A rapid review of loneliness experienced by primary caregivers of children with autism spectrum disorder

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

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TABLE OF CONTENTS

ACKNOWLEDGEMENTS iv
PERMISSION LETTER FROM SUPERVISOR vi
DECLARATION FROM AUTHOR vii
LIST OF TABLES AND FIGURES viii
ABBREVIATIONS viii
SUMMARY ix
PREFACE x
STRUCTURE OF RESEARCH MINI-DISSERTATION xi
SECTION 1: OVERVIEW 13
Introduction 13
  Autism Spectrum Disorder 13
  Prevalence of Autism Spectrum Disorder 14
  The Caregiver of a Child with Autism Spectrum Disorder 15
  Caregiving Experiences 16
Caregivers' Experiences of Loneliness 17
Problem Statement 19
Method of Investigation 20
  Step 1: Conducting a Scope Review 20
  Step 2: Screening of Scientific Literature for Further Analysis 21
  Step 3: Scientific Appraisal Tool to Appraise the Remaining Scientific Literature 22
  Step 4: Synthesis of Evidence 22
Phase 1: Familiarize Yourself with Your Data 23
Phase 2: Generating Initial Codes 23
Phase 3: Searching for Themes 23
Phase 4: Reviewing Themes 24
Phase 5: Defining and Naming Themes 24
Phase 6: Producing the Report 24
Ethical Considerations 24
Rigour 25
Conclusion 27
References 28

SECTION 2: Manuscript 34
Abstract 36
Goal of the Research Study 39
Research Approach and Design 39
Data Analysis 50
Findings and Discussion 50
  Theme 1: Burden of Care and Challenges Experienced by Caregivers 50
  Theme 2: Social Isolation and Social Interactions that Play a Role in the Experiences of Loneliness 54
  Theme 3: Stigma and Discrimination Impacting the Experiences of Loneliness 58
  Theme 4: Coping Mechanism Alleviating the Experiences of Loneliness 60
Limitations and Recommendations for Future Studies 62
Conclusion 63
References 64
SECTION 3: CRITICAL REFLECTION 70
Critical Reflection on the Research Process 70
  Data Collection 71
  Data Analysis and Interpretation 72
  Findings 73
Conclusion 73
References 75
ADDENDUM B (HREC ETHICS APPROVAL LETTER) 78
ADDENDUM C (LANGUAGE EDITING CERTIFICATE) 80
ADDENDUM D (TURN-IT-IN REPORT) 81
ADDENDUM E (SOLEMN DECLARATION AND PERMISSION TO SUBMIT) 82

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PERMISSION LETTER FROM SUPERVISOR

I, Mrs Lelanie Malan (Study Leader), herewith give permission for Razina Shaik to submit this mini-dissertation entitled *A rapid review of loneliness experienced by primary caregivers of children with autism spectrum disorder* for examination purposes.

Lelanie Malan

Supervisor/Promoter

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Date: 2023.08.10 12:20:13 +02'00'

DECLARATION FROM AUTHOR

I, Razina Shaik, declare that this research study titled: *A rapid review of loneliness experienced by primary caregivers of children with autism spectrum disorder* is work done by me. This research study serves as partial fulfilment of the Master's degree in clinical psychology done at the North-West University's Potchefstroom campus. This work has never been submitted for examination. All necessary consent has been obtained from the relevant parties to conduct the research. Throughout the research, all sources used were referenced, and all reference material were acknowledged according to the American Psychological Association (APA 7th edition).

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Razina Shaik

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LIST OF TABLES AND FIGURES

Section 2

Table 1: Data Extraction

Figure 1: Identifying Relevant Scientific Literature for Inclusion

ABBREVIATIONS

APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
DSM-5	Diagnostic and Statistical Manual of Mental Disorders 5th Edition
ID	Intellectual Disability
JBI	Johanna Briggs Institute
TD	Typically Developing
WHO	World Health Organization

SUMMARY

A rapid review of loneliness experienced by primary caregivers of children with autism spectrum disorder.

Keywords: Autism Spectrum Disorder, caregiver, child, experiences, loneliness, rapid review, social isolation.

Caregivers are a critical health resource in caring for a child with Autism Spectrum Disorder (ASD). Therefore, caregiver psychological health is crucial, because if impaired it will impact on treatment outcomes and interventions for these children. One of the aspects indicated in poor caregiver psychological health is loneliness. This research study aimed to understand the experiences of loneliness of caregivers of children with ASD by way of a rapid review. The data collected for this rapid review research study were identified by following a structured approach that culminated in the inclusion of 13 research studies that met the requirements of scientific rigour after adhering to the quality appraisal tool. Thematic analysis was then applied to identify recurrent themes from the extracted data. This resulted in the identification of four themes: (1) Burden of care and challenges experienced by caregivers; (2) Social isolation and social interactions that impact on the experiences of loneliness; (3) Stigma and discrimination that play a role in the experiences of loneliness; and (4) Coping mechanisms alleviating the experiences of loneliness.

This research study also identified future directions for further investigations on the aspect of loneliness of caregivers of children with ASD. The research study thus revealed that a lack of awareness, a lack of support, and challenges associated with caregiving a child with ASD impacted on caregivers' experiences of loneliness, and recommended that future studies should focus on caring for the carer. The research study further recommends that interventions are required which encompasses creating awareness of ASD within society and addressing the need for interventions that ensure provision for social inclusion and social support for the caregivers of children with ASD, thereby holistically aiming to alleviating the sense of loneliness of these caregivers and ultimately assisting health professionals in interventions that aim to promote caregivers' psychological health.

PREFACE

- This mini-dissertation forms part of the requirements for the completion of the Master of Arts in Clinical Psychology. It has been prepared in article format in adherence to rule A.5.4.2.7 of the North-West University and Faculty of Health Sciences yearbook.
- The manuscript (see Section 2) will be submitted for possible publication in the *Journal of Psychology in Africa (JPA*).
- The manuscript was prepared according to the North-West University guidelines and APA 7th edition.
- COMPRES approval was obtained for this rapid review research study (refer to Addendum A).
- Ethical approval was obtained for this rapid review research study NWU-00097-22-A1 (refer to Addendum B).
- This mini-dissertation was submitted to a qualified and registered language editor (refer to Addendum C).
- This mini-dissertation was submitted to turn-it-in for similarity testing (refer to Addendum D).
- Consent for submission of this mini-dissertation for examination purposes has been given by the research supervisor, (Mrs Lelanie Malan) in partial fulfilment of requirements for the degree *Master of Arts in Clinical Psychology* at the North-West University, Potchefstroom Campus (refer to Addendum E).

STRUCTURE OF RESEARCH MINI-DISSERTATION

This mini-dissertation encompasses three sections. Section 1 includes a literature overview that aims to assist the reader by presenting the relevant information regarding the structure and components of this research study (pp. 1-16). Section 2 consists of the research manuscript. This comprises the methodology employed, the presentation of the findings of the research study, the discussion of the findings, the limitations, and recommendations of the research study. The section then provides the conclusion of the research study. (pp. 25-53). Thereafter, Section 3 comprises a critical reflection of the primary researcher in conducting this research study which resulted in the completion of this mini-dissertation (pp.63-67).

SECTION 1: OVERVIEW

Introduction

The literature overview in Section 1 aims to assist the reader in contextualising the problem statement of the research study. Section 1 provides the reader with a broad understanding of the relevant concepts explored in this mini-dissertation. The concepts covered in the literature overview include the definition and clinical presentation of Autism Spectrum Disorder (ASD) in children, and the challenges associated with ASD and the prevalence of ASD. Further, both positive and negative caregiver experiences associated with caregiving a child with ASD are explored. Moreover, Section 1 then broadly orientates the reader on the aspect of caregivers' loneliness when caring for a child with ASD. Thereafter the methodology, ethics, and rigour that are required to produce a study of high quality are discussed.

Autism Spectrum Disorder

ASD is a complex neuro-developmental condition that involves continued challenges in non-verbal communication, speech and social interaction across multiple contexts (McGuire, 2015). ASD affects social communication, which includes social initiations like starting play or conversations with others (Hume et al., 2021; Steinbrenner et al., 2020). ASD further affects social reciprocity, which involves turn-taking (Hume et al., 2021). Lastly, ASD affects synchrony, which involves meaningfully linking conversation on a topic, including the understanding, and expressing of appropriate non-verbal behaviours, such as gestures or facial expressions (Steinbrenner et al., 2020). The above impairments in social communication can thus result in limited engagement in social interactions with peers and the lack of establishment of social relationships for the child with ASD (Lai et al., 2015).

Moreover, ASD includes restricted, repetitive patterns of behaviours, interests or activities that limit or impact daily functioning (Rosen et al., 2021). These restrictive and repetitive behaviours may include stereotypical behaviour or speech, fixation or interests in specific topics, and strict adherence to routines, schedules, or settings with discomfort experienced when the above-mentioned are changed or are altered (Steinbrenner et al., 2020). These restricted and repetitive behaviours can impact on the individual's participation and engagement at home, at school, and in the community (Steinbrenner et al., 2020). In its most severe form, restrictive and repetitive behaviours are expressed in self-injurious behaviour, such as excessive head-banging (Steinbrenner et al., 2020).

According to the Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5), autism is a "spectrum" condition (American Psychiatric Association [APA], 2013). Therefore impairments and severity of social interaction, speech and non-verbal communication challenges of ASD will differ across the spectrum (Knapp et al., 2009). Some children who are diagnosed with ASD may have average or above-average intelligence and need little support to function independently, while other children may have severe intellectual disability, limited or no verbal communication, and very limited adaptive behaviour (Steinbrenner et al., 2020). Therefore, the amount of physical and emotional support that a child diagnosed with ASD will need varies across the spectrum (Knapp et al., 2009). Furthermore, as ASD is a spectrum condition with a range of disabilities, the DSM-5 has also included the classification of the range of support an autistic individual would need in activities of daily living, which is that of "requiring support", "requiring substantial support", or "requiring very substantial support" (APA, 2013).

Prevalence of Autism Spectrum Disorder

Globally, the prevalence of ASD has been rising (Zeidan et al., 2022). For example, it increased from 1 in 10,000 people in the 1960s to 1 in 100 people over the last few decades (Zeidan et al., 2022). However, most research on ASD has been conducted in high-income regions such as North America, with a dearth of research within low and middle-income countries, like South Africa (Abubakar et al., 2016). According to Abubakar et al. (2016), a recommended starting point to having an adequate research framework in these low and middle-income regions is to have standardised screening and diagnosis of ASD (Abubakar et al., 2016; Pillai et al., 2021). Early universal screening and diagnosis in these regions and in previously disadvantaged communities like South Africa are further required to assist in fostering an understanding in society that ASD is a neuro-developmental condition (Pillai et al., 2021). This understanding could assist in creating more effective community outreach programmes that could increase awareness on ASD (Pillai et al., 2021). In addition, creating awareness of ASD could assist in informing cultural beliefs and misconceptions about the child with ASD within these culturally diverse communities (Cardon & Marshall, 2021). Awareness of ASD could further assist in reducing stigma, feelings of loneliness and social isolation in caregivers of children with ASD (Viljoen et al., 2019), thereby assisting in providing the much needed social support to caregivers of children with ASD, which could ultimately decrease the burden of care for caregivers (Pillay et al., 2021).

Moreover, early detection and intervention of ASD are crucial for treatment outcomes (Pillai et al., 2021). However, in South Africa, children are diagnosed late, and due to a lack of cost-effective services, also receive access to services much later (Gordon et al., 2020; Pillai et al., 2021). In addition to a lack of services, there is also a scarcity of specialist service providers in most low and middle-income countries like South Africa (Durkin et al., 2015). Therefore it is unlikely that sufficient highly trained therapists will ever be available to provide important healthcare services to children with ASD (Franz et al., 2018). Given the above, the World Health Organization (WHO) therefore recommended that involving parents and caregivers of young children with ASD in treatment delivery is a potentially powerful mechanism to deliver early intervention in low-resource settings (WHO, 2022).

The Caregiver of a Child with Autism Spectrum Disorder

Caregiving a child with ASD can often be a difficult and stressful process for families and caregivers (Cardon & Marshall, 2021). Some of the difficulties caregivers experience can be attributed to the burden of care and demands associated with caregiving a child with ASD (Cardon & Marshall, 2021). The burdens of caregiving could include financial strain, whereby caregivers leave their paid occupations to fulfil caregiver duties (Bravo-Benítez et al., 2019). In addition, caregiving duties often result in restricted movements and time constraints imposed on caregivers, whereby they are unable to go anywhere without taking their child with them (Reddy et al., 2019). Furthermore, due to time constraints, caregivers find that they do not have time to fulfil other responsibilities, such as taking care of their other typically developing (TD) children (Nicholas et al., 2016), or having time for self-care or for social interactions outside of the home (Currie & Szabo, 2020). Caregiver time constraints can be attributed to the constant supervision and care of the child with ASD (Williams & Murray, 2015). From the above, it would seem that the main challenge for caregivers is to manage their child's ASD symptoms effectively and balance this caregiving role with the requirements of everyday living (Reddy et al., 2019). For this research study, a primary caregiver was defined as parents, mothers, fathers, siblings, grandparents, or guardians of children who are 2 to -18 years of age, diagnosed with ASD, who act as primary caregivers who are responsible for the day-to-day care and maintenance of these children (Lainhart, 2015).

Caregiving Experiences

Caregiving can have both positive and negative outcomes (Quinn & Toms, 2019). On the one hand, positive caregiver experiences include an increase in tolerance, empathy, spirituality and meaning-making of raising a child diagnosed with ASD (Reddy et al., 2019). On the other hand, negative experiences of managing the child’s chronic condition create overwhelming caregiving demands (Reddy et al., 2019). Caregiver demands of providing daily care for and managing challenging behaviours of their children with ASD result in caregivers’ experiences of burnout and chronic fatigue (Nicholas et al., 2016). Caregivers’ experiences of burnout and fatigue could be due to the lack of support or opportunities for reprieve from caregiver duties in the form of respite care (Currie & Szabo, 2020). Stress and negative emotional experiences of rejection, stigma and discrimination of caregivers in society for having a child with ASD may contribute to caregivers experiencing feelings of uncertainty, helpless, and incompetence (Reddy et al., 2019). These experiences may then result in caregivers experiencing mood disorders such as anxiety and depression and ultimately to caregiver experiences of psychological ill-health (Bravo-Benitez et al., 2019). The above-mentioned are therefore key predictors that further influence experiences of loneliness of caregivers of children with ASD (Raina et al., 2005). The experiences of loneliness is thus highlighted as another major challenge faced by caregivers of children with ASD (Vasileiou et al., 2017).

Caregivers' Experiences of Loneliness

Literature indicates that loneliness can be defined as feelings of a lack of companionship, a loss of a sense of belonging and connection with others (Cacioppo & Cacioppo, 2018). Loneliness is thus experienced by caregivers as a feeling that can come and go, or it can be something that caregivers of children with ASD feel all the time (Adashek & Subbiah, 2020). Loneliness may further be experienced differently by caregivers, depending on their cultural perceptions and societal context. Collectivistic cultures may provide protection against experiences of isolation and loneliness for caregivers, while other cultural beliefs could contribute to isolation due to the stigma associated with ASD (Cardon & Marshall, 2021). Stigma, fear, self-blame, and embarrassment due to the behavioural issues associated with ASD increase primary caregivers' experiences of loneliness, social isolation, and self-isolation (Chan & Lam, 2018). Research further indicates that caregivers' experiences of declining psychological health are particularly a culmination of the behavioural challenges that present in the child with ASD (Currie & Szabo, 2020).

Caregivers experience shame and marginalisation if the child with ASD exhibits inappropriate behaviour, like flapping, twirling, tantrums or mouthing objects (Carpenter &

Austin, 2007). Both children with ASD and their caregivers thus experience rejection for these challenging behaviours which are outside of social expectations and codes of conduct (Currie & Szabo, 2020). These challenges perpetuate more discrimination and isolation for caregivers when they are judged for not coping with the demands of caring for a child with ASD (Williams & Murray, 2015). Caregivers thus experience feelings of incompetency and guilt due to their inability to help their child with ASD to manage their challenging behaviours (Karst & Van Hecke, 2012). As a result, caregivers feel shunned, dismissed, and uncomfortable because of the complex behaviour of the child with ASD (Carpenter & Austin, 2007).

Consequently, there is an increased necessity for the caregiver to be vigilant in their surroundings (Williams & Murray, 2015). Therefore, to mitigate and control for the child's behaviour, caregivers chose to rather stay at home to manage the behaviour of the child with ASD effectively in familiar surroundings (Karst & Van Hecke, 2012). Staying at home culminates to social isolation and withdrawal from social settings (Currie & Szabo, 2020). Consequently, social isolation may exacerbate emotional distress, increased negative moods, and heightened symptoms of depression of caregivers, which ultimately exacerbate the feelings of loneliness (Chan & Lam, 2018). Moreover, caregivers and children thus learn to navigate the world as not fitting in (Williams & Murray, 2015), thereby contributing to social exclusion and further isolation (Currie & Szabo, 2020).

