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The hidden cost of caring: Caregiver burden in neurodevelopmental disorders

O custo oculto de cuidar: O fardo do cuidador nos transtornos do neurodesenvolvimento

El costo oculto de cuidar: La carga del cuidador en los trastornos del neurodesarrollo

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Abstract

Introduction: Caregivers of children with Neurodevelopmental Disorders (NDDs) experience a multidimensional burden that affects their physical, emotional, social, and financial well-being. This burden is intensified in contexts marked by social vulnerability, limited specialized services, and persistent stigma. Symptom severity — such as autism, intellectual disabilities, and complex comorbidities — further increases caregiving demands. This article aims to discuss the nature of caregiver burden among parents of children with NDDs, examining the factors that shape it and the intervention strategies suggested in recent literature. Methods: An integrative literature review was conducted following a structured methodological framework. Articles published between 2015 and 2025 were identified in PubMed using descriptors related to caregiver burden and neurodevelopmental disorders. Results: Eighteen studies met the inclusion criteria. Findings consistently indicated high levels of psychological distress, fatigue, sleep disturbances, and social isolation among caregivers. Interventions such as telehealth, peer support, and family-centered practices demonstrated positive outcomes in reducing stress and strengthening resilience. Discussion: The analysis shows that caregiver burden arises not only from clinical demands but also from structural factors, including inequitable access to services and insufficient public policies. Resilience-promoting strategies and multiprofessional support can mitigate these effects, but they remain underutilized in underserved settings. Conclusion: Caregiver burden represents a significant public-health concern requiring intersectoral action. Strengthening inclusive policies, expanding access to specialized and telehealth services, and improving professional training are essential to support caregivers and promote better developmental outcomes for children with neurodevelopmental disorders.
Keywords: Caregiver burden; Neurodevelopmental disorders; Mental health; Psychological resilience.

Resumo

Introdução: Cuidadores de crianças com Transtornos do Neurodesenvolvimento (TNDs) vivenciam uma sobrecarga multidimensional que afeta seu bem-estar físico, emocional, social e financeiro. Essa sobrecarga é intensificada em contextos marcados por vulnerabilidade social, serviços especializados limitados e estigma persistente. A gravidade dos sintomas — como no autismo, deficiência intelectual e comorbidades complexas — aumenta ainda mais as demandas do cuidado. Este artigo tem como objetivo discutir a natureza da sobrecarga do cuidador entre pais de crianças com TNDs, examinando os fatores que a moldam e as estratégias de intervenção sugeridas na literatura recente. Métodos: Foi realizada uma revisão integrativa da literatura seguindo um framework metodológico estruturado. Artigos publicados entre 2015 e 2025 foram identificados na PubMed utilizando descritores relacionados à sobrecarga do cuidador e transtornos do neurodesenvolvimento. Resultados: Dezoito estudos atenderam aos critérios de inclusão. As evidências indicaram consistentemente altos níveis de sofrimento psicológico, fadiga, distúrbios do sono e isolamento social entre os cuidadores. Intervenções como teleatendimento, apoio entre pares e práticas centradas na família demonstraram resultados positivos na redução do estresse e no fortalecimento da resiliência. Discussão: A análise mostra que a sobrecarga do cuidador decorre não apenas das demandas clínicas, mas também de fatores estruturais, incluindo acesso desigual a serviços e políticas públicas insuficientes. Estratégias de promoção de resiliência e apoio multiprofissional podem mitigar esses efeitos, mas permanecem subutilizadas em contextos vulneráveis. Conclusão: A sobrecarga do cuidador representa um importante problema de saúde pública que exige ações intersetoriais. Fortalecer políticas inclusivas, expandir o acesso a serviços especializados e de teleatendimento, e aprimorar a formação profissional são medidas essenciais para apoiar cuidadores e promover melhores desfechos no desenvolvimento de crianças com transtornos do neurodesenvolvimento.
Palavras-chave: Sobrecarga do cuidador; Transtornos do neurodesenvolvimento; Saúde mental, Resiliência psicológica.

