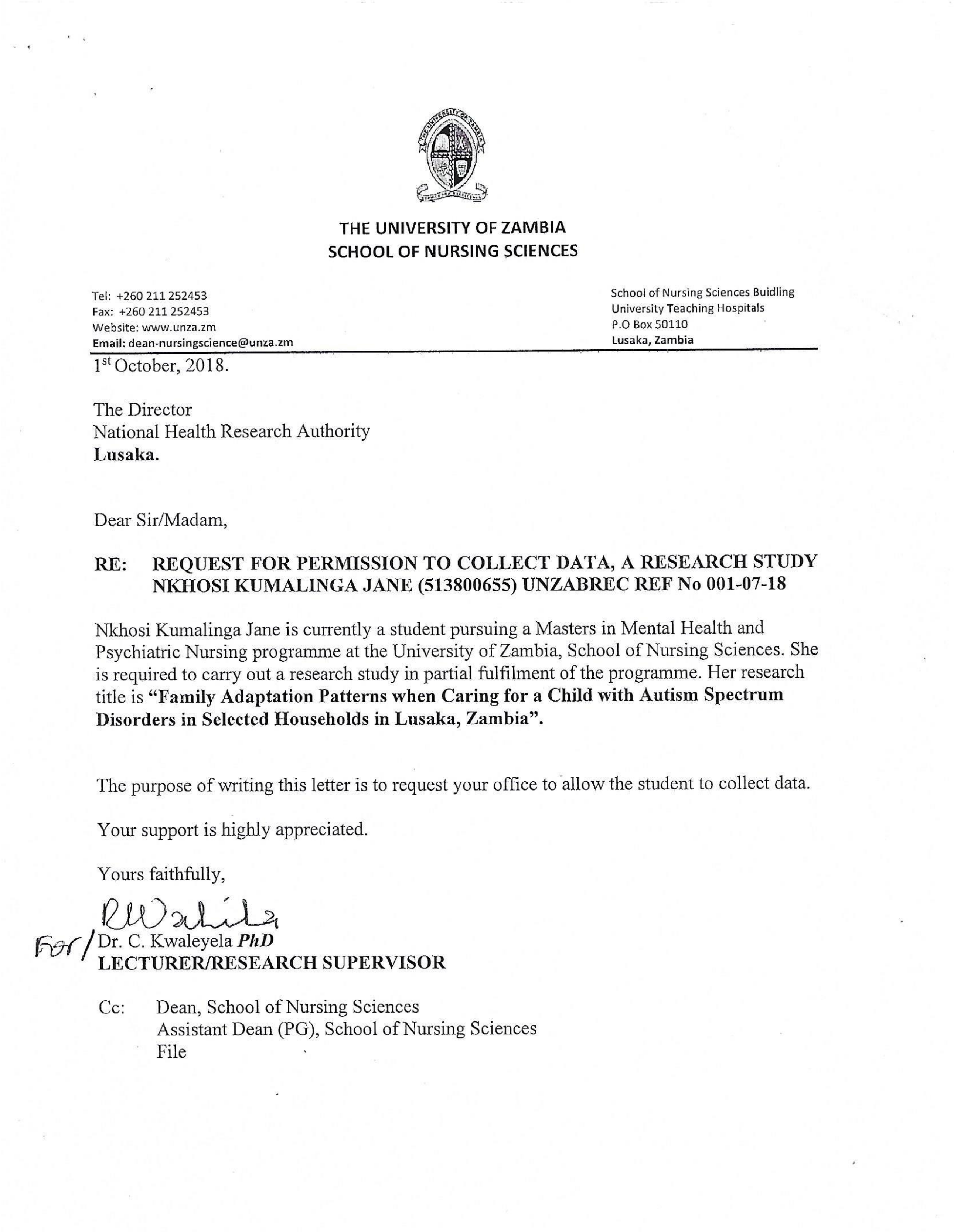
- Please be reminded to send in copies of your research findings/results for our records. You're also required to submit electronic copies of your publications in peer-reviewed journals that may emanate from this study.

