Resilience of a caregiver of a child with autism spectrum disorder in resource-constrained contexts

by

Saabirah Moosa

Submitted in partial fulfilment of the requirements for the degree

MAGISTER EDUCATIONIS

(Educational Psychology)

Department of Educational Psychology

in the Faculty of Education

at the

UNIVERSITY OF PRETORIA

Supervisor: Dr Anna-Barbara du Plessis

OCTOBER 2020

DECLARATION OF ORIGINALITY

I, Saabirah Moosa (student number 14039762), declare that this mini-dissertation titled: *“Resilience of a caregiver of a child with autism spectrum disorder in resource-constrained contexts”* which I hereby submit for the degree Magister Educationis in Educational Psychology at the University of Pretoria, is my own work and has not previously been submitted by me for a degree at this or any other tertiary institution.

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Ms. S. Moosa
October 2020

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DEGREE AND PROJECT	MEd Resilience of a caregiver of a child with autism spectrum disorder in resource-constrained contexts	
INVESTIGATOR	Ms Saabirah Moosa	
DEPARTMENT	Educational Psychology	
APPROVAL TO COMMENCE STUDY	01 June 2020	
DATE OF CLEARANCE CERTIFICATE	09 October 2020	
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CC	Ms Bronwynne Swarts Dr Anna-Barbara du Plessis

This Ethics Clearance Certificate should be read in conjunction with the Integrated Declaration Form (D08) which specifies details regarding:

- **Compliance with approved research protocol,**
- **No significant changes,**
- **Informed consent/assent,**
- **Adverse experience or undue risk,**
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- **Data storage requirements.**

EDIT DECLARATION

I, Wilna Swart, solemnly declare that in October 2020 I completed a professional language-edit of Ms Saabirah Moosa's Master's mini-dissertation titled 'Resilience of a caregiver of a child with autism spectrum disorder in resource-constrained contexts'.

Ms Moosa composed a well-constructed and clearly presented paper to produce a scientific academic paper of superior quality. She clearly not only complied with the requirements but aimed for excellence.

I furnished Ms Moosa with comprehensive editorial comments, notes and recommendations, in addition to editorial amendments in tracked mode, which Ms Moosa accepted or rejected at her discretion.

Ms Moosa was reminded, although her personal writing style prevailed throughout, that avoiding plagiarism remained her responsibility.

I wish Ms Moosa every success in this very important academic endeavour.

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Wilna Swart
Full Member

Western Cape Branch: Secretary
Membership number: SWA010
Membership year: March 2020 to February 2021

083 333 6810
wilnaswart7@gmail.com

www.editors.org.za

ACKNOWLEDGEMENTS

In celebration of this academic milestone that I have achieved, I would like to express my deepest gratitude to the following people:

- Dr Anna-Barbara du Plessis, my research supervisor, for her selfless dedication, endless guidance, support and motivation throughout the process;
- Ms Wilna Swart, for her meticulous efforts in editing this study;
- My parents, sister and brother, for their unwavering sacrifices and support, and for providing me with the strength and opportunities to reach for my dreams and persevere, all of which have been pertinent to my success.

ABSTRACT

Knowledge regarding Autism Spectrum Disorder (ASD) in resource-constrained contexts is profoundly minimal. This is alarming because approximately 90% of individuals living with ASD reside in low- to middle-income contexts. Caregivers of children with ASD experience significant stressors and challenges, which may predispose them to psychological difficulties. Therefore, it was beneficial to investigate the resilience factors that allowed caregivers to remain resilient in the continued care of their children with ASD.

A descriptive case study design provided an in-depth understanding of the resilience of such a caregiver. Purposeful sampling involving a participant from previous research, a 29-year old mother of two, who resided in a resource-constrained context, was utilised as the initially proposed sampling was impossible to perform owing to the COVID-19 lockdown in South Africa at the time. The data collection protocol included one telephonic semi-structured interview at the convenience of the participant. Inductive thematic analysis of the results indicated that the participant experienced unique challenges that placed her resilience at risk, such as limited knowledge, finances and access to healthcare, and also unique resilience-enabling factors such as online social resources.

Key words:
Autism Spectrum Disorder, case study, resilience, resource-constrained, semi-structured interview and case study design

TABLE OF CONTENTS

LIST OF TABLES

LIST OF ABBREVIATIONS

APA	American Psychological Association
ASD	Autism Spectrum Disorder
COVID-19	Coronavirus Disease of 2019
DSM-5	Diagnostic and Statistical Manual, Fifth Edition
HPCSA	Health Professions Council of South Africa
ID	Identification document
NGO	Non-governmental organisations
NPO	Non-profit organisations
SERT	Social-ecological resilience theory
UP	University of Pretoria
WHO	World Health Organisation

1. CHAPTER ONE: INTRODUCTION AND OVERVIEW OF THE STUDY

The first chapter explores the rationale, purpose and aims of the study, in addition to the research questions, working assumptions, clarification of main concepts, the paradigmatic and methodological choices, quality criteria and the ethical considerations of the study. Subsequent chapters elaborate on the concepts introduced in Chapter 1.

1.1 INTRODUCTION AND RATIONALE

Autism Spectrum Disorder (ASD) is a long-term neurodevelopmental disorder characterised by communicative and behavioural challenges (American Psychiatric Association, 2013; Nolen-Hoeksema, 2013; Smith, Hoogenhout, Ing, Thomas, & De Vries, 2013)[1]. It is one of the developmental disorders with a current, but increasing, worldwide prevalence of 1% (Smith et al., 2013; World Health Organisation, 2017). One possible explanation for this increase is a greater awareness of ASD (Carbone, Farley, & Davis, 2010; Smith et al., 2013; WHO, 2017), but there may also be other reasons.

Owing to the unexpected rise in prevalence, investigating the resilience of caregivers of children with ASD is important for several reasons. Firstly, despite the increased awareness regarding ASD, much of what is known about ASD emanated from well-resourced countries, whereas knowledge about ASD in resource-constrained contexts is minimal (De Vries, 2016). This is alarming because an estimated 90% of individuals living with ASD live in low- to middle-income contexts (De Vries, 2016). The resilience factors that caregivers draw on, which enable them to continue with the care they provide, largely depend on context. This therefore emphasises the need to investigate the resilience factors relevant to caregivers of children with ASD in resource-constrained contexts in South Africa (Parsons, Cordier, Lee, Falkmer, & Vaz, 2019).

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[1] For this dissertation, the researcher applied the APA 6th edition referencing style.

Secondly, being a caregiver of a child with ASD can be a strain and demanding in many different ways, therefore making caregivers vulnerable to psychological difficulties that include, but are not limited to, distress, depression and anxiety (Hare, Pratt, Burton, Bromley, & Emerson, 2004; Hoefman et al., 2014; World Health Organisation, 2017). Moreover, caregivers experience challenges associated with simultaneously undertaking their daily activities and caring for a child with ASD (Hoefman et al., 2014). Furthermore, these individuals sometimes experience financial difficulties (Hoefman et al., 2014). It can thus be concluded that caring for an individual with ASD is challenging and investigating the resilience factors that allow these caregivers to persevere may be of value.

Thirdly, the improved well-being of the caregiver can enhance the effect of interventions on a child diagnosed with ASD (Hoefman et al., 2014). Therefore, it may be beneficial to identify the resilience factors that contribute to the well-being of caregivers in resource-constrained contexts, where access to professionals such as paediatric neurologists, educational psychologists, occupational therapists, and speech and language therapists is limited.

The fourth reason for researching the resilience of caregivers of children with ASD is extracted from a longitudinal study conducted by Gray (2002). According to Gray (2002), the initial period prior to diagnosis, intervention plan development or placement of a child is the most stressful. Once this has been achieved, caregivers and family generally experience a positive change (Gray, 2002). However, in a resource-constrained context, quality healthcare is often financially and logistically out of reach and government healthcare is therefore the most accessible (Statistics South Africa, 2017). The disadvantage, however, is that although government healthcare is said to be accessible, it may not have the capacity to accommodate all children with ASD (Tilahun, Hanlon, Fekadu, Tekola, & Baheretibeb, 2016). Thus the stressful time before a diagnosis is made, which Gray (2002) mentioned, is prolonged. Consequently, the effect on caregivers and families of children with ASD in resource-constrained contexts may be worse than in well-resourced contexts.

Lastly, my personal motivation for undertaking this research is situated in an observation made at a well-resourced school for children with ASD. Despite the access to resources, the effect of attending to an individual with ASD remained demanding. The neurological condition, ASD, piqued my interest with regard to how caregivers in resource-constrained contexts coped with the very same challenges, and possibly a greater number of challenges, considering their lack of access to resources. Owing to the lack of research available on the resilience of caregivers in resource-constrained contexts and my personal motivation regarding this topic, the research inquiry into this topic was justified.

1.2 PURPOSE AND AIMS OF THE STUDY

Owing to the growing number of individuals with ASD and the considerable difficulties caregivers of children with ASD are faced with, as foregrounded in the previous section, the purpose of this study was to investigate the resilience of caregivers of children diagnosed with ASD in resource-constrained contexts. This study moreover aimed to use literature review to identify the resilience factors of caregivers of children with ASD in well-resourced contexts. Furthermore, the objective was to identify which of these resilience factors present in well-resourced contexts were also present in and accessible to caregivers of children with ASD in resource-constrained contexts. This was achieved by exploring the resilience factors of caregivers in resource-constrained contexts in an attempt to uncover resilience factors different from the known factors found in mainly well-resourced contexts. By doing this, greater awareness regarding ASD and resilience factors was created, which might put in motion the creation of supportive measures for caregivers of individuals diagnosed with ASD, especially in resource-constrained contexts.

1.3 RESEARCH QUESTIONS

This study was guided by the following research questions:

1.3.1 Primary question

What are the resilience factors of caregivers of children with ASD in resource-constrained contexts?

1.3.2 Secondary questions

What are the resilience factors of caregivers of children with ASD in well-resourced contexts?

Which resilience factors of caregivers of children with ASD present in well-resourced contexts are also available to caregivers in resource-constrained contexts?

1.4 WORKING ASSUMPTIONS

The working assumptions of this study were as follows:

- Resilience factors are present in caregivers of children with ASD.
- Resilience factors utilised by caregivers of children with ASD can be discussed through language.
- Owing to the differences in access to services and resources, differences in the resilience factors of caregivers of children with ASD (Ungar, 2018) in both well-resourced and resource-constrained contexts are expected.
- There are caregivers in resource-constrained contexts who accessed the health system and obtained diagnosis and/or intervention.
- Caregivers of children with ASD are open to sharing their experiences with children with ASD and the resilience factors they rely on.

1.5 CONCEPT CLARIFICATION

Key concepts relevant to this study are described in subsections 1.5.1 to 1.5.4, which are presented below, namely resilience factors, caregiver, Autism Spectrum Disorder and resource-constrained context.

1.5.1 Resilience factors

Resilience is the ability to withstand adversity, and the process of successfully adapting when faced with the challenge or adversity (Ebersöhn, 2014; Theron, 2016; Walsh, 1996). Resilience factors refer to the available resources that enhance the ability to overcome challenges successfully (Wu et al., 2013). Such resources may include psychological, social, cultural, and physical resources (Ungar, 2008).

Furthermore, according to Ungar (2004), resilience factors refer to both personal and environmental characteristics that buffer against self-defined challenges. These characteristics are multidimensional and differ across contexts and challenges (Theron, Liebenberg, & Ungar, 2015; Ungar, 2004). In this study, resilience factors refer to the different resources utilised by caregivers of children with ASD to adapt successfully in the face of difficulty.

1.5.2 Caregiver

According to Faida (2016), a caregiver is any person responsible for the care and assistance of individuals who are unable to care for themselves fully. Such a person may provide unpaid care for any individual requiring assistance with the activities of daily life, or alternatively, may assume the role of a caregiver as an occupation and may receive a salary, both of which are models of caregiving (Hohler, 2012). Furthermore, caregivers are a diverse group of individuals who provide long-term care and support in a direct and indirect manner to an individual who is incapable of independent self-care (Moss, Kurzawa, Daly, & Prince-Paul, 2019).

The term caregiver is often used when referring to parents, or people functioning in the role of parents, as many children in resource-constrained contexts are not raised by their biological parents, but by family members residing in multigenerational homes (Hall, Richter, Mokomane, & Lake, 2018). In this study, a caregiver refers to an adult who attends to the needs of a child with ASD within a resource-constrained context. This includes, inter alia, biological parents, grandparents, family members or any member of the community.

1.5.3 Autism Spectrum Disorder

ASD is a long-term neurodevelopmental disorder distinguished by two core features, which are as follows (APA, 2013):

1. ‘Persistent deficits[2] in social communication and social interaction across multiple contexts’ (p. 88) These deficits are characterized by deficits in

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[2] Terminology was extracted from the DSM-5, and do not intend to offend proponents of the social view of disability.

reciprocal social interaction, in non-verbal communicative behaviours and in developing and maintaining social relationships.

2. 'Restricted, repetitive patterns of behaviour, interests, or activities' (p. 88) Repetitive motor movements or speech, the insistence of sameness in one's environment and routine, fixated or abnormal intensity of focus and hyper- or hypo-reactivity to sensory inputs characterise these patterns.

In this study, the participant was a caregiver of a child who was diagnosed with ASD. Individuals diagnosed with ASD exhibit both the aforementioned core symptoms, although in differing degrees, and therefore lie on different points on the autism spectrum.

1.5.4 Resource-constrained contexts

Resource-constrained contexts are environments that face increased scarcities with regard to skill, financial, infrastructural and technological resources (De Silva, Uyarra, Oakey, Audretsch, Lehmann, & Starnecker, 2012). According to James, Barbara, Mladen and Velazquez-Berumen (2017), resource-constrained contexts have a shortage of skilled health workers, as well as healthcare facilities from which residents could obtain services. Resource-constrained contexts moreover comprise low access to physical resources, unequal education and low socio-economic levels (Ebersöhn, Maree, & Vermaak, 2008).

In this study, a resource-constrained context refers to any environment in which caregivers of children with ASD experience a lack of access to the relevant and the necessary skilled individuals and resources. Areas regarded as resource-constrained contexts include non-urban areas.

1.6 THEORETICAL FRAMEWORK

In this study, the researcher used Ungar's (2011) social-ecological resilience theory (SERT). The SERT rests on four main principles, namely decentrality, cultural relativity, atypicality and complexity. For the purpose of this study, the researcher focused on the first three factors only (Ungar, 2011). The aforementioned SERT guided this study by providing greater understanding of resilience and the origin of its prevalent factors. Chapter Two discussed Ungar's SERT in more detail.

A reason for selecting this theoretical framework was that it encompasses a broader conceptualisation of resilience, one which includes the environment and also takes into consideration varying cultures and how resilience differs across cultures (Ungar, 2011). Furthermore, this theoretical framework considers that resilience factors may not appear to be resilience-enabling on the surface, and that therefore a deeper understanding of each individual's ecology is required to understand their personal resilience. This links with the chosen epistemology of interpretivism, which seeks to explore the unique experiences of every individual (Christensen, Johnson, & Turner, 2015; Creswell, 2009; Ponterotto, 2005).

1.7 PARADIGMATIC CHOICES

The paradigmatic choices of this study are discussed in subsections 1.7.1 and 1.7.2, which follow below. The paradigmatic choices, in addition to the advantages and limitations of each choice, are explored in greater depth in Chapter Three.

1.7.1 Epistemology

The selected epistemology of this study is interpretivism. The key assumption therein is that knowledge exists as the multiple socially constructed subjective realities of each individual, as opposed to a single objective reality shared by everyone (Ponterotto, 2005; Wahyuni, 2012). The aim of interpretivism is essentially to understand the subjective experience of human beings and this is achieved by obtaining descriptions from individuals who experienced a particular phenomenon (Houghton, Hunter, & Meskell, 2012). Moreover, because interpretivism focuses on an individual's personal point of view, it is applicable to this research study on the resilience of caregivers of children with ASD. Interpretivism consequently seeks to acquire a deep understanding of caregivers' subjective and specific experiences in caring for children with ASD in resource-constrained contexts (Houghton et al., 2012;).

1.7.2 Methodological approach

The preferred, and therefore selected, methodological approach is the qualitative research approach. Qualitative research focuses on understanding particular individuals and their subjective meanings in a specific context (Christensen, Johnson, & Turner, 2015; Creswell, 2009). According to both Creswell (2009) and Willig (2013), a qualitative research approach allows the participants and their subjective meanings and experiences to be heard and, moreover, generates a comprehensive record thereof (Willig, 2013). Considering that this study seeks to explore the resilience of caregivers of children with ASD, the qualitative methodological approach is suitable, because both the personal and subjective accounts of each caregiver's experience in caring for a child with ASD are heard.

Although the references to well-resourced contexts may create the impression of a comparative study, research findings of well-resourced contexts were consulted to glean more resilience factors, and identify possibilities to research when considering resource-constrained contexts.

1.8 OVERVIEW OF RESEARCH CHOICES

A brief overview of the research choices of this study is presented below. The choices in addition to the advantages and limitations are explored in more depth in Chapter Three.

1.8.1 Research design

For this study, a descriptive case study design was utilised (Christensen et al., 2015; Willig, 2013). A descriptive case study design entails obtaining and generating in-depth descriptions of only one or more cases experienced by a particular individual or individuals within a specific context (Christensen et al., 2015; Creswell, 2009; De Vos, 2002; Willig, 2013). The purpose of this study is to obtain an in-depth understanding of the resilience of caregivers of children with ASD in a resource-constrained context, therefore, the selected design is suitable. According to Yin (2009), a descriptive case study design can enhance the understanding of a social phenomenon within a resource-constrained context.

1.8.2 Selection of the research site

For the purpose of this study, the Itsoseng Clinic in Mamelodi[3] was conveniently sampled as the research site. The Itsoseng Clinic is under the auspices of the UP, and the client base is predominantly from resource-constrained contexts. Conveniently selecting this research site ensured that the participant was easily accessible to the researcher, hence it was advantageous (Christensen et al., 2015; Etikan, Musa, & Alkassim, 2016). A limitation of conveniently selecting this research site is the lack of generalisability of the findings to the greater population (Etikan et al., 2016; Jager, Putnick, & Bornstein, 2017). The aforementioned limitation holds no relevance for the study, as the purpose of the study was to explore the resilience of a caregiver of a child with ASD in a resource-constrained context in depth, as opposed to achieving generalisability.

1.8.3 Selection of participants

This study, which focused on the Itsoseng Clinic in Mamelodi, enabled the researcher purposefully to select participants. Purposeful sampling entails selecting participants according to relevance to a study by utilising selection criteria (Creswell, 2009; De Vos, 2002). The researcher planned to purposefully select a maximum of three participants. (see Chapter Three for the reasons for selecting only one participant. The remainder of the chapter discusses the research as if three participants were selected.) The selection criteria for this study were as follows:

- All participants were to be or had been caregivers of children with ASD.
- All participants were to reside or had resided within a resource-constrained context at the time of caregiving a child with ASD.
- All participants were able to communicate in conversational English.
- All participants had to provide informed consent.

By applying these criteria, the sample became more homogenous with the participants, who had experienced the specific phenomenon being studied (Ritchie &

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[3] The Itsoseng Clinic is run by the Department of Psychology, UP. It is situated in a resource-constrained context and renders psychological services to clients living in resource-constrained contexts.

Lewis, 2003). The advantage of this is that rich and meaningful data of value to the phenomenon being studied was derived (Christensen et al., 2015).

1.8.4 Data generation and documentation

The selected data-generation methods included face-to-face, semi-structured individual interviews, naturalistic observations and a reflective journal. (see Chapter Three for an explanation of the data-generation methods which had to be adapted when only one participant was selected.) The data documentation methods included audio-recordings of the interviews along with their corresponding written transcripts, field notes (of the observations) and a written reflective journal (of the researcher’s own thought processes during the research) (Christensen et al., 2015; Creswell, 2009; De Vos, 2002; Silverman, 2006). Comparing data from the aforementioned multiple sources through a process called triangulation enhanced the trustworthiness and authenticity of this study (Creswell, 2009; Ritchie & Lewis, 2003).

By utilising face-to-face, semi-structured interviews as data-generation method, the researcher could engage in probing, with the aim of this study in mind, while encouraging rich expressions from participants (Silverman, 2006). The researcher planned to conduct at most three such interviews (depending on the availability of participants), as this aligned with the purpose of this study, which sought to understand the resilience of caregivers of children with ASD in resource-constrained contexts. The researcher moreover remained aware of the limited focus of the study as a mini-dissertation.

The first data documentation method utilised was audio-recording of the interviews. Audio-recordings were relevant to the study in that they served as records of the participants’ state and feelings at the moment the interviews took place, which consequently resulted in enhanced understanding of the phenomenon by the researcher (Willig, 2013). This moreover aligns with the aim of the study, as previously mentioned. The second data documentation method involved verbatim transcripts. Transcripts were made of all the audio-recordings of the interviews conducted (Willig, 2013). This concept refers to the spoken word accurately converted into written text (Halcomb & Davidson, 2006).

The researcher planned to utilise naturalistic observations during interviews as an additional data-generation method (Creswell, 2009; Flick, 2018). Observations may be advantageous as they allow the researcher to identify what participants may be feeling or unwilling to talk about. Possible observations include hesitancy and tears. The corresponding data documentation method was field notes. Field notes entail taking notes of the observations made (Creswell, 2009), thereby possibly enriching verbal interview data.

The last data generation method the researcher used was a written reflective journal in which all personal thoughts, feelings or bias, in addition to the specific ideas or issues raised during the interview process, were written down immediately after each interview (Creswell, 2009; Halcomb & Davidson, 2006; Kuckartz, Metzler, & Kenney, 2002). This was beneficial in that it allowed the researcher to take a reflective stance during the study and to avoid (or limit) interference or threats relating to researcher bias (Christensen et al., 2015; Creswell, 2009; Willig, 2013).

