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Perception of the Risk of Muscle Illness Among Caregivers of People with Autism Spectrum Disorder

Perception Of The Risk Of Muscle Disease Among Caregivers Of People With Autism Spectrum Disorder

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Summary

The ongoing care of individuals with Autism Spectrum Disorder (ASD) involves persistent physical demands that expose caregivers to significant risks of muscle and musculoskeletal disorders. However, how these risks are perceived directly influences pain recognition, attention to one's own physical limitations, and self-care practices. In this sense, this study aimed to analyze the perception of the risk of muscle disorders in the context of caring for individuals with ASD and its implications for caregiver health. This is a narrative literature review, qualitative in nature and descriptive-analytical in approach, based on studies published between 2010 and 2025, identified in the SciELO and Google Scholar databases, using descriptors related to caregiving, ASD, musculoskeletal disorders, and risk perception. The results indicate that the perception of the risk of muscle disorders among caregivers is generally fragile and constructed late, since pain and physical discomfort tend to be naturalized as an inherent part of the act of caregiving. It has been observed that repetitive physical exertion, lack of technical guidance, and sociocultural factors contribute to the neglect of early signs of bodily overload. In the care of people with ASD, the unpredictability of demands and the need for constant vigilance direct the caregiver's attention primarily to the person being cared for, reducing the perception of their own physical limitations.

It is concluded that limited or delayed risk perception acts as a central element in the maintenance and chronicity of preventable musculoskeletal conditions among caregivers.

Keywords: Caregiver. Musculoskeletal Disorder. Autism Spectrum Disorder.
Risk perception.

Abstract

The ongoing care of individuals with Autism Spectrum Disorder (ASD) involves persistent physical demands that expose caregivers to significant risks of muscle and musculoskeletal disorders. However, how these risks are perceived directly influences pain recognition, attention to one's own physical limitations, and self-care practices. In this sense, this study aimed to analyze the perception of the risk of muscle disorders in the context of caring for individuals with ASD and its implications for caregiver health. This is a narrative literature review, qualitative in nature and descriptive-analytical in approach, based on studies published between 2010 and 2025, identified in the SciELO and Google Scholar databases, using descriptors related to caregiving, ASD, musculoskeletal disorders, and risk perception. The results indicate that the perception of the risk of muscle disorders among caregivers is generally fragile and constructed late, since pain and physical discomfort tend to be naturalized as an inherent part of the act of caregiving. It was observed that repetitive physical efforts, lack of technical guidance, and sociocultural factors contribute to the neglect of initial signs of bodily overload. In the care of people with ASD, the unpredictability of demands and the need for constant vigilance direct the caregiver's attention primarily to the person being cared for, reducing the perception of their own physical limitations. It is concluded that limited or delayed risk perception acts as a central element in the maintenance and chronicity of preventable musculoskeletal conditions among caregivers.

Keywords: Caregiver. Musculoskeletal Disorder. Autism Spectrum Disorder. Risk Perception.



1. INTRODUCTION

The care of people with Autism Spectrum Disorder (ASD) has become established as a relevant topic in the fields of health and social sciences, due to its multiple implications. what this condition entails for individuals, their families, and especially for those who They assume the role of caregivers. Because it is a neurodevelopmental condition that It requires prolonged monitoring and ongoing support; care often goes beyond the The technical scope changes and begins to structure daily family life, requiring constant reorganizations in the routine. in social relations and in the distribution of responsibilities (SANTOS; HORA, 2025; SILVA et al., 2020).

This care involves ongoing physical demands that expose caregivers to risks. significant muscle soreness. However, the adoption of preventive practices and Self-care is directly related to how these individuals recognize and interpret it. such risks. Weakness in risk perception can lead to the normalization of pain, to the postponement of seeking healthcare and the worsening of potentially preventable muscle conditions (ALENCAR; SCHULZE; SOUZA, 2010; BRITO; LUCENA; LUCENA, 2020).