Resumen
Introducción: Los cuidadores de niños con Trastornos del Neurodesarrollo (TND) experimentan una carga multidimensional que afecta su bienestar físico, emocional, social y financiero. Esta carga se intensifica en contextos marcados por vulnerabilidad social, servicios especializados limitados y un estigma persistente. La gravedad de los síntomas —como en el autismo, la discapacidad intelectual y las comorbilidades complejas— aumenta aún más las demandas del cuidado. Este artículo tiene como objetivo analizar la naturaleza de la carga del cuidador entre padres de niños con TND, examinando los factores que la determinan y las estrategias de intervención sugeridas en la literatura reciente. Métodos: Se realizó una revisión integradora de la literatura siguiendo um framework metodológico estructurado. Se identificaron artículos publicados entre 2015 y 2025 en PubMed utilizando descriptores relacionados con la carga del cuidador y los trastornos del neurodesarrollo. Resultados: Dieciocho estudios cumplieron con los criterios de inclusión. Los hallazgos indicaron de manera consistente altos niveles de malestar psicológico, fatiga, trastornos del sueño y aislamiento social entre los cuidadores. Intervenciones como la telesalud, el apoyo entre pares y las prácticas centradas en la familia demostraron resultados positivos en la reducción del estrés y en el fortalecimiento de la resiliencia. Discusión: El análisis muestra que la carga del cuidador surge no solo de las demandas clínicas, sino también de factores estructurales, incluido el acceso desigual a los servicios y las políticas públicas insuficientes. Las estrategias de promoción de la resiliencia y el apoyo multiprofesional pueden mitigar estos efectos, pero siguen estando subutilizadas en contextos vulnerables. Conclusión: La carga del cuidador representa un importante problema de salud pública que requiere acciones intersectoriales. Fortalecer las políticas inclusivas, ampliar el acceso a servicios especializados y de telesalud, y mejorar la capacitación profesional son medidas esenciales para apoyar a los cuidadores y promover mejores resultados en el desarrollo de los niños con trastornos del neurodesarrollo.
Palabras clave: Carga del cuidador; Trastornos del neurodesarrollo, Salud mental; Resiliencia psicológica.

1. Introduction

The caregiver burden associated with caring for children with neurodevelopmental disorders (NDDs) is a multifactorial and multidimensional phenomenon, manifesting as a complex overload across the emotional, physical, social, and economic spheres of family life (Maridal et al., 2021; Nam & Park, 2017). The literature consistently identifies this burden as a global challenge with a significant impact on parents' quality of life and mental health (De Leeuw et al., 2024; Keniş-Coşkun et al., 2020; Maridal et al., 2021).

In the emotional domain, caregiver burden is characterized by high levels of psychological distress, with caregivers exhibiting elevated rates of mental suffering across diverse cultural contexts (Nam & Park, 2017; Pandey & Sharma, 2018). This exhaustion is exacerbated by the chronic nature of caregiving, uncertainty regarding the child's future, difficulties in managing disruptive behaviors, and the constant need for vigilance (Kelson & Dorstyn, 2025; Patel et al., 2022).

The demanding daily routine also imposes substantial physical strain, expressed through sleep disturbances, physical symptoms, and persistent fatigue (Klein et al., 2024; Maridal et al., 2021; Materula et al., 2024), particularly in cases involving motor impairments or multiple comorbidities (Keniş-Coşkun et al., 2020).

Moreover, the social and economic dimensions of caregiver burden reveal that many caregivers must reduce or abandon professional activities, resulting in financial hardship, social isolation, and a sense of marginalization—often reinforced by stigma (Banga & Ghosh, 2017; Zorcec & Pop-Jordanova, 2020). This vulnerability is even more pronounced in low- and middle-income countries, where gaps in public policies and the scarcity of specialized services intensify families' psychological distress (Ademosu et al., 2021; De Leeuw et al., 2024).

Given this scenario, which illustrates the complex interaction between individual caregiving demands and broader structural determinants, this article aims to discuss the nature of caregiver burden among parents of children with NDDs, examining the factors that shape it and the intervention strategies suggested in recent literature.

2. Methodology

2.1 Study Design and Search Strategy

This integrative review followed the methodological framework proposed by Souza et al. (2010), comprising six steps: problem identification, literature search, data collection, critical appraisal, discussion of results, and synthesis of evidence. The guiding question was: “What scientific evidence published in the last ten years addresses caregiver burden among parents of children with neurodevelopmental disorders?”

The search was carried out exclusively in the PubMed database using the descriptors: "Caregiver Burden" AND "Neurodevelopmental Disorders" AND "Child", with Boolean operators. The review included peer-reviewed articles published in English between 2015 and 2025.

2.2 Inclusion and Exclusion Criteria

Inclusion criteria: empirical studies involving caregivers of children with any neurodevelopmental condition; clear assessment or discussion of caregiver burden; publications between 2015–2025; English-language full texts.

