

Caring for Children Diagnosed with Autism Spectrum Disorder: Caregivers' Experiences

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Abstract

Although awareness about autism has increased in developed countries, more so than in developing countries, autism spectrum disorder (ASD) remains poorly understood by most South Africans, especially those in remote areas and in areas where research is limited. Furthermore, intervention services are often scarce or not available due to lack of knowledge amongst healthcare professionals. The current study aimed to explore caregivers' experiences of children with ASD in the Ehlanzeni District, Mpumalanga, South Africa. The study adopted a qualitative approach, and data was collected using semi-structured interviews, in which an interview guide was used. Twelve participants were selected purposively from the three different schools in the Ehlanzeni District and interviewed for the study. The data was analysed using thematic content analysis. The study adhered to ethical considerations. The findings of the study indicated that caregivers of children diagnosed with ASD experienced psychological stress; social stress; financial burden; lack of family support; and reported unavailability and accessibility of services. Therefore, information regarding a range of inexpensive interventions and educational programmes should be available for caregivers in order to reduce their psychological and social stress. Medicines should be available and accessible within the district to avoid caregivers having to travel long hours to access them, and to reduce their financial burden. Caregivers' support groups should also be established.



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Introduction and Background Information

Autism spectrum disorder (ASD) is a neuro-developmental disorder which is characterised by impaired communication, repetitive behaviours, impaired social functioning and restrictive interest (DePape and Lindsay 2015). The number of children diagnosed with ASD (hereafter children with ASD) is increasing worldwide and South Africa is no exception (Mthimunye 2014). ASD can be stressful for both the child and the caregiver, particularly the caregiver. A caregiver can be defined as a person who looks after a sick, elderly or disabled person on a regular basis, and can be either a family member or a paid individual (Van Rooyen 2016). In the current study, a caregiver is an individual who is responsible for providing day-to-day care to a child diagnosed with ASD. Caregivers' whole lives change completely and a normal day to them will comprise of a structured and set routine that they have to adhere to on a day-to-day basis (Mthimunye 2014). Apart from the stress experienced, caregivers of children with ASD also have to deal with stigma and public isolation because of the children's behavioural problems (DePape and Lindsay 2015).

Caring for children with ASD comes with higher demands, and requires more time, effort and patience than caring for children who do not have ASD, which at times is strenuous for caregivers. All these might lead to the caregivers experiencing psychological and mental health problems, such as stress, anxiety and depression (Hoefman et al. 2014). Financial problems might also arise, as some of the caregivers may be unemployed or not earning enough income to sustain the child's health, which requires constant treatment from a health specialist. However, knowledge of the caregivers' experiences could perhaps result in the development of strategies and appropriate services that could ease their burden of caring for a child with ASD (Hoefman et al. 2014).

Gona et al. (2016) state that although awareness about autism has increased in developed countries, more than in developing countries, ASD remains poorly understood by most South Africans, especially those in remote areas and in areas where research is limited. Mthimunye (2014) reported that since the African community still believes that this condition occurs among western communities, this could contribute to further isolation of families with ASD children. Healthcare facilities lack a significant number of trained professionals to provide care and support to caregivers upon diagnosis. This is a major problem in public healthcare facilities. Society may also stigmatise the condition because of poor knowledge, which makes it even more challenging for the caregivers (Mthimunye 2014).

According to Gona et al. (2016), the prevalence of ASD in African countries is still unclear. As a result, it is quite difficult to estimate the number of children diagnosed with ASD in low- and middle-income countries, more especially African countries. This

is because knowledge and awareness is still low, leading to late diagnosis (Bakare and Munir 2011). Chambers et al. (2017) demonstrated that there are no prevalence studies for ASD in South Africa due to lack of standardised screening and diagnostic tools. Furthermore, Malcolm-Smith et al. (2013) state that intervention services are often scarce or not available at all which could further increase the caregivers' stress levels.

