




Parenting Children with Autism Spectrum Disorder (ASD) in Eswatini: An Assessment of the Challenges and Possible Intervention Strategies



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ABSTRACT

This study examined the experiences of parents raising children with autism spectrum disorder (ASD) in Eswatini. ASD is a complex neurological condition that affects brain function, leading to difficulties in various developmental areas such as social interaction, communication, and behaviour. It usually becomes apparent within the first three years of a child's life. This qualitative study, grounded in bioecological systems theory, aimed at uncovering the challenges faced by 20 parents of children with ASD in Eswatini, as well as the strategies they employ to manage their children's unique behaviours and the effective parenting approaches they use to care for them. Through in-depth, semi-structured interviews, this study sheds light on the experiences of these parents, using interpretative phenomenological analysis to identify emerging themes and patterns. The findings obtained revealed various challenges, including lack of financial support, lack of awareness, delayed diagnosis and difficult access to support services, among others. The study recommended strategies that can support parents living with autistic children, including various forms of therapy, teaching self-regulation, giving love, joining support groups, learning more about the condition and acquiring skills to manage the condition. The findings could offer valuable information to policymakers and support services, helping to develop future welfare plans, educational resources, and social support systems for vulnerable families in Eswatini and potentially other developing countries.

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INTRODUCTION

Eswatini's estimated prevalence of autism spectrum disorder (ASD) is 84.80, meaning that 84.80 out of 10,000 children receive a diagnosis of ASD.¹ ASD is recognized as a significant public health concern within global mental health services.² It is estimated that 1 in 100 children worldwide is affected by ASD.³ Approximately 75 million people globally live with autism, making up about 1% of the world's population. Qatar has the highest rate of diagnosed autism, while France has the lowest. Boys are about four times more likely to be diagnosed with autism than girls. While research on autism in Africa is

¹ Jinan Zeidan et al., "Global Prevalence of Autism: A Systematic Review Update," *Autism Research* 15, no.5(2022):778–90.

² World Health Organization., "Autism Spectrum Disorders: A Global Perspective. WHO," 2013.

³ World Health Organization., "Autism Spectrum Disorders: A Global Perspective. WHO."

growing, a concise estimate of the prevalence of ASD in Africa is not available. According to a survey of the literature, most of the African research on ASD was carried out in South Africa and Nigeria, with only a small number coming from eastern and northern Africa.⁴ An estimated 1% of autism research comes from sub-Saharan Africa.⁵

ASD is a neurological and developmental condition characterized by challenges in social communication and interaction, as well as restricted, repetitive behaviours and limited interests.⁶ These symptoms typically appear in early childhood and persist throughout life. More than 70% of individuals with ASD have at least one co-occurring psychiatric disorder, with over 40% experiencing two or more.⁷ Common comorbidities include anxiety disorders, attention deficit/hyperactivity disorder (ADHD), depression, intellectual disabilities, and seizures.⁸ The severity of these symptoms and their impact can vary widely among individuals, and the manifestations of ASD may range from mild to severe, often changing over time.⁹ With these existing attributes, ASD children need more consideration, and caring for them can be quite demanding. ASD affects not only the individual; families of individuals with ASD often face significant emotional and financial challenges due to high levels of anxiety, stress, and isolation associated with caregiving, as well as the extensive financial resources required.¹⁰ Studies reveal the prevalence of psychological disorders such as depression, anxiety, and obsessive-compulsive disorder among parents of individuals with a diagnosis of ASD.¹¹ Parents of children with ASD report higher levels of parenting stress compared to any other child-related disability today.¹² They may have a higher frequency of depression, fragility, exhaustion, and hopelessness. The levels of children's disruptive behaviour, resulting from difficulties with emotional dysregulation (outbursts and aggressive behaviour), are believed to be proportional to the levels of stress experienced by parents.¹³

Many families mistakenly view ASD as a disease and report experiencing stress regarding their child's future, along with chronic sadness stemming from the perceived loss of a "normal" child.¹⁴ Children with autism are often prescribed specialized therapies, educational interventions, assistive technologies, and other forms of support during major life transitions, which can be financially burdensome for families, especially those from lower socioeconomic backgrounds. These costs can have devastating effects on families.¹⁵ Families of children with ASD typically require up to three times more

⁴ A. Abubakar, S. Khan, and R. M. Santos, "Autism Research in Sub-Saharan Africa: A Review of the Literature.," *African Journal of Psychiatry* 19, no. 5 (2016): 1–8.

⁵ Yun-Ju Hsiao et al., "Parental Stress, Family Quality of Life, and Family-Teacher Partnerships: Families of Children with Autism Spectrum Disorder," *Research in Developmental Disabilities* 70 (November 2017): 152–62, <https://doi.org/10.1016/j.ridd.2017.08.013>.

⁶ Sepideh Ebrahimi Meimand et al., "Burden of Autism Spectrum Disorders in North Africa and Middle East from 1990 to 2019: A Systematic Analysis for the Global Burden of Disease Study 2019," *Brain and Behavior* 13, no. 7 (2023): e3067.

⁷ Yue Yu, Sally Ozonoff, and Meghan Miller, "Assessment of Autism Spectrum Disorder," *Assessment*, 2024.

⁸ Rachel Holden et al., "Investigating Bullying as a Predictor of Suicidality in a Clinical Sample of Adolescents with Autism Spectrum Disorder," *Autism Research* 13, no. 6 (June 21, 2020): 988–97, <https://doi.org/10.1002/aur.2292>.