Yours sincerely,

APPENDIX XII PERMISSION LETTERS

a. **Letter of permission to National Health Research Authority (NHRA)**
b. **Application to NHRA for authority to conduct research**
c. **Approval from NHRA to conduct research**
d. **Request to District Education Board Secretary (DEBS) to conduct request**
e. **Letter of permission from DEBS to conduct research**

a. Request letter of permission from Department of Nursing Sciences to NHRA



THE UNIVERSITY OF ZAMBIA
SCHOOL OF NURSING SCIENCES

Tel: +260 211 252453
Fax: +260 211 252453
Website: www.unza.zm
Email: dean-nursingscience@unza.zm

School of Nursing Sciences Buidling
University Teaching Hospitals
P.O Box 50110
Lusaka, Zambia

1st October, 2018.

The Director
National Health Research Authority
Lusaka.

Dear Sir/Madam,

RE: REQUEST FOR PERMISSION TO COLLECT DATA, A RESEARCH STUDY NKHOSI KUMALINGA JANE (513800655) UNZABREC REF No 001-07-18

Nkhosi Kumalinga Jane is currently a student pursuing a Masters in Mental Health and Psychiatric Nursing programme at the University of Zambia, School of Nursing Sciences. She is required to carry out a research study in partial fulfilment of the programme. Her research title is **"Family Adaptation Patterns when Caring for a Child with Autism Spectrum Disorders in Selected Households in Lusaka, Zambia".**

The purpose of writing this letter is to request your office to allow the student to collect data.

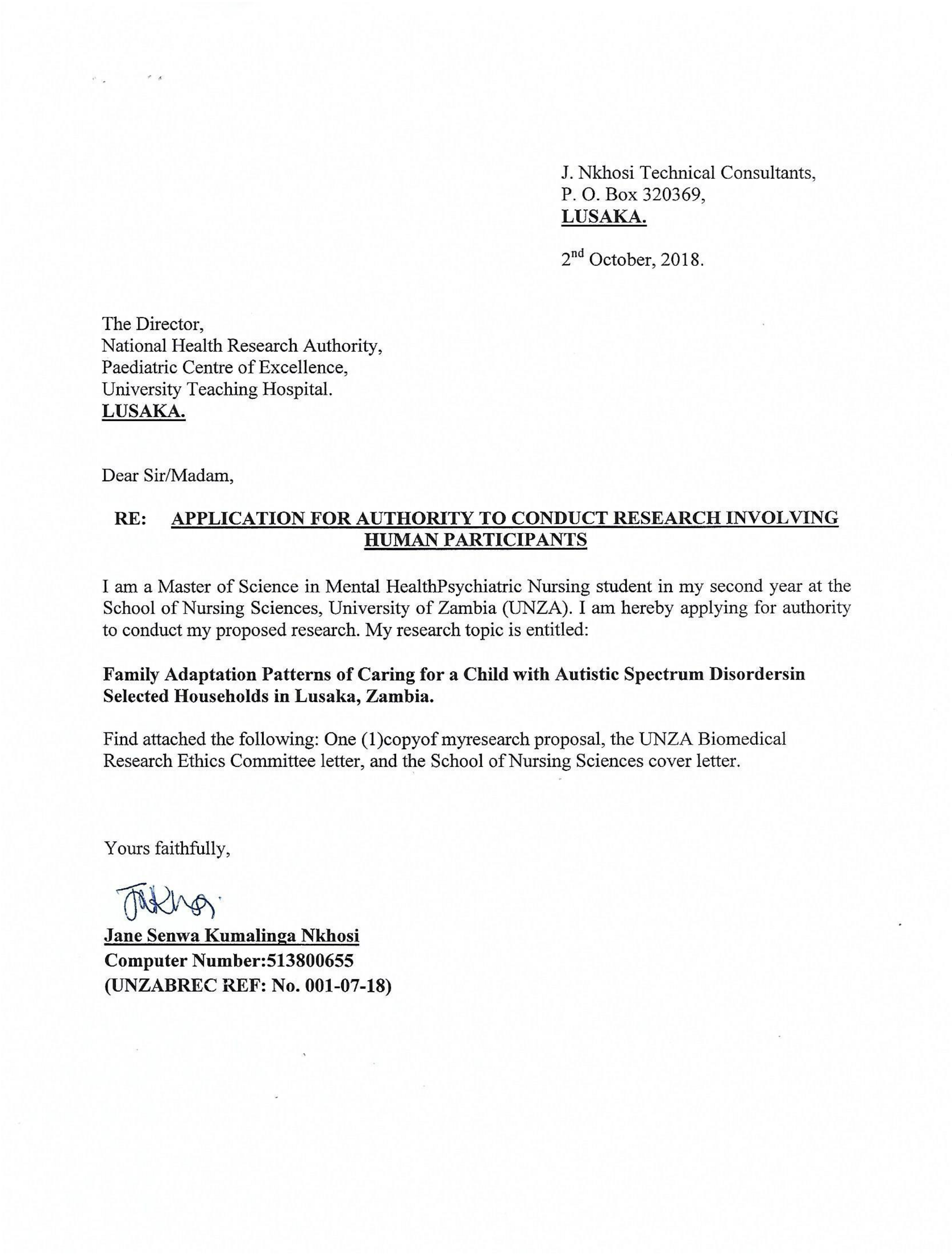
Your support is highly appreciated.

