

Challenges of Caregivers Having Children with Autism in Kenya: Systematic Review

Abstract

Background: Caring for children with Autism Spectrum Disorder (ASD) is demanding, especially where access to services and support are inadequate. The present study aimed to systematically review the challenges associated with the caregivers whose children have autism. **Materials and Methods:** A systematic review design was utilized. The searches were conducted from February 2019 to January 2020. A qualitative analysis that was based on meta-aggregation approach and thematic analysis was used. Thereafter, data was presented into themes. The quality of all included studies was assessed using the Critical Appraisal Skills Program (CASP). **Results:** The search generated 909 articles of which only 9 met the inclusion criteria. The main findings were discussed under the following three thematic domains: 1) Stigma, 2) Financial burden, and 3) Caregiving burden. **Conclusions:** Evidence from the data reviewed showed financial burden faced by the caregivers whose children are diagnosed with ASD. This was manifested through both direct and indirect cost of treatment. Another key finding was that majority of the caregivers faced stigma from the community. This implies the low level of awareness of the ASD within the community. The present study calls for more programs on the present research problem within the community so as to increase awareness. Furthermore, the current advocacy of Universal Health Coverage programs in the country should incorporate ASD children.

Keywords: *Autistic disorder, caregivers, child, Kenya*

Introduction

Autism Spectrum Disorder (ASD) is a developmental disability with age of onset in childhood (under 3 years old).^[1] Additionally ASD is a family of neuro-developmental disorders which is characterized by definite impairments in social interactions, abnormalities in speech, and stereotyped pattern of behaviors.^[2] Although the etiology and pathogenesis of this disorder are still a matter of speculation.^[3] The consensus in the literature is that, autism is caused by both genetic and environmental factors.^[4] Globally 1 in 160 children has an ASD.^[5] In 2016, there were an estimated 62 million cases of ASD worldwide, accounting for a prevalence of 0.83%.^[3] However, this burden is currently underestimated since prevalence of ASD in the African region and other low or middle income regions is still unclear.^[6] During the same period there were about 800,000 individuals with autism in Kenya.^[7] ASD is diagnosed

clinically based on the presence of core symptoms.^[8] According to the current DSM-5 definition, the core symptoms of ASD consist in persistent deficits in social communication and social interaction across multiple contexts and in restricted, repetitive patterns of behavior, interests, or activities, which lead to clinically significant impairment in social, occupational, or other important areas of current functioning.^[3] Children with ASD become distressed when their surrounding environment is changed because their adaptive capabilities are minimal.^[9] They have co-occurring language problems, intellectual disabilities, and epilepsy at higher rates than the general population.^[9] At present, there is no cure, although there are interventions that may be effective in alleviating some symptoms.^[10] Treatments pursued by families include a range of behavioral, psychosocial, educational, medical, and complementary approaches that vary by a child's age and developmental status.^[11]

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Caring for children with a severe form of the condition is demanding, especially where access to services and support are inadequate.^[5] ASDs often impose significant emotional and economic burden on people with these disorders and their families.^[5] Autism is such a developmental disability which has a great impact on the family's adaptation and functioning more so the mother.^[12] Families with a child diagnosed of ASD have to pass through compromising; sacrificing, stressful, and adjustment lifestyle.^[12,13] The testimonials of the parents of autistic children in Mali, recently demonstrated how they are financially and emotionally burdened.^[14] Moreover the parents' children with ASD are known to experience higher levels of parenting stress compared to the parents of normally developing children.^[15] Utilizing 9 studies [Gona,^[16] Cloete,^[17] Elliott,^[18] Gona,^[19] Kamau,^[7] Obaigwa,^[20] Cohen,^[21] Ouma,^[22] and Chabeda-Barthe^[23]] available in Kenya on present research problem, the researchers aimed to systematically review the challenges associated with the caregivers whose children have autism. The research question adopted for the present study was: what are the challenges associated with the caregivers whose children have autism in Kenya?

