

**Exploring parents of autistic children's use of
respite care at a private facility in South Africa**

Nandi Robinson

2018

**Exploring parents of autistic children's use of respite care at a
private facility in South Africa**

by

Nandi Robinson

Submitted in partial fulfilment of the requirements for the degree

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(Educational Psychology)

Department of Educational Psychology
Faculty of Education
University of Pretoria

SUPERVISOR

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**PRETORIA
OCTOBER 2018**

Dedication

I dedicate this research to the promotion of public awareness of autistic spectrum disorder and a better understanding of the challenges faced by the parents of children with autistic spectrum disorder, and how the use of private respite care can assist in the management of this disorder.

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Acknowledgements

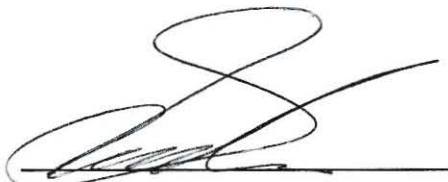
I would like to express my sincere gratitude to the following people without whose support I would not have been able to reach this milestone in my life:

- ❖ My mom, dad and friends, who have supported me throughout the completion of this study.
- ❖ Dr A. H. du Plessis, research supervisor, for his invaluable advice, guidance and inspiring motivation at difficult times during the research process.
- ❖ My language editor, Rika Opper.
- ❖ My technical editor, Estelle Botha.
- ❖ Last, but not least, my fiancé, Rory Atteridge, whose unfailing support and encouragement enabled me to complete this study.

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Declaration of Originality

I, Nandi Robinson (student number: 10252763), declare that the dissertation, 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.

A handwritten signature in black ink, appearing to read 'Nandi Robinson', written over a horizontal line.

Nandi Robinson

October 2018

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Ethical Clearance Certificate



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CLEARANCE CERTIFICATE	CLEARANCE NUMBER: EP 17/03/01
DEGREE AND PROJECT	M.Ed Parents of autistic children's use of respite care at a private facility in South Africa
INVESTIGATOR	Ms Nandi Robinson
DEPARTMENT	Educational Psychology
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CHAIRPERSON OF ETHICS COMMITTEE: Prof Liesel Ebersöhn

A handwritten signature in black ink, appearing to read 'Bronwynne Swarts'.

CC Ms Bronwynne Swarts
Dr Alfred du Plessis

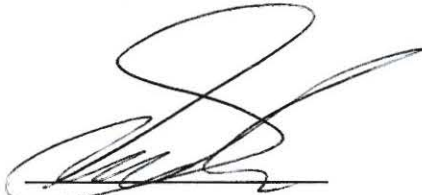
This Ethics Clearance Certificate should be read in conjunction with the Integrated Declaration Form (IDF) which specifies details regarding:

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

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Ethics Statement

The author, whose name appears on the title page of this dissertation, has obtained, for the research described in this work, the applicable research ethics approval. The author declares that she has observed the ethical standards required in terms of the University of Pretoria's *Code of ethics for researchers and the Policy guidelines for responsible research*.



Nandi Robinson

October 2018

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Abstract

Exploring parents of autistic children's use of respite care at a private facility in South Africa

by

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Supervisor: Dr Alfred Haupt du Plessis

Degree: M. Ed. (Educational Psychology)

The current incidence of autism in South Africa is 1:88 and is gradually increasing (Lindenberg, 2013). A number of South African schools that cater for learners with autistic spectrum disorder (ASD) have also emerged and aim to address the increasing demand for the assistance of both the children diagnosed with ASD and their families (American Psychiatric Association, 2013; Lindenberg, 2013).

By definition, respite care is an intermittent service offered to the parents of a chronically ill child to substitute them, when they are in need of a break, from their 24/7 responsibility in caring for their child (Neufeld, Query, & Drummond, 2001). Current literature alludes to difficulties experienced by children with ASD with regards to their psychological, emotional and social functions, which suggests that there may be a very real need for respite care (Benderix, Nordström, & Sivberg, 2006; Desai, Divan, Wertz, & Patel, 2012; Molteno, Molteno, Finchilescu, & Dawes, 2001; Pengelly, Rogers, & Evans, 2009; Whitaker & Hirst, 2002; Woodgate, Ateah, & Secco, 2008).

The purpose of the current study is to explore the unique experiences of parents of children diagnosed with ASD who utilise private respite care services in South Africa. Primary research question: What are the experiences of South African parents of children diagnosed with ASD who utilise private respite care in South Africa? In conducting this study, a qualitative case study method and a research design, that utilised interpretivism as paradigm, was used to capture the unique experiences of parents utilising private respite care for their child with ASD. The

case study was confined to parents who had recently utilised respite care at a specific private respite care centre in South Africa. The data collection strategy encompassed semi-structured interviews in which three parents, representing three separate parenting styles, were interviewed. Measures were taken to ensure the quality of the data and ethically responsible research practice.

Key words

- Autism
- Autistic spectrum disorder (ASD)
- Experiences
- Respite care

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Declaration – Language Editor

EDITOR'S STATEMENT

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TO WHOM IT MAY CONCERN

Herewith I, FJ Opper, confirm that I undertook the language editing of
Ms Nandi Robinson's dissertation titled:

**Parents of autistic children's use of respite care at a private facility in
South Africa**



17 September 2018

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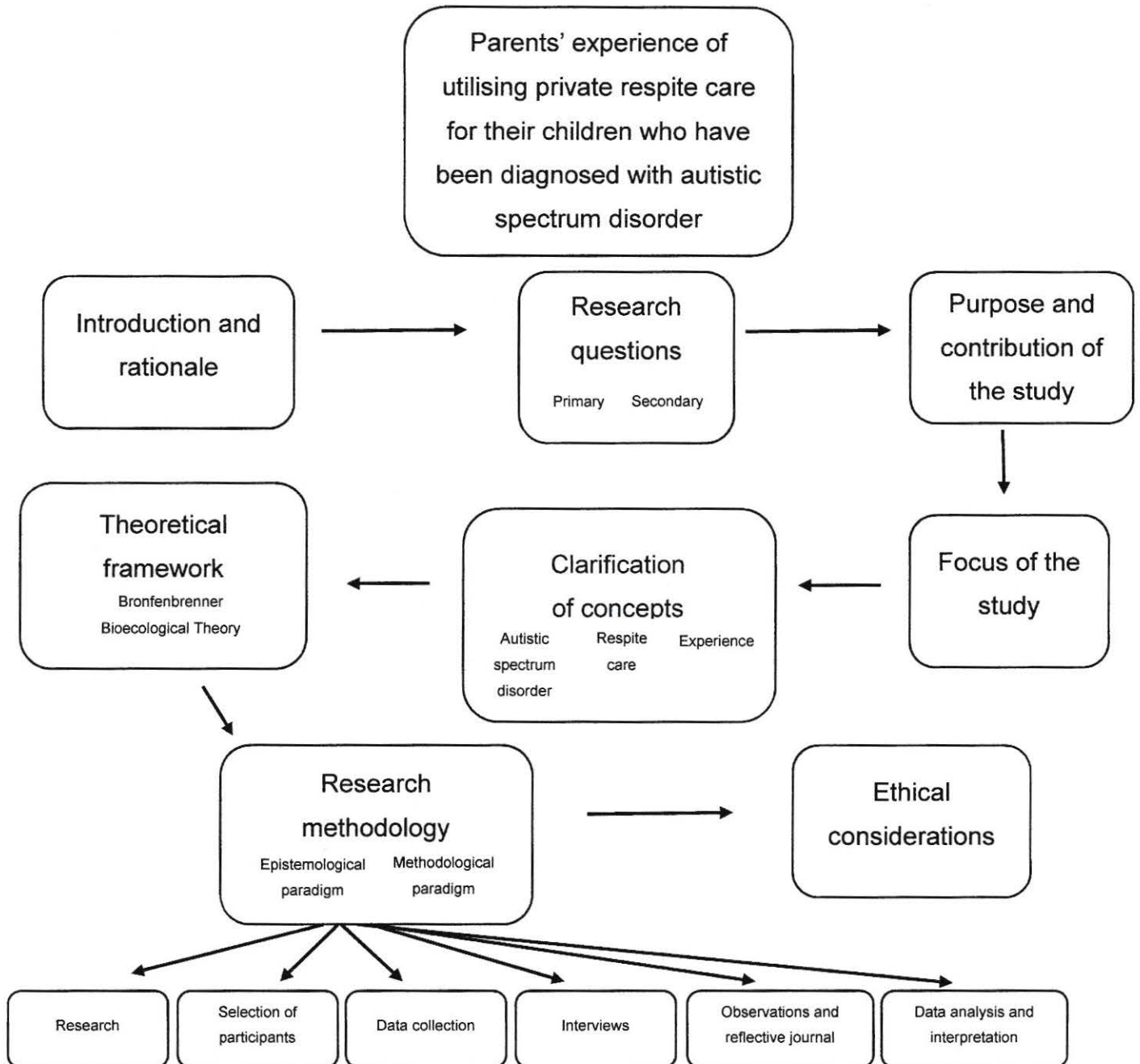
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CHAPTER 1



Chapter 1

General Orientation

1.1 INTRODUCTION AND RATIONALE

Despite the limited knowledge of many medical practitioners regarding the precise diagnosis of this neural developmental disorder (Bateman, 2013), ASD is becoming an increasingly familiar condition among South Africans. In 2013, at least 1 in every 88 South African children had ASD and the diagnosis of ASD was believed to be gradually increasing (Lindenberg, 2013). This could be due to the increased exposure given to ASD in the media and the consequent increasing awareness of the symptoms associated with this disorder. Television series, such as *Touch* and *The Good Doctor*, as well as several films and books also deal with the journey of children diagnosed with ASD (Applied Behavioural Analysis Programs Guide, 2017; Kring, 2012; Shore, 2017). Practitioners have become more aware of the need to accurately identify the symptoms associated with such a diagnosis and have therefore become more competent in using the diagnostic guidelines as specified in the Diagnostic and Statistical Manual of Mental Disorders – Fifth Edition (DSM – V), in order to make an accurate clinical diagnosis (American Psychiatric Association, 2013; Autism South Africa, n.d.).

A number of South African schools and facilities that cater for learners with ASD have been established to address the increasing demand for assistance for both the children diagnosed with ASD and their families (Hoefman, Payakachat, Van Exel, Kuhlthau, Kovacs, Pyne and Tilford, 2014). The best-known facilities of this kind, in Gauteng, include the Ernie Els Centre for Autism, the Amazing K Early Intervention Centre, UNICA School for Autism, Shalom, Lethabo Le Khutso – Autistic Haven, Key School, the Johannesburg Hospital School for Autism, the Vera School for Autistic Learners, Little Leaps, L.U.C.C.A. Support and Care Centre, Star Academy and The Sunshine Centre (Special Kids, 2016). These facilities, which include both government-sponsored and private care facilities, all cater for the unique needs of children with ASD.

Respite care is, by definition, an intermittent service offered to the parents of chronically ill children (Harper, Dyches, Harper, Roper & South, 2013). This service allows parents an opportunity to occasionally break away from the full-time

responsibility of caring for their child with special-needs (Neufeld, Query and Drummond, 2001). To date, research on respite care within the South African context has been associated mainly with catering for the needs of people with Human Immunodeficiency Virus or Acquired Immune Deficiency Syndrome (HIV/AIDS) (Mangena-Netshikweta, Tshitangano, Mudhovozi, & Tshililo, 2014; Mkwinda, Lekalakala-Mokgele, & Sengane, 2015), people with dementia (Gurayah, 2015; Kraijo, Brouwer, De Leeuw, Schrijvers, & Van Exel, 2012), and individuals diagnosed with a severe mental illness (Meiring, 2011). However, respite care may play an important role in the context of children with ASD since current literature alludes to difficulties regarding their psychological, emotional and social functioning (Benderix, Nordström and Sivberg, 2006; Desai, Divan, Wertz and Patel, 2012; Molteno, Molteno, Finchilescu and Dawes, 2001; Pengelly, Rogers and Evans, 2009; Whitaker and Hirst, 2002; Woodgate, Ateah and Secco, 2008).

The current study sought to explore the lived experiences of parents of children with ASD who have utilised private respite care within the South African context. Although children are the ones presenting with the varying levels of emotional, psychological and behavioural symptoms associated with this diagnosis, the parents are usually the ones who have to change and adapt their lives, to some extent, in order to accommodate and care for their children (Hoefman et al., 2014).

In other countries, such as Canada and the United States of America, significant research has been conducted on the psychological, emotional and social effects of having a child diagnosed with ASD. Both individuals and families who have made use of respite care services, offered at various facilities, have expressed their satisfaction with those services (Benderix et al., 2006; Desai et al., 2012; Molteno et al, 2001; Pengelly et al, 2009; Whitaker and Hirst, 2002; Woodgate et al., 2008). To date, the effects of utilising respite care within the South African context have not yet been sufficiently reported. This could be due to the lack of research done in this field and the limited academic literature available on respite care in this unique context. This apparent gap in the South African academic literature has provided an opportunity to undertake the current research and make a contribution to this field.

In 2012, I was employed as a manager at a private respite care facility. It was this exposure to the unique needs of both parents and children in the ASD community that ignited my interest in undertaking a thorough investigation of this service. The parents' needs, such as being assured that their children's most basic needs will be

met, that the caregivers will provide their children with the same kind of love and affection experienced at home, safety and security needs, as well as the provision of the most effective stimulating activities needed for the development of their child with ASD, sparked my interest in this exclusive service. Through my interactions and discussions with role players within this context, such as the children, parents and caregivers, the researcher became aware of the potential value and possible challenges associated with the provision of such a care facility to cater for the needs of children with ASD. This study was therefore initiated by the researcher due to her personal interest in the possible role of respite care in this field, and also due to the hiatuses that exist in literature regarding this important service in the ASD context.

1.2 RESEARCH QUESTIONS

1.2.1 PRIMARY RESEARCH QUESTION

This research study was guided by the following primary research question: How do the parents of children who have been diagnosed with autistic spectrum disorder experience the utilisation of private respite care in South Africa?

1.2.2 SECONDARY RESEARCH QUESTIONS

In addressing the primary research question, the following secondary questions were explored:

- ❖ What are the expectations of parents of children diagnosed with autistic spectrum disorder when they utilise respite care at a private facility in South Africa?
- ❖ To what extent does respite care at a private facility in South Africa meet the needs of parents with children who have been diagnosed with autistic spectrum disorder?
- ❖ How does respite care benefit (or does not benefit) parents with children diagnosed with autistic spectrum disorder?
- ❖ How can respite care at a private facility in South Africa be improved, according to parents with children diagnosed with autistic spectrum disorder?

1.3 PURPOSE AND CONTRIBUTION OF THE STUDY

The purpose of the current study was to explore the unique experiences of parents with children diagnosed with ASD when they make use of private respite care services within the South African context. Although a vast amount of research has been devoted to the psycho-social effects of having a child diagnosed with ASD on the family system, very little research has been conducted on the use of respite care as a means of maintaining and managing the needs of a child with ASD, and as a result we have little insight into the experiences of parents who have made use of such care offered in South Africa.

This research could contribute towards our understanding of parents' use of private respite care for children with ASD and may lead to further research dealing with children with other neural developmental disorders. Insight into the experiences of the parents of children affected by such disorders may also contribute towards improving respite care, and may influence policy with regard to the delivery of such a service. Respite care facility workers, managers and training staff in such facilities may also benefit from an improved understanding of the unique experiences of the parents who make use of such facilities.

1.4 FOCUS OF THE STUDY

During the study, I focused on the experiences of parents whose children had been diagnosed with ASD and their utilisation of private respite care for their children. The emphasis of this research was on the description of those experiences in order to enhance our understanding of the parents' experiences which, as pointed out earlier, is important in the light of the fact that this is an under-researched domain and for the potential benefit of role players involved in this field of care.

1.5 CONCEPT CLARIFICATION

The following key concepts are defined to enhance the clarity of my research:

1.5.1 AUTISTIC SPECTRUM DISORDER

Autistic spectrum disorder (ASD) is a neural developmental disorder pertaining to impairment in respect of growth and development in the brain or central nervous system (American Psychiatric Association, 2013). ASD is classified as a "pervasive

developmental disorder as the nature of the disorder is typically diagnosed within the first three years of an individual's life" (American Psychiatric Association, 2013, p. 50). Early diagnosis is likely to be dependent on the parents' ability to notice their child's atypical behaviour and their decision to seek a professional opinion. ASD is associated with deficits in social communication and atypical behaviour, and is heterogeneous in nature due to its unique presentation in each individual (Howlin & Charman, 2011; Lauritsen, 2013; Lord, Cook, Leventhal, & Amaral, 2000). In terms of presentation, the occurrence of ASD in a person will therefore range from mild to severe. ASD is diagnosed on the basis of meeting certain requirements as stipulated in the DSM-V (American Psychiatric Association, 2013). The DSM-V diagnostic criteria for ASD are provided in Appendix E.

1.5.2 RESPITE CARE

Respite care is a service offered to the parents of children with special-needs to enable them to enjoy a 'short break' from their obligations in meeting their child's special-needs (Harper et al., 2013). This unique service offers support, provided by the caregivers at a facility, to parents with children who have ASD. For the purpose of this study, potential participants were selected from parents who have used the services of a private respite care facility in Midrand. This facility is private in that it is not state owned and parents are liable for the full payment of the services offered. The facility offers residential care, which means that some children live there permanently. The facility also offers respite care to parents who seek to use the service intermittently when they are in need of a break. Participants were selected based only on their use of respite care in order to fulfil the purpose of exploring the experiences of parents who had used this service when they needed a break.

1.5.3 EXPERIENCES

Experience can be defined as an act of involvement whereby a person encounters subjective feelings and gains knowledge and skills in a specific situation (VandenBos, 2007). The current study aimed to explore the skills and knowledge acquired by parents of children with ASD with a view of elaborating on their experience of utilising private respite care services. This study looks at parents' decision to make use of respite care, the needs that prompted their use of this service and how they either benefited or did not benefit from the experience,

depending on how it was experienced socially, emotionally, educationally and behaviourally.

1.6 THEORETICAL FRAMEWORK

The theoretical framework upon which the current study was based is Bronfenbrenner's bioecological theory (1994), according to which the interaction between individuals and their environments has significant value and should be considered in relation to their unique environments. This framework is used as it signifies the importance of how the parent of a child diagnosed with ASD is influenced by their environment. The ecological environment encompasses five layers of systems that surround the individual and contribute interactively to his/her development (Bronfenbrenner, 1994).

The innermost layer is the Microsystem, which involves the psychological effects that impact directly on the parents of children diagnosed with ASD (Bronfenbrenner, 1994). In this study, the parents were the primary focus and an in-depth look was taken at how they experienced raising a child diagnosed with ASD, how it affected them physically, socially and psychologically, and how these experiences had influenced their decision to make use of private respite care.

The second layer surrounding the Microsystem is the Exosystem (Bronfenbrenner, 1994), which is characterised by its specific relationships within the Microsystem. In the case of this study, the Exosystem includes the difficulties that parents of children with ASD experience in maintaining their occupation.

The third layer, which is the Mesosystem, relates to the influence of the relationships that parents establish with people in their relatively close community (Bronfenbrenner, 1994). These relationships include interactions with members of the public, such as health care workers, and institutions such as schools and various private practice therapies, for instance speech and language therapy, occupational therapy and physiotherapy.

The fourth layer is the Macrosystem, which makes specific reference to policies and government or international decisions that influence the other layers (Bronfenbrenner, 1994). The White Paper, the Mental Health Act and the National Mental Health Policy Framework all emphasise the rights of individuals with disabilities and confirm that they will have the same rights and responsibilities as

other South African citizens (Department of Health, Republic of South Africa, 2013; Department of Social Development, Republic of South Africa, 2016; The Presidency, Republic of South Africa, 2002).

The last system is the Chronosystem, which depicts the life of an individual over his or her lifespan (Bronfenbrenner, 1994; Swick & Williams, 2006). In this system, the primary focus is the lifespan of the parents and their experiences while raising their child with ASD. Central to this theory is the individual and how interactions surrounding him or her affect his or her development.

The following section provides a summative overview of the methodology used to inform the research. An in-depth discussion of the methodology follows in Chapter 3.

1.7 RESEARCH METHODOLOGY

1.7.1 EPISTEMOLOGICAL PARADIGM (INTERPRETIVISM)

As part of the epistemological paradigm, an interpretivist world-view was utilised and qualitative research methodologies were employed to find evidence to support the purpose of the study. The ontology of interpretivism assumes that reality is based on an individual's subjective experience in a natural context, and thus the paradigm asserts that multiple realities exist (Gephart, 1999; Neuman, 2006). The purpose of the current study was to explore the unique experiences of the parents of children diagnosed with ASD who had used, or are currently still making use of private respite care.

1.7.2 METHODOLOGICAL PARADIGM

A qualitative methodological paradigm was used for this study to capture the unique experiences of the participants, as it was considered to be best for exploring such experiences (Creswell, 2014; Maree, 2013). Qualitative methodology focuses on obtaining data from participants by using, for example, interviews, photographs and document analysis (Creswell, 2013). A qualitative approach assisted in gaining insight into the experiences, feelings and multiple realities of parents of children with ASD who make use of private respite care in South Africa (Basit, 2010; Creswell, 2014; Maree, 2013).

The researcher based her study on a qualitative methodological paradigm due to the advantages offered by this methodology. The main aim of this study was to gain insight into the unique experiences of parents of children with ASD in South Africa, by conducting interviews with the selected parents to obtain rich information and observations.