1.8.5 Data analysis and interpretation

The researcher employed inductive thematic analysis to analyse and interpret the data accumulated for the study. According to Boyatzis (1998), inductive thematic analysis is a method of encoding qualitative data, often in the form of themes that are guided by the data collected, and the research questions. These themes refer to patterns identified in the data that both describe and organise the data and are grounded in the data collected (Boyatzis, 1998; Braun & Clarke, 2006; Willig, 2013). According to Braun and Clarke (2006), the six phases of thematic analysis are to familiarise oneself with the data, to generate initial codes, to identify themes, to review the themes, to define and name the themes and to produce a report. The study sought to explore the resilience of caregivers of children with ASD in a specific resource-constrained context. Therefore, participants were interviewed, generating data from which common meanings were extracted and themes consequently identified (Boyatzis, 1998; Willig, 2013).

For the purpose of this study, the researcher utilised ATLAS.ti, a qualitative data analysis programme. ATLAS.ti assists the researcher to arrange and manage data in a systematic manner (ATLAS.ti, n.d.).

1.8.6 Quality criteria

To ensure the quality of the research study, the researcher engaged in member-checking and reflexivity. Member-checking provided an opportunity for the participant to validate the accuracy of the interview transcript, as well as the themes extracted from the data (Creswell, 2009; Willig, 2013). Reflexivity encouraged the researcher to reflect actively on the research process to prevent the interference of personal bias and feelings from having an impact on the data (Christensen et al., 2015; Creswell, 2009). Both member-checking and reflexivity facilitated a process through which the trustworthiness and authenticity of the study was preserved (Creswell, 2009; Lincoln & Guba, 1985).

As stated by Major and Savin-Baden (2010), researchers are required to adhere to requirements relating to credibility, transferability, dependability, and confirmability. Credibility ensures that the results and findings of the research study are trustworthy and hence believable (Major & Savin-Baden, 2010). Member-checking, as conducted by the researcher in this study, ensured that the results and findings were credible (Korstjens & Moser, 2018). Transferability refers to the extent to which the results of a study may be applicable to different contexts through thick descriptions (Korstjens & Moser, 2018; Major & Savin-Baden, 2010). The researcher provided thick descriptions from which the reader might make a transferability judgement based on specific contexts of interest (Korstjens & Moser, 2018). Dependability suggests that the research may be trusted across time, and confirmability suggests that the researcher takes a neutral stance during the research study (Major & Savin-Baden, 2010). The researcher ensured that the context of the study was described well, that the steps taken throughout the research process were well-documented, and that personal bias did not have an influence, in so doing complying with both dependability and confirmability requirements (Major & Savin-Baden, 2010).

1.9 ETHICAL CONSIDERATIONS

The ethical considerations applicable to this study are discussed briefly in this section. The researcher elaborates on the ethical considerations applicable to this study in further detail in Chapter Three.

Research ethics are salient to any study and more so when human beings are involved (De Vos, 2002). Moreover, due to the nature of the study, where the resilience of caregivers of children with ASD in a selected resource-constrained context was explored, it was imperative to consider both research and professional ethics (Health Professions Council of South Africa, 2006).

Prior to the commencement of the study, ethical clearance was obtained from the Ethics Committee of the Faculty of Education of the UP. Moreover, informed and voluntary consent was obtained from a legally and psychologically capable individual prior to the study (De Vos, 2002; Gravetter & Forzano, 2016; HPCSA, 2016). Participants were made aware that they were free to stop participating at any point, without any negative consequences (Gravetter & Forzano, 2016; Silverman, 2006). The researcher remained transparent regarding any potential harm or risks, and confirmed and strictly maintained the participants' rights to privacy and confidentiality. Numbers were assigned to replace the names of the participants. The researcher did not behave in a racially discriminating or in a rude manner towards any group at any time (HPCSA, 2006).

1.10 OUTLINE OF THE CHAPTERS IN THIS MINI-DISSERTATION

Chapter One provides the background to the study regarding the resilience factors of caregivers of children with ASD. This chapter entails an introduction to and the rationale of the study, followed by a presentation of the purpose and aims of the study, the primary and secondary questions guiding the study, the working assumptions of this study, a clarification of the key concepts relevant to this study, as well as the paradigmatic and methodological choices appropriate for the study. Quality criteria and some ethical considerations were also provided.

Chapter Two entails an extensive account of the literature pertaining to the resilience of caregivers of children with ASD in resource-constrained contexts, guided by the primary and secondary research questions of this study. In addition, the applicable theory that formed the basis of the theoretical standpoint/s for this research was explored in Chapter Two.

Chapter Three includes a detailed discussion regarding the paradigmatic and methodological choices of the study, including the advantages and challenges concomitant with the aforementioned choices. Research design, sampling of the research site and participants, methods applied for collecting and documenting data, as well as methods to analyse and interpret the results were included in Chapter Three.

Chapter Four presents the results and findings of the data analysis, which were furthermore correlated with the literature review and theoretical viewpoint recounted in Chapter Two.

Chapter Five answers research questions, and explores a discussion and explanation of the findings displayed in Chapter Four. In addition, Chapter Five presents the potential contributions and limitations of the study.

1.11 SUMMARY OF CHAPTER ONE

In this chapter, the researcher explored the rationale, purpose and aims of the study, in addition to the research questions, working assumptions, clarification of main concepts, the paradigmatic and methodological choices as well as the quality criteria and the ethical considerations of the study.

In Chapter Two the researcher discusses an extensive literature review, grounding the resilience of caregivers of children with ASD in a resource-constrained context. It also includes an investigation into the theory applicable to this study, which formed the basis of the researcher's theoretical standpoints in this study.

2. CHAPTER TWO: LITERATURE REVIEW

2.1 INTRODUCTION

Chapter One provided a brief background of the research, lent clarification to the rationale, and stated the purpose and aims of the study. In addition, the research questions were stated, which gave direction to the research, including the paradigmatic and methodological choices which would provide the most relevant answers to the research questions.

Chapter Two and Chapter Three provide more detail on certain concepts and choices introduced in Chapter One. Chapter Two specifically entails a literature review of the available literature regarding the resilience of caregivers of children with ASD in resource-constrained contexts. The literature review includes international and national research conducted in resource-constrained and well-resourced contexts. Furthermore, Chapter Two entails an exploration into the appropriate theory that would form the basis of the theoretical standpoint of this research.

2.2 DIAGNOSTIC CRITERIA FOR A FORMAL DIAGNOSIS OF ASD

The diagnostic criteria for a formal diagnosis of ASD were included to facilitate an understanding of the disorder, and subsequently create an awareness of the challenges caregivers of children with ASD face on a daily basis. It is important to note that as a result of the transition from the DSM-IV to the DSM 5, the criteria for a diagnosis of ASD also transitioned whereby four previously separate categories of ASD have been consolidated into a single diagnostic category of ASD, with two categories of symptoms respectively (APA, 2013).

According to the Diagnostic and Statistical Manual (DSM-5) (APA, 2013), ASD is a neurodevelopmental disorder that typically begins during early development (APA, 2013). ASD is moreover a spectrum disorder, which suggests that the core challenges of this disorder are experienced in variant combinations and degrees of severity (Mash & Wolfe, 2016).The diagnostic criteria for ASD (indicated by A, B, C, D and E) according to the DSM-5 (APA, 2013) as well as criteria and sub-criteria are displayed below:

A. Persistent deficits[4] in social communication and social interaction across multiple contexts, currently or by history, as manifested in the following:

1. Deficits in social-emotional reciprocity, potentially ranging from abnormal social approach and failure of normal back-and-forth conversation; reduced sharing of interests, emotions, or affect; and failure to initiate or respond to social interactions.
2. Deficits in nonverbal communicative behaviours used for social interaction, potentially ranging from poorly integrated verbal and nonverbal communication; abnormalities in eye contact and body language or deficits in understanding and use of gestures; and a lack of facial expressions and nonverbal communication.
3. Deficits in developing, maintaining, and understanding relationships, potentially ranging from difficulties adjusting behaviour to suit various social contexts; difficulties in sharing imaginative play or in making friends; and the absence of interest in peers.

B. Restricted, repetitive patterns of behaviour, interests or activities, currently or by history, as manifested in at least two of the following:

1. Stereotyped or repetitive motor movements, use of objects or speech, including, but not limited to, simple motor stereotypes, lining up different toys or flipping objects over, echolalia, and idiosyncratic phrases.
2. Insistence on sameness, inflexible adherence to routines, or ritualised patterns of verbal or nonverbal behaviour, including, but not limited to, significant distress in response to minor changes, difficulties with transitions, rigidity in thinking patterns, greeting rituals, and the need to take the same route or eat the same food daily.
3. Highly restricted, fixated interests that are abnormal in intensity or focus, including, but not limited to, strong attachment to or preoccupation with unusual objects, and excessively circumscribed or perseverative interests.

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[4] Terminology extracted from the DSM-5, and do not intend to offend proponents of the social view of disability.

4. Hyper- or hypo-reactivity to sensory input or unusual interest in sensory aspects of the environment, including but not limited to, apparent indifference to pain or temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, and visual fascination with lights or movement.

C. These symptoms must be present in the early developmental period but may not become fully manifest until social demands exceed limited capacities, or they may be masked by learned strategies in later life.

D. These symptoms cause clinically significant impairment in social, occupational, or other important areas of current functioning.

E. These disturbances are not better explained by intellectual disability (intellectual developmental disorder) or global developmental delay.

The severity level of symptoms experienced ranges between Level 1 to Level 3, where Level 1 indicates that the individual requires support, Level 2 indicates the requirement of substantial support, and Level 3 indicates the requirement of very substantial support.

Based on some of the examples given in the aforementioned diagnostic criteria, it is logical to conclude that caregivers who have to deal with fixed routines, significant stress in the face of the smallest deviation from a routine, without the benefit of communication, often exacerbated by meltdowns because of sensory overloads, frequently suffer from the strain of coping with the effect of ASD (Hoefman et al., 2014). Therefore, it is important to identify the resilience factors caregivers draw from. The following literature review sought to identify the challenges of caregivers of children with ASD in both well-resourced and resource-constrained contexts to identify the different resilience factors used in the aforementioned contexts, and to explain the relevance of the social ecology of Ungar’s (2011) SERT.

2.3 CHALLENGES FACED BY CAREGIVERS OF CHILDREN WITH ASD

2.3.1 Socio-emotional challenges faced by caregivers

In accordance with studies conducted by the WHO (2017), Hare et al. (2004), Hoefman et al. (2014), Khanna, Madhavan, Smith, Patrick, Tworek, and Becker-Cottrill (2011) and Karst and Van Hecke (2012), it can be concluded that caring for children with ASD presents many possible negative outcomes for and challenges to caregivers. Stress, anxiety and depression are some of the most common negative outcomes experienced in both well-resourced and resource-constrained contexts (Carbone et al., 2010; Corman, 2009; Hoefman et al., 2014; Karst & Van Hecke, 2012; Khanna et al., 2011).

Parsons et al. (2019) conducted a study with parents and families of children with ASD in Western Australia, and they concurred with the aforementioned researchers that caregivers of children diagnosed with ASD experience significantly higher levels of stress than parents of typically developing children or children facing other disabilities. Marital discord and divorce are also prevalent among caregivers of children with ASD in both well- and low-resourced contexts (Carbone et al., 2010; Hoefman et al., 2014; Karst & Van Hecke, 2012; Khanna et al., 2011). Divan, Vajaratkar, Desai, Strik-Lievers, & Patel (2012) agreed with regard to the prevalence of marital discord and divorce, and stated that marital conflict might be ascribed to caregivers' insufficient understanding of ASD and the needs of children with ASD.

In addition, caregivers of children diagnosed with ASD also experience difficulties in carrying out daily tasks and activities while concurrently caring for children with ASD (Hoefman et al., 2014). In a study conducted in India, a developing country like South Africa, research findings suggested that caregivers of children with ASD adapted their work schedules as well as their social lives in order to care sufficiently for the children diagnosed with ASD (Divan et al., 2012). A study conducted by Hoogsteen and Woodgate (2013) documented the experiences of parents caring for children with ASD in resource-constrained contexts in Manitoba, Canada. The findings of this study indicated that despite facing difficulties in resource-constrained contexts, caregivers of children with ASD strived to obtain a balance while caring for children with ASD (Hoogsteen & Woodgate, 2013). This balance might only be achieved once caregivers received support from special schools, or coming into contact with other parents in the same situation, through whom they could rebuild their social lives (Divan et al., 2012).

Although social support is commonly identified as one of the strongest resilience factors across well-resourced and resource-constrained contexts, Hoogsteen and Woodgate (2013) found that being a caregiver of children with ASD might cause the potential isolation of caregivers in contexts where knowledge of ASD is minimal or absent, or where parents may not find others who can relate to their experiences.

The reason that the researchers believed caregivers could potentially become isolated relates to the demanding and time-consuming nature of caring for a child with ASD (Hoefman et al., 2014; Hoogsteen & Woodgate, 2013). In the study conducted with the parents of children with ASD residing in resource-constrained contexts in Manitoba, Canada, it was found that both family and parental life began revolving around the child with ASD, and considerable time and energy were spent on caring for such a child (Hoogsteen & Woodgate, 2013). Similarly, in research conducted by Divan et al. (2012) in India, it was found that mothers who enjoyed socialising prior to having a child with ASD, had become less sociable and more isolated due to the extensive time and care dedicated to the child diagnosed with ASD. Parents often become stressed, fatigued and burnt out, with little time left to socialise or destress and recuperate (Divan et al., 2012; Hoefman et al., 2014; Hoogsteen & Woodgate, 2013; Parsons et al., 2019).

2.3.2 Financial challenges

Another important challenge experienced by caregivers of children with ASD is the financial liability (Carbone et al., 2010; Hoefman et al., 2014; Karst & Van Hecke, 2012). This financial liability includes taking care of the practical demands such as providing support and appropriately accommodating the child’s daily care, education and healthcare (Karst & Van Hecke, 2012). In a study conducted in well-resourced areas in the United States of America and the United Kingdom, it has been found that caring for a child with ASD costs approximately $3 to $5 million more than caring for a child with neurotypical development (Smith et al., 2013). Generally, but specifically in South Africa, poorer households experience the crippling financial effect of caring for a child with ASD (Harris, Goudge, Ataguba, McIntyre, Nxumalo, Jikwana, & Chersich, 2011). It can therefore be concluded that access to the required funds in a resource-constrained context is limited; hence, the challenges and financial liability in this context may be detrimental.

A study conducted with caregivers in the United Kingdom indicated that although many of them did not wish to resign from their jobs and take on a more permanent caregiving role, this was often the case (Windle & Bennet, 2012). Caring for a child with ASD is not only stressful, it is time-intensive (Hoefman et al., 2014; Hoogsteen & Woodgate, 2013). This places caregivers of children with ASD in a predicament because the costly nature of caring for some children with ASD makes permanent, well-paid employment a necessity.

Furthermore, from an Ontario-based study conducted with eight mothers whose children had received a formal diagnosis of ASD, the financial plight due to caring for a child with ASD is evident (Fletcher, Markoulakis, & Bryden, 2012). Over and above the medical and therapeutic treatment costs for a child with ASD are a host of additional costs. Mothers from the Ontario-based study reported additional costs as ensuring a special or healthy diet for the child with ASD due to food intolerances (Fletcher et al., 2012).

Another reported financial expense was childcare and extra or private school lessons for all the children in a family, including the child diagnosed with ASD. As both parents are often employed in order to carry the financial burden of caring for a child with ASD, they cannot be home to care for and do schoolwork with their children, and the child diagnosed with ASD is even more likely to require specialised care or schooling (Fletcher et al., 2012; Karst & Van Hecke, 2012). From a study relating to ASD conducted in a resourced-constrained community in KwaZulu-Natal, it became evident that parents could not afford specialised care, and many parents sent their children to home-based crèches that cost approximately R100 per month, as it was the most feasible option available to them (Grinker et al., 2012). Some mothers from this study reported the unique cost of having to repair their homes more often than usual due to the aggressive behaviour that their children with ASD exhibit at times. Furthermore, mothers specifically reported that because of the behaviour displayed during their children’s worst tantrums, they often had to replace doors, repaint walls, and have furniture cleaned (Fletcher et al., 2012).

2.3.3 Lack of access to information and services

Caregivers in resource-constrained contexts are among those who experience difficulties in obtaining access to the appropriate professionals to assist with both diagnosis and further support, and may therefore be deprived of early intervention (Mitchell & Holdt, 2014; Tilahun et al., 2016).

In the findings of two ASD early detection studies conducted with 7- to 12-year-olds in South Korea, a well-resourced context, and 18- to 36-month-old Zulu-speaking children in South Africa, a resource-constrained context, Grinker et al. (2012) reported that despite the economic difference between these two contexts, underdiagnosis and a lack of availability of resources were prevalent in both contexts. This finding contradicts the belief that underdiagnosis as well as a lack of resources are challenges faced predominantly in resource-constrained contexts. Therefore, this is indicative of access to services being a worldwide challenge faced by parents in both resource-constrained and well-resourced contexts.

A study conducted with low-income, rural families from a minority group, much like many among the population in South Africa, it was found that children in this context received a diagnosis up to a year and a half later than their wealthier, white, urban counterparts (Grinker et al., 2012). It is consequently imperative to note that the burden of caring for a child with ASD in a resource-constrained context, such as South Africa, is much heavier owing to the larger proportion of the population residing in resource-constrained contexts (Pillay, 2014). This means that already limited available resources have to be shared by even more people.

South Africa is included in the geographically distinct sub-Saharan Africa, which is regarded as the poorest region in the world, and has the leading proportion of vulnerable children worldwide (Pillay, 2014). Furthermore, Pillay (2014) also reported that in the sub-Saharan African region, there are proportionally more school-aged children than there are educational psychologists. For example, in South Africa it was reported in 2014 that there were 1178 educational psychologists, who had to render services to more than 10 million school-aged children; 18 educational psychologists were allocated to 624,820 school-aged children in Namibia; 12

educational psychologists were available for 502,884 children in Botswana; 500 educational psychologists had to render services to over 44 million children in Nigeria; 10 educational psychologists were available for in excess of 4 million children in Zambia, 18 educational psychologists had to assist over 11 million children in Uganda, 15 educational psychologists were allocated to more than 11 million children in Kenya and 3 educational psychologists were available for in excess of 13 million school-aged children in Tanzania. These numbers reflect the scarcity of health services available to caregivers of children with ASD. Due to the developing nature of the aforementioned countries, less government funding is allocated for training and the appointment of educational psychologists, therefore educational psychologists are in great demand (Mitchell & Holdt, 2014; Pillay, 2014).

In addition, in resource-constrained contexts in South Africa, individuals requiring any form of medical care or professional services have to contend with travelling far, incurring exorbitant travel costs and coping with long queues to obtain access to healthcare services (Harris et al., 2011). According to a study conducted with parents of children with ASD in remote areas of Australia, it was found that such caregivers faced similar difficulties as caregivers in resource-constrained contexts in South Africa (Parsons et al., 2019). The vastly dispersed services are often centralised in a few urban areas, meaning that challenges with reaching appropriately skilled professionals are unique to all populations residing in remote areas, therefore having an additional influence on the stress levels that caregivers in remote areas may experience (Parsons et al., 2019). Mitchell and Holdt (2014) concurred with the aforementioned statement by reporting that, in South Africa, resources required for diagnosis and intervention of ASD remained available predominantly to the minority of well-resourced families caring for children with ASD.

In their study, conducted with 18- to 36-month-old Zulu-speaking children in a resource-constrained area in KwaZulu-Natal, South Africa, Grinker et al. (2012) reported that families residing in resource-constrained contexts that might have some funds available were predominantly concerned with survival as opposed to obtaining medical care or treatment for their children who had been diagnosed with ASD. The inclination to attend to daily needs to survive rather than to access medical care, therefore, acts as a barrier to the retrieval of available medical resources.

Moreover, in a study conducted by Mthimunye (2014), it was found among single mothers of children with ASD in a low-income community in the Western Cape of South Africa that communities lacked understanding of ASD and related disorders, resulting in misunderstandings and distorted beliefs about the condition (Donohue & Bornman, 2014; Tilahun et al., 2016). Mthimunye (2014), in that study, expressed believing that the resilience of caregivers might be hampered owing to the lack of psychoeducation related to ASD (Mthimunye, 2014). Mitchell and Holdt (2014) agree with Mthimunye (2014) that the lack of information regarding ASD may hamper the resilience of caregivers of children with ASD due to the years of uncertainty and distress they experience prior to receiving a diagnosis. The concurrence of Mitchell and Holdt (2014) relates to a different study they had conducted in South Africa with the parents of children who had received an ASD diagnosis.

2.3.4 Conclusion of challenges faced by caregivers of children with ASD

It can thus be seen that multiple difficulties are faced by the caregiver of a child with ASD, and that a lack of literature exploring the experiences of such caregivers in resource-constrained contexts prevails (Hoogsteen & Woodgate, 2013). It is consequently imperative to explore the resilience factors adopted by caregivers in resource-constrained contexts, in which caregivers are at an increased disadvantage due to their lack of access to knowledge, resources and services (Donohue & Bornman, 2014).

2.4 RESILIENCE FACTORS

2.4.1 Introduction

In the section that follows the researcher explored the various assets and resources that caregivers of children with ASD utilise to adapt sufficiently to the challenges associated with having a child with ASD (Wright & Masten, 2015).

