**A Mixed-Methods Analysis on Autism Spectrum Disorder (ASD) Awareness in Tanzanian Communities**

Suzana Sylivester[[1]](#footnote-1). Josue Mbonigaba [[2]](#footnote-2)

**Abstract**

**Background:** Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition characterised by deficits in social interactions and communication, repetitive behaviours, and restricted interests. While extensive research and early diagnostic frameworks have advanced ASD awareness in high-income countries, low- and middle-income countries (LMICs) such as Tanzania continue to face substantial challenges in the timely identification, diagnosis, and intervention of ASD.

**Objective:** This study investigates the prevailing levels of ASD awareness among Tanzanian households, comparing families raising children diagnosed with ASD to those with neurotypical children who do not have ASD.

Material and methods: To get a more complete understanding of the awareness, the study employed a convergent mixed-methods design. We conducted structured quantitative surveys (n = 512) alongside in-depth qualitative interviews (n = 6) with parents, primary caregivers, and frontline healthcare providers across urban communities.

**Findings:** The study reveals a critical awareness gap: although 57% of participants reported having heard the term "autism," over 75% demonstrated limited or no understanding of its core symptoms, etiology, developmental trajectory, or evidence-based interventions. Notably, misconceptions about the causes of ASD, often attributed to supernatural or moral explanations, persisted across both educated and uneducated populations. Additionally, health workers reported frequent misdiagnoses and delayed referrals, often stemming from cultural stigma and inadequate training on neurodevelopmental disorders.

**Conclusion**: The study concludes that awareness of autism remains limited among both parents of children with ASD and those with neurotypical children. While many participants recognized the term "autism," their understanding of its symptoms, diagnostic procedures, and interventions was minimal. Parents of neurotypical children often misinterpret autism as a mental illness, witchcraft, or attribute related behaviours to poor parenting. Similarly, parents of children with autism demonstrated limited knowledge regarding appropriate care, diagnostic processes, and available interventions.

**Policy implications**: The study highlights the critical need for multi-level public education strategies to address gaps in autism awareness and support in Tanzania. It emphasizes the importance of comprehensive, community-based awareness campaigns to facilitate early identification and reduce stigma, alongside targeted training for parents to strengthen caregiving and home-based support. Culturally responsive outreach, professional development for healthcare providers, and the inclusion of neurodevelopmental health in community health systems are also essential. Enhancing diagnostic capacity and delivering context-specific education on ASD can reduce delays in diagnosis, bolster family resilience, and improve developmental outcomes. The study advocates for policy engagement and cross-sectoral collaboration to embed ASD-responsive planning within national health systems.

**Keywords:** Autism spectrum disorder, Awareness, Screening, Community knowledge, Early diagnosis, Tanzania

1. **Introduction**

Autism Spectrum Disorder (ASD) is a complex neurodevelopmental condition characterized by difficulties in social communication, repetitive behaviors, and sensory processing challenges (APA, 2013). The disorder often coexists with other conditions, including intellectual disabilities and anxiety disorders (Waizbard-Bartov et al., 2023). Early diagnosis and intervention are crucial for improving developmental outcomes, but these depend on public awareness and access to support services (Dawson et al., 2010; Zwaigenbaum et al., 2015).

In low- and middle-income countries (LMICs) like Tanzania, significant barriers to ASD awareness persist, including cultural misconceptions and limited resources (Ruparelia et al., 2016; Abubakari et al., 2016). In many Tanzanian communities, ASD is often misunderstood as a spiritual issue, leading to stigma and delayed medical consultations (Bakare & Munir, 2011). This contrasts sharply with high-income countries, where increased awareness has led to higher reported prevalence rates, such as the CDC's report of 1 in 36 children diagnosed with ASD in the U.S. (CDC, 2023). In East Africa, however, community-level knowledge remains low, contributing to misdiagnosis and inadequate intervention (Masaba et al., 2021; Ruparelia, 2021).

Despite some progress in Tanzania, such as the establishment of the National Association of People with Autism in Tanzania (NAPA-T) and recognition of World Autism Awareness Day, empirical evidence on ASD awareness among the general population is lacking (Shah & Manji, 2022). Community-level awareness is critical, as early detection often begins within households (Manji & Hogan, 2015). Insufficient awareness not only affects health and education but also imposes economic burdens on families (Bakare et al., 2014; Abubakari et al., 2016; Mosadeghrad et al., 2019).

To address these issues, a mixed-methods study is being conducted to assess ASD awareness among Tanzanian parents and caregivers. This study aims to establish a baseline of awareness, identify barriers to early diagnosis, and provide insights for policy and intervention strategies. The findings will contribute to culturally responsive ASD awareness initiatives in LMICs, enhancing early detection and inclusive service delivery.

**2. Methodology**

**2.1 Research design**

This study employed a convergent mixed-methods design, integrating both quantitative and qualitative approaches to provide a comprehensive understanding of Autism Spectrum Disorder (ASD) awareness in Tanzanian communities. The use of a mixed-methods approach allowed for the triangulation of data, ensuring methodological complementarity, depth, and enhanced validity (Creswell & Plano Clark, 2018). Data were collected concurrently from parents, caregivers, and key informants to capture both measurable trends and contextual interpretations. This design was particularly suited to address the multi-dimensional nature of ASD awareness, enabling an exploration of both knowledge patterns and sociocultural influences.

