SUPPORT NEEDS OF PRIMARY CAREGIVERS CARING FOR CHILDREN WITH AUTISM SPECTRUM DISORDER IN KIMBERLEY

Submitted by

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Declaration

"I, Poppy Elizabeth Mathane, declare that the dissertation that I herewith submit for the Master of Nursing (MNursing) at the University of the Free State, is my independent work, and that I have not previously submitted it for a qualification at another institution of higher education."

Signature:  **Date:** 20 February 2023

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Table of Content

List of tables

List of figures

Operational and conceptual definitions

Autism Spectrum Disorder (ASD) According to the American Psychiatric Association (APA) (2013:5), ASD is a chronic neurodevelopmental disorder with various degrees, characterised by impairments in communication, socialisation and motor behaviour. Impairments in communication mean children are unable to form sentences by the age of five (5) years and still use one word or just murmurs to express themselves (O'Brien & Lushin, 2016:4). Impairments in socialisation implies an individual will not be able to recognise emotions, in the tone of voice and body language of others (American Psychiatric Association, 2013:5). Motor behaviour limitation occurs when there is a partial or total loss of the function of a body part, which may result in muscle weakness and poor stamina (O'Brien & Lushin, 2016:4). The symptoms associated with ASD are emotionally challenging since these children often respond poorly to parental affection. They, therefore, need more attention from their primary caregivers (Catalano et al., 2018:341). According to the DSM-5, ASD includes Asperger's, childhood disintegrative, Rett's, and pervasive developmental disorder (Kent et al., 2013:1242). For this research, the term autism spectrum disorder (ASD) will be used.

Child means every human being, male or female, below the age of eighteen (18) years, including adopted children. A child is a girl or a boy, a daughter, or a son (Children's Act 38 of 2005; Bajpai 2017:5). The operational definition for a child in this research refers to a child below 18 years with ASD who is cared for by a primary caregiver.

A primary caregiver could be a parent, family member, sibling, or grandparent. This person is responsible for the various caregiving activities of a child during their life stages. This concept may even be extended to an individual who cares for a child and can identify problems concerning the child they are taking care of. If this is the case, support from others may be necessitated (Children's Act 38 of 2005; Evian, 2011:140). In this study, a primary caregiver is any person in a child's life, for example, a mother, including those who care for orphans and children in homes; a father; a friend, neighbour or a family member caring for a dependent child. These adults are responsible for providing full-time care to a child and/or children with ASD.

Support needs are classified as care and support towards bio-psychosocial, physical, social, instrumental, financial, or emotional needs, coupled with information and training. Support needs may be providing support for a primary caregiver because they often have to cope with challenges

that may endanger their physical, bio-psychosocial, psychological and financial well-being while taking care of children affected by ASD (Kumar & Das, 2017:70; Catalano, 2018:341; Tilahun et al., 2016:2). In this study, support needs will refer to any support required to care for a child with ASD which the primary caregiver identifies. It may include but are not limited to assistance with financial, emotional, bio-psychosocial, physical, instrumental, and information needs.

Abbreviations

ABA	Applied Behaviour Analysis
ADHD	Attention–Deficit Hyperactivity disorder
APA	American Psychiatric Association
ASD	Autism Spectrum Disorder
CDC	Centres for Disease Control
CEO	Chief Executive Officer
DHIS	District Health Information System
DHP	District Health Plan
ECD	Early Childhood Development
HOD	Head of Department
HSREC	Health Sciences Research Ethics Committee
ICF	International Classification of Functioning
IMCI	Integrated Management of Childhood Illness
KZN	Kwazulu-Natal
NACOSA	Networking HIV and AIDS Community of Southern Africa
NGO	Non-Governmental Organisation
NHQIP	National Health Quality Improvement Plan
OCD	Obsessive–Compulsive Disorder
SASAA	South African Social Security Agency
SA	South Africa
SP	Specific Phobia

Abstract

Autism Spectrum Disorder (ASD) is a chronic neurodevelopmental disorder with various degrees, characterised by impairments in communication, socialisation and motor behaviour. The study aimed to explore and describe the support needs of primary caregivers caring for children with an autism spectrum disorder in Kimberley. Although studies on primary caregivers' needs were done in other countries and provinces, as well as on other childhood conditions requiring caregiving, there was no proof of this type of study done in Kimberley.

The research methodology used was a qualitative, explorative and descriptive design. Focus group discussions were used to collect data from participants recruited at the Robert Mangaliso Sobukwe Hospital in Kimberley. Twenty-seven (27) participants participated in four focus groups. Primary caregivers of children with ASD who were invited to participate had to fit the criteria of being a primary caregiver (including mom, dad, foster parent, friend, granny or anyone caring for the child). They had to understand and speak English, Setswana or Afrikaans (These are the languages predominantly spoken in Northern Cape), reside in Kimberley, taking care of a child and/or children below 18 years diagnosed with ASD. Primary caregivers had to give consent to participate in the study. As stated in Tesch's coding steps, an audio recorder was used during the focus group discussions and transcribed.

The themes identified during data analysis were healthcare, financial needs, basic education and social support needs. Sub-themes under healthcare focused on access to healthcare, health information, community awareness, and lack of knowledge on care aspects and training. Under financial needs, sub-themes identified were transport and nutrition. For basic education, ECD centre and special education were the sub-themes. Lastly, stigma, psychological well-being and family support formed part of the social support needs.

The trustworthiness of the information collected was supported by ensuring the criteria of credibility, transferability, confirmability and dependability. The researcher recommended that the support needs of primary caregivers caring for children with ASD should be attended to by family members, healthcare professionals and community members. Such recommendations focus on information, education and training of all stakeholders.

Chapter 1

OVERVIEW OF THE STUDY

1.1 INTRODUCTION

Research about primary caregivers taking care of children with autism spectrum disorder (ASD) in South Africa (Autism SA, 2000) is limited. Although the challenges faced by primary caregivers of children with ASD are relatively well documented in high-income countries, little is known about primary caregivers' support needs and ASD in South Africa (Dada & Samuels, 2016:1). According to the District Health Information system (DHIS, 2019), there was no research done in Kimberley, Northern Cape to determine the support needs of primary caregivers caring for children with ASD. DHIS is an open-source District Health Information Software adopted as the National Standard System for capturing, storing, analysing and reporting routine data. It enables healthcare professionals to manage and analyse transactional, case-based data records.

Globally, the prevalence of ASD stood at 62/10,000, with boys accounting for the highest number. In regions such as Eastern Europe and Africa, estimates were limited. World-wide, 34 countries' prevalence ranged between 1,09/10,000 to 436/10,000, with 100/10,000 as the median prevalence (Zeidan et al., 2022:779-781). In 2010 World-wide, it was found that white, non-Hispanic, black, and Asian populations were fewer than Hispanic children. Children that were 25 times more likely to be diagnosed with ASD were non-Hispanic white children in comparison with non-Hispanic black children (Zeidan et al., 2022:779-781; Baxter et al., 2015:601-613).

According to the Centre for Disease Control (CDC, 2018:75), 1% of the world's population has ASD. It is estimated that ASD prevalence in the United States is 1 in 59 births (CDC, 2018:75). The prevalence of ASD among children in the United States increased by 1.46 per cent from 2000 (1 in 150) to 2010 (1 in 68) (CDC, 2018:75; Nevison & Zahorodny, 2019:4721; Baxter et al., 2015:601-613). In 2010, 52 million ASD cases were diagnosed, equal to 7.6 per 1000 or one in 132 people (Baxter et al., 2015:601-612).

The prevalence of ASD in South Africa is unknown due to a lack of research conducted here and in Africa in general (Ametepee & Chitiyo, 2009:11-14; Abubakar et al., 2016:800-802;). However, according to Autism South Africa, there would be 933 new cases of ASD diagnosed in children each month. This means a caseload of 216 per week or 31 cases per day (Autism SA, 2000). Since 2000, it is estimated that over a million children have been diagnosed with ASD in SA (Autism SA,

2000). Initially, ASD had been thought to have a much higher prevalence in the United States. It is becoming clear that this disorder occurs in all countries, cultures and across genders (CDC, 2018:75). In South Africa, ASD, as a neurodevelopmental disorder, is not well understood by primary caregivers, healthcare practitioners and the community, although it is increasingly diagnosed across all cultural groups (Madlala, 2012:8-66; Dada & Samuels, 2016:1). Primary caregivers also experience a lack of knowledge resulting in unmet support needs (Dillenburger et al., 2013:1558).

According to Halter (2018:8), and the American Psychiatric Association (2013:5), ASD is a lifelong developmental disorder. It is a neurobiological and developmental disability that begins in the first three years of a child's life and affects the individual and the primary caregivers. It is a whole spectrum that includes Asperger's, childhood disintegrative disorder, Rett's, and pervasive developmental disorder. Children with ASD are challenging to care for due to behavioural problems, including temper tantrums and aggression. Aggressiveness is often regarded as an emotional outburst associated with emotional distress. These behaviour problems can pose potential physical harm to the primary caregiver, siblings, family members or friends (Halter, 2018:8; APA, 2013:5). A child with autism spectrum disorder (ASD) may also have other conditions, such as specific phobia (SP), obsessive-compulsive disorder (OCD), attention-deficit hyperactivity disorder (ADHD) and intellectual disability (Halter, 2018:8). These conditions complicate the difficulties for primary caregivers tasked to manage the child's behaviour (Halter, 2018:8; APA, 2013:5).

Although caring for children with ASD can be a pleasant experience for many carers, it can also put people at risk of severe stressors, whether financial, physical, biopsychosocial, information or emotional (Catalano et al., 2018:342). According to Talley et al. (2014:17), primary caregivers are at risk of negative physical, mental, financial and health effects, which emerge over time as care demands increase. Providing care for a loved one often entails helping with daily activities like eating and taking a bath. This responsibility negatively influences primary caregivers' overall health (Talley et al., 2014:17), influencing their social, emotional, physical and financial well-being and increasing stress levels (Belle et al., 2006:727).

Although having a child with ASD does not guarantee that there will be family difficulties, evidence suggests that primary caregivers frequently feel worn out, stressed, and lonely (Boyd, 2018:672). Primary caregivers tend to worry and feel frustrated. They need to be equipped with coping skills and stress relieve management to address their emotional needs (Kumar & Das, 2017:3). Beyond the scope of typical parenting, caring for a child with a chronic condition increases the risk of family

conflict, stress, and depression (Boyd, 2018:673). Primary caregivers must be taken care of emotionally, physically, socially, financially and bio psychosocially through access to qualified professionals trained to deal with their specific needs (Tilahun et al., 2016:7).

Taking care of children with ASD can be overwhelming for the parents as they tend to experience sadness and it may be hard to deal with emotions (Boyd, 2018:672). They may refuse to acknowledge the unacceptable truth that having children diagnosed with ASD is a lifelong disease. They may display anger and guilt (Catalano et al., 2018:341); according to Boyd (2018:672), they often experience grief. All the mentioned needs cause stress among caregivers. Primary caregivers' stress is caused by having to look after children who need close supervision and help. Their stress is increased due to a lack of support from different care services (Catalano et al., 2018:342).

According to Kumar and Das (2017:2), taking care of a child with ASD may lead to primary caregivers working without rest while their physical needs still must be met. Primary caregivers tend to feel exhausted. Any caregiver with an average child experience some fatigue, whereas primary caregivers with ASD children live with a deep sense of exhaustion. This fatigue continues well past the first few years as their children's development are delayed, for example, prolonged speech. Children without ASD can self- dress and potty train when they reach an average developmental age, but for children with ASD, it can take longer. Primary caregivers need support related to daily routines because caring for ASD children requires a lot of attention during their developmental stages (Provost et al., 2007:321).

Primary caregivers tend to be burdened with financial limitations and need financial support to buy specific food for their ASD children, take children for leisure activities and transport them to clinics/hospitals when faced with an emergency or in any event that requires medical attention or therapy. ASD children's nutritional needs could be costly if caregivers follow specific guidelines recommending special diets. Many caregivers cannot afford these special diets (Shattock & Whiteley, 2002:175). Families with children with ASD experience stigma, which is associated with shame. Primary caregivers' support needs should be carefully noted to inform relevant role players, and if possible, support interventions can be planned to alleviate their stress. However, when the needs of primary caregivers are investigated, it is crucial to keep the specific context in mind. A brief description of the informal caregivers' background within the context of the study will follow.

1.2 BACKGROUND AND CONTEXT OF RESEARCH

The Northern Cape is one of nine provinces of the Republic of South Africa. It has the lowest estimated population of 1,3 million compared to the other eight provinces (Stats SA, 2022). The Northern Cape consists of five districts: Frances Baard, John Taolo Gaetsiwe, Siyanda, Pixley Ka Seme and Namaqualand. Kimberley is situated in the Frances Baard District, consisting of locations such as Galeshewe, Vergenoeg, Homelite, Homestead, Homevale, Roodepaan, Club 2000, Phuthanang, Phomolong, Herlear, Klisser, Monument Heights, Carter's Glen, New Park Green Point, South Ridge, Eltoro, Fabricia and the surrounding squatter camps. See Figure 1, showing a map of Kimberly (Wikipedia, 2023:2).

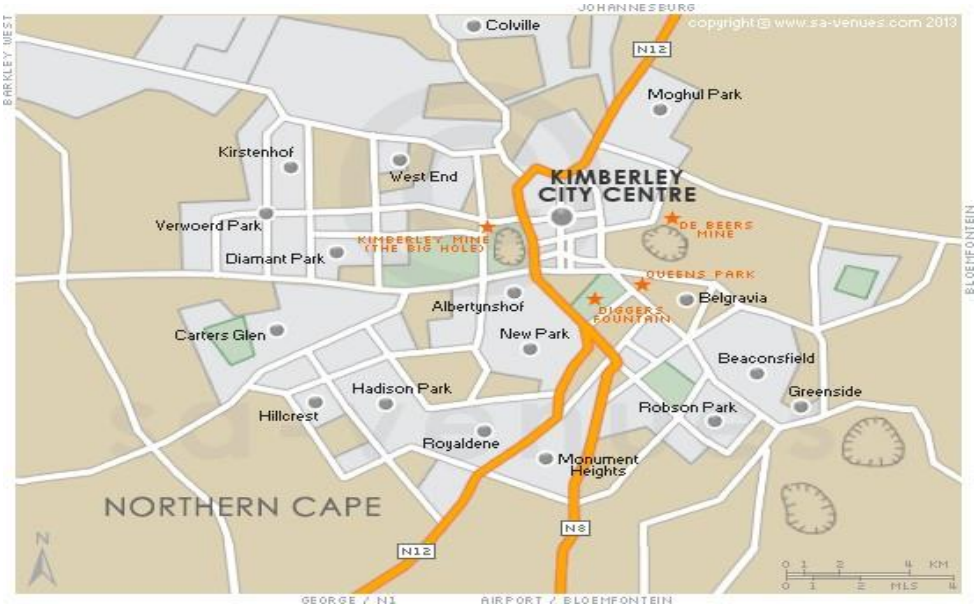

Figure 1-1 Map of Kimberley (Wikipedia, 2023:2)

Kimberley is a semi-urban community that is economically dependent on diamond diggings which helps them to feed their families by selling the excavated jewels. Kimberley has an estimated population of 520,000 people (Wikipedia, 2022:1). Community members speak Setswana and Afrikaans predominantly, but English is also spoken. Three schools out of 47 in Kimberley accommodate children with special needs, including those with ASD. They are Jannie Brink School, Elizabeth Conradie and Boitumelo School, as communicated by Gumede (2019). All three schools have professional nurses caring for the learners' health needs. As stated by Gumede (2019), three special primary schools in Kimberley are not enough to accommodate the needs of children with unique educational needs, but at least five schools are needed. As mentioned by Kruger (2023), the district coordinator of ECDs in Kimberley, there are no special ECDs for ASD children in Kimberley. However, some ECDs are taking children in with special needs and supporting these children with their education. It is difficult to determine how many ECDs are accommodating

children with ASD, as the ECD determines whether to enrol children with ASD or not.

This challenge affects primary caregivers because there are limited options for enrolling their children in special schools and special ECDs in Kimberley. This often results in primary caregivers resorting to any school that accommodates their children. In 2018, the Allied Manager suggested a WhatsApp group for the primary caregivers attending sessions at Allied Health. The WhatsApp group was meant to support each other, including health care support. The Allied Manager requested the Autism SA representative to be the administrator of the WhatsApp group because she always requested the WhatsApp group for primary caregivers. In 2018, the WhatsApp group was created, and primary caregivers could keep in touch with each other. However, towards the end of 2019, the WhatsApp group was terminated when the creator, the psychologist, moved to another province. The researcher heard about the WhatsApp group when she was recruiting the participants and one of the participants mentioned that they used to have the group as a support structure.

The support needs of primary caregivers of children with ASD must be identified and met to reduce the burden they face (Catalano et al., 2018:342). As part of the Child Health Directorate responsible for providing support and response to the overall health of the children in the district, the researcher constantly interacts with primary caregivers during support visits to the health facilities. During these support visits, the researcher continuously comes across primary caregivers who relate their experiences and challenges encountered with access to healthcare. The researcher decided to study the support needs of primary caregivers caring for children with ASD. Before planning possible approaches or initiatives could occur, the support needs of primary caregivers should be explored and described.

1.3 PROBLEM STATEMENT

Primary caregivers face limited support because they struggle to care for their children and themselves with insufficient resources due to poverty-stricken South Africa. Essential infrastructure and institutional efficiency are deteriorating with enormous health implications. Poverty in South Africa, which affects most populations through widespread food insecurity and the unemployment rate, makes it difficult for the primary caregivers to afford medication and therapy (Malik-Soni et al., 2021:1028; Seeking & Nattrass, 2015:162). Services for people with disabilities are rarely prioritised or sufficiently coordinated, despite the existence of government policies (Children Disability Act) that outline them (Geiger, 2012:31).

Although there is information available on the distress, financial burdens, information gaps,

physical, emotional, and biopsychosocial burdens (including exclusion from health and education services which are crucial for their development) facing the primary caregivers of children with ASD (c.f. 1.1), Modiakgotla, (2019), indicates that we know little about their support needs. Little is known about primary caregivers' support needs in South Africa, which results in a limited understanding of how primary caregivers care for their children with ASD (Dada & Samuels, 2016:1; Boyd, 2018:672; Modiakgotla, 2019). Without better comprehension and narration of the needs of caregivers caring for children with ASD, healthcare practitioners cannot truly support the primary caregivers.

1.4 PURPOSE OF THE STUDY

The purpose of the study was to explore and describe the support needs of primary caregivers caring for children with autism spectrum disorder (ASD) in Kimberley.

1.5 RESEARCH QUESTION

This research study attempted to answer the following question: "What are the support needs of primary caregivers caring for children with ASD?".

1.6 THE RESEARCH PARADIGM

A paradigm is a way of looking at the research (Polit & Beck 2017:738). It is the natural view – a worldview – that encompasses a set of philosophical assumptions and gives direction to the approach of inquiry (Polit & Beck, 2017:738). Researchers can create their own meanings and interpretations, which are paradigms (Merriam, 2009:8).

The naturalistic/constructivist paradigm is a method of inquiry that seeks to address the issue of human complexity by examining it truthfully. This will further accentuate the understanding of the human learning experience as it occurs in a naturalistic setting during a given period. Constructivists believe that reality is interpreted multifariously, and the purpose of research is to determine how an individual constructs their reality within a specific context (Polit & Beck, 2017: 722-724).

The researcher applied a constructivist paradigm because each primary caregiver brought their point of view, constructing their experience, needs and knowledge on the topic of the conducted study. The constructivist paradigm was chosen to seek a thorough understanding relating to the

support needs of the primary caregivers.

For this study, the primary caregivers were encouraged to state their insight grounded in their experiences through the subjective meaning of their own realities, which differ from one participant to another. Each primary caregiver had to subjectively verbalise their support needs based on their beliefs, attitude, and socio–cultural practices. These complex views of each primary caregiver were recorded and documented during data collection.

1.7 RESEARCH APPROACH

Qualitative research is based on believing in multiple realities, participants' viewpoints, not disrupting the natural context of the phenomenon and reporting data in a narrative style rich from the participants' commentaries (Polit & Beck, 2017:479). Creswell and Poth (2018:96) mention that qualitative research design is an interactive approach where researchers actively report their values. Researchers attempt to make sense of or interpret individual experiences by getting close to the study participants by perusing things in their natural environment. This applies to this research since the support needs of primary caregivers taking care of children with ASD are described.

1.8 RESEARCH DESIGN

A research design considers how human beings transform the world into a series of characterizations (Creswell & Creswell, 2018:7; Polit & Beck, 2017:743; Leavy, 2017:124). Furthermore, a qualitative research design is characterised by believing in multi-realities and participants' viewpoints, not disrupting the natural context of the phenomenon and reporting data in a literary style rich with participants' commentaries (Creswell & Creswell, 2018:260; Leavy, 2017:124). The researcher employed a qualitative design to gain in-depth knowledge of gaps identified by primary caregivers in terms of their support needs. An explorative and descriptive design was used to gain an understanding of primary caregivers' support needs.

1.9 RESEARCH METHOD AND TECHNIQUES

As described by Botma et al. (2010:41), the methodology includes the plan on how the researcher can get data from the participant and how the investigation will be carried out. In other words, this implies what the researcher will do to answer the research question. Data was collected from the primary caregivers through focus group discussions to explore and describe what their support

needs were.