Problem Statement

The researcher (who is the first author) once volunteered as a school counsellor at one of the schools for children with special needs in the Ehlanzeni District, Mpumalanga, South Africa. During her tenure as a volunteer, she observed that the teachers who are trained on how to deal with children with ASD were struggling to cope with them in class. Furthermore, these children were exhibiting violent behaviour because they could not express their feelings and needs due to deficits in their communication skills. According to Prata, Lawson and Coelho (2018) and Roughan, Parker and Mercer (2019), interventions, such as the psycho-education programme for parents with children with ASD, are crucial to increasing parents' understanding of ASD as well as helping them develop practical strategies to manage their children. Further, the programme teaches parents how to modify the environment around their children and implement ASD specific strategies to manage their children's behaviour which in turn has a positive impact in reducing aggressive behavioural problems. There is scarcity of studies on caregivers' experiences of children with ASD, and the few that are available have been conducted in developed countries. The school where the researcher volunteered is in the rural area of the Ehlanzeni District and at the time of the study had 23 children with ASD. The parents of these children were not involved in activities at the school, which motivated the researcher to explore how caregivers handle these children.

Aim of the Study

The study aimed to explore and describe caregivers' experiences of children with ASD in the Ehlanzeni District, Mpumalanga, South Africa.

Research Methodology

Research Design

A qualitative approach, using explorative, descriptive and contextual designs was adopted to explore caregivers' experiences of children with ASD (Creswell and Creswell 2018). This approach and designs enabled the researcher to gain a deeper insight into the experiences of caregivers of children with ASD and it also afforded the researcher the opportunity to probe and observe non-verbal communication cues from the participants during the interviews.

Study Setting

The study was conducted in the Ehlanzeni District, Mpumalanga, South Africa. The district is one of the three district municipalities located in the North-Eastern part of Mpumalanga and its capital city is Mbombela, previously known as Nelspruit. It has a total population of 944 665, and most people in the district speak iSiswati.

Population and Sampling

The study population comprised caregivers of children with ASD. Three schools were purposefully selected because they were admitting children with special needs including those with ASD. The researcher used purposive sampling to select 12 female caregivers. The participants were eligible for inclusion if they were caring for 5–12-year-old children with ASD, and were residing in the Ehlanzeni District.

Data Collection

The data was collected using face-to-face interviews, with the aid of an interview guide in order to eliminate unnecessary questions. The interview guide covered the following key components, namely, biographic information and experience of caring for a child with ASD. Data saturation was reached with the tenth participant. The interview guide was developed in English, then translated into iSiswati to accommodate caregivers who could not understand English. Fortunately, all the caregivers were literate and preferred to be interviewed in English. The development of the guide was guided by the literature on ASD. After development, it was pre-tested among caregivers of a similar background to those participants who did not form part of the final study. Following the pre-test, some questions were altered. The researcher obtained informed consent from participants before conducting the interviews. A voice recorder was used to record the interviews after the participants granted permission and notes were taken. The study adhered to ethical considerations.

Data Analysis

The recorded data was transcribed verbatim. Thereafter, thematic analysis was performed. Vaismoradi, Turenen and Bondas (2013) define thematic analysis as a method for analysing materials of life stories and reporting patterns (themes) within data. The researcher used the following processes as outlined by Braun and Clarke (2006) to analyse the data: read the transcribed data several times to gain overall meaning of the participants' responses; generated initial codes; searched for themes; reviewed themes; defined and named themes; and finally produced the report. The sub-themes were supported by excerpts from the participants' verbatim expressions.

Ethical Considerations

The University of Venda Ethics Committee issued the ethical certificate (Project no. SHS/18/PH/08/1505). The Mpumalanga Department of Education gave permission to conduct the study at the three schools and the principals of these schools allowed the researcher access to the schools. The participants were informed about the study and their rights as participants before they gave their consent to participate. They were also assured that any information they shared would not be made readily available to anyone else as raw data and that their identities would be protected when writing the report and manuscripts for publication. Further, the participants were made aware that they could discontinue at any given stage of the interview if they felt uncomfortable without any penalty.

Trustworthiness

Trustworthiness was maintained throughout the study by using the four concepts posited by Lincoln and Guba (1985), namely, credibility, transferability, dependability and confirmability, adapted from Maree (2016). The researcher ensured credibility by verbally paraphrasing the participants' responses and having them confirm their responses. The researcher also built a trusting relationship with the participants and created a trusting and familiar environment. Further, the researcher asked follow-up questions and sought clarity from the responses given. The researcher ensured transferability by giving a brief description of the data collection method that was used. To ensure dependability, the researcher used a voice recorder to ensure that she did not miss any information and made use of field notes to ensure that the data was transcribed verbatim. To ensure confirmability, the researchers compared the findings of the study with the extant literature.

