

https://dspace.org/

The influence of children displaying characteristics of autism spectrum disorder (ASD) on the lives of working parents: a case of the Northern Cape Province (NC) South Africa

Botha, Noluthando Daleen Elizabeth

2024

University of the Witwatersrand, Johannesburg

https://hdl.handle.net/10539/44848

Botha, Noluthando Daleen Elizabeth . (2024). The influence of children displaying characteristics of autism spectrum disorder (ASD) on the lives of working parents: a case of the Northern Cape Province (NC) South Africa [Masters dissertation, University of the Witwatersrand, Johannesburg]. WIReDSpace. https://hdl.handle.net/10539/44848

Downloaded from a DSpace repository. https://dspace.org/

The influence of children displaying characteristics of autism spectrum disorder (ASD) on the lives of working parents: a case of the Northern Cape Province (NC) South Africa



A report on a research study presented to

The Department of Social Work
School of Human and Community Development
Faculty of Humanities
University of Witwatersrand, South Africa

In partial fulfilment of the requirements
For the degree Master of Arts in Social Work by Course Work and Research Report in the field of Occupational Social Work

by

Noluthando Daleen Elizabeth Botha,

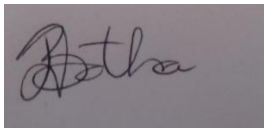
March 2024

DECLARATION

I, Noluthando Daleen Elizabeth Botha, declare that this research report is my own original work. The assistance obtained has been in the form of professional guidance and research supervision. I have acknowledged every source used by means of correctly citing and referencing all sources according to APA 7th edition format of referencing. It has not been submitted before for any degree or examination at any other university and it is submitted for the first time in partial fulfillment of the requirements for the degree Master of Arts in Social Work in the field of Occupational Social Work at the University of the Witwatersrand, Johannesburg.

Name: Noluthando Daleen Elizabeth Botha

Signature:



Date:14 March 2024

ACKNOWLEDGEMENTS

I wish to express my gratitude to:

Participants (Parents and Caregivers**),** thank you very much for allowing me into your spaces and entrusting me enough to share your experiences and vulnerabilities during our discussions. Being employed and caring for children showing characteristics of Autism is indeed an experience you must live to experience. You've made so many sacrifices to ensure that you create a safe, pleasant, and conducive environment for your child/ren. All the coping mechanisms and strategies, you've developed over the years are remarkable. Each one of you are amazing and is doing exceptionally well in raising your children.

My research supervisor Prof Edmarie Pretorius. I thank you for your patience with me. Thank you for encouraging me to have perseverance even when I felt like giving up. Thank you for your guidance and support during the entire research journey. I wish you to fulfilling retirement years.

Jay – Dee Peters, thank you for your friendship. Our telephone chats encouraged me to put in more effort so that I could finish my research journey. Thank you for believing in me, you and your family's support is highly appreciated.

My Father-in-law, Nelson Botha. Thank you, Tata, for your understanding at times when I could not visit you and perform my Makoti duties.

My Grandmother, Emma Booysen**.** Thank you for being a parent figure to me. Your love and prayers gave me the strength to carry through. Thank you that I could always take my kids to you during the school holidays so that I can have more time for my books. I honor and appreciate you for everything you've done for me and my four siblings before, during, and after the passing of our parents.

Lifa Botha**,** my better half, you're understanding, and continuous support are remarkable. Thank you for allowing me to pursue my dreams even at the expense of our quality time together. I appreciate your sense of humor, calmness, kindness, and your unconditional love for me.

My beloved children**,** Yolisa Botha, Thobile Botha, Unako Botha and Menzi Botha**.** You are my motivation to conquer the world so that you can have greater opportunities to become your best. Thank you for understanding when I could not spend quality time with you. I love you wholeheartedly.

My Heavenly Father**.** Dear God, your Grace and Mercy astonished me daily. Thank you for the gift of life and the innumerable blessings upon me and my family.

ABSTRACT

Raising children displaying characteristics of autism spectrum disorder (ASD) leads to various experiences for the working caregiver. The prevalence of ASD is globally estimated that one in every 160 children has ASD. The prevalence rate for ASD in Africa is not known. Based on qualitative research conducted with nine participants in the Northern Cape Province, South Africa, explores the experiences of working caregivers. Bronfenbrenner's ecological systems theory underpins the study. Purposive sampling, a type of non-probability sampling was used to select the nine participants who participated in the study. Semi-structured interview schedule comprising of open-ended questions was used to collect the data. Reflexive thematic analysis was used to analyse the data. The main findings from the study are that caregivers living and caring for a child with ASD characteristics are emotionally demanding and affect the quality of life and well-being of the working caregivers. Living and caring for a child with ASD characteristics influences and limits the social context of working caregivers. Living and caring for a child with ASD characteristics affects the work performance and career development of the working caregivers negatively. Working caregivers living and caring for a child with ASD characteristics need available, accessible, and affordable services to care for the child with ASD characteristics. Working caregivers living and caring for a child with ASD characteristics need continuous practical support and guidance in dealing with unforeseen and unknown circumstances they are confronted with. The main conclusion drawn from the study was that the working caregiver, as being the primary caregiver to the child displaying autism spectrum disorder can find themselves in distress if their support structure is not well established.

KEYWORDS

Autism Spectrum Disorder, Child, Employee, Caregiver.

TABLE OF CONTENTS

DECLARATION ..... **ii**

ACKNOWLEDGEMENTS ..... **iii**

ABSTRACT AND KEYWORD ..... **v**

TABLE OF CONTENTS ..... **vi**

LIST OF TABLES..... **vii**

LIST OF ABBREVIATIONS..... **viii**

Table of Contents

CHAPTER ONE……..……..1
INTRODUCTION……...1
Background of the study…… 1-2
Statement of the Problem and Rationale for the study 3-4
Research Question 5
Aim and Objectives 5
Definition of Concepts 6
Autism Spectrum Disorder (ASD)..... 6
Child 7
Employee 7
Caregiver 7
Limitations and delimitations of research……..……...7-9
Organisation of Research Report……..……9
CHAPTER TWO..... 10
THEORETICAL FRAMEWORK AND LITERATURE REVIEW..... 10
Theoretical Framework…….…… 10-12
Literature Review ……..…….……12
ASD and the characteristics of ASD …… ……..…... 12 - 13
Prevalence of ASD 14-15
Justifications for focusing on children with ASD 15-16
The experiences of caregivers showing characteristics of ASD……..16 - 19
Cultural perspectives on ASD 19
Coping mechanisms and existing interventions for caregivers of children with ASD
Characteristics 20
The role of the occupational social worker in the workplace…….…...22-23
Gaps in Literature…….……...23
Summary ……..…..23
CHAPTER THREE..... 24
RESEARCH METHODOLOGY ……..…..24
Research paradigm, approach and design..... 24
Population, sample, and sampling procedures.....25-26
Method of data collection……...……...……..27

Research instrument 28-29
Method of data analysis..... 29
Trustworthiness of the study 30-32
Ethical considerations..... 32
Voluntary participation.....…32
Informed Consent……...……...33
Confidentiality 33-34
Anonymity 34
Doing no harm..... 34
Summary…….….35
CHAPTER FOUR 36
PRESENTATION AND DISCUSSION OF THE ANALYSED DATA ……...….36
Demographic profile of the participants…….36
Themes developed from analysed data……...37
Theme 1: The emotional experiences of caregivers ……..……..38-44
Theme 2: The influence on the social context of caregivers……44-50
Theme 3: Work performance, wellbeing, and quality of life for working caregiver50-54
Theme 4: Experiences of working caregivers…….54 - 58
Theme 5: Strategies developed by caregivers……...58-63
Summary…….....63-64
CHAPTER FIVE ……...…65
KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS ……...…65
Research question, aim and objectives……65
Objective 1……...……66 - 67
Objective 2……...67 - 68
Objective 3……...…69 - 70
Objective 4……...70 - 71
Objective 5……71- 72
The main findings of the study……...…72-73
Conclusions…….73
Recommendations…….…… 74 - 75
REFERENCES……76 - 89
Appendix A: Participation Information Sheet…….…….....90 - 91
Appendix B: Consent Form for the Participation in the Study…….92
Appendix C: Permission to Contact Caregivers ……...……....93
Appendix D: Ethics Clearance……..94
Appendix E: Human Research Ethics Online Training……...…95
Appendix F: Research Instrument……..……...…96-101

LIST OF TABLES

Table 4.1 Demographic Profile of Caregivers ……36

Table 4.2 Identified Overarching Themes are Presented……37

LIST OF ABBREVIATIONS

Term	Definition
ASD	Autism Spectrum Disorder
CDCP	Centers for Disease Control and Prevention
CST	Caregiver Skills Training
NDP	National Development Plan
NCDOE	Northern Cape Department of Basic Education
QOL	Quality of Life
SDG	Sustainable Development Goals
WHO	World Health Organisation

CHAPTER ONE
INTRODUCTION

In the study, the experiences of caregivers who live with children displaying characteristics of autism spectrum disorder (ASD) were explored. In this chapter, background to the study, the problem statement and rational for the study are presented. The research question, aim and objectives that guided the study are explained. Key concepts are defined, and the limitations and delimitations during the study are highlighted. How the research report is organised, is described.

Background of the study

Children displaying characteristics of autism spectrum disorder (ASD) bring negative and positive experiences for their caregivers. While the current study intends to focus only on the experiences of the working caregivers, it is worth mentioning that the experiences provoked by children displaying characteristics of ASD can also affect other family members (Coussens et al., 2020). But caregivers of children displaying characteristics of ASD face increased resource needs, high levels of parenting-related stress, and social integration challenges. Most of the experiences of these caregivers are reported to be negative. However, it is noteworthy that children displaying characteristics of ASD may also present to their caregivers, positive personal growth (Estes et al., 2019).

Overall, caregivers and their children experience a decrease in their quality of life (QOL) when the child displays characteristics of ASD. Quality of life (QOL) is understood as an individual's subjective perception of their position in life, feasible through their physical, psychological, and social functioning (Nguyen, 2019; Reddy et al., 2019; Ueda et al., 2021). Many factors contribute to decreasing Quality of life (QOL) in families that have a child displaying characteristics of ASD. These include personal level factors such as reduced sleeping times or changes in the child's sleeping rhythms, the child's maladaptive behaviours, and other factors such as child mistreatment by the caregivers and community, and lack of work flexibility especially for the mother, who, in the South African context is often the primary caretaker of the child (Nguyen, 2019; Reddy et al., 2019; Ueda et al.,

2021). These experiences often lead to stress, depression, and anxiety for the parents (Ueda et al., 2021).

In the South African context, many of these challenges that are associated with children displaying characteristics of ASD in a family, are also met with a lack of timeous diagnosis and treatment, together with already constrained resources especially in townships, and rural provinces of the country. One of the examples of the rural provinces in South Africa is the Northern Cape (Matseke, 2020), a province that the current study intends to focus on.

Although it is not the focus for the current study, but further exacerbates the negative experiences of caregivers of children displaying ASD characteristics, in South Africa has been the Coronavirus (COVID-19), which led to an increase in many psycho-social ills. As shown by Ueda et al. (2021), owing to COVID-19, caregivers in different parts of the world including Italy observed that children with ASD engaged more in intense and frequent disruptive behaviours. Such behaviours were displayed by children during the time that caregivers had to work from home since the beginning of the COVID-19-induced lockdowns in March 2020 in South Africa. Many parents received an increased burden when children were no longer allowed to go to school to reduce the spread of COVID-19. Children staying home with their working caregivers increased their responsibilities such as household chores, and educational responsibilities to parents (Ueda et al., 2021). Thus, a combination of other potentially traumatic experiences may lead to detrimental life experiences, especially for parents of children displaying characteristics of ASD in South Africa, yet this seems to receive inadequate research and interventions in the country. Therefore, the student's study will focus extensively on the experiences of working caregivers who live and care for young children displaying characteristics of ASD. This is a crucial research gap that the student's study intends to fulfill and provoke new directions and interventions to support the caregiver, to improve their quality of life, and work productivity.

Statement of the Problem and Rationale for the study

In South Africa, the experiences of caregivers who live with children displaying characteristics of ASD are understudied. This also applies to the experiences of caregivers who may be working while they live and care for children displaying characteristics of ASD. While many studies were conducted to explore various psycho-social and economic challenges that were caused by the different crises in South Africa, for example, the COVID-19 pandemic, little of these studies concerned this population (Gittings et al., 2021; Mbeve et al., 2020; Mbunge, 2020). This limits the knowledge that exists in the South African context on the experiences, and what support and services are urgently needed for caregivers who live with children displaying characteristics of ASD (see also Gobrial, 2018). Noteworthy, while there is a wealth of research that focuses on parents' experiences in living and caring for children displaying characteristics of ASD, such research is mostly conducted in Western societies including the UK and USA (Gobrial, 2018; Reddy et al., 2019).

Limited research on caregiver's experiences of living with children displaying characteristics of ASD is detrimental to the progress of the South African society, considering that there is a high prevalence of ASD globally (Wang et al., 2020). For example, by the year 2018, 52 million people were reported to be on the spectrum globally (Gobrial, 2018). The Centers for Disease Control and Prevention (hereinafter referred to as CDCP) estimated that about 1 in 36 children had been identified with ASD (Maenner, et al., 2023). As discussed earlier, the extent of the existence of ASD globally can be associated with an increase in various psychological difficulties in families, including anxiety, stress, and depression. These factors result in decreased quality of life (QOL) for all impacted families, especially the caregivers, who will have to deal with the child daily (Reddy et al., 2019; Wang et al., 2020). Yet, a decrease in quality of life (QOL) reduces the chances that the world could achieve its Sustainable Development Goals Agenda 2023 (hereinafter referred to as SDGs) to improve the quality of life for all (2015). South Africa has also long committed to improving the lives of all living in the country through these Agenda National Development Planning – Agenda 2030 (South Africa National Planning Commission, 2012).

Furthermore, it must be noted that in the South African context, there is already a high rate of biological father absence (Van den Berg et al., 2021). The implication relative to the biological father's absence is that, in the absence of social fathers or other supportive family members, mothers have to single-parent their child or children displaying characteristics of ASD, hence exerting high levels of parenting stress on them alone. The high levels of parenting stress are believed to decrease parents' own abilities to be actively involved in caregiving and this contributes to dissatisfaction with QOL (Ueda et al., 2021; Wang et al., 2020). There is a risk then that this may continue to affect the South African context, if single parenting persists, especially in cases where the single mothers are the only breadwinner in the family. Yet, it has been shown that social support in the form of parenting together (mother and father), yields better results in caring for children displaying characteristics of ASD (Dunst et al., 1986; Ueda et al., 2021). This results in better management of the experiences, better psychological resilience, and a potential to yield less stress, depression, anxiety, and better QOL (Hadadian, 1994; Wang et al., 2020).

Therefore, the current study aims to explore the experiences of caregivers who live with young children displaying characteristics of ASD in the Northern Cape province, South Africa. The Northern Cape province is of interest in this study because of two main factors (1) being a rural province in South Africa, it is poorly resourced and with limited significant support for caregivers who are working while they live with children displaying characteristics of ASD. To the researcher's knowledge, there are only two Public Special Schools in the Northern Cape, one situated in Kuruman in the John Taolo Gaetsewe District and the other one in Kimberley, in the Frances Baard District. Both schools admit children with all neurodevelopmental conditions, including those displaying characteristics of ASD. As such, there is a long waiting list, and only a few children are admitted at a given time. The Public Special Schools confirmed that children displaying characteristics of ASD diagnosis can be on the waiting list for up to five years before they are considered for placement.

(2) There is inadequate research that has focused on the experiences of caregivers who are working while living and caring for children displaying characteristics of ASD. Therefore, the current study is important to conduct, and likely to partially address the research gap

that exists and to inform practice and interventions that are intended to support the working caregiver who lives and cares for children displaying characteristics of ASD and enhance the lives of the children and the QOL for their families. The findings might guide Occupational Social Workers and allied professionals to facilitate services that contribute to the well-being of the employees, and ultimately enhance their lives. It is also aligned with and contributes to the National Development Planning 2030 Agenda (2015).

Research Question

What are the experiences of working caregivers living and caring for children displaying characteristics of ASD?

Aim and Objectives

The primary aim of the study was to explore the experiences of working caregivers who live and care for children displaying characteristics of ASD in the Northern Cape Province, South Africa.

The objectives of the study were as follows:

- To explore the emotional experiences of caregivers living with children displaying characteristics of ASD.
- To explore how the social contexts of caregivers are influenced when they are living with children displaying characteristics of ASD.
- To establish in which ways living with and caring for children displaying characteristics of ASD disorder are affecting the work performance, well-being, and Quality of Life (QOL) of the working caregiver.
- To explore the experiences that working caregivers are facing when caring for children displaying characteristics of ASD.
- To establish what are the strategies parents have developed to manage caring for children displaying characteristics of ASD.

Definition of Concepts

Autism Spectrum Disorder (ASD)

The current study will use an established definition of ASD which views it as a neurodevelopmental disorder that is associated with the presence of social-communication deficits and restricted and repetitive behaviors (CDCP, 2019; Fernandez & Scherer, 2017; Nguyen, 2019). These are the key behavioural characteristics of someone with ASD. However, for greater scope, the current study will also consider other behavioural characteristics that are associated with ASD, which are; the presence of known medical, genetic, or other psychiatric disorders, and is heterogeneous, thus offering an opportunity to not exclude other characters that may not be clearly categorised (Ouimet et al., 2012; Ousley & Cermak, 2014).

The above definition is considered more comprehensive and relevant for the current study. However, it is noteworthy that some different ways and arguments exist in understanding and defining ASD. A choice of the school of defining ASD is crucial, as the different approaches inform different ways of diagnosis and potential treatments. There is a school of thought that attempts to understand ASD mainly from a biological perspective and explores the mental physiologies of the affected individual (Molendijk et al., 2009; Ouhtit et al., 2015; State & Šestan, 2012). Yet another school of thought argues for understanding ASD primarily from a psychological perspective, with more focus on the displayed behaviours of the affected individual (May et al., 2016; Molendijk et al., 2009; Russell & Norwich, 2012). The current study chooses to take a holistic approach that involves both perspectives to explore the experiences of working caregivers who live and care for children displaying characteristics of autism spectrum disorder.

Caregiver

The more traditional approach that has been used by social workers in defining and working with families, has considered any relationship, or living arrangement that involves children, as a family (Gavriel-Fried et al., 2014). A societal group that is related by blood (kinship), affinity, adoption, foster care, or the ties of marriage (civil, customary, or religious), civil union, or cohabitation, and goes beyond a particular physical residence

(White Paper for Social Welfare. RSA, 1997). Thus, in the student's study caregiver is considered any relationship or living arrangement that includes raising a child together; including where all biological parents may not be present, but the child is raised by any other available caregiver, including people who are not biologically related to the child, the child's cousins, aunts, and uncles (Geldard & Geldard, 2008; Pilkauskas & Cross, 2018).

Child

According to the Children's Act, 2005 (Act No. 38 of 2005), a child is described as any person below the age of 18 years. For the study the definition of the Children's Act will be adopted when doing the selection of participants, all working parents who live with children younger than 18 years who display characteristics of ASD would be considered as potential participants.

Employee

According to the Employment Equity Act, 1998 (Act No. 55 of 1998), an employee means any person other than an independent contractor who works for another person or for the State who receives or is entitled to receive, any form of remuneration. In my study, the definition by the Employment Equity Act will be adopted, as the study is interested in exploring the experiences of working parents who live with their children displaying ASD characteristics. The working parents should be employed at any Organisation or company within the Northern Cape.

Limitations and delimitations of the research study

The limitations and delimitations of the research study are explained in Table 1.1 below.