As reported by Wong (2008: 256) and Barbour (1999: 5), a focus group discussion is a type of qualitative data collection method in which the interviewer asks specific questions about a subject or issue to the participants in a group setting. In contrast to individual interviews, focus groups add the dimension of member interactions. Rather than the moderator clarifying some pressing issues, the group participants are prompted to speak with each other, trading thoughts and remarking on one another's encounters or perspectives (Wong, 2008: 256; Barbour, 1999:5). An independent and experienced moderator conducted the focus groups. The moderator encouraged the participants to voice their needs using open-ended questions, allowing them to explain it in their own words.

1.10 POPULATION AND UNIT OF ANALYSIS

A population in research refers to the number of people living together in the same place who are of interest to the researcher (Brink et al., 2012:131; Leedy & Ormrod, 2010:276; Polit & Beck, 2017:739). The target population is the entire group of individuals from which the sample is drawn (Polit & Beck, 2017:645). The unit of analysis is usually referred to as the population of interest to a researcher. These analysis units are fundamental to the researcher due to their experiences concerning the research problem (Polit & Beck, 2017:548; Streubert & Carpenter, 2011:134-136). The researcher set specific inclusion and exclusion criteria that were followed in selecting participants purposively. In this study, the target population were the primary caregivers taking care of children below 18 years with ASD in Kimberley. The analysis unit comprised 27 primary caregivers that voluntarily partook in four focus group discussions.

1.11 PURPOSIVE SAMPLING

In qualitative research, purposeful sampling is a standard method for selecting and identifying participants with rich information regarding the researched topic. Typically, rich cases are chosen to make the most of limited resources (Patton, 2002: 54). Primary caregivers attending sessions with children with ASD at Robert Mangaliso Sobukwe Hospital were purposively selected. The hospital was used as a recruitment site. The occupational therapist manager acted as a gatekeeper and assisted the researcher in identifying possible participants (primary caregivers) by verifying children with an ASD diagnosis. The criteria for purposive sampling included willing participants whose children (primary caregiver’s children) were enrolled in therapy at Robert Mangaliso Sobukwe Hospital and were available for a group discussion.

1.12 EXPLORATIVE INTERVIEW

An explorative interview is a pilot variation of the intended study. It is carried out to develop and improve the data collection procedure or methodology in preparation for the main study, as stated by Burns and Grove (2009:228). The researcher recruited seven (n=7) participants for the explorative interview. The researcher recruited seven (n=7) participants for the explorative interview and conducted one focus group. During the explorative interview at Robert Mangaliso Sobukwe Hospital, participants were requested to respond to two questions. There was no need to change questions as the participants understood and responded well to both questions. The data was not included in the data analysis.

1.13 DATA COLLECTION

Data collection is a way of obtaining information from the person who is asked and can respond to a question (Polit & Beck, 2017:13). A focus group discussion is a qualitative research method during which the moderator asks participants specific questions about the research subject. Focus group discussions provide an opportunity for interaction among members (Onwuegbuzie, 2009:6). Focus groups were used as a data collection method.

For effective data collection, participants were seated in a circle. The main door of the boardroom was closed to avoid any disturbances. A note was displayed on the door for “no disturbance”. The group discussion took place according to the agreement with the primary caregivers. Ground rules during the focus group discussion, such as recording, note taking and confidentiality (also among members), were explained. Information leaflets were distributed, and consent forms were signed (Addendum A, B and C). An audio recording was used to record the discussion, transcribed and used during data-analysis. The moderator conducted the focus group discussions and the participants responded well to the questions. Four group sessions with a total of 27 participants were conducted. All four sessions took approximately 45-60 minutes.

1.14 DATA ANALYSIS

Strydom, De Vos and Delport (2011:198) state that data analysis is organizing and structuring the collected data by creating meaningful quality to the interpretation. According to Joubert and Ehrlich (2007:323), there are no rigid rules for data analysis in qualitative research. Polit and Beck (2017:57) state that data analysis may entail transferring written data from transcribed records onto

computer files for analysis.

Tesch's coding steps by Creswell and Poth (2014:198) were used during data analysis and used an audio recorder to record all the information. The researcher typed field notes. Transcripts were printed, which allowed the researcher to read the data collected. The researcher listened to the audio repeatedly to ensure it was transcribed correctly. All scripts were put together to analyse data. Copies of scripts were made available to enable the researcher, co-coders and supervisor to read them and compile draft themes. Printed scripts were shared randomly. All similar themes were put together and the process was repeated. New themes were identified. Sub-themes were derived from the themes. Data collected were analysed, and the researcher and the supervisors discussed and agreed upon the four themes. Four themes and relevant subthemes emerged from the data analysis detailed in chapter 3.

1.15 TRUSTWORTHINESS OF THE STUDY

Korstjens and Moser (2018:120-121) describe rigour in qualitative research as a strategy to ensure the research's trustworthiness (credibility, transferability, confirmability, dependability). The researcher enhanced trustworthiness through the application of credibility, transferability, confirmability and dependability as follows:

Credibility was implemented by allowing the participants to give their descriptions as they applied to their needs and context. The formulated questions were tested through an explorative interview remaining unchanged for the study. Reflexivity was ensured by recognising the participants' values and analysing the ones that affected the data collection. Furthermore, equivalence was maintained by using the researcher as the note taker and one experienced moderator who conducted focus group discussion to ensure rich data was collected.

Transferability was ensured by the moderator asking the same questions to all the participants, which enhanced similar understanding.

Confirmability was enhanced using the audio recorder during the focus group discussions, which promoted accurate transcriptions. All the information collected during the focus groups was kept safe as soft copies, including the field notes. Original transcripts and codes are available for verification purposes.

Dependability was ensured through a detailed description of the research methodology. The

researcher kept an audit trail to ensure no data or evidence was missed. Authenticity was proven when the researcher could portray the experiences of the participants as they lived. Trustworthiness is discussed in more detail in Chapter 2.

1.16 ETHICAL CONSIDERATIONS

Ethics is a moral process referring to research techniques adhering to professional, legal and social responsibilities towards the study participants (Polit & Beck, 2017:727). In this study, the researcher upheld the Belmont principles of beneficence, respect for human dignity, rights of humans, and justice. The researcher and the moderator promoted beneficence by ensuring that the participants knew a psychologist was available for emotional support and debriefing if required after the focus group discussions. The participant's rights to autonomy were maintained. Before the focus group discussions, participants were informed and consented to participate in the study. It was explained that they could withdraw anytime and were not forced to participate (see addendums B and C).

The justice principle was maintained by ensuring that the participants were treated fairly and their privacy rights were protected. Every participant was allowed to speak, and the participants were treated fairly by scheduling group discussions according to the availability of participants. Participants were not reimbursed for participating in the study but were provided transport fees and refreshments.

Participants were ensured that all information would be managed with confidentiality, with no identifying information in any document or report. Confidentiality will be ensured by locking the audio recorder and the field notes in the researcher's office, which is only accessible to the researcher. It will be kept for five years. This research was approved by the Health Science Research Ethics Committee (HSREC) of the University of the Free State, the HOD of the School of Nursing, the CEO of Robert Mangaliso Sobukwe Hospital and the Head of the Northern Cape Health Department before data collection commenced (See addendums D, E, F and G).

1.17 SUMMARY

To formally present the study, the dissertation is divided into four chapters. Chapter one provided an overview. The overview included the problem statement, research question and purpose of the study. Furthermore, the population and sampling indicated who participated in the study, while the explorative interview refined the methodology used. Data collection and analysis followed, ensuring the organisation of data. This chapter ends with ethical considerations ensuring that professional,

legal and social obligations towards the participants were followed.

1.18 STUDY LAYOUT

This dissertation is presented in four chapters:

CHAPTER 1 Overview of the research study

CHAPTER 2 Research methodology

CHAPTER 3 Analysis and discussion of research findings

CHAPTER 4 Summary of research findings, recommendations, limitations and conclusion of the study

Chapter 2

RESEARCH METHODOLOGY

2.1 INTRODUCTION

A contextual overview of the research study, which includes the design followed by a description of the methodology, is provided in this chapter. This study is embedded in a qualitative research design with an explorative and descriptive approach. The research technique, population, sampling, data collection, and the analysis of data processes are also described. The chapter concludes with a discussion on trustworthiness and ethical considerations.

2.2 RESEARCH DESIGN

A research design is a blueprint the researcher uses to conduct the study (Burns & Grove, 2009:218). It further provides structure to the researcher's investigation of the identified problem and informs decision-making regarding the data collection methods. The researcher gathers data to answer the research question, and the design guides the collection and analysis process (Asenahabi, 2019:79; Leavy, 2017:124; Polit & Beck, 2017:743). This study selected a qualitative, explorative, and descriptive design. This enabled the researcher to explore and describe the support needs of primary caregivers taking care of children with ASD. A discussion of the research methodology processes is presented in the following sections.

2.3 QUALITATIVE RESEARCH

Qualitative research is characterised as exploratory and explanatory, allowing participants to share their lived experiences (Aspers & Corte, 2019:139; Sawatsky et al., 2019:14). Qualitative methods use text and image data, which differentiates it from quantitative methods because participants are allowed either to write or discuss information regarding the questions asked. Qualitative research tends to take a unique approach to data analysis and draw on various designs (Polit & Beck, 2017:506; Leavy, 2017:124). Qualitative researchers collect information from participants experiencing the problem under investigation (Creswell & Creswell, 2018:254-255; Polit & Beck, 2017:479).

Various sources of data collection, such as interviews, observations, field notes and focus groups, can be used by qualitative researchers to obtain information. When this is done, researchers verify

all received information, explain it, and organise it logically (Creswell & Creswell, 2018:255-256; Polit & Beck, 2017:479). Qualitative research encourages a holistic approach by integrating multiple viewpoints to produce an understanding of the “complete picture” (Berg & Howard, 2017:12; Merriam & Tisdell, 2016:137).

In qualitative research designs, researchers are referred to as the “apparatus” (Creswell & Creswell, 2018:254-255) due to the researcher’s presence during data collection and analysis. Researchers can understand how people establish meaning in their lives, the people they meet, and what they do. A researcher must always consider the strengths and limitations of a research method. The study's conceptualisation considered the strengths and limitations of qualitative research.

2.4 STRENGTHS OF QUALITATIVE RESEARCH

One of the strengths of a qualitative research design includes the researcher being able to gather rich information because it utilises open-ended questioning, which promotes in-depth response to the question asked (Almeida et al., 2017:371; Babbie, 2013:353-357; Creswell & Poth, 2018:2-11; Streubert & Carpenter, 2011:19-23). Furthermore, another strength of qualitative research includes the opportunity for a rich understanding of a specific phenomenon (Streubert & Carpenter 2011:22). The focus group discussion was specifically helpful in this regard.

Qualitative researchers can collect information by speaking directly with the participants and observing their behaviour (Creswell & Poth, 2018:2-11). For this study, a qualitative method was used to gather data regarding the support needs of primary caregivers taking care of children with ASD in Kimberley. In qualitative research, participants can speak their minds without being restricted. During the research process, the researcher received first–hand information from the participants and recorded it while it was occurring. Participants are allowed to tell their stories allowing the researcher to capture their life experiences (Creswell & Poth, 2018:10). These methods gave the qualitative researcher a rich description of a complex research problem and therefore, it could be comprehensively documented in a trustworthy manner (Almeida *et al.*, 2017: 371; Creswell & Poth, 2018:2-11; Polit & Beck, 2017:234). As with any other method, qualitative research has its limitations also.

2.5 LIMITATIONS OF QUALITATIVE RESEARCH

Some of the limitations associated with qualitative research and actions are presented in Table 2.1.

Table 2.1 Limitations of qualitative research and measures to address these

Limitations of Qualitative Research	Measures taken to address the limitation
The researcher is unable to report the private information that the participant is sharing with other participants or researchers (Creswell & Poth, 2018:264)	During the focus group discussion (qualitative), a primary caregiver divulged the name of the perpetrator that sexually abused her ASD child and further mentioned the name of the police station that she felt failed her child. The moderator, with experience in mental health nursing, supported the caregiver.
Qualitative research needs transcribing that takes time and requires accuracy (Creswell & Poth, 2018:264)	For this study, some of the transcribed audio was inaudible and the researcher had to listen to the audio recordings multiple times, which was time-consuming. The researcher was able to decipher the audio.
A weakness associated with the qualitative group discussion method includes the difficulty in recruiting participants (Creswell & Poth, 2018:273)	Two months were used to recruit participants with the assistance of the Allied Health manager, who acted as a gatekeeper. Due to the difficulty of recruiting participants in the community, the researcher had to get assistance from the Allied Health manager of the hospital, where she was awarded for locating the potential participants. The process was a success and she was able to recruit participants.

In qualitative research, strengths and limitations are analysed to understand the study processes better. The study employed an explorative design to investigate the support needs of caregivers of children with ASD. It provided the researcher with valuable information in answering the research question.

2.6 EXPLORATIVE DESIGN

The purpose associated with an explorative design is to uncover the unknown. It allows the researcher to obtain an in-depth understanding of the topic (Hunter et al., 2018:01; Ward et al., 2018:133). Researchers use exploratory designs to gather more information about a phenomenon by constructing a picture of how it occurs naturally (Brink et al., 2012:112; Polit & Beck, 2017:726; Springer, 2010: 125-132). In this study, little was known about the support needs of the primary caregivers caring for children with ASD in Kimberley. The focus group discussions allowed the researcher to explore the caregivers' support needs. The explorative design allowed the researcher to discover the main issues mentioned by the primary caregivers, followed by a description of those aspects. The next section addresses the descriptive design.

2.7 DESCRIPTIVE DESIGN

The main goal of descriptive research is to give an exact illustration of peoples' characteristics, activities and/or situations (Brink et al., 2012:112; Creswell & Creswell, 2018:257; Nassaji, 2015:129; Polit & Beck, 2017:726) by providing rich descriptions of complex situations (Marshall & Rossman, 2016:323). Descriptive design is further seen as a term that is broadly used to explain qualitative research (Kim et al., 2017:1-2; Polit & Beck, 2017:206). The researcher can describe what currently exists and discover new meanings (Marshall & Rossman, 2016:323). The purpose of a descriptive design for this study was to describe the support needs of primary caregivers for children with ASD in Kimberley. When little is known, descriptive research provides knowledge where needed.

2.8 POPULATION AND UNIT OF ANALYSIS

A population in research terms refers to the number of people that live together in the same place and who are of interest to the researcher (Brink et al., 2012:131; Leedy & Ormrod, 2010:276; Polit & Beck, 2017:739). The researcher chose primary caregivers of children with ASD residing in Kimberley as the study population. Kimberley has an estimated population of 520,000 (Wikipedia, 2022:1). Community members predominantly speak Setswana, Afrikaans or English. According to

the District Health Information system (DHIS, 2019), no data is available on the number of primary caregivers caring for children with ASD in Kimberley. Some of the reported race distributions include 63% Africans, 9% coloureds and 25% white persons (Wikipedia, 2022:1). Sampling and recruitment entail invitation of participants based on specific inclusion and exclusion criteria. The selection of individuals from a bigger population is known as sampling. The researcher must identify possible participants for a study. The researcher must know where to locate participants and identify and recruit them in relation to the study purpose and research questions (Leavy, 2017:75).

Purposive sampling allows the researcher to gather data from people and look for participants who can share their insight on the specific topic of interest. It further focuses on participants willing to participate in the study (Etikan et al., 2016:02; Polit & Beck, 2017:249). This type of sampling is used when one's goal is to include participants representative of a broad range of perspectives (Leavy, 2017:75). In this study, the primary caregivers taking care of children with ASD in Kimberley were purposively chosen.

Recruitment is a process by which participants are identified based on specific criteria and then requested to be part of the research (Polit & Beck, 2017:249). The researcher consulted the Head of the Department (HOD) of Allied Health to identify possible caregivers visiting the occupational therapist. The HOD informed the researcher about suitable dates when caregivers have appointments with Allied health professionals. The researcher approached caregivers during their scheduled appointments with the Allied Health personnel and they were informed about the research. The recruitment of participants for the focus group interviews was carried out with the assistance of the Allied Manager, who acted as a gate keeper. The gate keeper allowed the researcher to view the appointment book to check when the potential participants would visit the facility.

Participants were not known to the researcher. They were given an information leaflet (see addendum A) to obtain information about the study and decide if they were interested in partaking. Those that were interested in the study agreed to participate. The researcher was able to recruit participants in a trustworthy manner and immediately suggested suitable dates for the focus group discussions to the participants. The dates were discussed to determine when focus group discussions would suit the primary caregivers, not focusing on the researcher.

The unit of analysis is usually referred to as the population of interest to a researcher. These analysis units are fundamental to the researcher due to their experiences about the research problem (Polit & Beck, 2017:548; Streubert & Carpenter, 2011:134-136). The researcher identified

a specific population that acted as the unit of analysis: the primary caregivers of ASD children in Kimberley. Purposive sampling utilizes inclusion and exclusion criteria to select the participants, which applied to the study.

2.9 INCLUSION CRITERIA

Inclusion criteria are qualities the potential participants must have if they are eligible for the study. It consists of demographical, clinical, and geographical features and is opposite to exclusion criteria (Montes et al., 2017:12; Polit & Beck, 2017:728). Primary caregivers of children with ASD, who were invited to participate, had to meet the following inclusion criteria:

- Primary caregivers (including mom, dad, foster parent, friend, grandmother/father, or anyone caring for the child) that understood and spoke Setswana, Afrikaans or English, residing in Kimberley in the Northern Cape.
- Primary caregivers taking care of a child and/or children below 18 years diagnosed with ASD. The researcher obtained verification of the child's diagnosis from the Head of the Department (HOD) of Allied Health.
- Primary caregivers who gave consent to participate in the study.

The purposive selection of participants was based on the criteria above and exclusions were specified as explained below.

2.10 EXCLUSION CRITERIA

Exclusion criteria are features that eliminate participants who do not meet the criteria to be involved in the study (Montes et al., 2017:12; Patino & Ferreira, 2018:84; Polit & Beck, 2017:728). In this study, participants qualified to be part of the study but were unwilling to sign the consent forms because they saw it as a binding document. One inclusion criteria for this study was for participants to sign a consent form; if not, the participant would be excluded.

For this study, it was important to explore and describe the support needs of primary caregivers taking care of children with ASD, which led to selecting a specific method for data collection and analysis. One of the qualitative data collection strategies includes focus group discussions (Kim *et al*., 2017:1-2) as a method to explore and describe lived experiences. The researcher determined the abovementioned criteria and purposively selected participants assessed by the research methodology.

2.11 RESEARCH METHODOLOGY

According to Botma et al. (2010: 41), the research method is the plan on how the researcher can obtain data from the participant and how the investigation will be carried out. In other words, what the researcher will do to answer the research question and perform the research operations (Corbin & Strauss, 2014:04; Goundar, 2012:9; Pandey & Pandey, 2015:10). Assumptions underlying the various techniques should be known by the researcher to decide which technique will apply to the problem being studied (Corbin & Strauss, 2014:04; Goundar, 2012:9). It is important for the researcher to understand the research method used and to apply relevant research data quality and trustworthiness measures for the study. It will assist in knowing how to gather participant data and how the investigation can be carried through. Afterwards, the researcher conducted an explorative interview to pre–test the research question and the technique. The data collection process, using focus group discussions, is detailed below.

2.12 EXPLORATIVE INTERVIEW

An explorative interview refers to a small study the researcher conducts before the main study. The researcher therein tests the study technique and research question, predicts problems with the implementation and evaluates the appropriateness for participation (Green & Thorogood, 2009:57; Polit & Beck, 2017:265). The purpose is to develop and refine the methodology or data collection process before a main study. It is an opportunity for the focus group moderator to put their skills to the test (Green & Thorogood, 2009:57; Polit & Beck, 2017:265).

The researcher conducted an explorative interview with seven primary caregivers who were taking care of children with ASD that gave their informed consent. All the participants received information related to the study. It was well explained that only participants who consent to the focus group discussion will participate. Participants chose the time that was suitable for them. This explorative interview occurred in the boardroom of the Robert Mangaliso Sobukwe Hospital. The venue was familiar to the participants who attended different services there under the auspices of Allied Health services. This focus group discussion took about 60 minutes and COVID-19 national regulations were followed. The researcher facilitated the focus group discussion and tested the following questions:

1. What do you need in caring for a child with ASD?
2. How would you like to be supported?

This explorative interview was recorded and transcribed. A review of the exploratory interview indicated that the research questions and data collection technique were feasible. Conducting focus group discussions has some general guidelines that should be followed. The researcher, however, did not possess the skills to conduct focus group interviews and the services of an expert moderator were requested for data collection during the main study. However, the research questions remained unchanged and were used in the data collection process. The data collected during the explorative interview were not used as part of the main analysis.

2.12.1 DATA COLLECTION TECHNIQUES

The researcher plans a study in alignment with the research design and decides on the type and extent of information that should be collected (Polit & Beck, 2017:175). Due to the qualitative nature of the research, it was imperative to use research techniques that would provide appropriate answers to the research question. The data collection method used during this research was focus group discussion.

It is imperative to get permission before data is collected. The following permissions were obtained to proceed with the study: Health Science Research Ethics Committee (Addendum E) from the University of the Free State, Head of Nursing at the University of the Free State (Addendum D), Head of Northern Cape Health Department (Addendum G) and Chief Executive Officer (Addendum F) at the Robert Mangaliso Sobukwe Hospital. A focus group discussion was the best technique since the researcher was attracted to elicit information about the participants' support needs.

