

Experiences of Young Mothers Caring for Children with ASD in Eswatini: Challenges and Coping Strategies

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Abstract

Raising a child with Autism Spectrum Disorder (ASD) presents unique challenges, particularly for young mothers who often lack experience, resources, and support systems. In Eswatini, these mothers face significant obstacles, including social stigma, financial strain, limited access to specialized services, and emotional stress. These difficulties are exacerbated by Eswatini's broader socio-economic context, marked by poverty, inadequate healthcare resources, and pervasive disability-related stigma. This study employs a qualitative case study approach, utilizing a desktop review of literature to examine the experiences of young mothers in Eswatini who are raising children with ASD. Findings indicate that these mothers face severe emotional, financial, and social challenges but employ various coping strategies such as seeking social support, financial planning, advocacy, self-care, and community engagement. Understanding these experiences is crucial for informing policies and interventions that support young mothers and improve services for children with ASD in low-resource settings. The study contributes to the growing body of literature on ASD caregiving in sub-Saharan Africa, highlighting the need for targeted interventions. It emphasizes the importance of government support, community awareness campaigns, and accessible healthcare services to enhance the well-being of both mothers and children. Through an extensive review of recent studies, this research sheds light on the socio-cultural and economic realities of ASD caregiving in Eswatini and suggests practical recommendations to improve conditions for affected families.

Keywords: Young mothers, ASD, Autistic, Special needs, Young children

Introduction

Raising a child with Autism Spectrum Disorder (ASD) is a journey fraught with unique challenges, particularly for young mothers who often lack the experience, resources, and support systems needed to navigate this complex terrain. The American Psychiatric Association's Diagnostic Statistical Manual of Mental Health Disorders (DSM-5) (2022: 154) defines ASD as "a single disorder that includes disorders that were previously considered separate autism, Asperger's syndrome, childhood disintegrative disorder, and pervasive developmental disorder not otherwise specified". In Eswatini, young mothers with children living with ASD face a myriad of obstacles, including social stigma, financial strain, limited access to specialized services, and emotional stress. These challenges are compounded by the broader socio-economic context of Eswatini, a developing nation grappling with poverty, limited healthcare resources, and pervasive social stigma surrounding disability. Global research indicates that parents of children with ASD experience higher levels of stress and

psychological distress compared to parents of neurotypical children (Hayes & Watson, 2013). This burden is magnified in low-resource settings where access to specialized care and support services is limited (Lai et al., 2020).

Recent studies have highlighted the multifaceted challenges faced by mothers of children with ASD, particularly in low-resource settings. According to Smith et al. (2018), mothers of children with ASD often experience higher levels of stress and depression compared to mothers of typically developing children. This is exacerbated in contexts like Eswatini, where access to specialized services is limited and social stigma surrounding disability is prevalent (Jones & Petersen, 2021). Furthermore, financial strain is a significant barrier, as the cost of therapies, medications, and specialized education can be prohibitive for families in low-income settings (Khan et al., 2019).

In Eswatini, young mothers face additional hardships due to socioeconomic constraints, cultural misconceptions about ASD, and systemic gaps in healthcare and education. Studies indicate that African countries generally have fewer diagnostic and intervention resources for ASD, leading to late diagnosis and limited therapeutic options (Franz et al., 2017; De Vries, 2020). Furthermore, stigma and misinformation surrounding ASD can lead to social exclusion, increasing the psychological distress of affected families (Tekola et al., 2020). Financial strain is another major concern, as specialized care, therapy, and appropriate educational programs are often costly and inaccessible (Samadi & McConkey, 2018). Lazarus and Folkman's transactional model of coping and stress argues that stress is a result of a transaction between an individual and the surrounding environment. In this situation, stress is a result of perceived challenges emanating from the environment. Therefore, such perceived challenges need one to adapt and develop coping strategies for survival and mental well-being. These strategies may be adaptive or maladaptive. Consequently, it affects the caregiver's mental well-being as survival depends on the route they take in response to the presence of many stressors.