2.4.2 Social support as a resilience factor

The most commonly identified resilience factor and the strongest protective factor in both well-resourced and resource-constrained contexts seem to be social support

(Grant, Cross, Wraith, Jones, Mahon, Lomax, . . . Hare, 2013; Halstead, Ekas, Hastings, & Griffith, 2018; Hare et al., 2004; Karst & Van Hecke, 2012). Grant et al. (2012), Hare et al. (2004) and Karst and Van Hecke (2012) agree that social support as a resilience factor plays a role in reducing psychological distress among caregivers of children with ASD. In addition, Wright and Masten (2015) concur that social capital is a valuable resource that can aid the process of adaptation when facing any form of adversity or challenge.

Social support may either be in the form of formal or informal support (Ekas, Whitman, & Shivers, 2009). Formal support may entail support from community agencies, non-governmental organisations (NGOs) or non-profit organisations (NPOs), and informal support may entail friends, community members or extended family members on whom caregivers may rely for support (Ekas et al., 2009; Wright & Masten, 2015). From a study conducted with Caucasian mothers of children with ASD, it was found that the route followed when seeking informal support was first the spouse, then immediate family, and finally other parents of children with the same disorder (Ekas et al., 2009). Ekas et al. (2009) concurred with the findings of the previously mentioned study conducted by Mthimunye (2014) that social support obtained from other caregivers of children with ASD was a valued resilience factor. Informal support was most likely to be effective in promoting resilience in caregivers caring for a child with ASD. Resilience studies conducted in South Africa have indicated that female connections in the form of social capital are also likely to promote greater resilience (Ungar & Theron, 2019).

With the passage of time, the nature of social support has evolved from predominantly face-to-face contact to online social support groups through online platforms. A study conducted in South Africa with parents of children with ASD found that despite the presence of traditional social support groups, online support groups are much preferred (Cole, Kharwa, Khumalo, Reinke, & Karrim, 2017). The reason for this preference is barriers such as travel costs, childcare constraints, and lack of time and availability (Cole et al., 2017). Online social support groups provide caregivers with an opportunity to build social relationships with other caregivers of children with ASD, which, as found in the aforementioned study, have been found to be effective (Ekas et al., 2009; Mthimunye, 2014). Research also indicates that caregivers are likely to seek support from other caregivers in similar situations as they perceive the support received to be more congruent with their needs, and an online support group makes this possible while omitting logistical barriers such as distance, time and money (Haslam, Tee, & Baker, 2017). Even though online support groups eliminate the travel costs, travel time and money associated with arranging another caregiver when one caregiver attends a support group, online support groups still require access to the internet, the availability of data, and knowledge as well as skill to attend online sessions. It thus seems as if online support groups can be successful in achieving their goals when attended by caregivers of children with ASD in well-resourced contexts. Making online support groups accessible to people in resource-constrained contexts therefore requires further research.

In accordance with a study that explored the nature of online support, it emerged that support obtained from online platforms represented three types of support: information support, nurturing support, and instrumental support (Cole et al., 2017). Information support encompasses support in the form of information relating to coping strategies, treatment or intervention and presentation of the particular disorder at various developmental stages (Cole et al., 2017; Haslam et al., 2017). Nurturing support encompasses a portrayal of concern or care for the caregiver and their personal well-being, and instrumental support refers to support in the form of information relating to the access and availability of services and resources (Cole et al., 2017).

Online support groups may provide caregivers with a valuable feeling of control, independence, self-confidence and competence (Cole et al., 2017). Online support groups also provide a platform for social interaction between caregivers, and not only is this effective in promoting the resilience of caregivers or children with ASD, but it may act as a buffer against the potential isolation that such caregivers may experience (Cole et al., 2017; Ekas et al., 2009; Hoefman et al., 2014; Hoogsteen & Woodgate, 2013; Mthimunye, 2014) (see section 2.2.1 about the socio-emotional challenges experienced by caregivers).

According to the study by Mthimunye (2014), despite the absence of psychoeducation regarding ASD, it was found that mothers who shared their experiences and found commonalities with other mothers facing a similar situation, were able to develop good social support on which they could rely to buffer against the difficulties they faced in raising a child with ASD. Ungar and Theron (2019) reported that according to South African studies on resilience, connections to females rather than to males was likely to promote resilience. This finding is supported in the study conducted by Mthimunye (2014), in which social support networks developed among mothers sharing their common grievances acted as a valuable resilience factor for caregivers of children with ASD.

2.4.3 Intimate or marital relationships as a resilience factor

According to Walsh (2012), individual resilience is often encouraged by bonds formed with others, such as spouses, immediate family, extended family, and community members who support their well-being. Windle and Bennet (2012) reported on the important role that marital relationships played in the resilience of caregivers. High quality marital relationships have a favourable impact on reducing caregiver burdens and fostering resilience in caregivers (Walsh, 2012; Windle & Bennet, 2012). These relationships therefore also provide reassurance of the importance of social support in the lives of caregivers of children with ASD (Windle & Bennet, 2012). On the contrary, however, some caregivers experienced excessive marital discord and even divorce as a result of caring for a child with ASD, therefore the quality of the marital relationship is important to note (Divan et al., 2012).

2.4.4 Family routines and stability as a resilience factor

In a South African study conducted with families raising children with ASD, it was found that maintaining family routines and overall stability contributed to the resilience of caregivers (Schlebusch, Samuels, & Dada, 2016). On the contrary, according to Larson (2006), the strict maintenance of family routines may result in increased caregiver stress in the event that the routine is interrupted. Strategies to overcome interrupted routines include providing detailed information to the child with ASD or appealing to a child's special interests to encourage compliance (Larson, 2006).

2.4.5 Other resilience factors: Caregiver access to and use of mental health services

In well-resourced contexts, the most common resilience factor identified is the access to mental health services and their being used by the caregiver (Karst & Van Hecke, 2012). It is noted by Karst and Van Hecke (2012) that involvement in both psychological and psychiatric interventions for caregivers of children with ASD has positive implications in terms of resilience and adaptive coping, meaning that the accessibility of mental health services to the caregiver is resilience-enabling to caregivers in well-resourced contexts. Unfortunately, the lack of understanding of and access to mental health services and financial difficulties in resource-constrained contexts in South Africa act as barriers to obtaining mental health services with the same ease as in well-resourced contexts (Karst & Van Hecke, 2012; Mitchell & Holdt, 2014; Tilahun et al., 2016).

2.4.6 Additional resilience factors

Additional shared resilience factors encountered in both the aforementioned contexts include religious beliefs, community services, hope and optimism (Bekhet, Johnson, & Zauszniewski, 2012; Karst & Van Hecke, 2012). In a study conducted by Tilahun et al. (2016) in resource-constrained areas, it was found that in addition to support groups, caregivers frequently turned to prayer and religious beliefs to support them in challenging times. Where no formal religion is present, many caregivers utilise music and the arts as a form of support from which to draw resilience (Walsh, 2012). Where prayer and religious beliefs are pertinent in the daily lives of caregivers, their efficacy as a resilience factor is more likely to have a greater impact (Ekas et al., 2009). Ekas et al. (2009) also reported that spirituality and religiousness were associated with fewer depressive symptoms, and greater immunity against significant life stress such as when caring for a child with ASD. Therefore, it seems as if social support and religious beliefs are currently the resilience factors that are relied on in some resource-constrained contexts.

2.5 CONCLUSION OF RESILIENCE FACTORS

From the aforementioned discussion relating to resilience factors, it can be concluded that there are variations in the resilience factors caregivers of children with ASD utilise in well-resourced and in resource-constrained contexts. The context in which an individual resides can be likened to a social ecology and, according to Theron et al. (2015), variations in the social ecology of a caregiver plays a noteworthy role in the adaptation and hence the resilience of the caregiver. The social ecological resilience theory will now be discussed as the theoretical underpinning of the study, in section 2.6, which follows.

2.6 SOCIAL ECOLOGICAL RESILIENCE THEORY

2.6.1 Basic premise of the social ecological resilience theory

In order to conceptualise the social ecological resilience theory, it is necessary to understand resilience. Resilience is a multilevel adaptive process that promotes positive adjustment in the face of adversity (Theron et al., 2015; Walsh, 2016). The process of resilience is likely to result in recovery and growth, but it is important to note that the process not only depends on the individual but also on the systems interacting with the individual (Masten, 2018; Walsh, 2012). Internal and external resilience factors available to the individual, for example, internal traits, and social resources such as friends and family, buffer against risk or adversity in order to promote adaptive coping (Ebersöhn, Eloff, Finestone, Grobler, & Moen, 2015; Ebersöhn, Nel, & Loots, 2017).

This research study is situated in Michael Ungar's SERT (Ungar, 2011), which rests on four main principles: decentrality, cultural relativity, atypicality and complexity – the first three of which are applicable to this study. Complexity considers resilience over time, but this study is not a longitudinal study, therefore it was not regarded as applicable. According to Masten (2001), and congruent with Ungar's (2011) theory, both individual and environmental factors are equally important and have the potential to buffer against challenges in the face of adversity. Therefore, in this study it was imperative to consider the capacity of the individuals as well as their social and physical ecologies (environment) to facilitate the resilience of caregivers of children with ASD in culturally meaningful ways (Ungar, 2015). Divan et al. (2012) are in agreement, and state that the manner in which an individual is able to be resilient in the face of a significant stressor is not limited to individual factors, but is context-bound, making it essential to consider individual and contextual factors when seeking to explore the resilience of a particular group of people.

The consideration of both individual and environment factors when trying to understand the resilience of a particular group is the basic premise of Ungar's (2011) social-ecological theory of resilience. It was applicable to the proposed study in that the researcher sought to explore resilience factors of caregivers of children with ASD in resource-constrained contexts and to see how these factors might be comparable to those found in well-resourced contexts. Therefore, viewing the environment with the same importance as the individual in the resilience process, allowed the researcher to identify and understand resilience factors in varying environments.

2.6.2 Decentrality

Individuals do not exist in isolation; they interact with, and are influenced by their physical, social and environmental contexts (Windle & Bennet, 2012). Moreover, the environment is likely to play a larger role on outcomes than the individual and his or her traits. This argument aligns with the principle of *decentrality* (Ungar, 2011), which in essence decentres the individual to allow cognisance of resilience factors in the environment to occur. For example, an overlooked resilience factor in the environment may be neighbour with a vehicle to transport the caregiver and the child with ASD to a healthcare centre. It remains for the caregiver to be resilient and arrange the transport, but the presence of the vehicle is also a resilience factor. Decentrality is applicable to the study as the researcher sought to explore the resilience factors of caregivers of children with ASD in a specific environment, namely a resource-constrained context. Consequently, awarding the environment with the same importance as the individual in the resilience process may result in an enhanced understanding of resilience in a resource-constrained context (Masten, 2001; Ungar, 2011; Ungar, Ghazinour, & Richter, 2013).

According to Ungar and Theron (2019), resilience-enabling factors are internal and external, even in structurally disadvantaged communities. Therefore, the importance of exploring the individual in interaction with the environmental contexts is invaluable. Resilience is not only a product of the individual's attributes or behaviour, but it is also the interplay between the individual's attributes and behaviours, as well as any resilience enabling resources that the environment provides (Ungar, 2011). When the capacity of the caregivers' environment to provide them with the resources they need is greater, the likelihood increases that caregivers are able to take advantage of the resources and utilise them as a source to promote resilience (Ungar, 2015).

Information previously mentioned in section 2.3 of the literature review enabled the researcher to conclude that caregivers in resource-constrained contexts and well-resourced contexts do not always have the same resilience-enabling resources available to them in their environments. Caregivers in resource-constrained contexts contend with many challenges to access health practitioners, such as long travelling distances, expensive travel costs, long queues, and a shortage of professionals available in the system to provide the appropriate help when required (Harris et al., 2011). This is in contrast to caregivers in well-resourced contexts, where the most commonly identified resilience factor is access to appropriate professions, such as mental health practitioners, to provide assistance when required (Karst & Van Hecke, 2012). According to Karst and Van Hecke (2012), access to appropriate professionals has positive implications for the resilience of caregivers. This is, therefore, indicative of the substantial impact that the social and physical environmental contexts have on resilience.

2.6.3 Cultural relativity

In addition, this theoretical framework takes into consideration varying cultures and 'resiliences', and this is referred to as *cultural relativity,* which is the second principle (Ungar, 2011). According to Ungar (2008), what is regarded as a positive outcome differs cross-culturally, therefore this principle is valuable in guiding this study, which is situated in South Africa, a multicultural country. A mother in one culture may, for example, be regarded as resilient if she sends her child with ASD to a grandmother to be raised, to enable the mother to work and look after the other children in the family. By understanding the cultural variations in resilience, greater overall understanding of the phenomenon will be obtained and, moreover, a more holistic understanding of caregivers of children with ASD in resource-constrained contexts (Ungar, 2008, 2011).

Resilience is only recognised in a culture when there is a positive fit between the manner in which an individual is able to be resilient and the culturally circumscribed expectations of resilience (Ungar, 2011), therefore reiterating the importance of understanding what is conceptualised as resilient in a given culture.

2.6.4 Atypicality

The third principle, *atypicality*, concludes that resilience factors may not always appear to be positive without an understanding of an individual's ecology, as resilience factors predominantly depend on the environment (Ungar, 2011). Having a grasp of the individual's ecology can therefore aid us in understanding how what sometimes appears to be constraining to caregivers of children with ASD in a resource-constrained context may actually be resilience enabling. When failing to have an understanding of a caregiver's culture or ecology, researchers run the risk of overlooking resilience, as at surface level it may appear to be constraining or maladaptive (Ungar, 2015). It may be that socially acceptable means of coping are unavailable, and a caregiver is doing his/her best under the circumstances with the resources available, and is actually managing to be resilient in the face of many and serious life stressors (Ungar, 2015). An example of this would be when a caregiver of a child with ASD resorts to begging to provide food. Although begging is not socially accepted in every culture, the mother is being resilient in the face of adversity. It is therefore crucial to be cognisant of the aforementioned principles from Ungar's SERT when considering the resilience of caregivers of children with ASD in a resource-constrained context.

2.7 SUMMARY OF CHAPTER TWO

Despite the presence of various challenges faced by the caregivers of children with ASD, the prevalence of resilience factors among these caregivers is undeniable. In both well-resourced and resource-constrained contexts, mutual resilience factors include social support, religious beliefs and community services (Bekhet et al., 2012; Karst & Van Hecke, 2012). More specifically, in resource-constrained contexts, social support and religious beliefs such as prayer are the predominant resilience factors (Grant et al., 2013; Karst & Van Hecke, 2012; Tilahun et al., 2016). These are essentially protective factors utilised by caregivers, which contribute to their resilience in caring for children with ASD (Fergus & Zimmerman, 2005).

In this chapter, the researcher included a review of the literature relating to caregivers of children with ASD in both resource-constrained and well-resourced contexts, internationally and nationally. In addition, the researcher included an exploration into three of the principles in Ungar's SERT, namely decentrality, cultural relativity and atypicality. The social ecological resilience theory forms the basis for understanding resilience, and is also the basis for making sense of the results and findings of this study.

In Chapter Three the researcher provides a detailed exploration of the paradigmatic and methodological choices of the study. The researcher also included the potential advantages of these choices as well as any challenges of the choices that may be faced, together with potential solutions for each challenge to ensure good quality research.

3. CHAPTER THREE: RESEARCH DESIGN AND METHODOLOGY

3.1 INTRODUCTION

In Chapter Two, the researcher provided an account of literature relating to the resilience of caregivers of children with ASD in well-resourced and in resource-constrained contexts, guided by the primary and secondary research questions of this study. In addition, the applicable theory, the SERT, which forms the basis of the theoretical standpoints of this research, was explored in Chapter Two.

Chapter Three includes a detailed discussion regarding the paradigmatic and methodological choices of the study, including a description of the research design, and the procedures employed in selecting participating caregivers, and generating, documenting and analysing the data, as well as the advantages and challenges concomitant with the aforementioned choices. Due to the COVID-19 pandemic, it was imperative to amend the initial research plan and hence an application for an ethics amendment was submitted and subsequently approved to ensure ethical conduct.

3.2 PARADIGMATIC CHOICES

3.2.1 Epistemology

Interpretivism is the selected epistemology of the study, as the nature of interpretivism is to elicit deep understanding of a phenomenon in a specific context (Pham, 2018). Through adopting an interpretivist standpoint, the researcher could gain an in-depth understanding of the unique experiences of each caregiver of a child with ASD in a resource-constrained context. The aim of this research study is not to generalise findings, but rather thoroughly to explore the experiences of caregivers of children with ASD in resource-constrained contexts. Therefore interpretivism is an appropriate stance for this research study.

Through interpretivism, a deep understanding of specific phenomena, how they are interpreted and experienced in specific contexts is obtained, which is the main advantage of interpretivism (Astalin, 2013; Pham, 2018). An additional advantage of interpretivism is that social realities vary; therefore, numerous perspectives are created as a product of each individual’s different background and experiences (Wahyuni, 2012). Although the creation of various social realities and perspectives are advantageous in exploring a phenomenon, the subjective nature of interpretivism may pose a challenge to the researcher (Houghton, Hunter, & Meskell, 2012).

A further challenge attached to interpretivism is that because reality and experience vary for everyone, including the researcher, the beliefs and experiences of the researcher may remain pertinent during the research process (Ponterotto, 2005). To prevent the aforementioned researcher subjectivity, the strategy adopted by the researcher was to acknowledge the impact of her personal beliefs and bias on the research and thereafter to set the personal beliefs and bias aside or “bracket” it. This act of bracketing allowed the researcher to obtain the intended meanings of phenomena as experienced by the participants themselves (Houghton et al., 2012; Wahyuni, 2012; Willig, 2013). Obtaining intended meaning was accomplished by persistently identifying and acknowledging personal bias utilising a reflective journal and having frequent consultations with another researcher, namely the researcher’s supervisor.

Another challenge relating to interpretivism is that the researcher is unable to obtain every caregiver’s subjective experience due to the limited sample size (Creswell, 2009). Through obtaining fewer but denser descriptions from the participants, the researcher acquired an increased understanding of the resilience of caregivers of children with ASD in resource-constrained contexts (Creswell, 2009).

3.2.2 Methodological approach

According to Willig (2013), qualitative research seeks to describe, as opposed to measure and explain, the experiences and behaviours of participants. This aligns well with the purpose of this research study, which sought to explore the experiences indicating the resilience of caregivers of children with ASD in a resource-constrained context. Hence, for the purpose of this study, the researcher selected a qualitative research approach. A qualitative research approach enhanced the researcher’s understanding of each caregiver’s subjective experiences and meanings related to caring for a child with ASD in a resource-constrained context (Christensen et al., 2015; Creswell, 2009).

An advantage of qualitative research is the high ecological validity (Willig, 2013), meaning that qualitative data collection takes place in natural settings as opposed to artificial settings. Therefore it is not necessary to infer results about natural settings. According to Creswell (2009), qualitative research is moreover advantageous as it provides a holistic understanding of a particular phenomenon.

A potential challenge in qualitative research is the influence of the researcher and researcher bias (Christensen et al., 2015; Willig, 2013). Reflexivity, the researcher's constant and critical recognition of personal bias in the research process, was utilised to deal with this challenge (Christensen et al., 2015; Creswell, 2009; Willig, 2013). This was accomplished through bracketing, as explained in section 3.2.1. Moreover, member-checking was used in addition to reflexivity to prevent researcher bias from tainting the data and to enhance the trustworthiness of the study (Creswell, 2009). Member-checking entails inviting participants to engage in the fact-checking of information collected and the themes which had emerged. Through following this process, researcher bias is alleviated and trustworthiness is enhanced (Creswell, 2009).

An additional challenge qualitative research presents is a lack of generalisability due to qualitative research utilising small and unrepresentative samples (Willig, 2013). According to Creswell (2009), a strategy to overcome this challenge is to utilise rich and dense descriptions to communicate the findings of a study. This produces findings that are richer and more realistic, which therefore contribute to the validity of the findings (Creswell, 2009). When a meticulous description of the research context and processes, such as the selection of participants are presented along with the findings, every reader of the research can decide whether the findings are transferable to a similar context and people as to the participants (Korstjens & Moser, 2018).

3.3 METHODOLOGICAL PROCESS

3.3.1 Research design

For this study, the researcher employed a descriptive case study design. The utilisation of a descriptive case study design allowed the researcher to obtain an in-depth understanding of the resilience of caregivers of children with ASD in a resource-constrained context.

According to Willig (2013), case study designs adopt an idiographic perspective, and consider contextual data as of great importance. Therefore, utilising a descriptive case study design allowed the researcher to explore each individual participant's (see section 3.3.2 for selection of participants) experience of resilience in caring for a child with ASD in a resource-constrained context. This is as opposed to gaining a general understanding of the experience of caring for a child with ASD.

A descriptive case study design is advantageous for this study as, according to Gillham (2000), a descriptive case study design is useful where there is limited knowledge of a topic. The suitability and advantageous nature of descriptive case study design is clear, bearing in mind that not much is known regarding ASD in the selected resource-constrained context (De Vries, 2016). In addition, a descriptive case study design is more suitable for small-scale studies as opposed to large-scale studies (Walsh, 2001). Therefore, the researcher deemed this design to be valuable to the proposed study, which is small-scale, with a focus on a context about which limited available knowledge is available, namely the resilience of caregivers of children with ASD in a resource-constrained context (based on Walsh, 2001).

A potential challenge of a descriptive case study design is the lack of generalisability external to the specific case (Creswell, 2009; Walsh, 2001). However, as the purpose of this study is rooted in understanding the resilience of caregivers of children with ASD in the selected context, namely the resource-constrained context, obtaining a generalisable understanding of the phenomenon was not an essential outcome (Creswell, 2009). According to Astalin (2013), at times a case study design contains bias towards the verification of the researcher's bias. In order to resolve this challenge, the researcher actively practiced reflexivity so that she became conscious of her own personal bias, which might have prevented her from achieving a successful research process (Astalin, 2013; Christensen et al., 2015; Creswell, 2009; Willig, 2013).