2.12.2 FOCUS GROUP DISCUSSIONS

The process of facilitating participants by asking specific questions is known as a focus group discussion (Korstjens & Moser, 2018:278). Focus group discussions consist of a one-time meeting of people who don't know each another. However, they have a shared experience (Carey & Asbury, 2012:15-16; Lakshman et al., 2000:358; Korstjens & Moser, 2018:278).

During the discussion, participants can interact with one another, contributing to obtaining valuable insights (Onwuegbuzie, 2009:6). Descriptions of a focus group differ but usually include a semi-structured informal meeting facilitated by a moderator and guided by a research question (Carey & Asbury, 2012:15-16). According to Carey and Asbury (2012:15-26), the researcher or a moderator should have the ability and a strategy to conduct focus group discussions to address the topic (Almeida *et al.*, 2017:378). The aim is to collect rich and comprehensive information.

To conduct the focus group discussions, Krueger (2002:15), Nyumba et al. (2018:20) and Carey and Asbury (2016:15) advised that groups should consist of at least three to twenty- participants to collect rich information. Brink recommends five to fifteen participants for focus group discussions (2012:158). During this study, four focus groups were conducted with different numbers of participants in each group. The first group had seven (7) participants, the second group had six (6), and the third and fourth groups both had seven (7). Group discussions vary in duration (Korstjens & Moser, 2018:278). Regarding Polit and Beck (2017:511), a focus group discussion usually lasts 90–120 mins. The four focus group discussions were conducted between 45 – 60 minutes.

Data saturation determines the number of focus group discussions which happens when the information provided is repeated (Polit & Beck, 2017: 60). It took four focus groups to reach data saturation. Participants were able to voice and describe their support needs during each group. When researching a topic, the researcher should be aware that the participants will have different opinions (Kuo et al., 2017:83). Evidently, participants voiced their ideas on support needs. After the focus group session, refreshments were served. A focus group discussion has its strengths that enable researchers to collect data.

2.12.3 STRENGTHS OF FOCUS GROUP DISCUSSIONS

A focus group discussion is an ideal technique for collecting qualitative data because it is flexible, engaging, provides new insights, is time-efficient, and can produce content-rich data (Carey & Asbury, 2012: 12-26; Tracy, 2013:167). Typically, there are more than six participants in a focus group discussion, allowing for real-time disclosure of numerous insights. This is not possible in one-on-one interviews. Focus groups can also provide the researcher with a great deal of information comprising various perspectives in a short time (Polit & Beck, 2017:511; Tracy, 2013:167). As such, focus groups can be used to effectively explore and describe emotional experiences (Tracy, 2013:167). When the participants do not understand the questions, the researcher can clarify immediately, which will open the path for more data from the participants because they are clear on what has been asked. The researcher can observe non-verbal behaviour during the group discussion (and take field notes) to capture the true reflection of how the participant reacts versus what the participant was saying and can encourage interaction (Brink *et al*., 2012:153; Polit & Beck, 2017:511). Participants interacted positively with the moderator and the other participants. The moderator's experience conducting focus group discussions enabled her to observe and interact with the participants.

Brink *et al.* (2012:153), Korstjens and Moser (2018: 275) and Tracy (2013:168) agree that participants in focus group discussions are encouraged to speak freely about general issues and can support each other during the process. Additionally, participants do not need to know how to write and read. However, they can respond verbally to questions that have been clearly explained. The participants in the current study communicated their needs, shared some tips, and supported each other. Even though focus group discussions have some benefits, they also have limitations. There are several limitations to using these techniques, which are discussed below.

2.12.4 LIMITATIONS OF FOCUS GROUP DISCUSSION

Focus groups discussions take more time to conduct than surveys, while an individual can complete most surveys quickly (Nyumba et al., 2018:1; Smithson, 2000:103). These sessions can be challenging due to the discussion of sensitive topics. Then it may be difficult for some participants to talk, resulting in them not being honest (Polit & Beck, 2017:511; Punch & Graham, 2016:205). Participants tend to stop speaking out because they are uncomfortable and not talkative, ending up with limited information for the researcher (Korstjens & Moser, 2018:278; Polit & Beck, 2017:511; Punch & Graham, 2016:205; Tracy, 2013:156;). For this study, the moderator probed the participants to obtain more information. Some participants were more reserved than others, causing limited information from those participants.

There are instances whereby participants do not reflect their own views but rather those of other people (Hennink & Leavy, 2014:5; Punch & Graham, 2016:205; Tracy, 2013:173) and it occurred in the current study. Some participants spoke about other peoples' lived stories, influencing the genuineness of the information received. Intimidation by certain members is always expected and needs to be controlled positively (Nyumba et al., 2018: 7). No bullying was experienced during the focus group discussion. In this study, participants could share ideas on how to take care of their children. They shared contacts and channels on TV that were useful to the group.

2.13 PLANNING ARRANGEMENTS OF FOCUS GROUP

A plan should be implemented before the focus group process to ensure successful execution. To ensure that focus groups are as productive as possible, the recruitment of possible participants, choosing the moderator and developing the question protocol is crucial. Finding a space for the focus groups is only one of several material requirements. Other materials involved in focus groups are consent forms, a venue with tables and chairs, stationery, recording equipment and refreshments (Krueger, 2002:7).

After obtaining permission for the study, planning for the focus group discussion commenced. Recruitment of participants took place within four weeks after that. A total of 27 participants were recruited and the researcher was able to conduct four sessions. With the supervisors' advice, the researcher could approach the potential moderator through emails and calls. The moderator confirmed that she was available and agreed to conduct focus group discussions for this study. The time, date, and venue for each focus group discussion were confirmed with the moderator. The research questions were piloted and found to be appropriate.

Creating a respectful and trustful environment is critical for the participants as they need to feel safe (Petersen & Carlsson, 2021:2311). The venue chosen was known to the participants. The Allied Health services manager requested the venue, who granted permission. The size of the group was considered, including the seating arrangement (Adler & Salanterra, 2019:4). The venue provided had adequate tables and chairs for the number of participants. According to Krueger (2002:4), stationery and recording are critical for focus group discussions. An audio-recorder was arranged. Furthermore, consent forms and stationery were printed according to the number of expected participants. Refreshments were organised a week before with a caterer to ensure that the participants received some sustenance after the group sessions. The researcher ensured all the logistical arrangements were in place before embarking on the data collection.

2.14 DATA COLLECTION PROCESS

The main activity in a focus group is a group discussion with selected participants. As indicated by Polit and Beck (2017:725), the invited participants will not always attend the sessions as planned or agreed upon. In this study, some primary caregivers withdraw from the study for different reasons. Each session had more than five participants and lasted 45-60 minutes. Two sessions were held on one day to prevent the moderator from travelling too much from Bloemfontein. All sessions were held four weeks apart between December 2020 and January 2021.

The venue was private and doors could close during the focus group discussions. The arrangements to enhance the successful execution of the focus groups included adhering to COVID-19 regulations. These focus group discussions took place during the COVID-19 pandemic and some participants could not form part due to fear and illness. All participants that arrived received masks and sanitiser to reduce the possibility of transmission. COVID-19 screening was done, which took extra time before commencing each session.

Participants were screened by hospital COVID-19 screeners and were sanitised before coming into the venue. All were wearing masks correctly by covering both mouth and nose. Social distancing was maintained during the execution of the focus group discussion. Participants were welcomed in a clean environment without disturbances. At the door, participants were given an information leaflet followed by a verbal explanation about the study. The researcher and moderator explained the focus group process and allowed the participants to ask questions before they voluntarily signed the consent forms.

Participants were also informed that the group sessions would be recorded, ensuring truthful capturing of their opinions and recorded information would be kept confidential. They were also informed that information could be used to present the data. The researcher had a book and pen to ensure that capturing data manually was completed. The note taker had stationery to ensure that capturing data was done manually.

Participants were circularly seated on chairs. See Figure 2.1 for the positioning of participants in the room. The moderator asked the participants to introduce themselves after she introduced herself to create a conducive atmosphere. Primary caregivers appeared relaxed. The participants were able to respond to the moderator's questions, meaning they understood what was asked.

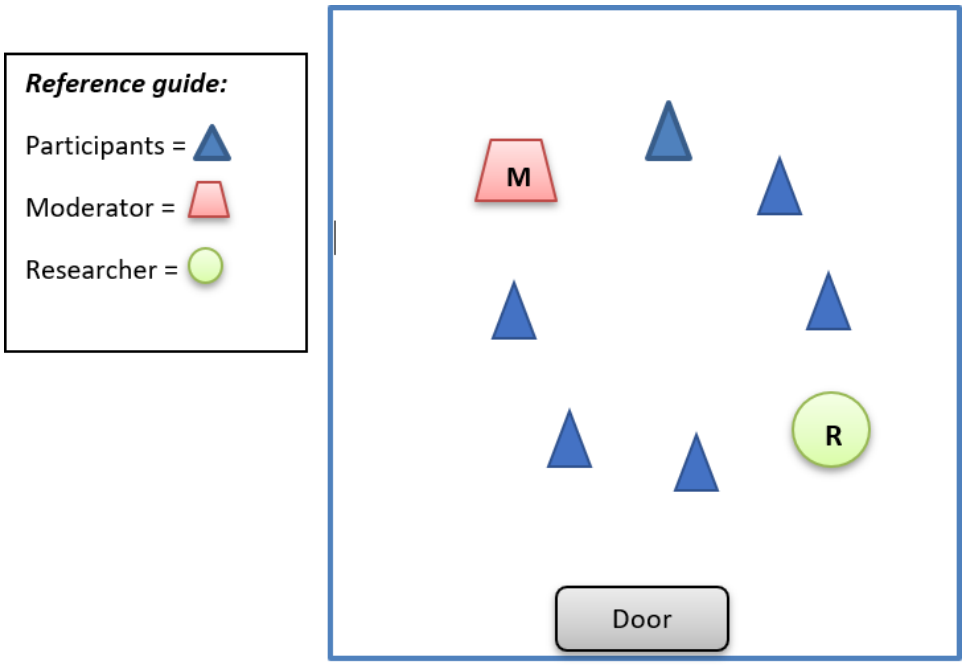

Figure 2.1 Positioning of participants during the focus groups

The focus group discussions were conducted in English since most of the primary caregivers preferred English, even though there was a time when two participants mixed English and

Afrikaans. Although mentioned as part of the inclusion criteria, Setswana was not a language spoken during the discussions. Once the primary caregivers indicated that they did not have any more additions or questions, the moderator concluded the discussions. The researcher and the moderator thanked the participants during each group for attending the group discussions. Refreshments were offered immediately after each group discussion as a token of appreciation. Data saturation was achieved after four focus group discussions and data obtained was included for data analysis. Data analysis should bring order and structure to the collected information.

2.15 DATA ANALYSIS

Analysing data means putting order and sense into the information that needs to be interpreted and understood (Strydom & Delport, 2011:397). According to Joubert and Ehrlich (2007:323), there are no rigid rules for data analysis in qualitative research. Polit and Beck (2017:57) state that data analysis may involve transferring the data from written documents onto computer files for analysis.

Focus group data is often analysed thematically. Data analysis steps according to Creswell and Poth (2014:189) and coding according to Tesch (cited in Creswell and Poth, 2014:189) were used. The hierarchical approach used as suggested by Creswell and Poth (2014:19) for data analysis included:

a. Organise and prepare data for analysis. This includes transcribing audio–data and typing field notes.
b. Read over all the data. A general sense of the information and its meaning will be reflected upon.
c. Start a detailed coding process through analysis of the data.

Tesch (cited in Creswell & Poth, 2014:198) lists and explain the steps of the coding process as follows:

1. One document is chosen randomly. While reading, the researcher will ask the specified question; thus, the underlying meaning of the information is identified.
2. Questions will be repeated to enable the researcher to compile a list of topics. All similar topics will be clustered together.
3. The list of topics is compiled and the researcher returns to the data. All the documents and transcriptions will be read. In the end, the researcher will return to the rest of the transcriptions and repeat the process. The topics will be abbreviated as codes. New categories and codes can be identified.
4. Descriptive wording for the topics is formulated and categories are developed. Topics can be grouped and interrelationships can be indicated.

5. A final decision on the abbreviations for each category is made and the codes are placed in alphabetical order.
6. The data belonging to each category will be grouped and a preliminary analysis will be performed.

Continuing with the steps, Creswell and Poth (2014:189) add the following:

d. Description. The completed coding process will be used to describe the themes for analysis. These themes represent the perspective of individuals and are supported by evidence from the study.
e. Representation of the qualitative narrative. A discussion of the themes conveys the findings of the analysis.
f. Interpretation of the data. This interpretation is a description of the lessons learned.

The moderator conducted the focus group discussion for this study, whereas the researcher took field notes. The researcher further typed the field notes to have a back-up of information. During the focus group discussions, an audio recorder was used to record the information that was shared. The audio recordings were sent to a qualified transcriber for transcription. Once the transcripts were received, the researcher arranged transcripts in the order in which groups were conducted. The researcher read all the transcripts identifying themes by coding similar content. Data coding adequately portrays the critical thinking process (Marshall & Rossman, 2011:212). A co-coder was used to confirm the codes identified by the researcher. Raw data was given to the co-coder. All the similarities and differences from what the participants pointed out were highlighted in different colours and written down. Transcripts were shared with co-coders, including the two supervisors, to co-code the data confirming the themes and subthemes. To ensure that the study is trusted, measures to enhance trustworthiness are detailed below.

2.16 MEASURES TO ENHANCE TRUSTWORTHINESS

Researchers in qualitative studies use various criteria, including different terminology, to evaluate a study's quality (Polit & Beck, 2017:161). A researcher's commitment to maintaining the quality and accuracy of their research is reflected in their trustworthiness. Data collection, interpretation, and methods are assessed based on their level of confidence (Polit & Beck, 2017:747). Study quality is thus ensured through trustworthiness, namely credibility, reflexivity, equivalence, transferability, confirmability, dependability, and authenticity. The researcher adhered to the criteria outlined, which will be discussed in the following sections.

2.16.1 CREDIBILITY

Credibility is a criterion for assessing trustworthiness in qualitative studies about confidence in the truth of the data (Polit & Beck, 2017:725). It is the level of trust in the actual value of the findings. It entails activities that enhance the probability that credible findings are produced and concentrate on validity and reliability (Creswell & Creswell, 2018:274; Polit & Beck, 2017:161; Streubert & Carpenter, 2011:48).

For this study, focus group discussions were conducted over two months because they depended on the participants' availability and recruitment success. A total of four sessions were held. Saturation was reached when participants started to repeat similar information and the decision to stop data collection was made in consultation with the moderator and study supervisors. The co-coders were requested to read the same transcripts to develop data themes. With the supervisors' support, the researcher co-checked the data and emerged the themes. All participants were allowed to give their views. The findings were a true reflection of the participants' views. To strengthen credibility, reflexivity is important and detailed next.

2.16.2 REFLEXIVITY

Reflexivity is a critical self-reflection about one's biases, options, and prejudices. It is a method used to strengthen credibility, avoiding biases from meddling with the process of judgement (Polit & Beck, 2017:161). Field notes were taken during focus group discussions for data analysis. The researcher did not write what she thought but what was said by the participants. Equivalence is enhanced and described below to ensure that information quality is provided and reported.

2.16.3 EQUIVALENCE

Equivalence is a concept utilised to detail the consistency and credibility of the moderator and reviewing coders (Kidd & Parshall, 2000:302). Furthermore, Kidd and Parshall (2000:302) point out that the internal consistence of co-coding is better when completed by one person. The assistance of three co-coders was requested. The supervisors confirmed the thematic analysis. To enhance equivalence, the moderator conducted the focus group discussions whilst the researcher took field notes, coded, and analysed the data. Data transferability implies whether the findings can be used in similar situations.

2.16.4 TRANSFERABILITY

Transferability is the degree to which the findings of a study or data can be transferred to other surroundings in a similar situation and reported (Babbie & Mouton, 2007:277; Polit & Beck, 2017:747; Streubert & Carpenter, 2011:406). For this study, there was a detailed description of the whole process, including the context and population, for any other researcher to decide whether it can be conveyed to their setting. To prove relevance and accuracy, confirmability is detailed below.

2.16.5 CONFIRMABILITY

According to Polit and Beck (2017:559) and Streubert and Carpenter (2011:406), confirmability is the potential for congruity amongst two or more independent people about the information's accuracy, relevance, or significance. Data collected from the active participants during focus group discussions helped confirm the information's accuracy. The researcher did not interfere with the data collection. She focused on writing field notes and audio recordings while collecting data. A skilled moderator conducted the focus group discussions, which did not allow the researcher to interfere; she had to remain neutral. The co-coders were given transcripts to assist with data analysis to reach a consensus about themes. The research process should be done consistently.

2.16.6 DEPENDABILITY

Dependability refers to the credibility of information over time and conditions. It ensures that rules of qualitative method are carried out (Babbie & Mouton, 2007:298; Polit & Beck, 2017:559). Four focus group discussions took place in two months. The same question was asked during each focus group discussion. During all the focus groups, the researcher took field notes and the moderator conducted the focus groups. The study can be repeated with similar participants in similar contexts. Authenticity is described below to showcase a variety of realities experienced by the researcher reliably.

2.16.7 AUTHENTICITY

Authenticity means the extent to which researchers fairly and reliably showcase a variety of realities (Polit & Beck, 2017:560). A text is only considered authentic when readers can enter their described life experience. Rich descriptions of the support needs of primary caregivers were provided by participants and captured as such. Ethical considerations are discussed below, attempting to protect the democratic rights of the participants.

2.17 ETHICAL CONSIDERATIONS

Ethical considerations concern the degree to which the research procedures conform with professional, legal and social responsibility towards the participants (Polit & Beck, 2017:727). Everyone should adhere to the codes of ethics to safeguard human rights. Ethical issues can occur at any time during the research. The Health Science Research Ethics Committee (UFS-HSD2020/1116/2710) of the Faculty of Health Sciences of the University of the Free State approved this study (Addendum D). Furthermore, the HOD of the Department of Health (Addendum F) and the CEO of Robert Mangaliso Sobukwe were permitted to conduct the study in the Northern Cape province (Addendum E).

The study considers the three primary ethical principles stated in the Belmont report. The Belmont report lays down the principles of justice, respect for human dignity and beneficence (Polit & Beck, 2017:139; Streubert & Carpenter, 2011:60).

Beneficence, as a principle, imposes a duty on the researcher to minimise harm and to maximise benefit (Polit & Beck, 2017:139). Although qualitative research is considered physically non-invasive, the researcher is still entering the participants' lives (Brink, 2012:33). The focus group discussion poses the risk of upsetting the participants. The moderator handled the primary caregivers with respect and avoided to ask primary caregivers' personal information that could expose them. Primary caregivers' consent forms stipulated that their identity and information would be protected as far as possible. The department where the focus group discussions were held had a psychologist if needed. The moderator and researcher observed no emotional harm during the focus group discussions.

Respect for human dignity ensures the participants' rights to autonomy are maintained. The participants' autonomy implies that the individual has the right to self-determination and may decide whether they would like to participate (Brink, 2012:32). Some primary caregivers withdrew from the study without any negative consequences. The primary caregivers that consented to the study were the only ones that participated in the focus groups.

The **maintenance of justice** implies that participants are treated fairly and that their right to privacy is protected. Coercion is an implied threat of penalty directed to a person if they do not participate in the research (Polit & Beck, 2017:722). However, this study was prevented since the researcher was not directly involved in the consultations provided to the primary caregivers. It might also include promising an excessive reward for agreeing to participate (Polit & Beck, 2017:140). Primary

caregivers were not reimbursed for participating in the study but received refreshments during the focus group discussions and were reimbursed for travel costs.

The **relationship of trust** between the researcher, moderator and primary caregivers was preserved. Confidentiality refers to the researcher's responsibility to prevent all data gathered from being divulged or made available to outsiders (Brink, 2012:35). Maintaining confidentiality is a measure that can be implemented to protect this critical relationship (Polit & Beck, 2017:142). In this study, confidentiality was maintained by not sharing the participants' full names during the focus group discussions. No personal information was shared during the presentation of the data. Fair treatment of participants was achieved through scheduling the focus group discussion sessions at a time comfortable to them and not necessarily for the researcher and the moderator. The voice recordings, field notes, hard drive and all other research documents will be kept safe for five years in a lockable cupboard at the researcher's office.

2.18 SUMMARY

This chapter summarises the research methodology used to answer the research question. Research methods and approaches were discussed, including their strengths and limitations. A brief overview of the population and unit of analysis, presented the participants. This chapter also describes the data collection and analysis procedures, trustworthiness and ethical considerations. A discussion of the data analysis and literature control will follow in the next chapter.

Chapter 3

ANALYSIS AND DISCUSSION OF RESEARCH FINDINGS

3.1 INTRODUCTION

Chapter two detailed the study methodology. The purpose of Chapter 3 is to communicate the research findings. Data collected during the focus groups, including the demographic data of the research participants, will be discussed. This chapter will further describe the themes and subthemes derived from the data analysis corroborated by a literature control.

3.2 DEMOGRAPHIC DATA OF THE PARTICIPANTS

Following is a demographic presentation of the study participants. This section will contextualise primary caregivers looking after children with ASD from Kimberley in the Northern Cape Province. Data from this study was collected through focus group discussions with purposively selected participants. It is relevant to provide demographic data as it enables the researcher to see if there are differences among people based on their characteristics, such as gender or ethnicity. This will allow the researcher to connect the views of different races and genders (Brink et al., 2012:91). The participants' demographic data were obtained before each focus group discussion. It consisted of age, race, and gender. The current study did not include any white participants. A summary of the demographic data of the study participants is presented in Table 3.1.