Time constraints are another factor that has been highlighted in caregivers' experiences of loneliness (Karst & Van Hecke, 2012). Time involved in caring for a child with ASD creates fewer opportunities for work and socialising, thus diminishing caregiver resources for social and emotional support (Karst & Van Hecke, 2012). In addition to the time factor, research has identified fatigue as another possible contributing factor to caregiver loneliness (Vasileiou et al., 2017). Caregivers experience fatigue in executing their caregiving duties, thereby withdrawing from participation in leisure activities and socialising (Karst &

Van Hecke, 2012). From the above-mentioned it would seem that caregivers of children with ASD experience interpersonal, intrapersonal and structural constraints that are amplified and pose a risk for caregivers' experiences of loneliness (Williams & Murray, 2015). The above-mentioned factors perpetuate loneliness, which has been linked to poor psychological and physical health of caregivers of children with ASD (Altan Sarikaya et al., 2021).

Problem Statement

Previous research has acknowledged the positive and negative experiences of the primary caregiver role (Karst & Van Hecke, 2012). However, there is limited research on the primary caregivers' experiences of loneliness (Altan Sarikaya et al., 2021). Gaining an understanding of the aspect of loneliness can guide mental health workers in interventions that promote the psychological health of caregivers of children with ASD (Currie & Szabo, 2020). The experiences of loneliness of the caregivers are important as they can have a negative impact on intervention programmes for children with ASD, and the quality of care of children with ASD (Olagunju et al., 2017). Although the experiences of loneliness related to the caregiver of the child with ASD are paramount (Vasileiou et al., 2017), caregivers' experiences of loneliness have not been given adequate attention (Altan Sarikaya et al., 2021). For this reason, the findings of this research study can provide a synthesis of the experiences of loneliness of primary caregivers, thereby providing a deeper understanding of the aspects of loneliness. Given the above overview, the focus of future studies should then be on caring for the carer (Ruparelia et al., 2017).

The following research questions guided the research study: *What evidence is available from the scientific literature on the experiences of loneliness of primary caregivers of children with ASD? How could this evidence inform our understanding to make appropriate recommendations for the psychological health promotion of caregivers of a child with ASD?*

Method of Investigation

A rapid review of scientific literature was used for this research study. Rapid reviews are a form of knowledge synthesis in which components of a systematic review process are simplified to produce information in a timely manner (Tricco et al., 2015). Due to the current increasing demands of the healthcare sector to have rapid access to scientifically informed research, to ensure evidence-based decision-making and practice (Ganann et al., 2010), rapid reviews have emerged as an efficient tool to gather scientific evidence to decision-makers more quickly and effectively (Garritty et al., 2021). Therefore rapid reviews are currently acknowledged as part of the knowledge synthesis family (Garritty et al., 2021). By means of a rapid review approach, the primary researcher was able to retrieve all the relevant scientific literature regarding the experiences of loneliness related to the caregivers of children with ASD. The data were then appraised, synthesised, and analysed in an appropriate scientific manner. Thus, the rapid review approach enabled the primary researcher to provide relevant information to the reader on current scientific literature on caregivers of children with ASD and their experiences of loneliness. This approach further allowed the primary researcher to identify gaps in the body of knowledge and make possible recommendations for future research. The research study employed the following rapid review steps to ensure rigour, transparency and that this research study is replicable (Garritty et al., 2021).

Step 1: Conducting a Scope Review

A scope review was conducted on various databases, in consultation with a North-West University’s Ferdinand Postma Library librarian, on 9 March 2021 and on 18 August 2021. A structured search was conducted through EBSCO Discovery Services (EDS). EDS is a search engine on the North-West University’s library search portal. It provides access to resources in the form of 73 international and national databases (Malabanan & Bayeng, 2019). Databases such as PsycINFO, MEDLINE, JSTOR Journals and American Doctoral

Dissertations, are included in EDS. A Google Scholar search was also utilised for completeness and to supplement the structured search.

For the purpose of this rapid review, all scientific literature based on the keywords of “loneliness”, “social isolation”, “social exclusion”, “lonely”, “caregiver”, “parents”, “mother”, “father”, “grandparents”, “sibling”, “guardian”, autism continuum”, “ASD”, “child”, “children”, was searched. Search terms and keywords were then combined or improved using Boolean operators, such as “AND”, “NOT”, “*”, and “OR” to produce more appropriate results. Boolean operators were used to identify scientific literature relevant to the research study to search for peer-reviewed literature published in books, Master’s dissertations, doctoral theses, and scholarly journals with full text, and these inclusion and exclusion criteria were applied to mitigate for bias.

Step 2: Screening of Scientific Literature for Further Analysis

The process of screening for scientific literature was done by two independent reviewers, namely the researcher (primary reviewer) and the study leader (secondary reviewer). Scientific literature was reviewed based on the abstract and title of the study. Scientific literature that did not include the keywords within the abstract and title and that did not meet the research study’s inclusion criteria was considered irrelevant. These were consequently excluded. Both the researcher (primary reviewer) and the study leader (secondary reviewer) independently reviewed the titles and abstracts of the scientific literature to identify the ones that were relevant to the rapid review question. In consultation with the co-leader (Prof Werner de Klerk), the scientific literature found was further narrowed down to ensure that the studies were specific to answering the study’s key research questions. The search progressed to the next step of the appraisal process, which involved overviewing the full text of the selected scientific literature. A final list of scientific literature was then compiled by the primary and secondary reviewers for quality appraisal.

Step 3: Scientific Appraisal Tool to Appraise the Remaining Scientific Literature

The Joanna Brigg's Institute (JBI) for qualitative studies' scientific appraisal tool was applied to the final selection of scientific literature selected for this research study. The purpose of this scientific appraisal tool was to assess the methodological quality of the selected studies and to determine the extent to which each of the studies addressed the possibility of bias in its design, conduct, and analysis. All scientific literature selected for inclusion in the rapid review (that is those that meet the inclusion criteria described in the proposal) was subjected to this rigorous appraisal by both the primary researcher and the study leader. The two served as critical appraisers. The results of this appraisal were then used to inform the synthesis and interpretation of the findings of this research study (Peters et al., 2020). The scientific literature was deemed relevant to the rapid review question. They were of a good quality, adhered to ethics and met the inclusion criteria as agreed upon by the researcher and study leader. The researcher then constructed a data extraction table of the relevant data to be extracted from the final selection of scientific literature. This included the publication information of the literature (i.e. authors, dates, and titles), the methodology, the participants, the findings, and the conclusion. The primary researcher thereafter conducted the thematic analysis, independently, which was then reviewed by the study leader and co-leader.

Step 4: Synthesis of Evidence

Lastly, the evidence was synthesised, and the findings were presented in a coherent manner that depicted the themes found in the data. Data were analysed using thematic analysis. Thematic analysis is a method of analysis that identifies patterns and themes within data. It was used to organise and describe the data in rich detail (Braun & Clarke, 2006). Thematic analysis was an effective method of analysis that was best suited for the research study as it enabled the researcher to synthesise the evidence by identifying recurrent themes in the relevant scientific literature, thereby organising the data to gain rich in-depth descriptions of the experiences of loneliness among primary caregivers of children with ASD. The themes that were identified were analysed, integrated, and summarised, which enabled the researcher to answer the research study's research questions. Braun and Clarke (2006) recommend a stepwise presentation for doing thematic analysis, which is discussed below.

Phase 1: Familiarise Yourself with Your Data

The researcher proceeded with reading and re-reading the selected scientific literature and noting down initial ideas. During this phase, the researcher's attention was drawn to information on what previous research has found regarding the experiences of loneliness among caregivers of children diagnosed with ASD. The possible implications for future research were noted. During this phase, the researcher did not aim to understand this information in any meaningful way.

Phase 2: Generating Initial Codes

In Phase 2, the researcher proceeded with generating initial codes depicting interesting features of the data in a systematic fashion by analysing the extracted data and highlighting the key features and information present within the data set (Braun & Clarke, 2006). Quantitative, qualitative, and mixed-methods studies were coded by focussing on how each of these studies narrated the results/findings in words and this narrative was used as data.

Phase 3: Searching for Themes

All the data were gathered that were relevant to the potential theme. The researcher collated the codes into potential themes. The themes that were identified were linked to the aims of the research study, of synthesising the scientific literature on the experiences of loneliness among caregivers of children with ASD. This helped the researcher to answer the research study's research questions.

Phase 4: Reviewing Themes

This phase involved checking if the themes worked in relation to the coded extracts. The researcher achieved this by rechecking identified themes against the extracted data. The secondary reviewer reviewed the themes and coded extracts independently. The reviewed themes and codes were then compared, discussed, and agreed upon before proceeding to the next phase of defining and naming themes.

Phase 5: Defining and Naming Themes

The researcher achieved this through ongoing analysis to refine the specifics of each theme and generated clear definitions and names for each theme. The secondary reviewer was consulted throughout this phase.

Phase 6: Producing the Report

Phase 6 was the final opportunity for the researcher to relate the analysis back to the research questions and the literature to produce a scholarly report of the analysis. A discussion was presented in a summarising paragraph that inferred the findings and reported on limitations of the research and recommendations for future studies in the field. The thematic analysis was conducted by the researcher and study leader independently. Ensuring intercoder reliability is critical in qualitative research (Braun & Clarke, 2019).

Ethical Considerations

The researcher obtained ethical approval (NWU-00097-22-A1) before the research study was conducted. The research study was classified as a no risk study by the Health Research Ethics Committee (HREC) at the North-West University. This rapid review research study involved reviewing available scientific literature, which tends to be bound by ethics (Ganann et al., 2010). Furthermore, this research study did not involve collecting data directly from human subjects. Therefore, the research study was considered as a no risk study.

The two reviewers for the research study were the researcher/primary reviewer (Razina Shaik, MA Clinical Psychology student) and the study leader/secondary reviewer (Mrs Lelanie Malan). The researcher/primary reviewer has attended and completed a relevant course titled *Basics of Research Integrity and Health Research Ethics* at North-West University, presented by the HREC in 2020. The researcher/primary reviewer is registered with the Health Professions Council of South Africa (HPCSA) as an intern clinical psychologist working under supervision. The study leader/secondary reviewer (Mrs Lelanie Malan) is a senior lecturer at North-West University and is registered with the HPCSA as both a Clinical and Research Psychologist. Mrs Lelanie Malan has attended the *Basics of Research Integrity and Health Research Ethics* training during 2020. Both the researcher and study leader worked collaboratively throughout the research process. Moreover, Prof Werner de Klerk, who is the co-leader of the research study, was consulted throughout the research process. Prof Werner de Klerk (Associate Professor and Registered Research Psychologist) has completed the Training and Resources in Research Ethics Evaluation (TRREE) online course (2021) as requested by HREC.

Furthermore, the research study followed the ethical principles recommended by Wager and Wiffen (2011), which include avoiding duplication, avoiding plagiarism and ensuring transparency. The researcher thus made a conscious effort to ensure accuracy, scientific integrity and that all ethical principles were adhered to. The above-mentioned is further elaborated on below.

Rigour

To ensure the rigour of findings, the researcher adhered to the rapid review methodology. The rapid review methodology involved refining the review question, which was achieved by the primary researcher in consultation with the study leader. Thereafter, according to rapid review methodology, a scope review was conducted, which involved consultation with a North-West University librarian, to identify possible scientific literature and test feasibility of the research study. Subsequently, inclusion and exclusion criteria were stipulated to mitigate researcher bias in the selection of scientific literature (Higgins et al., 2019). The use of two reviewers, in adherence to rapid review methodology, further mitigated the risk of bias (Ganann et al., 2010).

To ensure accuracy, Wager and Wiffen (2011) further suggest that at least two authors review the data extraction process. Therefore, the primary reviewer and secondary reviewer both screened the identified scientific literature independently for relevance. The JBI critical appraisal tool was then applied to assess the quality of scientific literature identified. Thereafter, thematic analysis of the final selection of scientific literature was done inductively and independently by the researcher and was subsequently reviewed by the study leader and co-leader as reviewers. Lastly, the evidence was synthesised, and findings were reported accurately. Moreover, according to the literature, rapid reviews should be transparent and replicable (Ganann et al., 2010). Therefore, the above-mentioned ensured that the research study was transparent and replicable.

Credibility was ensured by participating in prolonged engagement with the identified scientific literature. The primary researcher achieved this by reading and re-reading the scientific literature identified, thus ensuring prolonged engagement and familiarisation with identified scientific literature. Moreover, to ensure that researcher bias did not affect the credibility of the study, the secondary researcher continuously monitored the primary researcher’s progress and findings.

Scientific integrity was ensured by adhering to the ethical principles of avoiding duplication (Wager & Wiffen, 2011), which entailed that no rapid review studies were included in the selected scientific literature. The researcher avoided plagiarism by adhering to the appropriate use of in-text citations and providing a complete and accurate reference list. The researcher adhered to the APA 7th edition referencing guidelines. To further ensure scientific integrity, the mini-dissertation was submitted to turn-it-in, to assess for plagiarism.

This meant that all scientific literature utilised in the review study was published sources, thereby avoiding plagiarism by acknowledging and appropriately citing and referencing all authors (Wager &Wiffen, 2011).

Conclusion

In conclusion, this section consisted of a comprehensive literature overview. This literature overview contextualised the research study to enable the reader to gather insight about the research study. The relevant concepts informing the research study, the problem statement, the purpose of the research study, and the chosen methodology were explored and explained in detail. Lastly, the researcher reflected on the ethical considerations, and discussed the way in which the researchers adhered to ethical issues throughout the research study.

References

Abubakar, A., Ssewanyana, D., & Newton, C. R. (2016). A systematic review of research on autism spectrum disorders in Sub-Saharan Africa. *Behavioural Neurology, 2016*, 1–14. https://doi.org/10.1155/2016/3501910

Adashek, J. J., & Subbiah, I. M. (2020). Caring for the caregiver: A systematic review characterising the experience of caregivers of older adults with advanced cancers. *European Society for Medical Oncology Open*, *5*(5), e000862. https://doi.org/10.1136/esmoopen-2020-000862

Altan Sarikaya, N., Oz, S., & Ozturk, S. (2021). Perceptions of loneliness and well-being of psychiatric patients' families. *Perspectives in Psychiatric Care*, *57*(4), 1806–1811. https://doi.org/10.1111/ppc.12753

American Psychiatric Association (APA). (2013). *Diagnostic and Statistical Manual of Mental Disorders* (5th ed.). APA. https://doi.org/10.1176/appi.books.9780890425596

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. https://doi.org/10.1080/2159676x.2019.1628806

Bravo-Benítez, J., Pérez-Marfil, M. N., Román-Alegre, B., & Cruz-Quintana, F. (2019). Grief experiences in family caregivers of children with autism spectrum disorder (ASD). *International Journal of Environmental Research and Public Health*, *16*(23), 4821. https://doi.org/10.3390/ijerph16234821

Cacioppo, J. T., & Cacioppo, S. (2018). The growing problem of loneliness. *The Lancet, 391*(10119), 426, https://doi.org/10.1016/S0140-6736(18)30142-9

Cardon, A., & Marshall, T. (2021). To raise a child with autism spectrum disorder: A qualitative, comparative study of parental experiences in the United States and

Senegal. *Transcultural Psychiatry*, *58*(3), 335–350. https://doi.org/10.1177/1363461520953342

Carpenter, L., & Austin, H. (2007). Silenced, silence, silent: Motherhood in the margins. *Qualitative Inquiry*, *13*(5), 660–674. https://doi.org/10.1177/1077800407301179

Chan, K. K. S., & Lam, C. B. (2018). Self-stigma among parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *48*, 44–52. https://doi.org/10.1016/j.rasd.2018.01.001

Currie, G., & Szabo, J. (2020). Social isolation and exclusion: The parents' experience of caring for children with rare neurodevelopmental disorders. *International Journal of Qualitative Studies on Health and Well-Being*, *15*(1725362), 1–10. https://doi.org/10.1080/17482631.2020.1725362

Durkin, M. S., Elsabbagh, M., Barbaro, J., Gladstone, M., Happe, F., Hoekstra, R. A., Lee, L. C., Rattazzi, A., Stapel-Wax, J., Stone, W. L., Tager-Flusberg, H., Thurm, A., Tomlinson, M., & Shih, A. (2015). Autism screening and diagnosis in low resource settings: Challenges and opportunities to enhance research and services worldwide. *Autism Research*, *8*(5), 473–476. https://doi.org/10.1002/aur.1575

Franz, L., Adewumi, K., Chambers, N., Viljoen, M., Baumgartner, J. N., & De Vries, P. J. (2018). Providing early detection and early intervention for autism spectrum disorder in South Africa: Stakeholder perspectives from the Western Cape province. *Journal of Child and Adolescent Mental Health*, *30*(3), 149–165. https://doi.org/10.2989/17280583.2018.1525386

Ganann, R., Ciliska, D., & Thomas, H. (2010). Expediting systematic reviews: Methods and implications of rapid reviews. *Implementation Science*, *5*, 1–10. http://www.implementationscience.com/content/5/1/56

Garritty, C., Gartlehner, G., Nussbaumer-Streit, B., King, V. J., Hamel, C., Kamel, C., Affengruber, L., & Stevens, A. (2021). Cochrane Rapid Reviews Methods Group offers evidence-informed guidance to conduct rapid reviews. *Journal of Clinical Epidemiology*, *130*, 13–22. https://doi.org/10.1016/j.jclinepi.2020.10.007

Gordon, T., Booysen, F., & Mbonigaba, J. (2020). Socio-economic inequalities in the multiple dimensions of access to healthcare: The case of South Africa. *BMC Public Health*, *20*, 289. https://doi.org/10.1186/s12889-020-8368-7

Higgins, J. P., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M. J., & Welch, V. A. (Eds.). (2019). *Cochrane handbook for systematic reviews of interventions*. John Wiley & Sons.