**2.2 Quantitative component**

**2.2.1 Participants and sampling**

The quantitative arm of the study targeted parents and caregivers of children aged 3 to 17 years. The sample included two subgroups: caregivers of children diagnosed with ASD and those of typically developing children. A multi-stage sampling technique was utilized. In the first stage, Muhimbili National Hospital (MNH) was purposively selected as the reference facility, given its high volume of pediatric neurodevelopmental diagnoses. Hospital records were used to determine the prevalence of ASD cases across the five districts of Dar es Salaam, thereby guiding proportionate sampling from each district to ensure representativeness.

The Yamane (1967) formula was applied to calculate the appropriate sample size for ASD-affected families:

​

Where n is the sample size, N is the estimated population of children with ASD in Dar es Salaam, and e is the acceptable margin of error (set at 0.05). This resulted in a stratified sample of 194 caregivers of children with ASD, proportionately drawn from the five districts. An additional 318 caregivers of typically developing children were randomly selected from the same localities to provide a comparative baseline, leading to a total sample of 512 respondents.

**2.2.2 Data collection instruments**

Data were collected using a semi-structured questionnaire, administered through the Kobo Collect digital data platform and in-person visits. The questionnaire captured key variables related to ASD awareness, including knowledge of symptoms, causes, diagnostic pathways, and intervention options. Demographic and background variables such as age, sex, education level, and experience with developmental disorders were also recorded.

**2.2.3 Data analysis**

Quantitative data were analysed using STATA version 17. Descriptive statistics were computed to summarize participants’ baseline awareness of ASD. A Chi-square test of independence was applied to assess differences in awareness between caregivers of children with ASD and those of neurotypical children. To identify factors influencing ASD awareness, a multiple logistic regression model was developed. The dependent variable was overall awareness of ASD, while independent variables included sex, age, education level, prior exposure to developmental disorders, and whether the caregiver had a child with any health condition. Statistical significance was assessed at p < .05.

**2.3 Qualitative component**

**2.3.1 Participants and sampling**

Qualitative data were obtained through in-depth interviews with six key informants, including pediatricians, child psychologists, and special education specialists based in public hospitals, private clinics, and non-governmental organizations within Dar es Salaam. Participants were selected using purposive sampling based on their expertise in diagnosing, treating, or supporting children with ASD. This approach ensured the collection of rich, expert-driven insights into the landscape of ASD awareness and service provision in Tanzania.

**2.3.2 Data collection and analysis**

All interviews were conducted face-to-face, audio-recorded with consent, and transcribed verbatim. The data were analysed using reflexive thematic analysis, following the six-phase framework proposed by Braun and Clarke (2020). The stages included: familiarization with data, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing the report. The qualitative data were managed using NVivo 15 software, which facilitated systematic coding and organization of themes.

Themes were developed inductively from the data, allowing for emergent patterns to reflect participants’ lived experiences, perspectives on community beliefs, diagnostic challenges, and recommendations for awareness-building. This method ensured rigor and transparency in theme development, enhancing the trustworthiness of findings (Nowell et al., 2017).

**2.4 Integration strategy**

The study utilized a triangulation design to integrate quantitative and qualitative findings. Triangulation not only strengthened the validity of the results but also allowed for a richer understanding of the data by merging numerical trends with narrative explanations (Patton, 1999; Creswell & Plano Clark, 2018). The integration occurred primarily during the interpretation phase, wherein themes from the qualitative analysis were used to explain or contextualize patterns observed in the survey data. For instance, if survey results indicated low awareness of early ASD symptoms, qualitative insights from clinicians helped elucidate cultural or systemic reasons for such gaps.

This convergent approach enabled a holistic analysis of ASD awareness across diverse stakeholder groups, offering both breadth and depth in understanding how autism is perceived and acted upon in Tanzanian households and service systems.

**3. Results and Findings**

This section presents the findings, beginning with quantitative results and then qualitative insights, and concludes with an integrated analysis highlighting their similarities and differences.

**3.1 Quantitative findings**

**3.1.1 Demographic characteristics of participants**

The study sample consisted of 512 parents and caregivers of children aged 3 to 17 years across five districts in Dar es Salaam, Tanzania. Females constituted the majority (65%), while males represented 35% of the respondents. Most participants (75%) fell within the age bracket of 26 to 45 years, reflecting the prime parenting age group. In terms of education, 31.3% had completed primary education, 28.3% had attained secondary education, 26.6% held university degrees, and 10.29% had received vocational or college-level training. Only 0.59% had no formal education. Regarding household roles, 50.2% identified as heads of households, and 42.2% were spouses. Most respondents resided in households with one to four children.

Among participants with children presenting health-related issues, 75.8% reported their child as having a diagnosis consistent with Autism Spectrum Disorder (ASD). Notably, 86.3% of respondents indicated that they had encountered a child showing signs associated with ASD within the past three months, while 25% reported the presence of such symptoms in their own homes. Moreover, 57.0% of participants acknowledged having prior awareness of the term "autism."

