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Review Paper

Caregiver Burden in Autism Spectrum Disorder: A Review of Global Variations, Influencing Factors and Interventions among Parents

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ABSTRACT

Given the pervasive nature of the symptoms of Autism Spectrum Disorder (ASD), individuals with this condition often require long-term support and specialised interventions to ensure optimal functioning and quality of life. The result is an increase in what is termed caregiver burden, as care-taking responsibilities frequently fall on family members, particularly parents. The present review sought to synthesise existing literature on caregiver burden among parents of individuals with ASD, with a focus on examining the domains and determinants of caregiver burden. Alongside identifying patterns, similarities and variations across studies, the present review also explored psychological interventions aimed at alleviating caregiver burden. The findings show that caregivers of individuals with ASD experience various forms of burden, including emotional, financial, social, and time-related challenges. With regard to interventions, a multidimensional approach was deemed to be most effective in addressing the complex nature of caregiver burden. While approaches such as CBT and mindfulness emerged as promising, integrative interventions incorporating social support, skill-building, and family involvement were more favorable. Since current support systems focus primarily on the individual with ASD, comprehensive caregiver-focused interventions providing psychological support and increased access to services and practical resources are recommended for better overall outcomes.

Keywords: *Caregiver Burden, Autism Spectrum Disorder, Global Variations, Contemporary Issues, Care-giver Focused Interventions*

Autism Spectrum Disorder (ASD) affects approximately 1 in 100 children worldwide, highlighting the growing prevalence of the condition. (Elsabbagh et al., 2022; World Health Organization, 2023). Autism Spectrum Disorder (ASD) can be defined as a neurodevelopmental condition that has been increasingly diagnosed across the globe. The core feature of ASD involves persistent difficulties in understanding and engaging in social communication and interaction. It is also accompanied by restricted and repetitive patterns of behaviour, interests, and activities. Due to the nature of symptoms, it often requires long-

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term support and specialised interventions to help individuals with ASD achieve optimal functioning and quality of life (Hodges et al., 2020). As a result, caregiving responsibilities frequently fall on family members, particularly parents, resulting in caregiver burden for them (Pandey & Sharma, 2018).

The individuals who provide care to those with ASD play an essential role in their lives. Their role often involves supporting their daily functioning, managing their behavioural challenges, and ensuring that they have access to appropriate healthcare and educational services. The responsibility of providing care to someone with ASD often extends beyond routine parental duties as it requires additional efforts like ensuring continuous supervision, coordination of therapies, and advocating for appropriate services. In the field of rehabilitation, caregivers are recognised as an important part of the intervention process, as they contribute significantly to the implementation of therapeutic strategies and long-term support for individuals with ASD (Rojas-Torres et al., 2020). However, these responsibilities can be emotionally, financially, and physically draining for the caregivers, leading to what is commonly referred to as caregiver burden (Patel et al., 2022).

Caregiver Burden

Caregiver burden refers to the physical, psychological, social, and economic stress experienced by individuals who provide long-term care to a family member with a chronic condition or disability (Pandey & Sharma, 2018). In the context of ASD, multiple factors contribute to the caregiver burden. It involves factors such as the severity of the individual's symptoms (Patel et al., 2022), costs of therapy and specialised education, and the challenges of navigating healthcare and support systems (Pillay et al., 2024). Due to this, caregivers are often subjected to increased levels of stress, anxiety, and fatigue as they attempt to balance caregiving responsibilities with their personal, professional, and social commitments (Chua et al., 2023). In many cases, the continuous nature of caregiving can affect the overall well-being and quality of life of caregivers (Pandey & Sharma, 2018).

In rehabilitation settings and support services, the caregivers are considered to be of great importance for the success of the intervention. The outcomes often depend on the consistency of support provided to the individual with ASD in the home environment. Caregivers frequently act as mediators between individuals with ASD and service providers. This ensures that therapeutic strategies are also implemented in daily life (Rojas-Torres et al., 2020). Caregivers are still given only limited attention within healthcare and rehabilitation despite their importance and need. The current support systems and interventions are often primarily designed to address the needs of individuals with ASD, while the psychological and social needs of caregivers may be overlooked. This lack of attention can often lead to caregiver burden.