Yours faithfully,

For/ Dr. C. Kwaleyela ***PhD***
LECTURER/RESEARCH SUPERVISOR

Cc: Dean, School of Nursing Sciences
Assistant Dean (PG), School of Nursing Sciences
File

b. Application for Authority to conduct Research



J. Nkhosi Technical Consultants,
P. O. Box 320369,
LUSAKA.

2nd October, 2018.

The Director,
National Health Research Authority,
Paediatric Centre of Excellence,
University Teaching Hospital.
LUSAKA.

Dear Sir/Madam,

RE: APPLICATION FOR AUTHORITY TO CONDUCT RESEARCH INVOLVING HUMAN PARTICIPANTS

I am a Master of Science in Mental HealthPsychiatric Nursing student in my second year at the School of Nursing Sciences, University of Zambia (UNZA). I am hereby applying for authority to conduct my proposed research. My research topic is entitled:

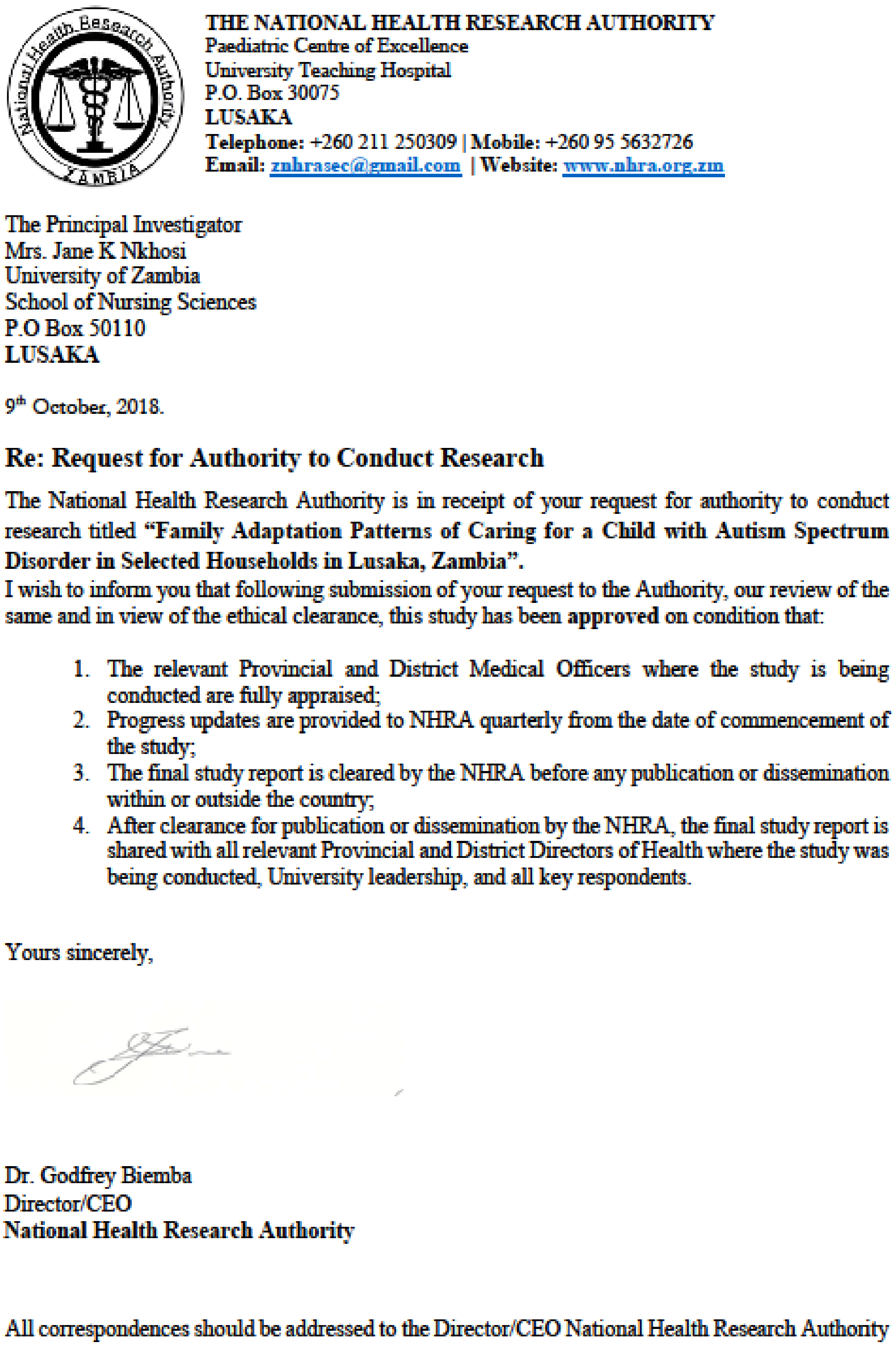
Family Adaptation Patterns of Caring for a Child with Autistic Spectrum Disordersin Selected Households in Lusaka, Zambia.

