EXPLORING PRIMARY CAREGIVERS’ EXPERIENCES OF CHILDREN WHO HAVE RECEIVED NEUROFEEDBACK AS AN INTERVENTION FOR AUTISM SPECTRUM DISORDER IN THE WESTERN CAPE

By

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A mini-thesis in partial fulfilment of the requirements for the degree of Masters in Psychology (Clinical) in the Faculty of Community and Health Sciences at the University of the Western Cape

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Keywords: Neurofeedback, Autism Spectrum Disorder, family ecology, primary caregiver, non-invasive intervention, Western Cape, thematic analysis, selection of intervention, microsystem, behavioural therapy
DECLARATION

I hereby confirm that the present thesis, Exploring primary caregivers’ experiences of children who have received Neurofeedback as an intervention for Autism Spectrum Disorder in the Western Cape, is solely my own work. It has not been submitted before for any degree or examination in any university and if any text passages or diagrams from books, papers, the Web or other sources have been copied or in any other way used, all references – including those found in electronic media – have been acknowledged and fully cited in the American Psychological Association (APA) referencing style.

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17 October 2016
DEFINITIONS AND TERMS

**Autism Spectrum Disorder:** The term is a broad category containing similar developmental disorders into which Autism Disorder falls (American Psychological Association, 2013).

**Diagnosis of Autism Spectrum Disorder:** This includes several conditions that used to be diagnosed separately: autistic disorder, pervasive developmental disorder not otherwise specified (PDD-NOS), and Asperger syndrome. These conditions are now all called Autism Spectrum Disorder (American Psychological Association, 2013).

**Neurofeedback:** This is a computer-aided training method in which selected parameters of the patient’s own brain activity, which can normally not be perceived, are made apparent to the patient, using video or sound to enable the patient to self-regulate (Eller, 2015).

**Non-invasive procedure:** This is a conservative treatment that does not require incision into the body or the removal of tissue (Eller, 2015).

**Primary caregivers:** This is used to refer to the mothers, fathers, grandparents or guardians of children with Autism who act as primary caregiver figures for these children and are responsible for the day-to-day care and maintenance of these children (Lainhart, 2015).
ABSTRACT

Autism Spectrum Disorder is a pervasive developmental disorder characterised by impairment in communication skills and social interaction, including the presence of stereotyped behaviour. Currently there is no cure for Autism Spectrum Disorder, resulting in the use of several treatment modalities, for example pharmacological, behavioural and non-invasive therapies, which include Neurofeedback, also called Neurotherapy, Neurobiofeedback or Electroencephalogram. Neurofeedback biofeedback is a training technique that presents the user with real-time feedback on brain wave activity. The objective of this study was to explore the experiences of primary caregivers of children with Autism Spectrum Disorder who have used the Neurofeedback intervention. This study used a qualitative research methodology with an exploratory research design. The purpose of the research was to explore experiences of primary caregivers whose autistic child experienced Neurofeedback as an intervention. This study probed each primary caregiver’s unique experience, and allowed the primary caregivers the freedom to express their experiences. A sample of five primary caregivers, comprising different racial and socioeconomic backgrounds, was purposively selected in the Western Cape. The data were collected by means of semi-structured in-depth interviews, which were transcribed verbatim and analysed using thematic analysis. The study found that the primary caregivers each experienced different results with regard to their autistic child who had received Neurofeedback as an intervention. This study also showed that this intervention directly affected the autistic child’s life with regard to their social, mood, behaviour, academic life and family structure. All the primary caregivers had a positive response to utilising Neurofeedback as an intervention for their autistic child with regard to reducing anxiety and enhancing the level of social interaction, which impacted the family positively. While multiple therapeutic interventions exist for primary caregivers to assist their autistic child, this study presents supporting evidence which suggests that Neurofeedback is an effective intervention that contributes positively to the management of Autistic Spectrum Disorder.
ACKNOWLEDGEMENTS

I would like to express special thanks to all those who have made this research study possible and successful as without you this study would not have been possible. I would like to convey my gratitude to my research supervisor Dr Athena Pedro for her guidance, support, motivation and mostly her faith in me throughout the process. Also very special thanks to my wife Tina Krynauw for her support and encouragement and allowing me the space to work. Without your motivation and belief in me this research study would not have been possible. Thank you to all lecturers from UWC psychology department who have supported me throughout this challenging academic year. Also thanks to the five primary caregivers participating in the study, for opening your hearts and thoughts to me and sharing your experiences. Your stories have taught and provided me valuable knowledge which I will carry with me forever. To all my friends and family: I appreciate your support and words of encouragement and motivation. Thanks to Norman Baines my copyeditor and good friend who has supported me throughout the years. And, most of all, the Lord for giving me the strength to carry on when times were tough, opening doors for me which seemed impossible to open, and for the wisdom to complete this study.
# TABLE OF CONTENTS

DECLARATION ....................................................................................................................... 1  
DEFINITIONS AND TERMS ................................................................................................... 2  
ABSTRACT ............................................................................................................................... 3  
ACKNOWLEDGEMENTS ....................................................................................................... 4  

CHAPTER 1: INTRODUCTION ......................................................................................... 8  
  1.1 Background ................................................................................................................ 8  
  1.2 Rationale .................................................................................................................. 10  
  1.3 Theoretical framework ............................................................................................. 11  
  1.4 Aim of the study ....................................................................................................... 12  
  1.5 Objectives of the study ............................................................................................. 12  
  1.6 Research questions ................................................................................................... 12  
  1.7 The significance of the study ................................................................................... 13  
  1.8 Summary .................................................................................................................. 13  

CHAPTER 2: LITERATURE REVIEW ............................................................................ 15  
  2.1 Introduction .............................................................................................................. 15  
  2.2 Definition and characteristics of Autism Spectrum Disorder .................................. 15  
    2.2.1 Definition .............................................................................................................. 15  
    2.2.2 Characteristics of the Autism Spectrum Disorder child ........................................ 17  
    2.2.3 Primary caregivers’ experience of Autism Spectrum Disorder ............................ 17  
  2.3 The prevalence of Autism Spectrum Disorder ......................................................... 18  
  2.4 Challenges that parents face with a child diagnosed of Autism Spectrum Disorder .............. 20  
  2.5 The effect of Autism Spectrum Disorder on the family ........................................... 20  
    2.5.1 The family ecology ............................................................................................... 20  
    2.5.2 Primary caregivers ................................................................................................ 23  
  2.6 Interventions for Autism Spectrum Disorder ........................................................... 23  
    2.6.1 Pharmacological interventions .............................................................................. 25  
    2.6.2 Behavioural interventions ..................................................................................... 26  
    2.6.3 Primary caregivers’ choice of different treatment modalities ............................... 27  
  2.7 Neurofeedback intervention for Autism Spectrum Disorder .................................... 28  
  2.8 Qualitative research studies on Neurofeedback and Autism Spectrum Disorder ......... 32  
  2.9 Primary caregivers’ experiences of Neurofeedback as an intervention ............... 33  

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CHAPTER 3: METHODOLOGY

3.1 Introduction .............................................................................................................. 35
3.2 Research design ....................................................................................................... 35
3.3 Research setting ....................................................................................................... 36
3.4 Participants and sampling ....................................................................................... 37
3.5 Procedure ................................................................................................................. 38
3.6 Data collection ......................................................................................................... 38
3.7 Data analysis ............................................................................................................ 40
3.8 Trustworthiness ....................................................................................................... 43
3.9 Reflexivity ................................................................................................................ 44
3.10 Ethics ........................................................................................................................ 45
3.11 Summary .................................................................................................................. 46

CHAPTER 4: RESULTS .................................................................................................... 47

4.1 Introduction .............................................................................................................. 47
4.2 A profile of the participants ..................................................................................... 48
   4.2.1 Participant 1 ....................................................................................................... 49
   4.2.2 Participant 2 ....................................................................................................... 50
   4.2.3 Participant 3 ....................................................................................................... 50
   4.2.4 Participant 4 ....................................................................................................... 50
   4.2.5 Participant 5 ....................................................................................................... 51
4.3 Presentation of themes ............................................................................................. 52
4.4 Theme 1: Selection and initial perceptions of multiple therapeutic interventions... 54
   4.4.1 Initial selections ............................................................................................... 55
   4.4.2 Ecological impact and choice of neurofeedback ................................................ 56
4.5 Theme 2: Behavioural problems leading to primary caregivers seeking out Neurofeedback intervention ................................................................. 58
   4.5.1 Social impairments .......................................................................................... 59
   4.5.2 Challenges pertaining to anxiety ....................................................................... 61
   4.5.3 Learning difficulties at school .......................................................................... 62
   4.5.4 Behavioural patterns before Neurofeedback intervention ................................ 63
4.6 Theme 3: Primary caregivers’ perceptions of the benefits of Neurofeedback intervention and their dissatisfactions ................................................................. 64
   4.6.1 Decrease in anxiety .......................................................................................... 65
4.6.2 Better impact on mood .......................................................................................... 66
4.6.3 Increased social ability .......................................................................................... 68
4.6.4 Primary caregiver dissatisfactions ........................................................................ 69

4.7 Theme 4: How Neurofeedback intervention impacted on the whole family system ...................................................................................................................... 70
4.7.1 Neurofeedback influenced the whole family positively ....................................... 70
4.7.2 Family system still functions the same even with Neurofeedback as an intervention ........................................................................................................... 71

4.8 Conclusion ............................................................................................................... 72

CHAPTER 5: DISCUSSION, CONCLUSION AND RECOMMENDATIONS ............... 74
5.1 Introduction .............................................................................................................. 74
5.2 Themes ..................................................................................................................... 75
5.2.1 Theme 1: Selection and initial perceptions of multiple therapeutic interventions ...................................................................................................................... 75
5.2.2 Theme 2: Behavioural problems leading to primary caregivers seeking out Neurofeedback intervention ................................................................................... 76
5.2.3 Theme 3: Primary caregivers’ perceptions of the benefits of Neurofeedback intervention and their dissatisfactions .................................................................... 77
5.2.4 Theme 4: How Neurofeedback as an intervention impacted on the whole family system ........................................................................................................ 78

5.3 Strengths and limitations of the research study ....................................................... 80
5.4 Recommendations for further study ......................................................................... 81
5.5 Contribution ............................................................................................................. 82
5.6 Reflection .................................................................................................................. 83
5.7 Conclusion ............................................................................................................... 84

REFERENCES .................................................................................................................. 86
APPENDIX A: INFORMATION SHEET .............................................................................. 93
APPENDIX B: CONSENT FORM ......................................................................................... 96
APPENDIX C: INTERVIEW GUIDE .................................................................................... 97

LIST OF TABLES
Table 4.1: Summary of demographic information of five primary caregivers .......... 51
Table 4.2: Conceptual framework ................................................................................. 52
CHAPTER 1: INTRODUCTION

1.1 Background

Autism Spectrum Disorder comprises a range of conditions classified as a lifelong neurodevelopmental disorder, characterised by persistent deficits in social communication and social interaction across multiple contexts (American Psychological Association, 2013). It can be diagnosed between the ages of 18 months and three years, generally recognised as the period when symptoms of a neurodevelopmental disorder become recognisable (Twoy, Connolly, & Novak, 2007). It is characterised by abnormalities in social interaction, communication skills and behavioural flexibility within a certain range of severity (American Psychological Association, 2013). This can include repetitive behaviours where patients may insist on “sameness” and resist even insignificant lifestyle changes. Autism Spectrum Disorder is considered as one of the most severe childhood disorders with the most complex developmental patterns (Robinson-Agramonte, Fraguela & Bergado-Rosado, 2015). Caring for a child with Autism Spectrum Disorder is demanding, and can cause severe familial stress (Gray, 2002). Although no evidence exists of a cure for Autism Spectrum Disorder, psychosocial and pharmacological interventions can improve the quality of life of such children and their families. However, due to the severity of the behaviour of a child with Autism Spectrum Disorder, antipsychotic medication and social-communication intervention have had limited maintenance results (Eller, 2015).

In recent years the diagnosis of Autism Spectrum Disorder has globally increased dramatically. In South Africa, it is estimated that Autism Spectrum Disorder affects one in every 110 children, making it the fastest-growing developmental disability today (Autism Western Cape, 2016). The National Department of Health has reported an estimated 500% increase in the diagnosis of Autism Spectrum Disorder in the Western Cape with on average
10 children being diagnosed at state hospitals on a weekly basis. This excludes children who are being diagnosed in private practice (Autism Western Cape, 2016). Therefore, it is clear that further research and reliable data in this area are needed (Larsen, 2012). There is a need to explore and further research the range of treatment modalities available to affected individuals and their families, intervention options for treating Autism Spectrum Disorder as well as the mitigating effects it has on the family system (Tanguay, 2000).

Neurofeedback is a relatively new non-invasive treatment option. The goal of Neurofeedback is to influence or change abnormal oscillatory activity, which is the binding-related gamma oscillations and excitatory/inhibitory imbalance, through modulation achieved through visual and auditory stimuli. The aim of Neurofeedback is to make clients aware of this activity and reward the inhibition of undesired, or enhancement of desired oscillatory activity (Eller, 2015). According to Jarusiewicz (2002) there is a 26% reduction in the core symptoms of Autism Spectrum Disorder after Neurofeedback intervention. There is no evidence yet that Neurofeedback intervention for Autism Spectrum Disorder has a long-lasting effect, although research by Jarusiewicz (2002) suggests that it may have such an effect.

According to Altobelli (2012), research has focused on the goals and objectives of Neurofeedback as an intervention for the child, but a limited number of studies have examined the experiences of primary caregivers of Autism Spectrum Disorder children receiving Neurofeedback intervention, hence the need for further study of these primary caregivers’ experiences (Altobelli, 2012). For the purposes of this study “primary caregiver” is defined as the child’s mother, father, grandparent or guardian.

Only a limited number of research studies have looked at the efficacy of Neurofeedback intervention. An increasing number of studies have looked at the objective outcomes of
Neurofeedback. However, only a few have used qualitative studies by addressing the experiences of primary caregivers with children who have received Neurofeedback therapy as a treatment intervention for Autism Spectrum Disorder (Altobelli, 2012). Thus, the limited number of published research studies that have examined the experience of Neurofeedback results in a gap in the literature and therefore a lack in contextual information as to how effective the Neurofeedback intervention is for the treatment of Autism Spectrum Disorder. This research study has explored the experiences of primary caregivers with Autism Spectrum Disorder children who have undergone Neurofeedback as an intervention, to explore whether they were satisfied or dissatisfied with the intervention, and also examined how the intervention influenced the family system.

1.2 Rationale

In many parts of South Africa a minority of people are aware of Autism Spectrum Disorder and even fewer are aware of the signs and behaviours that indicate that a child may have Autism Spectrum Disorder (Stephens, 2012). In addition, receiving an intervention for Autism Spectrum Disorder can be a lengthy process, hampered by inequalities in access to medical services. Consequently, many children in South Africa do not receive crucial interventions in the early years (Stephens, 2012). According to Eller (2015), studies providing information on Neurofeedback intervention for children suffering from Autism Spectrum Disorder are limited. Thus there is a need to explore aspects of non-invasive treatment options, like Neurofeedback, for Autism Spectrum Disorder in South Africa. This research study contributes to filling the gap in the body of knowledge and existing literature, directly contributing to understanding what specific problems with Autism Spectrum Disorder led primary caregivers to choose this intervention, how beneficial it was to the child, and how satisfactorily this intervention affected the whole family system. The purpose of this study was to gain qualitative insight into and understanding of the experiences of primary
caregivers with regard to change in behaviour of children who have received Neurofeedback as an Autism Spectrum Disorder intervention.

