International Journal of Community Medicine and Public Health
Arockiasamy APR et al. Int J Community Med Public Health. 2026 Feb;13(2):900-911
http://www.ijcmph.com
pISSN 2394-6032 | eISSN 2394-6040

DOI: https://dx.doi.org/10.18203/2394-6040.ijcmph20260014

Systematic Review

Caregiver burden in autism spectrum disorder among low-income countries: a systematic review

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Received: 22 December 2025
Revised: 06 January 2026
Accepted: 07 January 2026

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ABSTRACT

This review aims to examine the challenges faced by caregivers of children with autism spectrum disorders (ASD) in low-income countries (LICs), highlighting the financial, healthcare, and psychological burdens. The study seeks to explore how these challenges affect caregivers' well-being and identify potential solutions to alleviate their burden. A comprehensive literature review was conducted using peer-reviewed articles and studies focusing on caregiver burden in ASD within LICs. Data was collected from academic databases like ProQuest, PubMed, Embase, Science Direct including all the studies on financial constraints, healthcare access, cultural perceptions, and caregiver quality of life (QoL). Caregivers of children with ASD in LICs face significant challenges due to financial instability, inadequate healthcare infrastructure, and social stigma. This review examines the financial, healthcare, and psychological stressors affecting caregivers in LICs through a comprehensive literature analysis. Thirteen studies met the inclusion criteria and were synthesized in this systematic review. The reasons for the increase in the caregiver burden in LICs can be broadly divided into 3 groups: the role of the ASD severity and comorbidities, the caregiver related factors and other factors like the financial aspects of the caregivers. These studies indicate that primary caregivers, often mothers, experience heightened fatigue, poor mental and physical health, marital strain, and economic hardship, exacerbated by limited access to specialized support. Compared to other developmental disorders, ASD presents a greater burden on families in LICs, where resources are scarce. Research highlights a direct correlation between ASD severity and caregiver stress, underscoring the urgent need for targeted policies, improved healthcare services, and community-based support programs to mitigate caregiver burden and enhance QoL.

Keywords: Autism spectrum disorder, Caregiver burden, Low-income countries

INTRODUCTION

Autism is a developmental disorder characterized by a pattern of impaired social interactions and restricted or repetitive patterns of behaviour. It is a complex, lifelong disability that typically becomes apparent during the first three years of life. However, the condition is often missed and not diagnosed until later in a child's life, especially when the condition is mild or even moderate in severity.[1]

The diagnostic and statistical manual of mental disorders fifth edition (DSM-5 TR) divides the severity of autism spectrum disorders (ASD) into three levels based on the degree of impairment in adaptive and cognitive functioning. Individuals with level 1 severity require some support, while individuals with level 2 need substantial support and those with level 3 need very substantial support.

ASD is a complex neurodevelopmental condition characterized by persistent deficits in social communication and interaction across various contexts, as well as by behavioural patterns marked by restrictive and repetitive behaviours. The DSM-5-TR continues recognize impairments in these two primary domains: social communication and interaction, and restricted and repetitive behaviours and interests (American psychiatric association, 2022).[2] Recent reports suggest that the prevalence of autism in the Arab world ranges from 1.4 cases per 10,000 children in Oman to 29 per 10,000 children in the United Arab Emirates (Amr). While these rates are lower than those of the developed world, which are 39 per 10,000 for autism and 77 per 10,000 for all forms of ASD, it does not necessarily mean the condition is less prevalent in the Arab world.[3]

Research on caregiver burden began receiving attention in the late 1970s, and in recent years, more research has been generated on caregivers looking after patients with medical and psychiatric disorders. However, research in children and adolescents primarily focuses on medical conditions, with research on psychiatric disorders and caregiver burden needing to be improved.[4] A well-informed caregiver is an essential part of managing a child with ASD. A caregiver is defined by Kent et al as the person responsible for looking after someone who cannot function independently and requires assistance with activities of daily living. Caregivers are required to meet the needs of the child with ASD, manage challenging behaviour and follow through with professional recommendations from healthcare providers.[5]

Research has shown that biological mothers are usually the primary caregivers of children with ASD. Caregivers of children with ASD have reported elevated fatigue levels and increased physical and emotional health complaints, lower marital satisfaction levels, work challenges and financial constraints because of loss of income. In a similar vein, Karst et al reported a higher incidence rate of depression and anxiety among caregivers of children with developmental disabilities, including ASD.[6] Families with an autistic child may face a variety of issues, such as reduced parenting efficacy, high stress rate, mental and physical health issues, severe financial problems, time constraints, sibling adjustment issues, reduced social support, and family conflict.[7] As compared with many other disorders such as ADHD, intellectual disability (ID), ASD may have a greater effect on the family.[8] As a result, it will be challenging to raise autistic children in developed countries and can be even more challenging for parents and families from LICs.[9]