Hume, K., Steinbrenner, J. R., Odom, S. L., Morin, K. L., Nowell, S. W., Tomaszewski, B., Szendrey, S., McIntyre, N. E., Yücesoy-Özkan, S., & Savage, M. N. (2021). Evidence-based practices for children, youth, and young adults with autism: third generation review. *Journal of Autism and Developmental Disorders*, *51*(11), 4013–4032. https://doi.org/10.1007/s10803-020-04844-2

Karst, J. S., & Van Hecke, A. V. (2012). Parent and family impact of autism spectrum disorders: A review and proposed model for intervention evaluation. *Clinical Child and Family Psychology Review*, *15*(3), 247–277. https://doi.org/10.1007/s10567-012-0119-6

Knapp, M., Romeo, R., & Beecham, J. (2009). Economic cost of autism in the UK. *Autism*, *13*(3), 317–336. https://doi.org/10.1177/1362361309104246

Lai, W., Goh, T. J., Oei, T. P. S., & Sung, M. (2015). Coping and well-being in parents of children with autism spectrum disorders (ASD). *Journal of Autism and Developmental Disorders*, *45*(8), 2582–2593. https://doi.org/10.1007/s10803-015-2430-9

Lainhart, J. E. (2015). Brain imaging research in autism spectrum disorders: In search of neuropathology and health across the lifespan. *Current Opinion in Psychiatry*, *28*(2), 76–82. https://doi.org/10.1097/YCO.0000000000000130

McGuire, A. (2015). Diagnosing the diagnostic and statistical manual of mental disorders. *Disability & Society*, *30*(10), 1582–1585. https://doi.org/10.1080/09687599.2015.1062233

Malabanan, E., & Bayeng, A. (2019). Level of satisfaction and utilization of EBSCOhost among UPHSL students and faculty. *Digital Library Perspectives*, *35*(3/4), 205–215. https://doi.org/10.1108/dlp-03-2019-0009

Nicholas, D., Zwaigenbaum, L., Ing, S., MacCulloch, R., Roberts, W., McKeever, P., & McMorris, C. A. (2016). “Live It to Understand It.” *Qualitative Health Research*, *26*(7), 921–934. https://doi.org/10.1177/1049732315616622

Olagunju, A., Oshodi, Y., Umeh, C., Aina, O., Oyibo, W., Lamikanra, A., Lesi, F. A., & Adeyemi, J. (2017). Children with neurodevelopmental disorders: The burden and psychological effects on caregivers in Lagos, Nigeria. *Journal of Clinical Sciences*, *14*(1), 2–7. https://doi.org/10.4103/2468-6859.199162

Peters, M. D. J., Marnie, C., Tricco, A. C., Pollock, D., Munn, Z., Alexander, L., McInerney, P., Godfrey, C. M., & Khalil, H. (2020). Updated methodological guidance for the conduct of scoping reviews. *JBI Evidence Synthesis*, *18*(10), 2119–2126. https://doi.org/10.11124/JBIES-20-00167

Pillai, S., Makhetha, M., & Aldous, C. (2021). A study reflecting the demographics and comorbidities of children diagnosed with autism spectrum disorder at initial presentation to the Kwazulu-Natal children’s hospital. *SAJCH South African Journal of Child Health*, *15*(3), 125-129. https://doi.org/10.7196/SAJCH.2021.v15i3.01752

Pillay, S., Duncan, M., & De Vries, P. J. (2021). Autism in the Western Cape province of South Africa: Rates, socio-demographics, disability and educational characteristics in one million school children. *Autism*, *25*(4), 1076–1089. https://doi.org/10.1177/1362361320978042

Quinn, C., & Toms, G. (2019). Influence of positive aspects of dementia caregiving on caregivers' well-being: A systematic review. *Gerontologist, 59*(5), e584-e596 . https://doi.org/10.1093/geront/gny168

Raina, P., O'Donnell, M., Rosenbaum, P., Brehaut, J., Walter, S. D., Russell, D., Swinton, M., Zhu, B., & Wood, E. (2005). The health and well-being of caregivers of children with cerebral palsy. *Pediatrics, 115*(6), e626e636. https://doi.org/10.1542/peds.2004-1689

Reddy, G., Fewster, D. L., & Gurayah, T. (2019). Parents' voices: experiences and coping as a parent of a child with autism spectrum disorder. *South African Journal of Occupational Therapy*, *49*(1), 43–50. https://doi.org/10.17159/2310-3833/2019/vol49n1a7

Rosen, N. E., Lord, C., & Volkmar, F. R. (2021). The diagnosis of autism: From Kanner to DSM-III to DSM-5 and beyond. *Journal of Autism and Developmental Disorders, 51*(12), 4253–4270. https://doi.org/10.1007/s10803-021-04904-1

Ruparelia, K., Manji, K., Abubakar, A., & Newton, C. R. (2017). Investigating the evidence of behavioral, cognitive, and psychiatric endophenotypes in autism: A systematic review. *Autism Research and Treatment*, *2017*, 1–17. https://doi.org/10.1155/2017/6346912

Steinbrenner, J. R., Hume, K., Odom, S. L., Morin, K. L., Nowell, S. W., Tomaszewski, B., Szendrey, S., & Mcintyre, N. S. (2020). *Evidence-based practices for children, youth, and young adults with autism.* Evidence-Based Practices for Children, Youth, and Young Adults with Autism. The University of North Carolina at Chapel Hill, Frank Porter Graham Child Development Institute, National Clearinghouse on Autism Evidence and Practice Review Team., 1–140.

The Joanna Briggs Institute. (2015). *The Joanna Briggs Institute Reviewers' Manual 2015: Methodology for JBI scoping reviews.* Joanna Briggs Institute.

Tricco, A. C., Antony, J., Zarin, W., Strifler, L., Ghassemi, M., Ivory, J., Perrier, L., Hutton, B., Moher, D., & Straus, S. E. (2015). A scoping review of rapid review methods. *BMC Medicine*, *13*(1), 1-15. https://doi.org/10.1186/s12916-015-0465-6

Vasileiou, K., Barnett, J., Barreto, M., Vines, J., Atkinson, M., Lawson, S., & Wilson, M. (2017). Experiences of loneliness associated with being an informal caregiver: A qualitative investigation. *Frontiers in Psychology*, *8*, 585. https://doi.org/10.3389/fpsyg.2017.00585

Viljoen, M., Mahdi, S., Griessel, D., Bölte, S., & De Vries, P. J. (2019). Parent/caregiver perspectives of functioning in autism spectrum disorders: A comparative study in Sweden and South Africa. *Autism*, *23*(8), 2112-2130. https://doi.org/10.1177/1362361319829868

Wager, E., & Wiffen, P. J. (2011). Ethical issues in preparing and publishing systematic reviews. *Journal of Evidence-Based Medicine*, *4*(2), 130-134. https://doi.org/10.1111/j.1756-5391.2011.01122.x

Williams, K. J., & Murray, D. W. (2015). Negotiating the normative: The other normal for mothers of disabled children. *Journal of Family Studies*, *21*(3), 324–340. https://doi.org/10.1080/13229400.2015.1098560

World Health Organization (WHO). (2022). *World Health Organisation: Autism.* WHO. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders

Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Research*, *15*(5), 778-790. https://doi.org/10.1002/aur.2696

SECTION 2: MANUSCRIPT

As part of the mini dissertation, the following manuscript will be submitted for possible publication in the *Journal of Psychology in Africa.* However, for the purpose of examination, APA 7th edition guidelines will be followed.

MANUSCRIPT

Running Head: LONELINESS EXPERIENCED BY PRIMARY CAREGIVERS OF CHILDREN WITH AUTISM SPECTRUM DISORDER

A rapid review of loneliness experienced by primary caregivers of children with autism spectrum disorder

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Abstract

Caregiving a child with Autism Spectrum Disorder (ASD) is associated with many challenges that affect caregivers' experiences of loneliness. Due to the treatment outcomes of children with ASD being closely connected with the health and well-being of their caregivers, caring for the carer then becomes paramount. This rapid review research study reports on the findings of current scientific literature on the experiences of loneliness of caregivers when caring for a child with ASD. A final sample of 13 studies was included and analysed thematically, and the following four main themes emerged regarding the experiences of loneliness of caregivers of children with ASD: (1) Burden of care and challenges experienced by caregivers; (2) Social isolation and social interactions that play a role in the experiences of loneliness; (3) Stigma and discrimination that impact on the experiences of loneliness; and (4) Coping mechanisms alleviating the experiences of loneliness. Given the above-mentioned, the study recommends that future research should focus on caring for the carer. The study further recommends that future interventions of ASD should be holistic when creating awareness of ASD and thereby consider providing for social inclusion and social support for the caregivers of children with ASD, thus alleviating their sense of loneliness. The findings of the research study could assist health professionals in the psychological health promotion of caregivers and ultimately ensuring positive treatment outcomes for the child with ASD.

Keywords: Autism Spectrum Disorder, caregiver, child, experiences, loneliness, rapid review, social isolation.

Introduction

Autism spectrum disorder (ASD) is a complex neuro-developmental condition that involves persistent challenges in social interaction, speech, and non-verbal communication across multiple contexts (McGuire, 2015). According to the Diagnostic and Statistical Manual of Mental Disorders 5th Edition (DSM-5), autism is a “spectrum” condition (American Psychiatric Association [APA], 2013). Therefore, impairments and severity of social interaction, speech and non-verbal communication challenges of ASD will differ across the spectrum (Knapp et al., 2009). Some children who are diagnosed with ASD may have average or above-average intelligence and need little support to function independently, while other children may have severe intellectual disability, limited or no verbal communication, and very limited adaptive behaviour (Steinbrenner et al., 2020). Therefore, the amount of physical and emotional support that a child diagnosed with ASD will need varies across the spectrum (Knapp et al., 2009). Furthermore, as ASD is a spectrum condition with a range of disabilities, the DSM-5 has also included the classification of the range of support an autistic individual would need in activities of daily living, which is that of “requiring support”, “requiring substantial support”, or “requiring very substantial support” (APA, 2013).

The prevalence of ASD has been rising in many countries (Zeidan et al., 2022). Therefore, in low-resource settings like South Africa, the World Health Organization (WHO, 2022), has identified caregivers as a critical resource in ensuring positive treatment outcomes for children with ASD. Although caregivers have been highlighted as a critical resource, they remain undervalued and overlooked (Chan & Lam, 2018; Reddy et al., 2019; Samadi et al., 2022). Most interventions for ASD are evaluated only in terms of child outcomes, ignoring caregiver factors, such as loneliness (Vasileiou et al., 2017). Attention is thus drawn to the aspect of loneliness as it may have an influence on both the immediate and long-term outcomes of interventions for children with ASD (Pendergrass et al., 2019). Although previous research has identified loneliness as a factor associated with being an informal caregiver (Schulz & Tompkins, 2010), there is a paucity of evidence that seeks to understand loneliness as a phenomenon in depth (Vasileiou et al., 2017).

The literature thus revealed that caregivers are faced with numerous challenges that are unique to ASD which play a role in caregivers' experiences of loneliness (Cardon & Marshall, 2021). These challenges include but are not limited to the caregiving demands when catering for the ritualistic needs of the child with ASD (Hillman & Anderson, 2019). Limited resources and a lack of services for ASD also pose as challenges for caregivers as they feel excluded, uncertain, and alone (Reddy et al., 2019; Wei et al., 2021). Caregivers are further challenged when confronted with stigma, discrimination, and negative reactions from society for having a child with ASD (Bravo-Benítez et al., 2019; Chan & Lam, 2018). Consequently, caregivers experience struggles with social interactions resulting in social isolation, social withdrawal, and ultimately social exclusion (Currie & Szabo, 2020).

Problem Statement

The above-mentioned challenges thus have implications for the experiences of loneliness of caregivers, which ultimately pose a risk to caregivers' well-being and the treatment outcomes for children with ASD (Altan Sarikaya et al., 2021; Cardon & Marshall, 2021; Currie & Szabo, 2020; Olagunju et al., 2017; Schulz & Sherwood, 2008). The literature highlighted that further research into the aspect of loneliness was needed for possible interventions that mitigate for these challenges, thereby considering these caregivers as they navigate their way through providing care for their child with ASD, whilst managing their own requirements of daily living (Olagunju et al., 2017). The literature further revealed that there is a scarcity of interventions that provide social support and social inclusion which could assist in alleviating caregivers' sense of loneliness (Reddy et al., 2019).

Goal of the Research Study

Therefore, the goal of the research study was to synthesise the available scientific evidence on the experiences of loneliness of caregivers of children with ASD. The following research questions guided this review research study: *What evidence is available from the scientific literature on the experiences of loneliness of primary caregivers of children with ASD? How could this evidence inform our understanding to make appropriate recommendations for the psychological health promotion of primary caregivers of a child with ASD?*

Method

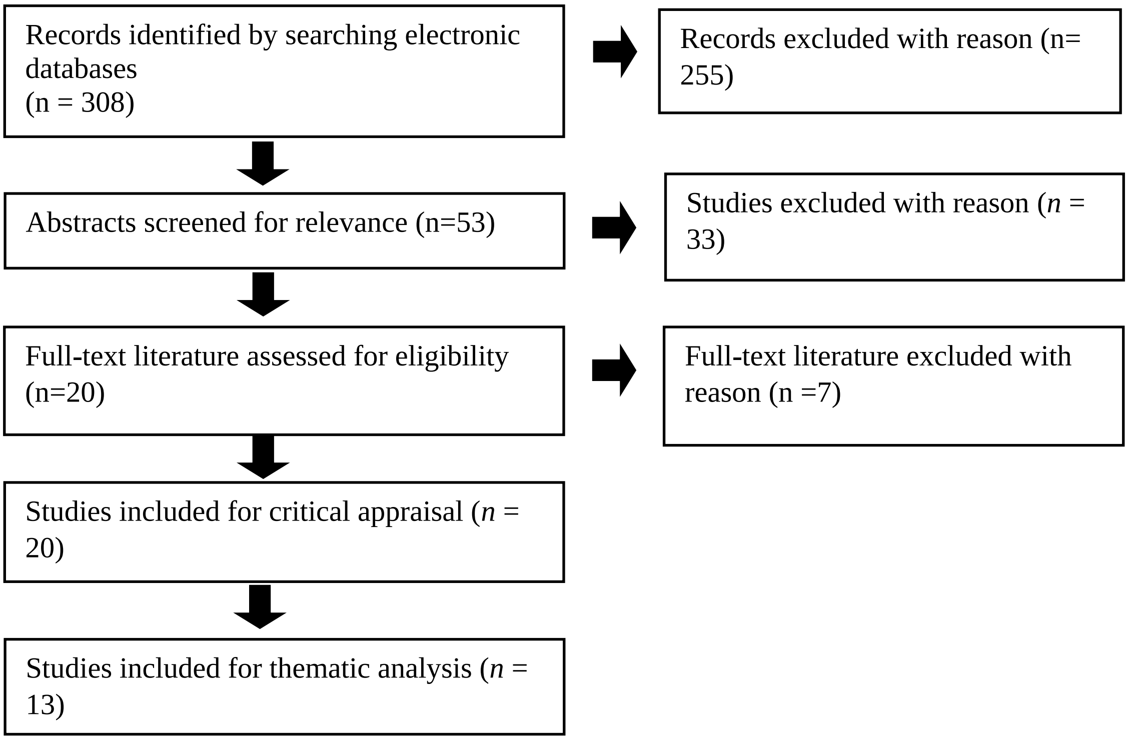
Research Approach and Design

A rapid review (Du Toit & De Klerk, 2022) of scientific literature was used for this research study, in order to identify relevant, peer-reviewed, scientific literature on the experiences of loneliness of caregivers of children with ASD. All scientific literature based on the following keywords was used, “loneliness”, “social isolation”, “social exclusion”, “lonely”, “caregiver”, “parents”, “mother”, “father”, “grandparents”, “sibling”, “guardian”, “autism continuum”, “ASD”, “child”, “children”. Boolean operators were used, such as “AND”, “NOT”, “*”, and “OR” to produce more appropriate results and to identify scientific literature relevant to the research study to search for peer-reviewed literature published in books, Master’s dissertations, doctoral theses, and scholarly journals with full text, in databases such as PsycINFO, MEDLINE, JSTOR Journals and American Doctoral Dissertations. A Google Scholar search was also utilised for completeness and to supplement the structured search.

The time frame used for this rapid review research study was for scientific literature published from 1994 to 2021. For the target population of the research study, the caregivers aged 18 years and older responsible for a child aged 2 to 18 years old with ASD were studied. This was justified by the aim of the research study, which was to synthesise and evaluate the current scientific literature on the experiences of loneliness of caregivers of children with ASD within the South African context and, in so doing, to inform our understanding for future research. Literature focusing on aspects other than caregiver experiences of loneliness was deemed as irrelevant and excluded. Initially, the search yielded 53 results. However, as illustrated in Figure 1, only 13 of the identified studies were finally included for review in this research study. Studies were excluded due to not meeting the inclusion criteria, not containing the research study's keywords, and further excluded were studies that were deemed irrelevant in answering the research questions of the study.