⁹ Vesna Marinović and Birgit Träuble, "Vicarious Social Exclusion and Memory in Young Children.," *Developmental Psychology* 54, no. 11 (November 2018): 2067–76, <https://doi.org/10.1037/dev0000593>.

¹⁰ Nader Salari et al., "The Global Prevalence of Autism Spectrum Disorder: A Comprehensive Systematic Review and Meta-Analysis," *Italian Journal of Pediatrics* 48, no. 1 (2022): 112.

¹¹ R. Schnabel, G. Guberman, and D. Holstein, "Mental Health Challenges in the Families of Children with Autism: An Examination of Stress and Intervention Strategies.," *Journal of Family Psychology* 32, no. 4 (2020): 330–344.

¹² Kenneth Curley et al., "Stress Reduction Interventions for Parents of Children with Autism Spectrum Disorder: A Focused Literature Review," *Youth* 3, no. 1 (2023): 246–60.

¹³ Amy S. Weitlauf, Melisa L. McPheeters, and A. Hagedorn, "The Impact of Challenging Behaviors in Children with Autism Spectrum Disorder on Parental Stress: A Longitudinal Analysis," *Pediatrics* 145, no. 2 (2020): 1–9.

¹⁴ Y. Akbulut, "The Impact of Autism on Families: A Qualitative Study.," *Journal of Autism and Developmental Disorders* 49, no. 6 (2019): 2485–95; M. Nuri, B. Nuri, and Z. Nuri, "Financial Burden and Coping Strategies of Families with Children Diagnosed with Autism in Africa.," *Autism Research and Practice* 33, no. 7 (2018): 235–248.; S. Lutz, M. Wilson, and M. Diamond, "Parenting Children with Autism: A Qualitative Perspective on Emotional Wellbeing.," *International Journal of Child Psychology* 67, no. 3 (2012): 543–557.

¹⁵ J. Wang et al., "Parent-Reported Health Care Expenditures Associated with Autism Spectrum Disorders in Heilongjiang Province, China," *BMC Health Services Research* 12, no. 1 (2012): 7.; N. Kudaibergenova, "The Effects of Autism on Families in Eswatini: Understanding Social and Economic Challenges.," *Social Development Review* 45, no. 2 (2018): 82–98; T. A. Lavelle, D. L. Kuo, and L. L. McIntyre, "Cost of Autism Spectrum Disorders in the United States: An Analysis of Economic Impact.," *JAMA Pediatrics*, 168, no. 4 (2014): 392–98; Emine Yassıbaş, "The Impact of Autism on the Family: A Literature Review," *Journal of Intellectual Disability Research* 59, no. 3 (2015): 232–43.

financial support than families with neurotypical children,¹⁶ placing significant strain on parents and the overall family dynamic.¹⁷ Parents and siblings of children with ASD often report relational conflicts,¹⁸ and parents face difficult decisions, such as taking time off work to care for their children.¹⁹

Despite autism studies gaining significant recognition worldwide in recent years, the experience of raising a child with autism in Eswatini remains largely underexplored and underrepresented. The country is still in the early stages of awareness of ASD. A lack of understanding of autism persists in various sectors, including healthcare, education, and the broader community. This knowledge gap makes it challenging for children and individuals with ASD to access essential services, leading to stigma, discrimination, and widespread misconceptions about the condition. Unfortunately, children with ASD are often misperceived as spoiled or misbehaving, which can result in some parents choosing to conceal their children to avoid social ridicule, further perpetuating the silence surrounding the issue.²⁰

In recent years, specialised services have become available primarily in hospitals in the main towns of Eswatini, Manzini and Mbabane. Parents accessed diagnostic, speech therapy, and occupational therapy interventions at the National Referral Psychiatric Centre in Manzini, Mbabane Government Referral Hospital, and with private practitioners.²¹

This research aims to better understand the lived experiences of parents raising children with ASD by investigating the unique challenges they face. It will explore potential strategies to improve support for these parents, ultimately improving their parenting effectiveness. This study has the potential to contribute to the existing body of research, offering novel perspectives that can inform clinical practice and enrich the training of psychologists, neurologists, occupational therapists, and other healthcare professionals at both undergraduate and postgraduate levels. The research questions that underlie this study are as follows.

1. What are the challenges faced by parents raising autistic children in Eswatini?
2. What strategies can be put in place to improve support for parents raising children with autism?

LITERATURE REVIEW

Parenting children with ASD is often challenging due to the children's core characteristics.²² The core characteristics of children with ASD are impairments in social interactions and communication and repetitive behaviours along with restricted interests.²³ Emerging evidence suggests that parents of children with ASD report more significant levels of parenting stress compared to any other child-related disability today.²⁴ Parenting a child with ASD is a more stressful and challenging experience, especially in countries like Eswatini, where numerous support services are limited.²⁵ In many communities, a lack of awareness and understanding of ASD can lead to misconceptions about the condition. At the family level, ASD has been misunderstood as “kuloywa” (the use of witchcraft on someone), whereas at the community level, it has been labelled as a “bad omen resulting in social isolation for both the child and

¹⁶ Nuri, Nuri, and Nuri, “Financial Burden and Coping Strategies of Families with Children Diagnosed with Autism in Africa.”

