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Caregiver Experiences in Caring for Children with Autism Spectrum Disorder (ASD) in Harare, Zimbabwe

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Abstract

Autism spectrum disorder (ASD) is a lifelong neurodevelopmental condition that leads to varying degrees of impairments in communication, social interaction, and behaviour, which can hinder a child's ability to function independently and engage socially. This study aimed to explore caregivers' perspectives of their daily experiences while caring for children with ASD. A qualitative phenomenological approach was used involving five individuals through in-depth interviews and nine participants in a focus group discussion, all selected through convenience sampling. The findings reveal significant physical, emotional, and financial challenges faced by caregivers, including stigma and discrimination from the community due to a lack of understanding, which often leads to social isolation. Considering the prevalence rate of ASD globally and here in Zimbabwe, active involvement of the government in capacity building, advocacy and intervention programmes from grass-root level (clinics) is recommended. Awareness campaigns and educational initiatives may also help to alleviate the public's myths and misconceptions concerning ASD.

Keywords: *caregiver, lived experiences, autism spectrum disorder (ASD)*

Introduction

Autism spectrum disorder (ASD) is a lifelong condition affecting many children and families around the world. The first studies on the prevalence of autism conducted in the 1960s and 1970s in Europe and United States estimated a range of 2 to 4 cases per 10 000 children (Lotter, 1978). In the late 1980s and 1990s, autism prevalence studies around the world showed dramatic increases (Mutemeri, Dzenga, Siddiq & Chen, 2019).

By 2020, the prevalence of ASD in the United States increased and estimated to 1 in 54 children (Aithal, Karkou, Makris, Karaminis & Powell, 2023). Boys were about four times more likely to be diagnosed with autism than girls. This marked 15% increase from the past report two years ago, and the highest prevalence since the Centre for Disease Control began tracking ASD in 2000 (CDC, 2018). People mostly focus on the child with ASD and disregard their caregivers and what they experience in the midst of having a child that needs special care and their own lives (Cloete & Obaigwa, 2019).

Despite the recognition of ASD in Africa over 40 years ago, very little is known about the prevalence, major developmental features and course of this disorder in African people (Baio, Wiggins, & Christenson, 2018). Families and children with ASD mostly go through an emotional rollercoaster from the moment they learn of the initial diagnosis throughout the confirmed diagnosis and the journey to try and make their child 'normal'. They may go through grief of loss of hope and good health of their child, to accepting their imperfect child (Quirke, & Hagen, 2017). Decreased parenting efficacy, high levels of stress, physical and mental health problems, time pressures, significant financial strain, sibling adjustment problems reduced social support and family discord (Cloete & Obaigwa, 2019, Aithal, Karkou, Makris, Karaminis & Powell, 2023, Karst & Van Hecke, 2016). Stress levels are disproportionately high when compared with those faced by parents of children with almost any other form of impairment or health issue (Abubakar, Ssewanyana, & Newton, 2016).

Other stressors, especially in African countries, include family conflicts around issues of the child's impairment, constricted social and recreational life difficulties in accessing health care facilities (Gray, 2016; Shivers, Sonnier-Netto & Lee, 2018). Raising a child with ASD often entails a physical, emotional and financial burden for families (Hansen, 2016; Daniels, Como, Hergüner, Kostadinova, Stosic, & Shih, 2017). Therefore, addressing this myriad of challenges faced by caregivers is important for promoting family well-being (Gupta, Khanna, Garg, Sethi, Khattar, Tekkar, & Schuchert, 2023).

Although caregivers encounter negative experiences, sometimes, they experience fulfilling roles in their children's daily care and development (Dira, Machailo & Scholtz, 2024). Many caregivers report significant emotional rewards and personal growth from their experiences (Kanja, Mwenje, & Githui, 2022). The caregivers and their children often form deep bonds that yield a profound sense of purpose. When the caregivers attune the needs of their children, this usually enhances the caregivers' ability to provide tailored support for their children (Tathgur & Kang, 2021).

The aim of this study was to examine the caregivers' accounts and realities of their day to day lived experiences as they care for children suffering from ASD and to identify the coping mechanisms employed by the caregivers in managing their lived experiences as they care for a child with ASD.

Methods

This study employed a qualitative approach using a phenomenological research design to explore the lived experiences of caregivers of children with autism spectrum disorder (ASD) in Harare, Zimbabwe. The methodology involved data collection through individual in-depth interviews and a focus group discussion (FGD) focusing on the participants' perspectives, challenges, and coping strategies. Five participants (four females and one male) were selected for individual interviews, and nine participants (seven females and two males) participated in the FGD. The population of the study were caregivers of children with ASD who were learning at a centre in Harare, and who had directly cared for a child with ASD from infancy to date. It could be biological mother/father, guardian or teacher of the child with ASD. Convenience sampling was employed, with participants volunteering based on availability and willingness (Creswell, 2018).