3.3.2 Selection of participants

The conveniently selected (Christensen et al., 2015) research site where participants were selected was the Itsoseng Clinic in Mamelodi, with which the Department of Educational Psychology, UP, had previously collaborated. The Itsoseng Clinic is run by the Department of Psychology, UP. It is situated in a resource-constrained context and renders services to clients living in resource-constrained contexts.

For the purpose of this study, the researcher had planned to undertake purposeful sampling. Purposeful sampling entails selecting participants in accordance with the principle of relevance to the study by utilising certain selection criteria (Creswell, 2009; De Vos, 2002). Selecting participants who met the selection criteria, indicated in the bulleted list below, meant that only the participants best suited to promoting an understanding of the phenomenon being studied were selected (Creswell, 2009). The sample selection criteria for this study, which had planned to involve three participants, were as follows:

- All participants were to be or have been caregivers of children with ASD.
- All participants were to reside or have resided within a resource-constrained context at the time of caregiving a child with ASD.
- All participants were to be able to communicate in conversational English.
- All participants had to provide informed consent.

By applying the abovementioned criteria, the sample became more homogenous, with all the participants having experienced the specific phenomenon being studied (Ritchie & Lewis, 2003).

Purposeful sampling is advantageous in that only participants who best contribute to answering the research question are selected (Creswell, 2009; Ritchie & Lewis, 2003). Through only selecting participants who make the best contribution to the research question, purposeful sampling is both a cost-effective, and time-effective sampling method (Creswell, 2009). Purposeful sampling is also advantageous in that it enables a detailed exploration and understanding of the phenomenon that the researcher wishes to study, which in this case is an exploration into the resilience of caregivers of children with ASD in a resource-constrained context (Ritchie & Lewis, 2003).

A possible challenge may be that the selection criteria might actually be biased towards the data generated. However, the abovementioned criteria are relevant to the research questions and attempt to increase the quality of the data generated. Another challenge might be finding participants who meet the selection criteria. A strategy employed to overcome this challenge could be the simultaneous use of snowball sampling (Christensen et al., 2015). Snowball sampling entails approaching each sampled individual and requesting him or her to identify other potential participants who comply with the selection criteria (De Vos, 2002; Emmel, 2013; Willig, 2013). Snowball sampling is advantageous in that it assists a researcher with finding participants who are not easily accessible and is also useful in investigating a reasonably unfamiliar phenomenon (Ritchie & Lewis, 2003).

A potential challenge that the researcher may face is that the referral chain can sometimes be broken, but requesting more than one referral can prevent a potential break in the chain (De Vos, 2002). Being cognisant of the intended small sample size, snowball sampling need only yield one or two additional participants.

Finally, for this study, only one participant was selected as opposed to the initially intended three participants, owing to limitations resulting from the COVID-19 pandemic. These limitations included a nationwide lockdown, preventing the movement of all citizens not offering essential services in order to curb the spread of the virus (Wiysonge, 2020) The lockdown occurred almost simultaneously with the sample collection phase of this research. Hence, as a result of the COVID-19 pandemic, the researcher's ability to access the Itsoseng Clinic in Mamelodi, as initially intended, was impossible at the time scheduled for the data collection. A potential participant was nevertheless identified. The mother of a child with ASD who had participated in a previous research project was considered as participant for this study. The participant is a parent of a child with ASD who previously visited Itsoseng

Clinic, and complied with all the required selection criteria. The previous researcher contacted the participant and asked her whether she would be willing to participate in another research project. The former participant agreed to participate and only then were her contact details provided to the researcher in this study. After explaining the nature of the research and requesting voluntary, informed consent, as required by ethics, the research could begin (see section 3.5 for the ethical guidelines).

3.3.3 Data generation and documentation

According to Willig (2013), the basic premise of qualitative data collection is that it is meant to ascertain subjected meanings generated by participants. It is for this reason that the researcher selected the data generation methods that are included below.

Data generation methods initially planned for this study included face-to-face, semi-structured individual interviews, naturalistic observations and a reflective journal. The consequent data documentation methods were audio-recordings of the interviews, with their corresponding written transcripts, field notes (of the observations) and a written reflective journal (of the researcher's subjective processes during the research process) (Christensen et al., 2015; Creswell, 2009; De Vos, 2002; Silverman, 2006). In order to enhance the trustworthiness and the authenticity of this study, data collected from the varied data-generation methods are compared for consistency through a process called triangulation (Creswell, 2009; Lincoln & Guba, 1985; Ritchie & Lewis, 2003).

3.3.3.1 Semi-structured interviews

The reason for initially selecting face-to-face, semi-structured interviews was that it would allow the researcher to elicit rich expressions from participants, while not losing cognisance of the main aim of the research (Silverman, 2006). The interview was anticipated to be conducted in a semi-structured manner, utilising open-ended questions, thereby allowing caregivers of children with ASD in a resource-constrained context openly and fully to express their views and experiences (Creswell & Creswell, 2018). The researcher in this study conducted one such interview, as this aligned with the purpose of this study, which sought to understand the resilience of caregivers of children with ASD in resource-constrained contexts, whilst keeping in mind the limited focus of the study, being a mini-dissertation.

Semi-structured interviews are based on pre-set questions to explore the phenomenon being researched, but allows for probing of answers by asking follow-up questions (Creswell & Creswell, 2018; Willig, 2013) (see Appendix A for the pre-set interview questions). Face-to-face interviews have the added advantage that non-verbal behaviour can be observed. Non-verbal behaviour can contribute to understanding (Willig, 2013), for example, looking away from the interviewer when sensitive issues are raised. Especially during a cross-cultural interview, as was the case in this research, non-verbal behaviour can assist in the smooth running of the interview. The interviewer can, for example, deduct from a frown on the participant's face during a question that the question should be reformulated, or asked using different phraseology.

At the time of data collection, due to the outbreak of the COVID-19 virus, the government put in place strict regulations, which included a nationwide lockdown and social distancing requirements. Travel limitations were especially strict during the first months of lockdown, when the data were to be collected. Due to the strict government regulations, the researcher was unable to conduct a face-to-face interview and therefore had to conduct a telephonic semi-structured interview with the one participant who was available.

The telephonic interview with the participant was conducted by means of a cell phone and the duration of the interview was 24 minutes and 42 seconds. After the interview, contact was made with the participant by means of a cell phone to probe and obtain additional information from the participant, and the duration of this conversation was 21 minutes and 38 seconds. An advantage of a telephonic interview is that it is less expensive, thus more cost-effective (Christensen et al., 2015), can be done without being in close proximity and also in the convenience of the interviewer's and the participant's homes. The reason that telephonic interviews are more cost-effective, is that travel costs are not incurred and the travel time to meet at a mutually agreed venue need not be taken. A potential challenge faced when conducting a telephonic interview is that the phone might have a negative impact on rapport-building. The researcher counteracted the aforementioned challenge by contacting the participant on more than one occasion prior to the interview, in order to get to know her better, and to establish a positive working relationship. The researcher devised some questions, to be answered by both participant and researcher, which were aimed at fostering a relationship with the participant.

Another challenge relating to the telephone interview during lockdown was that the participant had to use the phone in her house or yard, and the researcher could therefore not ensure that the venue would protect confidentiality, as the other household members would of necessity also have been in the house or yard. One might assume that the participant could find a place where she felt sufficiently confident to share her experiences. In the same way, one might also assume that the participant did not share certain sensitive information as she might have been concerned about who overheard. One way to maximise the confidentiality was to break the interview up into several sections, so that the participant, as a mother, would not be unavailable to her family for a long, uninterrupted period of time.

Telephonic interviews moreover present a challenge in that, in the absence of non-verbal behaviour during a conversation, interview fatigue can set in sooner. Where this occurs it prevents the rendering of deep, rich data, and promotes shallow answers (Block & Erskine, 2012). The researcher tried to prevent interview fatigue by giving the participant the option to conclude and continue at a later stage. The researcher in addition broke the interview up into two meaningful sections. The semi-structured interview based on each of the sections was done on one day, to ensure continuity, but one section was planned for the morning and one in the afternoon, to prevent fatigue. Breaking up the interview could also contribute to better confidentiality, as previously explained.

The interview was initially documented utilising an audio-recording of the phone call, after which a verbatim transcript was made (see Appendix B for the transcription of the interview). The use of an audiotape ensured that the researcher was able to remain present in the interview and not be distracted by note taking. In addition, audio-recording the interview also allowed the researcher to capture any emotional changes that might easily have been missed had an audio-recorder not been used (Creswell, 2009; Tessier, 2012). Emotional changes include, but are not limited to, intonation, laughter and hesitation (Tessier, 2012). Through the utilisation of an audiotape, the researcher was able to ensure more complete transcriptions of the interview conducted (Creswell, 2009).

3.3.3.2 Naturalistic observations

An additional data generation method that the researcher would have liked to utilise is naturalistic observations (Creswell, 2009; Flick, 2018). Naturalistic observations are advantageous as they build on direct experiences, inform participants' feelings and behaviours, and enhance verbal interview data obtained from participants (Creswell, 2009; Guba & Lincoln, 1981). Another advantageous aspect of naturalistic observations is that it allows the researcher to understand each participant's subjective experiences with increased depth (Guba & Lincoln, 1981).

Naturalistic observations are recorded in the form of field notes by the researcher. In order to promote the validity of field notes, the researcher should record observations timeously in an unstructured manner onsite (Guba & Lincoln, 1981). Ensuring that field notes are completed timeously will enable the researcher to document observations with depth and accuracy, and prevent the researcher from omitting important details that may have been forgotten owing to the passing of time (Guba & Lincoln, 1981).

Unfortunately, due to the COVID-19 pandemic and strict government regulations, the researcher was unable to conduct face-to-face interviews, and therefore had to conduct telephonic interviews. This prevented the researcher from utilising naturalistic observations, and recording observations in the form of field notes.

3.3.3.3 Reflective journal

The last data-generation method the researcher utilised was a written reflective journal. Any factors that may have had an influence on the interpretation of the findings of the study were documented in the written reflective journal (see Appendix C for an extract from the reflective journal) (Creswell & Creswell, 2018). The factors noted included, but were not limited to, the personal bias, thoughts, or feelings of the researcher throughout the process (Astalin, 2013; Christensen et al., 2015). By keeping this journal, the researcher was able to take a reflective stance, thereby limiting the intrusion of researcher bias as far as possible (Christensen et al., 2015; Creswell, 2009; Willig, 2013).

3.3.3.4 Data analysis and interpretation

The researcher employed inductive thematic analysis to analyse and interpret the data of the study. Inductive thematic analysis was useful in this study to identify and extract themes from the interview conducted with the caregiver of a child with ASD in a resource-constrained context. Inductive thematic analysis is valuable in that it seeks to stay as close as possible to the meanings inherent in the data, while identifying patterns in the data (Boyatzis, 1998). Inductive thematic analysis was selected as the preferred qualitative data analysis method, because it is non-limiting, and does not attempt to situate the data in a pre-existing coding frame, or in accordance with the researcher's analytical preconceptions (Braun & Clarke, 2006). This is a process of coding the data collected by the researcher and identifying themes that emerge across the data in order to achieve depth of understanding of a specific phenomenon (Braun & Clarke, 2006).

Braun and Clarke (2006) identified the six phases of thematic analysis. These are engaging and familiarising oneself with the data, generating initial codes, identifying themes, reviewing the themes, defining and naming the themes and producing a report (Braun & Clarke, 2006). For the purpose of this study, the researcher utilised ATLAS.ti, a qualitative data analysis programme, to arrange and manage data in a systematic manner in accordance with the selected qualitative data analysis method (ATLAS.ti, n.d.).

The researcher started the data analysis process by thoroughly reading through the interview transcript as well as field notes in order to engage with and familiarise herself with the data. While immersing herself in the data, the researcher practiced reflexivity, and remained cognisant of all personal thoughts, perspectives, and potential bias to prevent these factors from having an impact on the data. The

ATLAS.ti software captured the essence of the data and coded the data in a suitable manner (ATLAS.ti, n.d.). According to Willig (2013), in the final phase of inductive thematic analysis, the researcher makes connections between themes and draws conclusions about the data. For this specific study, themes and conclusions were drawn regarding the resilience of caregivers of children with ASD in a resource-constrained context. Themes were generated by reading through the interview transcript, identifying and grouping the same or similar statements together, and placing them under an umbrella term, after which a code was assigned.

Inductive thematic analysis was advantageous for the current study because of its flexible nature, as it works well with any selected epistemology and is accordingly well suited to interpretivism (Braun & Clarke, 2006). Moreover, according to Braun and Clarke (2006) and Lapadat (2010), inductive thematic analysis has the potential to provide both dense and rich contextual accounts of the data and this is closely aligned with the aims of this study, as previously mentioned.

A challenge in utilising inductive thematic analysis lies in determining data saturation with a sample size (Willig, 2013). However, this challenge is not relevant to the study, as this study did not seek to generalise the findings to a larger population. Instead, the study sought to lay a foundation for understanding the resilience of caregivers of children with ASD in a specific resource-constrained context. In this study, inductive thematic analysis was utilised to analyse data collected in the form of an interview transcript and a reflective journal. According to Willig (2013), a challenge when utilising interview transcripts with inductive thematic analysis is the possibility of limiting or structuring the responses of participants. The questions for the interview in this research were broad and open-ended so that the participant could feel free to express her views fully. Therefore, this challenge would be avoided.

3.4 ROLE OF THE RESEARCHER

The primary role of the researcher in this study was to pave the way for, and elicit the thoughts and feelings of, participants in relation to being a caregiver of a child with ASD in a resource-constrained context. Owing to the sensitive nature of the data collected from the participant, the researcher maintained an empathetic approach to ensure that the participant felt comfortable at all times, while working as accurately as possible to ensure the data were gathered correctly. While fulfilling the aforementioned primary role, the researcher had another important role to play, and that was to safeguard the participant, and to act in the participant's best interests (Sutton & Austin, 2015). In order to ensure that the researcher fulfilled this role, she acted in accordance with the ethical standards and principles elucidated in section 3.5 below.

3.5 ETHICAL CONSIDERATIONS

As mentioned in Chapter One, research ethics are especially salient when human beings are involved (De Vos, 2002). Both the applicable research and professional ethics associated with the study are explored in the subsections that follow (HPCSA, 2006).

3.5.1 Research ethics

After obtaining ethical clearance from the Ethics Committee of the Faculty of Education, the researcher was placed in contact with the participant. Initially the researcher planned to obtain voluntary and informed consent from participants through a detailed letter requesting participation in the study, in which the purpose and scope of the study was explained (see Appendix D for the original informed consent letter) (De Vos, 2002; Gravetter & Forzano, 2016; HPCSA, 2016b; UP, 1999). Unfortunately, due to the COVID-19 pandemic, the researcher had to use an alternative method to obtain informed consent for participation, as face-to-face contact was restricted. The researcher read and explained the detailed letter requesting informed consent to the participant in a telephonic conversation (see Appendix E for the adapted informed letter of consent, in which the adaptations are highlighted). The participant was made aware of potential harm or risks during the study and, moreover, that she could voluntarily withdraw from the study without facing any negative consequences (Gravetter & Forzano, 2016; HPCSA, 2016a; Silverman, 2006; Walsh, 2001). At the request of the participant, a copy of the letter was sent to her via WhatsApp.

The researcher respected the participant's right to confidentiality and anonymity (Gravetter & Forzano, 2016; HPCSA, 2016a; Silverman, 2006; Walsh, 2001). The participant was ensured that her identity as well as personal and identifying information would not be disclosed (De Vos, 2002; HPCSA, 2016a).

3.5.2 Professional ethics

The researcher acknowledged that her responsibility extended beyond the academic environment (UP, 1999). As mentioned, after a thorough evaluation of this study, permission to conduct this research was obtained from the Ethics Committee of the Faculty of Education. Furthermore, according to the UP's Code of Ethics (1999), it is crucial that the researcher maintains the principles of beneficence and non-maleficence, which translate to preventing harm or risk and promoting the well-being of participants. The researcher upheld the principles of beneficence and non-maleficence by obtaining ethical clearance from the Ethics Committee of the Faculty of Education. Furthermore, the researcher ensured that, in case a participant temporarily felt distraught, arrangements were in place to refer the participant to the appropriate therapists.

Moreover, in accordance with the UP's Code of Ethics (1999), the researcher maintained the utmost respect for the participant by recognising her autonomy and by behaving in a manner that was not discriminatory or demeaning to the participant in any way (HPCSA, 2006). Furthermore, the researcher remained truthful and accountable throughout the duration of the study, and ensured that all intellectual property utilised for the purpose of this study was appropriately acknowledged (UP, 1999).

3.6. QUALITY CRITERIA

The researcher planned to collect data from multiple sources and compare the data obtained through a process called triangulation (Creswell, 2009; Ritchie & Lewis, 2003). According to Creswell (2009) as well as Ritchie and Lewis (2003), the process of triangulation is likely to enhance the trustworthiness and authenticity of the study. However, as the observation data could not be generated, triangulation could not take place. Through member-checking, the accuracy of the transcripts and themes were verified with the participant. Personal reflexivity and discussions with the supervisor were efforts to eliminate researcher bias from contaminating data (see Appendix C for an extract from the reflective journal). Also see section 1.8.6 in Chapter One, where the quality criteria are introduced.

3.7 SUMMARY OF CHAPTER THREE

In this chapter, a detailed exploration of the pragmatic and methodological choices of the study is recorded. Chapter Three includes an exploration into the research design, the various procedures relating to the selection of participants, the generation, documentation and analysis of the data, as well as the advantages and challenges associated with each procedure. The responsibility of the researcher to behave ethically towards the participant is just as important as the responsibility of the researcher to generate, record and analyse data accurately. Both ethical research practices as well as meticulous research are required to deliver a quality research product, and were adhered to.

In the next chapter, the researcher presents the results of and the findings derived from the data analysis process, and integrates these findings with the literature review and the theoretical framework presented in Chapter Two.

4. CHAPTER FOUR: RESEARCH RESULTS AND FINDINGS

4.1 INTRODUCTION

In Chapter Three the researcher documented a detailed discussion regarding the paradigmatic and methodological choices of the study. In addition, the researcher detailed the research design, and all the procedures employed in selecting participants, obtaining and analysing data as well as the advantages and challenges associated with doing so. Ethical research and professional conduct guidelines were also elaborated on as part of the research process.

Chapter Four explores the results and findings of the data collected, based on the inductive thematic analysis of the data collected. The results and findings obtained from the data are integrated with the literature review and the theoretical framework presented in Chapter Two.

4.2 BACKGROUND AND CONTEXT OF THE PARTICIPANT

The research plan initially called for face-to-face, semi-structured interviews with at least three caregivers of children with ASD in a resource-constrained context, but owing to the sudden onset of the COVID-19 pandemic, and the resulting strict nationwide lockdown and social distancing regulations, the plan was modified to conduct a semi-structured telephonic interview with one participant, the mother of a child with ASD in a resource-constrained context.

The available participant was the 29-year-old mother of two children who resided in a resource-constrained context in the eastern part of Pretoria. The elder of the two children was a girl, aged 11 years, and the younger was a boy, aged 9 years, at the time. The participant was able to communicate in conversational English, although she sometimes struggled to put her thoughts into words, as was evident in the recorded interview. A copy of the interview questions was sent to the participant prior to the interview for perusal, and during a phone call shortly after, the interview questions were explained and clarified to the participant as she is not an English First Language Speaker.

From the cell phone conversations that had taken place, it seemed as if she had an outgoing and cheerful personality. She was married and, between her and her husband, her household was supported financially. She worked part-time as a domestic worker in the northern suburbs of Pretoria, and reported that during the pandemic it was exceptionally difficult to find a job and provide for her family. During the strict lockdown period, she was completely unable to travel to work, and she therefore experienced a halt in her income.

At the age of 18 years, the participant fell pregnant with her first child, the daughter. The participant began noticing that her daughter, at the age of three, was unlike other children. She noticed that "she can't play with other kids" (Appendix C, p. 4), that she was much quieter than other children, and that she preferred playing on her own. After approximately six to seven visits to the clinic, and the participant's daughter had in the interim turned six, she was informed that her daughter most likely had Autism Spectrum Disorder (ASD). Because of her financial status, she utilised public healthcare facilities, and she reported that there was a lengthy waiting period between visits and receiving feedback, in addition to which they had yet to receive a formal diagnosis. However, psychologists at the Itsoseng Clinic in Mamelodi were sure about the diagnosis of ASD. At this public healthcare clinic, the participant's daughter was placed on medication, Epilim Liquid[5] and Rispacor[6], to be taken daily. In addition, the clinic provided the participant with a list of her daughter's dietary requirements. The participant's daughter appears to be experiencing a Level 2 Severity of ASD, where she requires substantial support resulting in her inability to communicate and play with others, as well as to care for herself independently.

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[5] Epilim Liquid is prescribed for epilepsy, which commonly co-occurs with ASD (Landsberg, Krüger, & Swart, 2019)

[6] Rispacor is given to some people with ASD to deal with irritability associated with ASD.

4.3 RESULTS AND FINDINGS

Through the data-collection method of a semi-structured interview conducted by cell phone, the participant shared meaningful information relating to the challenges she experienced as the caregiver of a child with ASD in a resource-constrained context as well as the various resilience factors that enabled her to adapt successfully in the face of the challenges she experienced.