LICs are nations classified by the world bank as having a gross national income (GNI) per capita of $1,135 or less as of 2024. These countries often face economic hardships characterized by high poverty rates, low GDP, and limited access to essential services. IMF 2024 Healthcare systems in LICs are often underdeveloped, making it difficult for families to access specialized medical care, including support for children with ASD.[10] Financial instability further exacerbates the burden on caregivers, as many struggle to afford therapies, special education, and other necessary interventions. Additionally, inadequate educational infrastructure limits opportunities for children with ASD, while social stigma and cultural misconceptions contribute to their exclusion from society. Examples of LICs include Burundi, Somalia, Chad, the Central African Republic, and Malawi.[11] Understanding the unique challenges faced by caregivers in these regions is essential for developing targeted policies and support systems to improve their well-being.

Parents of children with ASD face social stigma influenced by their beliefs, limited knowledge, and inadequate special education and behavioural treatments. Their perceptions shape interactions with specialists, parenting approaches, and therapy choices.[12] According to previous research, the cultural and educational background of parents influences their views on ASD.[13] Expectations and attitudes about ASD can affect parents' and families' functioning and psychological well-being. As a result, it is necessary to compare parents' perceptions of ASD across cultures. Previous research has shown that stigma can lead to increased psychological distress among parents, affecting their mental health and overall family dynamics.[14]

The literature also indicates that parents of children with ASD generally report lower QoL compared to parents of typically developing children. Factors such as the age of caregivers, the severity of the child's autism, and the presence of parental mental health issues (like anxiety) were identified as contributors to impaired QoL.[15] Research suggests that these factors increase the risk of experiencing a higher burden, which in turn negatively impacts QoL. Family and/or friend support, coping strategies used, caring demands, and child perceptions have all been found to have a significant impact on parental QoL.[16] All previous studies have shown that parents of children with ASD had lower scores in one or more QoL dimension as compared with parents of typically developing children.

Questions of the literature review

The following questions were explored through a systematic review of the literature published between January 2015 and January 2025: I. What are the different factors influencing the burden of people caring for individuals with ASD? II. Is there a difference between LICs and high-income countries in relation to the caregiver's burden? III. What are the effective interventions available for the caregivers of autistic children? From what is learned through the literature review will guide future research in the right direction.

METHODS

For this systematic review ProQuest, Embase. Science Direct and PubMed have been utilized to search articles about caregiver burden in ASD within LICs. These databases were under the subscription of the national university of science and technology, Oman and were available for use by both the faculty and the students. The search was narrowed to articles between Jan 2015 and Jan 2025. This period was chosen since this would reflect the latest advances in the subject chosen.

The search was conducted across a comprehensive range of sources mentioned above using the MESH terms of ASD, caregiver's burden and LICs. including all the electronic documents.

Inclusion criteria

The authors determined that for studies to be eligible for inclusion they must contain all the three important factors-the studies should have been done in individuals only with ASD or who are comorbid with ID, should have assessed the care giver's burden with reliable and valid instruments and the study should have been done in the LICs.

Exclusion criteria

Studies focusing on caregivers of individuals with other neurodevelopmental disorders ADHD, ID, cerebral palsy, learning disorders were excluded. Studies focusing on caregiver burden conducted in high-income countries were excluded. Studies using non-validated tools with poor inter-rater reliability for assessing caregiver burden were excluded.

Search strategy

The search strategy was meticulously designed to ensure comprehensive coverage and retrieval of relevant studies. It integrated medical subject headings (MeSH), EMBASE Subject Headings, and free-text keywords, combined using Boolean operators ("AND", "OR") to refine precision and sensitivity. The key conceptual domains included caregiver burden/autism spectrum disorders/low-income countries. A representative PubMed search strategy employed the following string: ("caregiver burden"[MeSH terms] OR "caregiver burden"[All Fields] OR "family burden"[All Fields]) AND ("autism spectrum disorder"[MeSH Terms] OR "autism spectrum disorder"[All Fields] OR "ASD"[All Fields]) AND ("low-income countries"[MeSH Terms] OR "developing countries"[All Fields] OR "resource-limited settings"[All Fields]) as shown in Table 1.

