Autism Spectrum Disorder and Its Socio-Economic Burden in Sub-Saharan Africa: A Comprehensive Systematic Review

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Abstract

Autism Spectrum Disorder (ASD) is a lifelong developmental condition characterized by challenges in social communication, restricted behaviours, and sensory difficulties. Globally, ASD affects about 1 in 100 children and places a significant economic burden on families. While this burden is well-documented in Europe, limited evidence exists for sub-Saharan Africa. This systematic review explores the socioeconomic impact of ASD on families in the region by examining direct and indirect healthcare costs, lost productivity, and financial burden. A systematic search was conducted using EBSCOhost databases (MEDLINE, ERIC, and Academic Search Complete) covering publications from August 2019 to June 2024. Findings revealed that 41.6% of caregivers reported a moderate burden of care, while 33.8% experienced a high burden. Families with ASD children spent 20% of their income on therapies and school fees. Only two relevant studies from South Africa were identified, highlighting a critical evidence gap and the need for further research to inform supportive policies.

Keywords: Autism spectrum disorder (ASD), Socio-economic burden, Sub-Saharan Africa

1. Introduction

Autism Spectrum Disorder (ASD) is a complex lifelong developmental disorder characterized by deficits in social communication skills, restricted and repetitive behaviours, sensory difficulties, and occasionally intellectual impairments (Autism Speaks, 2012; Bhuiyan et al., 2018). Global records indicate that the prevalence of ASD has been rising in recent decades (Salari et al., 2022; Oksana et al., 2023; Wang et al., 2022; Zeidan et al., 2022). However, in many African countries, a lack of awareness, expertise, and resources hampers the understanding and management of ASD, constraining efforts to address its effects on affected individuals and their families (Abubakari et al., 2016).

Literature from European countries reveals significant socioeconomic impacts associated with ASD, including societal costs, educational expenses, healthcare costs, and productivity loss for parents (Knapp et al., 2009; Lavelle et al., 2014; Buescher et al., 2014; Cakir et al., 2019). Quantifying the burden borne by families with ASD is crucial for enabling governments and stakeholders to provide appropriate support. Despite this, there is scant information on the economic burden of ASD in Africa, particularly in sub-Saharan Africa. The inaccessibility of reliable data is often due to the lack of systematic recording and awareness. Many children with ASD in African countries are taken to traditional healers rather than medical facilities, where symptoms are misattributed to witchcraft practices, leading to underreporting and misdiagnosis (Bakare, 2014; Manji, 2013).

This systematic review aimed to investigate the socioeconomic impact of ASD on families in sub-Saharan Africa. Specifically, it examined the direct and indirect healthcare costs, loss of productivity among caregivers, and the financial burden experienced by families. The review also sought to identify the costly services utilized by children with ASD in the region. The study addressed key questions, including: What direct and indirect healthcare costs do families of children with ASD incur? To what extent does ASD affect the productivity of parents and caregivers? How financially burdensome is ASD for these families? Furthermore, which services are the most expensive for children with ASD in sub-Saharan Africa? As ASD prevalence rises and awareness increases, there is an urgent need for further research in this area. Robust statistical and descriptive evidence can help policymakers create informed and effective support strategies. Recent studies emphasize this need (Schmid et al., 2020; Liao & Li, 2020; Shahat et al., 2021).

2. Methodology

2.1 Search strategy

A systematic search was conducted using the EBSCOhost platform, focusing on the MEDLINE, ERIC, and Academic Search Complete databases. The search targeted relevant articles published between August 2019 and June 21, 2024. This timeframe was chosen due to the global rise in ASD prevalence, as noted by Zeidan et al. (2022), who reported that 1 in 100 children is now diagnosed with ASD, a significant increase from the 2012 global median prevalence of 62 per 10,000 reported by Elsabbagh et al. (2012). This upward trend suggests a greater likelihood of new research on the economic burden of ASD, specifically regarding direct and indirect healthcare costs and the lost work hours for caregivers, especially in sub-Saharan Africa. However, recent literature reviews on the economic impact of childhood disabilities, including ASD, still highlight a need for more studies in these areas, particularly in developing countries (Shahadat & Greco, 2021).