The existing studies on caregiver burden among parents of individuals with Autism Spectrum Disorder primarily explore the level of caregiver burden in a specific context, with limited consideration of global variations. There is a lack of integrated and comprehensive understanding of domains, determinants and barriers to care and their influence on the caregiver burden level. Furthermore, existing literature highlights the underemphasis on caregivers in rehabilitation settings. This review aims to address this by examining the caregiver burden across different contexts, with the associated influencing factors and provides recommendations for psychological interventions that aid in reducing the caregiver burden.

Objectives of the Review

The review aims to synthesise existing literature on caregiver burden among parents of individuals with Autism Spectrum Disorder. The review focuses on examining the domains and determinants of caregiver burden and identifying patterns, similarities and variations across studies. Furthermore, this review delves into exploring psychological interventions aimed at alleviating caregiver burden.

METHODOLOGY

Search Strategy

The articles included in this review were identified through the databases of PubMed and Google Scholar. PubMed and Google Scholar were selected because it has a large collection of peer-reviewed research articles in the fields of psychology and rehabilitation. Google Scholar also provides a formal database of what is termed “grey literature,” an essential component of an informative review. The search aimed to identify the latest and most relevant research articles examining caregiver burden among caregivers of individuals with Autism Spectrum Disorder (ASD).

The primary search keywords used for the literature search were “caregiver burden” AND “autism spectrum disorder” and “Caregiver burden in ASD” AND “Interventions.” The Boolean operator “AND” was used to search for articles that explored both these concepts simultaneously. The articles were then screened to identify studies that were directly relevant to the topic of caregiver burden in the context of ASD.

Inclusion and Exclusion Criteria

To ensure the currentness and relevance of the selected articles, an inclusion criterion of the year of publication was applied. Only peer-reviewed research articles published in the last 10 years (i.e. 2016 onwards) were considered. It ensured that studies that specifically focused on caregivers of individuals with ASD were included. The exclusion criteria involved articles that did not directly address caregiver burden or explored it in the context of other disabilities.

After screening the titles and abstracts of the identified articles, relevant studies were selected for further examination. The final articles included in this review were chosen based on their relevance to caregiver burden, methodological clarity, and contribution to understanding the experiences of caregivers of individuals with ASD.

RESULTS

Review of Existing Literature

Initial empirical evidence provides important context for understanding the baseline indicators of caregiving burden**.** A quantitative, descriptive, cross-sectional study conducted at the Child, Adolescent and Family Unit (CAFU) outpatient services at Charlotte Maxeke Johannesburg Academic Hospital (CMJAH) aimed at describing the socio-demographic profile and the level of burden experienced by the caregivers of children and adolescents diagnosed with Autism Spectrum Disorder. The study involved 77 participants, the majority of whom were female (72.3%) and primarily mothers with secondary or tertiary level of education and employment. The study employed two self-administering questionnaires, which included a sociodemographic questionnaire and the 12-item Zarit Burden Interview questionnaire. The results suggest that approximately 41.6% of the sample experience mild to moderate levels of burden, while 33.8% reported high levels of burden, and only 24.9%

reported little or no burden. The study highlighted that, irrespective of the fact that most of the caregivers reported that taking care of a child with ASD was stressful, only a minority claimed a negative effect of caregiving on their social life and personal relationships. The majority of the caregivers did not report fatigue or poor physical health. Most caregivers did not express a lack of time for themselves but experienced guilt for not spending sufficient time with the child in their care (van Niekerk et al., 2023).