Materials and Methods

The present study was conducted from February 2019 to January 2020. It utilized a systematic review design that adopted a meta-aggregation approach. The meta-aggregation process is based on identification of meaning of the findings from individual studies.^[24] This include the development of a review question; the conduction of a comprehensive search, the critical appraisal of studies selected for retrieval, extraction of findings, and the meta-aggregation of findings.^[24] According to Florczak's^[25] report, meta-aggregation is a process that identifies meanings from qualitative studies that may be from different methodologies and further abstracts those meanings into categories that are then synthesized. This makes the meta-aggregation approach suitable for the present study since studies that were utilized had different methodologies. Florczak's^[25] report further explains that this process is not linear but iterative and interpretive, producing statements that are useful for action. In other words, being useful for action implies that the statements can be useful for evidence-based practice. All descriptive or cross-sectional studies were included. An article was included if it met the following criteria: 1) Conducted in Kenya between 2012 and 2019, 2) had study participants as the caregivers whose children have autism, and 3) published in English. For the present study the caregivers were defined as parents or guardians to the children diagnosed with autism. Conference abstracts were excluded. For data sources and search strategies, a systematic search of articles was from the following databases: Scopus, Science Direct, PUBMED, OVID, and

Google Scholar. The following were the key words used in the search: "Challenges autism," "Caregivers whose children have autism," "Kenya," and "Parents whose children have autism." The reference list of included studies was manually searched for possible additional eligible articles. The searches were conducted from February 2019 to January 2020. In particular the researchers used the following search terms in PUBMED database: "Problems caregivers whose children have autism," "Challenges autism," and "Kenya." Thereafter selection of studies for inclusion in the review was as follows: Titles and abstracts of studies retrieved from each database search were stored in Mendeley Research Manager. Three review authors (BBM, JT, and RM) independently reviewed the titles and abstracts of all studies in the initial screening phase. Disagreements were solved by discussion. The same steps were taken for full-text screening of the results. For data extraction and management, using a standardized data extraction form, three review authors (BBM, JT, and RM) independently extracted data from eligible studies including first author's last name, year of publication, study location, participant characteristics, study design utilized, and major findings of the study. Quality assessment was performed as follows: Three review authors (BBM, JT, and RM) independently assessed the quality of all included studies using the Critical Appraisal Skills Programme (CASP). Each included study was scored on 14 aspects: 1) whether the study aims/objectives were clear; 2) whether the study design was appropriate for the stated aim(s); 3) whether the study sample size was justified; 4) whether the study the target/reference population was clearly defined; 5) whether the selection process was likely to select subjects/participants that were representative of the target/reference population under investigation; 6) whether the risk factor and outcome variables measured appropriate to the aims of the study; 7) whether the risk factor and outcome variables were measured correctly using instruments/measurements that had been piloted or published previously; 8) whether the methods (including statistical methods) were sufficiently described to enable them to be repeated; 9) whether the basic data was adequately described; 10) whether the response rate failed to raise concerns about non-response bias; 11) whether the authors' discussions and conclusions were justified by the results; 12) whether the limitations of the study were discussed; 13) whether there were no any funding sources or conflicts of interest that may affect the authors' interpretation of the results; 14) whether there was an ethical approval or consent of participants.^[26,27] The reviewed studies that scored 5 out of 14 points were considered of low quality; 6 to 10 points score were categorized of moderate quality, and finally high quality studies were those with a score above 10 points. BBM assessed the quality of the included studies while JT and RM checked the assessed studies. Only studies with moderate and high quality were included. Disagreements