Data were collected using individual semi-structured interviews and a follow-up FGD. The researchers observed ethics like informed consent; taking into consideration that the children that the respondents cared for were a marginalised, special population; children with ASD. Therefore, the respondents were informed of the possible risks and benefits of participating in this study. For example, this could evoke the pain that they had since forgotten about or this could help them deal with unfinished business that related to the care and support of their children. Respect for autonomy was also considered in that the participants had the right to refuse to engage into or to discontinue the face-to-face interviews and the focus group discussion, even when they were half way through, should they feel this way (Creswell, 2013).

Non-maleficence was ensured in that open-ended questions were used, in which participants would share their experiences in a way that was non-threatening and empathetic (Creswell, 2018). Examples of questions that were asked were: Would you please share how you execute activities of daily living with (pseudonym) with regards to bathing, dressing up, feeding and feeding times, toilet use during day and night, play time with you/and the family and friends at home and at school, school activities, sleeping habits, be it day or night? How have you maintained (pseudonym) in good health; any special diet? What are the challenges that you face as a caregiver?

Such questions inquired about the caregivers' experiences with a child diagnosed with ASD who would be in their care. Their responses would give the realities of the day to day lived experiences of the caregivers as they care for children suffering from ASD. Data analysis was conducted using NVivo software to identify themes and patterns in the interview and FGD transcripts (Braun & Clarke, 2019). Thematic analysis was used, focusing on semantic themes to represent participants' experiences explicitly (Braun & Clarke, 2019).

Findings

The goal of this qualitative study was to explore the lived experiences of caregivers in raising children with ASD in Zimbabwe so as to have an in-depth understanding and knowledge of the caregivers' perspectives. This would in turn provide a practical framework and guidelines for effective help and support when working with caregivers of children diagnosed with ASD and their families. The researchers explored the perceptions and experiences of 5 caregivers who all turned out to be parents of children with ASD who attended specialised school in Harare. One participant had 2 children, a boy and a girl, that were living with ASD. The girl was the only female of the children whose parents were interviewed face to face.

Table 1: Demographic information of the face to face individual interview respondents

Name of parent	**Age of parent**	**Sex of parent**	**Marital Status**	**Highest Level of Education**	**Occupation**	**Total # of children in care**	**Total # of children with ASD**	**Age of child with ASD**
A	34	Female	Married	Diploma	Unemployed	3	1	6
B	38	Female	Married	Certificate	Employed	2	1	8
C	41	Female	Single	Bachelor's	Employed	1	1	8
D	44	Male	Married	Bachelor's	Unemployed	2	1	19
E	37	Female	Married	Bachelor's	Employed	3	2	8 and 5

In the focus group discussion (FGD), 9 caregivers who also turned out be parents of the children attending specialised education attended. The FGD lasted for 103 minutes.

Table 2: Themes that emerged from the Interviews

	CAREGIVERS				
THEMES	**1**	**2**	**3**	**4**	**5**
1. Delays and concerns about the development of child	X	X	X	X	X
2. Need for help seeking	X	X	X	X	X
3. Overwhelming family adjustments and navigating the new system		X	X	X	X
4. Challenges with daily living activities		X	X	X	X
5. Social exclusion of the children	X	X	X	X	
6. Difficult communication with the children	X	X	X	X	X
7. Stigma and discrimination		X	X		X

Findings from the FGD and Individual Interviews according to the emerging themes

Key extracts from respondents’ accounts are provided so that they give evidence to the development of particular themes or where they illuminate a theme.

Delays and concerns about the development of child

All the respondents agreed that there was a delay, regression or unresponsiveness that their child displayed, which led them all to be concerned about their child. This outcome and concern led them to seek help in one way or another. From the individual interviews, Respondent 4 specifically mentioned that her child regressed after he got the 18 months immunisation injection and that was the beginning of her child’s negative condition.

Respondent 2 mentioned that she had twins., However, one of the twins lagged behind distinctly from the onset. The twin had a major operation at around 3 months, which she thinks may have caused or worsened the lagging behind of the twin living with ASD.

> “I noticed how my son kept falling to one side of his head and I took him to see a neurologist at 18 months…”

Help seeking behaviour

All the members present at the FGD agreed that, as much as they had previously noticed that something was not well with the communication of their child and the unresponsiveness when the child was called by name, they all experienced confusion and suspicion. They were always in suspense, and had unanswered questions. Six of the nine people who participated in the FGD were honest to divulge that they, at some time, tried to seek help from traditional healers or the Apostolic sects or simultaneously sought medical help out of desperation. The children were diagnosed at around 3 years while the child who got the latest diagnosis was diagnosed at the 5-year immunisation injection.

