

The Experiences of Families Raising an Autistic Child: Rapid Review

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Mini-Dissertation submitted in partial fulfilment of the requirements of
the degree Master of Arts in Counselling Psychology at the North-West
University

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LIST OF ABBREVIATIONS

APA	American Psychiatric Association
ASD	Autism spectrum disorder
COMPRES	Community Psychosocial Research
DOAJ	Directory of Open Access Journals
DSM-3	Diagnostic and Statistical Manual of Mental Disorders, 3 rd Edition
DSM-5	Diagnostic and Statistical Manual of Mental Disorders, 5 th Edition
EDS	EBSCO Discovery Service
FQOL	Family quality of life
NWU	North-West University

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- Firstly, I would like to thank God/Hu for his grace throughout this journey. It was not easy, but it was all worth it.
- Mom and Dad, and Mapula and Edward Phetoe, this one is for you. Thank you for everything you have done for me; your sacrifices were not in vain.
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- Nkoko Nora, your farmstead little girl has grown up to be the woman you always dreamed of.
- Magogo, thank you for your prayers.
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- Mrs Heleen, thank you for your ability of making sense of my confusion and your guidance throughout this whole journey. Your supervision assisted me all the way.
- May I say, “I am my ancestors’ wildest dream.”

SUMMARY

Autism is becoming more prominent in South Africa and in the rest of the world. The family that raises an autistic child plays a key role in the treatment and lifelong management of the child. This responsibility goes with demanding challenges that are unique to every child and situation. A deeper understanding of the psychosocial experiences and impact of autism and its symptoms on the involved families is ultimately essential in the development of relevant and scientific interventions and support programmes.

Objectives: The aim of this study was to conduct a rapid review to explore, analyse, synthesise, and integrate existing scientific literature on the pre- and post-diagnostic psychosocial experiences of families that raise an autistic child.

A good and integrative understanding of the experiences of these families is critical, as it provides insight into their unique challenges, daily realities, and the impact of autism on family dynamics. This study was guided by the following two research questions:

- 1) What are the psychological experiences of families that raise an autistic child pre- and post-diagnosis?
- 2) What are the social experiences of families that raise an autistic child pre- and post-diagnosis?

A rapid review was conducted to attempt to answer these two research questions. The rapid review focused on synthesising and integrating recent and relevant international and South African literature to gain a better understanding of the psychosocial experiences of families that raise an autistic child. The first step of the process was to conduct a systematic and explicit scope search. Various electronic databases, as well as the help of the North-West University librarian, were used to conduct a thorough and systematic literature search. The initial search produced 142 results. After the initial scope search, the identified studies were screened by title and abstract for relevance. After the screening process, 34 articles remained to be appraised. In the appraisal process, scientifically sound appraisal tools were used to identify those studies that should be included in the research study. Studies were excluded based on not being applicable to the review, not meeting the inclusion criteria, or being rated as poor-quality research. A final number of nine studies were identified for inclusion in the review. These studies were found to be relevant to the inclusion criteria and research questions, as well as of acceptable quality, as agreed upon by both reviewers.

A thematic synthesis was conducted in order to inductively analyse the findings from the nine retrieved studies. The data-extraction process was carefully planned in order to ensure that data were extracted accurately. The following themes were identified:

- Psychological experiences (pre- and post-diagnosis), which included emotions experienced, grieving process, parenting, and family dynamics.
- Social experiences (pre- and post-diagnosis), which included lack of support services and social awareness.
- Psychosocial coping strategies (pre- and post-diagnosis), which included isolation, information seeking, meaning-making, and support system.

The identified themes indicated that the psychosocial experiences of families that raise an autistic child were multidimensional and fit well within a contextual and systemic perspective. To address the needs and opportunities identified in this study, a contextual and systemic perspective is indicated. Internationally and in South Africa, family-focused research and the psychosocial wellbeing and quality of life of families are increasingly becoming the focus of research attention.

The family quality of life (FQOL) framework provides a positive approach that seeks to improve and optimise the quality of life of families that raise a child with a disability. The psychosocial themes identified in the analysis and synthesis of the identified articles in this study fit perfectly into the conceptual fields of the FQOL framework, namely individual concepts, family unit concepts, procedural concepts, and systemic concepts. A deeper and better understanding of the psychosocial experiences of families that raise an autistic child within these various concepts is essential for informing scientifically sound interventions and support programmes. The aim of these programmes and interventions should be to activate and sensitise the whole system involved so that families that raise a child with autism can experience satisfaction, joy, and quality family life. Recommendations in this regard include that families need to be informed of services available for autism and psychosocially supported so that they feel empowered to deal with the challenges at hand. In addition, they need to be ensured of reliable, competent, and supportive professional and personal support networks that work together to raise societal awareness and sensitivity towards children with autism and especially their families.

KEYWORDS: FAMILIES, EXPERIENCES, AUTISTIC, CHILD.

OPSOMMING

Outisme word toenemend meer prominent in Suid-Afrika en in die res van die wêreld. Die familie wat 'n outistiese kind grootmaak speel 'n belangrike rol in die behandeling en lewenslange bestuur van die kind. Hierdie verantwoordelikheid gaan gepaard met veeleisende uitdagings wat uniek is tot elke kind en situasie. 'n Dieper begrip van die psigososiale ondervindings en impak van outisme en die simptome daarvan op die betrokke families is noodsaaklik in die ontwikkeling van toepaslike en wetenskaplike ingrypings en ondersteuningsprogramme.

Doelwitte: Die doel van hierdie studie was om 'n vlugtige oorsig uit te voer om bestaande literatuur oor die pre- en post-diagnostiese psigososiale ondervindings van families wat 'n outistiese kind grootmaak te verken, te ontleed, te sintetiseer, en te integreer.

'n Goeie en geïntegreerde begrip van die ondervindings van hierdie families is noodsaaklik omdat dit lig werp op hul unieke uitdagings, daaglikse werklikhede, en die impak van outisme op familiedinamika. Hierdie studie is gelei deur die volgende twee navorsingsvrae:

- 3) Wat is die psigologiese ondervindings van families wat 'n outistiese kind grootmaak voor en ná diagnose?
- 4) Wat is die sosiale ondervindings van families wat 'n outistiese kind grootmaak voor en ná diagnose?

'n Vlugtige oorsig is uitgevoer in die poging om hierdie twee navorsingsvrae te beantwoord. Die vlugtige oorsig het gefokus op die sintetisering en integrering van onlangse en toepaslike internasionale en Suid-Afrikaanse literatuur ten einde 'n beter begrip te verkry van die psigososiale ondervindings van families wat 'n outistiese kind grootmaak. Die eerste stap in die proses was om 'n stelselmatige en eksplisiete omvangsoektog te onderneem. Verskeie elektroniese databasisse, asook die hulp van die NWU-bibliotekaris, is gebruik om 'n deeglike en stelselmatige literatuurondersoek te onderneem. Die aanvanklike ondersoek het 142 resultate opgelewer. Ná die aanvanklike omvangsoektog is die geïdentifiseerde studies volgens titels en opsommings getakseer vir toepaslikheid. Ná hierdie proses het 34 artikels oorgebly wat beoordeel moes word. Tydens die beoordelingsproses is wetenskaplik-gegronde beoordelingsinstrumente gebruik om die studies te identifiseer wat by hierdie navorsingstudie ingesluit moes word. Studies wat nie toepaslik was tot die oorsig nie, wat nie aan die insluitingskriteria voldoen het nie, of wat van swak gehalte beskou is, is nie in hierdie studie ingesluit nie. Uiteindelik is nege studies in die oorsig ingesluit. Daar is gevind dat hierdie studies

toepaslik was tot die insluitingskriteria en navorsingsvrae, en ook van aanvaarbare gehalte was, soos deur beide die hersieners ooreengekom.

'n Tematiese sintese is uitgevoer ten einde die bevindings van die nege gekose studies induktief te ontleed. Die data-ontginningsproses was noukeurig beplan ten einde te verseker dat die data akkuraat ontgin word. Die volgende temas is geïdentifiseer:

- Psigologiese ondervindings (voor en ná diagnose) het ingesluit emosies ondervind, die rouproses, ouerskap, en familiedinamika.
- Sosiale ondervindings (voor en ná diagnose) het ingesluit tekort aan ondersteuningsdienste, en sosiale bewustheid.
- Psigososiale hanteringstrategieë (voor en ná diagnose) het ingesluit afsondering, soeke na inligting, betekenisgeving, en ondersteuningstelsel.

Die geïdentifiseerde temas het aangedui dat die psigososiale ondervindings van families wat 'n outistiese kind grootmaak multidimensioneel is en dat hierdie ondervindings goed inpas in 'n kontekstuele en sistemiese perspektief. Ten einde die behoeftes en geleenthede aan te spreek wat in hierdie studie geïdentifiseer is, word 'n kontekstuele en sistemiese perspektief aangedui. Internasionaal en in Suid-Afrika, word familie-gefokusde navorsing en die psigososiale welstand en lewensgehalte van families toenemend die fokus van navorsing.

Die familie-lewensgehalte ("FQOL")-raamwerk voorsien 'n positiewe benadering wat poog om die lewensgehalte van families wat 'n gestremde kind grootmaak te verbeter en te optimaliseer. Die psigososiale temas wat in die ontleding en sintese van die gekose studies geïdentifiseer is pas perfek in by die konseptuele velde van die FQOL-raamwerk, naamlik individuele konsepte, familie-eenheid-konsepte, prosesuele konsepte, en sistemiese konsepte. 'n Dieper en beter begrip van die psigososiale ondervindings van families wat 'n outistiese kind grootmaak binne hierdie verskeie konsepte is noodsaaklik om wetenskaplik-gegronde ingrypings- en ondersteuningsprogramme te rugsteun. Die doel van hierdie programme en ingrypings behoort te wees om die hele betrokke stelsel te aktiveer en te sensitiseer sodat families wat 'n outistiese kind grootmaak bevrediging, geluk, en gehalte familielewe kan ervaar. Aanbevelings in hierdie opsig sluit in dat families ingelig oor dienste wat beskikbaar is vir outisme en psigososiaal ondersteun moet word sodat hulle bemagtig kan voel om hul uitdagings te oorkom. Hulle moet ook verseker word van betroubare, bevoegde, en ondersteunende professionele en persoonlike ondersteuningsnetwerke wat saamwerk om gemeenskaplike bewusmaking en sensitiwiteit teenoor outistiese kinders en veral hul families te skep.

Sleutelwoorde: Families, ondervindings, outisties, kind.

PREFACE

Article format

This mini-dissertation is part of the requirements for the completion of the Magister of Artium degree in Counselling Psychology. It has been prepared according to the article format regulations of the North-West University.

Journal

This manuscript is compiled in accordance with the requirements set by the *South African Journal of Child Health* for publication. Please take note that the article is presented according to the authors' guidelines of the abovementioned journal. The in-text citations, as well as the references of Section 1 and 3, were prepared according to the APA (American Psychological Association) publication guidelines.

Page numbers

For examination purposes, the pages are numbered from the title page and proceed from there onwards.

DECLARATION

I, Boitumelo Phetoe, declare that the mini-dissertation, titled “The Experiences of Families Raising an Autistic Child: A Rapid Review”, which I submit to the North-West University, Potchefstroom campus, is in compliance with the requirements set for the degree Master of Arts in Counselling Psychology. I further declare that this mini-dissertation is my own work and that the sources utilised have been acknowledged and correctly referenced. Language editing of this mini-dissertation was done as per the stipulated requirements. Furthermore, this mini-dissertation has not been submitted to any other university. I also acknowledge and understand that copies submitted for examination will become the property of the university.

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

Boitumelo Phetoe

Student number: 22969349

STRUCTURE OF THE MINI-DISSERTATION

The mini-dissertation will be submitted in article format, consistent with the Rules for the Classification of Thesis and Dissertations 7.1.11.9, which is structured as follows:

Section 1: Introduction, a brief literature review, the aim of the study, methodology, and ethical considerations.

Section 2: Research article: The Experiences of Families Raising an Autistic Child: A Rapid Review. This article will be written in accordance to the publication rules of the *South African Journal of Child Health*. This section and the reference list at the end of the section were compiled in accordance with the guidelines of the mentioned journal.

Section 3: Critical reflection on the study.

Guidelines to author: *South African Journal of Child Health*

- **Methods:** Outline the sources and selection methods, including search strategy and keywords used for identifying references from online bibliographic databases. Discuss the quality of evidence.
- **When writing:** Clarify the evidence you used for key statements and the strength of the evidence. Do not present statements or opinions without such evidence, or if you have to, say that there is little or no evidence and that this is opinion. Avoid specialist jargon and abbreviations and provide advice specific to southern Africa.
- **Personal details:** Please supply your qualifications, position and affiliations, and MP number (used for CPD points); address, telephone number and fax number, and your e-mail address; and a short personal profile (50 words) and a few words about your current fields of interest.
- Manuscripts must be written in UK English (this includes spelling).
- The manuscript must be in Microsoft Word or RTF document format.
- Text must be 1.5 line spaced, in 12-point Times New Roman font, and contain no unnecessary formatting (such as text in boxes). Pages and lines should be numbered consecutively.
- Please make your article concise, even if it is below the word limit.
- Abbreviations should be spelled out when first used and thereafter used consistently, e.g. “intravenous (IV)” or “Department of Health (DoH)”.

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NB: Only complete, correctly formatted reference lists in Vancouver style will be accepted. If reference manager software is used, the reference list and citations in text are to be unformatted to plain text before submitting..

- Authors must verify references from original sources.
- Citations should be inserted in the text as superscript numbers between square brackets, e.g. These regulations are endorsed by the World Health Organization,^[2] and others.^[3,4-6]
- All references should be listed at the end of the article in numerical order of appearance in the Vancouver style (not alphabetical order).
- Approved abbreviations of journal titles must be used; see the [List of Journals in Index Medicus](#).
- Names and initials of all authors should be given; if there are more than six authors, the first three names should be given followed by et al.
- Volume and issue numbers should be given.
- First and last page, in full, should be given e.g.: 1215-1217 not 1215-17.
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Some examples:

- *Journal references:* Price NC, Jacobs NN, Roberts DA, et al. Importance of asking about glaucoma. Stat Med 1998;289(1):350-355. <http://dx.doi.org/10.1000/hgjr.182>
- *Book references:* Jeffcoate N. Principles of Gynaecology. 4th ed. London: Butterworth, 1975:96-101.
- *Chapter/section in a book:* Weinstein L, Swartz MN. Pathogenic Properties of Invading Microorganisms. In: Sodeman WA, Sodeman WA, eds. Pathologic Physiology: Mechanisms of Disease. Philadelphia: WB Saunders, 1974:457-472.

PERMISSION TO SUBMIT THE STUDY

Permission to submit article for examination purposes

This mini-dissertation serves as partial fulfilment of the degree Magister of Artium in Counselling Psychology at the Potchefstroom campus of the North-West University. I, the supervisor of this study, hereby declare that the article titled “The Experiences of Families Raising an Autistic Child: A Rapid Review”, written by Boitumelo Phetoe, reflects the subject matter of the research. The co-author of the article that forms part of this mini-dissertation, namely Mrs Heleen Coetzee (supervisor and co-author), hereby give permission to the candidate, Boitumelo Phetoe, to include the article as part of a master’s dissertation and that the candidate may submit the article for publication in the *South African Journal of Child Health*. The contributions (advisory and supportive) of the co-author were kept within reasonable limits, thereby enabling the candidate to submit this mini-dissertation for examination purposes.



Mrs Heleen Coetzee
Supervisor and co-author

PROOF OF LANGUAGE EDITING



08 April 2020

To whom it may concern

Re: Proofreading and academic editing: B.K. Phetoe (student number 22969349)

I, J.L. van Aswegen of Grammar Guardians, hereby confirm proofreading and academic editing of the thesis entitled "The Experiences of Families Raising an Autistic Child: Rapid Review" by Boitumelo K. Phetoe in April 2020.

