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Original Article

Understanding autism spectrum disorder and coping mechanism by parents: An explorative study

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ABSTRACT

Objective: This study aimed to explore the perceptions of parents of children with autism spectrum disorder (ASD) and their coping strategies.

Methods: The data of the study was collected using face-to-face semi-structured interviews. The participants were purposefully selected from the three schools in Mpumalanga Province because they had children diagnosed with ASD and data was analyzed using thematic content analysis. In this study, primary caregivers were selected. In the end, 12 women were interviewed, and the data saturation was reached. Ethical considerations and measures to ensure trustworthiness were carried out throughout the study.

Results: The findings revealed two themes: caregivers' understanding and misconceptions of ASD and coping mechanisms used in dealing challenges of caring for a child with ASD; and five subthemes: lack of knowledge, cultural beliefs, prayer, strong support system, and acceptance.

Conclusion: Based on the findings, more awareness campaigns should be done on ASD to increase parents' understanding of the condition. Understanding the cultural beliefs of parents regarding ASD may assist health care professionals in developing care practices that are accepted in their culture, and may enhance parents' coping skills.

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What is known?

- This study echoes with the findings of the existing literature that parents of children diagnosed with autism spectrum disorder (ASD) lacked information about the condition.

What is new?

- The study revealed three unique findings surrounding the parents of children with ASD in South Africa. Firstly, parents were struggling to understand ASD and associated it with witchcraft. Their explanations are rooted in their culture among the unknown features that surround ASD. Thus consulted traditional healers first before western medicine. Secondly, most parents received support from friends and support groups than from

family members. Thirdly, the current study found that parents used acceptance as a way of coping, unlike their counterparts who used prayer.

1. Introduction

Autism spectrum disorder (ASD) is a condition that can be stressful for both the parents and the child, more especially the parents. It represents a group of neurodevelopmental disorders marked by impairments in communication, social functioning, and distinctive patterns of behaviors with onset during the early stages of development [1,2]. Furthermore, the indications are that children diagnosed with ASD have a predisposition to other mental difficulties and co-morbidities.

The global prevalence of ASD has dramatically increased over the past years, and it is regarded as the most common developmental disorder [3]. According to Kincaid et al. [4], “the prevalence of autism spectrum disorder is estimated to be one percent of the population”. However, Poovathinal et al. [5] contended that an

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epidemiological survey carried out in several countries across the globe to determine the prevalence of ASD estimated it to be 61.9/10000.

Although WHO [6] urges member states to promote sharing of best practices and knowledge about ASD and other developmental disorders, research demonstrates that knowledge of ASD is lacking as demonstrated by UK parents who found it difficult to reconcile having a child with ASD [7]. Similarly, a study of USA college students' knowledge and attitudes towards students on the spectrum demonstrated negative attitudes toward participating in university and classroom-based activities with students with ASD [8]. A study of family perceptions of ASD in China found that a large proportion of caregivers had limited understanding of ASD, and several misconceptions were evident including self-blame for their child's condition [9].

The incidence of ASD in African countries is unclear, making it difficult to estimate the number of children with ASD in both low- and middle-income countries. There still minimal knowledge of and awareness about ASD, which leads to late diagnosis [10]. According to Chambers et al. [11], there are no current studies on ASD in South Africa due to the lack of standardized screening and diagnostic tools. Further, resources for diagnosis and intervention in South Africa are often scarce or not available at all due to the absence of knowledge among healthcare professionals, caregivers, and communities at large [3].

Little is known about the condition because there is no data on the incidence of those children diagnosed with ASD in the study area. There is a lack of knowledge and understanding of ASD in communities, especially African communities. Some still believe that ASD only occurs among western communities and is caused by witchcraft [12]. Many parents do not know about ASD, and this is a growing concern. Similarly, healthcare facilities lack significant numbers of trained professionals who could provide care and support to parents upon diagnosis [12].