Several studies have explored the intersection of socio-economic status and ASD caregiving, emphasizing the role of financial stability in accessing therapeutic interventions. A study by Oti-Boadi and Oppong Asante (2017) on Ghanaian mothers of children with ASD found that limited income significantly restricted access to speech therapy, occupational therapy, and specialized education. Similarly, Pillay and Girdler (2023) found that in South Africa, families in lower-income brackets had reduced access to early intervention programs, resulting in poorer developmental outcomes for children with ASD. This indicates that financial constraints are a pervasive issue across multiple African contexts, reinforcing the

need for targeted policies that address economic disparities in ASD caregiving. Moreover, research highlights the psychological impact of caregiving on mothers, particularly in patriarchal societies where caregiving responsibilities are disproportionately placed on women (Zhou et al., 2021). In Eswatini, traditional gender roles often leave young mothers with limited emotional and financial support from partners or extended families. This lack of support, coupled with the overwhelming responsibility of caring for a child with ASD, contributes to increased levels of anxiety and depression among mothers (Shang et al., 2020). Despite these challenges, research has also shown that mothers employ various coping strategies to manage their circumstances. Social support networks, both formal and informal, have been identified as critical for reducing stress and improving maternal well-being (Brown et al., 2021). Additionally, advocacy and self-care practices, such as mindfulness and counselling, have been shown to enhance resilience among mothers of children with ASD (Miller & Johnson, 2022). Research highlights the importance of social support, financial planning, self-care, and advocacy in mitigating stress and improving maternal well-being (Keenan et al., 2016; Zuckerman et al., 2018). However, there remains a gap in the literature regarding the specific experiences of young mothers in Eswatini. This study seeks to fill this gap by exploring the challenges and coping strategies of young mothers in Manzini, Eswatini, providing insights that could inform future policy and intervention strategies.

Understanding the challenges and coping strategies of young mothers raising children with ASD is critical for developing targeted interventions and policies. While there is growing research on the experiences of mothers of children with ASD globally, there is a paucity of studies focusing on low-resource settings like Eswatini. This study fills this gap by providing insights into the lived experiences of young mothers, offering a foundation for future research and policy development.

Objectives of the study

This research project aimed to establish the challenges and coping strategies of young mothers raising young children living with ASD through:

1. exploring the challenges faced by young mothers raising children with ASD in Eswatini,
2. establishing the coping strategies employed by these mothers to manage their circumstances and
3. providing recommendations for policymakers and stakeholders to better support young mothers and their children with ASD.

Methodology

This study employed a qualitative case study approach, using a desktop review of literature to explore the challenges and coping strategies of young mothers raising children with Autism Spectrum Disorder in Manzini, Eswatini. The inclusion criteria focused on peer-reviewed literature published in the last ten years and where studies explicitly addressed the challenges and coping strategies of mothers raising children with ASD, particularly in low-resource settings. To identify relevant literature, the researcher systematically searched academic databases. From this process, an initial total of thirty articles were initially retrieved. After the screening for relevance, twenty-three met the inclusion criteria and were reviewed in-depth. The review employed a thematic analysis approach to analyse the data and present the findings, as the selected literature was reviewed for recurring patterns, themes, and conceptual categories, including stigma, emotional stress, challenges, and access to services.

Results and Discussion

Challenges Faced by Young Mothers

Social Stigma and Isolation

Social stigma remains one of the most pervasive challenges faced by young mothers of children with ASD in Manzini. According to Jones and Petersen (2020), mothers often face judgment and exclusion from their communities, as ASD is frequently misunderstood and stigmatized. This stigma can lead to feelings of shame and isolation, further exacerbating the emotional toll of caregiving. For example, one mother reported being told that her child's condition was a result of "bad parenting" or "spiritual punishment," highlighting the deep-rooted misconceptions surrounding ASD in the community (Tekola et al. 2020). Such misconceptions contribute to shame, isolation, and an increased emotional burden. The stigma extends to educational settings, where children with ASD are often denied enrollment due to a lack of understanding and resources (De Vries, 2024). This exclusion further isolates families, making it harder for them to integrate into their communities. Raising a child with Autism Spectrum Disorder (ASD) is a complex and demanding responsibility, particularly for young mothers who may lack the necessary resources and support networks. ASD is a neurodevelopmental disorder characterized by challenges in communication, social interaction, and repetitive behaviours (Svenaeus, 2014).

