








Brenda Corrêa Santos^{1*} 
 Daniel Lobato Ferreira Ferraz¹ 
 Camila Real Delega Rodrigues¹ 
 Marco Túlio Leandro Ribeiro¹ 
 Tamiris Christensen Bueno¹ 
 Mirlena Mansur Dionizio da Silva¹ 
 Márcio Ajudarte Lopes¹ 

Caring for those who care and promoting oral health to caregivers of patients with disabilities: a narrative review

Abstract:

This narrative review describes the profound impact faced by caregivers of individuals with disabilities, on their physical, mental, and oral health. Caregivers, particularly women, assist with both basic and complex daily tasks, often under high levels of stress, and in many cases, face challenges related to limited personal, social, or financial support. The continuous demands lead them to neglect their own care causing consequently high rates of chronic health issues, including hypertension, mental health disorders such as depression and anxiety, and oral health problems. Research shows that these health challenges are exacerbated by limited access to healthcare services and financial constraints, with caregivers frequently isolated from social and professional support networks. To address these gaps, our review emphasizes the need for targeted interventions that provide comprehensive support for caregivers. Programs that offer emotional, logistical, and financial assistance, as well as dedicated healthcare services—including oral health—can significantly improve caregivers' well-being. Our "Caring for those who care" initiative seeks to address these needs, and initial results underscore the importance of accessible, ongoing care for caregivers. This review advocates for systemic support structures that enhance caregivers' quality of life, ultimately benefiting the individuals under their care.

Keywords: Person with disabilities; Autism; Caregivers; Oral health.

INTRODUCTION

Currently, people with disabilities comprise approximately 1 billion individuals within the global population¹. These individuals experience intellectual, mental, physical, or sensory impairments that hinder their full integration into society on an equal footing with others².

The challenges faced by these individuals vary in degree and type, with some of them requiring the support of a caregiver. Caregivers assist with daily tasks ranging from basic activities, such as dressing, managing medications, and bathing, to more complex responsibilities, including

financial management and coordinating transportation, among others³.

These caregivers, the majority of whom are women, often sacrifice their social, professional, and personal lives to dedicate themselves to the care of the person with disabilities. In some cases, this commitment is a personal choice; in others, it may be at the request of the person needing care, or frequently due to a lack of viable alternatives⁴.

These circumstances often lead caregivers to experience extreme levels of stress, impacting their physical, psychological, and emotional health. Frequently, they may neglect their own well-being due to a lack of time for self-care and limited access

Statement of Clinical Significance

This study holds clinical relevance, as caregivers' health is often neglected by themselves as well as by public health policies. Therefore, this issue should be emphasized to encourage the development of new assistance programs aimed at supporting these individuals.

¹University of Campinas, Piracicaba Dental School, Oral Diagnosis Department – Piracicaba (SP), Brazil.

*Correspondence to: Email: b242150@dac.unicamp.br

Received on November 22, 2024. Accepted on March 21, 2025.

<https://doi.org/10.5327/2525-5711.283>



to healthcare structures that could ease the logistics of managing the needs of those they care for⁵. Oral health is similarly affected; caregivers often neglect not only their regular dental check-ups but also daily oral hygiene practices.

The objective of this study is to conduct a narrative literature review on the key information available in the literature regarding this topic, as well as to report an experience from our service and highlight the main findings from studies on the oral health care of caregivers of patients with disabilities.

LITERATURE REVIEW/DISCUSSION

Caregiver profile

The role of caregiving, whether for individuals with disabilities or for elderly patients, is one of the many responsibilities disproportionately assigned to women. A study shows that in the United States, women make up over two-thirds of the caregiver population⁶. In Brazil, the age of these women ranges from 26 to 86 years^{4,7,8}. These women are often isolated from their families or communities, regarded as having the natural duty to provide care. This caregiving responsibility is imposed upon them, leaving these caregivers with little choice but to fulfill this role^{7,9,10}. It is also important to emphasize that the care provided by these women extends beyond their full dedication to the person with a disability. Their responsibilities often encompass household care, domestic tasks, and care for other children in the family, leading these women to experience a double or even triple workload^{4,11}.