Exclusion criteria: editorials, letters, theses, conference abstracts, duplicated studies, or articles focusing exclusively on adolescents/adults.

2.3 Study Selection

The search identified 139 articles. After screening titles and abstracts, 32 were selected for full-text reading. Following full review, 18 articles met all criteria and were included in the final sample.

2.4 Data Extraction and Analysis

Data extraction included author/year, objectives, study design, sample characteristics, and main findings. A descriptive and thematic analysis was conducted to identify convergences, divergences, and research gaps.

3. Results

The selected studies demonstrate that caregivers of children with neurodevelopmental disorders experience significant emotional, social, and financial burden, intensified by factors such as stigma, service disruption, inadequate public policies, and the clinical complexity of the children. Interventions such as peer support and telehealth show potential to reduce caregiver burden and improve resilience and quality of life. Moreover, the severity of the child’s condition—including autism spectrum disorder, intellectual disability, and complex medical needs—correlates directly with increased parental distress, reinforcing the need for family-support strategies, caregiver education, and strengthened social support networks to mitigate the impact of caregiving. The results are presented in Table 1.

Table 1: Characterization of the sample extracted from the databases.

N	Author/Year	Journal	Topic/Objectives	Conclusion
1	Ademosu et al., 2021	The Lancet Psychiatry	Scoping review on the burden, impact, and needs of caregivers of children with mental health or neurodevelopmental conditions in LMICs.	Caregivers face emotional, social, and financial overload, worsened by inadequate policies and services.
2	Badesha et al., 2023	International Journal of Language & Communication Disorders	Systematic review of interventions to reduce caregiver burden in speech-language pathology.	Specific interventions may reduce burden, though evidence is limited.
3	Banga & Ghosh, 2017	Journal of Applied Research in Intellectual Disabilities	Impact of affiliate stigma on the psychological well-being of mothers of children with learning disabilities.	Stigma intensifies burden and harms maternal mental health.
4	Bhatia et al., 2015	East Asian Archives of Psychiatry	Evaluate burden and psychiatric morbidity in caregivers of individuals with intellectual disabilities.	High burden levels and high prevalence of psychiatric symptoms.

5	Chakraborti et al., 2021	Frontiers in Public Health	Scoping review on implications of peer support for families of children with disabilities.	Peer support reduces isolation and enhances resilience.
6	De Leeuw et al., 2024	Research in Developmental Disabilities	Impact of raising children with developmental or physical conditions in Ethiopia.	Significant financial and emotional strain due to scarce services.
7	Kelson & Dorstyn, 2025	Journal of Autism and Developmental Disorders	Systematic review on telehealth as a psychological intervention for caregivers.	Telehealth reduces caregiver burden and isolation.
8	Keniş-Coşkun et al., 2020	Journal of Pediatric Nursing	Relationship between burden, resilience, and quality of life in pediatric rehabilitation.	Higher resilience correlates with lower burden and better QoL.
9	Klein et al., 2024	Research in Developmental Disabilities	Parents' experiences raising children with developmental coordination disorder.	Significant burden and negative mental-health impacts.
10	Kowanda et al., 2021	Journal of Child Neurology	Service availability and burden during COVID-19.	Service interruptions increased caregiver burden.
11	Maridal et al., 2021	International Journal of Environmental Research and Public Health	Psychological distress among caregivers in Nepal.	High levels of anxiety and stress in caregivers.
12	Materula et al., 2024	Research in Developmental Disabilities	Needs of children with medical complexity and NDD from caregiver perspectives.	Unmet health and education needs worsen burden.
13	Nam & Park, 2017	Journal of Mental Health	Association between burden and depression in caregivers.	Strong correlation with depressive symptoms.
14	Pandey & Sharma, 2018	Journal of Nepal Health Research Council	Perceived burden in caregivers of children with ASD.	High emotional and social overload.
15	Patel et al., 2022	Asian Journal of Psychiatry	Burden and QoL in caregivers of children and adolescents with ASD.	Greater ASD severity = higher burden and lower QoL.
16	Purpura et al., 2021	Brain Sciences	Caregiver burden of school-aged children with NDD.	Family-centered care can reduce burden.
17	Turnage & Conner, 2022	Journal for Specialists in Pediatric Nursing	Integrative review on caregiver QoL in ASD.	Need for targeted caregiver support.
18	Zorcec & Pop-Jordanova, 2020	Prilozi	Needs and challenges of parents of children with ASD.	Parents report lack of support and emotional overload.

Source: Research data (2025).

