

**LIVED EXPERIENCES OF PARENTS OF CHILDREN WITH AUTISTIC
SPECTRUM DISORDER IN SOCIAL INTERACTIONS IN SELECTED SCHOOLS
OF LUSAKA DISTRICT ZAMBIA: A HERMENEUTIC PHENOMENOLOGICAL
APPROACH**

BY

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DECLARATION

I, **Hellen Kalumba Chalwe**, do hereby solemnly declare that this thesis represents my own work, except where otherwise acknowledged and that it has never been previously submitted for a degree or academic qualification at the University of Zambia or any other university.

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APPROVAL

This thesis by **Hellen Kalumba Chalwe** is hereby approved as having fulfilled the requirements for the award of the degree of Doctor of Philosophy in Educational Psychology by the University of Zambia.

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Board of Examiners

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Supervisor

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Date

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DEDICATION

This academic piece of work is dedicated to my parents. What else can I say without my Parents! *Mayo wandi* Theresa Kalumba Chalwe and *Tata wandi* Stanislous Bwalya Chalwe Ndaitwala (MYSRIP) laid a concrete foundation for me to ride on. I recall your hard work, determination, resilience, gentleness, intelligence, wisdom, sense of humour and leadership attributes. These you nurtured in me when I was young, and I am thankful for all that.

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ABSTRACT

Parenting a child is a challenging experience, let alone in social interaction with children with Autistic Spectrum Disorder (ASD). The type of ASD in a child goes with its complexity and it often puts parenting skills to the test. However, with worldwide challenges parents with children with disabilities encounter, it was imperative to undertake this study to establish the lived experiences of parents of children with ASD on social interaction in Lusaka District of Zambia. Without knowledge of whether the lived experiences of parents of children with ASD have ways in which they communicate /interact or not, it was further imperative to study how they managed children with ASD in their daily lives. The study used qualitative approach and a hermeneutic phenomenological research design which employed in-depth interviews to collect data. Non-probability criterion homogenous purposive sampling procedure was used to select parents of children with ASD from four special education units. The sample size comprised of 10 parents selected purposively. Qualitative data was analysed using N'vivo software package to organise and code before analysing of data. The study revealed that, parents of children with ASD did not have sufficient knowledge about ASD, especially on social interaction and more so, prior to diagnosis and consultation children. Additionally, it was established that parents did not have specific strategies on how to interact with children with ASD and that approaches were situational. The strategies, although not uniform ranged from: affectionate and rambling to fragmented emotional interactions with their children. Further, parents had challenges in communicating affectionately, particularly on unacceptable or inappropriate communicative touch, personal space, greetings and gestures. It was learnt that some parents felt embarrassed when they were unable to effectively interact with their children with ASD and when they exhibited behaviour problems in their attempt to interact with others. This often affected them as parents and their general socio-psychological well-being. It led to raised levels of stress, depression, divorce and anxiety, which reduced further, levels of interaction with children with ASD. The study concludes that parents of children with ASD in the study site, had a lot of challenges in their efforts to socially interact with their ASD children. The study recommends that Parents of Children with ASD be given sufficient knowledge on ASD as a condition and how to manage it especially in the area of communication, parents form, 'parent to parent support groups for purposes of sharing information amongst others and social interactions with their children with ASD. The study further calls for the provision of necessary adapted play parks for children to socialize with. The study further recommends training or educating parents of children with ASD on various strategies on how best to engage with children into meaningful social interactions. It would be more beneficial to regularly facilitate interaction between parents and professionals on how to access support services associated with coping mechanisms and managing of social interaction.

Key words: *autism spectrum disorder, lived experiences, social interactions, challenging behavior.*

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LIST OF ABBREVIATIONS AND ACRONYMS

ABA	Applied Behaviour Analysis
ADDM	Autism Developmental Disabilities Monitoring
ADHD	Attention-Deficit Hyperactivity Disorder
ASD	Autism Spectrum Disorder
DEBs	District Education Board Secretary
DRGS	Directorate of Research and Graduate Studies
DSM IV	Diagnostic and Statistical Manual
IACC	Intelligence Autistic Coordination Committee
ID	Intellectual Disability
IDEA	Individual with Disabilities Education Act
MoE	Ministry of Education
NDD	Neuro-developmental Disorder
PDD-NOS	Pervasive Development Disorder- Not Otherwise
PECS	Picture Exchange Communication System
QOL	Quality of Life
RRB	Restricted and Repetitive Behaviour
SES	Socio Economic Status
UNZA	University of Zambia

OPERATIONAL DEFINITIONS

The definition of concepts provides the context in which the terms have been used in the study (Maxwell, 2005). The researcher was obliged to define each term as she wanted the reader to know what they stood for. Thus, the section below provides the list of the terms that have been used in this study:

- Autism Spectrum Disorder:** A developmental obstacle caused by abnormal brain functioning which usually manifests before the age of three years, often accompanied with mental disability, epilepsy, hyperactivity, reclusion and acting out.
- Behaviour:** A way in which one acts or conducts oneself, especially towards others.
- Challenging Behaviour:** This term in this study was used to refer to behaviour that disrupted the learning and teaching process in school.
- Cognitive Abilities:** Ability of an individual to perform the various mental activities most closely associated with learning and problem solving.
- Communication Skills:** Ability one uses when giving and receiving different kinds of information.
- Comorbidities:** The occurrence of two or more forms of psychopathology in the same person, this has received a considerable amount of attention in the child literature.

Emotional Problems:	Reactions, which can include anger, guilt, anxiety, sadness, depression and despair.
Experiences:	In this study, “experience” refers to everything that the person has lived through in life, what has happened to him/her, and all the events or activities that a person has lived and can still recall.
Hermeneutics	The interpretations and meaning parents with ASD children give to their daily lived experiences while living with them.
Life cycle:	In this study, the life cycle refers to six stages that each family/individual goes through, that are discussed by Carter and McGoldrick (2016), starting from singlehood, couple, parent, transformed by adolescent, mid-age to late age stages
Lived Experiences:	Provides an understanding of experiences from those who have lived them.
Parents:	A biological parent whose gamete resulted in a child.
Phenomenology	A research approach focusing on people’s lived experiences comprising the daily activities, thoughts and impressions of an individual’s world within a specific context.
Social interaction	Communication process that involves the exchange of information, feelings and meaning by means of verbal and non-verbal messages, between two or more persons.

CHAPTER ONE: INTRODUCTION

1.1 Overview

Chapter one provides the context within which this study was conducted. Here, the background, statement of the problem, aim of the study, research objectives and research questions are presented. Other sub-sections of the chapter include the significance of the study and study location. Furthermore, the chapter explains the delimitation and limitations, definition of key terms and finally a synopsis of the thesis is given.

1.2 Background of the study

The drive of this thesis is based on a Hermeneutic Phenomenological study of lived experiences of parents of children with Autistic Spectrum Disorder (ASD) in Lusaka District of Zambia. In using the Hermeneutic approach, the researcher supports the struggle of bracketing, as progressive through the Transcendental Phenomenology of Edmund Husserl (1859-1938). The study anchors on the works of Martin Heidegger (1889-1976) tailored Hermeneutic Phenomenological. This exit is mainly because of the negative idea of suspending personal opinions and the turn for the interpretive narration to the description, as advanced by numerous philosophers such as Martin Heidegger, Maurice Merleau-Ponty, Jean-Paul Sartre, Emmanuel Lévinas, Jean-Luc Nancy and Jean-Luc Marion (Healy, 2012). Thus, this study endeavours to reveal to the world as experienced by the parents' social interaction through their life world stories.

1.2.1 Key Influences Supporting the Current Study

The influences underpinning the commencement of this research are that the researcher has a brother with ASD and seeing the experiences her parents went through; it became quite obvious that there was need to explore the lived experiences of other parents of children with

ASD in social interaction. In addition to that was the researcher's experience as a lecturer at a special college that provided the understanding of what it is like to care for learners with a life-long disability. Being a lecturer at a college setting, the researcher often provided care for many learners who fell sick and recovered, including those children with disabilities throughout their life span. Caring for such children can be stressful and many parents face challenges, difficulties and frustrations. Fortunately, the researcher's experiences showed that these parents often saw the joy in the small hurdles they overcame. Parents were taught new skills that were far beyond the scope of any parenting class. Parents adapted to the special needs of their children and always advocated on behalf of their children. Parents with children with a disability are thrown into a world of putting their own needs before those of their children with disabilities. They transition through novice learning of living with a child with a disability to a trained parent in the realm of their children's health. Caring for a disabled child is a continuous process where parents, who are the primary caregivers must be equipped with the skills and resources to be able to provide the best quality of life for their children. These parents are often faced with limited resources and purchases as well as a lack of support and services. When a child becomes sick or is faced with a disability, parents are forced to leave their home and go to hospitals seeking medical treatment and services that are unavailable to them. Parents encounter extra travelling expenses and living costs while managing their children with ASD. Children with ASD are an exceptional and unique population whose care takes a unique approach as there is no standard method to reward every child. While the researcher was at resource center at the University of Zambia, teaching learners with special needs, she had the opportunity to interact with parents with a newly ASD diagnosed child. As such, they engaged in an intense behaviour modification programme at the University Teaching Hospital. Children with ASD, including their parents require enormous support throughout their life time. It is the researcher's trust that improving and being empathetic of the lived experiences of parenting a

child with ASD, will assist lectures, teachers, policy makers, non-governmental organisations (NGOs) and other health care professionals to provide ongoing comprehensive care and support to these parents of children with ASD in social interaction.

In Zambia, there is little research done in the area of ASD, hence the prevalence of learners with ASD is not yet known and there is no data from the Central Statistics Office (CSO) or the Ministry of General Education in Zambia on learners with ASD. ASD is instead embedded in the intellectual disabilities category when it is supposed to be considered as an independent category of disability like other well-known disabilities such as visual, hearing, intellectual and physical disabilities. The condition in terms of social interaction with ASD is not very well known in Zambia, hence this study.

1.2.2 Underlying Assumptions

In a study, it is imperative to be clear about any underlying assumptions. Assumptions for this study were based upon the philosophical beliefs and characteristics of qualitative research through the philosophical framework of van Manen (Speziale and Carpenter, 2007; van Manen, 1990). In this study, the underlying assumptions were:

- (a) Phenomena are understood in diverse ways due to the numerous authenticities that occur and create unique meanings for individuals;
- (b) The study assumed that the sample of parents selected for the study naturally represented the population of parents of children with ASD;
- (c) The study assumed that the parents' taking part in the study would honestly share their genuine feelings and fears with the researcher;
- (d) It was assumed that after obtaining more information on the lived experiences of parents in social interaction with children with ASD from the sample of parents

participating in the study, any proposed solution would have a positive impact for several parents of children with ASD, and that;

- (e) Parents of children with ASD were the experts in describing their experiences of living with their children and discovering their world.

1.2.3 The Origins of Current Autism Spectrum Disorder (ASD) Symptomology- Leo Kanner

Prior to 1943, there was no “ASD” information for medical personnel as well as parents. These children simply existed with no hope for treatment or rehabilitation to function in the community. Bettelheim found out that children who would be labeled as autistic after 1943 and the acceptance of Leo Kanner’s study 1943 and reviewed by (Salhia, et al., 2014; Kim 2015) were thought to be savage children raised by animals rather than humans. This label of savage was assigned due to the animalistic behaviours that ASD children displayed, including a lack of speech as well as the shunning of human company and ferocious attacks. As observed by Bettelheim, the more people consider the behaviours of so-called regressive children, the more they look like those which people would consider as ASD today. Another aspect paying to the thought that these children were certainly raised by animals was the state in which they were occasionally found in, such as being alone with apparently no adult supervision. According to Bettelheim, this is due to parents’ becoming “disengaged” with their children, leaving them to fend for themselves in the wilderness or by not pursuing them when they roamed away from the family home.

Leo Kanner’s research changed the fate of these children (ASD) and their parents as the symptomology before, associated with “feral” children became accepted in mainstream psychology as “early infantile autism”. Through his longitudinal observations of eleven institutionalised children, Kanner solidified those symptoms which today we freely associate

with ASD; the disability to relate to others in ordinary ways, oddities in speech, an anxiously obsessive desire for sameness, and an obsessive fascination with objects. Though these four observations of Kanner have been broadened, they are still at the route of our present definition of ASD. Still up to now people consider the most prominent and unique symptom of ASD to be that of the inability to relate to others, something which evokes a great deal of stress and despair in parents (Silva, Schalock, 2012).

This behaviour is thought to occur in children universally at four months of age, but nearly all of Kanner's original sample of eleven mothers stated that this did not occur with their child. Given the lack of knowledge to the cause of this behaviour, it was attributed to the mother and her lack of warmth in interacting with the child. In fact, a significant number of observations were made in regard to the characteristics of parents of children with ASD. A great deal of their observed behaviours was similar to those displayed by the child, suggesting a common biological or genetic source. In his explanations of fifty-five parents of ASD children, Kanner found out that parents who programmed human relationships, were undemonstrative as partners and displayed perfectionist tendencies. The mechanisation of human relationships was defined by those parents who were not comfortable in the company of others; they preferred reading, writing, music or thinking. The married lives of these parents were seen as cold and formal, with little passion and attraction. As presumed the important number of observations Kanner made with regards to the parents of children with ASD, many of his contemporaries felt that he was suggesting a parental role in causing ASD. Hill (2015) proposed that the characters, arrogances, and behaviours of parents caused ASD. Parents were cold, obsessive, and mechanical in their attitude towards their children, therefore reinforcing the etiology of ASD. Hill (2015) instigated to express out against Kanner's suggestion of parental etiology, pointing to normally developed siblings, as well as children with ASD of warm and affectionate parents. While Kanner experimented little improvement in those institutionalised

children whom he studied, Hill, (2015) endorsed that the best course of treatment for these individuals would be to surround them with warm and affectionate adults, though he offered little evidence to support this hypothesis. ASD was seen as a disease which caused the behaviours in the child; therefore, little was found with respect to suitable treatments.

1.2.4 ASD Globally

Autism spectrum disorder (ASD) is a broad term that covers social-communicative deficits (e.g., deficits in social-emotional interaction, non-verbal communication, building and maintaining relationships), repetitive interests, and behaviours (e.g., stereotyped and repetitive motor movements, sameness, ritualistic, restricted and deep interest, more or less sensory stimulation) (DSM-5, 2014).

Parents usually notice signs in the first two or three years of a child's life. These signs often develop gradually, though some children with ASD reach their developmental milestones at a normal pace and then worsen. Along with this, there might be cases where all stated criteria are not observed. For example, an individual who does not have language development disorder might have difficulties in social communication (Haesen et al., 2011). The risk, irregularity or syndrome that is noticed at birth or shortly after the birth is generally a condition in which families do not know or are not ready for. ASD is a complex neurobiological disorder that inhibits a person's ability to communicate and develop social relationships. It is also characterised by restricted and repetitive behavior. Early speech or behavioral interventions can help children with ASD gain social and communication skills. Although there is no known cure, there have been cases of children who have recovered from the condition. Not many children with ASD live independently after reaching adulthood (Ruparelia, Abubakar, Badoe, 2016).

Globally, the recorded prevalence figures for ASDs are rising; and from a statistical point of view, this is undeniable when data is examined from both developed and developing countries. However, in many developing countries, the reported rates continue to be significantly lower than the developed countries Maguire (2013). Whether this truly reflects an absolute low prevalence, deficits in diagnostic skills, mal-adaptation of diagnostic criteria as it relates to cultural differences in behaviour, or under sampling are issues that continue to be discussed. In relation to the prevalence of ASDs, data emanating from developed nations appears more comprehensive and reliable, compared to that from developing nations. Despite this, one fact that can no longer be denied is that as it stands today, ASDs occur globally irrespective of culture, geography or degree of industrialisation; with variable degrees of tangible data from different regions of the world where studies have been conducted. Hence, contrary to what might have been believed in the past, especially in the developing countries, it is not a disorder of 'the West' or of advanced nations. The realisation of this fact is of particular importance in SSA and other regions of the world where awareness levels are still growing (Al-Ansari, Ahmed (2013).

While the ASD rate appeared to rise to 79 % over a 3-year period, the rate of developmental delay dropped to 36 % (Zablotsky, Black, Maenner, Schieve, Blumberg, 2015) and the combined prevalence of children diagnosed with ASD, developmental delay and intellectual disability did not change over the 3 years. The unchanging statistic of the sum data suggests that a number of children who were once tagged as having developmental delay or intellectual disability are now being identified as having ASD.

The global prevalence of ASD is reported to be increasing, Ruparelia, Abubaka, Badoe (2014) with the most recent estimates for the United States and Zambia inclusive indicating that one in every sixty-eight children aged eight years have some form of ASD. However, little is known on the prevalence of ASD as well as experiences of those who care for children living

with ASD in Africa. Further, the details of clinical presentations of this disorder remain elusive as well in this region. Reported rates of autistic spectrum disorders for example, have been rising in many countries over the past two decades (Wallace, Fein, Rosanoff, 2012). Less is known of what experiences those who are responsible for management of children with ASD go through. It remains unclear how much of available data represents an actual increase and how much reflects experiences and changes in diagnostic definitions and practices, as well as increasing awareness among parents, the general public and indeed within the medical profession (Bakare Munir, Bello-Mojeed, 2014).

1.2.5 Africa Trends with ASD

More than 100 genetic polymorphisms have been associated with ASD, with Africa having greater genetic diversity than any other continent. Without doubt, because of this, genetic studies of ASD in Africa could provide unique insights into the pathogenesis of the disorder. Environmental risk factors for ASD are poorly understood, but the incidence of the risk factors associated with ASD in high-income countries, such as pre-eclampsia, placental insufficiency, prolonged labour, induced labour, birth asphyxia, pre-term birth, and low birthweight, are also common in Africa (Elsabbagh, Divan, Koh 2012).

The universal occurrence of ASD was queried about twenty-six years ago. It was thought to occur only in western industrialised countries with technological development. Over the last decade, knowledge about ASD and its prevalence has been documented as being on the rise in different regions of the world, with most literature coming from the western world (Bedford, et al., 2012). It has been reported by Adamson (2012) that ASD in the African continent covering countries such as Ghana, Nigeria, Kenya, Zimbabwe, Zambia and South Africa. In 1970s, the prevalence of ASD in Africa was about 0.7 per cent among children with developmental disorder (Bakare, (2014) (Abubakar et al., 2016); (Ruparelia, et al. (2016)

though an Arab study involves two Northern African Countries (Tunisia and Egypt) found that prevalence of ASD was 11.5 per cent and 33.6 per cent among children with developmental disabilities in Tunisia and Egypt respectively (Bakare, 2014). A hospital-based population study in Nigeria found the prevalence of ASD to be 0.08 per cent (Bakare *et al.*, 2011), most likely influenced by the low help seeking behaviour for Childhood Neurodevelopmental Disorders (NDD). Prevalence among School children with Intellectual Disabilities in Nigeria was 11.4 per cent (Bakare *et al.*, 2012).

Notable studies on the prevalence of ASD were done on African immigrants living in Sweden. The prevalence rates of ASD among children of African immigrants living in Sweden were consistently higher when compared with the prevalence of ASD among the indigenous Africans population. Reasons for the higher prevalence of ASD among African parents outside the African continent are not clear but such findings may be related to the Vitamin D etiological hypothesis of ASD among other reasons. The current study learnt a lot from the aforementioned study in that it has highlighted those reasons for the higher prevalence of ASD among African parents. Reasons for the African continent are not clear but such findings may be related to the Vitamin D etiological hypothesis of ASD among other reasons, which raises the question as to whether this is the same for Zambian parents.

Table 1.1: Country of origin and various aspects of ASD addressed by African

Country of origin	Prevalence	Aspect of ASD	Year
Nigeria	11.4%	Intellectual Disabilities	2012
Egypt	11.5%	Developmental Disabilities	2008
Tunisia	33.6%	Social Behaviour	2011
Tanzania	15%	Knowledge on ASD	2015
Arab populations (Tunisia & Egypt)	0.08%	Neuro Developmental Disorder NDD	

Source: Autism in Africa: The Critical Need for Life Saving Awareness (2015)

About two and half decades ago, the universality of ASD was questioned. ASD was thought to occur mostly in Western cultures and countries with high technological development. Occurrence of ASD in Africa was then a subject of debate. Maenner.; Shaw; Baio; Washington; Patrick iRienzo; Christensen; Wiggins.; Pettygrove; Andrews.; (2016) resolved that those studies are required to address the open question of the universality of ASD. Over the last decade and a half, there has been documented evidence of an increase in the prevalence of ASD and knowledge about the disorder in other parts of the world.

ASD was previously perceived and documented to occur only in the well-resourced countries with high technological development. A few decades ago, some questioned the universality of ASD (Chiarotti and Venerosi, 2020). There has since been evidence of an increase in the prevalence of ASD and knowledge about the disorder in other parts of the world (Vaughn, Schumm & Sinagub, 1996). However, there remains a major gap in what is known about the global burden of ASD, in particular little is known about ASD in Africa.

Bakare and Munir (2014) conducted a literature review of ASD in Africa. They found twelve relevant articles but only two reviewed epidemiological data. The twelve (12) publications were broad studies of ASD including reports of African immigrants in Sweden Bejarano-Martín; Canal-Bedia; Magán-Maganto; Fernández-Álvarez; Martín-Cilleros; Sánchez-Gómez; García-Primo; Rose-Sweeney; Boilson; Linertová; (2019) and a study of nine Arabic speaking countries which included data from Tunisia and Egypt (Thomaidis; Mavroeidi; Richardson; Choleva; Damianos; Bolias; Tsolia, (2020). In their review, Bakare and Munir (2014) reported that children with ASD in Africa were diagnosed relatively late compared to those in high-income countries. The age of diagnosis was reported to range from eight years through to adolescence. Moreover, two of these studies revealed that over half of the children with ASD in their cohorts did not have any expressive language and/or had severe intellectual disability which may indicate that only the more impaired cases were identified (Thomaidis, Mavroeidi,

Richardson, Choleva, Damianos Boliias and Tsolia, 2020). This delay in diagnosis may also contribute to the lack of appropriate language skills in many of the children with ASD, partly because parents of children with ASD did not have access to early interventions. Further, the information available on ASD in Africa is so limited in scope that it does not give a clear picture on experiences of professional strategies that parents and caregivers should use to manage the different patterns of behaviour exhibited by children with ASD.

In his survey for a workshop presentation, Bakare asked psychiatrists and paediatricians in Nigeria about the causes of ASD. Many regarded ASD as having supernatural causes that were precipitated by perceived angered ancestral spirits, sinful wrongdoing, predominantly by the mother or the action of the devil (Bakare, 2011). They reported that it is a common pathway in Africa for a child with a neuro-developmental disorder to be taken first to a traditional healer before a parent seeks mainstream medical assistance. This potential delay in seeking mainstream medical assistance may contribute to late diagnosis and could be a further exacerbating factor in the more severe cognitive and expressive language outcomes reported in children with ASD. These findings highlight a need for earlier recognition and diagnosis of ASD in Africa. Although in well-resourced countries there are many “gold-standard” tools available to screen and diagnose ASD, there are no available validated tools from Africa (Morales-Hidalgo; Roigé-Castellvi; Hernández-Martínez; Voltas; Canals, 2018; Bakare *et al.*, 2011b).

The perception of abnormal behaviour may be mediated by culture and screening measures need to take into account contextual factors. Although major global advances in understanding the genetic and developmental aspects of ASD have been made, many aspects of the condition are still poorly understood. More specifically, there is no research to date exploring risk factors for ASD in Africa. There are reports of increased prevalence of ASD in children of Somali origin living in Stockholm (Chiarotti and Venerosi, 2020). Maternal birth outside the Nordic

countries living in Sweden and mothers of African origin living in the United Kingdom (Baird, McConachie & Scrutton, 2000). These findings propose that ASD in Africa may be more common than is recognised and emphasise the need for epidemiological research in Africa.

The period of onset of ASD symptoms among African children coincides with the period of less than five years that is characterised by vulnerabilities of African children to physical illness and infectious diseases associated with neurological consequences. Loomes; Hull; Mandy (2017) reported that the onset of ASD followed recovery from infection or physical illness in about 50 per cent of the studied population of Tanzanian children. Stereotypic repetitive repertoire of interest and/or behaviour may be less common among African children with ASD (Shattnawi; Bani; Al-Natour; Al-Hammouri; Al-Azzam; Joseph, (2021). There is an excess of non-verbal cases over verbal cases in clinical population of African children with ASD (Bakare & Munir, 2011a; Bello-Mojeed *et al.*, 2011). This could be as a result of late diagnosis and interventions. Studies originating from Africa among African children with ASD suggest that intellectual disability is the commonest co-occurring diagnosed condition among the children (Maguire, 2013; Kim, 2015; Shaw, *et al.*, 2014; The National Autistic Society 2014; WHO, (2013); Bakare & Munir, 2011).

The diagnoses of ASD are therefore infrequently made absolutely of Intellectual Disability which mostly misleads parents of ASD children in failing to comprehend different core areas of functions that ASD children depict, which involves parents going from one hospital to another in trying to find the answer to the problem that their children have. Children with ASD have other documented co-morbid conditions that include epilepsy and oculocutaneous albinism among others (Belhadj *et al.*, 2016; Bello-Mojeed *et al.*, 2011; Falk; Norris; Quinn, (2014). Most parents searched intensely for information following the diagnosis including attending as many talks and discussions related to ASDs as possible. Others reduced the intensity of their search for information subsequent to the critical period subsiding. This may

indicate that while all parents searched intently for information prior to and after the period of the diagnosis, only some remain active information-seekers. Different parents may have wanted and benefited from different amounts of information. Therefore, professionals and service providers need to be aware of the potential inconsistency in parents' information coping styles if they are to effectively meet the information and education needs of parents (Maenner, 2016). Although many studies world over have clearly shown the lived experiences of parents of children with different developmental disabilities, few studies have explicitly looked at the lived experiences of parents of children with ASD particularly in Lusaka District.

1.2.6 ASD has a Male Sex Predilection

Sexual predilections in disease prevalence are well-recognised, and female predilections have been reported consistently in a number of disorders with autoimmune aetiologies, while a male preponderance has been observed in some neurodevelopmental disorders. ASDs have also been observed to have a higher prevalence in males, compared to age-matched females; in a 4:1 ratio. This observation has been consistent across populations, regions and time; strongly suggesting the involvement of sex-specific biological factors in ASD aetiology (Halladay *et al.*, 2015; Bakare, Munir, Bello-Mojeed 2014).

ASDs are diagnosed in one in 68 children in the USA, affecting four times as many boys as girls. In the United States, ASD has been labelled a "national public health crisis, whose cause and cure remain unknown," by the CDC (2012). ASD knows no boundaries. It cuts across every nation, every ethnic, racial and social group. Indeed, although ASD is one of the most prevalent neurodevelopmental disorders in high-income countries like the United States, there is very little knowledge about the disorder in the low-income regions of the world such as Africa.

There is very little data on the prevalence of ASD in Africa, even though this region has a population of nearly 1 billion, 40% of whom are children younger than 14 years. Although, in recent years, public-health emphasis in sub-Saharan Africa has been on communicable conditions such as HIV, Malaria, and Tuberculosis, with the reduction in childhood mortality rates in the past two decades, non-communicable diseases (especially neurodevelopmental disorders) are likely to become a greater health burden in these countries. Some early studies have suggested that ASD could be a culturally-bound disorder, and that it might be rare in regions such as Africa. However, this is proving not to be the case.

Werling, Geschwind (2013) identified nine children with ASD in hospitals in six African countries. Shortly after this, many cases of ASD have been reported from Kenya, Zimbabwe, Nigeria, Zambia and Ghana. Furthermore, emerging evidence from immigration studies now suggest that ASD could be more common in Africa than initially believed.

1.2.7 Characteristics of ASD

Children with ASD usually have difficulty with social interaction. Some parents have said that before their child's diagnosis of ASD, they thought their child was just very shy. Children with ASD may have an unusual interest in objects. They may play with toys in different or unusual ways. For example, they may be able to tell you everything you need to know about car engines. Or they may be able to sit for hours spinning the wheels on a toy vehicle. Children with ASD often have a need for sameness. They may have difficulty with changes in routines, clothes, food, caregivers, and other parts of their environment. Such children may have great ability in one area and great difficulty in another. But not all children with ASD have the same abilities. For example, a child with ASD may have difficulty holding a pencil but have a strong memory for the words of songs or movies. On the other hand, they could be fabulous artists or have perfect pitch. A child may have difficulty knowing how to play a game with a peer but

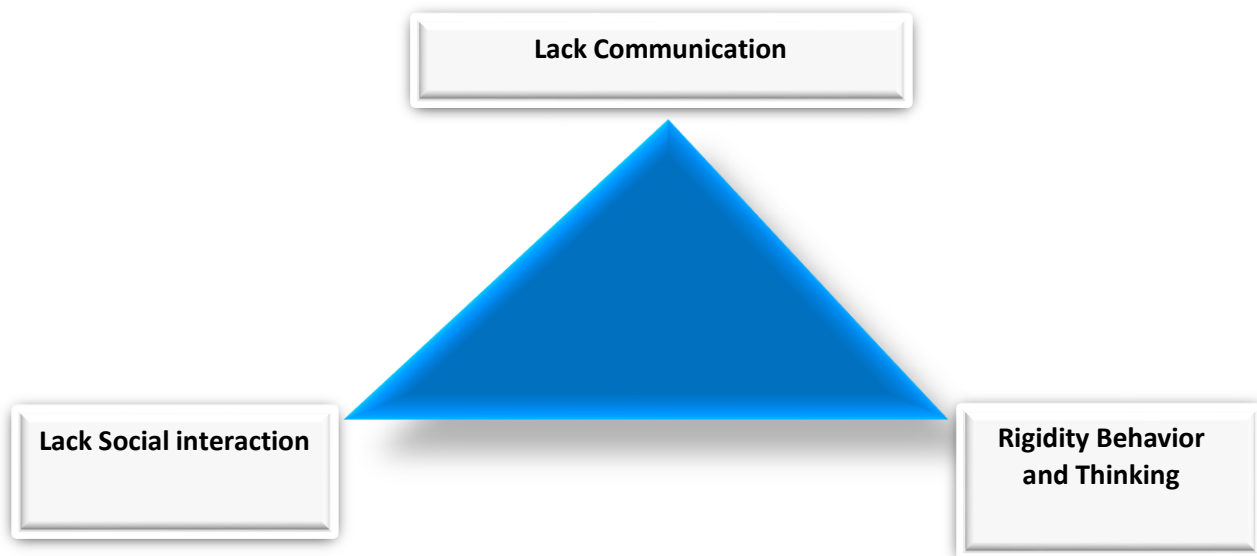
may have a very good understanding of how computers work. A child who does not speak may be able to build complex structures out of Lego. Children with ASD may also have unusually strong reactions to one or more of their five senses. For example, some children may react to bright sunlight. Others are excessively bothered by tags on their clothing or by loud noises. Many children may be bothered by these things, but children with ASD often have a stronger reaction to them. Children with ASD often have difficulty with the colour, smell, or texture of certain foods. This may limit what they will eat to only a few foods Shaw *et al.*, (2014).

Children with ASD may also do the same thing over and over again. For example, they may repeatedly flap their hands, jump, or walk on tiptoes. This is common. It is something that many parents with children with ASD talk about when they describe their children. The children may also have unusually intense and prolonged emotional reactions. For example, they may get very angry when asked to stop playing and get ready for lunch. These emotions do not match the situation they find themselves in. These reactions may occur as a result of the anxiety they feel when making changes in routine. Furthermore, children with ASD may talk constantly about specific things that interest them and be unaware that other people might not have the same level of interest (World Health Organisation, 2013).

The characteristics of people with ASD, related to their social interaction and socio-emotional development, are considered the most important elements of their behaviour. To be more specific, these people have deficits in social and emotional reciprocity from a young age. This manifests as they avoid social contact with the eyes, show no interest in the face of others, fail to understand the facial expressions and feelings of others, are interested in a limited extent to come into physical contact with their parents, have poor imitation and have difficulty understanding and using expressive gestures. A characteristic feature of children with ASD is loneliness, which indicates lack of motivation and minimal desire for social interaction (Panteliadou and Argyropoulos, 2011).

Relevant research confirms that children with ASD are lagging behind in all linguistic domains, namely phonology, vocabulary, syntax, morphology, and pragmatics. Their speech is characterised by stereotypical expressions, while very often, they discuss issues of interest to themselves without participating in a particular debate. They also repeat information that does not interest others or ask questions, of which they already know the answer (Polemikos, 2010). In addition, children with ASD have a disturbance in imagination, which they manifest with stereotypical behaviours, such as object rotation and hand blows. Another way of expressing their imagination is rituals, adherence to specific objects or play points that are not functional (Panteliadou and Argyropoulos, 2011). At pre-school age, where diagnosis is usually made of children with autism up to adulthood, their particular behaviours are becoming more and more distinct. Characteristic of children with ASD is their persistent involvement in sensory stimuli. In particular, they lick or place in their mouths items that are not eaten, smell some objects, click on different surfaces to hear their sound, turn their attention for a long time on shining lights or objects. Apart from those, some children with ASD rotate objects or flush their hands close to their eye level, flashing lights or looking at objects from different angles (Cohrs, Leslie, (2017).

According to Christakis (2011), the above characteristics are not observed in every child diagnosed with ASD. It is possible that the specific characteristics of the same child are displayed differently in other children. This fact documents the view that children with ASD cannot be categorised into homogeneous groups based on their characteristics. Each child is separate and is considered, according to his / her individual peculiarities.



Source: Own illustration based on current study

Figure 1.1: Experiences of Parents of children in social interaction with triad characteristic of ASD and associated Features

1.2.8 Challenges parents encounter with children with ASD

Many parents experience emotional strains, lack of information about the child's condition, health problems due to the child's disability, necessity to consult many specialists about treatment and education, difficulties in describing the situation of child to the others and concerns about the future of child (Hall, Roberts & Graff, 2011). Having an ASD child disturbs parents' view of life, their interactions with each other, and expectations of the future in a variety of ways (Nealy *et al.*, 2012). Most of the time, parents may blame themselves or each other for the state of the child. Additionally, parents are confronted with a burden and long-term crisis that surpasses their adaptation capacities because of more time, energy and money requirements (Neely-Barnes, Hall, Roberts & Graff, 2011).

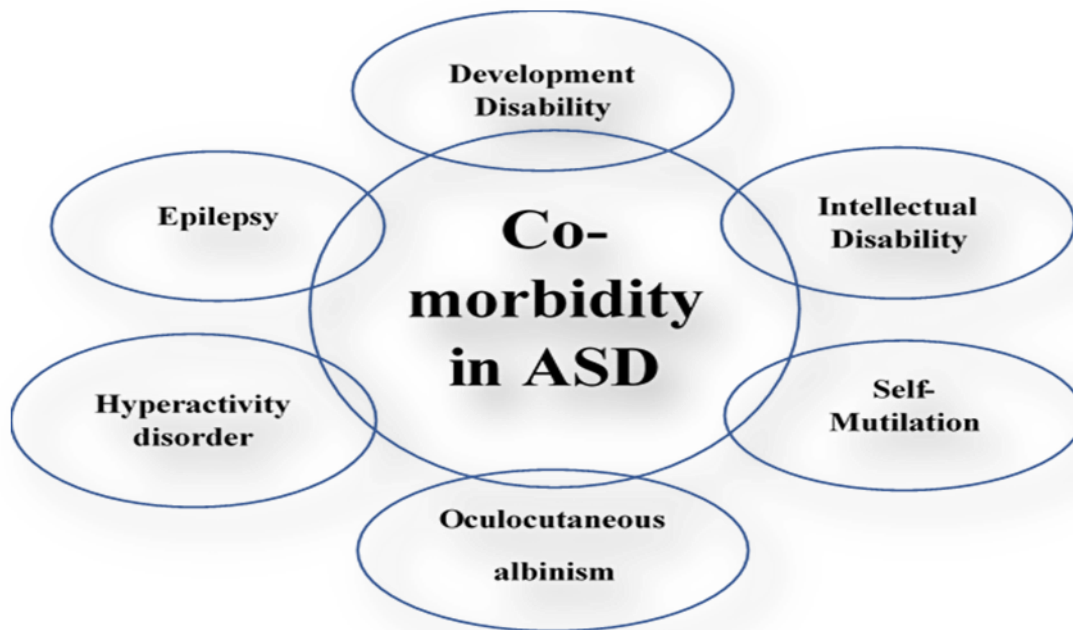
Consequently, these parents have stresses and these stresses spread through various magnitudes of family life. Parents of children with ASD often experience certain challenges such as anxiety, depression and low self-esteem including communication problems within the family that can lead to separation or divorce and social isolation feelings (Estes; Olson; Sullivan; Greenon; Winter; Dawson; Munson, 2013; Manuel, Michelle, Rajesh & Beth, 2003). Having a child with ASD may be associated with the inability to fully meet the daily needs of other family members and it can also be linked to stress and poor social relationships within the families (Neely-Barnes, 2011). Parents' stress may be influenced by the age, gender, type and the severity of the child's disability. Additionally, stress can be linked to the family's socio-economic status, as children with ASD need more specialised services which come with a certain price. Other encounters that may arise while taking care of a child with ASD include: spousal conflicts and increased responsibilities of child care which may be linked to parents not being able to have their own time alone as a couple.

Children with ASD often exhibit high levels of co-occurring behaviour problems (Bauminger, Solomon, and Rogers, 2010; Gray, Keating, Taffe, and Brereton, 2012; Hartley, American Psychiatric Association, 2013; Kanne and Mazurek, 2011; Mazurek and Kanne, 2010). Both internalising (e.g., depressed/anxious somatic complaints and withdrawal) and externalising (e.g., aggression, hyperactivity and property destruction) problems are often present in children with ASD. The social interaction deficits deceptive in Gray's *et al.*, (2012) observations of ASD children may be difficult for parents to accept because they are faced with children who seemingly have no interest in interacting with loved ones American Psychiatric Association, (2013). Grief as well as blame may begin to enter the narrative of the parent as they begin to recognise that their expectations of parenthood are likely to change drastically.

The emotional state of children with ASD may become heightened as the restrictive and repetitive behaviours of the ASD children become overwhelming and even violent towards the parent (Fairthorne; De Klerk; Leonard, (2015). Children with ASD are often highly restrictive in their interests, which can lead to highly explosive behaviours when these interests are disrupted. Unpredictable behaviours, lack of social interaction reciprocity, societal judgement, inadequate social supports as well as the prospect of life long care leads to significant challenges for parents of children with ASD in social interaction.

Parents can be left with little options in the way of satisfying their ASD child's interests, as only a few activities and objects will suffice. There may be fear attached to breaking these bonds with objects, as they often end in explosive tantrums or violent behaviours, which are a significant stressor for parents (Pisula, Kossakowska, 2010; (Grossi, Marcone, Cinquegrana, Gallucci, 2013). Given the overwhelming nature of not only the characteristics associated with ASD, but the behaviours apparent in ASD children, one should not be surprised by the stressors associated with parenting a child with ASD. It is observed and documented those parents of children with ASD exhibit the highest degree of stress in comparison to parents with both typical children and children with other medical and developmental conditions (Grossi, Marcone, Cinquegrana, Gallucci, 2013). Theory has moved away from Kanner's original assertion of suggesting that parental emotions were the cause for ASD in their children and towards the realisation that ASD is the source of these emotions and thus eliciting high degrees of parental stress (Wallace, *et al.*, (2012).

Children with ASD have additional medical or psychiatric conditions. This is called 'comorbidity' and the conditions are often called 'comorbid' conditions. Comorbid conditions can appear at any time during a child's development. Some might not appear until later in adolescence or adulthood.



Source: Child and Adolescent Unit, Federal Neuro-Psychiatric Hospital, New Haven, Enugu, Enugu State, Nigeria Developmental Medicine Center, Boston Children's Hospital, Boston, MA, US

Figure 1.2: Co-morbid Conditions among Children with ASD

Children with ASD have anxiety symptoms including tension, restlessness, hyperactivity, worry and fear. Furthermore, children with this condition would often ask the same questions repeatedly. They equally often tend to have problems to sleep and are awake most of the time. These children tend to exhibit impulse reactions which make them less focused as they are up and about most of the time. This is a contrast with children with deficit hyper-activity disorder (ADHD) where behaviours are extreme and have a large impact on the victim's day-to-day life. According to Walsh *et al.*, (2013) such behaviours mainly distract the children with ASD though. There are problems to diagnose intellectual disability for children under the age of six years old when the IQ is below 70, which is why children in this category experience challenges in carrying out their everyday tasks while ASD children have significant cognitive and language development delays. However, even though intellectual disability varies from person to person, children with ASD and intellectual disability have uneven skills indicating

that there are things they are good at and others that they find hard to do. In most cases, children with ASD have more trouble with social interaction, verbal skills such as talking, listening and understanding than with non-verbal skills like doing puzzles or drawing.

In the past, it was thought that 50 to 60 per cent of children with ASD had intellectual disability or developmental delays, but this is now thought to be at 30 to 40 per cent, with another at 20 to 25 per cent having borderline intellectual disability with an IQ of 71 to 85 (Patton, 1990). This drop might be attributed to the improvement in IQ testing for children with ASD. Early intervention and education are better at addressing the learning needs of children with ASD while more children without intellectual disability were diagnosed with ASD. Some researchers have argued that some children's developmental delays might be caused by their social learning difficulties rather than having a separate condition (Shtayermman, 2013).

Due to conditions in children with ASD, parents encountered difficulties in social interaction relating with their children particularly when their child needed something but was unable to express it. It was a challenge for parents of children with ASD to know when their child was sick, happy or sad and when the child needed something because of their inability to communicate, interact and RRB making them worry of what was going on in their children's minds. These are social interaction skills, social skills and core functioning areas which parents lack, thereby creating a distance between them and their children. Trust issues and emotional problems denied the bonding between parents and their ASD children, mostly because the child was inaccessible. Parents had problems in helping their children with ASD to create strong social interaction skills which could be accepted by their peers in order to build friendships and maintain strong relationships (Hall, Roberts & Graff, 2011). Furthermore, parents were concerned with their ASD children as they were unable to solve their problems effectively or to substitute greater interest in school and did not improve in academic skills which made these parents reflect on the future of their children's wellbeing. Children with ASD often show

delayed development in social interaction and social skills such as limited eye contact, lack of vocabulary to express difficult emotions and have increased risk of issues such as frustration, setting boundaries with others or use of aggression to communicate when learning new tasks. Parents mostly spent more time with their ASD children compared to other siblings while others quit their jobs to be with their children (Silva & Schalock, 2012).

Some parents reported that they had to give up their careers to provide full attention and care for their children with ASD. This was the biggest sacrifice that a parent had to offer to be able to take care of their child. These parents conveyed the importance they felt about parental involvement in their children's interventions and they believed that if the parents worked alongside with the other clinical therapists, this could provide the biggest positive intervention outcome for their children. Challenges that parent encounter according to Yang *et al.*, (2016) as a result of their inability to interact with their children and having had to deal with their children's behaviours of crying, hitting or throwing a tantrum. In addition, Parents alluded that instead of using verbal communication, their children often expressed themselves by screaming, crying and throwing tantrums. According to the parents, when he or she is mad, he would just shout because there is communication breakdown between the ASD child and the parents. This is the problem that stressed parents. Parents often feel overwhelmed by the behaviour of children with ASD which makes their interaction with their children sour, though it their primary responsibility of ensuring that ASD children are accepted in the family, which is very difficult. Siblings feel that their parents' attention and love is directed only at the child with ASD because of the constant attention given to them. Parents can be tremendously upset, which would lead to mental health issues such as depression, anger and stress, reduced well-being and poor life-satisfaction (Cohrs; Leslie, (2017). In addition, humiliation is highly experienced when an ASD child has committed a social misbehaviour. Parents experienced

humiliation because other people could be thinking unpleasant thoughts toward their ASD child (Zablotsky, Bradshaw, Stuart, 2013).

It is well-known that children with ASD have difficulty with “mind-reading” skills. Their ability to comprehend the mental states of others such as thoughts, intentions or beliefs in order to predict and understand behaviour often showed some deficiency (Benson & Kersh, 2011; Berger; Ingersoll, 2013). Based on the literature reviewed, the researcher was prompted to conduct the study in Lusaka District with a view to exploring the lived experiences of parents’ social interaction with ASD children. Parents assumed that it was undeniable that children with ASD influenced their parents’ lives. This was because most of the parents felt that they were the most affected by their children’s disability whereas some thought that the children’s other families were the most affected, hence isolating themselves from families, relatives, friends and socialisation. They do not want to expose their children to the society for fear of being labelled or to be bad mouthed (Barak-Levy & Atzaba-Poria, 2013; Barrett, 2012. Most parents with children with ASD are not competent and knowledgeable enough to help or handle their ASD children, especially in social interaction during times when they throw tantrums. Some of the parents self-confessed to feeling incapable and less inadequate to provide care to children with ASD (Olsson & Hwang, 2001; Cohrs & Leslie, 2017; Hayes & Watson, 2013).

Parents fail to comprehend their children with ASD because they pose challenges in communication, social interaction and rigidity in thinking and behaviour for parenting, since children or adolescents with ASD portray unusual and inappropriate behaviour such as easily breaking the law, exhibiting moody behaviours and obsessive-compulsive disorders. Caring for children with ASD can be demanding, especially in contexts of communication; social interaction and cognitive inflexibility or Rigidity and/or Behaviour. It has several comorbidities which result from the behaviours they portray and impose a huge emotional and economic burden on parents to the ASD children.