Parental beliefs on ASD impact their intervention choices [13]. Parents' beliefs about ASD shape their explanations of the condition, the time taken to seek help, and the type of help they choose for their children [14]. A study conducted in the USA among parents of children with ASD found that higher levels of spirituality were associated with viewing their child as providing a positive contribution to the family [15]. Thus, the current study aimed to explore the parent's understanding and the techniques they used for coping with their children diagnosed with ASD.

Many parents and caregivers of children diagnosed with ASD suffer from stress. Some stressors highlighted in the literature include tension, social isolation, financial burden, lack of family support, and the unavailability and accessibility of services [16,17].

2. Methods

2.1. Research design

Qualitative research using a phenomenological approach was conducted. Using explorative, descriptive, and contextual designs, the understanding of parents regarding ASD and their coping strategies in one district of Mpumalanga Province were explored. This approach enabled the researchers to gain a more in-depth insight into this phenomenon. Furthermore, it provided an opportunity to probe and observe non-verbal communication cues from the participants during the interviews [17].

2.2. Participants and sampling procedure

The study population comprised of parents of children with ASD. Three schools were selected because they admitted children

with various disabilities including ASD. The participants were purposefully selected from the three schools because they had children diagnosed with ASD. All fifteen parents were invited to participate in the study and none of them refused. Participants were eligible for inclusion if they were female and their children were 5–12-year-olds, and resided in the study area in Mpumalanga, South Africa. The rationale for choosing female is that they are the primary caregivers.

2.3. Data collection

Data were collected using face-to-face semi-structured interviews utilizing an interview guide that covered the biographical data, knowledge, and coping strategies of the parents of children diagnosed with ASD. The interview guide was developed in English, then translated into SiSwati language to accommodate those participants who do not understand English. It was pre-tested among parents of a similar background to the participants. Participants were SiSwati and English speaking, but data was collected in English since all of them could understand the language. The interviewer obtained their informed consent before commencing with the interviews. Appointments detailing venues and times were made. The interviews which lasted between 45 and 60 min were conducted by the second author between July and August 2018. Participants permitted the use of a voice recorder to record the interviews. The interviewer, a female who recently completed an honours degree in social work psychology and a master's student in Public health, took notes during the interviews. In the end, 12 women were interviewed, and the data saturation was reached. Participants and the interviewer have not related in any way.

2.4. Data analysis

The data were analyzed thematically by the researchers following the verbatim transcription of the interviews. The data were managed with a qualitative data management software NVivo (Version 12) using a general inductive approach. The predefined themes were explored and an inductive process was used to derive subthemes from the main themes. As coding occurred, a 'tree structure' was generated in which themes and subthemes were linked to one another. The interviewer went back to the participants to provide feedback about preliminary findings and securing their reaction. Verbatim expressions of participants supported the subthemes.

2.5. Trustworthiness

Trustworthiness was maintained throughout the study by using the four concepts from Maree [18]. The researcher paraphrased the participants' responses to ensure credibility and also built a relationship based on trust with the participants and created a safe and familiar environment. The researcher asked follow-up questions and sought clarity from the responses and briefly described the data collection method to ensure transferability. Also, the use of field notes when transcribing data and a voice recorder ensured the accuracy of the material. The researchers compared the findings of the study with existing literature to ensure confirmability.

2.6. Ethical considerations

Ethical approval was obtained from the University of Venda Ethics Committee (Project no: SHS/18/PH/08/1505). The Mpumalanga Department of Education permitted the study. Participants were fully informed about aspects of the study in the information letter before they consented to participate in the study. They were

assured that any information shared would not be identifiable as pseudonyms would be used. Participants were notified that they could terminate the process at any stage of the interview if they were uncomfortable.

3. Results

3.1. Participants' demographic information

A total of 12 participants were interviewed of which ten were the biological parents of the children diagnosed with ASD and two were adoptive parents. The table below illustrates the demographic information of the participants. Ten participants were African and two White women aged from 25 to 49 years. Participants were from low- and middle-income families. Their marital status ranged from single, married, and divorced (Table 1).