1.3 Theoretical framework

The study focused on primary caregivers’ experiences, which take place both in the environment of the family and in a broader social context. Therefore ecological systems theory, developed by Bronfenbrenner (1994), was considered the most appropriate tool for this research study. This is also called development in context or human ecology theory, which identifies environmental systems with which an individual interacts (Braun & Clarke, 2006; Corno & Anderman, 2015; Rosa & Tudge, 2013). This theory provides the framework within which community psychologists study individuals’ relationships within communities and the wider society. The theory provided an opportunity to develop different types of themes, since it suggests that development reflects the influence of five socially organised subsystems that are interlinked: microsystem, mesosystem, exosystem, macrosystem and chronosystem (Rosa & Tudge, 2013).

These different subsystems constantly interact with and influence each other. The microsystem is the individual’s immediate system of which they form part, for example family, school and peer groups in which individuals are closely involved in continuous face-to-face interactions with other familiar people (the level at which key proximal interactions occur). The mesosystem is a “system of micro-systems” or “linkages” associated with one another or connections between contexts (Bronfenbrenner, 1994, p. 40). The social agents in the microsystem are not isolated; they influence and are influenced by the other systems (Rosa & Tudge, 2013). The exosystem includes other systems in which an individual is not directly involved, but which may influence, or be influenced by, the people who have proximal relationships with the individual in their microsystems. Examples of factors in the exosystem
include neighbours, legal services, social welfare services and mass media. The macrosystem is the system that deals with the cultural context. It includes large-scale societal factors impacting people’s lives, ideologies and system beliefs (Rosa & Tudge, 2013). The macrosystem can be defined as the wider system of ideology and organisation of social institutions common to a particular social class, ethnic group or culture (Rosa & Tudge, 2013). Lastly, the chronosystem comprises the patterning of environmental events and transitions over a period of time (Santrock, 2009).

1.4 Aim of the study

The main aim of this study was to explore the primary caregivers’ experiences with regard to Neurofeedback as an intervention for Autism Spectrum Disorder in the Western Cape. In particular, this study explored whether the primary caregivers experienced any behavioural changes, or if they were satisfied or dissatisfied with the intervention and also examined how the intervention influenced or impacted on the family system.

1.5 Objectives of the study

- To gain an understanding of how the primary caregivers experienced the Neurofeedback intervention in terms of exploring if there were any behavioural changes.
- To explore and understand primary caregivers’ satisfaction and dissatisfaction with Neurofeedback intervention.
- To explore whether the intervention influenced the family system as a whole.

1.6 Research questions

The three research questions are:

- What are the experiences of primary caregivers with Autism Spectrum Disorder children who have undergone Neurofeedback as an intervention?
• Are primary caregivers satisfied or dissatisfied with Neurofeedback intervention?
• Has the intervention influenced the family system, and if so how?

1.7 The significance of the study

This study contributes towards addressing the lack of qualitative research studies of the experiences of primary caregivers whose children received Neurofeedback therapy for Autism Spectrum Disorder in the Western Cape and nationally. It contributes to the field of Autism Spectrum Disorder in South Africa through gaining understanding of Neurofeedback as an intervention as well as contributing to narrowing the gap in the body of knowledge and existing literature. The results of the study will be disseminated among primary caregivers and practitioners through seminars and publications. This research study has also provided the primary caregivers an opportunity to engage in self-reflection on their experiences of Neurofeedback as well as their experiences of selecting other intervention modalities and what the impact was within the family system.

1.8 Summary

The thesis consists of five chapters. Each chapter focuses on various aspects of the main theme. Chapter One is a brief introduction focusing on the main considerations of this thesis, comprising the research problem being addressed and discussed, and stating the purpose of the study. Chapter Two focuses on a review of the literature relating to the topic. It covers various aspects of the thesis such as Neurofeedback and Autism, the prevalence of Autism locally and nationally and how families experience Neurofeedback as well as the reasons for their choice for the Neurofeedback intervention. Chapter Three explains the methodology used for this study, and describes the method, data collection, analysis, selection of participants and ethical considerations. Chapter Four presents the findings that were collected and analysed. Chapter Five includes a discussion of the analysed data and the results, as well
as the implications of the findings. A brief consideration of the limitations of the study are discussed, including recommendations for future research studies.
CHAPTER 2: LITERATURE REVIEW

2.1 Introduction

This chapter reviews the literature relating to the diagnosis and characteristics of Autism Spectrum Disorder, and discusses the prevalence of Autism Spectrum Disorder worldwide, in South Africa and specifically in the Western Cape. In addition, the effect on the family’s ecology and specifically on the primary caregiver is discussed, highlighting the difficulty experienced in identifying appropriate treatment modalities.

Furthermore, the literature concerning interventions for Autism Spectrum Disorder is reviewed. These include both pharmacological and behavioural interventions, and can be classified as invasive and non-invasive. The role of the primary caregiver in choosing one or more interventions is discussed, with a focus on the choice of Neurofeedback.

The chapter gives a background to Neurofeedback and focuses specifically on research done on primary caregivers’ experience of the effects of Neurofeedback on their Autism Spectrum Disorder child.

2.2 Definition and characteristics of Autism Spectrum Disorder

2.2.1 Definition

Autism Spectrum Disorder is a brain-based condition characterised by social communication challenges and restricted repetitive behaviours, activities, and interests. It is the result of a neurological disorder that changes the way the brain functions, causing developmental delays or problems in many different skills from infancy to adulthood (Alberta, 2008). Every individual with Autism Spectrum Disorder is unique and generally faces challenges in
interacting and communicating with others, with other typical characteristics being a narrow range of interests, and engaging in obsessive repetitive activities (Lainhart, 2015).

According to *The Diagnostic and Statistical Manual of Mental Disorders* (DSM-5) (American Psychological Association, 2013) the essential diagnostic features of the Autism Spectrum Disorder child are persistent impairment in reciprocal social communication and social interaction (criterion A), and restricted, repetitive patterns of behaviour, interests or activities (criterion B). These symptoms are present from early childhood (criterion C) and limit or impair everyday functioning and (criterion D). The symptoms are not better explained by intellectual developmental disorder or global developmental delay (criterion E). The stage at which functional impairment becomes obvious will vary according to characteristics of the individual and his or her environment (American Psychological Association, 2013).

Within the diagnosis of Autism Spectrum Disorder, individual clinical characteristics are noted through the use of specifiers (with or without accompanying intellectual impairment; associated with a known medical/genetic or environmental/acquired condition; associated with another neuro-developmental, mental, or behavioural disorder) as well as specifiers that describe the autistic symptoms (age at first concern; with or without loss of established skills; severity). These specifiers provide clinicians with an opportunity to individualise the diagnosis and communicate a richer clinical description of the affected individuals. For example, many individuals previously diagnosed with Asperger's disorder would now receive a diagnosis of Autism Spectrum Disorder without language or intellectual impairment (American Psychological Association, 2013). There are three levels of severity within Autism Spectrum Disorder level 1 – “requiring basic support”; level 2 – “requiring substantial support”; and level 3 – “requiring very substantial support” (American Psychological Association, 2013).
Association, 2013). The DSM-5 contains an important revision of the previously valid diagnostic criteria of the DSM-IV-TR (APA, 2000). There is no longer a differentiation into four separate disorders. The former DSM-IV-TR diagnoses of Autistic Disorder (299.00), Asperger’s Disorder (299.80), Pervasive Developmental Disorder (299.80), Not Otherwise Specified (299.80) and Childhood Disintegrative Disorder (299.10) are now integrated in the DSM-5 as a cluster diagnosis under the Autism Spectrum Disorder (Eller, 2015). Autism Spectrum Disorder presents with a variety of characteristics.

2.2.2 Characteristics of the Autism Spectrum Disorder child

An autistic child reacts differently to environmental stimuli of hearing, smelling, tasting, moving around, which all can be affected (Hoffman, 2012). Their multisensory system is so acute that being in places with loud noises, strong smells and other sensory stimuli triggers social discomfort. Therefore high stimulus environments such as shopping malls or shopping centres can be sources of agitation and discomfort. As a result of the sensory overload autistic children will find it difficult to self-regulate because they are over-sensitive to outside sensory stimuli. Primary caregivers struggle to manage the behavioural problems exhibited by these children, which causes severely stressful situations for the primary caregiver (Hoffman, 2012). Behavioural problems such as socially embarrassing actions, temper tantrums, aggression, destructiveness, screaming and running away are often associated with Autism and often lead to dysfunctional social interaction. These behavioural traits extend to the child’s interactions in various environments such as school, presenting severe educational challenges.

2.2.3 Primary caregivers’ experience of Autism Spectrum Disorder

One of the main features of Autism Spectrum Disorder which affects caregivers is the impairment of social interactions and abnormalities of social behaviour. These types of
behaviour can appear to emerge as early as six to 12 months (Evans, 2007). An autistic child shows little if any interest in peers and lacks interest in forming relationships and showing empathy (Evans, 2007). Social behaviour is affected by Autism and causes dysfunction which is noticed by people other than the immediate family (Evans, 2007). This causes stress for the primary caregiver.

All parents or caregivers must cope with grief, worries about the future and the continuous struggle to find interventions. In addition to the stress they experience they are also faced with the uncertainty about what caused their child’s autism, as well as possible guilt (no matter how unjustified) over whether they did or failed to do something that led to their child's Autism Spectrum Disorder.

Primary caregivers do not always understand why their child exhibits these behaviours, and this contributes to their lack of understanding of the neurodevelopmental disorder (Hoffman, 2012). This lack of understanding often hinders the primary caregiver’s ability to manage this disorder. As a result primary caregivers’ stress is caused not only by tensions within the family, but also by external factors like social stigma and isolation, that make their lives more challenging. Research conducted by Kinnear, Link, Ballan, and Fischbach (2016) showed that the experience of stigma can be extremely damaging to the personal identity and wellbeing of the individual with Autism Spectrum Disorder and by extension, his or her family.

2.3 The prevalence of Autism Spectrum Disorder

Autism Spectrum Disorder is the fastest-growing serious developmental disorder in the world, with about 67 million people affected globally (Ahmed & Ahmed, 2015). According
to the Centre for Disease Control (2010), incidence of Autism Spectrum Disorder has increased dramatically over the last two decades.

International statistics confirm that one in 88 children is affected by Autism Spectrum Disorder (Autism South Africa, 2015). In South Africa the prevalence rate could potentially be over 270,000 people, with a predicted 5,000 new cases per year (van Biljon, Kritzinger, & Geertsema, 2015). In the Western Cape, the Department of Health reported an estimated 500% increase in the diagnosis of Autism Spectrum Disorder, with on average 10 children being diagnosed at government hospitals weekly (Autism Western Cape, 2015). This does not include children diagnosed in the private health sector (Autism Western Cape, 2015). The onset of Autism Spectrum Disorder takes place during the early developmental period, but in some cases symptoms are not recognisable until the child is much older – even up to the age of 13. Because of the delay between the onset and diagnosis, the reported prevalence rates increase with age in young children (Sadock & Sadock, 2011).

While rates of Autism Spectrum Disorder are consistent across cultures, there is a great variety by gender, with boys being affected far more than girls. Autism Spectrum Disorder affects one in 70 males, but only one in 315 females. A plausible reason for this may be that girls with Autism Spectrum Disorder are often better at masking their difficulties in order to fit in with their peers, and in general have a more even profile of social skills (Alberta, 2008).

Research about the stigma associated with psychiatric disorders reveals a large barrier for future studies about mental disorders. This could be because conceptualisations of Autism Spectrum Disorder may differ across cultural contexts as people may attach different meanings to Autism Spectrum Disorder and, therefore, understand it differently and manage the disorder differently. In the rest of Africa, an excess of non-verbal over verbal cases of
Autism Spectrum Disorder presenting to orthodox clinical practice has been observed (Ametepee & Chitiyo, 2009; Bakare, 2011). This may be due to poor knowledge and awareness about Autism Spectrum Disorder, inappropriate help-seeking behaviour, and inadequate child and adolescent psychiatric facilities and trained healthcare personnel (Autism South Africa, 2015).

2.4 Challenges that parents face with a child diagnosed of Autism Spectrum Disorder

The high prevalence rates in Autism present challenges to families and the broader communities. These families face challenges that set them apart from other family groups. More families will start to experience emotional devastation, especially just before and after the child is diagnosed. High prevalence rates result in parents struggling to find interventions; together with these interventions come complicated therapy schedules, the need to follow through on treatment at home, juggling family commitments with job responsibilities, and many other issues. The resources available that the government provides to a primary caregiver of a child who is in need of permanent care because of his or her disability and severity levels of Autism is limited. With the increase in prevalence rate these limited resources will become even more constrained, with the result that fewer families of low economic income groups can receive social grants.

2.5 The effect of Autism Spectrum Disorder on the family

2.5.1 The family ecology

Bronfenbrenner’s ecological model describes how the different subsystems within and outside the family structure operate at multiple levels, with the autistic child operating within a complex system of relationships affected by the multiple levels of the surrounding environment (Konza, 1999). The microsystem of a settled and co-operative child is likely to
reflect positive interactions with the parents or caregivers, who are attuned to the child’s emotional responses and needs. An autistic child who has behavioural challenges may exist in a punitive or hostile environment because the parents may find the child’s responses hard to manage (Konza, 1999).

Bronfenbrenner’s mesosystem encompasses connections among microsystems such as neighbourhood, home, school and supporting resources. All the different interactions from these supporting resources are likely to influence the autistic child’s development. The more positive interactions within this subsystem the more congruent the attitudes and ideas of the home, school and neighbourhood of upbringing will be and therefore will provide a better support system for the family (Konza, 1999).

The exosystem is a crucial subsystem that directly influences the autistic child’s development. Even though the child might not be a directly active participant within formal social settings the parents’ social support networks and community-based ties would constitute part of the exosystem of a child. If these settings are more favourable and supportive a better outcome for the autistic child would be possible. For example, a parent who has a work environment which is more understanding and allows paid sick leave to attend to the autistic child is likely to have a directly positive effect on the child, whereas a less favourable working environment that places high emphasis on deliverables, resulting in time spent with the child being less positive, will have an adverse effect on the child (Konza, 1999).

Bronfenbrenner’s macrosystem refers to the values, laws, customs and resources of a particular culture (Konza, 1999). Within the South African context different beliefs and cultural settings would have an effect on the child’s development.
Then, lastly, is the chronosystem, which refers to major life transitions that can happen to the family and have an impact on the autistic child (Konza, 1999). For example a family’s relocating to another city would tend to change or transition how the child interacts with all the other subsystems of the family structure.

According to Hoogsteen and Woodgate (2013), once a child is diagnosed with Autism Spectrum Disorder it becomes the focal point of the family system, which operates around the child, creating familial stress. It is important to understand a family’s ecology: what support and resources they have available to them, the family structure and what they struggle with are critical considerations before an intervention can be decided upon (Hoffmann, 2012). It is therefore crucial that when the parents decide on a treatment or intervention that all factors, advantages and disadvantages of the interventions are carefully considered and deliberated upon as to how not only the child is affected but the family system as a whole (Hoogsteen & Woodgate, 2013).

A challenge that can put additional stress on the parents and the family system is that the family itself may not fully comprehend the complete spectrum of difficulties the child faces in perceiving emotional states of others, and the child’s sensory integration problems where input may register unevenly, be distorted, and there may be difficulty in screening out background noise.