Respondent 4 said:

> "My family held a meeting behind my back about my child's restricted movement and his regular uncontrollable behaviour…My wife was broken; she cried non-stop as she felt helpless. We kept our son at home… So, now they (the family) called us to inform us that they had arranged as a family that we consult prophet or a traditional healer …we refused… (shrugging) they were angry"

Respondent 4 vowed that:

> "… even if I had the last penny in my pocket, I would rather pay a doctor than consult a nurse about Ashley because nurses know nothing and their injections are the cause this condition on my child."

Respondent 4 also said the exact statement in different words.

Overwhelming family adjustments and navigating the new system

All the parents including those who participated in the FGD agreed that, at first, they were worried about the day-today challenges of caring for their child with autism. They experienced difficulties finding balance and time to manage household tasks, other children and daily activities; but, as time went on, they adjusted.

Respondent 2 confessed this:

> "I was broken, when I was told that Thomas had Autism… I didn't even know what it was and kept on asking God kuti [that] why me…? My situation worsened because, that's the time that my husband abandoned me…I had to find suitable intervention programmes for him to take part in and to find out about appropriate schools for future's sake."

Respondent 5 said:

> "On the first one, I was in a real shock…It was after a 4 hour examination, doctor told me that it was definitely Autism…and I was like….WHAT…!!! These people (where she consulted previously) did not equip me with information… I have never seen heartless doctors… one of them said, "Prepare yourself that he might never speak, learn or communicate…" On Monday, when I told her nursery teacher, that's when she explained and went on Google to search for more information. Haaa…!!! This experience taught me to lean more on God and to trust him."

Challenges with daily living activities

The challenges that the parents experienced ranged from the child not being accepted in various schools as they could not put up with such children, changing soiled clothes or nappies to a grown child, no or little understanding in communication, and no social interaction. Other challenges included hitting or violent sometimes obsessions over specific objects and routines, and repetitive body movements, to mention a few.

Bathing and dressing

As previously mentioned, Respondent 5 had two children who had ASD. The girl who was the younger one of the two, was on the more severe end of the spectrum. She said:

> "At first, I was overwhelmed…but with time and because of my supportive and helpful husband, we managed to develop a routine on the family's daily activities of living..."

Feeding and eating habits

All the parents from the individual interviews and the FGD reported that their children were able to eat alone. However, Respondent 4 specified that it took a while for James to eat alone, although sometimes he would decide to be messy. Respondent 5 also mentioned about her daughter being a messy eater and that sometimes she wanted to be fed. Only Thomas and James took Risperdal and Epilim (medication).

Respondent 1 had this to say about her son:

> "Ashley eats very well; he's not a picky eater. He eats pretty much anything that he's supposed to be eating as long as it's gluten free… He has a way that he wants his carrots and potatoes cut. Sometimes you will find him smelling the food, if he's not familiar with it."

Respondent 2 also said:

> "At home, Thomas takes high protein and vitamin diet because he can chew but can't swallow chunks of solid food, so we used to blend his food and it would result him having diarrhoea. Now he eats spaghetti, rice, mashed potatoes and soup from meat."

Respondent 5 said:

> "My son doesn't like grainy food from infancy…he scratches it aside… even up to now and he doesn't eat fries, so he eats potatoes, which are his favourite food."

Toilet use and training

Data from the interview, participants indicated that toilet use was the most difficult task for almost all the children living with ASD. Most of them wore nappies irrespective of how old they were. Only Respondent 1's child wore a nappy at night, just in case of an emergency only and during the day, he wore panties.

Respondent 2 said:

> "Thomas wears nappies throughout the day…"

Respondent 3 said:

> "With all other issues, Tynos doesn't have problems… but on pot training, Oh… he has not been cooperative …For now, I have given up…"

Sleeping habits

The findings were that, during the day, no one slept as most of the children displayed ADHD tendencies of being hyper-active. So, the parents and the school agreed that no child would sleep during the day. All the parents indicated that their children mostly slept soundly throughout the night and were accustomed to routine.

Difficult communication and social exclusion of the children

Social play and communication

Both individual interviews and the FGD showed that the nuclear family members created time to play as a family, as taught from the Pathways Autism Trust and the Support Group. However, it occurred that for most of these children, isolated play was more common.

