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Caring and becoming ill: implications of ongoing care for people with autism spectrum disorder on the mental health of the caregiver.

Caring and becoming ill: implications of continuous care for the caregiver's mental health of people with autism spectrum disorder

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Summary

This study aimed to analyze the implications of continuous caregiving for individuals with ASD (Autism Spectrum Disorder) on the mental health of caregivers. It is a narrative literature review, qualitative in nature and descriptive-analytical in approach, conducted using studies published between 2013 and 2025 in the SciELO, Google Scholar, and PubMed databases. The analysis of the studies showed that continuous caregiving is associated with high levels of stress, emotional overload, anxiety, emotional exhaustion, and depressive symptoms, especially when caregiving is concentrated on a single caregiver and occurs in contexts of fragile support networks and insufficient institutional support. It was observed that the caregiver's psychological distress tends to build up progressively and silently, impacting quality of life, family relationships, social participation, and physical health. Furthermore, factors such as stigma, self-stigmatization, and difficulties in accessing services contribute to the intensification of mental illness. It is concluded that the mental health of the caregiver must be understood as an inseparable dimension of care for the person with ASD, and that it is essential to strengthen support networks, integrated public policies, and care strategies that recognize the caregiver as a subject of care.

Keywords: Mental illness. Caregivers. Ongoing care. Emotional overload.
Autism Spectrum Disorder.

Abstract

This study aimed to analyze the implications of continuous caregiving for individuals with ASD (autism spectrum disorder) on the mental health of caregivers. It is a narrative literature review, qualitative in nature and descriptive-analytical in approach, conducted using studies published between 2013 and 2025 in the SciELO, Google Scholar, and PubMed databases. The analysis of the studies showed that continuous caregiving is associated with high levels of stress, emotional overload, anxiety, emotional exhaustion, and depressive symptoms, especially when caregiving is concentrated on a single caregiver and occurs in contexts of fragile support networks and insufficient institutional support. It was observed that the caregiver's psychological distress tends to build up progressively and silently, impacting quality of life, family relationships, social participation, and physical health. Furthermore, factors such as stigma, self-stigmatization, and difficulties in accessing services contribute to the intensification of mental illness. It is concluded that the mental health of the caregiver must be understood as an inseparable dimension of care for the person with ASD, and that strengthening support networks, integrated public policies, and care strategies that recognize the caregiver as a subject of care are fundamental.

Keywords: Mental illness. Caregivers. Continuous care. Emotional overload. Autism Spectrum Disorder.

1. Introduction

Autism Spectrum Disorder (ASD) is a condition of Neurodevelopmental issues that require ongoing monitoring and long-term care. impacting not only the person diagnosed, but also the family context in which they live. Care is essential. The daily lives of families with people with ASD are frequently reorganized. due to the needs for therapeutic support, constant supervision and adaptation. due to behavioral and communicational particularities, which gives care a character permanent and highly demanding (BOHN; DAL MOLIN, 2023; JUSTIMIANO, 2024).

In this scenario, the caregiver's role becomes central, especially when caregiving... It focuses on a single family member, a recurring situation within the context of ASD (Autism Spectrum Disorder). As Bohn and Dal Molin (2023) point out, the organization of care tends to fall back mostly on mothers, due to social expectations and the fragility of their support networks. support and difficulties in sharing responsibilities. This arrangement favors prolonged periods of dedication intensify emotional involvement, broadening the exposure of the caregiver to situations of stress and psychological strain (RIBEIRO; MASSALAI, 2024).

The literature has indicated that continuous care may constitute a risk factor. for the mental health of the caregiver, insofar as it exposes them to high and persistent levels of stress, emotional overload and psychological suffering (VIEIRA, 2020; BOHN; DAL MOLIN, 2023). However, these repercussions are not always analyzed in an integrated way, considering care as a prolonged and cumulative process, capable of producing progressive psychological impacts over time. In addition, factors such as frailty support networks, insufficient institutional support, and the normalization of suffering. Emotional factors contribute to the invisibility of this illness (JUSTIMIANO, 2024).