Excluded were studies assessing different other disorders like ID, ADHD, other neurodevelopmental disorders. Studies on the same topics but done in the high-income countries were excluded. Many studies which were done exclusively during COVID 19 or the immediate aftermath of the pandemic were excluded. The PRISMA diagram of the process of inclusion and exclusion of the studies is presented in Table 2.

Assessment of methodological quality of studies

The methodologies employed across these studies assessing caregiver burden and related experiences present a strong dual emphasis on both quantitative rigor and qualitative depth. The quantitative research primarily utilized cross-sectional survey designs to measure prevalence, correlations, and predictive factors, drawing samples through techniques such as convenience sampling and stratified random sampling across studies conducted in Malaysia, Turkey, and Egypt.[17-19] Data collection relied heavily on standardized instruments, including the beck depression inventory (BDI), the beck anxiety inventory (BAI), the Maslach burnout inventory, the Zarit caregiver burden scale, and the modified parent satisfaction scale (PSS) questionnaire. Advanced statistical methods, such as simple and multiple linear regression analyses, were consistently applied to identify significant predictors of outcomes, often linking factors like child symptom severity to caregiver burden, resilience, and QoL. Furthermore, depression screening for intervention studies was conducted using the patient health questionnaire (PHQ-9), with confirmation sought via the structured SCID-I tool.

A complementary suite of qualitative methodologies was utilized to explore the nuanced lived experiences, coping strategies, and unmet needs of caregivers. Designs ranged from general qualitative research to specific phenomenological and case study approaches focused on uncovering detailed, contextualized experiences in countries like Nepal and Ghana.[20,21] Data were primarily gathered through in-depth or semi-structured interviews and focus groups to allow participants to discuss complex topics such as career concerns, social isolation, and service barriers. The analytical strategies adopted were rigorous and systematic, encompassing comprehensive techniques such as the seven-step data analysis method, framework analysis, thematic analysis (both deductive and inductive), and the use of Colaizzi's steps. The selected 13 studies are listed in Table 3 with the summary of results.

Table 1: MESH term search strategy.

PubMed	MESH term	Caregiver, ASD and LICs
Embase	Subject headings	Caregiver, ASD and LICs
ProQuest academic	Command line keywords	Caregiver, ASD and LICs
Science direct	Subject headings	Caregiver, ASD and LICs