Results

Twelve female caregivers whose children were between the ages of 5–12 years and with ASD participated in the study. The sample size was determined by data saturation. Of the 12 participants, 10 were the biological parents of the children with ASD and were blacks, while two were whites and had adopted the children. The participants' demographic information was as follows: their ages ranged between 25–49 years; they were from low- and middle-income families; six were single, five were married and one was divorced. They were labelled P1 to P12. The theme and sub-themes that emerged from the findings are shown in Table 1.

Table 1: Theme and sub-themes

Theme	Sub-themes
1. Caregivers' experiences of caring for a child with ASD	1.1 Psychological stress
	1.2 Social isolation and rejection
	1.3 Financial burden
	1.4 Lack of family support
	1.5 Accessibility and availability of services

Theme 1: Caregivers' Experiences of Caring for a Child with ASD

Parents experience a number of challenges when caring for a child with ASD (Hoefman et al. 2014). Caring for a child with such a disorder can be very strenuous thereby leading to stress and poor psychological well-being for the caregiver. The study findings demonstrated that caregivers experience a lot of challenges when it comes to caring for and raising a child with ASD because it requires time, effort and patience. The participants mentioned that they tend to experience psychological stress, social isolation and rejection as well as financial burden because children with ASD have a lot of financial needs to be catered for. Some of the participants mentioned that accessibility and availability of health care services was a problem, while others indicated that they did not have any support system. The sub-themes that emerged under Theme 1 are discussed below.

Sub-theme 1.1: Psychological Stress

The participants mentioned that they experienced psychological stress when it comes to caring for a child with ASD. Some even stated that they cannot cope with everything; it becomes so overwhelming that they end up not coping well with their situations. The following quotes depict how the participants experienced psychological stress:

It's not easy, it is difficult because even now he still wears pampers and people think I'm not training him not to wear pampers and I can't always be explaining his situation. That really affects me psychologically and I'm not really coping. (P4, 25)

It's very hard because he's constantly on my mind, he times me, so I have to rush home, if I stop somewhere, he knows and he performs, he's not happy that I'm late. I can't just be impulsive and do what I want, also I am the main purpose in his life so if I had to go away and something happens to me, nobody will want him, nobody will understand him the way I do, so psychologically it does play on your mind very much and you always worried if you leave him with people, you can't just leave him with anybody because he's got to be protected. (P3, 48)

In terms of psychological experience, it's really hard, some days are good some days are bad, especially with me and my surrounding. (P8, 32)

So psychologically I can say that it pains me because of the spectrum ... they are not really teachable, at home you want him to be independent and self-reliant. (P11, 29)

Psychologically sometimes it's hard for me because I want him to do things like normal kids, but he won't even reach that point, that disturbs me a lot. Sometimes I become very emotional and end up crying, sometimes I become stressed. (P1, 38)

Sub-theme 1.2: Social Isolation and Rejection

During the interviews, some caregivers mentioned that society neither accepts nor understands their children. Most of the time people stare at their children and as a result they avoid social interaction. A participant made the following important statement in regard to this issue:

Socially I prefer staying at home because at first he can speak one or two words that you can understand but then he starts speaking this other language that you don't understand and people will start staring and then they will start asking questions, as a parent you are still struggling as well because some of the things you don't understand, he wants something but you don't know what he wants and then he will start screaming and shouting then people think you don't discipline your child. I can't take him anywhere because he easily gets frustrated and people stare, it's only family that understand ... so it's not nice. (P5, 32)

The other unsettling issue for caregivers was lack of parental discipline when their children are mocked and rejected by their peers. One caregiver whose child experienced being rejected by peers said:

The problem with the children around my neighbourhood is that most of them do not understand his condition so they ostracise him, he's more marginalised, they don't accept him, they boo him, they laugh at him and that can be very disturbing even to a parent especially when you look at their parents and see them not doing anything about it; hence I think the parents they are also encouraging that because they are supposed to talk to their children and say no he's just a child, it's just that he's differently abled but he's a normal child like you ... you don't have to treat him differently. They are not handling the situation properly so instead of me fighting with them I would rather keep him to myself or in the house entertain him with toys, he likes phones. (P9, 47)