¹⁷ Lavelle, Kuo, and McIntyre, “Cost of Autism Spectrum Disorders in the United States: An Analysis of Economic Impact. ”

¹⁸ G. Divan et al., “Challenges, Coping Strategies, and Unmet Needs of Families with a Child with Autism Spectrum Disorder in Goa, India,” *Autism Research* 5, no. 3 (2015): 190–200.

¹⁹ Y. Akkuş, M. Küçük, and B. Yıldız, “Family Adjustment and Stress of Parents Raising a Child with Autism in Eswatini.,” *International Journal of Family Therapy* 42, no. 3 (2020): 456-469.

²⁰ E. Mvubu, “The Experience of Autism in Eswatini: Understanding the Impact on Families,” *South African Journal of Disability Studies* 22, no. 4 (2018): 50–58.

²¹ M. Dlamini, “Addressing the Challenges Faced by Families of Children with Autism in Eswatini. ,” *Swazi Journal of Health*, 9, no. 2 (2012): 55-65.

²² C., Dissanayake et al., “ An Exploratory Study of Autism Traits and Parenting,” *Journal of Autism and Developmental Disorders* 50, no. 7 (2020): 2593–2606.

²³ American Psychiatric Association, “Highlights of Changes from DSM IV TR to DSM 5,” American Psychiatric Association, 2013, <http://www.dsm5.org/Pages/Default.aspx>.

²⁴ M. S. Weinberg, S. Peterson, and L. Carter, “Parenting Stress in Families of Children with Autism Spectrum Disorder: A Meta-Analysis of Global Studies,” *Research in Autism Spectrum Disorders* 63 (2021): 101–437.

²⁵ K.K. Shattawi, K. K. Dodd, and W. L. McCarty, “Parent-Child Interaction and the Development of Autism Spectrum Disorder: A Cultural Approach,” *Research in Autism Spectrum Disorders* 29 (2020).N. Falk, K. Norris, and M. G. Quinn, “ Parenting Children with Autism Spectrum Disorder: The Impact of Stress and Other Factors,” *Journal of Autism and Developmental Disorders* 44, no. 8 (2014): 1983–96.

the family.²⁶ Incapacities like these yield other negative effects, such as heightened stress, risk of family poverty, alienation from community interaction, lowered status of children with ASD, and increased exposure to various forms of abuse, including sexual abuse.²⁷ Oftentimes, a lack of knowledge about ASD further negatively affects a child's development, increasing the need for additional support. The financial burden associated with raising a child with ASD can be substantial. Early diagnosis and intervention are crucial for optimal outcomes, yet access to specialized services and early intervention programs may be limited in Eswatini. Families can struggle with the treatments prescribed for autistic children, which can marginalize the children and their parents.²⁸

The lack of support for an autistic child has a profound impact on family dynamics, often leading to deteriorating relationships, heightened financial strain, and increased psychological distress.²⁹ Parents raising children with autism face immense challenges in addressing their child's behavioral issues, facilitating communication, teaching essential life skills, safeguarding their child from harm, and preparing them for adulthood.³⁰ In Eswatini, parents of children with autism spectrum disorder (ASD) face a range of personal and societal difficulties, as highlighted by Nkonyane et al.³¹ These include stigma, financial hardship, and strained relationships. Additionally, parents must contend with the developmental delays, communication struggles, and difficult behaviors associated with ASD. The education and healthcare systems also present significant barriers, with limited resources, insufficient training, and delayed diagnoses further exacerbating the challenges families experience.³²

Synthesis

ASD is a complex neurodevelopmental condition affecting individuals worldwide, including Eswatini. Globally, approximately 1% of the population is diagnosed with ASD.³³ Although research on ASD in Africa is growing, specific data on prevalence in Eswatini are limited. However, estimates suggest that Eswatini may have a higher prevalence than many other countries, with 84.80 out of 10,000 children diagnosed.³⁴ Individuals with ASD in Eswatini face significant challenges, particularly due to limited awareness and support services. Parents of children with ASD often experience immense stress and strain dealing with issues such as delayed development, communication difficulties, and challenging behaviours.³⁵ The lack of specialized services, including therapy and early intervention, further exacerbates these challenges. Societal stigma and misconceptions surrounding ASD also contribute to the difficulties faced by individuals with ASD and their families in Eswatini. Limited understanding of the condition can lead to discrimination, isolation, and a lack of support. Additionally, future research directions require addressing the needs of individuals with ASD in Eswatini, including increasing awareness of the condition, improving access to early intervention and specialized services, and providing support to families by working together with healthcare professionals, educators, policymakers, and community members. This can create a more inclusive and supportive environment for individuals with ASD in Eswatini.

THEORETICAL FRAMEWORK

Bronfenbrenner's Bioecological Systems Theory

²⁶ A. Khumalo and Z. Dlamini, "Cultural Attitudes and Social Stigma Surrounding Autism in Eswatini: Implications for Community-Based Support," *African Journal of Psychiatry* 22, no. 4 (2022): 345-356.

²⁷ Mvubu, "The Experience of Autism in Eswatini: Understanding the Impact on Families."

²⁸ S. A. Salgado, "Autism Services in Eswatini: Challenges and Opportunities for Healthcare Professionals," *Journal of Health Research* 44, no. 1 (2020): 29-40.

²⁹ Kudaibergenova, "The Effects of Autism on Families in Eswatini: Understanding Social and Economic Challenges"; Yassıbaş, "The Impact of Autism on the Family: A Literature Review."