Limitations	**Delimitation**
Participants might not feel comfortable to share information freely.	The Consent form was read and explained to the participant before the interview commenced. The participant was also given

	assurance on how the collected data is stored by the researcher. All soft copy information was kept on the password protected personal laptop of the researcher. All hardcopy information was kept at the researcher home in a locked cupboard with access only to the researcher. The participants' names or personal information will not be used in reporting on the research study, pseudonyms names were used.
Lack of trust from the participants and commitment from the participants from the inception until the end of the study.	Clarification of the study was shared with the participants on the Participation Information Sheet (PIS) which was sent to the participants before the interview. They familiarised themselves with the content of the PIS. On the day of the interview, the researcher revisited the PIS and the Consent form with the participant to clarify any uncertainties that the participant might have had. Although it is stated in the PIS that the duration of the interview would have been between 45 to 60 minutes, some interviews was extended to allow participants sufficient time to share their experiences.
Participants might not want to share honest opinions and views in the presence of their partners.	The researcher met the caregivers in separate meetings to collect the data.

The biased thinking, feelings, and experiences of the researcher could have an impact on the interpretation of the collected data.	The researcher reflected on every interview, made notes, and was very aware not to allow her own bias and views when interpreting the data. The student was guided by the Social Work Code of Conduct. In addition, an ethics course was attended at WITS, and an online Human Research Ethics Training Module for the Social Sciences and Humanities with Macquarie University was completed before the data collection process started.

Organisation of the Research Report

The introductory chapter contextualizes the background of the study, the problem statement and rationale for the study, and the research question, aim, and objectives. The research methodology applied is highlighted, and the key concepts are defined. Chapter two describes the theoretical framework underpinning the study and the relevant literature applicable to the study. In chapter three the research methodology is explained. Chapter four presents the data collected and the discussion of the analysed data. The final chapter addresses the key findings in relation to the objectives of the study, conclusions, and recommendations.

CHAPTER TWO

THEORETICAL FRAMEWORK AND LITERATURE REVIEW

This chapter focuses on the theoretical framework underpinning the research study and discusses the relevant literature to contextualise the study. Autism Spectrum Disorder (ASD) is defined, and the characteristics are unpacked. The prevalence of ASD is presented. The experiences of working caregivers in taking care of a child displaying ASD characteristics are explored. The importance of focusing on children with ASD is argued. Cultural perspectives on ASD are explained. Coping mechanisms and existing interventions for caregivers of children showing characteristics of ASD are highlighted. The roles of the occupational social worker in the workplace regarding services to working caregivers with children who are showing characteristics of ASD are discussed. Lastly, the gaps in the literature are highlighted.

Theoretical Framework

A theoretical framework is a relevant theory with different dimensions that is fundamental to guiding the research study, and the analysis and interpretation of the collected data (Connaway & Radford, 2021). Bronfenbrenner's model (1977;2007)) explores how different levels of systems within the social context engage with and influence the process of child development. The ecological systems theory is central to this research study because the theory explains an individual's interconnectedness in relation to various systems. According to Donald, Lazarus and Lowana (2010, p.40), Bronfenbrenner's model refers to four interacting dimensions fundamental to the process of child development, which are "the person factor (the temperament of the child or caregivers); the process factor (the patterns and forms of interaction in the family); the contexts (families, schools or local communities) and time (changes that take place over time in the child and the environment)". The four systems that interact with the chronosystem are microsystems, mesosystems, exosystems, and macrosystems. Central to the ecological systems theory, is an emphasis on the importance of the adaptive balance between the person and his/her environment. This is viewed by Germain (1973) as the goodness fit between the two, and it offers a novel way of viewing the important relationship between the person and their

environment. This helped in understanding the experiences of working caregivers who live and care for young children displaying characteristics of ASD.

Bronfenbrenner uses the concept of microsystem to refer to those who are the most immediate contacts in the child's life (Guy-Evans, 2020; MacBlain, 2021). For this study, these are the caregivers. Microsystems involve relationships, roles, and patterns in daily activities that influence interactions between the child and those close to the child, e.g., caregivers. In turn, the interactions affect the development of children (Donald, Lazarus and Lolwana, 2010). The study is interested in the patterns in the relationship between the child displaying characteristics of ASD and the working caregiver. Mesosystems are different microsystems that continuously interact with one another. What happens between the child and the caregivers, can influence how the child responds at the playgroup, school, or friends. The exosystems are systems in which the child is not directly involved. For example, the neighborhood, caregivers' workplaces, parent's friends, and the mass media (Guy-Evans, 2020; Livazović & Bojčić, 2020). However, the exosystems, e.g., the workplace might affect or be affected by the microsystem which in this case are the working caregivers and the child showing ASD characteristics. The influence of the children displaying ASD characteristics on their working caregivers is likely to affect caregivers' attitudes towards their work, as well as their behaviours at work, with friends, and in the home neighborhood.

The macrosystem refers to a broader context where individuals are located, with a focus on their culture or everyday way of life (Analisah & Indartono, 2019; Stanley & Kuo, 2022). Values, beliefs, and practices as well as social and economic structures in the macrosystem, influence all other social systems (Donald, Lazarus & Lolwana, 2010).

The chronosystem is related to the macrosystems, as it also speaks to the transitions and shifts in one's lifespan. All the systems in which developing children are involved are continuously changing and contributing to their development. There is a continuous interaction between changes and children's progressive development. The chronosystem is more open to understanding broader socio-historical contexts that may influence a person (Mulisa, 2019).

In summary, the ecological systems theory is relevant to this study because it offers an opportunity for the researcher to thoroughly understand the caregiver and their children as reciprocally affecting each other's daily lives. Considering the different systems as the lenses might assist in a better understanding of the transactional relationships between environmental conditions and human conditions (Guy-Evans, 2020; MacBlain, 2021; Pardeck, 1988). Thus, Bronfenbrenner's ecological systems theory offers a comprehensive theoretical base for social practitioners, as social workers to do comprehensive assessments and develop relevant interventions and programmes.

Literature review

In the literature review section**,** and the characteristics thereof are explained**.** The prevalence of is addressed, and the importance of researching the experiences of working caregivers while they live with and care for children displaying characteristics of is justified. The review focuses on the different experiences of the caregivers with children displaying characteristics, and various cultural beliefs about and provides an overview of the existing interventions and coping strategies of the caregivers with children displaying characteristics. The role of the occupational social worker in the workplace is highlighted.

ASD and the characteristics of ASD

The study considered ASD as a neurodevelopmental disorder that is associated with the presence of social-communication deficits and, restricted and repetitive behaviours (CDCP, 2019; Fernandez & Scherer, 2017; Nguyen, 2019). Gobriel (2018) has viewed ASD as a lifelong developmental disability that is characterised by qualitative impairments in social interactions, communications, and repetitive, stereotyped behaviours. A lifelong disability implies that caregivers of children displaying characteristics of ASD must live and deal with the ASD characteristics for the rest of their lives. To exacerbate the situation is the fact that ASD characteristics are not curable but might be manageable. Unfortunately, in developing countries with a few fortunate exceptions' children showing ASD characteristics are not receiving specialised treatment or any treatment at all (Fuentes, et al., 2014). It is noteworthy that

globally the prevalence of children showing ASD is growing, and this is also true for South Africa.

The first time some caregivers hear about ASD is when their child/ren is diagnosed by the child psychiatrist or development pediatrician. According to Nguyen (2019), caregivers living with children diagnosed with ASD are encouraged to acquire certain knowledge to make the necessary adjustments to their home to create a conducive and safe space for their children. Common ASD characteristics displayed by children might range from them finding it easier to follow a daily routine instead of sudden changes. Schedules and routines allow young children to believe that they have some degree of autonomy over their lives. If the child is used to seeing his or her mom arrive from work at 17h30 it becomes difficult to accept that the parent must work overtime without preparing the child in advance.

Often children with ASD characteristics are not aware of what might be a risk or danger. Therefore, caregivers must be extra careful and safeguard the living environment to ensure electrical appliances such as toasters, and heaters, are always kept safe. Some children may run away either from home or school, therefore caregivers or teachers should always be alert of this as the child might even run into danger such as an oncoming car. Autism South Africa hereinafter referred to as (A:SA, 2019) indicated another common characteristic is that children adore the sound of breaking glass or hitting, therefore, they recommend plastic plates, bowls, and glasses. Fluorescents or harsh lights can be distracting or painful to children displaying ASD characteristics. One of the ASD characteristics is the sensitivity to noise. There are certain noises that the child finds very irritating such as someone walking on wooden floors compared to carpet or tile floors. They are also sensitive to different smells. These children might find the teachers' deodorant fragrance or even the smell of clothes overwhelming. Clements and Zarkowska (2000) proposed a background scent to block the invasion of uncontrolled smells either in the child’s classroom or at home.

Prevalence of ASD

Since the 1970s, there has been a dramatic rise in the number of reports documenting increasing rates of ASD cases, especially in Western countries (Lenoir et al., 2009). Globally it is estimated that one in every 160 children has ASD (Paglia, 2020). The prevalence of ASD in many low- and middle-income countries is so far unknown due to a lack of available services, awareness of autistic spectrum disorders in both the unprofessional and professional public, and lack of confirmed diagnosis (Mayada et al., 2012).

Clinical Work in Africa on ASD only started three decades following the published work of Kanner and Asperger (Bakare & Munir, 2011). With a few studies documented it is evident that ASD exists on the African continent (Akande, 1999; Lotter, 1978; Mankoski et al., 2006; Moodley, 1992). However, with the few studies where the presence of ASD was studied, it was not in full detail. According to Watfa (2019), as many as 0.2 percent of children in the Sultanate of Oman aged 0 to 14 years are on the autism spectrum. Which is 15 times higher compared to a finding of 2011. It was found that only 1.4 cases per 10,000 children in the Sultanate of Oman have autism (Watfa.,2019). In developing countries ASD is under-diagnosed and several influences might have contributed. Developmental Pediatricians are often inexperienced in the diagnosis and management of ASD which makes it challenging to obtain a diagnosis. There are few psychiatrists specialising in childhood problems. In the context of the study, the nearest neurologist for caregivers in the Northern Cape is situated in Bloemfontein, Free State province. Although diagnosing ASD in children at early ages would be beneficial to the child, however, caregivers' lack of awareness about autism could lead to failure to recognise early symptoms and seek diagnosis and treatment for the displaying characteristics of ASD child.

The Department of Statistics South Africa recorded the South African population at approximately 62,02 million (Census, 2022). The Northern Cape Department of Basic Education confirmed that there are only 11 special needs schools in the province (NCDOE, 2023). According to Pillay, et al. (2021), the prevalence of autism in South Africa is unidentified which makes it difficult to know the distribution and needs of

children on the autism spectrum in education. A research study conducted in the Western Cape province of South Africa found a total of 940 children with ASD in a population of 1,154,353 children; this represents a rate of 0.08% and is below the 1% global estimated (Pillay, et al., 2021). However, the Western Cape represents only one province in South Africa, and it can, therefore, not be generalised to the South African population. Several individuals in low- to middle-income communities find themselves in a previously disadvantaged position with limited or no access to economic resources. All these factors are intertwined and contribute to the difficulties of accessing resources (Guler, et. al., 2018).

Justifications for focusing on children with ASD

Research showed that it is fundamental to pay attention to children displaying ASD characteristics and its effects on families, globally (Ridderinkhof, et al., 2020). Children can be seen as vulnerable but crucial members of society, as they are vehicles to carry on the existence of their families into the future. In addition, it is important that children become involved members of society (Coussens et al., 2020) argue that in the early years of a child's life, participation is essential for learning and development. Yet research has shown that children with disabilities such as children displaying ASD characteristics are at risk to have limited participation or be excluded (Wang et al., 2020).

Considering the expectations for children to progressively develop and be meaningfully involved in society, children displaying ASD characteristics face challenges, or some fail to develop and participate. Caregivers of these children are, therefore, burdened by the responsibilities to assist their children to fit in with other children without ASD characteristics. This responsibility by caregivers is considered a lifelong commitment to care, but most important in this study, such a responsibility imposes significant stressors on the caregiver and families in general and has been reported in various global studies (Coussens et al., 2020; Gobrial, 2018; Reddy et al., 2019; Wang et al., 2020).

Thus, caregivers become the lifelong close contact environment that reciprocates with their children displaying ASD characteristics. According to Bronfenbrenner's ecological systems theoretical perspective, parents formulate their ASD children's microsystem (Bronfenbrenner, 1977; Bronfenbrenner & Morris, 2007). This environment is foundational for children displaying ASD characteristics and their ability to develop and hopefully yield a fulfilling life for themselves and their caregivers, to improved quality of life (QOL) for all (Coussens et al., 2020; Ueda et al., 2021; Wang et al., 2020). However, when caregivers are subjected to this life-long responsibility, they are exerted mostly enormous pressure, especially if they are working caregivers, or perhaps the caregiver is the sole source of income or are supporting each other in the parent or partner subsystem in heterosexual relationships. A few studies have attempted to focus on working caregivers; however, studies mainly have a generic focus on the experiences of all caregivers who are caring for children displaying ASD characteristics as discussed.

The experiences of caregivers with children showing characteristics of ASD

An American study of caregivers of children displaying characteristics of ASD found that the stressors of the caregivers to be unique (Schieve et al., 2007, p.121). Caregivers frequently report feeling almost permanently in a state of crisis and describe facing exorbitant daily challenges. Partners were able to support each other to cope with the challenges of parenting children displaying characteristics of ASD during adolescence, although when fathers were distanced from their child it could cause marital dissatisfaction. The equivocal nature of these findings means it is important to explore in more detail the impact on parental relationships of raising a child displaying characteristics of ASD. It is not just the effect on the parental relationship that is important, but also on other family members, such as siblings (Schieve et al., 2007).

It is worth highlighting that, most of the literature discussed focuses exclusively on the general experiences of parents, and includes families, who live with a child showing ASD characteristics. However, limited to no research has focused exclusively on working caregivers' experiences of living with and caring for children with ASD characteristics, especially in a South African context, thus offering the current study

significance. The significance is more because the study is conducted in one of South Africa's most rural provinces which is the Northern Cape, relative to the rest of the provinces in the country. It comes with limited arguments that, the rural areas in South Africa receive limited research attention, more so for a rare topic such as the focus of the current study.

Although the diagnosis allowed an initial relief for the caregiver, for the purpose of the study focus is placed on the caregiver who lives with children displaying ASD characteristics. For most caregivers when they realise that their child displays ASD characteristics they must navigate and locate the unique services, in the form of resources and knowledgeable professionals, for supporting their child who displays ASD characteristics. Yet, these have proven to be hard to access on a global level (Gobrial, 2018; Lee & Meadan, 2021; Patel et al., 2013; Reddy et al., 2019; Vivanti et al., 2018). The scarcity (in various global countries for example in Malaysia, Egypt, China, and South Africa) of resources and knowledgeable professionals affects both children with ASD characteristics and the caregiver who must deal with the disorder (Gobrial, 2018; Reddy et al., 2019; Wang et al., 2020). Thus, the parents may be forced to use their own nonprofessional, and not scientifically proven methods to support their children (Chamak, 2019; Hu & Kärnä, 2019; Rivera-Figueroa et al., 2021; Sulek et al., 2019). Some of the key findings from previous research conducted in Egypt show high resource scarcity particularly, the lack of special schools, rehabilitation, social care services, and health services. The absence of these services has presented major concerns for caregivers particularly mothers of children displaying ASD characteristics (Gobrial, 2018).

Raising a child requires much effort and attention from caregivers but raising a child with special needs requires even more effort and attention (Dyson, 1998; Hadadian, 1994). Families of children with disabilities do experience more stress than children without disabilities (2003; Innocenti et al., 1992; Keller & Honig, 2004; Smith et al., 2001).

For the caregiver with a low-income making the necessary adjustments or replacements might not be a high priority if they have to priorities paying for the school or food of

his/her child instead. In a study done by Pretorius (1984), she found that 30,77 percent of the families she interviewed believed that their friends were avoiding spending time with their families. She further found that children displaying characteristics of ASD are less likely to accompany the family to certain social activities. Most of the families also felt embarrassed if the child experienced a meltdown in the company of friends or other family members Pretorius (1984). For caregivers who have children with ASD characteristics, shopping for essential household items can become a nightmare because children might experience the background noise of people talking, the smell of different perfumes, and the movement of people walking as overwhelming. Children with ASD characteristics cannot ignore or block out these, therefore they are more likely to experience a meltdown during shopping. This can be stressful and upsetting to the caregiver when other people look at them with the perception that they cannot control their children (A:SA, 2019).

Research has also shown that after diagnosis, caregivers and the rest of the families are forced to adjust their regular daily lives to accommodate the child with ASD. One prominent adjustment is dealing with the social isolation of the family that may follow the diagnosis (MacKenzie & Eack, 2021; Nagib & Williams, 2018; Reddy et al., 2019). Such adjustments may have a strain on the existing spousal relationships for the caregivers, and even with the siblings of the ASD child (Chan & Leung, 2020). For example, Reddy et al. (2019), reported on marriages that were broken down owing to the diagnosis of the child as ASD, and altered extended family relationships were also reported, including a loss of these relationships.

Furthermore, the efforts to support children with ASD characteristics may reduce the amount of time caregivers can dedicate to caring for other children in the families (Reddy et al., 2019). All these negatively affect the QOL of the whole family (Wang et al., 2020). There are also experiences of increased fatigue and anxiety, including the caregiver neglecting their own needs, as they focus on supporting the child with ASD displaying characteristics (Alenazi et al., 2020; Bradshaw et al., 2021; Daulay, 2021; Patel et al., 2022).

QOL is one of the key themes that has developed in previous research on living with and caring for children with ASD characteristics and how it affects the QOL of the parents and the rest of the family. It is a strain on the family social relations – which pushes away the potential social support systems and affects caregivers' psychological well-being (Durán-Pacheco et al., 2022; Lien et al., 2021; Reddy et al., 2019). Some of the factors contributing to the emergency of the mutilations on the social relations of the family, and psychological devastation in working caregivers, especially those with inflexible jobs, are, reduced sleep times (Reddy et al., 2019; Ueda et al., 2021).

Additionally, dealing with and supporting children displaying ASD characteristics leads to financial burdens owing to the costs encountered in the process of supporting the child (Durán-Pacheco et al., 2022; Lien et al., 2021). The experiences of the parents are different, where fathers may not be directly involved with the child when displaying ASD characteristics, their stress in relation to being a caregiver (providing financial support, helping with decision making, and other indirect roles), may also affect the mothers (Wang et al., 2020). Nonetheless, in the current study, the primary argument is that although many studies have exclusively focused on the mothers as primary caregivers (Gobrial, 2018) – both caregivers are affected by parenting children showing ASD characteristics.

Cultural Perspectives on ASD

The cultural perspectives on children displaying ASD characteristics assume that if the disorder occurs children lack appropriate, parenting and discipline. This perspective has caused frustrations and anger among caregivers when their children display ASD characteristics (Burkett et al., 2017; Donohue et al., 2019; Hebert & Koulouglioti, 2010). Thus, the lack of visible disability in children with ASD characteristics yields a belief that caregivers exert poor discipline on their children, and yet other communities believe in community discipline which also exert children to be abused. On the other hand, religion applied pressure on the caregivers by suggesting that ASD is caused by witchcraft and demon possessions (Gona et al., 2015; Reddy et al., 2019).

Coping mechanisms and existing interventions for caregivers of children with ASD Characteristics

Although the above discussion has demonstrated that there are significant challenges that are faced by the caregiver living with children displaying ASD characteristics of autism, research also noted important coping strategies and some existing interventions. These are worth reflecting on as these demonstrate some direction towards bettering the lives of both caregivers and children with ASD characteristics. Furthermore, they formulate the basis to build on the recommendations that will emerge from this study. Some of the key coping strategies included learning how to deal with their child displaying ASD characteristics.