Verbal communication

Respondent 3 and 4 echoed the same sentiments with four parents from the FGD that their children had greatly improved their communication skills through the Treatment and Education of Autistic and Communication Handicapped Children (TEACCH) programme. This is a structured learning environment that helps individuals with ASD to function by encouraging visual based engagement and communication, e.g., using pictures to reach their goals like when one gets into the toilet, they follow what is displayed on the picture. Two parents from the FGD testified that their children had significantly improved on their speech and language acquisition through the help of psychologists and social workers.

Respondent 2 said:

> "…on the internet, he (Thomas) could search games, the Lego instructions on how to build something because he couldn't express himself but he could type…"

Attending social gatherings

Results showed that most parents do not attend occasions like weddings together. Either one parent attends on behalf of the family while the other partner stays behind with the child with ASD or they both do not attend, but send their gift. From all individual interviews and FGD, this was the same response.

The other lady at the FGD talked about how people at church treated her. This was similar to what all four women from individual interviews mentioned. She said:

> "I feel most of the people at our church are judgemental. People don't understand…, and I don't really talk about my child's condition with everyone. They give me that suspicious look…yekuti wakajaidza mwana wako [like he is a spoiled brat]…(laughing as she says this)…. The other day he screamed in church and I couldn't help it…as I stopped him, he became louder. I just look away when people look at me…I have now resolved that if I want to go to church, I leave my child home, or I don't go at all…"

Stigma and discrimination

On stigma and discrimination, some of those experiences were noted above, especially when participants were attending social gatherings. In the FGD, three people discussed what they have experienced; how people whispered and looked at them when they passed-by.

Financial and relationship challenges

This response was from Respondent 1:

> "Our biggest issue is financial difficulties at the moment, especially with the current economic situation. We have other kids in the house that have needs as well…"

Respondent 4 was quoted saying:

> "… it also costs you in terms of relationships because with some relatives they won't understand. They will be so judgmental … it can take a toll on you and you end up excluding yourself from a lot of things because not everyone is going to understand and accept your child. So, it's very difficult…"

Defence mechanism was presented as a potentially successful coping strategy used by parents to reduce distress, and to increase social competence and resilience. They also believed God helped them. Unconditional love for their children was one characteristic that stood out for the researchers throughout all the interviews including in the focus group discussion. The love for their children overrode the burdens that come along with caring for the children with the developmental disabilities. They were ready to do anything to ensure the well-being of their children. All the parents acknowledged that they had basic essential knowledge to help their children.

Discussion

The researchers identified a gap in scholarly literature regarding caregivers' experiences in raising children with autism spectrum disorder (ASD) in Zimbabwe. Existing studies have generalised all disabilities, overlooking the distinct challenges posed by the ASD spectrum. Findings indicated that caregivers noticed developmental delays or regressions in their children, prompting them to seek help (Suma, Adamson, Bakeman, Robins & Abrams, 2016; Harrison et al., 2016; Hansen, 2016). Early intervention was linked to improved social and daily living skills, though most caregivers experienced initial struggles balancing caregiving with other responsibilities (Cloete & Obaigwa, 2019; Shorey et al., 2019). However, they adapted over time.

Caregivers faced restrictions to attend to social events, they were limited to autism-friendly settings, endured physical, emotional, financial challenges and experienced stigma from their communities (Tathgur & Kang, 2021; Wilson & Peterson, 2018). Congregants and neighbours judged their children, sometimes labelling them the "bewitched" ones. The specific needs of children with ASD may result in either the alteration of typical family routines or the prevention of engagement in family activities (Iadarola, Pérez-Ramos, Smith & Dozier, 2019). Despite these difficulties, caregivers found ways to navigate their roles. Boys were observed to have a higher prevalence of ASD than girls in the study, which is consistent with global findings (CDC, 2018).

Misconceptions about ASD led to accusations against mothers, attributing the condition to unfaithfulness, curses, or spiritual punishments. This lack of awareness fostered social isolation, reducing families' access to services. Addressing the stigma requires increased knowledge and awareness of ASD (Abubakar, Ssewanyana, & Newton, 2016).

International policies like the Convention on the Rights of the Child (1989) and the Salamanca Statement (1994) advocate for inclusive education. There was a worldwide paradigm shift from exclusion to inclusion in education in 1994 (Majoko, 2019). Inversely, this research highlights contrasting findings. Parents at the school. where the research was done adopted, preferred the TEACCH method. This is a structured and exclusive approach tailored for children with severe autism spectrum disorder (ASD). It incorporates visual aids to support communication and daily tasks. Inclusive education often groups children with diverse disabilities together, which may not address the varying needs of children with ASD.