Please contact me on 082 811 6857 or at jeanne@grammarguardians.co.za regarding any queries that may arise.

Kind regards,

A handwritten signature in black ink, appearing to read 'JL van Aswegen', is written over a horizontal line.

J.L. van Aswegen

Grammar Guardians

TURNITIN ORIGINALITY REPORT

A Turnitin check was conducted and the overlap was within reasonable parameters. Where an overlap was indicated, it was checked by the study leader and found to be acceptable and that proper referencing was done appropriately where necessary. The Turnitin report was generated separately for the three sections of the mini-dissertation and the overlap percentages found were: Section 1 Introduction: 12 %, Section 2 Article: 9%, and Section 3 Reflection: 1%.

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SECTION 1:

INTRODUCTION AND CONTEXTUALISATION OF THE STUDY

1.1 INTRODUCTION

The aim of Section 1 and this introduction is to help the reader better contextualise the problem statement of the manuscript. Section 2 is written in article format and integrates and condenses the available information. In order to provide context, Section 1 focuses on more and broader information on the relevant concepts named in the title and article. Attention is specifically paid to the following concepts: autism's clinical picture and clinical features, psychological experiences of families pre- and post-diagnosis, social experiences of families pre- and post-diagnosis, and the family quality of life (FQOL) framework.

1.2 PROBLEM STATEMENT AND LITERATURE REVIEW

Autism spectrum disorder (ASD) is a neurodevelopmental syndrome that significantly impacts the quality of life of those affected, and especially their families (Ozgur, Aksu, & Eser, 2018). Autism is seen as a global health concern and it is indicated that one in every 160 people is estimated to live with ASD, which amounts to 7.6 million disability life adjusted years (World Health Organization, 2013a). Christensen et al. (2018) found that since 1990 there has been a 70% increase in the number of children with developmental disabilities, including autism. It is clear that autism is becoming all the more prevalent, both internationally and in South Africa. In South Africa, it is indicated that one in every 86 children from the Western Cape is affected by autism (Springer, Van Toorn, Laughton, & Kidd, 2013). Few studies have been conducted in the rest of South Africa or even sub-Saharan Africa, but as autism is said to be found in every ethnic and social group, it can be predicted that it is unlikely that the statistics will be any lower in other provinces (Abubakar, Ssewanyana, & Newton, 2016; Harrison, Zimak, Sheinkopf, Manji, & Morrow, 2014).

Previous research is clear on the huge impact that autism has on families (Chambers, Wetherby, Stronach, Njongwe, Kauchali, & Grinker, 2016). As autism is becoming more prevalent, family-focused research on autism has become more relevant (Cridland, Jones, Magee, & Caputi, 2014).

Scientifically sound, accessible, and relevant support services have been indicated as a definite need to families that raise an autistic child (Hall & Graff, 2010). A deeper understanding of the impact of autism and its symptoms on the involved families is ultimately essential in the effective management of the autistic child and his/her environment (Ruparelia et al., 2016).

1.3 AUTISM: CLINICAL PICTURE AND CLINICAL FEATURES

According to the American Psychiatric Association (APA, 2013b), ASD is classified as a pervasive childhood developmental disorder. It is characterised by a triad of deficits in “social reciprocity, communication and restricted repetitive patterns of interest or behavior. The severity of the disorder is based on social communication impairments and restricted, repetitive patterns of behavior” (APA, 2013b, pp. 50-59). It is significant to note that with the publication of the Diagnostic and Statistical Manual of Mental Disorders, 5th Edition (APA, 2013b), only ASD is indicated as a possible diagnosis, with the assumption that this will include the previously named Asperger’s syndrome (APA, 2013a, p. 50). The current diagnosis refers to a spectrum of behaviours, including and ranging from high- to low-functioning individuals. Severity is based on social communication impairments and restricted, repetitive patterns of behaviour ranging from Level 1-3, where Level 3 requires very substantial support, Level 2 requires substantial support, and Level 1 requires support (Barton, Robins, Jashar, Brennan, & Fein, 2013).

1.3.1 Main features of autism

In understanding the disorder, Davis and Carter (2008) explain that no single behaviour is indicative of autism, nor will any child show all of the disorder’s deficits. The disorder presents differently in every affected individual and its appearance depends greatly on factors such as the severity of the disorder and comorbid conditions (APA, 2013c). The two main features of autism, namely deficits in social interaction and communication and repetitive and restricted behaviours, are outlined hereunder.

1.3.1.1 Social interaction and communication

The DSM-5 criterion, “deficits in social interaction and communication”, refers to both verbal and nonverbal deficits in language and communication, which are often noticeable during interpersonal interactions. This includes the inability to understand social cues and nonverbal communication such as body language and eye contact. Their gesturing is often absent or atypical (Foley-Nicpon, Fosenburg, Wurster, & Assouline, 2016) and they find it difficult to enjoy social interaction. Furthermore, they show an inability to initiate social interactions or share enjoyment of experiences, thoughts, and feelings with others (Ozgur et al., 2018).

1.3.1.2 Repetitive, restricted behaviours

Children with ASD also present with repetitive and restricted behaviours, which can be verbal or nonverbal (Barton et al., 2013). This could include self-stimulatory behaviours in the form of motor behaviours such as hand flapping and finger flicking and the use of objects in a stereotypical manner, such as the stacking or lining up of objects (Foley-Nicpon et al., 2016). Verbally, this entails words, sounds, or sentences being repeated without any understanding of their meaning. Importantly, these behaviours are repetitive in nature and can be outwardly unnecessary; however, these behaviours are calming to the autistic person (Ozgur et al., 2018).

1.3.2 Neurological origin and aetiology

Research indicates that there is no single known cause of ASD (Matelski & Van de Water, 2016). However, one of the largest exome sequencing studies of ASD, conducted by Satterstrom et al. (2018), indicated that unusual brain activity and atypical brain development during infancy appear to underlie the manifestation of autism symptomatology. The study explained that unusual brain development in autism occurs when the formation and connectivity of cerebral circuits are at their prime, which is the most productive and optimum stage of synaptic activity (Satterstrom et al., 2018). This unusual brain growth might disturb the development of typical cerebral connectivity, which is necessary for the operation of optimum neural pathways. Furthermore, the size of the cerebral vermis, defined as a region of the brain responsible for motor control and cognitive functions, might eventually lead to autism (Wolff & Piven, 2013; Petinou & Minaidou, 2017).

A study conducted by Stockman (2013) among toddlers with autism indicated abnormal brain overgrowth in the cerebellum, cerebral, and limbic structures. These areas are responsible for the processing and the use of higher-order cognitive, pragmatic, emotional, social, and language functions (Matelski & Van de Water, 2016). The above is supported by the broken mirrors theory, which suggests that the cause of autism is linked to reduced mirror neuron activity in the inferior frontal gyrus, which is a part of the brain's premotor cortex (Ramachandran & Oberman, 2007). The broken mirrors theory of autism claims that mirror neuron system dysfunction may be the cause of difficulties in imitation, language, empathy, the comprehension of actions and emotions, and understanding the intention of an action, which perhaps explains autistic people's inability to assess the intentions of others (Oberman, Hubbard, McCleery, Altschuler, Ramachandran, & Pineda, 2005).

1.3.3 Diagnosis, screening, and testing for autism

According to Wannenburg and Van Niekerk (2018), the early diagnosis of autism remains a rare process in especially certain disadvantaged communities. Indications are that most spectrum diagnoses are more prevalent around the age of six years and older, which results in younger children's families experiencing feelings of anxiety, stress, and confusion caused by difficulty in understanding their child's early development and especially developmental delays (Mandell, 2005). The search for diagnosis can be one of the most stressful periods, especially in South Africa with its limited resources, which results in parents being met with waiting lists for early intervention services (Guler, De Vries, Seris, Shabalala, & Franz, 2017).

The first important step, however, to obtaining a diagnostic process is based on the parents being able to recognise certain developmental delays and fallouts in the child's behaviour (Elder, Kreider, Brasher, & Ansell, 2017). Thereafter, professional screening can be conducted, which is based on attending to parents' concerns about their child's behaviour. However, the aim is not a diagnosis but rather an indication of high-risk possibilities of autism (Baird, 2003; Zwaigenbaum et al., 2015). A comprehensive diagnostic evaluation of an autistic child is based on the usage of a set of standardised interviews and observational assessment tools conducted by medical professionals, which include psychologists, speech therapists, occupational therapists, and/or medical doctors (Elder et al., 2017; Zwaigenbaum et al., 2015). However, studies indicate a need to translate screening tools into local languages in order to cater for South Africans in underdeveloped rural areas (Chambers et al., 2016). It is indicated that if the screening and diagnosis process is conducted properly, it could assist not only in alleviating stress for parents but also shorten waiting lists for intervention services, thereby reducing the long-term stress of autism on families and different systems involved such as education and healthcare systems (Wannenburg & Van Niekerk, 2018).

1.3.4 Autism in South Africa: The health and educational sectors

Families of children diagnosed with autism in South Africa indicated their level of dissatisfaction in terms of the disability-related support they received from the government, including health, financial, and educational services (Chambers et al., 2016; Wannenburg & Van Niekerk, 2018). Some families resort to expensive private disability-related intervention services, which not all families can afford. Furthermore, most medical aid plans do not provide full cover, which results in families relying on their own finances (Guler et al., 2017). Therefore, with the aim of assisting families with children diagnosed with autism, the Social Assistance Act (No. 13 of 2004) was amended to include families of children with mild to moderate disabilities in need of care and

support. However, most families of children with mild to moderate disabilities are still economically excluded from the care dependency grant because of their level of functioning. Each level requires a different level of support (African Child Policy Forum, 2011). A study conducted by Kiru and Cooc (2017), which evaluated the education facilities for students with disabilities in Brazil, Canada, and South Africa, indicated that families that raise children with disabilities face significant education-related costs. Although special-needs schools are available, these schools are often over-capacitated and often lack proper support services. Families are therefore forced to either enrol their child in mainstream schools that do not make provision for children with special needs, or in private schools, which are very expensive (Erasmus, Kritzinger, & Van der Linde, 2019). This financial burden can have a significant impact on not only the caregiver, but the whole family as well.

1.3.5 Family experiences

A family is an interactive and complex social system in constant interaction with one another and their respective and relevant contexts and systems (Minuchin, 1985). What impacts one family member (e.g. disability) therefore affects the entire family system, which suggests a need for family-centred research (Seligman & Darling, 2007). Research into families that raise children with ASDs is still underdeveloped (Cridland et al., 2014). Research is clear on the fact that children with autism pose a range of unique and distinct challenges to families (Clasquin-Johnson & Clasquin-Johnson, 2018). The impact of autism results in a variety of emotions experienced by families. These experiences range on a continuum from negative high levels of stress and anxiety to positive experiences of meaning-making and resilience (Guler et al., 2017). The impact of autism on a family as a whole is significant and is mainly experienced on a psychological and social level during both the pre- and post-diagnosis stages (Weiss, Wingsong, & Lunsky, 2013).

1.3.5.1 Psychological experiences of families pre- and post-diagnosis

Pre-diagnosis, families experience confusion and uncertainty regarding their child's behaviour. According to Wong, Yu, Keyes, and McGrew (2016), during this period, families tend to suspect something is not right with their child, but they do not report their suspicions. These suspicions include speech, language, eye contact, and behavioural problems that families become aware of prior to professional diagnosis. However, due to lack of knowledge and understanding of normal developmental patterns, autism, and other child developmental disorders, child diagnosis tends to be delayed (Chawarska, Paul, Klin, Hannigen, Dichtel, & Volkmar, 2006). This delay tends to

cause severe distress and intense emotional strain, including emotions consisting of feelings of anger and confusion, which may have negative physical health outcomes (Broady, Stoyles, & Morse, 2015). Pre-diagnosis families are mainly faced with experiences of uncertainty and apprehension with regard to the management of the symptoms and the impact of the possible diagnosis on the family system as a whole (Wong et al., 2016).

Post-diagnosis, the initial experiences are characterised by feelings of shock, despair, sadness, grief, and blame (Fernández-Alcántara, García-Caro, Pérez-Marfil, Hueso-Montoro, Laynez-Rubio, & Cruz-Quintana, 2016). It is also indicated that the diagnosis gives a sense of relief as well, which in some instances helps the family to feel informed and empowered. This guides the family in attempting to make sense and find meaning in the diagnosis and in working towards accepting autism and the daily challenges that accompany the diagnosis (Guler et al., 2017).

It is also indicated that South African families that raise an autistic child experience significant challenges in terms of proper intervention programmes and educational services (Erasmus et al., 2019). Limited access to appropriate interventions in the public health and education sectors in Africa and South Africa in particular contributes to the impact felt both pre- and post-diagnosis (Chambers et al., 2016; Kiru & Cooc, 2017). Research indicates that these families often feel helpless, scared, and alone in attempting to navigate themselves within the scarce systems aimed at supporting autistic children (Weiss et al., 2013). This intensifies the families' levels of stress and tends to affect all family members. In order to address the wellbeing of these families and to enhance their quality of life, it is important to first have a thorough, reliable, and scientific understanding of these families' experiences (Wong et al., 2016).

1.3.5.2 Social experiences of families pre- and post-diagnosis

On a social level, it is found that families have to give up normal family routines and socialisation practices, and also find it difficult to maintain employment (Cox, Eaton, Ekas, & Van Enkevort, 2015). The family members may start to isolate themselves from family, friends, activities, and the community with the aim of fully catering for and supporting the autistic child (Wong et al., 2016). The lack of awareness among society is what drives families into full isolation as they are stigmatised by the community, who blame them for their child's behaviour. Families start to isolate themselves to protect their child and family as a defence mechanism (Weiss et al., 2013). This may affect the family's ability to obtain needed social support and interaction, which may result in a general feeling of frustration (Guler et al., 2017).

From the abovementioned information it is clear that autism is becoming more prevalent and that it has a significant impact on families that raise autistic children. From the literature on the psychological and social experiences of these families, it is clear that they experience a variety of emotions, which vary from negative to positive (Weiss et al., 2013; Wong et al., 2016; Guler et al., 2017). For support and intervention programmes to be effective and scientifically sound, it is important that they must focus on the lived experiences of the families involved (Damiano, Mazefsky, White, & Dichter, 2014). As research on family-based support for especially families that raise a child with autism is becoming all the more popular and the focus of attention (Gabovitch & Curtin, 2009), the FQOL perspective provides a valuable framework to interpret and discuss the results of this study. The FQOL framework provides a conceptual organisation of various aspects that could contribute to helping these families live a quality life despite them having to deal with their autistic family member (Wang & Brown, 2009).

1.3.6 The family quality of life (FQOL) framework

The FQOL perspective provides a framework that is aimed at exploring positive approaches that can improve the quality of life of families that raise a child with a disability (Butler, 2018). FQOL is defined as “the goodness of family life” or the “conditions where the family’s needs are met, and family members enjoy their life together” (Park et al., 2003, p. 368). The outcome is that families function optimally within their home and community, support the development of their children, and contribute to the ongoing stability of societies (Isaacs et al., 2007).

In combination with FQOL research, Zuna, Summers, Turnbull, Hu, and Xu (2010) proposed a unified theory of FQOL that explains what causes FQOL to vary among families of children with intellectual and other disabilities, and to furthermore identify variables that positively impact a life of quality. The identified variables are: family unit concepts, individual family member concepts, performance concepts, and systemic concepts.

The family unit is defined as the collective number of individuals who consider themselves to be part of a family and who engage in some form of family activities together on a regular basis. This consists of two main aspects, namely family characteristics and family dynamics (Zuna, Turnbull, & Summers, 2009). Family-level characteristics are traits of the family that include the type of family (kinetic, stepfamily), the family’s income, the size of the family, the geographic location of the family, religious preference, and ethnicity. Family dynamics are aspects of interactions among two or more family members, which include family sense of coherence, adaptability, hardiness, and decision making (Zuna et al., 2010).

