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# An Interpretative Phenomenological Analysis of The Knowledge, Beliefs, and Coping Practices of South African Mothers Raising Children with Autism

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**KEYWORDS** Autistic Spectrum Disorder. Atypical Development. Low-and-middle Income Countries. Neurodevelopmental Disorders. Parenting. Psychosocial Support

**ABSTRACT** The study explored the knowledge, beliefs and coping strategies used by black South African mothers in raising a child with autism. Using a qualitative cross-sectional design, nine mothers of children with autism spectrum disorder or ASD were recruited through snowball sampling. The mothers' experiences were captured through individual semi-structured interviews and analysed through Interpretative Phenomenological Analysis (IPA). The findings revealed the mothers have a lack of knowledge about ASD. The majority of the mothers believed that autism was part of God's will or caused by spiritual witchcraft. The mothers relied on religious and spirituality to cope with the challenges of raising an autistic child. Spirituality is an important source of resilience that promotes acceptance among mothers' of children with autism. The support of other mothers was also found to be another source of coping. Understanding the mothers' experiences of raising a child with autism is important for the development and provision of psychosocial support.

## INTRODUCTION

Autism spectrum disorder (ASD) is a lifelong and complex neurodevelopmental syndrome with onset during early childhood (American Psychiatric Association 2013). It has a diverse etiology, which may be attributed to a complex interaction of genetic and environmental factors (Hus and Segal 2021). According to the International Classification of Diseases code's 10th revision (World Health Organisation (WHO) 2017; Diagnostic and Statistical Manual of Mental Disorders, 5th edition (DSM-5) by the American Psychiatric Association 2013), ASD is characterised by two distinct types of impairments, that is, firstly, social interaction and social communication deficits and, secondly, restricted, repetitive patterns of behaviour, interests or activities. These impairments are substantial obstacles to social participation and daily activities for children with ASD (Rios and Scharoun Benson 2020). The impairments typically occur prior to the age of three, (after 12 to 18 months of age) and are more likely to affect boys (WHO 2017). While ASD can occur on its own, evidence suggests that it can frequently co-occur with other neurodevelopmental disorders (NDDs) such as attention deficit/hyperactivity disorder (ADHD), intellectual disability, and seizures (Hus and Segal 2021).

The research suggests that ASD is common among children of many races, ethnicities, and social groupings (Masaba et al. 2021), as well as within and across geographical regions (Meiring et al. 2016). According to recent research, ASD rates are rising in both wealthy and developing nations (Zeidan et al. 2022). Current evidence suggests that ASD affects one out of every 100 children worldwide, with a male-to-female ratio of 4:2 (Zeidan et al. 2022). In Sub-Saharan Africa (SSA), ASD research is still scarce. Statistics derived from public health or education systems give proxy data on the population in the absence of epidemiological prevalence investigations in SSA (Pillay et al. 2021). A recent study conducted among a school based population in South Africa found that the male to female ratio was 5.5:1 (Pillay et al. 2021). In South Africa, it is predicted that over 270,000 people may have an ASD diagnosis, with over 5000 new cases every year (Van Biljon et al. 2015).

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The research showed that ASD continues into adolescence and adulthood, and it greatly impacts the independent functioning of a person (WHO 2017). ASD presents with a multitude of challenging behaviours that can hinder a child's social well-being as well as their education (Foo et al. 2015).The diagnosis not only impacts the individual diagnosed with ASD but it also has a significant impact on the primary caregiver; especially the mother, the family and the extended family in terms of their quality of life and psychosocial well-being (Bitsko et al. 2016). According to research conducted in other African countries, such as Kenya (Obaigwa and Cloete 2019) and Mali (Sangare et al. 2019), raising a child with autism is particularly difficult for families. A study done in Nairobi, Kenya found that mothers are more affected by the difficulties of raising an autistic child. According to the research, stigmatization causes many mothers of autistic children to suffer in silence and isolate themselves (Cloete and Obaigwa 2019).