were resolved by discussion between the three review authors. Lastly synthesis of results was carried out. In meta-aggregation a synthesized finding is defined as an overarching description of a group of categorized findings.^[24] Thematic analysis was adopted at this stage to categorize findings. Thematic analysis was suitable for the present study since it is a method of analyzing qualitative data. In this analysis, the researchers closely examined the data to identify common themes—topics, ideas, and patterns that come up repeatedly. According to Thomas and Harden’s^[28] description, thematic analysis has three stages: The coding of text “line-by-line”; the development of “descriptive themes”; and the generation of “analytical themes.” While the development of descriptive themes remains “close” to the primary studies, the analytical themes represent a stage of interpretation whereby the reviewers “go beyond” the primary studies and generate new interpretive constructs, explanations, or hypotheses.^[28] For the present study, stages one and two involved coding text and developing descriptive themes. The review authors (BBM, JT, and RM) independently highlighted (in yellow) results texts within an article being reviewed. Thereafter, simple descriptive texts (codes) were assigned to the highlighted texts. The texts gave simplest description of the challenges associated with the caregivers whose children have autism. This process was repeated to the other articles included in the present study. Stage three involved generating analytical themes. At this phase, the review authors (BBM, JT, and RM) looked for similarities and differences between the descriptive texts developed and started categorizing them into groups. Based on the interpretation of the developed descriptive texts; those that were of similar content were grouped together. It is at this point that the three themes of the present study emerged. The themes were 1) Stigma, 2) Financial burden, and 3) Caregiving burden. [Table 1]. Data was presented and organized under the three identified thematic domains. This was a secondary analysis and all identifiers of the individual participants were removed or presented using unique codes.

Ethical considerations

The study being a systematic review, the researchers did not involve the patients in collection of data. Hence an ethical consideration was not applicable to the present study. However, all the studies sampled had ethical approvals and consent of participants.

Results

Guidelines for Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) as demonstrated previously by Liberati *et al.*^[29] [Figure 1] were used. The search generated 909 articles of which 83 duplicate articles were removed. After the screening process of their titles and abstracts, only 14 articles were identified and were thereafter included in the full text review. The identified articles were further assessed using the adopted inclusion criteria. Among 14 articles only 9 met the inclusion criteria. Table 2 gives a further summary of publication year, study design, study participants, study settings, and study results of the articles reviewed.

Discussion

The present study aimed to systematically review the challenges associated with the caregivers whose children have autism. The findings were presented and discussed under three thematic domains: 1) Stigma, 2) Financial burden, and 3) Caregiving burden.

Stigma

Gona *et al.*’s^[16] study in Kenyan Coastal region demonstrated how caregivers are stigmatized; they are banned from church services for having a child with ASD. Similarly, a study conducted in Nairobi noted that the communities in

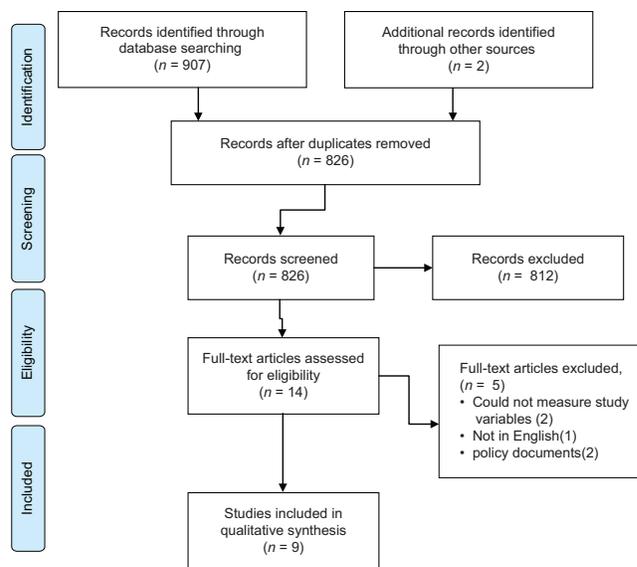


Figure 1: PRISMA flow diagram

Table 1: Description of thematic analysis table developed in the present study

Descriptive texts	Access category	Themes
“Caregivers banned from church services”; “family break-ups”; “Autism Spectrum Disorder (ASD) child would bring a curse”; “bad omen in society”	[Gona ^[16] Cloete ^[17] Kamau ^[7] Chabeda-Barthe ^[23]]	1) Stigma
“Caregivers travel over 100 miles”; “low socioeconomic status”; “little support from the government”; “unaffordable cost of care”	[Elliott ^[18] Gona ^[16] Kamau ^[7] Obaigwa ^[20] Cohen ^[21] Ouma ^[22] Chabeda-Barthe ^[23]]	2) Financial burden
“ASD children were reported to be chaotic”; “delayed milestones”; “more close monitoring needed”	[Gona ^[19] Kamau ^[7] Obaigwa ^[20] Cohen ^[21] Ouma ^[22]]	3) Caregiving burden