In a study conducted by Cardoso et al.⁷, it was observed that these caregivers, mostly mothers (in more than 80% of cases), had completed only high school in approximately half of the cases and were married. Additionally, 60% of these caregivers owned their homes, and 61% reported not working outside the home, with their primary occupation being “homemaker.”

Mental and physical health of caregivers

This intense dedication from caregivers, whether driven by love or obligation, has numerous direct impacts on their health. When it comes to mental health, the impacts are profound. Depression and stress have been the most extensively studied effects so far. Some studies have shown that this level of caregiving bears all the characteristics of chronic stress, marked by high levels of unpredictability, uncontrollability,

and prolonged psychological and physical tension. This stress can also affect other areas of caregivers' lives, such as relationships with other family members and their work^{12,13}.

Weight loss, fatigue, social exclusion, sleep disorders, emotional and social isolation, depression, and an increased use of psychotropic medications are some of the mental health impacts commonly reported by caregivers⁵. In a 2022 study conducted by Couto et al.⁵, more than half of the caregivers interviewed reported experiencing negative feelings such as irritability, despair, anxiety, and depression. These mental health challenges can lead to caregiver burnout, directly impacting the quality of care provided and, consequently, affecting the health of the care recipient.

On the other hand, some studies have shown that certain caregivers do not report high levels of anxiety and exhibit acceptance of their situation. This may be related to the fact that many caregivers gradually adapt to their circumstances, and what once seemed like a challenge eventually becomes the reality they are compelled to live with. Despite the high burden they face, many caregivers tend to downplay these feelings or any association with their caregiving role, as it involves family members and loved ones^{7,8,14}.

In their physical health, caregivers tend to have higher medication usage, higher rates of hypertension, and poorer dietary quality, and they often neglect regular medical and dental check-ups^{4,5,12}. In a 2005 study assessing working-age caregivers, three-fifths reported poor health, chronic conditions, or a disability. Additionally, they reported nearly double the rate of chronic illnesses compared to non-caregivers⁶.

Oral health

Although literature remains limited regarding the impact of these sacrifices on caregivers' oral health, it is presumed that, akin to their overall health, their oral health is also neglected¹⁵.

In a study conducted by Dias et al.¹⁴, it was observed that parents of children with Down syndrome had a higher rate of gingival bleeding. This finding reinforces the hypothesis that these caregivers may have deficiencies in their oral health, neglecting their own well-being due to the demands of caring for the individual. It is important to highlight that studies have already proven that poor oral health conditions in caregivers are directly linked to a high plaque index in the individuals they care for. This evidence suggests that implementing oral health education and

dental treatment for caregivers can be an effective strategy to also improve the oral health of patients with disabilities¹⁶.

Another study conducted in 2023 assessed oral health literacy among caregivers of individuals with special needs. Among its conclusions, it found that caregivers who had visited the dentist within the past year demonstrated better oral health literacy in certain domains compared to others. This finding reinforces that regular dental visits can improve both the caregiver's health and the oral health of the patient with disabilities¹⁰.

Social impact

In a study carried by Couto et al.⁵, respondents reported feeling they had a good quality of life, despite lacking the financial means to fulfill personal desires or engage in leisure activities. This reveals the impact of caregivers' full-time dedication to individuals with disabilities on their own employment opportunities. A 2005 study by Ho et al.⁶ further showed that caregivers are less likely to be actively employed and are more prone to absenteeism from work.

These issues also impact the economic situation of these caregivers, most of whom report low income and limited education, with approximately 48% having had no access to education or only a low level of education. This, in turn, affects their employment opportunities, which are mostly limited to informal occupations and manual labor⁷. Additionally, half rely on public transportation⁵, which can hinder their access to healthcare services, and only a minority have access to private health insurance⁶.