In contrast to family unit concepts, according to Zuna et al. (2010), **individual family member concepts** refer to aspects of the person with a disability, which may include a parent, sibling, or other individual family member. Within this concept are aspects that are predictors of FQOL, which include individual family member characteristics, demographics, and beliefs (Zuna et al., 2009). Individual demographics are basic traits such as the child's age, the type of disability, and the parents' education level, ethnicity, or employment status. Individual characteristics are multidimensional traits that might vary over time, such as child behaviour. Beliefs include individual family members' attributions of meaning and expectations, the meaning of the child's disability for the family, expectations about the child's future, or understanding/expectations about parental roles in partnership with professionals (Zuna, Brown, & Brown, 2014).

Performance concepts, according to Zuna et al.'s (2010) unified theory, include the formal services, support systems, and practices developed and offered to individuals with intellectual disabilities and their families. This entails a range of educational, social, and health-related services, which are expected to improve outcomes for the individual or the family. Support systems are seen as tangible resources provided that are expected to improve the outcomes for the individual or family. The last aspect is practices, which are seen as specific procedures or processes through which services and support are delivered (Zuna, Selig, Summers, & Turnbull, 2009).

The last concept, according to Zuna et al.'s (2010) unified theory, is **systemic concepts**, which entail a collection of interrelated networks organised to meet the family's needs, such as healthcare, educational, and legal systems. These further include policies that are established as guidelines to regulate the procedures for programme implementation.

This framework suggests that interactions between family members are influenced by resources and perceptions when confronted with a stressful situation (Zuna et al., 2010). In terms of families with autistic children, there is a level of dissatisfaction with the disability-related support offered by the government; including health, financial, and psychological services (Karst & Van Hecke, 2012). This results in families feeling as though they are in a state of "crisis", due to the lack of disability-related services available to autistic children and their families (Guler et al., 2017).

1.4 THE RATIONALE OF THE STUDY

From the abovementioned literature, it is clear that having a child with autism affects and influences families and the broader systems the families find themselves in. It is furthermore

clear that the challenges and stressors associated with raising an autistic child can significantly reduce the prognosis for effective interventions (Eikeseth, Klintwall, Hayward, & Gale, 2015). It is important to explore families' experiences in raising an autistic child in order to inform sound and scientific interventions and support programmes that can improve service delivery to these affected families (Karst & Van Hecke, 2012).

An integration of what previous studies found to be the main experiences of families affected by the diagnosis of autism, internationally and in South Africa, will be valuable in providing appropriate, relevant, and scientifically sound knowledge to inform professionals who develop support and intervention programmes aimed at enhancing the psychosocial wellbeing and quality of life of families that raise an autistic child. This information could also be valuable in informing policies, structures, and procedures developed to effectively manage children with autism in the South African health and educational sectors (Franz, Adewumi, Chambers, Viljoen, Baumgartner, & De Vries, 2018).

1.5 THE AIM OF THE STUDY

The aim of this study was to explore and review available scientific literature and then integrate and synthesise the best available scientific information on the pre- and post-diagnostic psychosocial experiences of families that raise an autistic child.

This information will be valuable in informing mental healthcare providers in terms of the development and implementation of appropriate and much-needed support services and intervention plans. The research questions for this study are as follows:

- 1) What are the psychological experiences of families that raise an autistic child pre- and post-diagnosis?
- 2) What are the social experiences of families that raise an autistic child pre- and post-diagnosis?

1.6 RESEARCH METHODOLOGY

1.6.1 Introduction to the rapid review process

A rapid review was conducted to answer the research questions. This consisted of systematic and explicit search and review methods that enabled the reviewers to identify, select, and critically appraise relevant studies to include in this study.

Schünemann and Moja (2015) explain that rapid reviews are a systematic, comprehensive, and explicit approach to search, appraise, and synthesise primary studies. However, there are various aspects in a rapid review process that can be rationalised in order to comply with the limited timeframe of such a review. These aspects, according to Harker and Kleijnen (2012), include:

- restricting the literature search by limiting the language, date, geographical context, and setting of the publications, and/or the number of databases searched, as well as searches of unpublished literature;
- limiting the timeframes for the studies to be retrieved and appraised; and
- limiting aspects of the review such as the screening of titles and abstracts or full text, data extraction, and critical appraisal.

Furthermore, available literature was retrieved by the researcher to determine if it is relevant, and irrelevant literature was excluded (Bambra, 2009).

1.6.2 Data collection

In order to appropriately identify available literature, the research follows five distinct, standardised phases, namely:

- search for keywords and search criteria in databases;
- critical appraisal of compliance with keywords, inclusion, and exclusion criteria;
- critical appraisal of quality of selected studies;
- extraction from the final group of selected articles; and
- data analysis.

These phases assist in limiting the data to be extracted (Schünemann & Moja, 2015).

1.6.2.1 Phase 1: Search for keywords in databases.

The following keywords were used to conduct the initial search:

- Experiences, perceptions, narratives, attitudes, views;
- Families, parents, mother, father, guardian, caregiver;
- Raising, upbringing, raise, caring, care;
- Autism, ASD, autism spectrum disorder, Asperger's, Asperger's syndrome, autistic disorder; and
- Child*

The following databases were consulted: Science Direct, Medline PubMed, SocINDEX with full text, Academic Search Premier, Psych INFO, Scielo, Emerald Insight Journals, Sage Journals Online, Directory of Open Access Journals (DOAJ), Africa-Wide Information, MasterFILE Premier / EBSCO, EBSCOhost CINAHL with Full Text / EBSCO, EBSCOhost Applied Science & Technology Source / EBSCO, and EBSCOhost ERIC.

1.6.2.2 Phase 2: A critical appraisal of compliance to keywords, as well as inclusion and exclusion criteria

The researcher and primary study leader independently reviewed the titles and abstracts of all initially selected studies in order to decide which ones should be included for further analysis. Due to there not being any disagreement in terms of which articles to include, there was no need for a third reviewer.

The searches were limited to studies in English, which were published between 1 January 1980 and 31 December 2018, as this is the timeframe chosen for this rapid review. This is based on the publication of infantile autism in DSM-3 during the year 1980 (APA, 1980). Thereafter, research started exploring this phenomenon more. It is interesting that in 1981 Lorna Wing changed the term “autistic psychopathy” to “Asperger’s syndrome” as she described it as a disorder separate from autism but on the same spectrum (Wing, 1981). In 2013, the APA integrated all of the abovementioned disorders into one diagnosis, namely ASD, with specifications with regard to the patient’s support needed for social communication and repetitive behaviours.

The target group of participants used for this study was the parents/caregivers of any autistic individual under 18 who is seen as a legal minor, and who is not fully capable of acting independently without assistance from parents or legal guardians (McGoldrick, 1991).

The inclusion criteria were as follows:

- *Full-text journal studies*, as they would ensure that no key aspects of the literature were omitted.
- *Peer-reviewed studies*, as they would add to the credibility of the study.
- *Published doctoral theses*, as they would be reliable and valid sources of information.
- *Published master’s dissertations/mini-dissertations*, as they would be reliable and valid sources of information.
- *Quantitative studies*, as these studies are empirical in nature and would contribute to answering the research questions.

- *Qualitative studies*, as they provide empirical evidence, which in most incidences is of explorative nature.
- *Mixed-methods studies*, only the qualitative section (Findings) of the study

The exclusion criteria were as follows:

- *Non-peer-reviewed studies*, as the purpose of this study is producing scientific findings, and some of the non-peer-reviewed studies are not always proven to be scientific in nature and could hamper the study as a result.
- *Review studies*, as the duplication of results may affect the credibility of the study.
- *Conference proceedings*, due to the time limit of the rapid review, as they require hand searching.

1.6.2.3 Phase 3: Critical appraisal of the quality of the selected studies

This phase focuses on the appraisal of the selected of full-text articles. These are assessed independently by the reviewer and supervisor. The following instruments were combined to guide the critical appraisal process: The Critical Appraisal Skills Programme (2018) and the Joanna Briggs Institute (2014) used for qualitative studies, and the Joanna Briggs Institute (2014) used for quantitative studies.

This assisted in ensuring that each study is scientifically based, properly designed, and had been appropriately executed. Articles selected during this process are reviewed and synthesised. The integrated appraisal instrument consisted of the following questions:

- Clear statement of the aims of the research?
- Research received ethical approval?
- Valid and reliable measurement?
- Data analysis sufficiently rigorous?
- Sample is representative of the population?
- Bias has been minimised in the selection of cases?
- Clear statement of findings?

1.6.2.4 Phase 4: Data extraction.

The following data were extracted from the final selected articles:

- Author(s);
- Title of study;
- Year of publication;
- Type of publication (journal, article, book chapter, etc.);
- Research design;
- Sample method and sample size;
- Sample description;
- Data-collection and data-analysis technique;
- Findings on experiences of raising an autistic child; and
- Recommendations and/or guidelines regarding further research and practice.

1.6.2.5 Phase 5: Data analysis

A thematic synthesis approach is used inductively. The researcher analyses the findings of the selected studies and combines them to identify the themes that emerged. This process assists in identifying patterns and providing a detailed interpretation of the data (Clarke & Braun, 2013). Braun and Clarke (2006) suggest the following six steps to perform thematic analysis:

- 1) acquainting oneself with the data;
- 2) generating preliminary codes;
- 3) identifying;
- 4) reviewing;
- 5) defining and labelling the themes; and
- 6) reporting the findings.

The application of the above phases directs the researcher in terms of comprehensively analysing, comparing, summarising, and synthesising published findings. This summarised and integrated information is found to be very valuable in order to answer the research questions and to add new knowledge to the field of psychology.

1.7 VALIDITY AND RELIABILITY

Grant and Booth (2009) suggest that rapid reviews should aim to be of high quality, rigorous, systematic, and clear and transparent about the methods used to conduct the review. In order to uphold this suggestion, validity and reliability were promoted by taking the following into account in the research process: 1) thoroughly planning the research process and following the steps carefully and reflexively, 2) thoroughly and systematically conducting the search and

appraisal process, and 3) documenting in a clear and transparent manner the steps that were taken and the decisions that were made with regard to the research (Tricco et al., 2015).

Lastly, the use of two independent reviewers assisted in ensuring that the study was rigorous and contributed to upholding trustworthiness. Furthermore, a critical reflection of the whole research process was conducted, which is included as part of this mini-dissertation in Section 3.

1.8 ETHICAL CONSIDERATIONS

Ethical approval was obtained as outlined by the Ethics Committee of the North-West University, Potchefstroom campus. In order to ensure an ethical and accurate process, the researcher adhered to the ethical principles as noted by Wager and Wiffin (2011), by focusing on avoiding redundant duplication and plagiarism and ensuring transparency in the findings and the accuracy of the results. To prevent possible plagiarism, the researcher and study leader observed the APA referencing guidelines, as well as submitting the dissertation to Turnitin, which is a software program designed to detect plagiarism.

Furthermore, any possible bias in the selection of studies was reduced by identifying inclusion and exclusion criteria beforehand and through the usage of critical appraisal. Due to the method of the research and it not being empirical in nature, no participants were physically required and no harm in a physical, psychological, or legal manner was therefore caused by the study. The foreseen benefits of this study will assist in increasing insight into the experiences of raising an autistic child. The benefits of this study therefore outweigh the risks, as measures were put in place to counter foreseeable risks. Lastly, no conflict of interest was reported.

1.9 CONCLUSION

To conclude, this section consisted of a comprehensive literature overview, which enables the reader to understand the methodology and its suitability as outlined in the initial research proposal of this study. In addition, the essential constructs used in the study were contextualised in an attempt to give the reader better insight into these constructs. This literature overview therefore served as an introduction to the research study, which is reported on in the research article (see Section 2).

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SECTION 2:

THE EXPERIENCES OF FAMILIES RAISING AN AUTISTIC CHILD: A RAPID REVIEW

ABSTRACT

Background: Autism is becoming more prominent in South Africa and in the rest of the world. The family that raises an autistic child plays a key role in the treatment and lifelong management of the child. This responsibility goes with demanding challenges, which are unique to every child and situation. A deeper understanding of the psychosocial experiences and impact of autism and its symptoms on the involved families is ultimately essential in the development of relevant and scientifically based interventions and support programmes.

Objectives: The aim of this study was to conduct a rapid review to explore, synthesise, and integrate existing scientific literature on the pre- and post-diagnostic psychosocial experiences of families that raise an autistic child.

Methods: A comprehensive and systematic keywords search was conducted and 142 relevant studies were found. These studies were then screened for their relevance with regard to inclusion and exclusion criteria. Nine articles, published between 2008 and 2018, were identified for final inclusion in the study. Data were analysed using a thematic synthesis approach.

Results: The thematic synthesis revealed ten themes that were anchored on families' psychosocial experiences of raising an autistic child, both pre- and post-diagnosis. The themes include psychological experiences (emotions experienced, grieving process, parenting, and family dynamics), social experiences (lack of support services, and social awareness), and psychosocial coping strategies (isolation, information seeking, meaning-making, and support system).

Conclusion: The analyses and synthesis of the identified articles indicated that the identified psychosocial experiences of families that raise an autistic child were multidimensional and fit well within a contextual and systemic perspective. It is clear that the psychosocial wellbeing and quality of life of these families, together with the contextual systems involved, are increasingly becoming the focus of research attention. The family quality of life (FQOL) framework provides a positive approach that seeks to improve and optimise the quality of life of families that raise a child with a disability. The psychosocial themes identified in the analyses and synthesis of the identified articles fit in the conceptual fields of the FQOL framework, namely individual concepts, family unit concepts, procedural concepts, and systemic concepts. A deeper and better

understanding of the psychosocial experiences of families that raise an autistic child within these various concepts is essential in informing scientifically sound intervention and support programmes.

INTRODUCTION

Autism is becoming more prevalent both internationally and in South Africa.^[1] Globally, one in every 160 people is estimated to be living with autism spectrum disorder (ASD).^[2] Scientifically sound, accessible, and relevant support services have been indicated as a definite need of families that raise an autistic child.^[3,4,5] A deeper and better understanding of the impact of autism and its symptoms on the involved families is indicated as essential to the management of the child and family as a whole.^[6,7,8]

ASD is characterised by persistent difficulties with social communication and interaction, as well as the presence of restricted and repetitive behaviours, interests, or activities.^[9] These difficulties have a significant lifelong impact, not only on the development of the individual, but also on the family.^[10] A study conducted by Nealy, O'Hare, Powers, and Swick^[11] explains that the impact of autism on a family is significant and is experienced on mainly two levels. The first level is pre-diagnosis, where the unknown and uncertainty about what is going on are prominent. The second level is post-diagnosis, where the uncertainty and apprehension of what the diagnosis entails and what will happen next are prominent. Families are an integral part of the management of these experiences as they normally are the first to detect symptoms and make choices about early interventions.^[12] What complicates this experience is the fact that there is no single behaviour indicative of autism, nor will any child show all of the disorder's deficits at any given point in time.^[13] There is thus not one set of guidelines or rules that will work for each autistic child, which intensifies the burden on the family to find a unique solution to their child's specific needs.