The field notes did not yield meaningful data. Member-checking was undertaken by sending a copy of the interview transcript, as well as the themes and subthemes extracted from the data, to the participant. The participant accepted the transcript as well as the themes and subthemes without any additions or changes.

In the section presented below, the results and findings obtained through data analysis are outlined.

The following two themes and their subthemes emerged from the data analysis process (see Appendix F for the themes which emerged through the use of ATLAS.ti):
Theme 1: Challenges experienced by the caregiver
Subtheme 1.1: Stigma
Subtheme 1.2: Difficulties with her daughter's behaviour
Subtheme 1.3: Financial status
Extracts from the transcribed interview which support Theme 1 and its subthemes are shown in red.

Theme 2: Resilience factors
Subtheme 2.1: Information and understanding
Subtheme 2.2: Public healthcare
Subtheme 2.3: Music
Subtheme 2.4: Social support
Extracts from the transcribed interview which support Theme 2 and its subthemes appear in green.

Theme 1: Challenges experienced by the caregiver

Table 4.1 presented on the next page contains the inclusion and exclusion criteria for Theme 1.

Table 4.1 Inclusion and exclusion criteria for Theme 1: Challenges experienced by the caregiver

Subthemes	Inclusion criteria	Exclusion criteria
Subtheme 1.1: Stigma	All words, behaviours and incidents that conveyed stigma towards being different or having ASD	All words, behaviours and incidents that did not convey stigma towards being different or having ASD
Subtheme 1.2: Difficulties with daughter's behaviour	All words, behaviours and incidents that imply challenging behaviour as a result of ASD	All words, behaviours and incidents that imply challenging behaviour, but not as a result of ASD
Subtheme 1.3: Financial status	All words, behaviours and incidents indicating stress or challenges as a result of financial status	All words, behaviours or incidents indicating an absence of challenges as a result of financial status

Subtheme 1.1: Stigma

It emerged from the data analysis that the lack of information regarding ASD and the failure on the part of community members to understand ASD led to stigmatisation of the participant and her child. She stated that many did not understand it. An example of the failure to understand ASD was attributing her daughter's condition to supernatural powers, "like someone bewitched you" (Appendix C, p. 8) or "let's go to church, I know someone that's going to heal her" (Appendix C, p. 8), or "something is not right, you must go see a sangoma[7]" (Appendix C, p. 22). The participant expressed frustration in response to the community's reaction to her daughter's condition, and she said that she often had fights with community members as a result, "but now I'm fighting with people" (Appendix C, p. 8). She said that it was

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[7] A sangoma is a traditional healer in Southern Africa.

really difficult that “other people don’t understand, and they think they know what it is” (Appendix C, p. 9).

The widespread lack of knowledge in the participant’s community and the negative connotations associated with mental illness were exacerbated by the inaccurate cultural understanding of ASD. According to the African culture, symptoms indicating mental illness are treated by traditional healers known as sangomas. Mental illness is not believed to exist in some African societies, but is considered to be the result of bewitchment (Mthombeni & Nwoye, 2018). The presumed bewitchment results in stigmatisation of members of an African society (Tilahun et al., 2016).

The aforementioned stigma was part of the reason why the participant did not have friends in the community. She stated that “some of them can understand but some of the people, they don’t understand” (Appendix C, p. 21). The participant indicated that when she did have friends, she would visit them and take her daughter along. She added that owing to the stigma and misconceptions related to ASD, she had experienced humiliating situations with her friends in the past, such as her daughter being accused of stealing. Specific stigmas attached to this participant’s child were being bewitched, being ill or being a thief.

Subtheme 1.2: Difficulties with daughter’s behaviour

Furthermore, the participant mentioned that she often experienced challenges caring for her daughter as the daughter did not always comprehend what was said to her. She said that sometimes after she had had her bath, if she is left unattended, she would go outside and get dirty all over again:

> You finished to bath her, then you tell her to sit down, then she can see that you are inside, then she can sit down. After some moments, you can see her outside on [in the] water or playing with water, or make herself wet again.” (Appendix C, p. 11)

The participant reported that perhaps if there were food items on the table, the daughter would mix everything, without any understanding of her actions: “she can take stuff, mix everything. If we left, like sugar, salt ... yeah, she can mix it; everything in one place" (Appendix C, p. 5).

The behaviour of the participant's daughter also influenced the mother's socialisation (see subtheme 2.4 for the link with socialisation). The participant recalled incidents where her daughter had broken things at her friends' houses and that, on a particular occasion, one of her friends had accused her daughter of stealing money. She recalled feeling "terrible" (Appendix C. p. 21) about it. It was after that incident that the participant had decided she would no longer associate with community members, and she made it clear that if they wanted to be her friend, they were welcome to visit her at her house, where her daughter would not be accused of anything.

Subtheme 1.3 Low financial status

Furthermore, the participant experienced significant challenges as a consequence of her low financial status. She mentioned the challenges related to the use of public healthcare, the absence of a social grant and dietary as well as hygiene requirements.

(1) Public healthcare

As a result of residing in a resource-constrained context and having a limited, inconsistent income, the participant used public healthcare services. If she had the money, she would have preferred to use private healthcare facilities. She stated that the clinic she visited did not help very much, and that they had not given her any explanation regarding ASD. When asked whether someone explained autism to her, she replied: "No, no, no!" (Appendix C, p. 8). In addition, she had to visit the clinic on numerous occasions: "I think more than six times" (Appendix C, p. 4). The public healthcare clinic was moreover a great distance form where the participant resided, and transport was therefore costly.

During a phone call after the interview, the participant stated that they, the parents, had been requested after months to visit the clinic to receive an update: "I'm going to see the doctor on the 22nd of June" (Appendix C, p. 17). The travel costs were excessive, considering that she was not working as much as usual due to the COVID-19 pandemic, and that transport costs had increased. However, she attended the appointment. The only update she received at the appointment was that the doctor was pleased with her daughter's progress: "she's very very happy about P's[8] condition" (Appendix C, p. 25), and that her daughter was still on the waiting list to receive an official diagnosis of ASD.

(2) Absence of necessary documents

The plight of the participant owing to her financial challenges was exacerbated by her lack of access to the social grant due to her as a result of her daughter's condition (RSA. *Social Assistance Act 13 of 2004)*). The participant unsuccessfully attempted to obtain this grant, but later she was informed that a social worker would assist her. She expressed concern regarding the financial implications of travelling to meet the social worker: "It's very easy to call them, yes, because it's going to cost me money for [a] taxi" (Appendix C, p. 25). She moreover had to contend with the uncertainty whether the appointment would even have a positive outcome. A formal diagnosis of ASD may also be required to apply for the grant.

The lack of ability to access a social grant appeared to be only one aspect of a more complicated scenario. The researcher later learnt that the reason the participant did not have access to the social grant was because she had misplaced her identification document (ID) before her daughter was born. As a result, when her daughter was born, she did not receive a birth certificate. In order to obtain the social grant, she was required to apply for a new ID, after which she had to arrange for a paternity test at her own cost, after which she was required to apply for a birth certificate.

According to the participant, during 2018, she was informed that her daughter could no longer attend school as she did not have a birth certificate. Therefore, the lack of

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[8] Pseudonym of the participant's daughter.

a birth certificate and the subsequent refusal of the daughter to attend school were two additional challenges that this participant had experienced.

(3) Dietary and hygiene requirements

Additional financial challenges included the specific dietary requirements of the participant's daughter, as indicated by the clinic. She had previously received information with dietary guidelines for her daughter, which she admitted had been effective, when she could afford them: "It's difficult sometimes because you can't give her the things she needs" (Appendix C, p. 12). However, the participant reported that the dietary requirements were costly as, in addition to the daily dietary requirements of the other members of the family, she was required to provide for her daughter's special requirements. The participant stated that "sometimes we don't have that money, so she has to eat what we have" (Appendix C, p. 11). She stated that a substantial challenge contributing to her stress and her ability to care for her daughter sufficiently is her lack of finances to fulfil all her daughter's needs.

A challenge that the participant had recently been experiencing was the added monthly cost of sanitary pads as her daughter had reached the age when she menstruated. She stated that she had to change her sanitary ware, and that she often used one packet of pads a day, which was costly as she did not earn much money:

> "She's on periods already but you know she change . . . maybe I can use three packets; (for) the whole packet can be finished for [in] one day. So, you know, if you don't earn lot of money, it's going to be very difficult." (Appendix C, p. 16)

(4) Conclusion

As seen from the abovementioned subthemes and the relevant extracts as evidence, the participant experienced a variety of challenges, including stigma, difficult behaviour and limited finances. The following section presents the data analysis regarding the resilience factors that the participant utilised to face her daily challenges as the caregiver of a child with ASD in a resource-constrained context.

Theme 2: Resilience factors

The participant reported a limited variety of factors that contributed to her personal resilience as the caregiver of a child with ASD. The section which follows includes an exploration into the resilience factors extracted from the interview transcript through the use of a data analysis tool, ATLAS.ti (n.d.).

Table 4.2 below contains the inclusion and exclusion criteria for Theme 2.

Table 4.2 Inclusion and exclusion criteria for Theme 2: Resilience factors

Subthemes	Inclusion criteria	Exclusion criteria
Subtheme 2.1: Information and understanding	All words, behaviours and incidents indicating appropriate psychoeducation regarding ASD, and the comprehension thereof	All words, behaviours and incidents indicating inappropriate or a lack of psychoeducation regarding ASD, and the comprehension thereof
Subtheme 2.2: Public healthcare	All words, behaviours and incidents indicating access to and use of public healthcare services	All words, behaviours and incidents indicating access to and use of private healthcare services
Subtheme 2.3: Music	All words, behaviours and incidents indicating the use of music to promote resilience and relieve stress	All words, behaviours and incidents that do not indicate music as resilience-enabling
Subtheme 2.4: Social support	All words, behaviours and incidents relating to physical and cyber-social support	All words, behaviours and incidents not relating to physical and cyber-social support

Subtheme 2.1 Information and understanding

The participant reported that she had a good relationship with her child, to whom she was the primary caregiver, but she admitted that it had not always been that way. She stated that she had experienced difficulty caring for, and understanding her child prior to understanding the condition that she had: “Yeah, if you understand it, yeah, you can take care of her right . . . if you understand her right, but you know, if you don't understand it, it's going to be very difficult for you” (Appendix C, p. 10). Her reason for not understanding the condition was that when she herself grew up, she had never seen anything like it, as stated in her own words: “for me, when we grow up, I never see anything like this” (Appendix C, p. 9). After she was informed that her daughter most likely had ASD, she claimed that in time she began understanding ASD better, and she learnt to love her daughter and show her love: “It was very difficult for me, but as the time goes on, then I start to, I learn to love her. That’s all [that] matters to me” (Appendix C, p. 9).

At the time of the interview she had a good relationship with her daughter as she was of the opinion that she could talk to her, laugh with her, and do anything with her that she did with her other child: “I can talk to her, we can laugh, we can do anything I do with my other child” (Appendix C, p. 10). Despite her daughter not wanting to play with other children, and communicating effectively, she was more than willing to be in the presence of her mother, her primary caregiver. It appeared that this special bond formed over time was cherished by the caregiver, and she stated that “to love her, to show her love and to show her that she is not different” (Appendix C, p. 10) is all that matters to her.

The participant conveyed her disappointment with going to the sangoma, as she had used some of her limited money to visit the sangoma, but this visit did not have a positive outcome for the daughter. The participant admitted to realising the traditional way of dealing with challenges did not support ASD, but was more constraining, as she has spent much money without receiving any benefit: “I have lost lots of money because people can say . . . this is witchcraft; this is what . . . this is, and you can go and spend lots of money but nothing can change” (Appendix C, p. 22).

For this participant, information about and understanding ASD contributed to having a meaningful relationship with her daughter. Information about and understanding ASD can thus be regarded as a resilience factor.

Subtheme 2.2 Public healthcare

Furthermore, after many visits to their local clinic, which is a public healthcare facility, the participant received a clear indication that her daughter had ASD, and she was placed on medication: Epilim Liquid and Rispacor. The prescription and availability of medication appeared to be a resilience-enabling factor for the caregiver, as she stated that once her daughter was on medication, she was able to "be a good girl" (Appendix C, p. 7) and behave, and this made it easier for her as caregiver to cope. The participant claimed that the medication helped to lighten the burden a little, "yeah, it helps a little . . . like, when she takes her medication, she can sit and she can . . . like, understand little bit . . . she will behave(s)" (Appendix C, p. 7).

Subtheme 2.3 Music

As expected, it is challenging to care for a child with ASD, and more so in a resource-constrained context. Therefore, the participant stated that when she had had a particularly difficult and stressful day, she turned to music as an escape and she claimed that it reduced her stress. She predominantly enjoyed uplifting music: "the music that I listen to, like, is this one of people dancing, then I know the stress will go down a little bit" (Appendix C, p. 14).

Subtheme 2.4 Social support

Furthermore, the participant stated that she received social support from close friends, and from a social support group on WhatsApp with other mothers of children with ASD. She was assisted by the social worker at the public healthcare clinic to access Facebook, where she joined a support group, and subsequently the WhatsApp social support group, to which she was added: "From clinic, the social worker help me" (Appendix C, p. 27). She received useful information from the group, and when her daughter was not well-behaved, it was common that she shared images on the WhatsApp group with other mothers, who also did the same, and that allowed her to feel less isolated and alone in her struggles. In her own words, she stated: "so you can see, oh, I am not alone in this" (Appendix C, p. 15).

4.4 DISCUSSION OF RESULTS AND FINDINGS

4.4.1 Awareness of differences

Parents are most likely to notice the first signs of a disorder in their children, and often in resource-constrained contexts become the main persons on whom the burden of care falls (Viljoen, Mahdi, Griessel, Bölte, & De Vries, 2019). This is supported by the information obtained from the participant, in which she stated that she identified differences in her child when she was three years old, and to date, she remained the primary caregiver of her child as she took care of her most of the time. According to Viljoen et al. (2019), the differences caregivers identify in their children are often a source of stress that have an impact on the caregivers' quality of life. In contrast, the participant in this study did not report it to be stressful as the research suggests. Instead, she reported that it was just difficult in that she did not always understand the disorder. The participant indicated that certain behaviours of her child contributed to stress, such as becoming dirty just after she had been bathed.

4.4.2 Resource-constrained context: Financial status

The participant falls within the section of South Africa's population that resides in a resource-constrained context. As suggested by the research conducted by Harris et al. (2011), living in a resource-constrained context is associated with long-distance travelling and incurring exorbitant travel costs when visiting public healthcare facilities. The participant in this study testified to these challenges associated with travelling to public healthcare facilities. She claimed that she travelled far and transport was often costly. She admitted that with her limited income she was not always able to bear the costs.

4.4.3 Public healthcare

She also described what appeared to be frustration when she visited the clinic on numerous occasions and received very limited assistance: “ooh, they did not help so so much; they did not help so much” (Appendix C, p. 17). This aligns with findings reported by Franz, Chambers, Von Isenburg, & De Vries (2017), who stated that in South Africa parents of children with ASD feel unheard and inadequately informed by service providers. This experience of feeling unheard and inadequately informed by service providers in resource-constrained contexts juxtaposes with the experiences of resilience-enabling support obtained from service providers in well-resourced contexts and is a good indicator of the disparity between resilience factors in these respective contexts (Karst & Van Hecke, 2012).

It was approximately five years since the participant had received the news that her daughter has ASD. However, owing to the large client base and limited resources available at public healthcare facilities, her daughter was yet to receive a formal diagnosis and remained on a waiting list. Parents of children in South Africa, much like the participant in this study, reported substantial delays in obtaining a formal diagnosis and also a lack of supportive services for their children (Franz et al., 2017). The delay in having a formal diagnosis also meant that the participant had to care for the child for five years without the benefit of a disability grant, which could have contributed to offsetting some of the costs of caring for her child. In addition, the delay in a formal diagnosis prevented early intervention, which is recommended for optimal development for children with ASD (Landsberg et al., 2019).

In resource-constrained contexts in South Africa, diagnoses are generally delayed due to the scarcity of qualified specialists to assist with diagnosis of and intervention in the case of children with ASD (Mitchell & Holdt, 2014; Tilahun et al., 2016; Viljoen et al., 2019). In contrast to assumptions that the underdiagnoses of ASD only occurs in resource-constrained contexts, research indicates that a lack of early detection, and the ongoing underdiagnoses of ASD is common across well-resourced and resource-constrained contexts (Grinker et al., 2012). It is nevertheless important to note that those in well-resourced contexts are more likely to receive a formal diagnosis earlier than those in resource-constrained contexts (Grinker et al., 2012).

This means that intervention can start sooner in well-resourced contexts, which in turn can contribute to more a favourable prognosis.

Medical care includes the prescription and retrieval of medication prescribed for disorders such as ASD, which is often a costly component of caring for a child with ASD (Grinker et al., 2012). As previously mentioned, the participant's daughter had been placed on two types of medication. Through the interview data, the researcher obtained the insight that the participant did not always have sufficient funds to meet the dietary needs of her family. She therefore did not have excess funds to purchase the medication prescribed for her daughter. The participant was fortunate to receive the medication from the clinic, despite the need to spend money on transport to the clinic to collect the medication. This was indicative that the participant remained a victim of the financial burden associated with caring for a child with ASD in a resource-constrained context. It also highlighted that her access to the clinic might be resilience-enabling, as she was not forced to choose between tending to the needs of her family associated with survival, and obtaining the medication required by her daughter (Grinker et al., 2012).

Owing to the overburdened healthcare system, and the scarcity of resources, it is easy to conceive why caregivers perceive the South African public healthcare system as a challenge (Mitchell & Holdt, 2014; Pillay, 2014). In the case of the participant in this study, despite facing challenges associated with the public healthcare system, it can be concluded that through the provision of prescribed medication, the participant's financial burden was lessened to a certain degree. Therefore, in contrast to research that highlights the common challenges posed by the public healthcare system, the participant had had a resilience-enabling experience of the South African public healthcare system, except for the delay in receiving a formal diagnosis of ASD.

4.4.4 Information about ASD

Notwithstanding the resilience-enabling aspects of the public healthcare system in South Africa, some challenges form part of such a healthcare system. According to the participant, she experienced attending the public healthcare facility as a challenge in that she was not provided with any educational information regarding ASD. She was informed that her daughter most likely had ASD, and that she would be placed on a waiting list to receive the formal diagnosis.

Moreover, the participant was provided with a pamphlet indicating appropriate dietary requirements suitable to her daughter, and she received daily prescription medication. The participant admitted that not having a proper understanding of her daughter's condition made ASD more difficult to understand and cope with, therefore, having a negative impact on her resilience as caregiver of a child with ASD in a resource-constrained context. The aforementioned aligns with the findings of researchers Mitchell and Holdt (2014), who agreed that the resilience of caregivers of children with ASD in resource-constrained contexts is affected by the lack of information regarding the disorder, and the resultant uncertainty that caregivers experience. This statement is further supported by the participant's experience, that when she received information regarding ASD and began understanding it better, she was able to accept the condition, as well as understand and love her daughter.

The lack of information provided by the clinic perpetuated the misinformation regarding ASD in communities, where a lack of psychoeducation regarding psychological disorders prevailed and therefore failed to deal with the stigma surrounding such disorders. When asked about her community's view on ASD, the participant responded by saying: No, they don't understand; they take it the other way around" (Appendix C, p. 8). She stated that the members of her community often believed a person with such a disorder is bewitched. According to Mthombeni and Nwoye (2018), in the African cultural context, ASD as a mental disorder does not exist. It is acknowledged and understood in ways that are starkly different from those in Western societies. This distortion in how ASD is viewed in the African cultural context often has a negative impact on early detection (Mthombeni & Nwoye, 2018).

The participant admitted that although she had never seen anything such as ASD when she grew up, and that she had not initially understood it, she realised that something about her child was different when the girl was approximately three years old, when she also began visiting the local clinic. The researcher believes that the participant's open-mindedness regarding her daughter's unknown condition proved to be resilience-enabling for her as she was able to start learning more about the disorder. She therefore understood it better at an earlier stage, as opposed to automatically adopting her community's outlook of bewitchment or illness.

Donohue and Bornman (2014) and Tilahun et al. (2016) reported that a lack of understanding of disorders in resource-constrained communities resulted in misunderstandings, distorted beliefs, and stigma. While discussing her community's view on ASD, it was clear that the participant experienced frustration that the people around her did not understand her daughter's condition. She also found it difficult that everyone around her did not perceive it to be a medical condition, but rather a bewitchment or an illness to be healed: "But now I'm fighting with people if people come here saying, 'let's go to church, I know someone that's going to heal her', ooh, I'll klap[9] that person" (Appendix C, p. 8). This extract is moreover indicative of the restricting and offensive effect that stigma can have on its recipients (Viljoen et al., 2019).

4.4.5 Social support

Despite the widespread lack of access to information regarding psychological disorders, and the misconceptions associated with them, the participant in the current study was able to join a WhatsApp group comprising other mothers who were primary caregivers of children with ASD. When asked about how she was able to gain access to the WhatsApp group, she stated that she had come across the group on Facebook with the help of the social worker, that she had left her contact details on the post, and that she had subsequently been added to the group.

The WhatsApp social support group was therefore a significant resilience-enabling factor as the participant was able to receive useful information in the form of books,

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[9] "Klap" is an Afrikaans word meaning "slap". The Afrikaans word is sometimes used in other languages to convey anger or frustration, and not actually slapping the offender.

or advice from other mothers of what might have worked for their children, as well as coping strategies that the mothers used. The participant stated that often many mothers shared information and complaints with one another, a common concern being their children's dietary preferences. Through this platform, the participant was able to gain a better understanding of ASD, what it typically entailed, and how one could manage it when caring for a child with ASD in a resource-constrained context. She received many useful tips on how to deal with challenges she might experience, and that was enriching for her. According to Cole et al. (2017), the support received from the WhatsApp social support group is referred to as information support. Essentially, the participant received information support from the mothers in the group regarding coping strategies and the presentation of the disorder (Cole et al., 2017).