1.7.3 RESEARCH DESIGN

Since limited research is available on the use of private respite care in South Africa, an instrumental case study design was used to gain insight into the subjective experiences of parents who have used or are currently using this unique service (Creswell, 2013; O'Donoghue, 2007). Three parents who all used the same respite care facility, Facility X, even though they represented three different parenting systems, were interviewed. Of particular interest in this study was to determine whether utilising respite care in a private facility was socially, emotionally and psychologically beneficial to the parents of children diagnosed with ASD. Inclusion and exclusion criteria were implemented prior to the start of the study and were adhered to in accordance with the ethical guidelines in the field of psychology, as stipulated by Allan (2001).

1.7.4 SELECTION OF PARTICIPANTS

Parents who met the criteria for inclusion were identified by Facility X (see Table 1.1). Potential participants were then approached and informed on the purpose of this research study, by making use of the Research Information Document (Appendix B). Once potential participants had been selected, they were approached and provided with an informed consent form (Appendix A), which they had to sign to confirm their voluntary participation. Three parents presenting three separate parenting systems were selected.

The process of selecting participants will be discussed in more detail in Chapter 3.

Table 1.1: Inclusion and exclusion criteria

Inclusion criteria	Exclusion criteria
Parents who are currently using private respite care, or have used it in the past 12 months	Parents suffering from a mental or other illness

Ability to communicate in English	Not being proficient in English
Having a child who has been diagnosed with ASD	Having a child diagnosed with a co-morbid condition

1.7.5 DATA COLLECTION

To capture the unique experiences of parents of children with ASD who utilise private respite care within the South African context, this study made use of the following data collection strategies: recordings, interviews, observations and a reflective journal.

1.7.5.1 Interviews

In this qualitative study, interviews were used for their observational and semi-structured benefits (Maree, 2013). The questions asked during the interview can be viewed in the semi-structured interview protocol (Appendix D). The participants were asked to take part in a semi-structured interview, that required them to share their experience of utilising private respite care for their child with ASD. Each interview took approximately two hours, with the actual duration dependent on the information obtained and whether additional prompting was required. Once the data had been analysed, the participants were also involved in a process of member checking for quality control purposes.

1.7.5.2 Observation and reflective journal

While conducting the semi-structured interview, I was both a participant and an observer (Brinkmann & Kvale, 2015). During the recorded interviews, I paid specific attention to the non-verbal behaviour of the participants, which contributed to my understanding of their experiences. Such observations were often confirmed by asking additional questions to clarify what had been observed. The observational data enhanced the quality of the interview and provided rich information for this study. A process of member checking was used to clarify concepts and ensure that the data collected for the study accurately reflected the data provided by the participants (Maree, 2013). To remain cognisant of my previous role as a manager at Facility X, I made use of a reflective journal so as to avoid researcher bias while reflecting on the questions and the answers obtained during the study and their possible further interpretation (Creswell, 2014).

1.7.6 DATA ANALYSIS AND INTERPRETATION

In the case of a qualitative study, it is imperative to understand the findings of the study in order for the results to make both an academic and a personal contribution (Basit, 2010). Since in the current study the main purpose was to explore the experiences of parents who utilise private respite care in a South African context, a thematic analysis was the most suitable for the interpretation of the information obtained (Creswell, 2014).

Steps in conducting research, as explained by Creswell (2013), are discussed in detail in Chapter 3, and the limitations of this study are dealt with in Chapter 5.

1.8 ETHICAL CONSIDERATIONS

The research was approved by the Ethics Committees of both the Faculty of Education and the Faculty of Health Sciences. All research-related activities were performed in line with the ethical guidelines for psychologists (Allan, 2001) and included the principles of informed consent, protection from harm, privacy and confidentiality.

1.9 DIVISION OF CHAPTERS

CHAPTER 2: A THEORETICAL FRAMEWORK FOR THE USE OF RESPITE CARE AT A PRIVATE SOUTH AFRICAN FACILITY BY THE PARENTS OF CHILDREN WITH ASD

This chapter starts with a definition of ASD, which is followed by a discussion of the clinical features and diagnosis, as well as the aetiology of ASD. Research relating to the experiences of parents of children diagnosed with ASD, intervention strategies, international respite care and the need for private respite care in South Africa are also explored.

CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY USED TO EXPLORE HOW THE PARENTS OF CHILDREN WITH ASD USE RESPITE CARE AT A PRIVATE FACILITY IN SOUTH AFRICA

This chapter deals with the epistemological and methodological paradigm used, the research design, defining the case study, data collection methods, the management and analysis of data, quality criteria, ethical considerations and concluding comments.

CHAPTER 4: RESEARCH RESULTS AND LITERATURE CONTROL

This chapter informs the reader of what was discovered during the research and relates the current research to the findings in existing literature.

CHAPTER 5: THEORETICAL FRAMEWORK, CONCLUSIONS AND RECOMMENDATIONS

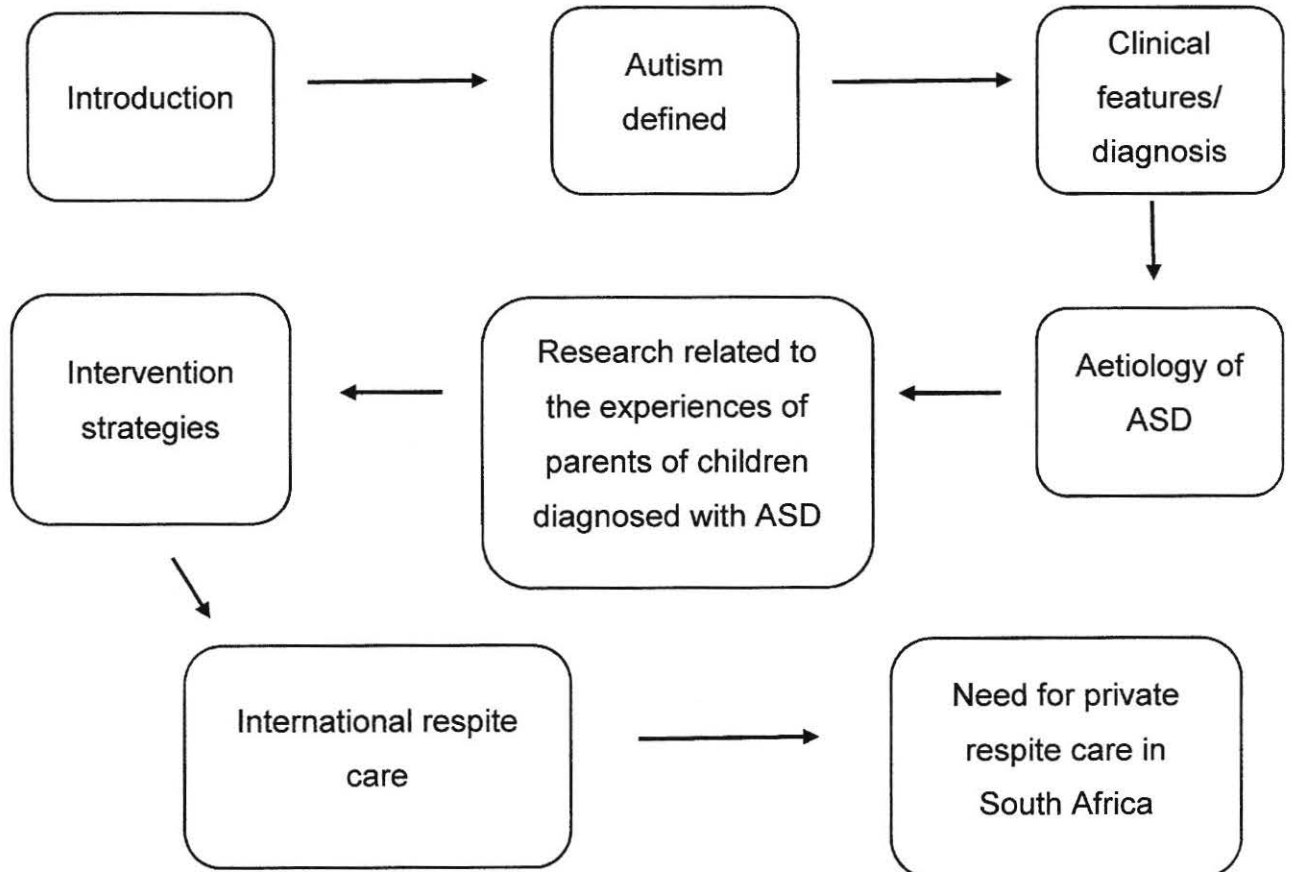
This chapter informs the reader of the findings of my research and relates it to the theoretical framework that was used to underpin the current study. It also summarises the research conclusions and provides recommendations for future studies.

1.10 CONCLUSION

A concluding paragraph is provided in which the purpose of the study is addressed on the basis of how the current study can contribute to further knowledge on children with ASD and how parents of children with ASD experience private respite care in South Africa.

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CHAPTER 2



Chapter 2

A Theoretical Framework for Parents of Children with ASD's Use of Respite Care at a Private Facility in South Africa

2.1 INTRODUCTION

This chapter provides an overview of literature related to this research study in exploring parents of children diagnosed with ASD and how they experience the service of private respite care in South Africa. It defines ASD and describes the clinical features as well as etiology associated with this disorder. Literature dealing with the experiences of parents of children diagnosed with ASD, intervention strategies, international respite care and the need for private respite care in South Africa was explored.

2.2 AUTISM DEFINED

Autism spectrum disorder (ASD) can be defined as a neural developmental disorder in which an individual can present with various symptoms classified across a spectrum (Autism Speaks, 2017). Prior to the publication of the DSM-V, ASD was diagnosed as a 'pervasive developmental disorder,' which included patients who did not meet the full criteria for a diagnosis of ASD. This was taken into consideration when the DSM-V was published in 2013 and ASD was categorised under the broad category of neural developmental disorders. This broad category has since included other disorders, such as Asperger's syndrome, childhood disintegrative disorder and pervasive developmental disorders not otherwise specified (American Psychiatric Association, 2013; Autism Speaks, 2017; National Institute of Neurological Disorders and Stroke [NINDS], 2017).

ASD is currently diagnosed by using specifiers, which allows for the identification of intellectual impairment, if there is any known additional condition associated with another disorder, as well as additional factors that contribute to the identification of this disorder, for example: problems with social interaction and challenges in communication (American Psychiatric Association, 2013). ASD is characterised by a wide range of symptoms, skills and levels of severity in terms of being a disability that is typically diagnosed on a spectrum (American Psychiatric Association, 2013; Autism Speaks, 2017). Based on the specifiers identified, clinicians need to

ascertain the level of severity according to the symptoms presented by an individual. These range from Level 1, being mild, characterised by the individual requiring some support, to a Level 3 severity, which is characterised by being classified on the severe end of the spectrum and being identified as requiring extensive support (American Psychiatric Association; 2013).

2.3 CLINICAL FEATURES/DIAGNOSIS

The development of ASD in individuals usually follows a common developmental pathway (American Psychiatric Association, 2013). In order to explore parents' experience of having a child diagnosed with ASD, it is important to unpack the specific criteria, as stipulated in the DSM-V, that warrant a formal diagnosis. The specific criteria for making this diagnosis, according to the DSM-V, can be found in Appendix E.

These criteria include a reference to ASD being a neural developmental disorder, which implies that the symptoms proposed in the DSM-V need to have manifested in the early developmental years of a child's life (American Psychiatric Association, 2013). The parents of a child who presents with atypical behaviour need to be aware of their child's challenges. However, parents might not become aware of their child's diagnosis until societal demands place constraints on the child's ability to conform to societal norms (Lord et al., 2000; Woodgate et al., 2008).

According to the DSM-V, a child who presents with specific characteristics can be diagnosed with ASD (American Psychiatric Association, 2013). However, due to the nature and relatively normal development of a child during the first 12 to 24 months, the assessment process and diagnosis of ASD is often delayed (Autism Speaks, 2017; Carr, 2006). Initial observations by parents include, observing that their child experiences difficulties with regard to social communication and social interactions, which is accompanied by developmental delays that are inconsistent with the child's chronological age. As the child's relatively abnormal development becomes a concern for the parents, they often consult the internet, their social network, a paediatrician or a general practitioner for more information (Lord, 1995; Osterling, Dawson, & Munson, 2002). These observations allow parents and practitioners the opportunity for an initial screening and further investigation towards a probable diagnosis.

A child presenting with symptoms of ASD would be initially screened by a practitioner who should be familiar with the diagnostic criteria for ASD. Once a probable diagnosis of ASD has been made, the child would benefit most from engaging with a multi-disciplinary team. This team comprises of various practitioners, such as a clinical psychologist, an educational psychologist, an occupational therapist, a speech and language therapist and an audiologist. These practitioners can collaborate with the parents and can create a profile of the presenting symptoms as well as ascertain whether the child meets the criteria of a formal diagnosis of ASD (Carr, 2006). The assessment process is essential for a formal diagnosis.

Since children normally develop in accordance with their chronological age, atypical interactions and developmental delays are noted (Carr, 2006). Typical features associated with the diagnosis of ASD is the presence of odd and repetitive behaviours and not engaging in typical play activities, especially with other children (Alli, Abdoola, & Mupawose, 2015; Bateman, 2013). The DSM-IV criteria makes reference to children experiencing “deficits in social communication and social interactions” (American Psychiatric Association, 2013, p. 50). This presents with challenges in “communicating with the family of the child diagnosed with ASD, as well as with society as a whole, in which communication is the primary mode of instruction and interaction” (Woodgate et al., 2008, p. 1077).

Children diagnosed with ASD also present with restricted and repetitive patterns of behaviour (American Psychiatric Association, 2013) that are confined by routine and structure. In their home environments, children often play with the same toys and adhere to stringent routines (Woodgate et al., 2008). When these routines are not adhered to, it often results in emotional meltdowns for the child, which places strain on the family to conform to the child’s routines (Lord et al., 2000; Woodgate et al., 2008). In South Africa, ASD has been commonly associated with co-morbid disorders such as intellectual disability, epilepsy and oculocutaneous albinism (American Psychiatric Association, 2013).

Clinicians report that these atypical interactions and developmental delays are red flags to the diagnosis of ASD and typically recommend further assessments in which the type, frequency and intensity of these forms of behaviour are analysed in order to warrant a clinical diagnosis (American Psychiatric Association, 2013; Bateman, 2013; Benderix et al., 2006). When diagnosing ASD, various informal and formal

assessments can be administered in order to obtain a complete analysis of the child's presenting symptoms. The most frequently used informal assessments include interviews with parents, caregivers and teachers (American Psychiatric Association, 2013; De Bildt et al., 2004; Dietz, Swinkels, Van Daalen, Van Engeland, & Buitelaar, 2006). Clinicians often combine formal and informal measures when exploring a possible diagnosis of ASD. One formal measure that is frequently used is the Childhood Autism Rating Scale, Second Edition (CARS-2) (Stevanovic, Vicari, & Fucà, n.d.).

Literature sources that deal with ASD and the DSM-V state that there is a possibility for a differential diagnosis in which various disorders mimic the symptoms of ASD (American Psychiatric Association, 2013; Autism Speaks, 2017). Disorders such as Rett's syndrome, language and social communication disorders, selective mutism, intellectual disabilities without ASD, stereotypical movement disorder, attention-deficit/hyperactivity disorder (ADHD) and schizophrenia provide alternatives to the diagnosis of ASD when certain characteristics presented by the child can be more convincingly associated with an alternative disorder.

With reference to the current study, parents may become aware of atypical behaviour from an early stage in their child's development, but will need the assistance of medical practitioners to distinguish between the symptoms of ASD and those of other disorders characterised by similar symptoms (American Psychiatric Association, 2013; Autism Speaks, 2017).

According to the psychodynamic theory, it is important to involve the parents in both the assessment and the intervention process to help them accept their child's diagnosis, understand it and play a vital role in the planning, maintenance and sustainability of therapeutic interventions. Interviews with parents would provide significant information on the family's history and the child's symptoms, routine and challenging behaviour. Reports obtained from parents and other caregivers, for example teachers, would add to the evaluation process.

2.4 AETIOLOGY OF ASD

The aetiology of ASD is concerned with the origin of ASD and various factors that contribute to the identification of the causes of ASD in individuals (American Psychiatric Association, 2013).

Controversial research provides probable causes of ASD in individuals and the researchers involved have associated both hereditary and environmental factors with the presentation of this disorder in individuals (Autism Speaks, 2017; NINDS, 2017). Research provides evidence connected to the aetiological factors that could lead to the presence of ASD symptoms (Autism Speaks, 2017). Bakare and Munir (2011) associate conditions such as post-encephalitic infections, genetic and auto-immune factors, and vitamin D deficiencies with aetiological factors contributing to ASD. While this does not suggest that every individual who has these conditions will be diagnosed with ASD, evidence exists that supports the notion that individuals who have these conditions could be at risk for being diagnosed with ASD, if they present with the additional criteria associated with this diagnosis, as stipulated in the DSM-V (American Psychiatric Association, 2013'Autism Speaks, 2017; Bakare & Munir, 2011).

Theories devoted to explaining the aetiology of ASD include the psychodynamic, biological and cognitive theories, which lend themselves to enhancing our understanding and knowledge of how ASD can be better explained (Howlin & Charman, 2011; Lang, Hancock, & Singh, 2016; Mayes, Fonagy, & Target, 2007). Each of these theories will be elaborated on and discussed in terms of its relevance to current knowledge.

The psychodynamic theory is based on the idea that the upbringing of children in a hostile home causes a child to present with symptoms that replicate those of a child with ASD (Bettelheim, 1967). This theory, also known as the theory of 'refrigerator parents', was based on the idea that the parents subconsciously reject their children and thus appear cold (Bettelheim, 1967, p. 510). This theory was underpinned by Bruno Bettelheim, a concentration camp survivor, who based his theory on his experience of social withdrawal, anxiety, depression and stereotypical behaviour that manifested as a result of having experienced trauma (Bettelheim, 1967). Bettelheim observed the behaviour presented by children diagnosed with ASD and assimilated his experience with that of other children. Carefully controlled studies carried out by Koegel, Schreibman, O'Neill, and Burke (1983) refuted the notion that inadequate parenting results in symptoms replicating those of ASD.

This theory is therefore not scientifically supported. However, the influence of social perception cannot be ignored and if communities support this theory it may place unfounded pressure on the parental system (Koegel et al., 1983). The additional

stress on parents who feel responsible for their child's disorder may lead to subsequent psychological guilt and stigmatisation (Autism Speaks, 2017; Koegel et al., 1983). Within the context of respite care, the very important aspect of psychological development is optimised by providing support to parents in order to regain the energy needed to sustain a beneficial relationship with their child.

Bernard Rimland (1964) offered a biological theory on the aetiology of ASD. He proposed that ASD is not caused by inadequate parenting, but rather by the use of certain vaccines (Cohmer, 2014; Rimland, 1964). Immunisation against measles, mumps and rubella (MMR) has also led to a controversial debate on whether the manifestation of ASD can be associated with the administration of these vaccines (Johnstone & MRC Autism Review Group, 2001). Although currently the evidence to support this theory is insufficient, many parents remain concerned about the possibility that these vaccines may cause ASD (Johnstone & MRC Autism Review Group, 2001; Volkmar, Lord, Bailey, Schultz, & Klin, 2004). Once again, social discourse may have a negative impact on parents' subjective well-being. This is where respite care may play a role in providing emotional support and guidance to parents of children diagnosed with ASD.

Additional knowledge on genetic factors, intrauterine environmental factors, perinatal complications, neuroanatomical factors, neurochemical factors and physiological factors, or a combination of these factors, have shed light on the possible aetiology of ASD (Carr, 2006). As a neural developmental disorder, ASD has been associated with the functioning of chemical connections between brain neurons or synapses (NINDS, 2017). Whilst this influences the development of this disorder, researchers have also identified genes that could be associated with a predisposition to this disorder (Yuen et al., 2017).

Parents could also display mild deficits in social communication skills and/or engage in tedious behaviour, which could be associated with ASD, and could be a possible factor contributing to the diagnosis of ASD in children (NINDS, 2017; Yuen et al., 2017). Furthermore, the presence of emotional disorders such as bipolar disorder and schizophrenia in families has been considered as an associated factor when diagnosing ASD in children (NINDS, 2017). During the developmental phase of an individual's unique deoxyribonucleic acid (DNA), an individual who is more likely to be diagnosed with ASD has more spontaneous gene mutations than the average individual (NINDS, 2017). It is possible that this gene mutation is a predisposing

factor that contributes to the development of this neural developmental disorder (NINDS, 2017). The Autism Research Institute has devoted much research to ASD and has linked several disorders that form part of, or are closely related to ASD (NINDS, 2017). These disorders include “Angelman syndrome, Asperger’s syndrome, Fragile X syndrome, Lanau-Kleffner syndrome, Prader-Willi syndrome, Rett syndrome, Tardive dyskinesia and Williams syndrome” (Autism Research Institute, 2017, para. 1).

Children diagnosed with ASD have also been found to, more frequently, have older mothers (Autism Research Institute, 2017). Other factors that could play a role are: the birth order of the child, use of medication during the pre- and perinatal periods of gestation, drug and alcohol abuse, prematurity, post-maturity and early or mid-trimester bleeding (Autism Research Institute, 2017). These are ideas that lend themselves to being possible aetiology factors in the diagnosis of ASD in children. However, there is still insufficient evidence to fully support the idea that these factors contribute towards the presence of ASD (Autism Research Institute, 2017).