Find attached the following: One (1)copyof myresearch proposal, the UNZA Biomedical Research Ethics Committee letter, and the School of Nursing Sciences cover letter.

Yours faithfully,

Jane Senwa Kumalinga Nkhosi
Computer Number:513800655
(UNZABREC REF: No. 001-07-18)

c. Approval from National Health Research Authority to collect data



THE NATIONAL HEALTH RESEARCH AUTHORITY
Paediatric Centre of Excellence
University Teaching Hospital
P.O. Box 30075
LUSAKA
Telephone: +260 211 250309 | **Mobile:** +260 95 5632726
Email: znhrasec@gmail.com | **Website:** www.nhra.org.zm

The Principal Investigator
Mrs. Jane K Nkhosi
University of Zambia
School of Nursing Sciences
P.O Box 50110
LUSAKA

9th October, 2018.

Re: Request for Authority to Conduct Research

The National Health Research Authority is in receipt of your request for authority to conduct research titled **"Family Adaptation Patterns of Caring for a Child with Autism Spectrum Disorder in Selected Households in Lusaka, Zambia".**
I wish to inform you that following submission of your request to the Authority, our review of the same and in view of the ethical clearance, this study has been **approved** on condition that:

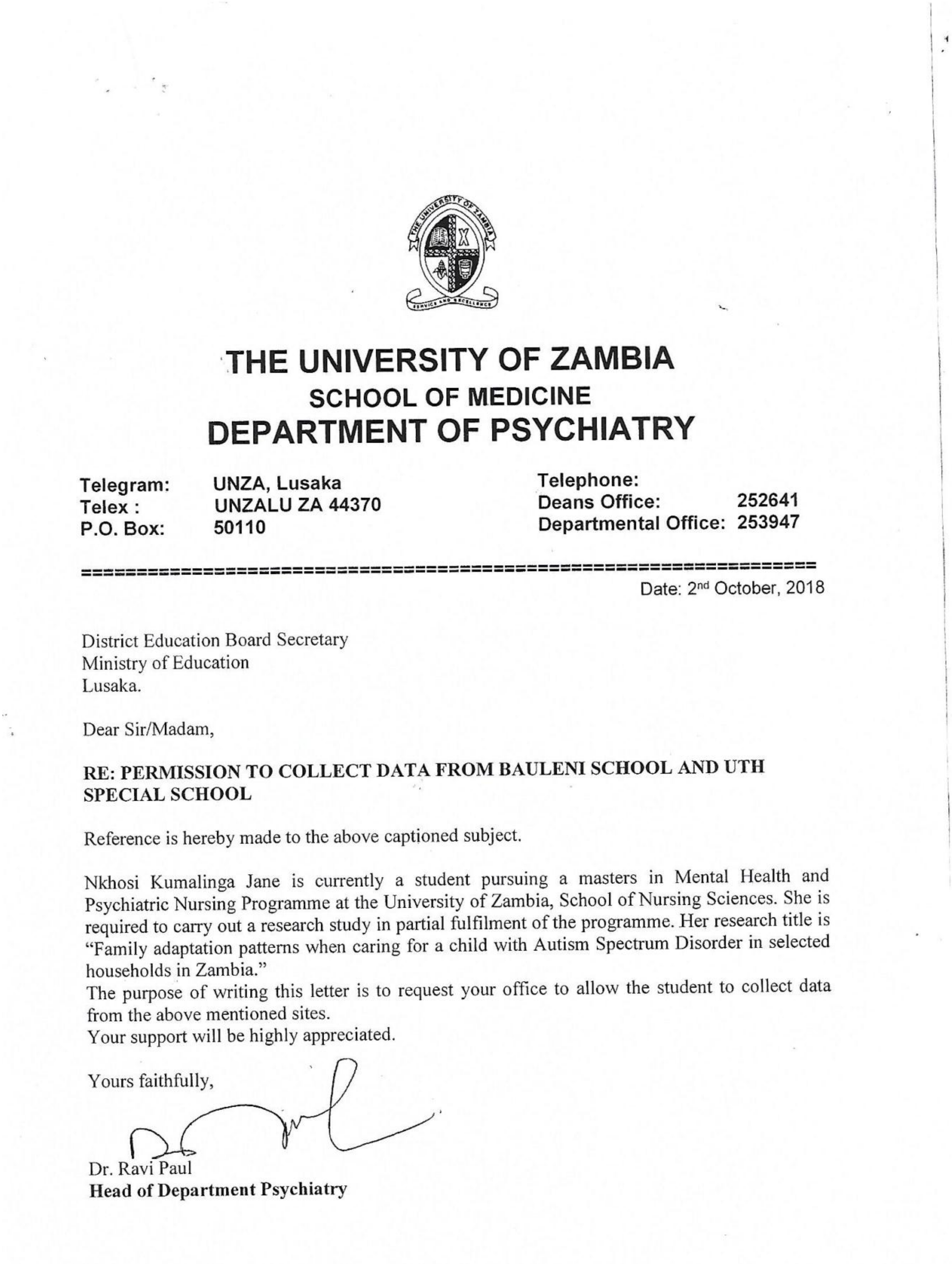
1. The relevant Provincial and District Medical Officers where the study is being conducted are fully appraised;
2. Progress updates are provided to NHRA quarterly from the date of commencement of the study;
3. The final study report is cleared by the NHRA before any publication or dissemination within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

Yours sincerely,

Dr. Godfrey Biemba
Director/CEO
National Health Research Authority

All correspondences should be addressed to the Director/CEO National Health Research Authority

d. Request for permission from District Education Board Secretary to collect data



THE UNIVERSITY OF ZAMBIA
SCHOOL OF MEDICINE
DEPARTMENT OF PSYCHIATRY

Telegram: UNZA, Lusaka
Telex : UNZALU ZA 44370
P.O. Box: 50110

Telephone:
Deans Office: 252641
Departmental Office: 253947

==

Date: 2nd October, 2018

District Education Board Secretary
Ministry of Education
Lusaka.