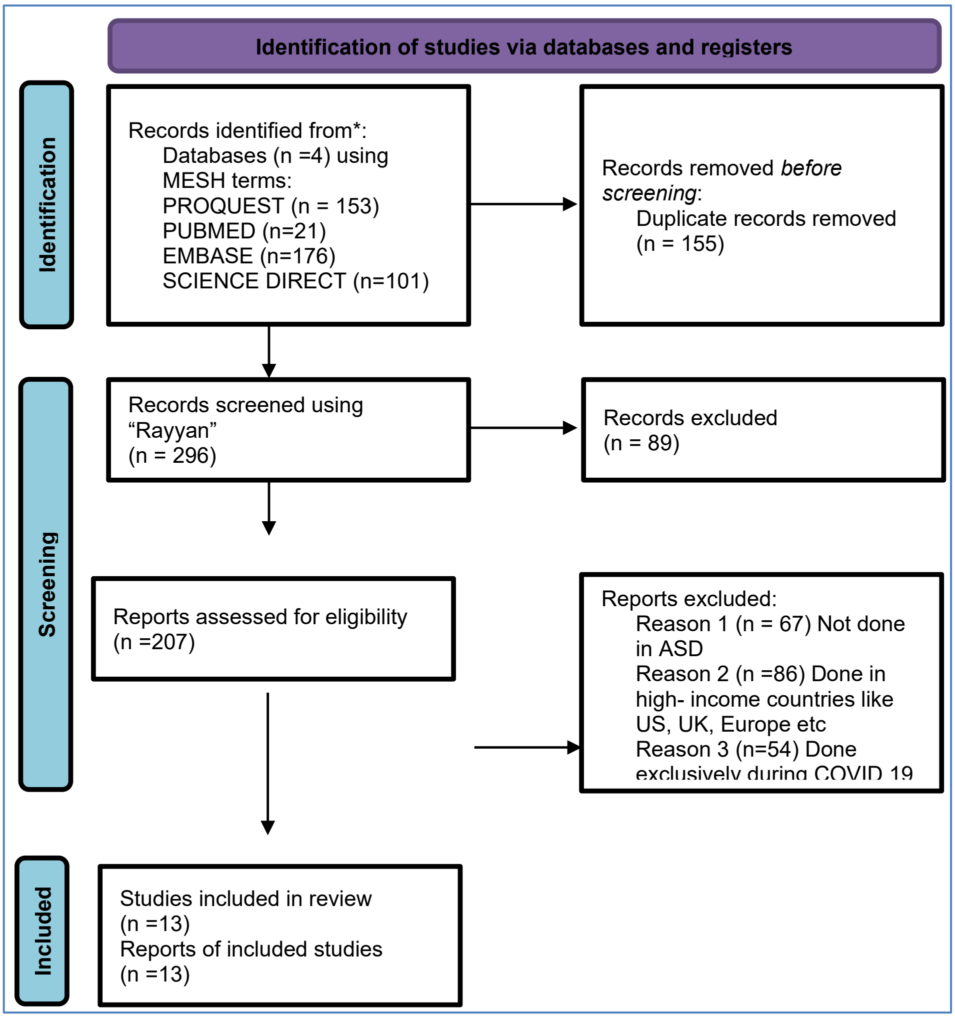

Figure 1: PRISMA 2020 flow diagram-caregiver burden in ASD.

Table 3: Summary of results of the included studies.

Authors	Country	Year	Results	Methods used
Ozdemir and Koç[26]	Turkey	2022	-Participants experienced difficulties focusing on work after their child's ASD diagnosis, leading to job changes or quitting. -Parents expressed a lack of hope and concern regarding their career futures due to uncertainties surrounding ASD. -Participants reported a shift in career plans to accommodate their child's needs, often postponing personal career aspirations.	-A seven-step method was employed for data analysis, including familiarization, and clustering themes. -The semi-structured interview form was developed based on the career construction theory for data collection. -Data collection involved face-to-face and online interviews, lasting around 40 minutes each.
Proctor et al[25]	India	2024	-The study involved 37 parents in focus groups discussing their experiences in rural South India. -Qualitative analysis revealed four main themes: peer support, social inclusion, knowledge sharing, and advocacy, each with sub-themes. -Parents reported enhanced QoL through knowledge sharing and peer support within the groups.	-A qualitative study recruited 37 participants from 17 parent groups through convenience sampling to explore their experiences. -Six focus groups were conducted six months post-intervention to gather insights. -Thematic analysis, both deductive and inductive, was employed to analyze focus group data.

Continued.

Authors	Country	Year	Results	Methods used
Kutuk et al[18]	Turkey	2023	-Parents of children with ASD experience significantly elevated burnout and depression levels compared to parents of healthy children. -Depression in mothers correlates with children's attendance in special education services. -Fathers' depression is linked to maternal depression and children's symptom severity.	-Study utilized a sociodemographic form to collect data on parents and children with ASD - BDI assessed parents' depression symptoms. -Maslach burnout inventory evaluated burnout levels among parents. -Multiple regression analysis was used to identify predictors of burnout.
Acharya et al[20]	Nepal	2021	-The study revealed that mothers experienced physical exhaustion and emotional disturbances while raising autistic children. -Mothers faced social isolation and economic challenges due to their child's condition. -The research identified five major themes regarding mothers' experiences, including coping strategies and daily life impacts.	-A qualitative phenomenological study design was employed to explore mothers' experiences raising children with autism. -Data were collected through in-depth interviews guided by specific guidelines. -Colaizzi's steps were utilized for data analysis.
Adib et al[17]	Malaysia	2019	-The study assessed satisfaction scores of 227 main caregivers using a modified PSS questionnaire -Caregivers waiting longer for consultations had reduced PSS scores, while satisfied caregivers had higher scores -Caregivers with medical problems and children in occupational therapy for over two months had reduced PSS scores at tertiary care -Factors like satisfaction with therapy appointments and waiting times positively influenced caregivers' PSS scores	-A cross-sectional study design was employed to assess caregivers' satisfaction -Stratified random sampling was utilized to select respondents from children with ASD attending follow-ups. -A modified PSS questionnaire was used to assess satisfaction scores of caregivers.
Salleh et al[22]	Malaysia	2024	-The study found an inverse relationship between perceived affiliate stigma and both resilience and QoL among parents of children with ASD. -The child's age at diagnosis and comorbidities also influenced parental perceptions of affiliate stigma and resilience.	-The study employed a cross-sectional design involving 144 parents of children with ASD from two hospitals in Kelantan, Malaysia. -Simple and multiple linear regression analyses identified significant factors associated with affiliate stigma, resilience, QoL.
Lee et al[27]	Mongolia	2021	-The study examined the experiences and needs of parents raising children with ASD in Mongolia, revealing significant challenges and barriers. -Parents reported negative experiences regarding services and supports available for their children with ASD. -Financial burdens and limited-service availability were major concerns expressed by the participants.	-The researchers employed a constant comparative method for data analysis, starting with an open-coding process to identify units independently. -Focus groups were utilized to gather in-depth insights from parents about raising children with autism in Mongolia. -The analysis was guided by ecological systems theory, examining caregivers' perceptions across different subsystems.