Several studies indicate that musculoskeletal pain is a recurring condition among... caregivers, progressively interfering with the performance of daily activities and in quality of life. However, this painful experience is not always recognized as a sign of illness or health risk, often becoming part of the routine as a consequence expected from the act of caregiving. Such a perception contributes to the maintenance of inadequate practices and to prolonged exposure to physical risk factors, especially in contexts of continuous and informal care (ALMEIDA; CONCEIÇÃO, 2013; MARTINS et al., 2020).

In this context, the perception of the risk of muscle disease plays a central role in the Understanding the dynamics involved in caring for people with ASD. The way in which... Caregivers perceive, minimize, or ignore bodily signals, which directly influences their attitudes. In the face of physical overload, self-care, and the search for health support. In the care of people with Autism Spectrum Disorder (ASD), characterized by unpredictable demands and the need for constant readiness, The caregiver's attention tends to focus on the needs of the person being cared for, reducing attention to the other person. to their own physical limits (CONSTANTINIDIS; PINTO, 2020; SANTOS; HORA, 2025).

Despite acknowledging the physical strain associated with ongoing caregiving, it is observed that The literature still favors analyses focused on describing symptoms, emotional impacts, and... quality of life of caregivers, with little in-depth analysis of the perception of risk of Muscle illness as an analytical axis. This gap limits the understanding of how caregivers They construct meanings about their own illness and how this perception influences their...



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prolonged exposure to physical risks (MARTINS et al., 2020; BRITO; LUCENA; LUCENA, 2020).

Given this scenario, the question arises: how is the perception of the risk of muscle illness... understood within the context of caring for people with Autism Spectrum Disorder and which What are the implications of this perception for the health of caregivers? Thus, this study aims to... The objective is to analyze the perception of the risk of muscle disease in the context of caring for people with Autism Spectrum Disorder and its implications for caregiver health, addressing the main risk factors for muscle weakness associated with caregiving activities, the consequences of low muscle weakness. perception of this risk for the progression and chronicity of muscle problems among caregivers and its relationship with self-care and prevention practices described in the literature.

2. MATERIALS AND METHODS

This study is a narrative literature review of a qualitative nature, with A descriptive-analytical approach, designed to analyze and discuss studies on risk perception. of muscular and musculoskeletal disorders among caregivers of people with Down Syndrome Autism Spectrum Disorder (ASD). The choice for this type of review is justified by the need for to understand, in a broad and interpretive way, how the factors associated with continuous care and to Physical demands influence how caregivers perceive the risk of illness.

The search for studies was conducted in databases such as SciELO (Scientific Electronic Journal of Economics). Library Online) and Google Scholar were used. Descriptors such as "Spectrum Disorder" were employed. "Autistic", "caregivers", "muscle disease", "musculoskeletal disorders", "pain" "musculoskeletal", "risk perception" and "physical overload". The definition of the descriptors considered the research problem and objectives, encompassing theoretical frameworks capable of supporting the proposed analysis.

Studies published between 2010 and 2025, of national scope and international, addressing the care of people with Autism Spectrum Disorder or other conditions that require ongoing care, as well as their physical and mental repercussions. musculoskeletal issues affecting caregivers, especially regarding their perception of risk of illness.

After selection, the studies underwent exploratory and analytical reading, followed by a descriptive and qualitative analysis, with emphasis on understanding the conditions of care and the requirements. physical factors involved and the way in which muscular and musculoskeletal illness is perceived by caregivers. The analysis sought to identify convergences, recurrences, and gaps present in the literature. allowing for an integrated interpretation of the findings in light of the proposed objectives, without the intention of Not to exhaust the topic, but to systematize relevant contributions to understanding the problem.



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investigated.

3. THEORETICAL FRAMEWORK

3.1 Caring for People with Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a condition of neurodevelopmental disorder characterized by persistent deficits in social communication and interaction, associated with restricted and repetitive patterns of behavior, interests, or activities, manifesting-whether in a heterogeneous way regarding support needs throughout development. According to Santos and Hora (2025) argue that this heterogeneity implies different levels of functional dependence. requiring continuous adaptations in the family context and in the organization of care. For Silva et al. (2020), such demands go beyond the individual implications of the disorder, imposing on the family a significant reorganization of their routine, especially with regard to the provision of care specialized and continuous.