Understanding the family’s ecology is as important as making the choice of intervention for the child (Hoffmann, 2012). Within the family structure there are a variety of important factors to take into consideration, like making the correct decision in choosing specific interventions are crucial in coping. Before primary caregivers choose intervention options for
their Autism Spectrum Disorder child they need to understand the effect on the whole family (Hoogsteen & Woodgate, 2013).

2.5.2 Primary caregivers

The primary caregiver undergoes many challenges in taking care of an autistic child, for example changing the family’s lifestyle, limited career progression, termination of employment and loss of income coupled with a lack of resources required for helping their autistic child (Mthimunye, 2014). The primary caregiver’s priorities change dramatically as they need to adjust to the autistic child’s needs which can result in the primary caregivers engaging less in their own social activities. This directly affects the lives of all family members (Mthimunye, 2014). Within the family structure the highest level of stress is experienced by the primary caregiver; therefore the availability of support within the family as well external support is very important. The primary caregiver’s personal characteristics also play a critical role in the ability to cope and to manage stressors. The availability of support within the family as well as external support is of vital importance in order for the primary caregivers to cope (Mthimunye, 2014). Therefore, being surrounded by people who offer support such as family members and friends who not only offer emotional support but also assist with family chores such as cooking, babysitting and assisting with the other siblings can make a huge difference to the family in need.

2.6 Interventions for Autism Spectrum Disorder

Autism Spectrum Disorders are among the most difficult childhood disorders and, therefore, are some of the most misunderstood (Evans, 2007). Problems with the evaluation of autistic children include day-to-day variability in symptoms and the nature of presenting problems including the severity levels and the lack of agreement on the underlying causes. Autism has led to great difficulty for primary caregivers in seeking multiple interventions and receiving
treatment recommendations which include, for example, medications, tranquillising, aversive stimulation and even dietary changes. The long-term success of these invasive treatments has been low (Perry et al., 2003).

During the last two decades many educational, psychosocial and pharmacological interventions have been utilised as interventions for Autism Spectrum Disorder. These interventions have been introduced to alleviate neurological, behavioural and developmental problems associated with autism and related disorders (Friedrich et al., 2015). Various empirical research studies have shown that the scientific validity of some of these interventions has proven to be ineffective and they are no longer in use (Friedrich et al., 2015). Some of the proposed interventions are time consuming and expensive, but they may also be intrusive and potentially harmful. In addition, the psychological cost to caregivers in terms of the false hope of a “miracle cure” is difficult to accept (Lainhart, 2015).

The many complex interventions and therapies for children presenting with Autism Spectrum Disorder include dietary, behavioural, educational and pharmacological interventions. Primary caregivers must manage these interventions, making the choice of intervention or therapy challenging (Mackintosh, Goin-Kochel, & Myers, 2012). With consistent, evidence-based treatment and often a multidisciplinary intervention programme, the primary caregivers are likely to see an improvement in their child’s behaviour, language and social interactions. Children on the autism spectrum are not homogenous and may respond to interventions and therapies differently (Eller, 2015). Primary caregivers find they have to try multiple treatments or intervention approaches to find what works best for their child and their family as a whole (Mackintosh et al., 2012). According to Altobelli (2012), the therapies that are the most widely chosen are behavioural therapies, which include skills-based therapies, and pharmacological interventions.
Literature has shown that interventions for Autism Spectrum Disorder can broadly be categorised as behavioural and pharmacological interventions. Families with an autistic child require substantial resources and significant time which is needed for interventions like behavioural treatment. The multidisciplinary intervention approaches for autistic children may cause the primary caregivers stress and at times cause disruption within the family system as these interventions often mean the caregiver transporting the child to the various treatment modalities usually several times per week. Behavioural interventions often require prolonged exposure before they are effective and may further compound the strain of the financial burden on the primary caregiver (Aman, Arnold, & Hollway, 2015).

Invasive treatment modalities like pharmacological interventions can cause potential undesirable side effects for the autistic child. Primary caregivers need constantly to be aware and cognisant of the administration of medicine and managing the process.

Currently there are palliative interventions for Autism Spectrum Disorder, but as yet there is no cure, and it presents as a lifelong disorder.

### 2.6.1 Pharmacological interventions

The first goal of pharmacological interventions for Autism Spectrum Disorder is to reduce the intensity of some of the associated symptoms such as irritability, hyperactivity, excitability, impulsivity, anxiety and aggression (Aman et al., 2015). The second goal is to focus on halting further abnormal brain development and compensating for prior abnormalities during brain development (Altobelli, 2012). The investigation of atypical antipsychotic drugs such as risperidone was done by the Research Units on Paediatric Psychopharmacology Autism Network (McDougal et al., 2005) which focused on aggression, temper outbursts and self-injury behaviours of autism. Risperidone showed persistent
efficacy and significant tolerability for short-term treatment of children with Autism Spectrum Disorder who exhibit these symptoms (Altobelli, 2012). Empirical research study has proven that pharmacological interventions for Autism Spectrum Disorder are effective for short-term treatments. However, research study also indicates that it is not always the best option for long-term treatment due to possible adverse side effects like increased appetite and weight gain as well increases in the body’s production of the hormone prolactin which can interfere with bone building and cause breast swelling. There may also be symptom recurrence upon termination of treatment (Aman et al., 2015).

2.6.2 Behavioural interventions

A variety of behavioural therapies are available, for example auditory and sensory integration training, occupational therapy, and most recently Neurofeedback intervention (Altobelli, 2012). Research studies have advocated for the continued use of behavioural interventions as the primary treatment options for Autism Spectrum Disorder (Altobelli, 2012). Behavioural therapy is an intervention that helps the child regulate his or her behaviour voluntarily. This is done by positive reinforcement which motivates the child to change behaviour. Brief, targeted behavioural interventions can improve social communication in toddlers and young children. Typically, benefits can be seen when interventions are delivered for at least six months (Ahmed & Ahmed, 2015).

While behavioural interventions have proven to be a successful treatment modality, the impact on the family often varies (Altobelli, 2012). Many people are involved in this type of intervention modality, such as teachers, therapists, doctors and psychologists, which creates an intense experience for the whole family. This high level of intensity can cause stress and tension. However, the multi-disciplinary teams of treatment also foster emotional and social
support. The development of a close relationship with the child is rewarding even though there is a high demand on the family members’ time and resources (Altobelli, 2012).

One of the main non-invasive treatment modalities for autism is sensory integration training which focuses on three main senses like the vestibular, proprioceptive and tactile senses. Even before birth, these interconnections start forming and continue to develop as the person matures and interacts with his or her environment. This type of intervention is important for Autism Spectrum Disorder children as it can facilitate attention and awareness, and reduce overall arousal (Alberta, 2008).

Occupational therapy intervention focuses on interaction (particularly motor and sensory interactions) and communication (Larsen, 2012). It also helps to develop adaptive strategies, including coping with transitions. Neurofeedback falls under the non-invasive behavioural intervention category which involves an intervention that is carried out by a machine that monitors brainwave activities through an electroencephalogram (EEG), which is a test used to detect abnormalities related to electrical activity of the brain. This procedure tracks and records brain wave patterns (Larsen, 2012).

2.6.3 Primary caregivers’ choice of different treatment modalities

Primary caregivers do not always have the necessary research information to make judgements about different interventions. Due to their need to help their autistic child, primary caregivers are often faced with trying to do their own research through the internet and by talking about intervention options at parent support groups and by general reading on different treatment modalities available for autism (Karst et al., 2012). In addition, considering the continued use of both scientifically validated and non-validated interventions by primary caregivers, research evidence alone may not be the only factor in the decision-
making process for primary caregivers. For example, little is known about the process that primary caregivers go through when they seek out and adopt one particular treatment over another. In order to help primary caregivers make informed decisions, it is important to know more about where they are accessing their information and what their expectations are with respect to the various interventions they may use (Ahmed & Ahmed, 2015).

2.7 Neurofeedback intervention for Autism Spectrum Disorder

Biofeedback (including neurotherapy) is built upon the cornerstone of technology, electronics, behaviourism, physiology and neurology (Demos, 2005). The first historic scientific research conducted on biofeedback was conducted in 1875 by an English physician, Richard Caton, who was the first to discover that the brain generated electricity (Robbins, 2000). He discovered that there are fluctuations in the brain’s electrical activity followed by mental activity (Demos, 2005). The experiments that Caton conducted were on exposed brains of animals which entailed the placement of electrodes (Demos, 2005). He also found that he could detect a weak flow of current across an unopened skull. This was the keystone to what would become the “brain’s electrical signature, the electrical encephalogram” (Robbins, 2000).

The main goal of Neurofeedback is to promote healthy brain wave patterns by training the brain. The brain produces electrical pulses that communicate with each other; these brain waves are the index of thoughts, behaviour and emotions (Pineda, Juavinett & Datko, 2014). This means that a person’s brain waves change based on their feelings or what they are doing. Neurofeedback as an intervention uses an EEG machine to monitor brain wave patterns. The most obvious problem in autism, when looking at the brain, is the level of integration and functioning (Othmer, 1999). The emotional core functioning allows us to function in socially-connected ways. Within our brain even our neural networks are organised by our emotional
functioning. There are developmental flaws in the structural connectivity of these networks. There is no reason to believe that our emotional networks should be impacted by just looking at the structural deficits in the brain’s white matter. However, at the level of functional connectivity, they clearly are (Othmer, 1999). This is where Neurofeedback is relevant, since this type of training brings the neural network of emotional connectivity back in alignment. It is fortunate that with autistic children the emotional connectivity lies largely in the functional domain and is clinically accessible. Brain wave activity can be consciously controlled to make the lines or graphics on a computer monitor move (Coben, Linden & Myers, 2010). This intervention makes thought patterns observable, allowing an individual to learn how to trigger thoughts which are healthy in nature and clearly visible as more desirable brain wave patterns. On average a training session lasts 45 minutes, and depending on the severity levels between 10 and 50 training sessions may be required (Altobelli, 2012).

Neurofeedback over the years has developed as a clinical tool that can be applied to the clinical challenges facing autism. Preliminary results indicated that children made good progress with this intervention so this prompted the wider use of this intervention with autistic children (Othmer, 1999). As reported by Othmer, (1999), “scientific understanding of the issues was advancing to the point where Neurofeedback work could now be understood in terms of an accepted model” (p. 11). Autism Spectrum Disorder is directly related to behavioural consequences and therapist approaches are broadly categorised as biomedical issues.

The direct benefit from this intervention is that the child will become much calmer, have better communication levels and will be better able to participate within the family system as a whole (Evans, 2007). In a 2011 review Holtmann et al. stated that the use of Neurofeedback training for Autism Spectrum Disorder was not supported by existing studies and that future
investigations need to clarify specifically which symptoms can actually be reduced with this form of intervention.

Published research on Neurofeedback is scant and similarly the literature published in the area of Autism Spectrum Disorder is also lacking (Mohamed, 2009). One of the main research studies conducted in this area was that of Goldstein, Sichel and Fehmi (1995). This study found that using Neurofeedback as an intervention for mild autism does have a positive outcome. Similarly, Jarusiewicz (2002) conducted a pilot study on Neurofeedback to determine its efficacy in assisting children with autism and revealed that Neurofeedback resulted in successful relief from most if not all of their major symptoms (Jarusiewicz, 2002). The study consisted of an experimental group diagnosed with Autism Spectrum Disorder and a control group with a similar diagnosis. The control group was given no Neurofeedback training, and the experimental group received 36 Neurofeedback training sessions over a period of 4.5 months. The results were significant, indicating a 26% reduction in autism symptoms in the experimental group compared to no reduction in the control group. After consulting with the primary caregivers on how the children functioned in their home and in general interpersonal relations, a remarkable improvement in socialisation, schoolwork anxiety, tantrum frequency and sleep patterns was reported by Evans (2007). According to Evans (2007), “these reports were commensurate with scores changes on the Autism Treatment Review Checklist (ATEC), which showed improvements in sociability of 33 percent, speech, language and communication of 29 percent and overall health of 26 percent, and sensory/cognition awareness 17 percent” (p. 326).

Given the wide range of sensory behavioural differences for individuals with autism, understanding the neural underpinnings of basic sensory processing in Autism Spectrum Disorder is important. Behavioural intervention trials, such as computerised training modules
and self-regulation programmes, need to be studied both for efficacy and to determine whether there is normalisation of neural activity in affected individuals (Evans, 2007). Calming of the brain for autistic children is an important factor. According to Evans (2007), “there is a close association between EEG frequencies and one’s state of arousal” (p. 27). The delta levels within the brain are much higher with Autism Spectrum Disorder. The EEG frequencies provide a clear measurement to determine whether the autistic child is becoming calmer or not (Evans, 2007).

According to Billeci (2013), Neurofeedback also helps the autistic child with his or her potential for additional insights and functional improvements. This is one of the few interventions that can make it possible for primary caregivers to conduct home training once the practitioner has established a method for a particular child after a number of sessions have been conducted (Billeci et al., 2013). The effectiveness of Neurofeedback still needs further systematic empirical evidence (Eller, 2015). The focus of this intervention is not treating the symptoms of a disorder but instead changing the individual’s brain activity through training interventions. It is a non-invasive approach, which means that this intervention focus is not on medication (Eller, 2015).

Neurofeedback can create long-term effects and have a longstanding impact after the termination of training and therapy (Evans, 2007). Since Autism Spectrum Disorder is unique in each individual, it is very important that treatment is individually based. Neurofeedback as an intervention for autism is ideal as it is completely individually based on the subject’s recorded brain activity (Burkett, 2005).

The experiences of primary caregivers with Autism Spectrum Disorder children who have undergone Neurofeedback as an intervention are as important as the responses of the children.
themselves. The effect of the intervention also extends to the family system as a whole, and there is value in examining this.

Neurofeedback is a promising alternative compared to the mainstream interventions, being more cost effective, of shorter duration, non-invasive in nature and easy to administer.

What makes Neurofeedback an attractive intervention option for primary caregivers with an autistic child is its comparably shorter treatment duration, its non-invasive approach, and the ease of administration (Aman, Arnold, Hollway, 2015). Neurofeedback is regarded as a non-invasive treatment option for Autism Spectrum Disorder, which is why it is important to compare this intervention to other treatment options (Burkett, 2005).

A disadvantage in the South African context is that Neurofeedback as an intervention is currently not accredited by the Health Professions Council of South Africa (HPCSA) as a registration category for treatment in terms of the Health Professions Act No. 56 of 1974. This makes it difficult for primary caregivers to gain access to the intervention or even to be made aware that such an intervention exists in South Africa as they still have to go through the normal channels of visiting a medical practitioner. This can also make it prohibitively expensive.

2.8 Qualitative research studies on Neurofeedback and Autism Spectrum Disorder

A limited number of studies have been conducted on this type of intervention (Larsen, 2012). Current research on Neurofeedback focuses more on the quantitative findings on Neurofeedback as an intervention for Autism Spectrum Disorder and therefore studies have been limited to findings regarding the efficacy of the intervention on the child and not many studies have been done that investigate the effects of Neurofeedback intervention on the primary giver and the family as a whole (Altobelli, 2012).
It is clear that further research and reliable information in this area is needed (Larsen, 2012). This research study contributes to filling this gap in the body of knowledge and existing literature, directly contributing to understanding what specific problems with Autism Spectrum Disorder led primary caregivers to choose this intervention, how beneficial it was to the child, and how satisfactorily this intervention affected the whole family system. The purpose of this study is to gain qualitative insight into and understanding of the experiences of primary caregivers with regard to change in behaviour of children who have received Neurofeedback as an Autism Spectrum Disorder intervention.