Although recent studies have identified high levels of stress and anxiety, emotional exhaustion and depressive symptoms among caregivers of people with ASD, such Demonstrations are not always analyzed in an integrated way. Ribeiro and Massalai (2024) They point out that some of the literature addresses these impacts in a fragmented way, without considering Continuous care as a prolonged process capable of progressively leading to mental illness in caregivers. This theoretical gap limits the understanding of the implications.

The psychological aspects of caregiving hinder the formulation of effective health promotion strategies. mental approaches focused on this group.

Given this, it becomes relevant to shift the analytical focus traditionally centered on... only in the diagnosed person, from a perspective that recognizes the caregiver as a subject. also marked by emotional, social, and psychological vulnerabilities. Understanding the The implications of ongoing care for the caregiver's mental health are shown to be fundamental for to broaden the debate in the field of ASD and to foster more sensitive reflections on the Challenges experienced in the daily life of a caregiver.

In this context, the need to deepen the understanding of the following becomes evident. effects of ongoing caregiving on the caregiver's mental health, especially considering that, despite the recognition of the high emotional burden associated with caregiving Regarding people with Autism Spectrum Disorder, analyses addressing this are still limited. Care is seen as a cumulative process of mental illness. Thus, the following arises. Problem: What are the implications of ongoing care for people with Disorder? Autism Spectrum Disorder and its impact on caregiver mental health?

Given this problem, the general objective of this study is to analyze the implications of ongoing care for individuals with ASD on the mental health of the caregiver. Specifically, the aim is to identify the main psychological impacts associated with ongoing care for people with ASD, analyzing how emotional overload, stress, and Mental exhaustion is addressed in studies on caregivers, and discussing how... Continuous care contributes to the long-term development of mental health problems.

2. Materials and methods

The methodological procedures adopted in this research consist of a review. A narrative of literature, qualitative in nature, with a descriptive-analytical approach, whose The objective was to analyze the implications of ongoing care for people with Disorder Autism Spectrum Disorder (ASD) for caregiver mental health. The choice for this type of review. It is based on the need to understand, in a broad and interpretive way, how the Prolonged care is discussed in the literature, especially with regard to overload. emotional, related to stress, psychological suffering, and mental illness processes. experiences lived by caregivers.

The search for studies was conducted in the SciELO (Scientific Electronic Commerce) database. Publications that were prioritized were those that were found in the following databases: Library Online, Google Scholar, and PubMed. that addressed family care in the context of ASD and its repercussions on mental health. caregiver, considering descriptors such as stress, anxiety, depression, overload emotional distress, burnout, and mental illness. The choice of descriptors took into account the The research problem and its objectives, seeking to encompass studies that discuss both the Ongoing care is needed regarding the psychological implications for the caregiver.

Studies published between 2013 and 2025, with a national scope, were included. and international, that addressed the care of people with Autism Spectrum Disorder and Its implications for the mental health of caregivers and family members were also considered. studies that, while not dealing exclusively with ASD, discussed ongoing care. in the context of chronic neurodevelopmental conditions, provided they presented Relevant theoretical contributions to understanding caregiver mental illness. Works that did not directly address the theme of care or that... were excluded. restricted to exclusively clinical aspects of the person with ASD, without considering the Caregiver experience.

The data analysis was conducted using a qualitative approach. Interpretative, based on a systematic and analytical reading of the selected studies. This stage its purpose was to examine how the literature has discussed the implications of Ongoing care for the mental health of people with Autism Spectrum Disorder. caregiver, considering the main psychological aspects associated with this process.