4. Discussion

A comprehensive analysis of the studies indicates that caregiver burden cannot be understood solely from a clinical perspective, but rather as the outcome of interactions between individual caregiving demands and broader socio-structural deficiencies.

Structural and Sociocultural Determinants of Burden

The sociocultural context emerges as a major modulator of caregiver burden. Caregiver distress is intensified in environments where stigma surrounding disability is pervasive, reinforcing isolation and feelings of guilt. Banga and Ghosh (2017) demonstrated that affiliate stigma negatively affects maternal psychological well-being, mediated by high levels of subjective burden.

Socioeconomic vulnerability further exacerbates this scenario. In low- and middle-income countries, caregiver burden is intensified by the scarcity of specialized services, limited access to rehabilitation, and the absence of supportive public policies (Ademosu et al., 2021; De Leeuw et al., 2024). In these contexts, caregivers report alarming levels of psychological distress and an urgent need for improvements in health, education, and social sectors (Maridal et al., 2021; Zorcec & Pop-Jordanova, 2020).

Conversely, evidence from more structured settings indicates that intersectoral policies, regular psychological support, and health education significantly mitigate caregiver burden and enhance well-being (Kelson & Dorstyn, 2025; Keniş-Coşkun et al., 2020).

Severity of the Condition and Long-Term Impact

The severity of the child's condition is a central factor shaping caregiver experience. The more severe the cognitive, motor, or behavioral impairments, the greater the physical and emotional demands placed on the family (Bhatia et al., 2015; Purpura et al., 2021; Turnage & Conner, 2022). Children with autism spectrum disorder or medically complex conditions require continuous supervision, frequent behavioral management, and—during crisis periods such as the COVID-19 pandemic—create even greater dependency on caregivers to facilitate therapy and daily care (Kowanda et al., 2021). These demands contribute to heightened levels of parental stress (Patel et al., 2022).

Importantly, caregiver burden is not limited to childhood. Individuals with intellectual disabilities often require lifelong care (Nam & Park, 2017). The literature suggests that caregiver distress frequently persists into the child's adulthood, especially in the absence of transition policies and adequate services for adults with neurodevelopmental disorders, which become new sources of anxiety and insecurity.

Resilience and Intervention Strategies

Given the chronicity and intensity of caregiver burden, coping strategies and resilience factors play a crucial role. Strengthening resilience—the capacity to adapt to adversity—and fostering adaptive coping mechanisms supported by family and social networks serve as protective factors against emotional distress (Chakraborti et al., 2021; Keniş-Coşkun et al., 2020).

Recent literature indicates that family-centered practices and peer support are promising strategies, as they promote shared experiences, reduce stigma-related impacts, and enhance caregivers' sense of belonging (Purpura et al., 2021). Telehealth-based psychological interventions have demonstrated effectiveness in reducing symptoms of depression, anxiety, stress, and psychological distress among caregivers, as well as expanding access to specialized care—particularly in regions with limited in-person services (Kelson & Dorstyn, 2025).

However, the effectiveness of care depends on a multiprofessional and intersectoral approach. Follow-up involving psychologists, therapists, educators, and even targeted speech-language interventions—shown to reduce emotional and financial burden (Badesha et al., 2023)—contributes to a more sustainable support model. Recognition of caregiver well-being as an indirect indicator of the quality of child care reinforces the urgency of formal support policies (Turnage & Conner, 2022).

Toward an Intersectoral Response

Overall, the reviewed studies converge on the need for an intersectoral approach integrating health, education, and social assistance.

Addressing caregiver burden cannot remain confined to clinical interventions, as it reflects structural, economic, and cultural determinants. Advancing inclusive public policies, expanding access to care technologies, ensuring multiprofessional support, and investing in ongoing training of health professionals are essential pathways to promote caregiver well-being and ensure the full development of children with neurodevelopmental disorders.

5. Conclusion

Caregiver burden among parents of children with neurodevelopmental disorders is shaped by clinical, emotional, socioeconomic, and structural factors. Emotional burden is compounded by physical exhaustion, financial hardship, and social isolation. Greater symptom severity and limited access to specialized services increase caregiver distress, particularly in

LMICs. Protective factors—such as resilience, peer support, and telehealth-facilitated interventions—can reduce perceived burden.

Addressing caregiver burden requires intersectoral public policies that integrate health, education, and social assistance. Recognizing caregiver well-being as a central component of child-centered care is essential for strengthening long-term health, inclusion, and quality of life for children with NDDs and their families.

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