2.9 Primary caregivers’ experiences of Neurofeedback as an intervention

According to Altobelli (2012), primary caregivers have specific types of experience that lead them to Neurofeedback as an intervention. Socialisation is one area where most primary caregivers hope that Neurofeedback may provide improvement as this is one of the most challenging factors children struggle to overcome.

In a study conducted by Altobelli (2012), primary caregivers of autistic children who received Neurofeedback as an intervention indicated that the intervention played a crucial role in the ability to provide the autistic child with a calming effect and a general sense of wellbeing, which in turn seemed to make the daily living of an autistic child more bearable and less distressing. The primary caregivers’ feedback in Altobelli (2012) study on the impact of Neurofeedback for the autistic child indicated that as primary caregivers they believed that the intervention was beneficial in reducing the symptomatology of Autism Spectrum Disorder and increasing the effect of other treatment modalities. According to Altobelli (2012), some primary caregivers expressed dissatisfaction with Neurofeedback as an intervention with reports of minor irritability in the autistic child following sessions and one
reporting mild sedation. Because autistic children have sensory sensitivity the gel used to attach the electrodes to the scalp can cause the child to be uneasy and increase anxiety (Altobelli, 2012). One of the dissatisfactions reported by the primary caregivers was the lack of research study available on Neurofeedback as an intervention for autism as well the lack of available practitioners (Altobelli, 20112).

Despite much research having been conducted on the traditional invasive treatment options on Autism Spectrum Disorder, little is known about the other non-invasive treatment options. This is true especially in South Africa, with Neurofeedback as an example of a non-invasive treatment option.

2.10 Summary

This chapter examined the literature regarding Autism Spectrum Disorder, how it impacts on the family system, its prevalence and statistics to indicate the status of Autism Spectrum Disorder in the Western Cape and in the South African context. The characteristics and assessment of Autism Spectrum Disorder were discussed, as well as the reasons for primary caregivers’ choice of various therapeutic modalities, for example behavioural, pharmacological and other alternative non-invasive interventions. Neurofeedback as an intervention for Autism Spectrum Disorder and the primary caregivers’ experiences of Neurofeedback as an intervention were examined. International literature indicates that South Africa is still lacking much research in the field.

The next chapter will focus on the methodology of the study.
CHAPTER 3: METHODOLOGY

3.1 Introduction

This study utilised a qualitative research methodology. This methodology sought an in-depth understanding of the primary caregiver’s experiences of children who have received Neurofeedback as an intervention for Autism Spectrum Disorder. Each primary caregiver’s experience of how Neurofeedback plays a role as an intervention is unique. A qualitative research methodology allows the researcher to gain insight into the primary caregivers’ personal experiences, gathering information about the subjective experiences and specifically accessing their experiences about the intervention (Bailey, 2007). It should also help in building a sense of trust between the researcher and the participant that enables the researcher to make connections or discern differences between primary caregivers’ experiences of Neurofeedback intervention. This study investigated the insider perspective to explore and to probe each primary caregiver’s unique experience, and allowed the primary caregivers the freedom to express their experiences to establish whether they were satisfied or dissatisfied with the intervention and how it influenced the family system as a whole.

3.2 Research design

This study used an exploratory research design. Exploratory studies are used when the topic or phenomenon to be studied is new and when data is difficult to collect (Babbie & Mouton, 2001). The study therefore employed an exploratory research design to explore the participants’ experiences through their own words. The participants’ experiences of the results of therapeutic modality were captured from an insider perspective, thus allowing the researcher to better understand how the participants experienced the effects of Neurofeedback.
on their child. The study also explored whether the participants perceived changes in their family life and if so what the nature of the changes was (Babbie & Mouton, 2001).

3.3 Research setting

This study was conducted within the Western Cape and participants were contacted through Neurofeedback practitioners, and autism-affiliated organisations in the Western Cape. The population of the Western Cape for 2015 was estimated at 5.8 million people representing approximately 10% of the national population. The population has continued to grow over the past six years at a rate of 9.6% (Autism Western Cape, 2015).

Neurofeedback is still fairly new in South Africa and therefore not yet well known. Most Neurofeedback practitioners are based in Johannesburg, some in Cape Town and Durban and a few in the rural areas (Van der Linde et al., 2016).

Researchers state that the clinical effects of Neurofeedback training can be considered clinically meaningful in the field of ADHD treatment, which is a disorder of not being able to focus attention appropriately, being hyperactive or impulsive and not being able to control behaviour, or a combination of these (Van der Linde et al., 2016). Throughout the Western Cape and within the South African context many parents seek Neurofeedback to treat their ADHD child. However, most recently Neurofeedback has started to be become more widely used and popular for treating Autism Spectrum Disorder as well, as it also stabilises the brain to reduce anxiety and depression, allowing for better functioning as a whole (Springer, Van Toorn, Laughton, & Kidd, 2013).
3.4 Participants and sampling

The researcher ensured that the participants chosen were racially, culturally, and socio-economically diverse. The sample consisted of five participants purposively selected based on the researcher’s judgement with relevance to the purpose of this study (Babbie & Mouton, 2001, p. 166). Purposive sampling is sometimes appropriate for a researcher on the basis of his or her own knowledge of the population, its elements, and the nature of the research study (Babbie & Mouton, 2001 p. 166). Purposive sampling allows the researcher to recruit participants that are knowledgeable and who are willing to provide the information and experiences the researcher is seeking. This type of sampling is used where there is a limited number of individuals that possess the trait of interest (Babbie & Mouton, 2001). Babbie and Mouton (2001) indicate that a small number of participants will provide sufficient data for analysis.

The sample was recruited through local autism support organisations as well as through mental health care providers that specialise in Autism Spectrum Disorder and Neurofeedback as an intervention. The criteria for participation included that the child had to have been diagnosed with Autism Spectrum Disorder and this was documented in the participant information form (Appendix A). Also, the children who completed Neurofeedback as an intervention for Autism Spectrum Disorder had to have received at least 10 sessions. The criterion that the patient must have completed at least 10 sessions of Neurofeedback treatment as a minimum number of sessions is applicable as specified by Altobelli (2012) whose research used this as the minimum required to achieve perceptible results.
3.5 Procedure

Permission and ethical clearance to conduct the study was obtained from the Humanities and Social Sciences Research Ethics Committee of the University of the Western Cape. Seven Neurofeedback practitioners within the Western Cape who are registered with HPCSA (a statutory body, established in terms of the Health Professions Act No. 56 of 1974 for all health professions in South Africa in a variety of disciplines such as psychology, occupational therapy, medical doctors) provided the researcher with a contact list of primary caregivers whose clients (i.e. autistic children) had received Neurofeedback as an intervention. The Neurofeedback practitioners secured the caregivers’ consent to being contacted by the researcher. An information briefing was held with each primary caregiver where the purpose of the study was explained, and in-depth information about the study, as well as its purpose and its possible benefits, was provided. At this meeting the primary caregivers were provided with an information sheet (Appendix A), and signed an informed consent form (Appendix B). All of the participants were informed regarding confidentiality and anonymity. The researcher then formulated a list of the times of the scheduled interviews as well as the venues where the one-on-one interviews were to be held. The researcher prepared all the logistics and allowed for the interviews to take place within the comfort of the participants’ homes or at a neutral venue. With consent from the participants, all the interviews were audio-taped and transcribed (Appendix B). All interviews ranged from 45 to 60 minutes in length.

3.6 Data collection

The data collection commenced when the research was approved by the Humanities and Social Sciences Research Ethics Committee of the University of the Western Cape.
Data was collected through semi-structured interviews. A semi-structured interview is a qualitative method which uses open-ended questions that offer participants the opportunity to respond in their own words and to express their unique personal perspective (Patton, 2002). Kvale (2010, p. 8) has defined semi-structured interviewing as “an interview with the purpose of obtaining descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomena”, and as such allowed the researcher to gain insight into the topic of interest. The fact that this research study utilised semi-structured questions ensured that the primary caregivers could respond in their own words and express their unique personal perspectives (Braun & Clarke, 2006). Kvale (2010) has defined semi-structured interviewing as “an interview with the purpose of obtaining descriptions of the life world of the interviewee with respect to interpreting the meaning of the described phenomena” (p. 57). Semi-structured interviews also allow the researcher to gain knowledge and insight without being overly directive. A consistent set of questions was asked by means of an interview guide that was used throughout the study. In this way, the interviewer asks spontaneous questions but stays within the focus and scope of the set interview questions. A semi-structured interview remains task-oriented and this serves as an important advantage (Braun and Clarke, 2006).

The interview schedule comprised two sections: section A concerned biographical information and section B prompted the primary caregivers to express their experiences to establish whether they were satisfied or dissatisfied with the intervention and how it influenced the family system as a whole (Appendix C). The interview questions were structured in such a way as to guide topics or subject areas within which the interviewer explores, probes and asks questions that allow the researcher to elucidate and illuminate that particular subject. The questions that were developed were intended to elicit experiences and to provide the researcher with insight and perceptions to answer the research questions that...
the study set out to answer. The interviewer remained free to build a conversation within a particular subject area, to word questions spontaneously, and to establish a conversational style, but with the focus on a particular subject that has been predetermined (Patton, 2002). These questions were open-ended and conversational in nature. The interviews were about 45 to 60 minutes in duration. The researcher also recorded the process notes in a journal that was referred to when conducting the analysis and writing up of the results. This was important for the data analysis as it fosters self-reflection, and self-reflection was important for understanding and meaning making. It also assisted in that it revealed emergent themes.

Throughout the interview process, the primary caregivers were emotional when sharing memories of the struggles that they endured because of their child living with Autism Spectrum Disorder. Overall, the mood of these caregivers was positive and they expressed appreciation for the fact that the researcher reflected and empathised with them on their shared experiences as they felt that their feelings were validated. This ensured that a good rapport was built with the result that the caregivers were more open in sharing their experiences in a contained manner as they felt that they could now trust the researcher. Further reflective experiences are highlighted in Chapter Five.

3.7 Data analysis

Analysis of the data was done using Braun and Clark’s (2006) thematic analysis method. This is widely used in qualitative research studies and focuses on examining the themes within the data. This method emphasises the organisation and rich description of data sets. Implicit and explicit ideas within the data are identified using the thematic analysis which goes beyond simply counting phrases or words in a text. Thus, coding is the primary process for developing themes and encoding the raw data prior to interpretation. The comparisons of
themes and the interpretations of these codes can be identified by theme frequencies, graphically displaying relationships between different themes and identifying their co-occurrence. Using the thematic analysis is appropriate as it captures the intricacies of meaning within the data set (Braun and Clarke, 2006).

Firstly, the recordings of the interviews were transcribed verbatim, and patterns of experiences were noted from the transcripts. Secondly, the researcher derived themes from the data. The data were coded according to relationships between one or more of the themes (Braun and Clarke, 2006).

To ensure that data are correctly identified, analysed and reported, a thematic analysis includes patterns (themes) within all the data (Braun & Clarke, 2006). A theme is “a recurring pattern, topic, viewpoint, emotion” (Bailey, 2007, p. 43). The different insights and knowledge from the participants were identified in relation to the research questions provided and analysed. Themes were more data driven than theory driven and the specific themes were derived accordingly. Rich and detailed data was provided through a thematic analysis which served as a flexible and useful tool (Braun & Clarke, 2006). The next step was elaboration, which was the process of focusing on the finer distinctions of the themes. The final step was to interpret, which involved interpreting the data according to the thematic categories derived from analysis, including reflection on how subjective experiences may have influenced data collection and analysis (Braun & Clarke, 2006).

The analysis could start once all the interviews were completed and transcribed. The themes or emergent concepts were created by using the interview transcripts (Babbie & Mouton, 2001). All data obtained from the interviews were coded and clustered, allowing the researcher to see the patterns and emerging themes. Each theme received different codes.
which were then applied to each interview, allowing for identification of patterns within the participants’ interview (Babbie & Mouton, 2001).

Thematic analysis was carried out using the five phases proposed by Braun and Clark. These steps are as follows:

1) **Understanding oneself with the data**

The researcher immersed himself in the data by repeated reading and became familiar with the depth and scope of the content. The next stage was to search for purpose and design within the transcribed texts. The patterns that emerged from the primary caregivers’ responses through the questionnaire were read by the researcher and relevant patterns were searched for (Braun & Clarke, 2006).

2) **Searching for themes**

The listing of subthemes in all the different and relevant data analysed took place at this stage. All different subthemes were combined to ensure an overarching theme and were sorted accordingly (Braun & Clarke, 2006).

3) **Reviewing themes**

It is important that the themes are refined at this stage. The data extracts must be consistent with the theme itself and the overall data which is assessed by the researcher. Through this process, the researcher is ensuring that a theme has a logical flow to try to fit a thematic plan into the data (Braun & Clarke, 2006).
4) Defining and naming themes

According to Braun and Clarke (2006, p. 82), “a theme captures something important about the data in relation to the research question and represents some level of patterned response or meaning within the data set”. The researcher captured the essence of each theme as well as each detailed aspect of the themes. The names and definitions of each theme were generated (Braun & Clarke, 2006).

The data collected from the semi-structured interviews yielded overarching themes, that resulted from specific questions and these themes were identified through analysis of responses from the primary caregivers (Braun & Clarke, 2006).

5) Producing the report

To be able to tell a complicated story to the readers that it is trustworthy and ensure that the data is valid, a final analysis write-up report was completed. This demonstrated the universality of the theme, as it was important to include enough of the data that was obtained. To make an argument regarding the research question it is necessary to go beyond mere description of the data and the analytical narrative needs to go further (Braun & Clarke, 2006).

3.8 Trustworthiness

“Credibility” ensures confidence in the “truth” of the findings (Merriam & Tisdell, 2015). By achieving credibility for this study, the researcher continually engaged with primary caregivers during the one-on-one interviews, the researcher obtained credibility. “Dependability” and “transferability” mean showing that the findings are consistent and repeatable and that they have applicability in other contexts (Merriam & Tisdell, 2015). The
researcher validated the dependability and transferability criteria through “thick description” and purposeful sampling. The researcher provided the purposefully selected participants with a detailed description of the nature of the inquiry (Creswell, 2007).

“Conformability” is the degree of neutrality or the extent to which the findings of a study are shaped by the participants and not by researcher bias, motivation, or interest (Merriam & Tisdell, 2015). This was ensured through an audit trail of all records and activities throughout the research process. Qualitative methods need to ensure trustworthiness of the findings and ensure that the findings occur as the researcher says they did (Creswell, 2007). The researcher ensured that the participants were not coerced in any way and they had every opportunity to express their feelings or withdraw from the study.

3.9 Reflexivity

To ensure a context of interactive meaning-making the researcher used reflexivity to reveal preconceptions and situational dynamics in which the interviewer and participants are jointly involved (Collins et al., 2000). The researcher has conducted previous research studies on Autism Spectrum Disorder, so it was important that the researcher maintained a critical self-reflection, sensitivity to and cognisance of his own views and opinions. The researcher acknowledged the frame of reference of the primary caregivers and was sensitive throughout the interview process, being mindful of the emotions that can be elicited from the primary caregivers as well the feelings that evoked in the researcher. The researcher had to keep in mind that he was a researcher and not a therapist. To ensure that the researcher was not biased while conducting the research study he tried to be aware of any preconceived ideas or assumptions. The researcher was therefore aware of how he might project his own subjective views on to the research, particularly because he had worked with parents of Autism.
Spectrum Disorder children before. The researcher was constantly aware of how he was experienced by participants and consistently ensured that the meaning of the information shared was not distorted. It was important that the researcher maintained critical self-reflection and was sensitive to and cognisant of his own views and opinions. The researcher has kept a self-reflective journal to facilitate reflexivity (Babbie & Mouton, 2001).