3.2. The themes and subthemes

3.2.1. Parents' understanding and misconceptions of autism spectrum disorder

Autism spectrum disorder is still a misunderstood condition and parents and communities at large still lack knowledge about ASD. Parents are often not informed about the disorder until the day of diagnosis and some experience confusion even after diagnosis. Their knowledge, understanding, and how they view autism differs from one caregiver to the other. However, most of them in the current study communicated that it is a developmental disorder. Some still struggled to understand it and lacked information about the condition. A few participants believed that ASD is associated with witchcraft or black magic because they mentioned that their children developed well during the first year of life, then changed. The subthemes identified under this theme are the lack of knowledge and cultural beliefs discussed below.

3.2.1.1. Lack of knowledge. When asked about their understanding of ASD, parents showed little knowledge as demonstrated by their explanations. Some mentioned that they still have no idea what ASD is, even though they have children on the spectrum. The following quotes indicate the lack of some of the parents' knowledge of ASD.

"Uh, when it comes to autism, I don't have much information but what I know is that most of the children who suffer from autism struggle a lot when it comes to speech and they also don't see things the way we see them, like everything around them is loud. That's what I understand about autism." (Participant 7)

"Autism ... what I understand about it, is that we had a bond with the child, I didn't know about autism. I still can't describe it." (Participant 2)

3.2.1.2. Cultural beliefs. Two participants expressed the view that they understand ASD as being something to do with witchcraft because they had watched their children developing well during the first year of their life, then everything changed. Therefore, they associated these changes with witchcraft. They also indicated that they had taken their children to sangomas and traditional healers to seek help as supported by the following statements.

"Uh ... autism ... I think sometimes it has a lot to do with witchcraft because my child, at first, he was talking but after two years he stopped talking, so I thought maybe he was bewitched, hence I took him to almost every sangomas in my area and even outside my area ..." (Participant 1)

"Eish ... uh I was hurt because this is my child and I want the best for her in life, it was difficult; I didn't take it well, I even took her to several sangomas, as I thought maybe she's bewitched because it is not normal for a child to just stop doing things she used to do before ..." (Participant 2)

3.2.2. Coping mechanisms used in dealing with challenges of caring for a child with an autism spectrum disorder

Participants in this study mentioned prayer and going to church as an essential aspect of their lives when it comes to coping and dealing with the challenges of caring for a child with ASD. Further, they stated that communicating their problems to God gives them hope that everything will be fine. The participants reported that having family, friends, and professionals that understand their situation helps them to alleviate the related stress; therefore, they cope well with their challenges. Lastly, they stated that accepting their children's situation is the best they can do and important when it comes to coping.

The subthemes are discussed as follows.

3.2.2.1. Prayer. Prayer could be considered as the core of faith and for many a helpful coping strategy. Parents in the current study reported that prayer helps them in times of distress and to manage the challenges of raising and caring for the child. Having faith in God is the strategy they use to cope with their children diagnosed with ASD. They stated that God knows best, so they leave everything in God's hands and hope for the best. This is evident in the following quotes.

"... praying a lot helps, sometimes you just reach a point where you have to understand that whatever situation you are facing is not a surprise to God, as He knew that it was going to happen in your life and he's got a better plan for you. I always put my trust in God." (Participant 2)

"I believe that when you raise an autistic child, you should treat them normally and also pray. God helped me a lot when it comes to raising the child. So, prayer helped me a lot to cope with and deal with this condition." (Participant 7)

Table 1
Participants' demographic information.

No	Age	Marital Status	Education	Occupation	Relationship with the child
1	38	Single	Diploma	Sensory therapist	Mother
2	48	Divorced	Matric certificate	Buyer	Mother
3	48	Married	Honours' degree	Teacher	Adoptive mother
4	25	Single	Diploma	Administrator	Mother
5	32	Married	Diploma	Information technology specialist	Mother
6	49	Single	Bachelor's degree	Teacher	Mother
7	36	Married	Advanced certificate	Teller	Mother
8	32	Single	Matric certificate	Unemployed	Mother
9	47	Married	Bachelor's degree	Teacher	Mother
10	32	Married	Matric certificate	Unemployed	Adoptive mother
11	29	Single	Matric certificate	Unemployed	Mother
12	38	Single	Grade 11	Domestic worker	Mother

3.2.2.2. Strong support system. Most of the participants mentioned that a strong support system helps to relieve stress. The participants indicated that support from family, friends, and professionals such as teachers and healthcare professionals are effective means of coping with difficulties. These statements are illustrated by the following.