³⁰ Autism Speaks, "Autism Speaks," June 11. <https://www.autismspeaks.org/about-us>, 2012.

³¹ Fanele Nkonyane, Thavanesi Gurayah, and Thanalutchmy Lingah, "Challenges and Coping Strategies of Parents of Children with Autism Spectrum Disorder in Eswatini," *Journal of Child & Adolescent Mental Health* 33, no. 1-3 (September 2, 2021): 32-41, <https://doi.org/10.2989/17280583.2023.2259428>.

³² Nkonyane, Gurayah, and Lingah, "Challenges and Coping Strategies of Parents of Children with Autism Spectrum Disorder in Eswatini."

³³ World Health Organization, "Global Impact of COVID-19 on Human Rights and Development," *WHO Technical Report Series*, 2023.

³⁴ Zeidan et al., "Global Prevalence of Autism: A Systematic Review Update."

³⁵ Nkonyane, Gurayah, and Lingah, "Challenges and Coping Strategies of Parents of Children with Autism Spectrum Disorder in Eswatini."

The research was influenced by Urie Bronfenbrenner's bioecological systems theory, which seeks to explain how various layers of environmental systems affect human development.³⁶ These five systems—micro-, meso-, exo-, macro-, and chrono-systems—are interconnected and shape individual well-being. This study applied bioecological systems theory to explore the distinct experiences of parenting children diagnosed with ASD in Eswatini. The Micro-System is the first and closest system, consisting of the interpersonal relationships between the developing individual and the people in systems with whom they actively engage on physical, emotional, psychological, and social levels.³⁷ This theory focuses on the interactions between individuals and their environment, with particular emphasis on the microsystem, including family, peers, and related social settings. The Meso-System, the second level of human development, examines the connections between two or more micro-systems.³⁸ Other systems include the Exo-System, which refers to external factors impacting larger systems such as health, education, and community; the Macro-System, which involves broader social elements like cultural beliefs and socioeconomic status; and the Chrono-System, which addresses events that affect individual development, such as starting school or experiencing a family death.³⁹ For autistic individuals and their families, the microsystem could be the most influential through direct contact, but all systems interact together and with external forces. For example, when the education system provides a positive environment for children with autism, that influences how they interact with their autistic peers, classmates, and friends. This may positively or negatively influence the child's condition, depending on the nature of these interactions. Together, these systems form unique experiences and developmental outcomes for parents and their children regarding acceptance, access, health, and inclusion. Bioecological systems theory is relevant as a theoretical lens for exploring how these factors interact to influence the experiences and challenges faced by parents of children with autism in Eswatini.

METHODOLOGY

An exploratory-descriptive qualitative research design was implemented to investigate the experiences of parents with ASD children. The qualitative approach provided a deeper understanding of the unique experiences faced by parents with ASD children and their families, focusing on the meanings carried by the participants.⁴⁰ The exploratory aspect helped examine the lived experiences of this population because limited data are available on this topic within the literature in Eswatini.⁴¹ The descriptive aspect of this study aimed to go beyond simple observation and data recording to gain insights and to provide a true picture of the challenges from the perspective of parenting an autistic child.⁴² This involved a deeper engagement with the data to interpret and understand the experiences of participants and the implications thereof, thereby enhancing understanding of how they experience the journey of parenting both at personal and community levels.⁴³

Population, Sample, and Sampling

As stated earlier, in Eswatini, the estimated prevalence of ASD is 84.80 per 10,000 children, indicating that 84.80 children in this population receive a diagnosis of ASD.⁴⁴ Following the research design, participants were recruited using purposive sampling. Eligible participants included parents or primary

³⁶ Urie Bronfenbrenner, *The Ecology of Human Development: Experiments by Nature and Design* (Cambridge, MA: Harvard University Press, 1979).

³⁷ M. Mabaso, "Exploring Bronfenbrenner's Bioecological Model: Understanding Human Development in Complex Environments.," *Journal of Developmental Psychology* 49, no. 6 (2020): 49-60.

³⁸ Y. Yang, "Bronfenbrenner's Ecological Systems Theory: An Overview.," *Online Psychology Degrees*, 2021.

³⁹ Urie Bronfenbrenner and Pamela A Morris, "The Bioecological Model of Human Development," *Handbook of Child Psychology* 1 (2007).

⁴⁰ D. E. Gray, "Ten Years on: A Longitudinal Study of Families of Children with Autism.," *Journal of Intellectual & Developmental Disability* 27, no. 3 (2002): 215-22.

⁴¹ D. Makwakwa and T. Makufa, "The Role of Parent Support in Raising Children with Autism in Eswatini.," *Journal of Special Needs Education* 35, no. 5 (2020): 1124-35.

⁴² D. Keen, J. Sigafos, and T. Attwood, "Parents' Perceptions of Interventions for Children with Autism Spectrum Disorder: A Qualitative Analysis.," *Journal of Autism and Developmental Disorders* 40, no. 12 (2010): 1537-1546.

⁴³ J. B., Brobst, J. R. Clopton, and C. Hendricks, "Parents of Children with Autism: The Importance of Social Support.," *Journal of Autism and Developmental Disorders* 39, no. 9 (2009): 1152-1163.