Some parents in the study reported repeatedly changing schools or caregivers, reinforcing the preference for specialised education as the most effective option. People with severe autism have a hard time communicating their needs verbally (Chambers et al., 2016). Despite many benefits to an inclusive setting and opportunities for social communication, this can pose numerous challenges for the children with severe impairments (Majoko, 2016).

This study highlighted various coping mechanisms employed by caregivers of children with autism spectrum disorder (ASD). Families at the school and its support group adopted playing together as a coping strategy, although many children with ASD preferred solitary play (Jellet, 2016). Speech deficits and social interaction challenges, common among children with ASD, added to the complexity of caregiving. In addition, belief in God and religious practices also served as a significant coping mechanism for many caregivers. Mothers of children with ASD also searched ways to rescue their children based on religious beliefs and using practices like praise, pilgrimage, gratefulness and trusting in God (Heydari et al., 2015).

Support from family, colleagues, and other caregivers was crucial in helping parents adjust to their child's condition. Support from both family and colleagues, particularly for those who were employed, played a crucial role in the caregivers' adjustment to their children's condition (Gona, 2016). Meeting others facing similar challenges fostered acceptance and encouraged adaptive coping strategies (Cloete & Obaigwa, 2019). Strong family cohesion was found to reduce stress over time. While divorce rates are typically higher among parents of children with ASD, 80% of the respondents were married and described their spouses as supportive, with some noting that their child's condition strengthened their relationship.

Despite numerous sacrifices, such as losing time, leisure, and peace at home, caregivers gained resilience, family unity, and a sense of purpose. In overprotecting their child, they may exclude them from social interactions with their peers (Tome, 2024). A WhatsApp support group formed by the school was invaluable for sharing advice and encouragement. It included caregivers of children in inclusive education settings who failed to find spaces in specialised schools.

Conclusion and recommendations

Caregivers criticised nurses for their lack of knowledge and sub-optimal support, with some being rude and unhelpful to identify the slow language development or isolative behaviour, which was misinterpreted as shyness (Elder, Kreider, Brasher & Ansell, 2017). The school played a vital role in disseminating information, enabling families to reduce medical expenses and feel more knowledgeable and confident about coping with ASD. Despite challenges, the caregivers demonstrated resilience, gaining confidence and coping skills through information, support systems, and their commitment to their children. and Researchers recommend the need to raise awareness and sensitise communities not to reject families with the condition as it is medical and not superstitious (Tome, 2024).

In the previous studies, the statistics and prevalence of autism spectrum disorder (ASD) in Zimbabwe were largely unknown owing to limited research in this area. To fill the knowledge gap that exists on ASD, cross-sectional surveys that reflect a more precise picture of a wider population, and that are more representative of the caregivers of children with ASD in Zimbabwe, are recommended. Longitudinal studies that follow up on these children that are being researched upon now are necessary as they subsequently grow into adults with ASD and how they have been incorporated in employment and self-help skills. This would thereby expand the evidence base. Statistics and information on ASD ought to be well documented like other community issues such as gender based violence and rape.

If the children with ASD are to be placed in the mainstream (inclusive) education, then trained facilitators are needed in those schools. It is therefore vital for people with ASD to be included in the discussions that concern them (advocacy) so that their voices are heard. It is important for service providers like general nurses and teachers to have a strong understanding of ASD in order to timeously refer and link families to appropriate services.

The diagnosis of ASD has caused confusion, shock, grief and loss of the ideal child that the caregivers would have anticipated. Parental feelings of disbelief, distress, anxiety, or sadness are common at the time of diagnosis and in the following months. It is against this backdrop that psychologists come in as an invaluable human resource to provide a comprehensive understanding of the needs, provide appropriate resources and most effective strategies to support the children with ASD and their families. The family, being the most important support system for any child and for the ones with ASD, plays a pivotal part in the enhancement and well-being of the child and of the overall family as a unit as the seek help. Hence, the family systems therapy would be effective in helping the child with ASD and his/her family.

References

Abubakar, A., Ssewanyana, D., & Newton, C.R., (2016). A systematic review of research on autism spectrum disorders in sub-Saharan Africa. *Behavioural Neurology*.

Aithal, S., Karkou, V., Makris, S., Karaminis, T., & Powell, J. (2023). Supporting the wellbeing of caregivers of children on the autism spectrum: A qualitative report on experiences of group dance movement psychotherapy. *PloS One, 18*(8), e0288626. https://doi.org/10.1371/journal.pone.0288626

Baio, J., Wiggins, L. and Christensen, D., L. (2018). Prevalence of autism spectrum disorder among children aged 8 years. *Autism and Developmental Disabilities Monitoring Network,* Borchard, T. J. (2019). *On being a positive caregiver: An interview with veteran caregiver Carol Bradley Bursack*. London: Sage Publishers.