**3.1.2 General Autism Awareness Among Respondents**

Despite more than half (57.0%) of the respondents being familiar with the term “autism,” a substantial proportion demonstrated limited understanding of key dimensions of ASD. Specifically, 76.56% of participants lacked knowledge of potential causes of autism. Similarly, 70.31% were unaware of early behavioral indicators, 76.95% had no knowledge of diagnostic procedures, and 77.15% were uninformed about available intervention services for children with ASD. These findings resonate with earlier research from low- and middle-income countries (LMICs), which consistently identify significant gaps in ASD literacy (Bakare & Munir, 2011; Masaba et al., 2021). Figure 1 illustrates these findings.

**Figure 1:** Autism awareness among the participants

**Source:** Researcher’s data analysis

**3.1.3 Perceived Awareness Levels Among Parents and Caregivers**

When participants were asked to self-assess their level of autism awareness across four core areas early signs, diagnosis, interventions, and general understanding—58.45% reported having a “very low” level of awareness. An additional 12.01% indicated a “low” level, while 13.43% claimed a “moderate” understanding. Only 10.94% and 5.18% reported “high” and “very high” levels of understanding, respectively.

On beliefs concerning early intervention and the curability of autism, 54.49% acknowledged the potential benefits of early therapeutic action, while 45.51% remained doubtful. Interestingly, 64.48% believed autism could be cured, a misperception inconsistent with prevailing scientific consensus (Lord et al., 2020). Regarding perceptions of community awareness, 68.75% perceived autism literacy in their communities as “very low,” while only 31.25% recognized some level of general awareness. These results are illustrated in Figure 2 and mirror findings from other studies in East Africa, which report limited ASD awareness in both urban and rural populations (Ruparelia et al., 2016; Shah & Manji, 2022).

**Figure 2:** The degree of autism awareness among the participants

**Source:** Researcher’s data analysis

**3.1.4 Association between District and community autism awareness**

A Chi-square test of independence revealed a statistically significant association between respondents’ districts of residence and their perception of community awareness of autism, X²(16) = 30.78, p = .014. This indicates that perceptions of autism awareness differ meaningfully across districts. Ilala District recorded the highest concentration of participants who reported “very low” awareness (n = 130), while Ubungo District displayed a more even distribution across awareness levels, suggesting relatively higher perceived community literacy in that locality. This geographic disparity reflects the unequal distribution of ASD outreach services and suggests the need for location-specific interventions (Alanazi et al., 2024). Figure 3 presents these findings.



**Figure 3:** The association of Districts and community’s autism awareness level

**Source:** Researcher’s data analysis

**3.1.5 Relationship between living with an autistic child and familiarity with autism**

To test the hypothesis that direct experience with autism enhances awareness, a Chi-square test was conducted comparing familiarity levels between parents/caregivers of autistic children and those without. Results were significant, X²(4) = 112.99, p < .001, with a Cramér’s V of 0.47, indicating a moderate to strong effect size. Caregivers of autistic children showed a significantly higher familiarity with the term “autism.” These findings affirm prior studies showing that personal experience with ASD fosters deeper knowledge and engagement (Anwar et al., 2018; Alanazi et al., 2024).

**3.1.6 Relationship between living with an autistic child and awareness of early symptoms**

Another Chi-square test explored associations between caregiving status and awareness of early autism symptoms. Results were significant, X²(4) = 111.27, p < .001, with a Cramér’s V of 0.47. Parents and caregivers of children with ASD reported significantly greater familiarity with early symptoms than those with typically developing children. These findings reinforce the argument that lived experience catalyses awareness of developmental red flags, as shown in Alanazi et al. (2024).

**3.1.7 Relationship between living with an autistic child and familiarity with diagnostic procedures**

Statistical analysis also showed a significant relationship between caregiving status and familiarity with ASD diagnostic procedures, X²(4) = 138.83, p < .001, with a Cramér’s V of 0.52, indicating a strong effect size. These results confirm that families managing ASD are more likely to be informed about screening pathways, aligning with international literature (Zwaigenbaum et al., 2015).

**3.1.8 Relationship between living with an autistic child and familiarity with available services**

Finally, a Chi-square test evaluated the association between having an autistic child and awareness of community-based autism services. The findings were statistically significant, X²(4) = 138.51, p < .001, with a Cramér’s V of 0.52. Respondents caring for autistic children demonstrated significantly greater familiarity with available services. This is consistent with studies highlighting that affected families often become more attuned to service landscapes due to necessity and advocacy engagement (Papadopoulos et al., 2022).

**3.2 Qualitative Findings**

**3.2.1 Demographic characteristics of key informants**

The qualitative arm of this study engaged six experienced healthcare professionals purposively selected for their direct involvement with autism-related services in Dar es Salaam. Participants included two paediatric neurologists, two occupational therapists, one autism spectrum disorder specialist, and one special needs intervention expert. The sample comprised five males and one female, aged between 34 and 46 years. Their diverse professional backgrounds provided comprehensive insight into the systemic, clinical, and social dimensions of autism awareness and service delivery in Tanzanian contexts.