While quantitative studies emphasize minor lifestyle disruptions, qualitative paradigms offer a considerably different perspective. In contrast to the findings of the quantitative research by van Niekerk et al. (2023), which reported only a minor effect on social and personal well-being, a qualitative study conducted in the Western Cape Province found significant levels of socioemotional stress among caregivers. The study explored the experiences of caregivers of children with Autism Spectrum Disorder regarding the difficulties faced in accessing educational and support services. Focus group discussions were conducted, revealing that caregivers experienced considerable emotional strain and frustration due to the lengthy process of gaining access to services for their children. The major theme that arose from the study was “We wait, and we wait,” which captured the essence of long waiting periods in accessing support services. The study highlighted how systemic hurdles and delays in accessing services contribute to caregiver burden. The burden resulting from these systemic barriers is also accompanied by substantial financial and time-related costs, leading to an increased sense of burden. The qualitative narrative shed light on multiple barriers to accessing services, which highlighted factors such as the limited availability of specialised schools, structural challenges within the service system, and poor communication from service providers as contributors to caregiver burden. These factors collectively led to increased caregiver burden by contributing to stress, financial strain, and time demands on caregivers. The findings highlight the role of external systemic resources in caregiver burden and the dire need to improve service accessibility and support systems to reduce caregiver burden (Pillay et al., 2024).

The significance of socioeconomic factors in determining the burden on caregivers is further supported by the cross-sectional study conducted by Patel et al. (2022) on a sample of 40 caregivers of children with autism with a mean age of 34.72 years. The study was conducted at the Child and Adolescent Psychiatry Outpatient Service at a government centre in northern India to examine the burden of care and quality of life in caregivers of children and adolescents with ASD. This investigation utilized the Burden Assessment Schedule (BAS) and the World Health Organisation Quality of Life Instrument, Short Form (WHOQOL-BREF), which indicated a high degree of burden on the caregivers of children diagnosed with ASD, with the mean burden of care on BAS being 71.73 ± 8.62. The study further identified higher levels of burden on caregivers from lower-income families, highlighting family income as one of the contributing factors to caregiver burden. This study aligns with previous research by Pillay et al (2024), which highlights financial strain as one of the factors leading to increased care burden.

Additionally, a study by Pillay et al (2024) sheds light on the role of the clinical severity of symptoms of ASD in the exacerbation of burden in caregivers, which is further supported by the research by Chua et al. (2023). A positive correlation is found between the severity of autism symptoms and the level of caregiver burden. It highlighted that symptom severity was also associated with poorer quality of life among caregivers (Patel et al., 2022), which is further supported by the study conducted by Turnage and Conner (2022), which suggests that the quality of life of parents of children with ASD was much lower than that of parents of children without ASD in the physical, psychological, spiritual and social health domains.

Another factor affecting the level of caregiver burden experienced was introduced in a cross-sectional study conducted by Christina N. Marsack-Topolewski and Fei Wang (2022). The study introduced the factor of compounding and non-compounding caregiving in caregiver burden. Compound caregiving is defined as situations in which caregivers provide support not only to their adult child with autism but also to other family members simultaneously. The study focused on exploring the dimension of caregiver burden associated with adults diagnosed with ASD among compound 1, compound 2, and non-compound caregivers. The data was collected from 320 caregivers aged 50 years and older through a web-based survey. The study identified four dimensions of caregiver burden, which encompass time dependence burden, developmental burden, emotional burden and financial burden. The findings reveal that, as compound 2 caregivers, compound 1 and non-compound caregivers experience higher levels of time dependence and developmental burden. The results shed light on different dimensions of caregiver burden among aging caregivers of adults with ASD. The study highlights how the accumulation of caregiving responsibilities can intensify caregiver burden across various dimensions. In contrast with the previous research, which takes into consideration only the severity of symptoms of ASD as a factor exacerbating caregiver burden (A. D. Patel et al., 2022), this analysis takes into account the overall caregiving context.

Extending this discussion to South Asian developmental contexts further reinforces these global patterns. In alignment with other studies, a descriptive study conducted in Kathmandu Valley, Nepal, also demonstrated a moderate to severe level of burden in most caregivers of children with ASD, with the average burden score of 41.49±12.25. The study opted for purposive sampling and selected 61 parents and employed the Zarit Burden Interview-22 questionnaire. The findings of the study suggested associations of factors such as anxiety and depression with higher levels of caregiving burden, while caregivers' level of education acts as a protective factor (Turnage & Conner, 2022). In contrast to the study conducted by van Niekerk, Stancheva, and Smith (2023), which reported only a minor effect on social and personal well-being, the results of this study indicate a noticeable impact on the emotional well-being and social life of caregivers as a result of caregiving responsibilities (Pandey & Sharma, 2018), which further aligns with the findings of study conducted by Pillay et al. (2024) which highlighted that caregivers experience significant level of emotional strain and frustration.