Once caregivers realise their child's ASD characteristics, they actively find strategies that could help improve their situation (Gobrial, 2018). This is crucial because caregivers are seen as the main system that can better effect changes in the lives of their children with ASD characteristics (Estes et al., 2019). Reddy et al. (2019) found that after the parents realised that it was difficult for them to go for social outings, they had to learn through their experience, how to manage these outings. This yielded better and more positive experiences for both the caregivers and the child with ASD characteristics. Furthermore, caregivers and children with ASD characteristics who initially struggled with effective communication found ways to constantly improve communication through experience and for others by enrolling their children in special schools (Reddy et al., 2019). Ultimately, improved communication has been reported to better support children with ASD characteristics to participate in the family system, and they were able to learn in schools – a fundamental developmental aspect (Coussens et al., 2020; Estes et al., 2019). Furthermore, after caregivers accepted these new realities of their children with ASD characteristics, they had their stress quelled (Reddy et al., 2019).

In addition, although discriminative, Reddy et al. (2019) study showed that caregivers with better resources could access intervention strategies such as speech therapy and audiology privately. These additional interventions brought relief to their daily challenges of living with and caring for children with ASD characteristics. It is also

evident that working caregivers have better access to resources, however, being a working caregiver affects both the caregivers and the child with ASD characteristics, and the family QOL (Ueda et al., 2021). Wang et al. (2020) study showed that caregivers working away from home felt less negative impacts on their quality of life, owing to living with and caring for children displaying ASD characteristics. To spend time away from their children with ASD characteristics allowed them to take a break (Ueda et al., 2021; Wang et al., 2020). Research studies found that when caregivers are working, they often have less sleep because they have to cope with work responsibilities as well as assisting the child to go to school or another caregiver during the day, and the finding is that the caregivers' stress levels will increase (Reddy et al., 2019; Ueda et al., 2021).

Adopting home activities such as engaging the child by watching television, and calming techniques, like bribery, adherence to certain routines allowing the child to show peculiar behaviour or taking time out and walking away to refresh to deal with children with ASD characteristics (Reddy et al., 2019).

There are alternative coping strategies that are useful for caregivers of children displaying characteristics of autism spectrum disorder. These include subscribing to certain constructive beliefs such as religion and culture, that yield emotional, character and spiritual growth (Gobrial, 2018; Reddy et al., 2019). This growth was found by Reddy et al. (2019) to overshadow the sacrifices that parents reported to have made in supporting and caring for their children with ASD characteristics. Such a positive approach to their lives helped them find more reasons to appreciate the value of their lives. Additionally, it resulted in their personal transformation, fostering characteristics such as perseverance, tolerance, understanding, compassion, patience, and hope – these also improved their well-being (Gobrial, 2018; Reddy et al., 2019). Their well-being helped them develop relevant networks and supported their efforts towards bettering the lives of their children with ASD characteristics (Gobrial, 2018).

Furthermore, prior to the 1970s children with moderate and severe disabilities used to be sent to institutions far away from home where the primary focus was caring for them instead of cognitive stimulation. However, the need arises for caregivers to

become the primary caregivers to their children, and especially to young children with disabilities. The World Health Organization (hereinafter referred to as WHO) in partnership with Programa Argentino para Niños, Adolescentes Adultos Condiciones Espectro Autista (PANAACEA) initiated the Caregiver Skills Training (CST) programme in Argentina (2021). The programme is aimed at supporting caregivers of children with developmental delays and disabilities such as ASD. The Sixty-seventh World Health Assembly (2014) adopted a resolution entitled "Comprehensive and coordinated efforts for the management of ASD disorders (ASD)," which was supported by more than 60 countries. The resolution urges WHO to collaborate with Member States and partner agencies to strengthen national capacities to address ASD and other developmental disorders.

The role of the occupational social worker in the workplace

A social worker is someone with certain knowledge, skills, and values because of the professional training received (William & Evans, 2013). The role of the Occupational Social Worker would be to provide services in all three practice areas. On the micro-level psycho-social support will be provided to the working caregiver and immediate family including the child displaying characteristics of autism spectrum disorder. One-on-one therapy sessions with the working caregiver and the immediate family can be provided to assess the needs and provide interventions to address the psycho-social needs or do referrals when needed. On a mezzo level, the OSW can establish group work sessions during working hours and request caregivers to voluntarily participate in the support group where they can share experiences and learn best practices among each other. On a macro-level, the OSW can render awareness campaigns amongst colleagues, senior management, organized labour unions, and the broader community to create a better understanding of autism and eliminate judgment towards the working caregiver who might find it overwhelming to cope with the dynamics of living and raising children displaying the characteristic of autism spectrum disorder. The OSW can advocate for inclusivity when meeting with social workers from the Department of Basic Education to encourage early interventions through cognitive stimulation at Early Childhood Development Centres which could enhance learners being enrolled

into mainstream at inclusive schools primary and high school education. to encourage cognitive stimulation. Engaging public and private sector at district and provincial office bearers for the establishment of private or public-owned Centres in communities that can accommodate children displaying characteristics of autism spectrum disorder. Once working caregivers have assurance that their children get equal education opportunities which could contribute to high-performing working caregivers and retaining employees in the Northern Cape province.

Gaps in the Literature

Autism spectrum disorder (ASD) affects individuals regardless of culture, ethnicity, or economic status. Most of the research studies on the prevalence of autism, diagnostic traits of autism, and its impact on life and families come from the United States and other high-income countries. There's a gap in the literature, not only about the prevalence of ASD in Africa but also concerning available treatments and resources. Limited to no research has focused exclusively on working caregivers' experiences of living with and caring for children with ASD characteristics, especially in a rural South African context.

Summary

In this chapter, the ecological systems theory underpinning the study was explained. The literature review highlighted the definition and characteristics of ASD, and the prevalence of ASD, and explored the experiences of caregivers in detail. Cultural perspectives on ASD were discussed, and coping mechanisms and intervention strategies were described. Gaps in the literature were mentioned and the role of the occupational social worker in the workplace regarding service delivery to caregivers with children with ASD characteristics was asserted. In the following chapter, the research methodology applied during the research process will be explained.

CHAPTER THREE

RESEARCH METHODS

This chapter explains and describes the research methodology applied during the research study. The research paradigm, approach, and design used are explained. The population, sample and sampling procedures, and the research instrument are described. The methods of data collection and data analysis are explained. The trustworthiness of the study and the ethical principles considered during the research process are addressed.

Research paradigm, approach and design

This study is located within the constructivist paradigm. Constructivism emphasises participants' own constructions and descriptions of their lived experiences, and it is believed that knowledge is co-constructed between the researcher and participant (Tashakkori et al., 2021). Constructivism asserts that people construct their own understanding of and develop knowledge of the world through their experiences and reflecting on those experiences (Adom et al., 2016). The researcher used this assertion in constructing the research methods that informed the data analysis. Constructivism as a research paradigm was suited for the study of the experiences of working caregivers living with and caring for children with ASD characteristics. Many qualitative studies are grounded in constructivism because they are interested in the experiences of people and the meanings they attach to the experiences.

A qualitative approach was used during the research study. Qualitative research is an approach that involves collecting and analysing data that is non-numerical, to understand concepts, opinions, and/or experiences (Amaratunga et al., 2002; Aspers & Corte, 2019). According to Creswell (2007), qualitative research is an approach to exploring and understanding the meaning individuals ascribe to a social or human problem. In addition, it allows the researcher to collect in-depth and thick data from participants to interpret the meaning that participants attached to the social issue. A qualitative approach was useful for the study because the study aimed to explore the experiences of working caregivers living with and caring for children with ASD characteristics using interviews. It allowed the researcher to explore and co-construct experiences during the interviews. During the

process of data analysis, the researcher engaged with the data to interpret and explain the meaning attached to the data (Flick, 2022). Qualitative interviews allowed the researcher to explore the experiences by listening to the participants' voices.

To achieve the aim of this study, the researcher applied the case study design. A case study design allows for the generation of an in-depth understanding of a multi-faceted or complex issue, such as the experiences of working caregivers who live with and care for children with ASD characteristics (Santa-Maria et al., 2021). This design was applicable because it explored a specific case within a real-world context. The focus was on a bounded context and to explore detailed experiences, to develop in-depth findings on a less explored topic (Wood et al., 2020). An advantage of the case study design is that it is flexible to collect data through various means and the ability to discover deeper causes of the study (Bitektine, 2008). The shortcomings of the case study design are that it is difficult to simplify the findings from one case to another in the research study. The researcher's personal views and preferences can influence the findings of the case study research (Bitektine, 2008).

Population, sample, and sampling procedures

A research population refers to the entire group that a researcher intends to conclude (Mthuli et al., 2021). In the study, the research population was families in the Northern Cape Province, South Africa who are living with children with special needs. The company the researcher worked for arranged the Special Needs training, and people from the Kathu and Kuruman communities were invited to attend the training in 2019. The researcher did not facilitate the training session. The training was provided by Independent Learning (Pty) Ltd. The population was the 54 caregivers who lived and cared for special needs children and who attended the training in 2019. As part of the training session, caregivers were requested to voluntarily participate in a survey and complete a questionnaire. The researcher had access to the completed questionnaires, with consent from Independent Learning (Pty) Ltd, and compiled the list with the details of the caregivers and the type of disability the child has. The sample for this study was drawn from the compiled list with contact details of the caregivers. A research sample refers to the specific group that a researcher will collect data from – thus deducted from the study

population (Brower et al., 2019). The researcher obtained permission from Independent Learning (Pty) Ltd to contact attendees and explore whether they would voluntarily participate in the research study. None of the caregivers who attended the training are known to the researcher on a personal level.

Purposive sampling, a type of non-probability sampling was used to select the nine participants who participated in the study. Purposive sampling is commonly used in qualitative research and is known as judgmental, selective, or subjective sampling (Andrade, 2021; Denieffe, 2020). The researcher relied on her judgment when choosing members of the population to participate in the study. The inclusion criteria were that potential participants:

- should reside in the Northern Cape area, and one or both caregivers should be employed.
- should voluntarily participate in the study.
- should live with and care for a child with ASD characteristics.

Of the 54 attendees on the compiled list, many did not indicate the special needs of their child or confirmed that their child displayed ASD characteristics. The researcher first contacted participants via telephone calls and WhatsApp to inform them about the study and invited them to participate. The researcher clarified her role during the introductory telephone conversation and explained the aim of the research study and emphasised that no one is obliged to participate in the study. All participants who showed interest in participating in the study were send both the participant information sheet (PIS), (Appendix A) and the consent form (Appendix B) via email so that participants can fimiliarise themselves with the content of the two documents. Although 10 participants were interviewed however, the researcher could only use the information from the nine because the 10th participant's child was a young adult of 22 years at the time of the interview and therefore, they did not meet the inclusion criteria. In the end, only nine potential participants met the inclusion criteria. The researcher and participant agreed on the most suitable date, venue, and time to conduct the semi-structured interviews. On the

day of each interview, the student would read the PIS with each participant to clarify any uncertainties and answer questions. The researcher also made sure the participants were clear on what they consented to. Before the interview commenced the researcher explained each question on the consent form to the participant, to allow for clarity questions and the participant had the option to agree or disagree verbally on the questions and then only sign the consent form. The researcher explained the Participant Information Sheet (PIS) to the participants (Appendix A).

Method of data collection

Semi-structured face-to-face interviews were the method of data collection. Interviews as a method of data collection involve at least two people who exchange information through a series of questions and answers (King et al., 2018; Knox & Burkard, 2009). This allowed the researcher to listen to the verbal communication and observe the non-verbal communication of the participants. The semi-structured interviews assisted with the collection of information such as participant's attitudes, perceptions, and reflections on their experiences (Boyd, 2001; Groenewald, 2003; Creswell, 2007; Flick, 2008). However, there are also some disadvantages of using a semi-structured interview. It might be time-consuming to conduct these types of the interviews, as it would need the researcher to probe as much as possible so that the participants' can share their experiences (Adeoye-Olatunde & Olenik, 2021; Alamri, 2019). Furthermore, the collection of data using semi-structured interviews requires a well-trained researcher that can apply all the interviewing skills like, active listening, knowing when and what questions to ask during probing (Adeoye-Olatunde & Olenik, 2021; Alamri, 2019). The researcher is a professional social worker and has been conducting therapeutic counselling sessions and interviews for several years. These skills were applied when semi-structured interviews were conducted with the participants. Each interview was conducted on a separate day to prevent fatigue, and to enable the researcher to reflect on the interview and make notes after every interview in order to put information into perspective. From the nine interviews two participants had to be interviewed on the same day at different time slots based on their availability and both participants reside in nearby towns.

Each participant was asked a maximum of ten semi-structured questions during the semi-structured interview. However, the researcher probed when clarity was required, and allowed sufficient time for the interview to allow caregivers to share information about their experiences of living and caring for children with ASD characteristics. Although the duration of the interview was scheduled for between 45 to 60 minutes, some of the interviews were longer than 120 minutes.

Upon receiving the signed consent form back from the participants all forms were scanned and saved in the electronic research folder on the researcher's laptop which is password protected, and the password is only known to the researcher. The hard copies will be kept in a safe for a period of 5 years and thereafter, it will be destroyed. The consent form (Appendix B) also seeks permission from the participant for the audio recording during the interview, so that all the details from the interview are captured, for transcription and analysis. (Creswell, 2007). The researcher used a smartphone to audio record the interview. The audio-recorded interviews were transferred from the smartphone to the researcher's laptop which is password-protected and saved as part of the research folder. Once the audio recordings were transferred from the smartphone to the laptop the audio recordings were deleted from the smartphone to ensure the safekeeping of the collected data.

Research instrument

A semi-structured interview schedule comprising of open-ended questions was prepared by the researcher prior to conducting the interviews during the research study (Wilkinson et al., 2004). The researcher designed the questions to elicit specific information topic, from the participants (King et al., 2018; Knox & Burkard, 2009). A semi-structured interview schedule was the research instrument of choice because it facilitated the start of the interview guided the conversation and allowed for probing some responses from the participants in more detail (Adeoye-Olatunde & Olenik, 2021; Bearman, 2019). Semi-structured interview schedules enhanced the opportunities for the researcher and the participant to have detailed discussions on the experiences of raising a child displaying ASD characteristics. It allowed the researcher to probe when the participant provided brief responses to the questions. The research instrument assisted in obtaining further

explanation and clarification from the participants' responses which added significant value to the discussions and sourced in-depth detail on the experiences (Warren, 2002; Rubin & Rubin, 2005).

One of the advantages of a semi-structured interview schedule is that it encourages two-way open communication between the researcher and the participant (Adeoye-Olatunde & Olenik, 2021; Alamri, 2019). It also allowed the student to listen carefully to the responses of the participants and ask questions that enabled the collection of well-informed rich data (Mahat-Shamir et al., 2021; Roulston & Choi, 2018). It allowed enough time for the participants to be able to openly speak about their experiences of living with a child displaying characteristics of autism spectrum disorder. Overall, these advantages will allow the student to collect rich data that will yield relevant information to answer the research question and achieve the aim and objectives of the study. In addition, the findings might contribute to knowledge in a less explored field of research.

Method of data analysis

Thematic Analysis (TA) is a method for identifying and analysing patterns of meaning in a dataset (Braun & Clarke, 2006). Fugard and Potts (2020) argue that it is best to regard thematic analysis as a family of methods. The outcomes of a thematic analysis highlight the most salient constellations of meanings, for example affective, cognitive, and symbolic dimensions. Thematic analysis is best suited to elucidating the specific nature of a given group of participants' conceptualisations of the phenomenon under study (Braun & Clarke, 2019). Reflexive thematic analysis was used for data analysis. According to Braun and Clarke (2019), reflexive thematic analysis is an approach to analyse qualitative data about people's experiences, views, and representations of a phenomenon. Reflexive thematic analysis offers tools and techniques within a qualitative values framework.

Reflexive thematic analysis involves six recursive phases namely, familiarisation, coding, generating initial themes, reviewing, and developing themes; refining, defining, and naming themes; and writing up (Braun & Clarke, 2019a;). The researcher applied the six recursive phases in the study. The first phase is familiarisation with the data. After conducting the interviews, the researcher read the transcripts multiple times listened to the

recordings during transcribing and made notes during the process (Braun & Clarke, 20019) to immerse herself in the collected data. The second phase is coding, and it is recognised as an inherently subjective process. According to Braun and Clarke (2019), it can either be semantic or latent. For the study, the semantic approach was used. This process has the potential to catch the student deeming understanding of data. Following the process of familiarisation, the researcher identified some key codes from the transcripts. Using tools such as highlighting ideas in the transcripts and then cutting and pasting as well as making notes helped the researcher to understand the data in the process of developing and formulating themes. The third phase is generating initial themes through data engagement mediated with all that they bring to this process. Using techniques such as organising, connecting the key findings that the researcher would have coded, and then clustering these under some broader themes. The fourth phase is reviewing and developing themes, by revising the broader themes that were generated moving the more similar ideas or quotations if needed, and possibly combining themes. In doing so, the researcher asked questions about the different themes that were linked to the research question. The fifth phase was refining, defining, and naming themes. Braun and Clarke, (2019) advise that too many or small themes or subthemes might lead to improper or fragmented and under-developed analysis. They recommend avoiding one-word theme names and domain summary types. The researcher considered the suggestions made by Braun and Clarke (2019) during this phase. A short description of each theme was written. These set the framework for the final step, namely producing the report. The final phase is writing the report. The researcher organised the research report to meet the requirements of the university on how to present the report. Analytic commentary was used to integrate existing literature and theory. Data were presented to respond to the research question, aim, and objectives of the research study.

Trustworthiness of the study

Qualitative research is subjective in nature and has been criticised, therefore qualitative researchers must ensure the trustworthiness of the research. The researcher ensured trustworthiness by considering the four constructs credibility, dependability transferability, and confirmability (Shenton, 2004).

Credibility(validity) refers to ensuring that the research findings are as congruent as possible within reality (Shenton, 2004; Wood et al., 2020). To ensure credibility the researcher adopted and followed well-established research methods and documented the research process in as much detail as possible. The researcher is also at an advantage because she is familiar with the Northern Cape province where the study was conducted. This will allow the researcher to be able to best understand the findings within their context and try to ensure that the participants answer the research questions with honesty. This challenged the student to think further and to work on the findings with appropriate scrutiny, to ensure that they are as close as possible to the reality of the participants' lived experiences. Furthermore, it ensures the confirmability of the study – another strategy to ensure trustworthiness (Haven & Van Grootel, 2019).

Dependability (reliability) is closely linked to credibility (Lincoln, 1995; Guba, 1981). To secure dependability the research process was documented in detail, which can enable other researchers to follow the process although similar findings might not be achieved. For readers of the research report to develop a thorough understanding of the methods and their efficiency, it is important to document the following in detail. The text must include units dedicated to the research design and its execution, a recitation of what was planned and executed on a conceptual level. The active detail of data gathering, addressing the details of what was done in the field; reflective evaluation of the project, and evaluating the efficiency of the process of inquiry undertaken (Shenton, 2004).

Transferability is a strategy used to ensure the external validity of qualitative research (Shenton, 2004). Qualitative findings can only report on the specific findings and context in which it was conducted. Therefore, it is difficult to transfer the findings to another context. However, studies have argued that the work of qualitative researchers provides enough details about the context and the participants so that other researchers can relate the findings to other contexts (Daniel, 2019; Munthe-Kaas et al., 2019). Hence, the researcher provided rich information about the research context and the participants. These should enable other researchers to apply the findings in similar contexts and populations. This also contributed to the dependability of the study because readers can make sense of the participants and the context in full (Shenton, 2004). By providing detailed information

about the study and the research process followed, other researchers can implement similar studies and possibly find similar findings.