**3.2.2 Summary of key informant interview themes and code distribution**

Interviews were structured around six core thematic domains: understanding of autism causes, recognition of symptoms, diagnostic procedures, intervention approaches, stakeholder awareness, and societal perceptions. Reflexive thematic analysis generated a total of 294 open codes, later distilled into 16 distinct themes. The highest number of codes emerged from discussions related to intervention strategies (n=129), followed by autism symptoms (n=79), diagnostic procedures (n=71), and perceived causes (n=15). These figures reflect the differential emphasis and depth with which each domain was addressed by informants (Braun & Clarke, 2020). A visual distribution of codes by question is presented in Figure 4.

**Figure 4:** Research questions and corresponding number of codes

**Source:** Researcher’s data analysis

**3.2.3 Thematic analysis: key informant narratives on autism awareness**

A central narrative thread across interviews was the increasing, albeit uneven, awareness of autism within Tanzanian communities. Key informants acknowledged incremental improvements but highlighted persistent structural and cultural barriers. One recurring theme was the role of non-state actors, particularly NGOs and advocacy groups, in spearheading awareness efforts. "Frankly speaking, the awareness of autism has been raised more by activists than by the government," noted one occupational therapist (Participant 2), reflecting a broader sentiment regarding gaps in public health policy and institutional engagement.

Another significant concern was the lack of awareness among primary stakeholders, particularly general healthcare providers and educators. Informants repeatedly underscored the insufficiency of autism-specific training even among paediatricians. As one occupational therapist remarked, "Most paediatric doctors don't understand autism beyond prescribing medication" (Participant 2). This knowledge gap was considered especially acute in rural and peri-urban areas.

Several respondents elaborated on the persistent stigma, misconceptions, and cultural myths that envelop autism in Tanzanian society. Autism was frequently mischaracterized as spiritual affliction or a consequence of parental wrongdoing, which aligns with earlier studies in African contexts (Bakare et al., 2011; Abubakari et al., 2016). Such misperceptions often delay diagnosis and result in harmful treatment-seeking behaviour. Informants reported instances of social isolation and emotional neglect experienced by children with autism. "No one calls the child to eat… they are just picked and fed without any words," recalled one specialist (Participant 6), emphasizing the psychosocial dimensions of stigma and exclusion.

On a positive note, several interviewees recognized the recent government initiatives to train autism specialists. "In 2024, the government began offering courses for autism specialists," reported a neurologist and paediatrician (Participant 4). However, such efforts remain nascent and geographically constrained.

A thematic map of the qualitative findings is presented in Figure 5.



**Figure 5:** Thematic map of key informant perspectives on autism awareness

**Source:** Author’s data analysis

**3.3 Integrated findings: mixed-methods synthesis on ASD awareness**

**3.3.1 Community awareness and public perception**

The triangulation of qualitative and quantitative findings illustrates a shared perception of insufficient community-level awareness of autism. Quantitatively, 68.75% of participants rated community autism awareness as "very low," with significant variation across districts (χ²(16) = 30.78, p = .014). Qualitative data reinforced this, identifying Ilala and Kinondoni as particularly under-informed, while Ubungo showed comparatively better awareness. Informants attributed this disparity to localized NGO efforts and media outreach, while also lamenting the absence of consistent government-led sensitization campaigns.

**3.3.2 Symptom recognition and diagnostic familiarity**

While 86.33% of caregivers had encountered children exhibiting autism-like behaviors, only 25% identified such symptoms within their households. This gap in self-reported awareness likely reflects internalized stigma or limited symptom recognition. Chi-square analysis demonstrated a significant association between living with a child with autism and familiarity with early symptoms (χ²(4) = 111.27, p < .001; Cramér’s V = 0.466), consistent with international literature (Alanazi et al., 2024). Qualitative data supported these findings, with informants reporting that parents often seek help only after behavioural challenges become unmanageable.

**3.3.3 Misconceptions and barriers to diagnosis**

Quantitative results revealed that 76.56% of participants did not know the causes of autism, and 76.95% were unfamiliar with diagnostic procedures. These findings were echoed in the interviews, where key informants cited pervasive myths, such as witchcraft, curses, or spiritual punishment, as prevailing explanations. Such misconceptions contribute to delayed care and reinforce the marginalization of affected families (Bakare et al., 2014). Informants emphasized the urgent need for culturally sensitive education campaigns and more extensive clinical training for primary healthcare providers, especially in resource-poor settings.

**3.3.4 Awareness of Intervention Services**

Awareness of intervention options was notably low, with 77.15% of survey respondents reporting unfamiliarity with available services. However, caregivers of autistic children were significantly more likely to be informed (χ²(4) = 138.51, p < .001; Cramér’s V = 0.5201), illustrating the impact of lived experience in enhancing knowledge. Interview data corroborated this, with most service users relying on NGO-supported centers and faith-based organizations due to the scarcity of government-run programs. Encouragingly, participants acknowledged the government’s recent training initiatives for occupational, speech, and behavioral therapists, though coverage remains inadequate.