According to Silva et al. (2020), the diagnosis of ASD initiates an adaptation process. family life marked by changes in routine, interpersonal relationships, and expectations regarding child development. In this context, care ceases to be occasional and becomes a more permanent part of the process. as an ongoing process, requiring constant dedication, permanent vigilance and prolonged therapeutic follow-up (NOHARA et al., 2017). Thus, caring for a person with Autism Spectrum Disorder involves dealing with demands that go beyond physical care. involving emotional, social, and organizational dimensions that directly impact daily life. of the caregiver.

Studies indicate that, in the Brazilian context, the responsibility for the care of people with The burden of Autism Spectrum Disorder falls largely on the family, especially on mothers. who assume the role of primary caregivers (SOARES; NASCIMENTO; ROCHA, 2025). According to the authors, this centralization of care within the family stems from both the insufficiency of effective public policies as well as the social normalization of the female role as caregiver, of In this way, overload is not limited to the volume of tasks, but is related to accountability. almost exclusively these women are concerned with the well-being and development of their children.

This concentration of care does not occur spontaneously, but is social and historical. constructed. As analyzed by Faro et al. (2019), the idealization of motherhood contributes to the mothers fully assume the demands of caregiving, reorganizing their routines and prioritizing the The needs of their children at the expense of their own. For Souza et al. (2022), the impact of A diagnosis of ASD triggers an ongoing process of family adaptation, in which the caregiver



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The principal then takes on expanded responsibilities, leading to an accumulation of tasks and an increase in workload. vulnerability to physical and mental overload.

Ribeiro and Massalai (2024) highlight that the continuous care of children with ASD requires full dedication, often accompanied by the renunciation of professional, social and personal life. self-care. According to the authors, the so-called "invisible burdens" of care manifest themselves through amidst physical and emotional exhaustion, social isolation, and persistent feelings of guilt and inadequacy, significantly reducing the spaces intended for rest, leisure and preserving one's own health.

From this perspective, care is not merely a practical activity, but a... an experience that reorganizes identities, social roles, and life projects. For Vieira (2020), mothers and Parents caring for children with ASD experience high levels of chronic stress when compared to caregivers of typically developing children, which highlights the impact prolonged continuous care. The author highlights the unpredictability of behaviors, the The intensity of therapeutic demands and constant concern about the future contribute to the maintaining this state of tension in daily family life.

Furthermore, the intensity and complexity of care are directly related to support needs of a person with ASD. According to Silva and Pansera (2023), the greater the degree The more functional impairment a person with ASD experiences, the higher their anxiety levels tend to be. The authors state that this scenario has repercussions due to the perceived burden and psychological distress experienced by caregivers. negatively impacting quality of life and family functioning, reinforcing the need for to understand care as a continuous and multifaceted process.

Furthermore, ongoing care involves practical, organizational, and surveillance demands that They then begin to structure the caregiver's routine. As discussed by Nohara et al. (2017), the act of caring for People with specific needs require constant adaptations in daily life and in the organization of their lives. time, incorporating repetitive tasks and ongoing responsibilities. Similarly, Almeida Conceição (2013) emphasizes that these demands, often naturalized in the context Family dynamics have an impact on the caregiver's quality of life, even if they are not always recognized. as health risk factors.

This understanding is expanded upon by Alencar, Schulze and Souza (2010) and by Vega-Vélez et al. (2021), when indicating that continuous care, in different contexts, is characterized by Overlapping physical, emotional, and organizational responsibilities. According to Martins et al. (2020), The persistence of these demands contributes to a reduction in quality of life and an increase in... perceived burden among caregivers, reinforcing the continuous and cumulative nature of caregiving.

In this context, the care of people with Autism Spectrum Disorder should be... understood as a complex phenomenon, traversed by social, economic and determinants



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cultural. As Silva et al. (2024) point out, the absence of structured support networks and Integrated public policies intensify the vulnerability of caregivers, amplifying the impacts of Continuous care for their health and well-being. Thus, discussing the care of people with ASD implies... to recognize the caregiver as an individual who also needs attention, support, and strategies. health promotion.