Whilst researchers are not yet able to identify precise biological characteristics associated with the aetiology of ASD, there are some findings that may be helpful in future research endeavours (Autism Research Institute, 2017). It has been found that the physical size of the brain of a child with ASD is larger than that of a normal child (Autism Research Institute, 2017). The difference is not present at birth, but becomes evident during a child’s early childhood years (Autism Research Institute, 2017). The region of the brain that is responsible for processing emotions, such as the amygdala, has been found to be less active in individuals diagnosed with ASD, which contributes to the social and emotional challenges with which children with ASD present (Autism Research Institute, 2017).

There have also been findings regarding the dysregulation of the serotonin system (Autism Research Institute, 2017). One third of individuals who have been diagnosed with ASD have experienced seizures similar to epileptic seizures, which most commonly have their onset in the early childhood years or during late adolescence (Carr, 2006).

2.5 RESEARCH RELATED TO THE EXPERIENCES OF PARENTS OF CHILDREN DIAGNOSED WITH ASD

The parents of a child diagnosed with ASD experience various psychological, emotional and social challenges that often diminish their well-being and influence their ability to provide adequate care to their child with special-needs (Benderix et al., 2006; Desai et al., 2012; Woodgate et al., 2008). Guilt, stress, depression, regret about sacrificed goals, exhaustion and social isolation are some of the most common consequences experienced by the parents of children diagnosed with ASD (Benderix et al., 2006; Pengelly et al., 2009; Woodgate et al., 2008).

In their book titled *On grief and grieving* (2005), Elizabeth Kübler-Ross and David Kessler (2005) provide a framework for the typical five stages of grief that parents go through when they experience loss, namely 'denial, anger, bargaining, depression and acceptance' (see Figure 2.1) (Kübler-Ross & Kessler, 2005). By exploring this framework and relating it to this study, it can be linked to parents experiencing the loss of their 'normal' child and having to adapt to a lifestyle that will effectively accommodate their child's special-needs (Benderix et al., 2006; Pengelly et al., 2009; Woodgate et al., 2008). Kübler-Ross and Kessler (2005) identify grief as a unique process during which the various stages are not always experienced along a linear continuum. Each stage of their framework will be briefly unpacked.

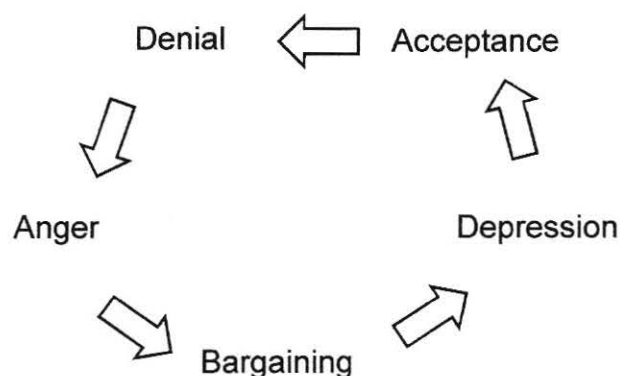


Figure 2.1: Kübler-Ross and Kessler's grief framework (2005)

2.5.1 STAGE 1: DENIAL

Kübler-Ross and Kessler (2005) identify the first stage in their grief framework as one during which individuals use denial as a means for survival. Shock is linked with

this stage and it is typically associated with a feeling that the meaning of one's life has been diminished (Kübler-Ross & Kessler, 2005). If this phase is related to the current study, denial can be associated with parents being unwilling to admit that their child may not be developing normally or being reluctant to accept their child's diagnosis of ASD (Desai et al., 2012). Parents' denial of their child's atypical behaviour could be influenced by their culture (Desai et al., 2012). One of the examples explored by Desai et al. (2012) relates to the Indian community and how a child's atypical behaviour is often normalised by ascribing it to the child's gender, for instance when communication difficulties are explained by pointing out that boys typically start speaking later than girls (Autism Speaks, 2017; Desai et al., 2012; National Autism Association, 2012).

In the South African context, the rich cultural diversity may impact parents' use of respite care for their child with ASD. This may stem from their denial of their child's diagnosis and their ability to meet their child's unique needs (Desai et al., 2012; Malcolm-Smith, Hoogenhout, Ing, Thomas, & De Vries, 2013). Bakare and Munir (2011) further elaborate on the aetiology of diagnosing ASD, which in the case of 43% of health-care workers may be linked to supernatural factors. In Africa, many people rely on spiritual beliefs for the aetiological explanation of neuropsychiatric disorders (Bakare & Munir, 2011; Desai et al., 2012). This can also be associated with the denial stage of Kübler-Ross and Kessler's grief framework.

2.5.2 STAGE 2: ANGER

According to Kübler-Ross and Kessler (2005), anger is a necessary feeling during the grieving process. The feeling of anger can extend to the child diagnosed with ASD, the child's family and people surrounding the family. In association with guilt, mothers have identified feelings of anger linked to a feeling that they are responsible for their child's diagnosis, the family for not assisting in identifying atypical behaviour and the maintenance thereof, the doctor for not being able to cure their child and society for not accepting their child the way he/she is (Benderix et al., 2006; Pengelly et al., 2009; Woodgate et al., 2008).

2.5.3 STAGE 3: BARGAINING

Kübler-Ross and Kessler (2005) describe the bargaining stage as one in which individuals try to negotiate and establish a temporary truce. Bargaining can be

associated with parents who find it hard to accept their child's diagnosis and often seeking a second opinion to confirm their child's initial diagnosis of ASD (Newtoautism.com, 2012; Roger & Evans, 2008). Denial prevails and desperation to prove the initial diagnosis wrong becomes a bargaining factor to re-establishing a sense of normality in the family's life (Woodgate et al., 2008).

2.5.4 STAGE 4: DEPRESSION

Depression is associated with a feeling of emptiness, and while many have defined this state as a sign of mental illness, Kübler-Ross and Kessler (2005) consider it a necessary stage in dealing with loss. Once parents have received confirmation of their child's diagnosis, feelings of disappointment were common as parents reported that they had to come to terms with their child not following the same developmental pattern as other relatively normal children (Ewart, 2003; Lutz, Patterson, & Klein, 2012; Schwartz, 2001).

In the broader context in which individuals and families live, an individual who meets the criteria for a diagnosis of ASD is often stigmatised (Corcoran, Berry, & Hill, 2015). Due to the apparent lack of knowledge and understanding among members of the public, interactions between parents and individuals from the public, outside the home, are often negative experiences (Schwartz, 2001). Some of the negative consequences of their child's diagnosis are feelings of humiliation, of being judged, and of social exclusion (Broady, Stoyles, & Morse, 2017).

Since children diagnosed with ASD often appear quite normal, members of the public generally expect them to behave normally (Neely-Barnes, Hall, Roberts, & Graff, 2011). It is this normal appearance that contributes to the stigmatisation and negative interactions experienced by the child and parents when in the presence of others (Corcoran et al., 2015). Conflicting feelings are reported by parents and while some feel that they should keep their child hidden from the public eye, others seek opportunities to take their child out in public, to promote awareness of ASD, but choose their audiences wisely (Ryan & Cole, 2009).

2.5.5 STAGE 5: ACCEPTANCE

Acceptance is the last stage of Kübler-Ross and Kessler's (2005) grief framework. This stage refers specifically to an individual's acceptance of this new realism as a permanent reality (Kübler-Ross & Kessler, 2005). During the subsequent

adaptation, individuals attempt to remain in touch with the past, but begin to accept that grief and an adjustment to their new norm is essential if they want to move forward (Kübler-Ross & Kessler, 2005).

According to research, once parents are able to accept their child's diagnosis, a period of adaptation follows in which the whole family is affected (Corcoran et al., 2015; Lutz et al., 2012). While adapting to the unique needs and demands of a child diagnosed with ASD, the family is placed under immense pressure (Lutz et al., 2012). This includes prior planning, commencing with daily activities, monitoring their child's behaviour and being aware of triggers in certain environments that affect the child's behaviour (Corcoran et al., 2015; Lutz et al., 2012).

Due to the high demand for attention and monitoring, parents have reported the need to change their lifestyle to accommodate their child's special-needs (Lutz et al., 2012). A major theme was parents having to change their occupations or giving up their jobs completely in order to be able to attend to their child's unique needs (Corcoran et al., 2015). This change also included the environment in which the child and family lived, and effects that having a child with this disorder has on the lifestyle of the family (Lutz et al., 2012). How respite care is experienced in relation to this was explored within the current study.

2.6 INTERVENTION STRATEGIES

Malcolm-Smith et al. (2013), who investigated 'the relationship between family routines, cognitive appraisal and family quality of life,' emphasise family resilience and identify family as a protective coping resource. They further state that a family with a child diagnosed with ASD often experiences challenges in respect of attempting to establish workable family routines (Malcolm-Smith et al., 2013), which in turn contributes to increased stress and affects the parents' ability to cope (Larson, 2006).

Various social media and other online support platforms exist to help parents of children with ASD to manage the challenges associated with this disorder (National Autism Association, 2012). These include The National Autism Association, which provides a social platform on which parents of children with ASD can post questions, concerns and recommendations, and share experiences (National Autism Association, 2012). By using this blog, groups can be created to connect parents

with other parents in the same area so that they can receive the specific support they require. Autism Now allows parents access to research and the latest news and information on ASD (The Arc, Autism Now, n.d.). My Autism Team (2018) is another social platform upon which parents can connect. The website, Care.com (2007) allows parents to seek caregiving support for their child with special-needs. Dads 4 Special Kids ([D4SK], 2014) is a social platform that allows fathers of children with special-needs to share their unique experiences and seek support from other fathers in the same situation. Autism Speaks offers various online learning tools and software to help parents of children with ASD through online programmes and activities to develop certain skills needed to manage their child's disorder more effectively (Autism Speaks, 2017). As mentioned above, ASD affects not only the child's life, but also that of the family (Autism Speaks, 2017). Autism on the Seas (2018) is a website developed to assist families to plan the kind of holiday that will be suited to their child's unique needs.

In South Africa, we have an organisation called Autism South Africa (A;SA), which provides access to various support groups. It also provides information on the definition of ASD, early warning signs parents should look out for when they suspect that their children are not achieving the normal developmental milestones associated with their chronological age, health care, and useful equipment and activities for children with special-needs (Autism Speaks, 2017). A;SA focuses on programmes aimed at improving the quality of life of individuals diagnosed with ASD, develops and improves services provided to parents of children with ASD, and raises public awareness of, and concern for people diagnosed with ASD (Autism Speaks, 2017).

According to both the psychodynamic and cognitive behavioural theories, applied behavioural analysis is currently the most frequently used and the most effective intervention technique for children diagnosed with ASD (Autism Speaks, 2017). This technique is based on the principle that if a child is rewarded for positive behaviour, the likelihood that the positive behaviour will be repeated will increase. Focusing on skills such as looking, listening and imitation assists in the development of the skills needed to read, maintain simple conversations and understand (Autism Speaks, 2017; Devita-Raeburn, 2016).

2.7 INTERNATIONAL RESPITE CARE

On an international level, countries such as Canada, the United States of America, Britain, India and Sweden have dedicated research to children diagnosed with ASD and explore topics such as diagnosing children with ASD, assisting children with ASD in schools and assisting families to cope with the psychological, emotional and physical challenges of caring for a child diagnosed with ASD (Benderix et al., 2006; Bromley, Hare, Davison, & Emerson, 2004; Desai et al., 2012; Pengelly et al., 2009; Woodgate et al., 2008). The advantages of providing families with the unique service of respite care was recently explored.

A Canadian study undertaken by Neufeld et al. (2001) points to the advantages to be gained from utilising respite care. Some of these advantages include; staff that are monitored under supervision, additional services such as speech therapy, physiotherapy and occupational therapy are provided, children interact with others with the same disorder, parents are given more free time to spend with their other children and take part in activities that are taken for granted by many 'normal' families (Neufeld et al., 2001). These activities focus on the family and on the personal well-being of the parents (Ling, Payne, Connaire, & McCarron, 2016). Personal well-being encompasses exercise, focusing on the self, shopping and leisure pursuits such as family vacations (Ling et al., 2016; Neufeld et al., 2001). Parents of children diagnosed with ASD who are unable to utilise the advantages offered by respite care, experience various psychological, emotional and social effects (Abbott, Bernard, & Forge, 2013; Alli et al., 2015; Bromley et al., 2004; Woodgate et al., 2008).

A study by Ling et al. (2016) highlights factors that influence parents' decision to utilise respite care. These factors include previous experiences of respite or related care, staff turnover, fears of limited time spent with their child, trust and hope that caregivers will care for their child in the nurturing way they are used to being cared for at home, available funds and the location of the respite care facility (Ling et al., 2016). Due to the nature of this unique service being offered to parents, these factors were of particular interest while the current study was being conducted within the South African context.

When respite care is being used, children are exposed to an unfamiliar environment and parents have to trust and hope that the caregivers are trained, equipped and

are able to offer the same nurturing care that their children are used to receiving at home (Neufeld et al., 2001). Ling et al. (2016) claim that parents who use respite care in addition to the personal accommodation of the child rely on previous experience of satisfactory respite care. Satisfactory care could be attributed to the facilities' suitability and the ability of the staff to cater for the child's unique individual needs (Ling et al., 2016). Parents utilising respite care want to be assured that staff are properly trained and have the experience and ability needed to meet not only the most fundamental needs of their child, but to also fulfil the unique parental role towards the child in the absence of the parent (Ling et al., 2016). Depending on the extent to which these expectations are met, parents will either be motivated or reluctant to utilise this type of specialised care for their child.

2.8 NEED FOR PRIVATE RESPITE CARE IN SOUTH AFRICA

In terms of the White Paper (Department of Social Development, Republic of South Africa, 2016), South African individuals with disabilities are entitled to protection. The Mental Health Act (The Presidency, Republic of South Africa, 2002) and the National Mental Health Policy Framework and Strategic Plan (Department of Health, Republic of South Africa, 2013) were developed to ensure that people with disabilities have the same rights and responsibilities as their fellow citizens (Department of Health, Republic of South Africa, 2013; Department of Social Development, Republic of South Africa, 2016; The Presidency, Republic of South Africa, 2002). Recent attempts by the Life Esidimeni Hospital to uphold this policy, specifically by deinstitutionalising patients into the community, were seen as a failure (Bezuidenhout, 2016; Child, 2017).

Health ombudsman Malegapuru testified in various tabloids that he believed that 129 patients had died as a result of government's efforts to save money and deinstitutionalise patients into the community (Child, 2017; WATCH: Moseneke pays tribute to Esidimeni victims, 2018). Non-profit organisations in South Africa are filled with patients and are reported to lack resources, finance and trained staff (Bezuidenhout, 2016; Child, 2017). The White Paper Financial Management for non-profit organisations (NGOs) outlines the challenges of managing non-profit organisations (Blackbaud, 2011). Some of those challenges relate to the dependency of non-profit organisations on donations in the form of resources and finance (Blackbaud, 2011). It is difficult to maintain the required standards at such facilities as income varies and cannot be guaranteed (Blackbaud, 2011).

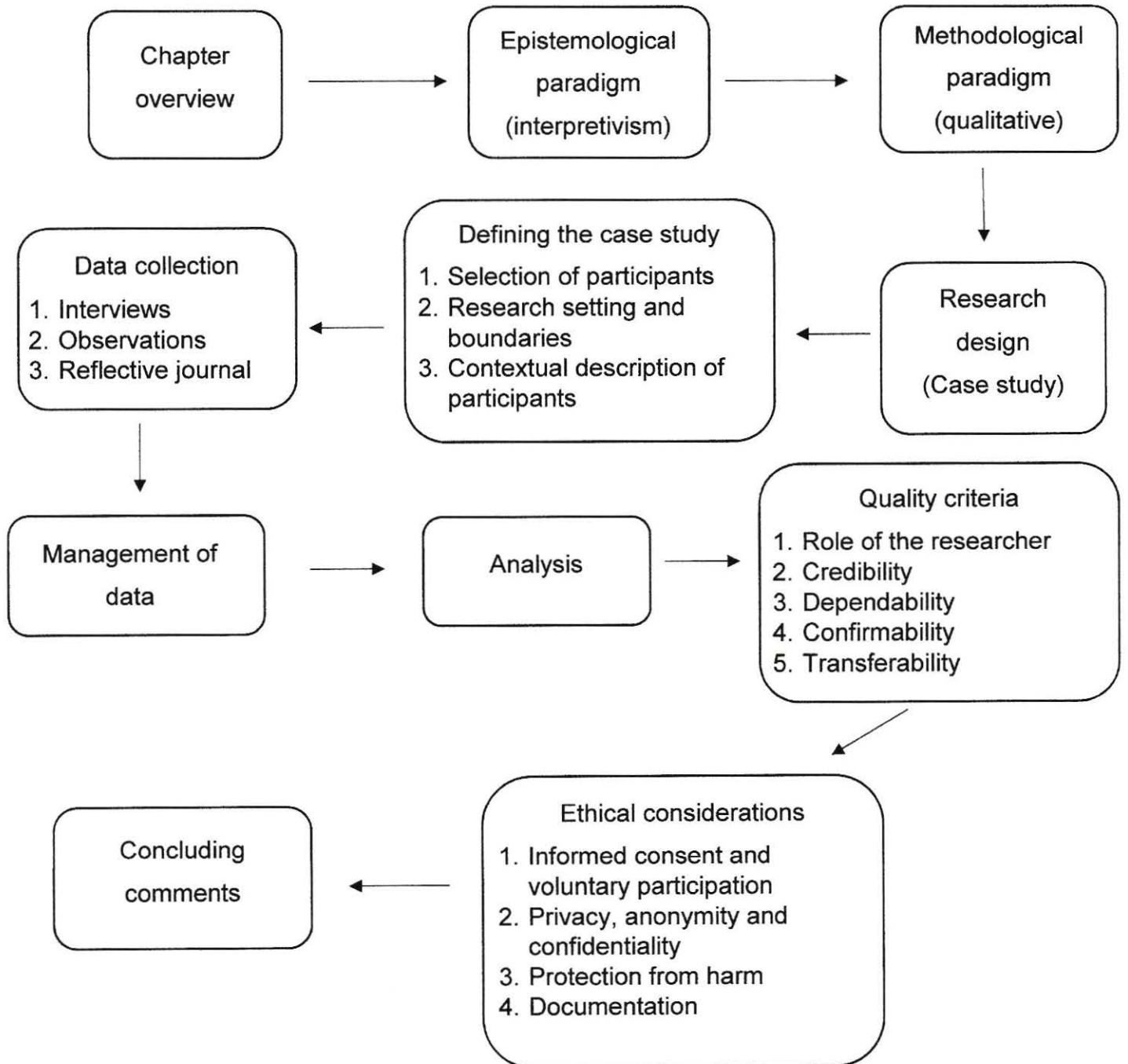
Since private respite care facilities are for-profit enterprises, they focus on profitability and maximising shareholder value (Child, 2017), which makes provision for such facilities to deliver, to a certain degree, a service to clients that is consistent, predictable, and reliable. The benefits of placing a child in a private facility depend on the affordability of this service, or alternatively the parents' ability to find a sponsor for their child. Spaces are limited in terms of the client to staff ratio, the availability of space for residential and respite care and the availability of adequately trained staff (Ling et al., 2016). Furthermore, health care providers such as occupational therapists, speech therapists and physiotherapists are able to offer their services to these facilities as a business opportunity (Ling et al., 2016; Neufeld et al., 2001).

2.9 CONCLUSION

In this Chapter the researcher provided a definition of ASD, the clinical features/diagnosis of ASD, the aetiology of ASD, explored research related to the experiences of parents of children diagnosed with ASD, intervention strategies, literature on international respite care and the need for private respite care within the South African context. In Chapter 3 the researcher presents the research methodology pertained to the study.

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CHAPTER 3



Chapter 3

Research Design and Methodology Used to Explore How Parents of Children With ASD Use Respite Care at a Private Facility in South Africa

3.1 INTRODUCTION

This chapter outlines the methodology used to address the purpose of this study, which was to explore the experiences of parents utilising private respite care for their children who had been diagnosed with ASD. These methods are appropriate for obtaining answers to the primary and secondary research questions of this study. The chosen research paradigm is outlined, after which the research design is discussed in more detail. The discussion of the methodology includes a description of the main data collection methods and analysis strategies, after which the focus shifts to how quality assurance and ethical aspects were implemented.

A bird's eye view of the research process implemented in conducting the current study is provided in Figure 3.1.