**3.3.5 Inclusion, stigma, and policy implications**

The study also documented the psychosocial burden of stigma. Informants described social exclusion, emotional neglect, and even abusive care practices within some families. These findings underscore the need to embed autism support within broader frameworks of disability inclusion, emphasizing public education, anti-stigma campaigns, and inclusive education policies (Kinnear et al., 2016; Papadopoulos et al., 2022). Embracing neurodiversity and recognizing autistic individuals as valuable contributors to society was emphasized as a vital next step.

**4. Conclusion and Recommendations**

This study provides a comprehensive mixed-methods investigation into Autism Spectrum Disorder (ASD) awareness among parents, caregivers, and healthcare professionals in Dar es Salaam, Tanzania. The findings reveal critical deficits in community awareness, recognition of early symptoms, understanding of diagnostic procedures, and accessibility to intervention services. Quantitative results established statistically significant associations between first-hand experience with autistic children and higher levels of autism-related awareness. However, broad segments of the population, particularly those without direct exposure, demonstrated limited understanding of the condition.

Qualitative insights from key informants reinforced these patterns, revealing systemic barriers including a shortage of trained specialists, widespread cultural misconceptions, and the absence of coordinated public awareness campaigns. In particular, autism continues to be misunderstood as a behavioural problem, mental illness, or even attributed to supernatural causes a trend consistent with findings from similar low-income contexts (Bakare et al., 2011; Ruparelia et al., 2016; Masaba et al., 2021). This misrepresentation has led to stigmatization, delayed diagnosis, and exclusionary practices within households and educational settings.

Encouragingly, the government’s recent investment in specialist training for occupational and speech therapists in 2024 marks a promising step forward. However, the overall landscape remains fragmented. Strengthening multispectral coordination between health, education, and community-based organizations is critical. The study recommends the following actionable strategies to improve ASD outcomes:

1. Expand culturally contextualized awareness campaigns using media, religious platforms, schools, and community forums.
2. Develop training curricula for frontline healthcare workers and educators to improve early identification and referral systems.
3. Establish decentralized diagnostic and intervention centers to increase accessibility, particularly in underserved districts.
4. Promote social inclusion policies that integrate autistic individuals into mainstream education, employment, and public life.
5. Foster multi-stakeholder collaboration, including partnerships with NGOs and parent-led advocacy groups, to amplify impact.

These recommendations align with global best practices advocating for inclusive, community-driven autism interventions in low-resource settings (WHO, 2023; Papadopoulos et al., 2022).

**5. Suggestions for Future Research**

Given the evolving understanding of autism in sub-Saharan Africa, this study opens several avenues for further scholarly exploration:

1. Longitudinal studies should be conducted to assess the sustained impact of awareness campaigns on early identification, service uptake, and community perceptions of ASD.
2. Ethnographic and cultural research is warranted to examine how indigenous beliefs, language, and family structures shape the framing of autism within Tanzanian communities.
3. Impact evaluations of government-led specialist training initiatives are needed to assess whether these programs translate into improved diagnosis and service quality.
4. Access and equity studies should explore geographic and socio-economic barriers to intervention services, particularly in rural and peri-urban districts.
5. Psychosocial research is crucial to understand the lived experiences of caregivers, including stress, stigma, coping mechanisms, and support system availability.

These future research directions will contribute to a robust, evidence-based foundation for inclusive autism policy and programming across East Africa.

**6. Limitations of the Study**

Despite its strengths, this study encountered several methodological and logistical limitations that may have influenced the generalizability of findings:

1. Stigma and social denial were significant barriers to participation. Some parents were reluctant to acknowledge their child’s diagnosis, while others refused to participate due to fears of community judgment.
2. Emotional distress and aggression were observed in cases involving severe ASD, which occasionally led to participant withdrawal or incomplete responses.
3. Socioeconomic vulnerability influenced participant engagement. A subset of respondents expressed expectations of financial support, possibly skewing their participation or responses.
4. Timing constraints posed challenges, as data collection often coincided with working hours, limiting access to working parents and reducing response rates among certain demographic groups.
5. Sample representativeness may have been affected due to the purposive sampling strategy employed for key informants and the geographic focus on urban districts within Dar es Salaam.

Future studies should consider triangulating multiple data sources, employing broader geographic sampling, and integrating culturally sensitive research engagement strategies to overcome these limitations.

**7. References and Appendices**

Abubakari, A., Ssewanyana, D., Newton, C. R., & Abubakar, A. (2016). A systematic review of research on autism spectrum disorders in Sub-Saharan Africa. Behavioural Neurology, 2016, 1-14. <https://doi.org/10.1155/2016/3501910>

Alanazi, M. F., Alruwaili, H. F. S., Alanazi, W. F., Alanazi, W. M., & Altaymani, A. F. M. (2024). Knowledge, attitude, and perception towards autism spectrum disorders among parents in Sakaka, Al-Jouf Region, Saudi Arabia: A cross-sectional study. Healthcare (Basel), 12(16), 1596. <https://doi.org/10.3390/healthcare12161596>

American Psychiatric Association. (2013). Diagnostic and statistical manual of mental disorders (5th ed.). <https://doi.org/10.1176/appi.books.9780890425596>

Anwar, M. S., Tahir, M., Nusrat, K., & Khan, M. R. (2018). Knowledge, awareness, and perceptions regarding autism among parents in Karachi, Pakistan. Cureus, 10(9), e3299. <https://doi.org/10.7759/cureus.3299>