Braun, V. & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology*, *3*, 77-101.

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

Bravo-Benítez, J., Pérez-Marfil, M. N., Román-Alegre, B., & Cruz-Quintana, F. (2019). Mind, Brain and Behaviour Research Centre (CIMCYC). *Spain International Journal of Environmental Research and Public Health, 16*(23), 4821,

Centre for Disease Control and Prevention. (2018). Prevalence of autism spectrum disorders aged 8 to 10 years. *Autism and Developmental Disabilities Monitoring Network*, 63(SS02), 1-21.

Chambers N. J., Wetherby A. M., Stronach S. T., Njongwe N., Kauchali S., Grinker R. R. (2016). Early detection of autism spectrum disorder in young isiZulu-speaking children in South Africa. Autism. Doi: 10.1177/1362361316651196

Chireshe, R. (2016). Special needs education in-service teacher trainees' views on inclusive education in Zimbabwe. *Journal of Social Science*, 27, 157-164.

Chirwa, M. S. (2017). *Experiences of parenting children with disabilities: A qualitative study on the perspectives of mothers of children with disabilities in Zambia* (Unpublished PhD thesis). University of Warwick.

Chitiyo, A. & Chitiyo, J. (2019). Autism spectrum disorder in Zimbabwe: A brief review of trends, conditions, challenges and intervention practices. *ResearchGate.* https://www.researchgate.net/publication/335504801.

Chitiyo, M., Zeleke, W., Mutemeri, A., Dzenga, C.G, Siddiq, S. A., & Chen, X. (2019). Views of Zimbabwean parents of children with autism apropos of the process of diagnosis and access to services. *The Zimbabwe Journal of Educational Research, 21*(1), 54-78.

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

Cremin, K., Healy, O., Spirtos, M., & Quinn, S. (2020). Autism awareness interventions for children and adolescents: A scoping review. *Journal of Developmental and Physical Disabilities*, *33*, 27–50.

Creswell, J. W., & Creswell, J. D. (2018). *Research design: Qualitative, quantitative, and mixed methods approaches* (6th ed.). SAGE Publications.

Daniels, A. M., Como, A., Hergüner, S., Kostadinova, K., Stosic J., & Shih, A. (2017). Support needs of families living with children with autism spectrum disorder. *Journal of Autism and Developmental Disorders*, *47*, 2314–2325.

Davis, N. O., & Carter, A. S. (2018). Parenting stress in mothers and fathers of toddlers with autism spectrum disorders: Associations with child characteristics. *Journal of Autism and Developmental Disorders*, *38*, 1278–1291.

Dira, P. M., Machailo, R. J., & Scholtz, S. (2024). Caregivers' voices: From the world of autism spectrum disorder. *Curationis, 47*(1), 1-11.

Dube, T., Ncube, S., Mapuvire, C., Ndlovu, S., Ncube, C., & Mlotshwa, S. (2021). Interventions to reduce the exclusion of children with disabilities from education: A Zimbabwean perspective from the field. *Cogent Social Sciences, 7 (1),* Article 1913848. https://doi.org/10.1080/23311886.2021.1913848

Elder, J. H., Kreider, C. M., Brasher, S. N., & Ansell, M. (2017). Clinical impact of early diagnosis of autism on the prognosis and parent-child relationships. *Psychology Research and Behavior Management*, *10*, 283–292. https://doi.org/10.2147/PRBM.S117499.

Estes, A., Swain, D. M., & MacDuffie, K. E. (2019). The effects of early autism intervention on parents and family adaptive functioning. *Pediatric Medicine, 2*, 21. https://doi.org/10.21037.

Fombonne, E., Quirke, S. & Hagen, A. (2016). Epidemiology of pervasive developmental disorders. In D.G., Amaral, G. Dawson & D. H. Geschwind (Eds.(. (2011) *Autism spectrum disorders* (pp. 90 – 111). New York: Oxford University Press. Available from the NAS Information Centre.

Frye, L. (2016). Fathers' experience with autism spectrum disorder: Nursing implications. *Journal of Pediatric Health and Care, 30*(5),453-63. https://www.rc.library.uta.edu/uta-ir/handle/10106/24922.

Gau, S. S., Chou, M., Chiang, H., Lee, J., Wong, C., Chou, W., & Wu, Y. (2017). Parental adjustment, marital relationship, and family function in families of children with autism. *Research in Autism Spectrum Disorders*, *6*(1), 263–270.