1.3 Statement of the Problem

As presented in the background section above, many research studies have been carried out on children with ASD in various countries. Many of these studies have focused on the stress that children with ASD go through, challenges and opportunities experienced in learning and teaching children with ASD as well as the psychological functioning of teachers handling children with ASD. Such studies have not necessarily addressed the issue of how parents of children with ASD socially interact with their own children and their lived experiences. The majority of such studies have involved children with ASD with a focus on educational attainment, instructional strategies as well as rehabilitation of such children (Fombonne, Marcin, Manero, Bruno, Diaz, Villalobos, Ramsay, Nealy, 2016; The National Autistic Society 2014; Chansa-Kabali, Nyoni & Mwanza, 2019; Wonani & Muzata, 2019; Nyoni Sepell, 2012; Hasangu, 2015). Although these studies have been conducted and have significantly contributed to the available knowledge on children with ASD across the globe, very little attention has been paid to how parents of children with ASD socially interact with their children, hence, seemingly creating a knowledge gap requiring investigation. It is against this background that the present study sought to explore the lived experiences of parents of children with ASD in the area of social interactions with their children in Lusaka District of Zambia.

1.4 Purpose

The research purpose is a statement of "why" the study is being conducted, or the goal of the study. The goal of a study might be to identify or describe a concept or to explain or predict a situation or solution to a situation that indicates the type of study to be conducted (Creswell, 2016). The purpose of this study was to explore the lived experience of parents of children with ASD in selected special schools in Lusaka District of Zambia.

1.5 Research Objectives

The research objectives that guided this study were:

- (i) To establish ways parents socially interact with their children with ASD.
- (ii) To describe parents' experiences in social interactions with children with ASD.
- (iii) To explore the coping mechanisms that parents employ in managing experiences of social interactions with their children with ASD.

1.6 Research Questions

The following research questions guided the study:

- (i) In what ways do parents interact socially with their children with ASD?
- (ii) What are the parents' experiences on their social interactions with their children with ASD?
- (iii) How do parents cope with the experiences of social interactions with their children with ASD?

1.7 Significance

The earliest practices of children can ensure their future success, and parenting is noted to be an influential factor (Bronfenbrenner, 1979; Lamb *et al.*, 2002). From the available literature, it is believed that parents with ASD experiences, characterised by abnormalities in social functioning, language and communication, and unusual behavioural interests, are a collection of five developmental disorders, namely Autistic disorder, Asperger's syndrome, Rett's disorder, Childhood disintegrative disorder and Pervasive developmental disorder not otherwise specified (American Psychiatric Association (2013)). This study, therefore, was

designed to contribute to the existing literature on the collaborative relationships between parents and children with ASD in Lusaka District. Improving knowledge of ASD among parents may, in turn, enhance the well-being and developmental outcomes of children affected with ASD. It is hoped that the findings would be significant because they would have the potential of generating interest and awareness on experiences of parents of children with ASD, surrounding social interactions in home settings in Zambia, as well as stimulating further investigations. In addition, the findings would also help parents, scholars, local people, policy makers and other stakeholders in improving the welfare of children with ASD through sharing insights on experiences necessary in formulating policies that would enhance the parental and community support to children living with ASD. Lastly, this study might stimulate interest in finding ways and means of improving social interactions between parents and their children with ASD in the studied district.

1.8 Delimitation and Limitation

1.8.1 Delimitation

Delimitation indicates the boundary of the study in the context of participants, content and geographical coverage. It is used to address how the study is narrowed in scope and covers several factors of which the researcher did not have control at all (Kasonde-Ng'andu, 2013). In this study, focus was on the lived experiences of parents with children with ASD in Lusaka District of Zambia. This was a qualitative research study which utilised the hermeneutics phenomenology approach to examine the lived experiences of parents with ASD children. The participating parents were those with children with ASD in the core area of functions (communication, social interaction and rigidity in thinking and behaviour) in Zambia. Lusaka District was chosen because it was convenient and reachable to the researcher (Chiarott & Venerosi, 2020).

Furthermore, the researcher felt that parents' lived experiences, views and attitudes towards children with ASD would contribute new knowledge to the existing body of knowledge on the lived experiences of parents with ASD in Lusaka District.

1.8.2 Limitation

For the purpose of being objective and self-critical of the study, the researcher paid particular attention to certain factors that challenged the study on lived experiences of parents in social interaction with ASD children. These included the researcher having a sibling with ASD which might be considered biased; the study being too detailed in terms of the number of participants and research questions asked as part of the data collection process. There were ten participants drawn from three geographical study areas namely low density, medium density and high-density areas with a background and lived experiences of parents of children with ASD. Thus, personal voice and experience of these parents provided rich, descriptive data while participants exhibited different characteristics and experiences on various themes of the study, thereby making a conclusion in some cases was rather difficult. As a result, this created difficulties in making accurate thematic analysis using Nvivo of the data collected. However, use of the in-depth interview guide and observational check list in the collection of data assisted in minimising the problem noted above. The data collected was therefore, reliable and valid to support the findings of the study.

The quality of research instruments used might have negatively contributed to the outcome of this study. For some questions on the interview guide, responses were used on the strength that they were used in other studies such as those done by (Wonani and Muzata, 2019; Mahbuba, 2015; Chansa-Kabali, Nyoni and Mwanza, 2019; Ludlow *et al.*, 2011). The researcher's concern was that such instruments were mainly designed to be used on all respondents separately. Although this may have posed challenges in the organisation of data.

The researcher used a combination of different types of participants and study location hence, the results were not compromised.

To some extent, the researcher's position on in-depth interviews might have had some influence on the responses given by the participants. For example, the participants were quite aware that the thesis on the lived experiences of parents' social interaction with ASD children in Lusaka District of Lusaka province of Zambia, may also be read by policy-makers, planners and that the contents of the thesis may to a certain extent, influence decisions on how parents could raise their children with ASD in their homes. Because of this, part of the information contained in this thesis could be considered suspect and unreliable in the generalisation of the findings of the current study.

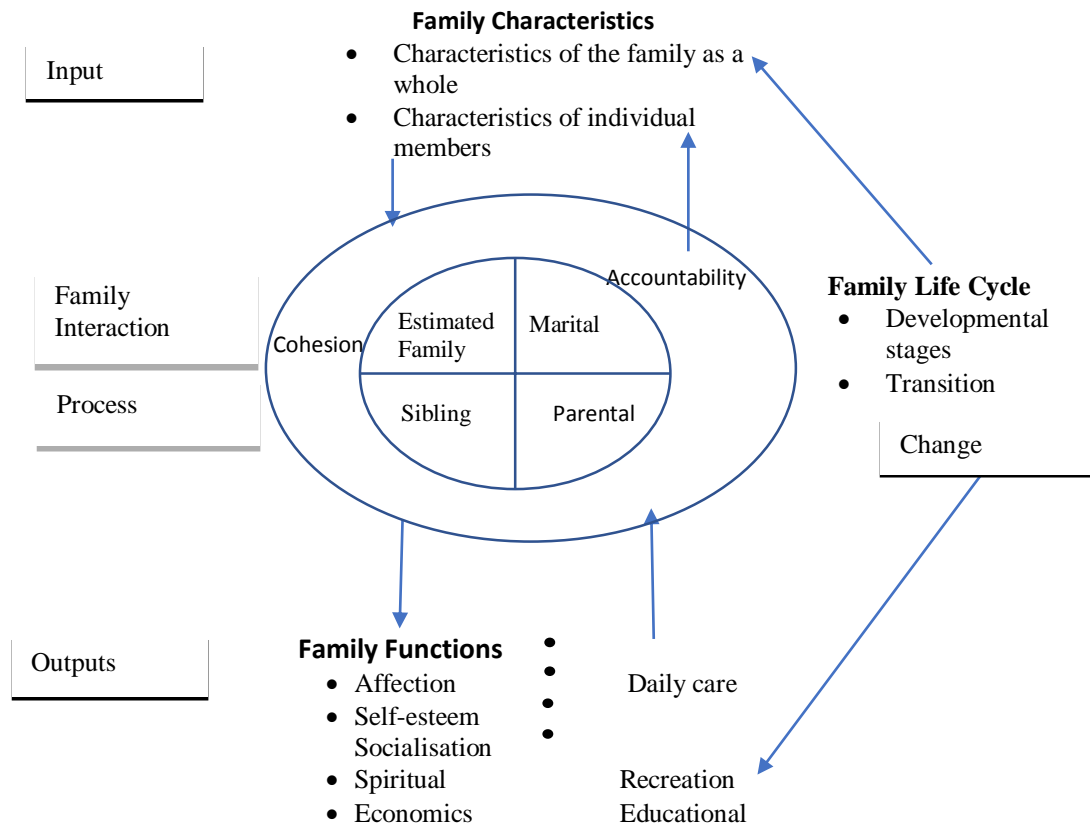
1.9. Theoretical Model

1.9.1 Family Life-Cycle Model

The Family Life-Cycle Model was used as a base for the present study on the lived experiences of parents' social interaction with children with ASD. There are several aspects that are covered by Carter and McGoldrick (2016), which include expected stages, changing patterns of the family life cycle, and the clinical perspective. The Family Life-Cycle explains dysfunction in relation to normal functioning. It frames problems that might arise within the family, growth as a system moving through a change and over time. The theory argues that a change in the family affects the life cycle of individuals within the family set up. The foundation of this theory is that families normally go through predictable changes through life events but at times, family and individuals such as parents can go through unpredictable events and changes such as taking care of an unexpected ASD child. As these changes occur, in a family and in particular parents of ASD child, must adapt accordingly in order to avoid

dysfunction as the care for a differently abled child such as the ASD child. The changes in the family may involve tasks that must be negotiated as they become complex, bring new roles; operations and put pressure on those close to the child.

It should be noted that this family life cycle is not a linear process as discussed by Carter and McGoldrick (2016), but is rounded, and enables one to understand some of the emotional, physical and relational experiences a family could go through differently, during different transitional stages. These changes might probably involve different experiences for different members of the family and be different for different families with an ASD child. It is noted by Carter & McGoldrick (2016) that as the families negotiate entry and exit of other family members with ASD, or as they negotiate this family expansion and contraction, more stress can be experienced by parents. Hence, they strive to maintain the balance, and realign their relationships to support the entry, exit and development of family members in a functional way (Carter & McGoldrick, 2016). The stages discussed commence from the Single adult, new couple and new parents.



Source: ©2001, 2006, 2001, 2016 *Families, Professional & Exceptionality: Positive Outcomes Through Partnerships & Trust*

Figure 1.3: Family System Framework: Emphasis on Family Life Cycle

Stage one: Independence

This first stage discussed by Carter and McGoldrick (2016) is termed “in between” stage. This is the stage where the young adult is thrown into independence, without, however, cutting emotional ties with the family of origin. The young adult might have physically left home, according to the writers, but not have started their family of procreation. However, at this stage they are still attached to the family of origin emotionally, with a major task ahead of them, which is to be completely independent holistically, while ensuring that they do not lose the relationship and bond with their family of origin.

Santrock (2014) states that the adequate completion of the launching requires the young adult to separate from the family of origin without completely cutting ties, or fleeing in a reactionary way to find some form of substitute or emotional refuge. Carter and McGoldrick (2016) further state that the satisfactory resolution of this stage is also dependent on the family of origin, regarding how the parents deal with separation themselves. From the family viewpoint, “the young adult has to be able to tolerate separation and independence, while remaining connected, tolerate differentness and ambiguity in career identity of adult children and acceptance of a range of intense emotional attachment and lifestyle outside the immediate family” Carter & McGoldrick, 2016).

How the identity of the young adult is formed, according to Carter and McGoldrick (2016), has much bearing on challenges faced by this novice adult at this stage, as well as social influence which results from the cultural life constructed by the society whence the young adult originates. The formation of the self, of the young adult is highly influenced by the interaction and the relationship with the family of origin’s “significant others”. It can result in a healthy identity as an adolescent has undergone a crisis and has made a commitment, foreclosure identity the adolescent has made a commitment but has not experienced a crisis, or identity diffusion where the adolescent has not met a crisis and not made any commitment on life issues (Santrock, 1996:392). Erickson (in Carter & McGoldrick, 2016), has been criticised for his biased definition of identity of young women to be based on their physical attributes alone, and of the man as being self-expressive. However, for both sexes, autonomy and attachment are functional goals at this stage.

The reality and culture that have been constructed in society as perceived by young adults, also has much bearing on the choices made by them. Hence, Carter and McGoldrick (2016) maintain that “human affiliation is just as important as self-enhancement”. The novice adult has to make and live with his or her choices regarding occupation, love relationships, lifestyle

and values. Hence, Carter and McGoldrick (2016) show that this period is the co-existence of two tasks: finding a balance between work vs. the self to expand one's horizons and to create initial adult life structures that are to have roots and continuity.

Hence, the young adult has to have an enormous reserve of courage energy, tolerance, and willingness to take risks. The basic tendency to actualise, maintain and enhance the experiencing self, (in Grobler *et al.*, 2003:17), is apparent at this stage. Carter & McGoldrick (1989:193) posit that sometimes, the young adult may short-circuit the stage by premature marriage, or by staying at home, or having a child before marriage. However, these are constructed realities which might be different from one country to the other which is one of the reasons for exploring these issues from the African perspective. In Zambia, the single adult seldom leaves home, and is regarded as a child until they are 21 or get married. The women's identity is developed around men, and, as a result, women only leave home when handed over by their fathers to their husbands on their wedding day, in order to continue to care for the families especially the men as receivers or beneficiaries for care.

Second stage: The new couple

This second stage culminates from the marriage agreement made by two single adults. This is the joining of families through marriage. The stage reached when the novice adult has presumably grown holistically, i.e., emotionally, physically and financially, and has now gained full independence from the family of origin, so that they are ready to start their own family.

Carter & McGoldrick (1989:209) indicate that this is the most complex and difficult transition of the family cycle, and often romanticised by wedding ceremonies. Some research reported by Gurin et al. (in Carter & McGoldrick, 2016), shows that women become more successful when single, and become more educated, holding important jobs, and are less likely to want to

marry, yet the opposite seems to be true for single men. Hence, the constructivism philosophy states that individuals construct their own truth. The perception and experiences of these complexities of all the stages are what the researcher was interested in, to explore from an African perspective. The authors continue to indicate that there is a lot of re-negotiating that has to be done by the family on issues that were initially defined individually for instance, space, money, time, culture, tradition and relationships.

As a result of the above cited issues, (Lu *et al.*, 2017; Roberts *et al.*, 2017) indicate that it is the stage for realignment with the extended families and friends to include the spouse. However, should the couple or the subsystem fail to mutually reach a consensus on how they would spend their time, space or finances, the system tends to become polarised in their views. Their family lifestyle would then be affected. More burdens of having to take care of their children and manage their homes, while being active economic contributors, has been reported in women on changing roles. Hence, some single adults' resort to cohabitation, or delaying marriage, or divorce, or not marry at all. Others decide to engage in sex before marriage, or just have a child, or have a childless marriage, as a different way of dealing with these complexities. Santrock (1996:477) further highlights that marriage is usually defined as the union of two individuals, yet, in reality, is the union of two entire family systems and the development of a new, third system with its own identity.

Due to the above observations, Carter & McGoldrick (2016) also highlight the impact on the couple, starting from the preparation for the wedding where the entire families from both sides want to be involved. The pattern is also established with the extended families; hence, the two have to negotiate new relationships with their parents, siblings with ASD, grandparents, nieces and nephews, and even friends and in-laws. The most challenging triangles are the ones that involve the mother-in law. Cultural differences are also another factor that cannot be

overlooked in coupling. However, the lived experiences of parents with ASD children in Zambian families interested the researcher the most.

Third Stage: The parents

The expansion of the new family continues at this stage. Children are born into the system which also moves the system to another generational level and adds more responsibility for the couple. Becoming parents' or families with children with a disability such as ASD, is the third stage in the family life cycle. This stage is assumed through pregnancy, adoption or step-parenting, and poses a change in the system, to which it has to adapt and reconstruct the Self, and in a match of experiences that presents to them mainly how to raise children.

This stage is characterised by ways of finding what best fits the couple after the child has been born with a disability. Schenck (2002) highlights emotional processes around the ability to accept the new member into the system, the adjustment of the marital system to make space for the children, joining in child rearing, and realignment of relationships with extended families, which are grandparents.

Carter & McGoldrick (2016) indicate that this stage is marked by having a child with ASD biologically, but its psychological and social outcomes might tend to outweigh the first. The reality constructed by the society about parenting a child with ASD and child rearing, and the identity or self of the family comes into play at this stage. Carter & McGoldrick (2016) note that contemporary young parents then opt for leaving their children to grow up with their grandparents or day-care centres. Dual-career parents are concerned with the safety of their children at day-care centres or with nannies because of the nature of the disability that the child has. However, the HIV epidemic and high levels of unemployment in different sub-Saharan countries has also shifted this responsibility to relatives and foster parenting. Furthermore, there is a large growing number of single parents in societies. As rightly put by Santrock

(1996:478), “the excitement and joy that accompanies the birth of the child is often followed by “postpartum blues” (depression); the joy of intimacy comes with the sorrow of exhaustion.”

Though this is the nodal event, it can create instability in the family in membership accommodation and functions. The challenges are manifested in terms of distance created by the child with ASD between the couple, where it is reported by Santrock (1996) that fathers tend to be less sensitive to these extreme demands and would spend most of their time trying to make a lot of money to pay the healthy bills for the child with ASD. Armstrong (in Carter & McGoldrick, 1989:237) has mentioned that at this stage, “marriage with ASD children creates a collision of paradigms, which means that is between espoused beliefs or attitudes of men and women and attitudes or policies of the older generations and work”. The reality and cultures that have been constructed by the community could come into play namely, that women are child caretakers and fathers are expected to be breadwinners, which creates challenges and tension in some families. Hence, according to Santrock (1996), couples with children find themselves having to create a balance between parental roles and self-actualising aspirations as adults. More issues could be created by the space, or lack of it, which the couple has created for their children. Sex, which has a challenge of privacy, the extended family’s involvement (which in some cultures could be perceived as collective responsibility), and sibling rivalry, are some of the other issues that are faced by the families with children.

Fourth stage: Families transformed by adolescence

According to the Carter & McGoldrick (2016) family life cycle, the families with adolescents represent the fourth family life stage. As the system is being governed by the relationship, the pattern that connects, the change in one sub-system results in a change in the entire system, “the organism reacts as the organised whole to this phenomenal field” (Grobler *et al.*, 2003:54). The major emotional process of this stage is the search for identity by the adolescent. This is

the SELF, as “a portion of the total perceptual field gradually becomes differentiated as the Self....an organised fluid but consistent conceptual pattern of perceptions of characteristic and relationships of the “I” or the “me” (Grobler *et al.*, 2003:9).

The SELF-structure that is created by all the members at this stage, is highly influenced by the interaction within the entire family, hence the change in the whole system. Thus, the self of the parents is also affected, and this indicates reciprocal influencing among members of the family, and the evaluation interaction with the significant others, which in this case are parents, siblings, grandparents, friends, the school and the church. The adolescents’ self or identity would be reconstructed with the entire self of other members, for instance, the parents and then learn to be more flexible with household rules.

While the adolescent pushes to gain independence and autonomy, the parent unit is also required to create that environment for growth, while proportionally still being able to nurture the novice adult. Hence, Carter & McGoldrick (2016) state that it is the stage where the family is transformed from being that of a protective unit to the one that has to prepare the adolescent child for the world of adults. Though the requirements from the system are the basic ones, it is said to be the most challenging stage for the family, hence termed the “transformation of the family system in adolescence” (Carter & McGoldrick, 1989: 255).

According to Santrock (1996:478), “the development of mature autonomy and identity is a process, transpiring over 10 to 15 years”. The rules and limits in the family are challenged. According to Santrock (1996), the families are either more authoritative or put more pressure on the adolescent, or become more permissive and allow more freedom, with consequences for both ways. Carter and McGoldrick (2016) have rightfully highlighted this shift also across generations. The authors indicate that this stage “is often parallel and coincides with changes

in parents as they enter midlife and with major transformation faced by grandparents in old age” (Carter & McGoldrick, 1989:255).

The balance or stability of the family is challenged. This has been the case in other stages for instance, when difference is introduced, that is, when the young adult gets married or the couple has their first child. The difference that is introduced by the novice adult in the system, challenges the family to find means to restructure the organisation. However, stability often happens after a certain degree of confusion and disruption in the family, but not unless flexibility and adaptive approaches, as suggested by Carter & McGoldrick (2016) are adopted by the family in raising an adolescent. Under certain conditions, involving primarily complete absence of any threat to the self-structure, experiences which are inconsistent with it may be perceived, and examined, and the structure of self, then revised to assimilate and include such experiences” (Grobler *et al.*, 2003:72).

The change that is experienced during this stage by the family includes the following: the grandparents are aging, dying, or experiencing an illness, and may want to be cared for. Adolescents, on their part, search for independence, autonomy, responsibility, commitment, emotional support, psychosocial support - outside the family unit, however, which is more challenging for the family. The tasks also include the rapid physical growth of the adolescent, sexual maturation during puberty and, mostly, the conflicting social expectations about sexual roles and norms of behaviour by the family, school, peers and the media (Carter & McGoldrick, 2016). However, the ability to make decisions depends on the environment that the family creates for the novice adult and his or her self-determined nature.

The healthy resolution of the challenges of this stage is, according to Carter & McGoldrick (2016), adopting the parental style of having flexible family boundaries and modulating parental authority to promote greater independence and developmental growth for the

adolescent. It is the understanding that autonomy for the adolescent means gradually being responsible for one's decisions, while still feeling the security of parental guidance. The socio-cultural factors also have a role to play in the development of the adolescent, which includes social class, education, ethnicity, sex, community expectations and HIV/AIDS. Hence, in some instances, pseudo-adults are developed, or teenage pregnancies result, early assuming of adult responsibility is experienced, or early marriage or cohabitation could come into play.

Fifth stage: Midlife families

The midlife stage is the fifth stage discussed in Carter & McGoldrick (2016), entitled launching children and moving on. The authors highlight three aspects in this stage, and an intergenerational approach has been adopted: Marriage function; Inclusion of in-laws and grandchildren, resolving relationships with aging parents. The marriage function has to be reconstructed at this stage. More time with each another becomes a possibility, which depends on how the marriage was constructed in the first place, as Carter & McGoldrick (2016) put it: "marital bond regains prominence". As more of their children move out, either going to tertiary education (college/university) or seeking employment, the family has to be able to usher them successfully by being able to maintain that emotional bond as the physical separation increases. Shtayermman (2013) (in Carter & McGoldrick, 2016) that during explains that at this stage, the couple could experience more freedom, independence and marital satisfaction. However, death, illnesses and a high rate of divorce is encountered at this stage.

The second major task during this stage is to accept a multitude of exits (when children move out and get married) and entries (when new members are born into the family either through having sons/daughters-in-law or grandchildren) into the family systems (Carter & McGoldrick, 2016). Dutta (2017) (in Carter & McGoldrick, 2016) highlights that, happiness in wives is having all their children successfully independent when they were expected to do so. Yet, for

men, the career path becomes an important thing at this stage. The choices made by the young adults could also be influenced by the family of origin. Other families will give the young adult liberty to make their choices in terms of career and marriage; yet, with some families, that is done through the aspirations of prior generations. It is at this stage that the family also experiences both contraction when their children are launched out and expansion when they have to incorporate other family members (grandchildren, sons/daughters-in-law). It is also shown that at this stage, the birth of the fourth generation shifts everyone in the line of responsibilities i.e., children become parents, siblings become aunts and uncles, and parents become grandparents. Grandparents in some societies are known as authority figures that help the parents to socialise their children (Carter & McGoldrick, 2016). However, in HIV/AIDS-ravaged societies, the grandparents have become primary caregivers. Dinisman, *et al.*, (2017) also points out that it is at this stage of the life cycle, the family plays an important role in linking generations and simultaneously adapting to midlife changes.

Carter & McGoldrick (2016) add that the other challenging task of this stage is that the couple has to deal with unfinished businesses with their elderly parents, who are now frail and rely on their children for medical and emotional support. The death of their spouse heightens that responsibility, and that becomes the major transition for the middle-aged person. Dinisman, *et al.*, (2017) postulate that the mother and her daughters have stronger relationships during their adult years than other dads. If the self of the family was created around children, this change could threaten the self of the couple. Erickson (in Carter & McGoldrick, 2016) has termed this stage as generativity vs. stagnation. As indicated earlier, any unresolved issues at earlier stages of development could result in stagnation of the marriage at this stage, and the individual never being happy with their achievements in life.

Sixth Stage: The Family in later life

This is the last stage, according to Carter & McGoldrick (2016), which is marked by the task of having to accept a shift in the generational role by the senior citizen. The issues, reported as myth by Carter & McGoldrick (2016), are that elderly persons have no families, that their children do not care about them, and that they are abandoned by their children in homes for the aged. Yet, family relationships continue throughout later life. This is the stage characterised by ill-health, aging, death and facing singlehood, but also the age of imparting wisdom on the younger generation. Dinisman, *et al.*, (2017) summarises the emotional processes of this stage, taken from Carter and McGoldrick that the elderly is faced with disabilities and death, which in most cases ends with the death of the spouse thereby leaving the partner single. The aging parent has shifted the generational roles, from being the caregiver of the family to be cared for by children or grandchildren. Carter & McGoldrick (2016) put it that how the family copes with this stage, depends on the type of relationships created over the years, and the ability of the system to adjust to losses and new demands.

Widowhood is another adjustment that is also an issue of concern for the senior citizen at this stage, which is marked by the remaining partner having to grieve over the loss. The situation could be aggravated when the widow(er) loses his or her home, or experiences financial problems, which could in turn affect their independence. The elderly has to maintain their own couple functioning in the face of physiological decline.

Carter & McGoldrick (2016) express retirement as being a significant milestone and adjustment for the marital pair. This stage has the major task of retirement. Santrock (1996) states that retirement alters a couple's lifestyle, requiring adaptation; hence, the elderly would have retired from work - and community involvement, sometimes. However, grandparenthood has become one of the greatest experiences for older adults. Mead comments on how a person

suddenly becomes involved at a distance in things that used to be “hands-on”, due to being “transformed by one’s own child”. In addition, grandparents and grandchildren may enjoy a special bond that is not complicated by the responsibilities or obligations and conflict inherent in the parent-child relationship.

The family life cycle theory suggests that successful transitioning may also help to prevent disease and emotional or stress-related disorders to parents. Whether you are a parent or child, brother or sister, bonded by blood or love, your experiences through the family life cycle will affect who you are and who you become. The more one understands the challenges of each stage of the cycle, the more likely they are to successfully move on (Desiningrum, Suminar, & Surjaningrum, 2019). There are some needs that disrupt the normal cycle such as the stress of daily living, coping with a child with ASD and medical condition, or other life crises. Ongoing stress or a crisis can delay the transition to the next phase of life, or ASD children growing up without the skills that they need to easily adapt and transition to the next phase of life. The Family Life-Cycle Model prompts researchers to make an exploration how parents of a child with a disability have concerns that might change from one stage to another. For example, parents of a child with ASD might feel sadness and disappointment about their child’s diagnosis and guilt for having such feelings. Global research has revealed that parents do not just fear but feel an absolute bout of terror when they hear the news of ASD as if it has caused a global erosion to the well-being of the family. Fear, as it is commonly known can seep into every aspect of a parents’ life and can go as deep as affecting the marriage.

Using family life cycle the parents’ can learn missed skills and improve cope with their ASD children and family’s quality of life at any stage. Self-examination, education, and counselling are ways to improve parents’ and family members’ life. These are also actions that can help parents with ASD deal with other issues, too, such as not going through a divorce or being a part of a non-traditional family structure. Depending on the nature of a child’s disability, some

stages of the Family Life-Cycle Model such as “launching children”, the stage at which individuals move out of the family home to exercise their independence might occur later than typically expected or not at all in the case of children with ASD (Das, Arunima, Kakoli, Bora, & Hazarika, 2017). It is critical that researchers and health care workers consider parents’ positions within this model and how challenges at different stages might affect caregiving.

The emotional and intellectual stages parents pass through from the time the children are born upto their retirement years as a member of a family are called the family life cycle. In each stage, one faces challenges in their family life that allow them to build or gain new skills. Gaining these skills helps them work through the changes that nearly every family goes through. Not everyone passes through these stages smoothly. Situations such as severe illness, financial problems, or the death of a loved one can have an effect on how well one passes through the stages. Fortunately, if a person misses skills at one stage, they can learn them in the later stages (Das et al., 2017). In the “families with the adolescent” stage, they might face issues with peer groups and accessing learning opportunities for their child at school. Moreover, although researchers have found that families of children with a disability experience similar challenges as other families, those challenges are often magnified.

1.9.2 Treatment of Theoretical model used

This part of the chapter deals with the adapted model used to support this study on the lived experiences of parents’ social interaction with ASD children. The adapted theory used in this study, is a modification of Carter & McGoldrick (2016) model on Family life-cycle. The modification was aimed at making the model more appropriate and applicable to the study on the lived experiences of parents’ social interaction of children with ASD in Zambia. In his study Chakulimba, (1986) reports of the meaning of modifying a public model to make it appropriate to a particular study. He alludes that such an action helps to take the model a step

further in its contribution toward understanding the public phenomena being studied as a result of the additional thought such a model brings to the study. In this study, the modified model used does not only bring out the extent of the social interaction between the child with ASD and their parents but also helps to explain some of the thoughts, morals and anxieties arising from exploring lived experiences that parents have with children with ASD. The theory argues that a change in the family affects the life cycle of individuals within the family set up.

There are nevertheless, difficulties that arise in the use of models in a real-world study such as this one. One of the difficulties is the request of a model which was formulated in a setting such as the western world but being functional in a study conducted in a developing country like Zambia. The issue of significance of such a theory to a study for example, on the lived experiences of parents' social interaction with ASD children, becomes an issue that needs consideration from the researcher. A researcher is faced with the problem of making a decision of which theory is likely to contribute meaningfully to the study. In this study however, the Family life-cycle model was implemented to support the study for a number of reasons. There are some models which are used in its original form, others are modified model providing the ability to interlink and bring out the significance of how parents with ASD can understand social interaction within the family and develop response challenging at each stage of the model (Carter & McGoldrick, 2016). The modified model applied in the study provided empathetic to parents of children with ASD in social interaction.

1.10 Organization of the Thesis

This thesis is organised in six chapters as follows: Chapter One comprises the background information, statement of a problem, aim, study objectives, and research questions. It also addresses the significance of the study, provides definitions of terms used, states the study delimitations and gives a brief introduction to the theory used in this study. Chapter Two

reviews the literature related to the study. This was systematically arranged according to research objectives. Chapter Three presents the methodology followed in this study, which includes the research approaches and design used, the population, the sample and sampling procedures, research tools used and the data collection procedures. After that, data analysis and ethical considerations are explained. The chapter also addresses issues of credibility, trustworthiness and limitations. Chapter Four provides the results/findings of the study and chapter five quantitatively discussed the findings. Qualitative data is organised in themes according data similarities with the help of Nvivo software. A summary of the results is given at the end of the chapter. In Chapter Six, the conclusion, contributions to the body of knowledge and recommendations are presented. The study ends with the references and appendices which include research instruments, sample of interview scripts, ethical clearance letter and permission letter.

1.11 Chapter Summary

The Chapter has given a brief background on the lived experiences of parents of children with ASD. The chapter provided the key influences supporting the current study, underlying assumptions, origins of current autism spectrum disorder, general challenges experienced by parents with ASD, a focus on the global perspective of Autistic Spectrum Disorder and African trends on ASD. The chapter also shed some light on the statement of the problem, purpose, objectives and research questions which guided the present study. The chapter further availed the significance, delimitations, limitations and the theoretical model. It additionally explained how the theoretical model was treated to make it more relevant before providing definitions for the key operational terms used in the study. The next Chapter reviewed related literature as well as studies conducted on the lived experiences of parents' social interaction with children with ASD.

CHAPTER TWO: LITERATURE REVIEW

2.1 Overview

This chapter reviews scholarly works related to the topic under study. Literature review is a very important undertaking in any research. Kombo and Tromp (2006) believe an effective literature review should provide a critical, organised and analytical orientation of the study and also be able to justify the need for one to study a particular topic or research problem. They state that a literature review helps to highlight the relationship between the past and the present study. While highlighting the importance of literature review in research in outlining academic knowledge and subject content relevant to a field. Mukherji and Albon (2015:247) define literature review as, “a critical analysis of related literature in a relevant field to that of the research being undertaken”. Research studies need to be based on a literature review to give perspectives of similar or related studies conducted in the field. A literature review illuminates the research and provides guidelines and comparisons between different contexts. World over, nations have tried to review their curricula to fit with international standards in order to educate a learner for the global village: many studies have been conducted on the topic. Thus, it adds rigour to research. In this study, review of related literature was guided by the title of the study: *Lived experiences of parents of children with Autistic Spectrum Disorder* as well as the objectives. The chapter equally provides a critical analysis of the different contexts in relation to this study.

2.1.1 Rationale for Literature Review

In this literature review, the researcher interacted with other studies with similar focus on the lived experiences of parents with disabilities. Therefore, knowledge gaps were identified and filled-up through this study. In choosing a Hermeneutics Phenomenological approach, it was important to note that phenomenological purists (Transcendental Phenomenologists) argue

against in-depth literature reviews because of the risk of increased researcher bias perpetuated by the influence from the literature. However, scholars with a more practical perspective argue that it is beneficial to “build upon earlier literature”. This helps to set the platform for deeper explanation, conceptual development and theoretical refinement (Creswell, 2016). To this effect, the study subscribes to the latter school of thought and in line with Hermeneutics Phenomenology as this study sought to build upon previous work to expand the discourse highlighted above (Creswell, 2016). Therefore, the reflections that follow represent what was revealed in the literature prior to conducting the present study.

In a study on Autism Spectrum Diagnosis (ASD), World Health Organisation (2013) observed that ASD was a clinical disorder. The study revealed that ASD was an extremely rare condition in approximately two to four out of every 10,000 children diagnosed. The study revealed that prior to this acknowledgment, children were often classified as emotionally disturbed or mentally retarded. The National Autistic Society (2014) also agreed with World Health Organisation (2013)’s study that ASD is extremely complex and has a wide range of symptoms. The society observed that ASD is categorised in the Diagnostic and Statistical Manual of Mental Disorders, IV ed. (DSM-IV) as a pervasive developmental disorder. The study concluded by stating that an individual diagnosed with ASD may communicate verbally or nonverbally, they may follow restricted and repetitive routines as well as exhibit restricted motor mannerisms.

2.1.2 Prevalence, Gender and Culture ASD

Prevalence, Gender and Culture ASD is becoming more prevalent particularly in children aged 18 years and under. The ASD prevalence ranges from five to sixty cases per 10,000. A study conducted by the Werling, (2013) using quantitative methods in Canada on the prevalence of ASD tended to be nine in every 1,000 children. Findings from the study indicated that ASD

affected one in every 110 children with a growing rate of 10 to 17 per cent per year. Due to the growing prevalence of ASD, interest in ASD and its effect on parents is evident. A study done by Giallo, Wood, Jellett & Porter, (2013) on ASD diagnosis, discovered that gender plays a role in the prevalence of ASD with more boys being diagnosed than girls. Findings indicated that the prevalence of ASD in males ranged from 7.3 per cent in Florida to 19.3 per cent in Missouri whereas the ASD prevalence among females ranged from 1.0 per cent in Florida to 4.9 per cent in Arizona. This brought the overall prevalence ratio across all sites to 4.5:1 with males obtaining 4.5 and females obtaining only one. However, the literature suggests that parental capacity to promote communication and interaction between children with ASD and parents overall may be affected by their own emotional state and wellbeing. For example, parental stress can compromise both parents' and children's coping resources and affect their ability to problem-solve (Friedman & Chase-Lansdale, 2002). Research on the challenges entailed in raising a child with ASD has raised concerns regarding parental wellbeing. Several common factors have been identified in this population including impaired mental and physical health, social isolation and lack of family coherence (Giallo, Wood, Jellett & Porter, 2013; Silva & Schalock, 2012). In the context of developing countries such as Zambia, such statistics of persons with ASD are scarce and hard to find as investment in research. This then provided an opportunity for research to explore the lived experiences of parents of children with ASD.

Dekkers, Groot, Mosquera, Zúñiga and Delfos (2015) indicated the prevalence rate of ASD as being 4.5 times higher in males than in females. This study also found out that the ASD prevalence was 14.5 per 1,000 males and 3.2 per 1,000 females in children aged eight years. According to Rice and CDC (2009), ADDM indicated that ASD increased across all sexes, racial or ethnic and cognitive functioning sub-groups from 2002 to 2006. Data from the ten ADDM sites with results from multiple surveillance years (4, 12) indicates a significant average increase of (57%) in identified ASD prevalence in 2006 compared to 2002 (range:

27% to 95%)". In addition to gender being a factor in the ASD prevalence, ADDM indicated that ethnicity plays a role in the ASD diagnosis. ASD is more prevalent in non-Hispanic white children than it is in non-Hispanic black children and Hispanic children. After combining data from all sites, non-Hispanic white children diagnosed with ASD ranged from 9.4 per cent to 10.4 per cent, whereas non-Hispanic black children ranged from 6.6 per cent to 7.8 per cent and Hispanic children from 5.3 per cent to 6.6 per cent (Rice and CDC, 2009). Early identification and interventions are important to examine among ASD children as the prevalence of this diagnosis is growing significantly. Statistically, Non-Hispanic white males are most at risk for ASD. Causes are still unknown. The above findings validate the concern of this study regarding diagnosis of children with ASD as being not enough, adequate concern should be on the lived experiences of parents of children with ASD.

2.1.3 Reactions of Parents after children are Diagnosis with ASD in Social Interaction

This section explores the reactions of parents after their children were diagnosed with ASD at various medical levels as well as contexts. Two levels with varying contexts are considered. These are: Developed and Sub-Saharan Africa contexts for easy comparative analysis of lived experiences of parents of children with ASD in the current study. To this effect, this segment provides a context in which the current study is located as a way to contributing to the discourse on parents with children with ASD.

At present, a number of studies on the diagnosis of ASD have been conducted including Nealy *et al.* (2012) whose purpose was to investigate parents after diagnosis of their children with ASD in Britain, it was observed that parents are often faced with grief, confusion, denial, isolation, guilt and depression. The study revealed that the period after diagnosis has been identified by parents of children with ASD as the most stressful life event associated with their child. This also found out that stress is compounded by parents' lack of knowledge about ASD

and a lack of resources to assist in comprehending the impact this challenge will have on the family system, leading to a reaction of guilt as parents search for answers as to why their child has been affected. However, there is need for studying the Zambian parent's situations as this can be of help in determining their reaction.

Kim (2015) conducted a case study in Korea on mothers' reactions after diagnosis. The study revealed that a depressed mother with a severe ASD daughter drowned herself a day after her ASD child was diagnosed. These cases shade some light on the extreme levels of stress of parents with ASD experience. Another study conducted by Ludlow (2011) in Bangalore, India revealed that a mother dragged her nine-year-old daughter who was found with ASD to the roof and threw her over the edge resulting in the death of the child. This happens because some parents suffer from psychological stress and anxiety, making them fail to accept the fate of having a child with such a disability. Depending on the strength of the disability and resources availability for coping, there were a few parents who tried to contemplate death for themselves or for the child. This happens because some parents suffer from psychological stress and anxiety making them fail to accept the fate of having a child with such a disability and this may be true of Zambian parents of children with ASD with their core area functions. This study has highlighted different reactions from parents of children with ASD, nevertheless, flaws are that there is no continued coordination between the professionals and parents to explore the parents' lived experiences after diagnosis.

Hayes and Watson (2013) postulated that family members were reported to be concerned about stigma, fearing that others would avoid, judge or exclude their ASD family member. Additionally, the study through its evaluative assessment of ASD, determined that family members also got worried of the labelling that would be assigned to a child with ASD throughout their lifespan of his or her educational experiences. The study further revealed that most parents experienced difficulties in accepting the fate of having a child with ASD after

receiving the results of the diagnosis conducted by professionals. Moreover, parents of younger children who most likely struggled to meet their child's past and current needs would be anticipated to face similar struggles in terms of meeting their child's future needs. Adjustment, including rearranging daily life was identified as a continuous activity for parents in order to cope and to adapt to their child's deficits associated with ASD. It should, however, be noted that parents of children with children with ASD experiences of rearing stress, their feelings of efficacy, the child's severity of symptomatology and its age are expected to be associated with parental coping strategies to their child's ASD. Regardless of various coping strategies, levels of stress and timing to adapt to the child's disabilities, a commonality is that parents' hopes and expectations for their child's development and future functioning are challenged by the diagnosis of ASD. Communities and families should therefore provide support as parent's need support for earlier expectations to be changed into new, more realistic ones. This may be true of Zambian parents of children with ASD.

In Canada, Ouellette-Kuntz (2012) mentioned that Parents' experiences around the time of the diagnosis predict future family adaptation to the child with ASD, parental stress, parents' information and learning needs as well as the quality of the parent-professional relationship. In light of this, the diagnostic process appears to have an all-encompassing influence on parents' perceptions, experiences and sense of empowerment in the immediate and long-term future. Despite the family's public health professional being the first point of contact for many parents, neither of these was perceived to be helpful by parents in terms of being able to answer specific questions or provide them with practical information on ASDs. Parents also reported wanting practical advice on how to apply what they learned from books or training programmes to everyday living with their child. In terms of the child's future, many parents were concerned about the child's level of independence and their ability to maintain relationships. Parents were also worried about what would happen to their child if they

themselves became ill and could no longer take care of them. However, there need to explore the lived experiences along with these changes, for these rearrangements include acceptance of the child in the affective domain and restructuring of interfamilial interaction, informing about the state of child, re-adaptation to the social environment, continuity of education, care and sharing of responsibilities.

According to Mihshtein *et al.* (2010), “the process of coming to terms with a diagnosis for one’s child, that is, accepting and feeling resolved with respect to it, is a daunting challenge for most parents”. The study acknowledged the fact that, in some situations, acceptance and resolution for a diagnosis can only occur when parental expectations of the child are adjusted to reflect their challenges. The study revealed that immediately following a diagnosis, parents often do not feel a sense of resolution, as they may still adhere to those standards which they previously felt their child should live up to. The study concluded by stating that if a parent cannot move to this stage of acceptance and resolution, they risk remaining in the grieving process for an extended period of time. These problems are very important because they can influence parents of children with ASD in one way or another. Hence this proposed study.

In another study, Cubells (2013), observed that after a diagnosis of ASD, parents are faced with a new reality of parenting. They have lost the child that they expected to have and are now confronted with a new challenge. This contributes to the ambiguous loss associated with a diagnosis of ASD. The lack of clarity in terms of the cause of ASD contributes to this ambiguity, leading parents to internalise blame, which increases the amount of emotional distress which they may already be feeling. In this study, in addition to adjusting their dreams of parenthood, parents of children with ASD must also change their expectations of family life, leading to additional feelings of loss. It was concluded that parents give up social lives, vacations, and personal dreams as their attention shifts to the new challenges of raising a child with ASD. To fill the above gaps, the present study examined the lived experiences of parents

in social interaction, the core area of difficulties in children with ASD in Lusaka District in Zambia.

In light of the above, Cappe *et al*'s. (2011) study asserts that there is increase in social isolation, a dangerous consequence of the grieving process, as social supports are empirically confirmed as contributing to positive mental health in parents of children with ASD. The study revealed that it is crucial for parents of children with ASD to identify that the grieving process after diagnosis is normal and expected, as parents are faced with “an end to the future as it was going to be”. The study established that parents find it difficult to think ahead to the future, as they are compounded by the amount of stress and grief associated with the diagnosis. Again, this is a dangerous consequence of grieving the loss of the expected life of the child, as parents must begin to assess their child’s needs early on in order to gain the appropriate support needed to live a successful life.

The study above is insightful in that it has demonstrated how parents find it difficult to think ahead to the future because they are compounded by the amount of stress and grief associated with the diagnosis. However, the reviewed study focused on the parents’ giving up their social lives, vacations and personal dreams to shift their attention to the new challenges of raising a child with ASD which begs the question as to whether this is the situation for Zambian parents.

2.2 Ways Parents Socially Interact with Their Children With ASD.

Studies done by Bauminger, Solomonand & Rogers (2010), Gray, Keating, Taffe and Brereton (2012), Hartley, Sikoraand & McCoy (2008), Kanne and Mazurek (2011) Mazurek & Kanne (2010) define Autistic Spectrum Disorders (ASD) as characterised by persistent impairments in reciprocal social interaction and communication across multiple contexts, along with the existence of restricted, repetitive and stereotyped rigidity and behaviours and interests. The American Psychiatric Association (2013) study advocates that those children with ASD often

exhibit high levels of co-occurring behaviour problems. Both internalising (e.g., depressed or anxious affect, somatic complaints and withdrawal) and externalising (e.g., aggression, hyperactivity and property destruction) problems which are often present in children with ASD.

In a study on social deficit in ASD children in Canada, Falk *et al.*, (2014) observed that children with ASD may be problematic for parents to accept them, as they are faced with a child who seemingly has no interest in interacting with loved ones. The study revealed that anguish, as well as responsibility start to enter the narrative of the parent, as they begin to recognise that their expectations of parenthood are likely to change drastically, and the feelings become intensified as the restrictive and repetitive behaviours of the children with ASD become overwhelming and even violent towards the parent. The study concluded by noting that children with ASD are often highly restrictive in their interests, which can lead to highly explosive behaviours when these interests are disrupted and unpredictable behaviours, such as lack of social reciprocity, societal judgment, inadequate social supports as well as the prospect of life long care led to significant challenges for parents of children with ASD. The current study benefited a lot from the aforementioned study as the findings pose a question as to whether or not ASD children's behaviour can drastically change, as the restrictive and repetitive behaviours become overwhelming, and even become violent towards their parent which leads to significant challenges for parents of children with ASD in Canada. Their study did not discuss ways in which parents of children with ASD apply a much more integrated approach in its design to understanding experiences as parents. The current study does bridge that gap through a hermeneutics phenomenological approach.