3. Theoretical Framework

3.1 Ongoing care and the emotional burden on the caregiver

The ongoing care of people with Autism Spectrum Disorder (ASD) constitutes-if it is seen as an experience marked by intense emotional involvement, reorganization of Family routine and increased daily responsibilities. As analyzed by Bohn and Dal. Molin (2023), from the diagnosis onwards, mothers (who frequently assume the role of primary caregivers) begin to experience an adaptation process that involves relinquishing... personal projects, redefining priorities, and increased emotional burden associated with care. In this context, care ceases to be restricted to the physical dimension and begins to encompass ongoing therapeutic support, constant attention to the person's behavior with ASD and ongoing adaptations to their needs, configuring itself as a process prolonged that directly affects the emotional balance of the caregiver (JUSTIMIANO, 2024).

Centralizing care leads to an accumulation of emotional responsibilities. organizational and affective aspects in a single subject. For Bohn and Dal Molin (2023) this Centralization does not occur spontaneously, but is associated with both the insufficiency of networks. formal and informal forms of support regarding the social expectations that historically attribute to Women take on the role of caregiver, especially in situations of illness or disability. This configuration favors prolonged periods of dedication and reduces the possibilities of Sharing the burden of care intensifies the emotional strain. Similarly, Ribeiro and Massalai (2024) point out that the almost exclusive responsibility of the caregiver The main goal is to increase the risk of psychological overload, as it limits spaces for... Rest, emotional support, and recognition of one's own needs.

Studies show that a diagnosis of ASD initiates a process of lived experience. prolonged emotional overload, which manifests itself in multifaceted ways, involving Stress, anxiety, feelings of helplessness, and psychological exhaustion. Vieira (2020), in analyzing The perceived stress and emotional symptoms in caregivers highlight the ongoing caregiving needs of caregivers. Managing individuals with ASD requires constant vigilance and a high level of emotional involvement, factors that... Over time, they compromise the caregiver's emotional balance and increase the risk of mental illness. In this sense, overload does not present itself as a one-off event, but as a cumulative experience, built in the daily routine of care and reinforced by Lack of breaks and support.

Justimiano (2024) observes that, for many families, caregiving takes on a more prominent role. central to the organization of daily life, redefining priorities and restricting spaces of Leisure, social interaction, and personal fulfillment for the caregiver. In this scenario, suffering Emotional aspects tend to be silenced or normalized, given the demands of the person being cared for. They take priority over the caregiver's needs. This process contributes to the making psychological suffering invisible, hindering its recognition as a problem of health and fostering trajectories of continuous emotional distress.

When analyzing maternal reports, Bohn and Dal Molin (2023) show that the burden The emotional state of the caregiver stems not only from the clinical characteristics of the disorder, but also from... continuous experience of vigilance, constant concern for the child's future and of a sense of ongoing responsibility for one's own development. According to the authors, the

The perception that caregiving is a non-transferable task intensifies involvement. emotional distress contributes to recurring feelings of exhaustion, as well as weakening the body. Perception of social support available to the caregiver.

Souza et al. (2022) highlight that the continuous care of children with ASD requires... The caregiver must maintain a posture of constant readiness, especially in the face of certain behaviors. Unpredictable events, emotional crises, or communication difficulties. This condition favors persistent states of psychological stress, in which the caregiver remains on alert, even during rest periods, hindering emotional recovery and mental relaxation. Furthermore, the unpredictability inherent in caring for people with ASD intensifies the Emotional overload.

Emotional overload is also expressed in the difficulty of balancing caregiving. with other dimensions of life, such as work, social relationships, and personal projects. Ribeiro and Massalai (2024) highlight that many caregivers report the interruption or abandonment of professional and social activities, which contributes to progressive isolation and to a feeling of loss of identity beyond the role of caregiver. This experience reinforces that Ongoing care not only impacts emotional health, but also compromises... autonomy, social belonging, and the possibility of building personal trajectories. independent of care.