Continued.

Authors	Country	Year	Results	Methods used
Estrin et al[31]	India	2023	-The study identified five themes regarding the recognition and reporting of autistic symptoms influenced by cultural factors. -Two additional themes emerged: the impact of diagnosis and family support. -Caregivers' interpretations of autism symptoms varied significantly between groups.	-Thirteen semi-structured interviews were conducted with caregivers of children in three groups: ASD, ID, and developmental milestones. -Interviews focused on caregivers' understanding and experiences regarding diagnosis and healthcare access. -Framework analysis was used to analyze the transcripts.
Ahmed et al[46]	Bangladesh	2017	-Study screened 188 mothers for depression, with 66 undergoing SCID-1 assessments -In-depth interviews were conducted with 10 mothers and 8 stakeholders -3 special educators were trained to support maternal training in June 2017. -The intervention aims to reduce maternal depression and improve child outcomes. -Findings will inform future mental health services for mothers of children with ASD in Bangladesh	-The study recruited 52 to 78 mothers of children with ASD from two schools for participation in the intervention. -Depression was screened using the patient health questionnaire (PHQ-9) and confirmed with the SCID-I tool. -In-depth interviews were conducted to gather perspectives on mental health services and training.
Acheampong et al[21]	Ghana	2024	-Caregivers experience higher levels of depression, particularly those caring for children with severe cognitive and behavioral impairments. -Cultural beliefs and stigma contribute to the challenges faced by caregivers, while community and familial support play crucial roles in coping. -Various coping strategies employed include religious support, traditional healing practices, and advocacy efforts, highlighting resilience of caregivers.	-The study employed a qualitative research approach using a case study design to explore coping strategies of caregivers living with autism. -A phenomenological approach was utilized to uncover and understand the lived experiences of caregivers.
Azubuike et al[23]	Nigeria	2024	-The study identified significant emotional distress, disbelief, and fear among caregivers at the early stage of their child's autism diagnosis. -Caregivers reported challenges in navigating healthcare systems and accessing personalized counseling, highlighting a need for improved support and accessibility. -Socio-cultural factors such as stigma and isolation were prevalent, affecting caregivers' experiences and their children's development.	-The study employed a qualitative research design to explore the experiences and unmet needs of caregivers of children with autism spectrum disorder in Nigeria. -Data were collected from twenty-three purposively selected caregivers using adapted questions from the PREPARE and Zarit burden interview tools.
Gabra et al[19]	Egypt	2021	-Half of the parents reported significant stigma, especially those with a severe burden. -Caregivers with severe burden experienced lower QoL compared to those with moderate burden. -The study identified interrelationships between burden, stigma, QoL, and parental mental health problems. -There was a lack of mild burden in ASD families, indicating issues in developing countries with public services.	-A cross-sectional survey was conducted from January 1, 2020, to April 1, 2020, at two centers in Assiut city. -Parents of autistic children aged 5 to 12 years with a clinical diagnosis of ASD were included. -Participants completed a comprehensive questionnaire and underwent clinical interviews to assess psychological problems.

Continued.

Authors	Country	Year	Results	Methods used
Baykal et al[3]	Turkey	2019	-The study found that autism symptom severity and caregiver depressive symptoms significantly predict caregiver burden scores -The main ASD symptom cluster affecting caregiver burden was language development issues -The findings suggest that caregiver burden is consistent across different socioeconomic levels in Turkish society -The study emphasizes the need for effective social support for caregivers	-Pearson correlation analysis assessed correlations between symptom degrees and caregiver burden, anxiety, and depression levels. -Multiple regression analysis identified predictive factors for caregiver burden with a significance limit of $p<0.05$ -Caregivers completed the BDI, BAI, and Zarit Caregiver burden scale

RESULTS

The vast body of research on this topic remains disproportionately focused on high-income nations. In LICs, caregivers navigate a landscape defined by unique and intensified pressures, including limited public health infrastructure, underdeveloped social support systems, and distinct socio-cultural factors that differ significantly from those in wealthier settings. These conditions combine to create a uniquely demanding environment for caregivers, heightening the risk of adverse outcomes for both the caregiver and the child.