Table 3.1 Demographic data of focus group discussions participants

	Session 1	Session 2	Session 3	Session 4
Total number of participants	7	6	7	7
Race African	4	5	5	6
Coloured	3	1	2	1
Gender Female	6	4	4	5
Male	1	2	3	2
Age 25 – 30	2	0	0	2
31 - 55	5	6	7	5

A total of 27 participants formed part of the four focus group discussions. Session one had a total of seven; session two, six; session three, seven; and session four had seven participants. Three group sessions had an equal number of seven participants. All the sessions consisted of participants that fully contributed during the focus group discussions. Session one consisted of four Africans and three coloured participants. Furthermore, session two had five Africans and one coloured participant. Session three had five Africans and two-coloured participants. Lastly, session four consisted of six Africans and one coloured participant. A total of 19 participants were female and 8 were males. This study consisted of four participants between the ages of 25 – 30, with the majority older than 30. The demographic information aims to describe the individuals who participated in the study. However, the researcher did not use this information to make a demographic comparison but to provide context.

3.3 THEMES AND SUB-THEMES

As analysis and interpretation progressed, researchers began identifying themes and sub-themes. The data analysis method involved clustering related types of information after transcripts were read. Narrative information was grouped into logical themes (Polit & Beck, 2017:59). The researcher, together with co-coders, substantiated four (4) themes with relevant sub-themes based on the participants' perspectives. The table below lists the themes derived from the participants' views, including sub-themes, to explain their support needs. See Table 3.2 for the themes and sub-

themes.

Table 3.2 Combined research findings reflected per theme and sub-themes

THEME	SUBTHEMES	OCCURRENCE
Healthcare	Access to healthcare Health Information Community awareness Lack of knowledge on care aspects Training	Focus group sessions 1 - 4
Financial needs	Transport Nutrition	Focus group sessions 1 - 4
Basic education	ECD Centre Special Education	Focus group sessions 1 - 4
Social Support needs	Stigma Psychological well-being Family Support Community Support	Focus group sessions 2 - 3

Each theme with the relevant sub-themes is discussed. Verbatim quotes from participants (support needs) are provided in discussing themes and sub-themes and references to related literature. *Some quotes could represent more than one theme due to the nature and content of the quote.*

3.4 HEALTHCARE

The International Classification Functioning (ICF) of disability and health defines healthcare as an environmental factor that makes up the physical, social and attitudinal environment in which people live and conduct their lives (Heerkens et al., 2017:187-204). According to the World Health Organisation, healthcare is an illness's preventative, diagnostic, care and good outcome (WHO, 2021). It focuses holistically on the client, including mental disorders such as ASD in children. The healthcare service is rendered at the community, family and health facility levels.

Healthcare is the provision of a comprehensive service package through the prevention, treatment, and management of an illness by healthcare practitioners (Medical, Nursing, and Allied Health) in protecting the individuals' mental and physical well-being (Sood et al., 2009:1).

3.4.1 ACCESS TO HEALTHCARE

Access to healthcare is defined as the ability to obtain access to appropriate practitioners, healthcare services and facilities, clinics, or hospitals (Jimenez, 2021:1). Limited healthcare service is defined as care that is associated with a shortage of services, unclear referral pathways and fewer screenings performed (Guler et al., 2018:1007; Malik-Soni et al., 2021:1029). Children with lifelong developmental disorders have limited access to specialist care, resulting in late diagnosis or misdiagnosis (Malik-Soni et al., 2021:1028). In Kimberley, primary caregivers of children with ASD communicated their struggles related to a lack of specialists, specialist care and resources for children with ASD. Some participants remarked:

> *"Because we don't really have specialists or experts, who can deal with autism" (session one, participant three).*
>
> *"There must be transport to take the child to the therapy that is not available in Kimberley" (session four, participant four).*
>
> *"Say for instance, a parent must go to Bloem for better diagnosis" (session one, participant seven).*

Evidently, the participants experienced that there are limited advanced healthcare services available in the Northern Cape which hamper access to care. Shortage of healthcare services, physician knowledge, reduced awareness of ASD and disparity remains a challenge that results in unmet primary caregivers' needs (Guler *et al.,* 2018:1007; Malik-Soni *et al*., 2021:1029). Barriers to accessing healthcare services throughout the ASD child's life must be attended to, ensuring they gain the necessary care (Malik-Soni *et al.*, 2021:1028). The comments by the primary caregivers in this research confirm the views of Kogan (2008:1149), who states that children with ASD tend not to receive the healthcare services they need. For example, they do not have access to specialist doctors who know ASD, compared to children without ASD who have access to healthcare.

The National Health Quality Improvement Plan (NHQIP) of South Africa is one of the interventions emanating from the Presidential Health Summit. This plan aims to identify the challenges children and primary caregivers face in accessing healthcare and adequate resources. In such a way, patients will not be disadvantaged (NHQIP, 2019:05; District Health Plan, 2022:29). Children with ASD will benefit from this plan because primary caregivers complain of services that are not available to them. They do not receive specialist care in Kimberley and must travel to Bloemfontein

to seek assistance. This issue led to the notion of caregivers that there is a lack of skilled and knowledgeable healthcare practitioners that can provide specialised services to children with ASD in Kimberley and not meet their demands. Several factors, including knowledge about available health services, information, and the perceived need for services, could influence how approachable healthcare services are to individuals (Donev et al., 2007:22,347). The public's awareness of healthcare services and resources, such as health educational programmes, may improve the information-seeking behaviour of individuals (Zimmerman & Shaw, 2020:174). The participants, as a need, repeatedly mentioned health information, which can be seen below.

3.4.2 HEALTH INFORMATION

Health information is characterised by understanding health concepts, medical conditions, and relevant health behaviour by healthcare users to become better informed (Zimmerman & Shaw, 2020:173). Health information about ASD is seen as information that is shared with primary caregivers who are taking care of children with ASD, including information on diagnosis, interventions, educational materials and promotion of health outcomes (Ghiasi, 2021:1320; Manouchka, 2019:2). Primary caregivers of children with ASD need more health information to raise and care for them due to their unique features. They experience frustration due to a lack of information (An et al., 2019:12; Ghiasi, 2021:1320; Murphy & Tierney, 2006:9). These primary caregivers have specific needs regarding health information relevant to their children. Their information needs are about improving their children's daily skills. The primary caregivers frequently mentioned that they need more health information and training. The following statements demonstrated this need:

> *"Maybe if they can also teach me. Maybe an expert or a sister who knows much about autism" (session four, participant one).*

> *"Must also be well informed about this particular condition" (session four, participant three)*

> *"If they can teach you how to take care of this particular child who has been diagnosed with autism" (session four participant one).*

Participants detailed the importance of getting information on ASD because it will assist them in caring for their children. Information and education support for families tend to be based on what healthcare practitioners believe parents need rather than asking parents themselves what their

needs are (Murphy & Tierney, 2006:9). Healthcare practitioners should be mindful of what the healthcare users and their relatives need to know about health conditions or lacking information that should be communicated to them. An et al. (2019:11) have identified that the health information needs of primary caregivers include information regarding diagnosis, interventions, and health outcomes. The primary caregivers in this research felt that their knowledge of ASD is inadequate. Participants elaborated on the specifics related to their health information needs:

> *"First of all, uhm, I need information about the disorder" (session one, participant one).*

> *"Information where to go to, how to handle the child with autistic…and, the doctors that you can go to" (session one, participant two).*

These statements show that the primary caregivers need information related to their children's diagnosis and where to find reliable information. For primary caregivers to see progress in healthcare mitigations on care, they should get information that will allow them to have insight into where to access information (Ghiasi, 2021:1320; Khara et al., 2020:1). As a result, informing primary caregivers about disease-specific skills is imperative, which could help them to improve their children's health prospects and understand the behaviour changes that are often observed. As part of the chronic condition management process (applicable to ASD), primary caregivers should be provided with information and encouraged to participate actively in managing their children's conditions. Helping families understand ASD is essential. They need to be provided with information about ASD treatment and how to cope with the condition (Khara et al., 2020:1; Murphy & Tierney, 2006:41). Their need for health information is extensive and the community must be made aware of ASD by providing information to them also. An informed community can provide better support to the primary caregivers.

3.4.3 COMMUNITY AWARENESS

Community information is seen as an organised effort to disseminate messages to educate the public and raise awareness of the severity and prevalence of any condition (Blasi et al., 2015:1; Zeidan et al., 2022:778). Health promotion in communities promotes awareness that results in a positive outcome. Community awareness and empowerment could promote primary caregivers' situation by providing more support related to stigma, access to care and health information assisting them in looking after their children (Broady *et al*., 2017:1). Communities' awareness can continue to play an essential role on health by reducing stigma and discrimination (Kohrt *et al*.,

2018:2; Grinker *et al*., 2012:1). Furthermore, involvement of church leaders, traditional leaders, and home prayer groups on raising awareness of health issues can have a positive impact on the community (Grinker *et al*., 2012:1-5). Typical comments about community awareness were:

> *"So, empowerment is very, very important for parents and the community because I know that like she said they label them already as mad" (session one, participant seven).*
>
> *"I also think that, uh, the community should get more information about children that's got autism" (session three, participant three).*
>
> *"So, we need some sort of arrangement from the government or some support from the community to have the information" (session four, participant eight).*
>
> *"So, if there is awareness for the community to know more about the situation" (session four, participant four).*
>
> *"But if you empower the community then you will see the major change that's happening. They will even look out for your child" (session one, participant seven).*

As reported by the participants, the community is not well-informed about ASD. Throughout the years, many communities lacked information and knowledge on ASD (Dillenburger *et al*., 2013:1558; De Houting, 2021:148) and that lack of knowledge as well as support to the primary caregivers, contributed to stigmatisation (Broady *et al*., 2017:6). Primary caregivers in the community are exposed to negative experiences and being judged; which may lead to social withdrawal (Broady *et al*., 2017:1; Khara *et al*., 2020:4; Divan *et al*., 2012:1).

If the community remains to be uninformed about children with ASD, it may lead to community stigmatisation which affects the family. The community needs to be made aware of ASD. The need for more awareness initiatives in the broader community will minimise stigmatising and labelling (Mithimunye *et al*., 2018:283) due to the lack of information (Stigma will be discussed later). Participants further identified knowledge of care aspects as a gap in healthcare practitioners that is the first point of healthcare provisioning.

3.4.4 LACK OF KNOWLEDGE ON CARE ASPECTS

Knowledge on care aspects is seen as providing decision-makers with the tools they need to turn information into knowledge. It includes support, care, confidentiality, communication, and dignity (Peteiro, 2018:1). Autism awareness is about giving information to the people to ensure that everyone is well informed on the condition, aware of what to expect, knows the diagnostic processes and treatment plans, and be aware of the signs and symptoms that need immediate response and support (Peteiro, 2018:1).

Since the number of ASD cases is increasing, ASD must be understood and managed correctly. Healthcare practitioners are the custodians of care for children with ASD. The environment and surroundings that have healthcare practitioners, who are knowledgeable on care aspects, can positively impact the lives of primary caregivers and their children (Klettlinger et al., 2015:3-6; Ormandyova, 2022:7). Primary caregivers tend to experience anxiety during their appointments with healthcare practitioners. But, when surrounded by knowledgeable healthcare practitioners, their anxiety can be reduced because they can handle the situation (Klettlinger et al., 2015:3-16). Healthcare practitioners often tend to be negative toward the primary caregivers and their children with ASD. It seems the healthcare practitioners are not compassionate and do not understand what the primary caregivers are going through (Klettlinger et al., 2015:16). Early observation of, and knowledge of, ASD children in a healthcare setting enable the children to obtain a correct diagnosis and treatment and further create patience around healthcare practitioners who tend to lack understanding and compassion. Positive outcomes are determined by knowledgeable healthcare practitioners (Klettlinger et al., 2015:15-16). The following statement from a participant describes the knowledge gap of ASD among healthcare practitioners:

> *"The essential services while they do not understand the condition and know what it's all about. You know they don't know how to treat this" (session one, participant two).*

From this participant's experience with healthcare, it shows that there are healthcare practitioners who do not have knowledge on how to care for ASD children. They need knowledge to care for ASD children in clinics/hospitals. It is vital that the healthcare practitioners are knowledgeable when it comes to the condition and should know what to expect to know the diagnosis and the treatment thereof (Parvin 2015:17). Lack of knowledge on ASD has been seen as a barrier to getting quality care from healthcare practitioners. Healthcare practitioners find it challenging to make a medical diagnosis due to children being unable to sit quietly. These children tend to jump, spin, and talk fast, impacting the management of ASD children, which becomes problematic. They may even

confuse this behaviour with hyperactivity due to not being well-informed. This implies that healthcare practitioners do not have adequate knowledge of care and the need for knowledge is critical for the participants. Healthcare practitioners need accurate knowledge of ASD care to adapt their approach to individual patient's behaviour and needs (Corden et al., 2022: 387; Parvin 2015:17). Participants identified the need to have knowledgeable healthcare practitioners:

> *"Because we don't really have specialists or experts, who can deal with autism" (session one, participant three).*

> *"Training for the health…. the sisters and what - what in the healthcare services (session three, participant five).*

The participants in this study seemed frustrated that there was an "apparent lack of knowledge" among the healthcare practitioners. Knowledge of care studies showed that healthcare practitioners have challenges in managing the relationship with children with ASD and wonder how to improve it, looking for valuable tactics (Corsano, 2020:486; Sampson & Sandra, 2018:99).

Healthcare professionals' knowledge on care is essential because the diagnosis of ASD depends on them, especially in primary care settings. They play an important role in ensuring the correct diagnosis and quality of care. Healthcare practitioners may need to provide care to children with ASD during their daily care responsibilities; hence they must know about such care practices (Juraszak, 2019:200). The participants further mentioned how staff working in essential healthcare services needs to know the condition because it is a challenge with them not understanding the condition:

> *"People know them better but the essential services while they do not understand the condition and know what it's all about. You know they don't know how to treat this" (session one, participant six).*

> *"So, it's the old thing empowering with knowledge and the parents, the essential services, the education system, getting the word out there (session one, participant seven).*

As much as the participants have challenges with unknowledgeable healthcare practitioners, they still need support from them and healthcare services. Improving the knowledge of primary caregivers, healthcare practitioners, educators, and the community on ASD through training is vital

to enhance the probability that effective treatment and care are provided to children with ASD. The training was one of the identified support needs from the participants, with its absence being viewed as a gap.

3.4.5 TRAINING

Educating and ensuring growth in others through skills and knowledge development is known as training. Training is teaching primary caregivers about certain behaviours of ASD children. Training will offer related knowledge and skills, enabling healthcare practitioners to diagnose and treat. Additionally, training is an act of teaching primary caregivers about certain behaviours of ASD children (Ayakaka, 2021:1; Lopatin, 2012:01; Squibb, 2019:6).

Training is further seen as rendering information and knowledge through using different methods, for example, role-play; group sessions; and video training to ensure understanding of an ASD diagnosis and interventions (Ayakaka, 2021:2; Squibb, 2019:6). According to Ayakaka (2021:27), healthcare practitioners need to have the knowledge and self-confidence to ensure that children with ASD receive care when needed. During the focus group discussions, the primary caregivers identified the need for healthcare practitioners to be provided with training on ASD. They need to know and understand ASD to provide adequate care. The statements below prove the plea for training:

> *"Training for the health…. the sisters and what…what in the healthcare services" (session three, participant four).*

> *"…. because she's not trained to help children or dealt with children that are raped" (session three, participant four).*

The participants expected the healthcare practitioners to have been trained. However, they expressed dissatisfaction as they could not get help from these "untrained" practitioners to deal with their children. Healthcare practitioners are not capacitated on ASD and need to be provided with training on this disorder. During data collection, participants identified the need to be supported on financial issues as they struggle to sustain their families and the healthcare expenditure related to ASD children.

3.5 FINANCIAL NEEDS

Financial need is the variation between expenditure and ability to pay. It refers to expenses that are important for an individual to be able to live and work (Kantrowitz, 2020:1). The financial needs of primary caregivers of children with ASD are seen as the need for monetary support to guarantee that basic needs such as healthcare, rent, transportation, additional supporting services (such as vocal and occupational training) are met (Aziz, 2014:886; Kantrowitz, 2020:1).

The poverty gap rate in Kimberley has increased since 2018 by one per cent and the unemployment rate stands at 24,9% (Social, economic review and outlook, 2018: 21). Poverty among Kimberley residents also affects the primary caregivers as it was discussed during the focus groups. Transport demands, special nutrients, and resources for appointments add to their financial problems. Food is a basic need for every individual, but not everyone has the financial ability to sustain such costs. Some cannot afford food and transport because of poverty, unemployment, crime, and disasters and they cannot be blamed (Donev et al., 2007:159). Health inequality results in psychological challenges that could have been avoided if financially supported (Donev et al., 2007:159). For one caregiver, financial challenges reached a point of despair:

> *"And because I don't have much money…. because if I had money, I know I would've taken her to a centre that I know will accommodate her. They charge about R10 500 (for a centre that accommodates children after 18 years) a month excluding food and accommodation. But I don't have that kind of money". She has turned 18 years. Meaning I have to find a nanny to look after her full time at home. I feel our system had little…. has written her off because there's nothing, they can do for her (Session three, participant six).*

Primary caregivers from households caring for children with ASD are overloaded with psychological and financial challenges. This heavy load on families caring for ASD children impacts family finances and they are faced with costly prescriptions and other healthcare costs (Befkadu et al., 2022:1; Ntre et al., 2018:985). Money is always a need when caring for a child with ASD (Befkadu et al., 2022:1; Ntre et al., 2018:985), as was evident in the current study. Participants mentioned examples of expenditure:

> "*I think you need money also and kos (food). What can you do? without it?" (Session three, participant two).*

"I need a home to start with. A proper home where I can raise her" (session three, participant one).

In this study, the participants highlighted hidden costs and had unrealistic expectations of being provided with a house and food. These human challenges are currently a big problem in SA, and not only for primary caregivers of ASD children. They have problems and are desperate to be supported financially. Every person's main objective is to accomplish financial welfare (Iramani & Lutfi, 2020:1). Several factors can impact the financial welfare of individuals and households. Participants mentioned their dire financial situation:

"They are unemployed they live off that grant that of that child" (session one, participant four).

"Now you must still pay for something that the government can help you with" (session one, participant three).

The participants want the government to come to their rescue financially. They are frustrated because the grant that they receive is not enough. The government might not realise that children with ASD need more extensive grants to survive. There was a plea to have people from the Department of Health and the National Government act as advocates for these children by reconsidering the grant amount.

Financial challenges such as the economic burden and the need to get more income to survive the high costs of ASD-related treatment, care and education are imperative to prevent primary caregivers from experiencing challenges (Befkadu *et al*., 2022:3; Khara *et al*., 2020:1). Financial stressors harm the health of the primary caregivers, which results in anxiety and stress (Murphy *et al*., 2006:183) Family-centered people can be supported to each other if they help one other financially (Donev *et al*., 2007:159; Murphy *et al*., 2006:183). Transportation as a financial need was emphasised by the primary caregivers who depend on these means to treat their children.

3.5.1 TRANSPORT

Transport carries people from one area to another by different means, for example, taxis or buses (Geldenhuys, 2019:55-56). According to Geldenhuys (2019:55), schooling and transport expenses in South Africa are challenging for parents. Taxi drivers must be paid for transporting children. This is draining the parents financially. Most parents use private drivers to transport their children from

Kimberley to Bloemfontein for treatment. Primary caregivers continue to experience financial challenges due to payment of transportation and medical services (Geldenhuys, 2019:1; Ladarola et al., 2020:2; Lubin & Feeley, 2016:1; Shattnawi et al., 2020:6).

During the group discussions, the participants stated that they must travel to Bloemfontein just to get a diagnosis because there are no neurodevelopmental specialists in Kimberley. As much as Kimberley has paediatricians, they refer patients to Bloemfontein for neurodevelopmental disorders such as ASD. Parents with medical insurance need to top up on their medical aids because they do not cover all the expenses. The quotes below elude what was said by primary caregivers:

> *"The people start paying for patient transport when they…. say for instance a parent must go to Bloem for better diagnosis" (session one, participant four).*
> *"Where you get money from nobody hence, we need transport as well. If you have to…I'm just going to make an example its her check-up day she's going to the hospital and you use the public transport and she has a meltdown" (session one, participant two)*

> *"So, it's really not nice even to use the public transport. So sometimes we feel like if I'm in my own car it would be so much easier and better. And to have that kind of money you know it's more expensive" (session one, participant five)*

Most primary caregivers rely on public transport to take their children to the school, clinic, or even another town. This can become very expensive and put more financial strain on the study participants. Even more so is that these children must attend special schools contributing to the high living costs. Financial strain when living with a child with ASD is found to be significant as their basic needs and ongoing care has several cost implications (Geldenhuys, 2019:55; Yonkman *et al.,* 2013:717). As much as primary caregivers identified transport as a need for their children with ASD, it was clear that nutritional necessities added to the financial strains. Children with ASD require special diets.

3.5.2 NUTRITION

Nutritional needs are the proportions of nutrients needed to support everyday health, growth and development among children (Ismail et al., 2020:1). In some ASD children, nutritional needs consist of a special diet that is (required) for growth. The special diet includes food with protein, for example, meat and boiled eggs. Often specific foods are preferred by children with ASD (Ansel,

2022:2; Kranz et al., 2022:18; Ismail et al., 2020:2). Children with ASD tend to be picky eaters and are very selective with types of food that they either like or dislike. This can result in malnutrition issues. Children may be admitted for more than ten days to ensure that they receive their nutritional status, which can be costly (Ismail et al., 2020:12).