Recent literature reviews on the economic costs of childhood disabilities, including ASD, reveal a limited number of studies from developing countries, with no representation from sub-Saharan Africa, highlighting the need for further research in these regions (Shahadat & Greco, 2021). In a literature review, Rogge and Janssen (2019) also identified a lack of studies from developing countries, with most previous research focusing heavily on the United States and offering minimal coverage of non-U.S. contexts, particularly with no representation from sub-Saharan Africa (Amendah et al., 2011; Sharpe & Baker, 2011). Again, the most recent systematic review by Xiaoli Liao and Yamin Li 2020 also lacks presentation in sub-Saharan Africa.

This systematic review aims to expand current knowledge by examining the latest studies in sub-Saharan Africa. Given the rising prevalence, it is likely that more research papers from this region will be available for review. Additionally, Search terms and their combinations are detailed in Appendix One. The search was restricted to studies involving children and adolescents, focusing on African countries, and limited to peer-reviewed articles published in English. The records identified through this search were screened at three levels: title, abstract, and full text. The full texts of articles that met the inclusion criteria were summarized based on the following parameters: author, objectives, sample size, research design, country, and results. The process and outcomes of the search are illustrated in the PRISMA flow chart (Figure 1), which details the number of records identified, screened, and included in the final review.

2.2 Eligibility Criteria

The inclusion criteria for this systematic review focused on records specific to sub-Saharan Africa. Previous studies, such as those by Schmid et al. (2020), which examined the economic burden ASD in the US, Canada, Brazil, and Europe, and by Shahat & Greco (2021), which compared the burden between developing and developed countries including some African nations, highlighted the need for more localized research in sub-Saharan Africa. This study addressed this gap by exclusively reviewing evidence from sub-Saharan African countries.

The search was restricted to studies involving children and adolescents within the geographical scope of African countries, and to peer-reviewed articles published in English.

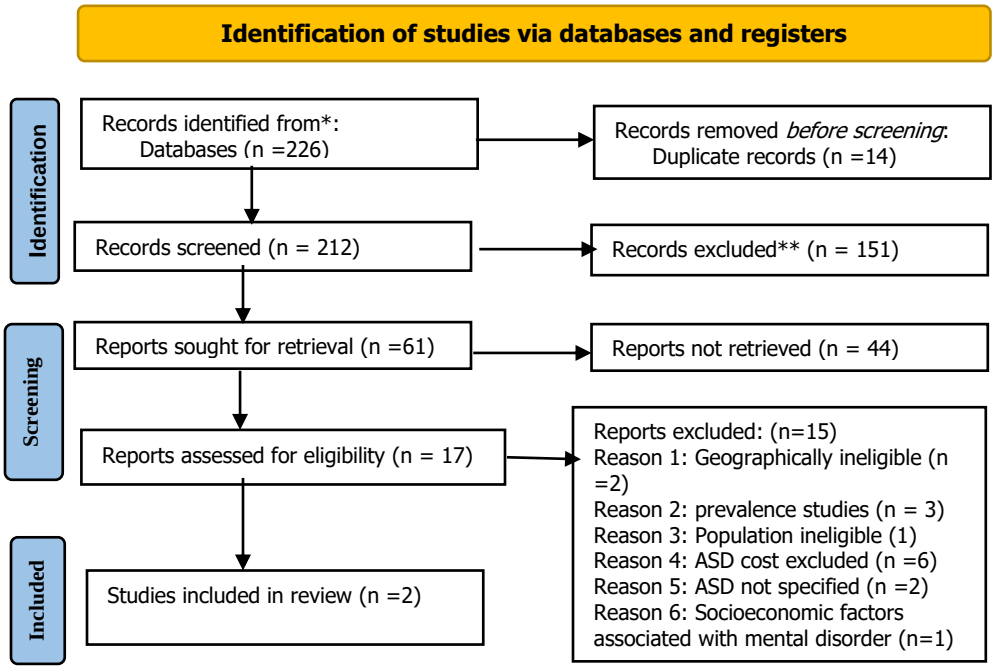

Figure 1: PRISMA Flowchart

From an initial list of 226 records, 14 duplicates were removed, leaving 212 unique records. These records were then screened based on their titles, abstracts, and full texts. Out of these, 61 records were identified as potentially relevant, selected based on the presence of keywords such as "Autism,"

"Autism Spectrum Disorder," "ASD," and terms related to socioeconomic effects like "economic expenditure," "economic costs," and "quality of life."