The objective of this review is to synthesize and summarize recent research findings from a diverse range of LICs-specifically Turkey, India, Nepal, Malaysia, Mongolia, Bangladesh, Ghana, Nigeria, and Egypt-to elucidate the primary factors contributing to caregiver burden. The results from the thirteen studies are grouped under three important headings to highlight the complex interplay between the child's condition, the caregiver's internal experience, and the external environment that shapes the burden of care.

The role of ASD severity and comorbidities leading to increased caregiver burden in LIC

A foundational component of caregiver burden is directly linked to the child's clinical presentation. The severity of ASD symptoms and the presence of comorbid conditions create tangible, day-to-day demands that significantly influence the level and nature of stress experienced by caregivers. Research across several LICs consistently demonstrates that as the intensity and complexity of a child's condition increases, so does the strain on the family unit.

Evidence from multiple studies underscores this direct correlation. A key finding from Turkey established that the severity of a child's autism symptoms is a significant predictor of overall caregiver burden scores, with challenges in language development emerging as a particularly impactful domain.[3] Further research in the same country found that fathers' depression levels were specifically linked to the severity of their children's symptoms, highlighting how the child's condition can differentially affect parental mental health.[18] This pattern is not unique to one region. In Ghana, caregivers of children with severe cognitive and behavioral impairments were found to experience notably higher levels of depression, indicating that the degree of functional impairment is a critical factor in caregiver distress.[21] Extending beyond core ASD symptoms, a study in Malaysia demonstrated that a child's comorbidities were a significant factor influencing parental perceptions of affiliate stigma and their capacity for resilience, suggesting that the complexity of a child's health profile can amplify social and psychological pressures.[22]

These findings collectively establish that the clinical characteristics of the child with ASD are a primary driver of caregiver burden. This direct impact sets the stage for a cascade of secondary psychological and social challenges that are borne directly by the caregivers themselves.

Caregiver-related factors: psychological and social dimensions of caregivers in LIC

Beyond the child's condition, a distinct set of factors intrinsic to the caregiver's own psychological state and social experience constitutes a major component of the overall burden. The relentless demands of caregiving, compounded by societal pressures, exact a profound toll on mental and emotional well-being. This section examines the consistent pattern of psychological distress and social marginalization reported by caregivers across diverse LIC settings.

The evidence points to a pervasive mental health crisis among caregivers of children with ASD in LICs, with elevated rates of depression, burnout, and emotional distress emerging as a consistent transnational phenomenon. In Turkey, parents of children with ASD have significantly elevated levels of burnout and depression compared to parents of typically developing children,[18] and caregiver depressive symptoms are a key predictor of the overall burden of care.[3] This is mirrored by the experiences of mothers in Nepal, who reported profound physical exhaustion and emotional disturbances, and caregivers in Nigeria, who described acute emotional distress, disbelief, and fear upon receiving their child's diagnosis.[20,23] The clinical significance of this psychological toll is underscored by a planned intervention in Bangladesh, which explicitly targets the reduction of maternal depression as a primary outcome.[24]

This internal psychological struggle is often amplified by external social forces. Across diverse cultural contexts in Africa (Ghana, Nigeria), the Middle East (Egypt), and Asia (Malaysia, Nepal), social stigma is a primary driver of social isolation and diminished QoL. In Egypt, half of the parents surveyed reported significant stigma, which was directly correlated with a severe level of caregiver burden.[19] Similarly, research in Malaysia identified a clear inverse relationship between perceived affiliate stigma and both caregiver resilience and QoL, quantitatively demonstrating the damaging effect of social judgment.[22] Studies in both Ghana and Nigeria identified cultural beliefs and stigma as major challenges that contribute directly to caregiver difficulties, an experience echoed by mothers in Nepal who reported facing social isolation as a direct consequence of their child's condition.[20-23] The critical need for robust social support to mitigate these pressures is a recurring theme (Baykal et al) with studies in India highlighting the positive impact of family and peer support networks in enhancing QoL and fostering social inclusion.[3,25] These internal psychological and external social challenges are inextricably linked to the tangible pressures that caregivers face.

Other factors: economic, career, and systemic pressures of caregivers in LIC

The burden experienced by caregivers is heavily compounded by a range of external factors. In resource-limited settings, severe financial constraints, profound career disruptions, and failures within public service systems create an additional layer of stress that can be as debilitating as the psychological and social challenges.