Bakare, M. O., & Munir, K. M. (2011). Autism spectrum disorders in Africa. African Journal of Psychiatry, 14(3), 208-210. <https://doi.org/10.4314/ajpsy.v14i3.3>

Bakare MO, Ebigbo PO, Agomoh AO, Menkiti NC. Knowledge about childhood autism among health workers (KCAHW) questionnaire: description, reliability and internal consistency. Clin Pract Epidemiol Ment Health. 2008 Jun 6;4:17. doi: 10.1186/1745-0179-4-17. PMID: 18538020; PMCID: PMC2430959. <https://pmc.ncbi.nlm.nih.gov/articles/PMC2430959/>

Braun, V., & Clarke, V. (2020). One size fits all? What counts as quality practice in (reflexive) thematic analysis? Qualitative Research in Psychology, 18(3), 328-352. <https://doi.org/10.1080/14780887.2020.1769238>

Centers for Disease Control and Prevention. (2023). Data & statistics on autism spectrum disorder. <https://www.cdc.gov/ncbddd/autism/data.html>

Creswell, J. W., & Plano Clark, V. L. (2018). Designing and conducting mixed methods research (3rd ed.). Sage Publications.

Dawson, G., Rogers, S., Munson, J., Smith, M., Winter, J., Greenson, J., ... & Varley, J. (2010). Randomized, controlled trial of an intervention for toddlers with autism: The Early Start Denver Model. Pediatrics, 125(1), e17-e23. <https://doi.org/10.1542/peds.2009-0958>

Kinnear, S. H., Link, B. G., Ballan, M. S., & Fischbach, R. L. (2016). Understanding the experience of stigma for parents of children with autism spectrum disorder and the role stigma plays in families' lives. Journal of Autism and Developmental Disorders, 46(3), 942–953. <https://doi.org/10.1007/s10803-015-2637-9>

Lord, C., Brugha, T. S., Charman, T., Cusack, J., Dumas, G., Frazier, T., ... & Veenstra-VanderWeele, J. (2020). Autism spectrum disorder. Nature reviews Disease primers, 6(1), 5. <https://pubmed.ncbi.nlm.nih.gov/31949163/>

Manji, K. P., & Hogan, M. N. (2015). Identifying gaps in knowledge, prevalence and care of children with autism spectrum disorder in Tanzania – A qualitative review. Tanzania Medical Journal, 26(2). <https://doi.org/10.4314/tmj.v26i2.3>

Masaba BB, Taiswa J, Mmusi-Phetoe RM. Challenges of Caregivers Having Children with Autism in Kenya: Systematic Review. Iran J Nurs Midwifery Res. 2021 Sep 2;26(5):373-379. doi: 10.4103/ijnmr.IJNMR\_156\_20. PMID: 34703774; PMCID: PMC8491821. <https://pubmed.ncbi.nlm.nih.gov/34703774/>

Mosadeghrad, A. M., Pourreza, A., & Akbarpour, N. (2019). Economic burden of autism spectrum disorders in Iran. Tehran University Medical Journal, 76(10), 665–671. <http://tumj.tums.ac.ir/article-1-9278-en.html>

Nowell, L. S., Norris, J. M., White, D. E., & Moules, N. J. (2017). Thematic analysis: Striving to meet the trustworthiness criteria. International Journal of Qualitative Methods, 16(1). <https://doi.org/10.1177/1609406917733847> (Original work published 2017)

Papadopoulos, D. (2021). Mothers’ Experiences and Challenges Raising a Child with Autism Spectrum Disorder: A Qualitative Study. Brain Sciences, 11(3), 309. <https://doi.org/10.3390/brainsci11030309>

Patton, M. Q. (1999). Enhancing the quality and credibility of qualitative analysis. Health Services Research, 34(5 Pt 2), 1189-1208. <https://pmc.ncbi.nlm.nih.gov/articles/PMC1089059/>

Ruparelia, K., Abubakar, A., Badoe, E., Bakare, M., Visser, K., Chugani, D. C., & Newton, C. R. (2016). Autism spectrum disorders in Africa: Current challenges in identification, assessment, and treatment: A report on the International Child Neurology Association meeting on ASD in Africa, Ghana, April 3-5, 2014. Journal of Child Neurology, 31(8), 1018-1026. doi: 10.1177/0883073816635748. <https://pubmed.ncbi.nlm.nih.gov/26979098/>

Ruparelia, Kavita (2021). Autism Spectrum Disorders in Tanzania: Awareness, Diagnosis, Risk Factors and Endophenotypes. PhD thesis The Open University.DOI: <https://doi.org/10.21954/ou.ro.0001389f>

Shah, A., & Manji, K. P. (2022). Assessment of knowledge of autism spectrum disorders among medical students at the Muhimbili University of Health and Allied Sciences: A semiquantitative study. Tanzania Medical Journal, 33(4), 74-84. <https://doi.org/10.4314/tmj.v33i4.521>

Waizbard-Bartov, E., Fein,D., Lord, C., & Amaral, D. G. (2023). Autism severity and its relationship to disability. Autism Research,16(4), 685–696. doi: 10.1002/aur.2898 <https://pubmed.ncbi.nlm.nih.gov/36786314/>

World Health Organization. (2023). Autism spectrum disorders. Retrieved May 5, 2025, from <https://www.who.int/news-room/fact-sheets/detail/autism-spectrum-disorders>

Yamane, T. (1967). Problems to accompany Statistics, an introductory analysis (2d ed). Harper & Row.