ASD children tend to be sensitive to certain kinds of texture and caregivers are obliged to introduce new types of food now and again to investigate what is tolerable and acceptable to them. Something that could also be costly if a child with ASD only likes specific textured food that must be bought. Otherwise, they may not eat anything else (Ismail, 2020:9; Hare et al., 2004:436). Children with ASD commonly prefer foods that do not have a smell and they are selective towards food due to their sensory, gastrointestinal and unusual eating and sleeping behaviours (Ismail, 2020:1-2; Kranz et al., 2022:18). Introducing new types of food can be challenging on top of a special diet, increasing the expenses (Shattnawi et al., 2020:6). Training and knowledge on nutrition can have an impact on the primary caregivers and the health of children with ASD. The knowledge assists primary caregivers in providing good care to their children with ASD (Peteiro, 2018:6). The primary caregivers expressed their children's nutritional challenges:

> *"…the challenges that they have. You have to sensory autism food you have to pay. Its more money you know. It's the sensory of the taste. Its separate foods" (session three, participant two).*

> *"They must get nutrition there. So that's why if the government for whatever reason they help me supporting the child (session four, participant four).*

It is evident that the type of food the children with ASD may prefer and the special diets they may require contribute to higher expenses, adding to their financial strains. Children with ASD have nutritional requirements that the community may not understand. This can further influence the community's view of ASD children and their "odd traits". The basic education of ASD children was another important element identified as a support need by the participants in this study.

3.6 BASIC EDUCATION

Basic education is a critical learning need that entails knowledge, skills, values, and numeracy to allow learners to develop. It is quality orientated, including Early Childhood Education (ECD), primary and secondary schools (Simbo, 2012:176). Regarding the South African School Act no 84 of 1996, everyone has the right to equal quality education. As one component of Basic Education,

ECD was one of the needs that participants identified to assist their children with ASD to receive basic learning.

3.6.1 ECD CENTRE

According to the Department of Basic Education (2022), an Early Childhood Development (ECD) centre is the peak education provider accountable for ensuring a solid foundation for learning through play. It provides a comprehensive programme approach that entails physical, social, emotional and motor development. ECD or preschool programmes are not compulsory and are offered at only a few government-funded schools (Pillay et al., 2021:1078). The South African Department of Social Development (SASSA) renders free educational services to ASD children, but these services are insufficient. Primary caregivers must opt for private centres instead, which are expensive and cannot be afforded by all. Primary caregivers believe these centres must provide an integrated service where all children with special needs can be accommodated (Pillay et al., 2021:1078). The primary caregivers stated the following:

> *"Some ECD centre will say you know what: we won't be able to handle the child" (session two, participant seven).*

> *"If parents could really have that where they know that this child at this age can go somewhere…. development place" (session two, participant seven).*

> *"There's a need for an ECD centre where people are properly trained" (session two, participant six).*

These views on the necessity of child developmental centres, specifically for ASD children, reiterate the primary caregivers' concerns regarding their children's education (Khabanyane, 2020:3). There is no research information available on the services rendered for ASD children in Kimberley. However, in Cape Town, primary caregivers believe that the teachers at the ASD centres are not trained to handle children's needs (Shattnawi *et al*., 2020:6). There have been struggles that hampered the education of children with ASD. Relating to Khabanyane (2020:2), capacity building, lack of resources and linkage between mainstream and special schools are challenges to the education system and the people affected.

3.6.2 SPECIAL EDUCATION

Educating learners in a manner that accommodates their differences, disabilities and special needs are known as special education. It includes the planned and systematically monitored arrangement of teaching methods in accessible settings (Mckenzi, 2021:53). A consultative process occurred previously to address special educational needs, which led to the development of the Education White Paper, number 6, which concentrated on special needs education, as well as building an inclusive education and training system in South Africa (Department of Education, 2022:2-8).

Special education in South Africa is available in all nine provinces. The Department of Basic Education ensures that the national guidelines and policies are implemented and monitored (Basic Education, 2014:1-7). According to the Department of Basic Education (2014:1-7), South Africa has special education for children with ASD. Special education is rendered both at government-funded schools and private schools. Concerning the Child Act 38 of 2005, all children between 7 and 15 must attend schools because basic foundational skills are built from grades 1-9. After that, learners can choose different pathways, including access to university or college programmes, or continue schooling after grade 9. If children with ASD cannot be accommodated in the right school, parents are often obligated to home-school or opt for full-time caregivers. Primary caregivers complained that there are not enough special schools in Kimberley to cater to children with ASD. The primary caregivers mentioned the following statements:

> *"Sodat ons kan centre kan nader kan bou because ons het nie baie special skole hier bokant nie (session four, participant four).*
> *("In order for us, to build a centre closer, because we do not have special schools here at the top") English translation of the above.*

> *"Ons het nie baie special skole hier bokant nie" (session four, participant five).*
> *("We do not have a lot of special school here at the top") English translation of the above.*

Education, as an important aspect of every child's daily life, even for ASD children, was verbalised by the participants as something their children need. Primary caregivers want to support their children's education. South Africa has a problematic past defined by Apartheid, a patrimony characterised by inequity in the education system, particularly in the special needs sector (Pillay *et al*., 2021:1078). However, this problem has not been resolved in South Africa as in other first-world countries. Children with disabilities in South Africa remain to experience difficulties accessing

special education. These schools maintain a specific criterion and children are screened and assessed (Pillay *et al*., 2021:1079; Basic Education, 2014:1-7). In Kimberley, all children with different disabilities are allowed in the same school. However, according to Brede *et al.* (2017:2), there are children with ASD who are still excluded from special education. In the interviews, there are three special schools in Kimberley (Modiakgotla, 2019), but the participants said there are no special schools. The moderator, unfamiliar with Kimberley's education setting, did not explore this further. The primary caregivers may refer to their need for a special school for ASD children. The three special schools allow different types of disabilities, which includes ASD. Participants think that they should have more special schools. Two primary caregivers further verbalised their need for a special school:

> "*… there's no special school specifically for autistic children" (session, identification, assessment one, participant two).*
>
> *"Only if we could have enough schools" (session one, participant three).*

Special education was indispensable to the primary caregivers. Mainstream schools and special schools form part of the South African education system. Special needs schools are not enough in South Africa and create a gap for the children who need special education (Patterson & Smith, 2011:331; Mithimunye, 2018:286). During the group discussions, the male participants were more subdued, but with this topic, they voiced that the government should build more special schools in Kimberley. Furthermore, they requested that qualified teachers are appointed. Receiving support from other people can lessen the burden on primary caregivers. Hence, primary caregivers identified social support as another need.

3.7 SOCIAL SUPPORT NEEDS

Receiving support as a person through social ties to other people, groups and a more significant community is known as social support. Social support is further described as a network of friends, community members and family always there when needed. They provide counselling, mental and monetary support (Haugan & Eriksson, 2021:137; Ozbay, 2007:37). Families raising children with ADS encounter many difficulties and need support systems to cope with physical, social, and mental demands in their home surroundings. Primary caregivers can cope with their daily activities with family and community support. Information sharing assists the community in understanding ASD as a condition. Community engagement continues to provide awareness and support to the primary caregivers and their children (De Houting, 2021:149; Ladarola et al., 2020:2).

Children with ASD tend to be attached to their primary caregivers because their parents are often oversensitive about their children. They believe that ASD children should be protected against any negativity from society (Cridland et al., 2016:203; Crowell et al., 2019:22; Modula, 2022:1; Shivers, 2019:23). Primary caregivers struggle emotionally when they feel alone and isolated (Cridland et al., 2016:203; Crowell et al., 2019:22). They experience psychological challenges and need support from their loved ones, as well as the community, to get through difficult times caring for their child. The participants voiced their need for social support:

> *"I'm thinking doctor (addressing the moderator) is it possible just like we have a home-based caregiver to have primary caregivers to help" (session four, participant three).*

> *"Could whatever come out of this could be forwarded to the MEC and the premiers office to say these are the challenges that can give as a parent or kids well even with autism are facing inner problems" (session three, participant four).*

Primary caregivers perceived a lack of social support, negatively impacting their emotional well-being and contributing to feelings of isolation (discussed in the section on stigma below). The researcher observed that the participants were overwhelmed when they mentioned the need to be socially supported by family and community. Even though primary caregivers are experiencing challenges, they still want to feel they can support their children with ASD. They want to see their children growing up well (Crowell *et al*., 2019:27; Modula, 2022:2). Family support is important to allow primary caregivers to cope when caring for ASD children during their daily activities (Modula, 2022:6). Support from family, community, schools and the church can lessen the burden from the primary caregivers (Modula, 2022:6). Families caring for children with ASD have been faced with stigma that results in children and their primary caregivers isolating themselves from the community.

3.7.1 STIGMA

Stigma happens when someone is viewed to have a characteristic that deviates from the community's stereotype of what is expected. People tend to efficiently devaluate and decrease the individual if stigmatised (Broady *et al*., 2017:2). Children with ASD and their families continue to endure stigmatisation from different people in the community. Furthermore, the diagnosis of ASD had a negative effect on the primary caregivers' social life and mental well-being. Caring for a child with autism increases stigmatisation for both primary caregivers and their children. Labelling autism and using terms to describe these children forms part of stigmatisation (Broady *et al*., 2017:2;

Grinker *et al.*, 2012:6; Papadopoulos 2021:2). The primary caregivers complained that their children are labelled and is highlighted by the quotes below:

> *"Because in our community they are stigmatising people who got autism" (session four, participant seven).*

> *"There's a lot of pressure on the parent when the child gets a meltdown. Because everybody is looking at you…. what's going on with your child? Can't you handle your child? So, there's lot of pressure on the parent (session one, participant seven).*

Importantly, participants felt stigmatised and indicated that they needed support from the community rather than rejection. The child's characteristics generally influence the decisions of primary caregivers to look for proper social support, such as professional-based assistance and respite services. These services help parents to address the child's problems and reduce the social stigma faced by the family (Papadopoulos, 2021:2). The primary caregivers acknowledge the role that stigma plays in the quality of their and their children's lives. Stigma is hurtful, as mentioned by the primary caregivers. Negative behaviour by the public against relatives of people with mental disorders is known as public stigma (Girma *et al*., 2014:2; Malik-Soni *et al.,* 2021:1031-1032). Because of stigma, families tend to hide their people with mental disorders and not disclose their illnesses. This results in families not being able to receive treatment on time (Girma *et al*., 2014:1; Grinker *et al.,* 2012:6). The following participant felt that the child is affected by how the community is treating him differently from others:

> *"Because even in our community they are stigmatising people who got autism" (session four, participant three).*

The participant is being stigmatised by her community, which results in unhappiness. Studies around the world have shown that families with children with ASD frequently experience stigma (Mensing, 2010:1). Families of children with ASD have confirmed that experiences of public stigma are common and may have adverse effects on both affected children and their primary caregivers (Zuckerman *et al.*, 2018:3202). The primary caregivers and their children further experience social stigma.

Social stigma is shame, insensitive, hostile stares, blatant exclusion, and discrimination against another person based on observable social traits. ASD diagnosis is known to be kept secret by other families to avoid stigmatizing (Broady *et al*., 2017:5; Goffman, 2018:1; Monnapula-Mazabane,

2021:10). The primary caregivers stated how their children are stigmatised. One participant mentioned that her child is labelled as mad. The other participant described how they were treated. The statements below mention what was said:

> *"I don't know about others but my child has already been labelled as 'n heks" (witch) (session one, participant five).*

> *"So, empowerment is very, very important for parents and the community because I know that like she said they label them already as mad" (session one, participant six).*

> *"Even though the pressure is there because it happened with us once when we were in the mall and our child had a meltdown. Immediately the people were looking at me and I had to tell myself just…..cut them and focus on your child" (session two, participant four).*

These participants mentioned that their children are given names to label them as previously described. Social stigma tends to leave primary caregivers feeling humiliated, judged, and socially excluded from communities. They tend to talk about them. Furthermore, it results in their children being socially excluded (Broady *et al*., 2017:5; Polaha, 2016:1).

Social exclusion results in isolation. Isolation is associated with loneliness and confinement (Ingram et al., 2021:935). Primary caregivers of children with ASD may experience isolated lives due to limited support from their communities and sometimes their primary support structures. Many parents feel overwhelmed when managing their child's support needs in the context of financial instability, the stigma surrounding ASD as well as isolation (Cridland et al., 2016:197; Murphy & Tierney, 2006:20).

Perhaps, because of challenges in navigating service systems, parents of children with ASD often experience more stress, high blood pressure and mental health problems than parents of children with other disabilities or typically developing children (Cridland et al., 2016:197; Murphy & Tierney, 2006:20; Ozbay et al., 2007:38). This could cause some disconnectedness within their communities or even close family. The primary caregivers explained how their children with ASD are isolated from others. The following statements highlight what was said related to isolation:

> *"En hulle voel ook hulle word afgesny" (session three, participant four).*
> *("They also feel they are isolated") English translation of the above.*

“Hulle verkies om hulle terug te trek en by die huis te bly” (session three, participant three).
(“They prefer to shy away and stay home”) English translation of the above.

“Prisoners in their own homes” (session three, participant two).

The primary caregivers and their children felt isolated from the outside world and opted instead to keep themselves and their children at home to avoid being stigmatised. Children with ASD are isolated from society and prefer to stay at home due to increased anxiety and negative attitudes from the community (Cridland *et al*., 2016:197). This support need must be considered when discussing the caregivers’ emotional well-being. Studies have shown the association between primary caregivers ‘emotional welfare and the negative impact it has on their well-being when caring for a child with special needs (Broady *et al*., 2017:5; Polaha, 2016:1). Families with children who have ASD are faced with social stigma impacting the primary caregivers’ psychological well-being.

3.7.2 PSYCHOLOGICAL WELL-BEING

Psychological well-being is generally defined as the effectiveness of the psychological functioning of an individual. It is further defined as having no fear or worry, uneasiness, sadness, and other psychological disorders (Cankir & Sahin, 2018:2550). Primary caregivers that are working and taking care of children with ASD tend to have less time for themselves in comparison to primary caregivers who are taking care of a child without the disorder. This can lead to psychological challenges and complications, such as severe tiredness, panic attacks and mental breakdowns (Geldenhuys, 2019:16; Fewster et al., 2020:41; Shattnawi et al., 2020:1).

Primary caregivers are further faced with different psychological challenges that include feelings of grief, financial strain, and family instability (Geldenhuys, 2019:16; Shattnawi et al., 2020:1). The health and well-being of the primary caregivers should be maintained to handle the challenges that come with caring for the child with ASD (Fewster et al., 2020:41; Geldenhuys, 2019:15). Primary interventions addressing emotional turmoil among caregivers are a necessity. The participants identified the need to have access to psychological services by saying:

“I think as a primary caregiver the kind of support I need should include access to psychological services” (session four, participant five).

"Counselling is very important and especially when you are taking care of someone" (session four, participant seven).

"So, I would need access to psychological services…to debrief" (session four, participant five).

"Afraid sometimes just to want to speak out and say we need help" (session one, participant seven).

The participants were not psychologically well and did not receive the counselling they deserved. They felt emotionally drained and needed support to encourage them. One of the participants never received counselling when the child was diagnosed with ASD and required ongoing counselling to cope with the child's condition. Psychological problems can start before primary caregivers obtain a final diagnosis and often worsen when they obtain a confirmed diagnosis. This causes different emotions throughout for the primary caregivers. Identifying problems, needs for services and resources for the future (Geldenhuys, 2019:72; Shattnawi *et al*., 2020:1) is vital before it can be provided. Family support plays a critical role in primary caregivers caring for children with ASD and support from the family can alleviate stress.

3.7.3 FAMILY SUPPORT

Family support is an offer of support from one person to another within a family (Martin & Borup, 2022:171). According to the primary caregivers, their children also face specific needs when the parents' needs are not met. The primary caregivers' experiences place excessive pressure on them due to the child's difficulties. This worsens when families are not supportive with helping with the children when they need to go away or with house chores (Kogan, 2008:1149; Geldenhuys, 2019:3; Hartley & Schultz, 2015:11).

Caregivers need support from the immediate family to help them with the child with ASD or to help the caregiver with some household responsibilities when the caregiver is working (Rosland, 2009:5). The participants of the study described how difficult it is to raise a child with ASD without the support of their families. The quotes attest to what the participants verbalised during the focus group discussion:

"I will need some support from some of my family members" (Session four, participant one).

"But also, you said the family support you. When am not around they must help me" (Session four, participant one).

"So, my girl (the primary caregiver has an older daughter) is permanently at home to take care of the child" (session one, participant six).

A family network may provide the necessary support during challenging times, and it seems that the primary caregivers in this study lack some family support. Primary caregivers experience more responsibility without the support of the family, which can lead to mental problems. Participants in the study conducted by Monnapula-Mazabane and Petersen (2021:5-8) and Shattnawi *et al*. (2020:10) believed that family support always strengthened their relationship.

For this study, among the participants, women raised the need to be supported by a helper who will assist them with the children while taking care of the household. A family member could assist the primary caregivers with their children, enabling the primary caregiver to take a break. Primary caregivers are inconveniently disturbed while they intend to rest and focus on themselves. They struggle to take a break (Murphy & Tierney, 2006:182-184). The break they intend to take includes going to places for rest and rejuvenation. Primary caregivers have difficulty going away from home to go and relax (Murphy & Tierney, 2006:182-184). Community support also plays a vital role in the primary caregivers' daily lives, which may be resourceful.

3.7.4 COMMUNITY SUPPORT

Community support is a source of assistance from neighbours, families, and the community. Some communities do not understand ASD as a condition (Klonover et al., 2022:1; Modula, 2017:5). The participants of the study echoed the importance of community support and highlighted that the community needs to be aware of children with ASD and how to support them:

"So, we need some sort of arrangement from the government or some support from the community" (session four, participant five).

"It takes a village to raise a child" (Session four, participant six).

These perspectives showed that community support is important to primary caregivers and could be crucial to their well-being. Drageset (2021:142) confirms the importance of community members' emotional support to primary caregivers influencing their well-being and general health. Limited

community support, on the other hand, led to loneliness and not feeling valued. A study by Modula (2017:5) revealed how families witness withdrawal from their communities because of their children's disorders. It is vital that children, despite their disorders or disability, should take part in community activities rather than be isolated (Egilson *et al.,* 2017:187). It is undoubtedly challenging for primary caregivers to raise a child with ASD impacting their well-being and quality of life. Some of them had to leave their jobs to care for their children. However, some primary caregivers became advocates for ASD and continuously motivated others to care for children with ASD.

3.8 SUMMARY

This chapter has given a broad view of the support needs of primary caregivers caring for children with ASD in Kimberley. A brief overview of the participants' demographic data and focus group discussion participants were provided. This chapter also identified and described the themes, sub-themes and occurrences derived from the data analysis. The support needs of primary caregivers caring for children with ASD were discussed and corroborated with the literature. Chapter four summarises the study's findings, recommendations, limitations, and conclusion.

Chapter 4

SUMMARY OF RESEARCH FINDINGS, RECOMMENDATIONS, LIMITATIONS AND CONCLUSION OF THE STUDY

4.1 INTRODUCTION

The themes and sub-themes that arose from the data analysis process were discussed in the preceding chapter. The research question was "What are the support needs of primary caregivers caring for children with ASD?". The study aimed to explore and describe the support needs of primary caregivers caring for children with ASD. This chapter presents a summary of the research findings and the recommendations that are made. Chapter 4 also offers a description of the study's limitations as well as the study's value and a personal reflection with a conclusion ending the chapter.

4.2 SUMMARY OF THE RESEARCH FINDINGS

The four focus groups generated rich data that were thematically analysed. The findings of the analysis resulted in four themes and relevant sub-themes. The summary of the findings associated to the themes and sub-themes are as follows:

4.2.1 HEALTHCARE:

- Participants verbalised that they need ***access*** to adequate healthcare, such as neurodevelopmental specialists, knowledgeable healthcare practitioners, clear referral pathways and healthcare services applicable and relevant to children with ASD in Kimberley.
- Participants identified ***health information*** as a need. They felt that trained and experienced healthcare practitioners in ASD may be able to supply related health information to them, enabling support in managing their children. Furthermore, knowledgeable healthcare practitioners could inform primary caregivers about ASD, increasing caregivers' knowledge of caring for their children.
- ***Community awareness*** appeared to be a vital aspect for the participants. Participants stated that the community should recognise ASD as a neurodevelopmental illness. Lack of community awareness leads to stigmatisation. If the community was more aware and knowledgeable about ASD and could provide more support to the primary caregivers.

- ***On* the *lack of knowledge on care aspects***, participants emphasised that healthcare practitioners lack knowledge on care aspects related to ASD, diagnostic processes and treatment. When healthcare practitioners are knowledgeable, they can support the primary caregivers in caring for ASD children.
- The participants recommended that healthcare practitioners obtain *training* on ASD to increase their insight into the condition. Trained healthcare practitioners can provide adequate care.

4.2.2 FINANCIAL NEEDS

- ***Transport*** to clinics, hospitals, schools, and specialists outside Kimberley appeared to be costly for the participants and most of them could not afford it.
- The participants requested to be supported with money that would improve their children's ***nutrition***. Due to an insufficient grant received from the government and unemployment, primary caregivers voiced their inability to afford special diets because it is too expensive.