The participant in this study reported that it was very difficult having members of her community who did not understand her daughter's condition, therefore having the online support group provided her with a place where she could learn more about ASD, and a place that made her feel understood and less isolated, which she described as feeling "I am not alone in this" (Appendix C, p. 15). This extract is indicative of the feelings of being isolated and misunderstood that caregivers of children with ASD in resource-constrained contexts sometimes feel when others in their communities are unable to relate to their experiences. In contrast, it is also indicative that a WhatsApp social support group can buffer against the isolation experienced by caregivers (Cole et al., 2017; Ekas et al., 2009; Franz et al., 2017; Hoefman et al., 2014; Hoogsteen & Woodgate, 2013; Mthimunye, 2014).

In addition, according to Haslam et al. (2017), caregivers gravitated towards obtaining support from other caregivers in similar positions, as they experienced such support to be more aligned with their needs. From the feedback obtained from the participant, it was clear that she concurred with this. Not only did she feel less alone in her plight, but she also felt supported in meaningful ways by other caregivers of children with ASD on the WhatsApp social support group.

Furthermore, a study conducted by Ungar and Theron (2019) found that connections to females were likely to promote resilience in caregivers. Therefore, the WhatsApp social support group, with other mothers of children with ASD, was a resilience-enabling factor for the participant and, according to Mthimunye (2014) and Ekas et al. (2009), social support obtained from other caregivers of children with ASD was greatly valued as a resilience factor by caregivers.

Resource-constrained contexts in South Africa faced the significant challenge of limited internet access, which has a direct impact on access to social media (Abubakar, Ssewanyana, De Vries, & Newton, 2016). It is important to note that not everyone residing in a resource-constrained context is able to afford data, access free Wi-Fi hotspots, and access social media, hence the participant may be unique in her ability to purchase data, and access the WhatsApp social support group. Therefore, the participant’s ability to do so is resilience-enabling to her personally. Moreover, not everyone is technologically inclined or sufficiently well equipped to access social media platforms such as WhatsApp and Facebook. Hence, the participant’s ability to access such platforms is yet again resilience-enabling to her. The participant was assisted by the social worker at the public health clinic to access Facebook and the social support group that she predominantly relies on for support, clearly showing the matter of connections that enable resilience (see section 4.3.1. for application of the findings to the theoretical framework).

In contrast, in well-resourced contexts, access to social media through Wi-Fi or data platforms as well as technological literacy is widespread and common. It can thus be concluded that social support groups accessed through social media are much more accessible to caregivers residing in well-resourced contexts, despite it being much preferred in resource-constrained contexts. The reason for this preference in resource-constrained contexts is that an online social support group eliminates various logistical challenges such as travel costs, availability of childcare in the absence of the caregiver, lack of time, and availability, which are commonly experienced by caregivers in resource-constrained contexts (Cole et al., 2017).

4.4.6 Music

Research indicates that social support and prayer are the predominant resilience factors in resource-constrained contexts (Grant et al., 2013; Karst & Van Hecke, 2012; Tilahun et al., 2016). The participant confirmed that social support was a pertinent resilience-enabling factor for her as a caregiver of a child with ASD in a resource-constrained context. She, however, contradicted research findings that state that prayer played an equally pertinent role in her ability to be resilient in her context (Grant et al., 2013; Karst & Van Hecke, 2012; Tilahun et al., 2016). A probable cause of the rejection of prayer as a key resilience-enabling factor could be due to the unpleasant remarks by the participant's community members, who insinuated the bewitchment of her daughter, or illness, as community members often stated that a member of the church would cure her.

Instead of prayer, the participant utilised music as a means of escape and as a stress reliever. According to Buchalter (2011), music assists in the reduction of stress, it helps people temporarily to disconnect from their daily problems, fosters healing, decreases pain, and results in the production and release of endorphins. The positive effects of music, as stated by Buchalter (2011), emphasise the use of music as a resilience factor. In addition, the participant must have access to music, possibly through her cell phone, where she can download music, or which she can use as a radio.

4.5 INTEGRATION OF RESULTS AND FINDINGS WITH THE SOCIAL-ECOLOGICAL RESILIENCE THEORY

In Chapter Two the chosen theoretical framework, the SERT, is explored. In the following section the researcher provided an integration of the results and findings with the selected theoretical framework.

4.5.1 The influence of decentrality on resilience

Ungar's principle of *decentrality* implies that the environment plays an important role in any individual's resilience (Ungar, 2011). In the case of this participant, her environment's capacity to provide her with the resources necessary to promote resilience was minimal. Despite the marginal capacity of her environment to promote resilience, it nevertheless promoted resilience in unique ways. One such unique way was her daily exposure to music on her commute to work and back in the taxi.

The participant resided in a resource-constrained context and utilised public transport. She reported that music was essential for her resilience as a caregiver of a child with ASD. The South African public transport is synonymous with the rapid spread of the newest musical hits, and every township has its own hits (Steyels, 2016). This indicated that on her daily commute, the participant was exposed to music she considered to be uplifting, which might in turn bolster her mood, reduce her stress and enhance her resilience (Buchalter, 2011). Similarly, the participant visited a public healthcare clinic, where she was able to obtain her daughter's monthly medication. Under normal circumstances, as the primary caregiver, the participant would incur the additional cost of the medication, consequently increasing the financial burden of caring for a child with ASD in a resource-constrained context. The potential additional cost of purchasing the monthly medication for her daughter was averted by the participant's access to the public health clinic, which was therefore resilience-enabling. This explicates the principle of *decentrality*, as the participant's environment directly provided her with a means to acquire resilience (Ungar, 2011).

Misconceptions regarding ASD are common, and stigma is easily attached to those affected in a resource-constrained context. The researcher's assumption was that any misconceptions associated with ASD were as a result of a lack of information regarding ASD in such communities, and the insufficient provision of psychoeducation by the public healthcare facilities that the members of these communities frequent (Mitchell & Holdt, 2014).

In the participant's community a firm belief in the church as a means of healing and curing prevails. As previously mentioned, in a resource-constrained context, prayer is found to be one of two frequently used resilience factors, social support being the second (Grant et al., 2013; Karst & Van Hecke, 2012; Tilahun et al., 2016). Although the environment in which the participant resided provided opportunities for engaging in prayer, and obtaining social support, these opportunities were tainted by the stigma and the miseducation-related views held by community members (Tilahun et al., 2016).

The participant stated that many referred to her daughter as being bewitched and recommended that she should visit the church or a sangoma, “something is not right, you must go see a sangoma” (Appendix C, p. 22) to obtain healing. As previously mentioned during the interview, when the participant discussed her community’s views on ASD, she came across as frustrated. She did not give any indication that she relied on prayer or going to church as a means of gaining resilience. She did approach sangomas, to whom she had lost much money as her daughter’s condition did not change. However, she provided an indication that the social support she relied on was not from her community, but rather from other mothers in “all of South Africa” (Appendix C, p. 24) in a WhatsApp social support group.

As the participant in this study accessed Facebook, a social networking site, in which she came across a post offering support to other mothers of children with ASD, she also had an opportunity to join a WhatsApp group. She was assisted by the social worker at the public healthcare clinic to access Facebook, after which she left her contact details in the comments section under a post for mothers of children with ASD, and she was later added to the WhatsApp social support group. The difficulty experienced with access to data, Wi-Fi hotspots or social media in such a resource-constrained context was a clear indication of the lengths that the participant went to and her initiative in being proactive and improve her situation (Abubakar et al., 2016). The researcher therefore confirmed her belief that had it not been for the participant’s open-mindedness, willingness, and initiative to find a means of acquiring resilience-enabling material and experiences through connections, her resilience would be largely absent.

4.5.2 The influence of cultural relativity on resilience

Ungar’s principle of cultural relativity reflects the variations in culture, and in the ways each respective culture views resilience (Ungar, 2011). The participant in the current study followed the Zulu culture. She stated that, according to the Zulu culture, dealing with problems or challenges appropriately was associated with sangomas, who are traditional healers. The Zulu culture is very much based on spirituality and the power of the ancestors, and the Zulu people often engage in several rituals involving sacrifices to obtain the blessings of the ancestors (Demand Africa, n.d.).

The participant in this study stated that in the past she had visited many sangomas and paid much money to achieve her daughter's healing, but to no avail. She claimed that she had now accepted her daughter's condition and her life as it was, but reported that from the perspective of the Zulu culture she was not viewed as resilient. She was viewed as a mother with no love or regard for her child's well-being as she had made the decision not to visit another sangoma. From a Westernised perspective, the participant's decision to visit a healthcare facility and access medication for her daughter was viewed as resilience-enabling. It can thus be concluded that resilience is varied across cultures, and, as is shown by the participant's experience, culture may be prescriptive in the ways that an individual is required to obtain resilience when faced with adversity (Ungar, 2011).

The participant here was found to be open-minded and flexible, and she no longer allowed the pressures of her culture to guide her resilience-enabling behaviour, and how she felt as a mother. Despite being of the Zulu culture, the researcher believed that the participant's open-mindedness enabled her to think outside the confines of her culture. The participant had even stated "I try and I try" (Appendix C, p. 23), which is indicative of her efforts to remedy her daughter's situation.

Furthermore, Ungar's SERT also states that, in some instances, resilience factors may appear maladaptive without the consideration of an individual's context (Ungar, 2011). This applies to the participant in this case because the interview data indicated that she did not have any social resources in her community, but instead she had made friends on the previously mentioned WhatsApp social support group. When asked about her social resources, she declared "maybe from friends, because I am on a group with people, with mother[s] of [children with] autism" (Appendix C, p. 14). Prior to understanding the beliefs of her community, and how hurtful they were by insinuating the bewitchment of her daughter, the researcher was under the impression that the participant lacked social support and isolated herself. Through understanding the context of her environment, it became clear that her isolation from members of her community was actually resilience-enabling, and protective in nature (Ungar, 2011). She did not turn to members of the community for support, which in turn prevented her from having to hear and deal with potentially frustrating remarks regarding her daughter and ASD. This act of “isolation” was thus resilience-enabling to this participant.

4.6 CONCLUSION

From the aforementioned data results, findings and discussion, it can be concluded that, as a caregiver of a child with ASD in a resource-constrained context, the participant in this study experienced challenges as well as resilience-enabling factors. In addition, it can be concluded that the resilience factors that were experienced varied across context and culture, therefore it is important to take context and culture into consideration to understand the resilience of any individual (Ungar, 2011).

In this chapter, the researcher explained the results and findings of the data analysis, and correlated them with the literature review, which were presented in Chapter Two. The researcher moreover also integrated the findings with the theoretical framework selected for the study.

In the next chapter, the researcher attempted to answer the research questions contained in this research study. In addition, the researcher also presented the potential contributions, limitations of and recommendations for the study.

5. CHAPTER 5: RESEARCH CONCLUSION, LIMITATIONS AND RECOMMENDATIONS

5.1 INTRODUCTION

In Chapter Four, a detailed account of the results and findings of the data collected was provided. An integration of the results and findings with the selected theory, the social ecological resilience theory, as well as the literature review found in Chapter Two, were presented.

This chapter contains a summary of all the previous chapters in the dissertation, the answers to the formally put research questions, and an exploration into the contributions and limitations of this study. In addition, the researcher made recommendations for future research on the topic relating to the resilience factors of caregivers of children with ASD in varied contexts.

5.2 SUMMARY OF CHAPTERS

In Chapter One the researcher provided the rationale, the purpose as well as the aims of the research study, after which the research questions and working assumptions were stated. In addition, the researcher proceeded to provide insight into the paradigmatic choices of the study, which included the theoretical framework, the epistemology, and the research methodology that underpin the study. The methodological choices, inclusive of the research design, sampling procedures, data generation, data documentation, data analysis and interpretation methods were also stated. Chapter One was concluded with the ethical considerations and quality criteria that were applicable to this research study.

In Chapter Two a concise definition of ASD was provided, after which an exploration into the various challenges and resilience factors experienced by caregivers of children with ASD across both well-resourced and resource-constrained contexts was described. Ungar's social ecological resilience theory, which consists of four principles – *decentrality, cultural relativity, atypicality,* and *complexity* – was selected as theoretical framework, and the suitability of this theory for the study was explored (Ungar, 2011).

In Chapter Three the paradigmatic choices regarding the epistemology (interpretivism) and methodology (qualitative research) were discussed. A discussion of the descriptive case study design, purposeful sampling, semi-structured interviews, and associated data documentation, interpretation and analysis methods followed. An exploration into exactly what the respective choices entailed as well as their concomitant advantages and challenges were detailed in Chapter Three.

In Chapter Four the results and findings of the research study were presented. The results indicated that the caregiver of a child with ASD in a resource-constrained context experienced both challenges and resilience-enabling factors. Some challenges, such as a lack of early detection and underdiagnosis of ASD, are prevalent in both contexts, whereas challenges such as access to appropriate medical professionals is the predominant challenge in resource-constrained contexts. Social support, among others, was identified as a common resilience factor across settings. The results and findings of the study were integrated with literature and Ungar’s social ecological resilience theory as the theoretical framework.

5.3 DISCUSSION OF THE RESEARCH QUESTIONS

The secondary research questions will be answered prior to the primary research question.

5.3.1 Secondary research questions

1. What are the resilience factors of caregivers of children with ASD in well-resourced contexts?

The literature review indicated that caregivers in well-resourced contexts have a variety of resilience factors available to them, which include social support, religious beliefs and prayer, community services, and use of the arts such as music (Bekhet et al., 2012; Ekas et al., 2009; Walsh, 2012).

A rather exclusive resilience factor available to caregivers of children with ASD in well-resourced contexts is the use of and access to private mental healthcare services for the caregiver (Karst & Van Hecke, 2012). Karst and Van Hecke (2012) confirmed the dynamic impact that access to both psychological and psychiatric interventions for caregivers has on caregiver resilience. It is therefore a strong resilience factor available to caregivers of children with ASD in well-resourced contexts that is unfortunately not easily attainable to caregivers in resource-constrained contexts owing to the public healthcare system being overburdened (Mitchell & Holdt, 2014; Pillay, 2014b).

In addition, according to a study conducted in the USA, socio-economic status, hence the context in which the individual resides, has an influence on caregiver education (Durkin et al., 2010). The caregiver of a child with ASD in a well-resourced context is thus likely to experience less stigma as a result of higher levels of education and understanding in this context (Purkis, 2016). Therefore, the reduced stigma experienced in well-resourced contexts is resilience-enabling for caregivers in well-resourced contexts.

Increased education, understanding, and financial resources positively influence the ability of caregivers in well-resourced contexts to access specialised facilities, as well as to obtain an early diagnosis of the child in their care (Durkin et al., 2010; Nowell, Norris, White, & Moules, 2017). Access to specialised facilities for children with ASD allows caregivers to achieve a balanced lifestyle, which in turn serves as a resilience-enabler (Divan, Vajaratkar, Desai, Strik-Lievers, & Patel, 2012). Moreover, obtaining an early diagnosis and effective treatment plan for the child in their care result in reduced stress and uncertainty of the caregivers, hence enhances caregiver resilience (Mitchell & Holdt, 2014; Purkis, 2016).

2. Which resilience factors present in well-resourced contexts are also available to caregivers in resource-constrained contexts?

Caregivers in resource-constrained contexts have certain resilience factors in common with the caregivers in well-resourced contexts. These are inclusive of social support, religious beliefs and prayer, community services, and using the arts such as music (Bekhet et al., 2012; Ekas et al., 2009; Walsh, 2012). Social support is commonly used across well-resourced and resource-constrained contexts, albeit in different ways. Based on the aforementioned, it seems that caregivers in resource-constrained contexts prefer online social support groups as it eliminates the logistical challenges such as distance to travel, taking up time, and travel costs (Cole et al., 2017). Although religious beliefs, prayer and community centres are accessible to caregivers in resource-constrained contexts, caregivers in these resource-constrained contexts are unlikely to utilise such resilience factors if it is experienced that community and church members stigmatise their children (Mthombeni & Nwoye, 2018).

Additional resilience factors available to caregivers in well-resourced contexts that are also available to caregivers in resource-constrained contexts, although these may present in different ways, include access to healthcare facilities, appropriate professionals such as educational psychologists and social workers (Mitchell & Holdt, 2014; Pillay, 2014a), and access to specialised facilities such as special schools (Fletcher et al., 2012; Karst & Van Hecke, 2012).

The most pertinent differences in the way in which caregivers in resource-constrained contexts are able to access resilience factors available in well-resourced contexts lie in the quality of the healthcare services and ease of access (Harris et al., 2011). Caregivers in well-resourced contexts are able to access private healthcare facilities with ease, and are likely to obtain an appointment with an educational psychologist timeously, as opposed to caregivers in resource-constrained contexts, who are liable to incur exorbitant travel costs to access educational psychologists or social workers at public healthcare facilities, where they may be met with long queues and potential disappointment (Mitchell & Holdt, 2014; Pillay, 2014a). Moreover, caregivers in well-resourced contexts have access to various options in specialised care and schooling for the child diagnosed with ASD, whereas caregivers in resource-constrained contexts commonly only have the option of sending the child in their care to a home-based crèche, which may not be appropriately supportive, but is affordable (Grinker et al., 2012).

5.3.2 Primary research question

The primary research question posed in Chapter One was:

What are the resilience factors of caregivers of children with ASD in resource-constrained contexts?

As previously mentioned, the resilience factors of caregivers of children with ASD in resource-constrained contexts include social support, religious beliefs and prayer, community services, and the arts, including music (Bekhet et al., 2012; Ekas et al., 2009; Walsh, 2012). In addition, caregivers in resource-constrained contexts have access to public healthcare facilities, which provide prescription medication for their children free of charge, therefore such access is a resilience factor.

Furthermore, in resource-constrained contexts where there is access to network towers and electricity, and where caregivers are able to purchase data, cell phones are a means to acquiring resilience. Cell phones enable caregivers in these contexts to gain access to social support groups on social media platforms such as the WhatsApp group accessed by the participant in this study. Gaining access to such platforms allows caregivers to interact with and gain support from other caregivers across South Africa. They can rely on these caregivers for information support, nurturing support and instrumental support, without having to travel out of their communities (Cole et al., 2017) (see section 2.4.2 for an exploration into the various types of support accessible from online support groups).

According to Buchalter (2011), exposure to music is likely to be resilience-enabling as it improves mood and may have a positive impact on the reduction of stress. Access to a cell phone and data enables caregivers in resource-constrained contexts to listen to music accessed through individual downloads or radio stations. In addition, access to music is also made easily accessible to caregivers in resource-constrained contexts, where they utilise public transport such as taxis, much like the participant in this study (Steyels, 2016).

Moreover, during the COVID-19 pandemic and strict nationwide lockdown, the participant in this study was at home more often as she was no longer able to travel to work. The lack of work and reduced financial income may have increased the stress of the participant, but possibly her access to the online social support group as well as to the music retrieved from her mobile phone enabled her to adapt to the situation. After the lockdown the participant stated that "yeah, it's better than that time I was home all the time … I am working three days: Monday, Wednesday and Friday" (Appendix C, p. 27).

The possibility of a care dependency grant by the Department of Social Services (RSA, DSS, 2020) can also be regarded as a resilience factor if it can be accessed. This grant, an amount of R1,860 per month, is given to caregivers of children with disabilities who require care. As the mother explained during the interview, she did not have the necessary documentation (ID) or money for the paternity test to apply for this grant. However, it has emerged that the application process allows for alternatives in the case of a lack of ID and birth certificate as well as the event of difficulties regarding paternity testing. Unfortunately, it appears that the incorrect knowledge about the grant application process was a factor preventing this grant from coming into effect and supporting the participant caregiver and her child.

5.4 RECOMMENDATIONS

5.4.1 Recommendations for research

It is recommended that data should be collected from a multitude of participants, which would enable future researchers to compare findings, and identify the resilience factors unique to each caregiver. Franz et al. (2017) recommend that a mixed-methods approach should be utilised to provide depth to the understanding of parental and familial perspectives with a view to enhancing and initiating local, regional, national and global ASD interventions. Adding a quantitative component such as a rating scale measuring caregiver stress and a qualitative component such as semi-structured interviews means that the data yielded by such a study are likely to indicate consistencies, contradictions, and hence produce greater specificity with regard to resilience, caregiver stress, and areas in which intervention is most needed. Moreover, longitudinal studies regarding the resilience of caregivers of children with ASD should be conducted in order to identify resilience over time, the potential progress or regression that caregivers may experience, and the reasons for that.

In addition, future studies should research the appropriate provision of psychoeducation regarding ASD in resource-constrained contexts and the effect thereof as this study indicates that such knowledge is largely misconstrued or even absent.

5.4.2 Recommendations for innovation

According to Abubakar et al. (2016), an urgent need for awareness of ASD prevails, and their recommendation is that partnerships should be initiated between parent-support groups, non-profit organisations, local and international ASD organisations, as well as the government and World Health Organisation, in order to facilitate promoting such awareness. Current awareness occurs predominantly through the internet and, as exemplified by the participant in the study, internet access is limited to many (Abubakar et al., 2016). Furthermore, Abubakar et al. (2016) recommend utilising more accessible platforms to promote psychoeducation, including mobile phones.

The researcher strongly believes that the aforementioned proposition has the potential to make a major breakthrough regarding psychoeducation relating to ASD in South Africa, more particularly in resource-constrained contexts. The reasoning behind this belief is that the participant in the study was able to learn more about the disorder, its manifestations, as well as ways in which to cope with its consequences through accessing a social support group on WhatsApp. Therefore, the use of such easily accessible platforms should be promoted with dynamism throughout resource-constrained contexts.