Abubakar (2016) carried out a study on the definition of ASD and its associated symptoms. The study revealed that parents are placed in highly awkward situations on a daily basis which in turn affects nearly every aspect of their lives. Abubakar noticed that his eleven subjects did

not use speech in the suitable, communicative fashion which would have been expected of a child their age. Out of the eleven children, three did not possess any form of speech, while eight were able to engage in repetitive speech which was apparently inadequate. The study revealed that children with ASD could list from rote memory numbers, rhymes and names, but could not combine these into meaningful phrases. Speech was not used to convey meaning or feeling; it was simply a repetition of words. This is significant of echolalia, the meaningless repetition of the words of others, which today is often an associated feature of ASD. The study was concluded by a final pattern, which Abubakar observed in these eleven children was a “fascination for objects which were handled with skill in fine motor movements”. The study showed that the children with ASD were hypersensitive to changes in these objects, including the ability to recognise the slightest change in position. This hypersensitivity to change is recognised in the current American Psychiatric Association definition of ASD, in terms of highly restricted and fixated interests. This study was pitched with a western context in mind, using a questionnaire tool to elicit data. Thus, left a knowledge gap for further study in a sub-Saharan African context.

Grossi, Marcone, Cinquegrana and Gallucci (2013) investigated parents and children with ASD in the United State of America. The established that children exhibited fear if their activities were changed and interfering with patterns of behaviour would often be met with rage due to changes in routine, furniture arrangement, and the order in which daily activities were carried out. The study also revealed that the description of the need for maintenance of routine likely reverberated with many parents of children with ASD today, as they point to their children’s excessive routines that resulted in violent behaviours as a significant source of stress and despair in the lives of parents and family members. Therefore, the study had significance for children with ASD and researchers concerned with lived experiences of

parents of children with ASD in order to establish their day to day lives in Zambia, Lusaka District in particular.

Pisula, Kossakowska (2010) conducted a study on challenges parents of children with ASD encounter in Belgium. It was observed that parents were left with little options in the way of satisfying their ASD children's interests because only a few activities and objects sufficed. The study also showed that children with ASD have repetitive activities including isolation, spinning, hand-flapping, and repetitive routines such as the turning on and off of lights. Nevertheless, their study had limited scope for generalisation of the study's conclusions due to the study's small population sample size. The study indicated that there could be fear attached to breaking bonds with objects as they often ended in explosive tantrums or violent behaviours which are a significant stressor for parents. Further, the study determined that behaviours of not interacting with family members apparent in children with ASD should not be surprised by the stressors associated with parenting a child with ASD. It was observed and documented that those parents of children with ASD exhibited the highest degree of stress in comparison to those parents both with typical children and children with other medical and developmental conditions. The findings, however, did not state the kind of knowledge and social skill parents needed to acquire in order for them to reduce stress.

A study carried out by Bayat (2018) established that parents with ASD children were involved in a variety of tough processes such as mobilising resources, becoming united as a family, and gaining a better appreciation of life. Further, the study noted that that parents of children with ASD experience greater stress and a larger number of caregiving challenges, such as health problems, greater feelings of restriction, and higher levels of parental depression than parents of children without ASD children. The study indicated that some parents experience difficulties with regard to financial assistance and inadequate support from the members of the family and communities and that parents of children with ASD face both the normal pressures and tensions

of family life. It also concluded that with regard to adjustments to the presence of the child with ASD, such parents usually require assistance in order to reorganise their lives towards positive adaptation. It is imperative for this study to discover how parents of children with ASD mobilise resources, become united as a family, and gain a better indebtedness of life mobilising resources, become united as a family and gaining a better appreciation of life.

In a study on raising a child with ASD in Britain, Smith (2017) observed that raising an ASD child may be too expensive than raising a typical child. Further, the study noted that expenses may arise from medical equipment and supplies such as wheel chairs, medical care, care giving expenses, private education, learning equipment, tutoring or specialised transportation. The study also revealed that parents of children with ASD also have to deal with complex issues related to the social interaction and child's education which can either be a sought private education or an adequate public or general education must be available. This study does provide an opportunity to confirm or disapprove the research findings within the Zambian context, given the apparent variations at play between Britain and Zambia, developed and developing countries respectively.

Fombonne, Marcin, Manero, Bruno, Diaz, Villalobos, Ramsay and Nealy (2016) piloted a study on encounters and problems parents of children with ASD face in Mexico. It was realised that parenting a child with ASD is not always full of trials and problems; some parents experience joy and satisfaction when parenting their children with ASD. On the overall, it was determined that parents managed the best that they could and that there was not one single strategy that was more influential than another. The study revealed that parents felt that they were successful in coping and that their lives were rewarding and valuable with whatever strategies they incorporated.

On the contrary, Cashin, an Australian, embarked on a hermeneutic phenomenological study to explore the lived experiences of parenting a child with autism. Here, the scholar discovered that having a child with autism overtook the parents' lives and changed their way of being in the world. The study indicated that parents experienced less of everything and that they were sucked into a "whirlwind of autism. Parents voiced concerns about having less spontaneity, less social contacts, less time to themselves and less material possessions. In 2018, DeGrace conducted a qualitative study to understand families' experience of parenting a child with ASD. The researcher learnt that these families lived their lives around the needs and desires of the child with ASD. The study revealed that they lived moment to moment and relied on routines around the child to meet the demands of daily life.

Woodgate & colleagues (2018) undertook a hermeneutic phenomenological study to explore the lived experience of Canadian parents who had a child with ASD. Through the interviews from sixteen families and similar to the findings of Cashin (2004), the major essence of parenting a child with ASD was the theme of living in a "world of our own". Just like children with ASD were encased in a world of their own, parents in Woodgate *et al.*'s study experienced similar feelings of being alone and isolated. However, what was unique to Woodgate *et al.*'s study was that from the perspectives of the parents, their sense of isolation was not self-imposed, but mainly the result of external sources. The study ascertained those parents described the importance of developing intense social interaction skills in order to help facilitate their children's development where parents became "super" parents and immersed themselves into helping their child develop their full potential. The study also unveiled the knowledge that parents' perspectives on "normal" development milestones were also described and celebrating these milestones was a sense of accomplishment and a way of coping for participating families.

On the overall, literature on the lived experiences of parents of children with ASD was quite limited and without focus on parents that lived in Lusaka District. It is imperative for the professionals concerned with a child with ASD to be aware of the concerns and meanings regarding parenting a child with ASD in order to offer parents with the most suitable ways of coping and empower them for positive attainment in their children with ASD.

Hansangu (2015) conducted a study in Lusaka, Zambia, whose purpose was to establish what parents, guardians and caregivers of children with ASD go through in the process of raising their children. Through interviewing sixty respondents, the study revealed that parents, guardians and caregivers had problems regarding the unacceptable behaviour from their children. In addition, some families were reported to have been socially isolated and suffered stigma while some marriages were stressed and some broke down. The above study is general in the approach and does not focus on the specific context surrounding lived experiences of parents of children with ASD. Whereas the situations are similar to the current study, data from the two studies was not generated using a Hermeneutics Phenomenological Approach to elicit the lived experiences of parents with children with ASD. These are the knowledge gaps, the current study addresses.

Shtayermman (2013) reported that marital stress is defined as “the accumulation of difficulties within a marriage, including lack of communication, difficulty resolving conflicts, and difficulty accepting each other”. Lack of social and spousal support will cause stress within a marital relationship, causing in a reduced quality of marriage. Within the context of raising a child with ASD, marital stress has been attributed to the lack of independence of the child not only in childhood, but as they enter adolescence and adulthood. To exploit the identified knowledge gap, the present study explores the lived experiences of parents of children with ASD using Hermeneutics phenomenological approach.

Benson, (2011) carried out an investigation on the marital relationship of parents of children with ASD in Estonia, Finland United States. It was observed that children without a disability, move into their own lives independent of parents, decreasing the stress and demands placed upon the parental unit. The independence of a child also leaves room for parents to move their focus away from children with ASD, and towards their marital relationship. This transition is not present in the lives of many parents of children with ASD, as their child care duties do not end in adulthood. Marital quality is significantly affected by the behaviours of the child with ASD with problem behaviours negatively associated with marital quality. Hartley *et al.*, (2010) admits that within quality of marriage is related to the psychological adjustment of the partners. If depressed mood is present within the marriage, the quality of the marriage will suffer. Raising a child with ASD directly impacts the psychological health of parents, particularly mothers, through the manifestation of depression. This study was pitched with a western context in mind using a questionnaire tool to elicit data. Thus, left knowledge gap for this study to explore the lived experiences of parents of children with ASD to Zambian parents in a sub-Saharan African context.

One aspect of Gau *et al.*'s (2012) study in New Deihi on how stressors associated with the child are immense that cause the relationship between mother and father to be compromised. The study observed that marital quality is directly related to maternal adjustment in raising a child with ASD. Other studies such as Lickenbrock *et al.*, (2011) and Benson, (2011) had contrary views on marital relationships of parents of children with ASD. Benson, (2011) reported that mothers feel supported by fathers, that they possess positive perceptions of their child with ASD, suggesting that a positive marital relationship is a key component to maternal coping. These studies, indicated that an explanation for this lower divorce rate can be offered by family systems theory, suggesting that parents may feel more inclined to stay together in the face of adversity.

Freedman *et al.* (2012) carried out a study on the effect of divorce on parents of children with ASD in Zimbabwe. It was observed that fathers often cope with the demands of parenting a child with ASD by becoming less involved and distancing themselves from the family. It was also unveiled that mothers' and fathers' divorce rates are high in parents of children with ASD. Inflated rates of divorce as high as 80 per cent have been reported by media outlets with little data to back up this claim. In his study on the advantages of parents with ASD children in marriage (Hartley *et al.*, 2010) concluded that parents may stay together because it feels safer than the unknown change which accompanies marital separation. Further, that parents may stay together in order to ensure that they provide financially for their ASD child's multiple needs. As a result, the marital relationship may be one of primary support, and the absence of spousal support could be frightening and compel parents to stay together. The findings present further opportunities for research considering that their studies were conducted in Zimbabwe, a different context from Zambia. In addition, though these independently conducted studies claim to have applied qualitative approaches to arrive at the findings, the voices of the parents of children were silently missing. To exploit the identified knowledge gap, the present study explores the lived experiences of parents of children with ASD using the Hermeneutics Phenomenological Approach.

2.3 Parents' Experiences of Social Interactions with Children with ASD

Schaaf *et al.* (2011) carried out an investigation on parents' experiences on children with ASD on interaction in Finland. It was observed that parents have to rearrange their daily routines to accommodate the child as he or she is unpredictable and often unable to regulate their behaviour. However, in some cases, parents reported that routines were much easier to follow in familiar spaces such as their own home, but more difficult in unfamiliar places such as another relative's home or out in the community. The parent often feared that if the child

became dysregulated, he or she would damage another's belongings. In unfamiliar places, parents often do not have the tools needed to prevent or cope with disturbances that could possibly set off the child. This resulted in parents taking less family vacations, attending limited community outings and isolating themselves from family and friends. Daire *et al.*, (2011) corroborated that parent reported morning routines to be the most difficult as most meltdowns occur during this time due to sensory issues, causing the child to be late for school and the parent to be late for work. Mealtime was challenging as a child diagnosed with ASD can be sensitive to certain textures of food, often refusing to eat. The current study on the other hand is anchored on the qualitative methodology, with a focus on the Phenomenology Approach whose agenda was to explore the lived experiences of parents of children with ASD in Lusaka District of Zambia.

A study by Ruparelia (2016) indicated that a child with ASD needs several services to assist in their care and can often times be financially stressful for the parents. The study uncovered that a child may need evaluations, home programs, and various therapies which can be expensive. In addition, after the child turns eighteen and the parent wants to continue having custody of that child, court and a nominal guardianship fee is required. If one parent has to give up his or her job to help with caretaking, this can be financially stressful as it leaves one parent to support the entire family. The findings of this study may not necessary reflect the same as those of Schaaf *et al.*, (2011) on the evaluations, home programs, and various therapies which can be expensive to parents of ASD children.

Albanese *et al.*, (2016) found that parents of children with ASD experienced increased levels of financial, emotional and physical stress. The findings also revealed that those parents faced challenges with respect to their financial life, stress in performing their childcare duties and stigma which might be different from the experiences of Zambian children. The work life of parents of children with ASD gets adversely affected. It has also established that parents with

lower educational backgrounds experience greater financial problems, leading to increased levels of subjective caregiver burden (Barak-Levy & Atzaba-Poria, 2013; Barrett, 2012). However, this may not be necessarily true for the Zambian parents of children with ASD, hence the need for the study. Empirical evidence has shown the relevancy of challenges faced by parents and other stakeholders in taking care of children with ASD (Ruparelia, 2016; Nyoni and Sepel, 2012; Hansangu, 2015).

One aspect of Paula's, study on ASD children in New Delhi was the desire for parents to regularly interact and communicate with ASD children. The study brought to light the information that parents experience worries and concern that their child may be potentially harmed because often, they cannot communicate verbally and are highly vulnerable. The study similarly showed that parents taking their children with ASD out in the community did not understand or be sensitive to the behaviours that children with ASD may occur. The study showed that parents were hesitant to take their kids over to friends or relatives houses because they feel as though they cannot socialise or relate. The study concluded that such leaves parents experiencing a sense of isolation from their friends, family and the community. These experiences in other countries might be true for parents in Zambia as well.

Banach, Iudice, Conway and Couse (2010) conducted a study on the learning of autistic children in India using hermeneutic phenomenology approach. One of the findings was that children with ASD result in scattered emotions for the parents. The study also brought to light that 52 per cent of the parents felt relieved, 43 per cent felt grief and loss, 29 per cent felt shock or surprise and 10 per cent experienced self-blame. Additionally, the study divulged that some parents were relieved that they were given an answer with regards to their child's symptoms, but this does not erase the stress that they endure while raising a child with ASD. Parents often experience stressful situations upon the initial diagnosis that relates to their child's behaviour. Adapting to this new lifestyle and the complexity of finding access to the appropriate services

useful to the parents is stressful (Banach *et al.*, 2010). The current study will use a Hermeneutic Phenomenology Approach but has a lot of insight from the aforementioned study in that the preceding study was conducted in India. However, it is not known whether or not parents often experience stressful situations upon the initial diagnosis that relate to their child's behaviour and whether adapting to this new lifestyle and the complexity of finding access to the appropriate services useful to the parents can be the case for Zambian parents, prompting the need to conduct the study in Lusaka District.

Smith's (2014) study on parents raising children with ASD revealed that insufficient support and feelings of helplessness lead to further social isolation and increased risk of mental health concerns such as depression. The study also uncovered that stigma attached to ASD, such as explosive behaviours, as well as the seemingly invisible nature of the ASD also contribute to social isolation of parents as they are confronted with a lack of societal understanding. The study further uncovered that the increase in time and attention which is required to raise a child with ASD lends itself to the social isolation which occurs for some parents. The study concluded that parenting a child with ASD entails increased visits to medical providers, special equipment for therapy, and even special treats for reinforcing the child with ASD as well as days may becoming consumed with obtaining services for the child, such as appropriate school supports, occupational and speech therapy, respite care, as well as home and community supports. It is imperative to explore the lived experiences of parents of children with ASD particularly in Lusaka District of Zambia which this study sought to address.

Daire *et al.*, (2011) purported that finding adequate care for children with ASD is difficult, as babysitters are often not prepared for the magnitude of care which the child requires. The study revealed that this makes leaving the home difficult for the parent, as they must plan significantly far ahead in order to ensure that all their child's needs are met. It was observed that bringing the child into the community adds to social isolation, as lack of public

understanding and tolerance of autistic behaviours often leave parents with little choice but to keep their child at home. The study concluded that parents have identified that since the diagnosis of their child, they have fewer social ties and a decrease in the quality of their social relationships. From the above study, the current study needs to set records straight by exploring the lived experiences of parents with children with ASD in social interaction ASD in Zambian Context.

Jones, Totsika, Hastings, Petalas (2013), conducted a study on mental health on mothers with ASD in South Africa. It was shown that mothers are more affected by having children with ASD than fathers which is in agreement with particularly in her exhibition of possible mental health consequences. The study indicated that those mothers of children with ASD report higher levels of psychological distress in comparison to fathers who often correlated with the severity of child behaviours. The study revealed that ASD possess one of the most complex behaviour profiles of any developmental disability, with those affected engaging in self-injurious behaviours, tantrums, and complex rituals. In addition to these disruptive behaviours, children with ASD also display disturbed sleep patterns, difficulties in feeding, prolonged toilet training, and lack of social or emotional reciprocity.

Yamada *et al.* (2007) corroborated Jones, Totsika, Hastings and Petalas' (2013) study that Mothers are considered to be more affected by these instances of social interaction behaviours due to the sheer amount of time they spend with their child. The study observed that Mothers of children with ASD spend an average of 9.5 hours a day on the direct care of their child, in comparison to mothers of typically developing children who spend 5.3 hours a day. As the primary caregiver, the mother's stress level is highly correlated to the number of problematic behaviours which their child engages and this is particularly relevant when children engage in self-injurious behaviours, such as head banging and biting. The above data justifies the need to conduct the current study to establish whether or not mothers of children with ASD reported

higher levels of psychological distress in comparison to fathers who often correlated with the severity of child behaviours to parents in Lusaka District of Zambia.

A study by Dabrowska and Pisula (2010) opposed the studies of Yamada *et al.* (2007) and Jones, Totsika, Hastings, Petalas' (2013) study on mothers as being more affected than fathers by the ASD. It was observed that mothers experience more distress due to the behaviours of their child, fathers are more affected by the impact the child has on their career and finances. The study upheld that fathers are also affected far more than mothers by the communication problems which their child displays, including lack of speech and social reciprocity. The study demonstrated that much like mothers, fathers express a sense of loss that occurs after the diagnosis of ASD, particularly seemingly in fathers of sons with ASD, as they must re-define the father and son relationship, possibly abandoning those dreams of bonding with their son through physical activities. Keller *et al.* (2014) approved Dabrowska and Pisula's (2010) study much like maternal mental health, paternal mental health can be positively affected through social supports, such as support groups. The current study had a lot to learn from the aforementioned study in that the previous study highlighted how mothers are more affected by ASD than fathers. It was observed that mothers experience more distress due to the behaviours of their child were enriched by the new roles that acquired raising a child with ASD and optimistic changes within themselves. It is not known if this is the case for Zambian parents whom the proposed study intends to envelope.

2.4 Coping mechanisms in managing Experiences of Social Interactions with Children with ASD

Coping is a process which encompasses one's appraisal of a stressor, individual factors such as personality, contextual factors such as other stressors and cognitive or behavioural responses to the stressor. A study by Hooyman and Kramer (2016), on coping mechanisms showed that

parents' acceptance process, associated with the birth of a child with disabilities is complicated by the parents' grieving the death of the "expected" baby while at the same time trying to accept the "imperfect" baby. The study, however, was silent on the joy of being able to hold and love their baby and learning their life is suddenly drastically changed. ASD Society (2011) was of the view that parents can cope with the stress of ASD by networking with other families who have been affected by the disorder. The study concludes by observing that parents need to use more support groups, other parents of children with ASD, social workers, occupational therapists, special education teachers and other mental health professionals. This provides parents with comfort in finding others who are experiencing similar situations as well as receive advice that will be useful in the parenting process. However, this study may not be able to fully investigate this factor unless it comes out from the respondents as a challenge.

Hill (2015) undertook a phenomenological approach in studying ASD children with the experiences of their Australian parents. This study included the nature of the stresses, the coping strategies used by parents and coping strategies that were most effective in helping parents manage successfully. The study divulged that parent of children with ASD suffer from exhaustion and stress due to the degree of the amount of care needed. It further established that Feeding, clothing, bathing and diapering an infant is much easier physically than doing the same tasks for someone who is big. The study concludes by indicating that having a child with ASD can dig deeper into the pocket of the parents. The current study does bridge that gap through a Hermeneutics Phenomenological Approach to describe the lived experiences of Zambian parents with ASD children in social interaction. The reviewed study shows that parents of children with ASD suffer from exhaustion and stress due to the degree of the amount of care needed, little is known about Zambian parents, whether the nature of the stresses, and the coping strategies used by parents in Australia were most effective in helping parents

manage social interaction successfully, thus prompting the need to establish whether this also applies to the 'Zambian parents' context using Lusaka District as a case.

Ekas, (2010) conducted a study on the issue of increase social interaction and social isolation of parents after their child has been diagnosed with ASD. It was observed that social interaction contributes to a decline in parental mental health. It was revealed that social supports have been identified as critical in reducing psychological distress in these parents, including informal supports such as friends and family members, and formal supports such as health care providers and schools. Though social supports have been identified as a highly effective coping response to the stressful nature of parenting a child with ASD, some parents still respond with mechanisms of isolation, including restricting their world to the care of their child and losing interest in other areas of their lives (Sharma *et al.*, 2013). It is imperative to explore the lived experiences of parents of children with ASD to establish whether the above finding can be applied to Zambian parents.

In a study on coping mechanisms Cubells (2013) uncovered that the social support from friends, family and spouses reduced depression and increased the well-being in parents of children with ASD. Benson (2017) adds that spousal support was quantified as the most helpful source of support as it provides respite, divides household responsibilities and shares the disciplinary role between one another. However, Benson's (2017) study did not disclose areas in which single parents required to get the support in social interaction for children with ASD.

The study by Meadan *et al.* (2010) above links well with that of Mancil, Boyd & Bedesem (2009) who researched on respite care of children with ASD in England. Their study described the views of parents with ASD children, coping styles utilised and showed respite care to be a significant support in coping with ASD children. Respite is a service in which another adult assumes the role of the parent for a child with ASD, giving the natural parents a break. The

study also determined that it reduces stress levels in both parents. In addition, the study upheld that that support groups, health and professional services and counselling, allow the parents to discuss current issues and gain knowledge of their child's ASD. A case study approach was utilised. The parents identified issues to do with coping mechanisms access to, and the use of information as important in their lived experience. Their study did not apply a much more integrated approach in its design to understanding lived experiences of parents. The current study does bridge that gap through a Hermeneutics Phenomenological Approach.

Hill & Fombonne (2015) clarifies the high prerequisite for support groups. Parents gained knowledge and were empowered to advocate in the community with other parents whose children were diagnosed with ASD. It also demonstrates the significance of social support when parents are coping with children with ASD. The study indicated that parents are able to adapt adequately when they receive support from others through networking. Information from health care providers and agencies is also helpful. It also intended to include prayer, exercise, deep breathing or relaxation exercise, writing in a journal, keeping a daily schedule of things to accomplish, advocacy, and individual, marital or parental counselling. It is imperative for the current study to discover whether or not parents of children with ASD in Zambia reveal the consequence of social support in coping with children with ASD.

The studies done by Al-Kandari et al., (2017) examined levels of spirituality and religious performance in mothers of children with ASD. It was determined that this factor had a considerable positive effect on coping in some circumstances. Religion had an impact on the mothers' levels of confidence, contentment and hope. Previous studies demonstrated that the greater the belief in God, the more the individual was able to focus on the important things in their life, so religious beliefs therefore improved their socio-emotional well-being and were a means of positive coping. Furthermore, Beighton & Wills (2017) examined the role of acceptance and commitment therapy (ACT) in parental stress. This study used a quantitative

design to examine the impacts of a two-day workshop where parents were taught various ACT techniques. The study reported positive improvements for many of the participants. However, this study may not be able to fully investigate this factor unless it comes out from the respondents as a challenge.

A longitudinal study by DePape & Lindsay (2015) used ethnographic methodology to examine ways in which parents of children with ASD coped over time. The study involved 35 parents (representing 26 families) in Australia over a two-year period. The study established that parental coping strategies changed over time and that respondent mentioned fewer coping methods when they were interviewed at a later date. They also placed less reliance on external services and interventions at a later date. This meant that some of their children had grown up without ever having been registered with an autism centre. DePape & Lindsay (2015) suggested this could mean that parental coping styles had improved or that levels of stress reduced over time. Indeed, the parents themselves suggested that the behaviour of their child had improved over time, even though they still demonstrated many autistic behaviours. The current study explored the lived experiences of parents of children with ASD. It assumed that it is crucial to become familiar with the parents' viewpoints since these offer an insight into the family realities and routine, and into how the family dynamics are affected by having a child with ASD.

In contributing on the same subject, Zablotsky *et al.* (2013) observed that parents of children with ASD were likely to benefit more in a behavioural or cognitive response used by an individual in order to reduce their level of suffering. This also has the potential of soliciting the desired resources and support services to enrich access to coping mechanisms of parents of children with ASD. Zablotsky (2013) contributed to this view by citing three methods; coping psychological well-being, coping acts as a moderator between stress and psychological well-being, and coping responses are influenced by the degree of the stressor present. In addition,

the style of coping which a parent decides to use, emotional problem, will affect their well-being as well as their relationship with their child. Problem-focused coping mechanisms have the potential of reducing psychological distress in parents, along with closer parent-child relationships. This has resurfaced in the aforementioned study: though not mandatory, most parents with children with ASD have their ways of coping mechanisms. This study will explore this aspect in the Zambian context and relate it to the lived experiences of parents of children with ASD.

Ekas *et al.* (2010) on the other hand, investigated emotion-focused coping mechanisms. The study revealed that predictive of increased psychological distress, as well as poorer parent and child social interaction. The results showed that problem-focused responses include seeking support, engaging in problem solving, focusing on the positive or accepting, and compromising or negotiating. He cited Emotion focused mechanisms including escaping, blaming, worrying, withdrawing socially, and feeling helpless. Problem-focused coping mechanisms are empirically validated to increase positive mood in parents of children with ASD, which plays a critical role in the psychological and physical well-being of parents. The emotional-focused coping mechanisms of blaming, withdrawing, and helplessness have been identified as decreasing daily positive mood, which is detrimental to the psychological well-being of parents.

In a study on several services and approaches to utilise when working with a child with ASD, Postorino, Sharp, McCracken, Bearss, Burrell, Evans, & Scahill (2017) learnt that parents of children with ASD were in need of consistent therapy with their children as well as assistance from knowledgeable professionals. MacFarlane and Kanaya (2009) indicated speech therapy being the most common service for children diagnosed with ASD as 87.3 per cent of parents utilised this source followed by occupational therapy with 67.5 per cent of parents' utilising this source. This study also indicated 45.6 per cent utilised behavioural management programs

while 42.7 per cent utilised learning strategies and study skills assistance. The study further revealed that in school, 83 per cent of parents used speech and language therapy, 64 per cent of parents used occupational therapy, 28 per cent used skills training, and 11 per cent used physical therapy. Findings in this study indicated that outside of school, 57 per cent of parents used care from family or friends, 12 per cent used special summer camp, 11 per cent used respite care and only one per cent used residential placement. Twenty-eight per cent of these parents used a case manager and only 8 per cent used a behavioural specialist. Forty per cent of these parents used medication, 10 per cent used supplements only and 8 per cent used a combination of the two. Picture exchange communication was used by 23 per cent of the parents outside of the home and 21 per cent used sensory integration therapy outside the home. Thirty per cent of parents used parent support groups and only 4 per cent used family counselling. Only one per cent of siblings used support groups.

Pisula & Kossakowska (2010) study contributed another effective intervention which is video modeling. Video modeling is used to target various behaviours in different aspects of functioning such as language, social behaviour, play, academics and adaptive skills in a child diagnosed with ASD. The purpose of this intervention is to facilitate observational learning. This intervention begins by determining the skill or behaviour to the target. Once the skill or behaviour is identified, the facilitator is required to write a script addressing that skill or behaviour, prepares a video and repeatedly shows the videotape to the learner. After the video is shown, the facilitator attempts to perform the target behaviour or skill and practice the behaviour or skill with the learner until the learner is able to perform the skill or behaviour on their own. Video modelling has been demonstrated in order to increase appropriate social interactions, improve conversation skills, improve daily living skills, improve play skills and reduce problem behaviour. It has been implemented alone or in a combination with other strategies. Even though, all these Coping mechanisms are faced by parents with children with

ASD, much work has not been done in Zambia to ascertain the particular problems that these parents are facing. With this, there is the need for this current study that will look at the lived experiences of parents of children with ASD.

Cook's (2011) study indicated social stories to be an effective tool when working with children with ASD. This showed improvement in classroom behaviour for learners following social stories. Social stories are short narratives used to promote positive behaviour. The study revealed that the language used in social stories was simple and that it emphasised what to do in certain situations after being provided with descriptions of the environment. Social stories allowed children diagnosed with ASD to learn social skills, deplete bad behaviour while improving communication skills and learn self-help skills. The study indicated that social stories resulted in mild to moderate improvement in target behaviours. Her social stories are used in the education of individuals with ASD and have proved to be effective.

Corbett and Abdullah (2005) carried out a study on self-stimulating behaviours such as bouncing, rocking and covering the ears all common in children with ASD. The study revealed that although these methods can be self-stimulating, they can also interfere with the child's ability to attend, communicate, learn and interact. Mays *et al.* (2011) buttresses Corbett and Abdullah's study when they posit that it is important for sensory interventions to be implemented in order for the child to focus and learn new skills. They add that sensory interventions also allow the child to register and regulate sensory stimuli responses which will prevent over reactive or under reactive behavioural responses to occur. Ascertained that occupational therapist is the weighted vest. The purpose of the weighted vest is to provide deep pressure stimulation for the child in order to calm the central nervous system. It is a sensory tool provided by the sensory integrative framework. The above aforementioned study used self-stimulating and sensory interventions as coping mechanism which is not unique to Zambia. Although this study did not delve into the intervention method but on the lived

experiences of parents of children with ASD in Lusaka Zambia, it was likely to come out as a coping method from parents of children with ASD.

In Lyons, Leon, Roecker Phelps, & Dunleavy (2010) study, 82 per cent of occupational therapists in schools reported using this intervention. They witnessed positive benefits of calming, increased attention and decreased self-stimulating behaviours. The study also established moderate improvements in focus and decreased distractions in the students while wearing the weighted vests for three students, negative outcomes occurred due to the weighted vest. In a school, setting, decreased negative self-stimulating behaviours, and a small increase in positive behaviours such as staying on task and following instructions were noted.

Play therapy is an intervention often used by occupational therapists when working with a child with ASD. Children are more apt to express themselves through play as it is one way in which a professional can enter the children's world. Play allows these children to solve problems by using toys as well as express any fears, anxieties, fantasies and guilt through objects. One researcher indicated that play has resulted in emotional, social and intellectual growth. Sand play is a technique often used in play therapy with children on the ASD spectrum as it provides high sensory stimulation. Children diagnosed with ASD play with toys in a sand tray and shape the sand. Sand play is categorised as an expressive therapy; children diagnosed with ASD typically share inner thoughts and feelings that they would not normally verbalise with their toys. One study reported sand play to be the most favoured therapeutic approach by children. That they would not normally verbalise. Over many years, literature indicated that play was effective in children experiencing several different issues, including ASD (Parker & O'Brien, 2011).

The study revealed that PECS's training is typically used with the nonverbal children with ASD as it increases communication by using picture cards. The study indicated that PECS

training enhanced speech as a means for communication as well as encouraged the students to use picture cards to communicate. In addition, PECS training teaches parents simple communicative words first, such as requesting for a drink or a toy. The study indicated a positive effect with this communicative function.

Gordon *et al.* (2011) conducted a study on Picture Exchange Communication System training (PECS). Wolfe, Condo and Hardaway (2009) carried out a study on several interventions used when working with a child with ASD, in which a few of the primary ones were identified. ASD has a wide spectrum, so interventions are to be used per case as some children may communicate verbally and some may communicate non-verbally. The study indicated that it is also important to identify their symptoms and presenting behaviours when choosing an intervention. The study revealed that Applied Behaviour Analysis (ABA) is commonly used when working with children with ASD. It showed four ABA's that have been identified to be effective including video modelling, visual strategies, social script fading and task analysis. Video modelling which has been described above, allows the student to observe a videotape of a model demonstrating a target behaviour that the student will then imitate. Visual strategies which are very similar to PECS, use a visual cue large enough for the student to see. However, there was an apparent gap between technology and practice, with parents of children with ASD encountering barriers to communication and interaction.

Lin, Tsai, & Chang (2018) introduced visual cues that prompt the student to engage in a behaviour. Social script fading is focused on social interaction through audiotape or a written script. Once the student masters the social skill that has been demonstrated, the script is reduced or faded out until the skill is performed without the script. It indicated that task analysis breaks down a difficult behaviour into smaller parts or fewer steps then positively reinforces each small positive response. Task analysis is effective when teaching personal hygiene. Another strategy of ABA is social stories which have been described above. Social stories are short

stories developed to direct the attention towards a difficult social skill or situation. The concepts and principles of ABA are directed to compose meaningful and functional behaviour change so the individual is able to live more independently. Further, there was need to empower parents of children with ASD with concepts and principles of ABA, to pave way for improved quality of life with children with ASD.

Nealy *et al.* (2012) and Mihshtein *et al.* (2010) provided information on how parents reacted after their children were diagnosed with ASD. Contributing on the same was Grossi, Marcone, Cinquegrana, Gallucci (2013) conducted a study on parents with their ASD children in United State of America. The study reported that children exhibited fear if their activities were changed and interfering with patterns of behaviour would often be met with rage due to changes in routine, furniture arrangement and the order in which daily activities were carried out. The three identified confines are gaps that warrant further exploration to produce insights on the lived experiences of parents in social interaction with children with ASD in Lusaka District of Zambia.

2.5 Knowledge Gap

As presented in the following literature review section, many research studies have investigated detailing the stresses, challenges and opportunities and the psychological functioning of parents with children with ASD. The majority of the studies involve children with ASD in education while some studies have researched the experiences of families of children with disabilities (Fombonne, Marcin, Manero, Bruno, Diaz, Villalobos, Ramsay, Nealy, 2016; The National Autistic Society 2014; Chansa-Kabali, Nyoni & Mwanza, 2019; Wonani & Muzata, 2019; Nyoni Sepell, 2012; Hasangu, 2015). However, very little attention was paid to parents of children with ASD in most of the studies done in Zambia. This is the knowledge gap that the present study sought to address, that is in terms of the literature on

information of parents' daily activities as well as their lived experiences in social interaction; to establish ways in which parents interact with their children with ASD; to describe the parents' experiences of social interactions with children with ASD and to explore coping mechanisms that parents employ in managing experiences of social interactions of children with ASD in Lusaka District.

2.6 Chapter Summary

In this Chapter, an attempt was made to review the related literature on lived experiences of parents' social interaction with children with ASD. The review focused on the literature of information on parents' daily activities as well as their lived experiences in social interaction; to establish ways parents interacts with their children with ASD; to describe the parents' experiences of social interactions with children with ASD and to explore coping mechanism parents' employ in managing experiences of social interactions of children with ASD in Lusaka district. Very little attention was paid to parents of children with ASD in most of the studies done in Zambia. This is the knowledge gap that the present study sought to address. The next chapter discussed the methodology that was used to collect the required data for the study.

CHAPTER THREE: METHODOLOGY

3.1 Overview

This Chapter provides an insight into the research methodology that was used to guide this qualitative study in order to investigate the lived experiences of parents in social interaction with their children with ASD. The philosophical framework of van Manen (1990) is explained and refers to the methodology while the process for carrying out the research is the method. Included within the method description is the research design used, target population, sample, sampling technique and data collection instruments employed in the study. Characteristics of participants, data collection procedure approach and data analysis procedure, strategies to achieve trustworthiness and ethical considerations are thereafter discussed. The Chapter ends with a presentation of the chapter summary.

3.2 Philosophical Assumptions of Phenomenology

In research, philosophy denotes the epistemological, ontological and axiological assumptions on which an inquiry is leaning. Generally, epistemology describes ‘how’ a researcher knows about the reality and assumptions about how knowledge should be acquired and accepted. The ontology explains ‘what’ knowledge is and assumptions about reality. Axiology reveals the assumptions about the value system (Pathirage et al. 2008). Greenbank (2003) observes that when researchers are deciding what research methods to adopt, they are influenced by their underlying ontological and epistemological position.

This in turn is informed by their values. Ontology is concerned with reality. It is the science of study of being. The reality can be external to individuals or produced by individual consciousness (Cohen et al., 2000). While applied to Hermeneutical Phenomenological Research, reality is perceived as an individual construct dependent on different situations.

Hereafter, it is rested on the belief that realities are multiple. Phenomenology denotes both a ‘philosophy’ and research ‘method.’ Edmund Husserl (1859-1938) is regarded as the father of Phenomenology. Husserl’s Phenomenology project has been stretched, challenged, and adapted by numerous philosophers, including Martin Heidegger, Maurice Merleau-Ponty, Jean-Paul Sartre, Emmanuel Lévinas, Jean-Luc Nancy, & Jean-Luc Marion thereby creating a dynamic and heterogeneous philosophical tradition. The rise of phenomenology as a philosophy began as an objection to ‘reductionism’ and is aimed at achieving a deeper and broader understanding of phenomena that can be attained from research.

The thrust of phenomenology is to understand how human phenomena are experienced in consciousness, in cognitive and perceptual acts, as well as how they may be valued. Primarily, phenomenology is the study of lived experiences that explore the meanings of experience (Van Manen, 1997). Phenomenological researchers are intrigued by ‘meaning’ in human experience. Therefore, a phenomenological study aims at understanding a participant’s experience of living in real life situations, not experimental situations. Phenomenologists argue that there are multiple realities and truths constructed by individuals within the social context of their lives. Therefore, there is no neutral (objective) reality or solitary form of truth, only the reality and truth as constructed by the individual’s experience (Munhall & Boyd, 1993). Phenomenology is a method of researching the essence or essential meanings of phenomena. Simply, phenomenology is “the study of essences” (Merleau-Ponty, 1962). The term essence refers to the essential meanings of a phenomenon; that which makes a thing what it is (van Manen, 1990). Heidegger (1977:3) describes the essence of a phenomenon as “the way in which it remains through time as what it is.”

Hermeneutic phenomenology is concerned with human experience as it is lived. The focus is to illuminate particulars and seemingly trivial aspects within experience that may be taken for granted in our lives in space and time, with a goal of constructing meaning and achieving a

sense of understanding (Wilson & Hutchinson, 1991). In addition, Langdrige (2007) argues that our experiences can be best understood through stories of a particular experience that people tell. To understand the life world, we need to explore the stories people tell of their experiences, often with the help of some specific hermeneutic circle. Lavery (2003) takes a self-reflection as the standpoint to generate meaning from lived experiences. For Lavery, data is to be interpreted using a hermeneutic circle that consists of reading, reflective writing and interpretation. As a qualitative research method, phenomenology takes the form of inductive approach to the world as a person has lived it.

Phenomenology is suited for researchers with an intent of fully describing an experience as it is lived by a study's participant (Burns & Grove, 2001). In this form of research, research participants describe their lived experience, and the words participants use in describing their experiences become the data of the study.

3.2.1 Philosophical Assumptions underpinning

The epistemological and ontological view adopted in this study embraces the nature of reality to be subjective, interpretivism constructed and only understood by examining the perceptions of the human actors. To this effect, reality is understood from multiple perspectives and is holistic and contextual in form. The study is aligned to a growing body of researchers arguing against positivism, pointing out that the social science deals with action and behaviour which are generated from within the human mind and so cannot be studied externally by the researchers (Bryman, 2008).

This is consistent with Merriam (1997) who argues that the key philosophical assumption of a qualitative researcher is that individuals interacting with their social world construct reality. It is assumed that meaning is embedded in people's experiences. Furthermore, the axiological assumption stance taken in this study considers the researcher's values as a critical ingredient

to the success of the study as values aid in determining what are recognised as facts and the interpretations thereof. To this end, the present researcher is actively involved with that which is being researched.

3.2.2 Choosing Phenomenological Inquiry among the Qualitative Approaches

This study advances the border of knowledge on the lived experiences of parents of children with ASD. It falls within the continuum of qualitative research approaches. Given that there are various approaches within qualitative research continuum, it become critical that the chosen approach is fully justified. What follows then is a set of qualitative research approaches that apply across disciplines. The researcher's aim is to justify the choice of a Phenomenology Approach over the other qualitative approaches through a comparative analysis of the various qualitative research approaches. The contrasted qualitative approaches are: (i) Grounded Theory; (ii) Ethnography; (iii) Case Study; (iv) Transcendental Phenomenology and (v) Hermeneutics /Interpretative Phenomenology.

3.2.2.1 Grounded Theory

Grounded Theory approach is a brain-child of Glaser & Strauss (1967), whose emphasis is learning from the data rather than imposing a prior theoretical position. Researchers in the grounded theory have a different objective, whose focus is to generate or discover a theory, while the phenomenological inquiry focuses on the meaning of people's experience toward a phenomenon, (Creswell, 2014). The thrust of the grounded theory approach is the development or generation of a theory closely related to the context of the phenomenon being studied. On the other hand, researchers in a phenomenological study seek to understand the meaning of experiences of individuals (not a group). The Grounded Theory looks at experiences and as many other data sources as possible to develop a more objective understanding of the subject of the study, hence does not fit to be used in this study while Phenomenology is mainly

interested in the "lived experiences" of the subjects of the study, meaning subjective understandings of their own experiences.

3.2.2.2 Ethnography Enquiry

An ethnography enquiry examines the culture of a given social group through time spent by combining participant: observation, in-depth interviews and document analysis in the informants' natural setting. This cultural understanding may help answer questions about, people's beliefs and practices, concerns, individual experiences in certain types of settings, among others. Researchers in ethnography examine the group's observable patterns of behaviour, customs and ways of life. According to Wolcott (1994:116), "The ethnographer's task is the recording of human behaviour in cultural terms." To the contrary, the research study at hand centres on lived experiences and not cultural and traditional norms. An ethnographic inquiry proposes an approach to the study of teacher preparation, placing the focus on the subjects' everyday experiences. It offers a specific point of view focused on the complexity of training processes, from the subjects' perspective.

3.2.2.3 Case Study

A case study is applicable in studies with an in-depth thrust having clear boundaries (Creswell, 2014). In a case study, researchers gather extensive information from multiple sources of information. Yin (1989) recommended six types of sources: documents, archival records, interviews, direct observations, participant observations and physical artefacts. In a case study, it is important for researchers to have contextual material available to describe the setting for the case and need a wide array of information about the case to provide an in-depth picture of it. However, in a phenomenological study, researchers collect data through primarily interviewing (Creswell, 2014).

In a phenomenological study, it is important for researchers to capture and describe how people experience some phenomenon how they perceive it, describe it, feel about it, judge it, remember it, make sense of it and talk about it with others. To gather such data, researchers must undertake in-depth interviews with people who have directly experienced the phenomenon of interest; that is, they have “lived experience” as opposed to second-hand experience (Patton, 2002:104). In this study, it was essential to have information on parents of children with ASD experiences from their perspective and in their own words. Therefore, documents, archival records, and physical artefacts, which are required in a case study, seemed less suitable for this study. Given the foregoing comparative analysis among the various research approaches on the purpose, data generation technique, and the form of results among the different qualitative traditions, a phenomenological method was the most suitable for this study.

Furthermore, within Phenomenology Research Discourse, there are two major schools of thought namely: Descriptive (Transcendental) Phenomenology and Interpretive (Hermeneutics) Phenomenology. Below is a further comparative analysis of the two schools of thought to warrant the choice of Hermeneutics over Transcendental Phenomenology.

3.2.2.4 Descriptive versus Interpretive Phenomenology

Two major schools of thought on phenomenology exist namely: Descriptive Phenomenology and Interpretive Phenomenology. Descriptive phenomenology is associated with Edmund Husserl whose aim was to capture the essence of participants’ experiences through structuring phenomena. In Descriptive Phenomenology, participants are regarded the experts, and the researcher is an instrument who describes, compares and distinguishes the information provided by participants and then constructs the information into a structured description. Nevertheless, interpretive (hermeneutic) phenomenologists take the freedom to interpret the

unspoken, unconscious, and hidden meanings they perceive to exist in the phenomenon under study, rather than simply provide a full description of the data (Cohen & Omery, 1994). This method permits researchers to make implications about informants' experiences beyond that which is conveyed. Put in other words, Interpretive Phenomenology is also known as Hermeneutic Phenomenology (Langdridge, 2007; Lavery, 2003) and as Existential Phenomenology (Spinelli, 2005).

In this study, the Hermeneutic Phenomenological Approach was chosen, as it was not only consistent with the reflective value on knowledge creation of the researcher but also due to the unique lived experiences of parents of children with ASD. Proponents of Hermeneutic Phenomenology Approach argue that it is impossible and undesirable to set aside or bracket researchers' experiences and understanding. Halling *et al.* (2006), observe that researchers need to come to an awareness of their pre-existing beliefs, which then makes it possible to examine and question them in light of new evidence. Further, Finlay (2008:17) postulates that researchers need to bring a "critical self-awareness of their own subjectivity, vested interests and assumptions and to be conscious of how these might impact on the research process and findings."

One of the views of Hermeneutic Phenomenology is interpretivism. The interpretivist paradigm is also called the "anti-positivist" paradigm (Ernest, 1994). It is also referred to as constructivism because it emphasises the ability of the individual to construct meaning. The rationale behind the choice of the paradigm was guided by the research phenomenon under study: 'lived experience' that is a social construct. Since the phenomena under study is situated within social science and not natural science, action and behaviour which are generated from within the human mind cannot be studied objectively by the researchers as advanced by Ernest (1994), Bryman (2008) and Warthall (2006). Warthall (2006) particularly observes that under Existential Phenomenology, within which is Hermeneutics Phenomenology, research should

not be conducted from a detached, objective, disinterested, disengaged standpoint. This is because, certain phenomena only manifest themselves to one who is engaged with the world (Warthel, 2006).

3.3 Research Design

A Hermeneutics Phenomenology Design was applied in studying the lived experiences of parents of children with ASD as illustrated in table 3. 1 below Heidegger’s study on ‘Being and Time’, which was further expanded by van Manen’s four reflective thematic areas on lived experiences.

Table 3.1: The four are: by van Manen (1997)

Lived space	Lived body	Lived time	Lived human relation
Spatiality	Corporeality	Temporality	Relationality

Source: Van Manen, 1997

In other words, lived experience takes place in ‘Space’, ‘Body’, ‘Time’ and ‘Relations.’ Owing to limited time available to conduct a longitudinal study, a cross sectional approach was preferred to longitudinal approach. This enabled the researcher to have a broader understanding of the lived experiences of parents of children with ASD (Body) with varying ages in years living with the child (Time) staying with siblings and other family members (Relations) within the same house environment (Space), (van Manen, 1997).