Figure 1

Identifying Relevant Scientific Literature for inclusion



Hereafter a data extraction table was constructed to organise the data in a systematic way.

Table 1

Data Extraction Table

Author(s), Title and Year	**Aim, Approach and Sample**	**Main Results/Findings**	**Conclusion**
Cardon & Marshall (2021) *To raise a child with autism spectrum disorder: A qualitative, comparative study of parental experiences in United States and Senegal*	*Aim:* To investigate parental experiences within the Senegalese community from a cross-cultural perspective. To compare themes related to parental caregiving for children with ASD between sub-Saharan African culture and Western culture (USA). *Approach:* Qualitative approach. *Sample:* n=14 caregivers of children with ASD: 7 mothers (USA); 3 mothers (Senegal); 2 fathers (Senegal); 1 grandmother (Senegal); 1 sister (Senegal).	Notable differences were reported in social and community support. Access to effective treatment services was insufficient among Senegalese families compared to American families. Senegalese traditional households and community bonds served as protective factors against social isolation and associated struggles reported in the USA sample.	This study reported on cultural and contextual variables in the Senegalese and the USA sample, which could affect parental experience when caring for a child with ASD. No instances of negative stigma were reported among the Senegalese; however, the Senegalese participants did express the challenges faced as caregivers and their support needs. The Senegalese first consulted local traditional healers for treatment of ASD. Spiritual and cultural beliefs thus played a role in the experiences of Senegalese caregivers of children with ASD. The study indicated a need for professionals to address these topics by communicating in an empathic and sensitive manner. The study indicated that social support among the Americans may be inadequate compared to the Senegalese, therefore this need in the USA should be addressed.
Cloete & Obaigwa (2019)	*Aim:* To explore the perspectives of caregivers who are responsible for caring for both family and children living with ASD and to	The prominent theme identified was the burden of care. Caregivers expressed their challenges with emotional dilemmas and the difficulties experienced with accessing	This study aimed to understand the everyday experiences of caregivers. Spiritual and cultural beliefs about the causes of ASD strongly influence the

Author(s), Title and Year	Aim, Approach and Sample	Main Results/Findings	Conclusion
Lived experiences of caregivers of children with autism spectrum disorder in Kenya	highlight the needs of children with ASD as well as the needs of their caregivers. *Approach:* Qualitative approach. *Sample:* n=24 caregivers; of which n= 1 Grandmother as caregivers of children diagnosed with ASD. n= 300 children with ASD who were attending the occupational therapy clinic at the hospital during the period of the study between June and July 2015.	vital services in the management of children with ASD. Findings further reveal that caregivers experienced social isolation and stigmatisation due to societal views that ASD as a punishment from the Gods. Mothers were blamed for having a child with ASD, causing further strain on marital relationships. The difficulty of accessing services was another theme identified by the study but not adequately reported on.	experiences of caregivers of children with ASD. Mothers were blamed for having a child with ASD and experienced rejection from partners, family, and community. Negative views on ASD impacted the development of care initiatives for children with ASD and their caregivers.
Dababnah & Parish (2013) *"At a moment, you could collapse”: Raising children with autism in the West Bank*	*Aim:* to understand the first-hand perspectives on caregiving experiences of caring for a child with ASD in the West Bank. *Approach*: Qualitative approach. *Sample:* n=24 Palestinian parents (20 Mothers; 4 fathers) of children aged 4-17, (14 boys and 8 girls), diagnosed with ASD. Participants were recruited in partnership with Palestinian National team for Autism.	The study found that parents reported high levels of emotional and financial burden due to caregiving and negative reactions from their extended families and communities. Some families displayed notable resilience while most struggled with daily challenges. The overall findings discovered that parents were exposed to psychological, emotional, and financial stressors.	Parents were unaware of ASD before their children's diagnoses. Discrimination, stigma and diagnosis denial by extended family members and the community deepened parents' feelings of shame and experiences of social isolation. Some parents coped by withdrawing, others increased social interactions and accessed information. Religion was found to be a coping mechanism for some of the participants. The study emphasised the importance of creating community awareness of ASD and the need for social support for parents in the West Bank.

Author(s), Title and Year	**Aim, Approach and Sample**	**Main Results/Findings**	**Conclusion**
Devenish et al. (2020) *A brief report: Community supportiveness may facilitate participation of children with Autism Spectrum Disorder in their community and reduce feelings of isolation in their caregivers*	*Aim*: To examine caregiver perceptions of community supportiveness and child participation and to examine the relationship between caregiver perceptions of community supportiveness and caregiver stress. *Approach:* Quantitative approach. *Sample:* n=48 children diagnosed with ASD (aged 5–12 years), and their caregivers (30 mothers; 9 fathers; 9 caregivers not reporting their gender). Caregivers reported on ASD symptom severity, adaptive functioning, and caregiver stress.	The study compared findings on child community attendance, child community involvement, and caregiver stress. The findings reported that most of the caregivers believed that environments did not support their child's participation, regardless of their child's symptom severity. The involvement of children was predicted by the support of the community. Caregivers who experienced a lack of community supportiveness experienced high levels of caregiver isolation.	The findings suggest that lower perceived levels of community supportiveness may lessen the involvement of children with ASD in community activities and increase feelings of isolation in their caregivers. The study provides awareness of the importance of amending community programmes to facilitate engagement, support for inclusion and participation of children with ASD. Increasing community support may therefore, also decrease caregivers' isolation.
Gosztyłe & Prokopiak (2019) *Mediating role of lack of support for the relationship between extraversion*	*Aim:* The purpose of this study was to verify the mediating role of received and perceived available social support in the relationship between extraversion and a sense of loneliness in parents of children with ASD and parents of children with Intellectual Disability (ID).	The study confirmed that perceived available support mediated the relationship between extraversion and a sense of loneliness in parents of children with ASD. The study found that extraversion in parents lessens their sense of loneliness when they perceive that social support is available. In the sample of parents of children with ID, perceived available support also mediated the relationship	The evidence from the study revealed the role of parents' subjective view on the availability of help from others. This indicates that perceived social support is more important for the psychological well-being of the parents than the support received. The study identified the need for social support and the need to build resources to inform parents about the

Author(s), Title and Year	**Aim, Approach and Sample**	**Main Results/Findings**	**Conclusion**
and sense of loneliness in parents of children with autism	*Approach:* Quantitative approach *Sample:* n=279 participants: 168 parents of children with ASD and 111 parents of children with ID, without autistic traits (231= mothers; 48=fathers participated in the study).	between extraversion and the sense of loneliness.	possibility and availability of forms of assistance in the immediate environment.
Hillman & Anderson (2019) *It's a battle and a blessing: The experience and needs of custodial grandparents of children with Autism Spectrum Disorder.*	*Aim:* To examine the first-person perspective of custodial grandparents of children with ASD including their sources of both stress and joy and to generate recommendations regarding how to best support these caregivers. *Approach:* Qualitative approach. *Sample:* n=117 custodial grandparents who serve as primary caregivers of children with ASD from 37 states (USA): 108 grandmothers; 9 grandfathers.	Grounded theory analysis revealed four overarching categories of experience (issues with adult children, caregiving burden, coping, and wisdom), these were further explained by 15 themes. The caregiver burden involved multiple challenges. Grandparents used various coping methods, including religion and firm moral beliefs. Grandparent as caregivers acknowledged the importance of being connected to friends, neighbours, and care providers in a combined effort to raise their grandchild.	The study reports that grandparents who serve as primary caregivers to their grandchild diagnosed with ASD provided safety and security for their grandchildren who would otherwise have been in foster care. Grandparents reported challenges with custody, ASD problem behaviours such as tantrums and eloping, insufficient ASD services, financial burden, 24/7 caregiving demands, social isolation, and fears for the future. Grandparents' coping included celebrations of progress, unconditional love, faith, and a positive focus. Grandparents' wisdom involved patience and insight. Recommendations were made for policy-makers and practitioners to provide a social net of support for these caregivers.
Ijalba. (2016)	*Aim:* To understand the experiences of raising a child with	Mothers expressed similar experiences their challenges, expectations and concerns	Hispanic immigrant mothers raising children with autism were often faced with challenges of their immigration status,

Author(s), Title and Year	**Aim, Approach and Sample**	**Main Results/Findings**	**Conclusion**
Hispanic immigrant mothers of young children with Autism Spectrum Disorders: How do they understand and cope with Autism?	ASD in a group of Hispanic immigrant mothers. *Approach:* Qualitative approach. *Sample:* n= 22 primary caregivers of children diagnosed with ASD: 10 Mothers (Mexico); 10 Mothers (Dominican Republic); 1 mother (Peru); 1 mother (Ecuador) who resided in USA for 11 years on average. N=4 mothers were single heads of households.	for their children. Three thematic categories emerged: Stigmatisation and isolation, Preconceptions about developmental milestones and ASD, and Mothers' Reluctance to speak Spanish with their children. All mothers in the study reported social isolation, stigmatisation, and a desire to be accepted. The lack of awareness of ASD contributed to social isolation for these mothers. Many mothers trusted in their religious faith to cure their children. They expressed cultural and personal beliefs about the nature of autism. Professional advice led mothers to believe that learning two languages could delay their child's language acquisition.	economic hardships, and advice against using Spanish with their children. A lack of awareness about autism played a role in social isolation. Autism was further viewed as temporary and associated with fear or sadness. It is important in evidence -based practice, to understand the caregivers' beliefs and perspectives and integrate these with research evidence and clinical expertise. Caregivers should therefore be encouraged to use their home language with their children. The study indicates that bilingualism supports cognitive and social domains. Professional training and parent education are required for the early identification of ASD. Parent education should be inclusive of other family members who could be sources of social support and affect decision-making in Hispanic families. Information about ASD should be spread through community outreach, home–school networks, and paediatricians, who remain key in informing Hispanic immigrant families.
Koukouriki et al. (2021) *Feelings of loneliness and*	*Aim:* To investigate the feelings of loneliness and social dissatisfaction in school-aged typically developing (TD) siblings of children with ASD.	The study found that siblings as caregivers of ASD children had significantly greater feelings of loneliness and social dissatisfaction compared to siblings of TD	Siblings caregivers of children diagnosed with ASD share the burden of responsibility for the child with ASD. Sibling caregivers might have limited access to opportunities for participation in

Author(s), Title and Year	Aim, Approach and Sample	Main Results/Findings	Conclusion
social dissatisfaction in siblings of children with Autism Spectrum disorders: The role of birth order and perceived social support.	*Approach:* Quantitative approach. *Sample:* n=233 siblings: 118 siblings of children with ASD; 56 Males; 59 Females and 115 siblings of TD children; 59 males. 59 Females and their parents participated in the study.	children, immaterial of the sibling's gender and other demographics.	social activities. Feelings of loneliness in ASD siblings were found to be linked with two aspects of social support. The social support received from the family itself and the social support received from friends. The study exposes ASD siblings' feelings of loneliness and provides some significant factors that might be useful when implementing intervention programmes that aim to address the needs of siblings and ultimately all family members of ASD children.
Lu et al. (2021) *Perceived social support and life satisfaction of Chinese Parents of children with autism spectrum disorder: loneliness as a mediator and moderator*	*Aim:* The study aims to explore the role of loneliness by investigating the relationships and mechanism between perceived social support, loneliness, and life satisfaction among Chinese parents of children with ASD. *Approach:* Quantitative approach. *Sample:* n=306 parents: 258 mothers and 48 fathers of children with ASD, in Guangzhou province, mainland China.	Perceived social support was meaningfully associated with loneliness and life satisfaction. Loneliness both mediated and moderated the relationship between perceived social support and life satisfaction. The findings indicate that to mitigate transient feelings of loneliness, it is important not only to provide parents with support but also to improve their satisfaction with social support and perceptions of the general availability of social support. Largely a non- judgemental social environment that allows social interaction and enhances a sense of connectedness and belonging should be formed and facilitated.	Formal support systems should be heightened to meet the unique needs of children with ASD thereby easing the challenges faced by their families. This study suggests that high levels of perceived social support and low levels of loneliness are socio-psychological resources that could be targeted to enhance the life satisfaction of Chinese parents of children with ASD.

Author(s), Title and Year	**Aim, Approach and Sample**	**Main Results/Findings**	**Conclusion**
Mahmood et al. (2015) *Coping strategies of mothers with ASD children.*	*Aim:* To explore mothers' coping practices with Children with ASD in Rawalpindi. *Approach:* Qualitative approach. *Sample:* n=10 mothers of children with ASD in Rawalpindi.	Findings generated two categories of coping. The positive/healthy and the negative/impaired coping strategies. The Positive coping strategies were a) Integration b) Networking c) Religion and the Negative coping strategies were a) Avoidance b) Ignorance c) Isolation.	The overall findings indicated that mothers reported experiencing social stigma and victim blaming. These were the main stressors shared by all the mothers in the study. Mothers employed coping strategies of educating themselves and integrating the ASD child into daily family routines. Findings indicated feelings of shock, grief, and acceptance were part of the mothers' reactions, to their child's autism diagnosis.
Navot et al. (2017) *Maternal experience raising girls with Autism Spectrum Disorder: a qualitative study.*	*Aim:* To investigate the maternal experience of raising a daughter diagnosed with ASD with normal intelligence and functional verbal communication. *Approach:* Qualitative approach. *Sample:* n= 11 mother-daughter dyads. Families were diverse in economic status. All mothers were working part/full time. 9 mothers married to daughter's biological father; 1 divorced/single; 1 divorced/remarried; Daughters were between 10-19 years old.	Results were clustered into two main sections, maternal experiences of raising a daughter with ASD and impact of ASD on the mother-daughter relationship. The themes identified were scepticism and delayed diagnosis, disbelief from others, a lack of information about girls with ASD, higher social demands in adolescence, puberty challenges around hygiene, disappointment about physical appearance, vulnerability in relationships and worries about future functioning. Mothers reported feelings of being excluded from the male-dominant ASD population and expressed a transformation in their relationship with their daughters. The mother-daughter relationship started with an early expectation of a close and intimate	The findings of this qualitative study highlighted the impact of gender on the maternal experience of raising a daughter with ASD. The study further contributes to an informed understanding of the needs of both mothers and daughters. The results can help providers support the mother-daughter dyad by recognising gender-specific challenges. The study indicated that ASD diagnosis in girls challenged maternal competence, reshaped maternal expectations of raising a girl, and created a different bond between mother and daughter.

Author(s), Title and Year	Aim, Approach and Sample	Main Results/Findings	Conclusion
		relationship with their daughter that then had to be adapted due to the ASD diagnosis.	
Semigina & Stoliaryk (2022) *“It was a shock to the whole family”: Challenges of Ukrainian families raising a child with autism.*	*Aim:* To examine to what extent families raising children with ASD are satisfied with the educational and social services in Ukraine and to identify the challenges in interactions of these families with services. *Approach:* Mixed method approach. *Sample:* n=90 parents of children diagnosed with ASD: 38 males; 52 females. All 90 were participants of the survey and 30 participated in the interviews.	The study found that the biggest challenges were related to staff preparedness, a lack of information about services available; unrealistic expectations from services; family experiences of emotional burnout; social stigma and social isolation of parents related to raising a child with ASD. Respondents evaluated the services they received, and inclusive education of ASD children, as unsatisfactory.	It is important for social workers to move away from assuming the expert role of a service provider and consider the need to collaboratively create intervention plans that are culturally sensitive and adapt to the needs of families raising children with developmental disabilities. Having verified information can help minimize parental stressors and combine their efforts, to assist in avoiding questionable treatments that are harmful to the child's health and are a financial burden to the family.
Zeman et al. (2011) *Strengths classification of social relationships among cyber mothers raising*	*Aim:* To add insight into how cyber mothers raising children with ASD experience their social relationships. To gain insight on aspects of social relationships that they perceive as inhibiting or as assisting. *Approach*: Qualitative approach.	The findings describe how mothers display their relationships on public blogs. These blogs may influence how other parents who browse the internet, searching for other sources of support, could understand their own relationships. These cyber mothers displayed intricate social worlds that included their emotional experiences, interpersonal relationships, and virtual interactions. Themes of inhibiting and	This study found that cyber mothers raising children with ASD are dynamic and complex individuals with strong commitments to their children. They experience intense frustration related to advocating for their child with ASD. In addition, they endure isolation for having a child with ASD. In the cyber world, these mothers viewed themselves and others as valuable resources for people

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children with Autism Spectrum Disorders	*Sample:* n=24 Blogs of cyber mothers (ages 32-45) of children (ages 5-9) diagnosed with ASD.	assisting relationships were identified. The themes that emerged under inhibiting factors were role strain and isolation. The themes that emerged under assisting factors were identified in the context of supportive relationships and partnerships that facilitate resilience.	searching for information on ways to foster success for their children.

Data Analysis

Thematic analysis enabled the researchers to examine the current available scientific literature on the experiences of loneliness of caregivers of children with ASD. This involved (1) Familiarising yourself with your data; (2) Generating initial codes; (3) Searching for themes; (4) Reviewing themes; (5) Defining and naming themes; and (6) Producing the report (Braun & Clarke, 2006). By employing these six steps proposed by Braun and Clark (2019) in a reflexive manner, thematic analysis allowed the researchers to identify recurrent patterns and themes within the available scientific literature, with the aim of linking these to the research questions and ultimately to generate a report on the findings, to inform our understanding and to make possible recommendations for future directions, thus achieving the aims of the rapid review study (Braun & Clarke, 2019).