4.2.3 BASIC EDUCATION:

- Participants highlighted that they do not have enough ***ECD Centres*** catering to children with ASD and trained teachers are lacking in Kimberley. They wanted to integrate centres that accommodate ASD children and children who do not have ASD.
- Primary caregivers complained that there are not enough special schools in Kimberley to cater to children with ASD who need ***special education*** and mentioned that they need more special schools in Kimberley.

4.2.4 SOCIAL SUPPORT NEEDS

- **Social support** was seen as an essential requirement by the participants, and they identified the need to be supported by families and their communities to get relief from their daily activities.
- **Stigma:** The participants pointed out that they felt that their children are affected by how the community members treat them differently. The primary caregivers complained that their children are labelled negatively, which results in psychological exhaustion. The participants felt **stigmatised** and indicated that they needed support from the community rather than rejection and isolation. Feeling lonely and resorting to being prisoners at home is what

participants felt because they encountered **isolation** from the community. When communities and families know the behaviour of children with ASD, they may not stigmatise ASD children.

- **Psychological well-being**: Participants strongly believed they need access to psychological support, debriefing, talking to someone and counselling, especially when their children with ASD are newly diagnosed.
- **Family support**: Participants emphasised the importance of family members' help caring for a child with ASD. Primary caregivers desired to be assisted with house chores and it isn't easy to do all household activities without the support of families. Primary caregivers identified that a helper would be of assistance to reduce the load on them.
- **Community support**: Participants wanted community support in caring for children with ASD, especially after being informed of their condition. Primary caregivers used the phrase "it takes a village to raise a child" to stress the importance of getting support from neighbours and the community. Awareness of ASD in the community will motivate the community to support the primary caregivers. Participants described the importance of primary caregivers and healthcare practitioners understanding ASD to make others aware.

Recommendations of this study are derived from the data analysis. Data collected were grouped into themes and sub-themes. The exact order used in Chapter 3 with the themes and sub-themes will be followed.

4.3 RECOMMENDATIONS

The support needs of primary caregivers were explored and described in this study. The participants were able to identify their needs when caring for children with ASD. It was imperative to know and understand the needs of primary caregivers to compile the recommendations that can assist them in the future. The recommendations are related to the themes and sub-themes identified.

4.3.1 HEALTHCARE

Recommendations addressing the healthcare themes include:

- The National Health Quality Improvement Plan (NHQIP) aims to achieve the best possible outcomes for the South African health system. These outcomes are measured in improved health status, access to healthcare, satisfied patients and staff, and the efficient use of

adequate resources through the implementation of quality assurance and improvement strategies, transforming existing service delivery challenges into skills and knowledge for quality improvement (NHQIP, 2019:06; DHP, 2022:30). This plan is already implemented in all districts in the Northern Cape, including Kimberley. Primary caregivers caring for children with ASD should benefit from this programme as they can access healthcare with adequate resources.

4.3.2 ACCESS TO HEALTHCARE

- The child directorate should collaborate with clinic managers to streamline appointments for caregivers with ASD children. Waiting periods should be shortened, preventing possible meltdown behaviour and the appointments of children with ASD should be prioritised.
- The shortage of social workers, psychologists, speech therapists, doctors and professional nurses continues to hamper the health system. The researcher recommends that Allied workers, such as dietitians, occupational therapists, physiotherapists and speech therapists, should be available at least every two weeks at the clinic. Sessions that they provide are needed by caregivers who have children with special needs. The availability of healthcare practitioners will improve access to healthcare as primary caregivers will be attended by healthcare practitioners at health facilities (Jimenez, 2021:1).
- Primary healthcare clinics should adopt smoother referral pathways for children with special needs, such as ASD. Clinic staff should communicate precise information to the primary caregivers on the referral pathways and processes. The Integrated Management of Childhood Illness (IMCI) guidelines on referral pathways should be followed. The process of assessing, classifying, identifying treatment and referral must be adhered to. The PHC nurse should consult the doctor to refer the child with ASD to a specialist in Bloemfontein because the new mental hospital in Kimberley still refers children with possible ASD to Bloemfontein. A better functioning referral system is required.
- The participants recommended that they be allowed to be prioritised in long queues to prevent children from getting meltdowns. Clinics are not prioritising children with ASD in waiting areas. Knowledge is essential to deliver care to primary caregivers. Healthcare practitioners' training will increase their insight into ASD, and they will then be able to provide adequate care (Ayakaka, 2021:27).
- The District Specialist Team, which consists of a primary healthcare specialist and family physician, should be consulted to investigate the possibility of a visiting

neurodevelopmental paediatrician or child psychiatrist seeing ASD children at least once a month in Kimberley.

4.3.3 HEALTH INFORMATION

- The health promotion officer at the district level could provide information to caregivers of children with ASD in the waiting area of the clinic while awaiting appointments. At present, health promoters are not focusing on ASD health information. Providing primary caregivers with information on ASD diagnosis and treatment is recommended (An *et al*., 2019:11).
- The Department of Health team should provide health information on ASD conditions at least once a month through face-to-face contact at the clinic. The health information team consists of professional nurses, peer educator leaders and health promotion officers. The district has health promoters, peer educators, ward base healthcare workers, professional nurses, and clinical mentors responsible for health information sessions at the clinic and community levels. Shared information between healthcare practitioners and primary caregivers should be continuous (Ghiasi, 2021:1320). Nurses should provide health promotion to the public quarterly on ASD. It is part of capacity building.
- Primary caregivers should be provided with situation-specific information by healthcare practitioners who understand ASD as a condition. This will encourage primary caregivers to become more active in managing their child's condition. The information must be made available to the primary caregivers. Many problems will be avoided when information is available. Health promoters and healthcare practitioners should present topics like ASD to the community quarterly.

4.3.4 COMMUNITY AWARENESS

- The health promotion directorate at the district level, with the support of Northern Cape Autism, can develop factsheets on ASD, which must be distributed. They can organise community dialogue that will help the community to understand ASD.
- The national health calendar must guide healthcare practitioners to integrate services that will enhance community awareness of ASD. Integration of services entails combining ASD awareness with non-communicable disease awareness, which is currently receiving more attention than mental health issues. Integration of services includes combining services, like cancer awareness day with mental health screening and awareness.
- The Northern Cape Autism provincial coordinator can collaborate with health facilities on

ASD awareness with the support of the child health coordinator. The need for more awareness initiatives for the broader community is recommended. This will minimize stigmatising and labelling of children with ASD.

- Primary caregivers and other stakeholders must promote social acceptance of ASD in the community. There is a need to promote ASD awareness by employing campaigns in communities, churches, schools and hospitals. As implementers on the ground, healthcare practitioners must increase their knowledge of ASD to lower misunderstandings. This can be done through pamphlets, posters, health talks through drama, community radio stations, television, and social media platforms such as newspapers, Facebook, and Twitter. News can increase community awareness of ASD (Alyami, 2022:12).

4.3.5 LACK OF KNOWLEDGE ON CARE ASPECTS

- The child health directorate must arrange workshops for healthcare practitioners at least every quarter regarding the care of ASD and children with other special needs. Healthcare practitioners must attend workshops to learn about caring for a child with ASD as part of continuous development. Knowledgeable healthcare practitioners can support primary caregivers in caring for children with ASD.
- The district communication office that communicates activities and updates for the Department of Health should continue to share information on different disabilities, with ASD included. Healthcare practitioners must continuously update the primary caregivers through community dialogues, health awareness materials, and health talks in waiting areas. This can also realise through household visits on any changes that involve their children's treatment care, appointments and transport arrangements.
- It is suggested that healthcare practitioners inform primary caregivers of their children's treatment and care to increase knowledge on care aspects of ASD. Essential service practitioners, such as educators and healthcare practitioners, should empower primary caregivers and those unaware of ASD. Primary caregivers must be given an opportunity to write down their challenges, which should be addressed within a reasonable timeframe (Geldenhuys, 2019:69).

4.3.6 TRAINING

- A training programme on ASD should be developed for healthcare practitioners. Such a programme may develop the capacities of healthcare practitioners, enabling them with

the knowledge and skills to provide adequate care. Role-playing demonstrations and group discussions for healthcare practitioners can assist in ASD training, helping to understand the content (Squibb, 2019:6).

- The training programme should include information on ASD screening, signs and symptoms, management and interventions, problem-solving, and coping skills. The district training manager can provide this training for healthcare practitioners. Due to an information gap in the community related to ASD, it is recommended that the community and healthcare practitioners are trained on ASD to obtain knowledge of the disorder. This will help them to provide care to children with ASD (Ayakaka, 2021:27).
- Adequate training could empower healthcare practitioners to be competent enough to support primary caregivers, strengthening caregivers' abilities to care for their children with ASD. Furthermore, it is important to train the primary caregivers to manage their children.

4.3.7 FINANCIAL NEED

4.3.7.1 Transport

- The referring healthcare practitioner should book the primary caregiver and the child on the hospital transport register immediately after obtaining an appointment with the specialist doctor. This will assist the primary caregiver in not stressing about reaching the specialist. The Department of Health has procured patient transport to transport patients to their appointments outside Kimberley. This could be employed for the study's population also.
- The primary caregiver should be provided with all details from the referring healthcare practitioner, namely the date and time of departure. It is recommended that the referral information be complete and accurate, reassuring the caregivers and lessening their anxiety.
- Currently, the Department of Education transports children to hard-to-reach schools and this service can be negotiated to include children with disabilities, such as ASD.
- Community leaders, councillors and non-governmental organisations can collaborate to assist the primary caregivers with transport needs. This can be done by accessing the funds made available by non-governmental organisations. The funds can be used to hire cars that will assist with transport. Sustainability can be a challenge. However, the community leaders and church leaders can request community transport to assist while waiting for the Department of Education to prioritise children with ASD.

4.3.7.2 Nutrition

- Dieticians at the primary healthcare clinic should provide onsite training on nutritional information for primary caregivers of children with ASD. They can assist with nutritional information and compile an affordable diet plan focusing on ASD children's special needs according to caregivers' income. The dieticians can present quarterly information sessions regarding nutritional needs specific to ASD children. They can address one topic at a time. Dieticians must draw up an affordable eating plan for the primary caregivers to ensure that children with ASD eat food appropriate to their needs. The provision of a special diet for children with ASD should be considered (Ismail et al., 2020:2).
- The dietician, with the support of the operational manager at the clinic, could establish vegetable gardens to produce nutritious food that will assist children with their diet.
- It is recommended that the dieticians visit the clinics at least twice a week. The number of children that needs nutrition intervention has increased. Currently, the dieticians visit the facility once a week. Professional nurses and doctors are the ones that refer patients to dieticians when there is a need.
- A special nutrition programme that NACOSA funds (Non-Governmental Organisation funder) in the district should add ASD children to their programme, rather than malnourished children only. The clinical programme manager can request a memorandum of understanding to be amended to accommodate children with ASD. This can be achieved with the assistance of the district child health coordinator.

4.3.8 EDUCATIONAL NEEDS

4.3.8.1 ECD Centre

- Providing primary caregivers and the community with the necessary support and information related to their children's early learning will help them gain insight into their children's education. The Department of Education urges educators to provide early childhood stimulation for all children. Early learning programmes for children are essential education that should be delivered for the primary caregivers to be motivated to take their children to these centres (Department of Social Development, 2015:27).
- The provincial ASD coordinator of the Northern Cape communicated the need for more special schools in Kimberley to Autism SA, requesting their help. There is no feedback up to date and this should be investigated further.
- The health promotion officer from the District Office of the Department of Health, peer

educators and community healthcare workers must be trained on ASD. They have to further embark on ASD awareness through ECD Centres. This can be done during integrated services visits at ECD Centres by dieticians, nurses, dentists and occupational therapists. The dedicated school health team visits the ECD centers monthly as part of the integrated school health programme.

4.3.8.2 Special education

- The researcher recommends that the civil society in Kimberley advocates for children with ASD to receive special education at government and private schools. There are three special schools in Kimberley. These schools render services to all children with special needs, including ASD. According to Pillay et al. (2021:1078), South Africa has special education for children with ASD. Special education is rendered both at government-funded schools and private schools.
- The participants should allow their children to attend school, despite their disabilities, because it is their right to obtain an education. All children should be allowed to attend school by their primary caregivers. Children with special needs, and those without, have to receive the same education (Mithimunye, 2018:280). In Kimberley, some primary caregivers keep their children home to avoid stigma.

4.3.9 SOCIAL SUPPORT NEEDS

4.3.9.1 Stigma

- Community radio stations, school meetings, community dialogues and churches can be used to raise ASD awareness. These awareness sessions can be implemented by healthcare practitioners, educators, pastors and community leaders during special school or church days or events. ASD information and awareness may lessen stigmatising situations.
- Awareness leaflets that provide important information on ASD and related behaviour, features and characteristics can be distributed to the community, healthcare practitioners and primary caregivers. Grinker *et al*. (2012:5) recommend sharing information sheets with schools to increase knowledge that could prevent stigma on children with ASD and their primary caregivers.
- A safe space, created by an occupational therapist or social worker, should be available where primary caregivers can be taught coping skills.

- Celebrating World Autism on the 2nd of April is a measure that can be used yearly to raise awareness of ASD. This is through the presentation of organised awareness campaigns.

4.3.9.2 Psychological well-being

- All primary caregivers should receive pre- and post-counselling regarding ASD diagnosis. The doctor should provide the counselling and when the need arises, the doctor can refer the primary caregivers to psychologists. The health and well-being of the primary caregivers should be maintained to handle the challenges accompanying caring for a child with ASD (Fewster *et al*., 2020:41; Geldenhuys, 2019:15).
- All primary caregivers suffering from emotional issues should be referred by healthcare practitioners as soon as possible for counselling. Psychologists visit clinics and then appointments could be scheduled for the primary caregivers needing support.
- The researcher calls for psychosocial support from caregivers of children with ASD that may alleviate some of the stress and isolation they experience. Such support may be provided either by their family, peer caregivers, healthcare facilities, the community, or local churches. However, it may be necessary that these individuals need to be empowered with the necessary knowledge and skills to provide adequate support to primary caregivers.
- Creating a support group by the professional nurse at the district may support primary caregivers with basic counselling and coping skills. The psychologist can be invited to present sessions once a quarter.

4.3.9.3 Family support

- Families should be empowered by the primary caregiver who is knowledgeable about ASD. This can be done through awareness of ASD during family visits and engagements. This recommendation can assist families in understanding the disorder and what primary caregivers are dealing with. Family support always strengthens relationships and the relations must be maintained. Family support is encouraged (Monnapula-Mazabane & Petersen, 2021:5-8; Shattnawi *et al.*,.2020:10).
- Families can create a get-together group that will often meet to ensure that everyone receives support from each other. Creating a WhatsApp group by one of the primary caregivers working for Autism SA in the Northern Cape can also help with the support. A primary caregiver will manage the group. This platform can assist primary caregivers in

sharing ideas on ASD and encouraging each other.

- Primary caregivers sometimes need respite care. It is recommended that primary caregivers get some time off for a day or a few days away from home, but they will need someone to look after their children. This off-time can only happen if families support the primary caregiver caring for the child with ASD. The primary caregivers experience excessive pressure due to the children's milestone difficulties. They can get worse when families are not supportive of helping the caregivers with the children when they need to go away or with house chores (Kogan, 2008:1149; Geldenhuys, 2019:3; Hartley & Schultz, 2015:11).

4.3.9.4 Community support

- Communities are encouraged to support primary caregivers in caring for children with ASD. It is recommended that the community be empowered with ASD knowledge, which can result in community support. Communities can support the primary caregivers with emotional support. If possible, the community can assist with food when the need arises. The participants are currently not receiving support from their communities because communities are unaware of ASD as a disorder. Drageset (2021:142) confirms the importance of community members' emotional support to primary caregivers, influencing their well-being and general health. They recommend community support.
- Communities should establish community support groups for primary caregivers that can meet bi-weekly. This initiative can assist primary caregivers in coping and motivating them to care for children with ASD. The civil society from the Premier's Office in Kimberley has funded Grassroots Edge, a non-governmental organization supporting the Department of Health-on-health system strengthening to start with a project that empowers communities. Those projects include parents' support and adherence clubs. The researcher recommends that Grassroots empower communities on ASD, which can result in community support.
- The creation of a community WhatsApp group is encouraged to create a platform that will support each other during periods of stress and when feeling overwhelmed. The community representative, also a parent of a child with ASD, will create the WhatsApp group with permission from the primary caregivers.

4.4 FUTURE RESEARCH

Future research could investigate the burden of primary caregiving related to ASD children in the Northern Cape. Understanding the views and experiences of a small population of ASD caregivers does not provide a true reflection of the situation. Further research should explore and describe perspectives regarding children with ASD related to support needs. In addition, research focusing on primary caregivers' experiences caring for individuals with ASD at various ages will provide a broader understanding of their lives, needs and support.

4.5 PERSONAL REFLECTION

The most important lesson the researcher took away from this experience was setting this objective earlier in life. Being a mother, wife, student, and employee is difficult while on this journey. Even though the road was challenging, I aimed to improve myself and others. This degree might present me with new opportunities.

The researcher used a qualitative research approach for the first time. Nothing seemed to make sense at the beginning. Even though the researcher knew what she wanted to research, she had trouble identifying a topic. This quest began with a year of research methodology training to gain background and research knowledge. The research journey began with the study proposal impacting the researcher's piece of mind. She had trouble, though, with the English vocabulary and phrasing of sentences.

Finding primary caregivers and getting ready for focus group discussions were stressful and demanding. The first focus group meeting, intended to be a pilot, did not go well since the researcher lacked experience. However, the moderator who was asked to help with the focus group helped the researcher understand how to run an effective focus group. Anxiety began to build on the first day of the focus group session, which the moderator was scheduled to lead. Given all the preparations that needed to be taken, including expenses, the researcher was concerned that the participants might not show up or arrive late.

Even though Chapter 3 was the most significant section of the study, the researcher had to review every transcript to ensure that the themes and sub-themes were developed with accurate descriptions of what the primary caregivers had to say. Because some of the transcripts were inaudible, it was necessary to listen to audio recordings several times. As a researcher, I think I've developed in the academic setting and will keep learning. This study encouraged me to acquire

computer skills. I was able to attend academic writing workshops along the way, and I'm eager to use what I learned.

4.6 LIMITATIONS OF THE STUDY

The researcher is aware that the exclusion of certain groups and ages might limit the study. The researcher conducted a pilot study, but because she was not skilled in conducting focus group discussions, she had to arrange another facilitator, which influenced the study's timeline. The collection of data during the COVID-19 pandemic was complex. Due to quarantine measures, participants who agreed to be part of the focus group discussion could not. To ensure more participants for the focus group discussions, dates had to be changed, which further influenced the study's timeline. Wearing a mask during the focus group discussions resulted in inaudible sounds, which required the researcher to listen to the audio recorder repeatedly and caused the data analysis delay. Qualitative findings cannot be generalized to other contexts but can still present an in-depth description of a primary caregiver of the ASD children population in Kimberley.

4.7 VALUE OF THE STUDY

The researcher used focus group discussions to explore and describe the support needs of primary caregivers caring for children with ASD. The study allowed the primary caregivers to share their experiences, challenges and support needs when caring for children with ASD. The researcher hopes the caregivers will support each other now that they have met through the focus groups. The study's findings may be valuable to various stakeholders, namely the Department of Health, Social Development and Education.

4.8 CONCLUSION

This chapter summarised research findings, offered related recommendations and state issues on the study limitations. The study's value and the personal reflection of the researcher were also noted. This study highlighted the challenging task of informal primary caregivers caring for children with ASD and the apparent lack of support leading to stress and frustrations. Primary caregivers of children with ASD voiced their experiences and this need to be heard.

REFERENCE LIST

Abubakar, A., Ssewanyana, D., de Vries, P.J., Newton, C.R. 2016. Autism spectrum disorders in Sub-Saharan Africa. Journal of the international psychiatry study: Lancet psychiatry: 3(9)800-2. Doi:10.1016/s2215-0366

Adler, K., Salanterä, S., Zumstein-Shaha, M.2019. Focus Group Interviews in child, youth and Parent Research: An Integrative Literature Review. International Journal of Qualitative Methods, 18. DOI:10.1177/1609406919887274

Almeida, F., Faria, D. & Queiros, A. 2017. Strength and limitations of qualitative and qualitative research methods. European Journal of Education Studies, 3(9):371-378.

Ametepee, L., & Chitiyo, K. 2009. What We Know about Autism in Africa: A Brief Research Synthesis. Journal of the International Association of Special Education, 10(1):11-14.

An, J., Na, Y. & Zhang, P. 2019. How do parents of children with ASD use information grounds to seek for ASD related information. ASIS&T. 56(1):10-20. doi:10.1002/pra2.3

Ansel, K. 2022. Autism spectrum disorders and diet: Kids eat right. https://www.eatright.org/health/health-conditions/intellectual-disabilities/nutrition-for-your- child-with-autism-spectrum-disorder-asd Date of access: 01 December 2022

Aspers, P. & Corte, U. 2019. What is Qualitative in Qualitative. Qualitative Sociology, 42:139-160. https://doi.org/10.1007/s11133-019-9413-7

APA (American Psychiatric Association). 2013. Diagnostic and Statistical Manual of Mental Disorders (DSM-5). 5th ed. Washington DC: American Psychiatric Association.

Asenahabi, B. M. 2019. Basics of Research Design. A guide selecting appropriate research design. International journal of contemporary applied researchers, (6)5:76-89.