In order to effectively treat children with autism, it is important to first diagnose effectively.^[13] The recent global increase in the prevalence of autism is in a large part attributable to changes in reporting practices.^[14] This may be due to better awareness and the broadening of diagnostic criteria.^[15] However, early diagnosis of autism remains rare, especially in certain disadvantaged communities.^[16] This is exacerbated by the fact that indications of most spectrum diagnoses and the essential symptoms are unfortunately only noticed around the age of six years and older.^[17] A study^[18] by McKenzie et al. (2015) found that prior to diagnosis, many families may suspect something is not right with their child, but they do not report their suspicions due to lack of

knowledge and understanding of normal developmental patterns, as well as of autism and its symptoms.^[19,20]

According to Meirsschaut, Roeyers and Warreyn,^[21] the fact that ASD is still considered an unusual disorder has a significant impact on families' reaction to the diagnosis, as well as the post-diagnostic management of the child. Studies^[22,23] indicate that post-diagnosis, the economic and educational status of the parents play a vital role in the management of ASD. Parents from low-income households with limited education may not fully understand the developmental challenges their child is experiencing.^[22,23] Additionally, professional help or assistance might not be readily available or accessible, which has disadvantageous effects on several areas of family functioning, such as adding extra strain on the parents (individually), marital relationships, as well as sibling relationships.^[24] This highlights the need for scientifically based and effective early interventions that will give relevant support also in under-resourced communities.

It is clear that autism has a significant impact on the psychological and social experiences of caretakers and families that raise an autistic child. The psychological impact on caretakers and families includes denial, emotionality, misinterpretation of the diagnosis, anger, disinterest, and dislike, and uncooperativeness towards the professional.^[12] Nissenbaum, Tollefson, and Reese^[19] add that parents of children with autism have a greater risk of suffering psychological distress as they experience increased stress, depression, parental burnout, concerns about their child's dependency, the effect on family life, poor physical health, and future psychosocial problems.^[12] Furthermore, a lack of applicable and relevant educational resources (schools, teachers, and learning material) and support also add to the emotional strain of the parents. Few schools are accommodative of children with autism, which results in most children with autism remaining at home, which places their education as the sole responsibility of their caregivers.^[22,25]

The social impact on the family is mainly based on the reaction from friends and extended family members. Poor societal awareness causes families to feel judged and isolated because of their child's diagnosis/condition.^[16,20] It is also indicated that raising an autistic child results in families giving up normal family routines and socialisation practices, as well as having difficulty maintaining employment.^[26,27] Over and above the aforementioned challenges faced by families of children with autism, limited sensitivity and accessibility in the public health and education sectors in Africa and South Africa intensify the parents' experiences of not being understood or helped.^[3,28]

In South Africa, it is indicated that one in every 86 children from the Western Cape is affected by autism.^[6] Few studies have been conducted in the rest of South Africa or even sub-Saharan Africa, but as autism is said to be found in every ethnic and social group, it can be predicted that it is unlikely that the statistics will be any lower in other provinces.^[3,7,8] It was also found that in South Africa, cultural explanations and interpretations of certain spectrum symptoms complicate the diagnostic and treatment processes. These cultural prejudices play an important role in the psychosocial experiences of the involved family.^[33] Some of these beliefs include the belief that the child's illness was brought about by ancestors as punishment for the family's wrongdoings or that the child's behaviour is linked to potential messages from their ancestors, while other beliefs link their child's symptoms to supernatural causes or ascribe the illness' causation to external supernatural forces.^[34] While most parents explore different cultural methods of diagnosing and healing with the aim of gaining a better understanding of their child's functioning,^[33] several studies suggest that 60% of the South African population would rather make use of traditional medicine and consultations with traditional healers in an attempt to gain a better understanding of their problem.^[35,36]

South African families that raise an autistic child are reportedly experiencing significant challenges in terms of proper intervention programmes and educational services.^[3,29,30] This has resulted in a high level of dissatisfaction with the disability-related government support, which includes health, financial, and psychological services.^[30] Families are left feeling as though they are isolated, alone, and in a state of 'crisis'.^[31,32]

Taking the abovementioned statistics and information into account, it could be deduced that a high number of families in South Africa are faced with unique challenges in caring for children diagnosed with autism.^[37] These families need appropriate and relevant services based on relevant and scientifically sound knowledge.^[38] An integrative understanding of the experiences of these families is therefore critical, as it provides insight into their unique challenges, daily realities, and the impact of autism on family dynamics. This study focused on integrating what previous studies have found to be the pre- and post-diagnosis psychosocial experiences of families affected by the diagnosis of autism, internationally and in South Africa. This information will be valuable in informing mental healthcare providers in the development and implementation of appropriate and much-needed support services and intervention plans. The research questions for this study were as follows:

- 1) What are the pre- and post-diagnosis psychological experiences of families that raise an autistic child?

- 2) What are the pre- and post-diagnosis social experiences of families that raise an autistic child?

RESEARCH METHODOLOGY

A rapid review was conducted to answer the research questions. This consisted of systematic and explicit search and review methods that enabled the reviewers to identify, select, and critically appraise relevant studies to include in this study.^[39]

Search strategy and selection criteria

A rapid literature search was conducted. EBSCO Discovery Service (EDS) provides access to national and international books, journal articles, and online resources from more than 60 databases. This includes databases such as Academic Search Premier, PsycArticles, PsycInfo, and Science Direct. The abovementioned databases contain accredited articles and provided the researcher with broad access to relevant scientific literature. Google Scholar was also used as one of the search engines to ensure thoroughness.

Search string

Level 1 (Title): experiences; perceptions; narratives; attitudes; views

Level 2 (Abstract): families; parents; mother; father; guardian; caregiver

Level 3 (Abstract): raising; upbringing; raise; caring; care

Level 4 (Abstract): autism; ASD; autism spectrum disorder; Asperger's; Asperger's syndrome; autistic disorder

Level 5 (Abstract): child*

Selection criteria

Full-text journal studies, peer-reviewed studies, review studies, PhD theses, and master's dissertations/mini-dissertations were included. Non-peer-reviewed studies, conference proceedings, and studies published in languages other than English were excluded. The search was limited to studies published from 1980 to 2019, because the first DSM that included infantile autism was published in 1980.^[40] However, the search string only produced studies published between 2000 and 2019.

The search string and criteria produced a total of 142 results of potential studies. The researcher screened the 142 article titles for relevance, after which 140 studies were identified with relevant titles. Of that 140, 106 studies were excluded due to inapplicability to the review question.

The abstracts of the 34 studies that remained were then independently reviewed by the researcher and the study leader/co-author. This was done to select those to be included for further analysis. Of the remaining 34 studies, 14 studies were further excluded due to them not meeting the inclusion criteria or being irrelevant to the research question. Studies excluded only explored one theme and did not encompass the whole experience, such as the role of stigma, sibling relations, and cultural perceptions. This resulted in 20 studies remaining, which were independently and critically appraised by both the researcher and co-author. A further 11 studies were excluded during the appraisal process due to poor quality of research methodology or ethics. Finally, nine studies were identified as studies that would be reviewed to explore the research question.

Appraisal process

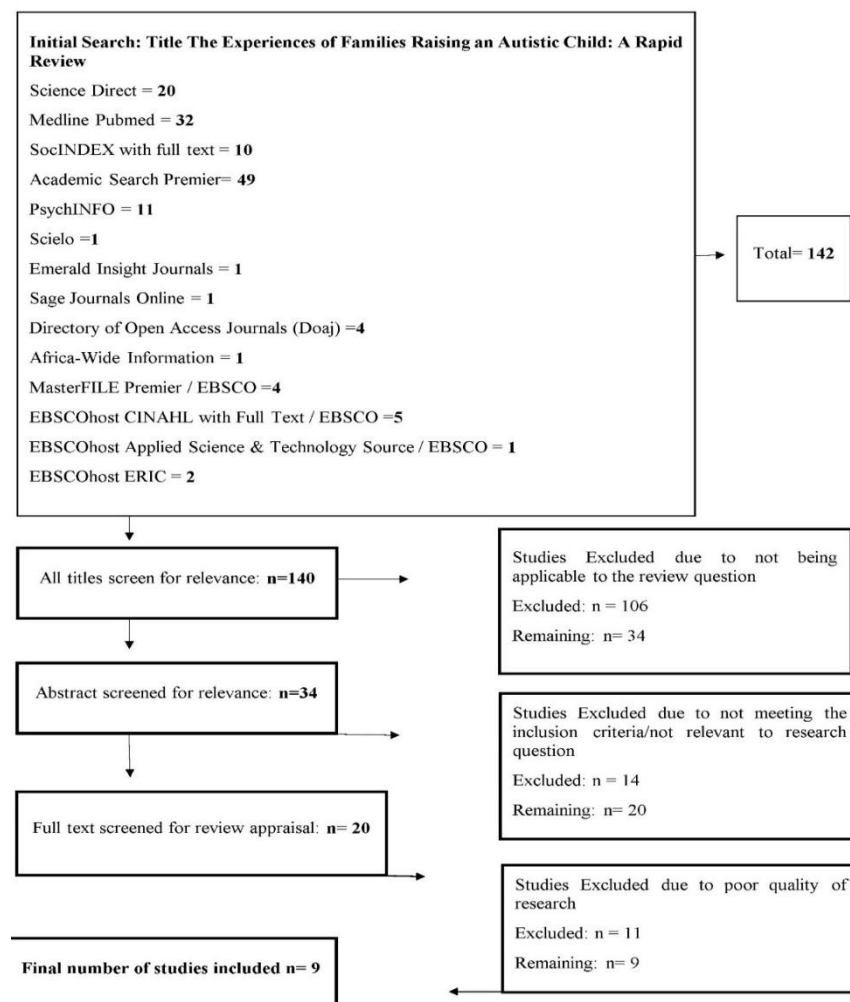
In the appraisal process, the guidelines as provided by the Critical Appraisal Skills Programme (2018) were integrated with the guidelines of the Joanna Briggs Institute (2014) for qualitative and quantitative studies. The integrated appraisal instrument consisted of the following questions:

- 1) Clear statement of the aims of the research?
- 2) Research received ethical approval?
- 3) Valid and reliable measurement?
- 4) Data analysis sufficiently rigorous?
- 5) Sample is representative of the population?
- 6) Bias has been minimised in selection of cases?
- 7) Clear statement of findings?

The 20 articles were independently appraised by the two researchers. Articles that were considered of high quality were given a score of above 5. However, most studies chosen for the study were scored 7, with the highest scoring 8, by both reviewers using the appraisal checklist. The two researchers compared their scores for the identified articles and came to an agreement on which articles should be applicable and relevant to include in the review. No disagreements occurred between the two reviewers and it was therefore not necessary for a third party to be engaged to assist in reaching consensus. Only articles that sufficiently qualified were included in the analysis as reflected in Figure 1. Upon application of a rigorous search, exclusion, and

appraisal process, a total of nine studies remained to be explored, reviewed, and analysed in order to answer the research question. The whole process of selecting the final nine studies included in the study is reflected in Figure 1.

Figure 1: Selection process



Data synthesis and analysis

A thematic synthesis was conducted in order to inductively analyse the findings from the nine retrieved studies. Thomas and Harden's (2008)⁴¹ steps were used in order to do this. These steps involved becoming acquainted with the data and preliminarily coding the findings. Thereafter, themes were identified, reviewed, given their final labels, and described.

The data-extraction process was carefully planned in order to ensure that data were extracted accurately. For further contribution to the accuracy of the study, both the researcher and the study leader read all the included studies.^[41] This process was independently conducted by the researcher and study leader in terms of exploring, summarising, and synthesising the findings from the selected studies. The following three stages were followed: line-by-line coding of the

findings, organisation of findings into related areas to construct/descriptive themes, and development of analytical themes.^[41]

ETHICAL CONSIDERATIONS

As this study did not carry any risks, ethical clearance was sought from the Community Psychological Research (COMPRES) before the research commenced. Research approval was also obtained. In addition to adhering to the research protocol, the authors applied the guidelines provided by Wagner and Wiffen^[42] to ensure accuracy and transparency, as well as to avoid duplication, fabrication, falsification, and plagiarism. Validity and reliability were promoted by following the steps in the research process in a thoughtful and reflective way. Furthermore, only articles that received ethical clearance or served as no-risk studies were included in the review. In order to ensure the credibility of the data, crystallisation was utilised; this meant that more than one reviewer worked on the material as each reviewer has a different viewpoint, in order to discover similar themes.^[43] The use of two reviewers further ensured and enhanced the trustworthiness of the study.

The researcher and study leader worked together in the review process^[43] Appropriate citations were included in order to acknowledge the authors of the studies. Furthermore, the study was submitted to Turnitin software, which tested the study for plagiarism.

RESULTS

Study selection

The nine studies that were included in this study varied in sociocultural contexts and location. The families in the studies included mothers, fathers, and caregivers that raise a child diagnosed with ASD. The studies typically involved focus groups, in-depth interviews, anthropological fieldwork, and self-administrated questionnaires as the data-gathering methods. The autistic children in the identified studies were between low and medium functioning, and ranged between the ages of five and 18 years. The research designs of the articles included in the review can be outlined as follows: six qualitative designs, one mixed-methods design, one quantitative design, and one qualitative meta-synthesis. The studies included in this review used data from three different continents and five different countries, namely Canada, Ireland, South Africa, the United Kingdom, and the United States of America. It is interesting to note that three of the studies^[45,46,47] refer to the experiences of fathers in raising an autistic child. These studies are especially valuable as fathers' experiences were previously neglected and not considered.^[44] To

gain a holistic understanding of the whole family's experiences in raising an autistic child, it is important to incorporate the experiences of the mother, father, any other primary caregivers, as well as the siblings.

After analysing and synthesising the articles, the following themes and subthemes emerged from the data. These themes were identified against the backdrop of the research questions focusing on pre- and post-diagnostic psychological and social experiences of families that raise an autistic child (see Table 1).

Table 1: Themes

<i>Psychological experiences (pre- and post-diagnosis)</i>	<i>Social experiences (pre- and post-diagnosis)</i>	<i>Psychosocial coping strategies (pre- and post-diagnosis)</i>
• Emotions experienced • Grieving process • Parenting • Family dynamics	• Lack of support services • Social awareness	• Isolation • Information seeking • Meaning-making • Support system

THEMES FROM INITIAL CODING

Psychological experiences: Pre- and post-diagnosis

On a psychological level, the impact on caretakers and families that raise an autistic child is multidimensional.^[54] The analysed and synthesised literature indicated that on a psychological level, the families' experiences centred around a variety of emotions experienced, as well as the experience of loss/grief. This is also evident in the psychological effects of uncertainties about parenting roles and a psychological shift in terms of family dynamics.

It is interesting to note that the psychological experiences differ pre- and post-diagnosis. The pre-diagnostic experiences are often negative as the parents verbalise the emotional strain of uncertainty and fogginess in not understanding their child's behaviour.^[20,49,50] This process is also verbalised and compared to the process of losing their 'normal' and 'ideal' child and experiencing uncertainty with regard to what to do next.^[20] Post-diagnosis, they experience a loss of their ideal parental experience, which means adjusting their parenting style and an adjustment of their family dynamics.^[20] This then creates a shift from more negative emotions to more positive emotions, as families adjust to the child's condition and understand the child better.^[49,50] The abovementioned process is elaborated on in the following subtheme descriptions.