Findings and Discussion

The following four themes emerged from the included studies: (1) Burden of care and challenges experienced by caregivers; (2) Social isolation and social interactions that play a role in the experiences of loneliness; (3) Stigma and discrimination that impact the experiences of loneliness; and (4) Coping mechanisms alleviating the experiences of loneliness.

Theme 1: Burden of Care and Challenges Experienced by Caregivers

The challenges associated with serving as a primary caregiver of a child with ASD pose a huge burden which plays a role in caregivers’ experiences of loneliness (Cardon & Marshall, 2021; Cloete & Obaigwa, 2019; Dababnah & Parish, 2013)**.** This was confirmed by a study conducted by Hillman and Anderson (2019), which captured the overwhelming challenges associated with serving as the primary caregiver and the implications these challenges have on the caregivers’ experiences of loneliness (Hillman & Anderson, 2019). The study found that grandparents who served as caregivers reported having struggles every day and just “[being] tired all the time” (Hillman &Anderson 2019). Caregivers experiencing chronic fatigue were further confirmed by other studies included in the review (Cardon & Marshall, 2021; Cloete & Obaigwa, 2019; Dababnah & Parish 2013). It was evident from these reviewed studies that chronic fatigue linked in with experiences of loneliness whereby caregivers were often too tired and lacked the energy to initiate or participate in social interactions with their own age peers (Hillman & Anderson, 2019). Consequently, caregivers remained socially isolated and withdrew further from social engagements, which directly contributed to them experiencing a sense of loneliness (Hillman &Anderson, 2019). In addition, these grandparents as caregivers indicated that their grandchild with ASD required constant supervision, regardless of the child’s age (Hillman & Anderson 2019). Thus, time constraints left no time for caregivers to have for themselves, or to connect with same age peers or for leisure activities, as the day was spent only in service of the child (Cardon & Marshall, 2021; Hillman & Anderson 2019), thereby increasing feelings of social isolation and ultimately experiences of loneliness (Cardon & Marshall, 2021).

Furthermore, grandparents, as caregivers, endured a huge financial burden in taking care of their grandchildren by making sacrifices for their grandchild’s ASD-related therapies and needs (Hillman & Anderson 2019). Grandparents in the study reported draining their retirement annuity and depleting their retirement funds, and having to go back to work to cover their grandchild’s expenses (Hillman & Anderson 2019). The financial sacrifices impacted on caregivers in that they did not have sufficient funds to cater for their social activities and outings, resulting in caregivers being restricted in opportunities to socialise, thereby isolating themselves and feeling alone (Hillman & Anderson, 2019). Other studies further confirmed the above findings whereby caregivers are forced to spend an excessive amount of time, attention, energy, and financial resources on the needs and routines of the child with ASD, which directly impacted on caregivers’ social life and psychological well-being by restricting caregivers' movements and opportunities for social inclusion (Cardon & Marshall, 2021; Dababnah & Parish, 2013; Semigina & Stoliaryk 2022), thus ultimately playing a role in these caregivers experiencing an increased sense of loneliness (Hillman & Anderson, 2019; Koukouriki et al., 2021; Lu et al., 2021; Semigina & Stoliaryk 2022). Furthermore, caregivers reported that they endured an emotional burden when taking care of children with ASD (Hillman & Anderson, 2019; Navot et al., 2017). Caregivers expressed experiencing feelings of shock, grief, guilt and self-blame, due to ASD being a life- long disability (Mahmood et al., 2015), requiring a life- time commitment of caregiving (Mahmood et al., 2015; Navot et al., 2017). Caregivers thus mourned the loss of the relationship they would have had with their child without the ASD diagnosis (Navot et al., 2017). Consequently, caregivers became withdrawn, felt excluded from parents with typically developing children and thus felt alone in this experience (Navot et al., 2017).

Moreover, the presence of a child with ASD in the family resulted in unique and bidirectional influences on the entire family system (Koukouriki et al. 2021; Mahmood et al., 2015). Siblings born after the child with ASD grow up in an ASD-oriented family environment with certain dynamics and functionality that have been shaped according to the needs and routines of the child with ASD (Cardon & Marshall, 2021; Koukouriki et al. 2021; Mahmood et al., 2015). The above left siblings feeling overlooked and isolated from their parents, which culminated in feelings of loneliness (Koukouriki et al., 2021; Mahmood et al., 2015). In addition, siblings assumed the role of caregivers to their sibling with ASD (Koukouriki et al., 2021; Mahmood et al., 2015). Siblings assisted with caregiving duties beyond that which was appropriate for their age (Lu et al., 2021; Mahmood et al., 2015; Semigina & Stoliaryk, 2022). Another study in this review further reported on siblings as caregivers experiencing a phenomenon known as "parentification" (Koukouriki et al., 2021), whereby siblings as caregivers have a load of responsibilities, such as increased household duties, caring for their affected sibling to allow free time for parents, and having to protect their sibling from hurting themselves or from being bullied by other children (Koukouriki et al., 2021; Lu et al., 2021; Mahmood et al., 2015; Semigina & Stoliaryk, 2022). The above left siblings as carers feeling lonely, socially excluded and isolated from their peers, due to the burden of caring that was imposed on them (Koukouriki et al., 2021; Mahmood et al., 2015). In addition, studies revealed that siblings as caregivers experience further isolation and loneliness as they are restricted in opportunities to participate in social clubs due to caregiving duties and the financial constraints imposed by the financial burden of the ASD child (Lu et al., 2021; Mahmood et al., 2015; Semigina & Stoliaryk, 2022). The review also revealed that siblings had low school attendance and performed poorly at school, due to their caregiving duties (Dababnah & Parish 2013). From the above it can be seen how the burden of care contributed to siblings feeling overwhelmed, socially excluded, socially isolated and ultimately experiencing a sense of loneliness (Koukouriki et al., 2021).

The study further found that mothers/women were seen as the gender responsible for carrying the burden of caregiver (Mahmood et al., 2015). Mothers as caregivers thus spent most of the day isolated with the child away from family and friends, resulting in experiences of loneliness (Mahmood et al., 2015). One mother in the study confirmed this when she reported that she felt isolated from her other children as she gave her ASD child more care and attention compared to her other children (Mahmood et al., 2015). Further findings revealed that the all-consuming role of the caregiver resulted in the neglect of other important tasks and further confirmed a lack of participation in social activities, which resulted in loneliness (Dababnah & Parish, 2013; Mahmood et al., 2015; Semigina & Stoliaryk, 2022). Another mother in one of the review studies demonstrated her experiences of role strain according to the specific roles she fulfilled. She wrote that she is okay, but just that she is very busy and that she is in need of a personal assistant, a secretary, a butler, a maid, a nanny, and a chauffeur, and maybe a clone or two (Zeman et al., 2011). From the above-mentioned it is evident that the caregiver burden is overwhelming, and caregivers play multiple roles when caring for their child with ASD. This consequently results in caregivers feeling overburdened, having no reprieve from caregiver duties, and no time for social engagements (Hillman & Anderson, 2019). Thus, caregivers feel excluded, isolated and experience a sense of loneliness (Hillman & Anderson, 2019; Zeman et al., 2011). Furthermore, caregivers in the study reported that they suffer from emotional burnout, which is provoked by low internal or external resources (Navot et al., 2017; Semigina & Stoliaryk 2022). The lack of ASD services, a lack of awareness of ASD, and the lack of support for caregivers of children with ASD further exacerbate the caregiver burden (Gosztyła & Prokopiak, 2019; Koukouriki et al. 2021; Lu et al., 2017). The study found how these contextual factors contributed to caregiver burden, and further revealed the implications of these factors on the caregivers' experiences of loneliness (Cardon & Marshall, 2021; Cloete & Obaigwa, 2019; Dababnah & Parish 2013).

Theme 2: Social Isolation and Social Interactions that Play a Role in the Experiences of Loneliness

Mothers portrayed themselves as not only lonely, but as isolated from others who might understand their experience (Dababnah & Parish 2013; Navot et al., 2017; Zeman et al., 2011). One mother identified her isolation and loneliness by simply stating that she is basically a hermit and that she keeps to herself (Zeman et al., 2011). Another mother expressed this theme when she wrote that she is without support and the closeness that she desperately needs, thereby resulting in feeling alone and forgotten (Zeman et al., 2011). Findings that report on mothers as caregivers of girls with ASD described mothers' desire to have a close relationship with their daughters; however, due to the challenges of ASD their expectations for intimacy as a mother and daughter were not fulfilled (Navot et al., 2017).

These mothers as caregivers felt isolated and experienced being excluded and alone as a result (Navot et al., 2017). Moreover, mothers are mostly seen as primary caregivers and spend most of their time alone, interacting only with the child with ASD compared to other members of the family (Dababnah & Parish 2013; Ijalba, 2016; Mahmood et al., 2015), consequently resulting in isolation from others and experiencing loneliness (Dababnah & Parish, 2013; Zeman et al., 2011).

However, other studies confirmed that isolation is experienced not only by mothers, but also the entire family (Cloete & Obaigwa, 2019; Dababnah & Parish, 2013; Mahmood et al., 2015; Semigina & Stoliaryk 2022). The studies revealed that complex responsibilities of family caregivers, coupled with work, appeared to take time away from engaging in meaningful friendships for family caregivers (Hillman & Anderson 2019), thereby resulting in social isolation (Hillman & Anderson, 2019; Zeman et al., 2011). Caregivers thus experience a lack of the sense of connectedness and belonging which ultimately contributes to their experiences of loneliness (Hillman & Anderson, 2019; Koukouriki et al., 2021; Lu et al., 2021; Mahmood et al., 2015; Zeman et al., 2011).

Findings further report that due to caregiving demands on younger siblings as caregivers, they are at risk of being deprived of adequate leisure time with their parents as well as other kinds of psychological care and nurturing from their parents (Dababnah & Parish, 2013; Koukouriki et al., 2021; Mahmood et al., 2021). The findings report further that the caregiving role imposed on younger siblings might not only pose a greater risk of feelings of loneliness and social isolation for these sibling caregivers, but also for mental health consequences, such as anxiety and depression for sibling caregivers (Koukouriki et al., 2021). Although they are younger than their ASD sibling, there is an expectation on these younger siblings to assist in caregiver duties and responsibilities that centred on the needs of the child with ASD (Koukouriki et al., 2021; Mahmood et al., 2015). Moreover, sibling caregivers endure embarrassment due to the challenging behaviours of the ASD child and this further isolates themselves from peers (Koukouriki et al., 2021; Mahmood et al., 2015). This rapid review study further found that feelings of loneliness in sibling as caregivers were found to be inversely associated with two aspects of social support, namely the social support received from the family itself, the availability and attentiveness of parents and the social support and acceptance received from friends for sibling caregivers (Koukouriki et al., 2021). Thus, the findings suggest that social support is related to better adjustment and might enhance the coping skills for typically developing sibling caregivers and thereby alleviating their experiences of loneliness (Koukouriki et al., 2021).

Findings from the included studies further report on Western cultures having higher levels of loneliness as compared to their Senegalese and Ukrainian counterparts (Cardon & Marshall, 2021; Semigina & Stoliaryk, 2022), particularly due to the norm of small, nuclear households (Cardon & Marshall, 2021), less frequent family interaction, preference for scheduled and structured social visits that can limit social interactions and increasingly infrequent socialisation with neighbours and the community, which ultimately culminates to experiences of loneliness (Cardon & Marshall, 2021).

Another interesting finding was noted from the same study in this review on Americans and the Senegalese, which allows the researcher to compare Western and African perspectives (Cardon & Marshall, 2021). This study highlighted that the Senegalese caregivers were more likely not to face social exclusion as compared to the Americans (Cardon & Marshal, 2021). The reason behind this was differences in family and community structures that may have also affected thematic differences between the American and Senegalese participant groups. In terms of caring for children with autism, African norms, in this case the Senegalese norms of living with extended family and in social communities, may serve as a protective factor against the recurring issue of a lack of support, thus also buffering them from psychological stressors and experiences of social isolation and loneliness (Cardon & Marshall, 2021). The Americans overwhelmingly reported social isolation and loneliness, because of the lack of exposure to other children, family contentions regarding parenting expectation, as described by Cardon and Marshall (2021), that went largely unmentioned by the Senegalese families.

Due to ASD disruptive behaviours, community and extended family did not accept the child and blatantly blamed caregivers for their child's disability (Cardon & Marshall, 2021; Cloete & Obaigwa, 2019; Dababnah & Parish 2013). This non-acceptance contributes to high levels of loneliness and may signal insufficient closeness in social relations and a lack of support, which then disrupts interpersonal well-being (Cardon & Marshall, 2021; Cloete & Obaigwa, 2019; Dababnah & Parish 2013). Therefore, according to evidence from the rapid review study, caregivers avoided social situations and become socially restricted (Ijalba, 2016; Mahmood et al., 2015). Social isolation was therefore a method adopted by caregivers to protect their children from the negative reactions of society (Cardon & Marshall, 2021; Cloete & Obaigwa, 2019; Dababnah & Parish 2013), consequently resulting in isolation from family circles and community participation, which impacted on loneliness (Cardon & Marshall, 2021). Social isolation and disengagement thus contributed to parents' overall experiences of stress, shame, depression, and exclusion, which contributed to a sense of loneliness (Cardon & Marshall, 2021). The evidence found that families face misunderstandings and social exclusion by family and friends and the community at large (Semigina & Stoliaryk, 2022). Another study reflected on a caregiver's experience, wherein she reports that due to a lack of understanding, people tend to look at caregivers in a negative light if their child exhibits challenging behaviours due to ASD (Ijalba, 2016). She cited this as the reason she does not go to anyone's house for a visit, thereby expressing her feelings of isolation and experiences of loneliness (Ijalba, 2016).

Theme 3: Stigma and Discrimination Impacting on the Experiences of Loneliness

Raising a child with ASD was associated with stigma, grief, and feelings of incompetence (Dababnah & Parish, 2013; Ijalba, 2016. Caregivers reported that they were discriminated against and struggled to be socially accepted because their children had ASD (Hillman & Anderson, 2019; Ijalba, 2016. The personal feelings of emotional burnout experienced by the caregivers were strengthened by social stigma related to ASD and the social isolation experienced by caregivers of children with ASD (Semigina & Stoliaryk, 2022), and these findings are consistent with past studies (Papadopoulos, 2021; Pepperell et al., 2018).

Evidence from the rapid review found that caregivers reported negative reactions from the public and social tension outside the home, including parent blame, ostracization, discrimination, and rudeness (Cardon & Marshall 2021; Dababnah & Parish, 2013; Devenish et al., 2020). Caregivers felt vulnerable when they were perceived as being uncaring to their child (Ijalba, 2016). Neighbours often expressed concern when children with ASD cried repeatedly, citing this as neglectful parenting (Ijalba, 2016). As one mother in the study expressed, her neighbour denounced her, and a social worker visited and checked her apartment to see how she treated her daughter (Ijalba, 2016).

Findings further report that ASD is associated with shame that can be witnessed among siblings as caregivers themselves (Mahmood et al., 2015; Navot et al., 2017). Siblings as caregivers complained of negative outcomes such as embarrassment, peer rejection, shame, and discrimination due to the challenging behaviours of their sibling with ASD (Dababnah & Parish, 2013; Koukouriki et al., 2021; Mahmood et al., 2015). Siblings as caregivers experience restricted mobility when they are confined at home with their ASD sibling due to their caregiving responsibilities (Dababnah & Parish, 2013; Koukouriki et al., 2021; Mahmood et al., 2015). Consequently, siblings as caregivers can only engage with their peers within the same proximity as their ASD sibling, thus exposing these caregivers to embarrassment and ultimately isolation (Mahmood et al., 2015). As evidenced in the review study when one mother expressed that her son would not let his friends come inside the house, he only talks to them outside. She further stated that on one occasion when he did let a friend inside the house when his brother was screaming, his friend asked him if his brother was retarded (Dababnah & Parish, 2013). Thus, the effects of discrimination and stigma can be seen in siblings as caregivers experiencing a loss of a sense of belonging among their peers linking into their experiences of loneliness and social isolation (Koukouriki et al., 2021; Mahmood et al., 2015).

Feelings of loneliness of caregivers were compounded by cultural norms and spiritual beliefs that ASD is evil and the child is believed to be possessed by evil spirits (Cardon & Marshall 2021*)*. African cultural beliefs on ASD viewed it as a punishment from the Gods. (Cloete & Obaigwa, 2019). The findings further revealed that mothers were blamed for the child’s condition (Cardon & Marshall 2021) and were told to get rid of their child (Dababnah & Parish, 2013). Negative reactions from outside the home forced parents not to discuss their child’s condition as a means of protecting their child from being discriminated against (Cloete & Obaigwa, 2019). Parents admitted actively hiding their children from the community, for fear of being shamed and labelled (Cloete & Obaigwa, 2019). Reports from parents in the findings serves as evidence of this, whereby, parents became withdrawn as they do not want to be embarrassed in front of people (Dababnah & Parish, 2013). Thus, discrimination from cultural norms and beliefs contributed to disengagement from society and left caregivers with feelings of shame, forced them to withdraw and thus increased their feelings of loneliness (Cloete & Obaigwa, 2019; Dababnah & Parish, 2013).