3.2 Muscle and Musculoskeletal Illness in Caregivers

Muscular and musculoskeletal disorders in caregivers can be understood as a phenomenon resulting from continuous exposure to physical, postural, and organizational demands inherent to the act of caregiving, especially when the person being cared for has functional dependence partial or total. According to Alencar, Schulze and Souza (2010), the act of caring involves carrying out frequent repetitive movements, the adoption of inadequate postures, and the application of physical force. Without adequate technical preparation, factors that favor biomechanical overload and the emergence of... musculoskeletal disorders. According to Martins et al. (2020), these conditions manifest themselves as a significant form among informal caregivers, whose caregiving routine occurs, for the most part, outside of structured environments lacking preventative guidance.

Unlike one-off activities, ongoing care is characterized by daily repetition. of physically demanding tasks, often performed without sufficient breaks for recovery. bodily. As highlighted by Almeida and Conceição (2013), the high prevalence of pain symptoms The relationship between caregivers relates not only to the intensity of physical effort, but also to its duration. prolonged care over time. For the authors, the absence of adequate intervals of Rest contributes to the development of persistent painful conditions, compromising progressively improving the caregiver's functionality.

Studies conducted in different care settings reinforce the understanding of Musculoskeletal illness as a phenomenon that cuts across the act of caregiving. According to Vega-Vélez et al. (2021) found that musculoskeletal injuries and complaints are frequent among caregivers. regardless of the clinical condition of the person being cared for, suggesting that the illness is less related to the specific pathology and more closely linked to the repeated and prolonged physical demands of Caution. This finding is corroborated by Martins et al. (2020), who showed that physical overload and the reduction in quality of life are recurring phenomena among caregivers subjected to continuous demands.

Among the most common musculoskeletal complaints, lower back pain ranks as... highlight. According to Santos et al. (2020), this body region is particularly vulnerable because due to the demands of supporting, bending, and rotating the trunk during caregiving activities, such as assistance.



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in transfers, mobility support, and maintenance of prolonged static postures. For Alencar, Schulze and Souza (2010) state that lumbar overload reflects not only immediate physical exertion, but also... Continuous repetition of inappropriate practices over time, favoring the worsening of complaints and functional limitations.

Musculoskeletal disorders should also be analyzed based on the interaction between factors. physical and psychosocial factors. According to Brito, Lucena and Lucena (2020), musculoskeletal pain in Caregivers are often associated with high levels of stress, which contributes to amplification of pain perception and reduction of coping capacity. For Nohara et al. al. (2017), this interaction reinforces the multifactorial nature of the illness, indicating that the complaints Muscular dysfunction cannot be attributed solely to physical exertion, but to the overall context. that care develops.

In the care of people with Autism Spectrum Disorder, these risk factors take on... particular characteristics. According to Silva, Deltrudes and Iwata (2025), situations of agitation Psychomotor difficulties, escape attempts, behavioral crises, and episodes of self-harm or aggression towards others. They require caregivers to take actions involving restraint, protection, and physical redirection, frequently performed abruptly and without adequate biomechanical preparation. According to Santos et al. (2020), the Unpredictable and repetitive caregiving situations can lead to overload in areas such as the spine. lower back, shoulders and upper limbs, in addition to contributing to the maintenance of tension. sustained muscular strain, increasing the risk of chronic pain and functional limitations over time.

Another relevant aspect refers to the absence of systematic prevention strategies and health guidance aimed at caregivers. According to Nohara et al. (2017), many caregivers They begin providing care without the technical preparation to handle the physical demands, which increases the risk of injury. due to inadequate postures and excessive effort. For Almeida and Conceição (2013), the lack of Professional support contributes to the adoption of compensatory strategies in the face of pain. perpetuating harmful movement patterns and increasing the risk of worsening the condition. musculoskeletal.

Thus, muscular and musculoskeletal disorders in the context of continuous care. It is configured as a complex process, marked by the interaction between physical overload, Organization of care and lack of preventive support. For Brito, Lucena and Lucena (2020), Understanding this illness requires moving beyond fragmented approaches and considering care. as a practice that exposes the caregiver to persistent health risks.