3.3.1 Limitations of Phenomenological Hermeneutic methods

In all research methodologies, there are limitations, and it is vital for the researcher to acknowledge these, specifically the methodology of choice. In general, phenomenology does not attempt to predict, generalise or generate theories (Speziale & Carpenter, 2007); instead, it aims to create a deeper understanding of the nature or meaning of everyday experience (van Manen, 1990). This is important as researchers are concerned with determining human

experience and gaining a greater understanding of parents' perspectives in order to increase their quality of life.

3.3.2 Suitability of Phenomenological Hermeneutic Method

Van Manen's (1990) phenomenology was an appropriate approach for this study as the researcher had prior experience with and knowledge of the phenomenon. Unfortunately, this knowledge was limited in scope and further understanding was warranted. Van Manen's method has been widely adopted by a variety of professionals, sociologists, psychologists and social scientists, including educationalist. His method is flexible and versatile as seen by its use in a range of research scenarios such as the lived experiences of critically ill patients' family members (Wagner, 2004), the lived experience of adolescents with depression amongst others (Woodgate, 2006). Van Manen's method permits an immediate exploration of the phenomenon and allows for even the most comprehensive issues to be explored with a detailed technique. According to van Manen, interviews serve a dual process by being able to develop relationships about the meaning of an experience and the ability to gather narrative data that will enhance the understanding of the phenomenon of study (van Manen). The intent of this study was to gain a deeper understanding of the meaning of the lived experiences of parents in social interaction with ASD children in Lusaka District.

3.4 Population

Population is defined as a group of patterns, objects from which samples are drawn from for measurement (Kasonde-Ng'andu, 2013). The target population for this study were parents of children with ASD in selected compounds of Lusaka District in Zambia. The rationale for selecting the parents in the study district was that parents should have had lived and interacted with ASD children on a daily basis, thereby qualifying them of having experiences as parents of children with ASD. The researcher hoped to collect quality data from such a population to

provide knowledge and experiences so as to vividly contribute new knowledge on the lived experiences of parents with children with ASD.

3.5 Sample Size

Sample size provides a response to research questions. To settle on the sample size, Marshall and Rossman (1995) document three broad approaches, namely convenience, judgement and theoretical sampling. According to Neuman (2003), qualitative research works focus on non-probability or a non-random sample, which entails that they seldom determine the sample size in advance. To this effect, the participants engaged consisted of parents of children with ASD. Neuman (2003) state that purposive sampling does empower the researcher the right to select cases with a specific purpose in mind, namely, to get information on the basis of their informativeness.

A sample can be said to be a small group or the accessible target population. It has the characteristics of a larger group or population (Kombo & Tromp, 2006). It is carefully, selected in order to be representative of the whole or entire population. Kasonde-Ng'andu (2013) sees a sample, as a subject of the population taken to be representative of the whole study population. A sample helps to reduce on number of participants in the research by making it manageable as well as controllable on the part of the researcher (Mugenda & Mugenda, 2003). This sample should have know-how characteristics and be accessible to the study under investigation. However, Creswell (2013) pointed out that there is no specific formula to determine the sample size in qualitative research. It is ultimately a matter of judgment and experience on the part of the researcher, and researchers need to evaluate the quality of the information collected in light of the uses to which it is applied. Although a sample of parents from 10 to 14 participants was proposed, the final sample size of 10 parents was determined by the completeness of the data and the achievement of theoretical saturation. The participants

were selected and recruited for the study from 10 special education units in Lusaka District. These participants were drawn from three geographical locations as follows: six (6) were from low density, two (2) medium density and two (2) from high density. The size of the sample was controlled by saturation of information which means the point at which repetition or confirmation of previously collected data occurs, thus there was no specific number of participants (Streubert Speziale & Carpenter, 2003).

3.5.1 Characteristics data for Parents of children with ASD

Table 3.2: Parent Participants were asked to give their age and education levels

Participants ID	Age	Educational level
A1	34	Diploma
A2	28	Secondary
A3	37	Degree
A4	27	Degree
A5	31	Diploma
A6	42	Primary
A7	29	Secondary
A8	44	Certificate
A9	36	Masters
A10	35	Degree

Source: Own illustration based on current study

In relation to age and education levels of the participants, a total of ten parents of children with ASD participated in this study. Among participants in the study were couples such as **A1** and **A2**; **A4** and **A5** and **A9** and **A10**. The ages of the parents ranged between twenty-eight (28) to forty-four (44) years old at the time of the study. The parents were recruited through special education schools. All the recruited parents had at least one child with ASD attending special school at the time of this study. All the parents of children with ASD's education levels were

comprehensive. These parents were from seven (7) different families, and they represented the parents in Lusaka District.

Table 3.3: Parent Participants and Gender

Care giver of ASD children	Total number of participants	Gender	
		Male	Female
Fathers only	0	0	0
Mothers only	6	0	6
Guardians	4	2	2
Total	10	2	8

Source: Own illustration based on current study

Participating parents in the study represented parents who had children with ASD in Lusaka district. Out of these, six (6) out of ten (10) parents lived with their mothers while four (4) out of ten (10) lived with both parents and no father lived with any of the children with ASD. The general finding was that more children with ASD lived with mothers only than with both parents respectively and one child lived with the father.

Table 3.4: Geographical location of parents

Geographical location of parents	Number of Parents
Low Density	6
Medium Density	2
High Density	2

Source: Own illustration based on current study

Six (6) parents were drawn from a low-density area, two (2) parents from a medium density area and two (2) from a high-density area. In the Zambian setup the ‘so-called low-density schools’ usually associated with social prestige, where parents in the middle or high social-economic status groups preferred to take their children. Such schools had better facilities than

those found in other schools which were perceived to be of lower standards. The general finding was that most parents of children with ASD came from low density areas.

Table 3.5: Characteristics of Children with ASD by Gender and Age

	Gender	Age	Total
Male	Female	Range	
2	0	1 - 4	2
4	0	4 – 8	4
1	1	8 – 12	2

Source: Own illustration based on current study

Eight (8) children with ASD were represented by A10 participants. A1 and A2 (couple) represented one (1) child with ASD and A9 and A10 (couple) represented one (1) ASD child. Seven (7) of eight (8) children were males while one (1) of eight (8) was female. The Table further shows that most children with ASD were in the range of four (4) to eight (8) years while two (2) of eight (8) children were in the range of one (1) to four (4) and eight (8) to twelve (12) respectively. The general findings of this study were that ASD affected more boys compared to females.

3.6 Sampling Procedure

Sampling is a method of deducing information about a whole population from a limited number of units. Only appropriate and proper development of the sampling technique will lead to authenticity of results. The importance of sampling in any type of research is highlighted by Punch (1998: 193) who asserts, ‘We cannot study everyone, everywhere doing everything. Sampling decisions are required not only about which people to interview or which events to observe but also about settings and processes.’ Sampling is closely linked to the purpose and research questions of the study. These questions lead to selection of samples from a large pool which further generalises results to the population (Neuman, 2011). In selecting participants

for this study, the researcher employed a purposeful sampling method to select those who could offer her comprehensive information about the phenomenon (Mayan, 2009). With purposeful sampling, the aim is not to generalise findings to a larger population, but to select participants who will help the researcher to understand the phenomenon in depth (Mayan, 2009). Therefore, the number of cases is less important with this approach than what the selected cases contribute to the understanding of the topic at hand (Stake, 1995).

In this study homogeneous sampling was used. All the participants in the sample are chosen because they have similar or identical traits. In this study, they are parents with children with ASD. The selected participants are the ones that are useful to a researcher. It is a type of purposive sampling and is the opposite of maximum variation sampling. Homogeneous samples tend to be small and made up of similar cases. The participants met the eligibility criteria as described above in paragraph 3.7.1. Participants were contacted, the purpose of the study was explained and an agreement to participate was obtained. The researcher picked on the participants because of a need for experts in lived experiences with ASD children (Polit & Hungler, 2004: 294).

3.6.1 Inclusion and/or eligibility criteria and Sampling

The sample is a subset of population selected to participate in a research study. It defines the selected groups of elements, that is, individuals, groups or organisations. The sample is chosen from the study population that is commonly referred to as the ‘target population or accessible’ (Burns & Grove 2003: 233; Polit & Hungler 2004: 290). In this study, the sample consisted of parents of children with ASD in Lusaka District. The participants (parents) that were chosen met the eligibility criteria set for the study. Eligibility criteria are the reasons for including the sample in the study (Polit & Hungler 2004: 290). The eligibility criteria of this study required the parents to:

1. Have a child with ASD in the house.
2. Have lived with a child with ASD for more than one year.

3.6.2 Exclusion criteria

All parents without a child with ASD and those not living with an ASD for less than one year in the house were excluded. The reason for exclusion was that they may not have gained enough experiences with ASD children.

3.6.3. Research Setting

Interviews were conducted where the parents desired in order to make them comfortable throughout the interview process. During the interview, it was important to create an environment free of distractions and with minimal interruptions. All interviews were conducted at the participants' homes. Being able to visit the participants' homes and to see where they lived in terms of community set an excellent context in which to conduct this study. To see where these parents lived, to meet siblings and the child with ASD added to the understanding of the lived experiences and what that meant to parents. Being able to meet with participants in their homes allowed for a deeper understanding of the meaning's parents ascribe to parenting a child with ASD.

3.7 Research Instruments

This study utilised three data collection instruments. These included an open-ended interview guide; a demographic form and the researcher's personal field note book.

3.7.1 In-depth Individual Interview Guide

An interview protocol was used as the primary instrument for collecting data. According to Wojnar and Swanson (2007), the meaning of a lived experience can only be captured through

one-on-one communication between the researcher and the participant. This involves active listening, interaction, and observation to capture the pure representation of reality in favour of the biased, preconceived representation. The interviews in this study involved responsive and relational dialogues with parents of children with ASD (Chilisa 2012). These dialogues were guided by an interview protocol, but in conducting these, the researcher was flexible enough to permit unanticipated or serendipitous moments (Simons 2009). Interviews were audio recorded, transcribed and then analysed to determine the themes/meaning units that emerged and to ultimately describe the essence of the experiences of these students (Moustakas, 1994).

Conversations were driven by questions regarding the participants' encounter with raising a child with ASD, how they experienced their life, how they interacted with children with ASD and how they were able to formulate strategies to cope with the challenges they faced. Fundamentally, the dialogues, as structured, placed the participants' lived experiences at the centre of the engagement, all the while the researcher sought stories, examples, and context-dependent articulations of strategy. The interview was primarily advantageous because it provided access to the participant's world. The role of an interview in a phenomenological study was excellently summed up by Patton (2002: 104) who stated that: {...it is about} ...how they perceive it, describe it, feel about it, judge it, remember it, make sense of it, and talk about it with others.

To gather such data, one must undertake in-depth interviews with people who have directly experienced the phenomenon of interest; that is, their lived experience. Interviews were audio recorded with the written consent of each participant, and, depending on the nature and depth of the conversation, interviews were between an hour to two in length. The researcher took notes in the very rare cases that the voice recorder malfunctioned and to capture the serendipitous moments such as the nonverbal expressions of the participants such as facial

expressions. Prior to the interview dialogues, the researcher attempted to bracket her own experiences and biases from those of the participants.

Creswell (2007) has surmised that the entire phenomenological interview can be summarised in terms of two broad questions: “what have you experienced in terms of the phenomenon?” And “What contexts or situations have typically influenced or affected your experiences of the phenomenon?” It therefore be asserted that researchers who use phenomenology are interested in understanding a person’s relatedness to the world (and to the things in it, which matter to them) through the meanings that they construct. Accordingly, in this phenomenological study, the researcher realised from the onset that the interview would not only provide direct access to the experiences of the students through their accounts, but rather through a process of inter-subjective meaning-making. Thus, the researcher desired to elicit and engage with the personal accounts of parents of children with ASD in Lusaka District (Patton, 2002). In the recruitment of members, the researcher made sure that within the group, there was homogeneity. This implies similarity in such characteristics as gender, social economic class, and age when the factor is not highly correlated with response to the issue under investigation. Homogeneity is important because learners who differ greatly have such different resources, problems, experiences, and perceptions they may share and that makes it is easy for the researcher to see differences in experiences (Krueger, 1988 & Merton, 1990).

The first interview sessions with parents occurred between January and May 2020. These interviews facilitated the collection of the rich data exploring the essence of parenting a child with ASD. The majority of the participants were female, some were married while some were divorced and stayed at home with their children. The interviews were conducted within an average of 1 hour 30 minutes. All care was exercised to minimise errors and reduce background noises and interruptions. Tape recording equipment was checked regularly. A second interview

session gave participants the opportunity to further expand on any thoughts or ideas or to add anything that they felt vital to the true meaning of the study.

In addition, it enabled the researcher the opportunity to clarify any previous information and to validate themes to allow for as much interpretive insight as possible (Van Manen, 1990). The second interview sessions with participants occurred between June and July 2020 because of COVID-19 pandemic which broke out in Zambia and other countries. All parents participated in the second interview. Follow-up interviews took place over the phone due to COVID-19 and took up to 50 minutes with an average of just over 15 minutes. All participants reported that the study results were clear and an accurate representation of their experiences.

3.7.2 Demographic Questionnaire

The second tool for data collection was taken from a demographic questionnaire developed particularly for this study (Appendix D). Parents were asked to fill in the questionnaire prior to being interviewed. Included on this form were questions on the participants' age, marital status, number of children in the household and their ages, age of the child diagnosed with ASD and the age of diagnosis. The form took five to ten minutes to complete, and any questions asked by participants were answered while the form was filled in. All participants filled in the demographic form.

3.7.3 Researcher's field Notebook

The final tool for data collection was from a field notebook kept by the researcher. This notebook contained all the field notes, thoughts and feelings before and after each interview. The notebook was also used to facilitate relationships with the parent participants by replicating the cultural differences, attitudes, feelings and morals by the researcher. Additionally, the researcher incorporated peculiar assumptions regarding ASD. This cognitive

process of putting down one's own philosophies to prevent verdicts on what one had witnessed and heard is called bracketing (Speziale & Carpenter, 2007) and was significant in the phenomenology method. It is essential for the researcher to remain mindful while collecting and analysing data in order for the interpretation to remain a reflection of the participant rather than that of the researcher's personal philosophies. Although the researcher's field notebook was a self-reflective process, the journal was shared with the researcher's supervisor to assist in data analysis and interpretation.

3.8 Data Collection

The researcher was responsible for the initial contact of all eligible participants by sending out a letter of invitation (Appendix A). If parents were interested in participating, there was the participants-initiated contact with the researcher through phone or email. The researcher then followed through with a phone call (Appendix B). The intention of this phone call was to explain the purpose of the study and to explore the parent's willingness to participate. Prospective participants then agreed or declined participation. All potential participants agreed to participate. When a parent indicated willingness to take part in the study, a convenient interview time and location was established. All participating parents were asked to take part in two semi-structured, open-ended interviews. Study information and consent forms were distributed prior to the commencement of the first interview. The researcher conducted all interviews with permission. All interviews were tape recorded as quotations were the primary source of data in the qualitative research. Interviews and field notes were transcribed and data analysis occurred concurrently with data collection.

3.9 Data Analysis

Kasonde-Ng'andu (2013) defined data analysis as a manipulation of the collected data for the purpose of drawing conclusions that reflect on the interest, ideas and theories that initiated the

study so as to uncover the underpinning structures and extracting cardinal variables thereby testing any underlying assumptions. The appropriate methods of data analysis, however, are determined by the data type, variables of interest and the number of cases.

3.9.1 Qualitative Data Analysis

The data collected in this study was subjected to rigorous analysis in order to obtain the desired meaning from which conclusions were drawn. Flick (2013: 5) defines qualitative data analysis as “the classification and interpretation of linguistic (or visual) material to make statements about implicit and explicit dimensions and structures of meaning-making in the material and what is represented in it”. The researcher considered the design adopted to guide this study. Scholars propose stages of data analysis with slight differences in the order taken.

For instance, Table 3.6 below provides an illustration of three approaches to qualitative data analysis:

Table 3.6: Illustration of three approaches to qualitative data analysis

S/N	Murheji & Albon, (2015)	Lodico et al, (2006)	Crewell, (2014)
1	Becoming familiar with data	Preparation & organising of data	Organising & preparing of data analysis (transcribing) typing field notes, categorising, sorting arranging data into different types.
2	Coding the data	Receiving and exploring the data	Reading and looking at all the data getting general ideas
3	Categorising the code	Coding into categories	Starting coding of the data
4	Identification of themes & relationships among the codes	Constructions of people, places & activities	Using the coding process to generate a description of the setting or people as a well categories or themes for analysis
5	Developing concept and arriving at generalized statement	Building themes & testing hypothesis	Advancing how the developing & themes will be represented in the qualitative narrative
6		Reporting and interpreting data	Making an interpretation in qualitative research of findings or results

Source: Own illustration based on current study

One advantage of qualitative data is that the researcher starts analysis right at the point when data is being collected, at the time of the interviews or discussions with the respondents. In this study, the researcher started familiarising herself with the data from the point of collection. All interview data with parents with children with ASD was recorded on an MP3 audio device. After every interview, the researcher listened to the audio recordings and made brief notes in her note book. The brief notes highlighted general ideas that came from participants. The researcher also transcribed the audio recordings, thus becoming even more familiar with the

data collected and helping to reflect on the interviews had revealed. This practice is recognised as applicable by Creswell (2014) saying:

Data analysis in qualitative research will proceed hand-in-hand with other parts of developing a study namely; the data collection and write-up of findings. While interviews are going on, for example, researchers may be analysing an interview collected earlier, writing memos that may ultimately be included as a narrative in the final report and organising the structure of the final report.

This enabled the researcher, especially that she used in-depth interviews to be able to improve her interviewing techniques and collect even richer data in succeeding interviews. At the completion of transcription, the researcher made a print-out of 215 pages of transcribed in-depth interviews. The data was subjected to rigorous reading and re-reading to ensure little or nothing relevant was missed out during analysis. Lodico *et al.*, (2006:305) observe that “qualitative researchers should continually read, reread, and re - examine all of their data to make sure that they have not missed something or coded them in a way that is inappropriate to the experiences of the participants.” The researcher went through each script to edit spellings, removing names of respondents and places for ethical reasons and highlighting key concepts that emerged from the interviews. (The verbatim records needed to remain without alteration).

This was to prepare the data for coding. After making corrections on the printed transcripts, the researcher made corrections on soft copies, named and ordered the transcripts. The transcripts were then separated according to their categories: interviews for parents of children with ASD (N = 10). The folders with data were then uploaded into Nvivo software for further organisation and systematic sorting, coding, categorisation and analysis.

Nvivo is a computer software package that helps to analyse qualitative data (Mukherji & Albon 2015). In Nvivo, each interview was coded and memos created to help remind the researcher of very important points. While coding was being done, Nvivo also provided a platform to edit

the transcripts and further provided the researcher with an opportunity to interact with the data. Memos created were able to help the researcher identify similarities and differences from coded data even before actual analysis itself. Observations were used to make comments on key points that were observed during coding. After data coding was done, a check through the codes was done and certain points that were wrongly coded were un-coded and recoded appropriately. Case codes were also created to easily provide a platform for comparison with data coded as internal codes. After all necessary coding was done, the researcher made sense of the coded data by running word frequency charts from the biographic participant data, cluster analysis and comparison diagrams.

These provided the basis for qualitative data analysis in this study. Thus, by use of cluster analysis, the researcher was able to identify coded themes and export the data under each theme to the main document. The comparison diagram helped the researcher to identify similar and different ideas between codes. Thus, similar concepts were grouped at the centre while differences were set on each side. While the researcher ran the actual analysis tools in Nvivo, analysis continued from one stage to another. This is perhaps the reason some scholars contend that analysis is actually an on-going process because the researcher interacts and starts making sense of the data right from the time data starts being collected. Creswell (2014a) acknowledges that data collection and data analysis must be a simultaneous process for qualitative research.

3.9.2 Methodological Rigour

Rigour in qualitative studies is a critical component to the research process. Strategies for enhancing the integrity of the study occurred throughout the procedure. Due to the fundamental differences in philosophical underpinning and the goals of the two main paradigms, qualitative studies cannot use the same terms to evaluate reliability and validity as in the quantitative

approach (Polit & Beck, 2008). However, the ability to demonstrate rigour in a research study is imperative to the creditability of that study.

Several authors have adapted different means of measuring rigour and validity in the qualitative methodology (Maggs-Rapport, 2001; Meyrick, 2006; van Manen, 1990; Whitemore, Chase & Mandle, 2001). Parallel to reliability and validity in quantitative research, standards for the trustworthiness are a unique approach adapted to qualitative research (Lincoln & Guba, 1985). The criteria developed by Lincoln and Guba were used to determine the trustworthiness of this study. The criteria addressed in this research study were credibility, dependability, confirmability, transferability and authenticity.

3.9.2.1 Credibility

Numerous steps were taken to ensure credibility in this study. First, the researcher is a professional within the field of education. Using this advantage, before collecting data, the researcher created rapport with participants to introduce herself as a member of the teaching profession and assured them on the significance of the study. This was to develop trust with participants. Furthermore, after in-depth interviews in data analysis, the researcher sent text messages to parents of children with ASD, requesting them to provide any other terms that were difficult to discuss and any other data that they could have forgotten telling the researcher.

The researcher received additional information from some parent participants. On 1st August, 2020, all the transcribed transcripts of the interviews were emailed to respective research participants so that they could read through and state whether some information could be removed from the interview or some information could be added. The comments made the researcher get back to the scripts to re-analyse the data and identify the positive elements of the study, thus a positive check on researcher subjectivity. Negative case analysis is part of credibility. Verbatims with contrary views were noted and recorded in the verbatims. However,

since they were fewer, they did not influence the final conclusions of the results and findings. As a researcher, it was only necessary to highlight views in a balanced manner. The analysis of qualitative data by use Nvivo qualitative software played a significant role in ascertaining the credibility of this study (see process in 3.9.2). Besides, every activity during data collection process was manually recorded in a diary on a daily basis. In Nvivo, reminders on key points related to data collected each day were noted down as key issues for analysis and reflection.

Further analysis by use of Nvivo qualitative analysis software enhanced the credibility of the findings for this study. Coding density of inappropriate and unclear responses was run in Nvivo. These processes helped the researcher to be focused and ensured that the data collected was credible enough.

3.9.2.2 Dependability

One other strategy used in qualitative research to ensure dependability is documentation. Ary et al., (2010) call it audit trail. In this study, data documentation was critical from the onset of data collection through analysis to reporting. Data was collected and stored according to the type collected. Qualitative data was coded in Nvivo in which memos or diaries were created for reference from time to time during analysis. The study collected detailed in-depth interview data which was transcribed into more than 243 pages. These were coded in Nvivo qualitative software, providing a high coding density on certain themes that came out (see appendix 'F'). This further satisfies the qualitative measure of dependability.

3.9.2.3 Confirmability

Confirmability is another measure for trustworthiness in qualitative research. It is a measure of biasness on the researcher. With this in mind, the researcher should be able to present findings that are not skewed to his or her interests. Ary et al., (2010) equate confirmability to

objectivity in quantitative research. Ary et al., (2010: 504) say confirmability and objectivity “both deal with the idea of neutrality or the extent to which the research is free of bias in the procedures and the interpretation of results.” Confirmability concerns the aspect of neutrality (Korstjen & Moser 2018). Korstjen & Moser (2018: 122) expound that, “You need to secure the inter-subjectivity of the data. The interpretation should not be based on your own particular preferences and viewpoints but needs to be grounded in the data.” Audit trail, just like in dependability is used as a strategy to ensure confirmability. Data analysis followed steps as described in 3.10.1. In this study, the qualitative findings from questionnaires confirm the results from interviews and observation and vice versa. Further, coding density in Nvivo qualitative analysis for instance cannot allow a researcher to skew the findings. Responses demonstrating understanding of the concept of curriculum adaptation were written by respondents through the open and close ended questionnaire. These were picked as they were and used as examples. These strategies ensured that the results of this study can be confirmed by other researchers.

3.9.2.4 Transferability

The fourth criterion is that of transferability or “fittingness” and is the ability of the findings to give meaning to others in similar settings (Speziale & Carpenter, 2007). Within this study, transferability was met by allowing the participants to understand the processes that occurred to determine how the interpretation of the data was achieved. In addition, comprehensive field notes were documented to provide ample descriptive data within the findings for others to evaluate the ability to find similar meanings in other contexts (Polit & Beck, 2008).

3.9.2.5 Authenticity

Authenticity is the final criterion in enhancing quality and integrity in qualitative research. Authenticity is the ability of the researcher to fairly and faithfully report the experiences of the

participants as they are lived (Polit & Beck, 2008). Going back to the participants to validate the findings achieved authenticity in this study.

In conclusion, to establish trustworthiness the researcher must earn the trust of the readers. Integrity within research begins with the research questions and continues throughout the entire procedure. In this study, verification and discussion of findings was continuously communicated between the thesis supervisors and the student researcher. Ongoing openness and flexibility throughout data collection and analysis were maintained with continued reflection to search for the true meaning of the essence. Regular communication with the thesis supervisors provided verification and furthermore, enhanced trustworthiness.

3.10 Ethical Considerations

Given the unpredictable nature of qualitative research, ethical dilemmas within issues surrounding informed consent, anonymity and confidentiality, data generation, publication, and researcher-participant relationships must be acknowledged and given special attention (Speziale & Carpenter, 2007). To remain ethically sound when working with human subjects, the ethical principles of autonomy, justice, non-maleficence and beneficence were implemented. The section that follows details the ethical issues that were considered in this study. Furthermore, the ethics committee cleared the research proposal as provided for in the university regulations. The ethical clearance reference for this study was REF. **HSSREC: 2020-September-013. See attached ethical clearance in appendix** (Appendix H)

3.10.1 Ethics Review

The purpose of an ethics review is to ensure that the ethical principles of conducting a research study are fulfilled. The research proposal was reviewed by the ethics committee at the

University of Zambia in order to maintain protection of all participants. The ethical principles of autonomy, non-maleficence, beneficence and justice will now be discussed.

3.10.2 Autonomy

To maintain the principle of autonomy, it was crucial to recognise the right of participants to freely choose whether to commence and continue with participation in this study. Once participation began, it was crucial to ensure that participation remained voluntarily. Informed consent was obtained from all participants through the signing of a consent and verbal consent was maintained throughout the interviews. Informed consent meant that the participants had been thoroughly informed about the research study, were capable of comprehending the information, and had the power to choose whether or not they wished to participate or decline participation (Speziale & Carpenter, 2007). Although participants signed a consent form, informed consent was an ongoing process occurring through each step. Furthermore, all participating parents were made aware that their participation was voluntary, that they would not be harmed, and that they may withdraw at any time without penalty.

Participants were allowed to decline the second interview. All participants completed the second interview. Further strategies were implemented to uphold the principle of autonomy. No dual relationships were present in the study. To prevent potential participants from feeling coerced into the study, the primary researcher did not have access to any names until participants contacted the researcher by email or telephone. Participants were all over the age of eighteen (18) and voluntarily consented to be interviewed. Interviews occurred at a time and location convenient to the participant and the approximate length of the interview was discussed prior to obtaining consent. Prior to obtaining consent, a description of the study purpose, methods of data collection and time commitments were discussed with the participant.

The researcher's student status, thesis advisor supervisors name, credentials, and university affiliation were also explained to the parents. Contact numbers for the researcher, supervisors and the Human Ethics Secretariat were provided to each participant. All information about the study was discussed verbally with ample time to answer any questions. Furthermore, risks and benefits to this study were discussed with the participants prior to attaining consent.

3.10.3 Non-maleficence

To maintain the principle of non-maleficence, the researcher must ensure that neither the researcher nor the research does any harm to the participant (Polit & Beck, 2008). Throughout this research project it was vital for the researcher to keep an ongoing awareness that the main purpose of the study might require that participants remember past and present experiences which had the potential to be difficult and evoke unpleasant feelings and memories. Due to the qualitative nature, "the psychological consequences of participating in a study are usually subtle and thus require close attention and sensitivity" (Polit & Beck, 2008: 170). Additionally, participants were vulnerable to losing personal and family privacy. The use of in-depth interviews presented both risks and benefits to the participants; therefore, participants were presented with a discussion regarding the nature of the interview and given plenty of opportunity for questions and further clarification. Furthermore, all participants were given the opportunity to withdraw at any point during this study.

When conducting qualitative interviews and provoking past memories, the possibility of distress occurring is always a potential adverse reaction. Some parents may become more aware of their feelings, and this may potentially cause stress and unwanted emotions. Care was taken to exercise sensitivity, and respect was honoured. Empathy and objectivity were also emitted by the researcher (Holloway & Wheeler, 1995). The researcher remained non-judgmental and eliminated any personal values or biases that could affect the research.

Due to potential distress, a plan for intervention was required prior to any interviewing. In the event that there were some unpleasant feelings, upsetting memories or increased stress, the plan was to stop the tape recording, validate the participant's feelings, and provide time. If the participant was able to recover and continue, tape recording continued and the interview proceeded. However, in an event that the participant was unable to continue, the interview ended and was proposed for another date. Fortunately, all participants were able to complete the interviews, with occasional stops due to bathroom breaks, phone calls or parents needing to attend to their children.

3.10.4 Beneficence

Doing good and preventing harm, also known as the ethical principle of beneficence, applies to providing confidentiality and anonymity to all research participants (Speziale & Carpenter, 2007). In research, beneficence is maintained by ensuring that the research is of maximum benefit to the participants while minimising any potential harm (Polit & Beck, 2008). Participants were assured confidentiality and anonymity, and parents were always treated with respect and dignity. Every effort was made to ensure that potential participants had sufficient knowledge to make an informed, autonomous choice. All participants were presented with both written and verbal information regarding this study, including a description of all potential risks and benefits. Additionally, participants were always encouraged to seek clarification and ask questions on an ongoing basis.

3.10.5 Justice

The ethical principle of justice refers to the participants' right to fair treatment, the right to privacy and the treatment of each person in accordance with what is morally right and proper (Polit & Beck, 2008). Regarding research involving humans, distributive justice requires that the researcher does not neglect or discriminate against individuals or groups who may benefit

from advances in research (Polit & Beck, 2008). The voice of parents of children with ASD was lacking in the literature. For this study, it was hoped that all parents who had a child with ASD while living in Lusaka District had the opportunity to participate. Due to the large geographical area and staff resources, some parents did not become aware of this study. However, the goal of the researcher was to make every attempt to include all parents that were willing to participate regardless of where they were located. Moreover, according to the principle of justice, it was imperative for the researcher to treat people who declined from the study after agreeing to participate in a non-prejudicial manner and to honour all agreements made with participants. No parents declined participation of this study. In addition, the researcher demonstrated sensitivity to beliefs, habits and lifestyles to people of different cultures and backgrounds.

3.10.6 Confidentiality

With all participants, the issues of privacy, confidentiality, and anonymity were discussed during the informed consent process. Although the nature of the in-depth interviews excludes participant anonymity, all efforts were made to ensure confidentiality. Due to small sample sizes and thick descriptions, anonymity and confidentiality can be difficult to maintain in phenomenology research (Holloway & Wheeler, 1995; Speziale and Carpenter, 2007). To maintain confidentiality no names were attached to any of the methods of data collection. Instead, code numbers (**A1, A2, A3, A4, A5, A6, A7, A9** and **A10**) were used on the demographic form. All information stored on a computer was protected with a password. All information including consent forms, audio taped data files, memory sticks, and coded field notes were kept in a locked cabinet inside the researcher's home, and a year after completion of the study, all data will be completely destroyed. A transcriptionist, the student researcher, and the thesis supervisors were the only people who had access to the audio taped interviews.

All participants were assigned a pseudonym and any potential identifying information was altered to maintain confidentiality.

3.10.7 Risks and Benefits

For this study, in addition to the risks discussed earlier, there were also potential benefits to sharing one's experiences. Participants were given the opportunity to voice thoughts and feelings of their lived experiences with the ultimate aim of helping other parents in similar situations. It was hoped that the information, knowledge, and understanding evolved from this study will enhance the lives of parents of children with ASD.

3.11 Chapter Summary

A qualitative phenomenological study took place as guided by the methodology of van Manen (1990). Data was gathered through in-depth semi-structured interviews, a demographic profile, and field notes. The research setting took place in mutually agreed locations and van Manen's human science method was used to analyse the generated data. In total, ten (10) parents participated in the interviews and all participants completed the follow-up interview. Data saturation was achieved through redundancy and the emergence of no new themes. Methodological rigor and ethical consideration were discussed with specific consideration of informed consent, anonymity, and confidentiality. The next chapter addresses the description of the sample and the findings of this study.

CHAPTER FOUR: PRESENTATION OF FINDINGS

4.1 Overview

The previous Chapter highlighted the method used to collect data for this study. This Chapter presents the findings whose data was collected through an in-depth interview guide. The results presented in this chapter are of the study conducted from 2019 to 2022, whose focus was on experiences of parents in the social interaction of children with ASD in their home settings in Lusaka urban of Zambia.

Such a presentation helps to give a view of social evidence about interpretative phenomenon of parents raising children with ASD in Lusaka District of Zambia, given that the findings reveal the phenomenology in which conditions, practices and experiences are framed. In accordance with the theoretical perspectives presented in Chapter One, the Chapter on findings is grounded on the importance of giving a voice to study participants who were parents raising children with ASD. This approach is in line with the epistemological standpoint of qualitative researchers and phenomenological methods of understanding the social worlds based on the lived experiences of research participants (parents) (Manen, 1997). The insights from this chapter provide a context for the subsequent chapters.

The presentation of the findings is guided by the research questions as follows:

1. How do parents interact with their children with ASD in the study sites?
2. What are the parents' experiences on their social interactions with their children with ASD?
3. How do parents cope with experiences of social interactions with their children with ASD?

The three research questions above formed the reflection point throughout Chapter Four and Chapter Five, as demonstrated by the themes that subsequently emerged.

4.2 Research Question 1: How do parents interact with their children with ASD in the study sites?

The analysis revealed major themes concerning how parents interact and communicate with children with ASD. A set of subthemes also emerged (see table 4.1)

Superordinate themes and Codes/ Near codes

Table 4.1: Ways parents communicated with children with ASD

Themes	Codes or Near Codes
Communicative modes	Affectionate interaction Rambling interaction Fragmented emotional interaction Tapping interaction
Social and Emotional Support	Reaction to the child’s diagnosis Showing love and interest Feeling of vulnerability persistent & resilient Expression of anger without being too aggressive Always staying positive Use of physical activities Uneven expressive actions Ensure affectionate & Respect

Source: Own illustration based on current study

Below is a detailed presentation of findings cited above on how parents interact with their children with ASD:

4.2.1 Affectionate communication and Interaction

Not being able to communicate is one of the major characteristics of ASD. Parents found it very stressful that their children could not hold conversations with them. Their challenge lain in the fact that the children could not say what was wrong with them. Regarding parents' understanding of how to interact with their children with ASD, all ten (10) parents reported that there were rare and brief instances of concern on how they communicated and interacted their children with ASD. The findings revealed that, parents were required to show more communicative modes using the affection interaction way with their children with ASD. Six (6) out of ten (10) parents said that affectionate interaction with children with ASD was considered an essential need. Affectionate interaction was identified as one of the ways that parents use in interacting with their children with ASD. What parents meant as affectionate interaction was; for example, when a child with ASD displayed deficits in social skills and behaved as though other persons were objects and not persons, parents used the affectionate method to initiate and develop symbolic play in order to interact with the child. This method does not guarantee the achievement of the intended ways of interaction. Four (4) out of ten (10) parents revealed that parents believed that communication modes gave a lot of challenges to parents of children with ASD, particularly in social interaction, thereby causing unacceptable or inappropriate behaviours such as touch, personal space, greetings and gestures of affection that lead to embarrassment in others. Five (5) out of ten (10) parents reported that they encountered an increased number of stressors and greater stress in trying to communicate with children with ASD. All ten (10) parents lacked social interaction with children with ASD.

Eight (8) out of ten (10) parents indicated lack of knowledge on how to socially interact with their children with ASD.

The above sentiments were evidenced by parent participant <A'6>, who observed that:

Once in a while when she wants to converse, we do. There are some things I can't understand and I feel bad about it because I wish I understood her and could respond positively but I can't. But generally, we are getting along well.

In agreeing with the experience above, <A'3> contributed that:

My son does not show me affection or interact with any one, all that he cares about is displaying a practical deed like offering an upset sister a shoulder, or displaying conservative practices of affection such as hugging. He occasionally exhibited aggressive behaviours such as spitting and pinching. When requested to give a hug, he would briefly place one or both arms limply around the other person. He preferred to be alone, exhibited poor eye contact, and rarely smiled.

In buttressing the explanation that there was less affectionate communication in social interaction in children with ASD, parent participant <A'5> reported that:

I have observed that my son has problems with gestures of affection and social interaction such as a hug or kiss he also experiences difficulties in reading social cues within a social interaction such as facial expression, a gesture or tone of voice is unpleasant to him.

4.2.1.1 Rambling affection in social interaction with Children with ASD

Regarding rambling affection, parent participants reported that this is the affection used as the structured framework of social interactions which helps the child with ASD to understand the energy that needs to be done at the right time through the organisation of space and the imagining of activities. Seven (7) out of ten (10) reported that this method is based on the capabilities and limitations of each child. Its main purpose is to help in the social interaction of

children with ASD. All parents reported that they needed to feel the emotional connection with their children just as much as children needed it from their parents.

In support of the notion that rambling affection and social interaction between parents of children with ASD was not definite, parent participant <A'4> had this to say that:

My son has unresponsively dangerous social interaction and withdrawal, he's into lonely self-stimulatory behaviour and he does not express any affection towards me which discourages me from attempting to interact with him, further reducing my opportunities for parental affection which mostly breaks me as a mother.

Contributing on the same issue of rambling affection and social interaction of ASD children, parent participant <A'7> added that:

I expect my child to run to me and hug me when I knock off from work because I haven't been home all day, but this is not the case with my child; she just looks at me from afar and comes nowhere near me even if I come home with gifts. I get no affection and there is no social interaction whatsoever. Sometimes I wonder if she knows that am the father or if she even knows that that's her mother and siblings, aaaaaa it's so disheartening.

For example, parent participant <A'1> had this to say:

*He lacks social interaction, no eye contact... he only knows copy, but he doesn't know how to use the word with other people [Alaa mwandi] (**I tell you**), this is the problem that's gives me headache. He exhibits limited expressive and receptive language, poor intonation and articulation, and little spontaneous speech. He engages in self-stimulatory behaviours such as hand-flapping, grimacing, and inappropriate laughter.*

Contributing on the same, parent participant <A'4> observed that:

My son often expresses himself by screaming, crying and throwing tantrums instead of using verbal communication, which rambles me and I had noticed at two to three months

of age that my child did not have good eye contact, and was sensitive to certain sounds and movement.

The above sentiments are further buttressed in the verbal account cited by parent participant <A'2> who expressed concern as follows:

I could not hold or hug my son but just look at him from afar. When asked to give a hug, he generally responded with a brief, weak effort. He would only occasionally exhibit social smiles, and would rarely make eye contact.

4.2.1.2 Fragmented Emotional interaction

Social skills are the development of an emotional bond with parents, combining the attention of eye contact and gestures, social smile, imitation of movements and understanding of the feelings of the other person. Fragmented emotional interaction is used to help parents of children with ASD understand the importance of social interaction for children. Nine (9) out of ten (10) parents reported that children with ASD need socialisation which is the process by which the unprotected child gradually becomes a self-conscious and informed person who has acquired the skills required by the culture in which he /she was born.

In support of these experiences, parent-participant <A'7> observed that:

It should be emphasised that children with ASD are highly heterogeneous concerning social disorder. My child has a lack of motivation for interaction, as such, he avoids interaction in most cases.

In contributing on the views above, parent participant <A'4> observed that:

My son avoids touch and eye contact, while at times he actively seeks interaction, but either lacks empathy or active interaction. He has an emotional organisation, resulting in the difficulty of communicating with those around him, with the consequences of socialisation difficulties and their family.

Indicated below are participant's <A'3> experiences:

Fragmented emotional interaction with my child with ASD is within the basis of my home which I achieve by means of organised activities which aim at acquainting my child and fostering trust in him.

Contributing on the same, another parent-participant <A'8> had this to say:

My son has high social-communicative deficits which influence his ability to engage in social interactions with me. These also influence my sons' social experiences and developmental outcome. He also experiences social communicative difficulties.

4.2.1.3 Tapping Interaction

The interaction between a parent and child with ASD is observed from an interaction between mother and child at home, in which the mother presents flashcards to be named to the child. It is these flashcards that are tapped. When the parent makes it relevant for the child to answer the question by either completing a verbal question, the child taps on the presented object prior to answering the question. Five (5) out of ten (10) parent participants reported that this type of method is tiresome and mostly frustrates the child with ASD. Two (2) out of ten (10) said they have never used that type of method.

It was imperative to establish the strategies parents embraced to manage their children with ASD in terms of communication. Parent participants were asked whether or not communication with ASD children was conceivable. The findings showed that all the ten (10) parent participants expressed concern on the verbal communication between them and their children. In shading light on these experiences, parent-participant, <A'7> expressed ignorance on tapping method by observing that:

My son has a marked impairment in the use of multiple nonverbal behaviors such as eye to eye gaze, facial expression, body postures, gestures to regulate social

interaction” and “delay in, or total lack of development of spoken language.

The findings described hardships and slowness that children exhibited in developing language and speech. In support of this, parent participants had this to say:

My child is six (6) years old and yet he cannot speak. Communication with him is really a challenge. He displayed extensive, expressive, receptive and spontaneous speech, which primarily consisted of asking questions, “What's this called? What's it for?” He exhibited articulation problems. He also engaged in grimacing, inappropriate laughter, and preoccupation with objects. He rarely made eye contact, played with others, or initiated hugs.

In contributing on the same, parent participant <A'3> observed that:

[.....] No, he doesn't say 'Mom.' It breaks my heart. If he would only say 'Mom,' I would be so happy for my son, but he doesn't.

Other parents equally expressed concern over the significant lack of verbal and nonverbal communication with their children as was evidenced in the observations some of the parent participants who said:

My child has profound communication deficits, he uses few simple sentences and could not carry on meaningful reciprocal conversation.

On the contrary, even though some children do not use verbal communication, they did express non-verbal communication such as a head tilt, fist bump or rough play. This was evidenced in the verbal account given by a parent participant who said that:

My child doesn't speak, but sometimes, all I get is a head tilt, other times a fist bump.

Other parents recognised the difference in the children's communication. For example, parent participant <A'2> noted:

His machine 'referring to his mind' works differently. In short, the mind of my child works differently. He expresses

hunger by crying or throwing something. A normal child verbally demands what they want when they need something, but when our child throws something, we should know that he or she is thirsty. Understanding him or her took me six months. Well, indeed, it exhausted me very much.

Similar sentiments came from parent participants <A'2> who stated that:

My child has limited attention to speech, including failure to respond to his name he equally does not coordinate responsiveness between individuals and objects and does not follow the stare point gestures of others or shifting gaze between people and objects for the purpose of directing another's attention, and directing effect to others through gaze. It is very difficult to communicate and know what he wants....

Similar sentiments were expressed by parents' participants <A'8> who indicated that:

My own child has never called me mum; all I wish is for her to at least just call me mum.

The general findings from the study were clearly that it can be deduced that debatably, children with ASD had their own unique way of communicating with family and friends. Some used oral language, others used non-verbal communication, while others used signs such as those indicating hunger, crying, tilting the head and bump as a means of communication with parents. It needed a subject which required investigation to understand their communication challenges. On the whole, the results showed that communication with children with ASD posed a challenge to all the parent participants.

4.2.2. Social and Emotional support

The theme on social and emotional support was identified by all parent participants when they were asked about the overall impact of raising a child with ASD. Most of the Parents became tearful during interviews when describing their feelings and reported overwhelming emotional reactions to their child's diagnosis, daily struggles related to the child's caregiving, and

thoughts about the child's development and future. Regarding emotional reaction to the Child's diagnosis, some participants reported that various negative emotional reactions occurred following the child's ASD diagnosis. Parents in one way or the other have to contend with their ASD children interacting with the world. The parents were of the view that when they take the children out, they usually comport themselves, especially when they explain to them and ask them too corporate. They explained that however, when the children are hyper, they throw tantrums here and there. One parent explained that when she learned of her son's diagnosis, she entered a phase of depression and felt distressed.

This was evidenced by parent participant <A'3> who explained that:

After the initial diagnosis I couldn't get out of bed and face the day, I felt mentally exhausted and depressed.

Parent <A'6> reported that:

I felt disconnected from myself. I felt always tired and wanting to stay in bed, and I did not control my child's behaviour.

Furthermore, most of the parents reported a sense of guilt and shame after the diagnosis of ASD, which in turn resulted in their distress and emotional fatigue.

I believed that I did something wrong; I blamed myself because my child was not normal; I wondered if this condition was caused by my behaviour as a mother. I was distressed for a long time after the diagnosis, and I cried every day before sleeping.

Parent participant <A'2> noted:

I had the impression that I was at fault for my child's disorder; am I the source of the problem?

Although some Parents felt guilty, one parent appeared to appreciate that she had not caused her child's ASD. She narrated as follows:

Because I read many books and I researched the scientific data, I'm aware that ASD was not caused by my behaviour as a mother.

4.2.2.1 Feelings of Helplessness and Frustration

All parents reported feelings of helplessness regarding the challenging daily childcare demands.

My son needs much attention and focus, 24 hours a day in order to control his behavioural difficulties. You know, it's very frustrating to have to treat his needs every day. Sometimes, I feel I do not love this child enough, and this thought makes me experience a sense of guilt.

Moreover, all parents in this sample exhibited feelings of distress linked to not knowing what they could do, or who they could rely on to help their child. This sense of uncertainty emerged as a sense of frustration.

For example, parent <A'4> expressed herself in the following manner:

I am lonely, I do not have a partner, and it's hard to be a single mother when you have a child with special needs; commonly, I experience fear and uncertainty in managing my child's demands; not knowing how to help my son when he engages in repetitive behaviour. I'm confused."