The intensive, often all-consuming nature of caring for a child with ASD frequently forces a direct and difficult trade-off with a caregiver's professional life and the family's financial stability. Qualitative findings from Turkey revealed that parents experienced significant difficulty focusing on work, which often led to changing jobs or quitting entirely after a child's diagnosis, with many postponing their own career aspirations indefinitely.[26] In Mongolia, financial burdens were cited by parents as one of their most significant concerns, reflecting the high cost of care and limited financial support.[27] Similarly, mothers in Nepal specifically identified economic challenges as a major component of their burden, alongside physical exhaustion and social isolation.[20]

The immense personal and economic sacrifices made by caregivers are often exacerbated by inadequate or inaccessible institutional support. The struggle to navigate fragmented, under-resourced, or ineffective public systems is a consistent theme across LICs. Parents in Mongolia reported overwhelmingly negative experiences with limited-service availability, citing it as a major barrier to receiving adequate support.[27] In Nigeria, caregivers described profound challenges in navigating complex healthcare systems and accessing specialized counseling,[23] while a study in Malaysia identified specific systemic flaws, such as long waiting times for consultations, which directly and negatively impacted caregiver satisfaction.[17] Perhaps most tellingly, a study in Egypt noted the complete absence of "mild burden" cases among its participants, a striking finding the researchers concluded suggests significant, systemic failures in public service provision.[19]

DISCUSSION

Factors influencing the care giver burden

Severity of autism symptoms

Several studies found that the severity of ASD symptoms is a significant predictor of caregiver burden. Caregivers experience increased burden as the severity of symptoms in their children rises. In a cross-sectional study conducted in Malaysia, Chua et al found that specific problem behaviors in children with ASD, such as irritability, social withdrawal, stereotypic behavior, and hyperactivity, were positively associated with increased caregiver burden. The research suggested that interventions targeting these problem behaviors could alleviate the burden on caregivers.[28]

Impact of language and communication issues in the child

Among the various symptoms of ASD, language and communication problems were identified as having the greatest impact on caregiver burden. The study highlighted that difficulties in language development not only affect the child but also significantly increase the emotional and physical strain on caregivers.[29] These challenges can lead to feelings of frustration and helplessness, as caregivers often struggle to find effective ways to support their child's communication needs while managing their own stress levels.

Comorbidity with ID and increase in caregiver burden

The high prevalence of co-occurring conditions in individuals with ASD (with studies showing rates as high as 83-96% having at least one co-occurring condition) suggests that this increased burden is a reality for the vast majority of caregivers of individuals with ASD.[30] ASD frequently co-occurs with ID, with studies estimating that between 30% and 70% of individuals with ASD also have ID. Conversely, the prevalence of ASD among individuals with ID varies widely, with reported rates ranging from 4% to 28%. The presence of ID in individuals with ASD significantly impacts cognitive and adaptive functioning. Studies suggest that individuals with ASD and co-occurring ID tend to exhibit greater symptom severity compared to those with ASD alone. Cognitive profiles indicate that children with ASD and ID often have deficits in both intellectual functioning and adaptive behaviors, with many falling within the mild to moderate ID range. Moreover, the severity of ID influences the male-to-female ratio in ASD diagnoses; while ASD is generally more common in males, the gender disparity decreases in individuals with severe ID.

Caregivers of individuals with both conditions face increased demands in daily care, supervision, and medical management, often requiring continuous, long-term support. The level of impairment associated with ID further amplifies caregiver stress, as individuals with lower intellectual functioning typically need more intensive assistance with basic life skills, communication, and behavioral regulation.

Additionally, caregivers must navigate complex medical, educational, and social service systems to ensure adequate support, which can contribute to emotional and financial strain. Studies indicate that caregivers of individuals with ASD and ID experience higher levels of stress, anxiety, and depression compared to caregivers of individuals with ASD alone, underscoring the need for comprehensive support systems that address both the individual's and caregiver's well-being.

Caregivers' mental health

Caregiver depressive symptoms were also found to be a critical factor contributing to overall caregiver burden. The study indicated that higher levels of depression in caregivers corresponded with increased burden, suggesting that the mental health of caregivers is closely linked to their caregiving experience.[31] In a similar vein research by Yao et al indicates that high levels of anxiety and depression among caregivers are closely linked to increased caregiver burden, as these emotional states can diminish one's capacity for effective coping and support.[32]

Caregiver's physical health

The physical and mental health of the caregiver is a significant predictor. Caregivers who experience their own health issues often report higher levels of burden and stress, which can negatively impact their ability to provide effective care for individuals with autism. (Sanchez) This cycle of stress and health decline can lead to a deterioration in both the caregiver's well-being and the quality of care provided, highlighting the importance of support systems as well as resources for the caregivers.[33]