Theme 4: Coping Mechanism Alleviating the Experiences of Loneliness

Denial of the condition was one of the coping mechanisms implemented by the caregivers to adapt to having a child with ASD (Cardon & Marshall, 2021; Dababnah & Parish, 2013). Another coping mechanism suggested by the research is religion (Cardon & Marshall, 2021 Dababnah & Parish, 2013; Hillman & Anderson, 2019). Caregivers who believed in God were likely to accept the condition of their children. As noted in the study by Dababnah and Parish (2013), a parent described her despair and belief in God when she noted that she does not want to make a big deal about the ASD diagnosis and will still thank God for everything.

It was revealed that some caregivers in the review study viewed ASD as a blessing rather than a burden (Dababnah & Parish, 2013). Some caregivers believed that ASD is temporary, and that God will heal their children of this disability (Cardon & Marshal, 2021; Dababnah & Parish, 2013). Another participant in this study reported that when she starts crying, she would go to “wudoo”, which is a ritual washing for prayer (Dababnah & Parish, 2013). The evidence here suggests that religion was a coping mechanism implemented by caregivers (Cardon & Marshal, 2021; Dababnah & Parish, 2013; Hillman & Anderson, 2019). Religious coping was found to be effective as it reduces psychological distress and alleviates experiences of loneliness (Dababnah & Parish, 2013; Hilman & Anderson, 2019). The importance of religion is highlighted in-terms of acceptance, coping, and meaning-making in the caregiving process (Dababnah & Parish, 2013). Religious beliefs and spiritual practices were all found to form the basis of facilitating adjustment and coping for caregivers, thereby minimising feelings of loneliness (Dababnah & Parish, 2013).

Another coping mechanism employed was that of information seeking (Mahmood et al., 2015; Zeman et al., 2011). Thus, awareness could also be another form of coping to alleviate loneliness for caregivers of children with ASD. Findings from this rapid review study suggested that education and knowledge of ASD had a very positive impact on caregivers (Mahmood et al., 2015). By information seeking and informing themselves on ASD, caregivers accepted caregiving as a challenge (Mahmood et al., 2015). Information seeking created opportunities for socialising (Mahmood et al., 2015; Zeman et al., 2011). Thus, lessening social isolation and educating not only themselves as caregivers, but others in the community on ASD assisted caregivers with meaning-making of the ASD diagnosis, thereby alleviating the experiences of loneliness (Mahmood et al., 2015).

The findings indicated that support was another coping mechanism in combatting caregiver experiences of loneliness. Perceived social support was found to be significantly and positively related to life satisfaction (Lu et al., 2021; Zeman et al., 2011). The findings indicate that good interpersonal relationships are vital for caregivers' well-being and prosperity by fostering connection and a sense of belonging (Gosztyła & Prokopiak, 2019; Lu et al., 2021). Furthermore, the idea that help is available from others mediates the sense of loneliness in caregivers of children with ASD (Gosztyła & Prokopiak, 2019). Moreover, caregivers with higher perceived social support usually tend to ask for help when facing difficulties in aspects regarding ASD, therefore mitigating feeling alone and forgotten (Gosztyła & Prokopiak, 2019; Lu et al., 2021). Social support may help to reduce negative social comparison, promote purpose and meaning for the caregiver, and increase a sense of competency through companionship and belonging (Lu et al., 2021). The above positive effects of social support are likely to contribute to the well-being of all family members and alleviate experiences of loneliness (Gosztyła & Prokopiak, 2019; Koukouriki et al., 2021).

Implications of the Research Study in the South African Context

In the South African context, due to limited resources in health care and a lack of awareness, a lack of sufficient services and sufficiently trained professionals on ASD (Pillai et al., 2021), it becomes paramount that healthcare professionals understand the dynamic and importance of the caregiver role in the treatment outcomes for the child with ASD (Cloete & Obaigwa, 2019). Social exclusion and isolation continue to have implications for caregivers (Cardon & Marshall, 2021; Cloete & Obaigwa, 2019). There is an urgent need for healthcare professionals involved in the treatment of the child with ASD to consider the impact the above factors have on caregivers' sense of loneliness (Cardon & Marshall, 2021; Cloete & Obaigwa, 2019). Further importance is placed on interventions that are culturally sensitive to mitigate experiences of loneliness (Cloete & Obaigwa, 2019). In addition, interventions should be holistic and all-encompassing by not only involving the child with ASD, but also the caregivers and the family of the child with ASD (Gosztyła & Prokopiak, 2019; Koukouriki et al., 2021; Lu et al., 2017). Consequently, the above considerations for the caregivers will assist to mitigate the risks that caregiving demands impose on the psychological health of caregivers. Moreover, this understanding, based on the above-mentioned evidence gathered by the research study, could ultimately assist mental health professionals in initiatives and interventions that aim to promote the psychological health of caregivers of children with ASD.

Limitations and Recommendations for Future Studies

The experiences of loneliness of caregivers of children with ASD are a topic that is understudied. New and emergent scientific literatures might have been excluded which were published before the study concluded. Therefore, this scientific literature might have been overlooked. Additionally, as ASD is a condition that is not fully understood in developing countries, these caregivers' experiences might not have been accurately represented and thoroughly documented within the studies included in this rapid review, therefore it cannot be generalised to all caregivers of children with ASD.

It is recommended that future studies should focus on caring for the carer. Previous research has already established that caregivers bridge an important gap in under-resourced countries, where treatment outcomes of the ASD child are dependent on the caregiver. Therefore, caregivers' health and well-being should be considered and promoted. As ASD is a lifetime commitment for caregivers, the efforts of future research can assist health professionals in broadening their understanding to provide initiatives and interventions that support caregivers and their families as they navigate through the challenges of caring for a child with ASD.

Conclusion

The findings from this rapid review research study concluded that caregivers of children with ASD are confronted with numerous challenges associated with caring for a child with ASD (Cardon & Marshall, 2021; Cloete & Obaigwa, 2019; Dababnah & Parish, 2013; Hillman & Anderson, 2019). Societal views and other contextual factors such as a lack of awareness, a lack of support and a lack of services heavily influence the experiences of loneliness of caregivers of children with ASD (Gosztyła & Prokopiak, 2019; Koukouriki et al., 2021; Lu et al., 2021; Zeman et al., 2011). This rapid review research study further presented findings on the coping mechanisms employed by caregivers to alleviate their experiences of loneliness. The research study further confirmed that caregivers endure stigma discrimination, rejection, and negative reactions from society, therefore they experience a sense of loneliness when they are excluded from society and isolated with their child with ASD (Cardon & Marshall 2021; Dababnah & Parish, 2013; Devenish et al., 2020). The importance of the caregiver role was highlighted and confirmed as a critical health source in the South African context, which should be considered and preserved (Pillai et al., 2021).

References

American Psychiatric Association (APA). (2013). *Diagnostic and statistical manual of mental disorders* (5th ed.). APA. https://doi.org/10.1176/appi.books.9780890425596

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Braun, V., & Clarke, V. (2019). Reflecting on reflexive thematic analysis. *Qualitative Research in Sport, Exercise and Health*, *11*(4), 589–597. https://doi.org/10.1080/2159676x.2019.1628806

Bravo-Benítez, J., Pérez-Marfil, M. N., Román-Alegre, B., & Cruz-Quintana, F. (2019). Grief experiences in family caregivers of children with autism spectrum disorder (ASD). *International Journal of Environmental Research and Public Health*, *16*(23), 4821. https://doi.org/10.3390/ijerph16234821

Cardon, A., & Marshall, T. C. (2021). To raise a child with autism spectrum disorder: A qualitative, comparative study of parental experiences in the United States and Senegal. *Transcultural Psychiatry*, *58*(3), 335–350. https://doi.org/10.1177/1363461520953342

Chan, K. K. S., & Lam, C. B. (2018). Self-stigma among parents of children with autism spectrum disorder. *Research in Autism Spectrum Disorders*, *48*, 44–52. https://doi.org/10.1016/j.rasd.2018.01.001

Cloete, L., & Obaigwa, E. O. (2019). Lived experiences of caregivers of children with autism spectrum disorder in Kenya. *African Journal of Disability*, *8*. https://doi.org/10.4102/ajod.v8i0.435

Currie, G., & Szabo, J. (2020). Social isolation and exclusion: The parents' experience of caring for children with rare neurodevelopmental disorders. *International Journal of Qualitative Studies on Health and Well-Being*, *15*(1725362), 1– 10.

https://doi.org/10.1080/17482631.2020.1725362

Dababnah, S., & Parish, S. L. (2013). “At a moment, you could collapse”: Raising children with autism in the West Bank. *Children and Youth Services Review*, *35*(10), 1670–1678. https://doi.org/10.1016/j.childyouth.2013.07.007

Devenish, B., Sivaratnam, C., Lindor, E., Papadopoulos, N., Wilson, R. B., McGillivray, J., & Rinehart, N. J. (2020). A brief report: Community supportiveness may facilitate participation of children with autism spectrum disorder in their community and reduce feelings of isolation in their Caregivers. *Frontiers in Psychology*, *11*. https://doi.org/10.3389/fpsyg.2020.583483

Du Toit, R. E., & De Klerk, W. (2022). Guidelines for conducting rapid reviews in psychology research, *Journal of Psychology in Africa, 32*(6), 640-647, https://doi.org/10.1080/14330237.2022.2121468

Gosztyła, T., & Prokopiak, A. (2019). Mediating role of lack of support for the relationship between extraversion and sense of loneliness in parents of children with autism spectrum disorder and parents of children with intellectual disability. *Official Journal of the Italian Society of Psychopathology*, *25*, 51–57. https://www.jpsychopathol.it/wp-content/uploads/2019/07/01_Gosztyla-1.pdf

Hillman, J. L., & Anderson, C. (2019). It’s a battle and a blessing: The experience and needs of custodial grandparents of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *49*(1), 260–269. https://doi.org/10.1007/s10803-018-3761-0

Ijalba, E. (2016). Hispanic immigrant mothers of young children with autism spectrum disorders: How do they understand and cope with autism? *American Journal of Speech-Language Pathology*, *25*(2), 200–213. https://doi.org/10.1044/2015_ajslp-13-0017

Knapp, M., Romeo, R., & Beecham, J. (2009). Economic cost of autism in the UK. *Autism*, *13*(3), 317–336. https://doi.org/10.1177/1362361309104246

Koukouriki, E., Athanasopoulou, E., & Andreoulakis, E. (2021). Feelings of loneliness and social dissatisfaction in siblings of children with autism spectrum disorders: The role of birth order and perceived social support. *Journal of Autism and Developmental Disorders*, *52(11)*, 4722–4738. https://doi.org/10.1007/s10803-021-05308-x

Lu, M., Wang, R., Lin, H., Pang, F., & Chen, X. (2021). Perceived social support and life satisfaction of Chinese parents of children with autism spectrum disorder: Loneliness as a mediator and moderator. *Research in Autism Spectrum Disorders*, *87*, 101829. https://doi.org/10.1016/j.rasd.2021.101829

Mahmood, H., Saleemi, M. A., Riaz, H., Hassan, Y., & Khan, F. N. (2015). Coping strategies of mothers with ASD children. *The Professional Medical Journal*. *22*(11), 1454-1463. https://doi.org/10.17957/tpmj/15.3078

McGuire, A. (2015). Diagnosing the diagnostic and statistical manual of mental disorders. *Disability & Society*, *30*(10), 1582–1585. https://doi.org/10.1080/09687599.2015.1062233

Navot, N., Jorgenson, A. G., & Webb, S. J. (2017). Maternal experience raising girls with autism spectrum disorder: A qualitative study. *Child Care Health and Development*, *43*(4), 536–545. https://doi.org/10.1111/cch.12470

Olagunju, A., Oshodi, Y., Umeh, C., Aina, O., Oyibo, W., Lamikanra, A., Lesi, F. A., & Adeyemi, J. (2017). Children with neurodevelopmental disorders: The burden and psychological effects on caregivers in Lagos, Nigeria. *Journal of Clinical Sciences*, *14*(1), 2–7. https://doi.org/10.4103/2468-6859.199162

Papadopoulos, D. (2021). Mothers' experiences and challenges raising a child with autism spectrum disorder: A qualitative study. *Brain Sciences*, *11*(3), 309. https://doi.org/10.3390/brainsci11030309

Pendergrass, A., Mittelman, M., Graessel, E., Özbe, D., & Karg, N. (2019). Predictors of the personal benefits and positive aspects of informal caregiving. *Aging and Mental Health*, *23*(11), 1533-1538. https://doi.org/10.1080/13607863.2018.1501662

Pepperell, T. A., Paynter, J., & Gilmore, L. (2018). Social support and coping strategies of parents raising a child with autism spectrum disorder. *Early Child Development and Care*, *188*(10), 1392–1404. https://doi.org/10.1080/03004430.2016.1261338

Pillai, S., Makhetha, M., & Aldous, C. (2021). A study reflecting the demographics and comorbidities of children diagnosed with autism spectrum disorder at initial presentation to the Kwazulu-Natal children's hospital. *SAJCH South African Journal of Child Health*, *15*(3), 125-129. https://doi.org/10.7196/SAJCH.2021.v15i3.01752

Reddy, G., Fewster, D. L., & Gurayah, T. (2019). Parents' voices: Experiences and coping as a parent of a child with autism spectrum disorder. *South African Journal of Occupational Therapy*, *49*(1), 43–50. https://doi.org/10.17159/2310-3833/2019/vol49n1a7

Samadi, S. A., McConkey, R., Nuri, H., Abdullah, A., Ahmad, L., Abdalla, B., & Biçak, C. A. (2022). Screening children for autism spectrum disorders in low- and middle-income countries: Experiences from the Kurdistan region of Iraq. *International Journal of Environmental Research and Public Health*, *19*(8), 4581. https://doi.org/10.3390/ijerph19084581

Schulz, R., & Sherwood, P. R. (2008). Physical and mental health effects of family caregiving. *American Journal of Nursing*, *108*(9), 23–27. https://doi.org/10.1097/01.naj.0000336406.45248.4c

Schulz, R., & Tompkins, C. A. (2010). Informal caregivers in the United States: Prevalence, caregiver characteristics, and ability to provide care. In *The Role of Human Factors in Home Health Care. Workshop Summary*. National Academies Press. https://www.ncbi.nlm.nih.gov/books/NBK210048/

Semigina, T., & Stoliaryk, O. (2022). "It was a shock to the whole family": Challenges of Ukrainian Families raising a child with autism. *STEPP: Socialinė Teorija, Empirija, Politika Ir Praktika (Social Theory, Empirics Policy and Practice)*, *24*, 8–23. https://doi.org/10.15388/stepp.2022.34

Steinbrenner, J. R., Hume, K., Odom, S. L., Morin, K. L., Nowell, S. W., Tomaszewski, B., Szendrey, S., & Mcintyre, N. S. (2020). *Evidence-based practices for children, youth, and young adults with autism.* Evidence-Based Practices for Children, Youth, and Young Adults with Autism. The University of North Carolina at Chapel Hill, Frank Porter Graham Child Development Institute, National Clearinghouse on Autism Evidence and Practice Review Team., 1–140.

Wei, H., Li, Y., Zhang, Y., Luo, J., Wang, S., Dong, Q., Tao, Y., Gong, L., Feng, Y., Shi, M., Cao, Z., Liu, Y., Chen, L., Liu, X., Dai, Y., Qu, L., Song, Z., Chen, J., Li, T., & Cheng, Q. (2022). Awareness and knowledge of autism spectrum disorder in Western China: Promoting early identification and intervention. *Frontiers in Psychiatry*, *13*. https://doi.org/10.3389/fpsyt.2022.970611

World Health Organization (WHO). (2022). *World Health Organisation: Autism* WHO. https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders

Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M. S., Saxena, S., Yusuf, A., Shih, A., & Elsabbagh, M. (2022). Global prevalence of autism: A systematic review update. *Autism Research*, 15(5), 778-790. https://doi.org/10.1002/aur.2696

Zeman, L. D., Swanke, J., & Doktor, J. (2011). Strengths classification of social relationships among cybermothers raising children with autism spectrum disorders. *School Community Journal*, *21*(1), 37–51. http://files.eric.ed.gov/fulltext/EJ932199.pdf

SECTION 3: CRITICAL REFLECTION

Section 3 provides a critical reflection of the primary researcher in conducting this rapid review research study, culminating in the submission of this mini-dissertation.

Critical Reflection on the Research Process

While conducting the rapid review study, I soon found out that it was not as easy as it seemed. Since the rapid review process was not one with which I was familiar, it left me feeling unsure. I was advised by my supervisors to read up and familiarise myself with the rapid review process and methodology. Given the above uncertainty and the historical challenges since the inception of my research process during my M1 year in 2020, I was beginning to feel like completing my research study was an insurmountable task that I would not be able to achieve. I felt defeated; however, I pushed on, holding on to whatever hope I had left.