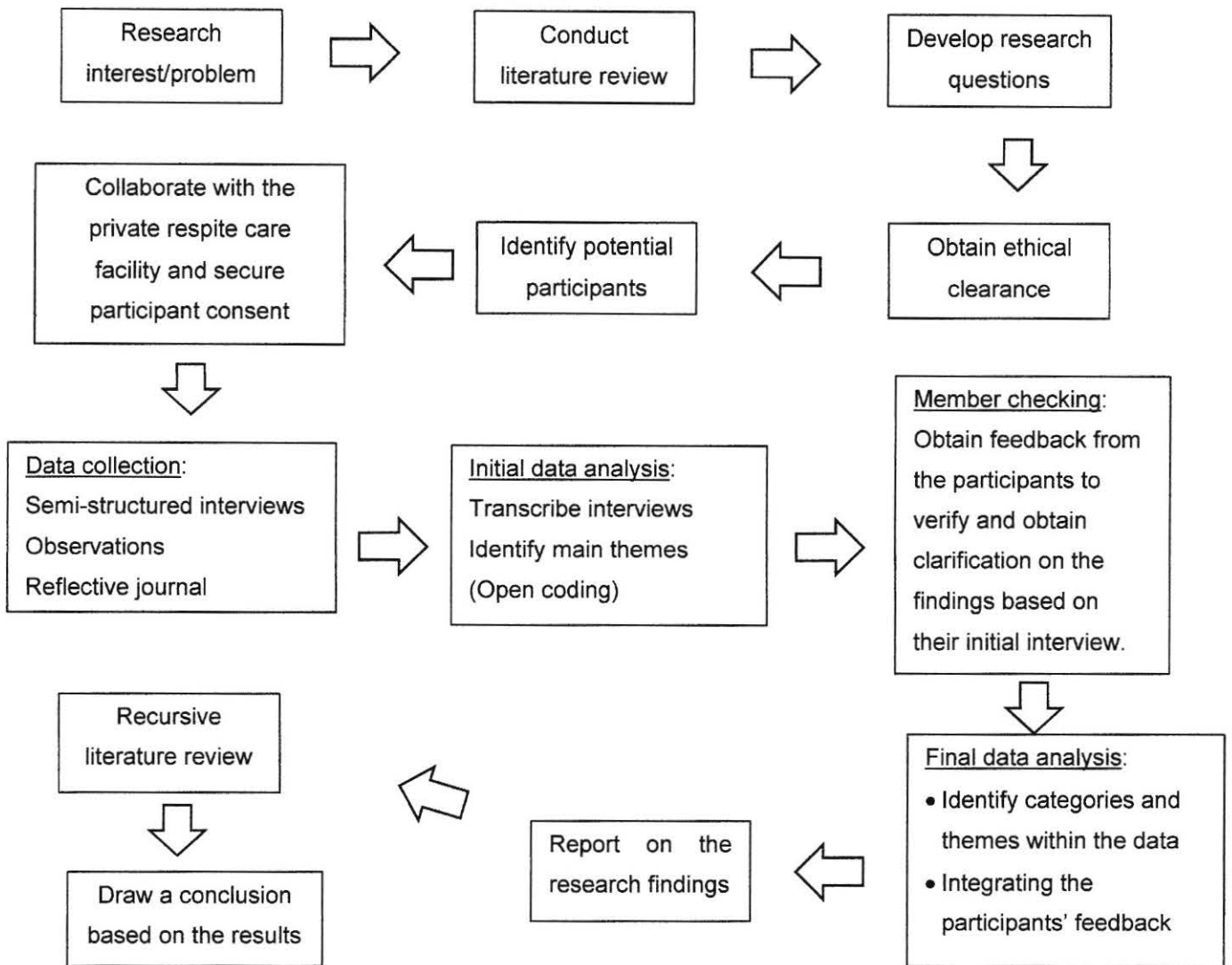


Figure 3.1: Bird's eye view of the research process

3.2 EPISTEMOLOGICAL PARADIGM (INTERPRETIVISM)

The philosophical underpinnings of the interpretivist paradigm includes both hermeneutics and phenomenology (Maree, 2013; Yin, 2014). Hermeneutics allows for the interpretation of textual data that is utilised to understand individuals within their social context (Baxter & Jack, 2008). Phenomenology explores the meaning individuals assign to their specific experiences and is focused on gathering rich information through the use of qualitative research methodologies such as observations, interviews and the use of a reflective journal by the researcher (Baxter & Jack, 2008; Creswell, 2014; Maree, 2013; Yin, 2014).

Interpretivism is not based on objectivism, but rather on the subjective nature of an individual's experience within a natural context (Gephart, 1999; Neuman, 2006). Since each person can be deemed unique, the ontology of interpretivism assumes that for each individual there are various realities that are reliant on time and context (Baxter & Jack, 2008; Creswell, 2014). The interpretivist paradigm was therefore best suited to the current study as the researchers' aim was to explore the unique reality of each participant's experience in utilising private respite care for his/her child diagnosed with ASD.

To accurately reflect each participant's experience, interpretivism requires a process of engagement by the researcher (Maree, 2013). The researcher approached Facility X and requested permission for this research to be undertaken by interviewing clients who have used or are currently utilising private respite care services (See Appendix C). A research document outlining the purpose of the study was given to both the facility representatives and the potential participants and informed consent was obtained (See Appendix A and B).

Interpretivism is complemented by research-collection techniques that are used to provide in-depth information on each participant's unique contextual experiences (Creswell, 2014; Maree, 2013). Data is therefore often collected in a naturalistic environment. In the current study, participants were allowed to share their experiences regarding the use of private respite care, to explain how this service has benefitted them (or not), and to make recommendations about how it could be further improved to best meet their needs.

The interpretivist paradigm is often supported by observations that allow for the collection of information about the participants' experiences and interpretations, which allows for meaning to be assigned to the data being collected (Kaplan & Maxwell, 1994; Maree, 2013). The interpretivist paradigm is also complemented by ontology, which is based on exploring participants' experiences (Terre Blanche & Durrheim, 1999). Ontology aims to explore the meaning people assign to their experiences within their social context and through a natural setting (Kuhn, 1977). This study is based on epistemology in which the meaning participants assign to their own experiences is explored and interpreted in collaboration with the researcher (Guba & Lincoln, 1994). This interaction allows the researcher to adopt the role of a participant observer, which implies that the researcher engaged in

activities with the participants and recognised the meaning the participants assigned to their actions through their social context (Guba & Lincoln, 1994).

3.3 METHODOLOGICAL PARADIGM (QUALITATIVE)

Qualitative research is a methodological paradigm that allows for the exploration and gathering of descriptive data relating to a particular topic of interest (Maree, 2013; Silverman, 2010). A qualitative methodology is complementary to the interpretive paradigm as it often takes place within a naturalistic setting (Maree, 2013).

Qualitative research offers the researcher a number of advantages. The first is that research of this type is predominantly based on a process of gathering data to inform the meaning that participants assign to their individual experiences (Atieno, 2009; Flanagan, 2013; Maxwell, 2013). Each interview was conducted within a naturalistic setting and offers the participants an opportunity to share their own unique feelings, opinions and experiences in an environment that promotes confidentiality and comfort (Baxter & Jack, 2008; Creswell, 2014; Maree, 2013). The data obtained is therefore specific to each individual. This is both an advantage and a disadvantage as the process by which the data is obtained as well as the results are specific to both the individual and the setting and thus cannot be reproduced (Creswell, 2014; Guba & Lincoln, 1994). However, due to the nature of this study, the aim was not to generalise and replicate previous studies, but rather to explore and inform readers on the unique experiences of parents utilising private respite care within the South African context.

3.4 RESEARCH DESIGN (CASE STUDY)

A research design refers to the specific methods used to gather the data needed to address both the primary and secondary questions relating to the study (De Vaus, 2001). The experience of parents of children with ASD who have used or are currently using private respite care within the South African context were then further explored through this research design in order to obtain an understanding of, and assign meaning to their experiences (Creswell, 2014; Maree, 2013; Yin, 2014).

Due to the limited research available on respite care and the use of this service for children diagnosed with ASD in South Africa, the use of an instrumental case study design offered an opportunity for an in-depth exploration of the experiences of

participants who have or are currently making use of private respite care services. It also allowed research to be conducted as a means to broaden current knowledge in the use of this service.

The current research design can thus be further described as a descriptive exploratory case study. A descriptive case study design serves to describe a specific topic of interest within its natural context (Baxter & Jack, 2008; Yin, 2014). As per the descriptions of an explorative descriptive case study design, the current study sought to explore and describe how parents experience the utilisation of private respite care.

Criticism of the use of a case study design relate, among other things, to its potential lack of rigour (Guba & Lincoln, 1994; Maree, 2013; Silverman, 2010; Yin, 2014). Due to the nature of the methods used to explore participants' experiences, researchers often question its basis for replication. Case studies have also been criticised for their lack of generalisability (Carr, 2006; Creswell, 2013, 2014; Maxwell, 2012; Yin, 2014). As previously mentioned, the aim of the study was not to be able to generalise the results, but rather to provide information on how parents of children with ASD experience the use of private respite care in South Africa.

Due to the nature of the process of obtaining information from participants in a natural environment and having participants share their unique experiences, the case study cannot be replicated (Creswell, 2014; Maree, 2013; Yin, 2014). The data gathered was contextually unique to specific participants utilising private respite care for their children with ASD. The generalisability of the results obtained is therefore limited (Creswell, 2014; Maree, 2013). Although the purpose of a qualitative study is not to generalise, Silverman (2010) claims that even single case studies, if rigorously engaged with, may hold some level of generalisability.

This study may provide insight into how the service of respite care could be utilised within the ASD context. Case study research is also criticised for its enhanced potential for researcher bias (Creswell, 2014; Maree, 2013). To reduce this risk, the researcher included various quality assurance measures, such as recordings, transcriptions, member checking, follow-up interviews and inter-researcher reliability of the data analysis checks, which will be discussed later in this chapter (Maree, 2013).

3.5 CASE STUDY DESIGN

3.5.1 SELECTION OF PARTICIPANTS

In order to explore the experience of parents whose child who has been diagnosed with ASD and who have or are using a private respite care facility in South Africa, the researcher made use of purposeful sampling. Due to the limited knowledge of the service offered by respite care facilities in South Africa, and more specifically of the use of this service for children diagnosed with ASD, purposeful sampling was applied on the basis of where it was available. Since the facility used in this study was the only facility in South Africa offering private respite care, participants could only be recruited from there. Potential participants to be interviewed had to meet the criteria for inclusion in this study (see section 1.7.4, Table 1.1) and were selected on the basis of their ability to provide insight that would make it possible to answer the research questions.

Potential participants had to meet the following requirements: they had to have a child diagnosed with ASD; had to be proficient in the English language (as this was the language in which the interview would be conducted); and had to have utilised private respite care for their child during the preceding 12 months. Participants who suffered from a mental or other illness that would drastically affect the results of this study were excluded. In addition, if participants were not proficient in the English Language and have a child diagnosed with a co-morbid condition, they were also excluded.

The participants formed part of a purposeful sampling population as they were selected on the basis of their ability to fulfil the requirements of the study by understanding and seeking meaning in each of their unique situations (Creswell, 2014; Maree, 2013). The participants in the study were therefore carefully selected to inform the purpose of the study. Three participants, reflecting three different parenting styles, agreed to participate in the study.

3.5.2 RESEARCH SETTING AND BOUNDARIES

Due to the sensitive nature of the study, it was essential for the researcher to create a suitable private environment in which the participants felt comfortable to share their experiences (Creswell, 2013; Maree, 2013). Participants were given the opportunity to choose an interview venue in which they would feel comfortable.

Permission was also obtained from Facility X and a room for the researcher's use was made available in the facility, which ensured travel convenience, privacy and confidentiality. The first interview was conducted at Facility X. The second was conducted at the participant's home as she could not afford to travel to the facility and also indicated that she would feel more comfortable to conduct the interview at her home. The third participant was interviewed at work in a private conference room as she could not be interviewed at home for personal reasons and chose not to go to Facility X as her son was there and she found it too difficult to face him.

In all three settings, the participants were assisted by creating an environment in which they would feel comfortable and safe, and where confidentiality could be guaranteed. Participant 1 had her interview at the facility in which in a private room was provided to conduct the interview. Participant 2 wanted to have the interview at her home due to financial constraints and her feeling more comfortable at her home. Participant 3 had her interview at her work in a private conference room due to personal reasons for not wanting to see her son at Facility X.

3.5.4 CONTEXTUAL DESCRIPTION OF FACILITY X

Facility X is a special needs facility that was established in 2015 and is situated in Midrand, Gauteng. Facility X offers both residential care as well as respite care for children and young adults with special needs, these include severe and complex learning difficulties, language and communication impairments, Epilepsy, Autistic Spectrum Disorders, Behavioural Difficulties, Cerebral Palsy and Down's Syndrome. For the purpose of this study, participants were selected from those that had or are still using the service of respite care for their child who has been diagnosed with ASD.

3.5.3 CONTEXTUAL DESCRIPTION OF THE PARTICIPANTS IN THIS STUDY

As mentioned earlier, three participants volunteered to participate in the current study. The first participant was a single Caucasian mother of an eight-year-old boy who had been utilising respite care since 2014. She separated from her former boyfriend when their son turned two years of age due to the demands placed on them by trying to meet their son's unique needs. Since the birth of her child, the participant had been seriously injured in a car accident that resulted in medical

complications that affected her health. Prior to making use of respite care, she had used external support services to assist her with her son. When she had to 'downsize' due to financial constraints, she had decided to discontinue the use of external services and tried to raise her son on her own. However, "it just got too much in the end" (Interview P1, transcription U99, p. 3) and she eventually resorted to making use of private respite care.

The second participant was a Caucasian mother of two children. Despite a healthy pregnancy, her son, who was born via a caesarean section at 38 weeks, had severe health challenges. He had undergone seven surgeries before the age of two years as he struggled with inguinal hernias on both sides. The mother reported that she had seen a variety of specialists, including a paediatrician, a neurologist, an occupational therapist and a psychiatrist. Her son was eleven years of age at the time of the interview and had received his first formal diagnosis of ASD at the age of one year. He initially attended a government school, but did not cope well in this environment due to symptoms of enuresis. She then placed him in a special-needs school which he attended as a day scholar. The routine and the demands made by the school placed strain on her relationship with her husband and younger daughter, as her son did not sleep at night and was inclined to harm his sister. The family could not cope with the constant demands placed on their home life and careers and the management of their son's special-needs. This resulted in the parents seeking support from Facility X.

The third participant was an African mother of three children. Her eldest son was diagnosed with ASD at the age of 2 years after she had noticed that he was having seizures. She reported that after his third birthday he had started displaying "odd behaviours" such as; "hanging on to things, collecting bottle-tops, not playing with toys, being clingy to certain things and his language completely disappearing" (Interview P3, transcription U34, p. 1). The mother had placed her son in a day-care facility at the age of 3 years, but received complaints because of his inability to cooperate with the staff, which was due to his lack of communication skills. Since she could not find a facility that would accommodate her son's special-needs, she resorted to asking for support from her family. Her son's aggressive behaviour eventually resulted in her seeking support from local hospitals specialising in ASD, but due to his destructive and flighty behaviour, she was unable to secure a permanent placement for him. The participant's career became strained due to the financial burden placed on her and the constant demand to meet her son's special-

needs. When she was forced to keep her son at home, members of her community objected to his presence. She tried, in vain, to obtain assistance from external services such as social workers, the police, psychiatric hospitals and government resources, and her son's destructive behaviour was eventually the cause of her attempted suicide. Her relationship with family members and her youngest son became strained as they lived in fear of her aggressive older son. During a court case, the mother was introduced to a staff member of the Facility X who offered to take her son in. He is now 19 years of age and still resides at Facility X.

3.6 DATA COLLECTION

3.6.1 INTERVIEWS

The researcher conducted an interview with each of the three participants. The interviews were semi-structured and were conducted in a natural environment in which the participants felt comfortable and at ease (Creswell, 2014; Maree, 2013). Additional questions were asked for clarification and/or to gather further information that could add value to the study. As mentioned, the first interview took place at Facility X, whereas the other two interviews were conducted off-site due to personal reasons communicated by the participants. Semi-structured interviews allowed for guidelines to be followed in order to gain insight into the experiences as lived by the participants (Creswell, 2014; Yin, 2014). The semi-structured interview questions were used and further questions were asked for verification to ensure that the answers elicited conformed to the purpose of the study (Maree, 2013). The questions that were put to the participants related to their personal experiences of having a child diagnosed with ASD and their feelings regarding utilising private respite care for their child with ASD. The interview schedules that were provided can be viewed in Appendix D.

3.6.2 OBSERVATIONAL NOTES

During the interview process, the researcher made use of qualitative observations to add value to the information provided by the participants (Creswell, 2014; Maree, 2013). The researcher paid specific attention to the participants' non-verbal communication, for example gestures, body language, facial expressions, eye contact, tone of voice and tempo of speech (Elmir, Schmied, Jackson, & Wilkes, 2011; Kothari, 2004; Oltmann, 2016).

The noting of non-verbal communication provided contextual content for the information being shared with the researcher and could potentially add value to the shared content (Elmir et al., 2011; Kothari, 2004; Maree, 2013; Oltmann, 2016). While making notes, the researcher remained cognisant of the empathetic listening skills needed to conduct the interviews, the nature of which required me to remain engaged with the participants as they shared their experiences (Kothari, 2004; Yin, 2014). The researcher's notes were brief and were only made when she felt that they were necessary and could add contextual value that could either confirm or deny what the participant was saying (Baxter & Jack, 2008).

3.6.3 REFLECTIVE JOURNAL

The keeping of a reflective journal was a strategy the researcher used to reflect on her own presuppositions, decisions, experiences, thoughts and actions throughout the research process (Etherington, 2004; Harrison, MacGibbon, & Morton, 2001; Ortlipp, 2008). Such a journal is used by researchers to write notes about their thoughts, feelings and actions before as well as during events related to their research study. This especially included the period of data collection and the analysis of the data, which led to the research findings.

In the researchers' journal, she acknowledged the potential for research bias impacting the research process as she had previously worked at Facility X. The use of a reflective journal assisted in creating transparency and keeping a trail of thoughts as well as allowed the researcher to become more aware of observations and non-verbal cues that could be used to gather more information on parents' experience.

3.7 MANAGEMENT OF DATA

Once the researcher had completed the research analysis and reported on the findings, all electronic and hard copies of the data were secured for safekeeping in Room 3-45 of the Aldoel Building on the University of Pretoria's Groenkloof Campus.

3.8 ANALYSIS

For this study the researcher made use of thematic text analysis, as described by Braun and Clarke (2006). Thematic text analysis infers that the researcher collects, transcribes, analyses, understands and develops a thematic text analysis map, in

which themes and subthemes within the data pertaining to the aim of the particular study are identified (Braun & Clarke, 2006; Tuckett, 2005).

The first step in analysing my data was to transcribe all the interviews conducted with the participants. While doing this, the researcher was able to thoroughly familiarise herself with the data (Braun & Clarke, 2006). The early stages of data analysis started with the researcher generating initial codes when reading through the transcriptions. This allowed the researcher to start categorising the data into meaningful groups/codes (Tuckett, 2005). Once the transcriptions had been provisionally coded, the researcher was able to search for themes within the data. This part of the data analysis is also known as axial coding (Boyatzis, 1998; Braun & Clarke, 2006; De Vaus, 2001).

Axial coding required that the researcher identify and reflect on the various ways in which the data may depict a relationship between the variables (Boyatzis, 1998; De Vaus, 2001). Selective coding was then performed by analysing the core categories obtained from the data and relating these categories to one another in order to best represent their relationships. An analysis of the relationships that were identified between the concepts and constructs revealed an identifiable pattern between these variables. By coding the data I was able to break down, conceptualise and re-create the findings obtained from the interviews (Boyatzis, 1998).

Throughout the study, thematic concept analysis was used (Boyatzis, 1998; De Vaus, 2001). This method allowed the researcher to identify and compare relationships between the identified themes (Braun & Clarke, 2006; De Vaus, 2001). Once themes had been identified, the researcher was able to group related themes together and create conceptual thematic categories. By grouping the data and creating categories, the researcher was able to analyse the differences and similarities that became apparent through the analysis of the data presented in the transcriptions.

The main themes identified during the data analysis were interpreted by using current literature as well as the contextual setting in which the interviews had been conducted. The interpretation and analysis of the data obtained required that the researcher identify the main themes within the data and reconstruct them in such a way that the data could be compared with the relevant literature to confirm or deny the hypothesis regarding South African parents' experiences when utilising private

respite care for their children who had been diagnosed with ASD, and to allow the researcher to compare the findings with current literature in order to identify plausible patterns and trends within the study (Braun & Clarke, 2006; Mouton, 2001).

3.9 QUALITY CRITERIA

This section starts with the acknowledgement of the role of the researcher, after which the criterion for trustworthiness implemented in this study will be discussed, as recommended for qualitative studies by Lincoln and Guba (1985).

3.9.1 ROLE OF THE RESEARCHER

Throughout this study the researcher adopted a number of roles to ensure that the researcher would achieve the purpose of the study. The researcher acknowledged her previous role as a manager at Facility X. Measures such as the screening of potential participants prior to the interview process was followed throughout to ensure that confidentiality and anonymity was maintained. Once the initial screening had been completed, the researcher adopted the role of a researcher, which involved the selection of potential participants and the establishment of a relationship based on trust and a feeling of comfort (Creswell, 2014; Maree, 2013). Due to the delicate nature of the interview, trust and empathic understanding allowed the participants the opportunity to share their experiences in an environment that offered comfort.

During the interview, the researcher demonstrated empathy, by listening and engaging with the participant, to elicit honest answers from the participants and asked probing questions to elicit the kind of in-depth information that was required for the study (Maree, 2013). As previously mentioned, the researcher used the semi-structured interview protocol to guide her interview with the participants (Creswell, 2014; Maree, 2013). Field notes and the keeping of a reflective journal helped her to remain cognisant of her role as a researcher and to ensure that her own experience as a manager at Facility X would not influence her research (Maree, 2013).

The researcher practised the technique of being an active listener, by listening to what the participant had to say, so as to ensure that the participants felt that their stories and experiences were important (Creswell, 2014). Since the aim of the

research was to explore the participants' experiences, engaging in her role as an active listener ensured that they were being heard and would feel that their stories were important to the study, and that the researcher acknowledged their shared experiences.