3.10 Ethics

The current study ensured ethical norms such as obtaining informed consent by explaining the benefits, rights and responsibilities of the potential primary caregivers prior to their recruitment (Appendix A). The researcher provided the primary caregivers with an information sheet and consent form to be signed (Appendix B). The participants were assured that their identity would remain confidential and were assured that the information obtained would only be used for the purposes of the research project. Each primary caregiver was told what the main aim of the study would be as well as how it would contribute directly to them and to understanding and treating Autism Spectrum Disorder in South Africa through gaining understanding of Neurofeedback as an intervention, and contributing to narrowing the gap in the body of knowledge and existing literature. The researcher explained to each primary caregiver what was expected of them in that they needed to meet certain criteria as well as that the investigation consisted of open structured questions and that they could freely express themselves in the answering of these questions. It was clearly explained by the researcher that the findings and results of this research study may be shared with primary caregivers and practitioners through talks or leaflets. Participants’ permission to record the interview was obtained and the data has been stored in a safe place, locked away in a secure cupboard. Audio data will be destroyed at a reasonable time after the completion of the study. The primary caregivers’ rights to privacy were respected by means of confidentiality which
was maintained by means of keeping all the interview recordings, field notes, reflective journals and the signed consent forms locked away at all times, to be destroyed after the research was completed. The primary caregivers were further advised that they had the right to withdraw from the study at any time without any negative consequences. Debriefing the primary caregivers at the end of the research session was vital as it benefits both the researcher and primary caregivers (Haslam & McGarty, 2010). An important goal of debriefing is that it educates the participants about the research and addresses any concerns or miscommunication, leaving the primary caregivers with positive feelings about their participation in the research study (Haslam & McGarty, 2010). It also provides the researcher with a sense of what the emotional state of the participants is and if necessary the researcher may refer participants to a psychological counsellor or psychologist for further assistance.

3.11 Summary

In this chapter, the research process used to conduct this study has been discussed. This commenced with a description of qualitative research. The research design was described, and the choice of data collection methods was also justified. The data analysis techniques that allow for the categorisation of data collected during this study were explained. To conclude this chapter, ethical considerations were discussed. The following chapter focuses on expanding on themes derived from data categories, to be followed by a detailed discussion of the findings of the research study.
CHAPTER 4: RESULTS

4.1 Introduction

This chapter focuses on identifying themes and the subthemes that emerged in the study and answering the research questions.

The research questions are directed at understanding the experiences of primary caregivers with Autism Spectrum Disorder children who have undergone Neurofeedback as an intervention, and finding out whether the primary caregivers were satisfied or dissatisfied with Neurofeedback intervention and whether the intervention influenced the family system, and if so, how.

Previous research studies have shown that extensive data have been collected in a quantifiable manner and in numerically measurable methods on the efficacy of Neurofeedback on Autism Spectrum Disorder. However, primary caregivers have not had sufficient opportunity to share their experiences of the Neurofeedback intervention and how it influences their family. A gap identified in research, especially as it pertains to South African research, is created by the lack of research on Neurofeedback as an intervention for Autism and how primary caregivers experience this intervention and how it influences their family structure. A child with Autism Spectrum Disorder presents challenges for primary caregivers in all aspects of child rearing. Primary caregivers often pursue a variety of intervention modalities to help their autistic child. In this study the researcher therefore explored the experiences of five Western Cape primary caregivers to determine their subjective viewpoints with regard to Neurofeedback as an intervention, finding out whether the primary caregivers were satisfied or dissatisfied with Neurofeedback intervention and whether the intervention influenced the family system.
This study made use of a qualitative data collection method, namely semi-structured interviews, observations and reflective journals, to ensure that the account was rich and comprehensive (Creswell, 2007). A thematic analysis was produced which provided a descriptive representation of the findings. All the interviews were transcribed from audio recordings and field notes. Common themes were identified and extracted through repeated reading of and reflection on the transcripts, reflective journals and notes. Data were coded during the process of data reduction and the coding process allowed themes to emerge and patterns of experiences to be noted. In the process finer nuances emerged in the themes. The themes were then linked to the literature to gain a deeper understanding of the issue under investigation. The last stage was to interpret the data according the thematic categories obtained from the analysis and reflective comments on how subjective experiences may have influenced data collection and analysis (Braun & Clarke, 2006). Four themes emerge from the interview data, namely:

- **Theme 1**: Selection and initial perceptions of multiple therapeutic interventions;
- **Theme 2**: Primary caregivers’ perceptions of the benefits of Neurofeedback intervention and their dissatisfactions;
- **Theme 3**: Primary caregivers’ perceptions of the benefits of Neurofeedback intervention and their dissatisfactions; and
- **Theme 4**: How Neurofeedback intervention impacted on the whole family system.

### 4.2 A profile of the participants

During the interview of the five participants brief demographic information was requested. Primary caregivers had to meet certain criteria in order for them to participate in the study. All of the participants had to reside within the Western Cape region, and in order to recruit a diverse sample, when selecting participants, race, culture and socio-economic factors were
considered. The criteria for selecting the participants were that their children had to have been diagnosed with Autism Spectrum Disorder and that they had received a minimum of 10 sessions of Neurofeedback. The criterion that the patient must have completed at least 10 sessions of Neurofeedback treatment as a minimum period for the treatment to have perceptible results was based on the benchmark used by Altobelli (2012).

Although a broad definition of “primary caregiver” was used as a means of sampling, in this study the primary caregivers were all parents; four were mothers, and one was the father. A brief description of each of the participants will be provided. For the purpose of anonymity, the participants are referred to by number.

4.2.1 Participant 1

Participant 1 is a married, Caucasian, Christian female primary caregiver who speaks English. Her twelve-year-old son was diagnosed with Autism at the age of 16 months. He is a high-functioning autistic child and is currently attending a private international school where he is following a mainstream curriculum in the morning and in the afternoon attends social skills training and private remedial classes. Her son has received multiple intervention modalities for his Autism, with Neurofeedback the most recent intervention. He has received a total of 45 sessions over a period of six months. He has a younger brother who is nine years old and is diagnosed with ADHD. The family lives in the southern suburbs of Cape Town. Both primary caregivers are working. The father is a businessman who runs multiple businesses and is often away from home. The mother is working from home running her own advertising agency. The family belongs to a high-income group.
4.2.2 Participant 2

Participant 2 is a married, Indian Muslim female who speaks Afrikaans. Her ten-year-old son was diagnosed with Autism Spectrum Disorder at the age of 18 months. They live in the northern suburbs of Cape Town. Her child is a high-functioning autistic child who is placed in a special needs school. He has a twin brother who attends a mainstream school. Her son has received 31 Neurofeedback sessions during 2016. They decided to try Neurofeedback as they had tried many different interventions which they felt did not really help him. The mother reported that her son is very good at sport and she opted for Neurofeedback to help him improve his sports performance as there had been drop lately in his performance. Both parents are employed. The father is a tradesman and mother is working in the clothing industry. The family belongs to a low-income economic status group.

4.2.3 Participant 3

Participant 3 is a married, Caucasian female who speaks Afrikaans. Her seven-year-old son was diagnosed with Autism Spectrum Disorder at the age of 24 months. They live in the northern suburbs of Cape Town. He has four siblings. Her autistic child is relatively high functioning and is in a normal mainstream school. He also receives extra remedial classes after school in a day-care centre which the school offers. Her son began Neurofeedback treatment at the beginning of 2016 and has received 11 sessions. The father is working and the mother is a “stay-at-home mom”. The family belongs to a middle-income group.

4.2.4 Participant 4

Participant 4 is a divorced Xhosa female who speaks Xhosa and English. She has been divorced for more than six years. Her eleven-year-old daughter was diagnosed with a mild form of autism and thus is high functioning. She attends a mainstream school and receives after-care remedial classes. They live in the southern suburbs of Cape Town. Her daughter
started to receive Neurofeedback intervention during 2016. Her mother indicated that she had received about 15 sessions in total. The reason she why she opted for Neurofeedback was to help her child with her learning and attention and concentration abilities. The family system belongs to a middle-income group.

4.2.5 Participant 5

Participant 5 is a married Cape Malay male who speaks English. His twelve-year-old son was diagnosed with Autism Spectrum Disorder at one year old. He is a very low functioning autistic child. He is currently not in school and stays at home with his mother who is looking after him full time. His father is employed full time by the Western Cape Government. They live on the Atlantic seaboard of the Western Cape. His son started with Neurofeedback during 2016. His son has received more than 40 sessions of Neurofeedback. He tried a variety of therapeutic treatment modalities before Neurofeedback. The family system belongs to a middle-income group.

Table 4.1: Summary of demographic information of five primary caregivers

<table>
<thead>
<tr>
<th>Attributes</th>
<th>Participant 1</th>
<th>Participant 2</th>
<th>Participant 3</th>
<th>Participant 4</th>
<th>Participant 5</th>
</tr>
</thead>
<tbody>
<tr>
<td>Racial, religious, culture group identified with</td>
<td>Caucasian, Christian, English</td>
<td>Indian, Muslim, Afrikaans</td>
<td>Caucasian, Christian, Afrikaans</td>
<td>Xhosa, African, Christian, English/Xhosa</td>
<td>Cape Malay, Muslim, English</td>
</tr>
<tr>
<td>Child with Autism</td>
<td>12 year old boy</td>
<td>10 year old boy</td>
<td>7 year old boy</td>
<td>11 year old girl</td>
<td>12 year old boy</td>
</tr>
<tr>
<td></td>
<td>Diagnosed ASD – 16 months</td>
<td>Diagnosed ASD – 18 months</td>
<td>Diagnosed ASD – 24 months</td>
<td>Diagnosed ASD – 24 months</td>
<td>Diagnosed ASD – 12 months</td>
</tr>
<tr>
<td>Neurofeedback sessions</td>
<td>45 sessions</td>
<td>31 sessions</td>
<td>11 sessions</td>
<td>15 sessions</td>
<td>40 sessions</td>
</tr>
</tbody>
</table>
4.3 Presentation of themes

The themes that emerged after the coding of the data are presented in this section. The conceptual framework of the themes and subthemes is illustrated in Table 4.2. Four themes were refined into subthemes and are presented as 12 subthemes. These themes and subthemes mentioned below are outlined in this table, together with quotations from interview transcripts to illustrate points and to support the findings.

Table 4.2: Conceptual framework

<table>
<thead>
<tr>
<th>Themes Identified</th>
<th>Description of Themes</th>
<th>Subthemes</th>
<th>Examples</th>
</tr>
</thead>
</table>
| Selection and initial perceptions of multiple therapeutic interventions | Primary caregiver’s challenges and experiences of interventions. | • Initial selections  
• Ecological impact and choices | • We have tried so many interventions and all promised a lot. That’s how I ended up with Neurofeedback. I contacted practitioners to learn more about this intervention.  
• As parents, we can only keep trying. It is like fishing in the ocean. Perhaps one day, I will catch the fish.  
• Over 15 different interventions. I did my own research on Neurofeedback. But allowed me not to get my hopes up. |
| Behavioural problems leading to primary caregivers seeking out Neurofeedback intervention | What specific problems were experienced that led them to opt for Neurofeedback | • Social impairments  
• Challenges pertaining to anxiety  
• Learning difficulties at school  
• Behavioural patterns before | • How do we teach him social cues? His lack of social awareness was a huge concern for us.  
• We soon realised that anxiety is the biggest problem for our autistic child. |
<table>
<thead>
<tr>
<th>Themes Identified</th>
<th>Description of Themes</th>
<th>Subthemes</th>
<th>Examples</th>
</tr>
</thead>
</table>
| Neurofeedback intervention | • Anxiety caused him to not function with regard to his school work and overall functioning.  
  • He struggles throughout his school years, not to have the ability to concentrate and to learn effectively.  
  • Regular tantrums and angry outburst happened that we felt needed some type of intervention to help him. | Neurofeedback intervention | |
| Primary caregivers’ perceptions of the benefits of Neurofeedback intervention and their dissatisfactions | Efficacy is determined through observation of any beneficial changes or more specifically the therapeutic effect of a given intervention | Decrease in Anxiety  
  • Better impact on mood  
  • Increased social ability  
  • Primary caregiver dissatisfaction with regard to availability and research on Neurofeedback as well tactile sensitivity | • My child can actually control his anxiety level better now after Neurofeedback.  
  • I felt that anxiety caused my child not to allow for self-expression. After the intervention she expresses herself more.  
  • It provided my child with more motivation and feeling better about himself as Neurofeedback provided self-regulation which he could actually see on the screen how his brain level function when anxiety decreases.  
  • It made a huge difference in his social interaction with other peers in his sport teams. He |
### Themes Identified

<table>
<thead>
<tr>
<th>Description of Themes</th>
<th>Subthemes</th>
<th>Examples</th>
</tr>
</thead>
<tbody>
<tr>
<td>interacted better in sport groups which resulted that he played better in team sports.</td>
<td></td>
<td></td>
</tr>
<tr>
<td>I struggled to find registered practitioners who have good references. Also not enough information was available.</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### How Neurofeedback intervention impacted on the whole family system

- The intervention showed immediate factors that impacted on the family and its members.
- Neurofeedback influenced the whole family positively
- Family system still functions the same even with Neurofeedback as an intervention
- I am so glad that his anxiety levels decreased significantly it led to my family working better as a whole unit.
- It helped my whole family to have less conflict because our child is more manageable.
- Even after Neurofeedback his aggression levels are still high, not sure if it helped at all.

### 4.4 Theme 1: Selection and initial perceptions of multiple therapeutic interventions

This theme highlights the initial difficulties presented to caregivers upon discovering that their child might be autistic. They have to struggle with multiple possible treatment modalities, none of them being perceived as completely satisfactory.

The experience of these treatments has an ecological dimension, as we see participants making decisions about the choice of modality as a family concern and a family choice.
The theme therefore has two subthemes, namely the caregivers’ initial experiences of the initial selection of interventions, and the ecological dimension of making their choice, specifically Neurofeedback as an intervention.

### 4.4.1 Initial selections

Bronfenbrenner’s microsystem suggests that factors which are closely related to the direct family structure would have a direct impact on the individual members of the family (Konza, 1999). The primary caregiver’s choice of seeking help for their autistic child coupled with what treatment modalities to choose would play a direct role in the development of their child. For some parents a child’s diagnosis of Autism Spectrum Disorder can be devastating. Many caregivers raised concerns about the uncertainty of what their next step should be when the possibility was raised that their child was presenting with signs of Autism Spectrum Disorder. The caregiver’s first step was usually to go to a paediatrician or other specialist for an assessment. This is when their journey with treatment interventions starts. Many primary caregivers reported obtaining behaviour therapy or speech and language therapy; occupational therapy; and pharmacological intervention for the child, as these are the common initial interventions available for remediating the symptoms of Autism Spectrum Disorder. After the initial therapeutic intervention processes have started, the caregivers are often left on their own to manage their autistic child and to monitor the impact these interventions have. Many of the primary caregivers do not have the financial means to sustain treatment, follow-up visits with medical doctors or other specialised practitioners. This results in them doing their own research with regard to multiple intervention options as the first point of standard interventions may not be effective for their autistic child. As one parent said:
Participant 1: All interventions have their own theories and have worked for some children. We do not know which one will work for him [the child with autism]. As parents, we can only keep trying. It is like fishing in the ocean. Perhaps one day, I will catch the fish.

