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Caregiver Burden and Neurodivergence: The Role of Public Health Services in Supporting Families

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Abstract

This essay examines caregiver burden in families of neurodivergent individuals and the role of public health services in developing supportive responses. It acknowledges that caregiving responsibilities, barriers to accessing services, indirect costs, and social inequalities may exacerbate family strain, while recognizing that neurodivergence does not, in itself, constitute an inevitable cause of distress. A theoretical and reflective approach was adopted, drawing on scientific studies and institutional documents selected for their thematic relevance. The discussion addresses the objective and subjective dimensions of caregiver burden, caregivers' mental health, continuity of care, accessible communication, intersectoral collaboration, and the participation of neurodivergent individuals. It is argued that educational and psychological interventions, although relevant, are insufficient when not accompanied by material support, accessible services, and effective coordination. Primary health care is highlighted as a strategic setting for

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identifying family needs, providing attentive and responsive listening, and coordinating community resources. A rights-based approach is advocated, one that simultaneously recognizes the autonomy of neurodivergent individuals and the needs of those who provide care. The essay concludes that addressing caregiver burden requires integrated public policies, outcome evaluation, and social participation, while avoiding the exclusive attribution of responsibility to families. Equity also requires attention to territorial and socioeconomic disparities.

Keywords: Caregivers; Family Health; Autism Spectrum Disorder; Mental Health; Public Health.

Introduction

Caring for a neurodivergent person may involve practical tasks, coordination with services, therapeutic follow-up, and advocacy for rights. The intensity of these activities varies according to support needs, age, economic circumstances, and resource availability. Therefore, caregiver burden should not be understood as an inevitable consequence of neurodivergence, but rather as the result of interactions between specific needs and family, social, and institutional responses (KAPP et al., 2013; WORLD HEALTH ORGANIZATION, 2022).

The literature on families of autistic children describes high levels of parental stress in certain contexts, associated, among other factors, with barriers to accessing services, co-occurring behavioral difficulties, and insufficient support. These findings should not be indiscriminately generalized to all families or confused with negative assessments of autistic people. Research should acknowledge positive experiences, emotional bonds, and different ways of organizing care (HAYES; WATSON, 2013; KARST; VAN HECKE, 2012).

Social inequalities influence who provides care, for how long, and with what consequences for employment, health, and community participation. The absence of geographically accessible services may shift to family members coordination tasks that should be shared by teams and institutions. A public health approach requires attention to social determinants, equity, and continuity of care (MARMOT et al., 2008; WORLD HEALTH ORGANIZATION, 2022).

This essay examines caregiver burden associated with neurodivergence and discusses the role of public health services in supporting families. It proposes a non-blaming, rights-based perspective that simultaneously recognizes the autonomy of neurodivergent individuals and the needs of those who provide care, considering

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the potential of primary health care, intersectoral networks, and participatory interventions (NICOLAIDIS et al., 2011; PELLICANO; DEN HOUTING, 2022).

Methodology

This is a theoretical and reflective essay employing a narrative approach, based on empirical studies, reviews, and institutional documents addressing family caregiving, autism, neurodiversity, mental health, and the organization of public services. References were intentionally selected according to their thematic relevance and conceptual significance; no systematic review, meta-analysis, or formal assessment of the methodological quality of the studies was conducted.

The argument was organized around five themes: conceptualization of caregiver burden, inequalities in the distribution of caregiving responsibilities, psychosocial consequences, service responses, and the participation of families and neurodivergent individuals. The discussion distinguishes findings primarily derived from caregivers of autistic children from broader propositions concerning other neurodivergent conditions and age groups. The recommendations are interpretive and require contextualized evaluation in specific service settings.

Discussion

Caregiver burden encompasses objective dimensions, such as time spent providing care and associated costs, and subjective dimensions, such as persistent worry and the perceived lack of support. Its measurement requires attention to context, as the same workload may be experienced differently depending on available resources, family relationships, and expectations. Reducing the experience to a single indicator obscures diverse needs and capacities (HAYES; WATSON, 2013; KARST; VAN HECKE, 2012).

Research on autism documents differences in average stress levels among certain groups of parents and caregivers, but also considerable heterogeneity across studies. Interpreting these findings requires consideration of samples, measurement instruments, co-occurring conditions, and available resources. It is methodologically inappropriate to attribute family distress exclusively to the diagnosis without examining how support is organized (HAYES; WATSON, 2013; LORD et al., 2020).

The concentration of caregiving responsibilities in a single individual may compromise rest, paid employment, and self-care. Institutional recognition of this distribution is essential for developing feasible care plans. Attention to socioeconomic inequality helps prevent standardized recommendations from becoming impossible demands for families with limited resources (MARMOT et al., 2008; WORLD HEALTH ORGANIZATION, 2022).

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The process of identifying needs and accessing services may involve repeated appointments, travel, and the need to provide the same information multiple times. Fragmentation increases the invisible coordination work undertaken by families. Transparent pathways, designated professionals, and consent-based information sharing may reduce this burden and improve continuity of care (LORD et al., 2020; WORLD HEALTH ORGANIZATION; UNITED NATIONS CHILDREN'S FUND, 2022).