3.9.2 CREDIBILITY

Credibility refers to the researcher's ability to obtain information from participants that reflect the true perspective of their experiences (Shenton, 2004). Shenton (2004) claims that credibility can be utilised to further improve the reliability and validity of information obtained during a qualitative research study (Shenton, 2004). Each participant was provided with an interview protocol to inform them of the questions that would be asked during the interview. Participants were asked to elaborate on their answers in order to provide in-depth information and, where needed, they were asked to clarify information that could be misinterpreted. This allowed the researcher to ensure the credibility of the information obtained, which was further verified through member checking after the initial data analysis. Constant research supervision was also provided (Maree, 2013; Shenton, 2004).

3.9.3 DEPENDABILITY

Dependability addresses the researcher's ability to accurately describe the research process, which would in turn assures the credibility of the study and thus enable other researchers to replicate the study as closely as possible to the original study (Lincoln & Guba, 1985). Due to the unique circumstances in which a qualitative case study research is conducted, the replication of such a study is largely reliant on the nature of the context in which it is carried out (Maree, 2013). To ensure the dependability of the researchers' research, the themes were thoroughly defined and were further supported by verbatim quotes that were provided as evidence.

3.9.4 CONFIRMABILITY

Confirmability implies that the findings of the research study accurately represents the participants' experiences (Shenton, 2004). According to Miles and Huberman (1994), it is essential that researchers make their predispositions as transparent as possible when conducting a study. The researcher made the reader aware of the fact that she had previously worked at Facility X and took the necessary steps to keep note of her own biases that might have impacted the study by keeping a

reflective journal. Furthermore, the researcher made use of triangulation by using her field notes and observations, reporting the findings of the research to the participants and implementing a process of member checking during which they were asked to clarify what the researcher had reported on during their interviews and to either confirm or rectify my understanding of what they had said (Creswell, 2014; Maree, 2013; Shenton, 2004). The results of the study were therefore confirmed with the participants to guarantee that their experiences were correctly reflected.

3.9.5 TRANSFERABILITY

Transferability infers that the findings pertaining to the current research can be applied to other situations (Guba & Lincoln, 1994; Shenton, 2004; Silverman, 2010). Qualitative research conducted by way of case studies is not replicable since the case study and information relating to the participant are unique and cannot be simulated (Creswell, 2014; Maree, 2013). To ensure transferability, according to Firestone (1993) as well as Guba and Lincoln (1994), the researcher should ensure that adequate information is provided on the context in which the study is done in order to allow the reader of the study to be able to make a transfer. Section 3.5.2 of Chapter 3 provided a thorough account of the research setting participants in the study and the context in which they utilised private respite care.

3.10 ETHICAL CONSIDERATIONS

Ethical clearance was attained from the University of Pretoria's Faculty of Education and the Faculty of Health Sciences Research Ethics Committee in July 2017. Facility X, based in Midrand, Gauteng, was provided with a document outlining the purpose of the research. Facility X, was provided with a document to give to potential participants in which informed consent would be obtained from participants who would be willing to voluntarily partake in the study (see Appendix A). Facility X was provided with additional documentation in which it was requested by the researcher to allow her to use its clients as participants in the study. In this document (Appendix C), the inclusion and exclusion criteria were stipulated and an outline was provided of what was needed from the facility and how they would be protected. Once potential participants had been selected based on the stipulated criteria, they were approached and requested to voluntarily participate in the study.

The following ethical considerations were adhered to: informed consent and voluntary participation, privacy, anonymity and confidentiality, protection from harm and documentation pertaining to this research study is discussed in further detail below.

3.10.1 INFORMED CONSENT AND VOLUNTARY PARTICIPATION

Prior to the study, each participant was given a research information document in which the following was provided: an outline of the purpose of the study; the criteria for being selected as a participant; what would be required of participants; benefits of taking part in the study; and any foreseen physical discomfort, harm or psychological distress. Potential participants were also allowed to ask questions and seek additional information pertaining to the study. Each participant signed a certificate of consent in which they agreed to voluntary participation in the current study. They were told that they could discontinue their participation in the study at any time without any negative consequences. Permission was also obtained from Facility X prior to commencing with the study. Sites at which some of the interviews took place were inspected to ensure that privacy and confidentiality would be kept during the interviews.

3.10.2 PRIVACY, ANONYMITY AND CONFIDENTIALITY

Throughout the study, respect for confidentiality and anonymity were maintained. This was done by allowing the research participants to choose their own pseudonyms to be used throughout the study. Participants were assured of the safeguarding of all data collected throughout the study and all electronic data was encrypted with a password. Participants were also made aware of the sensitivity surrounding the study and were informed that they would be free to withdraw from the study at any time without having to give reasons for their decision and with no negative consequences for them.

3.10.3 PROTECTION FROM HARM

Participants were assured that participation was voluntary and, before the commencement of the study, they were provided with an agenda regarding the type of questions that would be asked. Each participant was interviewed in an environment that had been screened for privacy and a setting that would be conducive to the sharing of sensitive information. All the information provided by the

participants were recorded and both the written and the electronic copies, which were password encrypted, were kept in a locked cupboard in the researcher's home. Due to the nature of the research study, participants were given a letter of referral to be used if either the researcher or a participant felt that additional support was needed after the interview. All services were made available free of charge and all the therapists were registered as counsellors with the Health Professions Council of South Africa (HPCSA).

3.10.4 DOCUMENTATION

Each participant was briefed on the purpose of the study, the expectations of the researcher and the participants, and any potential harm that could come from participating in the study. Participants were provided with an opportunity to ask questions and were free to choose to participate, or not to participate in the study. Those who agreed to participate signed an informed consent certificate in which the assurance was given that they would be protected and that confidentiality as well as anonymity would be maintained at all times.

All the transcriptions of the interviews were recorded. Transcriptions and notes were stored in a locked cupboard in my home and electronic copies were password encrypted. Once they had been analysed, all the research documents that had been compiled during the study were safeguarded at the University of Pretoria, Department of Educational Psychology, Faculty of Education, Room 3-45.

3.11 CONCLUDING REMARKS

Chapter 3 provided information relating to the research design, paradigm and research methodology utilised in the current study. A detailed description of the results obtained in the study will be provided in Chapter 4 and the interpretation of the results will be discussed in Chapter 5.

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Chapter 4

Research Results and Literature Control

4.1 INTRODUCTION

In Chapter 4, the researcher discusses the results of the analysis of the information obtained from the research participants. Through the use of thematic data analysis, five themes were identified. Under each theme, subthemes and categories were subsequently identified. The five main themes are presented in Figure 4.1. These themes are supported by excerpts from the transcriptions of the interviews conducted with the participants. While in order to be brief in this mini-dissertation, not all verbatim quotes are provided, transcript references are provided for verification purposes. Privacy and confidentiality were maintained by using different letters as pseudonyms for the participants. To provide the reader with further insight into the prevalence of the various themes, subthemes and categories, basic frequency scores are provided in Table 4.1.

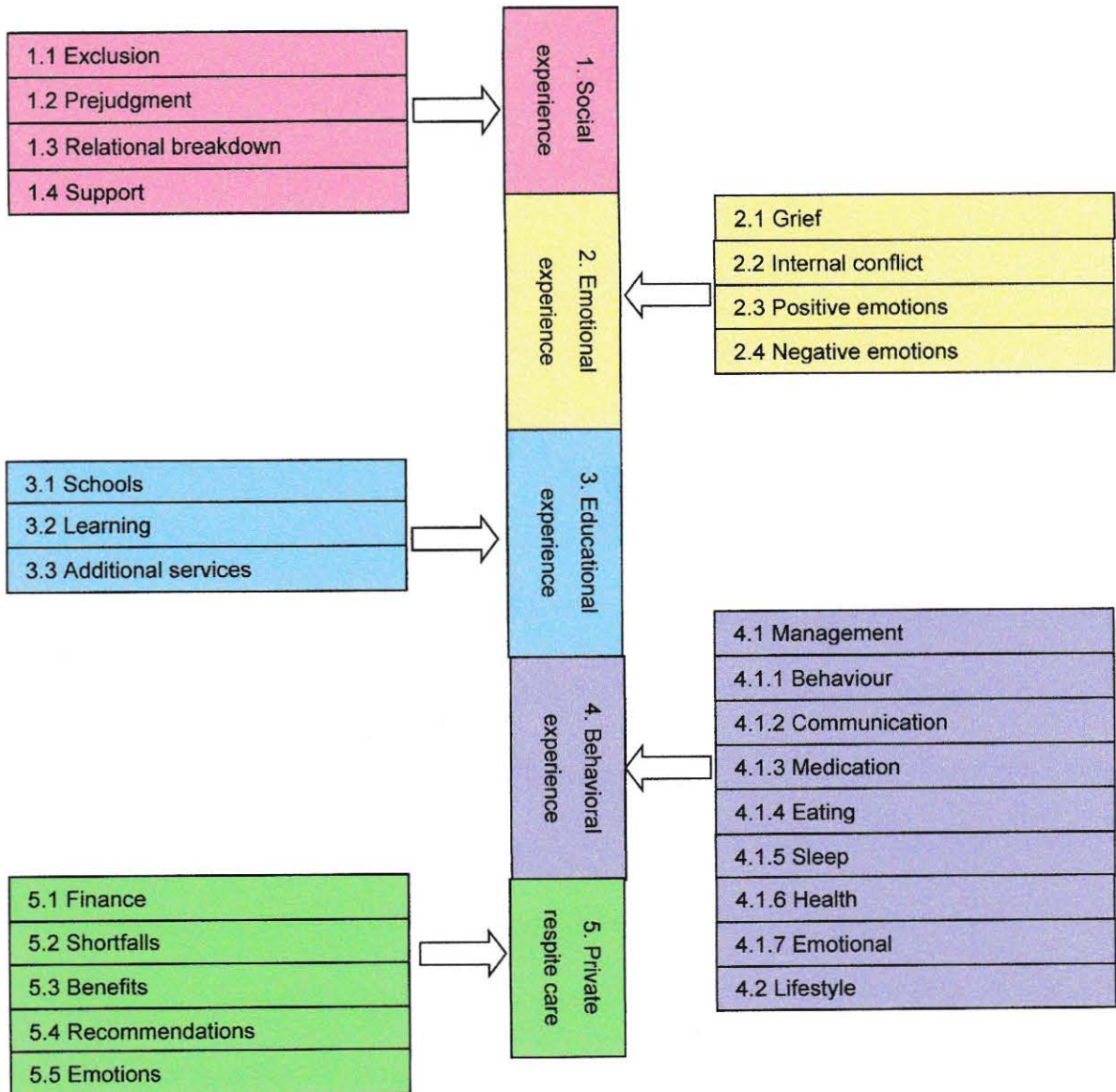


Figure 4.1: Main themes, subthemes and categories of the results

Table 4.1: Results of the data analysis indicating the five main themes, their related subthemes and categories, and their frequencies (Themes 1–5)

P1–3= Participant's individual interview		P1	P2	P3	Total
1. Social experience	1.1 Social exclusion	4	1	13	18
	1.2 Prejudgement	6	6	12	24
	1.3 Relational breakdowns	2	8	12	22
	1.4 Support	7	20	30	57
2. Emotional experience	2.1 Grief	5	27	47	79
	2.2 Internal conflict	1	8	7	16
	2.3 Positive emotions	2	6	13	21
	2.4 Negative emotions	9	49	85	143
3. Educational experience	3.1 Schools	3	10	8	21
	3.2 Learning	0	9	0	9
	3.3 Additional services	2	19	27	48
4. Behavioural experience	4.1 Management				
	4.1.1 Behaviour	14	31	40	85
	4.1.2 Communication	7	4	3	14
	4.1.3 Medication	1	8	10	19
	4.1.4 Eating	3	1	1	5
	4.1.5 Sleep	2	2	0	4
	4.1.6 Health	3	7	4	14
	4.1.7 Emotional	5	4	6	15
	4.2 Lifestyle	6	19	27	52
5. Private respite care	5.1 Finance	1	1	1	3
	5.2 Shortfalls	4	23	0	27
	5.3 Benefits	20	7	14	41
	5.4 Recommendations	6	11	1	18
	5.5 Emotions	1	0	0	1

The data that was used to arrive at the research results and the descriptions of the subthemes as well as categories were obtained from direct quotations from each of the research participants' input during the interviews. The three participants were identified as P1, P2 and P3. Additional abbreviations were used to identify the

participants' children, spouses, friends, family members, service providers and the facility from which they had been selected. For example, RR refers to Participant 1's child, CC refers to Participant 2's child, M refers to Participant 2's husband and LL refers to Participant 3's child.

To address the research aims and the research questions of this study, the research questions were divided into key concepts. The findings based on this research and the literature control are detailed below.

4.2 FINDINGS

To address the aims of this research, the researcher identified themes, subthemes and categories based on the participants' responses.

4.2.1 THEME 1: SOCIAL EXPERIENCE

Social experience can be defined as the 'direct observation of, or participation in society or its organisation as a basis for knowledge' (Adapted from: Social, 2018a, 2018b). Parents use respite care because of their children's inability to relate to a society who does not understand them and consequently treats them differently. The theme of social experience is further subdivided into additional subthemes such as social exclusion, prejudgement, relational breakdowns and support.

4.2.1.1 Subtheme 1: Social exclusion

Social exclusion as discussed in this study can be defined as the act of excluding individuals or a group from society based on their associated cultural perceptions, values and norms that typically shape interaction (Adapted from: PACS, 2016). It is as a result of social exclusion of their child with ASD, and often also of the immediate family members who are unable to conform to society norms, perceptions and values due to the special-needs of the child with ASD, that parents experience the need for respite care.

Participant 1 commented on how other children had teased her son (Interview P1, transcription U274, p. 7) and how people had told her that her son should not be present in the public domain (Interview P1, transcription U293, p. 8). Participant 3 shared how she had been ill-treated by members of the public and felt that she and her son had to withdraw from their own community, in which they had become

'targets' (Interview P3, transcription U77, p. 2; Interview P3, transcription U402, p. 9; Interview P3, transcription U267, p. 6).

4.2.1.2 Subtheme 2: Prejudgement

Prejudgement refers to people "forming an opinion about a situation or a person before knowing or considering all the facts" (Prejudge, 2018, para. 1). Parents are judged by members of a society who do not understand their situation on what they need to do to manage their child's unique needs. Parents therefore resort to using respite care to avoid being judged by society.

Participant 1 felt that society's general lack of knowledge about ASD caused them to judge not only her son's behaviour, but also the way she managed him (Interview P1, transcription U275, p. 8; Interview P1, transcription U285, p. 8). Participant 3 shared her experience of being judged by those around her and shared how she had been threatened as a result of her son's challenging behaviour after it had been witnessed and experienced by the community (Interview P3, transcription U233, p. 7; Interview P3, transcription U77, p. 3). Participant 2 felt that because of her son's normal appearance, she was not taken seriously by health care professionals when she sought medical support (Interview P2, transcription U659, p. 16).

The following excerpt supports this subtheme:

- *... I would tell them like look he has global developmental delay ... can you just kind of like approach him a little bit differently ... but because he looks [so] damn normal ... I always used to say we have to put him in a wheelchair, then they will pay attention to me* (Interview P2, transcription U659, p. 16).

4.2.1.3 Subtheme 3: Relational breakdown

A relational breakdown is "a problem within a relationship caused by poor communication" (Lalor, 2013, para. 3). Since parents of children diagnosed with ASD experience difficulties in their relationships with those around them, which is reported to typically become strained, they often seek assistance by making use of respite care to make it easier for them to maintain healthy relationships.

All three participants reported strained relationships with their spouses, other children and additional family members. Participant 1 reported that she had become a lone parent because of the constant arguments between her and her son's father,

who had struggled to adapt to his son's needs (Interview P1, transcription U222, p. 6; Interview P1, transcription U214, p. 6). This was also expressed by Participant 2, who found it so difficult to maintain a conversation with her husband that it often resulted in shouting and arguments (Interview P2, transcription U198, p. 5; Interview P2, transcription U23, p. 1). Participant 3's inability to manage her son's behaviour had caused a strained relationship with her family and friends (Interview P3, transcription U132, p. 4; Interview P3, transcription U401, p. 9; Interview P3, transcription U287, p. 7). The strained relationship between her son with ASD and his brother also contributed to her decision to place him in respite care.

The following excerpt supports this subtheme:

- *... my other son ... he was 2 or 3 then. It started traumatising him because he wouldn't sleep at night, he was scared of LL* (Interview P3, transcription U252, p. 6).

4.2.1.4 Subtheme 4: Support

Support refers to 'helping someone emotionally or in a practical way' (Adapted from: Support, 2018). Parents seek support from a respite care facility as they often receive no assistance for their child with special-needs from people and organisations in their communities.

All three participants commented on the lack of support from their families, people around them, and more specifically from the health care sector (Interview P1, transcription U80, p. 3; Interview P1, transcription U38, p. 2; Interview P2, transcription U367, p. 9; Interview P3, transcription U262, p. 7).

The following excerpt supports this subtheme:

- *Nobody cares, the institutions (referring to government institutions, such as a hospital) are there because they are meant to be there. Constitutionally (referring to the law of institutions being identified as service providers) they are meant to be there but they don't do anything* (Interview P3, transcription U349, p. 8).

All three participants mentioned their need for additional support. Participant 1 commented on the advice from the private respite care facility that supports her (Interview P1, transcription U38, p. 2), Participant 3 commented on her need for a

government grant for additional financial support (Interview P3, transcription U214, p. 6), Participant 2 admitted herself into a clinic for additional support (Interview P2, transcription U381, p. 9). She subsequently established a Whatsapp group and created a social platform in the form of a blog for additional support.

The following excerpt supports this subtheme:

- *... my blog ... I can just type [my heart out] ... it feels good when people say something ... It's good therapy for me* (Interview P2, transcription U244, p. 6).

4.2.1.5 Literature control: Social experience

Benderix et al. (2006) refer to social exclusion as social isolation. Parents who are caring for a child with ASD feel that they have to isolate themselves because of society's disapproval of the behaviour of children with ASD. Ludlow, Skelly, and Rohleder (2012) also maintain that the public perceives children with ASD as being 'naughty' and tend to be critical of the parents' parenting style. Corcoran et al. (2015) refer to the section on prejudgement as stigmatisation and report on the negative interactions parents experience as a result of the general public's lack of understanding of the reasons for the child with ASDs' seemingly 'uncontrollable' behaviour. Social communication and interaction difficulties challenge the family of the child with ASD and thus contribute to relational breakdowns within the family (American Psychiatric Association, 2013; Woodgate et al., 2008), with the result that parents often seek support from people around them, such as family, friends, medical practitioners and respite care (Corcoran et al., 2015).

4.2.2 THEME 2: EMOTIONAL EXPERIENCE

An emotional experience can be identified as 'relating to people's practical contact with and observation of facts or events relating to their emotions' (Emotional, 2018). This theme is related to the grief framework as proposed by Kübler-Ross and Kessler (2005). As a result of the parents' emotional experience, they have found support through the use of respite care. Within this theme are subthemes relating to grief, parents' internal conflict and their experience of both positive and negative emotions.

4.2.2.1 Subtheme 1: Grief

Grief refers to ‘an instance or cause of intense sorrow’ (Adapted from: Grief, 2018). In Chapter 2, the researcher discussed the grief framework as proposed by Kübler-Ross and Kessler (2005). Within this model, they identify five specific stages (denial, anger, bargaining, depression and acceptance) commonly experienced when a person is confronted with grief.

Denial is the first stage of grief as identified by Kübler-Ross and Kessler (2005). Participant 2 experienced denial when her son’s condition was initially diagnosed. Her attempts to “*prove the doctors wrong*” (Interview P2, transcription U67, p. 2), coupled with being convinced that her internal feeling, referred to as her “*gut feeling*” (Interview P2, transcription U131, p. 4) regarding her son’s diagnosis, could be associated with this particular stage in Kübler-Ross and Kessler’s framework. This was also evident when she commented on her parents-in-law’s refusal to accept that their grandson had ASD (Interview P2, transcription U633, p. 15).

The following excerpt supports this subtheme:

- *M’s parents don’t even, they live in the Eastern Cape, they don’t even like [to] admit to themselves that they have a disabled child, grandchild* (Interview P2, transcription U633, p. 15).

Participant 3 shared her experience of her son’s father denying their child’s condition: “... *he doesn’t want to speak about it*” (Interview P3, transcription U519, p. 12). She had separated from her son’s father before the child’s birth, but subsequently informed him that he had a child who had been diagnosed with ASD. The father does not make any contact with her and only pays child support because his current wife feels it is his obligation as a father (Interview P3, transcription U144, p. 4).

Anger is the second stage in Kübler-Ross and Kessler’s (2005) grief framework. Participant 2 felt anger when she received her son’s diagnosis and said, “*We were just not ready to receive that type of news*” (Interview P2, transcription U62, p. 2). Other feelings, such as guilt and a feeling that life was “unfair” were also noted. Participant 2 shared her experience of feeling guilty when she said: “... *it’s just the mind just never stops. There’s a lot of guilt and a concern*” (Interview P2, transcription U182, p. 5). Participant 3 shared her struggle to understanding why

this had happened to her son and how she felt that it was unfair: “*And it is just not fair, it is just absolutely not fair*” (Interview P3, transcription U702, p. 17) “... *this is not my fuck-up, and I’m sorry for the language, it’s not (my) fuck-up. It’s the universe’s fuck-up, it’s the Creators fuck-up. I did not do anything for LL to be like this.*” (Interview P3, transcription U677, p. 16).