In this context, over the past two years, our service has been providing dental care to caregivers of our patients with disabilities, offering the opportunity for both caregiver and care recipient to receive simultaneous treatment in our facilities. This initiative aims to optimize travel logistics for both parties and

ensure that patients with disabilities do not go without care while their caregivers are attending appointments. Since the inception of our project, titled "Caring for those who care," we have observed a positive initial adherence to treatment, with a substantial number of patients attending assessment appointments. We frequently encounter patients requiring comprehensive rehabilitation, intensive periodontal therapy, multiple extractions, and restorations due to suboptimal hygiene practices. Remarkably, many of these patients are relatively young and of working age. Regrettably, a significant proportion of them discontinue treatment after the assessment appointment, citing various reasons, thus underscoring the challenges associated with providing dental care to these caregivers.

We recently attended a 36-year-old female patient, who serves as both mother and caregiver to a 2-year-old male patient. Her son underwent surgery to remove a teratoma, which was obstructing the entire oral cavity at 26 days old. Currently he exhibits palatal sequelae, tracheostomy, gastrostomy, and hypersecretion. Due to these conditions, the child needs comprehensive care. The mother sought dental assessment for the first time, having never visited a dentist before. Upon physical examination, she presented with a remarkable accumulation of calculus in an esthetic area, severe periodontitis, and bleeding gingiva (Figure 1A). Despite the substantial calculus accumulation, radiographic examination revealed minimal bone loss, allowing for the preservation of all her teeth following periodontal treatment (Figure 1B). Subsequent supragingival and subgingival scraping of the upper and lower arches successfully removed all calculus deposits (Figure 1C). Additionally, oral hygiene instructions and mouth rinses with 0.12% Chlorhexidine were provided. The patient underwent gingival healing following scaling and is currently undergoing periodontal monitoring for treatment maintenance and monitoring of periodontal pockets.



Figure 1. (A) Accumulation of calculus was observed in the aesthetic region during the initial clinical examination. (B) The panoramic radiograph reveals minimal bone loss despite significant clinical accumulation of calculus. (C) Clinical presentation following the initial anterior teeth scaling session.

CONCLUSION

Among the studies analyzed in this work, gingival bleeding was the most common oral alteration reported among caregivers of patients with disabilities. This finding highlights how caregivers may neglect their own self-care while prioritizing the well-being of their dependents. Implementing oral health assistance programs for caregivers, alongside general healthcare support, is essential. In our clinical experience, such cases are common, underscoring the need for targeted interventions. Supporting caregivers not only improves their own health but also positively impacts the oral health of the patients they care for.

AUTHORS' CONTRIBUTIONS

BCS: Conceptualization, Data curation, Investigation, Writing – original draft, Writing – review & editing. DLFF: Data curation, Writing – review and editing. CRDR: Data curation, Writing – review and editing. MTLR: Data curation, Writing – review and editing. TCB: Data curation, Writing – review and editing. MMDS: Data curation, Supervision; Writing – review and editing. MAL: Data curation, Supervision, Writing – review and editing.

CONFLICT OF INTEREST STATEMENT

Funding: This study was financed in part by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior – Brasil (CAPES) – Finance Code 001.

Competing interests: The authors have no relevant financial or non-financial interests to disclose.

Ethics approval: Not applicable.