3.3 Perception of the risk of muscle disease and prevention strategies

The perception of the risk of muscle illness among caregivers is a central element for understanding the dynamics involved in ongoing care, especially in contexts marked by high physical demands. According to Alencar, Schultze and Souza (2010), the way in which The caregiver perceives (or does not perceive) the risks associated with caregiving activities, influencing... directly related to adopting preventive behaviors, such as seeking guidance and taking care of... their own health. For Martins et al. (2020), low risk perception tends to favor The normalization of pain and physical discomfort contributes to the perpetuation of inappropriate practices. and for the progression of musculoskeletal disease.

In the context of informal care, the perception of risk is often mediated by factors. Cultural and social factors that attribute a moral, affective, and responsibility-related character to the act of caring. familiar. As highlighted by Silva, Deltrudes and Iwata (2025), caregivers of people with Special needs individuals tend to prioritize the needs of the person being cared for over their own needs. health, which reduces attention to the early signs of illness. This logic favors invisibility. of the caregiver's physical suffering, since pain comes to be interpreted as an inherent part of Its role is to provide care, and not to indicate a health risk.

The literature suggests that the perception of the risk of muscle disease is influenced by accumulated experience in caregiving and the level of information available to the caregiver. According to Nohara et al. (2017) found that many caregivers begin providing care without adequate technical guidance, which limits the ability to recognize improper postures, excessive exertion, and early signs of Physical overload. For Brito, Lucena and Lucena (2020), the lack of knowledge related to Poor ergonomics and prevention mean that the risk is only recognized when the pain has already occurred. installed, it begins to significantly interfere with daily activities and functionality. of the caregiver.

Another relevant factor relates to the way in which muscle disease manifests itself. gradual and cumulative, making it difficult to immediately associate with caregiving activities. According to Almeida and Conceição (2013) state that the slow progression of pain symptoms contributes to the caregiver's understanding. Continue your activities even in the face of physical discomfort, delaying the recognition of illness as a health risk. This process is reinforced, according to Vega-Vélez et al. (2021), by The tendency of caregivers to delay seeking professional help, especially when pain... It does not completely prevent the performance of daily tasks.

Empirical evidence deepens this understanding by indicating that the recurring presence of Musculoskeletal pain often precedes the recognition of the illness as a risk factor.



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health. In the field study conducted by Almeida and Conceição (2013), high levels were observed. prevalence of pain symptoms among caregivers, especially in regions such as the lumbar spine and the upper limbs, even when they maintained their caregiving activities without interruptions. According to the authors, the persistence of pain over time favors its incorporation. as a habitual element of the routine, reducing its identification as a sign of overload or illness. These findings show that the perception of the risk of muscle illness tends to occurring late, only when the pain begins to interfere more significantly with... functionality and in the caregiver's daily activities.

In the care of individuals with ASD, the perception of risk can be further compromised in due to the unpredictability of care requirements and the need for constant readiness. For Constantinidis and Pinto (2020) argue that the continuous attention required for the care of people with ASD displaces The caregiver's focus shifts to the immediate needs of the person being cared for, reducing their ability to... to recognize one's own physical limits. In the analysis of Santos and Hora (2025), this displacement It favors the minimization or neglect of signs of fatigue and bodily discomfort, prolonging the Exposure to excessive exertion increases the risk of muscle soreness over time.

Empirical evidence corroborates this understanding by demonstrating that pain musculoskeletal disorders, even when they do not result in immediate functional disability, interfere significantly impacts the daily lives of caregivers. In a field study conducted with female caregivers of In children with chronic neurological conditions, Santos et al. (2020) identified that, although the scores Even if functional disability scores were considered low, lower back pain had a negative impact on... Daily tasks and the quality of life of caregivers. According to the authors, the presence of pain Persistent pain was associated with significant impairments in the domains of pain and mental health, demonstrating that Muscle ailments tend to be underestimated when they don't abruptly compromise the functionality. These findings reinforce that the perception of the risk of muscle illness is not not necessarily linked to the established physical disability, but to the way in which the pain is experienced. interpreted and incorporated into the care routine.