The challenges I experienced throughout the research process tested me to my limits. In 2020 I had chosen a research supervisor. My then supervisor had challenges that in-turn impacted me severely, posing as delays in feedback and gaps in supervision. For my part, I remained empathic and understanding and we both tried our very best to navigate through the process. Upon reflection, this experience resulted in a growth point for me. I became aware that I had qualities of resilience, endurance, and patience. However, despite all my efforts, 2020 ended with me achieving no movement and no progress in the research process at all. It was as if the whole year had been wasted.

At the beginning of the 2021 academic year, I requested to be assigned to another supervisor. At this point, I felt that I was stuck and required intervention, failure of which would have resulted in me not completing my research. My request was partially fulfilled, and Mrs Malan intervened as my co-supervisor. In July 2021, my supervisor sadly informed me that she would no longer be supervising me. This news left me devastated, with the uncertainty and anxiety of not achieving my qualification. I was then, upon request, assigned to a new supervisor and co- supervisor. The change in supervision was promising and instilled a new hope for my completion. However, the real work seemed to only have started then. The rest of the year was spent trying to gain momentum on the time lost and to finally get some direction on achieving completion of the initial stages of the research process.

In 2022, I submitted my research proposal for approval to the small group committee, to the COMPRES scientific committee, and to the HREC ethics committee at the university, within a period of three months. This was a huge accomplishment, of which I was rather proud. My confidence was restored in the research process, and by June 2022, I had received HREC approval for the study. At the end of August 2022, my study title was registered, and I could finally see myself completing what I had started. The remainder of the year was spent in ensuring that I fully comprehended the rapid review methodology by reading up and consulting with my supervisors. By October 2022, I had finally started conducting the research study. At this point I felt sufficiently informed and confident enough to enjoy doing my research.

Data Collection

Data was collected by employing the guidelines of the rapid review methodology. These guidelines were important to me as it allowed me to reflect on the required steps. It provided structure in conducting the research study. The following rapid review steps, as set out by Ganann et al. (2010), were followed in the research process for conducting rapid reviews. The first step was to conduct a scope review of various databases, which was achieved through consultation with a North-West University librarian. Inclusion and exclusion criteria were then applied to mitigate for bias. The second step was to screen scientific literature for further analysis. This was done by Mrs Malan and I, independently. Scientific literature that was irrelevant and that did not meet the proposed research study's inclusion criteria were discussed, decided upon, and excluded. Whenever any disagreements arose, we met with Prof Werner de Klerk, who provided clarity for consensus. A decision was then made on the final number of scientific literature that was identified for the rapid review. The scientific literature was relevant to exploring the rapid review question, of: *What evidence is available from the scientific literature on the experiences of loneliness of primary caregivers of children with ASD? How could this evidence inform our understanding to make appropriate recommendations for the psychological health promotion of primary caregivers of a child with ASD?* Furthermore, the included scientific literature was appraised as being of good quality as per the standard set out by the JBI scientific appraisal tool (Peters et al., 2015; The Johanna Briggs Institute, 2015). Thereafter Mrs Malan and I did the thematic analysis independently. Lastly, by applying the fourth step, the evidence found was synthesised, and I reported on the findings. This entire process was overseen by both Mrs Malan and Prof de Klerk. They provided valuable guidance and feedback that ensured adequate monitoring that the research was conducted in a scientifically appropriate manner.

Data Analysis and Interpretation

Data were analysed using thematic analysis. Thematic analysis is a method of analysis that organises and identifies patterns and themes within data, thereby describing the data in rich detail (Braun & Clarke, 2006). Reflecting on the analysis phase of the study, it was apparent that employing thematic analysis for the research study was an effective and best suited method, as it allowed us as researchers to stay close to the data and gain a rich and in-depth description of the experiences of loneliness of primary caregivers of the child with ASD. Themes and patterns were identified, integrated, and summarised, enabling me to answer the review question of the proposed study. The entire process of analysis was achieved by employing the recommend stepwise presentation of Braun and Clarke (2006) in a reflexive manner throughout the analysis phase. The back-and-forth engagement with the data allowed me a closeness with the evidence that proved valuable in understanding what the scientific literature was reporting on. This allowed an accurate unbiased interpretation of the findings. It taught me how to present evidence from the scientific literature, and not what I was assuming from it. Although this was challenging, I overcame this by consulting with my supervisors and peers, thereby mitigating for subjectivity and bias within the research process. Further, by adhering to the rapid review methodology, I ensured rigour (Ganann et al., 2010).

Findings

Reporting on the findings was overwhelming. I knew what I wanted to say and what I had found; however, it was a huge task in bringing it all together. I spent a lot of time ruminating on how I was going to present the findings in a logical, coherent, manner that flowed. The most prominent finding was that caregivers had many challenges that impacted on their experiences of loneliness. There was a lack of adequate interventions that considered or even mitigated caregivers' experiences of loneliness. The findings also suggested that a lack of awareness and a lack of services for ASD exacerbated caregiver loneliness. The findings thus highlighted the importance and the need for interventions that promotes social inclusion and support for caregivers of children with ASD. To ensure that what I was reporting on made sense and was an accurate representation of the findings, I continually consulted with my supervisors and reflected on the findings. In addition, after attending a three-day workshop to sharpen my research acumen at the North-West University's COMPRES Focus Area, the findings were further peer-reviewed by a researcher at COMPRES. From the above-mentioned I was able to confidently report and interpret the findings and proceed with submitting my dissertation for grading.

Conclusion

In conclusion, conducting this research was a humbling process. It reminded me that every process closes only when the timing is right. It taught me that some processes are beyond one’s control and that we should respect and trust the flow of each process. I emerged from this experience with a deep understanding and appreciation of processes and how one process needs to be closed before another can be opened.

By conducting this research study, the respect and admiration I had for the caregivers of children with ASD intensified. As I worked through the evidence, my knowledge and understanding about their struggles and their courage grew. Thus, the knowledge I acquired from research on this topic enabled me to have a holistic understanding of the experiences of loneliness of these caregivers as they navigate their way through being available to the needs of their child with ASD. This research study left a curiosity and motivation in me to explore more on this topic and to further broaden and build on this knowledge, working toward my future endeavours in providing care for caregivers of children with ASD.

References

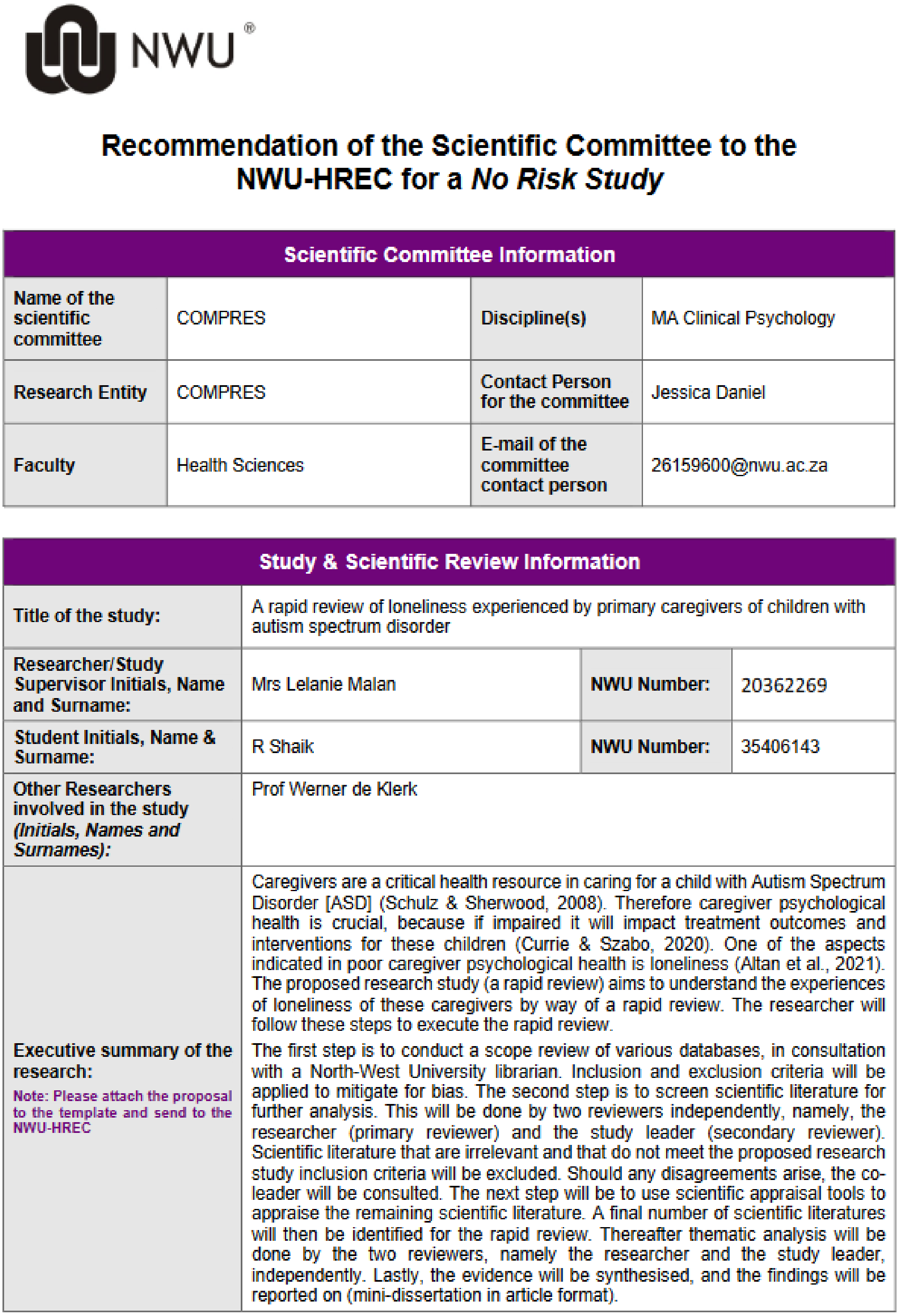
Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Ganann, R., Ciliska, D., & Thomas, H. (2010). Expediting systematic reviews: Methods and implications of rapid reviews. *Implementation Science*, 5, 1–10. http://www.implementationscience.com/content/5/1/56

Peters, M. D. J., Marnie, C., Tricco, A. C., Pollock, D., Munn, Z., Alexander, L., McInerney, P., Godfrey, C. M., & Khalil, H. (2020). Updated methodological guidance for the conduct of scoping reviews. *JBI Evidence Synthesis*, *18*(10), 2119–2126. https://doi.org/10.11124/JBIES-20-00167

The Joanna Briggs Institute. (2015). *The Joanna Briggs Institute Reviewers' Manual 2015: Methodology for JBI scoping reviews*. Joanna Briggs Institute.

ADDENDUM A: COMPRES APRPOVAL LETTER



NWU®

Recommendation of the Scientific Committee to the NWU-HREC for a *No Risk Study*

Scientific Committee Information			
Name of the scientific committee	COMPRES	**Discipline(s)**	MA Clinical Psychology
Research Entity	COMPRES	**Contact Person for the committee**	Jessica Daniel
Faculty	Health Sciences	**E-mail of the committee contact person**	26159600@nwu.ac.za

Study & Scientific Review Information			
Title of the study:	A rapid review of loneliness experienced by primary caregivers of children with autism spectrum disorder		
Researcher/Study Supervisor Initials, Name and Surname:	Mrs Lelanie Malan	**NWU Number:**	20362269
Student Initials, Name & Surname:	R Shaik	**NWU Number:**	35406143
Other Researchers involved in the study *(Initials, Names and Surnames):*	Prof Werner de Klerk		
Executive summary of the research: Note: Please attach the proposal to the template and send to the NWU-HREC	Caregivers are a critical health resource in caring for a child with Autism Spectrum Disorder [ASD] (Schulz & Sherwood, 2008). Therefore caregiver psychological health is crucial, because if impaired it will impact treatment outcomes and interventions for these children (Currie & Szabo, 2020). One of the aspects indicated in poor caregiver psychological health is loneliness (Altan et al., 2021). The proposed research study (a rapid review) aims to understand the experiences of loneliness of these caregivers by way of a rapid review. The researcher will follow these steps to execute the rapid review. The first step is to conduct a scope review of various databases, in consultation with a North-West University librarian. Inclusion and exclusion criteria will be applied to mitigate for bias. The second step is to screen scientific literature for further analysis. This will be done by two reviewers independently, namely, the researcher (primary reviewer) and the study leader (secondary reviewer). Scientific literature that are irrelevant and that do not meet the proposed research study inclusion criteria will be excluded. Should any disagreements arise, the co-leader will be consulted. The next step will be to use scientific appraisal tools to appraise the remaining scientific literature. A final number of scientific literatures will then be identified for the rapid review. Thereafter thematic analysis will be done by the two reviewers, namely the researcher and the study leader, independently. Lastly, the evidence will be synthesised, and the findings will be reported on (mini-dissertation in article format).		

Potential risk level:	No risk	☒	**Motivate:** Proposed study is a rapid review which would not directly impact human participants.
Recommendation for the REC:	Exempted from review	☒	**Motivate** (e.g. systematic review not impacting on human participants, laboratory work with human cell lines etc.): Proposed study is a rapid review which would not directly impact human participants.
Any additional comments	Motivate: Click here to enter text.		
Chairperson of the committee	Prof CHM Bloem		
Committee members present during the review **Note: Ensure no conflict of interest**	**Prof Herman Strydom** **Dr Erika Hitge** **Mrs Amori Marais**		
Date of review	2022/05/25		

Signature of Chairperson

Date: Click here to enter a date.

Signature of Research Director

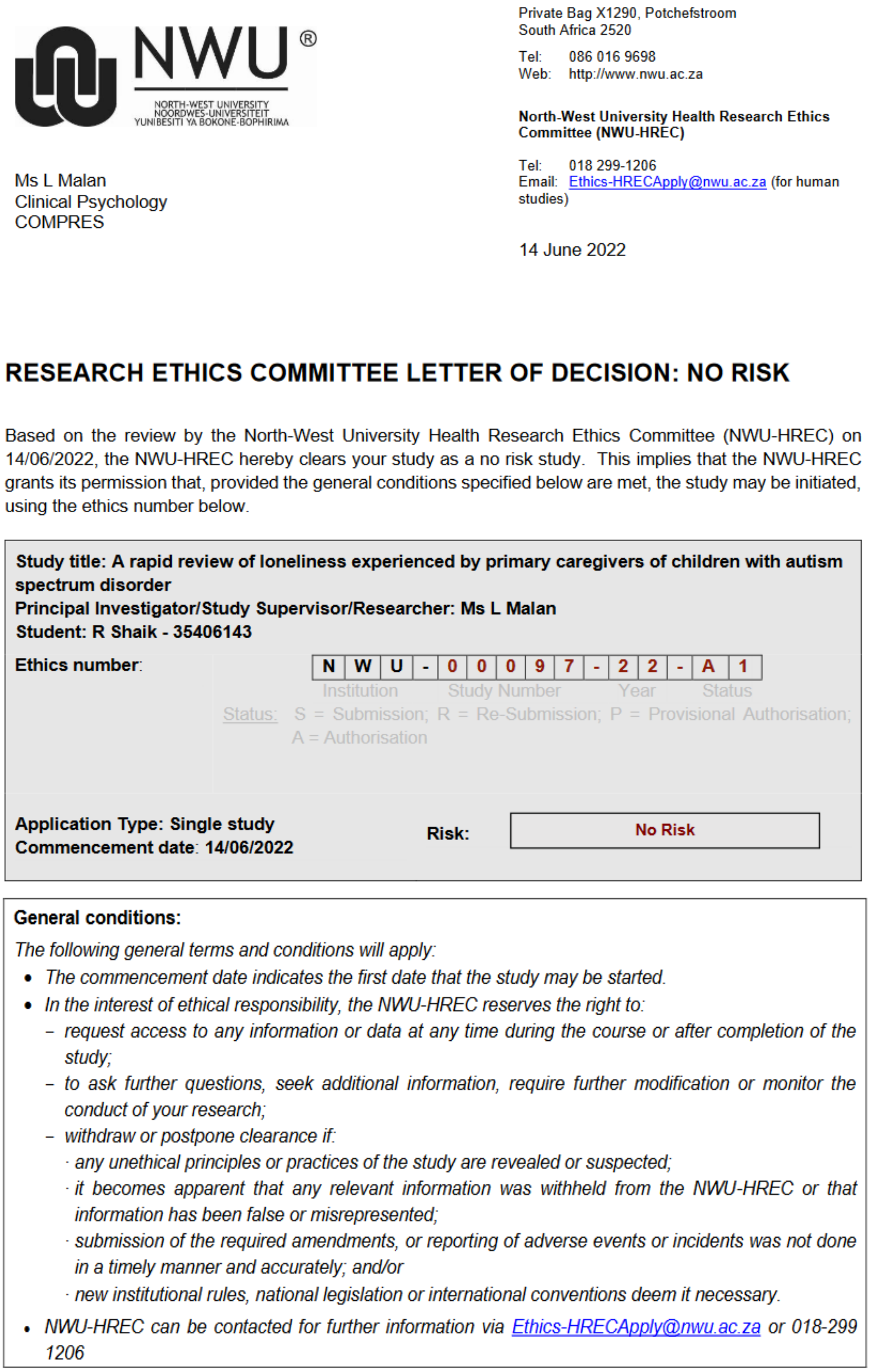
Date: 2022/05/26

Form developed by Prof Minrie Greeff, 1 March 2017
Form updated by Prof Minrie Greeff, 31 January 2019
Form updated by Prof Minrie Greeff, 8 May 2019
Form updated by Prof Minrie Greeff, 23 July 2019
Form updated by Prof Minire Greeff, 10 August 2019

Original details: (23239522) G:\My Drive\9. Research and Postgraduate Education\9.1.5.6 Forms\9.1.5.6_SC Approval_No Ethics_Human Participants.docm
10 August 2019

File Reference: 9.1.5.6

ADDENDUM B: HREC ETHICS APPROVAL LETTER



Private Bag X1290, Potchefstroom
South Africa 2520
Tel: 086 016 9698
Web: http://www.nwu.ac.za

North-West University Health Research Ethics Committee (NWU-HREC)
Tel: 018 299-1206
Email: Ethics-HRECApply@nwu.ac.za (for human studies)

14 June 2022

Ms L Malan
Clinical Psychology
COMPRES

RESEARCH ETHICS COMMITTEE LETTER OF DECISION: NO RISK

Based on the review by the North-West University Health Research Ethics Committee (NWU-HREC) on 14/06/2022, the NWU-HREC hereby clears your study as a no risk study. This implies that the NWU-HREC grants its permission that, provided the general conditions specified below are met, the study may be initiated, using the ethics number below.