According to Patton (1990), **confirmability** is the impartiality in science making use of instruments that are independent of human skill and perception. However, he highlights the challenges of confirming actual objectivity, because the tests and questionnaires are designed by humans, and the imposition of the researcher's biases is unavoidable. As the researcher, it was important to be aware of my own biases (Miles and Huberman, 1994). This eliminated imposing my beliefs and thinking on the information obtained from the participants (Shenton, 2004). By using direct quotations from participants supporting the themes in the presentation and discussion of the findings confirmed that these were the experiences of the participants and not the ideas of the researcher.

Ethical considerations

Before conducting this study, the researcher applied for ethics clearance from the Departmental HREC (non-medical). An ethics clearance certificate was achieved, and the protocol number is Protocol Number: SW23/02/01. It is essential to obtain ethics clearance from the University of the Witwatersrand since the research involves human beings (Arifin, 2018; Yarborough, 2021). In addition, the researcher completed the Human Research Ethics Online Training Module for the Social Sciences and Humanities with Macquarie University, and a copy of the certificate is attached, see Appendix E. After receiving ethics clearance, the researcher proceeded with the collection of data. The ethical principles considered during the research study are described below.

Voluntary participation

Voluntary participation is a decision taken by the potential participants on whether they wish to freely participate in a study (Marshall, et al., 2014). The researcher explained to the participant that they could stop the interview at any given time should they feel uncomfortable continuing with the study. The participant was informed that they do not have to answer any questions if they do not want to. The participants will not get any direct benefits if they choose to join the research study and they will also not lose any services,

benefits, or rights if they decide not to join. Taking part in the research study will not cost the participant anything and they will not be paid for being in this research study. The researcher shared a copy of the Participation Information Sheet (PIS) (Appendix A) with the participants via email so that they were informed about the research study. Information on possible dates, venues, and times was decided upon with the participant. On the day of the semi-structured interview, the researcher discussed the PIS with the participant to ensure voluntary participation was understood and this allowed the participant to decide if they wished to voluntarily participate or not. Once they decided to participate, they verbally agreed and signed the Consent Form (Appendix B) before the interview commenced.

Informed consent

In qualitative research informed consent means that human participants can choose to enter a research project voluntarily after they were given detailed information about the aim of the study and what it entails (Xu, et al., 2020). They will then understand what it means to participate in the study and be informed about the study they must give consent before they participate in the research (Klykken, 2021). The researcher invited the participants to take part in a semi-structured interview. The consent form clearly states what they consent to, e.g., to be interviewed and for the interview to be audio-recording, confidentiality and anonymity are mentioned, and how the data will be used.

Confidentiality

Participants who decide to participate should be given the assurance by the researcher that all information obtained from the research will be treated as confidential. Confidentiality cannot be guaranteed during the interviews because the researcher will know who she is interviewing. However, the researcher can guarantee the confidentiality of the information in writing up the research report by not mentioning the name or any other personal information of the participants. The researcher kept all softcopy documents in an electronic research folder on a password-protected laptop. The password will only be known to the researcher. The NASW and ASWB (2005) ethics on practitioners' use of technology state, that social workers shall safeguard client confidentiality when using technology in their

practice and file all services, taking extra precautions to protect client information in the electronic record. Furthermore, the NASW Code of Ethics (2018) defines ethical obligations, including the ethical obligation to maintain client confidentiality. All hard copies will be kept at the student's home in a safe. The information will be destroyed after 5 years. It is the researcher's responsibility to maintain the participants' confidentiality to ensure clients' rights to confidentiality, dignity, and respect. If practitioners assure confidentiality to the client could lead to fostering trust in work relationships, inspiring participants to be vulnerable in the sessions to share potentially embarrassing information and be rest assured that the student will respect the confidentiality of the client (Downs, 2015).

Anonymity

The data that will be collected should be treated as confidential and should be anonymised. When sharing the findings of the research study, the researcher did not include the participants' names or anything else that could identify them. With the permission obtained from the participant, other researchers may use the data collected from this research study, but the name and any personal information will not be used or passed on. With the permission being obtained from Independent Learning Pty (Ltd), potential participants were informed that permission was obtained, however, they were still allowed to decide if they wished to continue with the telephonic discussion when the researcher called to introduce herself and the research study.

Doing no harm

Ethical considerations must be ongoing to ensure no harm is caused to the participants and for the trustworthiness of the study, not neglecting the importance of the research ethical guidelines (NASW, 2018). As a social worker, it is important to pay attention to the critical reflection on one's own views, values, and feelings, and on the outcome, one achieves, are vitally important and not impose these on clients. Therefore, the researcher had no intention to cause any harm to the participants but rather to respect their rights and privacy during the research process. The risk category for the research study was low and therefore, no more than what happens in everyday life. However, should some of the

questions the researcher asked made the participants feel sad or upset the researcher had a distress protocol in place and stopped the interview and continued another time. The participant was informed that if they needed some support or counselling services following the interview, services were available free of charge at Families South Africa (FAMSA) in Kathu.

Summary

In chapter three, the research methodology applied during the research process was explained in detail. In chapter four, the presentation and discussion of the collected data are presented.

CHAPTER FOUR

PRESENTATION AND DISCUSSION OF THE ANALYSED DATA

This chapter presents and discusses the data gathered during semi-structured interviews with nine caregivers of children with ASD characteristics. The demographic profiles of the participants are presented in Table 4.1. The themes developed from the thematic analysis of the collected data are presented in Table 4.2. This is followed by a presentation and explanation of the data per theme. These are critically discussed and supported or contrasted by direct quotations from participants, applicable literature, and the theoretical framework relevant to the research study. A summary concludes the chapter.

Demographic profile of the participants

In Table 4.1 the demographic profile of the participants is presented.

Table 4.1: Demographic profile of Caregivers (N=9)

Demographic Factor	Subcategory	No
Gender	Female	8
	Male	1
Race	African (Black)	4
	Coloured	2
	White	3
Gender of child	Female	2
	Male	8
Location	Kathu	4
	Kimberley	1
	Kuruman	1
	Postmasburg	2
	Upington	1

In Table 4.1 the demographic factors, subcategories, and number per factor and subcategory are presented. Nine caregivers participated in the research study. Of the nine participants, eight were female and one was male. In terms of race, four participants were black Africans, two were coloured and three were white. Of the children with ASD characteristics were all diagnosed and eight were male and two were female. One of the participants had two children, one boy and one girl with ASD characteristics. In terms of location, four participants were from Kathu, one from Kimberly, and one from Kuruman. Two participants were from Postmasburg and one from Upington. In the original planning of the research study, the sample size was 10 caregivers however, only nine caregivers were interviewed. The reason was that one of the criteria was that the child must be younger than 18 years of age. One of the potential participants sampled did not meet the inclusion criteria for caring for a child younger than 18 years of age. Caregivers are from different towns in the Northern Cape which could be regarded as a representation of the Northern Cape.

Themes developed from analysed data

In Table 4.2, the identified overarching themes are presented.

Table 4.2: Overarching Themes

Themes developed from the collected and analysed data
1. The emotional experiences of caregivers
2. The influence on the social context of caregivers
3. Work performance, wellbeing, and quality of life for the working caregiver
4. Experiences of the working caregivers
5. Strategies developed by caregivers

The five themes are presented, supported by direct quotations from participants, and the ecological systems theory as the underpinned theoretical framework. According to Donald, Lazarus and Lowana (2010, p.40) Bronfenbrenner's model refers to four interacting dimensions fundamental to the process of child development, which are "the person factor (the temperament of the child or caregivers); the process factor (the patterns and forms of interaction in the family); the contexts (families, schools or local

communities) and time (changes that takes place over time in the child and the environment)". The four systems that interact with the chronosystem are microsystems, mesosystems, exosystems, and macrosystem. and literature supporting or contrasting the theme are integrated. The presentation and discussion of the analysed data supported with literature review from Chapter 2.

Theme 1: The Emotional Experience of Caregivers

This theme explains the emotional experiences of caregivers living with children displaying ASD characteristics. In the context of the sample, most of the caregivers were mothers except for one father participant. Caregivers identified a range of emotions: anxiety, fear, overwhelmed, heartbroken, worry, stress, frustration, anger, heavily burdened, exhaustion and teary. Although most of the experiences of caregivers are reported to be negative, noteworthy children displaying characteristics of autism may also present positive personal growth (Estes et al., 2019). The participant experienced fear and anxiety due to her son being bullied and self-harming. The participant mentioned:

"And that was a very big thing. I was living in fear. At one stage, I had to hide every night because then we didn't know about the meltdowns with autistic children, and he would grab a knife to cut himself. So, we had to start hiding knives and stuff like that. And I was living in fear because I must be at work thinking what if he goes home alone."

The participant felt anxious and fearful when the son had to travel without her. Mesosystems are different microsystems that continuously interact with one another. What happens between the child and the caregivers, can influence how the child responds to external family members. The participant reacted as follows:

"Him visiting extended family for three weeks. And it was horrible for me because I was thinking, I'm not there. How's my child going to survive? Who's going to do the stuff, the special stuff? There's nobody there to do that. And I've got a big, big fear because latrine toilets are used in the community where the extended family lives and the fact that my autistic son needs to use that at times makes me fear for his safety."

The constant fear and anxiety felt by the caregivers when their children are under the supervision of someone else. Most of the caregivers feel that they alone, are in a better position to deal with the conditions of their children. It is a strain on the family social relations which pushes away the potential social support systems and affects caregivers' psychological well-being (Durán-Pacheco et al., 2022; Lien et al., 2021; Reddy et al., 2019). They expressed concerns about the child's well-being and safety, especially when not around. Another participant had the following to say:

"There are only a few family members that understands my son, most would usually be judgmental showing and expressing that my son is ill-disciplined. So, I prefer to be close to him if I can for him not to experience prejudice and to be ill-treated because he is differently abled."

The caregiver felt scared but also hurt by some of the words that the child had to say although she understood where it was coming from and knew she had to control the child regardless. The caregivers also expressed being heartbroken seeing the helpless condition their children would be in. One participant had the following to say:

"*Every time I get from work, I would find him sleeping in a dark room. It broke my heart to see my baby in that state because you don't want to see your child like that. He's got the most beautiful, loving personality."*

Another caregiver expressed feelings of anger and frustration when dealing with their child's behaviour, especially when it comes to controlling their emotions and understanding their child's special needs. The caregiver mentioned instances where she has reacted angrily, screamed at the child, and later regretted the actions. The caregiver becoming angry and frustrated by external factors explains an individual's interconnectedness in relation to various systems (Donald, et al.,2010). She wishes to control her emotions better, especially when dealing with her child's special needs, and acknowledges moments of anger and difficulty in disciplining her child. She mentioned:

“I remember when she threw the phone, I took a belt and gave her a hiding. And sometimes even the way I... I have those times that I will scream at her. And I will only feel emotional in the way she’s looking at me. It's like she's saying, but mommy, I'm not doing this purposely. But then the damage is already done. I just wish I can be able to control my emotions. Not forgetting that I'm dealing with a child with a special need, although I don’t want her to feel that she is different from other kids except that she cannot speak. But I would really be angry with the things that she does at times.”

Caregivers also experiences frustration and irritation when people don't understand their child's autistic behaviour in public settings like the mall. In a study done by Pretorius (1984) majority of the families also felt embarrassed if the child experiences a meltdown in the company of friend or other family members. Caregivers have developed strategies to stabilise their children's emotions during meltdowns but feel people still don't comprehend ASD. One of the caregivers note

Sometimes it's kind of frustrating when you go to the Malls, and she starts maybe crying for something. And people would look, because she's very tall, her height is too high. So, people will start seeing a child that is not disciplined. They don't understand, but then I try to turn a blind eye on them. Because obviously they don't even understand what it means to care for children with autism. And I cannot even explain to them by that time what is happening.

Participants characterised their emotional experiences caring for a child with autism as challenging, frustrating, and overwhelming. The cultural perspectives on children displaying ASD characteristics assume that if the disorder occurs children lack appropriate, parenting and discipline. This perspective has caused frustrations and anger among caregivers, when their children display ASD characteristics (Burkett et al., 2017; Donohue et al., 2019; Hebert & Koulouglioti, 2010). Caring for a child with autism is emotionally challenging due to the demands of controlling the child in challenging situations. The

experiences often lead to stress, depression, and anxiety for the caregiver (Ueda et al., 2021). The Participant mentioned:

'Whenever he's fighting, my parents, especially my mother, who looks after him when I am at work, does not have the strength to control him. Remember these kids with autism, I don't know whether it's only my son or what, but he's so powerful at the age of 14 years. Because when he grabs you, the strength he shows is like a man of 55 years or 45 years. So, the only thing that makes me sad, is when I need to be at work and cannot assist my parents to control him whenever he wants to fight. That's why I'm getting too emotional. And when I look at my mother, sometimes it's like it's too much for her. She's taking my responsibilities. So, at times when I'm here at work and she's there, and she's struggling with one, two, and three, that is a time when I'm too emotional and I will be disturbed at work for that whole day."

The Participant shared that:

"Growing up, he grew up just like a normal child. So, we did not even realise that he might be having challenges. When he turned 03 years, and he could still not speak that's when we became worried. He has certain meals because there's a lot of things that he doesn't eat. Even if you prepare food for him, you mustn't... Like, if you prepare lunch, you should not add vegetables because then he will not eat the food. Mince and rice are his favorite meal; however, we don't add mix vegetables to the mince otherwise he will not eat it. Even if you prepare any type of meat, you mustn't add vegetables. He enjoys liquids a lot. It can be water, Powerade, cold drinks, things like that. And he also enjoys sweets. Like... That's where the challenges also come in, because. At one stage, he was experiencing a toothache, and we didn't even know because he cannot communicate to us. We realised he was just crying. So that's one of the challenges that we have with him."

Participants mentioned the emotional challenges associated particularly with child's speech development. Untrained caregivers struggle to understand the needs of their children when they cannot express them in speech. The misunderstanding between the caregiver and the

child with autism often culminates into a meltdown or violent confrontations which are often difficult to calm down. Abdoola, Alli, and Mupawose (2015) in a study concluded that parents and children with ASD experience challenges in communication and interaction. The situation between the caregiver and the child is often worsened by the lack of support systems in the form of doctors and specialist who understands the condition and are accessible to the caregivers for information and knowledge.

The emotional experiences of caregivers are worsened when they must work and provide for the family and the children with autism. Majority of the caregivers' experiences emotional challenges in raising their children with autism, especially when they must work and are unable to provide full attention to them. The caregivers mentioned that taking care of a child with special needs is emotionally overwhelming and requires a lot of attention and time. Caregivers highlighted the importance of spending time with the child and providing emotional support. When they must also be at work, their time is split between caregiving and work. It would be naturally expected that either work or the caring of the child will suffer. Having a caregiver sitting at work worrying about the care being offered to their child who requires special attention because it is contributing to poor work performance. The central of the ecological systems theory is an emphasis on the importance of the adaptive balance between the person and his/her environment (Germain, 1973). Most caregivers find it difficult to balance work responsibilities which could be regarded as the caregivers' exosystem which is influenced microsystem of caring for the autistic child and caregivers finding it difficult to balance between the microsystem and exosystem responsibilities (Guy-Evans, 2020; Livazović & Bojčić, 2020). When the support caregivers, usually members of the family who help with childcare, are also struggling, it is stressful and causes an emotional strain. The caregivers felt frustrated and overwhelmed at times, especially during challenging situations like Covid 19 lockdowns. Another caregiver mentioned:

"[In 2019] it was the only training that we received. But we were having this other WhatsApp group. One of the parents with an autistic child introduced me to the lady and she added me to the autism support WhatsApp group. The group is the only place where

I'm getting information. Sometimes a parent is sharing [information], or one of the social workers is giving visual training. Sometimes when that training is taking place, I'm at work and busy and I cannot attend it. So, I'm really getting little time to join that group. [The group] is called Parent Network Northern Cape. Yeah. That's where we as caregivers share our experiences of raising children with different disabilities."

Another source of emotional frustration for caregivers is the meltdowns that are often experienced by their children. One of the participants stated that she felt overwhelmed when her son became aggressive, and she struggled to control him. It leads to emotional distress that manifests in reactions that can either be excessive or underwhelming. Most of the caregivers expressed the importance of understanding and managing their children's meltdowns in a calm manner and acknowledged the challenge of managing their own emotions and expressed a desire to improve their knowledge and skills to deal with their emotions.

The participants mentioned that another challenge and frustration is the lack of guidance to deal with the growing child with ASD characteristics. The little training and experiences acquired was useful when their children were younger, but as they grow older, the nature of their care has different dimensions, and it is often unknown. The caregivers expressed concerns about their child's growth and development, especially as they become a teenager and adult. The caregivers struggle with finding the right support and resources to help them and their children. The caregivers worry about what will happen to their children if they are no longer there to care for them. The worry caregivers feel was highlighted by Gobriel (2018) when he viewed ASD as a lifelong developmental disability that is characterised by qualitative impairments in social interactions, communications, and repetitive, stereotyped behaviours. A lifelong disability implies that caregivers of children displaying characteristics of ASD must live and deal with the ASD characteristics for the rest of their lives hence caregivers in the study indicated that the feel stressed about their child's future and are emotional due to uncertainty about their child's education and development. They fear for their child's safety, particularly in relation to their understanding of their changing body and potential exploitation. In the context of this

emotional turmoil caregivers find themselves in, they expressed their wish for the establishment of support group of parents facing similar challenges to be informed about new developments in the field of ASD, share ideas and comfort each other.

Theme 2: The Influences on Social Context of Caregivers

Caring for a child with special needs is likely to alter the social context of the caregivers. Taking care of a child with special needs is emotionally demanding and requires a lot of attention and time. One of the participants explained: *my social context is influenced by my relationship with my ADHD son, who is on the high end of the ASD spectrum*.

As the mother caregiver, she plays a significant role in her son's life. She understands him better and can handle and control him effectively. She now views and relates to her social context through the lenses of the emotional demand and time required in caring for her son. When the son is rejected by his father, she struggles as well. She noted:

"He's on the high spectrum of ADHD. And then the rejection came. He couldn't accept the rejection that his father pushed him away. And then, you know, the older he became, if you have the full autistic spectrum, non-verbal, hearing, stuff like that, you pick it up very quickly. But my son, I don't know if you've watched The Good Doctor, but you get the autistic spectrum, then you get the higher or intelligence standard of being on the spectrum."

The mother caregiver struggles with the rejection of her son from his father and the challenges of being a working parent. The social context is also restructured by the fact the child is highly intelligent but struggles with socialising. The situation modifies her social context in that she must limit her socialisation cycle to suit the comfort of her son. Otherwise, she must design a structure in which she socializes outside the limited social cycle of the son. Adding to the situation, the mother caregiver revealed that her son is gay, and they have been supportive of his identity.

"*I'm not sure how to say it. But he had that trust in me as his mother. You're not born like, sorry, you're born like that. You don't wake up and decide you're like that. He is gay. And we took it with smiling faces. You know, there was nothing. We were like, my boy, there's nothing wrong. It's absolutely nothing. You know, he's gone to do his nails before. And he's got his long nails, but it only lasts three days. It irritates him, you know. And he's not shy to walk in public. He dresses the way he dresses. He dresses very European. Pearls, he loves pearls, and that's his thing. You wouldn't think it's a child from this area at all. He doesn't care what people think about him"* Despite somewhat strong legal protections afforded LGBTIQA+ people in South Africa, they are still subjected to forms of social exclusion which sometimes manifests in the form of violence towards them. Being a gay autistic child adds another layer to the social context of the caregiver and sometimes influences the social context negatively. The child already draws negative attention, in a society that is not well-versed with ASD. Being an autistic gay child will in many ways draw more negative attention in a country that is not fully accommodative of LGBTIQA+ people.