Participant 3: I have tried them all; I tell you all practitioners believe their intervention is the best. I have learned as a parent if I keep on trying I hope and pray I will found at least some type of intervention that will make a difference for my child.

For primary caregivers to make a decision about which intervention to choose or even a combination of a variety of treatment modalities can be a difficult decision. The initial phase of selecting treatment interventions can be very stressful and confusing; primary caregivers are often left alone in seeking out and adopting one particular intervention.

4.4.2 Ecological impact and choice of neurofeedback

The mesosystem of Bronfenbrenner emphasises the interactions of the Microsystems, for example the assistance and availability of treatment to assist primary caregivers with regard to the understanding of Autism Spectrum Disorder as well what different treatment modalities are available and which treatments are more appropriate than others in seeking the best result for their child (Konza, 1999).

Given the low awareness of the nature of the disorder, caregivers struggle to understand not only the symptoms but also the confusing array of potential treatment modalities.

The ecological approach reveals the potential for a diagnosis of some disorder such as autism to disrupt the emotional system of the caregivers and the family. These mixed feelings about Autism Spectrum Disorder contribute to the distress about selecting treatment modalities (Hoffmann, 2012). For the primary caregivers who had tried many treatment modalities it became frustrating, which influenced their perception of these treatment modalities. This
influenced their daily lives within the family system, for example school behaviour and social interactions.

Within this sub-theme parents showed awareness of the different interventions that were available. Throughout the interviews this sub-theme emerged strongly as a result of many treatment modalities that primary caregivers had tried over years, and how these experiences of different interventions led them to Neurofeedback, for example:

Participant 1: So right in the beginning we picked up issues and learning difficulties and we sent him for sensory integration work. We have done listening skill therapies, we have even done hypnosis. We have even done kinesiology work that actually worked well and also craniosacral therapy. It was because of this therapy that we realise his anxiety levels are high and needed to be treated. That is how we ended up with Neurofeedback, as I read up on how it could possibly help with his anxiety. But I tried so many therapies I thought it was just another one to tick off that wouldn't help anyway.

Participant 2: But because we worked at the remedial school we came across other parents who were trying different things. Like Neurofeedback that it worked really well and she would recommend it. We as parents were desperate and were willing to try it out.

Participant 5: I think I must have tried over 15 different treatment things. We started with occupation therapy and that was more like having fun so I couldn’t see that it improved anything and we did listening therapy, the first listening therapy that came out in this country it was quite controversial and that had a little bit of effect so it was quite effective. Then I did research on the comparison between autism and ADHD, and that is when I saw Neurofeedback that is a new intervention for the autism spectrum as well. From the onset I told my husband that we shouldn’t get our hopes up as autism can’t be cured and it’s a non-invasive therapy so it probably not effective.
It is clear from the experience of these three participants that that choice of Neurofeedback came after the experience of multiple treatment modalities. Their choice of Neurofeedback came as a result of a combination of research, and word of mouth. One participant was even able to draw a conclusion based on making a comparison between ADHD and Autism Spectrum Disorder.

An ecological dimension is evident in the fact that joint decisions were made, reflecting the family as a microsystem. In all three instances mentioned above the participants made it clear that “this is how we ended up with neurofeedback” (Participant 1) or “we as parents” (Participant 2) made a choice (Participant 2), or “I told my husband” (Participant 5).

It is noteworthy that for three of the participants the choice of Neurofeedback was not made with great confidence; it was just another box “to tick” or just another intervention to try.

It is also evident that caregivers had a degree of awareness of the potential of interventions, a concern about specific symptoms, like anxiety, and a sense of desperation, in one case.

One of the main factors for the primary caregivers to have opted for Neurofeedback was the way in which the intervention is administered, as it is a non-invasive approached which allows for calmness when administered. All of the primary caregivers had tried multiple intervention avenues for better sociability, but felt that Neurofeedback had a lot to offer in this regard for their autistic child.

4.5 Theme 2: Behavioural problems leading to primary caregivers seeking out Neurofeedback intervention

Before discussing the experiences of primary caregivers with Neurofeedback, it is important first to discuss what specific problems were experienced that led these participants to opt for
Neurofeedback. All of the primary caregivers were asked to describe their autistic child. While the symptomatology of each child was different, a common theme emerged: specific experiences and problems associated with Autism Spectrum Disorder and how these problems influenced their decision to choose Neurofeedback as an intervention. This type of finding does not address the experiences of the primary caregivers of Neurofeedback as an intervention, but it does have relevance to the different types of experience the primary caregivers have when making decisions about Neurofeedback as an intervention option. The most relevant difficulties indicated by the primary caregivers had to do with anxiety, social impairments, learning difficulties at school and behavioural patterns before Neurofeedback intervention. Some of examples mentioned by the primary caregivers were regular temper tantrums, angry outbursts and mood dysregulation which often led to dysfunctional social interactions in settings such as school.

Bronfenbrenner emphasises that influences within the environment are bi-directional and reciprocal. Children have an impact on their environment just as the environment has an impact on them. Therefore, to determine what the behavioural problems associated with Autism Spectrum Disorder are for the primary caregivers is important as these behavioural characteristics influence the behaviour of others in their immediate environment (Konza, 1999).

4.5.1 Social impairments

All of the primary caregivers saw their children as having social impairment. One primary caregiver described how her child struggled with basic social interactions like greeting someone appropriately and not being able to read facial expressions. Another primary caregiver described how her son could not detect normal social cues like when to talk loudly or softly. This resulted in him being aggressive as he did not understand why people became
impatient with him. Another primary caregiver described lack of social alertness and how this caused relationship problems. She observed that her child spoke very loudly, overriding adults, resulting in frustration and stress whenever she had to take her child into public situations. Each child’s social ability differed from the rest, but each primary caregiver raised concerns about social interaction and cues which resulted in high anxiety levels for the child and for them as primary caregivers as well as how this impacts on the family.

Participant 1: So with the behavioural side of things he struggled, so in other words how do you greet someone, how do you look them in the eye? The actual basics the invisible curriculum stuff and how to interpret facial expressions and things like that was a huge challenge for us.

Participant 2: Mostly from a social aspect I was very concerned as it influenced him in such a way that he couldn’t socially function at school. And in the end it turned out that the Neurofeedback helped with his social engagement.

Participant 3: Socially there was a concern for us as parents because he can’t read other people’s emotions and he can’t read social cues at all. He is oblivious to the fact that he is blundering in or saying it wrong or too loud or incorrect and because he blunders on and he is such a friendly outgoing kid, people take it as a good thing as opposed to a bad thing. He was very aggressive when he was little and then I took him out of school for three months. So yes, his social behaviour was lacking severely behind the norm.

Participant 4: He is lacking social alertness which has brought its own complications in terms of his social interactions and relationships in general because he doesn’t have the skills so he can deal with social interactions, that brings a whole new adjustment phase.

Participant 5: I would say he does not understand social cues, there is definitely that component of autism.
The ecological perspective is the standpoint for conceptualising the changing maturing person in a relation to the changing environment (Hoffmann, 2012).

The ecological approach to perception is applied to the social domain. It relates to emotion perception, impression formation, and causal attribution. Autism Spectrum Disorder has a direct impact on cognitive approaches; therefore, the role of ecological perception is very important to gain relevant social knowledge of an autistic child (Hoffmann, 2012).

4.5.2 Challenges pertaining to anxiety

Most primary caregivers raised concerns about their child’s high anxiety levels coupled with mood and obsessive-compulsive behavioural tendencies. As a result some children showed temper tantrums with aggression which affected their daily lives. For example, when an autistic child feels frustrated, coupled with confusion, anxiety or lack of control because of behavioural responses which they find difficult to communicate, they express their needs through behaviour which is often aggressive, rather than through communicating it verbally.

Participant 2: So it was more specific the anxiety how he can control his own anxiousness and seeing it and function that way? His anxiety impacted on all facets of his life and even greatly impacted on us as a family.

Participant 3: For the first time we could see how his anxiety affected him whereas I just thought it was academically with learning difficulties but his anxiety levels made it worse.

Participant 5: You can’t fix Asperger’s, you’re trying to help them cope within that. So it is the anxiety for us without a doubt is the number one issue because everything else that follows you can overcome like learning difficulties and all of that and you can teach a child to be socially engaged if they are not anxious, but if they are anxious they shut down completely.
Participant 1: The biggest problem with Asperger’s is anxiety that is your biggest problem because once you have anxiety you can’t study, you can’t learn, you can’t function.

Primary caregivers became aware of the social interactions and learning difficulties without realising how high their children’s anxiety levels were. Primary caregivers assume that children with Autism Spectrum Disorder prefer social isolation and low social contact. However, as primary caregivers they soon realised how their autistic children became aware of their social disconnectedness and wished it could be different for them. Hence, the primary caregivers who discussed their children’s anxiety levels seemed to feel that anxiety itself was the most distressing component of their autistic child’ symptoms.

4.5.3 Learning difficulties at school

School-related difficulties include struggles with teacher interaction, anxiousness, attention and concentration span.

Participant 1: So right in the beginning we picked up issues and learning difficulties. Especially with regard to my child’s interaction with his school teachers who does not know how to treat my child. This worsened his academic performance. He struggled with sustaining attention which resulted an increase in his anxiety causing him to stress significantly.

Participant 2: I think [my son’s] alertness levels are very low so he is a dreamer and as an autism child in that sense his academics and learning are impacted because he is so “fast asleep” all the time he is not learning.

Participant 3: With Autism Spectrum Disorder they shut down completely and constantly struggle with learning at school.

Participant 4: So now because of autism she struggles at school which means her homework will never get done because she can’t focus on the task at hand.
Participant 5: With regard to learning difficulties it’s not only the academic that he struggles with but it’s the learning on how to communicate. This impacts on his overall functioning in school.

Some of the primary caregivers discussed how their experience with a school for disabled children was unsatisfactory. One primary caregiver mentioned that they “didn’t get” what autism was about. “We got the impression that [my son] is more of a liability – something they didn’t want there.” Most primary caregivers raised the concern how they struggle to keep their children focused on their school work and that the further they fell behind the more anxious they became. This resulted in their child interacting less socially with the teachers and peers. One primary caregiver mentioned her biggest hope for her child was for him to be calmer and knowing that him being calmer would improve his academic chances. That was why she opted for Neurofeedback.

4.5.4 Behavioural patterns before Neurofeedback intervention

To establish if an intervention is effective in treating a patient one must first determine the behavioural factors specifically related to autism. Here are some of the practical examples that the primary caregivers mentioned before their child’s Neurofeedback intervention:

Participant 2: With him his emotions wasn’t consistent he became much more aggressive and confronting and irritated and stuff than before and that’s why we opted for Neurofeedback to determine if it would help with his behaviour.

Participant 4: My child couldn’t regulate any of her behaviour. This was very concerning for me even with multiple treatments that I have tried it didn’t help.

Participant 5: Temper tantrums and his anger would build and then you could see he was going to explode and he wouldn’t be able to notice when it would happen.
Participant 3: I think [his] alertness levels are very low as his mind starts to wander off then suddenly he becomes a very highly strung child.

Impaired socialisation and vocalisation are experienced almost all the time by children with Autism Spectrum Disorder (Hoffmann, 2012). Impaired vocalisation can be an emotional stressor as they do not have the capacity to articulate their emotional state verbally. A difficulty in learning is that children with Autism Spectrum Disorder tend to find their own way of studying. Most schools attempt to mould children in a specific learning structure and method which can be ineffective for an autistic child (Hoffmann, 2012). This all increases the child’s anxiety and aggression levels; hence the assumption is often made that they are of lower intelligence and this is not necessarily the case (Aman et al, 2015). This motivates how external factors like school work and socialisation with peers can cause stress for an autistic child which causes them to start acting out in an aggressive way, and being irritated much of the time.

4.6 Theme 3: Primary caregivers’ perceptions of the benefits of Neurofeedback intervention and their dissatisfactions

Caregivers were asked what beneficial changes they had noticed once Neurofeedback intervention occurred, and what dissatisfactions they had. Four sub-themes emerged: decrease in anxiety; better impact on mood; increased social ability and some dissatisfactions with the intervention. The caregivers recounted their own personal experiences on how beneficial the intervention was for their autistic child, and most provided their perceptions of how the intervention improved their child’s functioning within the family system. There were also some primary caregivers who raised dissatisfactions about their experience with the intervention. According to Bronfenbrenner’s ecological systems theory these positive and negative experiences can have a direct impact within the microsystem of the whole family, but changes to the microsystem can cause small changes to occur in other settings (the
mesosystem), for example better functioning with peers at school and within the community (Bronfenbrenner, 1994).

4.6.1 Decrease in anxiety

Most participants noticed a decrease in their anxiety levels, such as anger and frustration, in their children following Neurofeedback.

Participant 1: Mostly from an academic point of view I went for that so that he could cope in school better and it actually turned out that the Neurofeedback helped with the anxiety. For the first time we could see how his anxiety affected him whereas I just thought it would be academic that it would help … Because of Neurofeedback his verbal proficiency increased whereas before he couldn’t express himself as to what was wrong whereas now he is a lot more expressive because he could control his anxiety all that calm, gentle happiness was more prevalent as a result he didn’t need to be anxious all the time.

Participant 5: Mostly from an academic point of view I went for that so that he could cope in school better and it actually turned out that the Neurofeedback helped with the anxiety. For the first time we could see how his anxiety affected him whereas I just thought it would be academic that it would help but it helped us so much more.

Participant 4: But, when she did the brain profiling the anxiety was so very clearly I don’t remember which brain wave it is but she just picked up the brain wave and that is the one she focused on and that was the calming one and that affected his anxiety.

Participant 3: He said he found that he was able now to control the anxiety. He said as he feels the anxiety increase he could then actually points to the base of his neck and then he shows like something is climbing at the back of his head and he says as it is getting there I know that I can just push it back down again. Meaning to push the anxiety right back I think that illustration of my son
spoke a thousand words for us. We knew then that Neurofeedback definitely helps him to contain his anxiety levels.

Few of the mainstream treatments for Autism Spectrum Disorder directly focus on associated features such as anxiety. Four primary caregivers reported that they had concerns about their children’s anxiety prior to receiving Neurofeedback as an intervention. These primary caregivers welcomed the reduction of their children’s anxiety levels because of Neurofeedback, especially because many other interventions that they had tried, which had not been effective. The primary caregivers clearly indicated their awareness that the intervention consciously corrects abnormal electrical activity in the brain waves, which some contributed to the autistic child’s pre-existing anxiety levels. These parents’ perception was that through the provision of constant Neurofeedback training, an autistic child can learn to better control anxiety levels and replace them with more calm and relaxing feelings.