Theme 1: Emotions experienced

The emotions experienced by families that raise a child with autism are broad and extensive. The emotions also vary depending on the phase of diagnosis and treatment the family find themselves in. It is noticeable that emotions experienced during this process vary on a continuum from negative to positive.^[47,49]

Studies conducted among families indicated that pre-diagnosis, families experience vast negative emotions such as confusion and helplessness^[20,52] as they suspect that something is wrong with their child; however, due to the fact that physical features in autism are sometimes absent, families are faced with the inability to understand their child's behaviour.^[50,51] These difficulties include a lack of communication, inexplicable anti-social behaviours, and tantrums.^[40] All these generate high levels of anxiety, parental stress, as well as general psychological distress.^[46,47,48] Therefore, in order to attempt to make sense of everything, families start having numerous medical consultations with different professionals.^[52] This means that families must process different emotions attached to the process, which include feelings of confusion, anger, and helplessness.^[49,51] Although the idea of finding an answer gives a feeling of hope, the fact that the child has a problem that they might never understand results in further increased feelings of distress.^[45] The unfamiliar medical jargon and overwhelming amount of new information, combined with the difficulty of finding the appropriate and relevant support services, contribute to an overwhelming feeling of confusion, which causes parents to internalise blame and feelings of guilt.^[48,49,52]

Upon receiving the diagnosis of autism, it is indicated that families experience pronounced emotional distress, which includes shock, despair, and devastation.^[20,47,49,52] Studies have indicated that a lack of knowledge/understanding of the disorder, as well as the lifelong nature of the diagnosis, contributes to the fact that the news that they have a child with autism is viewed as 'devastating news' by families.^[20,45,51,52] Some parents reported total surprise and dismay as, according to them, their child did not display any usual behaviours that might be expected from children with autism.^[49,51]

After receiving a diagnosis, parents start to think about the causes of autism, which results in feelings of blame towards themselves.^[45,51] This blame is often wider than an individual experience as one of the studies indicated that parents also experience blame from society and people outside their family, including healthcare professionals.^[20,48] Cultural and religious beliefs also play a role as parents attempt to make sense of the diagnosis; these beliefs include

parents linking the cause to black magic and punishment from God, and often ancestral rejection for moving far from family or not performing certain cultural rituals for the child.^[51]

Thereafter, families start experiencing feelings of anger, depression, and despair. It was found that this anger was mainly directed at healthcare professionals,^[48,49,50,51] firstly for making a diagnosis, and secondly for not 'taking their concern seriously and acting sooner than later'.^[45] A study conducted by Woodgate, Ateah and Secco^[20] stated that in this phase, parents also experience feelings of loneliness and isolation. They describe raising an autistic child as 'living in our own world', their lives as 'an endless routine of treatments and therapy', and missing having what they describe as 'a normal life'.^[50,52]

It is also important to mention that some studies do mention some positive emotional experiences upon receiving the diagnosis, which include feelings of relief upon hearing the diagnosis, as they have something that explains their child's condition, which finally clarifies their concerns.^[20,48,50] Furthermore, studies indicate that post-diagnosis emotions are associated with greater levels of understanding and acceptance of the child's situation, as they become more patient and understanding, which allows them to experience more moments filled with joy.^[47,50,52] Studies have indicated that receiving the diagnosis is a stepping stone as it allows parents to begin coping with it and to reconcile any feelings of guilt they had pre-diagnosis.^[48,52]

Theme 2: Grieving process

The experience of grief and loss is prominent in the synthesis of the psychological experiences of families that raise an autistic child.^[20,46,48,49,51] It is indicated that the lack of knowledge about the normal developmental behaviour of their child, combined with the absence of any visual features of autism, makes it difficult for families to identify that there is a real problem with their child's functioning and behaviour. The gradual or sometimes sudden realisation that something is wrong creates a feeling of loss, which leaves the families to grieve and to feel that they are losing their child and cannot do anything about it.^[49,51,52]

Studies compare this emotional process to the Kubler-Ross stages of grief, which entail the different phases of denial, anger, bargaining, depression, and acceptance in pre- and post-diagnostic experiences of the involved families. It is important to note that these phases do not always follow in chronological order and that each individual will experience their grief uniquely.^[20,52]

During the pre-diagnosis stage, the absence of physical and medical symptoms and a lack of knowledge pertaining to normal development and autism often create a safe space of denial for

the families and caretakers.^[44,50] This involves families attempting to make sense of the child's behaviour by justifying the child's behaviour, e.g. 'The child is just too quiet', or comparing the child with other family members, e.g. 'The father was late to develop, yet still turned out fine'. Pre-diagnosis, families use denial as a defence mechanism to deflect the built-up anxiety that something might really be wrong with their child. After the diagnosis is made, the denial is used to soften the initial shock and to pretend that perhaps the diagnosis is not true or accurate.^[48,52]

In the next phase, families mention feelings of anger. This anger is mainly experienced due to feelings of frustration and helplessness because they do not know what they can do to assist their child.^[46,52,51] Some studies suggest that this anger is often directed towards the parents themselves for not being able to 'fix' their child^[20,45,51] and for not identifying the symptoms earlier to proactively help their child.

In the depression phase, it is indicated that parents go through a phase of severe sadness as they feel the loss of their ideal child and their ideal parental experience^[20] by 'mourning their normal child' and 'the life they envisioned'.^[47,49] Families express that instead of looking forward to their children going to college, getting a job, and becoming a spouse, families now face a future of economic, emotional, and family cohesion challenges.^[20,47,50] In one study,^[49] a parent defined the diagnosis as 'death in your family' and stated: 'You still have that person here, but something dies.' Other parents stated: 'Your world falls apart and what dreams you have for your child are gone.' Parents expressed the diagnosis as having a ripple effect, as the initial diagnosis was the time when the loss was felt the greatest, but the sense of loss continues throughout a lifetime, which is also felt by the family.^[20,48,50]

During the bargaining phase, families indicate that they start bargaining and asking questions with the aim of seeking answers to understanding and managing their child's problem.^[45] In some cases, this bargaining process is linked with existential questions with regard to religion, spirituality, and faith.^[20,45,51] Caretakers indicated that during this time they struggled with questions such as: 'Is my lack of belief in ancestral connection the reason for my child's behaviour?', 'Is my neglect of traditional and spiritual rituals the reason for my child's diagnosis?', and 'If I start to do everything my religion/God asks of me, will my child be healed?'^[49]

The identified studies indicated that the progression through the stages of grief guided the families to the finale phase of acceptance. Ultimately, most families come to accept the disability as being part of the family, therefore putting all other emotions behind them and working to better their lives and the lives of their children.^[20,45,48] Some even indicated that after moving

through all these phases of grief, they could eventually manage to find some true meaning in the fact of having a child with autism.^[45] Some families indicated that this phase of acceptance made them realise that ‘they had to go through the feelings of anger and blame so that they can get to a point where they accept their situation and can cherish moments of joy brought by their autistic child’.^[20] In the acceptance phase, families indicated that they experienced new energy and capacity to start exploring resources to assist their child.^[20,46]

Theme 3: Parenting

Research is clear on the fact that parenting children is challenging and psychologically and emotionally taxing on parents.^[22] When developmental difficulties and deviances are present, the pressure on the parents, as well as the challenges they must deal with, are even more exhausting.^[19] The analysed studies identified the knowledge of different parenting styles, the capacity to adapt, and the effective application thereof as mentionable psychological stressors to the parents and families of autistic children.^[20]

Pre-diagnosis, families expressed that due to indicators of the disorder often being unclear and vague,^[52] they did not modify their initial parenting style, which caused severe distress to themselves, as well as to their autistic child. The unpredictability and rigidity in their autistic children’s reaction towards their parenting attempts left them in a total state of uncertainty and increased vigilance.^[20] Post-diagnosis, families had to start adjusting their parenting style, with the aim of dealing with and managing the uncontrollable and/or unpredictable tantrums and aggression of their autistic child.^[52] They had to adapt and venture on unfamiliar terrain in attempting to deal with uncontrollable and unpredictable behaviour, and navigating their approach and style in search of answers.^[48]

In the beginning, families reported heightened levels of vigilance, saying that it felt as if they were ‘walking around on eggshells’.^[20] They wanted to meet their child’s needs and protect them from any form of distress, but really did not know what they were supposed to do. The analysed studies indicated that most parents reported that having a strict and predictable routine increased their watchfulness and preparation for anything^[48] and made it much easier to manage and predict their autistic child’s behaviour. These strict and predictable routines decreased the parental stress experienced and, according to a study by Kayfitz, Gragg, and Orr (2010),^[50] both mothers and fathers reported more positive experiences and lower levels of parenting stress. On the other hand, these strict and predictable routines also increased the psychological burden on the parents as they had to be prepared and consistent the whole time. They reported that it left no room for any daily changes and even normal mood fluctuations within themselves, and that they

had to change into ‘robots’ to keep their child safe and contained.^[48] In one study conducted among fathers, one father expressed that he viewed parenting an autistic child as ‘stressful, scary, very frustrating, but most amazing’.^[46]

In summary, the identified studies indicated that although the initial experiences of parenting an autistic child were very stressful and unpredictable, the positive rewards and outcomes when they tried something new were immeasurable. They indicated that they learned that adapting to new and creative ways of parenting was a valuable experience of growth for them as parents.

Theme 4: Family dynamics

On a psychological level, systems theory indicates that if one part of a system is malfunctioning or changes its patterns of functioning, it inevitably affects the whole system.^[53] In raising an autistic child, the initial pre-diagnosis lack of understanding of the child’s behaviour, as well as the mandatory adjustments and changes that occur post-diagnosis, inevitably impacts on the family’s daily interactions and dynamics.^[49] When analysing the data for this study, two main subthemes with regard to the affected family dynamics emerged. The first subtheme focused on the disruption of family cohesion, and the second subtheme focused on the time involved in raising an autistic child. Furthermore, engagement with extended family members is limited as the child’s unpredictable behaviour can result in family members isolating themselves from family gatherings.^[46,50]

During the pre-diagnosis phase, confusion and uncertainty result in families spending a great deal of time looking for answers and consulting with professionals in the process of attempting to understand their child.^[20,48] Family cohesion is disrupted as the time and energy that were previously used for one-on-one interactions with the spouse, other siblings, and family members are now solely allocated to the demands of understanding and seeking help for one child.^[52] Family cohesion and connection are directly impacted by this focused attention and the ripple effect thereof has an influence on various dimensions of family cohesion and functioning.^[48,49]

Post-diagnosis, the knowledge of what is going on and especially what autism is all about helps family members to understand why the sacrifices are being made and more clarity is gained on what each one’s role and expectations within the family system are. The reality, however, is still that many changes and adaptations must be made by all the other family members to accommodate one child. One father summarised this as follows in a study:^[46] ‘Everything is then focused around, um, the child with ASD, so the other kids in the family, or the family unit then basically has to conform to the needs of, or the demands then of [the child with ASD] ... And we

all have an element of, I guess, sacrifice when it comes to that.’ Parents reported their other children feeling as if they were not treated the same as the child with autism.^[48] It is, however, also indicated in the analysed studies that as families progress through the process of attempting to understand and adapt the system accordingly, they start realising the importance of having a life that is not solely focused on helping their child with autism develop to their full potential.^[48] They mentioned that there is a process where they become aware of the importance of creating a balance between parenting their autistic child and engagement with their other children and family members.^[49,52] Interestingly, it was reported that caring for an autistic child can also have some positive effects on family cohesion. A study^[46] indicated that mothers were often the prime carers and therefore had to sacrifice their professional life to take care of their child’s needs, while fathers worked long hours to take over the financial responsibilities of the family. Relying on each other and viewing their significant other as their ‘main, or sole, source of support’^[52] therefore assist in building family cohesion. In one study, parents expressed that as time progressed, the care for their autistic child became a team effort, thus enhancing family cohesion and meaning-making in the process of helping and guiding their autistic daughter/son/brother/sister. It is indicated that as the process of acceptance continues, the autistic child also finds their own unique role within the family, and the previously neglected siblings are often very protective and supportive of their autistic brother/sister. A new family identity is formed in the fact that they are different than other families, which further enhances family cohesion.^[20]

Within the second subtheme of time consumption it is prominent that the pre-diagnostic process of attempting to find answers takes up a great deal of family time. Days and hours are spent in the consultation rooms and test facilities of professional people and the whole family’s routine and schedules are organised around these appointments. Not only do the physical appointments take a great deal of time, but the proper preparations and arrangements to keep the autistic child calm and content to prevent build-up of frustration and meltdowns take a toll on the whole family, which directly affects time spent together and with other family members and siblings involved.^[48]

Upon receiving the diagnosis, it was interesting to note that parents started scheduling time for themselves as they indicated that they felt frustrated by the lack of time they had for themselves and their family, thus leaving them feeling overwhelmed by family demands.^[45] They expressed that scheduling ‘own time’ and ‘family time’ prevented them from feeling overwhelmed and built capacity for them to be able to deal with unexpected and difficult situations.^[48] One mother indicated in a study^[20] how valuable it was for their whole family when she scheduled her

autistic daughter's therapy sessions around her normal, developing son's hockey matches so that they could ensure that the whole family attended his matches and that organising and scheduling time made it possible for everyone in the family to attend.

Families expressed that autism affects both family cohesion and family time both pre- and post-diagnosis.^[20,49] Families therefore expressed a need to find a balance and making time not only for family members but for the caregiver as well. Autism is a lifelong diagnosis^[48,52] and creating and maintaining a balance within this context are crucial. It is also indicated that communication and relying on one another as a family have a valuable influence on family cohesion and each family member's experience of their sense of belonging.^[46]

Social experiences: Pre- and post-diagnosis

The literature is clear on the definite effect that raising an autistic child has on the social experiences of the family and caretakers involved.^[52] Social psychology theories emphasise the importance of social interaction, social coherence, and a feeling of belonging.^[53] When an autistic child is introduced into a system, all the levels of the system's functioning are impacted.^[22] Everything on a social level that was comfortable, familiar, and helpful to these families change because they are isolated and stigmatised and left in the dark to cope on their own.^[48] The social experience themes and subthemes that emerged from the analyses and synthesis of the identified articles are: (1) the lack of relevant and proper support serviced, and (2) a lack of general social awareness and stigmatisation. It was also interesting to note from the literature that proper social interaction, connection, and support were identified as some of the most powerful coping mechanisms in these difficult times.

Theme 5: Lack of support services

In the analysis of the identified articles, it was clear that families that raise an autistic child felt that on a social support services level, nothing came easy and that pre- and post-diagnosis they had to 'fight all the way to be recognized and to be helped'. They stated that they felt the government system (referring specifically to the health and educational sectors) was not geared to cater for people with autism, leaving them alone, isolated, and self-reliant.^[47]

Within the health sector, it was noted that as soon as they started realising that something was not right with their child (pre-diagnosis), they started searching for answers.^[46,47,49,51,52] This entailed countless appointments with different healthcare providers. In some cases, they immediately got the answers they needed;^[48] however, for the majority of parents the search for

answers took longer. Socio-economic status and the unavailability of proper diagnostic services and facilities resulted in general ignorance and incorrect or delayed diagnoses, which caused distress and feelings of helplessness and frustration that significantly influence the implementation of a proper scientifically based treatment plan for the child.^[20]

Within the health sector, it was stated that upon receiving the diagnosis, families were faced with a new set of challenges. The majority of the parents experienced challenges and difficulties in navigating the system.^[50] These challenges entailed receiving ineffective and unclear communication from health professionals.^[46,47,50,52] Lack of resources and proper support from the system placed families under extra financial strain where they had to pay out of their own pocket for services or drive long distances to access treatment facilities. It is interesting to note that the analysed articles make special mention of the significant distress fathers experience due to financial uncertainties, problems, and difficulties.^[46] It is also indicated that this experienced incompetence of the health sector resulted in caretakers and families doubting the competence, expertise, and commitment of the health professionals they had to trust with the treatment of their children.^[46,48,52,50]

Within the education sector, parents indicated their concerns regarding their child's future and proper school and educational facilities, resources, and support. Additionally, the availability of and access to a school that caters for children with autism is especially concerning.^[52] It was also indicated that the limited understanding of autism by teachers in schools made it difficult to resolve behavioural issues that originate from the disorder. This often results in conflict between teachers and parents where the family's parenting style is judged because of the teacher's own ignorance.^[47]

The analysed articles emphasised that the lack of support services families are faced with during pre-diagnosis has a significant impact on making a proper diagnosis and thus has a ripple effect on the treatment and efficient management of the child. Families are left frustrated and helpless, feeling alone in their fight to help and support their child. Post-diagnosis, the lack of proper and scientifically based support within the health and educational sectors puts an extra burden on especially families from lower socio-economic groups. This also results in families distrusting the competence and commitment of support workers within the health and education sectors, leaving these families to feel alone, isolated, and rejected by society, which forces them to do everything by themselves.