Table 2: Description summary of the articles reviewed

First Author	Year	Design	Objective	Participants	Age	Setting	Quality score	Results
Gona ^[16]	2017	Qualitative design and applied a phenomenological methodology	To explore the life challenges of raising a child with autism on the Kenyan coast	37 parents	Above 18	Coastal Kenya	12	Challenges include stigma, lack of appropriate treatment, financial, and caring burdens regardless of their religious and cultural backgrounds.
Cloete ^[17]	2019	Descriptive phenomenological study	To explore the perspectives of caregivers who are responsible for caring for both family and children living with Autism Spectrum Disorder (ASD) and to highlight the needs of children with ASD as well as the needs of their caregivers	300 caregivers	Above 18 years	Kenyatta National Hospital	14	The burden of caring for children with ASD was identified. Children with ASD and their caregivers experience isolation and stigmatization.
Elliott ^[18]	2018	Qualitative design	Prevalence of ASD and challenges they face	1354 respondents	18-35 years	45 counties	10	Both those with a family member with autism and who have autism themselves agree that more support from the government is needed, with just 16% saying they have enough support from the government. Out of the larger sample of those who know people with autism, 74% say those with autism do not get enough support from the government.
Gona ^[19]	2015	Qualitative design and applied a phenomenological methodology guided by the Explanatory Model framework	To explore parents' and professionals' perceived causes and treatment of ASD	103 participants (parents and health professionals)	Above 18	Coastal Kenya	14	Treatment varied from traditional and spiritual healing to modern treatment in health facilities, and included consultations with traditional healers, offering prayers to God, and visits to hospitals.
Kamau ^[7]	2017	Exploratory research,	Study sought to understand the difficulties that parents, caregivers and special needs providers encounter as they experience the diagnosis, and treatment of autism in Kenya.	50 participants	Above 18	Nairobi	11	This study found out that a lot of parents mostly mothers of children with autism retreat and suffer in silence. Additionally there is also a lack of institutional support.

Contd...

Table 2: Contd...

First Author	Year	Design	Objective	Participants	Age	Setting	Quality score	Results
Obaigwa ^[20]	2019	Descriptive, phenomenological	The purpose of this study was to describe challenges faced by caregivers of children with autism spectrum disorder to access the crucial services in Kenya	300 participants	Above 18 years	Kenyatta National Hospital	14	Caregivers faced difficulty in accessing support and crucial services in the management of children having ASD. Furthermore social and financial challenges were also noted
Cohen ^[21]	2012	Qualitative study	To illustrate several obstacles that children with autism face in Kisumu, Kenya in accessing the successful intervention services that they so desperately need.	Parents of seven children in the autism unit	Above 18 years	Kisumu	11	Inaccessibility of early intervention services to children with ASD were noted. The resources to support children with autism are not nearly accessible enough for the many families in Kisumu that are in desperate need of assistance for their children.
Ouma ^[22]	2016	Guided by the theory of social constructivism methodology	To investigate the outcomes of mothers' involvement in early identification and intervention for children with autism.	172 parents	Above 18 years	Nairobi	12	The research found that some mothers identified children with autism as early as two years while others were identified as late as thirteen years.
Chabeda-Barthe ^[23]	2019	Ethnographic study methodology	To demonstrate why there needs to be a societal change in the way child developmental disability is understood, and handled in a developing country such as Kenya	90 questionnaires were filled out by parents	Above 18 years	Nairobi County	13	More needs to be done to change the community's attitude toward disability

which the participants live believed that ASD is caused by women's previous forbidden cultural actions or through marriage to members of certain prohibited tribes.^[17] The stigma and rejection has sometimes resulted into family break-ups as the child's mother is divorced.^[7] Corroborating this findings, in an Ethiopian study, families with an ASD child face similar stigma as they are denied to rent houses.^[30] Tekola *et al.*^[30] explained that the property owners believed that those children with ASD would bring a curse to them and their families.^[31] This review notes that the caregiver is stigmatized by the community and friends through rejection. Some further face blames of having brought the disease to the community. This is attributed to the poor understanding of the ASD disorder within the community. Some communities have associated the occurrence of ASD to witchcraft, curses, and bad omen.