The participants stated that they have limited social interactions, priorities being at home when off work, and struggle to attend social events. The lack of social life is due to the demanding nature of caring for their child with ASD characteristics. One participant mentioned that "*raising a child with autism has a significant impact on our social life.*"
The caregivers do not have much of a social life because they feel responsible for being at home and giving their children full attention. Attending social events or parties is challenging due to their caregiving responsibilities. Additionally, the caregiver expressed a desire to connect with other caregivers in similar situations to share experiences and provide support.

"Oh, yeah, yeah. No, it's affecting my social life big time because I don't have a social life at all because I'm only at home. When I'm off at work, I feel like it's my responsibility to be at home so that I relief my mother who takes care of my son when I am at work. So, I don't socialize a lot because when I'm at work, these four days, five days, Saturday, I mean Friday night, when I knock off duty, I'm going home. So, I do not really attend anything

unless maybe it's something like church-related events that is where I'm going or sometimes where I'm invited to address women's own domestic violence, work-related matters. That's where I get to attend. But in general, I don't socialize, when I am not at work because that time, I cannot leave my mother with them for five days"

The social context of the caregiver is influenced by the need to educate others about their child's disability and behaviour. Parents often take their children with special needs to social gatherings to raise awareness and understanding in the community. Coussens et al. (2020) argued that children must become involved members of the society from early years of a child's life, participation is essential for learning and development. Support groups on social media provide valuable support and shared experiences for parents of children with autism. Parents often face challenges in managing their child's behaviour in public settings, but they learn to adapt and educate others about their child's needs. Within the ecological systems theory, the macrosystem refers to a broader context where individuals are located, with a focus on their culture or everyday way of life (Analisah & Indartono, 2019; Stanley & Kuo, 2022). In the macrosystem context, the values, beliefs, and practices as well as social and economic structures are developed and influence all other social systems (Donald, Lazarus & Lolwana, 2010). One caregiver stated:

"Yeah, you must understand that when going to friends, they are not used to a child like this. But I can also not leave my child at home just because I want to enjoy time with friends. I usually take him with me. I believe that maybe you are also teaching somebody around you really about the reality of the behaviour of these children so that they can get used to it. So that one day when you are not around, they'll be able to help because it will not help that you are putting them away and really you don't want people to know about them. My brothers they really enjoy being around him because I'm not staying with my brothers, but they will always invite me so that I can visit them with my son. So, they are getting use to him, even my eldest daughter who is not staying with me she will always ask that I should bring my son along when I visit her. So, we socialise by visiting close relatives since they know him and understands the type of food he eats and what he drinks. I've learned at a very early stage that when I go out, I will go out with him he will not

speak he will not do anything about its people will be looking at him. but why is he behaving like this then we'll have to explain the type of disability that he's having, I think I'm doing that so that socially people start to understand that there are kids that have the disability and if they get into the circle if you travel from here you go to another town you get the same then you'll be aware of this type of behaviour. So, this kid is also experiencing this so, that's how you teach the community around this type of disability".

It becomes the responsibility of caregivers to educate society around them about the disability and the behavior of children with autism. Parents feel frustrated when their child needs constant attention and interrupts their work or any other social engagement. Parents worry about their child's future and emotional well-being as they struggle to find the right support for their child's needs. Parents try to stay patient and listen to their child's needs. Another participant mentioned:

"It is particularly stressful because we always think about his future. When he was young, we never knew if he could function in a school. Then he went to a primary school, but they didn't know how to work with him and that gave him a big setback. We realised it too late, and it was COVID-19, everything was mixed up. But it is particularly emotional because you do not know what to do or when he is not doing well, you do not pay enough attention. We do not spend enough time with him. I work half day and my husband works full day, and [caring for him] *it is a lot of work. For now, we are still talking to Reinette. My son is going for the first five years. And the next five years, three years. And with school, it is good to plan. You can already plan. But in the beginning, it was very emotional. For me it was very stressful because he had to go for medication to help with his concentration. Me and my husband did not know anything about autism when our son was diagnosed. They said he would be fine but during COVID-19, we realised that he will not be fine. We had to call his doctor who had put him back on medication to help him with concentration and to get him back to school."*

The caregiver's social context is influenced by the challenges and perceptions related to caring for a child with autism. Caregivers generally wish for better communication with

their children. Caregivers often face judgment and lack of understanding from others in public settings. The caregivers emphasized the importance of education and support for parents of children with autism to improve communication and understanding between them. Another participant had the following experience:

"The only thing that we do is if maybe she wants, for instance, a teddy bear that is R300. I will tell her, no money. Go and look for something else. But she would be... It won't be that kind of meltdown that she would... You know, she does the mumbling thing. So, the other people, when they look, they see a child that is stubborn, you know, and all that. But not that kind of meltdown that she would throw things on the floor. She would... she understands? Because that's why I'm saying these kids are manipulative. She knows. But when she does that, I don't like it. And I think my face would also show her that. And the only thing I've realised is that when I'm with people, she knows it's difficult for me to discipline her. I can't. So, she will do everything while I'm with people. But when I go home, because she's very aware that my mama, will never touch me in front of people. Because people will come and say, I don't do that. So, once we go to the car, she will go and sit at the back. Because she knows. So, she understands. That's why I'm saying these kids are aware"

Caregiving children with autism impacts the social context of caregivers leading to misunderstandings and superstitions within families, especially related to cultural beliefs. It can also create challenges in terms of discipline and protection, particularly as the individual being cared for grows older and faces new experiences.

One of the participants shared "*we are coming from different families. And most people think that sometimes it has something to do with culture. They are so superstitious. They think that maybe he is being bewitched. If I take him maybe to churches, he will be okay. I did take him. There was a time when I was desperate. In 2016. I took him to church. And they couldn't help him. And then he was not okay himself. He was crying a lot. I felt like that day I really abused my child. Because he was hysterical. He didn't want to go to church. After we went out, he didn't want to go in. And to them it was all about, this child*

needs deliverance…. But with the family, they understand that there is a problem with him. But still, as much as they know that there is a problem with him, they are still not treating him okay. And other children, they are laughing at him".

The social context of the caregivers is impacted in various ways, such as feeling pressure from others to conform to cultural beliefs or practices regarding their child's condition. There may be concerns about how others perceive the child, leading to feelings of desperation and guilt. Caregivers may also worry about the future, especially when considering the child's transition into adolescence and adulthood.

The caregiver's social life is greatly impacted by the responsibility of raising a child with autism. In one case a police official with three children, two of whom have disabilities, one with epilepsy and the other with autism is faced with challenges including difficulties in communication and finding suitable schooling. Balancing work as a police official with caregiving responsibilities is emotionally and socially taxing. This participant highlighted the lack of social life and the challenges in attending courses due to childcare responsibilities. Support from colleagues and the importance of understanding management are noted.

The participant also mentions the impact of COVID-19 on caregiving and the struggles of finding suitable treatment for a child with autism. It was a relief to be at home with their child during COVID-19. They mentioned challenges with buying essential items due to closures. Spending more time with their child made them feel better. They mentioned the increase in prices affecting the family financially.

Caring for the child has affected the social context by limiting the ability to socialize with friends or other families due to the child's needs and behaviors. A study done by Wang et al. (2020) indicated that children with disabilities such as children displaying ASD characteristics are at risk to have limited participation or be excluded. Often caregivers become the lifelong close contact environment that reciprocates with their children displaying ASD characteristics. According to Bronfenbrenner's ecological systems

theoretical perspective, parents formulate their ASD children's microsystem (Bronfenbrenner, 1977; Bronfenbrenner & Morris, 2007). This environment is foundational for children displaying ASD characteristics and their ability to develop and hopefully yield a fulfilling life for themselves and their caregivers, to improved quality of life (QOL) for all (Coussens et al., 2020; Ueda et al., 2021; Wang et al., 2020). Caregivers mentioned that the child communicates better with adults than with other children, leading to more interaction with adults than peers. The child's social interactions can sometimes lead to emotional outbursts or meltdowns, especially when faced with unkind behavior from others.

One of the participants mentioned, "*we are more family-oriented than friends and prefer socializing in environments where the kids can play…. it is important of exposing the children to different social environments to develop social skills".* The participant's social context is influenced because they take their children with disabilities wherever they go, educate others about disabilities create awareness, and teach those around them about their children's behaviour and disability. All the participants expressed the need for a support group for caregivers with children with ASD characteristics and facilities like a special needs school to ensure proper care and support in the long term.

Theme 3 - Work performance, wellbeing, and quality of life for the working caregiver

Caring for a child with ASD Characteristics is challenging. The caregivers split their time between work and caring for the child. Work is essential for the parent to afford the special care that the child needs. The child also demands the caregiver's time and care but usually cannot reconcile the two. When a child demands more of the caregiver's time, work is likely to suffer as being a working parent and taking care of a child with special needs is challenging, affecting work performance and wellbeing. In this instance, the exosystems, which is the workplace of the caregiver is affecting the microsystem which prioritise to care for the child showing ASD characteristics (Guy-Evans, 2020; Livazović & Bojčić, 2020).

One of the participants said "*You're forever in tears because you're so heavily burdened. I remember in the beginning, sorry, you're getting me to cry also now. If I arrive at school, I'm already so exhausted. To start my first lesson or to give it the necessary energy to teach. And then I would just go out and cry. After that, I would feel better. Luckily, I had colleagues that understand because we are teaching at a special needs school. I don't know, but an autistic child is equal to six children. So, with my two autistic children, it feels like a hundred. So... when my husband is not here, sometimes makes it worse. I feel like I'm running this thing by myself, which I am because I'm the only one, making this thing work. So, wherever I go, whatever I do, they are a big part of it. There's no break. I was thinking of resigning because my life can't just be work and home because there's no break for me. It's like I'm coming from work and then I'm having little extra energy or patience to share with my own children. So, I'm coming from the thousand and I'm coming to the hundred. So, it still, you see, doesn't balance it out.*"

The participant highlighted the contestation between caring for her two autistic children and working with special needs children. She simply has no break between caring for her own children and working with special needs children. Raising a child requires much effort and attention from parents and caregivers but raising a child with special needs requires even more effort and attention (Dyson, 1998; Hadadian, 1994). In the case of the participant, she feels overwhelmed having to raise her own children with autism and also working with special needs children as well. Families of children with disabilities do experience more stress than children without disabilities (Britner et al., 2003; Innocenti et al., 1992; Keller & Honig, 2004; Smith et al., 2001). She believes that resigning would be a way to try and make sure she properly takes care of her children while maintaining her well-being. It is hardly imaginable that the caregiver in this situation would perform at work or that her well-being and quality of life is anything that can be positive. Another participant mentioned:

"Yeah, it does impact me negatively. Sometimes I'm not able to perform. For example, I must come to my projects every week, but it happens that he's sick, or I must take leave. I feel like it's not okay because I cannot really come and say, okay, I'm not going to come.

Sometimes I'm tired. I can't really perform. I can't work at all because my mind is with him. Or maybe if something like right now, they suspended him because of the transport. They wanted me to take him myself, because of the transport. I didn't pay transport. So, he stayed with me. I didn't come to this side because I felt like, well, he's not going to school. Let me also just stay, so that I can assist with all the schoolwork that they do. But he was frustrated. He didn't want to do it with me. Because I think he feels like you're not my teacher."

The work performance, well-being, and quality of life of caregivers are significantly impacted by the responsibilities of raising a child with special needs. A participant mentioned struggling with stress, constant headaches, overthinking, exhaustion, forgetfulness difficulty in maintaining relationships. Taking medication to cope with daily challenges is often needed. There are also experiences of increased fatigue and anxiety, including the caregiver neglecting their own needs, as they focus on supporting the child with ASD displaying characteristics (Alenazi et al., 2020; Bradshaw et al., 2021; Daulay, 2021; Patel et al., 2022). This caregiver finds it difficult to cope and uses medication to get her through the day and meet all expectations that are awaiting her at work and home. Balancing work, personal life, and caregiving duties becomes overwhelming. Concerns about the child's development, protection, and future care also contribute to the emotional and mental burden on the caregivers. Many parents may be forced to use their own nonprofessional, and not scientifically proven methods to support their children (Chamak, 2019; Hu & Kärnä, 2019; Rivera-Figueroa et al., 2021; Sulek et al., 2019) which is the case for this caregiver. Another participant mentioned:

"So, you try and, like I was talking to one parent, you ask God just to help you through this phase and at least to ensure that one day this child will live as normal as possible and that he will be able to be living a functional life, where he's able to go to a workplace and to provide for himself. Instead of one day becoming this handicapped or disabled individual in society that can't participate, that can't live a fruitful life. So, you try at least."

Being a working caregiver and taking care of a child with special needs is challenging, affecting work performance and well-being. The participants son's condition led to depressive episodes and meltdowns, impacting their quality of life. The participant highlighted the importance of structure and discipline in managing their child's condition, which affects their own work performance and well-being. The participant emphasised the need for proper planning, scheduling, and support for parents of children with special needs to maintain work performance and well-being. The caregiver is taking medication for depression and sleep issues to cope with the stress caused by raising a child with autism. She is unable to balance work, personal life, and caregiving responsibilities. She experienced constant headaches, difficulty focusing on tasks, struggled to maintain romantic relationships and socialise due to the demands of caregiving. The participant said:

"Now it's worse, because now it's the work, and I'm also studying. I'm not able to balance my personal life and my work life. Because I am always all over the place. And sometimes, I will forget stuff. Like what the supervisor is saying now, I totally forgot. It's now because he's telling me that I must think about so many things. So, it does affect my work negatively. Sometimes I have to choose if I should take care of him. Sometimes he doesn't want me to work. There are times when he feels like I really need your attention today and we're not going to do anything. And then he'll just sleep by me on my lap. There's nothing that I can do. Sometimes I'll work while he's here, but still it takes longer, and I'm not able to reach my targets when it's like that. I'm not able to finish work on time. And the more I get behind, the more I must do and then I'm in a hurry, and that's when I make mistakes. Travelling is adding to the challenges because every Friday I'm going that side, then Sunday I'm coming back. I've decided I'm going to resign."

However, understanding the child's diagnosis and being on proper medication brought peace to the participant's heart, although the fear of separation from the child remains a significant concern. The caregivers' emphasised the importance of understanding and empathy from employers, as well as the need for support and flexibility in the workplace to ensure a happy employee. Work performance, well-being, and quality of life are impacted by the challenges of taking care of a child with special needs, leading to frustration and

emotional stress. Parents feel uncertain about their children's future, which affects their ability to focus on work and spending time with their children. Some participants felt that they could have advanced further in their careers if they did not need to prioritise their children with autism. At times, they expressed feelings of regret and frustration. The caregivers' well-being is affected because they often feel they are not doing enough for their children. There are also experiences of increased fatigue and anxiety, including the caregiver neglecting their own needs, as they focus on supporting the child with ASD displaying characteristics (Alenazi et al., 2020; Bradshaw et al., 2021; Daulay, 2021; Patel et al., 2022). Participant's work performance, well-being, and quality of life are affected by the challenges of balancing work and caring for children with autism. The ecological systems theory explains an individual's interconnectedness in relation to various systems which is what caregivers express when feeling regret and frustration with raising children displaying characteristics of ASD. Bronfenbrenner's model (1977;2007)) explores how different levels of systems within the social context engage with and influence the process of child development.

Theme 4 - Experience of a working caregiver

The caregivers who participated in this study were all working, and they reported having diverse experiences. The caregivers seek more support from colleagues and managers from work so that they can manage the demands of caring for their children with autism and work. The caregivers reported struggling to balance work responsibilities with caregiving duties. One of the participants mentioned:

"You're forever in tears because you're so heavily burdened. Having to prepare my two autistic children in the mornings [by the time] I arrive at school, I'm already so exhausted. Then teaching children with special needs made me feel like I am teaching 1000 learners in my class. But luckily for me, I have colleagues that understands because they also teach learners with special needs. So, I was at a stage where I could not get myself out of bed [because of] depression."

It often leads to tears and frustration. Several participants have considered resigning from work or even changing their jobs in search of a better balance between work and caring for a child with autism.

Another participant noted:
"My son likes to fight. He comes across a little bit aggressive, but the time at his pre-school might have worsen the situation. There was always a child he was fighting with at the pre-school. The teacher would explain he was sitting still and playing, but then one of the children would interrupt or take one of the things that he's playing with. He was not into speaking then, so he would bite. I remember more than twice that we had to pay doctor's fees because he's bitten some children purple and blue. Now we are [in a situation], that a child in his class, he was with since Grade 1, is bullying him. He will tell you; he's been bullying me for two years now."

Sometimes the aggression of children with autism makes excessive time demands on the caregivers to manage the aggression at the expense of work. The working caregiver, especially the mother plays a significant role in the child's life and caregivers require understanding not judgment from work colleagues and managers. Seeking understanding and empathy from colleagues and employers is not always easy, it comes with experiences that present difficulties to caregivers. When other support systems like family members or professional help fail, the mother caregiver is the last line of care for the child, and career development may be hampered. The caregiver is constantly struggling to access new information to help in coping with the child now, and in the immediate future. On the other hand, the workplace is also exerting pressure to continuously develop the skills of its employees to remain relevant in a dynamic market. These pressures leave caregivers feeling drained, unable to think or keep going because of the emotional burden.

A participant mentioned "*sometimes we laugh, and we have fun and then sometimes we're just very overwhelmed. We just feel like you can't, you're drained, you can't think, you can't lift your body up. I was there that I can't lift myself up. So, yeah, I don't know, I don't*

know. Maybe with time it gets a little bit easier as they grow up. But in the beginning of this whole thing, you know, it was hectic. I must say it was hectic. I don't know."

One of the caregivers who was part of essential services during COVID-19 found it challenging to balance work and caring for a child with autism. Her work performance was affected and although she developed strategies to manage and care for their child, they face financial challenges related to the cost of adult diapers and medication. Dealing with and supporting children displaying ASD characteristics leads to financial burdens owing to the costs encountered in the process of supporting the child (Durán-Pacheco et al., 2022; Lien et al., 2021). The participant had the following to say:

"It was the time that I realised how demanding ASD children is like. I was lucky because now I was an essential worker so, I managed to go out and buy. I was not, then I could have stayed at home without having his adult diapers and stuff. One of the challenges we were facing at that time, was those that are selling them, like that place in town, was closed for a few days then it was a bit difficult. But being with him really is like... I feel better and relieved as now my mother is relieved from the duties."

During COVID-19- 19 the economy and social activities were shut down. It became more difficult to meet the special needs of children with autism, but it meant that the caregiver spent more time with the child. Because the caregiver was considered an essential service, she could go out there with little restrictions to seek supplies for the child. The suppliers were also shut down which made it difficult for any other caregiver to find essential supplies for their children with autism. It was also reported that suppliers of necessary items like adult diapers took advantage of the situation in raising the prices which added to the caregiver's financial constraint.