Parent participant <A'6> reported feeling:

*"Burned out and feeling empty of available energy"
"overall empty, empty physically and mentally" particularly
when I cannot not effectively cope with my child's behaviour.*

Parent participant <A'4> described her frustration related to trying to reduce her child's disruptive behaviour, which she felt incapable of doing as expressed below:

“I think the feeling of powerlessness is the worst, you want to do the best for your child, but you realise that you are not able to offer help”.

One father described feeling frustrated as part of the process of raising a child with ASD

“Living with a child with ASD is totally different from what the textbooks write. You can actually be easily frustrated when you hold full responsibilities of raising a child with special needs”.

This was evidenced in the following verbal accounts as contribution on the same, parent participant <A'9> observed that:

When we learned that our child had ASD, it was human, we felt sad always to ask what sin we had to endure. We did not know how we would interact with our child. However, this did not last long, my wife and I agreed to provide treatment, and my wife applied for three (3) months leave to accompany my child to therapy at the University Teaching Hospital even if within three months there were no significant changes, we had agreed that my wife would resign and focus on our son.

Similar sentiments came from parents' participant <A'6> who mentioned that:

I was in shock and denial because of the stereotype of autism that was more exaggerated, so I didn't think my son had this.

In contributing on the views above, parent participant <A'4> observed that:

My world fell apart. It crossed my mind whether I had been a good mother. I cried a lot; a lot of terrible thoughts came in to my mind. I was afraid I'd have a heart attack.

Similar sentiments were expressed by parent participant <A'7> who stated that:

I felt an intense rage and then frustration afterwards: Why me? I felt helpless not knowing how to deal with the social

interaction situation ... uncertainly as reported by the parent participant.

Below is a verbal account given by parent participants <A'10> and <A'8>:

For me it was a relief because finally, I knew what made my child different and I got down to work looking for information on social interaction and resources everywhere, as well as ways of helping him. I avoid paralysis. I felt that one must try harder, press harder, and take more care

In support of the above views, parent participant <A'8> had this to say:

We were prepared for a diagnosis like this. We weren't surprised. We expected it. We just wanted to hear from the doctors what we could do, what treatment we should provide him with.

Contrary to the feeling of shock, denial, sadness and anger, relief, preparedness and difficulties in identifying support services, the diagnosis of children with ASD in social interaction to some parents, was a relief and they instead were looking forward to ways of dealing with the new challenge.

4.2.2.2 Romantic relationships

Five (5) out of ten (10) parents reported constant worry about the long-term impact of ASD on the child's future. Indeed, the transition from childhood to adolescence and adulthood generated anxiety for all parents involved, regardless of the child's age. Moreover, uncertainty about the child's education and, subsequently, job opportunities, living conditions, and the ability to adapt successfully to adulthood contributed to an intense sense of worry.

The essence of her future-oriented fears was reported by parent participant <A '7> of a 9-year-old girl with ASD.

"You start worrying what's going to happen to her long term. I'm thinking of how my child will fit in society 10–20 years from now, will she have the ability to create romantic

relationships? Will she be able to study in college to earn money and live independently? ”.

Parent participant <A’9> worried and felt:

“Uncertainty regarding my son’s transition from kindergarten to elementary school.”

In addition, some parents referred to the possible trajectory and consequences of ASD for the child’s future mental health state as follows:

“I wouldn’t imagine (my child) being diagnosed with something long-term either, bi-polar or sort of.... (Trails off) ”.

At this point of the interview, parent participant <A’6> seemed unable to find the appropriate words to express what other long-term concerns could be, indicative of her anxiety about the future.

“It’s not just the concern for the poor school outcomes and related-barriers to finding a job, but it’s the concern of development psychiatric comorbidities in the future, it’s just an overwhelming thought.”

4.2.2.3 Knowledge on ASD

In order to establish whether or not parent-participants had knowledge on how to socially interact with their ASD children, the study revealed that nine (9) out of ten (10) were of the view that they did not have sufficient knowledge on how best to interact with their children in home settings. Otherwise, most parents lacked social interaction with ASD children. Parents indicated lack of knowledge on how to socially interact with their children with ASD. Instead, parents expressed serious challenges in an attempt to socially interact with their ASD children as expressed below:

This problem surfaced when their ASD children were diagnosed with the condition as revealed by parent-participants' <A'3> observation that:

I had no knowledge on how I should interact with my child with ASD right from time he was diagnosed, I only became knowledgeable about ASD and how to socially interact with my child after constant visits to the hospital, interacting with professionals and advice from service organisations.

In support of the above experiences, parent-participant <A'7> expressed ignorance by observing that:

I didn't know how to actually talk to my child. We did not know how socially interact well since I had no idea on how to socially interact with my child until I started getting support from professionals at the nearby clinic.

In corroborating the views above, parent-participant <A'3> had this to say:

[Sigh.....] actually, I do not understand. He has such a weak social life that most of the time he was worried. He doesn't like to socialise with others in the home. We go to church, and he really doesn't like to mix with friends. He wants to play by himself and only knows me alone, really, interacting with the child is quite difficult.

Based on the above results, it was clear that parents had worrying experiences on how to talk with the children, strengthen their social interaction lives and regularly, the much-needed support on how to interact with children with ASD from professionals. The parent-participants did have sufficient information and skills on how to socially interact with their children.

In short, the study showed lack of knowledge by parents on social interactions which may have resulted in failure by parents to provide social support to their ASD children during interactions at home, school and the community. The rare and brief instances of affectionate communication, rambling affectionate and fragmented emotional connections as ways of

parental interaction with ASD children may be explained by professional help and advice from hospitals and organisations.

4.2.2.4 Social and Emotional Support in relation to social interaction

Parent participants in this study received encouragement from family and friends during their hard times. For example, parent participant <A'5> explained that she is always encouraged by the words her mother spoke to her. She described the first incident when she first learnt of the situation:

My mother just tapped my shoulder, smiled and said, “my daughter, you would still have become the great person you are if you had ASD. The mother determines what her child will become, I believe in you, so you have to believe in yourself”. From that time onwards I focused on making my daughter a better person

Parent participant <A'9> contributed by saying that:

I get support from within my family and friends, the support which reduced my feelings of depression, improved my overall mood and decreased parenting stress as well as increased social interaction with my child.

Similar sentiments came from parent participant <A'8> who submitted that:

Am a single parent, have reduced levels of support, which is mostly troubling me on how to handle my child with ASD in social interaction with my child alone without my husband.

In support of the above submission, parent participant <A10> had this to say:

I fail to obtain emotional support in social interaction from other families with ASD children for my ASD child because there are no groups formed so that I can join. Please it is imperative to form more formal social support groups as they can be a helpful resource for parents in the same category.

Similar sentiments were expressed by parent participant <A'3> who stated that:

It was support from family members and friends that significantly reduced my levels of depression and increased my social interaction with my child.

The above view was reinforced in the following verbal accounts given by parent participant <A'5> who supplied that:

The child's behavioural issues in social interaction challenge and prevent me from physically leaving home because of my child's needs. Some behaviours cause destruction to my home and cause destruction around the house such as holes punched in walls, food thrown at walls, faeces smeared on furniture, books ripped apart and light fixtures dismantled. My boy just enjoys about an entire roll of toilet paper, and he'll unroll the whole thing and put it in the toilet. He likes to stick things in the drain. He flushes things down the toilet, and he has a tendency of eating toothpaste to a point where he's eaten it and then goes into his room and throws it all up.

These notably, there were different experiences exhibited by parents' which left them emotionally weak over failure to interact with their own children. Participating parents in the study revealed that they received support from within the family and friends, which reduced in social interaction, improved the feeling of depression and the overall mood, and decreased parenting stress as well as increased parenting efficacy. The reactions ranged from positives such as relief, preparedness over interaction with children with ASD to negative experiences such as; misinformation, emotional breakdown resulting in failure to emotionally support the children as well.

4.2.2.5 Uneven expressive in connections with social interaction

In an attempt to establish uneven emotional connection, parent participants were asked to explain how they managed their children with ASD in terms of uneven emotions in social

interaction with ASD children and other siblings. The findings from all the ten (10) participants revealed that parents expressed concern over a fragmented nature of emotional connection with their children.

On the contrary, even though some children do not express fragmented emotional connections with their parents, they did express their relationship to the outside world by thoughts and feelings. They also exhibited more emotions to non-living objects. This was evidenced in the verbal account given by parent participant <A'9> who said that:

My child does not purposefully use or even fully appreciate the communicative value of emotional expressions, but there is no reason to assume that they are less emotional than other children. However, an emotional state does not automatically imply unemotional awareness.

As illustrated above in the verbal account of parent participant <A'7> who observed that:

I feel isolated from my child as there is no emotional connection relating to my child's developmental delay and lack of communication,

Similar sentiments came from parents' participant <A' 6> who mentioned that:

I feel 'heartbroken' by the fact that I did not know if my child realised that I was not just a child care provider but rather a dedicated parent called 'mom'.

The above sentiments are also illustrated in the verbal account of parent participant <A'1> who observed that:

When I used to work out of the town a lot, it seemed like he didn't even miss me when I was gone. He was 4 years old when we discovered he had ASD.

In support of the notion that there was less affectionate communication in children with ASD, parent participant <A'3> reported that:

I had an affectional bond or tie with my child during the first year of life before diagnosis with ASD.

The overall finding was that those children with ASD were considerably less steadily attached to their parents than children without ASD, but were able to form secure attachment relationships. The parent-child relationship echoed less flexible, sensitive and synchronous interactive behaviours as a result of the social impairment of children with ASD.

Arising from the findings above, there are two broad themes surrounding how interaction was done namely: communicative interaction and dependence on social–emotional support to interact. It is evident that parents of children with ASD interact with their children using: affectionate, rambling, fragmented emotional actions, tapping and expressions of love during interactions. On the part of social and emotional support, the study revealed that parents used as a mode of interaction: allowance of expression of anger without being aggressive as they interacted with the child, and during interaction regularly parents use physical activities to communicate with children with ASD.

4.3.0 Research Question 2: What are the parents' experiences on their social interactions with their children with ASD?

After the analysis of the second research question, the analysis revealed two (2) themes concerning parents experiences on social interaction with children with ASD: Family interactive experiences and Social interactive experiences for each of the superordinate themes, a set of sub themes also emerged (see table 4.1).

Table 4.2: Experiences of parents which affect interaction with Children with ASD

Themes	Codes and Near Codes
Family interactive experiences	Poor relationship with spouse Relationship with sibling Loss of individual freedom Limited Family finances
Social interactive experiences	Stigma and Discrimination Inadequate sleeping time Unruly behaviour among Children with ASD Mental stress on parents Anxiety control Lack of Self – efficacy Quit job/school

Source: Own illustration based on current study

4.3 Family interactive experiences

4.3.1 Relationship with Spouse

The second superordinate theme captured by parents of children with ASD experiences had caused a change in family life, as the whole familial ecology had to adapt to a new reality; namely that the child needed special parental treatment and long-term care. Eight (8) out ten (10) parent participants in this study noticed that after the child’s diagnosis, their relationship with their spouse changed. Most parents in this sample felt as though they had neglected the needs of their spouse, leading to emotional distance and deterioration compared to previously healthy connections.

More specifically, parent participant <A'5> reported:

“There are times that you feel disconnected from your spouse, and the child’s needs are the priority; the husband is sort of second, third down the line if there are other kids.”

For instance, parent participant <A'1> submitted that:

“I feel so tired and exhausted from the child’s and house responsibilities; therefore, at night, I feel unable even to kiss and hug my husband, in addition to spending more romantic time with him”.

In addition, the parent participant identified a marked difference in their spouse’s behaviour following the diagnosis of ASD.

Typically, parent participant <A'2> felt that her spouse had:

“Shut his brain down, often expressed aggressiveness and emotional distance.”

Some parent participants, showed a negative change that affected their relationship and communication; hence, they experienced mental stress

In support of this, parent participant <A'5> had this to say:

“a sense of loss”.

Parent participant <A'3> described problems in the spousal relationship as follows:

“I judged and criticised my husband because he had a different perspective on the child’s treatment; we fought a lot, yelled and screamed; we just didn’t get along. The child’s condition affected our intimate life and finally, we divorced”.

Only parent participant <A'7> reported that hope for relief and positivity in family life developed when her child at times displayed a positive behaviour change and improved his adjustment to school.

4.3.1.1 Relationships with Siblings

Parent participants described in predominantly negative terms how having a child with ASD influenced their relationship with their other typically developing children. This was frequently indicated by a reduction in the time for the other sibling and mother spent together in shared activities.

“My son has become unfortunately the center of the family life, which I don't like at all. However, my husband and I both have limited available time and energy to focus our attention on the needs of the typically developing sibling. This often leads to feelings of guilt and inappropriate parenting.”

Additionally, parent participant, <A'4> advanced that:

“My son feels neglected and experiences negative reactions towards me as a mother.”

In support of the notion that there was negative predominantly with siblings, ASD parent participant <A'3> reported that:

“One day after a disagreement with my first-born child, the child said to my husband and I, “you do not love me enough; the center of your lives is caring for my sibling's special needs,” it was overwhelming to hear!

4.3.1.2 Loss of individual freedom

It was imperative to establish parents' experiences of social interaction on loss of family freedom experienced in home settings as parents interact and manage children with ASD. The study revealed that parents devoted more time to care and attempted to develop positive

interactions with the ASD children. Due to this, parents slowly withdrew from interacting with other people as well as most social activities in the home and the community. As a result of the demand of caring for the children with ASD, parents reported role restriction and limitations in pursuing their own career because of the presence of a child with ASD in the home. That was evident in the response of one of the parents- participants <A'10> who said that:

...freedom is limited for the sake of the child. Every time I had to be at home to welcome her back from school and socially interact with him. I am afraid to even leave him alone because of his mental challenge.

This was also evidenced in the following verbal account given by parent participant <A'9> who recounted that:

The presence of my ASD child has affected my social life and relationships with friends. For example, my friends or other family members seldom spend time with me. Friends ask parents not to bring their child to social events, I do not participate together in out-of-the-home activities or social events, and siblings tend to avoid bringing friends home. I have completely lost contact with most friends, relatives, or even with their extended family.

In support of the above recounted experiences, parent participant <A'2> had this to say:

I do not have the ability to meet with friends because of my busy schedules and lack of proper social interactions with my ASD child. I do not want to socialise with friends who do not have children who have a disability because we have little in common and my child's challenging behaviours such as throwing tantrums, crying and hitting, causes me to focus more attention on my child, reducing the time available for me to have a social life.

Parents spent more time caring for children with ASD, hence lost freedom and withdrew from many social activities in the home. They also lose freedom of interaction with other people at home and in the community. However, the most challenging situations arise due to flimsy

help and services available for ASD children to the extent that just finding an expert on ASD was a challenge, extending to non-availability of services such as behavioural therapy, social interactions, physical therapy (PT), occupational therapy (OT) and speech therapy.

4.3.1.3 Loss of Family Freedom

It was imperative to establish parents' experiences of social interaction on loss of family freedom received in home settings as parents interact and manage children with ASD. The study revealed that parents devoted more time to care and attempted to develop positive interactions with children with ASD, because of this, parents slowly withdrew from interacting with other people as well as most social activities in the home and the community. As a result of the demand of caring for children with ASD, parents reported role restriction and limitations in pursuing their own a career because of the presence of a child with ASD in the home. That was evident in the response of participant <A'10> who said that:

...freedom is limited for the sake of the child. Every time, I had to be at home to welcome her back from school and socially interact with him. I am afraid to even leave him alone because of his mental challenge.

In support of the above stated view, parent participant <A'2> had this to say:

I do not have the ability to meet with friends because of my busy schedule and lack of proper social interaction with my ASD child. I do not want to socialise with friends who have children who have a disability because we have little in common, and my child's challenging behaviours, such as throwing tantrums, crying, and hitting, causes me to focus more attention on my child, reducing the time available for me to have social life.

Parents spent more time caring for children with ASD, hence lost freedom and withdrew from many social activities in the home. They also lost freedom of interaction with other people at home and in the community. However, the most challenging situation arose from flimsy help

and services available for ASD children to the extent that just finding an expert on ASD was a challenge, extending to non-availability of services such as behavioural therapy, social interactions, physical therapy (PT), occupational therapy (OT) and speech therapy. This was illustrated in a verbal account given by participant <A'6> who said that:

Beginning with the time of diagnosis, it was difficult and very hard to identify support services, that is, identifying how can access social interactions and coordinating services by healthcare providers. The best help came from hospitals, but the centers were often inaccessible. [Sigh...] 'pamulu paifyo' (meaning 'in addition to that') there is a shortage of ASD-related health care services like behavioural therapy, physical therapy (PT), occupational therapy (OT), and speech therapy, each with long waiting lists.

The parents explained that it was really difficult for them to travel nor socialise with their children because of their condition. Each time they did that, they drew more attention from the public, which made them feel rather emotional and as if they had lost their freedom in the family.

4.3.1.4 Limited Family Finances

Taking care of children with ASD is expensive since they require extra services and care than children without ASD. In this study, parents brought out various ways in which taking care of a child with ASD was more expensive than taking care of a child without a disability. Financial strain emerged as a major concern; families in this study were forced to make significant lifestyle adjustments. This was caused by various factors, needed for services and higher costs for intense interventions. All parents complained that medical expenses were expensive for them. They explained that the routine check-up that their children with ASD had to do as part of the intervention plan is very expensive (i.e., speech and occupational therapy, psychotherapy). Traveling expenses were another item that stretched the limited family finances for the parents. Parents shared that they have to always avoid public transport

(“dropping”) to prevent them from having to face people who were not ready to accept their children or make any contact with them. For example, a father described an experience he had on a public transport, which led to him resorting to dropping off. He explained, “when going somewhere with him, you always have to take dropping”.

Two (2) parent participants stated that they had to stop their child’s speech therapy and behavior therapy due to financial difficulties.

“These therapies are too expensive and exceeded the family financial resources. Only a small amount of the total cost is covered by public insurance”.

In addition to the above experiences, seven (7) out ten (10) parent participants reported that parents faced a shift in career paths to fulfil the everyday requirements of childcare.

“My husband left his career and works as a taxi driver to earn more money, and even that, is not enough to save some money for his future.”

Parent participant <A’4> was forced to stop working whereas others made career-related sacrifices, such as seeking an employer more understanding of the demands of raising a child with ASD.

“I have had to put on hold many things. I stopped working and left my PhD studies to give my full attention to my child’s care”

The explanation below was evidenced in the verbal account given by a parent participant who said that:

I feel greater delays in accessing medical care, increased necessity for vigilant parenting, constant self- and child-advocacy.

4.3.2 Social interactive Experiences

4.3.2.1. Stigma and Discrimination of ASD Children

Most of the parent participants reported that they experienced ASD stigma and were forced to remain at home frequently, rather than going out. Stigma was seen not to be handled well in some parents of children with ASD. Six out of ten parents with children with ASD shared that, “when you outwardly express your love for your child with ASD, it not only makes them feel comfortable but also helps others accept them. As such, when people try to stigmatise the child, the parent should show the child a stronger love in the presence of those who stigmatise them”. Reasons for stigma included negative social stereotypes regarding mental illness and disability as illustrated below:

“You understand other people looking at you differently, like we are coming from a different planet. I think society does not accept both my child and I. stigma has changed my inner self; I hide from others that my child has autism and receives specific treatments.”

The impact of ASD stigma in this description is powerful and highlights the social pressure experienced by these parents.

According to parent participant <A'2>, the impact of living socially excluded is

“Mentally and physically exhausting”

Moreover, seven (7) out of ten (10) parent participants narrated that their children were treated differently by typically developing children in school, as well as by teachers and other parents.

“In school other children do not want to either play with my child or to speak with him. They believe he is crazy and call him not by his name but as, “hey autistic”.

The following sentiments came from parent participant <A’9> who mentioned that:

“Some mothers may take away their child from my child; they are afraid of the stigma arising from playing with an ASD child.”

Parent participant <A7> reported that:

Furthermore, several mothers described feeling embarrassed about their child’s behavior when the child met relatives.

In support of this, parent participant <A’5> had this to say:

“Other people believe that ASD is associated with bad parenting and a mother’s inability to control her child.”

This situation seemed to have an enormous negative impact on the parents’ social interaction because of their children. Parent participant <A’6>lamented:

My child was once discriminated at a family party. I noticed that he was not made to join the other children as they were singing in readiness to cut the cake. My child was pushed aside. Even though my child could not talk, he could have mumbled and followed the other children but could not just be accepted by peers. I will not forget that day, but I just kept quiet.

The results above, revealed that it was so hurting to parents of children with ASD upon realising that their children are mocked and is discriminated by the society. Parents feel that due to stigmatisation and discrimination, their children's social adjustment caused isolation or rejection which equally affected the parents. The majority of the parent-participants, eight (8) out of ten (10) believed that they were the ones most affected socially and emotionally by their children's condition. This view was confirmed by parent-participant <A'4> who remarked:

It is hard for my child to interact or socialize with her peers and to even visit relatives. Each time we pay a visit to our relatives we had to explain a lot about her social life, ability to interact, emotions. That made me decides not to go with her when visiting our relatives.

In short, parents as well as ASD children were socially stigmatised and discriminated against. This made it difficult to freely interact with other people in the neighbourhood or the community.

4.3.2.2 Social Life

Parent participants reported a significant decrease in the quantity and quality of their social ties and relationships. Factors that helped establish this situation were a fear of stigmatisation by others, a feeling that parents of children with ASD could no longer relate to old friends since the latter did not have similar concerns, limited time to spend socially, and an inability to bring children to social gatherings due to behavioral concerns.

In support of this, parent participant <A'6> had this to say:

"I had close friends from college who don't have a child with a disability, and I really like it very much. Now, I have more ASD mommies. I get bored of communicating with ASD mommies, but I feel comfortable, and they're comfortable. To be honest, I miss my old life. I miss one of my best friends.

However, when you have a child with autism, your whole life is affected [crying]”.

Most participants reported a tendency to avoid meeting other families and relatives with typically developing children, and they explained that this had a negative effect on the social life of the family and children.

In contributing on the same, parent participant <A’4>) had this to say:

“Of course, I avoid going to social events (i.e., birthdays, party, weddings); these events are not for a family who have a child with ASD; there is a high risk of social judgment when the kid becomes nervous.”

Importantly, the employed mothers were more likely to feel socially included compared to a parent without employment outside the home.

“I’m very lucky to have my job and career; I feel accepted at work, and I can show a different aspect of my identity. I am not only the mother of a child with ASD.”

4.3.2.3 Lack of enough sleeping time

In order to establish whether or not children with ASD had problems with lack of sleep-in relation to social interactions, parent participants were asked what strategies they employed to assist their children who faced lack of sleep. Research findings show that seven (7) out of ten (10) participants attested to their children’s lack of sleep. The findings from parent participants showed that quality sleep was vital for helping them get good mental health, physical health, and safety. The findings from this study revealed that most children with ASD had sleep problems. Parent participant <A’3>) submitted that:

A good night’s rest isn’t guaranteed for me. My child has trouble falling and staying asleep. Am ‘heartbroken’ by the fact that I do not know if my child is sick or what because of lack of sleep.

In buttressing the submission above, parent participant <A'9> asserted that:

One example of the ups and downs of my daily experience in relation to social interactions was the lack of sleep because of the child's erratic sleep schedules and the need to maintain vigilance, watching the child through the night.

Still on the same experiences, other parents narrated how their children did not sleep for long from birth until they were about 4 years of age, and how that affected them as parents. This was evidenced by parent participant <A'5> who explained that:

It was really hard. I ate candy bars, I drank coffee in the middle of the night, and then sometimes he would surprise me and fall asleep, and since I'd had coffee, I'd have to take Piriton (sleeping pills) to try to get to sleep so I could be sleeping when he was sleeping. The synergistic effects of Piriton and coffee, could not have been good for my body. I was just exhausted all the time.

On the contrary, three (3) out of the ten (10) parent participants alluded that even though their children had ASD, the children sleep but wake up very early, before everyone is up. Clearly, it can be deduced that lack of sleep was commonly expressed by most of parent's participants of ASD children. The meltdowns or tantrums, severe sleep related problems and elopement, made care of the ASD children difficult in reference to sleep. Almost all of the children had sleep related problems that kept families awake and alert at night, a situation which emotionally affected parents of ASD children in the studied families.

4.3.2.4 Unruly behaviour in relation with social interaction

In order to establish whether or not children with ASD exhibited unruly behaviour in relation to social interactions, parent participants were asked to highlight the strategies they implored to control the unruly behaviour. Research findings show that eight (8) out of ten (10) participants attested to their children's unruly behaviour during social interactions. This is behaviour such as throwing tantrums and emotional outbursts that made it hard for parents

to go to public places with them, while the remaining two (2) parents participants felt that children with ASD showed no social interactions and un-ruly behaviour most of the time.

This was evidenced in the following verbal account where participant <A'3> indicated that:

My child's behavioural and social interaction issues are a challenge to an extent that we are unable to physically leave home because of the child's needs. For example, he has these episodes of tantrums and unruly behaviour. Because of non-social interactions, we can't even mingle well with our friends and other families for fear of how he may react.

One of the most important themes identified in the course of analysis was an inherent sense of loss of control over the child. The majority of them found the maladaptive behaviours to be challenging and stressful to handle because these individuals were likely to lack desirable social behaviour and reflect stereotypical behaviours. It became extremely difficult for parents to manage social interactions.

For instance, the above concerns were reflected in the responses of participants as participant <A'1 > stated that:

He behaves aggressively and stubbornly, pacing back and forth, especially behaving like that in public which is quite an embarrassment. When we go to someone's house, he would pick some decorative or any other items in the house and throw it as a part of his aggressive response. This gets very embarrassing for us and so, we do not socialise or even go out of the house for this reason.

Similarly, parent participant <A'5> asserted that:

He is very stubborn, will throw things not understanding that it is valuable, which leads to great loss at times. His aggression is a big problem.

Majority of them reported a sense of helplessness with regards to social interactions and controlling their behaviour. Such an experience often led to conscious avoidance of social interactions.

Participant <A'3> equally stated that:

I cannot have my friends at home because he cannot bear the presence of people at home. This leads to shouting and all that aggression.

In underwriting the above views, parent participant <A'2> had this to say:

Severe behaviours my child portrays include aggression towards others such as pinching, hitting, scratching, biting, head butting and throwing toys or items. This results, among other casualties in welts and bruises, a broken nose, and a sibling's black eye. He hits and kicks. He's bit us and gets physically aggressive with us.... For example, the sister just took him to play and on the way home on the bus, he was attacking the her the whole time. When they came home, his sister got scratches down her face and a bloody nose, she's bitten up, because her [brother] was freaking out on her.

Similar sentiments from parent participant <A'6> were that:

My son displays some appropriate receptive and expressive speech, but most of it is echolalia. He engages in gazing and hand posturing, and numerous off-task behaviours including tantrums, leaving his seat, and reaching for objects. He exhibits irrational fears of certain objects and extreme attachment to others. He prefers to play alone and frequently stiffens upon contact, hence no social interactions.

Based on the findings, parent participants testified to unruly behaviour in relation to social interactions with children with ASD, which mostly occurred when they were in unfamiliar places. That implied that ASD children had no social interactions triggering tantrums, cried and hit their bodies to the wall causing humiliation to parent participants.

4.3.2.5 Anxiety on behavior of the child

Parents of children with ASD in social interactions reported having feelings of lack of control and anxiety over the child's behaviours, which included being aggressive towards themselves or others as well as self-abusive behaviour which was the best predictor of stress for parents.

Therefore, all the parents spoke about challenging behaviours as well as social interactions as major causes of stress. Parents described the desire to see their children fully functioning, normal children and self-efficacy of parents of children with ASD. In support of this, parent participant <A'5> had this to say:

I see my friend's children narrating poems, stories, and at times this makes me ask myself why I do not have a child like them, I feel disheartened.

There was also a strong wish to see their children gaining certain degree of independence as they grow older, for instance parent participants <A'3 > explained that:

I see kids doing all their work by themselves, they are very independent whereas, he is not. He is entirely dependent upon me.

Based on the findings, parent participants testified that feelings of lack of control and anxiety over their ASD children resulted from challenging behaviours which included tantrums, mood swings, repetitive behaviours, self-injurious behaviours. These behaviours were viewed highly challenging by the parents, leading to feelings of embarrassment in public.

4.3.2.6 Self-efficacy of Parents of Children with ASD

In an attempt to establish self-efficacy felt by parents with children with ASD in the study district, it was important to establish parent participants experiences in raising children with ASD in relation to social interaction. The responses were that all parent participants acknowledged the lack of confidence in helping their children deal with problems. They also experienced as evidenced by a contribution of parent participant <A'4> that:

It is critical to know how to control my child with ASD using with the facilities we get in our country, as well as how to contribute to more complications I receive. Parental self-efficacy has been connected with increased levels of us parents with ASD.

Similar sentiments came from parent participant <A'6> who indicated that:

As a parent I feel unsure and confused about the ideal course of treatment for my child.

This was echoed by parent participant <A'5> who acknowledged that:

As a parent with a child with ASD, I experience low self-esteem. Most times, I lack confidence in helping my child address difficulties during experiences such as social anxiety or difficulties with nonverbal communication during social interactions. Additionally, it often leaves the feeling of unsureness and confusion about the optimal course of treatment for my child.

In support of the above views, parent participant <A'10> expressed his views on the study as a dream come true for him and his family by observing that:

I'm glad that someone is doing this kind of research. Certainly, it's been a challenge in terms of social interactions. If you've talked to my wife at all, you've heard that it's been a challenge!" (He then placed his head into his hands and began to weep, which was not often the case with fathers).

This observation of overwhelming emotion was common among all the males interviewed as well as many other parents' participants. Many families described their lives as an unpredictable "roller coaster" because of the daily challenges they experienced in social interactions when they are caring for their child.

In support of the view expressed above, parent participant <A'1> had this to say:

My child with ASD mostly responds to familiar environments in to acting upon it.

The findings were that the enormous demands associated with raising a child with ASD also required continued support from external sources. In contributing on the same same

transactional effects, parent participants generally responded that the stress placed on parents and families often contributed to and worsened the difficulties in dealing children with ASD.

4.3.2.7 Quitting Jobs for the Sake of the Child

The study also revealed that parents had to make a bitter choice of having to quit jobs in order to pay attention and regularly interact with their child. One parent-participant revealed that she decided to leave her job and take care of her child. When probed why, she stated that it was because she could not find a suitable house maid for him as most of them could not afford to care for the child due to their lack of social interaction behaviour problems. Parent-participant <A'3> confirmed the decision of leaving the job for the sake of her child with ASD. She had this to say:

I was working in a brewerie company before finding a place for the child in one of the special schools. I had to leave my job and a promotion in compromise for my son and we had to re-locate for his sake. That was a blow to the family especially on the financial front.

It was evident from the results, that because of the demanding nature of caring and socially interacting with children with ASD, some parents saw it fit to quit certain jobs in preference for those that provide an opportunity to have a quiet time with their children.

4.3.2.8 Mental stress experienced by parents in social interaction with their ASD children

Caregiving to ASD children is not an easy task. Parents in this study expressed how difficult it was to take care of their children. Most of them, especially the younger parents complained that their children with ASD could not do anything for themselves. For example, a mother said she has to do everything for her son right from when he wakes up until he goes back to bed. In support of the explanation, parents accepted having experiences of mental stress. Parent participant <A'5> had this to say that:

As a parent of an ASD child, I feel typically that am most affected by my child's disorder, which lowers my quality of life and leads to more depression, anger, anxiety, and marital complainst.

In support of this parent participant <A'2> said that parents were motivated to stick to routines to reduce the risk of problem behaviour. She had this to say:

One day, my husband ... hadn't poured a glass of milk for my son for breakfast and my child thought that his dad had ruined his whole day. ... He didn't understand that his dad doesn't know that he routinely takes a glass of milk ... I told my husband that he has to ask him if he wants a glass of milk and let him say "yes." Because if you don't ask him, then he gets mad when you give it to him ... It's like a dance. Social interactions are not achieved by my husband.

From the findings, this study revealed that parents who had family and relatives support were found to be more likely to have peace and less stress. Similarly, most parent participants' relationship between social support and stress levels reported lower levels of social interactions which results from three primary sources characteristics and behaviour problems of children with ASD. The findings also revealed that lack of professional, educational and support resources, and negative social attitudes towards ASD parents create lack of understanding and empathy for the problems faced by ASD children in terms of social interactions.

4.3.2.9 Fears and worries in social interactions related to the future

Another major theme identified from the narratives, was fears and worries in relation to social interactions in the future. Parents were highly fearful and expressed future related anxiety. They were afraid of not just what the future held for their children but also about who would look after their child later.

For instance, parent participant <A'6> had this to say:

The future really makes me worried, who is going to take care of her when I will not be there or if something happens to me?

Such a life associated with anxiety among the parents stipulates a sense of vulnerability. This was viewed as highly stressful by the parents, leading to anxiety. As the children were dependent on their parents for the majority of needs and activities, parents displayed feelings of helplessness in terms of social interactions and future related anxiety as they were worried as to who would provide care for their children if they died. On the whole, the findings showed that parents of children with ASD had no knowledge of social interactions before their child was diagnosed and that they had challenges in interacting socially with their children with ASD.

4.4 Research Question 3: How parents coped with the experiences of social interactions with their children with ASD

The analysis revealed five (5) major themes concerning the coping strategies that parents with children with ASD employ in managing their lived experiences on a daily basis. These are: Safety strategies, prevention strategies, punishment strategies, spiritual and discussing with professionals. For each of the superordinate themes, a set of sub themes also emerged (see table 4.3).

Table 4.3: Coping strategies of parents of children with ASD

Themes	Codes or Near codes
Safety strategies	<ul style="list-style-type: none"> • adjusted their living circumstances. • Supervision and monitoring • modifying their living circumstances • Reactions and expectations in order to carry out the responsibilities required of them. • Reacting in more constructive ways, which encouraged better coping • use of intervention
Prevention strategies	<ul style="list-style-type: none"> • isolation and avoidance and these served to decrease positive mood. • Sticking to fixed routine • social isolation • Self-reliance • Stressful condition • appropriate intervention could help support the adaptation process • mediate stress by developing the ability to resist and recover from stressful feelings • self-reliance
Punishment strategies	<ul style="list-style-type: none"> • Non- compliance • Disruption of activities • Unwanted social behaviour of ASD children
Spiritual & Religious strategies	<ul style="list-style-type: none"> • greater the belief in God • religious beliefs therefore improved their socio-emotional well-being • acceptance and commitment therapy
Discussion with Professional strategies	<ul style="list-style-type: none"> • support from relatives or groups can significantly affect parents' perceptions of stress, and can therefore enhance coping • social support • strengthening of bonds between the parents • respite services • specialist care • support from the child's peers

Source: Own illustration based on current study

4.4.1 Safety Strategies

4.4.1.1 Adjusting Activities

With regards to managing stress arising from interaction with ASD children, the study revealed that six (6) out of ten (10) parents tended to give in to demands of the children. This being achieved by accommodating the needs of the children and sharing thoughts in a calm manner with them. Additionally, parents made efforts to modify the social environment from time to time to accommodate and make children more interactive. It was also evident that families, with the advice of physiotherapists, provided a lot of play materials which encouraged children to freely interact with parents and other siblings in the homes. On managing of non-compliance everyday interactive tasks and activities to reduce stress, parents tended to use sanctions such not allowing children with ASD to play favour right games on the phone, computers nor not accompanying parents to shopping malls. Often these adjustments in activities helped to bring children under control thereby the management of children less stressful. These results were supported by the views of parent-participant <A'3> who expressed sentiments:

We adjust activities to accommodate demands of our child to reduce the risk of unwanted social behavior. This includes doing things at the time of day when the child functioned best, attending events together and taking outings, and adjusting expectations depending on our child's mood. It helps reduce anxieties and stress from me as a parent and the child as well.

In the sam vein, parent-participant <A'10> observed that:

As parents, we have opted to adapt behavioural tokens where when a child's tasks are achieved, we take the child out or give extra time on the most favorite game, thereby controlling the social behavior of the child.

It was clear from the results that parents used adjustment of activities through modifying the environment and use of suctions to socially control children with ASD, hence reducing stress in parents as they manage the children.

4.4.1.2 Supervision and monitoring as a strategy used by parents

It was imperative to establish whether or not parent participants used supervision and monitoring as a coping style for children with ASD in the study district. The responses from the parent participants were that there was need to supervise their children at all times. The study also revealed that parents needed to stay alert and ready to always intervene to avoid damage. Here is an experience as evidenced by the contribution of parent participant <A'4>:

My child has no proper schedule, if we're lucky, he gets up at 6, and if we're not, he gets up at 03- 04 hours... And the minute he's up, you're on... there is need to keep him in [the house] at times we try to feed him ... make sure he's entertaining himself in a quieter way.

The general findings were that there was need for maintenance of routine with many parents of children with ASD today, as they point to their children's excessive routines that resulted in violent behaviours as a significant source of stress and despair in the lives of parents and family members.

4.4.2 Prevention Strategies

4.4.2.1 Sticking to fixed routine as a strategy for managing ASD children

On the issue of routine as a strategy for promoting social interactions with children with ASD, the study established that, seven (7) out of ten (10) parents were of the view that by sticking to fixed routines in daily activities for example, for mealtimes, bedtimes, bathing times and dressing times, parents were able arrest or reduce on incidences of novel or unexpected or

outburst behavior from children with ASD. It was clear from the study that, maintaining routines for children helped in creating a smooth interaction for ASD child.

Out of the ten (10) participants who participated in the study, eight (8) approved those daily routines for children with ASD were to be followed. Parent participant <A10> indicated that:

Routines were much easier to follow in familiar places such as their own home, however more difficult in unfamiliar places such as another relative's home or out in the community.

In support of the above stated view, parent participant <A'5> had this to say:

Morning routines are the most difficult as most meltdowns occur during this time due to sensory issues, causing the child to be late for school and the parent to be late for other programmes.

Parent participant <A8> stated that:

We have to change our daily routines in social interaction significantly to support and accommodate our child with ASD. Having to get the child ready before getting ourselves ready each day and this often affected our social interaction with our child and professional life.

This was also evident in what parent participant <A'3> reported as follows:

[...] the days that are the hardest for me are Mondays, the public holidays, even when it was raining, I really had to work hard... to keep my child occupied. I opted to even use picture plans or lists to notify my child about the upcoming activities, so that he knew exactly what to expect.

In support of this view, parent participants <A'4> explained that:

I am able to talk to my child through the steps, through a white board which is one of the copings strategie, as my child is nonverbal. I write it out for him to see exactly what's going to happen, for example when you want to inform my child that we're going to have to drink tea before we can leave, we need to do this.

In contributing on the same, parent participant <A'2> had this to say:

Sometimes, I use “social stories” or scripts to model the steps of an activity or show my child pictures of new people or places to increase understanding in advance. It is important in helping my child to accept new things [...] if there’s somebody else coming to our home, I inform him to avoid a trigger point for a massive meltdown.

Parent participant <A'1> contributed on the matter by saying that:

When he tries something new for first time, he really gets mad, the second time he becomes a little pissed but does it, and the third time he does it, it is fine.

4.4.2.2 Stressful conditions for Parents

The parent participants were asked to narrate coping strategies they employed in terms of accommodating children with ASD in their daily lives. Results showed that all the ten (10) parent participants provided information on adapting routines to accommodate the child by following the child’s ‘unique rules’ for how things should be done, which involved tolerating the child’s preference for uniformity, providing the same meal each night and following accurate arrangement of activities. Sentiments by parent participant <A'3> were that:

My child has a pillow, and a blanket which he uses every night or day when he wants to sleep. I always put the pillow over the top, but before he nuzzles in, I have to have a drink of water ready to go because if I don’t, he screams out for water when I am gone. So, he has the smallest sip of water... and then he lies down and if I don’t have the pillow there, he screams for that too. I avoided doing things that my child disliked, which were likely to provoke problem behaviour.

In support of the above contribution, parent participant <A'1> had this to say:

We have planned activities to accommodate our child so as to reduce the risk of problematic behaviour, which includes doing things at the time of day when the child functioned best, attending events when they were less crowded and

locating activities of interest for our child in advance of outings and adjusting expectations depending on our child's mood. For example, after a day at school, we reduced anxieties to allow our child's energy levels to be exhausted

In agreement with these strategies, parent participant <A'10> explained the following strategies:

As parents, we have opted to adopt behavioural goals, so that our child's tasks were achievable. We give him extra time to complete tasks and we make sure that we take hints from our child when determining whether to pursue an activity: for example, when we get up in the morning, we observe what he's like when he gets up and then we'll make plans of what we're going to do.

4.4.3 Punishment Strategies

4.4.3.1 Coping with non-compliance on everyday tasks and activities by ASD children

In order to establish how parents coped with non-compliance of everyday tasks and activities for children with ASD, parent participants were asked whether or not it was easy to cope with non-compliance by ASD children. The response was that parents reported intervening to assist the child with daily activities such as dressing. The study also determined that parental interventions reduced performance demands, thus decreased the risk of frustration-related problematic behaviour caused by an ASD child. Here is what a parent narrated:

As a result of my daughter's problematic behaviours, I have to do everything for her, including dress her, feed her and help her complete daily hygiene tasks. My child would just lie on her bed looking at the ceiling or wall while holding the clothing in her hand until I go to help him, but I am actually aware that my child is capable of dressing himself and would often do so quickly before going to a preferred location such as a mall.

In support of the experience above, parent participant <A'3> observed that:

As a father of a child with ASD, I have problems with my child who would just sit down and refuse to be moved. I have to wait it out and try to coax him. Sometimes, I gently persuade him to reduce the likelihood of non-compliance by introducing activities that my child likes.

Parent participant <A'1> added to the observations by observing that:

I use a reward coping strategy for positive behaviour charts and negotiating to motivate good behaviour and obedience with daily activities. I also praise my child for appropriate behaviour, continuing with routine demands, despite my child's protests, using a variety of strategies and social stories. I also use verbal reprimands in response to problem behaviour such as "Don't," or "Stop".

Similar sentiments were expressed by parent participant <A'6> who explained that:

As a mother I shouted, yelled and conveyed negative Effect in response to aggression or problematic behaviour. I have tried using time-out but felt that it was totally ineffective with my child because he would yell or leave the time-out area.

In contrast to the above strategies, parent participant <A'5> had this to say:

I use physical punishment in response to the problematic behaviour of my child for I came from old-school parenting, and I found that spanking and other forms of punishment such as removing items or privileges, had little effect on my child behaviour.

Still on on the same theme, other parents narrated how they are always observing an ASD child in order to avoid accidents for the children are not afraid of heights and do not understand danger. This was evidenced by parent participant <A'7> who submitted that:

At our home, we had installed metal bars, alarms, and multiple locks on doors and windows to prevent the child from escaping and running away. We often felt safer at home rather than outside the home because of our familiarity with

our home's safety features and fear of the chances of the child's running away when in public.

Clearly, Supervision was required to ensure timely parental intervention, particularly when out in the community. Indicators of the child's stress and emotional state were a particular target of parental vigilance. Parents reported making an effort to keep the child's mood stable. High levels of stress and anxiety are common as are self-injurious behaviours, among parents' desire to be alone; behaviour which can be perceived socially as challenging to others was common physical contact with their children who find it quite uncomfortable. This requires an incredible balance between what is due to an ASD child and how it presents uniquely in each individual and what is a potential sign of abuse for parents to have a feeling of comfort. It can be assumed that the child's influence on the parents' life is irrefutable.

4.4.3.2 Disruption outings

In terms of coping with the children with ASD during outings, parent participants reported that setting importance and picking battles when deciding whether to insist on things to achieve the risk of outbursts and difficult behaviour also give freedom with regards to rules and expectations that applied to other family members was coping strategies parent participants used to their ASD children for example, excusing the child from sitting at the table to eat with the family or allowing the child to withdraw or engage in repetitive calming behaviours in public. On attempts to reduce on the likelihood of extreme disruptive behavior during social interactions, the study revealed that parents used outings to for example, play parks to avoid risk of outbursts and difficult social behavior from their children. Children saw an outing as having been given freedom, which they needed to treasure, thereby helping to reduce on chances of unwanted behaviors as parents interact with the children. It was also found that parents at times allowed the children to withdraw or engage in repetitive activities as a way of calming behaviours.

Three (3) parent participants individually stated that the coping style they used was trying to impose routine related demands on their children by not supporting off in the face of problem for the unruly behaviour would only infuriate stress levels in the home and might lead to the break-up of the family like seeking out-of-home placement for the child.

In support of this, parent participant <A3> had this to say:

I give in to my child's demands for activities or attention to reduce the likelihood of extreme disruption. If my child wants to get into the car and have a ride, I must do it, otherwise he gets ill-tempered, yells at midnight and you won't believe it, many nights I have driven him around from 21 hours till he sleeps, then I sleep for a few hours and go for work.

In a bid to establish ways in which parents socially interact with their children with ASD, probe the parents' experiences of social interactions with children with ASD and explore coping mechanisms that parents employ in managing experiences of social interactions with their children with ASD, the study established that five (5) out of ten (10) parents believed that creating sensory stimuli type of environment in the home helped to occupy children for a while, thereby controlling social behaviour. Six (6) out of ten (10) parent-participants reported that a stimulant home environment helped to avoid aversive behaviour. This involved avoiding use of noisy machines and minimising exposure to problematic food items which makes children hyperactive. It was also clear that, parents attempted to avoid situations, activities, events and places which appeared to exacerbate unwanted behaviour. They instead preferred exposing the child to environments that motivated or stimulated positive social interaction with parents and other siblings in the home.

This coping strategy was supported by parent-participant <A'5> who reported that:

I avoided events that were over or under-stimulating to my child, which involved feared stimuli, over-excitement, new or different environments that tend to limit social

interaction. Social activities make it difficult for me as a parent to control the child. I also avoid outings with the child like shopping, visiting restaurants and taking my child to my friend's houses or family events, or strictly controlled the time the child spent there.