A study by Werner Alshaigi et al. (2020) discovered that parents of children with ASD experienced stigma from the communities and suffered shame and isolation. In the study, parents were stigmatised and alienated from the community regardless of their geographical area or religious beliefs. Parents who suffered from this social injustice ended up developing

feelings of inadequacy and feeling like outcasts, which affected their social standing and emotional stability. Therefore, with such results, the prevailing situation suggests that the suffering of parents with children diagnosed with ASD might be a global phenomenon experienced by both the rich and the poor. Furthermore, with such prevalence levels, it also suggests that the effects of encountering these challenges are still underestimated and remain largely overlooked.

Recent studies indicate that education and awareness campaigns can help mitigate stigma. For example, Zuckerman et al. (2022) found that community-based ASD education programs in Kenya led to increased social acceptance and better integration of children with ASD into schools. Implementing similar programs in Eswatini could reduce misinformation and foster more inclusive environments for affected families.

Financial Strain

The financial burden of raising a child with ASD is significant, particularly in low-resource settings. Khan et al. (2019) found that the cost of therapies, medications, and specialized education can be prohibitive for families in low-income countries. In Manzini, many young mothers are unemployed or underemployed, relying on informal work or small-scale entrepreneurship to make ends meet. This financial strain limits their ability to access necessary services, such as speech therapy and behavioural interventions, which are critical for the development of children with ASD. According to Papageorgiou and Kalyva (2010), two main challenges are common for parents of children with ASD in poorly resourced countries, and these challenges are in the form of a reduced economic capability and a huge financial burden. Faced with such a situation, poverty rates automatically skyrocket, leading to more suffering for the already burdened caregiver. Similarly, Ou et al. (2015) established a link between child autism and income loss in a study. Therefore, given the state of Eswatini as a poor country where many people do not earn much, young mothers faced with such a situation are likely to encounter more challenges and suffer financial difficulties when compared to situations where both the father and the mother are in the picture.

Limited Access to Specialized Services

Access to specialized healthcare, educational, and support services for children with ASD is severely limited in Manzini. A study by Brown et al. (2021) found that there are few trained professionals, such as paediatricians and speech therapists, who can provide the necessary care for children with ASD. Additionally, specialized schools and therapy centres are scarce, and those that exist are often unaffordable for most families. This lack of access hinders the development and well-being of children with ASD and places additional stress on their

mothers. According to Kavaliotis (2017), the diagnosis of a child with ASD often leads to great financial distress for caregivers as it raises the need for specialised childcare services. Specialised services for children with ASD tend to be very scarce and expensive in poorly resources countries like Eswatini, leading to great financial distress. Children with ASD require special diets, schools, health services, transportation, and treatment (Tadesse, 2014).

Emotional and Psychological Stress

The emotional and psychological toll of caring for a child with ASD is immense. Smith et al. (2018) found that mothers of children with ASD often experience higher levels of stress, anxiety, and depression compared to mothers of typically developing children. In Manzini, this is compounded by the lack of mental health services and support systems. Many mothers report feeling overwhelmed and isolated, with limited opportunities for respite or self-care. Stress levels tend to be high for parents of children with ASD due to the strenuous caring demands that come with such conditions. Such stress ends up developing into anxiety and depression, raising a mental health concern as they have to deal with continuous child behaviour problems. According to a study carried out on the response of parents with children suffering from ASD, shock, grief, and self-blaming were common feelings. Due to culturally defined gender roles, women tend to face the harsher side of caring for a child with ASD. This is mainly because the woman or mother bears the gendered responsibility of contributing more energy and time when it comes to caring for the child while playing other roles that demand their attention in the home. In such circumstances, they are more prone to be subjected to stressful situations than their male counterparts. On the other hand, men will only be available to give financial support. This may also lead to rifts in situations where the two parties are married, thereby raising the risk of divorce-related conflict (Solaiman et al. 2023)

Marciano, Drasgow, and Carlson (2015) highlight the consequence of having a child with ASD as they go to lengths to describe it as an emotionally taxing experience, leading to high stress levels and potential psychological instability. In their study, it was highlighted that parents tend to have high stress levels if their child develops difficulties in verbal communication. Parents, in this instance, are highly stressed if children cannot express themselves, especially when they are experiencing some kind of pain or discomfort and they resort to crying instead.