“... my family also, when I need something I know I can go to them and ask for help, and when I just need to be away from my child because sometimes it becomes too much for me I know I can send him off to my sister and she can take care of him because she works with children with special needs and that makes me feel like I'm not abandoning him, but I'm just taking out time for myself.” (Participant 10)

“... so I also have my friend who is a colleague and a teacher, so she loves my child so I can say he's got a second mother with her so most of the time when I have to go on workshops or when I want to have my time she offers to take my child and be with him, and other three colleagues can help me with my child, and he's very comfortable with them that also helps me to cope.” (Participant 12)

“Currently, there is a group on WhatsApp wherein his teacher added me, so they share challenges that they come across, and whenever they have a discovery of some sort about autism they share on the group.” (Participant 7)

“... but now that I get support from the school it's better. I also attended support groups at the hospital, and that helps me to understand that he's not the only one and that he has improved in a lot of things and that he can do most of the things by himself...” (Participant 4)

3.2.2.3. Acceptance. The participants reported acceptance of the child with ASD as a way of coping with the challenges. The participants said that as soon as they start to accept their children as they are, the better they deal with their children's conditions. This is evident in the following statements.

“Accepting that he's different but most importantly knowing that he's your child at the end of the day even if he was an able child, he will still need your guidance. You must also accept that they are not going to excel in everything they will still need you to hold their hand.” (Participant 8)

“Hmmm, now it's not much of stress because I think we have accepted him the way he is so it's more or less like we ok.” (Participant 6)

4. Discussion

This study explored the understanding and coping strategies of parents with children diagnosed with ASD in one district of Mpumalanga using individual face-to-face interviews. The findings show that parents have little understanding of ASD, despite their children being diagnosed with the condition. This absence of information about a condition, in this case, ASD, is acknowledged as associated with significant problems in managing the situation as seems to be illustrated in the current study. Furthermore, inadequate knowledge may contribute to the delay in parents identifying the problem and seeking services for their autistic children. Statements during the interviews indicate that some parents realized there was a problem when their children started to regress after two years. The current findings reveal limited knowledge about autism, which is in line with the findings of studies conducted by Campbell et al. [19], Simmons [20] and Rakap et al. [21] who found that parents of children with ASD had little understanding about its symptoms and features. Furthermore, Madlala [22] reported an absence in knowledge about ASD among parents, communities, and health care professionals, especially general practitioners as compared to psychiatrists. Similarly, Mthimunya [12] also reported

that some parents are not adequately informed about ASD and had never heard of it until the day of diagnosis as seen in these findings when some parents indicated that they did not know or understand ASD completely.

It is not clear what exactly contributed to this lack of knowledge among parents in the current study; whether it was due to the lack of knowledge among health care providers or information not disseminated as indicated in one study conducted in the USA [23].

The current findings demonstrate that some parents viewed autism as related to witchcraft. Their explanations are rooted in their culture among the unknown features that surround ASD and require attention and understanding. The available data indicates that parents from different cultures have different ideas about ASD [24]. Health care professionals must acknowledge the significance of these cultural views concerning ASD, and this may assist them to interact with these families. This highlights the need for health care professionals and other support services for children with ASD to be aware of the different beliefs held by the parents and achieve practices that are sensitive and culturally competent. In the African culture, a child diagnosed with ASD may be linked to a potential message from their ancestors or sign of lack of goodwill from their neighbors. Therefore, they seek traditional healing systems. This is consistent with Madlala [22] and Ruparelia et al. [25] who reported that some parents regard ASD as having supernatural causes precipitated by angered ancestral spirits, sinful wrongdoing or actions of the devil. Also, in the African culture, it is usual for children to be taken to the traditional healers first, before seeking medical assistance, and consequently, delaying the diagnosis.