In support of the notion that the parents had to modify the environment in which an ASD child lived, parent participant <A'6> had this to say:

I do not spend more hours out, it's one hour maximum, otherwise, it can be a disaster regularly. My child's challenges with tolerating new environments resulted in my staying at home with her so as to reduce the risk of an outburst or behaviour that others would find annoying or distressing. Avoiding outings altogether is the coping strategy that I use for my child's favorite for consistency We stayed home most of yesterday. We couldn't go anywhere and because it's his routine, I couldn't leave my house.

Arising from the results above, it was evident that a stimulant environment, avoidance of problematic food and exposure to certain environments through attending events, helped parents to have control over possible unwanted behaviour.

These results were supported by parent- participant <A3> who had this to say:

I give in to my child's demands to avoid outbursts when in home or public. It helps to minimise unnecessary attention or reduce the likelihood of extreme disruption if my child wants to be too difficult.

Still contributing on the same discussion, another parent-participant observed that:

I have come to learn that my child is ill-tempered and yells at midnight. You won't believe it, many nights I have driven him around from 21 hours till he sleeps, then I sleep for a few hours and go for work. We can't just understand each other at times.

In short, parents used outings and repetitive activities to control the social behavior of their ASD children.

4.4.3.3. Unwanted social behavior of ASD children

The current study determined that parenting a child with ASD can be extremely stressful and can affect a parent's physical and psychological well-being. This was a view shared by nearly all the parents interviewed and all of them emphasised the demanding nature of the care needed. It was imperative to establish whether or not parent participants responded to the problematic behaviour caused by children with ASD. Parent participants reported that distracting the children with ASD, with activities could divert them from problematic behaviours and pre-empt empty outbursts in challenging situations. The study equally determined that interruption often involved specific activities or items

Here is what was said by participant <A'4>:

[...] in my house, I use technology for my child, such as phones, tablets and other hand-held devices which play a key role in keeping my child away from problems and give me some free time, though at times, I ignore his demands and also teach him what is appropriate behaviour by providing verbal explanations

One parent participant supported the above strategies by saying:

"It's stressful, life changing and not what you planned".

A number of participants also spoke of the challenges they faced when they were out in public with their child as follows:

"We can't travel, that's for sure. Everything we want to do, we have to think, what are we going to do with (son)? Where are we going to put him?"

In support of the above view, parent participant <A'1> spoke of the impact on their social life, saying that it reduced the number of family visits and visitors.

4.5 Spiritual & Religious strategies

Six (6) out of the ten (10) parents mentioned religion as a way in which they dealt with their child-rearing responsibilities. Most of the participants suggested that having a child with ASD strengthened their belief in God, and they spoke of the patience necessary to raise him or her.

For example, one parent participant <A'6> said that:

“I begun to pray more when I discovered that my child had autism. For me, this was an important religious experience.”

In buttressing the same discussion, other parent-participants explained that:

“I started reading more about my religion, wanting to know more, like what did I do wrong? You keep asking God like, please, God, cure my child, and what can I do in return?”

Participant <A'1> A father said he felt he would be rewarded by God for being accepting of his child and having patience throughout the challenging behaviour:

“We cope with it with acceptance, with thanking God, and of course when you do that, God will help you to help him as well... once you accept the first shock of the problem with patience you will be rewarded... because you are patient for the sake of almighty God”

On the whole, the findings on experiences of parents of children with ASD with regards to social interaction has indicated three significant themes. These are (i) safety strategies where parents had to adjust activities and to exercise close supervision and monitoring on children with ASD. With regard to the theme of Prevention Strategies, the study cited sticking to fixed routine and avoiding stressful conditions whereas with the theme of punishment strategies, the study cited Non-compliance, Disruption of activities and Unwanted social behaviour in ASD children.

The current study explored the lived experiences of parents of children with ASD. It assumed that it is crucial to become familiar with the parents' viewpoints since these offer an insight into the family realities and routine, and into how the family dynamics are affected by having a child with ASD.

4.6 Chapter Summary

The overall finding of this study was that those children with ASD were considerably less steadily attached to their parents than children without ASD but were able to form secure attachment relationships. The parent-child relationship echoed less flexible, sensitive and synchronous interactive behaviours as a result of the social impairment of children with ASD.

Arising from the findings above, there are two broad themes surrounding how interaction was done namely: communicative interaction and dependence on social-emotional support for interaction. It is evident that parents of children with ASD interact with their children using: affectionate, rambling, fragmented emotional actions, tapping and expressions of love during interactions. On the part of social and emotional support, the study revealed that parents used as a mode of interaction: allowance of expression of anger without being aggressive as they interacted with the child, ensuring that as parents, they remained positive during interaction and regularly using physical activities to communicate with children with ASD.

Furthermore, data revealed that such a future associated with anxiety among the parents stipulates a sense of vulnerability and this was viewed as highly stressful by the parents, thereby leading to anxiety. As the children were dependent on their parents for majority of the needs and activities, the parents displayed feelings of helplessness in terms of social interactions and future related anxiety as they were worried as to who would provide care for their children if they died. On the whole, the findings showed that parents of children with

ASD had no knowledge of social interactions in ASD before their child was diagnosed and had challenges in interacting socially with their children with ASD.

The findings on experiences of parents of children with ASD with regards to coping strategies on social interaction indicated three significant themes. These are: (i) safety strategies, where parents had to adjust activities and exercise close supervision and monitoring on children with ASD. With regard to the theme Prevention Strategies, the study cited sticking to fixed routine and avoiding stressful conditions, whereas with the of theme punishment strategies, the study established non-compliance, disruption of activities and unwanted social behaviour of ASD children. Where this chapter presented the study findings, the next chapter discusses the findings.

CHAPTER FIVE: DISCUSSION OF FINDINGS

5.1 Overview

The previous chapter presented findings of the study on the lived experiences of parents in social interaction with children with ASD in Lusaka District of the Lusaka province of Zambia. This chapter will present a discussion of findings. The study will refer to the literature and theories presented in the earlier chapters of this study to reflect, confirm and extend the current knowledge base and discuss lived experiences of parents in social interaction with children with ASD. In presenting the analysis and discussion, the discussion is presented generally under research objectives. However, objectives have been discussed separately. Below is the discussion of the findings:

5.2 Ways parents socially interact with their children with ASD

Following the idea by Johnson, Frenn, Feetham and Simpson, (2011) that the core source of meaning of the phenomenon lies in the deepest layers of experience that are still, however, accessible for reflection, it can be claimed that the parents' discourse reveals a clear impact the ASD has on the evolution of the family's social interaction. The appearance of a child with ASD in the family causes extreme emotional tension to the parents that is difficult to overcome. It can be compared to experiencing a catastrophe and affects the family's future functioning. The research findings reveal a particularly high level of tension at the moment of the first suspicion and upon learning the diagnosis, and the results of research by Johnson et al. (2011) show the trend of a prolonged emotional tension of the kind. The results of the analysis of the parents' discourse that parents of children with ASD have rare and brief instances of some ways of personally interacting with their children with ASD were observed among the parents' narratives. The rare and brief instances of affectionate communication, rambling affectionate and fragmented emotional connections as ways of parental interaction with children with ASD.

These findings are in line with (Almeida, 2010) who also found that some parents start or hold a conversation with children with ASD by understanding non-verbal communication cues including body language and facial expressions that gives context to what is being said. The study revealed that parents make and maintain eye contact. Further analysis of the study findings revealed that emotional burden of the child's diagnosis, makes parents have the feelings of frustration implying that there will be numerous caregiving duties to parents impacted negatively parental mood and well-being and created feelings of helplessness and powerlessness that increased pessimism regarding the future of their affected child. The findings of the research by Nealy et al. (2012) confirm the phenomenon. As a result, the phenomenon of a family raising a child with ASD generates the need for the parents' observations regarding the emotional impact of the child's diagnosis concur with wider evidence from qualitative studies of parents of children with a range of developmental and mental health disorders who commonly expressed a desire not only to explain the individual experience, but further to search for the answer to an existential question, namely "why did this happen to us?"

The study revealed that parents experience distress and emotional turmoil in relation to their child's potentially dangerous and unpredictable behavior and functional dependency upon hearing their child's diagnosis. Similar findings were reported Smith et al., (2010) who found that parents' felt the following, "52 per cent felt relieved, 43 per cent felt grief and loss, 29 per cent felt shocked or surprised and 10 per cent self-blamed themselves. The study findings indicated the above categories to be true as one parent was relieved that her son was diagnosed with ASD and not with deafness while the other three parents indicated feelings of shock, grief and sadness. One study indicated that parents had to re-arrange their daily routines in order to accommodate their children with ASD because the children were unpredictable and often were unable to regulate their behaviour (Schaaf *et al.*, 2011). These parents expressed how the

society lacked awareness on the condition of their children and how judgments from the society led to social withdrawal among the parents of children with ASD.

However, social withdrawal was not just as a result of society's perception towards the children with ASD but also emanated from the challenging behaviours of the children such as time constraints and the increased burden to provide care. Based on the first research objective, results revealed that the majority of the parents of children with ASD were of the view that they did not have sufficient knowledge on the condition and how best to socially interact with their children with ASD. It was clear that parents had no adequate knowledge on ASD and how to care and manage their children.

This situation forced parents to experience anxiety, inadequacy, loneliness and worry on how best to socially interact with ASD children. They did not know what the problem was and what to do with social interaction problems surrounding their children. It was for this reason that parents expressed feelings of being abounded, discriminated and segregated because of the condition of their children. The Family Life-Cycle theory explains dysfunction in relation to normal functioning. It frames problems that might arise within the family course as a system moving through a change and over time. The theory argues that a change in the family affects the life cycle of individuals within the family set up.

Some parents' felt that the information on nature of their children's condition and how to manage them, could be shared or exposed to them through televisions or radio broadcast and social media like Facebook. Parents also felt that information on how to socially interact and support their children with ASD, could as well be shared in the community centres like churches. The study establishes that in as much as parents with children with ASD remained ignorant of the condition, how to best manage and interact with children with ASD prior and after diagnosis and how to access consultation with health professionals, it remains difficult

for parents' to ably socialise with their children. The foundation of the Family Life-Cycle is that families normally go through predictable changes of life's events, but at times, family and individuals such as parents can go through unpredictable events and changes such as taking care of unexpected children. As these changes occur in a family and in particular to parents of a child with ASD, they must be able to adapt accordingly in order to avoid dysfunction as they care for a differently abled child such as the children with ASD.

The results were in line with the study conducted by Neely-Barnes, *et al* (2011), who observed that lack of awareness or inaccurate information regarding ASD children prevents parents from noticing the early signs of ASD and developing workable approaches on how to interact with children. The study observed that increase in public awareness on ASD, dispels misconceptions and inaccurate information on the condition and regular exposure of parents to acceptable practices on how to manage the children, had the potential of easing the stress parents often when through. The confusion among parents, regarding areas associated social interaction, care and management of ASD children needed more education so as to enable parents better understand and interact with children. Which is in line with the findings of Ökcün (2012) who reported that, parents had varying levels of agreement on popular topics discussed in public such as vaccines, dietary restrictions, genetics, prenatal care, social behaviors and management of children with ASD. It should be noted that the theory is in agreement that stages enable one to understand some of the emotional, physical and relational experiences a family could go through during different transitional stages. These changes might probably involve different experiences for different members of the family and be different for different families with a child with ASD. It is noted by Carter & McGoldrick (2016) that as the families negotiate entry and exit of other family members with ASD, or as they negotiate its expansion and contraction, more stress can be experienced by parents. Hence, they strive to maintain the

balance, and realign their relationships to support the entry, exit and development of family members in a functional way.

With regard to parents' experiences on social and emotional support as they cared for their children with ASD, the study revealed that, parent-participants experienced loneliness, anger and sadness as they faced challenges in their efforts to interact and care for children with ASD in homes. However, another one (1) out of ten (10) parent-participants experienced relief, focused and became more confident went left to interact with the child as pleased and indeed when medical personnel were available to provide professional, social and emotional support as opposed to people in the neighbourhood and community. These results were in agreement with Chimhenga and Musarurwa (2011) who postulated that some parents do not have knowledge on the children's condition. Lazarevic, & Kopas-Vukasinovic, (2013) reported that parents were unable to meet the high travelling expenses to and from the hospitals to seek professional support on how to care for a child with ASD. It is evident from the study that, some parents experienced shock, self-denial, sadness and anger; and difficulties as they interact socially with children. Nonetheless, parents became better equipped on how to deal with the new challenges surrounding interaction with their children. Poverty featured strongly as a challenge amongst the parent-participants with children with ASD.

In this study, parents revealed that they were faced with severe socio-economic conditions which negatively affected their ability to interact with professionals regarding the children's condition. It was clear that, some parents are unable to meet the high travelling expenses to and from hospitals to seek information and acquire skills on how to deal with the condition of the children as well as effectively interact with them socially. Terms the as the "in between" stage. This is the stage where the young adult is thrown to independence, without, however, cutting emotional ties with the family of origin. The young adult might have physically left home, according to the writers, but not have started their family of procreation. This second

stage culminates from the marriage agreement made by two single adults. This is the joining of families through marriage. The stage is reached when the novice adult has presumably grown holistically, i.e., emotionally, physically and financially, and has now gained full independence from the family of origin, so that they are ready to start their own family.

Building on Carter & McGoldrick (1989:209) indicates that the most complex and difficult transition of the family cycle, are often romanticised by wedding ceremonies thus, the results shows that women become more successful when single, and become more educated, holding important jobs, and are less likely to want to marry, yet, the opposite seems to be true for single men. Hence, the constructivism philosophy states that individuals construct their own truth.

In this case, parents of children with ASD experienced a powerful societal discourse such as discrimination which greatly undervalued their care for Children with ASD, resulting into them being emotionally burdened with the issue of how best to interact with children with ASD. Similarly Little & Clark (2006), is in agreement with the experiences of raising a child with Asperger's Syndrome and non-verbal learning disorders, with a specific focus on the joys and worries of parents with children in life, it was evident that when parents feel involved in raising a child with ASD by being supported and having closer interacting with children, they felt positive and joyful in raising such child.

The findings have also shown that the parents in caregiving, responsibilities and burdens increased after having their child was diagnosed with ASD, thereby leading to significant manifestation of stress among the parents in social interaction. Raising a child with ASD in relation to social interaction was a challenging task which was accompanied with many responsibilities. This is particularly crucial because, the responsibilities increase and aggravate various issues when the child has ASD due to the high demands. Parents also indicated emotional changes due to the burden, being cranky, feeling exhausted, being stressed and

dealing with anxiety and depression as a result of parenting a child with ASD. This is consistent with a study done by Sawyer *et al.* (2010); which acknowledged the increased aggressive behaviours and anxiety, and relative mental health problems when compared to other parents.

In fact, Neely-Barnes, *et al* (2011), provide further evidence to this argument when they reported that raising a child with ASD in social interaction had an impact on the emotional wellbeing of parents as a result of the increased burden of parenting, the feeling of incompleteness, desire for a typically developing child, hopes and fears about the future of the child, increased financial implications and other such factors while parenting. The perception and experiences of these complexities of all the stages are what the researcher was interested in, to explore from an African perspective. The authors continue to indicate that there is a lot of re-negotiating that has to be done by the family on issues that were initially defined individually, for instance, space, money, time, culture, tradition and relationships.

The data has provided evidence to the fact that parenting a child with ASD in relation to social interaction was not just accompanied with psycho-emotional implications but was also found to have financial implications. Parents spoke of the financial burdens they experienced due to parenting a child with ASD in order to meet the expenses of their child's needs and demands, medications, speech therapies, special education and other such expenses. Furthermore, parents alluded to the fact that caregiving impacted negatively on their work life. Most of the parents stated that the financial burdens were challenging, taxing and led to significant stress. Caregiving impacted negatively on their work and work life because the child depended on them for needs and attention all the time. Parents found it difficult to strike a balance between work and caregiving of their child thereby leading to financial losses and a sense of loss of control of their own life. Benson, Kersh (2011) made this point that parents experienced declines in career-related growth which further led to increased stress. This loss of control over one's life and financial implications were viewed as major stressors by the parents. The

accounts revealed the parents' recognition of the possibility of positive outcomes for all their efforts in future. Majority of them were somewhat hopeful that they would, along with support from professionals, succeed in developing the full potential of their child.

The findings have also shown that parents with children with ASD had problems with communication, emotional expression and maladaptive behaviours. This is particularly crucial because ASD is one of the neurodevelopmental disabilities. Parenting a child with autism spectrum disorder in relation to social interaction can lead to significant stress as it is often accompanied by various challenges.

The study revealed that mental health issues and stress seem to be more prevalent in parents of children with autism than parents of children with other developmental disabilities. In exploring parents' lived experiences of raising a child with ASD in social interaction, it was revealed that parents faced increased levels of stress, depression and anxiety. The dissatisfied parents' mental health needs were reported to pose a significant risk to the psychological, physical and social well-being of the parent of the child affected by ASD and so endangered the adaptive functioning of the family as well as the potential of the child. The study further revealed that family members of individuals with ASD often had mixed feelings about labeling their loved ones with the term 'ASD', because it represented a life-long disability. Parents were reported to be concerned about stigma, fear of being avoided by others, to judgement or exclusion of their family member with ASD. Additionally, parents felt that due to the increased work needed in order to take care of a child with ASD, there was a significant effort put on the child's wellbeing rather than their own lived moments and that they relied on the routines around their child to meet the demands of everyday life. The study revealed that there was inherent loss of control, fear of the future, shrinking self and emotional transformations. The findings revealed that inadequate education, healthcare and stigma constitute the main issues for parents raising an ASD child. It equally revealed that ASD impacted negatively on

social life and emotional wellbeing. It was also established that not having enough sleep during the night and not being able to take naps during the afternoon led to parent's constant exhaustion. Besides that, constant attention towards their child prevented parents not to look at and care for their own well-being. Overall, the well-being of parents of young children with ASD was experience in time, space and the body, because their limit of awareness and their focus were directed towards the well-being and needs of their child with the ASD. Hence, Carter and McGoldrick (2016) also highlight the impact on the couple, starting from the preparation for the wedding where the entire families from both sides want to be involved. The pattern is also established with the extended families; hence, the two have to negotiate new relationships with their parents, siblings with ASD, grandparents, nieces and nephews, and even friends and in-laws. The most challenging triangles are the ones that involve the mother-in law. Cultural differences are also another factor that cannot be overlooked in coupling.

In the light of these findings, it is important to appreciate the need to center lived experiences of parents of children with ASD in social interaction on the theoretical theory covered by Carter and McGoldrick (2016), which includes expected stages, changing patterns of the family life cycle and the clinical perspective which through participation, children “acquire skills and competencies, connect with others and communities, and find purpose and meaning in life”. In the present study, the finding was that those children with ASD spend more time in familiar activities such as reading and quiet recreation and less time in formal activities and active recreation. However, it did not agree with those of Hall, Roberts and Graff (2011) and Goldstein and Schwebach (2004) who observed that parents enjoyed the child's unique characteristics. Learning from the child while gaining personal insight and spending time together were the highlights of the positive raising experience.

The study revealed that parenting a child with ASD was extremely stressful and life changing for children with ASD had rigidity in social interaction and unable to recognise positive ways

in which the ASD condition had impacted in their lives. Furthermore, the study revealed that a child with ASD allowed the family to see life from a strengths-based perspective and helps the parents and siblings become more empathetic and compassionate to other kids who may be viewed as different. It is clear from the findings of the present study that the differences in the results of this study and those of the studies cited above were partially due to variations in the location of the studies and exposure of the participants. While results from Cappe *et al.* (2011) and Hall, Robertsand and Graff's (2011) study concentrated on the reactions of parents in western countries, the findings of this study included views of parents in low, medium and high-density settings, whose views appear to be significantly different from those of participants in other environments.

The study findings also revealed that parent participants had basic knowledge about the social interaction of their ASD children and inadequate instructional resources. These elements were seen as clear indicator of failure to meet the goals and objectives in exploring the lived experiences of parents of children with ASD and the nature of social interactions with children with ASD. It was further established that regardless of their educational level, income status, and ethnic background, parents desire to have a successful and independent life, and that across study ages, parents needed information about ASD social interaction including support to help and care for their children's day to day living. It could overwhelmingly be stated that parents' beliefs on their roles and manner in which such roles were perceived by parents' themselves could have a bearing on how parents viewed and valued their efforts in raising their children in their homes.

The study findings further established that parents with children with ASD used affectionate communication when interacting with their children, where responsive and accommodative to the views, opinions, interests, ideas, suggestions and concerns of parents and communities on their communication. The study findings showed that parents believed that children with ASD

had challenges in affection, communication and particularly unacceptable or inappropriate in terms of touch, personal space, greetings and gestures that led to embarrassment in others. The study further reported distress associated with their children's infrequent expressions of affection. Based on the results of the present study, parents of children with ASD reported that they encountered increased stressors and greater stress compared to parents of a typical child or a child with another form of developmental disorder. Parents in the studied district were however seen interacting with their ASD children while others did not interact with their ASD children. The self-structure that is created by all the members at this stage, is highly influenced by the interaction within the entire family, hence, the change in the whole system. Thus, the 'self' of the parents is also affected. This indicates reciprocal influencing among members of the family, and the evaluation interaction with the significant others, which in this case are the parents, siblings, grandparents, friends, school and church. The adolescent's 'self' or identity would be reconstructed with the entire 'self' of other members, for instance, parents. The adolescent would then learn to be more flexible with household rules.

The findings also revealed that social interactions differed according to families with children with ASD, but research still entails that there were a lot of inconsistencies and no consensus as to how these interactions should be coded.

This is in line with the findings of Grossi, Marcone, Cinquegrana, Gallucci (2013) who reported that parent-child interaction strongly influences the emotional, behavioural and cognitive development of young children with ASD. Further, the studies undisputable findings cited that the child's lack of rambling affection had effects on the parents' life. Additionally, the findings showed that parents did not receive affection from their children with ASD as evidenced by the children's nature of not hugging or not having physical contact. In addition, some parents believed and felt that they were the most affected by their children's disability whereas others thought that the other children were the most affected. Although many parents

felt that the lack of their children's affection also affected the nuclear family and the extended family, Adamson, *et al.*, (2012) concluded that mothers used an interaction style characterised by more support and structure and clearer instructions in interaction with their children without ASD. The major response obtained from the data collection process using interviews on the issue of communication and emotional connections between parents and children with ASD, was that the majority of parents clearly deduced that children with ASD had their own unique way of communicating with family and friends. Some used oral language, others used non-verbal communication while others used signs for hunger, crying and tilting their head and bumping into walls as a means of communication with their parents.

Further investigations are required in order to understand the communication challenges for children with ASD. On the overall, the study results showed that communication with children with ASD was a challenge for all the parent participants in the study. This was in line with Pisula, Kossakowska (2010) and Dunn *et al.* (2001) who stated that impairments in social interactions may have an impact on parental interactive behaviour. Pisula, Kossakowska (2010); Shtayermman (2013); Hansangu (2015) and Noh *et al.* (1989) suggested that parenting was particularly affected by the child's lack of adaptability for example, the child's failure to adjust to changes in the social environment, suitability of the parents' awareness of the child as less intelligent and occurrence of demands and harshness regarding the child's minor behavioural problems such as crying, disobeying, seeking attention and requesting help. This made it difficult for parents to emotionally connect with their children with ASD. Further, the study findings of parents' experiences in raising a child with autism spectrum disorder (ASD) in social interaction convey a complex and extremely challenging life. ASD is a lifelong developmental disability characterised with qualitative impairments in three domains, these are social interaction, communication and repetitive, and stereotyped behaviour. Ultimately,

the nature of parent-child interactions differs in families with children with autism spectrum disorder (ASD).

From the study results, it was imperatively noted that when parents were involved in raising a child with ASD in social interaction, they felt the positive aspects and joys of raising a child with ASD. In a study conducted by Little and Shtayermman (2013), the experiences of raising a child with Asperger's Syndrome and non-verbal learning disorder in relation to social interaction, were explored with a specific focus on the joys and worries that came into the life of a child with ASD. The authors felt that "only through a deeper understanding of parents' experiences can ASD experts and other professionals develop, promote and evaluate intervention strategies aimed at improving the daily lives of these children and the families." Enjoying the child's unique characteristics and learning from the child while gaining personal insight and spending time together were the highlights of the positive raising experience. The overall finding in this study was that those children with ASD were considerably less steadily attached to their parents than children without ASD, but were able to form secure attachment relationships, yet the parent-child relationship echoed less flexible, sensitive and synchronous interactive behaviours as a result of the social impairment of children with ASD.

In summary, it can be echoed that arguably, parents feel their child with ASD created new problems, conflicts, and the dyadic relationship was weakened. Parents felt isolated from their child in relation to the child's developmental delay and lack of communication. Some families described being 'heartbroken' by the fact that they did not know if the child realised that they were not just a child care provider, but rather a dedicated family member called "mom, dad, sister, brothers, cousins, uncles and aunties among others.

5.3 Parents' experiences in social interactions with children with ASD

In this study, the lived experiences of parents of children with ASD had a significant change in the entire family system, including an increase in problems with spouses, sibling relationships as well as economic impacts. Further, parents prioritised the needs of their children with ASD and focused on coping with the elevated childcare challenges, which resulted in changing family dynamics. These concerns expressed by the parents, echoed those in previous studies with parents of children with disabilities, which identified a breakdown in the relationship between family members and insufficient available time and energy for mothers to commit to their spouse or the siblings of the child with ASD. The findings are supported by Smith, Hong, Seltzer.; Greenberg; Almeida, (2010) who noted that a higher rate of divorce for parents of children with ASD than in families of children without disabilities. Moreover, even for parents who remain married, raising a child with ASD is associated with lower marital satisfaction compared to that of married parents of typically developing children. Therefore, the impact of ASD on family life and relationships lends some support to family focused approaches, which suggest that a family member with autism exerts pervasive and bidirectional influences on the family system.

This is in line with Carter & McGoldrick's (2016) theory which states that it is the stage where the family is transformed from being that of a protective unit to the one that has to prepare the adolescent child for the world of adults. Though the requirements from the system are the basic ones, it is said to be the most challenging stage for the family, hence, termed the "transformation of the family system in adolescence"

The current study findings are in conformity with the works of Lickenbrock *et al.* (2011) that stated that there was a lack of research on the wellbeing of the parents of children with ASD according to Benson, (2011). In recent years, more studies have been conducted, whose

findings indicate that it has become apparent that children with ASD did have serious effects on parents in terms of anger, depression, guilt and doubts about their ability to parent.

Moreover, Benson, (2011) asserts that problems within the family as a result of the effects of ASD include divorce, problems between parents and their non-disabled children, and financial problems. A minority of respondents however did not agree with the assumption that children with ASD put their parents under a lot of stress because parents were human beings who possessed all the usual parental trappings and may not always do what was best for their children as well as for their family. Therefore, parenting a child with ASD was extremely demanding and as a result, there were enormous difficulties and pressures that parents faced. Schaaf *et al.* (2011) and Daire *et al.* (2011) concluded that a strong marital bond helped to diminish the stress that was put on the parents.

In this study, another experience voiced by the parents was lack of freedom on the side of parents and siblings as a result of the presence of a child with ASD in the home. The study showed that parents devoted more time to care and attempt to develop positive interactions with an ASD child at the expense of other siblings in the home. Because of this situation in the home, other siblings slowly started withdrawing from interacting and caring for children with ASD. As a result of the demands of caring for the child, parents became restricted and faced limitations in caring and interacting with the child. Furthermore, pursuing their own career also became difficult, because of the presence of an autistic child in the home. The study equally revealed that stigma and discrimination were another challenge that interfered with the parents' ability to socialise and interact with other parents in the neighbourhood and community. It was evident that society still did not accept the children with ASD as part of the members of the society, thereby restricting social interaction. This situation seemed to have an enormous negative impact on the parents socially because of their children. The findings are supported by DeMyer (2015), who noted that parents were unable to strike a balance between both

children in the homes and this was viewed as highly stressful by the parents. The parents experienced feelings of guilt and helplessness as they were unable to give enough time to the other children. The present study seemed to suggest that, parents' helplessness and inability to strike a balance between the autistic kid and the typically developing child led to more parental stressful experiences.

The findings have also shown that parents with children with ASD experienced stigmatisation and discrimination and had limited socialisation with the child and other people. Further, the parents of children with ASD also showed an increase in depression, less enjoyment of the child with ASD, lower self-esteem and decreased sense of fulfilment with their wives. Additionally, fathers also tended to be affected by the reactions of their child's mother. Indeed, the fact that many mothers tended to primarily focus on the disabled child. This tendency increased the fathers' concern for their spouses. The study further, revealed that having a child with ASD actually strengthened the marriage. This nevertheless, was a very rare finding with the majority of the results reporting a substantial impact on the level of marital satisfaction.

In this study, parents experienced meltdowns or tantrums, severe sleep-related problems and elopement from children with ASD. Further, parents acknowledged that it made the care of ASD children difficult in relation to sleep. Almost all of the children with ASD had sleep-related problems that kept families awake and alert at night, a situation which emotionally affected parents of children with ASD in the studied families. These findings were in agreement with those of Matson and Goldin (2013) which found sleep disturbance to be the second most common comorbid physical condition studied after epilepsy. While research is increasing in the area of sleep problems in ASD, there is need for more research. Relationships were found between the lack of sleep during daytime to be challenging behaviour in individuals with ASD. In addition, those poor sleeps with ASD had more behavioural problems than good

sleepers with ASD. In short, it could be concluded that parents go through a lot of stress due to children's lack of sleep.

The study demonstrated that between homes and families, the majority of respondents observed that it was imperative to establish whether or not resource and quality of life (QOL) in terms of medical care was experienced by parents with ASD children. Based on the findings, arguably, parents felt embarrassed to be with other people because of behaviour problems of their children with ASD which affected their social and psychological well-being. That perhaps contributed to the raised levels of stress, depression and anxiety that hence resulted in limited isolation among parents and their children. The findings also revealed that mothers of children with ASD devoted more time to providing childcare and completion of household work with less allocated to participating in leisure activities compared to fathers.

The study findings also established that parents' helplessness and inability to strike a balance between children with ASD and the typically developing child which made them feel guilt and helpless as they were unable to give enough time to the other child or children. It was uncovered that many children felt that they did not receive the same amount of attention from their parents compared to their disabled sibling and called it an unfair treatment. Most of the parents stated that their children with ASD were subjected to judgment from the society, and called names like "mad, dumb, useless, burden, abnormal possessed" and other such inhumane terms. In short, parental deficits could be understood in the context of the challenges that these parents face. Amplified levels of stress, sleep deficiency and fatigue have been linked to parents of children with ASD and were likely to negotiate their mental and physical functioning. Additionally, stigmatisation increased caregiving responsibilities and the high financial demands of caring for children with ASD. This study also revealed that having a child with ASD reduced parental opportunities to interact with others thus inhibiting parents' capacity to make positive changes in their environment. These findings are in line with Schieve

et al. (2007) who explained that parents of children with ASD were considered to be of lower status by society compared to parents of normal or typically developing children.

The study findings established that medical treatment and finances, most parents attested to facing financial problems. Financial support and provision for the children with ASD's future financial security, depending on the parental economic resources, might be useful to enhancing both parents and their children's livelihoods. Finances could improve the parental physical environment and increase both child and parents' access to health services. In addition, low-income parents' experiences of service support are often negatively reported and parents may appear reluctant to seek help for themselves or for their children. Developing and implementing therapeutic interventions which are sensitive to the needs of low-income families might be beneficial. For example, building on community-based interventions which rely on common support and promote parental empowerment could help to support these parents. Parenting a child with ASD involves additional challenges due to the children's communication difficulties, self-care limitations as well as their unpredictable and aggressive behaviours. Mothers were commonly reported as the primary caregivers of children with ASD therefore absorbed the majority of the caregiving burden.

5.4 Coping mechanism parents employ in managing experiences of social interactions with ASD children

There were a number of coping mechanism which parents of children with ASD used in managing social interaction. The first coping mechanism was safety strategie using adjust Activities. The study revealed that parents tended to give in to demands of the children by accommodating needs of children and sharing thoughts in a calm manner with the children. Additionally, parents' made efforts in modifying social environment from time to time to accommodate and make children more interactive. It was also evident that, families provided

under the advice of physiotherapists a lot of play materials which encouraged children to freely interact with parents' and other siblings in the homes. This coping strategy on managing of non-compliance everyday interactive tasks and activities to reduce stress, parents tended to use suctions such not allowing children with ASD to play favour right games on the phone, computers nor not accompanying parents' to shopping malls. Often these adjustments in activities helped to bring children under control and making the management of children less stressful. Through accommodating needs of the children, it was easy to experience a period of calmness and have a fruitful interaction with their children when parents gave in to some demands made by the child. In supporting the findings, Dominick *et al.*, (2007) revealed that parents tended to give in to demands of ASD children. Additionally, in attempt to improve interaction with children, parents made modifications to their home environment by providing toys and other learning materials to accommodate diverse interactive needs. It was clear from the results that parents' used adjustment to activities through modifying environment and use of suctions socially control children with ASD, hence reducing stress in parents' as they manage the children.

The study also found that supervision and monitoring was used as a coping style for children with ASD in the study district. The study also revealed that parents needed to stay alert and ready to intervene always to avoid damage and you have to be super-fast. Bearss *et al.*, (2016) asserted that there was need for maintenance of routine likely reverberated with many parents of children with ASD today, as they point to their children's excessive routines that resulted in violent behaviours as a significant source of stress and despair in the lives of parents' and family members.

Study findings further revealed that parents were of the view that, by sticking to fixed routines in daily activities for example, for mealtimes, bedtimes, bathing times, dressing times, parents were able arrest or reduce on incidences of novel or unexpected or outburst behavior from

children with ASD. It was clear from the study that, maintaining routines for children helped in creating a smooth interaction with ASD child. The parent participants were asked to narrate coping strategies they employed in terms of the accommodating children with ASD in their daily life. Results showed that all the ten (10) parent participants provided information on adapting routines to accommodate the child by following the child's 'unique rules' for how things should be done which involved tolerating the child's preference for uniformity and providing the same meal each night and following accurate arrangements of activities.

The other coping strategy parents used was non-compliance with everyday tasks and activities for children with ASD, parent participants were asked whether or not it was easy to cope with non-compliance by ASD children. The response was that parents' reported intervening to assist the child with daily activities such as dressing. The study also found out that parental interventions reduced performance demands and thus decreased the risk of frustration-related problem behaviour caused by an ASD child. Consistent with the findings, Matenge (2015) indicated that slowly introducing new things to the child using existing routines helped to improve communication as well as social interaction with the child. These results were also supported by Mandyata (2015) who noted that introducing things step-by-step, visiting places 'just to look' with the child helped to reduce on stress experienced by parents and improved social acceptance of their own children. Contributing on the same other parents narrated how they are always observing an ASD child in order to avoid accidents for they are not afraid of heights and do not understand danger. Clearly, Supervision was required to ensure timely parental intervention, particularly when out in the community, indicators of the child's stress and emotional state were a particular target of parental vigilance. Parents reported making an effort to keep the child's mood stable. High levels of stress and anxiety are common as are self-injurious behaviours, among parents' desire to be alone; behaviour which can be perceived socially as challenging to others was common physical contact with their children find it quite

uncomfortable. This requires an incredibly balance between what is due to ASD child and how it presents uniquely in each individual and what is a potential sign of abuse for parents to have a feeling of comfort. It can be assumed that the child's influence on the parents' life is irrefutable.

Study findings further revealed that coping with the children with ASD during outings, parent participants reported that setting importance and picking battles when deciding whether to insist on things to achieve the risk of outbursts and difficult behaviour also give freedom with regards to rules and expectations that applied to other family members was coping strategies parent participants used to their ASD children for example, excusing the child from sitting at the table to eat with the family or allowing the child to withdraw or engage in repetitive calming behaviours in public. On attempts to reduce on the likelihood to experience extreme disruptive behavior during social interactions, the study revealed that parents' used outings to for example, play parks to avoid risk of outbursts and difficult social behavior from their children. The study also found that children saw an outing as having being given freedom which they needed to treasure thereby helping to reduce on chances of unwanted behaviors as parents interact with the children. It was also found that parents at times allowed the children to withdraw or engage in repetitive activities as a way of calming behaviours. Findings by Schaaf *et al.*, (2011) add that coping style impose routine related demands on their children by not supporting off in the face of problem for the unruly behaviour would only infuriate stress levels in the home and might lead to the break-up of the family like seeking out-of-home placement for the child.

5.5 Relevancy of the Family Life Cycle Model in the Context of Zambia

The Family Life-Cycle Model was relevant to the Zambian context for the present study on the lived experiences of parents' social interaction with children with ASD, because there are

several aspects that are covered by the model which apply to the Zambian culture. It also includes anticipated stages, changing patterns of the family life cycle. The theory argues that a change in the family for example, arrival of a child with a disability, affects the life cycle of individuals within the family set up. It explains dysfunction or disruption of normal functioning of the family due to expected change in family practice, communication and socialising amongst people due to the presence of a child with a disability. In the context of the present study, a child with ASD affects the life of parents and other siblings, calling for improved coping strategies in social interaction. The Family Life Model was relevant to understand psychological and emotional experiences parents of children with ASD go through as they socially interact with children with ASD in their daily lives. The study reports that some parents experienced various negative emotional reactions following the child's ASD diagnosis. Parents in one way or the other have to contend with their ASD children in interacting with the world. The parents were of the view that when they take the children out, they usually comfort themselves, especially when one explains and asks them to cooperate. However, when they are hyper, they will throw tantrums here and there. One parent explained that when she learned of her son's diagnosis, she entered a phase of depression and felt distressed. The foundation of this theory is that families normally go through predictable changes through life events, but at times family and individuals such as parents can go through unpredictable events and changes such as taking care of an unexpected ASD child. As these changes occur, in a family and in particular in parents of an ASD child, they must be able to adapt accordingly in order to avoid dysfunction for children with ASD. The changes in the family may involve tasks that must be negotiated as they become complex, bring new roles, operations and put pressure on those close to the child. Hence, the families have to have an enormous reserve of courage, energy, tolerance, and willingness to take risks.

The model expresses that sometimes, the young adult may short-circuit the stage by premature marriage, or by staying at home, or having a child before marriage. However, these are constructed realities which might be different from one country to the other, which is one of the reasons for exploring these issues from the African perspective. In Zambia, the single adult seldom leaves home, and is regarded as a child until they are 21 or get married. The women's identity is developed around men, and, as a result, women only leave home when handed over by their fathers to their husbands on their wedding day, in order to continue to care for the families, especially the men as receivers or beneficiaries for care.

5.6 Constructed Framework to Document and Interpret Lived Experiences

This section is an extension of the findings and discussion of chapters. It responds to the last research objective focused on developing a framework for documenting and interpreting lived experiences of parents of children with ASD in social interaction in Lusaka District. The emergent framework is nicknamed *Kalumba's Hermeneutics Acrostic Analysis Framework* (KHAA framework), a result of twenty four months of deep reflection on the lived experiences of parents of children with ASD in social interaction. The multidimensional framework consists of three segments namely: (i) documentation, (ii) Analysis, and (iii) interpretation segments. In addition, the framework is situated within experiential philosophy and highlights the role of Words and Language in uncovering the hidden essence in 'Being and Time' as advanced by Heidegger and other proponents such as Ricoeur, Gadamer and Merleau-Ponty. The first part answers the 'why'. The KHAA framework question is then followed by 'what' and 'how'.

5.6.1 Why Kalumba's Hermeneutics Acrostic Analysis Framework (KHAA)

According to Finkelstein (2001), a good framework enables someone to see something which one does not understand as it can be seen from different viewpoints. Thus, 'this multi-dimensional replica of reality can trigger insights that one might not otherwise develop'

(Finkelstein, 2001:3). In a like manner, the KHAA framework is inspired by Heidegger's view as documented by Benjamin (1989:8) who argued that words and language are not wrappings in which things are packed for the commerce of those who write and speak. It is in words and language that things first come into being and are. It is in this vein that the conceptualisation of the KHAA framework is based on essential words as given by parents of children with ASD in Lusaka District. The words depict their felt lived world while interacting with their children with ASD. To this extent, the KHAA framework provided a framework for documenting patterns based on the essences generated through the lived experiences of parents of children with children with ASD. In addition, the framework aided in developing a story line during the writing phase of findings and discussion chapters. The significance of the KHAA framework lies in what Zalaghi & Khazaei (2016:24) refers to as 'making the infrastructure of... knowledge more scientific.' In this vein, the framework contributes to the already existing infrastructure of Hermeneutics Phenomenology by illuminating the 'hidden.' According to Serafin (2016), Heidegger's ontological position attempts to phenomenologically describe the hidden, or the invisible, phenomena in its movement of disclosure.

Heidegger portrays his entire philosophy as "phenomenology of the invisible" (Heidegger, 1986: 399). To this extent, the proposed KHAA framework conforms to the tenets of Hermeneutic Phenomenological approach as it uncovers or discloses the hidden 'essences' in the lived experiences of parents of children with ASD. In addition, the KHAA framework conforms to inductive reasoning (Godfrey & Hudson, 2010). For example, Bernard (2011) observes that in inductive approach, 'at the end of research as a result of observations, theories are constructed'. The inductive approach embraces generation of patterns based on the observations and developing a theory for those patterns (Zalaghi & Khazaei, 2016:25). The key benefit derived through the inductive method is that there is no necessity for any pre-fabricated framework. While essences generated are generalised, they should be verified through a logical

method called deductive approach (Zalaghi & Khazaei, 2016). Further, while the inductive approach uses the data to generate ideas, the deductive method starts with an idea and uses the data to verify or disapprove the idea (Holloway, 1997). In this vein, the KHAA framework finds its space in the current study as an innovation developed through inductive logic. The framework could be used as a snap-short of verifying the emergent themes within a short space of time available in connection with ASD children. In other words, the KHAA framework offers the researcher and other stakeholders interested in the research process, an eagle's view of the emergent pattern within the findings. The framework offers a 'valuable format to communicate knowledge' on the lived experiences as perceived by the participants (Schadewitz & Jachna 2007:1). Furthermore, the framework is good in determining saturation of the sample when emergent themes are related and similar, and no longer new. Qualitative researchers agree on 'sample saturation' as the determinant point to end further sampling process. However, little is known on how the saturation point looks like. Therefore, the framework could be useful to novices in qualitative research dealing with the challenges related to determining saturation point.

5.6.2 What the KHAA framework is about

The first segment of the KHAA framework (documentation) is made-up of columns and rows in excel spreadsheet application software. While each participant heads a column, the roles have letters of the alphabet (A-O). Pseudonyms were used to represent participants, as provided within the ethical considerations. However, due to limited space when pasted in print, the KHAA framework has been split in two, namely: KHAA framework (A-G) and KHAA framework (H-O). Key participant's views are isolated using key descriptors. The descriptors are colour coded Words to represent the emergent themes. Red colour represented 'disablers'

while green colour represented ‘enablers.’ For details on KHAA framework (A-G) and (H-O), see table below.

5.6.3 KHAA framework architecture described

Table 5.1: The KHAA framework is a product of 10 stages through the research process as depicted,

1	Recruited participants using the inclusion/exclusion criteria.
2	Identified the lead participant with richest experience on the phenomenon.
3	Shadowed the lead participant using a voice recorder and still camera to capture evidence.
4	Conducted in-depths interviews for all participants.
5	Conducted an in-depth interview at the end of the data generation process for selected participants to authenticate research findings.
6	Listened to the recorded voices of participants over time until researcher was fully immersed into the text.
7	Transcribed the whole interviews for holistic representation of findings.
8	Designed an Acrostic framework with rows ordered alphabetically and columns bearing participants’ pseudonyms.
9	Extracted and documented essences using key words that represent lived experiences of participants.
10	Analysed and interpreted themes using Nvivo to organise and categorise while reflecting on the research objectives until themes were clear.

Source: Own illustration based on current study

5.6.4 KHAA Framework A – G

Once data has been generated using the in-depth interview research tool and listening to the recorded voices of participants over time by researcher in order to be fully immersed into the text has been achieved, then extraction of documented ‘essences’ which describes lived experiences of participants, using key words follows. The process of generating essences was enhanced through a designed Acrostic framework with ‘rows’ ordered alphabetically and ‘columns’ bearing participants’ pseudonyms. In table 5.2, essences run from A – G while in Table 5.3 they run from H – N.

Table 5.2: KHAA Framework: Kalumba’s Hermeneutic Acrostic of Analysis of parents of children ASD lived experiences in Lusaka

District					
	Parent Participants <A’3>	Parent Participants <A’5>	Parent Participants <A’7>	Parent Participants <A’9>	Parent Participants <A’2>
A	adjusted their living circumstances, modifies their living circumstances	Supervision and monitoring	Supervision and monitoring, use of intervention	Sticking to fixed routine, modifies their living circumstances	Sticking to fixed routine, reacts in more constructive ways, which encouraged better coping
B	isolation and avoidance, these served to decrease positive mood.	Stressful condition	mediate stress by developing the ability to resist and recover from stressful feelings	self-reliance	appropriate intervention could help support the adaptation process
C	humour and withdrawal	Disruption of activities	Non-compliance	Social isolation	Unwanted social behaviour of ASD children
D	Disruption of activities	Specialist care	Supervision and monitoring	Sticking to fixed routine	Social isolation
E	Greater belief in God	Acceptance and commitment therapy	Unwanted social behaviour of ASD children	Supervision and monitoring	Acceptance and commitment therapy
F	use of intervention	Unwanted social behaviour of ASD children	React in more constructive ways,	Sticking to fixed routine	Supervision and monitoring
G	Supervision and monitoring	Respite services	use of intervention	Sticking to fixed routine	Greater belief in God

Source: Own illustration based on current study

Description: rows running from 'A to G' represent the emergent themes using prominent words from the five parent participants respectively. These headed five columns as demonstrated above. In turn, each cell had a provision for comments based on the reflections and interpretations of the emergent themes.