4.6.2 Better impact on mood

It is important to understand the micro system which focuses on the individual functioning within the family structure and how it can affect the different levels of subsystems. Each autistic child expresses and experiences their emotions uniquely. If family or community members interpret these emotional cues wrongly it can affect the child’s emotional wellbeing (Bronfenbrenner, 1994). Young children struggle to understand their own emotions and, because they do not always know how to always express emotions, being misunderstood can result in increased stress levels (Aman, Arnold, Hollway, 2015). For autistic children this is especially significant, and the study revealed that the visual clues given by Neurofeedback appealed to their children’s desire to experience a concrete or tangible effect. Some of the primary caregivers explained that autistic children are fixated on detail and that they need to see first to believe in or to practise change. This is what the primary caregivers liked about
Neurofeedback, as it provided an evidence-based approach for their children where they could actually see how their brain waves work on the screen and then practise relaxing. This made the breakthrough for them, enabling them to practise the techniques at home. So the intervention assists the child’s environment to expand, enabling him or her to acquire increasingly positive self-regard and feelings of happiness which contributed to better school performance and increased social interactions with peers. One of the participants expressed the following which formulated the sub-theme:

Participant 1: He got stuck not able to express himself as a result his mood become low. With neurofeedback I think it was the interactiveness which allowed his mood to increase for the better.

Participant 2: So being able to articulate his emotions and where it is extremely important for us as a family. So the earlier they get into Neurofeedback the better as it helped his mood by better communicating towards us as a family and socially.

Participant 3: The alertness levels concerning his emotions were consistently better after neurofeedback.

Participant 4: I don’t know what that means now suddenly the fascination of seeing ones brain waves. It just kept Asperger kids fascinated by the brain wave and you love that. And now you can actually see look at that wow it really does work. I should say now breathe deeply, do this, lower your heart rate and he would physically watch his heart rate drop, he would watch his brain waves come right because it is hard on yourself to know that that is happening especially for Asperger kids who are not always body aware as well. So just being more aware of this changed his whole mood, he became less irritated with himself which I as the parent felt happy with knowing my child is happier than he was before.

The primary caregivers clearly stated that through this intervention the child learned how his or her body and mind would react to stressors. This meant that the child experienced a feeling
of happiness at being able to control a situation which previously resulted in irritability and even anger.

4.6.3 Increased social ability

Two of the primary caregivers recognised better social awareness and social ability for their children. One primary caregiver mentioned that because of Neurofeedback his team sport participation was better and even went as far as to indicate that because of Neurofeedback her son got into first teams while previously he struggled even to participate in sports. One primary caregiver believed that she could socially connect better with their child because of Neurofeedback which allowed her to better train her child in social skills appropriate to a conventional social framework.

Participant 5: It also gave us a way to talk to him we talk about social inappropriate behaviour so we could say that it is not socially appropriate right now, you can do it at home, but you can’t do it outside or in the public, so we were able to get him frameworks as well.

Participant 2: His team sport after Neurofeedback just flew, he got into all the first teams after that and I think it was that social interaction that being to operate in a team and working with the coach he functioned better with.. So before neurofeedback he was only in the first team for water-polo and then after that he was in four first teams. And his social interaction skills improved, he could organise a social function after that which was a big step for us.

Participant 3: After Neurofeedback my child and I are actually mates we get along with each other, we spend time with each other, we don’t clash and we both realise when his symptoms escalates. He now knows when to stop. There is no trying to catch him to make him stop, he does that himself now.
**4.6.4 Primary caregiver dissatisfactions**

Most of the primary caregivers noted more benefits from Neurofeedback than dissatisfaction. Generally the participants noted definite improvement in their child. However, there were two aspects relating to the intervention that concerned some of the primary caregivers.

One area of concern does not relate to the intervention itself, but rather to the availability of the intervention and the limitations of current research about the intervention for autistic children.

One other concern with the intervention was that one child was sensitive to the electrodes on the scalp and this caused some discomfort. This is supported by the diagnostic criteria of Autism Spectrum Disorder whereby autistic children are hyper- or hypo-reactive to sensory input or have unusual interest in sensory aspects of the environment (American Psychological Association, 2013).

Participant 1: I suppose the availability of it. If it was more assessable especially in Cape Town I think it would make the intervention more popular. I don’t know it’s not that readily available even in South Africa as a whole.

Participant 5: I definitely think that as a parent I struggled to found out what exactly does neurofeedback do? I looked on the internet but it was not clear what it specifically mean for autism and as a treatment. I think there needs to be more research done on this.

Participant 3: My son didn’t like the electrodes cap that was placed on his head. He is very tactile sensitive. And he became stressed and lost focus while this was on his head.
4.7 Theme 4: How Neurofeedback intervention impacted on the whole family system

Bronfenbrenner’s ecological theory views individuals as existing within a set of systems “like a set of Russian dolls” (Bronfenbrenner, 1994, p. 39). The family forms an inner system of proximal processes within which the child functions. Thus the effect of a treatment modality on the child will influence the microsystem of the family and by extension the mesosystem of the family’s social interactions, which include interactions in “such settings as school, peer group, and workplace” (Bronfenbrenner, 1994, p. 39). This theme therefore examines the families’ responses and the positive and negative aspects of the child’s behaviour within these systems.

4.7.1 Neurofeedback influenced the whole family positively

The primary caregivers mentioned positive results because of Neurofeedback and their child’s interaction within the family system as it emerged as a strong sub-theme.

Participant 3: [His] anxiety has hijacked our whole family for years I mean it’s like living with an alcoholic, you don’t know what is going to walk in the door. So now we as a family function better because my child is much calmer now.

Participant 1: I don’t have this fear inside of me all the time that he is going to freak out. I mean I still do a little bit because it is never going to go away but I don’t have that sort of panic, and he’s really happy. And a happy child is a happy parent which impact my family as a whole being more happy.

Participant 4: It was wonderful because the anxiety was down he was lovely to have around whereas before he was always the volatile difficult child and after neuro training he just calmed down. So I always described it before he always swam upstream and now with neuro training he swam downstream with us all as a family.
Raising a child with autism has serious negative psychological effects on the primary caregivers and siblings. The social support structure is a critical factor that can reduce some of these negative psychological effects. Most primary caregivers indicated that because of Neurofeedback their child’s anxiety was more controlled. As one primary caregiver stated, before Neurofeedback their child’s anxiety “hijacked” the whole family and that the family had to be consistently aware of how to treat their child. It resulted in the whole family being in a state of anxiety. Another primary caregiver mentioned that the family had a fear of when the child was going to have another breakdown with aggressive tendencies. Once again Neurofeedback resulted in reduced anxiety levels, meaning that the family system as a whole was functioning better. Depending on how strongly the family system operates, which includes possible factors like giving each spouse personal time, not handling critical situations alone, and sharing household responsibilities, will influence the effectiveness of the intervention. This finding is supported by research done by Bronfenbrenner (1994), who explained the interaction between factors in the child’s maturing biology, his immediate family/community environment, and how the societal landscape fuels and steers his development.

4.7.2 Family system still functions the same even with Neurofeedback as an intervention

Despite the positive sentiments of caregivers expressed above, one participant noted that although there was “mild” improvement, there was little or no beneficial effect on the family as a whole.

Participant 5: I think and I want you specifically to know about [my son] … it was negative on the family because of the increased aggressiveness and irritation even after Neurofeedback he still was aggressive. Even at school he fights with other boys and even with the neighbours’ son. So yes there were some other mild
benefits but mostly the family still stress because of the demands of an autistic child. I mean let’s look at his school environment, he constantly fights and annoys his peers in class.

This primary caregiver still feels family stress even though there were some small improvements which derived from Neurofeedback for him as an individual. The effect that the intervention had on the family system as a whole was not better. The high level of aggression was still enough to cause conflict within the family. The escalation of social interaction within other settings such as peer interaction within his school environment resulted in even more stress for the child and for the family.

4.8 Conclusion

From the findings it is clear that primary caregivers are confused and even stressed when their child has been diagnosed with Autism Spectrum Disorder, as the burden lies on them to get the help which they feel their child needs. The first step is usually to seek medical advice about treatments to follow. However, each autistic child is unique and therefore these initial treatment modalities might not necessarily be effective for the child. Due to many of the parents’ financial constraint they are left alone to select further interventions, It is at this stage that parents start to do their research and try to apply different interventions. Neurofeedback in one of the many types of interventions options, and specifically one of the non-invasive treatment options.

This study shows that to the primary caregivers Neurofeedback as an intervention can give rise to major emotional improvements for their child, having a positive influence on mood, reducing anxiety, being generally calmer in many situations and leading to better integration into all phases of their lives including school, at home and in social situations. It was evident in the findings that Neurofeedback does have some disadvantages like lack of availability of
the intervention within the Western Cape, as well causing some stress to the tactile sensitive autistic child. Mostly the primary caregivers indicated that the intervention influenced their family positively, allowing the family to operate better with their autistic child and shift the focus more healthily to the family unit as a whole, rather than focusing on the autistic child. One primary caregiver mentioned, however, that even after multiple sessions with Neurofeedback as an intervention the severity of their autistic child’s behaviour still outweighed the positive effect that the intervention had, resulting in the family still experiencing frustration and high stress levels.

In this chapter, I have presented the data from the research and discussed the four themes and 11 subthemes that emerged in this study. In Chapter 5, I report on the themes and subthemes, the strengths and limitations of the study and my recommendations.
CHAPTER 5: DISCUSSION, CONCLUSION AND RECOMMENDATIONS

5.1 Introduction

This chapter focuses on answering the research questions, and discussing and interpreting the themes that emerged in the study. This is followed by a review of the strengths and limitations of this study and recommendations are made for possible future studies. This chapter will conclude with the researcher’s reflections on the research process.

To gain insight into the primary caregivers’ experiences of Neurofeedback as an intervention for their autistic child the following research questions were posed:

- What are the experiences of primary caregivers with Autism Spectrum Disorder children who have undergone Neurofeedback as an intervention?
- Are primary caregivers satisfied or dissatisfied with Neurofeedback intervention?
- Has the intervention influenced the family system, and if so how?

Using Bronfenbrenner’s ecological theory, the four main themes can be understood at various ecological levels (Rosa & Tudge, 2013). The experiences of the primary caregivers and how neurofeedback as an intervention influenced the whole family system make up the microsystem of the individual autistic child and the family. The selection and initial perceptions of multiple therapeutic interventions fall on the level of the exosystem, and speak to the experiences the primary caregiver had with opting for multiple interventions (Rosa & Tudge, 2013). The types of behavioural problems associated with Autism Spectrum Disorder for the primary caregivers seeking out Neurofeedback intervention speak to the level of the mesosystem and how these behavioural problems are associated with one another, such as the primary caregivers’ perceptions of the benefits of, and dissatisfaction with Neurofeedback as an intervention for their child (Rosa & Tudge, 2013). How Neurofeedback as an intervention
impacted on the whole family is regarded as system of which the primary caregivers form a subsystem. The family system forms part of the microsystem and how the different factors relate to one another do not only directly impact the individual but also the rest of the family and can be extended to the level of the mesosystem, such as in the child’s school and direct community members and peers (Rosa & Tudge, 2013).

5.2 Themes

The four themes that emerged during the data analysis phase of the study offered insight into the experiences that primary caregivers have with regard to Neurofeedback as an intervention for their autistic child. The four categories, namely knowledge and understanding of the intervention, behavioural problems associated with Autism Spectrum Disorder for the primary caregivers seeking out Neurofeedback intervention, primary caregivers’ perceptions on the benefits Neurofeedback as an intervention for their autistic child and their dissatisfaction with it, and how Neurofeedback as an intervention impacted on the whole family system, are discussed in the sections that follow.

5.2.1 Theme 1: Selection and initial perceptions of multiple therapeutic interventions

The primary caregivers described how their choice of intervention was based on frustration, desperation or willingness to try out different treatment modalities. Each primary caregiver had subjective viewpoints on what evidence there is for the beneficial change in autistic children using Neurofeedback as an intervention. Some of the primary caregivers reported that they would be ready to try any intervention if there was a possibility of assisting their child improve in any way and that it is not harmful to their child. All of the primary caregivers reported that they had tried multiple interventions with some interventions being more effective than others. They were so used to trying multiple modes of intervention that it had become the norm for them to keep on researching more possible interventions and trying
more interventions. This gave them, as primary caregivers, a sense of self-awareness to
provide the best for their autistic child and show them that they will not give up but pursuing
possible treatments and interventions with the mindset of “you never know this one may be
the one”. This is an important motivation within the ecology of the different families.

5.2.2 Theme 2: Behavioural problems leading to primary caregivers seeking out
Neurofeedback intervention

The primary caregivers of autistic children have a close community of support structures.
These support structures can be at schools, support groups, autism support groups, and
awareness campaigns, among others. As a family and as primary caregivers it is very
important for them to help their autistic child to adapt as best as possible within their
community. Most primary caregivers made it clear that they bring their autistic child for
therapy because the child is struggling with social interaction within his or her community.

All of the participants in this study said that their child’s core problem was one of high
anxiety levels. Not only does the high anxiety cause stress for their child, but it also has an
impact on other intervention modalities and their success. One primary caregiver indicated
that she was looking for an intervention which would not be overwhelming for her child as
her child could not read social cues or act on emotions. As a result, the primary caregiver was
seeking a different type of intervention which was less stressful and more calming for her
child. One primary caregiver said that she heard from another primary caregiver whose child
was diagnosed with ADHD that Neurofeedback had been helpful and that it might even help
for autism. The primary caregiver wanted to try Neurofeedback in the hope that it could
possibly have an impact on the child’s social interactions, and that the intervention can
directly help the child to self-regulate by reducing his anxiety levels and learn to control his
aggression better and replace it with a calmer and more relaxed feeling.
One primary caregiver mentioned that school teachers do not know how to communicate or treat her autistic child and this worsened his academic performance. Another indicated that her child “shuts down” completely at school, not knowing how to communicate effectively with school teacher or peers. The primary caregiver felt that communication formed an integral part in school life and hoped that Neurofeedback could directly help their child in learning to speak better and communicate more effectively to teacher and peers, which would in return assist the school to better manage their child’s needs. Therefore, Neurofeedback plays a direct role in the readiness and preparations for an autistic child to attend school, as one of the major concerns is where children with autism are dysfunctional at school and that this affects the teacher and other children.

5.2.3 Theme 3: Primary caregivers’ perceptions of the benefits of Neurofeedback intervention and their dissatisfactions

The findings showed that all of the primary caregivers perceived some benefit from Neurofeedback intervention. There were multiple improved areas that the primary caregivers mentioned, the key ones being the reduction in anxiety, increased social ability and improvement in mood. The immediate payoff for the child that received sessions of Neurofeedback intervention was that he or she just felt more comfortable in themselves. One primary caregiver mentioned that the benefit of Neurofeedback was twofold in the sense that her son’s management of his anxiety was much better, resulting in less stress for him, and at the same time reducing the stress within the family as a whole. Examples were mentioned like reduced anxiousness about doing homework, resulting in a more peaceful and relaxed atmosphere at home.

Another major beneficial change was in terms of better insight into mood and emotional regulation. This follows from the fact that affect regulation is intimately coupled to arousal
Neurofeedback training enables the child to better regulate influences which play a role in their daily lives, because it trains the brain and makes it much more stable in controlling circuitry, leading to better emotional stability. So in general the child will go through life more in control of their emotions and their behaviour than before. The primary caregivers clearly indicated better results in communication, improved speech and improved behaviour with a much calmer approach, and there were report-backs from teachers to the primary caregivers indicating better behaviour in school, and in social situations. In terms of Bronfenbrenner’s ecological system (Bronfenbrenner, 1994), this indicates better interaction in the child’s mesosystem, extending from its family to life at school and in society.

There were also reports of dissatisfaction with Neurofeedback. Autistic children experience tactile sensitivity and one of the primary caregivers complained that her child did not like the electrodes on their scalp. This was the only complaint about the intervention itself.