Autism SA (Autism South Africa). 2015. ASD Prevalence. https://aut2know.co.za. Date of access: 13 June 2020.

Autism South Africa. 2000. https://www.aut2know.co.za. Date of access: 31 October 2019.

Ayakaka, G. 2021. Healthcare professionals' knowledge about autism spectrum disorder in children A Systematic Literature Review. School of Education and Communication (HLK) Jönköping University. (Dissertation – MSc).

Aziz, O.F.A. 2014. The need of families of autism spectrum disorder (ASD) and their relation to certain variables. Life Science Journal, 11(7):886-896 (ISSN: 1097-8135). Babbie, E. & Mouton, J. 2007. The practice of social research. 11th edition. Cape Town: Oxford University Press.

Babbie, E. 2013. The practice of social research. 13th ed. Belmont, CA: Wadsworth, Cengage Learning.

Bajpai, A. 2017. Child rights in India: Law, policy and practice., 3rd ed: India: Oxford.

Barbour, R. S. 1999. Developing focus group research: Politics, Theory and practice. London: Sage.

Baxter, A., Brugha, T., Erskine, H., Scheurer, R., Vos, T., & Scott, J. 2015. The epidemiology and global burden of autism spectrum disorders. Psychological Medicine, 45(3), 601-613. doi:10.1017/S003329171400172X

Befkadu, B., Adamek, M.A., & Ero, D. 2022. The financial challenges of parents of a child with autism in Addis Ababa, Ethiopia: A qualitative study. Journal of Social Science and Management Studies, 1(1):1-7.

Belle, S. H., Burgio, L., Burns, R, et al. 2006. Enhancing the quality of life of dementia caregivers from different ethnic or racial groups: A Randomized, Controlled trial. Annals of Internal Medicine.; 145(10):727-738. doi:10.7326/0003-4819-145-10-200611210-00005

Berg, B.L & Howard, L. 2017. Qualitative Research Methods for the Social Sciences. 9th edition. California State University: Pearson.

Brede, J., Remington, A., Kenny, L., Warren, K., & Pellicano, E. 2017. Excluded from school: Autistic students' experiences of school exclusion and subsequent re-integration into school. Autism & Developmental Language Impairments, 2. https://doi.org/10.1177/2396941517737511

Brink, H., Van der Walt, C. & Van Rensburg, G. 2012. Fundamentals of Research Methodology for Healthcare professionals.3rd edition. Juta: Cape Town.

Broady, T. R., Stoyles, G. J., & Morse, C. 2017. Understanding carers' lived experience of stigma: the voice of families with a child on the autism spectrum. Health & social care in the community, 25(1):224–233. https://doi.org/10.1111/hsc.12297

Botma, Y., Greeff, M., Mulaudzi, F.M. & Wright, S. C. D. 2010. Research in Health Sciences. Cape Town: Pearson Publishers.

Boyd, M. A. 2018. Psychiatric Nursing: Contemporary Practice. 5th ed. Philadelphia: Wolters Kluwer.

Burns, N. & Grove, S.K. 2009. The practice of nursing research appraisal, synthesis and generation of evidence. 6th edition. Missouri: Saunders Elsevier.

Cankir, B. & Sahin, S. 2018. Psychological well-being and job performance: the mediating role of work engagement. Hitit University Journal of Social Sciences Institute, 11(3):2549- 2560. Doi:10.17218/hititsosbil.487244

Carey, M.A., & Asbury, J.-E. 2012. Focus Group Research. 1st ed. Routledge. https://doi.org/10.4324/9781315428376

Catalano, D., Holloway, L. & Mpofu, E. 2018. Mental Health intervention for parent carers of children with autism spectrum disorder: practice guideline from a critical interpretive synthesis (CIS) systematic review. International Journal of Environmental Research and Public Health, 15(2):341. DOI: https://doi.org/10.3390/ijerph15020341

Centre for Disease Control. 2018 Data and Statistics on Autism Spectrum Disorder. 2018.www.cdc.gov. Date of access: 19 September 2019.

Children's Act 38 of 2005.

Creswell, J.W. & Creswell, J.D. 2018. Research design Qualitative, Quantitative, and mixed methods approaches. 5th edition. SAGE: Los Angeles.

Creswell, J.W. & Poth, C.N. 2018. Research Design: Qualitative, Quantitative and Mixed methods approach. 4th edition. SAGE: California.

Corbin, J. & Strauss, A. 2014. Basics of Qualitative Research techniques & procedures for developing grounded theory: SAGE California.

Corden, K., Brewer, R. & Cage, E. 2022. A Systematic Review of Healthcare Professionals' Knowledge, Self-Efficacy and Attitudes Towards Working with Autistic People. Journal of Autism and Developmental Disorders, 9:386–399 https://doi.org/10.1007/s40489-021-00263-w

Corsano, P., Cinotti, M. & Guidotti, L. 2020. Paediatric nurse's knowledge and experience of autism spectrum disorders: An Italian survey. Journal of child healthcare for professionals working with children in the hospital and community, 24(3):486-495. Doi:10.1177/1367493519875339

Cridland, E.K., Jones, S.C., & Stoyles, G. 2016. Families Living With Autism Spectrum Disorder: Roles and Responsibilities of Adolescent Sisters. Focus on Autism and Other Developmental Disabilities, 31(3):196–207. DOI: 10.1177/1088357615583466

Crowell, J.A., Keluskar, J., & Gorecki, A. 2019. Parenting behaviour and the development of children with autism spectrum disorder. Comprehensive Psychiatry, 90:21-29.

Dada, S.L., & Samuels, A.E. 2016. South African families raising children with autism spectrum disorders: Relationship between family routines, cognitive appraisal and quantity of life. Journal of Intellectual Disability Research, 60(5):412-423. DOI: https://doi.org/10.1111/jir.12292

De Houting, J., Higgins, J., Isaacs, K. et al. 2021. 'I'm not just a guinea pig': Academic and community perceptions of participatory autism research. Autism, 25(1):148–163.

Department of Basic Education (2022) Special need education (6). www.DBE.gov.za. Date of access: 08 February 2023.

District Health Information System. 2019. Frances Baard District-Sol Plaatje Sub District. www.DOH.gov.za. Date of access: 4 December 2019.

Dillenburger, K., Jordan, J. A., McKerr, L., Devine, P., & Keenan, M. 2013. Awareness and knowledge of autism and autism interventions: A general population survey. Research in Autism Spectrum Disorders, 7(12):1558–1567. https://doi.org/10.1016/J.RASD.2013.09.004

Divan, G., Vajaratkar, V., Desai, M.U. et al. 2012: Challenges, Coping Strategies, and Unmet Needs of Families with a Child with Autism Spectrum Disorder in Goa, India.
Autism Research; 5(3):190–200. doi:10.1002/aur.1225

Drageset, J. 2021. Social support. In: Haugan, G. & Eriksson, M. Health promotion in healthcare-vital theories and research. Faculty of nursing and health science, Nord University: Springer.

Donev, D., Pavlekovics, G., Kragelj, L.Z. 2007. Health promotion and disease prevention. A handbook for teachers, researchers, health professionals and decision makers.
Germany: Hans Jacobs.

Egilson, S.T., Jacobsdóttir, G., Ólafsson, K., & Leósdóttir, T. 2017. Community participation and environment of children with and without autism spectrum disorder: parent perspectives. Scandinavian Journal of Occupational Therapy, 24(3):187-196. DOI: 10.1080/11038128.2016.1198419

Etikan, I., Musa, S.A., Alkassim, R.S. 2016. Comparison of Convenience Sampling and Purposive Sampling. American Journal of Theoretical and Applied Statistics, 5(1):1-4. doi: 10.11648/j.ajtas.20160501.11

Evian, C. 2011. Primary HIV Clinical Care: a practical guide for healthcare personnel in primary care centres. 5th edition. Jacana Publisher: South Africa.

Fewster, D.L., Uys, C., & Govender, P. 2020. Interventions for Primary Caregivers of Children with Autism Spectrum Disorder: A cross-sectional study of current practices of stakeholders in South Africa. South African Journal of Occupational Therapy, 50(1):41-48. https://dx.doi.org/10.17159/2310-3833/2020/vol50no1a7

Geiger, M. 2012. Communication training for centre-based carers of children with severe or profound disabilities in the Western Cape, South Africa. African Journal of Disability, 1(1). doi:10.4102/ajod.v1i1.10

Geldenhuys, A. 2019. The Financial and Psychological cost of raising a child with Autism Spectrum Disorder Spectrum Disorder A qualitative study. University of KwaZulu-Natal. (Dissertation).

Ghiasi A. 2021. Health information needs, sources of information, and barriers to accessing health information among pregnant women: a systematic review of research. The journal of maternal-foetal & neonatal medicine: the official journal of the European Association of Perinatal Medicine, the Federation of Asia and Oceania Perinatal Societies, the International Society of Perinatal Obstetricians, 34(8), 1320–1330. https://doi.org/10.1080/14767058.2019.1634685

Girma, E., Möller-Leimkühler, A. M., Müller, N., Dehning, S., Froeschl, G., & Tesfaye, M. 2014. Public stigma against family members of people with mental illness: findings from the Gilgel Gibe Field Research Center (GGFRC), Southwest Ethiopia. BMC international health and human rights, 14:2. https://doi.org/10.1186/1472-698X-14-2

Goffman, E. 2018. Social stigma. En.wikipedia.org/wiki/social stigma (free encyclopaedia). Date of access: 01 December 2022.

Goundar, S. 2012. Research Methodology and Research method. Victoria: University of Wellington.

Green, J. & Thorogood, N. 2009. Qualitative Methods in Health Research. London: Sage Publications.

Guler, J., de Vries, P. J., Seris, N., Shabalala, N., & Franz, L. 2018. The importance of context in early autism intervention: A qualitative South African study. Autism: the international journal of research and practice, 22(8), 1005– 1017.ttps://doi.org/10.1177/1362361317716604

Gumede, N. 2019. The number of Special schools in Kimberley, Department of Education. [Personal interview]. 5 Sep., Kimberley.

Halter, M.J. 2018. Varcarolis foundations of psychiatric mental health nursing. A clinical approach. 5th ed. St. Louis, Missouri: Elsevier.

Hare, D.J., Pratt, C., Burton, M. 2004. The health and social care needs of family carers supporting adults with autism spectrum disorder. Journal of learning disabilities, 8(4):425-444. DOI:10.1177/1362361304047225

Hartley, S.L. & Schultz, H.M. 2015. Support Needs of Fathers and Mothers of Children and Adolescents with Autism Spectrum Disorder. Journal Autism Dev Disorder, 45(6):1636– 1648. doi:10.1007/s10803-014-2318-0.

Heerkens, Y.F., De Brouwer, C., Engels, J. 2017. Elaboration of the contextual factors of the ICF for occupational health. Journal of prevention, assessment and rehabilitation, 57(2): 187-204. DOI:10.3233/WOR-172546

Hennink, M. M., & Leavy, P. 2014. Understanding Focus Group Discussions, Understanding Statistics. Oxford University Press: New York. https://doi.org/10.1093/acprof:osobl/9780199856169.001.0001, Date of access:1 December 2022.

Hunter, D.J., Mc Callum, J & Howes, D. 2018. Defining Exploratory – Descriptive Qualitative (EDQ) research and considering its application in healthcare: Global Science & Technology forum publications. https.//nursing-conf.org/accepted-descriptive papers/#acc- 5b9bb119a6443.

Iadarola, S., Pellecchia, M., Stahmer, A., Lee, H. S., Hauptman, L., Hassrick, E. M., Crabbe, S., Vejnoska, S., Morgan, E., Nuske, H., Luelmo, P., Friedman, C., Kasari, C., Gulsrud, A., Mandell, D., & Smith, T. 2020. Mind the gap: an intervention to support caregivers with a new autism spectrum disorder diagnosis is feasible and acceptable. Pilot and feasibility studies, 6(124). https://doi.org/10.1186/s40814-020-00662-6

Ingram, J., Hand, C.J., & Maciejewski, G. 2021. Social isolation during Covid 19 lockdown impairs cognitive function. Applied Cognitive Psychology, 35(4):935-947. https://doi.org/10.1002/acp.3821

Iramani, R., & Lutfi, L. 2021. An integrated model of financial well-being: The role of financial behaviour. Accounting, 7:691-700. DOI:10.5267/J.AC.2020.12.007

Ismail, N. A. S., Ramli, N. S., Hamzaid, N. H., & Hassan, N. I. 2020. Exploring Eating and Nutritional Challenges for Children with Autism Spectrum Disorder: Parents' and Special Educators' Perceptions. Nutrients, 12(9):2530. https://doi.org/10.3390/nu12092530

Jiménez, D.S, Mayorga, J.A.V., Ubilla, M.E.R., Hernández, N. B. 2021. NeutroAalgebra for the evaluation of barriers to migrants access in Primary Health Care in Chile based on PROSPECTOR function, Neutrosophic Sets and System, 39(1):1-9. http://fs.unm.edu/NSS2/index.php/111/article/view/1216

Joubert, G. & Ehrlich, R. 2007. Epidemiology a research manual for South Africa. 2nd ed. Cape Town: ABC Press.

Juraszek, K., Kalisz, Z., Maszudzinska, A. et al. 2019. Healthcare professionals' knowledge of autism spectrum disorders. Journal of Education, Health and Sport, 9(8):199-215. eISNN 2391-8306. DOI http://dx.doi.org/10.5281/zenodo.3371694.

Kantrowitz, M. Saving for college. https://www.savingforcollege.com/authors/mark- kantrowitz Date of access: 01 December 2022.

Kent, R.J., Carrington, S., Gould, J. et al. 2013. Diagnosing Autism Spectrum Disorder: Who will get a DSM-5 diagnosis. Journal of child psychology and Psychiatry, 54(2):1242-1250. https://doi.org/10.1111/jcpp.

Khabanyane, N.L. 2020. Parents experiences of accessing education for autistic learners in primary school. Durban:University of KwaZulu Natal. (Dissertation – MSc).

Khara, R., Kalankesh, L.R., Shahrokhi, H., Dastgiri, S., Gholipour, K., & Feizi-Derakhshi, M. 2020. Identifying the Needs of Families of Children with Autism Spectrum Disorder from Specialists and Parents' Perspectives: A Qualitative Study. Iranian Journal of Psychiatry and Behavioral Sciences, 14(4):1-10. https://doi.org/10.5812/ijpbs.107203

Kidd, P.S. & Parshall, M.B. 2000. Getting the Focus and the Group: Enhancing Analytical Rigor in Focus Group Research. Qualitative Health Research, 10(3):293-308.

Kim, H., Sefcik, J.S & Broadway, C. 2017. Characteristics of Qualitative Descriptive Studies: A systematic Review. Research in nursing & health, 40(1), 23–42. https://doi.org/10.1002/nur.21768

Klettlinger, D., Wirfel, L., Bielak, B. 2015. Caregiver Perceptions of Healthcare Providers and Environments Related to Children with Autism Spectrum Disorder. Honors Research Projects. 97. Univ of Akron http://ideaexchange.uakron.edu/honors_research_projects/97

Klonover, E., Maytles, R., Trachtingot, I., & Bergman, Y. S. 2022. Sense of community, meaning in life, and satisfaction with life among Ultra-Orthodox Jews: A mediation model. Journal of community psychology, 10.1002/jcop.22914.

Kogan, M. D., Strickland, B. B., Blumberg, S. J., Singh, G. K., Perrin, J. M., & van Dyck, P. C. 2008. A national profile of the healthcare experiences and family impact of autism spectrum disorder among children in the United States, 2005-2006. Pediatrics, 122(6), e1149–e1158.

Kohrt, B.A., Asher, L., Bhardway, A. 2018. The role of communities in Mental Healthcare in low and middle-income countries: A meta-review of components and competencies. International journal of environmental research and public health, 15:2-31. doi:10.3390/ijerph15061279

Korstjens, I. & Moser, A. 2018. Practical guidance to qualitative research: Trustworthiness and publishing. European Journal of general practice, 24(1):120-124. DOI: 10.1080/13814788.2017.1375092.

Kranz, S., Lukacs, J., Bishop, J., & Block, M. E. 2022. Intergeneration transfer of diet patterns? Parental self-report of diet and their report of their young adult children with ASD. Plos one, 17(2):e0263445. https://doi.org/10.1371/journal.pone.0263445

Krueger, R. 2002. Designing and conducting focus group interviews. University of Minnesota: St Paul: Thousand Oaks, CA: Sage

Kumar, R. & Das, A. 2017. Needs of Caregivers of persons with Mental illness: Rehabilitation Perspective, Indian Journal of Psychology work, 8(2):70-74.

Kuo, P.B., Woo, H., Bang, N.M. 2017. Counsellor Education and Supervision: Advisory relationship as a moderator between Research self-efficacy, motivation, and productivity among counsellor education doctoral students. Counselor Education and Supervision, 56(2):81-160.

Lakshman, M., Charles, M., Biswa, M., Sinha, L. & Arora, N. K. 2000. Focus group discussions in medical research. The Indian Journal of Pediatrics, 67:358-362. https://doi.org/10.1007/BF02820688

Leavy, P. 2017. Oxford library of psychology. The Oxford Handbook of Qualitative research. Oxford University Press: New York.

Leedy, P.D. & Ormrod, J.E. 2010. Practical research planning and design. 9th Edition. New Jersey: Pearson.

Lubin, A., & Feeley, C. 2016. Transportation Issues of Adults on the Autism Spectrum: Findings from Focus Group Discussions. Transportation Research Record, 2542(1):1–8. https://doi.org/10.3141/2542-0

Madlala, N. 2012. African primary caregivers understanding and experience of having a child with Autism. Pietermaritzburg: UKZN. (Dissertation-Masters).

Malik-Soni, N., Shaker, A., Luck, H., Mullin, A. E., Wiley, R. E., Lewis, M. E. S., Fuentes, J., & Frazier, T. W. (2022). Tackling healthcare access barriers for individuals with autism from diagnosis to adulthood. Pediatric Research, 91(5), 1028–1035. https://doi.org/10.1038/s41390-021-01465-y

Manouchka, J. 2019. Autism evaluation: a what to expect educational brochure. The State University of New Jersey. (Thesis – PhD).

Marshall, C. & Rossman, G.B. 2011. Designing Qualitative research. 6th edition. California: Sage publication.

Mithimunye, B.S, Roman, N.C., Pedro, A.S. 2018. Factors which enhance or hinder meeting the educational needs of autistic children in Western Cape Province, South Africa. A parent's perspective. International journal of special education, 3(2):279-294.

Monnapula-Mazabane, P., & Petersen, I. 2021. Mental health stigma experiences among caregivers and service users in South Africa: a qualitative investigation. Current psychology (New Brunswick, N.J.), 1–13. Advance online publication. https://doi.org/10.1007/s12144-021-02236-y

Mensing, R. 2010. Stigma reduction technique campaigns for practitioners in a rural community: mental health. Minnesota State University: Mancato. (Dissertation – Master of Social Work).

Merriam, S.B. 2009. Qualitative Research A guide to Design and implementation. 3rd edition San Francisco: Jossey – Bass, John Wiley and Sons.

Merriam, S.B. & Tisdell, E.J. 2016. Qualitative Research A guide to Design and implementation. 4th edition. San Francisco: John Wiley and Sons.

Modiakgotla, C. 2019. The support needs of primary caregivers caring for children with autism spectrum disorder, Department of health [Personal interview]. 9 May 2019., Kimberley.

Modula, M. 2022. The support needs of families raising children with intellectual disability. African Journal of Disability, 11. doi:https://doi.org/10.4102/ajod.v11i0.952

Montes, M., Menezes, A. Wehrmeister, F.C. et al. 2017. Adherence to inhaled therapies of COPD patients from seven Latin American Countries, The Lassyc study. Plos One, 12 (11). doi:https://doi.org/10.1371/

Murphy, T. & Tierney, K. 2006. Parents of children with Autistic Spectrum (ASD): A survey of information needs. (Report to the national council for special education research initiative).

Nassaji, H. 2015. Qualitative and descriptive research: Data type versus data analysis. Language Teaching Research, 19(2), 129–132. https://doi.org/10.1177/1362168815572747

Nevison, C., & Zahorodny, W. 2019. Race/Ethnicity-Resolved Time Trends in United States ASD Prevalence Estimates from IDEA and ADDM. Journal of autism and developmental disorders, 49(12), 4721–4730. https://doi.org/10.1007/s10803-019-04188-

Ntre, V., Papanikolaou, K., Triantfafyllou, K. 2018. Psychosocial and Financial Needs, Burdens and Support, and Major Concerns among Greek Families with Children with Autism Spectrum Disorder (ASD). International Journal of Caring Sciences, 11(2) 985-995.

Nyumba, T., Wilson, K., Dernick, J. 2018. Methods in Ecology & Evolution. The use of focus group methodology: Insights from two decades of application in conversation. Methods in Ecology, 9(1): 20-32. https://doi.org/10.111/2041-210X.12860

O'Brien, K.H. & Lushin, V. 2016. Parental mental health: addressing the unmet needs of caregivers for children with autism spectrum disorder. International Journal of Education, 55(12):4.

Onwuegbuzie, A. J. 2009. A qualitative framework for collecting and analysing data in focus group research: Sam Houston State University, Huntsville, Texas.

Ormandyova, R. 2022. Healthcare encounters for children with autism within various medical settings: planned medical visit and emergency setting. A Systematic Literature Review. School of education and communication (HLK) Jönköping University. (Thesis – PhD).