Glizzard, J. & Overall, K. (2017). Livi.ng with autistic spectrum disorder: Parental experiences of raising a child with autistic spectrum disorder (ASD). *Support Learn*, 27, 37-45

Gona, J. (2016*). Autism and other neurodevelopmental disabilities on the Kenyan coast: Challenges, perceived causes and rehabilitation options* [Monograph].

Gona, J., Newton, C., & Rimba, K. (2016). Challenges and coping strategies of parents of children with autism on the Kenyan coast. *Rural and Remote Health, 16*(3517).

Gupta, N., Khanna, M., Garg, R., Sethi, V., Khattar, S., Tekkar, P., ... & Ann Schuchert, S. (2023). Exploration of caregiver experience for children with ASD: An in-depth perspective. *Advances in Autism, 9*(3), 217-240.

Hansen, L. K. (2016). *Development and validation of a survey of knowledge of autism spectrum disorder* (Unpublished master’s thesis). Hattiesburg, University of Southern Mississippi. Retrieved from https://aquila.usm.edu/masters_theses/141.

Harrison, A. J., Long, K. A., Manji, K. P., Blane, K. K. (2016). Development of a brief intervention to improve knowledge of autism and behavioral strategies among parents in Tanzania. *Intellectual and Developmental Disabilities, 54*(3), 187–201. Doi: 10.1352/1934-9556-54.3.187.

Hirota, T., & King, B. H. (2023). Autism spectrum disorder: A review. *JAMA, 329*(2), 157–168. https://doi.org/10.1001/jama.2022.23661.

Hodges, H., Fealko, C., & Soares, N. (2020). Autism spectrum disorder: Definition, epidemiology, causes, and clinical evaluation. *Translational Pediatrics, 9* (Suppl 1), S55–S65. https://doi.org/10.21037/tp.2019.09.09.

Iadarola, S., Pellecchia, M., Stahmer, A. et al. (2020). Mind the gap: An intervention to support caregivers with a new autism spectrum disorder diagnosis is feasible and acceptable. Pilot Feasibility Stud., 6, 124. https://doi.org/10.1186/s40814-020-00662-6.

Iadarola, S., Pérez-Ramos, J., Smith, T., & Dozier, A. (2019). Understanding stress in parents of children with autism spectrum disorder: A focus on under-represented families. *International Journal of Developmental Disabilities*, *65*(1), 20–30. https://doi.org/10.1080/20473869.2017.1347228.

Jacobs D, Steyaert, J., Dierickx, K & Hens, K. (2019) Parents' views and experiences of the autism spectrum disorder diagnosis of their young child: A longitudinal interview study *European Child & Adolescent Psychiatry*, *31*(1), 94- 118.

Jellett, R. (2016). *Raising a pre-schooler with an autism spectrum disorder: The impact on parent and family wellbeing, and the role of the home learning environment* (Unpublished master's thesis). Swinburne University of Technology. https://researchbank.swinburne.edu.au/file/42400988.

Kanja, M. W., Mwenje, M., & Githui, P. (2022). Effects of caregiving of children with autism disorder on the psychological wellbeing in selected integrated primary schools in Nairobi County, Kenya. *International Journal of Education, Psychology and Counselling, 7*(45), 328-342.

Lindsey, R.A., Barry, T.D. (2018). Protective factors against distress for caregivers of a child with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 48*, 1092–1107. https://doi.org/10.1007/s10803-017-3372-1.

Majoko, T. (2016). Inclusion of children with autism spectrum disorders: Listening and hearing to voices from the grassroots. *Journal of Autism and Developmental Disorders, 46*(4), 1429–1440. Doi: 10.1007/s10803-015-2685-1.

Majoko, T. (2019) Inclusion of children with autism spectrum disorder in mainstream early childhood development: Zimbabwean parent perspectives, *Early Child Development and Care, 189*(6), 909-925. DOI: 10.1080/03004430.2017.1350176.

Mazibuko, N., Shilubane, H., & Manganye, S. (2020). Caring for children diagnosed with autism spectrum disorder: Caregivers' experiences. *Africa Journal of Nursing and Midwifery*, *22*(2), 14.

McAuliffe, T, Thomas, Y., Vaz , S., Falkmer .,T. & Cordier, R. (2018). The experiences of mothers of children with autism spectrum disorder: Managing family routines and mothers' health and wellbeing. *Australian Occupational Therapy Journal*, 66(1) 68-76,

Meiring, M., Seabi, J., Amod, Z., Vorster, A., & Kern, A. (2016). Transition for adolescents with autism spectrum disorder: South African parent and professional perspectives. *Frontiers in Psychiatry, 7*(39). Doi: 10.3389/fpsyt.2016.00093.