It has been shown that a large amount of research on autism has predominantly taken place in developed countries and among middle-class white families (Hastings and Brown 2002; Wing and Potter 2002; Seligman and Darling 2007; Koegel and LaZebnik 2014). However, not enough is known about the experiences of caregivers of autistic children in South Africa or in other low-middle income countries (Bauer et al. 2022). Parents and caregivers of children with autism in developed countries have consistently reported significant levels of stress and caregiving challenges (Rios and Scharoun Benson 2020). These stresses range from emotional and financial stress, diagnosis challenges, difficult family adjustments, social life restrictions and concerns about the child's future. Furthermore, mothers raising children diagnosed with autism experienced financial burden, inadequate provision of health care and education, negative emotional well-being, stigma and social isolation (Gobrial 2018). The research showed that caregivers of children with ASD are burdened with a high level of responsibility and have an impaired quality of life (Ten Hoopen et al. 2021; Patel et al. 2022).

Even though some research has been conducted in developing countries (Gona 2017), there is still a lack of research on black African caregivers' experiences of raising children diagnosed with autism (Franz et al. 2017; Bauer et al. 2022). This study informed a broader project, which explored the lived experiences of black South African caregivers raising children with autism spectrum disorder. In this paper in-depth interviews were used to explore the knowledge, beliefs, and coping practices of mothers in order to better understand the psychosocial needs of families with autistic children. This will add to the existing body of knowledge and research on the impact of ASD on families, making more relevant and effective interventions possible.

### Research Objective

The objective of this study was to learn more about the knowledge, beliefs, and coping strategies of mothers who raise children with ASD.

### Specific Objectives

1. To describe the knowledge that caregivers have about ASD.
2. To describe the beliefs that caregivers' have about ASD.
3. To highlight the techniques caregivers use for coping with their children living with ASD.

### Research Questions

1. What kind of understanding do mothers have about their children's diagnoses?
2. What challenges do mothers of children with ASD experience and how do they cope?

## METHODOLOGY

### Research Approach and Design

A qualitative phenomenological perspective with an interpretative design steered the descriptions of the mothers' experiences of raising an autistic child. In qualitative research, participants are encouraged to give form and meaning to their experiences in their own words, resulting in a detailed narrative of what they experienced. Given the subjective and extremely personal nature of the mothers' experiences, a qualitative approach was considered appropriate for this study.

## Research Setting

The research was conducted in Tshwane Metropolitan Municipality, in the Gauteng Province, South Africa. Participants were recruited with the assistance of a local non-profit organisation (NPO) that provides support to caregivers of children with autism spectrum disorder in the Tshwane Metro.

## Participants and Sampling

A total of nine biological mothers who had children with a confirmed diagnosis of ASD between the ages of 4 and 11 years were recruited with via purposive and snowball sampling strategies. A local NPO that provides support services to families with an autistic child was contacted via an email to request the assistance with recruitment. Information about the study was provided to the NPO and they were requested to share the information leaflet with the families. Mothers who were interested in learning more about the study were able to send a 'Please Call Back' message or a WhatsApp message to the researcher who was then able to call the potential participant back. Only individuals who understood the nature of the study and were able to provide informed consent were included in the study. Each consenting participant was asked to share the research information with other potential participants. The sample size was determined by the theory of saturation (Wagner et al. 2012). Data saturation was reached at the ninth interview. Eligibility into the study included being biological mothers, raising a child with a confirmed diagnosis of ASD made by a medical professional such as a psychiatrist, psychologist, or pediatrician, and residing in Pretoria. Details of the participants are presented in Table 1.

## Data Collection Procedure

A semi-structured interview schedule was developed in line with the principles of IPA to extract themes of knowledge, attitudes and beliefs, coping mechanisms and challenges in families with a child with ASD. Data was collected through semi-structured interviews with the mothers, using open-ended questions to explore and gain a deeper understanding of their experiences. Interviews were conducted in a non-directive way at a date, time and place convenient to the participants to reduce any burden on the part of the participants. The participants were either interviewed at their homes or at their place of work, and the interviews lasted between 45 to 90 minutes. Each participant received a detailed explanation of the study's purpose in their preferred language, and interviews began only after each mother signed a written informed consent form. All the interviews were audio recorded with the permission of each participant.