Stage 3 in the grief framework is the bargaining process, during which individuals try to negotiate and establish a temporary truce (Kübler-Ross & Kessler, 2005). Participant 2 provided evidence of bargaining through her experience of feeling guilty about her son’s disorder and taking him to therapy. She explained: “... *you almost please yourself or appease yourself by ok, I’ve taken you to therapy*” (Interview P2, transcription U227, p. 6).

Stage 4 of the grief framework is characterised by feelings associated with depression (Kübler-Ross & Kessler, 2005). Participant 2 indicated that she had gone through this stage after realising that her son’s disorder was for life (Interview P2, transcription U106, p. 3). Because of her depression, she had admitted herself into a clinic. She still needs anti-depressants to cope with the situation (Interview P2, transcription U381, p. 9). She also talked about the difficulties her husband experienced in dealing with his son’s diagnosis: “*He doesn’t open up, so he’s just getting sadder and sadder and skinnier and skinnier*” (Interview P2, transcription U435, p. 11).

Stage 5, the acceptance stage, is the last stage of Kübler-Ross and Kessler’s (2005) grief framework. Participant 1 shared her experience of realising that her son had special-needs, that he should be treated differently and should be treated with more care and understanding.

The following excerpt supports this subtheme:

- *He’s [just] a different type of child* (Interview P1, transcription U299, p. 8).

Participant 2 felt at ease once she had come to terms with her son’s diagnosis and was entering the acceptance stage. She expressed relief when she received the final diagnosis of her son’s condition: “*Finally, at last*” (Interview P2, transcription U124, p. 4). Acceptance helped her to develop an understanding of her son’s unique behaviour: “*He is not just being naughty ... There’s reasons*” (Interview P2, transcription U127, p. 4). Once she had accepted her son’s condition, Participant 2

stopped trying to fix her son: *“I’ve been trying to fix CC for a long time, but I’m slowly much better at not fixing him anymore”* (Interview P2, transcription U418, p. 10). She elaborated by saying that she realised that she should *“stop trying something that wasn’t working”* (Interview P2, transcription U33, p. 1). Participant 2 started accepting her son’s behaviour and became content with just being with him through the progression of his disorder, *“... just being around him ... if he’s quirky or difficult, just being around him while he is like that and not trying to take it away from him ... it’s a whole new approach”* (Interview P2, transcription U423, p. 11). Her acceptance was further evident from her comments: *“it grew on us gradually”* (Interview P2, transcription U170, p. 5) and *“... you grow with it”* (Interview P2, transcription U173, p. 5). She shared how her husband had come to terms with his son’s disorder and how he had accepted that his dreams for the boy would not be realised – *“he had to let go of that (expectation/dream)”* (Interview P2, transcription U431, p. 11).

4.2.2.2 Subtheme 2: Internal conflict

Internal conflict can be defined as ‘relating to a serious disagreement within the mind’ (Adapted from: Conflict, 2018; Internal, 2018). Parents of children diagnosed with ASD who experience conflicting internal emotions around the diagnosis of their child and the management of those emotions often seek support from a respite care facility to help them to deal with their conflicting emotions.

Participant 1 shared how, when she found that she was unable to manage her son’s special-needs, she had tried to understand her loss and had struggled because of her inability to live up to her idea of what being ‘a good mother’ involved.

The following excerpts support this subtheme:

- *In the beginning when I first used to bring him here I used to feel very guilty ... I’m a bad mother* (Interview P1, transcription U249, p. 7).
- *I’m just doing the best that I can ... I could’ve given him up for adoption. I could have left him on the side of the road* (Interview P1, transcription U249, p. 7).
- *I don’t think I’m a bad mom. I think I’ve made the right decisions ... I think that RR is a lot better than what he was (now being in respite care) and that’s the main thing* (Interview P1, transcription U252, p. 7).

Participant 2 experienced internal conflict when she had to take her son to the hospital after he had sustained an injury. She felt as if she was ‘*torturing her son*’ and commented: “*I’m the one who again, that’s how I feel I’m now the one who now brought you here for some torture*” (Interview P2, transcription U316, p. 8).

For Participant 3, her internal struggle at some stage revolved around extreme thoughts about taking her own, or her son’s life, and considering how such an act would affect her other children. The transcriptions reported the following as evidence of this internal conflict:

- *I had finally gathered the strength to just end it all because I was not gonna continue. It was pointless, and if I was going to kill LL coz one of my options was that I’m going to kill LL and I’m going to go to jail. I’m going to get out in 20 years and at least my other children are still small* (Interview P3, transcription U339, p. 8).

She elaborated on this internal struggle by sharing her thoughts about her child and how she felt the need to hide her emotions to survive her perceived loss:

- *People think because I don’t go and see LL that I have forgotten, and I haven’t, I cry inside ... I was on end each day, he doesn’t leave my head* (Interview P3, transcription U415, p. 10).
- *He consumes my thoughts* (Interview P3, transcription U416, p. 10).
- *I just walk around chatting to people, laughing and I just cry inside* (Interview P3, transcription U734, p. 17).

4.2.2.3 Subtheme 3: Positive emotions

Positive emotions refer to ‘the expressing of, or implying affirmation, agreement or permission as a state of feeling’ (Adapted from: Emotion, 2018; Positive, 2018). Parents often express feelings of affirmation, agreement or permission in dealing with their child’s diagnosis of ASD.

All three participants expressed a positive emotion associated with hope, which is facilitated by the use of respite care. Participant 1 held on to the hope that as her son grew older, his future endeavours would become easier. “*I think in my mind I just said to myself this is not gonna, this is not always [going to] be like that ... at some stage when he gets a little bit older and he is more calm ... maybe towards the Standard 4-ish thing. I think things will be very different*” (Interview P1,

transcription U137, p. 4). Participant 2 held on to the hope that she would get positive answers with regards to her son's diagnosis and stated: "*Eventually I didn't stop, I did everything*". When her son's condition was finally diagnosed, she was happy: "*Ooh no, I was so happy*" (Interview P2, transcription U120, p. 3). She elaborated by giving credit to her husband for his commitment to his son: "*Very dedicated to CC*" (Interview P2, transcription U410, p. 10). Participant 3 held on to the hope that her son would be properly cared for and acknowledged him by saying: "*LL has got the most beautiful smile*" (Interview P3, transcription U321, p. 8).

4.2.2.4 Subtheme 4: Negative emotions

Negative emotions can be defined as 'expressing or implying denial, disagreement or refusal as a state of feeling' (Adapted from: Emotion, 2018; Negative, 2018). All three participants admitted that there had been a time when they had suffered an emotional breakdown and could no longer cope. At such times, they had sought the support offered by respite care. Participant 1 commented, "*I couldn't do it anymore, ... I think I just started hitting my breaking point*" (Interview P1, transcription U80, p. 2), and Participant 2 said: "*... my world just fell apart. And I just said I can't do this*" (Interview P2, transcription U372, p. 9). Participant 3 shared the following: "*I didn't want to live. It was just too much, I didn't want to live and I didn't want to leave my other children in this cruel world. I hated life, I hated everything*" (Interview P3, transcription U373, p. 9).

These emotional breaking points were accompanied by additional negative feelings such as hurt, stress, exhaustion, guilt, regret, loneliness, anger, worry/concern, desperation, uncertainty, feelings of being overwhelmed, resentment, hate, loss, suffering and depression, which were evident in all three participants' transcriptions.

The following excerpts support this subtheme:

- *It's just a lot and it's constant and it's exhausting* (Interview P2, transcription U226, p. 6).
- *I was just desperate and alone and angry that no-one was coming to help me ... It's a lot of negative self-destructive thoughts all the time* (Interview P2, transcription U386, p. 10).
- *Even if he doesn't sleep under my roof, I mean, I think of him all day. And I worry* (Interview P2, transcription U460, p. 11).

Participant 2 further commented that she felt as if she was always '*settling*' in terms of finding institutions to assist her with her son's care and needed constant '*reassurance*' from the facility to ease her worry and anxiety about not having her son at home (Interview P2, transcription U346, p. 9).

Participant 3 referred to the various negative feelings experienced as follows:

- ... *the constant phone calls, the anxiety* (Interview P3, transcription U91, p. 3);
- ... *they would complain about LL. It was like exhausting* (Interview P3, transcription U175, p. 5);
- ... *and doesn't hurt anybody and we're all anxious and thinking that he's going to do something* (Interview P3, transcription U192, p. 5);
- *I sit every day worrying* (Interview P3, transcription U419, p. 10); and
- *if I keep living in this constant depression* (Interview P3, transcription U429, p. 10).

Participant 3 elaborated by sharing that all these negative feelings had led to her contemplating suicide as she felt that she could not do anything more to assist her son. To her, respite care assisted in managing such feelings:

- *I've used all the resources* (Interview P3, transcription U465, p. 11).
- *I had decided I'm just going to bomb the house with all of us there. I mean I had it all figured out. I heard it from Google. I had the swiftest ways to end all our lives* (Interview P3, transcription U345, p. 8).

4.2.2.5 Literature control: Emotional experience

Ludlow et al. (2012) report that parents who struggle to manage their children's behaviour experience a huge amount of stress. Van Tongerloo, Wijngaarden, Van der Gaag, and Lagro-Janssen (2014) maintain that most parents of children with ASD feel guilty and consequently become more likely to develop depression and other anxiety disorders. Corcoran et al. (2015) report that parents whose children are diagnosed with ASD experience denial, grief and disappointment, and often experience stress, strain, worry, concern and exhaustion while trying to manage their children's behaviour.

4.2.3 THEME 3: EDUCATIONAL EXPERIENCE

An educational experience can be defined as 'the direct observation of, or participation in serving to educate or enlighten as a basis of knowledge' (Adapted from: Education, 2018; Educational, 2018). Parents of children who have been diagnosed with ASD shared their direct observation of, or participation in seeking educational services for their children. The lack of support from the education system has increased their need for respite care.

4.2.3.1 Subtheme 1: Schools

A school can be defined as 'an institution for educating children' (Adapted from: School, 2018). All three participants shared their experience of trying to find suitable schools for their child with special-needs and the challenges faced when trying to get them admitted into schools. This has contributed to parents' decision to seek assistance from a respite care facility. The challenges referred to above included a shortage of schools, being placed on waiting lists, being rejected, being told that they did not meet the admission requirements of the schools, the heavy financial burden and schools not providing adequate feedback or not being able to care for their child's special-needs.

All three participants commented on the problems relating to admission requirements, waiting lists and rejection by various institutions.

The following excerpts support this subtheme:

- *We also tried remedial schools. And remedial schools they rejected us twice (Interview P1, transcription U322, p. 9).*
- *He was not potty-trained yet, but that was a requirement (Interview P2, transcription U30, p. 1).*
- *I've called everywhere in the country ... and put on waiting lists (Interview P3, transcription U65, p. 2).*
- *So most places I went to almost all of the places I went to it was an issue that they can't take him he doesn't speak and the fact that he has autism and then he doesn't speak it would be a no no (Interview P3, transcription U72, p. 2).*

- *The government institutions do not want him, the government wants nothing [to do with her son], the South African government wants nothing to do with LL, absolutely nothing* (Interview P3, transcription U448, p. 10).

4.2.3.2 Subtheme 2: Learning

Learning can be defined as ‘the acquisition of knowledge or skills through study, experience, or being taught’ (Learning, 2018). Parents of children who have been diagnosed with ASD seek support from a respite care facility to help them manage their children’s behaviour. Participant 2 had a blog that she devoted to her son. She explained that this was not only an outlet for her, but also a platform where other parents could seek information, and mentioned that by answering other parents’ questions, she learnt more about her son’s condition: *“You find people who are touched by it (the participants blog) and who are informed by it ... it’s a platform for educating”* (Interview P2, transcription U257, p. 7). *“To try and answer a question I first just go read up and just make sure I am right on my answer so then I’m teaching myself”* (Interview P2, transcription U259, p. 7).

This is of vital importance as she pointed out that *“South Africa [doesn’t] know what autism is”* (Interview P2, transcription U569, p. 14), highlighting the lack of knowledge on this specific condition and the need for more education on ASD. She highlights the fact that there has been an increase in the frequency of children diagnosed with ASD. *“There is a big lack of just defining it and telling people like it is real and it’s not going away and it is actually being diagnosed more and more”* (Interview P2, transcription U675, p. 16). This was shared when she related her experience of taking her son to hospital: *“I’ve taken him to hospital at times when he was ill, just running a fever or something, when he was so small and with all the ear infections and stuff ... I would tell them look, he has [a] global developmental delay, ... can you just kind of like approach him a little bit differently. But because he looks [so] damn normal there was none of that ... so I always used to have to put him in a wheelchair. Then (only) will they pay attention to me ... and notice that he is different”* (Interview P2, transcription U660, p. 16). This excerpt highlights the problems faced by parents who have a child with special-needs, but does not present with any physical disabilities.

Participant 3 also shared her thoughts on the lack of support from schools and hospitals due to the lack of education on this disorder in the community.

- *We went back and forth to hospitals and things and there were medications given, he was given this treatment and I didn't even know what the treatment was because I think at that point, doctors just needed to put us at ease by giving us something* (Interview P3, transcription U105, p. 3).
- *They would complain about LL, it was exhausting* (Interview P3, transcription U176, p. 5).
- *Nobody cares in the public sector. I mean you go to a social worker in the public sector and they ask you what autism is* (Interview P3, transcription U584, p. 14).

4.2.3.3 Subtheme 3: Additional services

Additional services are services that are extra or supplementary to what is already available (Adapted from: Additional, 2018; Service, 2018). Parents of children diagnosed with ASD seek additional support and thus pursue the use of respite care. Additional services such as the assistance provided by a domestic worker (Participant 1), occupational therapists, physiotherapists, speech therapists, neurologists, psychiatrists, general practitioners, emergency service employees, social workers and psychologists were mentioned.

4.2.3.4 Literature control: Educational experience

Ludlow et al. (2012) report on the lack of support services and the need for additional services to support parents. Mackintosh, Myers, and Goin-Kochel (2005) evaluated the benefits of educating parents on ASD and found that some parents were empowered by shared knowledge on ASD, while others experienced increased anxiety because of the negative perceptions of their children's disorder. Myers and Johnson (2007) highlight the benefits of educational intervention in schools and emphasise the use of therapies such as applied behavioural analysis therapy, and structured teaching methodologies, such as TEACH, speech and language therapy, occupational therapy and sensory integration therapy to assist children, and assist parents in managing their child's behaviour as well as enhancing the communication skills of their children with ASD. Thomas, Morrisher, and McLaurin (2007) report that speech and language therapy is the most frequent therapy used for children with ASD.

4.2.4 THEME 4: BEHAVIOURAL EXPERIENCE

Behavioural experience can be defined as an act of involvement whereby a person encounters subjective feelings and gains knowledge and skills in a specific situation (Adapted from: Behaviour, 2018; Experience, 2018). In the case of this study it would refer to the experiences of a participant before the services of respite care were sought (VandenBos, 2007). This theme is broken down into two subthemes, namely management and lifestyle, and how these behavioural experiences relate to parents' decision to make use of respite care. The subtheme management is further subdivided into the categories behaviour, communication, medication, eating, sleep, health and emotions, which further explains why parents resort to making use of respite care.

4.2.4.1 Subtheme 1: Management

Management refers to a process that involves planning, organising, leading and controlling (Koontz & Weihrich, 1990). With reference to the current study, management can be associated with parents' experience of control or a lack thereof with regards to the symptoms with which their children with ASD present, which might result in their decision to make use of the support offered by respite care. This can be broken down into additional categories to provide further evidence for why parents seek support from the services provided at a respite care facility.

4.2.4.1.1 Category 1: Behaviour

Marriam Webster defines behaviour as 'the way in which someone conducts oneself or behaves' (Behaviour, 2018). The three participants all commented on how they struggled to manage their children's behaviour. The stress caused by this resulted in parents opting for the use of respite care services.

Participant 1 commented that she found it extremely difficult to manage her son (Interview P1, transcription U17, p. 1), which made it difficult to discipline him (Interview P1, transcription U26, p. 1).

Participant 2 explained that her son's behaviour made it difficult to manage him. She also mentioned that he was violent, was not reaching his developmental milestones, had low muscle tone and experienced sensory difficulties.

The following excerpts support this category:

- *Developmental milestones were never reached, some of them at almost 11 he hasn't reached yet* (Interview P2, transcription U25, p. 1).
- *Spinning that little wheel of that little car, he's not playing with the car, he's just (moving it), *tik *tik *tik* (Interview P2, transcription U86, p. 3).
- *Flopping around here ... he can't keep still* (Interview P2, transcription U105, p. 3).
- *OCD type child* (Interview P2, transcription U136, p. 4).
- *Sensory processing things* (Interview P2, transcription U137, p. 4).
- *Biting himself* (Interview P2, transcription U175, p. 4).
- *Screaming, ballistic uncooperative child* (Interview P2, transcription U190, p. 5).
- *Him being so violent* (Interview P2, transcription U393, p. 10).

Participant 3 also commented on her child's violent behaviour, which was a threat not only to himself, but also to those around him.

The following excerpts support this category:

- *New people removing him from his environment and he resisted* (Interview P3, transcription U54, p. 2).
- *Uncontrollable behaviour, him running away, going up rooftops and trees* (Interview P3, transcription U70, p. 2).
- *LL wouldn't sit still* (Interview P3, transcription U77, p. 3).
- *LL would be grabbing them (people around LL) and grabbing the teachers and try grab people's glasses and try break people's fingers ... he just wanted to hurt anything that breathes* (Interview P3, transcription U121, p. 3).
- *Destroying property* (Interview P3, transcription U131, p. 4).
- *He almost killed me* (Interview P3, transcription U240, p. 4).
- *Terrorising the society* (Interview P3, transcription U268, p. 7).
- *He [has] hurt himself* (Interview P3, transcription U369, p. 7).

4.2.4.1.2 Category 2: Communication

Communication can be defined as 'the imparting or exchanging of information by speaking or writing, or by using some other medium' (Communication, 2018). All three participants commented on their children's inability to communicate and how

this made it very difficult to manage them. Parents opted for respite care as they were unable to communicate with their children and therefore struggled to manage them.

Participant 1 mentioned that her son only started speaking at the age of four years (Interview P1, transcription U22, p. 1), and that it had been difficult to make him understand what was being communicated to him (Interview P1, transcription U24, p. 1). "*Reasoning with him was also difficult*" (Interview P1, transcription U32, p. 1).

Participant 2 stated that it was difficult to get her son to understand what she was saying (Interview P2, transcription U205, p. 5) and that due to his limited vocabulary, he was unable to communicate with her (Interview P2, transcription U488, p. 5).

Participant 3's son also had a limited vocabulary (Interview P3, transcription U49, p. 1) and used gestures to try to communicate with her (Interview P3, transcription U104, p. 2).

4.2.4.1.3 Category 3: Medication

Medication refers to 'a medicinal substance, or to the act of medicating' (Adapted from: Medication, 2018). All three participants mentioned the use of different types of medication, such as Ritalin, Risperidone, Lithium, Lamictol, Rescue Drops and Sildenafil to assist in regulating their child's emotions (Interview P1, transcription U143, p. 4), reduce their anxiety (Interview P2, transcription U153, p. 4) and further manage their behaviour (Interview P3, transcription U562, p. 13).

4.2.4.1.4 Category 4: Eating

Eating is the act during which 'a person puts food into his/her mouth, chews it and swallows it' (Adapted from: Eat, 2018). Participants 1 and 3 both mentioned their children's lack of appetite (Interview P1, transcription U168, p. 5) and occasional refusal to eat (Interview P1, transcription U173, p. 5; Interview P3, transcription U102, p. 3).

4.2.4.1.5 Category 5: Sleep

Sleep is 'the natural periodic suspension of consciousness during which the strength of the body is restored' (Adapted from: Sleep, 2018). Participants 1 and 2 reported that their children did not sleep well (Interview P1, transcription U226, p. 6; Interview

P2, transcription U583, p. 14) and needed to be comforted when they were unable to sleep (Interview P1, transcription U227, p. 6).

4.2.4.1.6 Category 6: Health

Health is the state of being free from illness or injury (Health, 2018). Participant 2 mentioned that her child was prone to middle-ear infections (Interview P2, transcription U42, p. 2) and injuries (mostly from biting) that became infected (Interview P2, transcription U175, p. 5). Since he was unable to tell her when he was experiencing pain or had been injured, his injuries often went untreated unless they were noticed by someone and treated (Interview P2, transcription U286, p. 7). When he was younger, Participant 3's son would get sick (Interview P3, transcription U610, p. 14) and experienced seizures (Interview P3, transcription U27, p. 1).

4.2.4.1.7 Category 7: Emotions

Emotion is defined as a state of feeling (Emotion, 2018). Participant 1 shared how her son screamed most of the time as a result of negative emotions he was experiencing (Interview P1, transcription U217, p. 16), and Participant 3 told of her son's "*lonely cries*" (Interview P3, transcription U112, p. 3) and said that he hated the people around him (Interview P3, transcription U222, p. 6).

4.2.4.2 Subtheme 2: Lifestyle

Lifestyle can be defined as the way in which a person lives (Lifestyle, 2018). The participants' lifestyles were determined by how they were able to manage their children's symptoms. Management involves planning, organising and controlling (Koontz & Weihrich, 1990). Parents' inability to manage their children's behaviour would have affected their lifestyles and would have encouraged the use of respite care.