Similarly, some parents in the current study denied their child's diagnosis of ASD citing witchcraft or black magic, which is in line with the findings of Guler et al. [26]. One participant observed a child growing normally and starting to communicate, but after two years he regressed and could no longer speak while the other witnessed a child who just stopped doing things she used to do. Both of these instances raise suspicions in parents who are not informed. It is not surprising to hear that some parents took their children to sangomas in their search for answers, as no one provided them with explanations for the abnormal behavior and changes they observed in their children.

Parents relied on prayers to deal with everyday challenges in caring for their children. For them, it was God first. Prayer helped some parents to easily accept their children's condition. According to them, everything happens for a reason, and God knew it would happen to them and made a plan beforehand. The findings are not unique to other studies that reported parents relied on religious practices such as attending church and seeing their spiritual leaders cope with their children's condition; some said that it helps them to understand and accept the child [22,27]. Similarly, Simmons' [20] study on the perceptions of wellbeing and coping mechanisms of caregivers of individuals with autism found that faith was a critical factor relied upon by some parents for the strength to continue to provide care for their children. One can conclude that these parents relied on prayers and hope instilled by their religious faith to enable them to accept their children's condition.

The support of family, peers, and school plays a crucial role for parents to assist them in dealing with the challenges of caring for their children with ASD. Family is the first support system that a person needs to remain strong, physically, and emotionally. Therefore, parents of children with ASD need support from the family members to enhance their emotional wellbeing, which in the current study was reported to be lacking. Reliable support systems are critical in reducing the adverse psychological effects which might occur in caring for a child with ASD. The findings in Hoffman's study indicated that a strong support system is crucial and an integral part of the coping milieu [28]. Mount and Dillion

[29] demonstrated that parents reported that support groups help them manage the challenges more successfully because they can share their experiences with others in the same situation.

Other work similarly explored how mothers of children diagnosed with ASD manage their situations. In the current study, we found that parents used acceptance as a way of coping. Once they accepted their children as a gift from God, they were happier. Also, they accepted the diagnosis without question, which made their lives easier. In contrast, DePape and Lindsay [1], Mount and Dillion [29] and Reddy et al. [27] demonstrated how parents of children with ASD used prayer to cope with daily lives.

5. Limitations of the study

The research study only focused on female parents. It would have been ideal if male parents were also interviewed; they could have brought a different opinion about the child's disease. This would have made the study findings more representative and generalizable to a broader population. Furthermore, the researcher only interviewed participants from one district and excluded those not in the region.

6. Recommendations

The study findings illustrate the limited knowledge surrounding ASD among parents and the community at large. Therefore, this research recommends that the Department of Health develops targeted ASD public awareness campaigns to increase knowledge about the condition. Parents need more information regarding the range of interventions and educational programs available for their children. The current findings can assist practitioners to learn about ASD and develop culturally relevant practices that are evidence-based. Furthermore, understanding misconceptions build a structure for campaigns to address these misunderstandings. Various social media platforms such as radio, television, pamphlets, and websites can help to disseminate information on ASD from health care professionals. The current coping strategies used by parents can be enhanced, and new evidenced-based methods introduced.

7. Conclusion

This research increased our perception of parents' understanding of ASD and coping with a child diagnosed with ASD. Parents know very little about ASD. Some parents still believe that a disorder like ASD can be caused by witchcraft and took their children to traditional healers seeking help. The information from this study may benefit parents of children with ASD and inform health professionals who provide services to children with ASD and their families. Awareness campaigns may assist in empowering parents and the community at large. Furthermore, understanding the beliefs of parents regarding ASD may assist in developing the culture-specific intervention.

CRedit authorship contribution statement

Nomfundo Mazibuko: Conceptualization, Methodology, Software. **Hilda Shilubane:** Conceptualization, Software, Writing-Original Draft, Writing - Review & Editing.

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Declaration of competing interest

The authors have no conflict of interest to declare.

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Appendix A. Supplementary data

Supplementary data to this article can be found online at <https://doi.org/10.1016/j.ijnss.2020.08.003>.

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