Any study mentioning autism was selected for further screening (17 records). Additionally, studies referring to mental, neurological, or developmental disorders were also considered, given the potential misclassification of ASD under these categories. This broad inclusion aimed to capture studies where ASD might be grouped with other disorders, resulting in the selection of 44 records for further screening.

Of the 151 records excluded, many focused on unrelated disorders such as musculoskeletal conditions, hypertension, alcohol use disorders, and other health issues like HIV-related costs and diabetes. The final screening reduced the pool to 17 records, from which only two studies met the full inclusion criteria after thoroughly reviewing their full texts. The data extraction involved summarizing the studies' objectives, sample sizes, research designs, countries of origin, and key findings. The review then synthesized results into themes addressing the socioeconomic effects of ASD in sub-Saharan Africa, including impacts on household welfare, direct and indirect healthcare costs, and the economic burden on caregivers.

3. Results and Discussion

3.1 Results

3.1.1 Overview of full-text screening results

Out of the 17 full-text studies assessed for eligibility in the systematic review, 15 (88.2%) were excluded from the final analysis based on defined exclusion criteria Figure 2 provide details of the excluded studies to illustrate the distribution of these exclusions. 40% were excluded because they did not specify or include autism spectrum disorder (ASD) costs, which was a core requirement of the analysis. 20% were prevalence-focused studies, which did not assess the socioeconomic or cost-related aspects of ASD. 13.3% were excluded due to geographical differences, focusing on regions outside the defined study context (i.e. studies not centred on sub-Saharan Africa). 13.3% did not specify ASD-related costs, even though the costs of mental or neurological disorders were discussed more broadly. 6.7% were excluded due to population ineligibility, often because the population studied did not match the inclusion criteria (e.g. not children with ASD). 6.7% addressed socio-economic factors related to general mental impairment, but not specifically ASD.

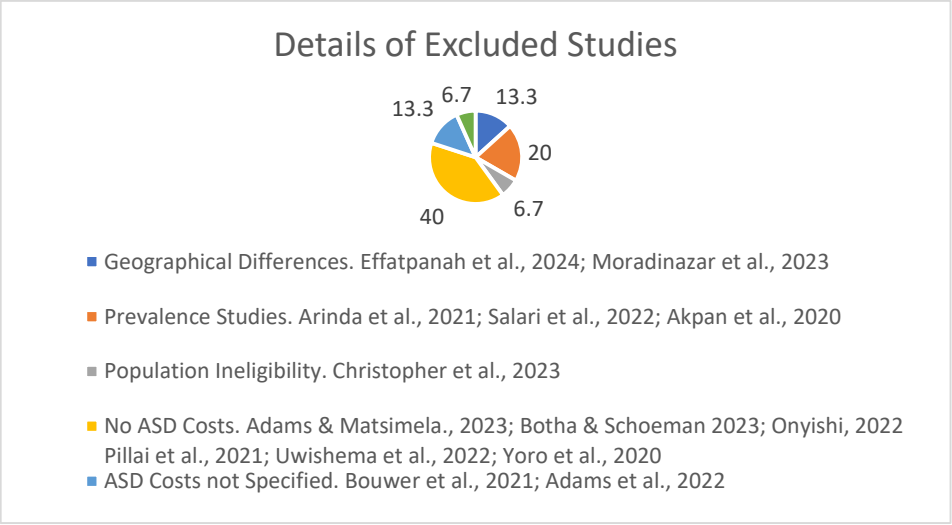

Figure 2: Details of excluded studies
Source: Researchers' source data

3.1.2 Overview of the included studies on the economic burden of ASD

The systematic review identified two empirical studies from sub-Saharan Africa that directly addressed the economic burden associated with autism spectrum disorder (ASD). These studies, summarized in Table 1, explored caregiver burden and the financial costs incurred by families raising children with ASD.