Due to the growing prevalence of ASD and the associated caregiver burden, the literature highlights diverse interventions aimed at reducing caregiver burden among parents of children with ASD. Current empirical trends utilize various methodologies such as systematic reviews and meta-analyses, and report convergent findings. A meta-analysis of randomised controlled trials conducted by Guo et al. (2025) revealed the efficacy of cognitive behavioural therapy (CBT) in significantly reducing depressive symptoms in parents of children with special needs, indicating its role in alleviating emotional aspects of caregiver burden. Similarly, a systematic review and meta-analysis conducted by Burgdorf et al. (2019) showed that mindfulness-based interventions effectively reduced parenting stress while also improving child psychological outcomes, suggesting a dual benefit. In alignment with this research, the study conducted by Da Paz and Wallander (2017) and Rojas-Torres et al. (2020) through narrative and systematic reviews, shed light on the role of parent-mediated and mental health-focused interventions in enhancing coping and reducing distress. This claim was supported by the study conducted by Bradshaw et al. (2022), which highlighted the importance of integration of caregivers into therapeutic processes to enhance both parent and child outcomes.

In addition to these individual-focused interventions, several studies focused on exploring group-based interventions and their effectiveness in reducing caregiver burden. A study conducted by Sabanciogullari and Yıldırım (2025) reported significant improvements in parents' psychological resilience, life satisfaction, and family functioning on the implementation of a group counselling education program, highlighting the benefits of structured group-based support. Similarly, the study conducted by McKenzie et al. (2022) evaluated an intervention known as Systemic Autism-related Family Enabling (SAFE), which is based on a family-based therapeutic approach and is drawn from techniques of Family Therapy, Attachment Narrative Therapy and known preferences of individuals with autism. The results reported improvements in family experiences and coping by increasing the confidence to reflect and solve problems, in addition to improving communication and reducing feelings of loneliness, leading to reduced social and emotional burden. Furthermore, a correlational and mediation research design identified social support and positive cognition as key mediators between caregiver burden and family resilience, suggesting that interventions must incorporate these components to be effective (Chen et al., 2025).

DISCUSSION

The existing literature highlighted that the experience of burden among caregivers of individuals with Autism Spectrum Disorder (ASD) is systematically spread across multiple interconnected dimensions, including emotional, financial, social, and time-related domains (Marsack-Topolewski & Wang, 2022). The studies indicate that caregiver burden is not merely limited to the physical responsibilities of caregiving but can also cause psychological stress. This stress is heavily driven by external variables such as frustration due to difficulties in accessing appropriate support services (Pillay et al., 2024)), the ongoing management of severe symptoms (Patel et al., 2022) and the long-term nature of caregiving responsibilities (Chua et al., 2023; Pandey & Sharma, 2018; Patel et al., 2022). Collectively, these findings highlight the complex and multifaceted nature of caregiver burden associated with ASD. This often leads to self-blame and feelings of guilt, especially when parents perceive themselves as incompetent or unable to fully meet their child's needs. These emotional pressures significantly comprise the mental well-being of caregivers and contribute to long-term psychological stress.

The studies also highlight the financial and time-related aspects of caregiver burden. Caring for individuals with ASD is inherently resource-intensive due to the high costs of therapies, specialised education, and healthcare services. The study conducted by Patel et al. (2022) indicates that caregivers from lower socioeconomic backgrounds are more prone to experience higher levels of burden due to limited access to resources and support services. This financial strain, paired with continuous time investment often affect the social life and personal well-being of the caregiver. Research on caregivers of adults with ASD shows a higher level of time-dependent burden, particularly among compound 2 caregivers who provide support to multiple family members at a given point in time (Marsack-Topolewski & Wang, 2022). This highlights the complexity of caregiving roles and the potential for cumulative stress when caregivers are responsible for multiple dependents.