Theme 6: Social awareness

Social psychology theory states that if something is different, not conforming, and you do not have knowledge or understanding of why it is different, society will judge and reject it.^[54] These experiences of being rejected, stigmatised, isolated, and judged are on a daily basis in the foreground of what families that raise an autistic child experience. The lack of knowledge and social awareness of not only the broader community and society but also of even extended family members has a significant influence on the social functioning of these affected families.^[48]

Pre-diagnosis, families indicated that they experienced stigmatisation and prejudice from society, as well as family members, pertaining to their child's behaviour.^[20] Prejudices experienced by parents were mainly informed by incorrect conceptions of normal development, as well as different cultural beliefs regarding the aetiology of a child's behaviour, which resulted in parents becoming exhausted and vulnerable to societal judgment.^[51] Thus, not only is their child judged but also the parents' parenting style and relationship with their child. It is further noted that even when the family makes an effort to navigate their way in obtaining understanding of their child, they are faced with further judgement from family, society, and professionals, including statements on their 'lack of awareness of their child's behaviour at an early stage' and 'how their ignorance caused their child severe distress'.^[20,49] Some of these isolating and marginalising experiences include incompetent and unsupportive professionals not providing the appropriate resources and support needed. In these instances, the families experienced that the professionals compensated for their incompetence by judging the parents' parenting style and self-developed attempts to understand and help their child.^[44,48,47] Families expressed that constantly having to fight the system and the stigma that accompanies autism made them experience a sense of helplessness as they are constantly labelled and marginalised.^[48]

Upon receiving the diagnosis, families expressed that they endeavour on the route with extended family members and communities not to judge and label but to rather attempt to gain knowledge and understanding.^[49,51] Raising awareness and advocating for people with autism become the responsibility of the affected families on their own, with very little support and help from the system and the government.^[45,47,49,51,52]

Lack of social awareness regarding autism results in families constantly being judged and stigmatised, not only by the community but also by extended family members. To take your child with you to the shop or to a social gathering always poses a risk of ending in disaster and you as well as your child being judged and labelled. A lack of social awareness, empathy, and

acceptance leads to these families living a life where they find safety and acceptance only when they isolate themselves from the eyes and tongues of society.

Psychosocial coping strategies

With the abovementioned experiences in mind, it is clear that families that raise an autistic child experience a different dimension and level of parenting stress. People respond to stress with different coping strategies.^[57] It was interesting to note that in the analysis of the identified studies, the integration of the psychosocial experiences of these families naturally leads to the identification of certain psychosocial coping strategies that these families developed and used to survive day in and day out. Both mothers and fathers reported that if they could manage to decrease their parental stress, they would be able to experience and report positive experiences and interactions not only with their autistic child, but also with their other children.^[20,45,49,50] The four main coping strategies identified are isolation, information seeking, meaning-making, and establishment of a support system.

Theme 7: Isolation

In the first subtheme, parents indicated that they found that pre-diagnosis and before the implementation of an applicable intervention strategy, they used isolation from social settings to protect their child and to decrease their own parental stress. Parents expressed that isolation is, however, a consequence of having to invest time and energy in supporting their children.^[20,46] Parents therefore opted to stay in familiar surroundings where routines could be maintained. In a study,^[58] one parent expressed that ‘people tend to be ignorant and if you listen to them and what they say, so we tend to be very closed off now, me and the wife don’t really mix with anybody’. The analysed studies indicated that due to a lack of awareness of autism and what it entails, they experienced people as rude, unsympathetic, and judgmental about their child’s behaviour.^[48] The families indicated that they resorted to isolation; describing it as a consequence of having to invest time and energy in supporting their child and that they did not have the energy to also attempt to manage society’s perceptions and judgements. They indicated that they found that with isolation it was possible to protect their child and manage the child’s behaviour by choosing familiar and predictable surroundings where routine can be maintained.^[48,49]

Theme 8: Information seeking

In this second subtheme, the families used information seeking and the gathering of relevant and scientific information to empower themselves. In one of the studies conducted,^[20] several parents

indicated that they took formal courses on autism in order to understand more about the diagnosis and to learn how to work with their child at home. This assisted families in maintaining some sense of control over the diagnosis, to protect them from feeling helpless and to increase their feeling of self-efficacy.^[49,52] It also increased the families' sense of resilience. One parent^[48] confirmed this by stating: 'It is not as bad as all that and once you know about it and you can learn to deal with it, it is not a death sentence.'

Theme 9: Meaning making

The third subtheme, namely to create meaning, is very closely related to the second subtheme of seeking information. It was interesting to note that one of the most powerful benefits of more information and knowledge was the fact that it empowered and assisted parents and families in developing a greater appreciation of the smaller milestones performed by their autistic child. Knowledge helped them to understand how much bravery and effort small daily tasks and accomplishments took from their child and assisted them in preserving and developing a sense of hope. The families indicated that seeing and being aware of the small changes and milestones in their autistic child's behaviour guided them to a new view of what life and success are about and actually finding meaning in and a new viewpoint of their child's diagnosis.^[52]

Theme 10: Support system

The fourth psychosocial coping mechanism identified was the establishment of a safe and understanding support system. The identified studies showed that families that raise an autistic child found it very valuable to engage with other families that raise an autistic child. It is indicated that they found psychosocial support in exchanging information and discussing a range of issues and shared concerns and challenges. Some of the main topics where their common experiences were especially valuable were topics such as learning how to navigate the system (health and education), as well as guidelines and recommendations for interacting with various professionals.^[48] The families experienced this support as an opportunity to share problems and provide one another with emotional and practical support not understood by typical families and well-equipped professionals. This instilled a sense of confidence in families about their parenting, providing a sense of 'relief and hope', and above all forming connections and making friends.^[20,50,52]

Some of the families indicated that they also received support from their close family members, such as spouses.^[20,46,50,52] This made them feel that they were not alone and helped them to feel comfortable to reach out and support those around them.^[51] Their family's support and

acceptance helped the families to make time for themselves as they could engage in recreational activities such as writing poetry, exercising, art, and embracing the concept of 'me time' when they knew there was somebody who would look after their autistic child.^[48]

Research confirms that raising an autistic child provides intense and unique challenges that put the involved families under severe psychosocial stress. The analysis of the identified studies indicated that in dealing with this stress, families developed certain psychosocial coping mechanisms to help them cope with difficult circumstances. These coping mechanisms include using isolation to protect their child and themselves, seeking information, finding meaning in the diagnosis, and establishing an understanding, accepting, and reliable support system.

In summary, it can be concluded that the psychosocial experiences synthesised from the identified studies indicate that the main psychological experiences of families that raise an autistic child are a variety of emotional responses, a feeling of grief and loss, parenting challenges, and changes in the family dynamics and cohesion. On a social level, the main experiences reported were the lack of support services and how the lack of social awareness leads to the burden of stigmatisation and uninformed prejudice. Families used psychosocial coping mechanisms such as isolation, seeking information, meaning-making, and the establishment of a support system to lower their parental stress and to open themselves up for experiencing positive moments.

DISCUSSION

The objective of this article was to explore the pre- and post-diagnosis psychosocial experiences of families that raise an autistic child. The analysis and synthesis of the identified articles indicated that the identified psychosocial experiences of the families that raise an autistic child were multidimensional and fit well within a contextual and systemic perspective. It was interesting to note in the results how the various contextual systems (individual, micro-, meso-, exco-, and macrosystem) interactively influence one another and play an integral role in the psychosocial experiences of not only the autistic individual, but also the family and caretakers as part of the microsystem. The integral role that families play in raising an autistic child is increasingly acknowledged and confirmed. The family is the primary support system for these children and the responsibility in this regard stretches over a lifespan. It is clear that the psychosocial wellbeing and quality of life of these families, together with the contextual systems involved, are increasingly becoming the focus of research attention.^[30] The family quality of life (FQOL) framework had its origin^[57] in this focus.

The FQOL framework provides a positive approach that seeks to improve the quality of life of families that raise a child with a disability. FQOL focuses on the “goodness of life” or the ‘conditions where the family’s needs are met, and family members enjoy their life together as a family and have the chance to do things which are important to them’.^[58] It is a multidimensional framework measured by indicators common to all families that make provision for both internal dynamics (cohesive family interactions), as well as external support, resources, and dynamics.^[30] This framework is a good fit for the integration and synthesis of this study’s results as it underlines this study’s argument that a better understanding of a family’s psychosocial functioning and experiences is important for the effective management of not only the affected individual but the family system as a whole as well. The outcome of the FQOL approach is that proactively supporting families with children with disabilities can build capacity and skills for them to deal with challenges and adversities. It is further indicated that a family that is living an optimal and quality life within their home and community will be able to contribute to the ongoing stability of society as a whole.^[58,59,60] This framework pays attention to a family’s quality of life by focusing on the following four concepts: (1) individual family member concepts, (2) family unit concepts, (3) performance concepts, and (4) systemic concepts.

The FQOL framework proposes that these four concepts interact with one another and that singly or in combination these concepts predict a family’s quality of life, which can be used to identify the family’s strengths, needs, and priorities to focus on. The first FQOL concept is the individual family member, which refers to aspects of the involved individual family members’ demographics, characteristics, experiences, and beliefs.^[59]

In the analysis and synthesis of the identified studies, the main individual family member concepts that influenced the families’ quality of life were the various emotions experienced by the parents and involved caregivers, with specific focus on the grief process and the experience of loss. It was interesting to note how the individual emotions experienced by families differed pre- and post-diagnosis. Pre-diagnosis, the uncertainty about what is going on and the helplessness accompanying the uncertainty were prominent. Post-diagnosis, feelings of guilt, self-blame, and sadness were prominent. The theme of loss was especially prominent as the families verbalised that they had an intense feeling that they had lost their ‘healthy, ideal child’ and all their dreams and hopes for him/her. Other identified individual family member concepts that influenced the family’s quality of life were the changes parents had to make in their parenting styles and how the child with autism affected the individual members’ experiences of family cohesion, family role changes, and the lack of time spent together as a family. It is clear that on an individual family member level, the challenges and adversities that affect the

individual family members' psychosocial wellbeing and quality of life are vast and intense. To balance these challenges, it is interesting to take note of the psychosocial coping mechanisms the families mentioned that helped them to cope and to strive towards a better quality of life. The main coping mechanism mentioned on an individual level was how they used isolation to protect their autistic child and themselves. It was also interesting to note how the gathering and seeking of information to improve their understanding and skills empowered these families. Their quality of life was enhanced by being able to focus on small milestones and finding new meaning in what life and success are really about.

The second concept is the family unit concept, which is the collective number of individuals who consider themselves to be part of a family and who engage in some form of family activities together on a regular basis.^[59] The reviewed studies indicated that a higher level of family distress was experienced pre-diagnosis as families had to adapt and venture on unfamiliar terrain in attempting to deal with unpredictable and uncontrollable behaviour that impacted on the whole family's functioning. The analysed studies indicated that this family distress resulted in over-vigilant parents attempting to monitor every move of the child.^[20,44,47,49] This, however, negatively affects the family dynamics as a great deal of attention and care are given to the child and less to other members of the family.^[44,48,51,52] Family resources and support are channelled to the child with the aim of protecting and understanding; however, it negatively impacts on sibling and marital relations.^[44,49,50] Research^[21,30,31,33] indicates that in the early developmental years of a child's life, the family is typically the primary environmental influence on a child, and this includes sibling relations. Studies^[16,19,23,27] further indicate that having a sibling with a developmental disorder can leave other children with feelings of confusion, isolation, and frustration. This also affects the parents as they are more prone to serious mental health problems and an overall decrease in wellbeing and physical health.^[12,21]

The family's social life is affected in this regard due to lack of awareness and knowledge pertaining to autism among the general public, which often results in families constantly being judged.^[48,44,48,52] Some parts of society ascribe the child's behaviour to external supernatural forces, meaning that they believe that the child's symptoms and behaviour are punishment from the ancestors or from God.^[33,34,36,50] With the aim of avoiding societal judgement, families therefore tend to isolate themselves from societal gatherings and start obtaining information with the aim of understanding their child.^[52] Studies^[48,51] further indicate that it is very common for the parents of children with autism to suffer from feelings of isolation and exhaustion due to society's lack of understanding and the stigmatisation of their child's behaviour. Families are therefore forced to give up their social lives, vacations, and personal dreams as their attention

shifts to assisting their child and gaining a better understanding of the child's behaviour.^[12] Regardless of the above, when families receive the diagnosis, there often seems to be a positive effect on those affected^[49] as the diagnosis offers a sense of relief. Due to families having a certain level of understanding and acceptance of the child's situation,^[20,52,48] receiving the diagnosis strengthens relationships, especially with their spouses. They start working together, which is emotionally rewarding and increases their emotional bond with their spouse, which results in the improvement of their parenting style and family dynamics.^[50,51,52] In the analysed studies, it was interesting to note how the families' quality of life was enhanced by building new support systems with other families with children with autism. The shared challenges and experiences gave a sense of belonging and acceptance that helped to enhance the general psychosocial wellbeing and quality of life of families that are raising an autistic child.

The third concept is the performance concepts, namely the formal services, support structures, and practices developed and offered to individuals with disabilities and their families.^[59] Services are a range of educational, social, and health-related activities expected to improve the outcomes for the individual or the family as a whole (counselling, medical/dental care, or therapies such as speech-language therapy). The reviewed studies indicated that the lack of resources and proper support from the system resulted in families driving long distances to access treatment facilities. Furthermore, families were faced with incompetence within the health sector, as some children were misdiagnosed, referred from one place to another without any answers, and ill-treated by professionals. This resulted in caretakers and families doubting the competence, expertise, and commitment of the health professionals they had to trust with the treatment of their children.^[48,52,50] The analysed studies indicated that they experienced that they had to 'fight' the system every step of the way, which had a definite impact on the psychosocial wellbeing and the quality of life of the family. This 'not helping' and 'not understanding' the families experienced from the indicated support services made them feel very alone and scared. It seems that families compensated for these feelings by equipping themselves with information on the disorder, raising awareness among communities and family members, and relying on reliable social support from friends and family members who assisted them in making meaning of the diagnosis.

Lastly, the systemic concepts entail a collection of interrelated networks organised to meet the various needs of society, such as healthcare, education, and legal systems (e.g. healthcare systems and policies).^[59] On a systemic level, it was clear that families experienced the available structures and policies within the health and educational sectors as lacking. Pre-diagnosis studies indicated that the lack of social support services, as well as proper knowledge and structures

within the health sector, affect the ability to obtain a proper diagnosis. This has a detrimental effect on the effective treatment of the child as a proper diagnosis is needed to guide proper and effective treatment. Upon receiving the diagnosis, families are faced with financial constraints as they must cater for the child's treatment, knowing that it is a lifelong commitment. Very few schools and educational facilities make provision for children with autism. Those that do make provision cost a lot of money, which leaves many families with nowhere to go to educate their children and develop their skills and abilities.^[62] On a societal level, these families are faced with stigmatisation and judgement on a daily basis. Society is not open to anything that is different from what they consider to be normal. They attempt to make it fit in by criticising and judging the parents' parenting style, as well as the cultural compliance of parents with certain beliefs and traditions. General lack of social awareness results in families feeling isolated and unwelcome in society due to their child's behaviour.