Another caregiver was on the point of giving up because she had no option but to work and carry the burden and mentioned:

"*I'm tired. I feel like I can't do everything by myself. But I think maybe [family members] realised that something was wrong. My niece told my sister that I'm always stressed because of the school fees and the rent and everything. My sister decided to assist me, but. she could not come and promised to come the following weekend. My brother came with the wife because they wanted to understand what is wrong, what is happening. We sat down and kind of talked. They said this is just a phase, you've been through a lot. From the day you realised that your son was diagnosed with autism you were the only one who was running around. So why would you want to give up now? I don't have life right now. My life is revolving around my kids"*

The caregiver felt her life is caught up between her work responsibilities and caring for her autistic child. The working caregivers admitted that work was challenging, especially when considering the demands of taking care of a child with special needs. Although a few have managed to create a balance that does not affect their work performance, most of the caregivers stated that their work performance was affected. The caregivers expressed a desire for more support and resources for caregivers of children with autism. The caregivers also emphasised the importance of remaining calm and not judging the caregiver or the child in difficult situations, especially if the autistic child experiences a meltdown.

They mention their spare time is dedicated to their children, affecting their ability to attend courses outside of normal working hours and socialise with friends. Additionally, they express a desire for a support group for caregivers in similar situations. Most caregivers find it highly beneficial when they can share experiences with others facing similar challenges. Family support such as grandparents and siblings play a significant role in the children's lives. Caregivers were also keen on attending professional courses to learn more about the child's diagnosis because knowledge helps with balancing work and caring for the child with autism. Caregivers express a desire for more support and resources for caregivers of children with autism. The participant mentions difficulties with managing their child's behaviour, particularly moments of aggression. The caregiver highlights the financial strain caregivers experience like the purchasing of necessary supplies like adult

nappies. The participants feel a sense of relief and fulfillment when they have time to spend with their autistic children. Bronfenbrenner uses the concept of microsystem to refer to those who are the most immediate contacts in the child's life (Guy-Evans, 2020; MacBlain, 2021). For caregivers to experience a sense of relief when they spend time with their child displaying ASD characteristics explains that the microsystems involve relationships, roles, and patterns in daily activities that influence interactions between the child and those close to the child, e.g., caregivers. The interactions affect the development of children (Donald, Lazarus and Lolwana, 2010).

Theme 5 – Strategies Developed by the caregiver

In the absence of knowledge and understanding concerning the behavior and needs of child with autism caregivers came up with copying strategies to enhance understanding, improve communication, manage meltdowns, and respond to the social pressures or stigma associated with children with autism. A caregiver is hardly prepared for the child with autism and expect normal development and behaviour until a diagnosis is received. A child misbehaving is normally disciplined by the caregiver to communicate the undesirability of such behaviours. However, discipline may not have the same effect on a child with autism, which is a source of frustration between caregiver and child. Caregiver had to come up with strategies many of which are captured in this study namely caregiver patience, avoiding judging both caregiver and child, providing a supportive environment for child, dedication to the wellness of child, helping child become independent, keeping sjambok to deter misbehaviours, research about child's condition and even by treating the child as normal.

Caregivers of children with characteristics of autism must learn new set of skills fast to avoid a frustrating relationship between the child and the caregiver. The caregiver mentioned the importance of staying calm during the child's meltdowns and avoiding yelling or hitting. They just must find a way to calm themselves and deal with the misbehaviour tendencies of their children. Another caregiver intimated that they have developed strategies to support her child with autism by being patient, not judging the

child and hold off reacting only doing so in the safety of the child. Caregivers also emphasise the importance of understanding and not interfering when a child with autism is having a difficult time. A caregiver stated:

"I know where it comes from, and I know how to control it. When he has a meltdown or when he goes off at me, I blank out. I keep quiet. I don't say a word. Not at all. Because once I'm going to raise my voice and start screaming back, remember he's blanked out at that moment. He doesn't know what he's doing or what he's saying. He doesn't. It blanks out completely, the whole brain. And that's why from the beginning, I just keep quiet, or I turn my back and I walk away. And then he comes to me, and he apologises".

Another caregiver mentioned:
"My mother doesn't get angry. Now the only thing that helps us is to carry a sjambok. Because when you are carrying it, then he will not run, but he will just back off a bit. But whenever he will watch you, and whenever he sees you are losing concentration, maybe he will attack you. So, she doesn't get angry. There was a doctor that told me that I must just rub him. But the other thing that has been developed is that when he is angry, and I am showing him a happy face, like laughing. At times he is getting irritated, but at times he is going to calm down and start laughing also. But that one is not every day"

Another strategy mentioned by a caregiver was "*We have a boxing bag that we've hang on the outside, so we try to teach him, if you're angry, you cannot box any of the family members but rather to go to the boxing bag hanged on the outside to box the anger out, but it is not always easy as it sounds."*

Another strategy shared was *we also use a technique, where I will try, to direct his attention to something else. "It's definitely a technique that works, and with his mind, when he gets something else, we'll talk about some things randomly, and we'll talk about things that interest him, like helicopters, and airplanes, and about the propeller that spins. He'll watch those videos all day long, to see how steep the helicopter is. We only have that,*

when we talk to people, he can watch those videos, because we found out that makes him rest."

Some caregivers responded to autism needs in their children by developing a structure that brings comfort and understanding to their children with autism. Once caregivers realise their child's ASD characteristics, they actively find strategies that could help improve their situation (Gobrial, 2018). All the participants had to be responsive and find strategies on how to handle their child who displayed characteristics of autism. This is crucial because caregivers are seen as the main system that can better effect changes in the lives of their children with ASD characteristics (Estes et al., 2019). A parent prepares the child a week in advance for appointments and creates a structured schedule for daily activities. Every activity must not be random but rather deliberate and expected by the child, no surprise as they would bring great difficulty to the child. Another caregiver mentioned they need to prepare the child for potential changes in routine.

"I can't be at home now and tell him, my son, you must be at the doctor at 10 o'clock. There's no way. There's no way. You must prepare them a week before the time. He's 17. Two weeks back was the first time ever that he's been to a dentist. Because with them, they don't do stuff like that. And I had to prepare him a month before the time. And every week, I had to remind him. I even put a board up in the house, you know, for him to follow. Because you must have discipline, and structure. You must work, to get the proper wording, a schedule. If you're off your schedule, that's a flop. That's a complete flop."

In dealing with a society that expects a child to act normally, caregivers have embarked on educating others about autism and providing a supportive environment for the autistic child. Whereas it would have been common in African cultural settings to keep these children away from society for fear of harm to the child and the caregiver herself. However, more caregivers are open to the strategy of taking their children out to educate and bring awareness to society about children with autism. Caregivers in the study sample advocated for creating awareness and understanding in public settings to support children with autism.

A caregiver engages the siblings of the child with autism to fill in the gaps when the child who is non-verbal tries to communicate and the caregiver is trying to figure out what the child needs. In the mesosystem continuous interaction with one another in the context is important. For the caregiver to ensure there is continued interaction she involves her other children to form part of the discussion between herself and the autistic child, however, she also feels that she is neglecting her other children. The caregiver said:

"…it does have an effect because having normal children you wouldn't really worry much about them like you worry about your autistic child most of the time, I will usually ask my other son when I don't understand what my autistic child is communicating and then, the brother will communicate what my autistic child need. If the brother is not there I will just be in the dark and I won't know what is happening or what my autistic child needs..."

Showing affection when the child is facing a difficult time, helps to calm the child. A caregiver noted:

Most of the time I just take him and put him on my lap. You know when you treat him like that then at that moment, he is feeling that he's getting the attention that he needs. He will laugh, and you know you gave him the attention he needed. You do all those things just to bring him closer so that he can get the feeling that you are responding to his needs.

The caregivers developed strategies such as asking the child to come to their room to calm down and talk, sharing sessions with the child, discussing school experiences, and sending messages when with family. They highlighted the importance of understanding the unique needs of children with autism. Additionally, the caregiver expressed the need for proper medication and a correct diagnosis to bring peace of mind. Additionally, setting up courses for research and seeking professional help were other strategies mentioned. They also mentioned the importance of spending more time with their child.

The caregiver developed strategies by treating her son as a normal child rather than an autistic child. She mentioned treating her son as a normal child, while other family members viewed him as a child with special needs. Treating the child with autism as such means the child receives special treatment from the caregiver and those around the child. Treating him as normal places the child under pressure to catch up with peers and the expectations of society on normal children. Caregiver's report adopting both strategies in dealing with their children with autism and a more comprehensive study on the impact of these seemingly competing strategies ought to be done. The caregiver shared an experience of teaching their children to use a specific toilet facility and discussed their children's behavior in different settings.

Caregivers also highlighted the critical importance of a supportive family system in place, including their grannies, brothers, sisters, and nieces. Despite the requirements of layers of support for the child with autism, caregivers encourage the child to be allowed or trained to try to manage certain tasks independently. Caregivers must be equipped to acquire and process information, particularly on handling a developing child with autism in terms of understanding his changing body and private parts. Additionally, they expressed a desire for more information about new developments in autism.

The caregivers have developed strategies to support their autistic children by being patient, nonjudgmental towards their children, educating others about autism, and providing a supportive environment for their children. Caregivers also emphasised the importance of understanding and not interfering when a child with autism is having a difficult time. Additionally, most of the caregivers advocate for creating awareness and understanding in public settings to support children with autism. The chronosystem is related to the macrosystems, as it also speaks to the transitions and shifts in one's lifespan. All the systems in which developing children are involved, are continuously changing, and contributing to their development. There is a continuous interaction between changes and children's progressive development. The chronosystem is more open to understanding broader socio-historical contexts that may influence a person (Mulisa, 2019). The need for caregivers developed to educate the broader society about autism.

Caregivers developed strategies to cope with emotional challenges which include seeking therapy, doing research, and trying to balance work responsibilities with caregiving duties. It was mentioned by a caregiver:

"I developed strategies by pushing myself to make sure my child is well, seeking government assistance, and believing in a source of strength. I normally encourage my child with autism to try and manage certain tasks independently."

The caregiver sought information and support from a specialised teacher in autism, who provided guidance and education about autism. She mentioned feeling depressed and overwhelmed before receiving this support. The caregiver expressed a desire to resign from her current job due to the challenges of caring for her child with autism. The exosystems are systems in which the child is not directly involved. This could include the neighbourhood, caregivers' workplaces, parent's friends, and the mass media (Guy-Evans, 2020; Livazović & Bojčić, 2020). The exosystems underpins in this instance of the caregiver feeling overwhelmed and that the workplace of the caregiver is affected by the microsystem. The influence on the caregiver is to the extent that she considers resigning due to the challenges she experiences of caring for her child who display characteristic of ASD.

Summary

The ecological systems theory underpins the study and from the information presented in this chapter, it indicates the interconnectedness of the caregiver with the ASD child, the work environment, and the broader society. The thematic analysis was used to analyse the data and five themes were developed. Through the five themes it is evident that caregivers experience emotions and majority of the caregivers highlighted the negative emotional experiences. Caregivers view and relates to their social context through the lenses of their ASD children. The work performance, wellbeing, and quality of life of the working caregiver while living and caring for the ASD child is impacted as caregivers often finds it difficult to balance between work and the needs of the ASD child. All primary caregivers developed strategies over the years through experiences to create a comfortable

environment for all family members inside and outside the home. In the final chapter, the key findings, conclusions, and recommendations are addressed.

CHAPTER FIVE

KEY FINDINGS, CONCLUSIONS AND RECOMMENDATIONS

In this chapter the research question, aim and objectives and key findings are presented. Relevant sections of the literature review (Chapter 2) and findings from the empirical study (Chapter 4) will be integrated to support the findings. The achievement of the aim and objectives of the study will be assessed. The chapter ends with conclusions, and recommendations developed from the findings.

Research question aim and objectives

The **research question** posed was

> *What are the experiences of working caregiver living and caring for children displaying characteristics of autism spectrum disorder?*

The research question was answered by conducting a qualitative research study, using face-to-face interviews to collect data from the working caregivers who live and care for children displaying characteristics of autism spectrum disorder. Nine interviews were conducted with caregivers who met the inclusion criteria. The data was analysed by the researcher. From the data analysis, themes were identified which were discussed in chapter four of the research report. Five themes emerged from the research study and were utilised to answer the research question.

The **aim of the study** was to explore the experiences of working caregivers who live and care for children displaying characteristics of autism spectrum disorder in the Northern Cape Province, South Africa.

The primary aim of the study was achieved through the following objectives:

Objective 1: To explore the emotional experiences of caregivers living with children displaying characteristics of autism spectrum disorder.

All nine caregivers willingly shared the emotional experiences that they undergo while living and taking care of children displaying characteristics of autism. Six of the caregivers felt overwhelmed in trying to meet work demands and parenting the child or children who display characteristics of autism spectrum disorder. Three of the participants disclosed that they are relying on prescribed medication for them to accomplish their responsibilities at work and home. The experiences often lead to stress, depression, and anxiety for the caregiver (Ueda et al., 2021). The caregivers expressed feelings of guilt for having to be at work and not spending enough time with the child. Three parents mentioned that they were considering resigning so that they could spend more time with their child or children displaying characteristics of autism. One parent chooses a part-time job so that she can have more time to spend with her son.

Through the study, all nine caregivers indicated that they have a constant feeling of fear and anxiety when the child displaying characteristics of autism spectrum disorder is in the care of extended family members or friends when the caregiver must attend to other priorities. Fear for the safety and well-being of the child and others, especially if the child displays anger or experiences a meltdown which might result in self-harm or harm to others. Most of the caregivers feel that they alone are in a better position to deal with the conditions of their children, especially with many extended family members not being aware of autism and having the view that children displaying characteristics of autism are ill-disciplined.

Four caregivers expressed feelings of anger, frustration, and irritation when dealing with their child's behavior, especially in a public setting. Two caregivers indicated that they apply emotional intelligence when dealing with the behavior of their children, by suppressing feelings of anger and frustration but rather showing feelings of happiness, calmness, non-judgmental, and understanding towards the child during meltdowns or difficult experiences. Caregivers feel frustrated with the limited resources and support

provided in the Northern Cape, especially with the availability of special needs schools. The Northern Cape Department of Basic Education conducted a survey (NCDOE, 2023) and confirmed that there are only eleven special needs schools in the entire province. The Northern Cape is the largest province by land area yet the smallest by population size (1 355 629) in South Africa. With only eleven special needs schools in the province, in some instances, caregivers do not have the opportunity to enroll their children at special needs schools and two caregivers decided to relocate to other towns in the Northern Cape so that their children can enroll at the special needs schools. The two caregivers expressed feelings of loneliness since their support structure including their partners are staying in other towns of the Northern Cape. Three of the caregivers expressed that they do not want to feel pity for their children displaying characteristics of autism instead they prefer to treat their child displaying characteristics of autism the same as other children in the house so that their children become happy, independent, and productive citizens of the country. The other six caregivers feel sorry and worried about the future of their children, especially if they are no longer there as the caregivers to provide and care for their children who display characteristics of autism. One of the participants is fond of the inquisitiveness, questing, and honesty of her children. She enjoys the conversations with her children and trying to understand their way of thinking.

Through the study, it is evident that caregivers experience emotions both negative and positive. Most of the caregivers expressed negative emotions, and some cried during the interview; however, the caregivers are aware that they are the primary caregivers for their children displaying autistic characteristics and gain strength, hope, and courage knowing that their children need them.

Objective 2: To explore how the social contexts of caregivers are influenced when they are living with children displaying characteristics of autism spectrum disorder.

Five of the caregivers indicated raising a child who displays autistic characteristics has a significant impact on their social life to the extent that they confirmed that they do not have a social life at all. The five caregivers mentioned that they do not have much of a social life because they feel that their responsibility is to be home and give attention to the

child displaying characteristics of autism. They adjusted the lifestyle of the family to accommodate their child who displays autistic characteristics by limiting social interactions with extended family, friends, or shopping. In a study done by Pretorius (1984) she found that 30,77 percent of the families she interviewed believed that their friends were avoiding spending time with their families and most of the families felt embarrassed if the child experienced a meltdown in the company of a friend or other family members. Being home in a familiar and conducive environment with their children is of the essence for the five caregivers.

Seven of the caregivers mentioned that they would not necessarily attend social gatherings unless it is a family funeral, work-related training, religious events, or connect with other parents in similar situations to share experiences and provide support. Families need to be able to accommodate the child displaying ASD characteristics and deal with the social isolation of the family that may follow the diagnosis (MacKenzie & Eack, 2021; Nagib & Williams, 2018; Reddy et al., 2019). If ever the caregiver takes their children along to the social gatherings, they need to prepare the child who displays characteristics of autism well in advance for the social gathering.

Three of the caregivers reported that they take their children displaying characteristics of autism to social gatherings to raise awareness and understanding in the community. Their social context is influenced by the need to educate others about their child's disability and behavior. Two types of transformations or life-changing experiences are identified with families living with children with disabilities. The first one is personal transformation and the second one is relational transformation. Personal transformation could mean that family members adopted new roles in the family or attained new qualities, such as advocating for the child living with a disability or find avenues to strengthen their faith (Scorgie & Sobsey, 2000).

Objective 3: To establish in which ways living with and caring for children displaying characteristics of autism spectrum disorder are affecting the work performance, wellbeing, and Quality of Life (QOL) for the working caregiver.

All nine caregivers indicated that their work performance, well-being, and quality of life is affected negatively because they are constantly worried about the wellbeing and safety of their children who display characteristic of autism. All caregivers who participated in the study expressed that they become worried when they receive a call from the child's school, grandparents, or nannies. The caregivers confirmed that they usually jump to conclusions and think the worse as to what could have happened with their child who display characteristics of autism. The phone call will usually require the caregiver to collect the child from school or additional support is needed if the child is taken care of at home. Two of the caregivers are educators and they indicated that once they are being informed to collect their children from school, they need to stop teaching lessons for the rest of the day to fulfil the caregiver responsibility to their child who display characteristics of autism. Three caregivers confirmed that if it so happens that they cannot leave work at that stage, they will not fully concentrate at work which result in them not delivering task to the best of their abilities.

Five caregivers reported that their children have disrupted sleep patterns which result in the caregiver's sleep patterns also being disturbed and caregivers not getting enough sleep.

Six of the caregivers indicated that raising a child displaying characteristics of autism is financially demanding to meet the day-to-day essential needs of their children. All caregivers mentioned that their children have special diets, additional medical cost is incurred if the medical aid does not cover the medical service or medication, paying high fees at special schools and transport. Four of the caregivers are single parents and the only breadwinners in their families. More and more South Africans is feeling the financial constraints with the slow economic growth in the country, the GDP increased by 0,1% and the unemployment rate rose to 32.1% in the fourth quarter of 2023 (Statistics SA, 2024). In Reddy et al. (2019) study, caregiver with better resources could access diverse intervention strategies such as speech therapy and audiology privately, which also brought relief in their daily challenges of living with and caring for children displaying characteristics of autism

spectrum disorder. Seemingly the intervention children displaying autism characteristics received is dependent on the economic status of the caregivers.

Wang et al.'s (2020) study shows that caregivers working away from home felt less of negative impacts in their quality of life, owing to living with and caring for children displaying characteristics of autism spectrum disorder. Two of the caregivers confirmed that they feel stagnate and no longer have time to care for themselves or pursue their dreams. For them life evolve around their children displaying characteristics of autism, while their partners who works away from home continue to live their lives as normal.

Objective 4: To explore the experiences that working caregivers are facing when caring for children displaying characteristics of autism spectrum disorder.

Three caregivers indicated that preparing children who display characteristics of autism spectrum disorder in the mornings for school is exhausting because of the excessive time and attention demands on the caregiver. These parents explained that for them to be productive at work they first need to find themselves after their kids are dropped off at school and before they can perform their daily task at work. Four caregivers indicated that their children are non-verbal and often they do not understand what message the child is trying to convey, unless the child pull them towards what they need, or the child's siblings who can speak would usually understand what the need might be and explain to the caregiver what his or her sibling need. Eight of the caregivers indicated that they often overlook the needs of their other children by diverting all their time, energy and attention to the child displaying autism characteristics. This is confirmed by Reddy et al., (2019) who highlighted the efforts to support children displaying characteristics of autism spectrum disorder within the family may reduce the amount of time that caregivers must dedicate to caring for other children with the families.