Finance burden

Previous studies noted that guardians travel over 100 miles from remote parts of the country for monthly clinic to a national hospital.^[7] This is because almost all the expert professionals are largely available within the confines of big cities.^[7] Furthermore results of the present study noted that, caregivers' financial crisis state is worsened by their low socioeconomic status in the society. Chabeda-Barthe *et al.*^[23] noted that majority of these children with disabilities in Kenya, live in the rural areas. Another study in Nairobi revealed that majority caregivers had little support from the government.^[17] For the families with poor knowledge about the disease, they keep on seeking care from traditional healers with no much improvement in their ASD child.^[16] Elsewhere in Jamaica, similar trends of challenges were noted.^[32] In majority of the

low and middle-income settings, access to support and rehabilitation services for children with disabilities are often lacking.^[33] In Ethiopia caregivers noted that they are asked triple fee (compared to normal school fee) in special schools for their ASD child.^[30,31] Similarly in Nigeria center for learning for children with autism are mostly in cities such as Lagos, Abuja, and Port Harcourt.^[13] The analyses of the present study reveals that majority caregivers whose children are diagnosed of ASD are financially burdened. This may be attributed to the indirect and direct costs of care of the ASD child.

Caregiving burden

Cloete and Obaigwa's^[17] study demonstrated that the ASD children were reported to be chaotic by their caregivers. Additionally the caregivers noted that the ASD children have occurrences of delayed milestones, this could imply that they needed more close monitoring compared to their counterparts who were normal.^[16] Associated phenomena with ASD children include mental retardation, emotional indifference, hyperactivity, aggression, self-injury, and repetitive behaviors such as body rocking or hand flapping.^[8] The ASD children may have restricted behaviors which present as resistance to change or highly restricted fixated interests, which are abnormal in intensity or focus.^[4] Some parents have disregarded their own children due to the caregiving burden in Ethiopia.^[30] In Bangladesh, mothers reported that their most challenging part of raising their autistic child was to manage their hyperactivity and social interaction.^[12] Similar trends were noted in Jamaica.^[32] The results of the present review imply that the caregiving or the parenting role to ASD children is challenging. This is attributed mostly to the unique clinical manifestations of the ASD children.

Implication in nursing practice

One of the advanced nursing care procedures emphasized by nursing organizations around the world is patient or nursing advocacy; more so to the vulnerable children diagnosed with ASD.^[34] Maryland and Gonzalez stated that nurses, in addition to within hospitals, should support patients and their families in other social environments including economic, educational and research, health care delivery, and legislative policies.^[35] For instance families are often willing to share with the nurse both the clinical and non-clinical problems.^[35,36] This information is mostly gathered through nursing assessment which includes information concerning the patient's individual physiological, psychological, sociological, and spiritual needs.^[37] Appreciation of some of the social factors (non-clinical)^[38] that influence health-related behaviors and health status itself can help nurses develop more effective treatment plans when caring for these vulnerable groups.^[39] The child developmental problems combined with the socioeconomic disadvantage are most responsible for the health inequalities faced by ASD children's families hence the need for nurses advocacy.

Conclusion

Despite Kenya adopting the Universal Health Coverage (UHC) as advocated by the World Health Organization; evidence shows existing challenges faced by caregivers whose children are diagnosed with ASD.^[40,41] Universal health coverage implies that all persons as well as communities can use the curative, promotive, preventive, palliative, and rehabilitative health services they require, ensuring that the employment of these services does not expose the user to financial challenges. However, majority of the data analyzed showed financial burden faced by the caregivers when seeking treatment especially those from rural areas. Another key finding was that majority of the caregivers faced stigma from the community. This implies the low level of awareness of the ASD within the community. The present study calls for more programs on the present research problem within the community so as to increase awareness. Furthermore, the current advocacy of UHC programs in the country should incorporate ASD children. For the limitations of the present study; the review could not analyze studies that were purely quantitative since in the present study, the research problem was only measured by a qualitative approach.

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Conflicts of interest

Nothing to declare.

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