## Data Analysis

The data was analysed using IPA with the aid of NVivo7 software. In preparing data for analysis, several tasks were undertaken. Firstly, all data from audio-recorded interviews were transcribed verbatim. Secondly, the researcher then translated the transcripts into English, as the transcription had been done first in the language that they were originally recorded in. To prevent loss of meaning during the transcription process and to preserve the informal style of the language, phras-

**Table 1: Socio-demographic characteristics of study participants**

| *Parent name* | *Employment status of parent* | *Child age and gender* | *Other disabilities present in the child* | *Birth order* |
|---|---|---|---|---|
| Participant 1 | Employed | 11-year-old boy | Visually impaired | Last of 3 children and only son |
| Participant 2 | Unemployed | 6-year-old boy | No | Last of two children |
| Participant 3 | Employed | 7-year-old girl | No | Only child |
| Participant 4 | Employed | 11-year-old boy | No | Second of 2 boys (both have ASD) |
| Participant 5 | Employed | 5-year-old boy | No | Only child |
| Participant 6 | Employed | 11-year-old boy | Epilepsy | Last born of 3 children |
| Participant 7 | Employed | 7-year-old boy | No | First of 2 children |
| Participant 8 | Employed | 11-year-old girl | No | Only child |
| Participant 9 | Employed | 4-year-old girl | ADHD | Only child |

es and expressions used by participants that held specific cultural meanings were retained. Finally, the researcher removed identifiers from the data to preserve participant anonymity. No names or forms of identification were used or mentioned during the process of transcription, and only pseudonyms were used.

In line with Interpretative Phenomenological Analysis (Osborn and Smith 2003) the following steps were used to analyse the data. The first author examined and coded all transcripts by noting salient issues emerging from the participant's lived experiences. This was accomplished by reviewing each transcript and making notes on the transcripts to find the commonalities and differences amongst the transcripts.

First, the first author transformed the notes into emerging themes. Subsequently, the emerging concepts were categorised to provide meaning to the participant's experience of the research topic. Each category was used to provide general descriptions of the shared experiences of the participants, and derive any overarching themes (Alase 2017).

Following this, the themes were linked in a meaningful way, by identifying main themes, and by linking all the sub-themes that emerged within each main theme, from the transcripts.

Thereafter, the second author and third authors were consulted to review the main themes and the sub-themes, with the identified themes further narrowed down, in order to improve the validity of the data analyses that followed. Disagreements were resolved through discussion among all three authors.

### Trustworthiness

To ensure credibility, rapport was formed and the use of paraphrasing of participants responses throughout the interviewing process. Open-ended questions with follow-up and clarifying questions were used. The data collecting techniques and procedures were defined in depth to ensure transferability. All interviews were audio recorded, and field notes were taken to ensure accuracy in data transcription. Initial codes were established by the first author and discussed and checked by the second and third authors before finalisation to guarantee confirmability during the transcribing process (Babbie and Mouton 2001).

### Ethical Consideration

The study received ethical approval from Sefako Makgatho University Research Ethics Committee (SMUREC/M/207/2018:PG). An information leaflet informing potential participants about the study was distributed after gaining permission from the NPO's director. All the participants who contacted the researcher provided informed consent. Issues of confidentiality and anonymity were discussed with each of the participants. Any identifiable information was removed and pseudonyms were used to protect the identity of the participants.

## RESULTS

The predominant themes that emerged were knowledge about ASD, mothers' explanatory models of the child's differentness, and challenges and coping strategies.

### Theme 1: Knowledge about ASD

The mothers expressed challenges with regard to inadequate knowledge about ASD.

#### *Mothers' Willingness to Exchange Health Information in Order to Improve ASD Awareness and Care*

The majority of the mothers expressed that there was a lack of information about ASD. As a result, some felt compelled to share their experiences in order to generate information to facilitate improving awareness of the disorder. This was highlighted by one of the participants who said, "*These people [caregivers of ASD] do not have information and they don't know, so it's my duty to make them aware of something called autism and that is what my child is suffering from.*" (Participant 1, mother's age 45 years)

While another said, "*I took part in this study because I felt it would be a great contribution in terms of giving insight to the study and raising more awareness about the illness.*" (Participant 9, mother's age 30 years)

#### *Lack of Understanding for What They're Dealing With*

As a result of lack of knowledge about ASD most of the mothers were unable to understand the behaviour of their children.