Sub-theme 1.3: Financial Burden

The participants outlined that children with ASD have a lot of financial needs and at times they cannot cover all the costs. Most of the participants mentioned that their children do not eat what other people in the house do and some of the children use nappies because they cannot talk and do not have a sense of what is happening around them. The participants indicated that they also spend a lot of money paying for therapists and buying medication as some of the things are not available in government hospitals and also their school fees is expensive, as illustrated by the following statements:

Financially it's very taxing because to start with I'm not even happy with him being in a government school, I feel like I'm being a bad parent, it's just that I cannot afford to enrol him at a private school because it's too expensive and I won't be able to meet all the demands of that particular school. So that is why he's in a government school but really it is expensive, even the therapy sessions that I take him to, the medical aid cannot cover all the costs I have to pay the shortfall. (P1, 38)

The thing with them is that there are specific foods that they eat so you cannot just buy any type of food. They are very choosy and very sensitive in anything, for instance before my son eats, he will smell whatever you give him to eat. So you need to buy the things that he wants, you cannot just buy any food; for example, with cereals he only eats cornflakes so you need to buy cornflakes; he doesn't like bread and they are saying bread is not good for them, so all those special foods are expensive and soya milk is very expensive. So, it is very strenuous when it comes to finances. (P5, 32)

He's still on nappies, just a pack of 13 cost R160 so that takes four days so how do we cope financially with that? He eats non-stop everything goes to the mouth of course he's got his own likings and preferences so financially it's a huge burden. (P11, 29)

Financially you really spend a lot when you have a child with autism, school fees are expensive, there's specific food, paying for occupational and speech therapists is expensive, it's just too much. (P6, 49)

Another participant added that:

Uh special food as well he didn't eat this and now, he only eats this [gluten-free products] so it's costly all these gluten-free products are very expensive. (P4, 25)

Sub-theme 1.4: Lack of Family Support

One participant reported that she does not have support from her family; she mentioned that her family members are not helping her at all. The following quote supported this statement:

Another thing is that I'm not coping really well because I don't get support from my family. Uh I am neglected by my own family. I'm paying someone to look after my child so that I can be able to go to work because my sisters want nothing to do with my child. (P2, 48)

Sub-theme 1.5: Accessibility and Availability of Services

The participants indicated that accessibility and availability of services is a challenge in the district. Some of the participants mentioned that at times medication for their children is not available in public hospitals around the province and they have to go as far as Steve Biko Hospital in Pretoria to access medication. The following quotes depict how the participants face challenges in terms of accessibility and availability of services:

Uh he's on medication and we fetch the medication at Steve Biko Hospital, and transport is arranged by the hospital – it's just that he doesn't like being in one place for too long. So, he gets tired travelling a long distance, sometimes he throws tantrums. (P10, 32)

So right now, the government structure overlooked our children's situation because the schools for children with mental illnesses are not enough, it's like they have written them off because they think they won't amount to anything in life which is not always the case. (P1, 38)

... schools ... I don't think the government really understand what autism is because yes our children are impaired, but it doesn't mean that we write them off. (P4, 25)

Discussion

The study findings indicate that caregivers' psychological well-being is affected as they worry about the ASD children's temper tantrums, which may distract alternative caregivers. This is demonstrated by their fear of leaving the child with someone as well as their crying. In a study on parental care-seeking pathway and challenges for ASD children, the authors indicated that parents agreed to be experiencing stress as a result of their children's diagnoses (Mahapatra et al. 2019). Similarly, the caregivers in the present study mentioned that they experienced stress as a result of people's comments when in public places. In addition, thinking about the future of the child also increased the stress of some caregivers. This is in line with the findings of Al-Dujaili and Al-Mossawy (2017), Hoffman (2012) and Lai et al. (2015), who reported that parents of children with ASD have poorer psychological outcomes and experience higher levels of psychological stress than parents who are caring for children without ASD. Furthermore, it is possible that their fear could prevent them from social interaction that might ease their stress.

The majority of children with ASD stay with family members in their communities. The parents continue to experience social rejection and financial challenges (economic injustice) (Bishop-Fitzpatrick et al. 2016; Howling and Magiati 2017). The caregivers expressed their feelings when in public places with their children with ASD. Some caregivers were unhappy with the attitude displayed by peers on their children with ASD, more especially that parents of those children did not do anything to make them aware that such children are differently abled and should not be criticised nor rejected. This is in line with DePape and Lindsay (2015) who reported that parents of children with ASD often received negative criticism from strangers when they were out in public. Strangers believed that their children were acting out and should be disciplined.