Zwaigenbaum, L., Bauman, M. L., Choueiri, R., Kasari, C., Carter, A., Granpeesheh, D., ... & Wetherby, A. (2015). Early intervention for children with autism spectrum disorder under 3 years of age: Recommendations for practice and research. Pediatrics, 136(Supplement 1), S60-S81. <https://publications.aap.org/pediatrics/article-abstract/136/Supplement_1/S60/33948/Early-Intervention-for-Children-With-Autism>

**Appendix I**: P**articipants’ Demographics Characteristics**

|  |  |  |  |
| --- | --- | --- | --- |
| **Characteristics** | **Category** | **Frequency (N=512)** | **Percentage (%)**  |
| **District\_Wilaya**  | Ilala Kigamboni KinondoniTemeke Ubungo | 163 70  81 87 111  | 31.84 13.67 15.82 16.99 21.68  |
| **Sex**  | FemaleMale  | 333179 | 65.0434.96 |
| **Age Group** | 18-25 26-35 36-45 46-55 56-65 66\_\_above  | 39 195 189 70 16 3  | 7.62 38.09 36.91 13.67 3.13 0.59  |
| **Education**  | 1. College Education 2. Informal Education 3. Primary Education  4. Secondary Education 5. University Education 6. Vocational Education  | 52 3 160 145 136 16  | 10.16 0.59 31.25 28.32 26.56 3.13  |
| **Relationship to household head** | child household head relative spouse  | 20 257 19 216  | 3.91 50.20 3.71 42.19  |
| **Household Size** | 1  2 3 4 5 6 7 8 9 10 11 12  |  2 31 100 119 87 70 44 29 14 10 2 4  | 0.39 6.05 19.53 23.24 16.99 13.67 8.59 5.66 2.73 1.95 0.39 0.78  |
| **Number of children in the household** |  0 1 2 3  4 5 6 7 11  | 3 168 165 106 46 18 4 1 1  | 0.59 32.81 32.23 20.70 8.98 3.52 0.78 0.20 0.20  |
| **Number of children with health concerns**  | 1. no 2. Yes  | 388 124  | 75.78  |
| 24.22  |
| **Health concerns of children**  |  1. Allergic Conditions 2. Autism 3. Blood Disorders 4. Diabetic and neuro issues 5. Gastrointestinal Disorders 6. Hearing impairment 7. Other Health Conditions 8. Physical Impairment  9. Respiratory Impairment 10. Seizure Disorders 11. Speech Impairment  |  3 94 2 1 2 2 4 4 4 4 4  | 2.42 75.81 1.61 0.81 1.61 1.61 3.23 3.23 3.23 3.23 3.23  |
| **Frequency of meeting a child with signs associated with autism in children**  | 1 2 3 4 5  | 70 175 84 78 105  | 13.67 34.18 16.41 15.23 20.51  |
| **Having a child with signs associated with autism in children**  |  no yes  | 381127  | 75.0025.00  |
| **Heard the term autism before the survey** |  no yes  | 220 292  | 42.97 57.03  |

APPENDIX…**The chi-square test between Districts and Community Autism Awareness level**

|  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- |
| Districts | Very Low  | Low  | Moderate | High  | Very High  |
| Ilala | 130 | 22 | 8 | 2 | 1 |
| Kigamboni | 46 | 20 | 2 | 1 | 1 |
| Kinondoni | 60 | 17 | 3 | 0 | 1 |
| Temeke | 57 | 26 | 2 | 1 | 1 |
| Ubungo | 59 | 37 | 11 | 2 | 2 |
|  |  |  |  |  |  |

**APPENDIX III: Total Themes generated from the codes created**

|  |  |  |
| --- | --- | --- |
| Themes  | No. of Participants | No. References |
| Awareness | 6 | 25 |
| Autism-Related Symptomatic, Behavioral, and Developmental Challenges | 6 | 34 |
| Exceptional abilities and hidden talents | 2 | 5 |
| Neurodevelopmental diversity and childhood challenges | 6 | 15 |
| Biological and genetic factors | 3 | 3 |
| Environmental and external factors | 5 | 10 |
| Preventive and protective measures | 1 | 2 |
| Challenges and costs of autism diagnosis | 3 | 11 |
| Comprehensive autism diagnosis awareness | 5 | 30 |
| Comprehensive autism diagnostic practices | 5 | 14 |
| Cultural beliefs and stigma surrounding autism | 5 | 16 |
| Barriers to autism treatment and support | 5 | 31 |
| Comprehensive autism therapies and medical interventions | 5 | 30 |
| Parent involvement, empowerment, and support | 4 | 19 |
| Therapy effectiveness, individualized support, and early interventions | 5 | 34 |
| Community engagement, awareness, and advocacy for autism | 4 | 15 |