Seeking understanding and empathy from colleagues and employers is not always straight a cut, it comes with own experiences which present difficulties to caregivers. When other support systems like family members or professional help fail, the mother caregiver is the last line of care for the child, career development hampered as time is demanded in caring

for the child. Due to the high demand for care five caregivers confirmed that they constantly tired even if they sleep for many hours, they are forever tired. Two of the caregivers indicated that on some days they do not feel like getting out of bed. There are also experiences of increased fatigue and anxiety, including the caregiver neglecting their own needs, as they focus on supporting the child displaying characteristics of autism spectrum disorder (Alenazi et al., 2020; Bradshaw et al., 2021; Daulay, 2021; Patel et al., 2022).

All nine caregivers indicated that they experience mistrust, and they feel more at ease when they themselves care for the child displaying characteristics of autism spectrum disorder. Thus, it has a strain on the family social relations which pushes away the potential social support systems, and caregivers' psychological well-being (Durán-Pacheco et al., 2022; Lien et al., 2021; Reddy et al., 2019). Six caregivers indicated that during the Covid-19 lockdowns they experienced frustrations because they had to be home with their children for longer. Three of the caregivers indicated that Covid-19 lockdown strengthen their family relationship because they got the opportunity to spend more time with their child or children who display characteristics of autism and got a better understanding of what they like and dislike.

Objective 5: To establish what are the strategies parents have developed to manage caring for children displaying characteristics of autism spectrum disorder.

What was discovered during the interviews is that all nine caregivers are aware that autism spectrum disorder is not curable neither a demon that needs to be cast out. In fact, caregivers developed strategies through experiences that works for them. Eight caregivers indicated that they wish to gain more knowledge about autism especially since their children are growing into adolescence stage. Caregivers are struggling to access new information to help in handling the child in the immediate future. Below is some of the strategies mentioned by the caregivers:

- Four caregivers indicated that their other children are assisting with communication between themselves and the child who display autism characteristics if the child is non-verbal.

- All nine caregivers indicated that they manage their outings.

- Three caregivers indicated that support from colleagues and families who understand what it means to raise a child displaying characteristics of autism.

- All nine caregivers indicated that adherence to routines is crucial and any deviation from the routine should be communicated with the child well in advance.

- All nine caregivers indicated that their children are picky eaters. It is important for them to get an understanding of the preferred diet meals of the child to avoid wasting money on meals that the child will not enjoy.

- Further coping strategies included adopting home activities that was helpful such as distraction of the child through watching television, and calming techniques.

- Two of the caregivers taught they children to rather divert the anger towards an object, like a boxing bag rather than towards self or others.

- Six of the caregivers indicated that advocating for their children and making people in their surrounding aware of autism is another way to reach out for support in society.

The main findings of the study

The main findings from the study are summarised below.

- Finding 1: Living and caring for a child with ASD characteristics is emotionally demanding and affects the quality of live and wellbeing of the working caregivers.

- Finding 2: Living and caring for a child with ASD characteristics influences and limits the social context of working caregivers.

- Finding 3: Living and caring for a child with ASD characteristics affects the work performance and career development of the working caregivers negatively.

- Finding 4: Working caregivers living and caring for a child with ASD characteristics need available, accessible, and affordable services to care for the child with ASD characteristics.

- Finding 5: Working caregivers living and caring for a child with ASD characteristics need continuous practical support and guidance in dealing with unforeseen and unknown circumstances they are confronted with.

Conclusions

The information derived from this study contributed to the limited information available pertaining to the experiences of the working caregiver who lives and care for children displaying autism spectrum disorder within the Northern Cape, South Africa context. The ecological systems theory was underpinned for the study to get an understanding of the working caregiver's interconnectedness in relation to various systems. Furthermore, it provided an understanding of the emotional experiences of the caregiver both positive and negative. The influence on the social context when living and caring for a child displaying autism spectrum disorder, choose family outings carefully. Insight into the work performance, well-being, and quality of life for the working caregiver who often struggle to reconcile between the responsibilities of being an employee and a caregiver who must be responsive to the needs of children displaying characteristic of autism spectrum disorder. The study, furthermore, provided insight of the experiences of working caregiver who used the interview session as an opportunity to be vulnerable and to voice their feelings and experiences as for most of the participants it was the first time getting to share their experiences without being judged. In the study working caregivers also share strategies that they initiated to create a conducive environment for the child displaying autism characteristics and the rest of the family members. It is evident in the study that the working caregiver, as being the primary caregiver to the child displaying autism spectrum disorder can find themselves in distress if their support structure is not well established.

Recommendations

Support and training on how to care for children with ASD characteristics throughout their life cycles should be provided to working caregivers who live and care for children displaying autism characteristics.

Considering that there are only 11 special need schools in the Northern Cape Province, the establishment of affordable private or public centers in different parts of the Northern Cape province that should be monitored by the Northern Cape, Department of Basic Education within the five districts to ensure sustainability and effectiveness.

Early interventions at these Centres through cognitive stimulation programmes for learners who are on the lower and medium spectrum to be adopted into the mainstream school system at primary and higher school so that the working caregivers could enroll their children at schools in close proximity where they live.

Autism South Africa to consider providing training to the primary caregiver, partner of the primary caregiver, siblings to the child who display autism characteristics, grandparents, extended family members and the larger community where the families reside. This will result in awareness of autism among the broader community and support is given to the primary caregiver instead of being judgmental towards the caregiver and the child who display characteristics of autism.

Employers and colleagues of working caregivers should also be made aware of and informed about autism so that they can show empathy towards caregivers when they experience challenging behaviours from their kids.

As part of the Employee Wellness Programme, employers must include psycho-social support for the working caregiver who might find it difficult to cope with the dynamics of living with children with ASD characteristics.

Social Workers, Teachers, Nurses, Doctors, or any other helping profession should advocate at every opportunity for children displaying autism spectrum disorder characteristics and their primary caregivers, especially in the Northern Cape where

most of the population is not aware of ASD. They should also take initiative to establish support groups in their immediate and surrounding communities.

Medical Aids should consider Autism as a chronic illness so that services such as speech therapy, occupational therapy have unlimited benefits to lessen the financial burden of co-payments on the primary working caregiver.

Although children displaying characteristics of autism spectrum disorder do not necessarily have visible disabilities they should also be given right of way in the supermarkets or malls when the caregiver are with the autistic child.

When healthcare screenings are conducted at schools by the Department of Health or privately appointed healthcare practitioners' autism screening should also be considered, so that the necessary referrals can be made for early assessments and diagnosis.

Future research could explore experiences of the siblings to autistic children. Another study could seek insight into the experiences of the father caregiver because in this study 90% of the participants hold the role of a mother caregiver. Another study can investigate the knowledge of autism among extended family members.

REFERENCES

Adeoye-Olatunde, O. A., & Olenik, N. L. (2021). Research and scholarly methods: Semi-structured interviews. *Journal Of The American College Of Clinical Pharmacy, 4(10),* 1358-1367.

Adom, D., Yeboah, A., & Ankrah, A. K. (2016). Constructivism philosophical paradigm: Implication for research, teaching and learning. *Global Journal Of Arts Humanities and Social* Sciences, *4(10),* 1-9.

Alamri, W. A. (2019). Effectiveness of qualitative research methods: Interviews and diaries. *International Journal of English and Cultural Studies, 2(1),* 65-70.

Alenazi, D. S., Hammad, S. M., & Mohamed, A. E. (2020). Effect of autism on parental quality of life in Arar city, Saudi Arabia. *Journal of Family & Community Medicine, 27(1),* 15.

Alli, Aaishah & Abdoola, Shabnam & Mupawose, Anniah. (2015). Parents' journey into the world of autism. *South African Journal of Child Health. 9*. 81. 10.7196/SAJCH.7942.

Al-Mamri W, Idris AB, Dakak S, Al-Shekaili M, Al-Harthi Z, Alnaamani AM, Alhinai FI, Jalees S, Al Hatmi M, El-Naggari MA, Islam MM. (2019). *Revisiting the Prevalence of Autism Spectrum Disorder among Omani Children: A multicenter study.* PMC.

Amaratunga, D., Baldry, D., Sarshar, M., & Newton, R. (2002). Quantitative and qualitative research in the built environment: application of "mixed" research approach. *Work Study. Vol. 51 No. 1*, pp. 17-31

Analisah, C.D., & Indartono, S. (2019). Ecological Theory: Preventing Student Bullying to Promote Culture of Peace. *Joint proceedings of the International Conference on Social Science and Character Educations (IcoSSCE 2018) and International Conference on Social Studies, Moral, and Character Education (ICSMC 2018).*

Andrade, C. (2021). The inconvenient truth about convenience and purposive samples. *Indian Journal of Psychological Medicine, 43(1), 86-88.*

Arifin, S. R. M. (2018). Ethical considerations in qualitative study. *International Journal of Care Scholars, 1(2), 30-33.*

Aspers, P., & Corte, U. (2019). What is qualitative in qualitative research. *Qualitative Sociology*, *42*(2), 139-160.

Bakare, M. O., & Munir, K. M. (2011). Autism Spectrum Disorders (ASD) in Africa: *A Perspective. African Journal of Psychiatry, 14(3), 208–210.*

Bearman, M. (2019). Eliciting rich data: A practical approach to writing semi-structured interview schedules. Focus on Health Professional Education*: A Multi-Disciplinary Journal*, *20*(3), 1-11.

Bitektine, A. (2008). Prospective Case Study Design: Qualitative Method for Deductive Theory Testing. *Organizational Research Methods, 11(1),* 160-180.

Boyd, C.O. (2001), Philosophical foundations of qualitative research", in Munhall, P.L. (Ed), *Nursing Research: A Qualitative Perspective*, (3rd ed.) Jones and Barlett Pub.

Bradshaw, J., Gillespie, S., McCracken, C., King, B. H., McCracken, J. T., Johnson, C. R., ... & Scahill, L. (2021). Predictors of caregiver strain for parents of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *51*(9), 3039-3049.

Braun, V., & Clarke,V. (2019a). Reflecting on reflexive thematic analysis. Retrieved at: https://www.youtube.com/watch?v=BhL113ye9Ss

Bronfenbrenner, U. (1977). Lewinian space and ecological substance. *Journal of Social Issues, Volume, Issue 4.*

Bronfenbrenner, U., & Morris, P. A. (2007). The bioecological model of human development. *Handbook of child psychology*, *1*.

Brower, R. L., Jones, T. B., Osborne-Lampkin, L. T., Hu, S., & Park-Gaghan, T. J. (2019). Big Qual: defining and debating qualitative inquiry for large data sets. *International Journal of Qualitative Methods*, *18*, 1609406919880692.

Burkett, K., Morris, E., Anthony, J., Shambley-Ebron, D., & Manning-Courtney, P. (2017). Parenting African American children with autism: The influence of respect and faith in mother, father, single-, and two-parent care. *Journal of Transcultural Nursing*, *28*(5), 496-504.

Chamak, B. (2019). Lobbying by association: The case of autism and the controversy over packing therapy in France. *Social Science & Medicine*, *230*, 256-263.

Chan, K. K. S., & Leung, D. C. K. (2020). The impact of child autistic symptoms on parental marital relationship: Parenting and coparenting processes as mediating mechanisms. *Autism Research*, *13*(9), 1516-1526.

Children's Act, Act No. 38 of 2005. Pretoria, South Africa. Government Printers. Retrieved from https://www.gov.za/documents/childrens-act

Clements, J. & Zarkowska, E. (2000). *Behavioral concerns and autistic spectrum disorder: explanations and strategies for change.* London: Jessica Kingsley Publishers.

Connaway, L. S., & Radford, M. L. 2021. *Research Methods in Library and Information Science (7th ed.).* Santa Barbara: Libraries Unlimited.

Coussens, M., Van Driessen, E., De Baets, S., Van Regenmortel, J., Desoete, A., Oostra, A., ... & Van de Velde, D. (2020). Parents' perspectives on participation of young children with attention deficit hyperactivity disorder, developmental coordination disorder, and/or autism spectrum disorder: a systematic scoping review. *Child: Care, Health and Development*, *46*(2), 232-243.

Creswell, J.W. (2007), *Qualitative Inquiry and Research Design: Choosing Among Five Traditions*, Sage, Thousand Oaks, CA.

Daniel, B. K. (2019). What Constitutes a Good Qualitative Research Study? Fundamental Dimensions and Indicators of Rigour in Qualitative Research: *the TACT Framework. 10.*34190/RM.19.113.

Daulay, N. (2021). Home education for children with autism spectrum disorder during the COVID-19 pandemic: Indonesian mothers experience. *Research in Developmental Disabilities*, *114*, 103954.

Denieffe, S. (2020). Commentary: Purposive sampling: complex or simple Research case examples. *Journal of Research in Nursing: JRN*, *25*(8), 662.

Donald, D., Lazarus, S., Lolwana, P. (2010). *Educational Psychology in Social Context: Ecosystemic Applications in Southern Africa.* Oxford University Press Southern Africa.

Donohue, M. R., Childs, A. W., Richards, M., & Robins, D. L. (2019). Race influences parent report of concerns about symptoms of autism spectrum disorder. *Autism*, *23*(1), 100-111.

Downs, L. (2015). The duty to protect a patient's right to confidentiality: Tarasoff, HIV, and confusion. *Journal of Forensic Psychology Practice, 15(2),* 160–170.

Dunst, C. J., Trivette, C. M., & Cross. A, H. (1986). Mediating influences of social support: Personal, family, and child outcomes. *American Journal of Mental Deficiency*, *90,*403-417.

Durán-Pacheco, G., Silkey, M., Johnson, M., Liu, C., Clinch, S., Law, K., & Loss, G. (2022). Effect of Children's Autism Spectrum Disorder Severity on Family Strain and Sleep Quality: A Cross-Sectional Online Survey in the US. *Journal of Autism and Developmental Disorders, 1-14.*

Dyson, L. L. (1998). A support program for siblings of children with disabilities: What siblings learn and what they like. *Psychology in the Schools. 35i 1).* 199.

Employment Equity Act, Act No 55 of 1998. Pretoria, South Africa: Government Printers. Retrieved from https://www.gov.za/documents/employment-equity-act

Estes, A., Swain, D. M., & MacDuffie, K. E. (2019). The effects of early autism intervention on parents and family adaptive functioning. *Paediatric Medicine (Hong Kong, China)*, *2*.

Evans, B. (2013). How autism became autism: The radical transformation of a central concept of child development in Britain. *History of the Human Sciences*, *26(3)*, 3-31.

Fernandez, B. A., & Scherer, S. W. (2017). Syndromic autism spectrum disorders: moving from a clinically defined to a molecularly defined approach. *Dialogues in clinical neuroscience*, *19(4)*, 353.

Flick, U. (2022). *An introduction to qualitative research*: Sage, London.

Fuentes, J., Armijo-Olivo, S., Funabashi, M., Miciak, M., Dick, B., Warren, S., Rashiq, S., Magee, D. J., & Gross, D. P. (2014). Enhanced therapeutic alliance modulates pain intensity and muscle pain sensitivity in patients with chronic low back pain: an experimental controlled study. *Physical Therapy*, *94*(*4)*, 477–489.

Fugard, A. & Potts, H.W.W. (2020). *Thematic Analysis*. SAGE Publications Limited.

Gavriel-Fried, B., Shilo, G., & Cohen, O. (2014). How do social workers define the concept of family. *British Journal of Social Work*, *44*(*4*), 992-1010.

Geldard, K. & Geldard, D. (2008). *Counselling Children: A Practical Introduction (3rd ed.). London*: SAGE Publications Ltd.

Germain, C. B. (1973). An Ecological Perspective in Casework Practice. *Social Casework*, *54(6)*, 323-330.

Gittings, L., Toska, E., Medley, S., Cluver, L., Logie, C. H., Ralayo, N., ... & Mbithi-Dikgole, J. (2021). 'Now my life is stuck!': Experiences of adolescents and young people during COVID-19 lockdown in South Africa. *Global public health*, *16*(6), 947-963.

Gobrial, E. (2018). The lived experiences of mothers of children with the autism spectrum disorders in Egypt. *Social sciences*, *7*(8), 133.

Gona, J. K., Newton, C. R., Rimba, K., Mapenzi, R., Kihara, M., Van de Vijver, F. J., & Abubakar, A. (2015). Parents' and professionals' perceptions on causes and treatment options for autism spectrum disorders (ASD) in a multicultural context on the Kenyan coast. *PloS One*, *10*(8), e0132729.

Groenewald, T. (2003), *The contribution of co-operative education in the growing of talent:* Rand Afrikaans University

Guba, E.G. (1981), Criteria for assessing the trustworthiness of naturalistic inquiries: *Educational Communication and Technology Journal 29,* 75–91.

Guler, J., de Vries, P. J., Seris, N., Shabalala, N., & Franz, L. (2018). The importance of context in early autism intervention: A qualitative South African study. Autism: *The International Journal of Research and Practice, 22(*8), 1005–1017.

Guy-Evans, O. (2020). Bronfenbrenner's ecological systems theory. Last reviewed on January 17, 2024

Hadadian. A. (1994). Stress and social support in fathers and mothers of young children with and without disabilities. *Early Education and Development. 5*, 227-235.

Haven, L. T., & Van Grootel, D. L. (2019). Preregistering qualitative research. *Accountability in Research*, *26*(3), 229-244.

Hebert, E. B., & Koulouglioti, C. (2010). Parental beliefs about cause and course of their child's autism and outcomes of their beliefs: A review of the literature. *Issues in Comprehensive Pediatric Nursing*, *33*(3), 149-163.

https://www.gov.za/documents/white-papers/social-welfare-white-paper-01-aug-1997

Hu, X., & Kärnä, E. (2019). *Prospects for Education of Children with Autism Spectrum Disorder in China and Finland.* In Educating Students with Autism Spectrum Disorder in China and Finland (pp. 225-236). Springer, Singapore.

Innocenti. M. S. Huh, K,,& Boyce. G. C. (1992). Families of children with disabilities: Normative data and other considerations on parenting stress. *Topics in Early Childhood Special Education. 12,* 403-427.

King, N., Horrocks, C., & Brooks, J. (2018). *Interviews in qualitative research*.: Sage.

Klykken, F. H. (2022). Implementing continuous consent in qualitative research. *Qualitative Research, 22*(5), 795-810.

Knox, S., & Burkard, A. W. (2009). Qualitative research interviews. *Psychotherapy research*, *19*(4-5), 566-575.

Lee, J. D., & Meadan, H. (2021). Parent-mediated interventions for children with ASD in low-resource settings: A scoping review. *Review Journal of Autism and Developmental Disorders*, *8*(3), 285-298.

Lenoir, Y. (2009). *Educational Intervention, a theoretical construct for analyzing teaching practices*.: Research Gate.

Lien, K., Lashewicz, B., Mitchell, J., & Boettcher, N. (2021). Blending traditional and nurturing fathering: Fathers of children with autism managing work and family. *Family Relations*, *70*(1), 264-281.

Lincoln, Y. S. (1995). Emerging Criteria for Quality in Qualitative and Interpretive Research. *Qualitative Inquiry, 1(3*), 275-289.

Livazović, G., & Bojčić, K. (2020). Revisiting the clockwork orange: A review of theories of aggressive behaviour from the perspective of the ecological systems theory. *Policija i sigurnost*, *29*(3/2020.), 0-0.

MacBlain, S. (2021). *Learning theories for early years practice*.: Sage.

MacKenzie, K. T., & Eack, S. M. (2021). Interventions to improve outcomes for parents of children with autism spectrum disorder: a meta-analysis. *Journal of Autism and Developmental Disorders*, *1*-25.