All three participants agreed that their children's condition had changed their lifestyles and that it was challenging to maintain a balance between meeting the needs of their children and preserving their careers.

The following excerpts support this subtheme:

- *And I lost my job* (Interview P2, transcription U566, p. 14).

- *I could never take him in a shop with me after work. Just quickly we need to get a bread and a milk and ... next minute he's falling on the floor (Interview P2, transcription U128, p. 4).*
- *I couldn't even go to the meeting where they now told us what the diagnosis was because I had to work (Interview P2, transcription U103, p. 3).*

Participant 2 shared how her relationship with her husband had changed after it became evident that their son had special-needs: *"We were more relaxed. We were more talkative. We were more spontaneous. As far as just going camping or going to a friend or inviting people over (this was her experience prior to having her son)."* (Interview P2, transcription U159, p. 4). She also talked about how having a child with special-needs forced them to change their attitude: *"We had to quickly stop judging others because we were also now a different family"* (Interview P2, transcription U157, p. 4).

Participant 2 elaborated on her struggle to maintain the lifestyle she had established with her husband and other child, and how this was a challenge:

- *... that's hard to do constantly you walk in here after five, everybody is hungry, you have to put in a load of washing, you have to have a conversation with your husband, which we could never have because the minute we would try and speak he (CC) would [be] trying to join us or copy ... we could never just finish up a conversation (Interview P2, transcription U203, p. 5).*

This resulted in her rethinking the way she spent money: *"Even now that he doesn't live here ... you think twice before you just go and spend a lot of money on a fun outing at Monte [Casino]"* (Interview P2, transcription U180, p. 11).

With regards to the challenges of trying to keep a job while also caring for her child with special-needs, Participant 3 said:

- *... I just could not take the strain ... the constant phone calls, the anxiety, not knowing if I am going to be at work for the whole day or I'm going to be called because something has happened (Interview P3, transcription U92, p. 3).*
- *I've lost two jobs. Not because I was fired, but because I left because it becomes uncomfortable because you [are] this employee who is never there,*

you've got stories every day, you not performing because you never there
(Interview P3, transcription U418, p. 10).

Participant 3 experienced financial strain as a result of her son's destructive behaviour:

- *I owed strangers money, I owed my family money, I owed everybody money. I got paid to pay things, pay things that LL was breaking* (Interview P3, transcription U232, p. 6).

She emphasised how her son's needs had consumed most of her time and how this had strained her relationship with her other children:

- *And our lives became about LL doing his things* (Interview P3, transcription U260, p. 6).
- *I would wait for him to either take a nap or I would drug him so that I could go to the shops and get us food* (Interview P3, transcription U293, p. 7).

4.2.4.3 Literature control: Behavioural experience

Having a child diagnosed with ASD and learning to manage the condition is reported to have a significant impact on the lifestyles of both the child and family (Benderix et al., 2006; Schlebusch, Samuels, & Dada, 2016; Sivberg, 2002a, 2002b; Van Tongerloo et al., 2014). Alli et al. (2015) emphasise the difficulties parents are confronted with in managing their child's behaviour and how this impacts on their families. Of particular importance is the difficulty with regard to communication and parents' struggle to communicate with their child with ASD (Alli et al., 2015). Keenan, Dillenburger, Doherty, Byrne, and Gallagher (2010) report on how parents struggle to deal with their child's abnormal sleep patterns and challenging behaviour, which inevitably leads to stress. Although there is no cure for ASD, Louw, Bentley, Sorsdahl, and Adnams (2013) report on the use of medication to help parents to manage their child's behaviour. The treatment of children with ASD with drugs such as risperidone, antidepressants and stimulants reported by Louw et al. (2013) is aligned with the findings of the current study.

4.2.5 THEME 5: RESPITE CARE

Respite care can be defined as an intermittent service offered to the parents of children with special-needs who are in need of an occasional 'short break' from their

obligations in caring for their child who presents with challenging behaviour (Harper et al., 2013). For the purpose of the current study, participants were selected from a private respite care facility that offers this service to the parents of children diagnosed with ASD.

4.2.5.1 Subtheme 1: Finance

Finance is defined as the management of money (Finance, 2018). Finance as a subtheme of respite care relates to the funding of respite care services (Kurt, 2018). The financial strain placed on families as a result of having to pay for private services was explored.

The following excerpts support this subtheme:

- *Because money is an issue even if you are earning a good salary you can't just always ... you kind of have to spend your money wisely (Interview P2, transcription U264, p. 7);*
- *... only people who are willing to take him is the private health care, which costs a lot of money (Interview P3, transcription U451, p. 10).*

4.2.5.2 Subtheme 2: Shortfalls

Shortfalls within this context relate to the negative aspects associated with the service provided by private respite care facilities (Shortfall, 2018). Themes such as poor management, lack of communication and problems with the staff of Facility X were noted.

Participant 2 commented on how the management of Facility X had changed, which had also resulted in changes with regards to the services offered and the staff.

- *But I felt a bit concerned towards the time that we left that the same standard was not still there when the manager, the owner X, left (Interview P2, transcription U274, p. 7).*
- *But when management changed I don't know what happened with as far as their food and stuff, but I have pictures of CC being so skinny (Interview P2, transcription U342, p. 7).*

Participant 2 further commented on the lack of communication from Facility X.

- *True as Bob, the nurse there said he was gonna drain this (an injury her child had). So he stuck a needle in this finger and he pulled out the blood. Without my permission, my consent nothing (Interview P2, transcription U292, p. 7).*
- *I've sent messages which were just read and not answered (Interview P2, transcription U500, p. 12).*

Participant 2 commented on the quality of service rendered by the staff at Facility X and how they were unable to take proper care of her child.

- *Their medical staff wasn't taking very good care of a hand injury that CC had (Interview P2, transcription U277, p. 7).*
- *Staff that was there at Facility X were not trained (Interview P2, transcription U351, p. 9).*
- *They were bathed and fed and that's about it (Interview P2, transcription U354, p. 9).*
- *Being on their cell phones (Interview P2, transcription U362, p. 9)*

4.2.5.3 Subtheme 3: Benefits

Used in this context, the term benefit relates to the advantages associated with respite care service (Benefit, 2018). The benefits to utilising respite care that were mentioned included: receiving advice/support, a change in the child's behaviour, educational benefits, the convenient location and the services offered by the staff. Specific reference was made to how this service allows both the parents and their children a chance at life and ultimately contributes to a better life – psychologically, socially, physically and emotionally.

Participant 1 mentioned the following benefits that respite care has afforded her and her son:

- *He's (her son) [has] calmed down a lot from being here (at the respite care facility) (Interview P1, transcription U27, p. 1).*
- *The advice I was getting was helping me cope (Interview P1, transcription U37, p. 2).*
- *... it got us back on our feet (Interview P1, transcription U103, p. 3).*

- ... *he is learning stuff* (Interview P1, transcription U111, p. 3).
- *They have taken more time with RR* (Interview P1, transcription U116, p. 4).
- *He is off* (referring to her son's medication) (Interview P1, transcription U147, p. 4).
- *RR, he has his friends here* (Interview P1, transcription U258, p. 7).
- ... *better off here* (at the respite care facility) *with his friends like T because they all living in the same world* (Interview P1, transcription U259, p. 7).
- *People here are more sympathetic* (Interview P1, transcription U305, p. 8).
- ... *bonding has actually improved* (referring to her relationship with RR) (Interview P1, transcription U346, p. 9).

Participant 2 commented as follows on the facility's appearance and how the environment facilitated her son's social growth:

- [The] *place was beautiful* (Interview P2, transcription U270, p. 7).
- *The location is aesthetically pleasing to the eye* (Interview P2, transcription U272, p. 7).
- *Sensory room was stunningly beautifully done they enjoyed it, he did look happy* (Interview P2, transcription U339, p. 9).
- *I don't want him to grow up alone so I'm keeping him in a group setting* (Interview P2, transcription U529, p. 13).
- *While it was managed properly it was good* (Interview P2, transcription U329, p. 8).

Participant 3 commented on the additional services that were offered by the private respite care facility:

- *They have horse-riding* (Interview P3, transcription U599, p. 14).
- ... *one-on-one's with psychiatrists* (Interview P3, transcription U599, p. 14).
- *Occupational Therapists (OT)* (Interview P3, transcription U600, p. 14).
- *House nurses* (Interview P3, transcription U606, p. 14).

She commented on Facility X's management of her son's violent behaviour, and how the staff had been trained to deal with this kind of behaviour as well as meet her son's basic needs.

- *LL was violent with them as well (Interview P3, transcription U368, p. 9).*
- *He's broken things and they've had to fix them where he's hurt himself and they've had to take him to doctor's to access resources (Interview P3, transcription U369, p. 9).*
- *Grooming and just all those sorts of things there, so that the child is sort of at home...you have private people who go there and look after the grooming of your child (Interview P3, transcription U3603, p. 14).*
- *The basic needs, you have them there (Interview P3, transcription U608, p. 14).*

Participant 3 explained how respite care had saved her life and said it was comforting to know that her son's basic needs were being met. She added that private health care is very expensive, but that they were the only people willing to take her son (Interview P3, transcription U450, p. 10).

4.2.5.4 Subtheme 4: Recommendations

A recommendation can be defined as a suggestion or proposal regarding the best course of action, especially one put forward by an authoritative body (Recommendation, 2018). During the semi-structured interview, participants were asked whether there was anything they would recommend or suggest to improve the service of respite care. Their suggestions included offering feedback to parents, a controlling body to facilitate more formal collaboration between the facility and parents, and making services of this kind available throughout South Africa.

All three participants offered recommendations to improve the current service of respite care. This can be done by improving communication as well as increasing the availability of respite care facilities.

Participant 1 recommended the following:

- *... feedback like, he is not eating his food ... progress reports at the end of the month to each parent to say these are the difficulties that we experienced with your child this month (Interview P1, transcription U184, p. 3).*

- ... *increasing the number of schools that have residential facilities (respite care)* (Interview P1, transcription U308, p. 8).

It was clear that Participant 2 regarded communication as a major concern. She recommended that:

- ... *the facility communicate more with parents* (Interview P2, transcription U333, p. 8).
- ..., *please just a WhatsApp, just tell me ...* (Interview P2, transcription U336, p. 8).
- *You need some reassurance every day* (Interview P2, transcription U337, p. 8).

She further emphasised the need for a more formal platform and suggested that there should be a controlling body:

- ... *a [corporate] body or a somewhere where you can lodge a complaint* (Interview P2, transcription U510, p. 9).
- ... *proper neutral body that you can go and state your case* (Interview P2, transcription U514, p. 13).
- ... *they should have parent governing bodies ... it should be more formal with meetings and agendas* (Interview P2, transcription U523, p. 13).

Participant 3 also recommended the establishment of more respite care facilities in South Africa (Interview P3, transcription U568, p. 13).

4.2.5.5 Subtheme 5: Emotions

Emotion is defined as a state of feeling (Emotion, 2018). Emotion within this section, refers to both the children as well as parents state of feeling when utilising the service of respite care.

The following excerpts support this subtheme:

- ... *he misses home hey* (Interview P1, transcription U132, p. 4).
- *Any kid would just want to be home all the time* (Interview P1, transcription U134, p. 4).
- *It kills me kind of* (Interview P1, transcription U135, p. 4).

- ... concerned me has been like does he have enough blankets at night (Interview P1, transcription U158, p. 5).
- Like clothes, um, like only a mom could ever do it (Interview P1, transcription U159, p. 5).

4.2.5.6 Literature control: Private respite care

Chan and Sigafoos (2001) highlight the significant decline in stress and the increased ability to cope with caring for their child's special-needs by mothers who make use of respite care. The mothers who participated in this study reported that they were happier and conveyed an increased sense of well-being (Chan & Sigafoos, 2001). Harper et al. (2013) maintain that when respite care is used, both the parents and the family are less stressed and their quality of life improves. It was further reported that respite care reduces the social isolation/exclusion of families in the community and offers an educational aspect in that parents have an opportunity to learn from trained respite carers and to observe how the workers interact with the children in their care (Chan & Sigafoos, 2001).

4.3 CONCLUSION

In this chapter, the researcher presented the results of my data analysis by providing and discussing the various themes, subthemes and categories found in the data. In the next chapter, the researcher will report on the findings of the study through the interpretation lens as related to the research questions and the theoretical framework of this study.

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Chapter 5

Theoretical Framework, Conclusion and Recommendations

5.1 INTRODUCTION

In this chapter, the findings of the research are discussed in relation to the underpinning bioecological framework. The primary and secondary research questions, as posed in Chapter 1, are then addressed. The limitations of the current study are explored and its contribution to both research and practice is highlighted, followed by concluding remarks.

5.2 THEORETICAL FRAMEWORK

The theoretical framework used in the current study was based on Bronfenbrenner's (1994) bioecological theory. The five levels of this framework provided me with the framework in which the findings are now presented.

The first level of Bronfenbrenner's bioecological theory is the Microsystem, which involves the psychological effects that have a direct impact on the parents of children diagnosed with ASD. It was found that on a physical level, parents find it difficult to cope with their child's behaviour, which in turn affects their social experience. Within the social environment, parents feel excluded or opt to exclude themselves as they are being prejudged by their own families. They also experience a breakdown in their relationships with members of their immediate family, largely due to a lack of support, misunderstanding and a lack of guidance on how to manage their child's disorder.

Parents reported that relationships with their spouses, family members and other children had become strained. It was found that emotionally, parents experience a sense of grief associated with their children's condition, and that Kübler-Ross and Kessler's (2005) stages of grief framework is applicable to parents dealing with the realities of managing a child with ASD.

Conflicting emotions relating to the desire to be good parents and the problems associated with dealing with their child's challenging behaviour, as well as concerns about avoiding public criticism while trying to deal with their children's behavioural problems were found to impact this level. The negative emotions that are

experienced contribute to emotional breakdowns, which in turn contributes to parents' decision to seek assistance in the form of respite care to manage their child's behaviour and promote their own psychological well-being.

The Exosystem involves the influences of systems outside that of the Microsystem (Bronfenbrenner, 1994), which can still potentially impact on the family Microsystem, as experienced by the parents. The experiences of parents who find it difficult to continue in their occupations were noted as experiences on this specific level. Parents reported that they had lost their jobs or had chosen to resign because they were unable to commit themselves to full-time employment while also managing their child's needs without support. Findings indicated that parents of children with ASD often felt guilty and anxious when they arrived at work; they were never sure that they would be able to complete a day's work as there was always a possibility that they would be called away to attend to their child.

The Mesosystem relates to the influence of the relationships that parents form with people in their relatively close communities (Bronfenbrenner, 1994). These relationships include interactions with members of the public, for example health care workers, staff at institutions such as schools, and various private practice therapists, including speech and language therapists, occupational therapists and physiotherapists. This was predominantly experienced in a negative way. It was found that, at times, parents even felt threatened by community members who tended to judge them because of their child with ASDs' behaviour. Consequently their relationships with members of the public became strained.

Parents of children with ASD also felt that they were not sufficiently supported by medical services, so they often reached out to their communities for support. Such support was provided mainly in the form of additional services and respite care. Private respite care was found to offer a 'caring community' for their child in which they were free from prejudice and seemed to be better understood. Private respite care was found to be like a home for a child with ASD and parent, and was a safe place in which they formed relationships with children experiencing a similar situation. They further felt cared for as additional services, such as occupational therapy, speech therapy and medical services are available in the private respite care environment.

The Macrosystem specifically involves the policies and government or international decisions that influence the other levels (Bronfenbrenner, 1994). The White Paper, Mental Health Act and National Mental Health Policy Framework emphasise the rights of people with disabilities and state that they have the same rights and responsibilities as other South African citizens (Department of Health, Republic of South Africa, 2013; Department of Social Development, Republic of South Africa, 2016; The Presidency, Republic of South Africa, 2002). The researchers' research revealed that parents experienced a lack of support from the government, with regard to their need for specialised health care services and the availability of facilities to assist, them in caring for their child with ASD. Health care providers were found to assist only to a limited extent. Findings emphasised the need for more private respite care facilities that are better equipped to provide specialised care for parents of children diagnosed with ASD.

The Chronosystem refers to the five themes identified from the results and how experiences are influenced by the various systems and/or evolve over time (Bronfenbrenner, 1994). The main finding in terms of this system relates to the parents' experience of loss or grief, which can be associated with Kübler-Ross and Kessler's (2005) grief framework and parents need to seek support in the form of respite care to assist them socially, emotionally and psychologically. As with the chronological development of the grief process, the parental experience was also found to develop chronologically from being in denial to finally accepting their situation.

The findings of this study indicate that respite care plays an important role in assisting parents to move towards acceptance as it provides various supportive elements. Those elements include providing relevant information on ASD, professional care and behaviour management, as well as access to professional opinions and services.

5.3 ADDRESSING THE RESEARCH QUESTIONS

Five predominant themes were identified to inform the findings of this study. Each of those themes contributed towards answering the primary and secondary research questions outlined in Chapter 1.

My research was guided by the following primary research question:

How do the parents of children who have been diagnosed with autistic spectrum disorder experience the utilisation of private respite care in South Africa?

The results obtained through this study indicate that parents of children diagnosed with ASD are in desperate need of support. It was especially evident that parents experience challenges with the social, emotional, educational and behavioural management of their child's special-needs. The parents involved in this study sought, and received support through the use of private respite care to alleviate their negative experiences. The exploration of the primary research question also produced answers to the secondary questions. My research revealed that parents of children diagnosed with ASD experience many challenges, and that the services offered by private respite care provide valuable support. The following secondary questions were addressed in order to expand on the findings of this study in support of the primary research question:

5.3.1 SECONDARY QUESTION 1

What are the expectations of parents of children diagnosed with autistic spectrum disorder when they make use of respite care at a private facility in South Africa?

The expectations of parents are, that they will be helped to effectively deal with their negative social, emotional, educational and behavioural experiences. In terms of negative social experiences, parents who make use of respite care are assisted by being provided with an environment in which their child is socialised with other children with the same disorder. This enables them to socialise without having to attend to their child's special-needs, which tends to result in negative social feedback from people around them. Negative emotional experiences are alleviated through the use of respite care as parents feel supported and assisted in managing their child's challenging behaviour. Educational experiences are also supported as private respite care provides children with opportunities to learn and relieves parents of the stress of trying to find schools that are willing, and able to accommodate their children. The difficulty experienced by parents trying to find placements for their child with ASD in schools was one of the main challenges identified during this study.

Parents experience numerous challenges in attempting to manage their child's behaviour. The private respite care facility is able to offer support for parents by, not only relieving them of this responsibility for a short period of time, but also offering advice on how best to manage their children's challenging behaviour. Parents' challenges could be related to the needs they experience with regard to managing their negative experiences. It was found that parents who made use of private respite care expected to be supported in this regard.

In line with what was discussed with reference to the systemic experiences of the parents in the foregoing sections of this chapter, it was found that parents using private respite care expect support in respect of:

- providing safety from a, sometimes hostile, social environment;
- emotional protection for their child and themselves;
- educational opportunities and stimulation for their child; and
- support in terms of managing their child's behaviour through professional advice and physical management when exhausted.

5.3.2 SECONDARY QUESTION 2

To what extent does respite care at a private facility in South Africa meet the needs of parents with children who have been diagnosed with autistic spectrum disorder?

The findings indicated that the social needs of parents who experienced, among other things, exclusion due to prejudice towards their children, were adequately addressed through private respite care.

On an emotional level, parents experienced feelings associated with grief and internal conflicting emotions. The findings of the current research indicate that the support received from the private respite care facility assist parents in transitioning between the stages of grief as identified by Kübler-Ross and Kessler (2005) and address their internal struggles by meeting their children's unique needs.

In terms of educational experiences, parents mentioned their challenges with schools, such as being put on waiting lists, not meeting the requirements of schools and being rejected by various schools. The private respite care facility was found to

act as a learning platform for parents, who were helped to better understand their children. All three participants mentioned the availability of various additional services offered by Facility X to help their children, such as the use of a sensory room, horse-riding and on-site medical care. Other services that were mentioned were; assistance by a domestic worker and the involvement of occupational therapists, physiotherapists, speech therapists, neurologists, psychiatrists, general practitioners, emergency services, social workers and psychologists.

Challenges experienced with regards to the management of their child's behaviour was the most significant finding related to private respite care and was indicated as the main reason why parents made use of private respite care. In terms of management, parents identified challenges with their child's behaviour, communication skills, the use of medication to influence behaviour, eating difficulties, sleeping difficulties, health problems and emotional difficulties. Parents also mentioned how having a child with ASD had forced them to change their lifestyle, for instance by changing their occupations, or how they experienced stress at work as a result of trying to meet their child's emotional, psychological and social needs.

5.3.3 SECONDARY QUESTION 3

How does respite care benefit (or not benefit) parents with children diagnosed with autistic spectrum disorder?

The parents reported that the benefits offered by utilising respite care included receiving advice/support from the private respite care facility. Parents also reported that they had received advice on how to manage their child's challenging behaviour and that Facility X provided an environment in which their child could socialise with staff and children who understood/accepted them. It was found that the main concern of parents was that they did not want their child to grow up alone and felt that Facility X offered an environment in which their child was not alone and received the necessary social, emotional and psychological support. Parents also reported that the management of their child's behaviour improved as a result of the emotional and physical relief (break) made possible by the use of private respite care. At facility X, children were exposed to educational benefits and sometimes even progressed academically, despite predictions to the contrary made by health professionals.