Social support

The level of social support available to caregivers can mitigate feelings of burden. Caregivers with strong support networks often report lower levels of stress and a greater sense of well-being, which underscores the need for community programs that foster connections among caregivers and provide access to necessary resources.[34] Both formal and informal social support were identified as a partial mediator in the relationship between caregiver burden and QoL. This suggests that enhancing informal support networks could improve the QoL for these parents.[35]

Others

The burden experienced by caregivers of individuals with autism is influenced by multiple factors other than the ones mentioned. Longer caregiving durations are often associated with increased stress, while financial strain, including the cost of care and the caregiver's economic situation, further exacerbates the burden.[36] Coping strategies also play a crucial role, as effective mechanisms can help alleviate stress and prevent overwhelming emotional responses in the caregivers.[37] Additionally, demographic factors such as age, gender, and the caregiver's relationship to the care recipient also impact the level of burden experienced by care givers across different mental illnesses.[38]

Future directions and interventions to address the caregivers' burden

The review also underscores the urgent need for more research and policy interventions tailored to the unique socio-economic and cultural contexts of these regions. Addressing these challenges requires a comprehensive approach that includes increased awareness, improved access to affordable healthcare and education, financial assistance programs, and community-based support networks.

Ultimately, recognizing and alleviating caregiver burden is essential not only for the well-being of caregivers but also for improving the long-term outcomes of children with ASD in LICs. It is crucial to implement strategies to support caregivers so that they can care for the children with ASD. Several approaches can help caregivers maintain their well-being while continuing to provide care.

Mental health support

Caregivers of children with ASD should be encouraged to seek mental health support through therapy, counseling, or support groups. Individual or group therapy can provide a safe space to discuss feelings of stress, frustration, and exhaustion.[39] Cognitive behavioral therapy (CBT) has been shown to be effective in managing caregiver anxiety and depression.

Respite care and time for self-care

Respite care services offer caregivers temporary relief by providing professional support for the individual with ASD. This allows caregivers to take breaks and focus on their own needs, which is essential for long-term sustainability in caregiving.[40] By prioritizing their own well-being, caregivers can enhance their ability to provide quality care and maintain a healthier balance in their lives. Establishing a routine that includes regular self-care activities can significantly improve caregivers' mental health, enabling them to recharge and better cope with the challenges they face.[41]

Education and training

Caregivers who receive proper training in behavioral management strategies, communication techniques, and crisis intervention are better equipped to handle challenges. Training programs can help caregivers feel more confident and reduce feelings of helplessness, ultimately leading to improved outcomes for both caregivers and those they support. Additionally, ongoing education ensures that caregivers stay informed about the latest best practices and developments in their field, fostering a culture of continuous improvement and resilience.[42]

Social support networks

Engaging with other caregivers through local or online support groups can help reduce feelings of isolation. Sharing experiences and coping strategies can provide emotional support and a sense of community. Building these connections not only enhances emotional well-being but also empowers caregivers to navigate challenges more effectively, ultimately enriching the care they provide.[43]

Access to resources

Governments and nonprofit organizations can play a role in providing financial assistance, special education resources, and community programs for caregivers. Policies that allow for paid caregiver leave and financial aid for therapy and treatment can alleviate some of the burden. These resources can significantly improve the QoL for both caregivers and those they care for, fostering a more sustainable caregiving environment that prioritizes mental health and well-being.[44]

Healthy lifestyle habits

Encouraging caregivers to engage in physical activities, maintain a balanced diet, and practice mindfulness or relaxation techniques can help improve their overall well-being. By promoting self-care and resilience among caregivers, communities can ensure that they are better equipped to handle the challenges of their roles while maintaining their own health and happiness.[45]

A holistic approach to caregiver support will ultimately enhance the well-being of both caregivers and individuals with ASD, fostering a more sustainable and fulfilling caregiving experience.

CONCLUSION

The review highlights the significant burden experienced by caregivers of children with ASD in LICs, emphasizing the multifaceted challenges they face. Limited access to healthcare, financial strain, lack of specialized educational services, and deep-rooted social stigma contribute to increased stress, anxiety, and overall diminished well-being among caregivers. Unlike high-income countries, where structured support systems and government policies help mitigate these burdens, caregivers in low-income settings often struggle without adequate institutional or community support.

Funding: No funding sources
Conflict of interest: None declared
Ethical approval: Not required

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Cite this article as: Arockiasamy APR, Arockia Philip Raj CV, Al-Mutori MHS, Amr M. Caregiver burden in autism spectrum disorder among low-income countries: a systematic review. Int J Community Med Public Health 2026;13:900-11.