5.5 CONTRIBUTION OF STUDY TO THE EXISTING BODY OF KNOWLEDGE

The main contribution of this study is the creation of awareness and the initial exploration into the understanding of the resilience-enabling factors utilised by the caregiver of a child with ASD in a resource-constrained context. Through understanding the preferred and accessible resilience factors in resource-constrained contexts, more suitable supportive interventions may be introduced in such contexts, thereby promoting resilience.

5.6 LIMITATIONS OF THE STUDY

The main limitation of the study is that only one participant participated in the study, and her doing so by means of a telephonic semi-structured interview. Initially, it was intended that the study would involve three participants, but owing to the extraordinary circumstances that prevailed during the COVID-19 pandemic, this was impossible. The outcome was a limited sample size consisting of one participant only, which suggests that the researcher was unable to obtain access to the subjective experiences of various participants (Creswell, 2009). A limited sample size negatively affects the generalisability and even the transferability of a study. However, in the case of this specific study, the purpose of the study was not to generalise findings to a larger population, but rather to obtain an understanding of the resilience of caregivers of children with ASD in a resource-constrained context.

As a result of the interview being conducted telephonically, an additional limitation of the study was the lack of naturalistic observation of the participant during the interview. Naturalistic observation of the participant would have informed the participant’s non-verbal thoughts and feelings, which might have enhanced understanding of the resilience of a caregiver of a child with ASD in a resource-constrained context.

Moreover, the researcher was unable to compare data from a variety of data-generation methods and ensure triangulation owing to using only a single form of data collection, namely the semi-structured interview conducted telephonically. However, this limitation was combatted to a certain degree through the use of member-checking, which ensured the accuracy of the data collected and analysed (Creswell, 2009). Consequent to the nature of the participant’s schedule, member-checking was difficult to conduct as she was at work most days, or at home caring for her child and hence had limited to no time for a lengthy phone call. The participant did, however, agree to receive transcripts of the interview and the extracted themes, which she had read and verified.

Furthermore, some of the interview and additional probing conversations took place during the week, at approximately 20:00 in the evening. Moments prior to the scheduled phone calls, the participant would have ended her day by having bathed her children and put them to bed, after she had come home from work, cooked a meal, and fed her family. Considering that the participant often had a full working day prior to the phone calls, it is reasonable to assume, as an added limitation, that she had forgotten to mention certain resilience factors that were usually present. The interview and additional conversations occurred during the COVID-19 pandemic, a time during which the participant mentioned that she had had difficulty finding work. The participant's difficulty finding work may have resulted in increased stress, hence causing the participant to be biased about the financial challenges she experienced, which is consequently an additional limitation.

5.7 CONCLUSION

In conclusion, the researcher in this study reaffirms the importance of understanding the resilience factors of caregivers of children with ASD in resource-constrained contexts. Resilience factors vary across contexts and cultures, and it is essential to understand these variations in order to effect positive change in supportive interventions for caregivers of children with ASD in resource-constrained contexts.

It is through this study that the researcher's own interest was satisfied regarding the way that caregivers in resource-constrained contexts are able to cope with the universal challenges associated with caring for a child with ASD without the same accessibility to and quality of resilience-enabling resources as in well-resourced contexts The researcher learned that there was no single defining factor that allowed caregivers in resource-constrained contexts to cope with the same challenges as those in well-resourced contexts, but that a dynamic interplay between self and environmental factors took place, which led to resilience. It is thus important for healthcare practitioners such as educational psychologists to realise that resilience factors also operate in resource-constrained contexts.

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7. APPENDICES

7.1 APPENDIX A – INTENDED INTERVIEW QUESTIONS:

1) Tell me about yourself?
2) How long have you been coming to the Itsoseng Clinic?
3) When did you realise that the child in your care was different from other children?
4) How is the child in your care different from other children?
5) When did the child in your care receive a diagnosis of Autism Spectrum Disorder?
6) What happened after the child in your care received a diagnosis?
7) Was this helpful for you in any way and if so, how?
8) What do you understand by the term Autism Spectrum Disorder?
9) What does your community understand by Autism Spectrum Disorder?
10) How did you as a caregiver experience life before the diagnosis was made?
11) How did you as a caregiver experience life after the diagnosis was made?
12) What challenges do you face daily in caring for a child diagnosed with Autism Spectrum Disorder?
13) Describe what your mood is like most of the time?
14) How do you cope with these challenges?
15) What else do you think you need that would help you to overcome these challenges?
16) How do you feel about the overall health care facilities you have access to?
17) What has been your personal experience of the services offered to support the child under your care?

7.2 APPENDIX B – PARTICIPANT - INTERVIEW TRANSCRIPT AND ADDITIONAL INFORMATION OBTAINED FROM PROBING

Participant: Hello?

Researcher: Hi, Participant. How are you?

Participant: I'm good and you?

Researcher: I'm well thanks. How have you been since the last time we spoke?

Participant: I'm alright and you

Researcher: I'm well thank you.

Participant: … Hello

Researcher: Hello, can you hear me?

Participant: Yes, I can hear you

Researcher: It's getting cold now hey

Participant: Yeah, it's getting cold, and it was P's birthday but I never see you wishing her well

Researcher: Oh, my word! You must please give her all my love. How old is she now, 12 years old?

Participant: No… yes... no she's 11 years now

Researcher: Oh, my word 11! She's a big girl now

Participant: Yeah, she's a big girl now, yeah

Researcher: And you're such a young mum

Participant: Yeah, such a young mum yes

Researcher: So how was the birthday? Was it nice? Did she have fun?

Participant: Yeah, it was nice.

Researcher: Okay, just at home with family?

Participant: Sorry?

Researcher: I said you just spent the birthday at home, with family?

Participant: Yeah, with family, yes

Researcher: Okay that's nice, you can't go out in this cold, shew!

Participant: Ooh its very cold, it's very very very cold.

Researcher: At night its worse than the morning, hey

Participant: Ooh it's very worse ooh, you know especially if you wake up early and P she don't like the cold

Researcher: Really?

Participant: Yeah

Researcher: Oh man! And they say the next two days are going to be very very cold

Participant: Yeah, I heard that also, they said it's gonna very be very very cold this week

Researcher: We just have to dress warm and stay indoors

Participant: We have to stay indoors, yeah you are right there oooh, it's terrible.

Researcher: I'm telling you, but I like Winter hey, I prefer the cold rather than the heat.

Participant: Yeah oooh

Researcher: I don't like to feel hot

Participant: Yeah but you know Winter you can wear more jerseys and be like

Researcher: Exactly!

Participant: Yeah and then Summer you can't do anything

Researcher: Exactly! You just feel hot and you're feeling irritated, like you don't want to do anything

Participant: Anything. Yeah, you can wake up and you are tired already because of the heat

Researcher: Exactly, exactly!

Participant: Yeah but with this Winter you can be alright all the time

Researcher: Yeah, a little bit lazy but okay

Participant: Yes, so what's up?

Researcher: Okay, so today I was thinking maybe we can do some of the interview questions if you have time.

Participant: Oh, yes. It's okay

Researcher: So, uh, how much time do you have today?

Participant: Now?

Researcher: Yeah

Participant: About 10 minutes to 15 minutes I have.

Researcher: Okay. So, let's see how many we can do. And then maybe we can have a phone call again tomorrow. Would that be fine with you?

Participant: Yeah, it will be fine. It be fine because I'm not, I'm home now there's no problem at all

Researcher: Okay, perfect. Okay. So, should we start with the first question?

Participant: Yeah, you can start with the first question

Researcher: So, the first question is, tell me about yourself.

Participant: Oh, about myself?

Researcher: Yes

Participant: Ooh, I am Participant, I have two kids and I've got a husband yeah that's yeah that's all I can say

Researcher: Okay alright, and then how, how long have you been coming to Itsoseng Clinic. So how many times have you been to Itsoseng Clinic with P?

Participant: Oh, with P, okay okay

Researcher: Yeah

Participant: Oh, I think more than six times

Researcher: Okay

Participant: Six times seven, yeah

Researcher: Okay. And then when did you realize that P is different from other children?

Participant: When she's about three.

Researcher: Okay.

Participant: She's about three years. Yeah, she was about three years, but when she was growing up, she was, she was like crawling fast fast in front of other kids yeah.

Researcher: Yeah

Participant: And she was moving moving fast**,** she was doing all the stuff fast fast.

Researcher: Okay, and what else did you notice was different?

Participant: With P?

Researcher: Yes

Participant: That she can't play with other kids.

Researcher: Okay, but why, can you tell me more about that?

Participant: About that?

Researcher: Mmhmm

Participant: She can she can prefer to be alone all the time and do her own stuff.

Researcher: Okay

Participant: And keeping quiet

Researcher: Okay so she likes to be on her own more than anything?

Participant: Yeah, she likes to be on her own more than anything, yes

Researcher: Okay

Participant: Yeah

Researcher: So, you say she, she likes to play alone and do things alone, she doesn’t like to play with other kids very much.

Participant: No she don’t want, she don’t like it at all

Researcher: And how is she different from other children?

Participant: Like she can't talk and she don't know what she do like, actually she don't know what she do. Yeah, she can take stuff, mix everything. If we left, like sugar, salt yeah she can mix it everything in one place.

Researcher: Okay. So she doesn't really know what she's doing very well.

Participant: Yes, yes, yes, yes.

Researcher: Okay

Participant: Yes

Researcher: And then when did she, when did they tell you that she has Autism Spectrum Disorder?

Participant: Okay. When she was six years.

Researcher: Okay, so she was 6 years and she's 11 now?

Participant: Yeah.

Researcher: So it has been 5 years. Yeah.

Participant: It's been 5 years when she's on a medication yes.

Researcher: Yes. And what happened after she got the diagnosis?

Participant: She’s not get diagnosis yet, we are, they are still busy there by that clinic, they said that she's on the list.

Researcher: Okay. So she still has to go in.

Participant: Yeah. She still has to go in. She did, they did not do her yet.

Researcher: Okay. But after they told you she might have Autism Spectrum Disorder, did they give you any helpful information or anything?

Participant: No, no, they just, it's just when we go, because we sat at the (indistinctive), they just give us medication only.

Researcher: Okay, what medication was she on?

Participant: Can I find it, the box for you?

Researcher: Yeah, that's fine. You can send it to me also, tomorrow is fine.

Participant: Also. I can send you all. I can read it for you.

Researcher: You can send me a picture on WhatsApp or anything. Whatever is easy for you.

Participant: Alright okay, so I will send it tomorrow.

Researcher: Okay, perfect. So you didn't receive any helpful information or anything at that time?

Participant: No, no, no, no, not yet not yet and she is also not getting her grant, that's what makes me worried that one

Researcher: Okay so tell me something Participant, after they put her on medication, do you think it helped a little or?

Participant: Yeah it helps a little, a little

Researcher: And how does it help?

Participant: Like when she takes her medication, she can sit, and she can and like understand little bit

Researcher: Okay

Participant: And because before she went, if like when we did not give her the pills you can see that she is different today

Researcher: Yeah

Participant: but yeah, if we give her the medication, she will be a good girl, she will behaves.

Researcher: So you think she's gotten better since she's been on the pills?

Participant: Yeah

Researcher: Okay

Participant: Yes

Researcher: So it's been helpful for you to have her on the medication?

Participant: Yes it's still helpful yes.

Researcher: And tell me, Participant, what do you understand if someone says Autism Spectrum Disorder?

Participant: What I understand?

Researcher: Yes, what do you understand it to be?

Participant: Oh I did not understand it yet

Researcher: Okay

Researcher: And, um, when you went to the clinic and they were telling you that it might be Autism, did anybody explain to you maybe what it is?

Participant: No, no, no.

Researcher: Okay, and in the community where you live, do you think there that people there, understand what is Autism Spectrum Disorder?

Participant: No, no, they don't understand it, they take it the other way around

Researcher: What do you mean by that?

Participant: Ah you know, you know what other people think, people they can think it's witch, they don't believe on that stuff, you know?

Researcher: Oh, so they believe it's like someone bewitched you or something like that?

Participant: Yes 100% yes.

Researcher: Okay, so you think they don't understand properly, there's misinformation?

Participant: Yeah, no they don't understand it properly, yeah

Researcher: Okay

Participant: But now I'm fighting with people if people come here saying "let's go to church, I know someone that's going to heal her, ooh I'll klap that person

Researcher: Oh my word!

Participant: because I'm sick now, I'm tired of that

Researcher: Yeah, I understand, especially because you know it's what it is because you understand

Participant: Yeah, I understand

Researcher: but I think other people don't understand and they think they know what it is

Participant: Yeah, they don't understand, especially the community where you live, they will never understand that

Researcher: Yeah. So, so do you find that difficult, like having everybody around not understand.

Participant: Yeah, it's, it's very difficult. You know, sometimes, it's difficult.

Researcher: Okay

Participant: Yeah

Researcher: And then tell me, before, how did you as a caregiver for P experience life before you knew that she might have Autism Spectrum Disorder?

Participant: You mean the experience I have?

Researcher: Yes. Before you knew that she might have this problem.

Participant: Before I knew, ay, like what, what, what was what I was doing before?

Researcher: Like how, how were you experiencing caring for her looking after her before you knew that she might have Autism Spectrum Disorder

Participant: Oh before I was not understanding it me either, because I me and for me when we grow up, I never see anything like this.

Researcher: Yes, exactly.

Participant: Yeah, so for me, from before, it was very difficult for me or I'm, you know? Yeah. It was very difficult for me, but as the time goes on, then I start to, I learn to love her, that's all matters to me

Researcher: Yes, exactly

Participant: Yes, that's all matters to me, to lover her to show her love, and to show her that she's not different

Researcher: Yes, exactly! Okay

Participant: Yeah. Yeah, I can talk to her, we can laugh, we can do anything I do with my other child.

Researcher: Yes

Participant: Yes, the normal one

Researcher: So, it's interesting, you said she likes to be by herself, but it seems like you have a very good relationship with her, you're very close to her.

Participant: Yeah, we have a good, very good relationship

Researcher: Okay, so you are basically, you are her primary caregiver, you take care of her most of the time.

Participant: Yeah, I take care most of the time, yes

Researcher: Okay. And so, so before you knew that she might have autism, it was difficult because you didn't understand it. And then afterwards you you started understanding, so it got a bit easier

Participant: Yes, yes, I start to understand it, yes

Researcher: Okay and then because you understood it, did it make it easier to care for her?

Participant: Yeah if you understand it yeah you can take care of her right if you understand her right, but you know, if you don't understand it, it's going to be very difficult for you

Researcher: Yes, so how, can you tell me more about how it was difficult for you before you understood it

Participant: Uh like before I knew that she must not eat the other stuff, when we did, because she was like more more more before I knew that she must not eat the other stuff, she must still eat the other stuff.

Researcher: Okay

Participant: Mmm

Researcher: And then what challenges do you face daily in caring for P? Um, like what do you find is difficult every day when you care for her?

Participant: Mmm, like, like, like help that's what I I I always suffer for her because she want different stuff, things and me I don't have that stuff, you know.

Researcher: Okay, can you tell me more about that

Participant: She when you, you know sometimes**,** where we stay because we, we are not that rich where we stay, when you maybe, like now if it's cold, and you you finished to shh bath her then you tell her to sit down, then she can see that you are inside, then she can sit down, after some moments, you can see her outside on water or playing with water, or make herself wet again

Researcher: Okay so you're saying she doesn't understand if you tell her something

Participant: Yeah. Yes, yes, yes.

Researcher: Okay, and what else do you find is difficult?

Participant: Umm, the food

Researcher: Yes, tell me

Participant: Ummm, she don't eat the food we eat

Researcher: Okay, so what does she eat?

Participant: … (background noise) sorry?

Researcher: What does she eat?

Participant: Oh, this one, they give us the the paper at clinic, what she must eat, what she must not eat

Researcher: Yes, okay

Participant: Like when we buy ourselves bread, we must buy her her own bread, sometimes we don't have that money so she has to eat what what we have

Participant: What she must eat, but she must not eat bread or the bread. Sometimes we don't have that money. So, she has to eat what what we have, and it's going to confuse her

Researcher: Okay so, it's difficult sometimes because you can't give her the things she needs

Participant: Yeah, yeah yeah.

Researcher: Okay! I understand you, okay

Participant: Yeah

Researcher: And tell me Participant, how do you feel most of the time, what is your mood like most of the time?

Participant: Most of my time, most of my time, most of my time if I’m with her, I’m happy

Researcher: Tell me more about that

Participant: Because if I’m with her, I'll be happy than to give her to someone then I know that I can take care of her.

Researcher: Yes, okay.

Participant: Yeah, yeah.

Researcher: So, you look after her very well, you manage to take care of her very well

Participant: Yeah, I look after her very well

Researcher: And Participant, we spoke about the challenges just now the things you find difficult. Can you tell me how you manage with the, with all the difficulties that you face? Like a different food and when she doesn't listen, how do you manage with that? How do you cope with it?

Participant: Oh, I don’t cope. I don't cope with it. Sometimes it’s hard what can I say

Researcher: Yeah

Participant: Yeah but sometimes

Researcher: So, what do you think helps you sometimes to just

Participant: Sorry?

Researcher: What do you think helps you?

Participant: What do I need?

Researcher: No. I mean like when, when, when say you're having a difficult day with premium looking after her, what do you think helps you get through that day?

Participant: What do I do?

Researcher: Yes. Like, for example, like what do you do that will help you feel maybe less stress?

Participant: I just play music and I'll be fine.

Researcher: Okay. So, you like music?

Participant: Yeah.

Researcher: What music do you listen to?

Participant: Sorry?

Researcher: What music do you listen to?

Participant: The music that I listen to, like is, this one of of of people dancing dancing then I know I know the stress will go down a little bit

Researcher: Okay, so it puts you in a better mood?

Participant: Yeah

Researcher: Okay

Participant: Yes

Researcher: And then what else helps you cope when you stress about P or when you worry about her or when things are difficult,

Participant: you said what, uh what? I did not hear correctly

Researcher: Okay. So when, when you having like stress or you're having a difficult day, or you're worried about P, what helps you get through that? Like for example, do you get support from your friends, from your husband, from the church? What do you think helps you when when you're having a difficult time?

Participant: Maybe from friends because I am on group with people with with mother of Autism

Researcher: Okay! So, you are in a social support group

Participant: Yes, I am in social support group yes

Researcher: So, on WhatsApp?

Participant: Yeah on WhatsApp, yeah

Researcher: Okay. And do you find that to be very helpful for you?

Participant: Yeah, it’s very helpful for me, yes

Researcher: Okay. Can you tell me a little bit of like, why, what information do you get from there that helps you?

Participant: Oh, okay like when I'm I'm when I ask those ladies what they will manage, they will send us the books, what they do with their children also

Researcher: Okay

Participant: Yes

Researcher: Okay, so that helps you manage

Participant: Yeah, they help me a lot yeah. If I send them pictures also, of P being naughty, they can send other mothers also they can send their children being naughty so you can see oh I am not alone in this

Researcher: Okay, so you feel like there are also other people, so it makes you feel better.

Participant: Yes, yes yes yes. And only that's the one that makes me feel better to them. If I have long day, I can talk to them

Researcher: You feel better after?

Researcher: Okay, and what else? What else helps you? ... (background noise – her husband asked for something) are you still okay to talk Participant?

Participant: Yeah, my husband asking something, yeah, we can go on now. Sorry about that

Researcher: No problem it's okay. And tell me, what else do you need or do you think you need, that would help you with your challenges?

Participant: Ummm what I need

Researcher: So, what else will help you make it easier to look after P?

Participant: Oh, okay okay, umm, no I think that one only its help me a lot that one

Researcher: Okay. But I mean, if there were something else that you could have that would help you take care of her better, what do you think it would be?

Researcher: Anything you could just make it easier for you and better for her?

Participant: Oh, okay. If we find we need that will be fine

Researcher: Okay, tell me more about that?

Participant: I mean the stuff P wants, me I'm fine but P is the problem, the stuff she wants

Researcher: Okay so if you can take care of her needs better

Participant: Yeah, if I take care of her needs better, yeah, because like now she's on she she she's on periods already but you know she change maybe I can use 3 packets for the whole packet can be finished for one day, so you know if you don't earn lot of money it's going to be very difficult

Researcher: Yes, it's expensive

Participant: Yeah.

Researcher: Okay

Participant: If uh for her only the needs she want that one that she can get food and everything that she the one they said she must eat at the clinic not for us

Researcher: Okay, okay I understand, and then how, how do you feel about the healthcare facilities you've been to. So, any clinics or any healthcare facilities that you have taken P to? How do you feel about it?

Participant: It's alright there it’s okay there at the clinic only there where we go, and there where you are, where you were you

Researcher: Yes

Participant: Yes, they called me and they said they will not forget about they will let us know

Researcher: Okay, o they will let you know when to come back,

Participant: yes, to come back, yes

Researcher: Okay, and do you feel like it's helpful to go there? Do you feel like they help you? You're happy with the service you getting there.

Participant: Yeah, it’s very nice, it’s okay

Researcher: Okay, and then what has been your experience of the services that they offer to support P? … (background noise) Can you hear me?

Participant: Yes, I can hear you

Researcher: Okay, what has been your experience of the services that they offer to help P at the hospital?

Participant: Ooh they did not help so so much they did not help so much, I wish they can do, maybe if they do the diagnosis if maybe she will be better because yeah if maybe they help us at the clinic everywhere but now I’m going to on the 22 I’m going to see the doctor on the 22 of June

Researcher: Okay so you’re going back to the hospital 22 June

Participant: Yes

Researcher: Yes. Okay. And is there anything else you want to add? Anything at all?