The FQOL framework indicates that these four concepts interact individually and in combination with one another to give an indication and a prediction of a family's possible quality of life and thus psychosocial wellbeing. With the abovementioned in mind, it is clear that families that raise an autistic child experience challenges on all four these levels. To address the psychosocial wellbeing of these families and to enhance their quality of life, it is important to pay attention to the specific challenges, needs, and opportunities on all four these conceptual levels.^[59]

Although South Africa is known for good policies and legislative frameworks, the implementation and operationalisation of these policies and visions prove to be a dilemma. Although some of these policies with regard to support to families with children with disabilities have been implemented, the large number of people who need to be helped by the few service points and healthcare workers available results in many families still needing assistance. Research^[62] furthermore indicates that children with mild to moderate disabilities are still being excluded from the grant service. In many instances this means that children with autism are excluded from the grant service, which creates a huge financial burden for the parents. A study^[30] conducted by Schlebusch, Dada, and Samuels in South Africa, which used the FQOL framework, found that families who received proper disability-related services were mostly satisfied with their family's quality of life, as they were receiving support. This suggests that families that do not receive or who are on the waiting list for support are likely to feel so overwhelmed and defeated that it influences their overall quality of life.

It can be concluded that autism is becoming more prevalent both internationally and in South Africa.^[1] Research is clear on the fact that the family that raises an autistic child plays an integral part in the effective treatment and management of the child's life and future. The identified and

analysed studies indicated that the psychosocial experiences of the involved families are unique and challenging. To optimise these families' quality of life, it is important to pay attention to the various FQOL concepts and to attempt to minimise the experienced adversities and to optimise the moments of wellbeing and meaning in each of these conceptual fields. Evidence-based, concise intervention programmes, based on the psychosocial experiences of families that raise an autistic child, are of the utmost importance in enhancing these families' quality of life. On an individual concept level, it is important to pay attention to the pre- and post-diagnosis emotional experiences of the affected families. Proper support and proactive counselling are important to assist with the helplessness before the diagnosis and the feeling of loss after the diagnosis. It is also important to facilitate the changes that are expected in parentings styles, family cohesion, and time spent together. In terms of the family unit concepts, the establishment of proper social support services and support groups for families and people who share the experience of the challenges of raising an autistic child will be very valuable. The deliberate implementation of social awareness programmes to protect families from stigmatisation and being judged will enhance quality of life on the family unit level. In terms of the performance concepts level, there must be clear communication and concise and consistent structure and lines of reporting and managing children with autism. Proper training and sensitising of the healthcare workers who are the first point of referral will make a huge contribution to the quality of life of these families. Lastly, in terms of the systemic concepts level, the evaluation of policies that are not implemented and utilised optimally will aid in ensuring that what we have on paper is also what is happening on the ground level. The need for proper and easily accessible educational facilities and support systems could be highlighted as a crisis for families that raise an autistic child.

Therefore, through using the FQOL framework for families that raise an autistic child, practitioners will be provided with ways to think about and work towards what brings fulfilment and joy to the families they serve through viewing the parent/caregiver as the 'expert'; during which time supportive resources must be made available in order to enable them to build their knowledge and understanding of the specific needs for children with autism. Furthermore, societal awareness and sensitivity need to be created if an autistic child is to be accepted and supported by society, and so that integration into society for families and autistic children will not be difficult.

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SECTION 3:

CRITICAL REFLECTION ON THE STUDY

3.1 INTRODUCTION

This study set out to summarise the best available research on the psychosocial experiences of families that raise an autistic child. This was done by conducting a rapid review on the available literature. After a proper literature search, applicable articles were identified. Thematic analysis was used to analyse, synthesise, and integrate the content of these articles. Ten themes of psychosocial experiences of families that raise an autistic child were identified. These identified themes could be valuable to inform interventions and support programmes aimed at enhancing the psychosocial wellbeing and quality of life of families that raise a child with autism. This section provides the researcher's critical reflection on the research process and focuses on personal reflections, as well as general reflections, on whether the study went as planned, whether the research aim was met, and whether the research question was answered. Attention is also paid to the identification of possible limitations and recommendations.

3.2 PERSONAL REFLECTION

My first encounter with autism was when I was practising as a social worker and a mother asked me, in Setswana, what doctors meant when they said her daughter was diagnosed with autism, as she did not understand what the doctors meant or what the problem with her child was. For me as a professional it was an embarrassment that I too did not know how to explain the condition to the mother in a way she would understand. Above all, I was empathic towards the mother because she was raising this child and did not understand what was wrong and how best to help her. I then took it upon myself to offer assistance to the mother, while also educating myself. This created an interest in autism that I pursued during my M1 year through research.

What fascinates me most about autism are the unseen symptoms of autism that can make it hard even for qualified professionals to diagnose it and even more difficult for families to "understand". How do families live with someone they do not understand? Imagine the emotional turmoil they must be going through; now imagine this whole situation within disadvantaged communities – where hospitals are not a short distance away, these children grow up "differently" and are misunderstood.

The strength these families must have to continue making the child a part of the family pre- and post-diagnosis and the sacrifices they must make are commendable. However, for me the true

strength lies within the autistic child, in their ability to be different and just wanting to be embraced.

During my master's year, we were properly introduced to the diagnosis and intervention models for autism. It was during my internship year at the Institute of Psychology and Wellbeing's Care2Kids programme when I got a real glimpse into the lives of families that raise an autistic child. At that point, I noticed that families of different backgrounds and races have one thing in common: they all want the best for their child and were willing to sacrifice everything to best assist their child and be better caregivers. They were not concerned about what people would say if they heard their child was autistic; all they wanted was to support their child.

I then attended the annual Autism Symposium in 2019, which assisted me in seeing that there are families that are surviving and making meaning of this unseen disorder, and embracing it as part of their daily lives, regardless of how difficult it was in the beginning. During the listening group technique conducted by Rumando Kok and Prof. Chris Venter, which explored parents' experiences with children diagnosed with ASD. Parents shared their experiences of having a child diagnosed with autism. What was interesting was that parents' experiences were similar to my review study. The themes included emotional experiences of shock and the effect on the family structure. Furthermore, families had to implement different methods to cope with the diagnosis. This shed light on my interest that families throughout the world have similar experiences and were all in need of support.

3.3 REFLECTION ON THE RESEARCH PROCESS

The research journey began with a research concept paper and a discussion of the research with the supervisor. At first, the plan was to conduct a qualitative research study on mothers with autistic children. However, due to the challenges of finding participants and obtaining ethical clearance, the researcher and supervisor agreed to change the research design and to conduct a rapid review instead. The rapid review enabled the researcher to systematically identify and critically appraise selected studies about the experiences of families that raise an autistic child (Arksey & O'Malley, 2005). Changing from a qualitative study to a review study was difficult as I had never conducted a review study before. Furthermore, I felt as though I would not be getting the "real" research experience. However, after the process was explained to me, I understood that studies were based on real subjects' experiences throughout the world. It brought hope, especially as I would be exploring a larger population's experience. Furthermore, I did not have to change my research topic drastically as I would still be exploring my interest in autism and families' experiences, but using a different methodology.

The first step for the rapid review was to conduct a thorough literature search using the North-West University's (NWU) database, the EBSCO Discovery Service (EDS) search portal. This was done in collaboration with the NWU librarian dedicated to health sciences, Mr Nestus Venter. This process helped to give direction to the next phase, which was the conceptualisation of my study and the drafting of my proposal. Making the shift from a qualitative study to a review study in terms of drafting the proposal was not as difficult, as I had already familiarised myself with literature on autism. The proposal was presented to the internal scientific small group, as well as the school's Community Psychological Research (COMPRES) group. Certain changes were suggested, after which final approval of the study was obtained from the small group, as well as COMPRES.

The retrieved studies were then screened for their relevance to the inclusion and exclusion criteria. Critical appraisal of the identified articles was based on two set guidelines, and eventually identified nine articles, published between 2008 and 2018 for final inclusion in the study.

The data were analysed using a thematic synthesis approach. In this process, while grouping the themes, I at first empathised with families and the difficulties they face with not understanding what was wrong with their child. The themes allowed me to realise the need of parents to be supported, as well as how the lack of awareness by society contributed to parental stress and alienation. Seeing the study come together through these themes was amazing; however, what was more amazing was that these were experiences from families all over the world. They had one common need, namely support, which assisted me in drafting my recommendations for further research and intervention strategies.

3.4 RESEARCH FINDINGS

Based on the families' pre- and post-diagnostic psychosocial experiences of raising an autistic child, ten themes were identified from the reviewed studies. The themes were split into three criteria, namely psychological experiences, social experiences, and psychosocial coping strategies.

Psychological experiences included emotional experiences, grieving process, parenting, and family dynamics. Social experiences included lack of support services, and social awareness. Psychosocial coping strategies included isolation, information seeking, meaning-making, and support system.

As autism is unique to every child and is thus difficult to recognise, families experience a range of emotions as their child's difficulties become prominent, which makes it hard to understand their child's development (Padden & James, 2017) and results in emotional experiences of confusion and uncertainty about their child's problem that are mainly negative before diagnosis. Families compare this process to the loss of their ideal child, as they are uncertain how they can help their child. Regardless of families receiving the diagnosis, studies report that they experience the post-diagnosis period as stressful because they lose their ideal parental experience due to the diagnosis, which means adjusting. However, upon receiving the diagnosis, families experience a shift from negative emotional experience to more positive experiences.

Social experiences pre- and post-diagnosis entail the experiences that families have in society regarding raising an autistic child. Families' social experiences as identified in this study emphasise the lack of support services and social awareness. This results in the affected families having to adjust their coping style in order to navigate their way through challenges they face both pre- and post-diagnosis.

Psychosocial coping strategies are strategies that families develop and use to survive every day. These strategies help to decrease their parental stresses with the aim of fully supporting not only the diagnosed child, but the whole family as well. Upon initiating these strategies, families are able to have more positive experiences and therefore start making meaning of this experience.

The identification of the themes sparked emotions of sadness within me in terms of the challenges that families experience in search of answers. I was also angry at the lack of services or even support in place for families, which makes raising an autistic child difficult. At first, I sympathised with the families, but as the process went on, I became more empathetic. I then realised that these families did not in any way need sympathy; all they needed was support in order to best get through this situation. This also made me understand the necessity of raising awareness in order to stop people feeling sorry for families, but rather understanding that this diagnosis affects the whole community. Gaining relevant and appropriate information and being supportive are therefore best for families.

3.5 LIMITATIONS

The study limitations are based on the characteristics of design or methodology that impacted or influenced the interpretation of the findings from the research. Due to the research not involving participants, it made it a no-risk study; however, limitations were still encountered.

The researcher initially wanted to conduct a qualitative study with mothers who raise autistic children; however, the recruitment of participants posed difficulties, as they are a vulnerable targeted group. Gaining ethical clearance from the community gatekeeper was therefore a problem. This resulted in the researcher and study leader re-discussing the study and deciding to conduct a rapid review instead. Some of the challenges that were present with the rapid review were as follows:

- A lack of studies that explored this specific topic/phenomenon, as most of the available literature and research focused on the pathology of autism and covered topics such as the development and increase in the prevalence of autism. Contrastingly, the researcher was interested in exploring families' experiences of raising a child with autism. However, this served as a strong and positive aspect as the researcher could address this gap that served as a research opportunity.
- Upon conducting the literature search and identifying studies that were applicable, the challenges identified were the age and level of functioning among children with autism as these differed. This meant that families' experiences would be different as children grew up and families learned to adjust. The researcher and reviewer therefore had to ensure that the age range within all studies was between five and 18 years.
- This research was a small-scale study and was conducted within the limited scope of a master's mini-dissertation. Furthermore, during the keyword search it was important to identify studies that were in conjunction with the keywords searched for the studies. However, this resulted in most studies being excluded as they explored different phenomena together with the experiences of families and therefore did not answer the research question.
- The included studies explored families' experiences from five continents, and showed that the geographical location can have an influence on the experiences due to the availability of resources within certain countries. For example, families in Canada have more resources than families in South Africa.
- Three of the studies explored fathers' experiences of raising an autistic child. This might have an effect on the results as the experiences would be subjective and not encompass families' experiences. However, when comparing the experiences, similarities and differences were noted. Furthermore, the research question aimed to explore families, parents, mothers, fathers, guardians, and caregivers.

3.6 CONCLUSION AND RECOMMENDATIONS FOR FUTURE RESEARCH

Sections 1 and 2 indicated that there is a need for appropriate and relevant services aimed not only at autistic children, but the whole family. This support and relevant services should be based on relevant and scientifically sound knowledge, which will assist in appropriately informing mental healthcare providers in the development and implementation of support services and intervention plans. After the completion of this study, the following recommendations are made:

- The lack of studies that explore families' experiences serves as an indication that more research is required.
- Provided services must be aimed at the whole family and not just at the autistic child, as the whole family system is disrupted by autism. Creating support systems is therefore important in assisting families that raise an autistic child. This includes equipping healthcare workers with proper tools to provide a comprehensive diagnosis and treatment plan.
- Research indicates an increase in the prevalence of autism in South Africa and in the rest of the world, which serves as an indication for the need for autism awareness aimed at combatting societal misconceptions of the disorder.
- Families need to be proactively informed of what autism is, as well as the psychosocial challenges they will be faced with.
- Families need to be psychosocially supported so that they can feel empowered to deal with the challenges at hand.
- Families need to be ensured of reliable, competent, and supportive professional and personal support networks.
- Deliberate communication and awareness programmes should be implemented to work together with families to raise societal awareness and sensitivity towards children with autism and especially their families.

The autism community in South Africa is still a minority. If we were to take the statistic that one in every five children is autistic, imagine how many children are undiagnosed and how many families there are that do not understand their child or know where to start. What is difficult with this disorder is that it differs with every child, and therefore not one diagnosis fits all of them, which makes it even more difficult to diagnose and to manage. However, working within the Care2Kids unit gave me hope and motivated me to become active in doing more about helping, supporting, and raising awareness within my small space. More studies need to be conducted that

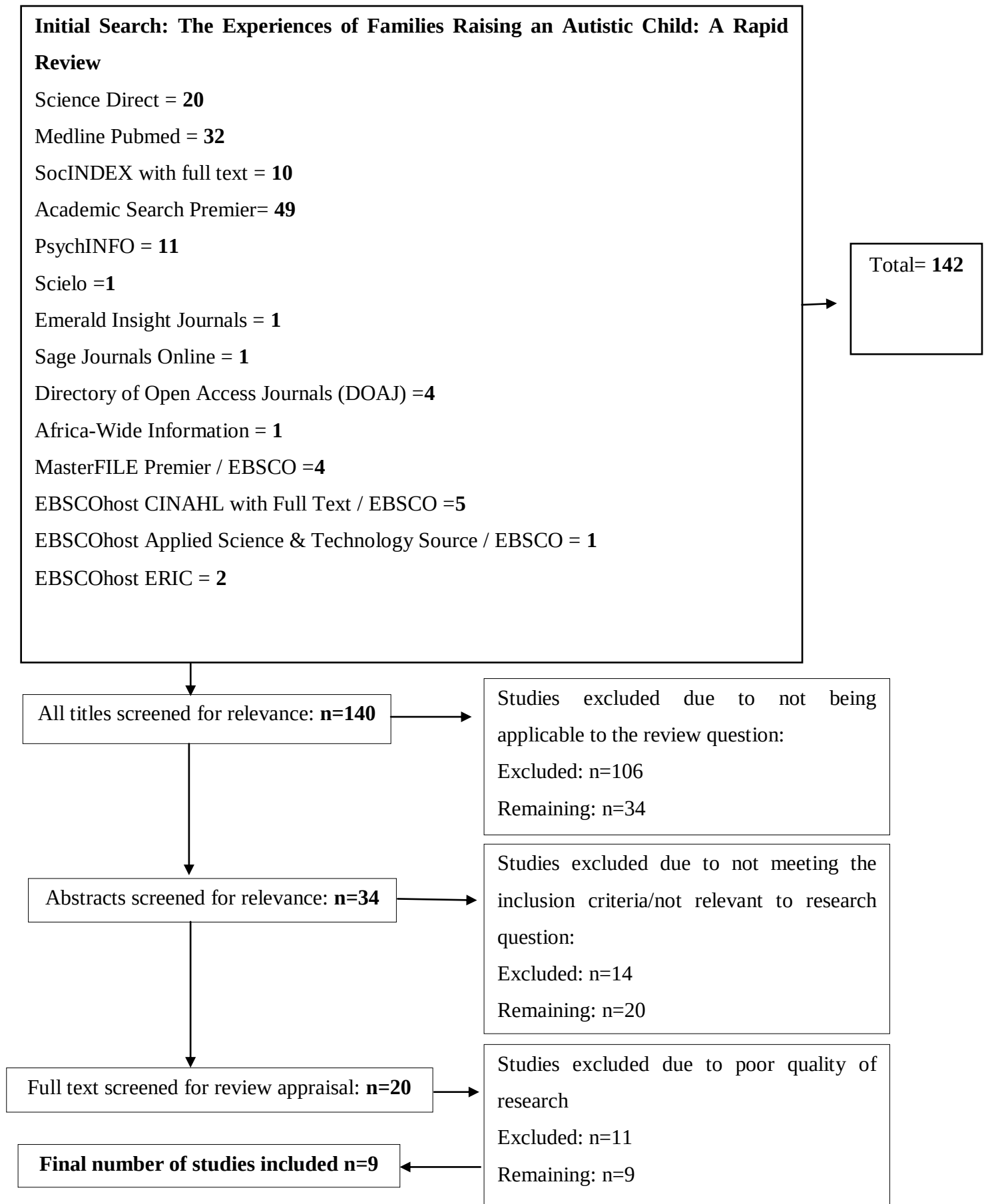
not only explore their experiences, but that are also aimed at creating intervention tools for families that raise an autistic child.