Musopero, O. (2016, September 04). Autism in Zimbabwe, a call to action. *Sunday Mail*. Retrieved from https://pure.uvt.nl/ws/files/9988857/Gona_Autism_19_01_2016.pdf.

Patton, M. Q. P. Rice, C. E., & Lee, L. (2017). Expanding the global reach of research in autism. *Autism*, 21(5), 515–517.

Roberts, J., & Simpson, K. (2016). A review of research into stakeholder perspectives on inclusion of students with autism in mainstream schools. *International Journal of Inclusive Education*, 20(10), 1084–1096.

Rugoho, T., & Maphosa, F. (2017). Ostracised: Experiences of mothers of children with disabilities in Zimbabwe. *Gender Questions, 4*(1), 18- 37.

Schlebusch, L., Samuels, A. E., Dada, S. (2016). South African families raising children with autism spectrum disorders: Relationship between family routines, cognitive appraisal and family quality of life. *Journal of Intellectual Disability Research, 60*(5), 412–423.

Shivers, C. M, Sonnier-Netto. L., & Lee G.K, (2018). Needs and experiences of family caregivers of individuals with autism spectrum disorders across the lifespan.

Shorey, S., Ng, E., Haugan, G., & Law, E. (2019). The parenting experiences and needs of Asian primary caregivers of children with autism: A meta-synthesis. *PubMed.* https://doi.org/10.1177/1362361319886513.

Smith, L., Malcolm-Smith, S., de Vries, P. J. (2016). Translation and cultural appropriateness of the autism diagnostic observation schedule-2 in Afrikaans. *Autism*.

Spain, D., Sin, J., Paliokosta, E., Furuta, M., Prunty, J. E., Chalder, T., Murphy, D. G., & Happé, F. G. (2017). Family therapy for autism spectrum disorders. *Cochrane Database of Systematic Reviews*, *5*. Doi: 10.1002/14651858.CD011894.pub2.

Stroustrup, B. (2018). *The C++ Programming language* (4th ed.). London: Amazon.

Suma, K., Adamson, L.B., Bakeman, R. Robins, D., L & Abrams, D., N. (2016). After early autism diagnosis: Changes in intervention and parent–child interaction. *Journal of Autism Developmental Disorders,* 46, 2720–2733.

Synergies Economic Consulting. (2017). Economic costs of autism spectrum disorder in Australia. Synergies Economic Consulting. Retrieved from aeiou.org.au.

Tathgur, M. K., & Kang, H. K. (2021). Challenges of the caregivers in managing a child with autism spectrum disorder: A qualitative analysis. *Indian Journal of Psychological Medicine, 4*3 (5), 416–421. https://doi.org/10.1177/02537176211000769.

Tilahun, D., Hanlon, C., Fekadu, A., Tekola, B., Baheretibeb, Y., & Hoekstra, R. A. (2016). Stigma, explanatory models and unmet needs of caregivers of children with developmental disorders in a low-income African country: A cross-sectional facility-based survey. *BMC Health Services Research, 16*(1), 152. Doi: 10.1186/s12913-016-1383-9.

Tome, A. R. (2024). A critical analysis of the challenges faced by young people with neuro-developmental disorders in accessing sexual reproductive health services in Zimbabwe: A case of Zimcare Trust, Zimbabwe. *Journal of Social Issues in Non-Communicable Conditions & Disability, 3(*1), 209–222.

United Nations Children’s Fund (UNICEF). (2013). The state of the world’s children 2013: Children with disabilities. Retrieved from http://www.unicef.org/sowc2013.

United Nations. (2013). Addressing the socioeconomic needs of individuals, families and societies affected by autism spectrum disorders, developmental disorders and associated disabilities. (Report No. 67/82). Retrieved from: www.un.org/disabilities/documents/resolutions.

Van der Mark, J., E. & Verrest , H. (2016) Fighting the odds: Strategies of female caregivers of disabled children in Zimbabwe, *Disability & Society, 29*(9), 1412- 1427. https://doi: 10.1080/09687599.2014.934441.

WHO Rehabilitation 2030. (2017). A call for action plan: The need to scale up rehabilitation. World Health Organization, Geneva. Retrieved from http://www.who.int/disabilities/care/NeedToScaleUpRehab.pdf.

WHO. (2019, November 7). *Fact sheet on autism spectrum disorders*. WHO.

Wilson, S. A., & Peterson, C. C. (2018). Medical care experiences of children with autism and their parents: A scoping review. *Child Care, Health and Development, 44*(6), 807–817. https://doi.org/10.1111/cch.12611.

Xiaoli, L., Xianyang, L., & Yamini, L. (2019). Stigma among parents of children with autism: A literature review. *Asian Journal of Psychiatry*, *45*, 88-94.