5.6.4 KHAA Framework H – N

Table 5.3: KHAA Framework: Kalumba’s Hermeneutic Acrostic of Analysis of parents of children ASD lived experiences in Lusaka District

	Parent Participants <A’3>	Parent Participants <A’5>	Parent Participants <A’7>	Parent Participants <A’9>	Parent Participants <A’2>
H	Greater belief in God	Greater the belief in God, religious beliefs therefore improved their socio-emotional well-being	Acceptance and commitment therapy, greater belief in God	Religious beliefs improved their socio-emotional well-being	Greater belief in God, acceptance and commitment therapy, greater belief in God
I	social support	support from relatives or groups can significantly affect parents’ perceptions of stress, and can therefore enhance coping	strengthening of bonds between the parents	respite services, social support	social support respite services
J	Loss of individual freedom	Anxiety control	Limited Family finances	Mental stress on parents	Poor relationship with spouse
K	Limited Family finances	Lack of Self – efficacy	Relationship with sibling	Stigma and Discrimination	Poor relationship with spouse
L	Stigma and Discrimination	Soul life	Stigma and Discrimination	Limited Family finances	Mental stress on parents
M	Soul life	Limited Family finances	Poor relationship with spouse	Relationship with sibling	Limited Family finances
N	Less sleeping time	Stigma and Discrimination	Mental stress on parents	Poor relationship with spouse	Relationship with sibling

Source: Own illustration based on current study

Description: rows running from ‘H to N’ represent the emergent themes using prominent words from the five parent participants respectively. These headed five columns as demonstrated above. In turn, each cell had a provision for comments based on the reflections and interpretations of the emergent themes.

5.6.5 KHAA framework: Analysis and Interpretation

The second part of the KHAA framework consists of an analysis and interpretation segment. In this segment, the framework creates all the elements covered during the findings from the objective as demonstrated in the Figure below it. In this vein, the quality of interpretation is enhanced through a critical reflection, otherwise referred to by Hermeneutics proponents as ‘Hermeneutics circle’ of the entire process of generating evidence.

5.6.5.1 KHAA framework for interpreting lived experiences of parents with children

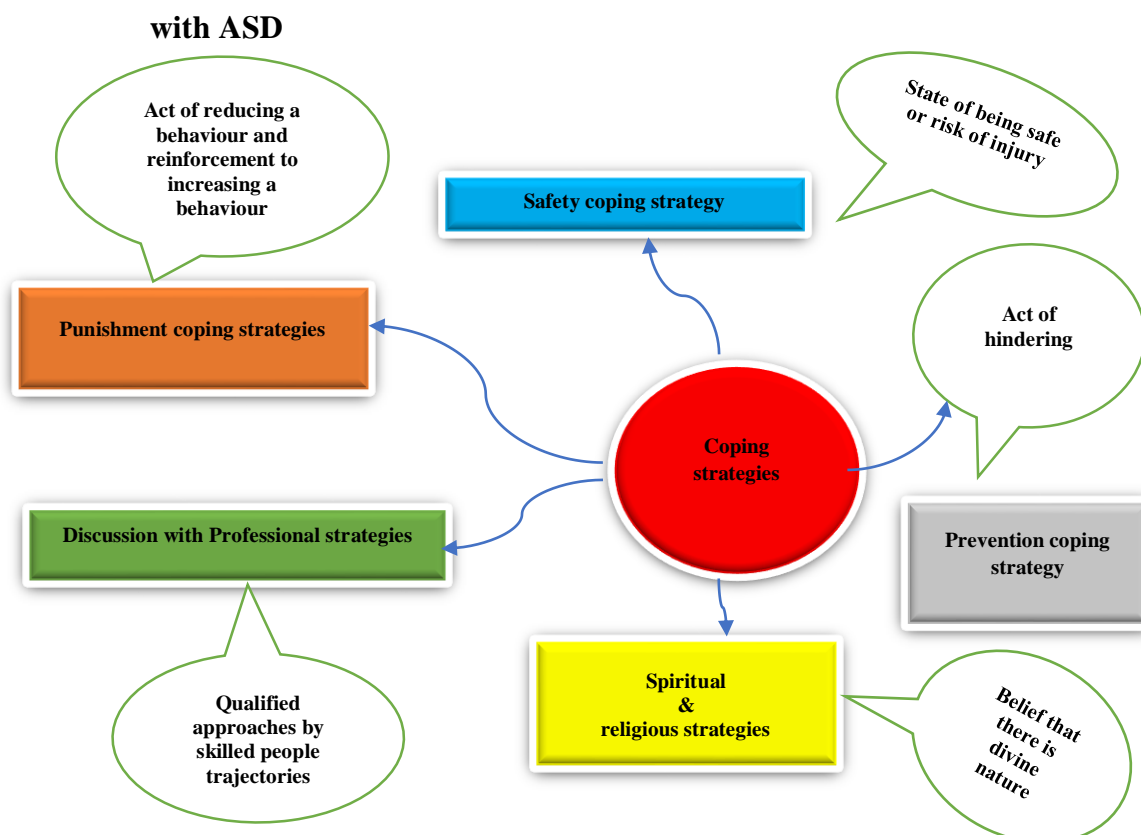


Figure 5.1: KHAA framework for interpreting lived experiences of parents with children with ASD

5.7 Chapter Summary

This chapter has presented a discussion of findings in relation to the study of lived experiences of parents of children with Autistic Spectrum Disorder in social interactions in selected schools of Lusaka District, Zambia. The theory presented in the earlier chapters of this study. The study has demonstrated that parents of children with ASD willingly participated in the in-depth interviews on the lived experiences ‘*of parents in social interaction with ASD children*’. The Chapter provided several factors that influenced the current forms and practices of parenting children with ASD in their daily lives, ranging from establishing ways parents socially interact with their children with ASD, to establishing the parents’ experiences of social interactions with children with ASD and exploring coping mechanisms parents employ in managing experiences of social interactions with their children with ASD. In addition, it was clear from the discussion that the majority of parents suffered from exhaustion and stress due to the degree of the amount of care needed for feeding, clothing, bathing and diapering, indicating that having a child with ASD required digging deeper into the pockets of the parents. In a nut-shell, the proposed KHAA framework offered a window through which this researcher viewed reality as lived by parents of children with ASD in Lusaka District. In addition, the framework empowered the novice researcher to determine sample saturation based on the similarity of prominent words from the participants and then documented emergent themes accordingly to third objective. Further, this framework aided the researcher in developing a story line based on the emergent themes during the write-up process.

CHAPTER SIX: SUMMARY, CONCLUSION AND RECOMMENDATIONS

6.1 Overview

The previous chapter presented the analysis and discussion of findings. This chapter presents the conclusions and recommendations on the lived experiences of parents of children with ASD in selected schools in Lusaka District Zambia. The chapter also demonstrate the contributed this study has to the body of knowledge and Implications for Practice. Lastly, suggestions regarding new areas of future research are identified for future academic debate.

6.2 Summary of the Study

Arising from the previous Chapters, the purpose of the study was to establish the lived experiences of parents in social interaction with children with ASD in Lusaka District of Lusaka Province of Zambia. In considering the findings of this study, though they may not be generalisable, it is fair to argue that they represent a significant portion of the experiences of parents with regard to their social interaction with children with ASD. It was evident that parents of ASD children lived a worrying life over the condition of children and experienced numerous negative experiences in social interaction with their children. These ranged from lack of social and emotional support, inability to provide interactive resources, loss of family freedom, stigmatisations and discrimination, to quitting jobs for the sake of providing social security for their ASD children.

The study has particularly shown that under diverse experiences in their attempt to socially interact with their children with ASD, parents are willing to adopt different strategies in coping with the challenges posed during social interaction with their children. Based on the results in this conclusion, recommendations have been made in this chapter. The Family Life-Cycle Model was used to establish the lived experiences of parents of children with ASD in social

interaction. There are several aspects that are covered by Carter and McGoldrick (2016), which include the expected stages, changing patterns of the family life cycle, and the clinical perspective. Through this model, the researcher was able to explore the lived experiences of parents of children with ASD in social interaction. The model helped the researcher to understand the stages that human beings pass through and that the emotional processes, including stress are dependent on actual expectancies that parents manifest with regard to the significance and outcome of a specific encounter such as having a child with ASD.

The study was guided by the following objectives:

1. To establish ways parents socially interact with their children with ASD
2. To probe the parents' experiences of social interactions with children with ASD; and
3. To explore coping mechanism parents, employ in managing experiences of social interactions with their children with ASD.

Ten (10) respondents participated in the study consisting of parents of children with ASD. The parents were selected using a purposive sampling technique with the help of special schools where children with ASD studied. Teachers assisted in identifying parents to talk to about their 'lived experiences in social interaction with their ASD children.' Primary data was generated using in-depth interview guides.

In order to ensure reliability and validity of the data collected to support the study, the researcher used a member checking qualitative technique to establish tenets of credibility in trustworthiness. It was done through sharing of a brief summary of the interview scripts and findings with the participants in order to review whether the findings depicted their lived experiences of raising children with ASD in relation to social interaction.

6.3 Findings

The following findings emerged from the study:

- (i) The overall finding of the study was that children with ASD were considerably less steadily attached to their parents than children without ASD, but were able to form secure attachment relationships, though the parent-child relationships echoed less flexible, sensitive and synchronous interactive behaviours as a result of the social impairment of children with ASD.
- (ii) It is evident that parents of children with ASD interact with their children using: affectionate, rambling, fragmented emotional actions, tapping and expression of love during interactions.
- (iii) Use of coping strategies such as emotional support as a mode of interaction, allowance of expression of anger without being aggressive as they interacted with the child, ensuring as that as parents, they remained positive during interaction and regularly using physical activities to communicate with children with ASD.
- (iv) Anxiety among the parents specifies a sense of vulnerability and this was viewed as highly stressful by the parents, hence leading to anxiety as the children were dependent on their parents for the majority of the needs and activities.
- (v) Parents displayed feelings of helplessness in terms of social interactions as well as future related anxiety, as they were worried as to who would provide care for their children if they died.
- (vi) On the whole, the findings showed that parents of children with ASD had no knowledge of social interactions in ASD before their child was diagnosed and that they had challenges in socially interacting with their children with ASD.

- (vii) Results of this study showed that parents used safety strategies as coping strategies to adjust activities and to put a close supervision and monitoring to children with ASD.
- (viii) Parents used prevention strategies such as sticking to fixed routine and avoiding Stressful conditions. For punishment strategies, parents used Non-compliance, Disruption activities and unwanted social behaviour of ASD children.

6.4 Implications for Practice

The findings of this study have instructional implications related to the lived experiences of parents of children with ASD in Lusaka District. It is evident from the findings that parents of children with ASD lacked adequate knowledge and ways on how to socially interact and communicate with children with ASD in their home settings. Furthermore, some parents of children with ASD had wrong conceptions after their children were diagnosed with ASD. The findings of this study, regarding the lived experiences of parents of children with ASD indicate lack of relevant knowledge and ways in parents could communicate and interact with their children with ASD in their homes. In order to yield an effective parent-child interaction, the parents need to be given enough information on ASD as well as being exposed to professional interactions with experts in the studied area. According to Cooper, Hooper & Thompson (2012), knowledge of the subject matter in order for them to develop appropriate pedagogical skills of interaction and communication are needed. The researchers further concluded that ASDs are more common in modern times than in the past. This is due to the recognition of incidents and the sensitisation of parents and communities, and not due to the increase in the phenomenon. They further urged that people should keep in constant touch with knowledge on ways in which parents can interact with their ASD children.

6.5 Conclusion

Based on the three research questions that this chapter has presented, the findings that were arrived at through qualitative data strongly suggested that the parents of children with ASD had a number of challenges that had greatly contributed to compromising their social interaction. Findings for the first objective revealed that parents of children with ASD had problems in communication and interaction with their children. Specifically, that they experienced emotional problems, feelings of vulnerability and frustration regarding child's future and had no knowledge of ASD. Furthermore, that parents experienced rare and brief instances of affectionate communication, rambling affectionate and fragmented emotional connections as ways of parental interaction with ASD children. Additionally, the data revealed that parents had family problems in terms relationships with spouses and siblings, and loss of freedom. In addition, parents experienced social problems such as facing the stigma and discrimination of having a child with ASD, which in turn changed their social life. The findings also revealed that parents with children with ASD employed safety strategies in which parents had to adjust activities, employ supervision and monitoring of children with ASD. They also employed prevention strategies where parents had to stick to fixed routines and avoid stressful conditions. Parents equally employed punishment strategies that they used for punishing children with ASD if they threw tantrums and engaged in disruptive activities.

The chapter isolates challenges that the study presented as a result of lived experiences of parents of children with ASD. It is also clear from the study, that although parents held positive views about ASD children, they were discouraged by a number of challenges encountered in raising children with ASD. Among the challenges countered were lack of knowledge about ASD, inadequate diagnostic centers or hospitals, lack of facilities for intervention and treatments. Limited time and lack of trained personnel, negative attitudes from professionals and lack of funding from government to centres or hospitals were equally amongst the

challenges faced. Nevertheless, parents were still optimistic that their children would benefit from their parental love and care rendered to their children on a daily basis. Based on the findings, it can be concluded that raising a child with ASD can be extremely stressful and life changing. Most parents may have a negative experience for their child with ASD and often have mixed feelings about labeling their loved ones with the term ASD because this represents a life-long disability. Parents were reported to be concerned about stigma. They fear being avoided by others, judged or being excluded from them with their ASD child. These are the lived experiences of parents with ASD children in Lusaka District of Zambia.

6.6 Recommendations

In view of the findings and conclusion above, the following recommendations were made:

1. Community heads, with support from Community Based Rehabilitation (CBR) should ensure formation of parent-to-parent support groups so that parents can share information and learn from each other on how to care and promote meaningful social interaction between them and their ASD children.
2. Parents with ASD children to be provided with knowledge on ways to interact and communicate with children with ASD. They should be provided a wider understanding of ASD at every health facility. All health facilities should also educate people with information (knowledge) on ASDs
3. Health professionals to help parents of children with ASDs to form parent to parent support groups where they can share experiences on their social interaction with their children with ASD.
4. Parents of children with ASD to access support services from schools where children with ASD learn to enable parents explore coping mechanisms in managing social interactions with their ASD children.

6.7 Originality of this thesis, innovations and contribution to new knowledge

It is important that I address the issue of originality in this thesis, not only because it is one of the criteria for assessing quality in doctoral research, but also, because it ensures that the study made significant contributions to parents' experiences of children with ASD from a Zambian perspective. The originality of this thesis is that it exposes the trends of the emerging and contemporary struggles for understanding the experiences of parents of children with ASD. The theoretical frameworks and perspectives of the Family Life Cycle, which guided the research are practical and now tested examples which have been strongly recommended by renowned researchers such as by Carter & McGoldrick, World Health Organisation, Santrock, Grobler, Families, Professional & Exceptionality, Positive Outcomes Through Partnerships & Trust that have been mentioned in chapter two.

The study used the qualitative method research approach and more specifically, the 'Hermeneutic Phenomenological Design' to analyse the lived experiences of parents of children with ASD in the Lusaka District of Zambia. It is one of the few studies in Zambia to empirically appraise the current situation of parent's experiences of children with ASD based on ways in which parents interact with children with ASD, experiences of parents of children with ASD and the strategies parents employ in coping with children with ASD in their day to day lives. The significance of this study also lies in the fact that there are very limited prior empirical and theoretical studies, if any that have been conducted to explore the lived experiences of parents of children with ASD using qualitative methods. Therefore, this study makes a considerable contribution to the literature and largely, to the field of parents of children with ASD in Zambia. The study thus lays a ground for future studies. The conclusions on this study are not imposed on the study but reflect various situations and views expressed by parents of children with ASD in the study and supported by literature.

The study has contributed to the awakening debate on the relevance of experiences of parents of children with ASD. The aspects that were at the centre of this study are: *'In what ways do parents interact socially with their children with ASD, what are the parents' experiences on their social interactions with their children with ASD, and how do parents cope with the social interaction experiences with their ASD children?'* To the best knowledge of the researcher, some of the information gathered during this research has not been documented anywhere. The new knowledge includes that of the revelation that parents of children with ASD not having adequate information on the ASD. In this study, parents were not adequately equipped to socially interact and communicate with their children with ASD, despite living with them for many years, and as a result, this affected their communication, interaction and understanding of the pedagogical content knowledge of the subject. Once again this is a point for further research on other parents of children with ASD as it has been recommended in this thesis. The other new finding is that parents of children with ASD faced marital problems, stigmatisation and discrimination from the family and community at large. Indeed, through the application of theoretical perspectives to the problem, the study investigated had made this work unique in the sense that while literature reviewed indicated that most studies were on ASD children in education, this study used the theoretical perspectives which are anchored on the family life cycle to analyse and explain that families normally go through predictable changes through life events, but at times, family and individuals such as parents can go through unpredictable events and changes such as taking care of an unexpected child with ASD. The researcher, thus made a critical analysis of some of the findings and highlighted some issues that may require further research. This study established that there is need to facilitate regular interaction between parents and professionals so that parents can access support services to enable them explore coping mechanisms in managing social interactions with their ASD children.

6.8 Suggestions for Further Research

Research on any topic in education is never ending or exhaustive. Thus, the mentality that should shape and control the minds of education researchers, scholars and evaluators is one which indicates that if there is nothing wrong with an aspect of education, then researchers, scholars and evaluators should be looking into possibilities of improving it before anything wrong happens. In lived experiences of parents of children with ASD under study, it can be said that there was already something wrong as findings, discussions and recommendations have indicated. Therefore, the study suggests the following possible areas for further research:

- i. The perception of both parents of children with ASD in Zambia.
- ii. To question fathers of children with ASD on their lived experiences in Zambia.
- iii. The impact of ASD on families with limited sources of income. This would include families who have children with ASD, but do not have access to extra financial support in Zambia.

REFERENCES

- Abubakar A, Ssewanyana D, Newton CR (2016) A Systematic review of research on autism spectrum disorders in sub-Saharan Africa. *Behavioural Neurology*. 3501910, <http://dx.doi.org/10.1155/2016/3501910>
- Adamson, L.B., Bakeman, R., Deckner, D. and Nelson, P.B. (2012). Rating parent–child interactions: Joint engagement, communication dynamics, and shared topics in autism, Down syndrome, and typical development. *Journal of Autism and Developmental Disorders*, 42(12), 2622–2635.
- Al-Ansari, A.M., Ahmed, M.M. (2013) Epidemiology of autistic disorder in Bahrain: prevalence and obstetric and familial characteristics. *Mediterranean Health Journal*. 19, 769-774.
- Albanese, A.L., San Miguel, S.K. and Koegel, R.L. (1995). Social support for families. In R.L. Koegel and L.K. Koegel (Eds.), *Teaching children with autism: Strategies for initiating positive interactions and improving learning opportunities* (pp. 95-104). Baltimore: Paul H Brookes Publishing.
- Al-Farsi, Y.M., Al-Sharbati, M.M., Al-Farsi, O.A., Al-Shafae, M.S., Brooks, D.R., Waly, MI. (2011) Brief report: Prevalence of autistic spectrum disorders in the Sultanate of Oman. *Journal of Autism Developmental Disorders*. 41, 821-825.
- Al-Kandari, S.; AlSalem, A.; Abohaimed, S.; Al-Orf, F.; Al-Zoubi, M.; Al-Sabah, R.; Shah, N. Brief Report: Social Support and Coping Strategies of Mothers of Children Suffering from ASD in Kuwait. *J. Autism Dev. Disord.* 2017, 47, 3311–3319. [CrossRef]
- Altieri, J. and Von Kluge, S. (2009). Family functioning and coping behaviours in parents of children with autism. *Journal of Child and Family Studies*, 18(1), 83-92. doi: 10.1007/s10826-008-9209-y
- American Psychiatric Association (2013) *Diagnostic and Statistical Manual of Mental Disorders*, 5th ed.; DSM-5; American Psychiatric Association: Washington, DC, USA.
- American Psychiatric Association DSM-5 Development (2003). Retrieved from <http://www.dsm5.org/>.

- Anagnostou, E., Zwaigenbaum, L., Szatmari, P., Fombonne, E., Fernandez, B. A., Woodbury-Smith, M., ... Scherer, S. W. (2014). Autism spectrum disorder: Advances in evidence-based practice. *Canadian Medical Association Journal*, 186(7), 509–519. doi:10.1503/cmaj.121756
- Anells, M. (1996). Hermeneutic phenomenology: Philosophical perspectives and current use in nursing research. *Journal of Advanced Nursing*, 23(4), 705-713.
- APA, American Psychiatric Association. (2013) *Diagnostic and statistical manual of mental disorders*. 5th ed. Washington, DC. pp. 50–59.
- Armitage, S.; Parkinson, M.; Halligan, S.; Reynolds, S. Mothers' Experiences of Having an Adolescent Child with Depression: An Interpretative Phenomenological Analysis. *J. Child Fam. Stud.* 2020, 29, 1617–1629. [CrossRef]
- Autism Society (2011). Retrieved from <http://www.autism-society.org> autism spectrum disorders. *Topics in Early Childhood Special Education*, 26(3), 179–187. doi:10.1177/02711214060260030 501.
- Baird, G., McConachie, H. and Scrutton, D. (2000). Parents' perceptions of disclosure of the diagnosis of cerebral palsy. *Arch Dis Child*, 83(6), 475-480.
- Bakare MO, Munir KM, Bello-Mojeed MA. (2014) Public health and research funding for childhood neurodevelopmental disorders in Sub-Saharan Africa: a time to balance priorities. *Healthc Low Resour Settings*; 2: 2014.1559.
- Bakare MO, Munir KM, Bello-Mojeed MA. (2014) Public health and research funding for childhood neurodevelopmental disorders in Sub-Saharan Africa: a time to balance priorities. *Healthc Low Resour Settings*; 2: 2014.1559.
- Bakare, M.O, Ebigbo, P.O, Ubochi, V.N. (2012). Prevalence of Autism Spectrum Disorders among Nigerian Children with Intellectual Disability: A stopgap Assessment; *J Health Care Poor Underserved*; 23: 513-518.
- Bakare, M.O, Munir, K.M. (2011b). Autism Spectrum Disorders in Africa, A Comprehensive Book on Autism Spectrum Disorders, Mohammad-Reza Mohammadi (Ed.), Chapter 10; ISBN:978-953-307-494-8. InTech, Available from: <http://www.intechopen.com/articles/show/title/autism-spectrum-disorders-in-africa>.

- Bakare, M.O, Munir, K.M., Kinney, D.K. (2011b): Association of hypomelanotic skin disorders with autism: links to possible etiologic role of vitamin-D levels in autism? Hypothesis; 9(1): 1-9.
- Bakwin, H. (1954). Psychological Aspects of Pediatrics- Early Infantile Autism. *The Journal of Pediatrics*, 45(4), 492-497.
- Banach, M., Iudice, J., Conway, L. and Couse, L. (2010). Family Support and Empowerment: Post Autism Diagnosis Support Group for Parents'. *Social Work with Groups*, 33, 69-83. doi: 10.1080/01609510903437383.
- Barbosa, M. A. M., Chaud, M. N., & Gomes, M. M. F. (2008). Experiences of mothers of disabled children: A phenomenological study. *Acta Paul Enferm*, 21(1): 46-52.
- Baron-cohen, Leslie, J. K., Seltzer, M.M. and Greenberg, J. S. (2011). Longitudinal effects of adaptability on behaviour problems and maternal depression in families of adolescents with autism. *Journal of Family Psychology*, 25(4), 601–609. doi:10.1037/a0024409.
- Barrett, B.; PACT Consortium; Byford, S.; Sharac, J.; Hudry, K.; Leadbitter, K.; Temple, K.; Aldred, C.; Slonims, V.; Green, J. Service and Wider Societal Costs of Very Young Children with Autism in the UK. *J. Autism Dev. Disorder*. 2011, 42, 797–804.
- Barrow, D. M. (2017). A phenomenological study of the lived experiences of parents of young children with autism receiving special education services. Unpublished doctoral thesis. Portland: Portland State University.
- Barry, C. A., Stevenson, F. A., Britten, N., Barber, N., & Bradley, C. P. (2001). Giving voice to the lifeworld. More humane, more effective medical care? A qualitative study of doctor-patient communication in general practice. *Social Science & Medicine*, 53(4), 487–505.
- Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research*, 51(9), 702-714.
- Bedford, R., Elsabbagh, M., Gliga, T., Pickles, A., Senju, A., Charman, T. and Johnson, M. H. (2012). Precursors to social and communication difficulties in infants at risk for autism: Gaze following and attentional engagement. *Journal of Autism and Developmental Disorders*, 42(10), 2208–2218.
- Behrman, R.E., Kliegman, R.M. and Jenson, H.B. (2000). *Nelson Textbook of Pediatrics*. (16th Ed.). Philadelphia, PA: W.B. Saunders Company.
- Bejarano-Martín, Á.; Canal-Bedia, R.; Magán-Maganto, M.; Fernández-Álvarez, C.; Martín-Cilleros, M.V.; Sánchez-Gómez, M.C.; García-Primo, P.; Rose-Sweeney, M.;

- Boilson, A.; Linertová, R.; (2019) Correction to: Early Detection, Diagnosis and Intervention Services for Young Children with Autism Spectrum Disorder in the European Union (ASDEU): Family and Professional Perspectives. *J. Autism Dev. Disorder.* 2019, 50, 3395–3396.
- Bekhet, A.K.; Matel-Anderson, D. Risk and Protective Factors in the Lives of Caregivers of Persons with Autism: Caregivers' Perspectives. *Perspect. Psychiatr. Care* 2016, 53, 199–207. [CrossRef]
- Benson, P. R. (2017). The impact of child and family stressors on the self-rated health of mothers of children with autism spectrum disorder. *Autism*, 1-13.
- Benson, P.R. and Kersh, J. (2011). Marital quality and psychological adjustment among mothers of children with ASD: Cross sectional and longitudinal adjustment. *Journal of Autism and Developmental Disorders*, 41, 1675–1685. doi:10.1007/s10803-011-1198-9.
- Benson, P.R.; Karlof, K.L. Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *J. Autism Dev. Disord.* 2009, 39, 350–362. [CrossRef]
- Beresford, B.A. (1994). Resources and strategies: how parents' cope with the care of a disabled child. *Journal of Child Psychology and Psychiatry*, 35(1), 171-209.
- Beresford, B.A. (2021). Expert opinions: A national survey of parents' caring for a severely disabled child. Social Policy Research Unit, UK: University of York.
- Berger, N.I.; Ingersoll, B. (2013). An Exploration of Imitation Recognition in Young Children with ASD Spectrum Disorders. *ASD Res.*, 6, 411–416, doi:10.1002/aur.1303.
- Bettelheim, B. (1959). Feral Children and Autistic Children. *American Journal of Sociology*, 64(5), 455-467.
- Bishop, S.L.; Richler, J.; Cain, A.C.; Lord, C. Predictors of perceived negative impact in mothers of children with autism spectrum disorder. *Am. J. Ment. Retard.* 2007, 112, 450–461. [CrossRef]
- Blumenthal-Barby, J. S. (2017). 'That's the doctor's job': Overcoming patient reluctance to be involved in medical decision making. *Patient Education and Counseling*, 100(1), 14–17. doi: 10.1016/j.pec.2016.07.010

- Blumer, H. (1969). *Symbolic interactionism: Perspective and method*. Los Angeles, CA: University of California Press.
- Bouma, R. and Schweitzer, R. (1990). The impact of chronic childhood illness on family stress: A comparison between autism and cystic fibrosis. *Journal of Clinical Psychology*, 46(6), 722-730.
- Boyd, B.A. Examining the Relationship Between Stress and Lack of Social Support in Mothers of Children with Autism. *Focus Autism Other Dev. Disabil.* 2002, 17, 208–215. [CrossRef]
- Braunstein, V. L., Peniston, N., Perelman, A., & Cassano, M. C. (2013). The inclusion of fathers in investigations of autistic spectrum disorders. *Research in Autism Spectrum Disorders*, 7(7), 858– 865. doi:10.1016 /j. rasd.2013.03.005
- Brereton, A.V., Tonge, B.J. and Einfeld, S.L. (2006). Psychopathology in children and adolescents with autism compared to young people with intellectual disability. *Journal of Autism and Developmental Disorders*, 36(7), 863–870.
- Brian, J. A., Smith, I. M., Zwaigenbaum, L., & Bryson, S. E. (2017). Cross-site randomized control trial of the social ABCs caregiver-mediated intervention for toddlers with autism spectrum disorder. *Autism Research*, 10, 1700–1711.
- Brian, J. A., Smith, I. M., Zwaigenbaum, L., Roberts, W., & Bryson, S. E. (2015). The social ABCs caregiver-mediated intervention for toddlers with autism spectrum disorder: Feasibility, acceptability, and evidence of promise from a multisite study. *Autism Research*, 9(8), 899–912. doi:10.1002/aur.1582
- Brobst, J.B., Clopton, J.R. and Hedrick, S.S. (2009). Parenting children with autism spectrum disorders: The couple’s relationship. *Focus on Autism and Other Developmental Disabilities*.
- Brobst, J.B.; Clopton, J.R.; Hedrick, S.S. Parenting children with autism spectrum disorders: The couple’s relationship. *Focus Autism Other Dev. Disabil.* 2009, 24, 38–49. [CrossRef] *Brain Sci.* 2021, 11, 309 16 of 16
- Bryson, S.E., Rogers, S.J. and Fombonne, E. (2003). Autism spectrum disorders: Early detection, intervention, education, and psychopharmacological management. *The Canadian Journal of Psychiatry*, 48(8), 506-516.
- Cadman, T.; Eklund, H.; Howley, D.; Hayward, H.; Clarke, H.; Findon, J.; Xenitidis, K.; Murphy, D.; Asherson, P.; Glaser, K. Caregiver Burden as People with Autism

Spectrum Disorder and Attention-Deficit/Hyperactivity Disorder Transition into Adolescence and Adulthood in the United Kingdom. *J. Am. Acad.*

- Cantwell, J.; Muldoon, O.; Gallagher, S. The influence of self-esteem and social support on the relationship between stigma and depressive symptomology in parents caring for children with intellectual disabilities. *J. Intellect. Disabil. Res.* 2015, 59, 948–957.[CrossRef]
- Cappe, E., Wolff, M., Bobet, R., Adrien, J.L., (2011). Quality of life: a key variable to consider in the evaluation of adjustment in parents of children with autism spectrum disorders and in the development of relevant support and assistance programmes. *Quality of Life Research*, 20, 1279-1294.
- Carman, K. L., Dardess, P., Maurer, M., Sofaer, S., Adams, K., Bechtel, C., & Sweeney, J. (2013). Patient and family engagement: A framework for understanding the elements and developing interventions and policies. *Health Affairs*, 32(2), 223–231. doi:10.1377/hlthaff.2012.113
- Carr, A. and O'Reilly, M. (1996). Service needs of carers for people with intellectual disabilities: Profiles of high-need and low-need groups. *Irish Journal of Psychology*, 17(1), 48-59.
- Carter, B., & McGoldrick, M. (1988). *The changing family life cycle: A framework for family therapy* (2nd ed.). New York, NY: Gardner Press.
- Cashin, A. (2004). Painting the vortex: The existential structure of the experience of parenting a child with autism. *International Forum of Psychoanalysis*, 13(3), 164- 174.
- Ceka, A., & Murati, R. (2016). The role of parents in the education of children. *Journal of Education and Practice*, 7(5): 61-64.
- Center for Advancing Health. (2010, April 09). A new definition of patient engagement: What is engagement and why is it important. *Engagement Behavior Framework*, 1–17.
- Center for Disease Control and Prevention. (2012, March 30). Prevalence of autism spectrum disorders Autism and developmental disabilities monitoring network, 14 sites, United States.
- Centers for Disease Control and Prevention (2014). Prevalence of autism spectrum disorders among children aged 8 years—Autism and Developmental Disabilities Monitoring Network, 11 Sites, United States, 2010. *MMWR Surveill. Summ.*, 63, 1–21.

- Central statistical Office (2015). Selected Socio- economic Indicators Report of 2015. Vol. 11 (2), Lusaka, COS.
- Central Statistical Office (2018). Census of Population and House- demographic survey report. Lusaka, CSO.
- Cetinbakis, G.; Bastug, G.; Ozel-Kizil, E. (2021) Factors contributing to higher caregiving burden in Turkish mothers of children with autism spectrum disorders. *Int. J. Dev. Disabil.* 2018, 66, 1–8. [CrossRef]*Brain Sci.*, 11, 309 15 of 16
- Chadwick, O.N., Momčilović, N., Rossiter, R., Stumbles, E. and Taylor, E. (2018). A randomised trial of brief individual versus group parent training for behaviour problems in children with severe learning disabilities. *Behavioural and Cognitive Psychotherapy*, 29(2), 151-167.
- Chan, K.K.S.; Lam, C.B. Self-stigma among parents of children with autism spectrum disorder. *Res. Autism Spectr. Disord.*,48, 44–52. [CrossRef]
- Chansa-Kabali T., J. Nyoni and H. Mwanza (2019) Awareness and Knowledge Associated with Autism Spectrum Disorders among University Students in Zambia. *Journal of Autism and Developmental Disorders*. Vol. 49, (9) pp 3571–3581. September.
- Charmaz, K. C. (2014). *Constructing grounded theory* (2nd ed.). Thousand Oaks, CA: Sage.
- Charmel, P. A., & Frampton, S. B. (2008). Building the business case for patient-centered care. *Healthcare Financial Management: Journal of the Healthcare Financial Management Association*, 62(3), 80–85.
- Chiarotti, F.; Venerosi, A. (2020) Epidemiology of Autism Spectrum Disorders: A Review of Worldwide Prevalence Estimates Since 2014.*Brain Sci.*, 10, 274. [CrossRef]
- Child Adolesc. Psychiatry* 2012, 51,879–888. [CrossRef] [PubMed]
- Chimhenga, S., & Musarurwa, C. (2011). Educating children with special needs: The African context. Retrieved from <http://www.savap.org.pk>
- Christensen, D. L., Baio, J., Van Naarden Braun, K., Bilder, D., Charles, J., Constantino, J. N., CDC, C. f. D. C. a. P. (2016). Prevalence and characteristics of autism spectrum disorder among children aged 8 years–autism and developmental disabilities monitoring network, 11 Sites, United States, 2012.
- Clayman, M. L., Gulbrandsen, P., & Morris, M. A. (2016). A patient in the clinic; a person in the world. Why shared decision making needs to center on the person rather than the medical encounter. *Patient Education and Counseling*, 100(3), 600–604.

- Cohen, L., & Manion, L. (2005). *Research methods in education* (4th ed) London: Routledge.
- Cohrs, A.C.; Leslie, D.L.(2017) Depression in Parents of Children Diagnosed with Autism Spectrum Disorder: A Claims-Based Analysis. *J. Autism Dev. Disord.* 2017, 47, 1416–1422. [CrossRef]
- Committee on Children with Disabilities (2001). Technical report: The pediatrician's role in the diagnosis and management of autistic spectrum disorder in children. *Pediatrics*, 107(5), e85.
- Conway, J. B. (2011). Public and patient strategies to improve health system performance. *Topics in Early Childhood Special Education*, 23(1), 19-27.
- Corbin, J., & Strauss, A. (2008). *Basics of qualitative research: Techniques and procedures for developing grounded theory* (3rd ed.). Thousand Oaks, CA: Sage.
- Coulter, A. (2011). *Engaging patients in healthcare*. New York, NY: McGraw-Hill Education.
- Craig, F.; Operto, F.F.; De Giacomo, A.; Margari, L.; Frolli, A.; Conson, M.; Ivagnes, S.; Monaco, M.; Margari, F. Parenting stress among parents of children with Neurodevelopmental Disorders. *Psychiatry Res.* 2016, 242, 121–129. [CrossRef] [PubMed]
- Creswell, J. W. (2014). *Research design, qualitative, quantitative, and mixed methods approach* (4th Ed.). New York: Sage Publications.
- Cridland, E.K.; Jones, S.C.; Magee, C.A.; Caputi, P. Family-focused autism spectrum disorder research: A review of the utility of family systems approaches. *Autism* 2013, 18, 213–222. [CrossRef]
- Cubells JF (2013) Prevalence of autism spectrum disorders in China. *Shanghai Archives of Psychiatry.* 25, 176–177.
- Dabrowska, A. and Pisula, E. (2010). Parenting stress and coping styles in mothers and fathers of pre-school children with autism and Down syndrome. *Journal of Intellectual Disability Research*, 54(3), 266–280.
- Daire, A.P., Munyon, M.D., Carlson, R.G., Kimemia, M., Mitcham, M. (2011). Examining Distress of Parents of Children with and Without Special Needs. *Journal of Mental Health Counselling*, 33(2), 177-188.
- Davis, N.O. and Carter, A.S. (2008). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders*, 38(7), 1278–1291.

- Dawson G. *et al.* Affective exchanges between young autistic children and their mothers. *J Abnorm Child Psychol* 1990; 18(3):335–45.
- DeGrace, B.W. (2004). The everyday occupation of families with children with autism. *The American Journal of Occupational Therapy*, 58(5), 543-550.
- Dekkers LMS, Groot NA, Mosquera END, Zúñiga IPA, Delfos MF (2015) Prevalence of Autism Spectrum Disorders in Ecuador: A Pilot Study in Quito *J Autism Dev Disord.* 45(12): 4165–4173. doi:10.1007/s10803-015-2559-6
- DePape, A. M., & Lindsay, S. (2015). Parents' experiences of caring for a child with autism spectrum disorder. *Qualitative Health Research*, 25(4), 569–583. doi:10.1177/1049732314552455
- DePape, A.-M.; Lindsay, S. Parents' Experiences of Caring for a Child with Autism Spectrum Disorder. *Qual. Health Res.* 2014, 25,569–583. [CrossRef] [PubMed]
- Derguy, C.; M'Bailara, K.; Michel, G.; Roux, S.; Bouvard, M. The Need for an Ecological Approach to Parental Stress in Autism Spectrum Disorders: The Combined Role of Individual and Environmental Factors. *J. Autism Dev. Disord.* 2016, 46, 1895–1905.[CrossRef]
- Divan, G.; Vajaratkar, V.; Desai, M.U.; Strik-Lievers, L.; Patel, V. Challenges, coping strategies, and unmet needs of families with a child with autism spectrum disorder in Goa, India. *Autism Res.* 2012, 5, 190–200. [CrossRef]
- Dominick, K.C., Davis, N.O., Lainhart, J., Tager-Flusberg, H. and Folstein, S. (2007). Atypical behaviours in children with autism and children with a history of language impairment. *Research in Developmental Disabilities*, 28(2), 145–162.
- Dowling, M. (2007). From Husserl to van Manen. A review of different phenomenological approaches. *International Journal of Nursing Studies*, 44(1), 131-142.
- Dyches, T.T.; Wilder, L.K.; Sudweeks, R.R.; Obiakor, F.E.; Algozzine, B. Multicultural Issues in Autism. *J. Autism Dev. Disord.* 2004,34, 211–222. [CrossRef]
- Edwards, A., Brebner, C., McCormack, P., & MacDougall, C. (2016). The early intervention message: Perspectives of parents of children with autism spectrum disorder. *Child: Care, Health & Development*, 43(2), 202–210. doi:10.1111/cch.12428
- Eisenberg, L., Kanner, L. (1956). Childhood Schizophrenia Symposium, 1955: 6. Early Infantile Autism, 1943-1955. *American Journal of Orthopsychiatry*, 26(3), 556-566.

- Ekas, N.V., Lickenbrock, D. M. and Whitman, T.L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 40, 1274–1284.
- Ekas, N.V.; Lickenbrock, D.M.; Whitman, T.L. Optimism, Social Support, and Well-Being in Mothers of Children with Autism Spectrum Disorder. *J. Autism Dev. Disord.* 2010, 40, 1274–1284. [CrossRef]
- Elford, L. M. (2014). Mothers' lived experience of parenting an infant/young child with special needs in a rural context. Unpublished Masters Dissertation. Ontario, Canada: The University of Western Ontario, Canada.
- Elsabbagh M, Divan G, Koh YJ, et al. (2012) Global prevalence of autism and other pervasive developmental disorders. *Autism Res*; 5: 160–79.
- Elsabbagh M, Divan G, Koh YJ, et al. (2012) Global prevalence of autism and other pervasive developmental disorders. *Autism Res*; 5: 160–79.
- Elsabbagh, M., Divan, G., Koh, Y.-J., Kim, Y. S., Kauchali, S., Marcín, C., Fombonne, E. (2012). Global prevalence of autism and other pervasive developmental disorders. *Autism Research*, 5(3),160–179. doi:10.1002/aur.239
- Elsabbagh, M., Divan, G., Koh, Y.J., Kim, Y.S., Kauchali, S., Marcin, C., et al. (2012) Global prevalence of autism and other pervasive developmental disorders. *Autism Research*. 5, 160-179.
- Estes, A., Munson, J., Dawson, G., Koehler, E., Zhou, X.H. and Abbott, R. (2009). Parenting stress and psychological functioning among mothers of preschool children with autism and developmental delay. *Autism: the international journal of research and practice*, 13(4), 375–387.
- Estes, A.; Olson, E.; Sullivan, K.; Greenon, J.; Winter, J.; Dawson, G.; Munson, J. Parenting-related stress and psychological distress in mothers of toddlers with autism spectrum disorders. *Brain Dev.* 2013, 35, 133–138. [CrossRef]
- Fairthorne, J., Fisher, C., Bourke, J. and Leonard, H. (2014). Experiences impacting the quality of life of mothers of children with autism and intellectual disability. *Psychology Research*, 4(8), 666–684.

- Fairthorne, J.; De Klerk, N.; Leonard, H. Health of mothers of children with intellectual disability or autism spectrum disorder: A review of the literature. *Med. Res. Arch.* 2015, 3. [CrossRef]
- Falk, N.H.; Norris, K.; Quinn, M.G. (2014) The Factors Predicting Stress, Anxiety and Depression in the Parents of Children with Autism. *J. Autism Dev. Disorder.* 2014, 44, 3185–3203. [CrossRef]
- Ferguson, G. (2014). Including children with disabilities in mainstream education: An Exploration of the challenges and considerations for parents' and primary school teachers. Unpublished Masters Dissertation. Dublin, Ireland: Dublin Institute of Technology.
- Fleischmann, A. (2005). The hero's story and autism: Grounded theory study of websites for parents of children with autism. *Autism*, 9(3), 299–316. doi:10.1177/1362361305054410
- Fletcher, P.C., Markoulakis, R. and Bryden, P.J. (2012). The costs of caring for a child with an autism spectrum disorder. *Issues in Comprehensive Pediatric Nursing*, 35(1), 45–69.
- Fombonne E (1999) The epidemiology of autism: A review. *Psychological Medicine*. 29, 769-86 [2] Lotter V (1966) Epidemiology of autistic conditions in young children: I. Prevalence. *Social Psychiatry* 1, 124–137.
- Fombonne E, Marcin C, Manero AC, Bruno R, Diaz C, Villalobos M, Ramsay K, Nealy B (2016), Prevalence of Autism Spectrum Disorders in Guanajuato, Mexico: The Leon survey *J Autism Dev Disord* Volume 46, 1669–1685
- Foo, M., Yap, P.M.E.H. and Sung, M. (2015). The experience of Singaporean caregivers with a child diagnosed with autism spectrum disorder and challenging behaviours. *Qualitative Social Work*, 14(5), 634–650.
- Fragkiadaki, E.; Triliva, S.; Balamoutsou, S.; Prokopiou, A. The path towards a professional identity: An IPA study of Greek family therapy trainees. *Couns. Psychother. Res.* 2013, 13, 290–299. [CrossRef]
- Franz L, Chambers N, von Isenburg M, de Vries PJ (2017) autism spectrum disorder in sub-Saharan Africa: A comprehensive scoping review. *Autism Research*. 10,723-749. doi: 10.1002/aur.1766.

- Freedman, B.H., Kalb, L.G., Zaboltsky, B. and Stuart, E. A. (2012). Relationship status among parents of children with autism spectrum disorders: A population-based study. *Journal of Autism and Developmental Disorders*, 42, 539–548. doi:10.1007/s10803-011-1269-y.
- Freedman, B.H.; Kalb, L.G.; Zablotsky, B.; Stuart, E.A. Relationship Status among Parents of Children with Autism Spectrum Disorders: A Population-Based Study. *J. Autism Dev. Disorder*. 2012, 42, 539–548. [CrossRef]
- Gau, S.S., Chou, M., Chiang, H., Lee, J., Wong, C., Chou, W. and Wu, Y. (2011). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders*, 6(1), 1–8.
- Gau, S.S.F., Chou, M.C., Chiang, H.L., Lee, J.C., Wong, C.C., Chou, W.J., W, Y.Y. (2012). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders*, 6, 263-270.
- Gau, S.S.-F.; Chou, M.-C.; Chiang, H.-L.; Lee, J.-C.; Wong, C.-C.; Chou, W.-J.; Wu, Y.-Y. Parental adjustment, marital relationship, and family function in families of children with autism. *Res. Autism Spectr. Disord*. 2012, 6, 263–270. [CrossRef]
- Gentles, S. J. (2015). Making your own way: A grounded theory study of how parents of children with autism navigate intervention (Doctoral thesis). McMaster University, Hamilton, Ontario, Canada. Retrieved from <http://hdl.handle.net/11375/18077>
- Gentles, S. J., Charles, C., Ploeg, J., & McKibbin, K. A. (2015). Sampling in qualitative research: Insights from an overview of the methods literature. *The Qualitative Report*, 20(11), 1772–1789.
- Gentles, S. J., Jack, S. M., Nicholas, D. B., McKibbin, K. A., & Szatmari, P. (2014). A critical approach to reflexivity in grounded theory. *The Qualitative Report*, 19(44), 1–14.
- Gibson, A. N. (2017). A survey of information source Preferences of parents of individuals with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 47(7), 2189–2204. doi:10.1007/s10803-017-3127-z 16 S. J.
- Gobrial, E. The Lived Experiences of Mothers of Children with the autism spectrum disorders in Egypt. *Soc. Sci*. 2018, 7, 133. [CrossRef]
- Goldstein, H. Communication intervention for children with autism: a review of treatment efficacy. *J Autism Dev Disorder* 2004; 32:373–96.