The number one reason I chose to study psychology was to try to make a difference to people's lives. That was also the aim of my research. I hope it shed light on families' experiences throughout the world, and that it especially serves as encouragement to families, by showing them that they are not alone in this, and that other parents are going through similar challenges; they should therefore not give up hope. Furthermore, I hope this study empowers families and shows them that they are the experts when it comes to interventions for autistic children; they must therefore take a stand and start actively advocating for their children.

3.7 REFERENCES

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- Padden, C., & James, J. (2017). Stress among parents of children with and without autism spectrum disorder: A comparison involving physiological indicators and parent self-reports. *Journal of Developmental and Physical Disabilities*, 29(4), 567-586. doi: 10.1007/s10882-017-9547-z

ADDENDUM 1: SCHEMATIC REPRESENTATION OF SELECTED STUDIES



ADDENDUM 2: CRITICAL APPRAISAL OF REVIEW REPORT

The Experiences of Families Raising an Autistic Child: A Rapid Review

- Critical Appraisal Skills Programme (2018) and The Joanna Briggs Institute (2014) for qualitative studies
- The Joanna Briggs Institute (2014) for quantitative studies

R1= Ms Boitumelo Phetoe

R2= Mrs Heleen Coetzee

Relevant titles	Clear statement of the aims of the research?		Ethical approval		Clear research design		Valid and reliable measurement		Data analysis sufficiently rigorous?		Sample is representative of the population		Bias has been minimised in selection of cases		Clear statement of findings?		Total	
	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2
1. Al Khateeb, J., Kaczmarek, L., & Al Hadidi, M. (2019). Parents' perceptions of raising children with autism spectrum disorders in the United States and Arab countries: A comparative review.	0 unclear	1	0	0.5	1	1	1	1	1		1 review	1	1	1	0	1	5	7.5
2. Burrell, A., Ives, J., & Unwin, G. (2017). The experiences of fathers who have offspring with autism spectrum disorder.	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	8	8
3. Byrne, G., Sarma, K., Hendler, J., & O'Connell, A. (2018). On the spectrum, off the beaten path: A qualitative study of Irish parents' experiences of raising a child with autism spectrum conditions.	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	8	8
4. DePape, A., & Lindsay, S. (2014). Parents' experiences of caring for a child with autism spectrum disorder.	1	1	0 No-risk study	0	1	1	1	1	1	1	1	1	1	1	1	1	7	7
5. Chell, N. (2005). Experiences of parenting young people with a diagnosis of Asperger's syndrome: A focus group study.	0 unclear	1	1	0	0 focus group	0	1	1	1	1	1	1	1	1	1	1	6	6.5
6. Desai, M., Divan, G., Wertz, F., & Patel, V. (2012). The discovery of autism: Indian parents' experiences of caring for their child with an autism spectrum disorder.	0 unclear	0.5	0 unclear	0.5	1	0.5	0 unclear	1	1	1	1	1	1	1	1	1	5	6.5

Relevant titles	Clear statement of the aims of the research?		Ethical approval		Clear research design		Valid and reliable measurement		Data analysis sufficiently rigorous?		Sample is representative of the population		Bias has been minimised in selection of cases		Clear statement of findings?		Total	
	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2
7. Dieleman, L., Moyson, T., De Pauw, S., Prinzie, P., & Soenens, B. (2018). Parents' need-related experiences and behaviors when raising a child with autism spectrum disorder.	1	1	0 in acc to ethics	0.5	1	0.5	0 unclear	1	1	1	1	5 participants	1	1	1	1	6	7
8. Frye, L. (2016). Fathers' experience with autism spectrum disorder: Nursing implications.	1	1	0 scientific committee	1	1	1	1	1	1	1	1	1	1	1	1	1	7	8
9. Glazzard, J., & Overall, K. (2012). Living with autistic spectrum disorder: Parental experiences of raising a child with autistic spectrum disorder (ASD).	1	1	0	0	0	1	0 unsure	1	0	50 questionnaire 2 participants	0	0	0	0	1	1	2	4
10. Ho, H., Fergus, K., & Perry, A. (2018). Looking back and moving forward: The experiences of Canadian parents raising an adolescent with autism spectrum disorder.	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	8	8
11. Hoogsteen, L., & Woodgate, R. L. (2013). The lived experience of parenting a child with autism in a rural area: Making the invisible, visible.	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	8	8
12. Kayfitz, A., Gragg, M., & Orr, R. (2010). Positive experiences of mothers and fathers of children with autism.	1	1	1	1	1	1	0	1	1	1	11	1	1	1	1	1	7	8
13. Keenan, M., Dillenburger, K., Doherty, A., Byrne, T., & Gallagher, S. (2010). The experiences of parents during diagnosis and forward planning for children with autism spectrum disorder.	0 unclear	1	1	1	0	0	1	1	0	0	1	1	1	0	0 unclear no rep of stats	1	4	4
14. Minhas, A., Vajaratkar, V., Divan, G., Hamdani, S., Leadbitter, K., & Taylor, C., ... Rahman, A. (2015). Parents' perspectives on care of children with autistic spectrum disorder in South Asia: Views from Pakistan and India.	1	1	1	1	1	1	0	1	1	1	1	1	1	1	1	1	7	8

Relevant titles	Clear statement of the aims of the research?		Ethical approval		Clear research design		Valid and reliable measurement		Data analysis sufficiently rigorous?		Sample is representative of the population		Bias has been minimised in selection of cases		Clear statement of findings?		Total	
	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2	R1	R2
15. Munroe, K., Hammond, L., & Cole, S. (2016). The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an autism spectrum disorder: An interpretive phenomenological analysis.	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	8	8
16. Paynter, J., Davies, M., & Beamish, W. (2017). Recognising the “forgotten man”: Fathers’ experiences in caring for a young child with autism spectrum disorder.	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	8	8
17. Pottas, A., & Pedro, A. (2016). Experiences of father carers of children with autism spectrum disorder: An exploratory study.	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	8	8
18. Sukmak, V., & Sangsuk, N. (2018). Living a tormented life: Caregivers' experiences of caring for a child with autism in Northeastern Thailand.	1	1	1	1	1	1	1	1	1	1	0 24 children, 7 parents	1	0 did not specify	1	1	1	6	8
19. Tait, K., Fung, F., Hu, A., Sweller, N., & Wang, W. (2015). Understanding Hong Kong Chinese families’ experiences of an autism/ASD diagnosis.	1	0	0	1	1	1	1	1	1	1	0 Did not explain recruitment process	1	0	1	1	1	5	7
20. Wang, H., & Casillas, N. (2012). Asian American parents’ experiences of raising children with autism: Multicultural family perspective.	0 unclear		1		1		0 unclear		1		1		1		1	1	6	8
21. Woodgate, R., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism.	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	1	8	8

ADDENDUM 3: SUMMARY OF THE INCLUDED STUDIES

Study	Aim of the study	Methodology	Sample	Measurement	Core findings
1. Byrne, G., Sarma, K., Hendler, J., & O'Connell, A. (2018). On the spectrum, off the beaten path: A qualitative study of Irish parents' experiences of raising a child with autism spectrum conditions.	Aimed to describe the experiences of a sample of Irish parents who have a child on the autistic spectrum.	Qualitative design. Semi-structured interviews.	Ten Participants, eight of the participants were mothers and two were fathers.	Semi-structured interviews aimed to provide a broad framework for the exploration of parents' experiences of raising a child with ASD.	Themes include: • Frustration • Guilt • Blames self • Anger: Themselves healthcare, family members • Isolation • Rigid parenting style • Vigilant • Fight for services • Mainly focusing on child • Failing to fix child • Unpredictable behaviour • Expected child; ideal child • Expected parental experiences
2. DePape, A., & Lindsay, S. (2014). Parents' experiences of caring for a child with autism spectrum disorder.	Aimed to explore the experiences of parents who care for a child with ASD.	Qualitative meta-synthesis.	Thirty-one articles for inclusion (involving 160 fathers and 425 mothers).	Thematic synthesis that integrated qualitative evidence, searching 10 electronic databases and reviewing 4 148 abstracts.	Themes include: • Pre-diagnosis ○ Typical development ○ Atypical development ○ Searching for answers • Diagnosis ○ Relief and devastation ○ Guilt and blame ○ Family life adjustment ○ Daily life. ○ Finances and career ○ Impact on parents ○ Impact on siblings ○ Impact on spouse ○ Going out in public ○ Navigating the system ○ Parental empowerment ○ Coping strategies

Study	Aim of the study	Methodology	Sample	Measurement	Core findings
3. Frye, L. (2016). Fathers' experience with autism spectrum disorder: Nursing implications.	Aimed to describe fathers' experience with ASD using their own words and identifying any resources needed to help them actively engage in their role as a father of a child with ASD.	Qualitative design. Single-case, multiple-participant, phenomenological approach case study.	Ten fathers participated in this single-case, multiple-participant case study.	Phenomenological approach case study was conducted to describe the experience of fathers of children with ASD.	Themes include: • Patience • More tolerant • Emotional • Accepting of the child • Appreciate small moments • Making adjustments • Child is a misfit • Child is monster • Affects family cohesion • Loss of expected child; ideal child • Loss of expected parental experiences • Money challenges • Teamwork • Grief and loss that are like those that occur when experiencing a death
4. Hoogsteen, L., & Woodgate, R. L. (2013). The lived experience of parenting a child with autism in a rural area: Making the invisible, visible.	Aimed at exploring the lived experiences of parents who are parenting a child with autism while living in a rural area.	Qualitative design, hermeneutic phenomenology.	Twenty-six families served as primary data.	Semi-structured, open-ended interviews that were audio recorded.	Themes include: • Lack of understanding from others • Isolating child from family, society • To isolate child, cannot predict and always explaining • Disconnect between child, family, and society • Expected child; ideal child • Expected parental experiences • Hopeless burden • Worry • Abandonment
5. Kayfitz, A., Gragg, M., & Orr, R. (2010). Positive experiences of mothers and fathers of children with autism.	Aimed at exploring similarities and differences in the positive experiences of mothers and fathers who are raising a school-	Quantitative study.	Twenty-three mother/father pairs who are raising children with autism.	Following questionnaires were used to explore both mothers and fathers' experiences: • Demographic questionnaire • Parenting stress • Positive experiences of raising their children	Themes include: • Patience • More tolerant • Accepting of the child • Appreciate small moments • Making adjustments • Sense of control

Study	Aim of the study	Methodology	Sample	Measurement	Core findings
	aged child with autism.				• Love • Increase self-efficacy • Increase resilience • View child holistically • Behaviour improvement
6. Munroe, K., Hammond, L., & Cole, S. (2016). The experiences of African immigrant mothers living in the United Kingdom with a child diagnosed with an autism spectrum disorder: An interpretive phenomenological analysis.	Aimed at investigating mothers' experiences of caring for their children and how they made sense of their difficulties and diagnosis.	Qualitative, interview-based design.	6 mothers who are raising children with autism.	Eight open-ended questions, with prompts. These related to parents' experiences of caring for their children, of receiving and making sense of their diagnosis, their contact with services, and their cultural background.	Themes include: • Caring for a child we did not expect • All-consuming • Maintaining privacy versus seeking support • Loss • The pain of stigma and rejection • Others' judgements • Impact on maternal identity • Expected child; ideal child • Expected parental experiences • Frameworks of meaning • Diagnosis • Religious beliefs • Cultural beliefs • Negotiating conflicting cultural beliefs • Shifting cultural allegiances
7. Paynter, J., Davies, M., & Beamish, W. (2017). Recognising the "forgotten man": Fathers' experiences in caring for a young child with autism spectrum disorder.	Aimed at investigating the experiences of fathers of young children with ASD.	A mixed-methods design was used, with quantitative questionnaire data and qualitative interview data being collected.	Eighteen fathers initially completed a mailed questionnaire and eight of these fathers were then interviewed via telephone.	Quantitative measures for most components of the double ABCX model were used for this study with the exceptions of family wellbeing and internal resources. The qualitative method was an in-depth, semi-structured telephone interview.	Themes include: • Draining • Daily grind • Fear • Devastating • Stressful • Emotional burden • Numbing • Hopeless burden • Worry • Abandonment

Study	Aim of the study	Methodology	Sample	Measurement	Core findings
					• Denial • Depression • Not trusting own capabilities • Parenting skills being judged and questioned • Daily grind • Loss of expected child
8. Pottas, A., & Pedro, A. (2016). Experiences of father carers of children with autism spectrum disorder: An exploratory study.	Aimed at exploring the carer experiences of fathers of children with ASD.	Qualitative design.	Eight South African fathers between the ages of 38 and 45 were the interview informants.	The father carers completed in-depth interviews on their emotional reactions to the diagnosis, the effect of care on their interpersonal relationships within the family, available resources for care, and carer satisfaction.	Themes include: • Rescoping their futures to include the care of a child with ASD • Relationship issues • Access to and management of resources • Information and support • Carer compassion and satisfaction
9. Woodgate, R., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism.	Aimed at describing the experiences of parents who have a child with autism.	Qualitative design, hermeneutic phenomenology.	Sixteen families of children with autism.	Qualitative interviews where parents were asked open-ended probes to describe what life was like for them before, during, and after their child was diagnosed with autism.	Themes include: • Vigilant parenting • Sustaining the self and family • Fighting all the way (advocacy) • Educating self and others • Loss • Career sacrifices • Poor resources • Hard to obtain a diagnosis • Strain on marriage • Family support system

ADDENDUM 4: PROOF OF TRAINING



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7 March 2018

Dear Ms Boitumelo Ragiso Phetoe

PROOF OF ATTENDANCE AND ASSESSMENT

This letter certifies that you have attended the 2 day ethics training and successfully completed the associated assessment.

The Basics of Health Research Ethics

(Accreditation number: PSB002/037/01/2018 from University of Free State CPD accreditation department accredited by the HPCSA)

Presenter: Prof Minrie Greeff (Head of the Health Sciences Ethics Office for Research, Training and Support) on 22 and 23 January 2018.

This letter of attendance, as proof of ethics training and assessment, is valid for 3 years and expires on 31 January 2021 (Where applicable, Ethics CEUs awarded: 14 CEUs).

Yours sincerely,

Prof Minrie Greeff
Head of Health Sciences Ethics Office
for Research, Training and Support

Prof Awie Kotzé
Executive Dean: Faculty of Health
Sciences

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7 March 2018

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