The lack of intervention by parents made some of the participants choose to isolate themselves and keep their children indoors because of being rejected by peers. As Alnazly and Abojedi (2019) found and in the present study some caregivers experienced depression as demonstrated by social withdrawal. According to Shilubane et al. (2014),

depression is a mediating factor of suicidal behaviour; therefore, the caregivers' depressive behaviour requires immediate intervention by health professionals.

Financial difficulties were identified in all the interviews and Hoefman et al. (2014) mention underemployment and unemployment as the cause of caregivers' financial problems. The caregivers mentioned that their children are selective in terms of what they want to eat. They further indicated that the therapy sessions were very expensive and they ended up paying the difference since medical schemes paid the approved rate charged. The current findings are in line with Bashir et al. (2014), and Matenge (2012) who indicated that ASD causes financial strain on families in several ways, they need money for therapists and treatment not covered by medical schemes. The findings of Yingling, Hock and Bell (2018) and Yingling et al. (2017) also highlighted that most children with ASD do not access needed services due to costs and unavailability. These authors' findings are in line with the current findings as some caregivers mentioned that they wanted to send their children to a better school that has resources for the benefit of the child, but due to financial constraints they failed. This is supported by Clasquin-Johnson and Clasquin-Johnson (2018) who indicated in their study that there are limited options in selecting a school for a child with ASD because they are expensive.

In their study, the results of which are similar to those of the current study, Hoefman et al. (2014) found that some family members and friends never showed any support in their children's situation. Similarly, Madlala (2012) indicated that parents found it hard to cope with their children because of the poor support they were receiving from their families. Since the family is regarded as the primary support system, and most caregivers in the present study were single parents, either because they had never married or were divorced, it is unsurprising that caregivers experienced psychological stress as they had no one to lean on. This is in line with O'leimat, Alhussami and Rayan (2019) who in their study of the correlates of psychological distress among parents of children with psychiatric disorders, found parental psychological distress to be significantly correlated with marital status.

The caregivers stated that it is tiring for them and their children to travel a long distance to Pretoria for treatment. Similar results were obtained in DePape and Lindsay's (2015) study which found that parents experienced challenges when trying to access services for their children with ASD and was perceived as tiring for their children since they are not used to confined spaces. Unlike in the current study, where caregivers reported limited government schools that cater for children with disabilities, Mahapatra et al. (2019) indicated that services were available. Hoffman (2012) and Mthimunye (2014) further stated that schools that accommodate children with ASD are not enough and the few schools that are available have certain criteria for admission in which the child may not be successful in some cases therefore, forcing them to stay at home.

Limitations of the Study

The study findings cannot be generalised because they are applicable to a specific context with a small population and qualitative nature, which is meant only to generate hypothesis.

Recommendations

Based on the study findings, the authors recommend that medication should be made available at the district level to avoid caregivers travelling long distances. Furthermore, tailor-made interventions/strategies to support caregivers should be developed. Support groups for caregivers of children with ASD should be established. There are no studies on experiences of caregivers in the Ehlanzeni District, therefore the current study will provide a reference for future studies on interventions development to make care of ASD children easier. Development of an instrument to measure caregivers' experiences, challenges, perceptions and behaviours or coping strategies could assist in this as a quantitative comparison.

Conclusion

The study increased the authors' insight into the experiences of caregivers and the impact of caring for ASD children on their psychological being. The study reflects that the education and the health care systems for ASD children in South Africa are not fully developed. It is evident that community members do not have sufficient knowledge of ASD. There is a need to conduct public awareness about ASD which could remove the stigma and enhance acceptance of children with ASD. Furthermore, support of families and community members could be enhanced. The fact that caregivers are not involved in activities at schools could mean that teachers do not know what to tell them, therefore, there is a need to empower teachers and caregivers with information on ASD and available services. Once caregivers are well informed through counselling and workshops, fears and anxiety could be removed. In addition, policy makers should develop policies that will ensure fair distribution and accessibility of services to ASD children in all the provinces of South Africa. Future studies may determine knowledge of caregivers in the Ehlanzeni District and explore their coping strategies.

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