Maenner MJ, Warren Z, Williams AR. (2020). *Prevalence and Characteristics of Autism Spectrum Disorder Among Children Aged 8 Years — Autism and Developmental Disabilities Monitoring Network*: United States, MMWR Surveill Summ.

Mahat-Shamir, M., Neimeyer, R. A., & Pitcho-Prelorentzos, S. (2021). Designing in-depth semi-structured interviews for revealing meaning reconstruction after loss. *Death Studies*, *45*(2), 83-90.

Marshall, P. A., Adebamowo, C. A., Adeyemo, A. A., Ogundiran, T. O., Strenski, T., Zhou, J., & Rotimi, C. N. (2014). Voluntary participation and comprehension of informed consent in a genetic epidemiological study of breast cancer in Nigeria. *BMC medical ethics*, *15*, 38. https://doi.org/10.1186/1472-6939-15-38

Matseke, M. G. (2020). Provision of water and sanitation during the Covid-19 crisis: comparative case study in predominantly urban and predominantly rural provinces. *Africa Journal of Public Sector Development and Governance*, *3*(1), 90-104.

Mayada et al. (2012) Global prevalence of autism and other pervasive developmental disorders. *Autism Res. 5*(3): 160–179.

Mbeve, O., Nyambuya, V. P., Munyoro, A., Dube, N., & Shumba, K. (2020). The challenges faced and survival strategies adopted by Zimbabwean informal traders that live in Johannesburg inner-city, during the COVID-19-induced lockdown in South Africa. *Journal of Social Development in Africa*, *31*-64.

Mbunge, E. (2020). Effects of COVID-19 in South African health system and society: An explanatory study. *Diabetes & Metabolic Syndrome: Clinical Research & Reviews, 14*(6), 1809-1814.

Miles, M.B & Huberman, A.M. (1994). *Qualitative data analysis: an expanded sourcebook, 2nd ed. California*: Sage.

Molendijk, L. P. G., Bleeker, P. O., Lamers, J. G., & Runia, W. T. (2009). Perspectives of anaerobic soil disinfestation. In *VII International Symposium on Chemical and Non-Chemical Soil and Substrate Disinfestation 883* (pp. 277-283).

Mthuli, S. A., Ruffin, F., & Singh, N. (2021). 'Define, Explain, Justify, Apply'(DEJA): An analytic tool for guiding qualitative research sample size. *International Journal of Social Research Methodology, 1*-13.

Mulisa, F. (2019). Application of bioecological systems theory to higher education: Best evidence review. *Journal of Pedagogical Sociology and Psychology*, *1*(2), 104-115.

Munthe-Kaas, H., Nøkleby, H., & Nguyen, L. (2019). Systematic mapping of checklists for assessing transferability. *Systematic Reviews, 8*(1), 1-16.

Nagib, W., & Williams, A. (2018). Creating "therapeutic landscapes" at home: The experiences of families of children with autism. *Health & Place, 52*, 46-54.

National Association of Social Workers & Association of Social Work Boards. (2005). *NASW and ASWB standards for technology and social work practice.:* Washington, DC.

National Association of Social Workers (NASW). (2018). Code of ethics. Retrieved from https://www.socialworkers.org/About/Ethics /Code- of- Ethic

Nguyen, A. (2019). *Environment and Surroundings: How to make them autism friendly, Autism South Africa in South Africa.*: Dizenyo Design

Northern Cape Department of Education. (2023) retrieved from http://ncdoe.ncpg.gov.za/

Ouhtit, A., Al-Farsi, Y., Al-Sharbati, M., Waly, M., Gupta, I., Al-Farsi, O., ... & Al-Adawi, S. (2015). Underlying factors behind the low prevalence of autism spectrum disorders in Oman: Sociocultural perspective. *Sultan Qaboos University Medical Journal*, *15*(2), e213.

Ouimet, T., Foster, N. E., Tryfon, A., & Hyde, K. L. (2012). Auditory-musical processing in autism spectrum disorders: a review of behavioral and brain imaging studies. *Annals of the New York Academy of Sciences*, *1252*(1), 325-331.

Ousley, O., & Cermak, T. (2014). Autism spectrum disorder: defining dimensions and subgroups. *Current developmental disorders reports*, *1*(1), 20-28.

Paglia L. (2020). C. Children diagnosed with "ASD" are first of all children. *European Journal of Pediatric Dentistry*, *21*(1), 8.

Pardeck, J. T. (1988). An ecological approach for social work practice. *J. Soc. & Soc. Welfare*, *15*, 133.

Patel, A. D., Arya, A., Agarwal, V., Gupta, P. K., & Agarwal, M. (2022). Burden of care and quality of life in caregivers of children and adolescents with autism spectrum disorder. *Asian Journal of Psychiatry*, *70*, 103030.

Patel, V., Kieling, C., Maulik, P. K., & Divan, G. (2013). Improving access to care for children with mental disorders: a global perspective. *Archives of Disease in Childhood*, *98*(5), 323-327.

Patton, M.Q. (1990*). Qualitative evaluation and research methods, 2nd ed. Newbury Park*: Sage.

Pilkauskas, N. V., & Cross, C. (2018). Beyond the nuclear family: Trends in children living in shared households. *Demography*, *55*(6), 2283-2297.

Pillay, S., Duncan, M., & de Vries, P. J. (2021). Autism in the Western Cape province of South Africa: Rates, socio-demographics, disability and educational characteristics in one million school children. *Autism*, *25*(4), 1076-1089.

Pretorius, E. (1984). *Die Invloed van die Outistiese Kind op die Gesinsisteem. Departement Maatskaplike Werk.* Universiteit Van Suid- Afrika.

Reddy, G., Fewster, D. L., & Gurayah, T. (2019). Parents' voices: experiences and coping as a parent of a child with autism spectrum disorder. *South African Journal of Occupational Therapy*, *49*(1), 43-50.

Republic of South Africa (RSA). (2001). *Department of Education. Education White Paper 6. Special Needs Education.*: Retrieved from https://www.education.gov.za/Portals/0/Documents/Legislation/White%20paper/Education%20%20White%20Paper%206.pdf?ver=2008-03-05-104651-000

Republic of South Africa (RSA). 1997. White Paper for Social Welfare. Retrieved from

Ridderinkhof A, de Bruin EI, van den Driesschen S, Bögels SM. (2020). *Attention in Children with Autism Spectrum Disorder and the Effects of a Mindfulness-Based Program.*: PMCID

Roulston, K. (2018). Qualitative interviewing and epistemics. *Qualitative Research*, *18*(3), 322-341.

Rubin, H.J. and Rubin, I.S. (2005), *Qualitative Interviewing: The Art of Hearing Data.:* Sage Publications, Thousand Oaks, CA.

Russell, G., & Norwich, B. (2012). Dilemmas, diagnosis and de-stigmatization: Parental perspectives on the diagnosis of autism spectrum disorders. *Clinical Child Psychology and Psychiatry*, *17*(2), 229-245.

Santa Maria Tomas, Vermeulen Walter J.V., & Baumgartner Rupert. (2021). Framing and assessing the emergent field of business model innovation for the circular economy: A combined literature review and multiple case study approach. "*Sustainable Production and Consumption. 26 (April):* 872-891.

Schieve LA, Blumberg SJ, Rice C, Visser SN, Boyle C. (2007). *The relationship between autism and parenting stress.: Paediatrics. ;119 (1), S114-S121: https://0-doi-org.innopac.wits.ac.za/10.1542/peds.2006-2089Q* PMID: 17272578.

Scorgie. K., & Sobsey. D. (2000). Transformational outcomes associated with parenting children who have disabilities. Mental Retardation. 38, 195-206. Search Institute. Retrieved 1/10/05 from https://doi.org/10.1352/0047-6765(2000)038%3C0195:TOAWPC%3E2.0.CO;2

Seligman. M., & Darling, R. B. (1989). *Ordinary families, special children: A systems approach to childhood disability.* New York: Guilford Press.

Shenton, A. K. (2004). Strategies for ensuring trustworthiness in qualitative research projects. *Education for information*, *22*(2), 63-75.

Smith. T. B., Oliver, M. N. I., & Innocenti, M. S. (2001). Parenting stress in families of children with disabilities. *American Journal of Orthopsychiatry. 7*/ (2). 257-261.

South Africa National Planning Commission. (2012). *Our future - make it work National Planning Commission National Development Plan 2030; Executive Summary.* Republic of South Africa Government. Available at; National Development Plan 2030 | South African Government (www.gov.za)

Stanley, K., & Kuo, N. C. (2022). "It Takes a Village": Approaching the Development of School-Family-Community Partnerships through Bronfenbrenner's Socio-Ecological Perspectives. *Journal of Human Sciences and Extension*, *10*(1), 13.

State, M. W., & Šestan, N. (2012). The emerging biology of autism spectrum disorders. *Science*, *337*(6100), 1301-1303.

Statistics South Africa. (2022). Census. Retrieved from https://www.statssa.gov.za/

Sulek, R., Trembath, D., Paynter, J., & Keen, D. (2019). Social validation of an online tool to support transitions to primary school for children with autism. *Research in Autism Spectrum Disorders*, *66*, 101408.

Tashakkori, Abbas & Johnson, R. & Teddlie, Charles. (2021). *Foundations of Mixed Methods Research: Integrating Quantitative and Qualitative Approaches in Social and Behavioral Sciences.* SAGE Publications, Inc.

Ueda, R., Okada, T., Kita, Y., Ozawa, Y., Inoue, H., Shioda, M., ... & Ozawa, H. (2021). The quality of life of children with neurodevelopmental disorders and their parents during the Coronavirus disease 19 emergency in Japan. *Scientific Reports*, *11*(1), 1-8.

United States America (USA). (2019). *United States of America Government. Department of Health & Human Services.* Centers for Disease Control and Prevention. https://www.cdc.gov/ncbddd/autism/data.html

Van den Berg, W., Makusha, T., & Ratele, K. (Eds.) (2021). *State of South Africa's Fathers 2021*. Cape Town/Stellenbosch: Sonke Gender Justice, Human Sciences Research Council, & Stellenbosch University.

Vivanti, G., Kasari, C., Green, J., Mandell, D., Maye, M., & Hudry, K. (2018). Implementing and evaluating early intervention for children with autism: Where are the gaps and what should we do. *Autism Research*, *11*(1), 16-23.

Wang, H., Hu, X., & Han, Z. R. (2020). Parental stress, involvement, and family quality of life in mothers and fathers of children with autism spectrum disorder in mainland China: A dyadic analysis. *Research in Developmental Disabilities*, *107*, 103791.

Warren, C. (2002), *"Qualitative interviewing", in Gubrium, J. and Holstein, J. (Eds), Handbook of Interview Research: Context and Method*, Sage Publications Limited, Thousand Oaks, CA.

Wilkinson S. (2004). *Focus group research. In Silverman D. (Ed.), Qualitative research: Theory, method, and practice* (pp. 177–199). Thousand Oaks, CA: Sage.

Wood, L. M., Sebar, B., & Vecchio, N. (2020). Application of rigour and credibility in qualitative document analysis: Lessons learnt from a case study. *The Qualitative Report*, *25*(2), 456-470.

Xu, A., Baysari, M. T., Stocker, S. L., Leow, L. J., Day, R. O., & Carland, J. E. (2020). Researchers' views on, and experiences with, the requirement to obtain informed consent in research involving human participants: a qualitative study. *BMC Medical Ethics*, *21*(1), 1-11.

Yarborough, M. (2021). Do we really know how many clinical trials are conducted ethically? Why research ethics committee review practices need to be strengthened and initial steps we could take to strengthen them. *Journal of Medical Ethics*, *47*(8), 572-579.

Appendix A

Participant Information Sheet

The study title: The influence of children displaying characteristics of autism spectrum disorder (ASD) on the lives of working parents: a case of the Northern Cape Province (NC), South Africa.

Good day

My name is Noluthando Daleen Elizabeth Botha. I am a registered student for the degree MA in Social Work in the field of Occupational Social Work at University of the Witwatersrand, Johannesburg. My supervisor is Prof. Edmarie Pretorius. I am conducting a research study about working parents living with children displaying characteristics of autism spectrum disorder (ASD).

I am inviting you to take part in a face-to-face semi-structured interview. If you decide to take part, your participation in this research study will last about 45 to 60 minutes for one day only. The face-to-face interview will take place at the most convenient venue and time as agreed by both the participant and the researcher. The recommended time would be during weekends to avoid inconveniencing the participant during working hours.

With your permission, I would like to audio record the interview. The hardcopy data will be stored in a safe at my home and the softcopy files will be saved on my personal laptop in a research folder that will require a password created by myself before the folder can be accessed. The only people who will have access to the collected data will be the researcher and her research supervisor. The information will be kept.

During the research activity, I will need to ask for some personal information about you, including your family structure, information about your child or children who display characteristics of ASD and experiences with your child. The information obtained will only be used for the purpose of the study and further distribution of the information will not happen unless prior permission is obtained from you.

The interview will be confidential and anonymous. When I share the findings of the research study, I will not include your name or anything else that could identify you. With your permission, other researchers may use the data collected from this research study, but your name and any personal information will not be used or passed on. Upon request from mining houses the research findings will be shared to confirm if there is a need for support services for parents living with children who display characteristics of autism spectrum disorder (ASD).

If you decide to take part in the research study, it should be because you want to volunteer. You do not have to take part. You can stop being in the study at any time. You do not have to answer any questions if you do not want to. You will not get any direct benefits if you choose to join the research study. You will not lose any services, benefits, or rights you would normally have if you decided not to join. Taking part in the research study will not cost you anything. You will not be paid for being in this research study.

The risks for this research study are no more than what happens in everyday life. However, some of the questions asked may make you feel sad or upset. If this happens, I will stop the interview and continue another time. If you need some support or counselling services following the interview, these are available free of charge at Families South Africa (FAMSA) in Kathu. The name of the counsellor is Marthie Trollip and her contact details for the counselling services are hope@famsaupt.co.za or 053 723 1564.

This research study will be written up as a research report. If you would like to receive a summary of this report, I will be happy to send it to you.

If you have any questions during or afterwards about this research study, feel free to contact me on 082 507 3382. If you have any concerns or complaints about the ethical procedures of this research study, you are welcome to contact the University Human Research Ethics Committee (Non-Medical), telephone +27(0) 11 717 1408, email hrecnon-medical@wits.ac.za.

Yours sincerely,
Noluthando Daleen Elizabeth Botha

Researcher:
Noluthando Daleen Elizabeth Botha
2244581@students.wits.ac.za
Cell: 082 507 3382

Supervisor:
Prof. Edmarie Pretorius
E-mail: Edmarie.Pretorius@wits.ac.za
Tel no: +27 11 717 4476

Appendix B

Consent Form

The study title: The influence of children displaying characteristics of autism spectrum disorder (ASD) on the lives of working parents: a case of the Northern Cape Province (NC), South Africa.

Name of researcher: Noluthando Daleen Elizabeth Botha

I, ……., agree to participate in this research project.

I agree to the following:

(Please circle the relevant options below)

The research study was explained to me. I understand what this study is about.	YES	NO
I understand that I can volunteer to take part in the study.	YES	NO
I agree that the interview may be audio recorded.	YES	NO
I agree that direct quotations from my interview may be used by the researcher in her research report.	YES	NO
I agree that my participation will remain anonymous (my name will not be used by the researcher in her research report).	YES	NO
I agree that other researchers may use the information I provide in my interview (depending on their own ethics clearance being obtained) but my name and any personal information will not be used or passed on.	YES	NO

…….. (signature)

…….(name of participant)

Signed at …….. on ……... (date).

Appendix C – Permission to Contact Caregivers

Independent Learning
(Pty) Ltd
Unit C Redek Place
Meadowbrook Business
Estate
Jacaranda Avenue
Olivedale
Johannesburg
2188

18 May 2023

University of the Witwatersrand

1 Jan Smuts Avenue,

Braamfontein 2000,

Johannesburg,

2050

Humanities Faculty

To whom it may concern

RE: PERMISSION IS GRANTED TO CONTACT PARENTS WHO ATTENDED SPECIAL NEEDS TRAINING IN 2019

Independent Learning acknowledged receiving the request from Noluthando Daleen Elizabeth Botha with student number 2244581. After careful consideration, permission is granted that she may contact the parents from the Northern Cape communities who attended the special needs training and completed the attendance registers in 2019.

As indicated in the request this is voluntary and no parent may be forced to participate in the study.

Warm Regards

Reinette Lombard

Educational specialist

Appendix D – Ethics Clearance

UNIVERSITY OF THE WITWATERSRAND JOHANNESBURG

SCHOOL OF HUMAN AND COMMUNITY DEVELOPMENT ETHICS COMMITTEE
CONSTITUTED UNDER THE UNIVERSITY HUMAN RESEARCH ETHICS COMMITTEE (NON-MEDICAL)

CLEARANCE CERTIFICATE	**PROTOCOL NUMBER: SW23/02/01**
PROJECT TITLE	The influence of children displaying characteristics of autism spectrum disorder (ASD) on the lives of working parents: a case of the Northern Cape Province (NC), South Africa.
INVESTIGATOR	**NDE BOTHA**
SCHOOL/DEPARTMENT OF INVESTIGATOR	SOCIAL WORK
DATE CONSIDERED	19 May 2023
DECISION OF THE COMMITTEE	Approved unconditionally
RISK LEVEL	LOW RISK
EXPIRY DATE	29 MAY 2026

ISSUE DATE OF CERTIFICATE 29 MAY 2023 **CHAIRPERSON** (DR L PETERSEN)

cc: Supervisor: PROF E PRETORIUS

DECLARATION OF INVESTIGATOR

To be completed in duplicate and **ONE COPY** returned to the Chairperson of the School/Department ethics committee.

I fully understand the conditions under which I am are authorized to carry out the abovementioned research and I guarantee to ensure compliance with these conditions. Should any departure to be contemplated from the research procedure as approved I/we undertake to resubmit the protocol to the Committee.

Signature Date 31/05/2023

PLEASE QUOTE THE PROTOCOL NUMBER ON ALL ENQUIRIES

Appendix E – Human Research Ethics Online Training

MACQUARIE University
SYDNEY·AUSTRALIA

Certificate

February 14, 2023

This is to certify that Ms. Noluthando Botha has successfully completed the Macquarie University Human Research Ethics Online Training Module for the Social Sciences and Humanities.

Macquarie University

Appendix F – Research Instrument

Course: Social Work	Degree Master of Arts in the field of Occupational
Purpose of the document:	Research Instrument (Semi-structured interview schedule)
Name of Student:	Noluthando Daleen Elizabeth Botha
Name of Supervisor:	Prof. Edmarie Pretorius
Student Number:	2244581

---

1. Tell me more about you and your family?

---

2. Tell me more about your child/children who is displaying characteristics of ASD?

---

3. Share with me the emotional experiences of parenting your child who is displaying characteristics ASD?

---

4. How does parenting your child who is displaying characteristics of ASD influences your social context?

---

5. During the COVID-19 national lockdown in South Africa (March 2020), what were your experiences caring for your child who is displaying characteristics of ASD?

---

6. Share with me the challenges that working parents are experiencing when caring for a child displaying characteristics of ASD?

---

7. How do you perceive parenting your child displaying characteristics of ASD influences your work performance, general wellbeing, and Quality of Life (QOL) for the working parents?

---

8. What are the strategies you have developed to manage caring for your child displaying characteristics of ASD?

---

9. If you had the opportunity, what would you like to do differently or change when caring for your child who is displaying characteristics of ASD?

---

10. If you were the employer, what kind of support would you have offered employees who are parents of children who display characteristics of ASD?