Study title: A rapid review of loneliness experienced by primary caregivers of children with autism spectrum disorder
Principal Investigator/Study Supervisor/Researcher: Ms L Malan
Student: R Shaik - 35406143

Ethics number:

N	W	U	-	0	0	0	9	7	-	2	2	-	A	1
Institution				Study Number						Year			Status	

Status: S = Submission; R = Re-Submission; P = Provisional Authorisation; A = Authorisation

Application Type: Single study
Commencement date: 14/06/2022

Risk: No Risk

General conditions:

The following general terms and conditions will apply:

- *The commencement date indicates the first date that the study may be started.*
- *In the interest of ethical responsibility, the NWU-HREC reserves the right to:*
  - *request access to any information or data at any time during the course or after completion of the study;*
  - *to ask further questions, seek additional information, require further modification or monitor the conduct of your research;*
  - *withdraw or postpone clearance if:*
    - *any unethical principles or practices of the study are revealed or suspected;*
    - *it becomes apparent that any relevant information was withheld from the NWU-HREC or that information has been false or misrepresented;*
    - *submission of the required amendments, or reporting of adverse events or incidents was not done in a timely manner and accurately; and/or*
    - *new institutional rules, national legislation or international conventions deem it necessary.*
- *NWU-HREC can be contacted for further information via Ethics-HRECApply@nwu.ac.za or 018-299 1206*

Please note: Due to the nature of the study i.e. (rapid review of previously published manuscripts), this study will be able to proceed during the current alert level, following receipt of the approval letter. No additional COVID-19 restrictions have been placed on the study except that the researcher must ensure that before proceeding with the study that all research team members have reviewed the North-West University COVID-19 Occupational Health and Safety Standard Operating Procedure.

The NWU-HREC would like to remain at your service and wishes you well with your study. Please do not hesitate to contact the NWU-HREC for any further enquiries or requests for assistance.

Yours sincerely,

Digitally signed
by Prof Petra
Bester
Date: 2022.06.14
10:08:32 +02'00'

NWU-HREC Chairperson

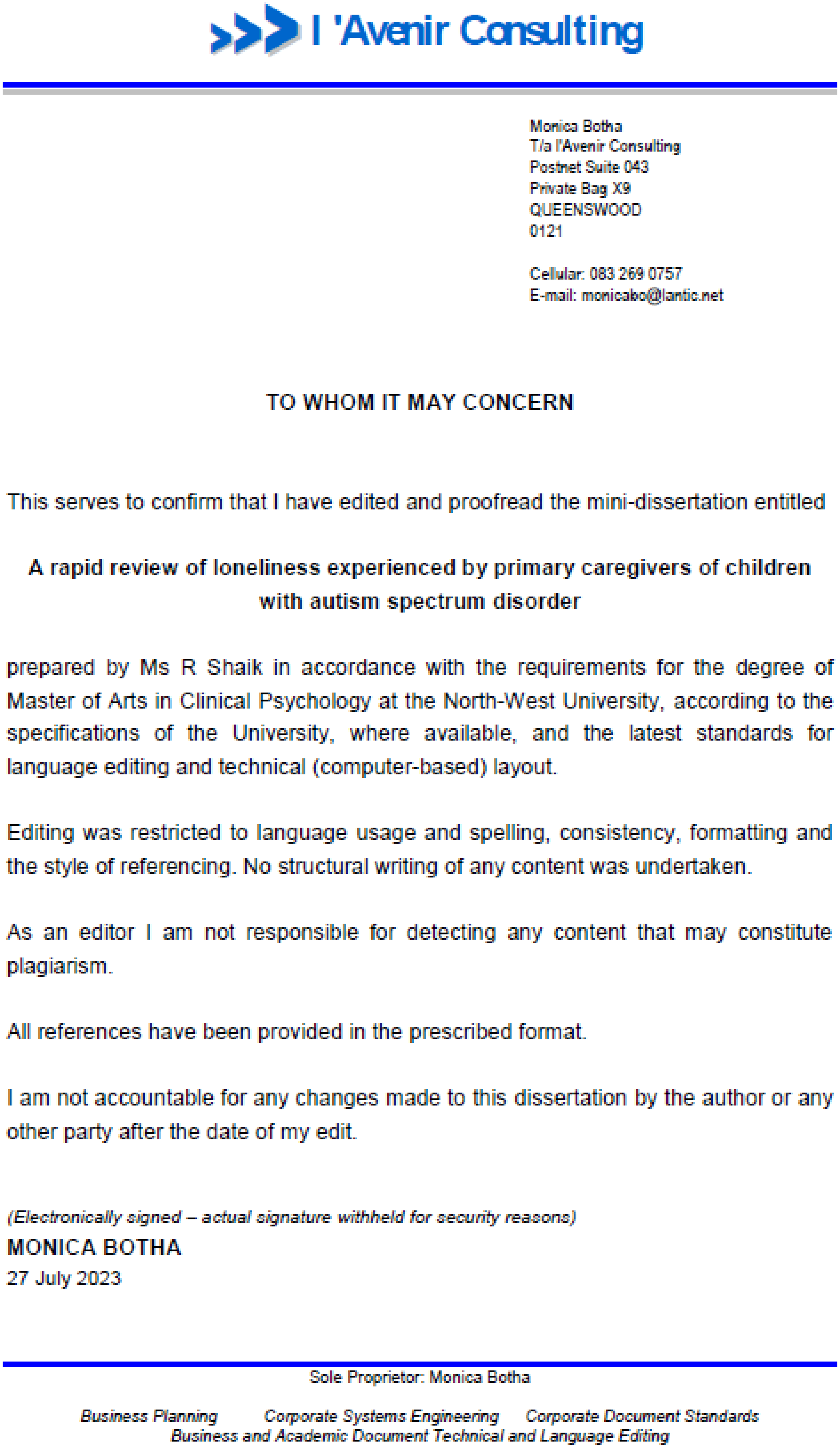
Digitally signed
by Wayne
Towers
Date: 2022.06.14
09:38:33 +02'00'

Head of the Faculty of Health Sciences Ethics Office for Research, Training and Support

Current details: (13210572) G:\My Drive\My Documents 20190227\NWU-HREC\NWU-HREC_Applications\NWU-HREC_Applications-2022\NWU-HREC_App05-20220615\NWU-00097-22-S1(L Malan-R Shaik)-NR\NWU-00097-22-S1(L Malan-R Shaik)-LoD\9.1.5.4.3_LOD_NWU-00097-22-A1_20220608.docm
3 June 2022

File reference: 9.1.5.4.3

ADDENDUM C: LANGUAGE EDITING CERTIFICATE



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TO WHOM IT MAY CONCERN

This serves to confirm that I have edited and proofread the mini-dissertation entitled

A rapid review of loneliness experienced by primary caregivers of children with autism spectrum disorder

prepared by Ms R Shaik in accordance with the requirements for the degree of Master of Arts in Clinical Psychology at the North-West University, according to the specifications of the University, where available, and the latest standards for language editing and technical (computer-based) layout.

Editing was restricted to language usage and spelling, consistency, formatting and the style of referencing. No structural writing of any content was undertaken.

As an editor I am not responsible for detecting any content that may constitute plagiarism.

All references have been provided in the prescribed format.

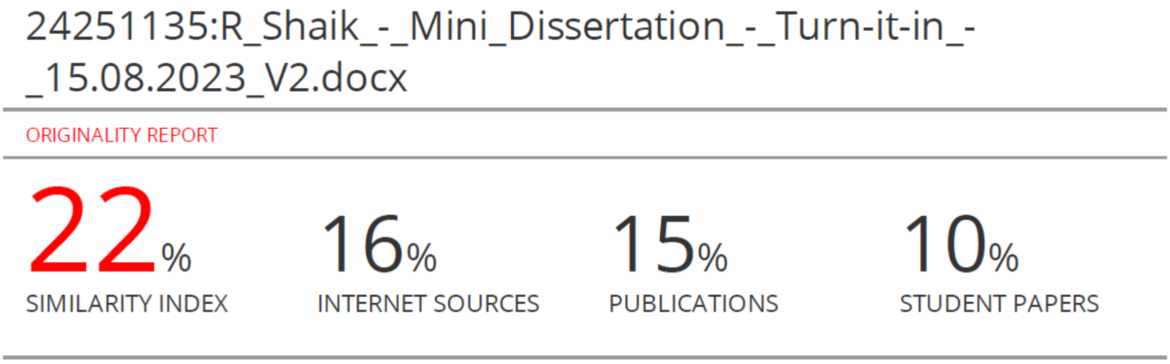
I am not accountable for any changes made to this dissertation by the author or any other party after the date of my edit.

(Electronically signed – actual signature withheld for security reasons)
MONICA BOTHA
27 July 2023

Sole Proprietor: Monica Botha

Business Planning Corporate Systems Engineering Corporate Document Standards
Business and Academic Document Technical and Language Editing

ADDENDUM D: TURNITIN REPORT

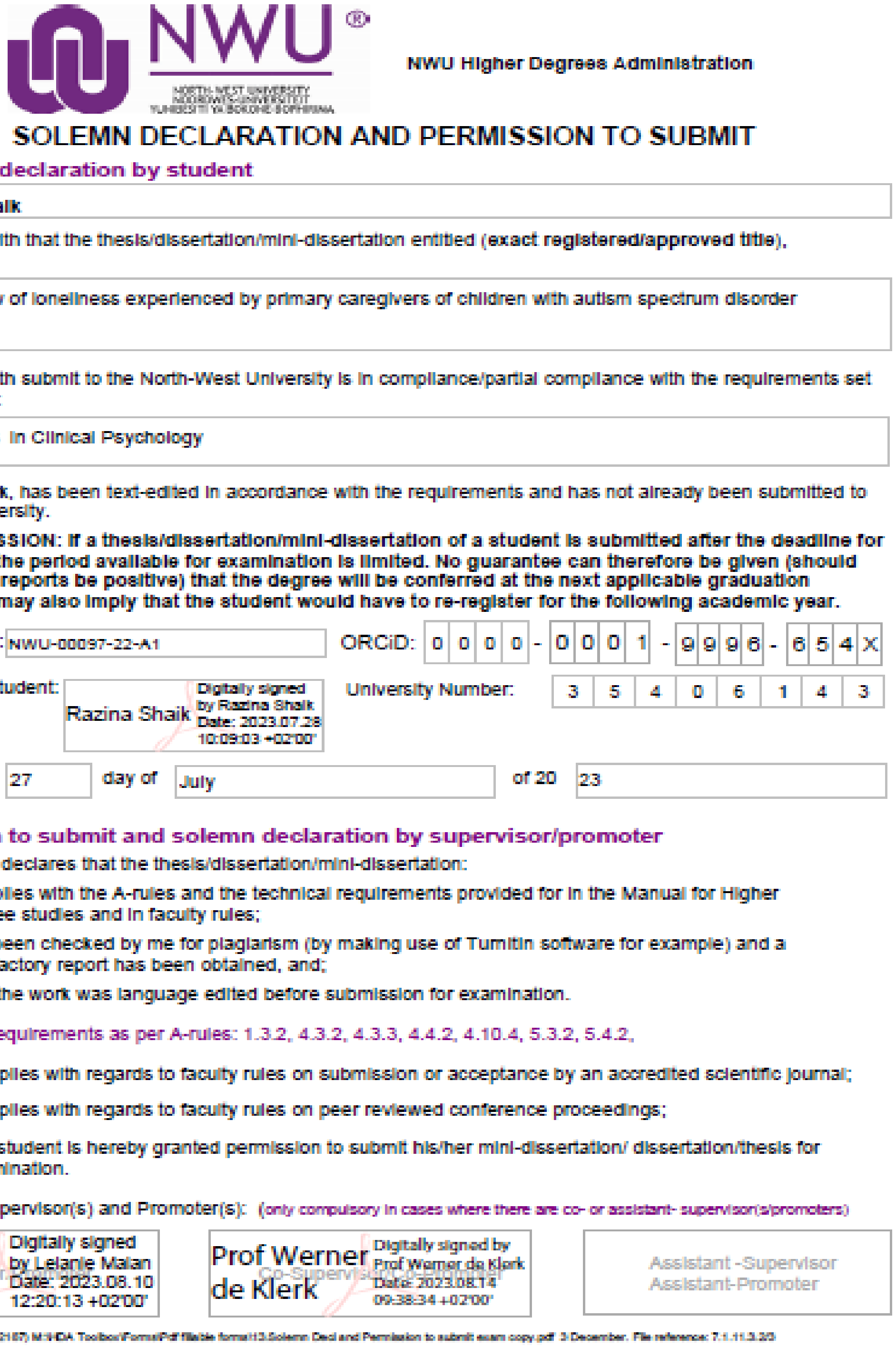


24251135:R_Shaik_-_Mini_Dissertation_-_Turn-it-in_-_15.08.2023_V2.docx

ORIGINALITY REPORT

22%	16%	15%	10%
SIMILARITY INDEX	INTERNET SOURCES	PUBLICATIONS	STUDENT PAPERS

ADDENDUM E: SOLEMN DECLARATION AND PERMISSION TO SUBMIT



NWU®
NORTH-WEST UNIVERSITY
NOORDWES-UNIVERSITEIT
YUNIBESITI YA BOKONE-BOPHIRIMA

NWU Higher Degrees Administration

SOLEMN DECLARATION AND PERMISSION TO SUBMIT

1. Solemn declaration by student

I, Razina Shaik

declare herewith that the thesis/dissertation/mini-dissertation entitled (**exact registered/approved title**),

A rapid review of loneliness experienced by primary caregivers of children with autism spectrum disorder

which I herewith submit to the North-West University is in compliance/partial compliance with the requirements set for the degree:

Master of Arts in Clinical Psychology

is my own work, has been text-edited in accordance with the requirements and has not already been submitted to any other university.

LATE SUBMISSION: If a thesis/dissertation/mini-dissertation of a student is submitted after the deadline for submission, the period available for examination is limited. No guarantee can therefore be given (should the examiner reports be positive) that the degree will be conferred at the next applicable graduation ceremony. It may also imply that the student would have to re-register for the following academic year.

Ethics number: NWU-00097-22-A1

ORCiD: 0 0 0 0 - 0 0 0 1 - 9 9 9 6 - 6 5 4 X

Signature of Student: Razina Shaik Digitally signed by Razina Shaik Date: 2023.07.28 10:09:03 +02'00'

University Number: 3 5 4 0 6 1 4 3

Signed on this 27 day of July of 20 23

2. Permission to submit and solemn declaration by supervisor/promoter

The undersigned declares that the thesis/dissertation/mini-dissertation:

- ☑ Complies with the A-rules and the technical requirements provided for in the Manual for Higher Degree studies and in faculty rules;
- ☑ Has been checked by me for plagiarism (by making use of Turnitin software for example) and a satisfactory report has been obtained, and;
- ☑ That the work was language edited before submission for examination.

Faculty specific requirements as per A-rules: 1.3.2, 4.3.2, 4.3.3, 4.4.2, 4.10.4, 5.3.2, 5.4.2, 5.10.2

- ☑ Complies with regards to faculty rules on submission or acceptance by an accredited scientific journal;
- ☑ Complies with regards to faculty rules on peer reviewed conference proceedings;
- ☑ The student is hereby granted permission to submit his/her mini-dissertation/ dissertation/thesis for examination.

Signatures of supervisor(s) and Promoter(s): (only compulsory in cases where there are co- or assistant- supervisor(s/promoters)

Lelanie Malan Digitally signed by Lelanie Malan Date: 2023.08.10 12:20:13 +02'00' Supervisor/Promoter

Prof Werner de Klerk Digitally signed by Prof Werner de Klerk Date: 2023.08.14 09:38:34 +02'00' Co-Supervisor/Co-Promoter

Assistant -Supervisor
Assistant-Promoter

Original details: (10512187) M:\HDA Toolbox\Forms\Pdf fillable forms\13.Solemn Decl and Permission to submit exam copy.pdf 3 December. File reference: 7.1.11.3.2/3