In this context, the ongoing care of people with Autism Spectrum Disorder It should be understood as a process marked by progressive emotional wear and tear. resulting from a combination of intense demands, prolonged responsibility, and fragility of support networks. As Justimiano (2024) argues, the absence of spaces for listening and Systematic attention to the mental health of caregivers fosters the normalization of suffering. psychological, contributing to trajectories of emotional illness that develop from in a silent and gradual way.

Therefore, the emotional burden on the caregiver should not be understood as not a secondary or occasional effect of care, but as a structuring element of experience of caring for a person with Autism Spectrum Disorder. As they point out Ribeiro and Massalai (2024) state that continuous care, when supported by high demands, Emotional factors have a direct impact on the caregiver's mental health. Recognizing this Overburdening this situation implies shifting the focus of care away from being exclusively centered on the person with ASD. for a broader understanding that includes the caregiver as a subject of rights and needs. and vulnerabilities.

3.2 Implications of ongoing care for the caregiver's mental health

The emotional overload associated with the ongoing care of people with Disorder Autism Spectrum Disorder (ASD) has been widely recognized in the literature as a factor. central to the impairment of the caregiver's mental health. Studies indicate that this prolonged care, characterized by constant vigilance, increased responsibilities and The reorganization of daily life creates conditions conducive to the development of suffering. psychological and mental illness, especially when sustained for long periods without adequate support (ILIAS et al., 2018; GENTLES; MCLAUGHLIN; SCHNEIDER, 2024).

From this perspective, Gentles, McLaughlin, and Schneider (2024) propose to understand the Stress experienced by caregivers of people with ASD as a phenomenon multidimensional, which goes beyond isolated emotional reactions and is configured as a A continuous process of psychological wear and tear. According to the authors, this stress results from... interaction between practical caregiving demands, emotional pressures, and social constraints. imposed by routine, producing cumulative impacts that progressively compromise the mental health of the caregiver. When these demands are not mediated by strategies of Coping mechanisms or support networks tend to favor the development of chronic stress and may triggering mental health issues (ILIAS et al., 2018).

Studies show that caregivers of people with ASD have high levels of autism spectrum disorder (ASD). of stress, anxiety, emotional exhaustion and depressive symptoms, especially when Care is provided in a focused manner and in contexts of insufficient emotional support. social (VIEIRA, 2020; BOHN; DAL MOLIN, 2023). These findings reinforce the understanding that psychological suffering is built up over time, especially when associated with fragility of support networks and the absence of spaces for emotional recovery resulting of the demands of care.

According to Chaim et al. (2019), caregiving burden often implies Giving up professional, social, and leisure activities, reducing opportunities for self-care. and social participation. This progressive restriction tends to limit sources of pleasure and support. emotional distress, which contributes to feelings of isolation, exhaustion, and loss of identity. personal. Thus, in addition to physical effort, the impact of care reaches subjective dimensions, because the reduction of spaces for rest and personal fulfillment can intensify tension. emotional distress and vulnerability to psychological suffering, especially when care is concentrated on a single family member.

From this same perspective, Ribeiro and Massalai (2024) highlight that the recurrence of intense emotional demands, coupled with the almost exclusive responsibility placed on the caregiver and The fragility of support networks contributes to trajectories of silent psychological suffering. This process is often normalized within the family context. It tends to compromise gradually improving the caregiver's psychological well-being, transforming the daily overload into mental illness over time.

Friesen's studies (2022), in turn, contribute to broadening the understanding of the implications of ongoing care, highlighting the psychological suffering of the caregiver. It stems not only from the objective intensity of the demands, but also from the way in which these demands are made. Demands are interpreted and addressed over time. According to Friesen (2022), Caregivers of people with ASD tend to experience high levels of stress and Emotional distress occurs when one perceives low predictability and little control over the... caregiving situations and insufficient personal and social resources to cope with the demands. everyday challenges. The author highlights that adaptive coping strategies can mitigate these challenges. The negative effects of stress, although they do not completely eliminate the impact of caregiving. continuous.