"*It's difficult because people don't understand, and they won't understand because they don't know the illness.*" (Participant 6, mother's age 51 years)

"*At first it was hard, like not knowing what you're actually dealing with.*" (Participant 7, mother's age 30 years)

### *Awareness of the Child's Differentness Early in Life*

Developmental difficulties were the main factors that contributed to their children's differentness. The majority of the mothers detected at different points that there was something wrong with their children's development, and many of them made the first observations about atypical development around the age of 18 months. While others noticed early atypical behaviours, for some mothers their children did not display any unusual behaviours associated with ASD that made them immediately suspect that their child might have ASD. As reflected in the following extracts.

"*He had an ordinary milestone like any other child until 18 months and started showing signs that I didn't know about.*" (Participant 1, mother's age 45 years)

"*I remember around age 1 he was still nonverbal, and I remember my mother making a comment like 'why is he not speaking he should be speaking by now'.*" (Participant 2, mother's age 36 years)

Furthermore, other mothers reported regression in communication and social skills in their children.

"*She was not adding more words to what she was already saying. And even the words that she had already started saying, kind of regressed.*" (Participant 9, mother's age 30 years)

"*I remember when she [my child] was 8 months she would even say Mama, you know. And she would pronounce the clicks sounds that babies make. I think when she was around 18 months, all that stopped and that is when I started panicking.*" (Participant 8, mother's age 35 years)

Lack of information regarding the condition, a lack of comprehension of their children's behaviour, and their children's uniqueness early in life all contributed to the mothers' perplexity and concern about what they saw as unusual development in their children.

## Theme 2: Mothers' Explanatory Models of the Child's Differentness

The mothers relied on multiple explanatory models for understanding illness regarding the cause of their child's disorder. For these mothers three explanatory models existed, namely, cultural, spirituality or religion, and biological causes.

### Bewitchment Related Attributions

#### *Supernatural Causes*

In this study, the mothers attributed the cause of the illness to supernatural cultural beliefs, believing that the ancestors are angry and that ASD is punishment for not pleasing them. In the following excerpt, mothers described their beliefs.

"*I did the rituals to appease the ancestors because I thought it was witchcraft.*" (Participant 6, mother's age 51 years)

"*I thought it was witchcraft, I cannot have two children with the same diagnosis, maybe somebody is bewitching me.*" (Participant 4, mother's age 38 years)

### Spiritual Involvement as a Possible Explanation

#### *Religion*

Most of the mothers had a strong reliance on Christianity, and this influenced their beliefs that God intended their children to have ASD.

"*I just said, you know what, God if this is you, it's okay.*" (Participant 5, mother's age 30 years)

"*He might have autism but he's just a gift as well.*" (Participant 1, mother's age 45 years)

"*Children are a blessing from God and when you have a child with special needs, it's more of a bigger blessing.*" (Participant 9, mother's age 30 years)

### Biological Understanding

#### *Birth Related Complications as Potential Causes*

The mothers also attributed the illness to biological causes. Perinatal factors such as the type of birth, baby delivery method, epidural anaesthesia and complications during baby delivery were reported as some of the causes of ASD.

"*I thought maybe those epidural needles, and everything caused my son to be autistic.*" (Participant 4, mother's age 38 years)

"*There was a little bit of delay…little bit of oxygen deprivation, that could have had a long-term effect on her.*" (Participant 9, mother's age 30 years)

### *Association of Child's Condition to Family History of Mental Illness*

Most of the mothers reported that their children's behaviour was consistent with their family history. Some of them believed that their children were genetically susceptible to ASD since their families had a history of mental illness such as depression and bipolar disorder.

"*We have a history of mental illnesses in the family. I have a cousin, who is battling with depression and bipolarity, and the closest link to me is my father who is bipolar… Maybe, it could have come out in a different way to my child and came out to her as being autistic.*" (Participant 9, mother's age 30 years)

"*We were a little bit concerned because in our family we have boys and they are generally slow with speech and everything, we thought maybe she's just one of those who are slow.*" (Participant 3, mother's age 34 years)

There is no doubt that culture, spiritual belief and biological factors influenced the caregivers' understanding of the causality of ASD in their children.

## Theme 3: Challenges and Coping with ASD

Having a child with ASD appeared to have a negative impact on the lives of these mothers and their extended families.