⁴⁴ Zeidan et al., "Global Prevalence of Autism: A Systematic Review Update."

caregivers of children with an ASD diagnosis. The study involved 20 participants who were recruited from the two autism centres available in Eswatini. The staff of these centres identified and recruited people who met the study criteria, introducing the study to interested parents. The parents received detailed information and contact details of the researchers, who further explained the study and conducted interviews through face-to-face meetings, phone calls and written responses.

Data Collection

The data generation method involved semi-structured individual interviews, each lasting between 13 to 20 minutes, which were recorded and transcribed. The sample comprised 20 parents. The interviews were recorded on audio tape and varied in duration from 10 to 20 minutes, including spoken responses and written contributions. To accommodate participants' language preferences, interviews were conducted in both English and SiSwati interchangeably. An interview schedule served as the primary instrument for data collection, featuring open-ended questions designed to encourage comprehensive and insightful responses from participants. The researchers employed prompting and probing techniques during the interviews to facilitate deeper discussion. Additionally, a pilot study was conducted to validate the research instrument.

Data Analysis

The SiSwati section was translated into English after the audio recordings were transcribed verbatim. Reflexive thematic analysis, an inductive approach that identifies themes and patterns of meaning across a dataset, was employed to analyze the transcripts.⁴⁵ The analysis followed the procedures outlined by Braun and Clarke⁴⁶ and the six-step process proposed by Clarke and Braun,⁴⁷ which includes familiarizing oneself with the data, coding, identifying themes, reviewing themes, defining and labeling themes, and writing up the findings. To fully immerse themselves in the data, the researchers read the transcripts multiple times. The coding process involved a thorough review of the entire dataset to identify data relevant to the research objectives. During this phase, the researchers went beyond mere description and summary, engaging in conceptual analysis, a key aspect of reflexive thematic analysis.

Ethical Considerations

Since all participants were drawn from autism centres in Eswatini, the researchers initially obtained letters of goodwill from the directors of these centres, clearly explaining the purpose of the research. All participants provided their informed consent by signing consent forms and confidentiality was strictly maintained. To protect participants' identities, code names were used in all transcribed material; for example, we assigned labels such as Par 1 for Parent One, Par 2 for Parent Two, and so on.

PRESENTATION OF FINDINGS AND DISCUSSIONS

The first research question sought to identify the challenges faced by parents who raise autistic children in Eswatini. From this research question, the following key themes emerged.

Challenges faced by parents who raise autistic children

Lack of awareness and understanding

Parents perceived limited awareness and insight into ASD by health professionals, educators, and the general public. Most of these parents went through a difficult period when they received their children's ASD diagnosis:

My son's diagnosis of autism was initially met with shock and confusion. It was my first time hearing the name. As I sought to understand this condition, more shock came from some healthcare professionals who would also ask me what this "autism" was. (Par 2)

⁴⁵ Virginia Braun and Victoria Clarke, "Thematic Analysis: A Practical Guide," 2021; Victoria Clarke and Virginia Braun, "Teaching Thematic Analysis: Overcoming Challenges and Developing Strategies for Effective Learning," *The Psychologist* 26, no. 2 (2013).

⁴⁶ Braun and Clarke, "Thematic Analysis: A Practical Guide."

⁴⁷ Clarke and Braun, "Teaching Thematic Analysis: Overcoming Challenges and Developing Strategies for Effective Learning."

Parents attributed delayed diagnosis and misdiagnosis to the limited awareness of health professionals. Oftentimes, a lack of knowledge about ASD further negatively affects a child's development, increasing the need for additional support. The financial burden associated with raising a child with ASD can be substantial. This finding echoes the sentiments shared by Mvubu that limited awareness had detrimental effects, such as delayed intervention, overwhelming stress for families, and alienation of autistic children and families from community interaction, as well as poor quality of life.⁴⁸

Lack of financial support from the Government.

The diagnosis of a child with ASD brings financial challenges, amongst others. Parents of children with ASD were burdened with the expense of school, therapy, medication, and travel costs.

We have not received a disability grant even though we have registered our child with autism with the social welfare department every year since he was two years old in 2019. Now, he is six years old. (Par 1)

There are times when my child skips therapy because of the unavailability of travelling and therapy costs. (Par 18).

Individuals with autism, despite facing significant challenges, are often not recognized as eligible for the support and services available through social welfare programs. This lack of recognition leads to their marginalization and results in limited access to the essential resources and services they require. Autistic children frequently need specialized therapies, educational interventions, assistive technologies, and other forms of support during key life transitions, all of which can be prohibitively expensive for families of lower socioeconomic status.⁴⁹ Nuri et al. highlighted that families of children diagnosed with ASD require up to three times more financial support than families with only allistic children, which can place significant stress on parents and strain the overall family dynamic.⁵⁰

Lack of empathy from healthcare professionals

Parents frequently expressed frustration with the perceived lack of empathy of healthcare professionals during visits to healthcare institutions for the treatment of their children with ASD.

Despite significant efforts to seek medical attention for my daughter, I encountered numerous challenges. Her strong physical presence and anxiety in unfamiliar settings, stemming from limited social experiences, hindered access to healthcare. Adherence to strict protocols prevented healthcare providers from providing in-person assistance, leading to instances of remote medication prescriptions. (Pt 19)

Parents felt that medical experts did not fully appreciate the challenges they faced as caregivers and often did not take into account their child's behaviour and needs.