Primary health care can identify early signs of exhaustion, sleep disturbances, anxiety symptoms, and material difficulties among caregivers. Such identification does not mean pathologizing family caregiving, but rather providing opportunities for attentive listening and access to resources. Assessment should include preferences, support networks, and risk situations while safeguarding confidentiality and autonomy (WORLD HEALTH ORGANIZATION, 2022; WORLD HEALTH ORGANIZATION; UNITED NATIONS CHILDREN'S FUND, 2022).

Psychoeducational interventions can help family members understand support needs, manage routines, and learn about their rights. However, education does not replace the actual provision of services and should not turn caregivers into therapists without adequate support. The appropriateness of these interventions depends on mutually agreed objectives, follow-up, and adaptation to actual living conditions (KARST; VAN HECKE, 2012; WORLD HEALTH ORGANIZATION, 2022).

Psychological support for caregivers may be indicated when significant distress is present, but it should coexist with organizational responses. Referring an individual for one-to-one support without addressing long waiting times, transportation difficulties, or the absence of home-based assistance risks individualizing a structural problem. Promoting mental health requires action at the different levels that determine psychological distress (MARMOT et al., 2008; WORLD HEALTH ORGANIZATION, 2022).

Communication between professionals and families should be clear, respectful, and accessible. Contradictory or excessively technical explanations increase uncertainty and hinder decision-making. The participation of neurodivergent individuals themselves, according to their preferences and communication needs, helps ensure that family support is not organized without considering their rights and priorities (NICOLAIDIS et al., 2015; PELLICANO; DEN HOUTING, 2022).

A neurodiversity-affirming approach makes it possible to distinguish support needs from assumptions of inferiority or incapacity. Families may require intensive support without this justifying the reduction of a neurodivergent person to a source of

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distress. Professional discourse should recognize social and sensory barriers, value individual strengths, and avoid exclusively deficit-based models (KAPP et al., 2013; PELLICANO; DEN HOUTING, 2022).

The heterogeneity of the autism spectrum precludes uniform solutions. Communication needs, assistance with daily activities, and clinical care vary considerably. Individualized plans that are reassessed over time make it possible to distribute responsibilities more appropriately, particularly during transitions from childhood to adolescence and adulthood (LORD et al., 2020; ZEIDAN et al., 2022).

The availability of community-based support and respite from caregiving may contribute to the sustainability of family care arrangements. Establishing these services, however, requires funding, transparent eligibility criteria, and appropriately trained professionals. When services are insufficient, generic recommendations for caregivers to “get more rest” become unrealistic and potentially blame-inducing (MARMOT et al., 2008; WORLD HEALTH ORGANIZATION, 2022).

Coordination among health care, education, social assistance, and employment services is particularly important. Clinical follow-up alone does not address the need for school inclusion, income protection, accessibility, and community participation. An effective network should define responsibilities, facilitate referrals, and enable families to understand the available pathways (UNITED NATIONS, 2006; WORLD HEALTH ORGANIZATION; UNITED NATIONS CHILDREN’S FUND, 2022).

Barriers experienced by autistic adults in health care services also affect family support dynamics. Difficulties with appointment scheduling, sensory-demanding environments, and communication problems may create avoidable dependence on third parties for tasks that could be performed independently with appropriate accommodations. Improving accessibility protects autonomy and may reduce family caregiving burdens (NICOLAIDIS et al., 2015; RAYMAKER et al., 2017).

Caregiver participation in service evaluations provides information about indirect costs, waiting times, and continuity of care, but it does not replace the participation of neurodivergent individuals. Participatory processes should accommodate different and sometimes divergent perspectives. Co-production of priorities promotes more legitimate interventions and prevents institutional convenience from unilaterally determining which outcomes are considered important (NICOLAIDIS et al., 2011; PELLICANO; DEN HOUTING, 2022).

Finally, family support policies should be evaluated using indicators that extend beyond the number of appointments, including time burden, effective access to support, well-being, continuity of care, and satisfaction with shared decision-making. Data disaggregated by geographic area and socioeconomic status may reveal

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inequalities concealed by aggregate averages. Evaluation should be accompanied by social participation and the continuous review of services and responses (MARMOT et al., 2008; WORLD HEALTH ORGANIZATION, 2022).

Conclusion

Caregiver burden in the context of neurodivergence is a relational phenomenon shaped by social conditions and cannot automatically be attributed to the characteristics of the individuals receiving care. Family experiences depend on the intensity of support needs, the distribution of responsibilities, and, crucially, the capacity of public services and policies to provide accessible, coordinated, and respectful responses.

Public health services can contribute through attentive listening, the identification of distress, psychosocial support, longitudinal coordination, and intersectoral collaboration. The effectiveness of these strategies requires funding, outcome evaluation, and the participation of caregivers and neurodivergent individuals, while preserving the autonomy of both. Implementation studies may clarify which combinations of support produce better outcomes across different contexts.

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