Participant: No, is that one only

Researcher: Okay, so I have good news, we are done with the interview, that was nice and quick

Participant: Okay

Researcher: So, thank you so much for your time. And for agreeing to help me out

Participant: Alright, okay, you are welcome, I thank you also

Researcher: I will speak to you again soon, you must let me know how it goes at the hospital and how is P okay?

Participant: Yes, I’m going to let you know, alright, okay

Researcher: Okay, thank you Participant

Participant: Alright okay you are welcome

Researcher: Okay enjoy your evening

Participant: Yeah, you too. Bye.

Additional information obtained through probing:

Researcher: How did you join the WhatsApp group with other mothers that have children with Autism?

Participant: At Facebook, on Facebook we leave our numbers and then the other lady add us on her group

Researcher: I see! It seems very good

Participant: Yes, we share especially food many mother is complain for it

Researcher: Okay that's very good it seems so helpful! It's amazing. Do you have to buy data every time or do you use Tshwane free Wi-Fi?

Participant: No, I buy data all the time

Researcher: Participant, I just wanted to ask you a few questions just to help me a little bit better,

Participant: Okay

Researcher: Has P[10] ever been to school?

Participant: Who?

Researcher: P?

Participant: Yeah, she has a school, she was in (inaudible)

Researcher: Okay, what grade is she in now?

Participant: Now P is not going to school now, since last last of last year she's not going to school, because you remember I told you about the birth problem?

Researcher: No, you didn't tell me

Participant: Oh, P she doesn't have a birth certificate that's the problem we have here

Researcher: Yeah

Participant: Yeah that's why she don't get her grant because she don't have her birth certificate so at school they said no here we want kids with birth certificates and P must stop, then P stopped, it was 2018

Researcher: Okay I see, so no birth certificate? How come?

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[10] "P" refers to the participant's child. The name of the child has been omitted in order to protect the confidentiality of the participant, and her child.

Participant: because me I don't have an ID that's why

Researcher: Ah I see!

Participant: Yes

Researcher: So that's why they are not giving the grant?

Participant: Yeah that's why

Researcher: So, what can you do?

Participant: I don't know really, because they were saying I must go do the test the paternity test

Researcher: Yeah

Participant: Yeah and its costing 3.5 and I don't have that money, I go to the social worker, she say home affairs is very tough now, you have to do the blood test results to show that this is your child, maybe you want to take someone's child because she can't talk, she's abnormal so maybe you want to take advantage of her

Researcher: Okay, I understand. So why do you not have an ID?

Participant: I lost my ID long time ago

Researcher: Okay so you will first have to make an ID before you can do anything

Participant: Yeah so, I don't have an ID yeah

Researcher: Okay I understand. Another thing I wanted to ask you is, do you have a lot of friends in your community where you are living?

Participant: No, I don't have, you mean friends? Me I don't have friends

Researcher: Can you tell me why because you seem so friendly

Participant: You know with P, you can't visit with her that's the problem. When you go like you want to go stay with the other lady, she can touch stuff and you know people are not, some of them can understand but some of the people they don't understand

Researcher: Yeah, I understand

Participant: Yeah so when I'm home I always lock my door and be at my place

Researcher: Okay, and how do you feel about that? Do you feel it's okay, or do you wish that you could visit your friends?

Participant: I wish I could visit but you know I accept it so I'm fine with it yes

Researcher: Okay

Participant: Yeah and I am used to that, so people can come to visit me, but me to other people to their place, I don't want I don't want that because you know may when you can leave there she can broke something and then because last I feel so terrible with the other lady she come here and take me then I go there with P and then she just send me SMS that she lost her money I must search P

Researcher: Aah

Participant: Mmm so I feel so terrible

Researcher: Yeah, so rather you don't go

Participant: So, I decided to stay at my place

Researcher: Okay

Participant: Because when I am here, no one can say P take something or P broke this or

Researcher: Yeah exactly, it's peace for you

Participant: Yeah

Researcher: And then another thing I wanted to know Participant, what culture do you follow, what is your culture?

Participant: Me, the culture I follow?

Researcher: Yes

Participant: Mmm I follow Zulu

Researcher: Okay so then in you know in your Zulu culture how do they say you must deal with things when life is difficult or when something is hard?

Participant: Ooh you know us you know, us people you know you can think if something is not right you must go see a you must go see a sangoma, you know a sangoma or a witch doctor?

Researcher: Yes

Participant: Yeah we believe in that

Researcher: Okay, so with P, have lots of your family or friends told you you must go see a sangoma?

Participant: Yeah and I have lost lots of money for that

Researcher: Yeah

Participant: I have lost lots of money because people can say ooh this is witchcraft this is what what ooh this is, and you can go and spend lots of money but nothing can change

Researcher: Yeah, so you don't go anymore to the sangomas or anything?

Participant: No now I don't go anymore, since I go I last go in 2019 now I don't go I'm not gonna go anymore, I'm done

Researcher: Okay so do your family and friends think maybe you are not doing the right thing or

Participant: Yeah, yeah they are thinking that I am not doing the right thing, you can hear someone say ooh you don't love her, why am I not doing this, but I have tried, I've tried

Researcher: So, your family do they think you have to keep going to the witch doctors or the sangomas or you are not doing the right thing if you don't go

Participant: Yeah, they are thinking that

Researcher: Okay, and how do you feel about that

Participant: Oh, you know these day I am okay with that, I am okay with everything because people can come here and tell you there's someone that is good sangoma they do that or she can do that or

Researcher: Mmm

Participant: But you I must use my own money, they don't give me the money

Researcher: Yeah exactly

Participant: So now I am saying no I am fine with it because I don't get enough money and then I have to take that small money to give to for that money I must buy P something to wear or I must buy her food or I must buy something for her

Researcher: So, Participant, do you think because you understand what Autism is and you know that it is actually a medical problem and not a sangoma or bewitchment or anything, do you think that is why you are so okay now and it doesn't matter what anybody tells you

Participant: Yeah, that's why I am okay now

Researcher: Okay I understand

Participant: Because I try and I try and I see no man, these things and they will be we are on groups on Facebook and everywhere you can see we can see we can face the challenges, remember I told you that I am on someone's that lady's group

Researcher: Yes, you told me on Facebook

Participant: Yeah and we saw lot of problems on there

Researcher: And then Participant, on that group, is it people from your community or everywhere all-around South Africa

Participant: Everywhere, everywhere all of South Africa we have lot of people on there

Researcher: Okay so that helps a lot

Participant: Yeah that helps a lot that one because someone can check a problem and the others can help each other. It’s only me I stay in Pretoria, you know last time there was in Durban this group I think 10 mother with children with special needs so they decided to meet before this Corona thing and with their kids and it was so nice you know they talk there they can share the problem

Researcher: And they can be friends because they understand

Participant: Yeah, they understand, even the kids they don’t face the same challenges with they can see but they are special needs kids

Researcher: Yeah

Participant: Yeah so it was very nice, I wish I could find someone near, here the others they are in Joburg and in centurion that’s where the other mothers they are

Researcher: How did it go today at the clinic?

Participant: It was okay, she se21e the doctor. The doctor was saying she’s very happy because the moment we get there they gave us chairs and she managed to sit down until we finished with the doctor.

Researcher: Okay, that’s good news.

Participant: Yeah, so the doctor was saying she’s very very happy about P’s condition, yes. So, I asked her about the money cause she must get a grant, she said I must get there on Friday so I can see the social worker because the social worker only come on Fridays. So the social worker can help me to get the (inaudible) and to get the grant for her.

Researcher: Yes, for everything she needs.

Participant: Everything she needs, yes.

Researcher: Okay so that’s really good news.

Participant: Yes, that’s very good news. That’s very good news. So, she said- and she said she’s very happy because she changed a lot.

Researcher: Yeah, so the doctor thinks she’s getting better?

Participant: Yes, that’s what she said. Like I told you that day that when she gets her medicine she can perform very well, yeah. So, the doctor was saying she’s very happy about that, about her condition.

Researcher: Okay so that’s very good, you must be feeling relieved now.

Participant: Sorry?

Researcher: I said I’m sure you must be feeling relieved now.

Participant: Yeah, I'm very relieved now, yes, I'm very relieved now and they gave us the other medication because it was nearly finishing so they gave us the other medication, but she said I must be back Friday and see the social worker.

Researcher: Okay, perfect!

Participant: Yeah, it's very perfect, I'm very happy.

Researcher: Yeah and I'm so happy as well because if you can get the grant and everything then I think it will be easier for you, you know?

Participant: Yeah, it will be very easy for me, yes it will be very easy for me.

Researcher: Okay, and what did they say about the diagnosis?

Participant: They said I must, you see where at (inaudible) 2:44 there at the Itsoseng (inaudible) yeah, they said I must go again there or to go there some of the other day to remind them because that's where my (inaudible) is there for the diagnosis.

Researcher: Okay, so you have to go back to them still.

Participant: Yeah, but I have that contact so they said if you got the airtime you can phone them and ask what.

Researcher: Yes, so maybe it's easier to call them neh.

Participant: Yeah, it's very to call them yes.

Participant: Okay.

Participant: I'm gonna call them because to go there is gonna cost money for taxi, so I'm gonna call them.

Researcher: Yeah, exactly.

Participant: So, I'm gonna call them.

Researcher: Okay, so I'm very happy to hear that. When you call (inaudible) 3:27 you must tell me what happens hey.

Participant: Okay I will. I will let you know.

Researcher: You must let me know.

Participant: Yeah, I'm gonna let you know. I will let you know again on Friday.

Researcher: Okay, perfect.

Participant: When we are there, yeah, what happened.

Researcher: Okay, no problem, thank you for letting me know hey.

Participant: Okay thank you so much.

Researcher: Participant, did you join the Facebook group by yourself and is that how you found the group with other mothers or did someone else tell you about it?

Participant: From clinic, the social worker help me

Researcher: And work and everything how is it going now?

Participant: It's okay

Researcher: Is it still a little slow now?

Participant: Yeah but I'm not working all the days, I'm working three days now but its better

Researcher: Yeah it is much better

Participant: Yeah it's better, its different than that that time I was home all the time

Researcher: It's better, at least now you are going to work

Participant: Yeah now I am working three days, Monday, Wednesday and Friday

Researcher: Okay so how are you going to work, with the taxi?

Participant: Yeah, I am going with the taxi

Researcher: Okay but you must be careful, wear your mask and everything

Participant: Yeah, I always do that

Researcher: Yeah you have to be very careful!

Participant: Yeah and protect P you know?

Researcher: Yeah, that's true, and how is your other child?

Participant: Ah he's fine this one, this one don't have any problems

Researcher: Yeah, back at school now?

Participant: No, he's still at home

Researcher: Still at home?

Participant: Yeah, they return last week then last month then that time the president talk then they say they must go home so they are home

Researcher: Ay ay ay so are you managing with them at home every day?

Participant: Oooh ay now you see now today I came from work now I have to cook ooh I'm very tired my body is killing me but I don't have any choice

Researcher: Yeah, I can imagine but you must rest and sleep early

7.3 APPENDIX C – REFLECTIVE JOURNAL

3 June 2020:
Phone call with participant for relationship building purposes:

The purpose of this phone call was to get well acquainted with the participant, and to build rapport such that she would be more willing to share her experiences openly and honestly. We exchanged general conversation ranging from what we do, what our hobbies are, how we spend our weekends and about the COVID-19 pandemic that is ongoing, among other things. Due to the COVID-19 pandemic, I was unable to conduct the interview in person hence the rapport building that may have been possible and perhaps easier in person was hampered. This phone call prior to the interview was my attempt at building rapport with the participant, and I feel that this interview ensured that the participant and I were comfortable with one another hence it did facilitate rapport.

4 June 2020:
A copy of the interview questions was sent to the participant, the participant read through the interview questions. I called the participant on this day to ensure she understood the interview questions, and to address any queries she may have had regarding the questions. This was done to ensure that the participant understood the questions, but also to ensure that she was comfortable answering the questions during the interview. I felt that this was necessary as the questions were in English and the participant is not an English first language speaker, although she is able to communicate in conversational English.

15 June 2020:
I conducted the interview with the participant telephonically. I did not expect there to be many resilience factors, but I was pleasantly surprised. I appreciated the participant’s openness and honesty regarding her community’s views on ASD and how she handles it daily, it indicated that misconceptions regarding mental health conditions are still rife, but resilience is still possible.

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7.4 APPENDIX D – ORIGINAL REQUEST FOR PARTICIPATION AND INFORMED CONSENT

REQUEST FOR PARTICIPATION AND INFORMED CONSENT

Dear Sir/Madam

I am currently registered as a student at the University of Pretoria and I am completing a Master’s programme in Educational Psychology. As part of my degree requirements I am to conduct a research study. I hereby request and invite you to participate in this study. The topic I am conducting my research on is:

“Resilience of caregivers of children with Autism Spectrum Disorder in resource-constrained contexts.”

The purpose of this study is to explore and describe the resilience of caregivers of children diagnosed with ASD in resource constrained contexts.

Your participation in the study will be valuable in contributing to greater understanding of resilience factors supporting caregivers of children with ASD in resource-constrained contexts.

The potential benefits of the study include awareness of supportive services currently available to caregivers and moreover the potential creation of supportive interventions in the future for caregivers of children with ASD in resource-

Room 4-1.7, Level 4, Building
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 1234
Fax +27 (0)12 420 5678
Email name.surname@up.ac.za
www.up.ac.za

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Lefapha la Thuto

constrained contexts.

This research study will be in the form of an audio-recorded semi-structured interview in conjunction with observations with approximately three caregivers of children with ASD in resource-constrained contexts. The interview will take place at the Itsoseng Clinic at a mutually agreed on time and date. A copy of the questions to be asked during the interview will be attached for you to review. The interview will take approximately 45 minutes and will move at your pace. After the day of the interview, there will be another meeting after the researcher has transcribed and analysed the interview. This meeting will once again be at the Itsoseng Clinic at a mutually agreed on time and date. The purpose of this meeting is for the participants to check that the transcripts and analyses by the researcher are correct.

Your identity and all personal information will not be known to anyone outside of the study. Moreover, to ensure your identity is protected, during the dissemination of results, a pseudonym will be utilised to protect your identity.

Your participation in the study is completely voluntary and you are allowed to withdraw from the study at any stage if you wish to do so, without any negative consequences. If at any stage you wish to withdraw from the study, kindly inform the researcher in a timeous manner. In the case of withdrawal, all data collected from you up until the point of withdrawal will be destroyed and therefore excluded from the overall findings of the study.

If you are willing to participate in this study, please complete the form below. Thank you for your consideration of this request.

Miss Saabirah Moosa (Researcher)	Dr Anna-Barbara du Plessis (Supervisor)
Telephone number: 0749757786	anna-barbara.duplessis@up.ac.za
Email: saabirah777@hotmail.com	

CONSENT TO PARTCIPATE IN THIS STUDY

I, ______________________________, confirm that I am willingly accepting to participate in this study and I am aware of the nature, procedure, potential benefits and possible inconveniences of participation.

Read through the below statements and if you are in agreement, please tick all the relevant blocks:

☐ I have read or had the details of the study explained to me and understand the study as it is explained in the invitation to participate.

☐ I had sufficient opportunity to ask questions and I am willing to participate in the study.

☐ I understand that my participation is voluntary and that I am free to withdraw at any time without negative consequences.

☐ I am aware that the findings of this study will be processed into a research report, journal publications and/or conference proceedings, but my identity and personal information will not be disclosed to anyone outside of this study.

☐ I agree to the audio recording of the interview.

☐ I agree to the researcher observing my non-verbal cues during the interview.

☐ I have received a copy of the informed consent agreement.

Date: ______________________

Name and surname: ______________________

Signature: ______________________

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Faculty of Education

7.5 APPENDIX E – ADAPTED REQUEST FOR PARTICIPATION AND INFORMED CONSENT

REQUEST FOR PARTICIPATION AND INFORMED CONSENT

Dear Sir/Madam

I am currently registered as a student at the University of Pretoria and I am completing a Master's programme in Educational Psychology. As part of my degree requirements I am to conduct a research study. I hereby request and invite you to participate in this study. The topic I am conducting my research on is:

"Resilience of caregivers of children with Autism Spectrum Disorder in resource-constrained contexts."

The purpose of this study is to explore and describe the resilience of caregivers of children diagnosed with ASD in resource constrained contexts.

Your participation in the study will be valuable in contributing to greater understanding of resilience factors supporting caregivers of children with ASD in resource-constrained contexts.

The potential benefits of the study include awareness of supportive services currently available to caregivers and moreover the potential creation of supportive interventions in the future for caregivers of children with ASD in resource-

Room 4-1.7, Level 4, Building
University of Pretoria, Private Bag X20
Hatfield 0028, South Africa
Tel +27 (0)12 420 1234
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Email name.surname@up.ac.za
www.up.ac.za

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constrained contexts.

This research study will be in the form of an audio-recorded semi-structured interview. The interview will take place via cell phone at an agreed-on time and date. A copy of the questions to be asked during the interview will be given to you before the interview, if so requested. The interview will take approximately 45 minutes and will move at your pace. After the day of the interview, there will be another meeting after the researcher has transcribed and analysed the interview. This meeting will once again be either telephonically, or at the Itsoseng Clinic, at an agreed-on time and date. The purpose of this meeting is for you to check that the transcripts and analyses by the researcher are correct.

Your identity and all personal information will not be known to anyone outside of the study. Moreover, to ensure your identity is protected, during the dissemination of results, a pseudonym will be utilised to protect your identity.

Your participation in the study is completely voluntary and you are allowed to withdraw from the study at any stage if you wish to do so, without any negative consequences. If at any stage you wish to withdraw from the study, kindly inform the researcher in a timeous manner. In the case of withdrawal, all data collected from you up until the point of withdrawal will be destroyed and therefore excluded from the overall findings of the study.

If you are willing to participate in this study, please complete the form below. Thank you for your consideration of this request.

Miss Saabirah Moosa (Researcher)	Dr Anna-Barbara du Plessis (Supervisor)
Telephone number: 0749757786	Email:
Email: saabirah777@hotmail.com	anna-barbara.duplessis@up.ac.za

CONSENT TO PARTCIPATE IN THIS STUDY

I, ______________________________, confirm that I am willingly accepting to participate in this study and I am aware of the nature, procedure, potential benefits and possible inconveniences of participation.

Read through the below statements and if you are in agreement, please tick all the relevant blocks:

☐ I have read or had the details of the study explained to me and understand the study as it is explained in the invitation to participate.

☐ I had sufficient opportunity to ask questions and I am willing to participate in the study.

☐ I understand that my participation is voluntary and that I am free to withdraw at any time without negative consequences.

☐ I am aware that the findings of this study will be processed into a research report, journal publications and/or conference proceedings, but my identity and personal information will not be disclosed to anyone outside of this study.

☐ I agree to the audio recording of the interview.

☐ I have received a copy of the informed consent agreement.

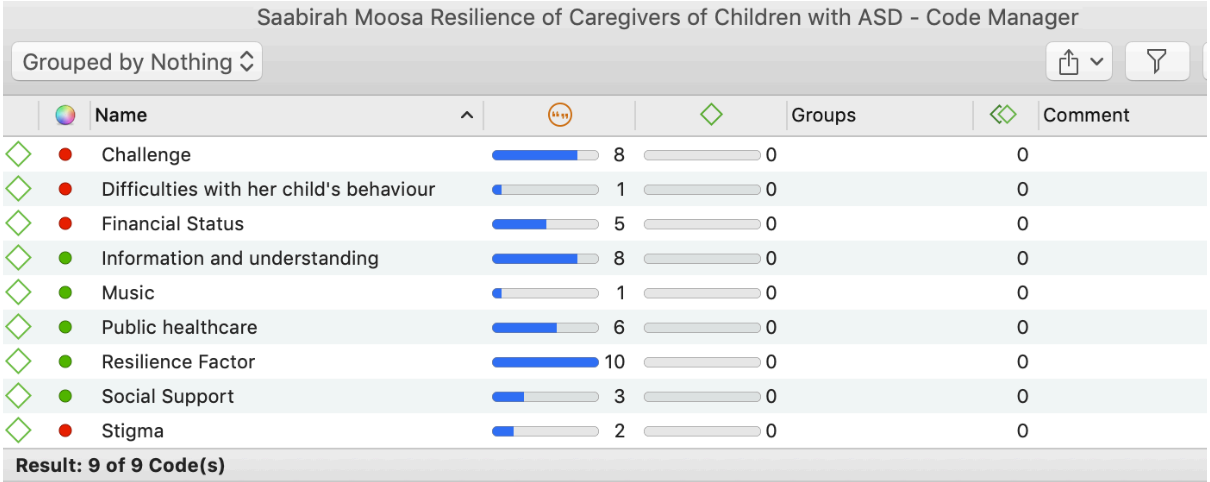
☐ It is not necessary to send me a copy of the informed consent agreement.

Date: ______________________

Name and surname: ______________________

Signature: ______________________

7.6 APPENDIX F – SCREENSHOT OF THEMES AND SUBTHEMES FROM ATLAS.TI



Saabirah Moosa Resilience of Caregivers of Children with ASD - Code Manager

		Name		◇	Groups		Comment
◇	🔴	Challenge	8	0		0	
◇	🔴	Difficulties with her child's behaviour	1	0		0	
◇	🔴	Financial Status	5	0		0	
◇	🟢	Information and understanding	8	0		0	
◇	🟢	Music	1	0		0	
◇	🟢	Public healthcare	6	0		0	
◇	🟢	Resilience Factor	10	0		0	
◇	🟢	Social Support	3	0		0	
◇	🔴	Stigma	2	0		0	

Result: 9 of 9 Code(s)