Because of the hardship with social interaction, this problematic behaviour adversely interferes with my child getting proper treatment. (Pt 12)

Many of these parents experienced a challenging and emotional period upon receiving their children's ASD diagnosis and the seeming lack of empathy from healthcare professionals.

My son's diagnosis of autism was initially met with shock and confusion. It was my first time hearing the name. As I sought to understand this condition, more shock came from some healthcare professionals who would also ask me what this "autism" was. (Par 2)

Experiences of embarrassment

⁴⁸ Mvubu, "The Experience of Autism in Eswatini: Understanding the Impact on Families."

⁴⁹ Wang et al., "Parent-Reported Health Care Expenditures Associated with Autism Spectrum Disorders in Heilongjiang Province, China."; Kudaibergenova, "The Effects of Autism on Families in Eswatini: Understanding Social and Economic Challenges."; Lavelle, Kuo, and McIntyre, "Cost of Autism Spectrum Disorders in the United States: An Analysis of Economic Impact."

⁵⁰ Nuri, Nuri, and Nuri, "Financial Burden and Coping Strategies of Families with Children Diagnosed with Autism in Africa."

Sometimes parents are embarrassed by their kids' behaviour and choose not to take them to places where they might not be able to handle it. Par 3 and Par 4 confirmed this:

When in town with my kid, he would cry uncontrollably and run around the store, and I would end up chasing her through the entire supermarket.

I was sitting in a kombi behind the driver, and my child suddenly burst out so loud that the kombi driver was shocked and nearly caused an accident.

Children getting lost

Parents also reported that their children got lost. Par 6 stated :

Sometimes, my child gets lost, and I go out to find him after he leaves the house, but other times, he finds his way home by himself.

Labelling and discrimination

Living and interacting with others is challenging when a child has autism. This is due to a lack of awareness of the condition and the associated challenging behaviours exhibited by the child with ASD. It is a general view that parents are incapable of disciplining their children or teaching them manners.

People in the neighbourhood where I live make negative comments about my child, and even his peers term him a spoiled child since they do not understand his condition. (Par 8)

I often find myself being overly protective in public settings due to concerns about my child's adherence to societal norms. Thus, people will stare and their faces say what they think, like we are failing to discipline our son, whereas he is special and not like other children. (Par 9)

Naturally occurring nonverbal clues in autistic children are just different. Parents believed that this was risky and potentially more damaging to their children with ASD. When they do not mean to be, autistic children are frequently accused of being disrespectful, impolite, or aggressive. They may use gestures and body language very little or not at all, or you may find it challenging to read their body language. In addition to having little to no facial expression, they could talk overly loudly or monotonously.⁵¹ All of these can be misinterpreted as rudeness or hostility, such as social isolation and bullying.⁵² This finding echoes the sentiments shared by Mvubu that ASD children are often misunderstood as spoiled brats.⁵³ Therefore, some parents opt to hide their children from ridicule and refuse to answer this challenge.

Counsellors' terminology in the Autism sector and how information is relayed to Parents

Parents expressed dissatisfaction with the commonly used terms in the autism sector and their persistent emphasis on autism's incurability without elaborating on the benefits and advantages of treatment and therapy, saying that:

Many of the big words used by medical professionals—such as therapy, cognitive, etc.—that I don't understand and that don't help me. Perhaps they could explain these terms in siSwati for me. (Par 10)

My neighbour and I were going to therapy when she abruptly stopped. When I asked her why she wasn't taking her child to therapy, she said that the therapist had informed her that there is no cure for Autism. It is something you are born with and will have for your whole life. So, she

⁵¹ American Psychiatric Association, "Highlights of Changes from DSM IV TR to DSM 5."

⁵² National Autistic Society, "Education Report 2023: Understanding Autism in School –Peer Relationships, Bullying, and Transitions," National Autistic Society, 2023, <https://www.autism.org.uk/what-we-do/news/education-report-2023>.

⁵³ Mvubu, "The Experience of Autism in Eswatini: Understanding the Impact on Families."

felt that it was a waste of time and money to continue seeing a therapist for something that is incurable. (Par 20)

The Counsellors/Therapists often use big terms when counselling, and this makes it difficult to understand what they are trying to share, leading to counselees not benefiting at all. Parents are further discouraged from continuing therapy due to the persistent emphasis of healthcare professionals on the incurability of autism without elaborating on the benefits and advantages of treatment and therapy, and participants felt it was a waste of money, time and energy.

Delayed developmental milestones

Parental concerns about ASD included managing their children's difficult behaviours, poor communication and interaction and delayed developmental milestones. Like parents of typically developing children, parents of children with ASD had comparable expectations.

At six years old, he has only recently begun to speak like a two-year-old. (Par 12)

The parents claimed that communication problems had a detrimental impact on their kids' health. Not being able to express themselves, children end up being violent towards their parents in a way to convey a certain message. Another parent shares the same sentiments:

Due to his limited verbal communication abilities, my son often relies on physical actions to express himself. When he experiences physical harm, he may imitate the aggressive behaviour towards me, inadvertently mirroring the violence he has endured. (Par 13)

Sometimes, he would bring you his food dish when he was hungry, but other times, he would sob uncontrollably, leaving me unsure of what to do. (Par 9)

Emotional/Psychological issues

The difficult behaviours displayed by their children with ASD also caused stress, depression, anxiety and anger issues for the parents. Par 10 expressed that:

I get stressed by his inconsolable cries, not knowing what he wants and how to help him.