**Source:** Researcher’s Data Analysis

APPENDIX IV**: provides selected illustrative quotes supporting each theme.**

|  |  |  |
| --- | --- | --- |
| **Theme**  | **Participants** | **Transcripts** |
| The role of media and NGO’s | Participant 2 | *“Frankly speaking, the awareness of autism has been raised more by activists than by the government...”* |
| *Participant3* | *“Most awareness campaigns are conducted by private organizations.”**“The media and specialized centers have played a crucial role in raising awareness.”* |
| Participant 4 | *“There is a wealth of information available online. Personally, I was never formally taught about autism in school; I learned through research and online resources.”* |
| *Lack of awareness among stakeholders* | Participant 5  | *“Awareness is low. Most parents only learn about autism after being informed during treatment. Very few parents are aware beforehand. Awareness begins when a parent asks, “Will my child ever be okay?” This is the main question from parents.”* |
| *Lack of specialists on autism* | Participant 2  | “*……But the problem is most of the pediatric doctors they don’t know well about autism and* *the people don't even know autism itself, in some cases, you meet there maybe with a specialist maybe let's say a doctor but you find that he doesn't even understand autism. He understands it only from the perspective of medicine, that he is okay, so that he can calm down, you will give him some medicine, he will be able to sleep, but he will sleep well without having the understanding that it is okay, why the child does not want to sleep, or why the child is shouting, why the child is so aggressive that, so they can know okay, this thing just needs the child to use medicine or..* |
| *Participant3* | *“Since rural healthcare providers lack experience with autism, they usually reassure parents by saying, "The child will eventually speak,"*  |
| *Participant 4* | *“Most others specialist have received brief training, but things are changing due to increasing demand from parents…”**here are other methodologies that can be used to help this child”* |
| *Government officials are not aware* | Participants 3:  | *“Another issue is the lack of awareness among government officials, policymakers, and hospital administrators”* |
| No widespread government campaign  | Participant 3 | *“There are no widespread government-led campaigns to raise awareness in different regions or communities. The focus has mainly been on training teachers rather than directly engaging communities.”* |
| Autism awareness is growing | Participant 4 | *“However, we must commend the Tanzanian government, which in 2024 introduced training courses for occupational therapists, speech therapists, and behavioral therapists. Over the next 3-4 years, the number of trained professionals is expected to increase.”* |
| Reducing fear and stigma | Participant 4 | *“Our purpose here is to reduce the fear, misunderstanding, and stigma surrounding autism. To achieve this, experts have introduced the concept of neurodiversity, which means that every human brain is different. Just as every person here is unique, individuals with autism have brains that are wired differently, but they are still part of our world. It is a natural variation that is part of humanity.”* |
| Mistreatment of autistic children | Participant 6 | *“Example Children with special needs experience different types of mistreatments in their families, whether intentionally or unknowingly. For example, if a child does not walk fast or walks slowly, the caregiver, instead of being patient, might scold the child by saying, "Hey, walk faster!" without realizing that the child's stride is short. In reality, the child is walking as far as they possibly can, but because their steps are short, it seems like they're moving slowly. This kind of treatment is a form of mistreatment that these children experience.”**Sometimes, the mother gets tired, especially if she is cooking and has other children to call for help. She might call the others, saying, "Come here, let's eat," while asking this child to bring her water or a cooking spoon or to check the food on the stove. The child hears the movements and names being called, but their name isn't called even once.**You find that when it’s time to eat, everyone else is called to the table: "Where is so-and-so? Call them to come and eat." But this child is never called and they are just picked up and placed somewhere. Nobody tells the child, "I am feeding you now." They just start feeding them. This hurts the child. They see all the actions happening around them but are not included in any of them. They must be included; they must be told, "Now we are eating," or "We are eating this food now." When they are not included at home, it affects them psychologically.* Myth and misconceptions |
| Participant 4 | “Misunderstanding. It’s dangerous to assume that boys naturally develop slower than girls or that “he’ll catch up eventually.” |
| Participant 6 | *“For example, Isaac Newton, the one who discovered gravitational force, he hadn’t even finished school; he was expelled.* *People with autism often get expelled from school because they are misunderstood”* |
| Medical conditions | Participant 3 | “Families must be educated about autism to understand that it is a medical condition, not a result of witchcraft or supernatural causes. Understanding autism as a scientific issue will encourage families to seek proper medical care rather than relying on misconceptions” |
| Embrace and support their uniqueness,Importance and inclusion | Participant 4 | *“These individuals are important members of our society, and it's crucial to accept and support them…..”* |

**Source: Researcher’s Data Analysis**

1. Email: ssylivester@rocketmail.com ; PhD Candidate, School of Accounting, Economics, and Finance, University of KwaZulu-Natal, Durban, South Africa. Assistant Lecturer, Department of Economics, Mwalimu Nyerere Memorial Academy, Dar es Salaam, Tanzania. [↑](#footnote-ref-1)
2. Email: mbonigaba@ukzn.ac.za ; Associate Professor of Economics; School of Accounting, Economics, and Finance, University of KwaZulu-Natal, Durban, South Africa [↑](#footnote-ref-2)