### *Disease Impact on Childbearing Plans in Families*

The mothers in this study recounted how their lives changed as a result of the diagnosis. As a result, most mothers were forced to make choices about how many children to have. Furthermore, some women expressed worry, concern and fear at the thought of having another child.

"*Raising my child has made me not want to have other children… I worry that I might get another child with autism.*" (Participant 8, mother's age 35 years)

"*I had hoped to have two kids, I still want to have two kids but because of her diagnosis and the fact that it's still relatively new and I am still trying to understand it, it has put those plans on hold.*" (Participant 9, mother's age 30 years)

### *Disease Impact on Sibling Relation and Child Rearing Practices*

Having a sibling with ASD, according to the mothers, had an impact on sibling relationships.

"*The 17-year-old brother is afraid of the younger brother.*" (Participant 4, mother's age 38 years)

In addition, the mothers reported that having an ASD child had an impact on their parenting relationship with their other children.

"*I have 3 kids, I felt guilty because I neglected the other kids, because my full attention was with him.*" (Participant 2, mother's age 45 years)

### *Disease Impact on Parental Relations*

Strain in relationships was reported by the mothers. Most of them reported problems with intimacy that led to breakdown in the relationship and in severe cases, even led to a divorce.

"*Having your partner blaming you and saying that you are the reason the child is this way.*" (Participant 8, mother's age 35 years)

"*It's a [strain…that is the reason why the relationship ended.*" (Participant 3, mother's age 34 years)

For most of the mothers, the child's diagnosis came with a cost to their relationships.

### *Resilience and Hopeful*

The mothers were able to cope and adjust to the stress caused by the child's ASD by reframing the difficult caregiving task into an optimistic circumstance.

"*My prayer and my hope is that he becomes more independent.*" (Participant 1, mother's age 45 years)

"*My hope is that she becomes an independent woman in a safe environment because she's a girl and she can't speak.*" (Participant 8, mother's age 35 years)

### *Seeking Support*

Despite the difficulties of raising a child with ASD, some mothers were able to seek help from other mothers of ASD children.

"*I shared my experience on our social support chat group…and I have learnt from other people's experiences, it has helped me a lot.*" (Participant 3, mother's age 34 years)

In addition to receiving support from other moms, the carers highlighted the help of other experts as well as some family and friends.

"*Her speech therapist is my support system.. . she has made herself available in order to support me.*" (Participant 9, mother's age 30 years)

"*The support system is great. His dad is very supportive and the people around us too. And my family, especially my younger brother. And with friends as well, they're very supportive and understanding."* (Participant 7, mother's age 30 years)

### *Religious or Spiritual Coping*

As coping mechanisms, the mothers turned to religious or spiritual resources. Positive religious appraisals and negative religious reframing, as follows.

"*Children are a blessing from God and when you have a child with special needs, it's more of a bigger blessing.*" (Participant 9, mother's age 30 years)

"*I just said, you know what, God if this is you, it's okay.*" (Participant 5, mother's age 30 years)

## DISCUSSION

The present study has sought to understand the knowledge, beliefs and coping strategies of black African mothers raising children with ASD. The study highlighted that mothers raising children with autism expressed concern about the shortage and unavailability of information about the illness, not only for themselves, but for the family members, as well as the broader community at large. This is in line with findings from earlier studies, which showed a paucity of ASD research studies in Africa (Shilubane and Mazibuko 2020; Pillay et al. 2021) since the majority of ASD studies were conducted in developed countries (Bauer et al. 2022).