I sometimes get tired of his outbursts and ask my assistant to take him away.

Not being able to calm the child down quickly causes the parent to become agitated as well, which strains the emotions of their parents and prevents them from providing the proper care for the child in that situation. This can be very distressing both for the child and the parent. Studies reveal the prevalence of psychological disorders such as depression, anxiety, and obsessive-compulsive disorder among the parents of individuals with a diagnosis of ASD.⁵⁴ Curley et al., indicated that parents of children with ASD report higher levels of parenting stress compared to any other child-related disability.⁵⁵ They may have a higher frequency of depression, fragility, exhaustion, and hopelessness.

Balanced Diet Issues

Parents of autistic children have reported that they find it difficult to include balanced/nutritious foods in their autistic children's meals since their children are selective eaters.

My son eats rice every day, so I had to find 100 ways of cooking rice in a balanced way, incorporating vegetables and all the necessary nutrients. (Par 14)

Children are not being fully supported by mainstream schools

Parents cited restricted educational options and inadequate preparation for teachers as obstacles to the educational system. Parents reported that teachers complained that Autistic children are disruptive in

⁵⁴ Schnabel, Guberman, and Holstein, "Mental Health Challenges in the Families of Children with Autism: An Examination of Stress and Intervention Strategies. "

⁵⁵ Curley et al., "Stress Reduction Interventions for Parents of Children with Autism Spectrum Disorder: A Focused Literature Review."

normal schools, and parents lamented that their children attend school just to be marginalized by teachers.

Our children are falling behind. The curriculum never focuses on our children's capabilities. My son attends public school; he occasionally arrives home with a completed task, but on other days, he has not accomplished anything. (Par 12)

There is no school for children with autism in Eswatini. Public and Private schools are not able to accommodate autistic children. Private schools that claim to specialise in the care of the autistic sell a pipe dream; they are only in it for financial gain. Our son is now home-schooled, a costly and demanding alternative. (Par 15)

Parents shared the many occasions they had been contacted to fetch their children during school hours, as the teachers could not cope with their children's challenging behaviours.

I enrolled my child in preschool, and the school informed me that they could not care for him because he requires extra care, and they even reimbursed my school fees (Par 10)

Although the integration of students with disabilities into regular classrooms alongside their typically developing peers provides opportunities for social interaction for all students, academically, it does not benefit them. Parents were concerned that their children's behavioural, and academic performance would always be inferior to others and were unsure how to help. This result supports the views expressed by the Swaziland Ministry of Education and Training that the majority of students with ASD leave regular primary schools in Eswatini before they reach secondary school, and their academic failure rate is rising.⁵⁶ Parents believed that schools were not properly set up for autistic children and that teachers were incapacitated. Similarly, the challenges Mpofu and Mkhathshwa emphasized were the absence of adequate facilities, inadequate training for teachers, a lack of funding, a lack of assistive technology, and a paucity of specialized staff in mainstreaming schools.⁵⁷

Limitations within the healthcare system

The barriers to the health system identified by parents included the lack of awareness of ASD, delayed diagnosis, limited specialised services, and a negative attitude of health professionals. The parents' perceptions were that health professionals had limited awareness of ASD. Parents attributed the delayed diagnosis to the health professionals' limited awareness:

Delayed diagnosis and misdiagnosis

It took us about 2 to 3 years to get to a correct diagnosis. At first, the expert opinion was that our son was deaf, therefore the speech delay, and we later found out it was autism (Par 16).

Parents expressed disappointment that healthcare professionals gave them the wrong diagnosis:

We brought him to the hospital when he was four years old, and he was sent to a theatre for tongue release, but he still couldn't speak. Only to be later diagnosed with autism (Par 17)

This finding echoes the sentiments shared by Mvubu that limited awareness had detrimental effects, such as delayed intervention, overwhelming stress for families, and alienation of autistic children and families from community interaction, as well as poor quality of life.⁵⁸

Difficulty Assessing Support Services

Parents shared their difficulties in accessing services. Some parents travelled long distances with their children to the main towns for therapy services:

⁵⁶ Swaziland Ministry of Education and Training, "Annual Report on Education Statistics and Inclusion in Schools for Children with Disabilities.," 2018.

⁵⁷ Phumuzani Mpofu and Nhlanhla Mkhathshwa, "The Practicality of Inclusive Education in Eswatini Primary Schools," *International Journal of Educational Management & Development Studies* 5, no. 4 (December 31, 2024): 158–77, <https://doi.org/10.53378/ijemds.353123>.

⁵⁸ Mvubu, "The Experience of Autism in Eswatini: Understanding the Impact on Families."

I travel from Siteki to Manzini with my son for Therapy because these services are unavailable in my region. There are times when my child skips therapy because of the unavailability of travelling and therapy costs. (Par 18).

His prescription drugs may occasionally be out of supply for several months at the National Psychiatric Centre and government institutions. I ultimately get it from a pharmacy, and the cost is high (Par 9).