- Gona, J. K., Newton, C. R., Rimba, K. K., Mapenzi, R., Kihara, M., Vijver, F. V., & Abubakar, A. (2016). Challenges and coping strategies of parents of children with autism on the Kenyan coast. *International Journal of Rural and Remote Health Research, Education Practice and Policy*, 16: 1-12.
- Government of Swaziland, (2010). Ministry of education and training education sector policy. Mbabane: Websters Printers.
- Grant, N., Rodger, S., & Hoffmann, T. (2015). Intervention decision-making processes and information preferences of parents of children with autism spectrum disorders. *Child: Care, Health & Development*, 42(1), 125–134. doi:10.1111/cch.12296
- Gray, D. E., & Holden, W. J. (1992). Psychosocial well-being among the parents of children with autism. *Australia and New Zealand Journal of Developmental Disabilities*, 18(2), 83–93.
- Gray, D.E. (1994). Coping with autism: stresses and strategies. *Sociology of Health and Illness*, 16(3), 275–300. doi:10.1111/ 1467-9566.ep11348729.
- Gray, D.E. (1997). Coping over time: The parents of children with autism. *Journal of Intellectual Disability Research*, 50(12), 970-976.
- Gray, D.E. (2002). Coping with autism: Stresses and strategies. *Sociology of Health and Illness*, 16(3), 275-300.
- Green, S. E. (2007). We are tired not sad: Benefits and burdens of mothering a child with a disability. *Social Science and Medicine*, 64: 150-163.
- Green, V. A., Pituch, K. A., Itchon, J., Choi, A., O'Reilly, M., & Sigafos, J. (2006). Internet survey of treatments used by parents of children with autism. *Research in Developmental Disabilities*, 27 (1), 70–84. doi: 10.1016/j.ridd.2004.12.002
- Greene, J., Hibbard, J. H., Sacks, R., & Overton, V. (2013). When seeing the same physician, highly activated patients have better care experiences than less activated patients. *Health Affairs*, 32(7), 1299–1305. doi:10.1377/hlthaff.2012.1409
- Grossi, D., Marcone, R., Cinquegrana, T., Gallucci, M. (2013). On the differential nature of induced and incidental echolalia in autism. *Journal of Intellectual Disability Research*, 57, 903-912.
- Gruman, J., Rovner, M. H., French, M. E., Jeffress, D., Sofaer, S., Shaller, D., & Prager, D. J. (2010). From patient education to patient engagement: Implications for the field of patient education. *Patient Education and Counselling*, 78(3), 350–356. doi: 10.1016/j.pec.2010.02.002

- Guba, E. G., & Lincoln, Y. S. (1989). *Fourth generation evaluation*. Newbury Park, London and New Delhi: Sage Publications.
- Hall, H.R. and Graff, J.C. (2011). The relationships among adaptive behaviours of children with autism, family support, parenting stress, and coping. *Issues in Comprehensive Pediatric Nursing*, 34, 4–25. doi:10.3109/01460862.2011.555270.
- Hartley, S.L. and Schultz, H.M. (2015). Support needs of fathers and mothers of children and adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 45(6), 1636–1648.
- Hartley, S.L., Barker, E.T., Seltzer, M.M., Floyd, F., Greenberg, J., Orsmond, G. and Bolt, D. (2010). The relative risk and timing of divorce in families of children with an autism spectrum disorder. *Journal of Family Psychology*, 24(4), 449–457.
- Hayes, S.A., Watson, S.L. (2013). The Impact of Parenting Stress: A Meta-analysis of Studies Comparing the Experience of Parenting Stress in Parents of Children with and Without Autism Spectrum Disorder. *Journal of Autism and Developmental Disorders*, 43, 629-642.
- Hayes, S.A.; Watson, S.L. The Impact of Parenting Stress: A Meta-analysis of Studies Comparing the Experience of Parenting Stress in Parents of Children with and Without Autism Spectrum Disorder. *J. Autism Dev. Disorder*. 2013, 43, 629–642. [CrossRef]
- Helland, W.A.; Helland, T. Emotional and behavioural needs in children with specific language impairment and in children with autism spectrum disorder: The importance of pragmatic language impairment. *Res. Dev. Disability*. 2017, 70, 33–39. [CrossRef][PubMed]
- Hibbard, J. H., Greene, J., & Overton, V. (2013). Patients with lower activation associated with higher costs: Delivery systems should know their patients' 'scores'. *Health Affairs*, 32(2), 216–222. doi:10.1377/hlthaff.2012.1064
- Hill AP, Zuckerman K., Fombonne E (2015) Chapter 2 Epidemiology of autism spectrum disorders. In M. d. l. A. Robinson-Agramonte (ed.) *Translational Approaches to Autism Spectrum Disorder*, DOI 10.1007/978-3-319-16321-5_2
- Hodgetts, S., Nicholas, D. and Zwaigenbaum, L. (2013a). Home Sweet Home? Families' experiences with aggression in children with autism spectrum disorders. *Focus on Autism and Other Developmental Disabilities*, 28(3), 166–174.

- Hodgetts, S., Savage, A., and McConnell, D. (2013b). Experience and outcomes of stepping stones triple P for families of children with autism. *Research in Developmental Disabilities*, 34(9), 2572–2585.
- Hoffman, C.D., Sweeney, D.P., Hodge, D., Lopez-Wagner, M.C. and Looney, L. (2009). Parenting stress and closeness: Mothers of typically developing children and mothers of children with autism. *Focus on Autism and Other Developmental Disabilities* 24(3), 178–187. doi:10.1177/1088357609338715.
- Hooyman, N. and Kramer, B. (2006). *Living through loss: Interventions across the life span*. New York, NY: Columbia University Press.
- Howlin, P. and Asgharian, A. (1997). The diagnosis of autism and asperger syndrome: Findings from a survey of 770 families. *Developmental Medicine and Child Neurology*, 41, 834–839.
- Iida, N.; Wada, Y.; Yamashita, T.; Aoyama, M.; Hirai, K.; Narumoto, J. Effectiveness of parent training in improving stress-coping capability, anxiety, and depression in mothers raising children with autism spectrum disorder. *Neuropsychiatric. Dis. Treat.* 2018, 14,3355–3362. [CrossRef]
- Ilias, K.; Cornish, K.; Kummar, A.S.; Park, M.S.-A.; Golden, K.J. (2018) Parenting Stress and Resilience in Parents of Children with Autism Spectrum Disorder (ASD) in Southeast Asia: A Systematic Review. *Front. Psychol.*, 9, 280. [CrossRef]
- Ilias, K.; Cornish, K.; Park, M.S.-A.; Toran, H.; Golden, K.J. (2019) Risk and Resilience Among Mothers and Fathers of Primary SchoolAge Children with ASD in Malaysia: A Qualitative Constructive Grounded Theory Approach. *Front. Psychol.*, 9, 2275. [CrossRef]
- Ilias, K.; Liaw, J.H.J.; Cornish, K.; Park, M.S.-A.; Golden, K.J. Wellbeing of mothers of children with “AUTISM” in Malaysia: An interpretative phenomenological analysis study. *J. Intellect. Dev. Disabil.* 2016, 42, 74–89. [CrossRef]
- Jones, T. and Prinz, R. (2013). Potential roles of parental self-efficacy in parent and child adjustment: A review. *Clinical Psychology Review*, 25(3), 341–363. doi: 10.1016/j.cpr.2004.12.004.
- Kanner L (1943) Autistic disturbances of affective contact. *Nervous Child* 2, 217-50.

- Kanner, L. (1944). Early Infantile Autism. *The Journal of Pediatrics*, 25(3), 211-217
- Kanner, L. (1965). Infantile Autism and the Schizophrenias. *Behavioural Science*, 10(4), 412-420.
- Karst, J.S. and Van Hecke, A.V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review*, 15(3), 247–277.
- Kasonde-Ngandu, S. (2013). *Writing a Research Proposal in Educational Research*. Lusaka: University of Zambia Press.
- Kim SK. (2015) Recent update of autism spectrum disorders *Korean Journal of Pediatrics*. 58, 8-14 [8] APA, American Psychiatric Association. (2013) *Diagnostic and statistical manual of mental disorders*. 5th ed. Washington, DC. pp. 50–59.
- King, G., Tucker, M.A., Baldwin, P., Lowry, K., LaPorta, J. and Martens, L. (2002). A life needs model of pediatric service delivery: Services to support community participation and quality of life for children and youth with disabilities. *Physical and Occupational Therapy in Pediatrics*, 22(2), 53-77.
- Kombo, D.K. and Tromp, D.L.A. 2006. *Proposal and thesis writing: An Introduction*, Nairobi: Pauline publications Africa. L. Olsen, R. S. Saunders, & J. M. McGinnis (Eds.), *Patients charting the course: Citizen engagement and the learning health system* (pp. 103–117). Washington, DC: National Academies Press.
- Konstantareas, M.M.; Papageorgiou, V. Effects of temperament, symptom severity and level of functioning on maternal stress in Greek children and youth with ASD. *Autism* 2006, 10, 593–607. [CrossRef]
- Kwok, S.; Wong, D. Mental health of parents with young children in Hong Kong: The roles of parenting stress and parenting self-efficacy. *Child Fam. Soc. Work*. 2000, 5, 57–65. [CrossRef]
- Lai, J. K. Y., & Weiss, J. A. (2017). Priority service needs and receipt across the lifespan for individuals with autism spectrum disorder. *Autism Research*, 19, 774–712.
- Lai, W.W.; Goh, T.J.; Oei, T.P.S.; Sung, (2015) M. Coping and Well-Being in Parents of Children with Autism Spectrum Disorders (ASD). *J. Autism Dev. Disord.* 2015, 45, 2582–2593. [CrossRef]

- Larkin, M.; Watts, S.; Clifton, E. Giving voice and making sense in interpretative phenomenological analysis. *Qual. Res. Psychol.* 2006, 3, 102–120. [CrossRef]
- Larson, E. (2006). Caregiving and autism: How do children's propensity for routinisation influence participation in family activities? *OTJR: Occupation, Participation and Health*, 26(2), 69–79.
- Lashewicz, B. M., Shipton, L., & Lien, K. (2017). Meta-synthesis of fathers' experiences raising children on the autism spectrum. *Journal of Intellectual Disabilities*, 69(2), 1–15.
- Lasser, J. and Corley, K. (2008). Constructing normalcy: A qualitative study of parenting children with Asperger's disorder. *Educational Psychology in Practice*, 24(4), 335–346.
- Law, M., Hanna, S., King, G., Hurley, P., King, S., Kertoy, M. and Rosenbaum, P. (2002). Factors affecting family-centered service delivery for children with disabilities. *Child: Care, Health and Development*, 29, 357–366.
- Lee, L.C., Harrington, R.A., Louie, B.B., Newschaffer, C.J. (2008). Children with Autism: Quality of Life and Parental Concerns. *Journal of Autism and Developmental Disorders*, 38, 1147-1160.
- Leipert, B. D., Matsui, D., Wagner, J., & Rieder, M. J. (2008). Rural women and pharmacologic therapy: Need and issues in rural Canada. *The Canadian Journal of Rural Medicine*, 13(4), 171–179.
- Lickenbrock, D.M., Ekas, N.V., Whitman, T.L. (2011). Feeling Good, Feeling Bad: Influences of Maternal Perceptions of the Child and Marital Adjustment on Well-being in Mothers of Children with an autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 41(7), 848-858.
- Lillian Wonania, Kenneth Kapalu Muzatab (2019) Parenting and Educating Children with Autism: Lived Experiences of Lusaka Parents' – Zambia.
- Lin, L.Y. Factors associated with caregiving burden and maternal pessimism in mothers of adolescents with an autism spectrum disorder in Taiwan. *Occup. Ther. Int.* 2010, 18, 96–105. [CrossRef]
- Lodder, A.; Papadopoulos, C.; Randhawa, G. Stigma of living as an autism career: A brief psycho-social support intervention (SOLACE). Study protocol for a randomised controlled feasibility study. *Pilot Feasibility Study*. 2019, 5, 1–8. [CrossRef]

- Loomes, R.; Hull, L.; Mandy, W.P.L. (2017) What Is the Male-to-Female Ratio in Autism Spectrum Disorder? A Systematic Review and Meta-Analysis. *J. Am. Acad. Child Adolesc. Psychiatry*, 56, 466–474. [CrossRef] [PubMed]
- Lopez, K.A. and Willis, D.G. (2004). Descriptive versus interpretive phenomenology: Their contributions to nursing knowledge. *Qualitative Health Research*, 14(5), 726-735.
- Lotter V (1967) Epidemiology of autistic conditions in young children: II. Some characteristics of the parents and children. *Social Psychiatry* 1, 163–173.
- Lotter V (1978) Childhood autism in Africa. *Journal of Child Psychology and Psychiatry*. 19(3), 231 – 244.
- Loukisas, T.; Papoudi, D. Mothers' experiences of children in the autistic spectrum in Greece: Narratives of development, education and disability across their blogs. *Int. J. Disabil. Dev. Educ.* 2016, 63, 64–78. [CrossRef]
- Lovell, B.; Moss, M.; Wetherell, M.A. (2012) With a little help from my friends: Psychological, endocrine and health corollaries of social support in parental caregivers of children with autism or ADHD. *Res. Dev. Disability.*, 33, 682–687. [CrossRef]
- Ludlow, A., Skelly, C. and Rohleder, P. (2011). Challenges faced by parents of children diagnosed with autism spectrum disorder. *Journal of Health Psychology*, 17(5), 702–711.
- MacFarlane, J.R. and Kanaya, T. (2009). What does it mean to be autistic? Inter-state variation in special education criteria for autism services. *Journal of Child and Family Studies*, 18(6), 662-669. doi:10.1007/s10826-009-9268-8.
- Mackintosh, V., Myers, B., & Goin-Kochel, R. (2005). Sources of information and support used by parents of children with autism spectrum disorders. *Journal on Developmental Disabilities*, 12, 41–51.
- MacNeil, B.M.; Lopes, V.A.; Minnes, P.M. Anxiety in children and adolescents with autism spectrum disorders. *Res. Autism Spectrum Disorder*. 2009, 3, 1–21. [CrossRef]
- Maenner, M.J.; Shaw, K.A.; Baio, J.; Washington, A.; Patrick, M.; DiRienzo, M.; Christensen, D.L.; Wiggins, L.D.; Pettygrove, S.; Andrews, J.G.; (2016) Prevalence of Autism Spectrum Disorder Among Children Aged 8 Years—Autism and Developmental

- Disabilities Monitoring Network, 11 Sites, United States,. MMWR Surveill. Summ. 2020, 69, 1–12. [CrossRef]
- Maggs-Rapport, F. (2001). Best research practice“: In pursuit of methodological rigour. *Journal of Advance Nursing*, 35(3), 373-383.
- Maguire C (2013) Autism on the Rise: A Global Perspective. Harvard College, *Global health Review*. 4 (1)
- Maljaars, J., Boonen, H., Lambrechts, G., Van Leeuwen, K. and Noens, I. (2014). Maternal parenting behaviour and child behaviour problems in families of children and adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, 44(3), 501–512.
- Mancil, G.R., Boyd, B.A. and Bedesem, P. (2009). Parental stress and autism: Are there useful coping strategies? *Education and Training in Developmental Disabilities*, 44(4), 523-537.
- Manen, M. V. (1990). *Researching lived experience*. London, ON: State University of New York Press.
- Marcenko, M., & Meyers, J. C. (1991). Mothers of children with developmental disabilities: Who shares the burden? *Family Relations*, 40(2), 186–190.
- Maridaki-Kasotaki, K. Understanding fatherhood in Greece: Father’s involvement in child care. *Psicol. Teor. Pesqui.* 2000, 16,213–219. [CrossRef]
- Mason, M. (2010). Sample size and saturation in PhD studies using qualitative interviews. *Forum: Qualitative Social Research*, 11(3), 8.
- Matson, J.L. *et al.* An evaluation of two methods for increasing self-initiated verbalisations in autistic children. *J Appl Behav Anal* 1993; 26(3):389–98.
- Matson, M.L., Mahan, S. and Matson, J. L. (2013). Parent training: A review of methods for children with autism spectrum disorders. *Research in Autism Spectrum Disorders*, 3(4), 868– 875.
- Mays, N.M, Beal-Alvarez, J. and Jolivette, K. (2011). Using movement-based sensory interventions to address self-stimulatory behaviours in students with autism. *Teaching Exceptional Children*, 43(6), 46-52. Retrieved from EBSCO Mega FILE database.
- Mazefsky, C.A., Day, T.N., Siegel, M., White, S.W., Yu, L. and Pilkonis, P. A. (2016). Development of the emotion dysregulation inventory: A promising method for creating sensitive and unbiased questionnaires for autism spectrum disorder. *Journal*

- of Autism and Developmental Disorders. <https://doi.org/10.1007/s10803-016-2907-1>.
- Mbewe, M. (2016) Effectiveness on picture exchange strategy on the communication skills development in Autistic children. Lusaka: UNZA.
- McCormack, L., Thomas, V., Lewis, M. A., & Rudd, R. (2017). Improving low health literacy and patient engagement: A social ecological approach. *Patient Education and Counselling*, 100(1), 8–13. doi: 10.1016/j.pec.2016.07.007
- McStay, R.; Trembath, D.; Dissanayake, C. Raising a Child with Autism: A Developmental Perspective on Family Adaptation. *Curriculum. Development. Disorder. Rep.* 2015, 2, 65–83. [CrossRef]
- Meadan, H., Halle, J.W. and Ebata, A.T. (2010). Families with children who have autism spectrum disorders: Stress and support. *Exceptional Children*, 77(1), 7–36.
- Miller, S.M. (1995). Monitoring versus blunting styles of coping with cancer influence the information patients want and need about their disease: Implications for cancer screening and management. *Cancer*, 76(2), 167-177.
- Milshtein, S., Yirmiya, N., Oppenheim, D., Koren-Karie, N., Levi, S. (2010). Resolution of the Diagnosis among Parents of Children with Autism Spectrum Disorder: Associations with Child and Parent Characteristics. *Journal of Autism and Developmental Disorders*, 40, 89-99.
- Miranda, A.; Mira, A.; Berenguer, C.; Rosello, B.; Baixauli, I. Parenting Stress in Mothers of Children with Autism Without Intellectual Disability. Mediation of Behavioral Problems and Coping Strategies. *Front. Psychol.* 2019, 10, 464. [CrossRef]
- Mockford, C., Staniszewska, S., Griffiths, F., & Herron-Marx, S. (2012). The impact of patient and public involvement on UK NHS health care: A systematic review. *International Journal for Quality in Health Care*, 24(1), 28–38. doi:10.1093/intqhc/mzr 066
- Montes, G.; Cianca, M. Family burden of raising a child with autism spectrum disorders. In *Comprehensive Guide to Autism*; Patel, V.B., Preedy, V.R., Martin, C.R., Eds.; Springer Science: New York, NY, USA, 2014; pp. 167–184.
- Montes, G.; Halterman, J.S. Child Care Problems and Employment among Families with Preschool-Aged Children with Autism in the United States. *Pediatrics* 2008, 122, e202–e208. [CrossRef] [PubMed]

- Morales-Hidalgo, P.; Roigé-Castellví, J.; Hernández-Martínez, C.; Voltas, N.; Canals, J. (2018) Prevalence and Characteristics of Autism Spectrum Disorder Among Spanish School-Age Children. *J. Autism Dev. Disorder.* 2018, 48, 3176–3190. [CrossRef]
- Morrison, E.E. (2007). A review of research on the use of weighted vests with children on the autism spectrum. *Education*, 127(3), 323-327. Retrieved from EBSCO MegaFILE database.
- Mylonas, K.; Gari, K.; Giotsa, A.; Pavlopoulos, V.; Panagiotopoulou, P. Families in Greece. In *Families across Cultures: A 30-Nation Psychological Study*; Georgas, G., Berry, J.W., van de Vijver, F.J.R., Kaşıkçıbaşı, C., Poortinga, Y.H., Eds.; Cambridge University Press: Cambridge, UK, 2006; pp. 344–352.
- Nealy, C.E., O’Hare, L., Powers, J.D., Swick, D.C. (2012). The Impact of Autism Spectrum Disorders on the Family: A Qualitative Study of Mothers’ Perspectives. *Journal of Family Social Work*, 15, 187-201.
- Nealy, C.E.; O’Hare, L.; Powers, J.D.; Swick, D.C. The Impact of Autism Spectrum Disorders on the Family: A Qualitative Study of Mothers’ Perspectives. *J. Fam. Soc. Work.* 2012, 15, 187–201. [CrossRef]
- Neely-Barnes, S.L., Hall, H.R., Roberts, R.J. and Graff, J. C. (2011). Parenting a child with an autism spectrum disorder: Public perceptions and parental conceptualisations. *Journal of Family Social Work*, 14(3), 208–225.
- Ntre, V.; Papanikolaou, K.; Triantafyllou, K.; Giannkopoulos, G.; Kokkosi, M.; Kolaitis, G. Psychosocial and financial needs, burdens and support, and major concerns among Greek families with children with autism spectrum disorder (ASD). *Int. J.Caring Sci.* 2018, 11, 985–995.
- Oliver, M. The social model of disability: Thirty years on. *Disabil. Soc.* 2013, 28, 1024–1026. [CrossRef]
- Ontario Ministry of Children and Youth Services. (2017). Ontario transforming autism services for children and their families [Press release].
- Osborne, L.A.; Reed, P. The Relationship between Parenting Stress and Behavior Problems of Children with Autistic Spectrum Disorders. *Except. Child.* 2009, 76, 54–73. [CrossRef]

- Ou, J.-J.; Shi, L.-J.; Xun, G.-L.; Chen, C.; Wu, R.-R.; Luo, X.-R.; Zhang, F.-Y.; Zhao, J.-P. Employment and financial burden of families with preschool children diagnosed with autism spectrum disorders in urban China: Results from a descriptive study. *BMC Psychiatry* 2015, 15, 3. [CrossRef] [PubMed]
- Ouellette-Kuntz H, Coo H, Yu CT, Lewis ME, Dewey D, Hennessey PE, Jackman PD, Breitenbach MM, Holden JJ (2012) Status report - National Epidemiologic Database for the Study of Autism in Canada (NEDSAC).
- Papadopoulos, D. A Case Study of Parent-Child Interaction Therapy for a Young Child with Autism Spectrum Disorder: Behavioral and Developmental Considerations. *Psychology* 2020, 11, 888–907. [CrossRef]
- Pappas, M.A.; Papoutsis, C.; Drigas, A.S. Policies, Practices, and Attitudes toward Inclusive Education: The Case of Greece. *Soc.Sci.* 2018, 7, 90. [CrossRef]
- Paula CS, Ribeiro SH, Fombonne E, Mercadante MT. (2011) Brief Report: Prevalence of Pervasive Developmental Disorder in Brazil: A Pilot Study. *Journal of Autism and Developmental Disorders.* 41, 1738–1742. doi: 10.1007/s10803-011-1200-6.
- Pisula, E., Kossakowska, Z. (2010). Sense of Coherence and Coping with Stress among Mothers and Fathers of Children with Autism. *Journal of Autism and Developmental Disorders,* 40, 1485-1494.
- Pottie, C.G. and Ingram, K.M. (2008). Daily stress, coping, and wellbeing in parents of children with autism: A multilevel modeling approach. *Journal of Family Psychology,* 22(6), 855–864. doi:10.1037/a0013604.
- Rafferty, D.; Tidman, L.; Ekas, N.V. Parenting experiences of fathers of children with autism spectrum disorder with or without intellectual disability. *J. Intellect. Disabil. Res.* 2020, 64, 463–474. [CrossRef] [PubMed]
- Ray, M.A. (1994). The richness of phenomenology: Philosophic, theoretic, and methodological concerns. In J. M. Morse (Ed.), *Critical Issues in Qualitative Research Methods* (pp. 117-133). Thousand Oaks, CA: Sage publications, Inc.
- Reid, K.; Flowers, P.; Larkin, M. (2005) Exploring lived experience. *Psychologist,* 18, 20–23.
- Rice, C. and Centers for Disease Control and Prevention. (2009). Prevalence of autism spectrum disorders: Autism and developmental disabilities monitoring network,

- United States, 2006. Morbidity and Mortality Weekly Report, 58(S-10), 1-20. Retrieved from <http://www.cdc.gov/mmwr/preview/mmwrhtml/ss5810a1.htm>.
- Rivard, M.; Terroux, A.; Parent-Boursier, C.; Mercier, C. Determinants of Stress in Parents of Children with Autism Spectrum Disorders. *J. Autism Dev. Disorder.* 2014, 44, 1609–1620. [CrossRef] [PubMed]
- Rotarou, E.S.; Sakellariou, D. Access to health care in an age of austerity: Disabled people's unmet needs in Greece. *Crit. Public Health* 2017, 29, 48–60. [CrossRef]
- Ruparelia K, Abubakar A, Badoe E, et al. (2016) autism spectrum disorders in Africa: current challenges in identification, assessment, and treatment a report on the International Child Neurology Association meeting on ASD in Africa, Ghana, April 3–5, 2014. *J Child Neurol*; 31: 1018–26.
- Ruparelia K, Abubakar A, Badoe E, et al. (2016) autism spectrum disorders in Africa: current challenges in identification, assessment, and treatment a report on the International Child Neurology Association meeting on ASD in Africa, Ghana, April 3–5, 2014. *J Child Neurol*; 31: 1018–26.
- Salhia, H.O., Al-Nasser, L.A., Taher, L.S., Al-Khathaami, A.M., El-Metwally, A.A. (2014) Systemic review of the epidemiology of autism in Arab Gulf countries. *Neurosciences (Riyadh)*. 19(4), 291-6.
- Sawyer, M.G., Bittman, M., La Greca, A.M., Crettenden, A.D. and Schaaf, R.C., Toth-Cohen, S., Johnson, S.L., Outten, G. and Benevides, T.W. (2010). The everyday routines of families of children with autism: Examining the impact of sensory processing difficulties on the family. *Autism: The International Journal of Research and Practice*, 15(3), 373–389.
- Semrau, M., Lempp, H., Keynejad, R., Evans-Lacko, S., Mugisha, J., Raja, S., ... Hanlon, C. (2016). Service user and caregiver involvement in mental health system strengthening in low- and middle-income countries: Systematic review. *BMC Health Services Research*, 16(1), 1–18. doi:10.1186/s12913-016-1323-8
- Shattnawi, K.K.; Bani, S.W.M.; Al-Natour, A.; Al-Hammouri, M.M.; Al-Azzam, M.; Joseph, R.A. (2021) Parenting a Child with Autism Spectrum Disorder: Perspective of Jordanian Mothers. *J. Transcult. Nurs.* 2020. [CrossRef] *Brain Sci.* 2021, 11, 309 14 of 16

- Shaw CA, Sheth S, Li D, Tomljenovic L (2014) Etiology of autism spectrum disorders: Genes, environment, or both? *OA Autism*. 2, 11
- Shtayermman, O. (2013). Stress and Marital Satisfaction of Parents to Children Diagnosed with Autism. *Journal of Family Social Work*, 16, 243-259.
- Silva, L.M. and Schalock, M. (2012). Autism parenting stress index: Initial psychometric evidence. *Journal of Autism and Developmental Disorders*, 42, 566–574. doi:10.1007/s10803-011-1274-1.
- Smith, A.M., Grzywacz, J.G. (2014). Health and Well-Being in Midlife of Children with Special Health Needs. *Families, Systems, and Health*, 32(3), 303-312.
- Smith, J.A.; Larkin, M.H.; (2009) *Flowers, P. Interpretative Phenomenological Analysis: Theory, Method and Research*; Sage: London, UK.
- Smith, J.A.; Osborn, M. (2008) *Interpretative Phenomenological Analysis*. In *Doing Social Psychology Research*; Wiley: Hoboken, NJ, USA, pp. 229–254.
- Smith, L.E.; Hong, J.; Seltzer, M.M.; Greenberg, J.S.; Almeida, D.M.; Bishop, S.L. Daily experiences among mothers of adolescents and adults with daily autism spectrum disorder. *J. Autism Dev. Disorder*. 2010, 40, 167–178. [CrossRef] [PubMed]
- Spain, D.; Sin, J.; Paliokosta, E.; Furuta, M.; Prunty, J.E.; Chalder, T.; Murphy, D.G.; Happé, F.G. (2017) Family therapy for autism spectrum disorders. *Cochrane Database Syst. Rev.*, 5, CD011894. [CrossRef]
- Stoner, J.B., Bock, S.J., Thompson, J.R., Angell, M.E., Heyl, B.S. and Crowley, E.P. (2005). Welcome to our world: Parent perceptions of interactions between parents of young children with ASD and education professionals. *Focus on Autism and Other Developmental Disabilities*, 20(1), 39–51.
- Strang, J.F.; Kenworthy, L.; Daniolos, P.; Case, L.; Wills, M.C.; Martin, A.; Wallace, G.L. Depression and anxiety symptoms in children and adolescents with autism spectrum disorders without intellectual disability. *Res. Autism Spectrtrum Disorder*. 2012, 6,406–412. [CrossRef]
- Stroebe, M., Schut, H., & Boerner, K. (2017). Cautioning health-care professionals: Bereaved persons are misguided through the stages of grief. *OMEGA (Westport): Journal of Death and Dying*, 74(4), 455–473. doi:10.1177/0030222817691870

- Syriopoulou-Delli, C.K.; Polychronopoulou, S.A.; Kolaitis, G.A.; Antoniou, A.-S.G. Review of Interventions for Inclusion of Children with ASD and Anxiety in Education. *J. Educ. Dev. Psychol.* 2020, 10. [CrossRef]
- The National Autistic Society (2014) What is Autism? www.autism.org.uk/about-autism.
- Thomaidis, L.; Mavroeidi, N.; Richardson, C.; Choleva, A.; Damianos, G.; Boliass, K.; Tsolia, M. (2020) autism spectrum disorders in Greece: Nationwide Prevalence in 10–11-Year-Old Children and Regional Disparities. *J. Clin. Med.* 2020, 9, 2163. [CrossRef]
- Tountas, Y.; Oikonomou, N.; Pallikarona, G.; Dimitrakaki, C.; Tzavara, C.; Souliotis, K.; Mariolis, A.; Pappa, E.; Kontodimopoulos, N.; Niakas, D. Sociodemographic and socioeconomic determinants of health services utilization in Greece: The Hellas Health I study. *Health Serv. Manag. Res.* 2011, 24, 8–18. [CrossRef] [PubMed]
- Valentine, K. (2010). A consideration of medicalisation: Choice, engagement and other responsibilities of parents of children with autism spectrum disorder. *Social Science & Medicine* (1982), 71(5), 950–957. doi: 10.1016/j.socscimed.2010.06.010
- Wallace S, Fein D, Rosanoff M, et al. (2012) A global public health strategy for autism spectrum disorders. *Autism Res*; 5: 211–17.
- Weiss, J. A., Whelan, M., McMorris, C., Carroll, C., & (2015) the Canadian Autism Spectrum Disorders Alliance. Autism in Canada: National needs assessment survey for families, individuals with autism spectrum disorder and professionals (1–51). Retrieved from http://www.casda.ca/wpcontent/uploads/2015/12/NationalNeedsAssessmentSurvey_July-30.pdf
- Weiss, J.A.; Cappadocia, M.C.; MacMullin, J.A.; Viecili, M.; Lunskey, Y. (2012) The impact of child problem behaviors of children with ASD on parent mental health: The mediating role of acceptance and empowerment. *Autism* 2012, 16, 261–274. [CrossRef]
- WHO, World Health Organization (2013) autism spectrum disorders & Other Developmental Disorders from Raising Awareness to Building capacity Geneva, Switzerland?

- Wong, C.C.Y.; Mak, W.W.S.; Liao, K.Y.-H. Self-Compassion: A Potential Buffer Against Affiliate Stigma Experienced by Parents of Children with Autism Spectrum Disorders. *Mindfulness* 2016, 7, 1385–1395. [CrossRef].
- Woods, R. Exploring how the social model of disability can be re-invigorated for autism: In response to Jonathan Levitt. *Disability.Soc.* 2017, 32, 1090–1095. [CrossRef]
- Yang ZL, Sun GL (2016) Research advances in candidate genes for autism spectrum disorder. *Zhongguo Dang Dai Er Ke Za Zhi.* 18, 282-7.
- Yoon, S.; Bellamy, J.L.; Kim, W.; Yoon, D. Father Involvement and Behavior Problems among Preadolescents at Risk of Maltreatment. *J. Child Fam. Stud.* 2018, 27, 494–504. [CrossRef]
- Zablotsky, B., Black, L.I., Maenner, M.J., Schieve, L.A., Blumberg, S.J. (2015) Estimated Prevalence of Autism and Other Developmental Disabilities Following Questionnaire Changes in the 2014 National Health Interview Survey. *National Health Statistics Report.* 13(87), 1-20
- Zablotsky, B., Bradshaw, C.P., Stuart, E.A. (2013). The Association between Mental Health, Stress, and Coping Supports in Mothers of Children with Autism Spectrum Disorders. *Journal of Autism and Developmental Disorders,* 43, 1380-1393.

APPENDICES

Appendix A: Informed Consent Form

Dear Respondents,

My name is **Hellen Kalumba Chalwe**, I am currently a student at the University of Zambia pursuing a PhD degree in Educational Psychology. This research is a major requirement for me to complete my programme. Thus, this exercise is purely academic.

1) Purpose

The researcher intends to investigate the lived experiences of parents in social interaction ASD children in Lusaka District in Zambia. The researcher is also interested in establishing ways parents socially interact with their children with ASD; to probe the parents' experiences of social interactions with children with ASD and to explore coping mechanism parents', employ in managing experiences of social interactions with their children with ASD.

2) Consent

Participation in this exercise is voluntary. You are free to decline to participate in this exercise at any point.

3) Confidentiality

All data collected from this research will be treated with utmost confidentiality. Participants are therefore assured that they will remain anonymous and untraceable in this research.

4) Rights of Respondents

All efforts will be made to ensure that the rights of participants are protected and respected. Participants are assured that they will suffer no harm as a result of participating in this exercise. Participants are free to seek any clarification at any point of the exercise and to inform the researcher if they feel uncomfortable about any procedure in this research.

5) Declaration of Consent

I have read and fully understood this document. I therefore agree or disagree to participate in this exercise.

.....

Signature

.....

Date

Appendix B: Demographic Information Form

1. Participant ID: _____
2. Age: _____
3. Place of birth: _____
4. Highest level of education completed:

5. Are you fluent in English /Nyanya /Bemba Language? Yes: _____ No: _____
6. Marital Status: _____
7. Are you employed? _____ IF yes: Fulltime: _____ Parttime: _____
8. Occupation: _____
9. Current living arrangement? _____
10. Please provide some brief information about your child (ren) with ASD

Child 1

Age: _____

Sex: _____

Grade/School level: _____

Child 2

Age: _____

Sex: _____

Grade/ School level: _____

Child 3

Age: _____

Sex: _____

Grade/School level: _____ Grade/ School level: _____

Child 4

Age: _____

Sex: _____

11. Are you the primary caregiver at least 50% of the time? _____

Appendix C: Interview Guide for Parents with Children with ASD in Their Core Area

Function

1. Tell me about your experiences as a parent raising a child in social interaction with ASD in Zambia.
2. When and how did you first find out that your child has ASD? What was your reaction?
3. Did you have any knowledge on in social interaction in ASD before having your child?
4. How do you manage your child with ASD in terms communication?
5. How do you manage your child with ASD in terms of social interaction?
6. How do you manage your child with ASD in terms of rigidity of thinking and behaviour?
7. What are your perception and experiences of the reactions of family, friends, and the community to your child's ASD in terms of social interaction?
8. What kind of support have you received from family and friends in relation to having an ASD child?
9. Tell me about programs that are available to help you and your ASD child in social interaction.
10. How does raising a child with ASD in social interaction affect your role in your family and community?
11. Tell me how raising a child with ASD in social interaction has affected your social life.
12. How has raising a child with ASD in social interaction in Zambia affected you physically and psychological?

13. Please describe for me, from your parental experience in social interaction with the ASD child pertaining, the economic impact of raising a child with ASD in Zambia.
14. Tell me about the challenges you encounter as a parent raising a child with ASD in social interaction.
15. Tell me your perspective of how parents' raising children with ASD in social interaction in Zambia can be better supported.
16. Is there anything else that you would like to share with me that would help me further understand your experiences as a parent raising a child with ASD in social interaction in Zambia?

Thank you for your co-operation

**Appendix D: Additional Questions (Parents' In-Depth Semi-Structured Interview Guide
(Parents')**

1. What are or were the hardest years when living with your child with ASD in social interaction?
2. What was your initial reaction when you were informed of your child's ASD diagnosis?
3. Were you aware of what ASD was? If not, how did you inform yourself on the diagnosis?
4. How did this diagnosis change your expectations for your child?
5. What outside sources did your child with ASD in social interaction receive? i.e., occupational therapist, respite, speech language pathologist etc.
6. How did having a child with ASD affect your daily routine in social interaction? Were you able to work full time or did you have to give up your career plans to care for him/her in the home?
7. How did your child's ASD affect your relationship with your other children? i.e., less attention towards them, more towards her)
8. How did in social interaction with your ASD child cause extra stress on your marital relationship? How were you two able to stay strong as a couple and help support one another through this?
9. How did you find in social interaction meaning and acceptance in having a child with ASD? (i.e., at what point did you accept that your child will be "different" than other children?)
10. What advice can you give other families who are raising a child with ASD in social interaction?
11. What have you learned from raising your child with ASD in social interaction?
12. How were you supported by extended family and how did they react to the diagnosis?

13. What are or were the hardest years when living with your child with ASD?
14. What are or were the best years when living with your child with ASD?
15. How is your relationship with your child now?
16. What helped you the most to find meaning and acceptance with your ASD child?

Thank you for your co-operation

Appendix E: Summary of Parents' Interviews Response-Research's Data

Name: In what ways do parents interact socially with children with ASD

<Files\\Parent interviews 1 one> - § 2 references coded [15.37% Coverage]

Reference 1 - 10.48% Coverage

<i>Themes</i>	<i>Codes or near codes</i>
Communicative modes	<ul style="list-style-type: none"> • <i>Affectionate interaction</i> • <i>Rambling interaction</i> • <i>Fragmented emotional interaction</i> • <i>Tapping interaction</i>
<i>Social and emotional support</i>	<ul style="list-style-type: none"> • <i>Reaction to the child's diagnosis</i> • <i>Showing love and interest</i> • <i>Feeling of vulnerability</i> • <i>persistent & resilient</i> • <i>Expression of anger without being too aggressive</i> • <i>Always staying positive</i> • <i>Use of physical activities</i> • <i>Uneven expressive actions</i> • <i>Ensure affectionate & Respect</i>
What are the experiences of parents of children with ASD social interaction	
Family interactive experiences	<ul style="list-style-type: none"> • Poor relationship with spouse • Relationship with sibling • Loss of individual freedom • Limited Family finances
Social interactive experiences	<ul style="list-style-type: none"> • Stigma and Discrimination • Soul life • Inadequate sleeping time • Unruly behaviour among Children with ASD • Mental stress on parents • Anxiety control • Lack of Self – efficacy • Quit job/school

How do parents cope with the experiences of social interaction with children with ASD

<i>Safety Strategies</i>	<ul style="list-style-type: none"> • <i>Adjust activities</i> • <i>Supervision and monitoring</i>
<i>Prevention Strategies</i>	<ul style="list-style-type: none"> • <i>Sticking to fixed routine</i> • <i>Stressful condition</i>
<i>Punishment Strategies</i>	<ul style="list-style-type: none"> • <i>Non- compliance</i> • <i>Disruption activities</i> • <i>Unwanted social behaviour of ASD children</i>

In what ways do parents interact socially with Children with ASD **Affectionate interaction** **Unruly behaviour like throwing of tantrums and emotional outbursts**

<i>communication</i>	Tapping interaction	<i>Challenges experienced by Children</i>
Managing Communication	Rambling interaction Difficult challenging	<i>Lack of desirable social behaviour and reflect stereotypical behaviour make extremely difficult for parents' to socialized</i>
Emotional support	Some help while others do not	<i>Coping strategies Rigidity thinking and Behaviour</i>
	Shock, denial, relief	<i>Other Family Members</i>
Further Contribution Impact on Social Life	Isolation	<i>Parental Reaction</i>
Knowledge About ASD Before Having a Child	No knowledge	
<i>Parents' Experience Raising a Child With ASD</i>	<i>Feeling of Isolation</i>	always
Lack of Sleep	stressful	
Low Self-Esteem	Always	
Robbed me of my life	Psychological stress	

<i>Coping strategies</i>	<i>Constantly Vigilant and watchful of the Child</i>	
<i>Rigidity thinking and Behaviour</i>		
<i>economic hardships</i>	Finances	
<i>School challenges</i>	Un predictive behaviour	

Appendix F: Part of Nvivo Data Output

Name: Challenges experienced by Parents in Social Interaction

<Files\\Parent interviews 1 one> - § 2 references coded [15.37% Coverage]

Reference 1 - 10.48% Coverage

- *The child's influence on the parents' life. The majority of the parents believe that they are the ones most affected by their child's disability, whereas others thought that the family's other children were the most affected. Although many felt that it affected the nuclear family, and the extended family, some parents reported their lives were not affected by having an ASD child. Most of the parents' reported that their child strengthened parental relations ("Communication between us is better now than before").*

Some of the parents' claimed that the child's ASD created new problems, conflicts, and impatience between the parents', and the dyadic relationship was weakened.

Reference 2 - 4.89% Coverage

- *'He is lack of communication, no eye contact... he only knows copy, but he doesn't know how to use the word with other people. This is the problem; this is the problem that's making us headache.' Instead of using verbal communication, their children often expressed themselves by screaming, crying, and throwing tantrums.*

<Files\\Parent interview 3 three> - § 1 reference coded [8.11% Coverage]

Reference 1 - 8.11% Coverage

- *Parents expressed medical concerns and extra stress when the child with an ASD is ill or has to pass a medical examination. The parents were concerned about*

the social adjustment of their child, and felt that he or she is socially isolated or rejected (“He has no friends”), and that there were not enough after-school recreational opportunities or services for children with developmental disabilities.

Files\\Parent interviews 1 one> - § 1 reference coded [4.15% Coverage]

Reference 1 - 4.15% Coverage

- *One example of the ups and downs of their daily experience was the lack of sleep because of the child's erratic sleep schedules and the need to maintain vigilance watching the child through the night. As a mother: “How do I take care of myself? How do I just get breaks?*

<Files\\Parent interview 3 three> - § 1 reference coded [4.83% Coverage]

Reference 1 - 4.83% Coverage

- *They described not having the ability to meet with friends because of their busy schedules and lack of proper childcare. They did not want to socialize with friends who had children who were neuro-typical because they had little in common.*

Files\\Parent interviews 1 one> - § 1 reference coded [4.15% Coverage]

Reference 1 - 4.15% Coverage

- *One example of the ups and downs of their daily experience was the lack of sleep because of the child's erratic sleep schedules and the need to maintain vigilance watching the child through the night. As a mother: “How do I take care of myself? How do I just get breaks?*

<Files\\Parent interview 3 three> - § 1 reference coded [4.83% Coverage]

Reference 1 - 4.83% Coverage

- *They described not having the ability to meet with friends because of their busy schedules and lack of proper childcare. They did not want to socialize with friends who had children who were neuro-typical because they had little in common.*

Files\\Parent interviews 1 one> - § 1 reference coded [4.49% Coverage]

Reference 1 - 4.49% Coverage

“No, he doesn't say ‘Mom.’ It breaks my heart. If he would only say ‘Mom,’ I would be so happy for my daughter, but he doesn't” In addition, many of the children with ASD do not show affection like hugging, but rather used nonverbal communication such as a head tilt, fist bump or rough play.

<Files\\Parent interview 2> - § 1 reference coded [11.01% Coverage]

Reference 1 - 11.01% Coverage

Behavioural challenges, parents experienced a significant lack of verbal and nonverbal communication with their child. All of the children had profound communication deficits. A few children were nonverbal and a few could use simple sentences, but the majority had only a few words in their vocabulary and none of the children could carry on meaningful reciprocal conversation. For many there was a delay of several years before they recognised a parent by calling her “mom” and some still had never said it.

<Files\\Parent interview 3 three> - § 1 reference coded [5.92% Coverage]

Reference 1 - 5.92% Coverage

- *“No, he doesn't say ‘Mom.’ It breaks my heart. If he would only say ‘Mom,’ I would be so happy for my daughter, but he doesn't” In addition, many of the children with ASD do not show affection like hugging, but rather used nonverbal communication such as a head tilt, fist bump or rough play.*

Appendix G: Approval Letter



THE UNIVERSITY OF ZAMBIA

DIRECTORATE OF RESEARCH AND GRADUATE STUDIES

Great East Road | P.O. Box 32379 | Lusaka 10101 | Tel: +260-211-290 258/291 777
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APPROVAL OF STUDY

9th October, 2020

REF NO.HSSREC-2020-SEPTEMBER-013

Ms. Hellen Kalumba Chalwe
C/O School of Education
Department of Educational Psychology,
Sociology & Special Education
University of Zambia
P.O Box 32379
LUSAKA

Dear Ms. Chalwe,

RE: "LIVED EXPERIENCES OF PARENTS IN THE CORE AREA OF DIFFICULTIES IN CHILDREN WITH AUTISM SPECTRUM DISORDER IN LUSAKA DISTRICT"

Reference is made to your protocol dated 7th September, 2020. HSSREC resolved to approve this study and your participation as Principal Investigator for a period of one year.

REVIEW TYPE	ORDINARY REVIEW	APPROVAL NO. HSSREC-2020- SEPTEMBER-013
Approval and Expiry Date	Approval Date: 8 th October, 2020	Expiry Date: 7 th October, 2021
Protocol Version and Date	Version - Nil.	8 th October, 2020
Information Sheet, Consent Forms and Dates	• English.	To be provided
Consent form ID and Date	Version - Nil	To be provided
Recruitment Materials	Nil	To be provided
Other Study Documents	Questionnaire	To be provided
Number of Participants Approved for Study	-	10

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Excellence in Teaching, Research and Community Service