REFERENCES

1. World Health Organization. World Bank . World report on disability 2011. Geneva: World Health Organization; 2011.
2. United Nations. Convention on the rights of persons with disabilities and optional protocol [Internet]. [accessed in Oct 16, 2024]. Available from: <https://www.un.org/disabilities/documents/convention/convoptprot-e.pdf> .
3. Mott J, Schmidt B, MacWilliams B. Male caregivers: shifting roles among family caregivers. *Clin J Oncol Nurs*. 2019;23(1):E17-24. <https://doi.org/10.1188/19.CJON.E17-E24>
4. Minayo MCS. Caring for those who care for dependent older adults: For a necessary and urgent policy. *Cien Saude Colet*. 2021;26(1):7-15. <https://doi.org/10.1590/1413-81232020261.30872020>
5. Couto GR, Fonseca EP, Amaral RC. Level of satisfaction and quality of life of caregivers of people with disabilities in secondary dental care. *Pesqui Bras Odontopediatria Clin Integr*. 2022;22:e210088. <https://doi.org/10.1590/pboci.2022.036>
6. Ho A, Collins SR, Davis K, Doty MM. A look at working-age caregivers' roles, health concerns, and need for support. *Issue Brief (Commonw Fund)*. 2005;(854):1-12. PMID: 16118908.
7. Cardoso AL, Silva-Junior GO, Bastos LF, Cesar ALM, Serrano LG, Dziedzic A, et al. Preliminary assessment of the quality of life and daily burden of caregivers of persons with special needs: a questionnaire-based, cross-sectional survey. *In J Environ Res Public Health*. 2023;20(3):2012. <https://doi.org/10.3390/ijerph20032012>
8. Pinho RCM, Barbosa ACS, Caldas-Júnior AF, Vasconcelos MMVB, Cimdões R, Santos MTBR. State, trait, and dental anxiety in caregivers of individuals with disabilities. *Special Care in Dentist*. 2017;37(4):168-75. <https://doi.org/10.1111/scd.12230>
9. McAllum K, Simpson ML, Unson C, Fox S, Kilpatrick K. The socialization of unpaid family caregivers: a scoping review. *Res Aging*. 2021;43(7-8):263-73. <https://doi.org/10.1177/01640275211005092>
10. Hutagalung ER, Soegyanto AI, Ahmad MS, Mandasari M. Analysis of oral health literacy in caregivers of special needs individuals in special schools and social institutions in Jakarta. *Dent J (Basel)*. 2023;11(9):221. <https://doi.org/10.3390/dj11090221>
11. Rodríguez-Rodríguez P. Informal support to older people in Spain and social protection for dependent elderly people. From familism to citizen's rights. *Rev Esp Geriatr Gerontol*. 2005;40(Suppl. 3):5-15. [https://doi.org/10.1016/S0211-139X\(05\)75068-X](https://doi.org/10.1016/S0211-139X(05)75068-X)
12. Schulz R, Sherwood PR. Physical and mental health effects of family caregiving. *Am J Nurs*. 2008;108(9 Suppl.):23-7; quiz 27. <https://doi.org/10.1097/01.NAJ.0000336406.45248.4c>
13. Magalhães IA, Dantas TS, Paulo JPM, Marçal FF, Viana TSA, Sousa FB, et al. Sociodemographic factors affect the quality of life and burden of caregivers in special care in dentistry. *Spec Care Dentist*. 2022;42(5):464-75. <https://doi.org/10.1111/scd.12710>
14. Dias C, Schwertner C, Grando D, Bidinotto AB, Hilgert JB, Schuch JB, et al. Caregiving of children with Down syndrome: impact on quality of life, stress, mental and oral health. *Spec Care Dentist*. 2022;42(4):398-403. <https://doi.org/10.1111/scd.12694>
15. Kelly K, Wolfe N, Gibson MJ, Feinberg L. Listening to family caregivers: the need to include family caregiver assessment in medicaid home-and community-based service waiver programs [Internet]. Washington: AARP Public Policy Institute; 2013 [accessed in Oct. 16, 2024]. Available from: <https://www.thescanfoundation.org/sites/default/files/the-need-to-include-family-caregiver-assessment-medicaid-hcbs-waiver-programs-report-aarp-ppi-ltc.pdf>
16. Baskaradoss JK, AlSumait A, Behbehani E, Qudeimat MA. Association between the caregivers' oral health literacy and the oral health of children and youth with special health care needs. *PLoS One*. 2022;17(1):e0263153. <https://doi.org/10.1371/journal.pone.0263153>