Table 1: Details of the Included Studies

S/N	Identity	Summary
1	**Title**: Caregiver burden among caregivers of children with autism spectrum disorder. **Author:** Van et al., 2023	**Aim:** To describe the socio-demographic profiles and determine the extent of the burden experienced by caregivers of children and adolescents with ASD. **Method**: A quantitative, descriptive, cross-sectional study using two self-administered questionnaires: a socio-demographic questionnaire and the 12-item Zarit Burden Interview questionnaire. **Participants**: Caregivers of children and adolescents with ASD **Key Findings**: Among the caregivers, 41.6% experienced mild to moderate burden, 33.8% experienced high burden, and only 24.9% reported no to mild burden. **Relevance to ASD Economic Burden**: High levels of caregiver burden imply indirect economic effects such as reduced productivity, income loss, or emotional stress
2	**Title:** Families raising children attending autism-specific government-funded schools in South Africa. **Author**: Erasmus et al., 2019	**Aim:** To describe socio-demographic characteristics and financial costs encountered by families whose children attend autism-specific government-funded schools in South Africa. **Method:** Cross-sectional quantitative study. Survey questionnaires were completed by 234 caregivers (representing 28.4% of the caregivers involved in the autism-specific schools nationwide). **Participants:** 234 caregivers of children with ASD **Key Findings**: Families are living on a relatively low monthly household income and spending significantly on school fees, transportation, medical insurance payments, and extracurricular therapeutic services. Monthly social assistance government grants were accessed by 46.6% of families, and 57% do not own their dwelling. **Relevance to ASD Economic Burden**: Demonstrates significant direct financial burden due to out-of-pocket spending, limited public support, and socioeconomic vulnerability

3.2 Discussion

Findings of this review have highlighted a significant gap in cost-specific research related to ASD in sub-Saharan Africa, as a considerable number of excluded studies lacked cost-specific data related to autistic children in the region. While many studies examined aspects such as prevalence, comorbidities, inclusive education, and general neurological care, they did not provide quantifiable data on the economic burden of autism. The exclusion of 40% of studies solely due to lack of cost data highlights the scarcity of financial analysis in ASD literature.

Furthermore, excluding studies based on unspecified costs (13.3%) or focusing on non-ASD mental conditions (6.7%) reveals a lack of disaggregated reporting. This weakens the ability to inform policy or allocate resources effectively for autism services. Additionally, geographical and population mismatches (20% combined) suggest more targeted research focusing specifically on context-relevant, region-specific data. The details for each research question are discussed in the subsequent section.

3.2.1 Direct and Indirect Healthcare Costs for children with ASD in sub-Saharan Africa

This review identified a significant gap in research on the direct and indirect healthcare costs of ASD in sub-Saharan Africa. Erasmus et al. (2019) reported that 20% of the household spending covers school fees and therapies, despite low-income levels and limited access to social grants. Financial support that was given to households with ASD children was in the form of subsidies (8.1%) and social assistance government grants (46.6%) to alleviate the high financial burden associated with ASD. However, the study lacked detailed breakdowns of healthcare expenses such as medical consultations, medications, or therapy sessions. The absence of proper data in the region may limit appropriate support for children with ASD and their families in the area, as the actual cost may be underestimated. Again, this may limit the region's ability to design evidence-based resource allocation strategies and social protection policies for individuals with ASD in the area.

Studies in other geographical contexts, such as in high-income countries, provide detailed healthcare costs for children and individuals with ASD; in this sense, they can provide a clear guide for resource allocation and support for children with ASD and their families. For instance, Buescher et al. (2014) estimated the lifetime cost of supporting an individual with ASD in the United States at approximately $1.4 million to $2.4 million, depending on the presence of intellectual disability. These included direct medical expenses, special education, and indirect costs such as lost parental income. Similarly, in the United Kingdom, Knapp et al. (2009) found the estimated cost of supporting children with ASD in the UK to be £2.7 billion per year, which indicates what it takes to help children with ASD.

3.2.2 Economic Impact of ASD on Caregivers in Sub-Saharan Africa.

Although no study in this review directly measured lost productivity or income, a study by Van et al. (2023) in South Africa using the Zarit Burden Interview, a 12-item questionnaire focusing on caregivers' burden found that 75% of caregivers experienced moderate to high levels of burden of care, suggesting

that ASD caregiving in sub- Saharan Africa likely imposes substantial indirect economic costs, including reduced employment and lost income. This is evidenced by the other regional context research that supports this interpretation, whereby Cidav et al. (2012) reported that mothers of children with ASD in the U.S. earned 56% less income than mothers of children without disabilities, mainly due to reduced work hours. It was found that caregivers of autistic children lost up to 7 hours per week in work time compared to those of a typical child. (Cidav et al., 2012), highlighting a measurable impact on productivity. These findings suggest that caregiver burden has substantial economic implications that remain underexplored in African contexts.