It was found that the fact that the private respite care facility was aesthetically pleasing contributed to the parents' positive experience. The benefit of additional facilities, such as a sensory room, was also found to contribute to the parents overall positive experience. Furthermore, the presence of adequately trained staff was found to be supportive in meeting the needs of children diagnosed with ASD and in managing their challenging behaviour. This service was found to have allowed both the parents and their children a chance at a better life as it catered for their psychological, social, physical and emotional needs.

However, despite the reported benefits of private respite care, it appeared that the quality of care provided was not always consistent and did not always meet the parents' expectations. These perceived shortcomings included poor management following the appointment of a new manager, after which the standard of care at the facility was reported to have digressed. Problems were also experienced with the staff, and parents felt that there was a lack of communication with regard to their child's care and progress. Staff were reported to lack the training needed to take care of the specific needs of children with ASD, consent for medical procedures was not obtained and staff were constantly talking on their cell phones when they were supposed to be attending to the needs of their patients.

5.3.4 SECONDARY QUESTION 4

How can respite care at a private facility in South Africa be improved, according to parents with children diagnosed with autistic spectrum disorder?

The participants in this study suggested a number of ways in which respite care could be improved. The most important of these was to improve communication and feedback to parents. They suggested that frequent progress reports and reassurance should be provided to keep parents informed on their child's experiences at the facility and how they could best support them at home. The parents also recommended the appointment of a controlling body at the respite care facility so that collaboration between the facility and parents could be addressed on a more formal platform. This was recommended with a view to increasing parental involvement in the running of the respite care facility and to facilitate formal procedures when addressing complaints and recommendations made by parents to improve the service offered. Lastly, parents recommended that more facilities

offering this unique service should be established in South Africa. Parents shared the challenges they had faced in trying to find schools that could accommodate their child's special-needs and offer either residential or respite care services. Due to the limited availability of these facilities, parents had turned to a private respite care facility, but had found that it was too expensive and therefore not a permanent solution. They felt that if more such facilities were available, they would have more options and might be able to find a facility that they could more easily afford.

5.4 LIMITATIONS OF THE STUDY

Potential limitations pertaining to the current study include the small size of the sample used. A larger sample might have provided additional information that might have expanded on the findings.

Furthermore, due to the limited facilities available for sampling, the sample was restricted to a single private respite care facility. Since private facilities are generally more expensive, the population was restricted to participants from the upper- and middle-class echelons of the population, which limited the interpretation of the research results. A more diverse sample in respect of socio-economic status, race and gender would have been preferable.

Due to the nature of this qualitative study, the focus was on exploring the use of private respite care by parents of children diagnosed with ASD. The purpose was therefore not to generalise the results, but rather to describe the three participants use of private respite care in South Africa in order to enhance the understanding thereof in the particular context. The limitation with regards to the generalisability of the findings of the current research may be viewed by some researchers as a limitation, based on their specific world views. Such views were, however, not shared in the design of my qualitative research study.

5.5 CONTRIBUTION OF THE STUDY

The researcher believes that her research contributes to the field of educational psychology in that it allows for an improved understanding of the complexity of the challenges faced by parents whose child have been diagnosed with ASD and who make use of private respite care. As a case study it allows for an in-depth understanding of the parents' experience of having a child diagnosed with ASD and

the various experiences they have in managing a child with this disorder by utilising private respite care.

Due to the limited research available on respite care in South Africa, the findings of this study provide insight into the experiences of parents of children diagnosed with ASD. As an exploration of the consequences of having a child with ASD, it provides insight into the parents' social, emotional, educational and behavioural experiences and how the use of private respite care can support them as they try to find ways to cope with the challenges they face. It also deals with benefits of using respite care, the shortcomings of the particular facility dealt with in this study and the participating parents' recommendations regarding the improvement the facility.

Through this study, professionals who work in the field of educational psychology will be made aware of the factors that contribute to the experiences of parents of children diagnosed with ASD and the potential role played by respite care. It may also enhance their insight into the nature of the parents' experiences with regard to the use of private respite care, their need for support, the way in which every aspect of their lives is affected and how the use of private respite care can assist them.

A further contribution of this study is that it may enhance the understanding of the use of private respite care by the parents of children with ASD and may lead to further research being conducted on children with other neural developmental disorders. Insight into the experiences of such parents may also contribute towards improving respite care and may influence policy with regard to the delivery of such a service. Respite care facility workers, managers and training staff in such facilities may also benefit from understanding the unique experiences of parents utilising such facilities.

5.6 RECOMMENDATIONS

5.6.1 RESEARCH

This study emphasises the need for the unique service of respite care to be more readily available. To verify the findings of this study, future research is recommended to explore respite care by employing both qualitative and quantitative measures. This may prove useful for an understanding of what such care entails and for tailoring respite services that will provide in the needs of parents using such

services in South Africa with a view to making them more effective and more widely available.

The following future research is recommended:

- A survey to be conducted of the current population of parents of children diagnosed with ASD who might consider using respite care.
- Similar comparative case studies conducted in South Africa and abroad.
- A quantitative study to establish how many respite care facilities are currently available to parents of children diagnosed with ASD and a supplemental qualitative study on the service currently being offered.
- A comparative study on the use of government institutions currently offering respite care for children diagnosed with ASD.
- A qualitative study focusing on the use of additional services by parents of children diagnosed with ASD.
- A comparative study of the current services available to parents of children with ASD and the ease of access to these services at a private respite care facility.
- A case study to further explore this service and how it can be improved, and to promote the establishment of respite care facilities and their accessibility in South Africa.

5.6.2 PRACTICE

The findings of this study hold implications as far as the use of private respite care by parents of children with ASD is concerned. The challenges that parents of children with ASD face, as shown in this study, emphasise the need for more support for parents, which includes that society should be made aware of their plight and be encouraged to understand their challenges, and show a greater willingness to accept and support them.

For educational psychologists and other professionals who deal with children with ASD and their parents, this study accentuates the vital importance of educating society on ASD. It is by educating society that an understanding and acceptance of this disorder will be established. The findings might have implications not only for the way parents are treated as a result of their child's challenging behaviour, but

might also help to equip medical practitioners to more effectively support the parents. In this regard it is important to emphasise the need for additional services to further support parents in understanding what their child needs and to help them to manage their child's behaviour.

Parents and service providers should be equipped with the necessary knowledge and practical tools needed to support their children with ASD. This study highlights the implications this disorder has not only for parents and their child, but also for families, society and service providers.

5.7 CLOSING REMARKS

Due to the increase in the number of children diagnosed with ASD, it has become essential for communities and government authorities to be made aware of the unique experiences of the parents of such children. With the limited resources and support available to these parents, they are in desperate need of respite care services, which would ultimately contribute towards building a South Africa that can accommodate these children and offer the necessary support to their parents. Since ASD is a lifelong disorder for which there is no cure, it is vitally important that the parents of children with this diagnosis be given the necessary social, emotional support and easy access to respite care facilities.

As a researcher, I hope that this case study will contribute towards providing a clearer perspective on the challenges that parents of children with ASD face and an awareness of the vital role of respite care.

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APPENDICES

Appendix A:

Invitation to Consent to Participation in a Research Study

Appendix B:

Research Information Document

Appendix C:

Invitation to Respite Care Facility X to Allow the Following Research Study to Take Place Using Clients Who are Using or Have Used the Facility

Appendix D:

The Parent Interview Protocol

Appendix E:

DSM-IV Criteria for Autistic Spectrum Disorder

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INVITATION TO CONSENT TO PARTICIPATION IN A RESEARCH STUDY
A research study of the University of Pretoria

Study title: Exploring parents of autistic children's use of respite care at a private facility in South Africa
Student investigator: Nandi Robinson

Dear Sir/Madam

With this letter I wish to invite you to participate in a postgraduate research study regarding your experiences as a parent utilising private respite care for your child who has been diagnosed with autistic spectrum disorder.

Before you decide whether to participate or not, it is important to understand why the research is conducted, and what it will involve. Please take time to carefully read the attached research information document (Appendix B).

Should you have any questions or require additional information pertaining to the study, please feel free to ask. Take note that your participation will be voluntary and you have the right to be fully informed about the research. You are therefore also not rushed to make a decision. Please feel free to contact my supervisor or myself at the following numbers or email address should you have any inquiries regarding the research process:

Researcher: Nandi Robinson
Email address: nandirobinson.edpsych@gmail.com
Contact number: 082 747 5211
Supervisor: Dr A. H. du Plessis
Email address: alfred.duplessis@up.ac.za
Contact number: 012 420 5503

If you would like to participate in the study, please complete and return the Informed Consent Declaration form below.

INFORMED DECLARATION

Please initial:

I confirm that I have read and understood all the information provided in the information letter relating to the above study, and I have had the opportunity to ask questions. Any questions I have about my participation in this project have been answered to my satisfaction.

I understand that this study is designed to enhance scientific knowledge and that all procedures have been risk assessed and approved by the Ethics Committee of the Faculty of Education at the University of Pretoria.

I fully understand that my participation is voluntary and that I am free to withdraw from this project at any time and at any stage, without having to give reasons for my decision to withdraw. I have read and fully understand this consent form.

Signed at _____ on _____ of _____ 2017.

Participant's name

Participant's signature

Miss N. Robinson
Researcher



RESEARCH INFORMATION DOCUMENT A research study of the University of Pretoria

Project title: Exploring parents of autistic children's use of respite care at a private facility in South Africa

Student investigator: Nandi Robinson
Email address: nandirobinson.edpsych@gmail.com
Contact number: 082 747 5211

Supervisor: Dr A. H. du Plessis
Email address: alfred.duplessis@up.ac.za
Contact number: 012 420 5503

What is the purpose of this project?

The purpose of this study is to explore the experiences of parents with a children diagnosed with autistic spectrum disorder who are utilising private respite care in South Africa.

A considerable amount of research has been devoted to the psychological, emotional and social effects of having a child diagnosed with autistic spectrum disorder (ASD), while very little research has been conducted on the use of respite care as a means of providing for and managing the needs of a child diagnosed with autistic spectrum disorder in the South African context. At this stage we do not have insight into the experiences of parents utilising respite care in the South African context as very little research has been undertaken on this topic.

Why have I been identified as a potential participant?

You have been identified because you meet the minimum inclusion criteria for participation in the study. The inclusion criteria are as follows:

- Participants need to have a child diagnosed with autistic spectrum disorder.
- Participants need to be able to proficient in the English language.
- Participants need to be utilising or must have utilised respite care at this specific respite care facility during the past 12 months.

What will I have to do?

You will be required to take part in a semi-structured interview, which will seek to explore your experience as a parent utilising private respite care for your child who has been diagnosed with autistic spectrum disorder. The interview will take approximately one hour. Afterwards you will be provided with a transcript of the interview and my preliminary analysis in order to verify that it is a true reflection of

your experiences. The verification interview (member checking) may require an additional interview of approximately twenty minutes.

Will I receive any financial reward or reimbursement of travel expenses for taking part?

Unfortunately no compensation will be given.

What are the benefits of taking part?

Expressing your experiences may be of therapeutic value. The results of this research may further have benefits for respite care in South Africa, which may be improved if the findings are implemented. The research may also be used to guide future policy on respite care.

Will participation involve any physical discomfort/harm/psychological stress?

Your participation involves sharing your experience as a parent utilising private respite care for your child, who has been diagnosed with autistic spectrum disorder. This is a highly sensitive topic and my research will be guided by semi-structured interview questions. Participant will not be forced to answer any questions that make them feel uncomfortable. Should the interview lead to any emotional challenges for participants, debriefing by a professional psychologist will be made available.

How will my involvement in this project be kept confidential?

All data collected during the course of this study will be kept strictly confidential and will be available only to the researcher and the supervisor of the study. All raw data, transcripts and audio recordings of the interviews will be password encrypted and will be locked in a secured cupboard during the collection and analysis phases of the research. After completion it will be stored at the Department of Educational Psychology at the University of Pretoria, Aldoel Building, Faculty of Education, Room 2-29.

Anonymity will be ensured through the use of pseudonyms in all transcripts and documents that report on the research.

How will my information be used?

The data collected during the interview will be used to compile a research report that will be made available online for perusal by other researchers. A subsequent research article may be published. The data will also be utilised by the researchers' supervisor, Dr A. H. du Plessis. The data may be used to inform future practice and training at the University of Pretoria.

Has the study received ethical approval?

A research protocol was submitted to the Faculty of Education's Research Ethics Committee, University of Pretoria, and written approval to undertake the research was obtained.

What if I am unhappy during my participation in the project?

As a participant, you are free to withdraw from the study at any time, i.e. before, during or after the study. Should you decide at any stage to end your participation, you will not be required to give a reason for your withdrawal. Any personal information or data that you have provided (both paper and electronic) will be

destroyed or deleted as soon as possible after your withdrawal. If you are concerned that regulations are not being adhered to, or that your interests are otherwise being ignored, neglected or denied, you may inform the supervisor of the current study, Dr A. H. du Plessis, who will investigate your complaint. (Tel: 012 420 5503; Email: alfred.duplessis@up.ac.za)

How do I take part?

You will be able to participate in the study by signing the informed consent form provided in this information letter.

Questions and information

Please feel free to ask any questions pertaining to the study, or to request additional information. Take note that your participation will be voluntary, and that you have a right to be fully informed about the research. You will therefore not be rushed to make a decision. Do not hesitate to contact my supervisor or myself at the following numbers or email addresses should you have any inquiries regarding the research process:

Researcher: Nandi Robinson
Email address: nandirobinson.edpsych@gmail.com
Contact number: 082 747 5211
Supervisor: Dr A. H. du Plessis
Email address: alfred.duplessis@up.ac.za
Contact number: 012 420 5503

Thank you in advance for your consideration.

Miss N. Robinson
Researcher

Dr A. H. du Plessis
Supervisor

CERTIFICATE OF CONSENT

I, _____ (please insert your name), have read the research information document, or its content has been conveyed to me. I have had an opportunity to ask questions about it and my questions have been answered to my satisfaction. I am aware of the fact that the researcher subscribes to the following principles:

- Voluntary participation, meaning that the participants may, at any stage, without prejudice, withdraw from the study.
- Informed consent, meaning that the participants will at all times be fully informed about the research process and purposes, and must have consented to their participation in the study.
- Safety in participation, meaning that the participants will not in any way be placed at risk or harmed as a result of the research.
- Privacy, meaning that confidentiality and anonymity of the human respondents should be protected at all times.
- Trust, meaning that the participants will not be exposed to any acts of deception or betrayal in the research process or its published outcomes.

I hereby voluntarily consent to participate in this research.

Signed at _____ on this _____ day of _____ 2017.

Participant's name [Please print]

Participant's signature

Name of witness [Please print]

Witness' signature

(A copy of the research information document has been provided to the participant.)

Researcher's signature

Appendix C:
**Invitation to Respite Care Facility X to Allow the Following
Research Study to Take Place Using Clients Who are Using or
Have Used the Facility**



UNIVERSITEIT VAN PRETORIA
UNIVERSITY OF PRETORIA
YUNIBESITHI YA PRETORIA
Faculty of Education

**REQUEST TO RESPITE CARE FACILITY X TO ALLOW THE FOLLOWING
RESEARCH STUDY TO BE UNDERTAKEN BY USING ITS PAST OR
CURRENT CLIENTS**
A research study of the University of Pretoria

Study title: Exploring parents of autistic children's use of respite care at a private facility in South Africa

Student investigator: Nandi Robinson
Email address: nandirobinson.edpsych@gmail.com
Contact number: 082 747 5211

Supervisor: Dr A. H. du Plessis
Email address: alfred.duplessis@up.ac.za
Contact number: 012 420 5503

Dear Keren

This letter serves to request permission to conduct a research study at your private respite care facility. I am currently enrolled in the Educational Psychology program at the University of Pretoria and am in the process of writing my masters dissertation. The purpose of the study will be to explore parents of autistic children's use of respite care at a private facility in South Africa.

I hope that the facility will allow me to recruit three parents who use your facility and who meet the inclusion criteria (see below) and are willing to be interviewed with a view to obtaining the data required for the purpose of the current study.

Inclusion criteria:

- Participants need to provide informed consent before taking part in the current study.
- Participants need to understand and be able to communicate in English.
- Participants need to have a child who has been clinically diagnosed with autistic spectrum disorder.
- Participants need to be currently utilising, or to have utilised respite care at this specific facility during the past 12 months.

Exclusion criteria:

- No participant will be used who could be considered to be suffering from a mental or other illness that would drastically affect the results of the current study.

Prior to conducting the current study, participants who meet the criteria for inclusion will be given a letter of invitation to participate in the study (Appendix A), as well as a research information document (Appendix B). The informed consent form will give potential participants an opportunity to choose whether to take part in the study or not. Parents who sign the informed consent letter will need to return the form to the primary researcher prior to commencing with the study. Participants will be reminded that they are free to withdraw from the research at any time and at any stage without having to give a reason for their decision. After signing the informed consent form, they will be given an opportunity to ask any questions and to confirm that they understand its contents and that they agree to the conditions for participation. Each potential participant will be briefed on the nature and purpose of the research.

For your information, a copy of the research document will also be provided to you to inform you of the nature of the research.

What will be required from your facility?

- Permission to approach your respite clients who meet the criteria for participation.
- Access to your clients' contact details.

How will you be protected?

The facility's name will not be used and will be kept confidential at all times.

Your permission to conduct this study will be greatly appreciated, I will follow up with a telephone call and will be happy to answer any questions or discuss any concerns that you may have at that time. Feel free to contact me or my study supervisor at contact numbers or email addresses provided.

I, _____, as supervisor of Oak Haven Respite Care Facility, hereby give Miss N. Robinson, the primary researcher, permission to approach clients who use/have used our facility in order to recruit participants for her study titled 'Exploring parents of autistic children's use of respite care at a private facility in South Africa.'

Signed at _____ on this _____ day of _____ 2017.

Supervisor, Oak Haven Facility
Signature

Miss N. Robinson
Researcher



THE PARENT INTERVIEW PROTOCOL
A research study of the University of Pretoria

Study Title: Exploring parents of autistic children’s use of respite care at a private facility in South Africa

Date: _____
Interview starts at: _____ Duration: _____
Interview ends at: _____
Venue: _____
Interviewer: _____
Interviewee: _____
Pseudonym: _____
Male/Female: _____

The aim of this interview is to explore parents with autistic children’s experiences of using respite care at a private facility in South Africa.

Questions:

1. What needs did you hope to have met when you decided to seek private respite care for your child?
2. How have you experienced your utilisation of private respite care for your child?
3. As a parent, what challenges (if any) did you face while utilising private respite care for your child?
4. How has utilising respite care benefited, or not benefited you as a parent?
5. How could respite care be improved, in your opinion?

Appendix E: DSM-IV Criteria for Autistic Spectrum Disorder

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Neurodevelopmental Disorders

Autism Spectrum Disorder

Autism Spectrum Disorder

Diagnostic Criteria

299.00 (F84.0)

A. Persistent deficits in social communication and social interaction across multiple contexts, as manifested by the following, currently or by history (examples are illustrative, not exhaustive; see text):

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

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).

B. Restricted, repetitive patterns of behavior, interests, or activities, as manifested by at least two of the following, currently or by history (examples are illustrative, not exhaustive; see text):

1. Stereotyped or repetitive motor movements, use of objects, or speech (e.g., simple motor stereotypies, lining up toys or flipping objects, echolalia, idiosyncratic phrases).
2. Insistence on sameness, inflexible adherence to routines, or ritualized patterns of verbal or nonverbal behavior (e.g., extreme distress at small changes, difficulties with transitions, rigid thinking patterns, greeting rituals, need to take same route or eat same food every day).
3. Highly restricted, fixated interests that are abnormal in intensity or focus (e.g., strong attachment to or preoccupation with unusual objects, excessively circumscribed or perseverative interests).
4. Hyper- or hyporeactivity to sensory input or unusual interest in sensory aspects of the environment (e.g., apparent indifference to pain/temperature, adverse response to specific sounds or textures, excessive smelling or touching of objects, visual fascination with lights or movement).

Specify current severity:

Severity is based on social communication impairments and restricted, repetitive patterns of behavior (see Table 2).

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

D. 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. Intellectual disability and autism spectrum disorder frequently co-occur; to make comorbid diagnoses of autism spectrum disorder and intellectual disability, social communication should be below that expected for general developmental level.

Note: Individuals with a well-established DSM-IV diagnosis of autistic disorder, Asperger's disorder, or pervasive developmental disorder not otherwise specified should be given the diagnosis of autism spectrum disorder. Individuals who have marked deficits in social communication, but whose symptoms do not otherwise meet criteria for autism spectrum disorder, should be evaluated for social (pragmatic) communication disorder.

Specify if:

With or without accompanying intellectual impairment

With or without accompanying language impairment

Associated with a known medical or genetic condition or environmental factor
(Coding note: Use additional code to identify the associated medical or genetic condition.)

Associated with another neurodevelopmental, mental, or behavioral disorder
(Coding note: Use additional code[s] to identify the associated neurodevelopmental, mental, or behavioral disorder[s].)

With catatonia (refer to the criteria for catatonia associated with another mental disorder, pp. 119–120, for definition) (Coding note: Use additional code 293.89 [F06.1] catatonia associated with autism spectrum disorder to indicate the presence of the comorbid catatonia.)

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