Among the implications, Lam et al. (2024) point to depression as one of the Most frequent problems faced by caregivers of children with Autism Spectrum Disorder. In In a meta-analysis that compiled 40 studies and involved 13,853 caregivers, the authors identified a high global prevalence of depressive symptoms, estimated at 45% (95% CI: 39.0–51.0), which highlights the significant magnitude of the psychosocial risk associated with caregiving. continuous. The findings also indicated relevant regional variations, with greater prevalences observed in European studies (54%) and in the Eastern Mediterranean region (53%), followed by Southeast Asia and the Western Pacific (40%) and the Americas (38%). Of In general, depressive symptoms were shown to be associated with the intensity of the demands of caution, given the fragility of social support networks and the uncertainty regarding development and future autonomy of the person with ASD, reinforcing the global and lasting impact of care. continuous study on the mental health of caregivers (LAM et al., 2024).

According to Roskam et al. (2021), in addition to depression and anxiety, caregivers of Children with ASD may develop parental burnout, characterized by emotional exhaustion. intense emotional detachment and feelings of inadequacy in providing care, resulting stemming from a persistent imbalance between high care demands and insufficient resources. In this context, caregivers are more vulnerable to this phenomenon, since that prolonged and highly demanding care tends to progressively reduce reserves. emotional factors and mechanisms of psychological adaptation.

According to Li et al. (2022), anxiety and stress are also frequently present. at clinically relevant levels, with differences by gender: mothers tend to report higher stress, anxiety, and depression levels compared to parents, especially when the Symptoms of ASD are more severe. In this context, the psychological suffering of the caregiver is not... It is not explained solely by the diagnosis, but by the interaction between care demands and characteristics of child/adolescent development and behavior, which They modulate the intensity of emotional distress (LI et al., 2022). Taken together, these findings Studies indicate that caregiver mental illness takes on multiple clinical forms. influenced by the complex interaction between care requirements and available resources.

According to Ilias et al. (2018), factors such as symptom severity, difficulties Financial problems and, especially, insufficient social support are repeatedly associated with Increased parental stress, while coping strategies and family resources They can function as protective elements. Therefore, ongoing care tends to be more effective. It becomes debilitating when the caregiver faces daily challenges with a weak support network and few resources. possibilities for dividing tasks.

According to Seçinti et al. (2024), the relationship between the characteristics of a person with ASD and the Caregiver illness often occurs indirectly, mediated by problems. emotional and behavioral factors, as well as internalized stigma, can intensify the association. between the demands of caregiving, parental stress, and depressive symptoms. From this perspective, the Studies suggest that it is not only the "severity" itself that matters, but the way in which... Difficulties are expressed in daily life and how the caregiver interprets them, especially when There is shame, self-blame, or fear of social judgment.

Lima et al. (2024) highlight that self-stigma in mothers and/or caregivers can contribute This scenario of psychological suffering interferes with the perception of support and the search for help. and in the way the caregiver evaluates herself and her experience of mothering/caregiving. Therefore, understanding stigma as a psychosocial component is fundamental to to explain why some caregivers exhibit poorer mental health even in certain contexts Similar to objective demands.

In addition to individual impacts, studies show that ongoing care has repercussions. significantly impacting quality of life and family relationships. According to Chaim et al. (2019), marital tensions, communication difficulties and reduced social interaction are recurring effects associated with the emotional overload of caregiving, creating a cycle in which the The caregiver's psychological distress interferes with family dynamics and, simultaneously, Weakened relationships intensify stress.

Along the same lines, Ahmed et al. (2023) demonstrate that the quality of life of Mothers and fathers who are caregivers may exhibit distinct patterns, associated with factors such as degree of Overload, availability of social support, and care context. These findings reinforce the the need to understand the caregiver's experience as situated, considering variables factors such as gender, economic conditions, support networks, and access to services indicate that... The impacts of ongoing care tend to accumulate over time, spanning multiple stages. dimensions of life.