Long waiting times for medical appointments, particularly in emergencies, often compel parents to seek care from private healthcare providers. (Par 13)

Parents complained about travelling from far places only to be given a future appointment and turned back, and also shortages of medication in these hospitals, which often resulted in disruptions to treatment regimens as purchasing from the pharmacy was costly. Specialised services are available primarily in hospitals in the main towns of Eswatini. Parents accessed diagnostic, speech therapy, and occupational therapy interventions at the National Referral Psychiatric Centre in Manzini, Mbabane Government Referral Hospital, and with private practitioners.⁵⁹

Strategies that can be implemented to improve support for parents living with children with autism

Parents who live with children with autism suggested several strategies that can be implemented to improve their support effectively. In navigating the complexities of raising a child with autism, the diversity of parenting support and the importance of individualized strategies were revealed. It was clear that there is no one-size-fits-all solution to parenting an autistic child. Parents suggested the following:

Therapy and Autism friendly therapists

Therapy is one of the effective strategies that parents revealed to raise their children.

We are currently pursuing speech and occupational therapy for our child. I needed to learn how to self-regulate and stimulate language for my son at home because there's only one speech and language therapy (Par 13)

We maintain a consistent daily steady schedule for our son; as such, children need routines.

Parents reported that autism-friendly therapists made their parenting easy;

My therapist is supportive and doesn't charge me if my child has meltdowns during therapy to the point where he is unable to participate. (Par 19)

Providing love

Parents reported that following a meltdown, their kids felt guilty about what they had done, over which they had no control, so they would console and show them love.

I ensure that I constantly show my child love. I just love him and tell him often, even if he might not reciprocate.

Self-regulation

Parents reported using self-regulation abilities and breathing methods to relax and soothe their children:

I taught my child how to self-regulate, co-regulation, and breathing techniques just to calm him. I have to do it and have to teach my child how to do it, even if he is overwhelmed now; it's easier to calm him down in a short period of time. (Par3)

Joining support groups

Parents revealed that support plays a key role. Education support, including lifelong learning, health, improving knowledge and awareness and social care, is essential to provide individuals with appropriate

⁵⁹ Dlamini, "Addressing the Challenges Faced by Families of Children with Autism in Eswatini. ."

resources and to help increase resilience. Parents revealed that being part of a parent support group has helped them learn from other parents, sharing evidence and best practices.

To access support, I always contact other parents. Other parents will have similar experiences, and knowing that others have been through it helps me to feel that I am not alone. (Par 4)

Some of the tools I used, I learned from other parents, like how to include all the minerals and vitamins in my child's meal, which has helped a lot. (Par7)

Parents reported experiences of spiritual exhaustion, where they would ask God why that was happening and ask for provision so they would derive a positive meaning of their journey through their spirituality, receiving spiritual support:

My church is autism-friendly. After I declared that my child had autism, they were very supportive, they understood, he moves around and climbs, and they let him be. (Par 3)

Learning and Skills

Parents revealed that knowledge was crucial to them. They want to be equipped with knowledge about autism,

I want to learn what autism is, what happens in the brain, and the challenging behaviours they are to exhibit. Once I know that, I also need skills on how to cope, self-regulate, and stimulate language in my child (Par 110)

Parents indicated that it gets better when their children become independent and can do things by themselves, as it takes the burden of caregiving from the parents.

Discussion Summary

From the study, it has been revealed that Eswatini parents of children with ASD had to bear an enormous caregiving load every day to manage the difficulties associated with ASD. The government does not fully support the journey of autistic children and their families financially, educationally, socially, and with the provision of health services. Special teachers are a necessity for the effectiveness of mainstreaming schools. There is a need for decentralisation of support services in order to be accessible to all children. Children with ASD require caregivers to be equipped with the information and be equipped with skills necessary to meet their day-to-day requirements and manage life. Dealing with ASD continues to be difficult due to a lack of resources, unfavourable public opinions of the disorder, and little understanding of it. Promoting interventions that are tailored to the needs of families of children with ASD requires cooperation from schools, support groups, and health professionals.

RECOMMENDATION

From these findings, it is therefore recommended that the government provide support in the form of disability grants, subsidies for healthcare, and education costs. It is also recommended that decentralizing autism specialist services to Tinkhundla centers could enhance accessibility for children with autism in rural areas and all the regions of Eswatini. Counsellors simplify their terminology and even use the siSwati language, or interpreters were possible to enhance understanding of the condition by the parents and the community at large. Although mainstream schooling was recommended for social integration, it was often necessary to provide specialised learning support where teachers have appropriate preparation and training to accommodate the specific needs of autistic children. Additionally, ongoing professional development for healthcare providers is essential to improve the quality of assessment and treatment for children with ASD, where the aim is for a therapist to think from the autistic person's perspective.

CONCLUSION

In conclusion, this study highlights the multifaceted challenges faced by parents raising children with autism in Eswatini, encompassing emotional, social, financial, and systemic barriers. Parents encounter

limited awareness and empathy from healthcare professionals, delayed or incorrect diagnoses, inadequate access to specialized services, and minimal government support, all of which intensify their stress and feelings of isolation. Social stigma, labelling, and discrimination further marginalize both the parents and their children, often resulting in self-isolation to avoid public embarrassment. Financial burdens are exacerbated by the high cost of therapy, medication, and specialized education, which is largely unavailable or insufficient in mainstream schools. Despite these obstacles, parents demonstrate remarkable resilience through strategies such as therapy, self-regulation techniques, love and emotional support, participation in support groups, spiritual engagement, and a commitment to acquiring knowledge and skills to better care for their children. These findings underscore the urgent need for comprehensive interventions in Eswatini, including public awareness campaigns, training for healthcare and educational professionals, expansion of specialized services, and financial support structures, to enhance the quality of life for autistic children and their families.

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