In this study, the mothers' lack of autism knowledge made it difficult for them to understand the signs of ASD displayed by their children. This finding is consistent with prior research, which indicated that parents face several problems when they try to make sense of their children's atypical development (Matenge 2015). Caregivers of ASD children in Ethiopia (Zeleke et al. 2021), India (Tathgur and Kang 2021), Sri Lanka (Mahagamage et al. 2021), Yemen (Taresh et al. 2020), and immigrants in Canada, similarly to South Africa, lack knowledge regarding ASD. ASD has a wide variation in terms of features, severity, and developmental outcomes, and presents with a multitude of challenging behaviours (Foo et al. 2015; Shanmugarajah et al. 2022). The current findings reveal that the majority of mothers, regardless of their socioeconomic or educational level, expressed a lack of knowledge regarding the signs, symptoms, features, and presentation of autism, a conclusion supported by earlier research (Tathgur and Kang 2021). Due to a lack of knowledge concerning ASD, most of the mothers in this study found their children's behaviour confusing and difficult to understand, which is consistent with earlier studies conducted in South Africa (Shilubane and Mazibuko 2020) and India (Shanmugarajah et al. 2022) and Kenya (Obaigwa and Cloete 2019). This is also a finding echoed among African populations living in the USA and UK (Papoudi et al. 2020). As this current study demonstrated, the lack of knowledge of ASD is associated with considerable difficulties in managing the condition. Similar to Tathgur and Kang (2021) and Mthimunye (2014), lack of knowledge may contribute to the delay in time it takes for parents to recognise the problem and seek the help for their autistic children.

In this study the absence of available knowledge about the condition compelled the mothers' to seek out ways to generate knowledge on this condition. This is evidenced through their proactiveness in seeking out and connecting with other parents with similar challenges, and their willingness to generate knowledge on the condition by participating in research and creating awareness of autism (Gentles et al. 2018).

The explanatory models of ASD for the mothers is in this study related to supernatural spiritual or religious, and biological causes. The supernatural explanations are rooted in their culture.

This finding echoes Bakare et al. (2009) that reported that African communities attribute the aetiology of autism to supernatural causes. Consistent with the African conceptualisation of illness to external supernatural forces or "*ukufa-kwa-Bantu*" (Mthombeni and Nwoye 2017: 102), the mothers reported experiences wherein they believe that the ancestors are angry, and view ASD as a punishment for not appeasing their ancestors. Similar findings were reported in Guler et al. (2018), highlighting that in the black African culture, illness diagnosis such as autism may reflect communication from the ancestors or hints of others' jealousy. Therefore, as demonstrated in this study, it is not uncommon for black African families with children diagnosed with autism or any other illness to seek out traditional healing systems before consulting Western medicine (Nwoye 2017). Studies from Mali (Sangare et al. 2019), Kenya (Cloete and Obaigwa 2019), and Senegal (Cardon and Marshall 2020) found that caregivers sought out treatment that ranged from consulting with traditional healers and spiritual healers before turning to more conventional medical treatments as a last resort. Supernatural powers attributed to acts of witchcraft, black magic, or curse are prevalent, suggesting a cultural understanding of ASD. Findings were reported in a study from Nairobi, where participants' groups believed that ASD was caused by women's historical cultural transgressions or by marriage to members of particular taboo tribes (Cloete and Obaigwa 2019). Similar findings were reported in a research study conducted among Muslims in Yemen, ASD is the consequence of a curse brought on by the evil eye of earlier misdeeds committed within the family. Teachers reinforced these misunderstandings among caregivers, according to Taresh et al. (2020), and actively advised families to seek out traditional healers, shamans, and religious healers instead of medical help. This highlights the importance of not only culturally informed research on ASD, but interventions that incorporate culturally sensitive and competent practices that reflect African and other traditional families' understanding of ASD.

Consistent with previous research (Cloete and Obaigwa 2019), spiritual or religious beliefs and spiritual values were accounted as another explanatory model of understanding a child's diagnosis of autism. This study found that some mothers related the child's diagnosis to an act of God's blessing. Similar to these findings, Jegatheesan et al. (2010), found that South Asian families in the United States viewed their children's diagnosis as a gift and felt blessed by God. Similar findings were echoed in Heidary et al. (2015) among Iranian families with children with autism. Iranian mothers felt closer to God after giving birth to a child with autism, while others explained the child's autism as a source of blessing and goodness in their lives (Heidary et al. 2015). For mothers who believed that the disability is of God, whether as a gift or punishment, was a means to forming a deeper connection with the deity (Tan et al. 2011).

Similar to Gona et al. (2015), as cited in Franz et al. (2017), perinatal difficulties such as birth complications were also reported as a cause of autism. For some mothers in this study their child's behaviour resembled that of other family members, which made them consider a possible hereditary disease in the family, a finding previously reported (Mercer et al. 2006).