Dear Sir/Madam,

RE: PERMISSION TO COLLECT DATA FROM BAULENI SCHOOL AND UTH SPECIAL SCHOOL

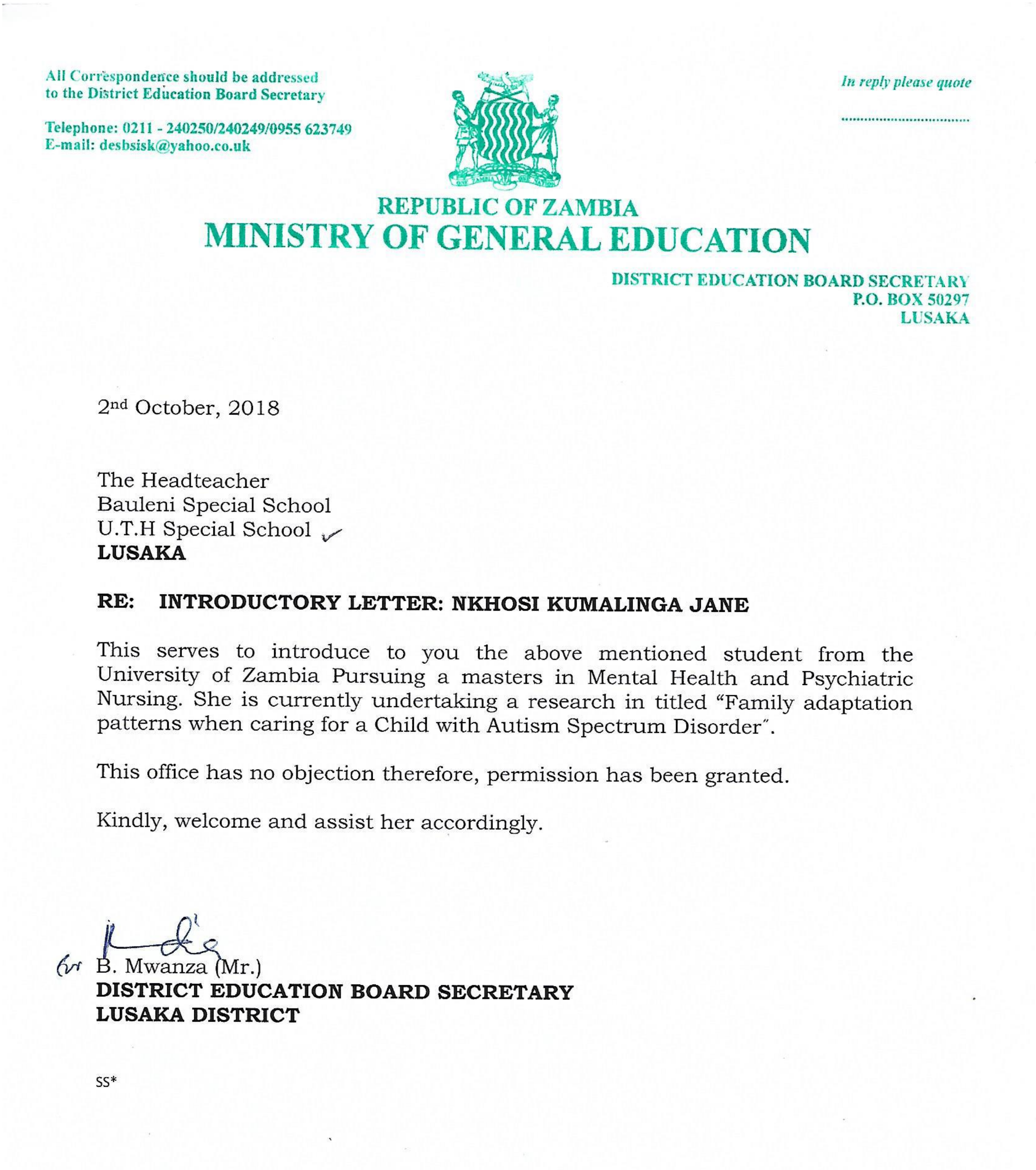
Reference is hereby made to the above captioned subject.

Nkhosi Kumalinga Jane is currently a student pursuing a masters in Mental Health and Psychiatric Nursing Programme at the University of Zambia, School of Nursing Sciences. She is required to carry out a research study in partial fulfilment of the programme. Her research title is "Family adaptation patterns when caring for a child with Autism Spectrum Disorder in selected households in Zambia."
The purpose of writing this letter is to request your office to allow the student to collect data from the above mentioned sites.
Your support will be highly appreciated.

Yours faithfully,

Dr. Ravi Paul
Head of Department Psychiatry

e. Letter of permission from DEBS to conduct research



All Correspondence should be addressed
to the District Education Board Secretary

Telephone: 0211 - 240250/240249/0955 623749
E-mail: desbsisk@yahoo.co.uk

In reply please quote

……………………………

REPUBLIC OF ZAMBIA
MINISTRY OF GENERAL EDUCATION

DISTRICT EDUCATION BOARD SECRETARY
P.O. BOX 50297
LUSAKA

2nd October, 2018

The Headteacher
Bauleni Special School
U.T.H Special School ✓
LUSAKA

RE: INTRODUCTORY LETTER: NKHOSI KUMALINGA JANE

This serves to introduce to you the above mentioned student from the University of Zambia Pursuing a masters in Mental Health and Psychiatric Nursing. She is currently undertaking a research in titled "Family adaptation patterns when caring for a Child with Autism Spectrum Disorder".

This office has no objection therefore, permission has been granted.

Kindly, welcome and assist her accordingly.

for B. Mwanza (Mr.)
DISTRICT EDUCATION BOARD SECRETARY
LUSAKA DISTRICT

SS*