Regarding prevention strategies, studies emphasize the importance of guidance. Professional and health education as fundamental elements to broaden risk perception. and reduce physical overload. According to Nohara et al. (2017), physiotherapy interventions aimed at Provided to the caregiver, this can help in recognizing inappropriate practices and encourage the adoption of... Preventive strategies, such as postural adjustments and organization of care activities. For Brito, Lucena and Lucena (2020), the combination of technical guidance and systematic monitoring It contributes not only to the reduction of musculoskeletal pain, but also to the improvement of functionality and quality of life for the caregiver.

Beyond individual interventions, studies highlight the importance of collective strategies.



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and structural factors in the prevention of muscle disease. As argued by Martins et al. (2020), the

Expanding support networks and sharing caregiving responsibilities are measures

relevant to reducing continuous exposure to intense physical exertion. For Paranhos (2024),

Public policies that recognize the caregiver as a subject of care are essential to break through this barrier.

with the logic of individual accountability, creating more favorable conditions for prevention of

harm to health and the promotion of well-being.

Finally, understanding the perception of the risk of muscle disease in the context of care.

Continuity implies recognizing that this perception is not constructed solely from experience.

Individual development is not limited to social, cultural, and organizational factors. According to Esper et al.

(2024), the lack of social recognition of caregiver work contributes to its naturalization.

of practices that expose these individuals to avoidable risks. For Silva, Deltrudes and Iwata (2025),

Strengthening risk perception and expanding prevention strategies requires shifting the focus of care from

From the realm of silent obligation to the realm of rights, ensuring technical and institutional support.

and social support for the caregiver.

FINAL CONSIDERATIONS

This study showed that the perception of the risk of muscle disease in the context

The care provided to people with Autism Spectrum Disorder is, in general, fragile and

built late. Although caregivers are exposed to continuous physical strain and

Regarding muscle risk factors, the literature reviewed indicates that these risks tend to be minimized.

naturalized or interpreted as inherent to the act of caregiving, which compromises recognition.

Early onset of illness and promotes remaining in conditions that are potentially harmful to health.

Studies indicate that low risk perception is directly related to how...

Musculoskeletal pain is experienced daily by the caregiver. The repetition of the pain causes her to...

It will be seen as part of the care routine, leading the caregiver to adapt progressively.

to the discomfort of being able to maintain activities, even if this increases physical strain. This

This process encourages the postponement of self-care practices and the maintenance of physically demanding tasks.

demanding even in the face of persistent signs of fatigue and bodily discomfort, contributing to the

progression and chronicity of potentially preventable muscle problems.

In the specific context of caring for people with ASD, the perception of risk is even more evident.

more compromised due to the inherent characteristics of this care. The unpredictability of

demands of care, coupled with the need for constant vigilance and the required physical readiness

In situations of agitation or behavioral crises, it directs the caregiver's attention almost...

exclusively for the person being cared for. This shift in focus reduces the ability to recognize



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one's own physical limitations contribute to neglecting early signs of illness.

prolonging exposure to excessive exertion and reinforcing the invisibility of bodily suffering.

of the caregiver.

The literature reviewed also indicates that the perception of the risk of muscle illness is influenced by multiple factors, including accumulated experience in care, the absence of technical guidance, the scarcity of information related to prevention and ergonomics, as well as Cultural and social aspects that give care a moral and affective character. These elements They act in a coordinated manner, making it difficult to identify the risk and reinforcing the understanding of pain. as an inevitable consequence of caregiving, especially within the family context.

It was also observed that musculoskeletal pain tends to be recognized as a problem. only when it begins to significantly interfere with functionality and daily activities from the caregiver, highlighting a delayed perception of the risk. This delayed recognition broadens the impacts of illness on the health and quality of life of the caregiver, reinforcing that the perception Risk assessment is a central element in understanding not only musculoskeletal disorders. in itself, but also the mechanisms that contribute to its persistence and worsening over time. time.

Thus, the study findings indicate that limited or delayed perception of risk of Muscle disease acts as a determining factor in the maintenance of musculoskeletal conditions. Avoidable risks among caregivers of people with ASD. The way risk is perceived influences this. directly the recognition of pain, attention to one's own physical limits, the incorporation of care and the possibility of interrupting practices that are harmful to health, forming the central axis. central to the relationship between ongoing care and illness.

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