But there was also dissatisfaction about the availability of locally licensed Neurofeedback practitioners willing to treat autistic children and the difficulty of obtaining research on Neurofeedback for autistic children. Some of the primary caregivers were thus dissatisfied with the accessibility of Neurofeedback as a service and treatment option. This is in part a consequence of Neurofeedback not being recognised by the HPCSA.

5.2.4 Theme 4: How Neurofeedback as an intervention impacted on the whole family system

Bronfenbrenner’s ecological model views the primary caregivers and an individual child as operating within a complex system of relationships affected by multiple levels of the surrounding environment (Rosa & Tudge, 2013). Neurofeedback as an intervention impacted the whole family system, directly affecting not only the development of the child but also the other family members within the home environment and the school environment as well,
resulting in the child and family functioning better within the mesosystem (Rosa & Tudge, 2013).

Most primary caregivers of this study indicated that Neurofeedback had a positive influence on the whole family. An autistic child within a family system does not only have an impact on the primary caregivers but the siblings are also affected. The focal point of the family is the autistic child, meaning there would be disruptions to the subsystems which would centre on siblings, and indeed all microsystems in the family. Not only do the primary caregivers lose their own intimacy, but the siblings that do not have a disorder suffer from the caregivers’ distraction, and the primary caregivers experience guilt feelings. Speaking about the family ecology, one primary caregiver mentioned that since her child started Neurofeedback he suddenly became much more talkative, even though the social interactions were still limited. As the sessions progressed her son became much calmer and more relaxed. His anxiety levels decreased, with the result that that they as a family could manage him much better and therefore the other subsystems of the family could receive more attention and the family begins to be less preoccupied with the autistic child’s behaviour. This allowed the primary caregivers and other siblings to reconnect emotionally. Practical changes that occurred after Neurofeedback were that her son could sit still for much longer periods of time. A teacher from his school reported that his behaviour started to improve, with better attention spans, and better learning. This positive change impacted the whole family’s internal environment (microsystem), but it also caused the family to reconnect with outside environments like socialising with friends, going out more and improving their quality of life (mesosystem).

One primary caregiver indicated that despite Neurofeedback sessions her child still showed aggressive tendencies and high frustration levels. Even though the intervention did help to
alleviate some anxiety levels for her son, there was no functional change in the family structure. The whole household was focused on her autistic child, almost fearing when the next aggressive acting-out behaviour might occur. As the primary caregivers explained it, “it’s like walking on eggs”. The high tension within the family caused strife within the marital and couple subsystem of the family. In this single instance, although Neurofeedback made a difference for the child, and therefore the mother reported that her son still continues with therapy, there is not enough improvements for the family to function better because of the intervention.

5.3 Strengths and limitations of the research study

One of the strengths of this research study was that families who were raising a child with autism were given the opportunity to share their life experiences of having a child with autism and sharing their personal stories. Valuable insight into the experiences of different aspects of Neurofeedback as an intervention while raising a child with autism was gained. Further, other families, and primary caregivers, friends and professionals can be made aware of Neurofeedback as an intervention and how it can influence the family life.

The sample size was the first limitation of this study. The researcher experienced difficulty in obtaining a sample population that fitted the participant criteria as Neurofeedback is still an emerging practice in South Africa. The number of practitioners who specialise in treating Autism Spectrum Disorder with Neurofeedback is limited, so gaining referrals from practitioners was challenging.

Another limitation to this study was that a small sample limited to Western Cape was used, which might not provide a good enough representation of the experiences of other primary caregivers raising a child with autism. A limited number of different cultural groups of the
primary caregivers was another limitation. The study only gained data from primary caregivers from four different cultural groups, namely African, White, Indian and Cape Malay primary caregivers. South Africa is characterised as multicultural and has a rich cultural diversity. More valuable information could have been obtained if more primary caregivers from different cultural groups were recruited and included in this study. However, due to the difficulty experienced in recruiting participants, it was very challenging to recruit a more diverse sample at this stage. A final limitation to this study was the time constraints in completing this thesis which led that no pre-testing measurement were done. If more time had been available, the researcher would have liked to have observed effects on extended family structures and sibling interactions specifically pertaining to Neurofeedback and conduct follow-up interviews with the five primary caregivers. However, since this is a mini thesis, the scope of this study is sufficient.

5.4 Recommendations for further study

This researcher’s inclusion criterion was that the autistic child had received at least 10 sessions. This suggests that the primary caregivers were generally satisfied with the intervention as they would have probably discontinued the intervention if they were not happy with Neurofeedback. Thus, the primary caregivers might have been biased in their perception of the benefits of Neurofeedback and minimised negative aspects or limitations of the intervention. Therefore, to expand the sample to include primary caregivers who have decided to discontinue the intervention may reduce the possibility of bias and highlight the experiences of caregivers.

Another possibility is that the perceived benefits from Neurofeedback that the primary caregivers highlighted could have been effects of other therapies but the primary caregivers may have been biased, viewing Neurofeedback in a favourable light in order to reduce the
cognitive dissonance caused by the sacrifices they had to make to obtain Neurofeedback intervention for their autistic child. In this light, further research could probe the comparative effects of different treatment modalities. Such a study could be conducted on the effects of Neurofeedback that isolates the effect of concurrent therapies to further explore the perceived benefits that were reported, also to taking into consideration is that a placebo effect may have influenced the primary caregivers, resulting in them seeing benefits that they were told to expect as a result of the Neurofeedback treatment.

Only primary caregivers’ perceptions were examined during this research study. As previously mentioned the primary caregivers’ perceptions of their experiences may have been influenced by various biases. Therefore, a study investigating the correlation between the primary caregivers’ perceptions and the practitioners’ perceptions would add value to the clinical findings and results of the research study. Perhaps this proposed research study may be further explored.

5.5 Contribution

This study gives a better and deeper understanding of primary caregivers’ experiences of their autistic child who has received Neurofeedback as an intervention. Some of the experiences might be similar but the satisfaction or dissatisfaction varies as every primary caregiver’s experience is different in its own way and in how it impacts on their family life. Many other primary caregivers can gain insight from the experiences of other primary caregivers who used this intervention for their autistic child. This study will not only contribute towards literature on Autism Spectrum Disorder but also contribute towards the field of Neurofeedback in general providing South African contextual information.
5.6 Reflection

As a student studying this year for Masters in Clinical Psychology and extensively covering diagnostic criteria of mental disorders, interventions and therapeutic approaches, I have developed a special interest in the field of autism, so this research study was very important and meaningful for me personally. As a student psychologist contracted to work for the clothing industry health care clinic in Athlone, part of my duties have been to provide psychoeducation for families affected by autism. As I interviewed the primary caregivers of this research study, I soon realised that most parents had high frustration levels with all these different types of interventions and they lack understanding of how it influences the family as a whole. The five primary caregivers that I have interviewed had experienced a variety of interventions of which one of them was Neurofeedback. All five primary caregivers reflected how they sought out Neurofeedback because of their own high anxiety associated with their children’s behavioural problems. Some of the questions that I asked were difficult for the parents to answer, as these questions brought back emotional memories of the struggles they endured through their earlier stages of the diagnosis of their child living with Autism Spectrum Disorder. At this stage debriefing was important which I did by empathising with them and reflecting on how difficult a period it had been for them. What was interesting is that all of the five parents that I interviewed have good support groups which are very valuable for families of special needs children. After building a rapport with the parents the data collected was information rich and seemed to be an accurate reflection of the views of the participants.

During this research process, I gained valuable insight into the families’ experiences. Some of these experiences shared on Neurofeedback as an intervention were mostly positive with beneficial results, while others were less impressed, with some dissatisfaction. It was also revealing to me that primary caregivers’ subjective responses differed, and that improvements
in their child’s behaviour or emotions which might seem insignificant to an outsider carried
great weight for them. It also appeared that primary caregivers enjoyed the opportunity to
share their stories within a psychologically safe environment.

5.7 Conclusion

Quantitative research has been conducted on what the efficacy of Neurofeedback is on
Autism Spectrum Disorder but little is known about the experiences of primary caregivers
and the family which has received this intervention for their autistic child. Autism Spectrum
Disorder is among the most difficult and most misunderstood childhood disorders (Evans,
2007). Problems with the evaluation of autistic children include day-to-day variability in
symptoms and the nature of presenting problems including the severity levels and the lack of
agreement on the underlying causes.

Primary caregivers have over the years tried multiple intervention modalities for their autistic
child (Altobelli, 2012). Autism has led to great difficulty for primary caregivers who have
become accustomed to utilising multiple intervention modalities, of which Neurofeedback is
one of many non-invasive intervention modalities for treating Autism Spectrum Disorder.
They have hoped that some intervention or a combination of interventions will make a
difference for their child even if it is a small change to improve their quality of life. This
research study tapped into the knowledge of what specific behavioural changes or concerns
about their autistic child that influenced them to try Neurofeedback. Most primary caregivers
raised behavioural concerns such as increase anxiety, learning difficulty, social adaptability
problems, aggression and mood related symptoms.

From the findings of this research study it is clear that Neurofeedback is most effective in
helping the autistic child with anxiety levels as well as communication and better mood
levels. Determining the cost-benefits analysis varies per primary caregiver as one small change in their child that is positive is enough to have made it beneficial for them.

Since Neurofeedback directly contributes to these factors, it also contributes to the family social structure, in that it helps the autistic child to prepare for school by enabling him or her to communicate better, and reduces anxiety when not in familiar spaces. Better interaction with peers, siblings, teachers and primary caregivers is also experienced as a benefit resulting from Neurofeedback as an intervention.

This research study will make other primary caregivers more aware that there are other non-invasive treatment options for their autistic child. This applies also to practitioners who might explore other non-invasive interventions in treating autism. It is important to continuously contribute to the body of knowledge within South Africa specifically with Neurofeedback as an intervention for Autism Spectrum Disorder and further research studies in this area is essential as it informs parents, teachers and people in general who are keen to find out more about this intervention and what it entails.

Raising a child with autism is challenging. The experiences shared in this research study are unique and profound. After many unmet expectations of many treatment modalities and the continuing effort to keep on trying interventions options such as Neurofeedback to stand a chance to better their child’s life, these primary caregivers and families found courage, perseverance and hope. They deserve society’s admiration for their optimism and strength.
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91


APPENDIX A: INFORMATION SHEET

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INFORMATION SHEET

**Project Title:** Exploring primary caregivers experiences of children who have received neurofeedback as an intervention for Autism Spectrum Disorder in the Western Cape

**What is this study about?**

This is a research project being conducted by Johann Krynauw at the University of the Western Cape and I’m inviting you to participate in this research project as a parent whose autistic child has received neurofeedback as an intervention within the Western Cape. The purpose of this study is to explore parent’s experiences of children who have received Neurofeedback (NFB) as an intervention for Autism Spectrum Disorder (ASD) in the Western Cape.

**What will I be asked to do if I agree to participate?**

An in-depth interview will be conducted and you will be asked to discuss certain questions posed. The questions that will be addressed will be related to your experiences of your child who has received Neurofeedback (NFB) as an intervention for Autism Spectrum Disorder (ASD), as well as what parental perceptions are there on the satisfaction and dissatisfaction with neurofeedback intervention and how does this influence the family system as a whole? As a parent you will have valuable insight and experiences on what the problems associated with Autism would be for seeking out the intervention of neurofeedback. The interviews will
be conducted in the comfort of the participants’ own venue or at an Autism Support Organisation within the Western Cape. The interview will be done within 45 to 60 minutes.

Would my participation in this study be kept confidential?

Your identity as participants will remain anonymous and the information obtained will be kept confidential. To help protect your confidentiality, the information you provide will be totally private; no names will be used so there is no way you can be identified as a result of participating in this study. Your information will be anonymous and treated confidentially. If we write a report or article about this research project, your identity will be protected to the maximum extent possible.

What are the risks of this research?

All human interactions and talking about self or others carry some risks. We will nevertheless minimise such risks and act promptly to assist you if you experience any discomfort, psychological or otherwise during the process of your participation in this study. Where necessary, an appropriate referral will be made to a suitable professional for further assistance or intervention.

What are the benefits of this research?

This research is not designed to help you personally, but the results may help the investigator learn more about the primary caregiver experiences of children who have received Neurofeedback (NFB) as an intervention for Autism Spectrum Disorder (ASD) in the Western Cape. We hope that, in the future, other people might benefit from this study in order to understand what parental perceptions are there on the satisfaction and dissatisfaction of neurofeedback intervention and how does this influence the family system as a whole.
Do I have to be in this research and may I stop participating at any time?

Your participation in this research is completely voluntary. You may choose not to take part at all. If you decide to participate in this research, you may stop participating at any time. If you decide not to participate in this study or if you stop participating at any time, you will not be penalised or lose any benefits for which you may otherwise qualify.

What if I have questions?

This research is being conducted by Mr Johann Krynauw at the University of the Western Cape. If you have any questions about the research study itself, please contact Mr Johann Krynauw, e-mail: krynauwj@gmail.com.

Should you have any questions regarding this study and your rights as a research participant or if you wish to report any problems you have experienced related to the study, please contact:

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This research has been approved by the Humanities and Social Sciences Research Ethics Committee of the University of the Western Cape.
APPENDIX B: CONSENT FORM

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CONSENT FORM

Exploring primary caregivers experiences of children who have received Neurofeedback as an intervention for Autism Spectrum Disorder in the Western Cape

The study has been described to me in language that I understand. My questions about the study have been answered. I understand what my participation will involve and I agree to participate of my own choice and free will. I understand that my identity will not be disclosed to anyone. I understand that I may withdraw from the study at any time without giving a reason and without fear of negative consequences or loss of benefits.

This research project involves making audio recordings of you. This will ensure that credibility, dependability and transferability be maintained throughout the research study. The audio recordings will be secured by using password-protected computer files. After all transcribing of data has been done the audio recordings will be destroyed and deleted.

___ I agree to be audio-taped during my participation in this study.

___ I do not agree to be audio-taped during my participation in this study

Participant’s name: ............................

Participant’s signature............................

Date.................................
SECTION A (BIOGRAPHICAL INFORMATION)

This section of the questionnaire refers to background or biographical information. Although we are aware of the sensitivity of the questions in this section, the information will allow us to compare groups of respondents. Once again, we assure you that your response will remain anonymous. Your co-operation is appreciated.

Kindly provide the following information:

1. Participants gender?
2. Participates age?
3. Participant’s ethnicity?
4. Participants son/daughter’s gender?
5. Participants son/daughter’s age?
6. Please indicate the timeframe (weeks, months, and years) that your child received neurofeedback as an intervention?
7. Please note how many therapeutic sessions have your child received neurofeedback as an intervention?
SECTION B (KNOWLEDGE, UNDERSTANDING AND LIFE EXPERIENCES INFORMATION)

1. How many treatment modalities have you tried for your autistic child? And what was your experience in trying these interventions?

2. What made you as a primary caregiver decide to choose Neurofeedback as intervention in the first place?

3. What were the symptoms of your child before and after the intervention?

4. What was your experience as a parent on Neurofeedback as a treatment for your child?

5. Does your child seem different to you as a result of the Neurofeedback treatment?

6. What are the things you liked and/or disliked about Neurofeedback treatment?

7. Was there any problem that arose during or after the treatment process? Please elaborate.

8. After your child received neurofeedback as an intervention how did it affect and impact your family as a whole?

9. How was your child’s functioning before and after receiving Neurofeedback within his interacting environment for example with peers, school, family etc. Please elaborate.

10. What were your stress levels before and after your child received the intervention? Please elaborate.