According to Hayes and Watson (2013), the effects of ongoing care for people with Autism Spectrum Disorder (ASD) extends beyond the psychological sphere, also impacting the physical health of caregivers. with a higher prevalence of sleep disorders, chronic fatigue, musculoskeletal pain and Somatic symptoms, often associated with prolonged stress and overload. emotional. These findings reinforce the understanding of ongoing care as a risk factor. cumulative, capable of compromising the overall well-being of the caregiver over time.

Despite this scenario of vulnerability, studies point to the existence of factors protective measures capable of mitigating the negative effects of ongoing care on mental health. According to Ilias et al. (2018), social support and coping resources appear as factors. central to reducing stress and promoting psychological adaptation processes, suggesting that Interventions and policies should favor formal and informal support networks.

According to Peng et al. (2025), psychosocial interventions, such as support groups and Mindfulness-based practices have shown potential to reduce stress levels and to improve emotional well-being, although the literature highlights the need for approaches contextualized and integrated into the real conditions of families. The body of evidence suggests that such interventions are more effective when tailored to the specific needs of caregiver and combined with multidisciplinary support.

Within the framework of care policies and guidelines, it is recognized that care Comprehensive care for people with ASD requires network coordination and an interdisciplinary approach, which It also indirectly protects caregivers by reducing disruption and unnecessary travel. Services and information insecurity. Thus, strengthening the care pathway can have an effect. relevant to the mental health of the caregiver, by mitigating organizational factors that amplify the Caregiving burden and the need to promote consistent support.

Finally, Gentles, McLaughlin, and Schneider (2024) reinforce that the mental health of The caregiver should be understood as an integral part of the care provided to the person with ASD. lack of institutional support, fragmentation of services and discontinuity of support tends to amplify the psychological suffering of the caregiver, while policies Public and integrated care pathways can act as indirect protective factors. Recognizing and addressing the implications of ongoing care for the caregiver's mental health. It therefore constitutes a fundamental step towards building more effective care strategies. humane, sustainable, and effective approaches in the field of ASD (Autism Spectrum Disorder).

Final considerations

This study allowed for an integrated analysis of the implications of care. Continuous support for the mental health of caregivers of people with Autism Spectrum Disorder. highlighting that this experience is associated with significant impacts on mental health. of the caregiver, creating a context of high psychological vulnerability. The exposure prolonged intense emotional demands, constant vigilance, and accountability. affective disorders contribute to the development of chronic stress, anxiety, emotional exhaustion, and symptoms. Depression can occur, especially when care is concentrated on a single caregiver.

The studies analyzed indicate that such repercussions are not limited to characteristics of the disorder, but they stem from the daily organization of care. often marked by the fragility of support networks, by insufficient support This scenario contributes to institutionalization and the normalization of the caregiver's emotional suffering. for the postponement of the recognition of mental illness and for the maintenance and processes progressive signs of emotional exhaustion.

It was also observed that the caregiver's psychological distress has multiple repercussions. dimensions of daily life, including family relationships, social participation and activities work-related factors, producing cumulative effects on quality of life. The literature indicates that... The absence of spaces for listening, emotional support, and interventions directed at the caregiver tends to intensify these impacts over time.

In this sense, the findings reinforce the understanding of caregiver mental health as An inseparable component of care for individuals with Autism Spectrum Disorder. The incorporation of the caregiver as a subject of care in care practices and policies shows-

This is fundamental for promoting more integrated, sustainable, and sensitive interventions. complexities involved in ongoing care.

Therefore, advancing attention to the mental health of caregivers implies overcoming the making emotional suffering invisible and strengthening support strategies, qualified listening and expanding support networks. This perspective contributes to the development of practices of more humane, sustainable, and effective care, capable of promoting both the care of the person with ASD regarding the preservation of the mental health of those who practice it daily.

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