The literature also sheds light on the role of systemic barriers and hindrances in accessing services as a major contributor to caregiver burden. This structural failure leads to significant frustration among caregivers. Qualitative research exploring caregiver experiences has revealed that long waiting periods for specialised schools and therapeutic services create considerable emotional and practical difficulties for families (Pillay et al., 2024). These delays force caregivers to manage their child's needs without adequate professional guidance, which further increases stress and clinical uncertainty. Additionally, structural challenges such as the limited availability of specialised services, lack of trained professionals, and poor communication from service providers exacerbate caregiver burden. Such barriers highlight an urgent need for more efficient, accessible and responsive service delivery systems to support families affected by ASD.

Shifting the analytical lens to therapeutic solutions, the literature explores interventions aimed at reducing caregiver burden among parents of children with ASD, which primarily focuses on reducing emotional distress and parenting stress, highlighting their effectiveness in addressing the psychological dimensions of caregiver burden.

The reviewed studies highlight the effectiveness of CBT and mindfulness-based intervention at the individual level, while shedding light on additional positive outcomes such as improvements in resilience, family functioning, and relational dynamics within group-based and family-centred interventions. This suggests that caregiver burden is not solely an individual psychological issue but also a systemic and contextual one.

Limitations in Existing Literature

Despite the valuable insights provided by existing studies, several methodological limitations exist. Many studies have a small sample size, which critically limits the generalisability of their findings. There is also a lack of consideration of cultural and regional differences in most studies, which further influences the understanding of caregiving experiences. The lack of consideration of these is a major drawback, as different regions differ vastly in the support systems which they provide and their cultural responsiveness towards interventions. Hence, further research is needed to better understand how contextual factors shape caregiver burden and interventions.

Contemporary issues

From a contemporary perspective, the growing cases of ASD worldwide have increased the demand for services and support systems for affected individuals and their families. However, in many regions, existing services remain insufficient to meet the needs of caregivers. There is a lack of culturally fair diagnostic assessments, therapy services are insufficient, and there is a lack of specialised educational facilities. Furthermore, the mental health needs of caregivers are often overlooked within healthcare and rehabilitation systems, despite evidence indicating that caregivers themselves require psychological support.

On the whole, the literature highlights the urgent need for comprehensive and caregiver-focused interventions. The studies collectively demonstrate that rehabilitation and support programmes are not only required by individuals with ASD but also by their caregivers. This emphasises the necessity to shift clinical perspectives from focusing solely on the individual with ASD to adopting a dydiac approach that addresses the needs of caregivers by providing counselling, support groups, caregiver training, and accessible service pathways.

By strengthening support systems and improving service accessibility, it may be possible to reduce caregiver burden and enhance the overall well-being of families affected by ASD.

Conclusions and the Way Forward

Caregiver burden associated with the care of individuals with Autism Spectrum Disorder (ASD) is a complex and multifaceted issue that profoundly compromises the overall well-being of the caregiver. The literature reviewed in this paper highlights that caregivers of individuals with ASD experience various forms of burden, including emotional, financial, social, and time-related challenges. This is due to the nature of their responsibilities, which are often stressful and require continuous management of the needs of individuals with ASD, especially while facing challenges like system barriers, such as a lack of adequate support systems.

The existing research demonstrates that both individual-focused and family-based, and support-oriented interventions are effective in reducing caregiver burden among parents of children with ASD. While approaches such as CBT and mindfulness showed effectiveness, it was noted that integrative interventions that incorporate social support, skill-building, and family involvement were comparatively more effective. Overall, a multidimensional approach is essential to effectively address the complex nature of caregiver burden.

Despite the growing recognition of caregiver burden, the rehabilitation and healthcare systems do not focus on caregivers and their mental health. The current support systems primarily focus on the individual with ASD, while the psychological and social needs of caregivers still remain unaddressed. Addressing caregiver burden requires the development of comprehensive caregiver-focused interventions that provide psychological support, increased access to services, and the availability of practical resources for families to aid in reducing caregiver burden and promoting overall family well-being.

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Conflict of Interest

The authors declared no conflict of interest.

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