Ozbay, F., Johnson, D. C., Dimoulas, E., Morgan, C. A., Charney, D., & Southwick, S. 2007. Social support and resilience to stress: from neurobiology to clinical practice. Psychiatry (Edgmont), 4(5), 35–40.

Pandey, P. & Pandey, M.M. 2015. Research Methodology: Tools & Techniques. Bridge Center, Buzau.

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

Parvin, N., Haque, M. M., Bhuiyan, M. R., Haqe, M., Saha, P. K., & Islam, A. M. 2015. Knowledge on care of autistic child among the mother's attending Protibondhi Foundation, Dhaka. Bangladesh Journal of Medical Science, 14(2), 179–182. https://doi.org/10.3329/bjms.v14i2.21563

Patino, C. M., & Ferreira, J. C. 2018. Inclusion and exclusion criteria in research studies: definitions and why they matter. Jornal brasileiro de pneumologia: publicacao oficial da Sociedade Brasileira de Pneumologia e Tisilogia, 44(2):84. https://doi.org/10.1590/s1806-37562018000000088

Patterson, S.Y., & Smith, V. 2011. The Experience of Parents of Toddlers Diagnosed With Autism Spectrum Disorder in the More Than Words Parent Education Program. Infants & Young Children, 24:329–343.

Patton, M. Q. 2002. Qualitative Research & Evaluation Methods. 3rd ed. Thousand Oaks, CA: Sage.

Peteiro, M.F. 2018. Knowledge, skills and behaviours expected of adult care workers. UK. efaidnbmnnnibpcajpcglclefindmkaj/https://www.hoddereducation.co.uk/media/Documents/429116_U2_CG_L2_Adult_Care_01-22_286.pdf

Petersen, C. & Carlsson, E. 2021. Life with a stoma-coping with daily life: Experiences from focus group interviews. Clinical Nursing, 30(15-16):2309-2319. https://doi.org/10.1111/joen.15769.

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: the international journal of research and practice, 25(4): 1076–1089

Polaha, J., Williams, S. L., Heflinger, C. A., & Studts, C. R. 2015. The Perceived Stigma of Mental Health Services Among Rural Parents of Children With Psychosocial Concerns. Journal of pediatric psychology, 40(10):1095–1104. https://doi.org/10.1093/jpepsy/jsv054

Polit, D.F. & Beck, C.T. 2017. Nursing Research: Generating and Assessing Evidence for Nursing Practice. 10th ed. Philadelphia: Wolters Kluwer.

Provost, B., Lopez, B.R. & Heimerl, S.A 2007. Comparison of Motor Delays in Young Children: Autism Spectrum Disorder, Developmental Delay, and Developmental concerns. J Autism Dev Disorders. 37, 321-328. https://doi.org/10.1007/s10803-006-0170-6.

Punch, S., Graham, E. 2016. Interviewing Children at Home: Exploring the Use of Individual and Focus Group Interviews. In: Evans, R., Holt, L., Skelton, T. (eds) Methodological Approaches. Geographies of Children and Young People, vol 2. Springer, Singapore. https://doi.org/10.1007/978-981-4585-89-7_26-1

Rosland, A.M. 2009. Family involvement. Sharing the care: The role of family in chronic illness. California healthcare foundation. efaidnbmnnnibpcajpcglclefindmkaj/https://www.chcf.org/wp-content/uploads/2017/12/PDF- FamilyInvolvement_Final.pdf

Sampson, W.G. & Sandra, A.E. 2018. Comparative study on knowledge about autism spectrum disorder among paediatric and psychiatric nurses in public hospital in Kumasi, Ghana. Clinical Pract Epidemiol Ment Health, 30(14):99-108. https://doi.org/10.2174/1745017901814010099

Stats SA (Statistics South Africa). Consumer price index. (StatisticalreleaseP0141).https://www.statssa.gov.za/publications/P0141/P0141 October2022. pdf. Date of access: 7 February 2023

Sawatsky, A.P., Ratelle, J.T., & Beckman, T. 2019. Qualitative Research Methods in Medical Education. Anaesthesiology, 131(1):4-22. https://doi.org/10.1097/ALN.0000002728

Shattnawi, K.K., Saeed, W.M.B., & Al-Natour, A., et al. 2020. Parenting a Child with Autism Spectrum Disorder: Perspective of Jordanian Mothers. Journal of Transcultural Nursing, 32(5):474-483. DOI:10.1177/1043659620970634

Shattock, P. & Whiteley, P. 2002. Biochemical Aspects in Autism Spectrum Disorders: Updating the Opioid-Excess Theory and Presenting New Opportunities for Biomedical Intervention. Expert Opinion on Therapeutic Targets, 6(2):175-183. http://dx.doi.org/10.1517/14728222.6.2.175

Shivers, C.M., Sonnier-Netto, L., & Lee, G.K. 2019. Needs and Experience of family caregivers of individuals with autism spectrum disorders across the lifespan. Journal of Policy and Practice in Intellectual Disabilities, 16(1):21-29. https://doi.org/10.1111/jppi.12272

Simbo, C. 2012. Defining the term basic education in the South African Constitution: An International law approach. Law, Democracy and Development, 16:162-184. DOI:10.4314/LDD.V17I1.23

Smithson, J. 2000. Using and analysing focus groups: Limitations & possibilities. *International Journal of social research methodology*, 3(2):103-110.

Sood, A., Prasad, K., Chhatwani, L., Shinozaki, E., Cha, S.S., Loehrer, L.L., Wahner- Roedler, D.L. 2009. Patients' attitudes and preferences about participation and recruitment strategies in clinical trials. Mayo Clin Proc, 84(3):243-7. doi: 10.1016/S0025- 6196(11)61141-5

Springer, K. 2010. Educational research: A contextual approach. Wiley, Hoboken, NJ.ISBN: 978-0-470-13132-9.

Squibb, J.D., Davids, E. L., Harrison, A.J., Molony, M. A. & de Vries, P. J. 2019: Parent education and training for ASD: Scoping the evidence. Autism, 24(1):7-25. doi: 10.1177/1362361319841739

Streubert, H.J. and Carpenter, D.R. 2011. Qualitative research in nursing: Advancing the humanistic imperative. 5th Edition. Philadelphia; Lippincott.

Strydom, H., De Vos, A.S. & Delport, C.S.L. 2011. Quantitative data collection methods: questionnaires, checklists, structured observation and structured interview schedules. In: De Vos, A.S., Strydom, H., Fouche, C.B. & Delport, C.S.L. eds. Research at grass roots. For the social sciences and human services professions. 4th ed. Paarl: Paarl Print.pg. 198.

Strydom, H. & Delport, C.S.L. 2011. Sampling and pilot study in qualitative research. In: De Vos, A.S., Strydom, H., Fouche, C.B. & Delport, C.S.L. eds. Research at grass roots. For the social sciences and human services professions. 4th ed. Paarl: Paarl Print.pg. 398.

Tilahun, D., Hanlon, C. & Fekadu, A. et al. 2016. Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country. BMCHealthServicesResearch,16:152. DOI: https://doi.org/10.1186/s12913-016- 1383-9

Talley, R.C., Fricchione, G.L & Druss, B.G. 2014. The challenges of Mental healthcare giving. Research practice and policy. Georgia: Springer.

Tracy, S.J. 2013. Qualitative Research methods. Collecting evidence, crafting analysis, communicating impact. 1st edition. Wiley – Blackwell publication: John Wiley & Sons.

Ward, J.K., Comer, U. & Stone, S. 2018. On qualifying Qualitative Research: Emerging perspectives and the ‘’Deer’’ (Descriptive, exploratory, EU dictionary Repeat) Paradigm. Interchange, 49:133 – 146. https://doi.org/10.10007/sl0780-018-9313-

Wikipedia. 2022. Kimberley, Northern Cape. https://en.wikipedia.org/wiki/Kimberley,_Northern_Cape Date of access: 01 December 2022.

Wikipedia. 2023. Kimberley Map, Northern Cape. https://en.wikipedia.org/wiki/Kimberley,_Northern_Cape Date of access: 19 February 2023.

Wong, L. P. 2008. Focus group discussion: a tool for health and medical research. Singapore Med J; 49(3):256-261.

Yonkman, J., Lawler, B., Talty, J.L., O'neil, J., & Bull, M.J. 2013. Safely transporting children with autism spectrum disorder: evaluation and intervention. The American journal of occupational therapy, 67(6):711-6. https://doi.org/10.5014/ajot.2013.008250

Zeidan, J., Fombonne, E., Scorah, J., Ibrahim, A., Durkin, M.S. 2022. Global prevalence of autism: A systematic review update. Autism Research, 15(5), 778-190. https://doi.org/10.1002/aur.2696

Zimmerman, M.S., & Shaw, G. 2020. Health information seeking behaviour: a concept analysis. Health Information & Libraries Journal, 37(3):173-191. DOI: 10.1111/hir.1228

Zuckerman, K.E., Lindly, O.J., & Reyes, N.M, et al. 2018. Parents perceptions of community autism spectrum disorder stigma: Measure validation and associations in a multi-site sample. J Dev Disord, 48(9):3199-3200. https://doi.org/10.1007%2Fs10803-018- 3586-x

ADDENDUM A - PARTICIPANT INFORMATION LEAFLET

TITLE OF THE RESEARCH PROJECT: SUPPORT NEEDS OF PRIMARY CAREGIVERS CARING FOR CHILDREN WITH AUTISM SPECTRUM DISORDER IN KIMBERLEY.
REFERENCE NUMBER:

PRINCIPAL INVESTIGATOR: POPPY MATHANE

ADDRESS: University of Free State
205 Nelson Mandela Drive,
Park West, Bloemfontein
9301

CONTACT NUMBER: 051 401 7327 or 083 871 3293

Dear Participant

My name is Poppy Mathane and I am a student at the University of the Free State pursuing my Master's degree in Nursing Science (M. Soc.Sci). I would like to invite you to participate in a research project that aims to investigate the support needs of primary caregivers caring for children with autism spectrum disorders in Kimberley.

Please take some time to read the information presented here, which will explain the details of this project and contact me if you require further explanation or clarification of any aspect of the study. Also, your participation is **entirely voluntary** and you are free to decline to participate. If you say no, this will not affect you negatively in any way whatsoever. You are also free to withdraw from the study at any point, even if you do agree to take part.
This study has been approved by the **Health Sciences Research Ethics Committee (HSREC) at the University of the Free State** and will be conducted according to the ethical guidelines and principles of the international Declaration of Helsinki, South African Guidelines for Good Clinical Practice and the Medical Research Council (MRC) Ethical Guidelines for Research.

In South Africa, millions of children are diagnosed with ASD, however, only few professionals in the country can make a diagnosis. In Kimberley, no research has been done on the support needs of the primary caregivers caring for children with ASD.

I want to explore the support needs of primary caregivers caring for children with ASD in Kimberley. Focus group discussion will be conducted by me which will take 1 hour. You will be asked to describe support needs. You will not be exposed to psychological harm. Sensitive issues will be treated with care and respect. When counselling is needed you will be referred to the professional counsellor and will not be charged for the session. Your views and beliefs regarding needs will be respected. The results of the study will be presented in anonymous manner, i.e., without mentioning your name.

Confidentiality will always be maintained. If you request the results of the study, your request will be granted. You will benefit in knowing that your voice is heard and the Department of Health could use the recommendations to improve programmes that addresses the support needs of the primary caregivers in Kimberley.

Remuneration will not be granted but transport expenses and refreshments will be sponsored by me.

If you are willing to participate in this study, please sign the attached Declaration of Consent and hand in to Poppy Mathane.

Yours sincerely

……..

Poppy Mathane
Principal Investigator

ADDENDUM B - DECLARATION BY PARTICIPANT

By signing below, I.....agree to take part in a research study entitled **……...**

I declare that:

- I have read the attached information leaflet and it is written in a language with which I am fluent and comfortable.
- I have had a chance to ask questions and all my questions have been adequately answered.
- I understand that taking part in this study is **voluntary** and I have not been pressurised to take part.
- I may choose to leave the study at any time and will not be penalised or prejudiced in any way.
- I may be asked to leave the study before it has finished, if the researcher feels it is in my best interests, or if I do not follow the study plan, as agreed to.

Signed at (*place*) .....…….....……... On (*date*) ……...……... 20…...

.....

Signature of participant

ADDENDUM C - INFORMED CONSENT – FOCUS GROUP DISCUSSION

Dear Participant

I am a student at the University of Free State pursuing my Master's degree in Nursing Science (M. Soc.Sci). My research study title is: **SUPPORT NEEDS OF PRIMARY CAREGIVERS CARING FOR CHILDREN WITH AUTISM SPECTRUM DISORDER LIVING IN KIMBERLEY.**

The purpose of the research study is to describe the support needs of primary caregivers caring for children with Autism Spectrum Disorder, living in Kimberley.

I am trying to find out the primary caregiver's support needs of children diagnosed with Autism Spectrum Disorder in Kimberley. Focus group discussion will be held and conducted by me. The focus group discussion will last for one hour. During the focus group discussion, you will be asked to mention support needs. Thereafter, the discussion or opinions will be grouped and prioritized accordingly. All information will be handled confidentially/ secretly and will only be used for research purposes. The results of the study can be available on request to you, and you will also not receive any payment. Taking part is voluntary and can withdraw anytime.

Your participation will be much appreciated and valued. You may contact Ms Poppy Mathane, Cell no 0838713293, with further enquiries. If you are willing to participate, will you please complete the form below:

I.....am willing to take part in a focus group discussion describing the primary caregiver support needs of children with Autism Spectrum Disorder in Kimberley.

Signature of participant	**Signature of witness**
Date permission given	**Date permission witnessed**

ADDENDUM D - HOD SCHOOL OF NURSING

UNIVERSITY OF THE FREE STATE
UNIVERSITEIT VAN DIE VRYSTAAT
YUNIVESITHI YA FREISTATA

UFS·UV
HEALTH SCIENCES
GESONDHEIDSWETENSKAPPE

Idalia Loots Building
School of Nursing
27 April 2020

Dear Dr SM le Grange

Re: Ethics Application: Poppy Mathane (Master degree student) – Supervisor: R. Jansen and Co-supervisor: A Welman.

PROJECT TITLE: SUPPORT NEEDS OF PRIMARY CAREGIVERS CARING FOR CHILDREN WITH AUTISM SPECTRUM DISORDER IN KIMBERLEY

As the Head of the School of Nursing, I approve the candidate's proposal application to the Health Sciences Research Ethics Committee.

Yours sincerely

Prof Magda Mulder
Head: School of Nursing

ADDENDUM E - PERMISSION ETHICS COMMITTEE

Health Sciences Research Ethics Committee

28-Sep-2020

Dear **Mrs Poppy Mathane**

Ethics Clearance: Support needs of primary caregivers caring for children with Autism Spectrum Disorder in Kimberley.

Principal Investigator: **Mrs Poppy Mathane**

Department: School of Nursing Department (Bloemfontein Campus) APPLICATION APPROVED

Please ensure that you read the whole document

With reference to your application for ethical clearance with the Faculty of Health Sciences, I am pleased to inform you on behalf of the Health Sciences Research Ethics Committee that you have been granted ethical clearance for your project.

Your ethical clearance number, to be used in all correspondence is:**UFS- HSD2020/1116/2710**

The ethical clearance number is valid for research conducted for one year from issuance. Should you require more time to complete this research, please apply for an extension.

We request that any changes that may take place during the course of your research project be submitted to the HSREC for approval to ensure we are kept up to date with your progress and any ethical implications that may arise. This includes any serious adverse events and/or termination of the study.

A progress report should be submitted within one year of approval, and annually for long term studies. A final report should be submitted at the completion of the study.

The HSREC functions in compliance with, but not limited to, the following documents and guidelines: The SA National Health Act. No. 61 of 2003; Ethics in Health Research: Principles, Structures and Processes (2015); SA GCP(2006); Declaration of Helsinki; The Belmont Report; The US Office of Human Research Protections 45 CFR 461 (for non-exempt research with human participants conducted or supported by the US Department of Health and Human Services- (HHS), 21 CFR 50, 21 CFR 56; CIOMS; ICH-GCP-E6 Sections 1-4; The International Conference on

Harmonization and Technical

Requirements for Registration of Pharmaceuticals for Human Use (ICH Tripartite), Guidelines of the SA Medicines Control Council as well as Laws and Regulations with regard to the Control of Medicines, Constitution of the HSREC of the Faculty of Health Sciences.

For any questions or concerns, please feel free to contact HSREC Administration: 051- 4017794/5 or email EthicsFHS@ufs.ac.za.
Thank you for submitting this proposal for ethical clearance and we wish you every success with your research.

Yours Sincerely

Dr. SM Le Grange
Chair : Health Sciences Research Ethics Committee

Health Sciences Research Ethics Committee Office of the Dean: Health Sciences
T: +27 (0)51 401 7795/7794 | E: ethicsfhs@ufs.ac.za
IRB 00011992; REC 230408-011; IORG 0010096; FWA 00027947

Block D, Dean's Division, Room D104 | P.O. Box/Posbus 339 (Internal Post Box G40) | Bloemfontein 9300 | South Africa
www.ufs.ac.za

ADDENDUM F - PERMISSION LETTER FROM CEO (ROBERT MANGALISO SOBUKWE HOSPITAL)

DEPARTMENT OF HEALTH
LEFAPHA LA BOPHELO BO BOTLE
DEPARTEMENT VAN GESONDHEID
ISEBE LENKONZO ZENTLALONTLE

Robert Mangaliso
Sobukwe Hospital

Head Clinical Management: Medical

Du Toitspan Road
Private Bag X5021
Kimberley

Tel: 053 802 2147
Fax: 053 832 9435 /
086 617 4089

Reference / Tshupelo / Verwysings / Isalathiso :
Date / Leshupelo / Datum / Umhla : 2nd September 2020 Dr H Saeed

TO: Ms Poppy Mathane

RE: Permission to do research

Permission is hereby granted to conduct a medical research project at Robert Mangaliso Sobukwe Hospital, Northern Cape. Title proposed: "SUPPORT NEEDS OF PRIMARY CAREGIVERS CARING FOR CHILDREN WITH AUTISM SPECTRUM DISORDER IN KIMBERLEY"

Dr H Saeed
MBBS,H.Dip.Int.Med.(CMSA),M.Fam.Med.(UFS),
Specialist Family Physician, Affiliate Lecturer – UFS
Acting Head Clinical Management: Medical

02/09/2020
Date:

ADDENDUM G - PERMISSION LETTER FROM THE HEAD OF THE DEPARTMENT OF HEALTH (NORTHERN CAPE)

	DEPARTMENT OF HEALTH		**OFFICE OF THE HOD Executive Offices**
	LEFAPHA LA BOPHELO BO BOTLE		Northem Cape Department of Health Private Bag X5049
	DEPARTEMENT VAN GESONDHEID		KIMBERLEY, 8300 Tel: 053 830 2134
	ISEBE LEZEMPILO		Email: BMashute@ncpg.gov.za
Enquiries:		Date:	
Dipattisiso: Imibuzo: Navrae : Reference:	Mr. B Mashute	Umhla•.	10 September 2020
Tshupeio: Isaiathiso:	NC_202009 RPOOI		

Mrs. Poppy Elizabeth Mathane
Frances Baard Health District
119 Green Street
Kimberley
8301

Project Title: Support Needs for Primary Caregivers Caring for Children with Autism Spectrum Disorder in Kimberley.

Dear Mrs. Mathane

The application for gate-keeper's permission to conduct the above-mentioned research study at Robert Mangaliso Sobukwe Hospital was received and has been reviewed by the Northern Cape Department of Health.

Decision: Approval is granted to conduct this research study at Robert Mangaliso Sobukwe Hospital, jn Northern Cape Province.

Your Provincial Ethics Reference Number is NC_202009 RPOOI, kindly use that reference number in correspondence with the Provincial Health Research Coordinator.

Please note the following:

1. This approval is valid for a period of one year from the date of approval.
2. The researcher must request annual renewal of this approval and submit annual progress report to the Provincial Health Research Coordinator (BMashute@ncpg.gov.za).
3. The researcher is requested to make all the necessary arrangement with hospital CEO, before visiting the facility, to ensure that the provision of healthcare services is not affected when this project is conducted.

We are committed to achieving our vision through a ±cenmalized, accounEble, accessible and consändy improving health ere system within available resources. QJr aring multi-skilled, effecdve personnel use evidence-based informative heath care arW maturi parmerships for the benefit of our clients and paients-

Please note the following conditions:

1. This research project must be conducted at no cost to the Northern Cape Department of Health.
2. The approval is limited to the research proposal as submitted on the application.
3. There must be no modification or amendments on the research project.
4. The Research Unit may monitor this research project at any time.
5. At the completion of this research project, a copy of the final report must be submitted to the Research Unit.
6. The Northern Cape Department of Health Senior Management must be briefed on the outcome of the study prior publishing.

Dr Dion Theys
Acting Head of Department
Northern Cape Province
Department of Health

18/09/2020.
Date

ADDENDUM H - PROOF OF EDITING

WordHouse

To whom it may concern

2022-11-27

This letter confirms that the editing group, WordHouse, language edited the thesis:

Poppy Elizabeth Mathane

2010044697

SUPPORT NEEDS OF PRIMARY
CAREGIVERS CARING FOR CHILDREN
WITH AUTISM SPECTRUM DISORDER IN
KIMBERLEY

in accordance with the requirements in respect of the Degree

Master of Nursing

(MNurs)

At the Faculty of Health Sciences at the University of the Free State

Word House