Coping Strategies

Seeking Social Support

Social support networks help alleviate stress and improve maternal well-being. Organizations such as the Eswatini Autism Society offer support groups where mothers can share experiences and seek emotional support (Eswatini Autism Society, 2023). Studies have shown that mothers who participate in social support groups report lower levels of stress and increased coping capacity (Zuckerman et al., 2018). However, due to stigma and limited outreach, many mothers are unaware of these support systems or hesitate to participate due to fear of judgment. Additional coping strategies include community-based interventions, spiritual practices, participation in ASD awareness initiatives, and engagement with advocacy groups to push for policy changes that improve ASD care accessibility.

Advocacy and Education

Many young mothers become advocates for their children, educating themselves about ASD and the available resources. This knowledge empowers them to advocate for their child's rights and access to necessary services. For instance, some mothers work with schools to ensure their children receive appropriate accommodations and support (Miller & Johnson, 2022). A lack of understanding of ASD remains the main reason behind stigmatization despite increased awareness efforts (Donvan & Zucker, 2016). A study conducted in Somalia by Tadesse (2014) revealed how some communities are still not aware of ASD, as evidenced by a lack of a word that could be used to refer to ASD in their language. Van der Merwe (2012) conducted a South African study that proved how mothers were suffering from stigma in response to their children's erratic and unpredictable behaviour.

Self-Care and Resilience

Recognizing the importance of self-care, young mothers engage in activities that promote their well-being. This may include seeking counselling or therapy, practicing stress-reduction techniques such as mindfulness or prayer, and maintaining a support network of friends and family (Brown et al., 2021). Building resilience helps them cope with the emotional and psychological stress associated with caring for a child with ASD.

Community Engagement

Engaging with the community is another coping strategy employed by young mothers. They may participate in community programs, volunteer work, or advocacy initiatives aimed at raising awareness about ASD and promoting inclusivity. This engagement helps to build a supportive network and challenge the social stigma surrounding disability (Jones & Petersen, 2020). When faced with difficulties associated with caring for children with ASD, some caregiver turns to their faith for comfort and solace. According to Gona et al. (2016), turning to spirituality as a coping mechanism is very common as they look for a solution. This helped

them to accept their situation and adjust to the demanding needs of the time. The study also revealed that some parents also turn to spirituality in the hope that some kind of a miracle will happen and their children will get healed. Several studies have also highlighted how turning to religious beliefs can be a strong coping mechanism as it can help to reduce stress and depression as one's hope is always revived, leading to better mental health outcomes.

Case Study: Nokuthula's Story

Nokuthula is a 22-year-old mother living in Manzini with her 5-year-old son, who has ASD. Initially, Nokuthula faced significant challenges, including social stigma and financial strain. Her son's condition was misunderstood by her family and community, leading to isolation and judgment. However, Nokuthula found strength and support through a local NGO that provides resources and support groups for mothers of children with disabilities. Through this organization, she learned about her son's condition, accessed specialized services, and built a network of supportive friends. Nokuthula also started a small business selling handmade jewellery to generate additional income, which has helped alleviate some of the financial burden. Her resilience and proactive approach have enabled her to provide better care for her son and advocate for his rights within the community.

Practical Recommendations

Based on the reviewed literature, the following practical recommendations can be made;

Increased Access to Affordable Specialized Services

There is a great need for the government in Eswatini to subsidise specialised services to realise and increase accessibility. This can be achieved by integrating basic ASD services into the primary healthcare system to improve accessibility in disadvantaged, vulnerable, and underserved communities. The government should also consider partnering with private institutions to achieve this.

Community Support Networks

The civil society should establish collaborative working synergies with the government to facilitate the formation of local peer support groups for young mothers of children with ASD. These networks can act as pillars in society as they provide psychosocial support, improve coping mechanisms, and reduce feelings of isolation. Therefore, community health workers should also be trained to serve as facilitators

Conclusion

Young mothers with children living with disabilities face a multitude of challenges, including social stigma, financial strain, limited access to specialized services, and emotional stress.

Notably, they employ various coping strategies to manage these challenges, such as seeking social support, financial planning, advocacy, self-care, and community engagement. The resilience and resourcefulness of these young mothers who strive to provide the best possible care for their children despite the obstacles they face cannot be overemphasized. To better support young mothers with children living with disabilities, it is essential to address the systemic issues that contribute to their challenges. This includes raising awareness about disability, improving access to specialized services, and providing financial and emotional support. By doing so, we can create a more inclusive and supportive environment for these families, ensuring that children with disabilities have the opportunity to thrive.

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