The diagnosis of ASD has an impact on all family relationships, including marital and dating relationships, as well as those with non-autistic children (Angell et al. 2012; Karst and Van Hecke 2012). Similar to previous research, the findings of this study showed that a child's diagnosis of autism presents major difficulties for the family system (Hartley et al. 2009; Reddy et al. 2019). In this study, caregivers reported breakdown in the spousal relationship and/or divorce amongst parents of children with ASD. This is due to various factors like the demand for caregiving, feelings of blame causing one partner to be emotionally distant or absent, thereby neglecting their spousal relationship and focusing more on their parental relationship (Chan and Leung 2020).

In this study, having the support of other mothers was important for managing everyday challenges in caring for their children. This is not a unique finding since previous research showed that mothers of ASD children viewed support from other parents as significant owing to the similarities and uniqueness in their experiences (Leggett 2015). Parental support groups offer mothers of autistic children the tools to manage the daily difficulties and achieve goals in dealing with very challenging behaviours (Heidary et al. 2015). Similar to Mount and Dillion (2014), the mothers reported that seeking out the support from other

mothers helped them better manage the challenges since they shared experiences with others in comparable circumstances.

Caregivers who are raising a child with ASD frequently use religion or spirituality as a coping tool (Pearson et al. 2022). Importantly, for the mothers in this study having a relationship with God was deemed a valuable source for coping with an autistic child. Some of the mothers mentioned that raising children with autism was God's will, while others viewed their children as gifts or a blessing from God. This finding is in line with previous research (Jegatheesan et al. 2010; Gobrial 2018; Gona et al. 2017). The mothers reframed the experience of raising a child with ASD as positive thinking, which assisted the mothers to accept their reality, better manage daily routines and cope better (Ekas et al. 2019; Pearson et al. 2022). As in the current study, Indian moms thought that faith and religious practices had a substantial impact on the well-being of their ASD children (Shanmugarajah et al. 2022). The improvement of their children's behaviour was connected to their mothers' prayers. The religious reframing provided the mothers with strength and encouragement that they can take care of their child with ASD. Historically religious coping has been used as an easily accessible and cost-effective tool to deal and adjust to stressful and challenging circumstances (Pearson et al. 2022). It is critical for healthcare providers to comprehend what mothers of autistic children attribute to their parenting experience as a means of enhancing psychosocial support interventions.

## CONCLUSION

This study adds to the knowledge of South African mothers' experiences caring for children with autism spectrum disorders. The findings reveal that a lack of understanding of ASD remains a significant obstacle. Mothers have a variety of explanations for their autistic children's behaviour, with supernatural beliefs such as witchcraft or black magic, as well as religious attributions, being prominent sources. This is owing to the paucity of information about ASD. Religion was recognised as an integral part of the spirituality of mothers and a vital method of coping with the daily difficulties and challenges of raising a child with autism.

## RECOMMENDATIONS

If anything, these findings emphasise the need for increased public health awareness and policy responses to address health disparities and access, which disproportionately affect underserved groups. As a result, the researchers advocate a collaborative effort among numerous stakeholders, including families of children with ASD, health professionals, traditional or religious leaders, and government officials, to promote awareness and enact policy. The researchers recommend that the Department of Health and Social Development initiate large-scale public awareness initiatives aimed at increasing ASD knowledge at the community, regional, provincial, and national levels, as a first step. Information on where parents, particularly mothers who are the primary caretakers for children with autism, may get relevant information about treatment, support, and educational resources should be made public. The findings of this study can educate healthcare practitioners about mothers' explanatory models and aid them in developing culturally and contextually sensitive and appropriate therapies and practices to support families with an ASD child. The coping strategies adopted by the mothers in this study can be used to improve current health practices and promote evidence-based practices. Universal Health Coverage (UHC), as promoted by the World Health Organization, is suggested at the policy level. Childen with ASD should have access to rehabilitative health services they need. With UHC coverage, these services will not put the user and their families at risk of facing financial hardship.

## LIMITATIONS

Firstly, the sample size was relatively small and limited to the City of Tshwane, Gauteng Province. Secondly, the study was limited to Black South African caregivers and this might not be generalisable to other race groups and other African families. Lastly, the exclusion of fathers' participation was another limitation in the study. Therefore, the results of the study cannot be generalised for a larger population.

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