3.2.3 Costliest Services for children with ASD in SSA as compared to European Contexts.

The review did not identify studies from sub-Saharan Africa that compare service utilization costs with those in Europe or other international settings. However, despite attending a government school, Erasmus et al. (2019) pointed out that high expenditures are more contributed by non-core services such as transport and extracurricular therapeutic services, which may imply that even subsidized systems may not alleviate the full financial burden.

These results resemble the findings by Horlin et al. (2014) in Australia, indicating that the most significant expenses were behavioural therapies, special education, and informal care, each contributing thousands of dollars annually to family costs. The US study by Lavelie et al. (2014) found that children with ASD had a greater number of frequent visits to healthcare facilities, which contributes to higher healthcare expenditures than neurotypical children, indicating higher healthcare costs. Also, a greater number of children with ASD used more special education services than typical children. The findings from this review highlight the critical lack of cost-of-illness data in sub-Saharan Africa, which hinders effective policymaking and international comparisons.

4 Conclusion and Recommendations

4.1 Conclusion

This systematic review has highlighted significant gaps in understanding the socio-economic burden of ASD in Sub-Saharan Africa. Despite the growing prevalence of ASD globally, the paucity of research in this region hampers effective policy formulation and intervention strategies. The studies reviewed, primarily from South Africa, underscore the financial strain on families, with direct costs such as school fees and therapy services consuming a substantial portion of household income (Van et al., 2023; Erasmus et al., 2019). These

studies also reveal a significant caregiver burden, yet they lack comprehensive assessments of indirect costs such as productivity loss and long-term economic impacts.

The existing literature from developed countries, such as Europe and North America, provides a more detailed account of the economic impacts of ASD, including societal costs, educational expenses, healthcare costs, and productivity loss (Knapp et al., 2009; Lavelle et al., 2014). This contrast highlights the urgent need for detailed, context-specific research in Sub-Saharan Africa to inform effective policy and support measures.

4.2 Recommendations

The study recommends that future research should explore the socioeconomic burden of ASD in Sub-Saharan Africa in depth. This will help policymakers and stakeholders design and implement more effective and targeted interventions, which will improve the quality of life for children with ASD and their families across the region. A detailed explanation of the recommendations is provided in the next subsections.

4.2.1 Comprehensive Research Methodologies

Future studies should employ robust research methodologies that include control groups to provide comparative data. This approach will help in understanding the full extent of the socio-economic burden of ASD on families in Sub-Saharan Africa. Detailed assessments of direct and indirect costs are essential to comprehensively understand the economic impacts (Shahat & Greco, 2021).

4.2.2 Inclusion of indirect costs

Research should encompass a broader range of economic burdens, including indirect costs such as lost income due to reduced work hours, job loss, and decreased productivity. Understanding these aspects is crucial for developing comprehensive support systems for families.

4.2.3 Policy development and implementation

Policymakers must be informed by detailed and context-specific research to develop targeted interventions. This includes increasing financial aid, improving access to specialized educational resources, and providing respite care services for caregivers. Such measures can significantly alleviate the financial and emotional burdens on families dealing with ASD (Knapp et al., 2009; Lavelle et al., 2014).

4.2.4 Awareness and training programs

Increasing awareness and training about ASD among healthcare providers, educators, and the general public is essential. This can help in early diagnosis and intervention, reducing the long-term economic and emotional burden on families. Training programs should also be aimed at caregivers to equip them with better skills for managing ASD (World Bank, 2023; OECD, 2023).

4.2.5 Collaboration and funding

There is a need for collaboration between governments, non-governmental organizations, and international bodies to fund and support research and intervention programs for ASD. Financial support should be directed towards both research initiatives and the development of support systems for affected families (Schmid et al., 2020; Shahat & Greco, 2021).

4.2.6 Exploration of socioeconomic and educational contexts

Future research should explore the impacts of ASD across different educational settings and socioeconomic backgrounds. This will provide a more nuanced understanding of the financial burdens faced by families and help tailor interventions to meet the specific needs of diverse populations within Sub-Saharan Africa (World Bank, 2023; OECD, 2023).

4.2.7 Longitudinal studies

Longitudinal studies are needed to track the long-term economic impacts of ASD on families. Such studies can provide valuable insights into how the financial burden evolves over time and the effectiveness of various interventions (Knapp et al., 2009; Lavelle et al., 2014).

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