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The invisible burden of caregiving: the aging process among caregivers of people with autism spectrum disorder

Ynara Amaral dos Santos
Federal University of São Carlos
João Vitor Arnosti de Castro
Federal University of São Carlos
Thays Fontineles de Freitas
Federal University of São Carlos
Gabriela Martins-Cavichioli
Federal University of São Carlos
Ana Julia Souza Caparrol
Federal University of São Carlos
Denise Caroline Feitosa
Federal University of São Carlos
Aline Cristina Martins Gratao
alinegratao@ufscar.br
Federal University of São Carlos

Systematic Review

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Abstract

Objective

To analyze the scientific literature on the health of caregivers aged 50 years or older who take on the role of caring for individuals with ASD, considering the demands and challenges imposed by this role, as well as the scarcity of studies on this topic in the literature.

Methods

This systematic review analyzed emotional and psychosocial impacts among caregivers aged 50 years or older based on articles published between 2020 and 2025 available in SciELO, PubMed, and LILACS.

Results

Ten studies were included, most of which were quantitative, revealing high levels of stress, emotional burden, and reduced quality of life. Protective factors include family and social support, self-efficacy, and coping strategies. Crises such as the COVID-19 pandemic intensified caregiver burden and isolation; lack of information about ASD increases vulnerability.

Conclusion

Caring for individuals with ASD is a substantial challenge for older adults, requiring structured interventions, public policies, support networks, and targeted research to promote health and quality of life.

INTRODUCTION

Expectations regarding longevity have increased significantly, resulting in global population aging. In Brazil, this phenomenon is intensifying rapidly, bringing new challenges to society [1, 27]. Among these challenges is the growing participation of older adults in social roles that entail a high level of responsibility, such as caregiving. Although this stage of life is often associated with a period of slowing down and reduced physical and emotional demands, many older adults ultimately take on roles as providers and caregivers for family members. This reality highlights the complexities and challenges that emerge in this new social context [2, 11, 27].

In this context, providing specific support to caregivers is essential, as they frequently face multiple concurrent demands. These responsibilities can cause considerable strain, negatively affecting their physical and emotional health. Ongoing caregiving, combined with daily pressures, becomes a critical factor that requires attention and appropriate interventions [9, 13, 19–20, 23, 25, 28, 31, 12].

With new family arrangements, many older adults become caregivers for grandchildren or family members with special needs, such as individuals with autism spectrum disorder (ASD), a condition that impairs communication and social interaction and may present with symptoms such as verbal and nonverbal communication difficulties, repetitive behaviors, restricted interests, and challenges in interpersonal relationships, varying in intensity and presentation [4, 11, 14, 21–22].

ASD diagnosis has advanced substantially, with an emphasis on early identification and the implementation of appropriate interventions. This progress reflects not only greater precision in diagnostic criteria but also increased social and scientific awareness of the condition. In 2020, the prevalence of ASD was estimated at 1 in 36 children, representing an increase from the estimate of 1 in 54 children in 2016 [8]. This upward trend indicates both broader clinical recognition and the need for public policies and more effective care strategies [8, 22].

The impact of this situation is felt directly by caregivers, who face intense emotional and physical demands. Caregiver burden, understood as the physical, emotional, and social stress resulting from ongoing caregiving demands, compromises caregivers' quality of life and may affect the effectiveness of the care provided. In this regard, recent studies emphasize the importance of providing structured support and appropriate resources, promoting caregiver well-being and a healthier environment for people with ASD [9, 13, 19–20, 25, 28, 31]. In this context, providing specific support to caregivers is essential, as they frequently face multiple concurrent demands [10–11, 13, 15–16].

Although several studies address the effects of caregiving on family members of children with ASD, the focus is predominantly on adult caregivers. [13, 19–20, 23, 25, 28, 31] In contrast, few studies consider the experiences of older caregivers, who face unique demands related to aging that are linked to the impact of caring for an individual with ASD [10–11, 14, 24]. This gap makes it difficult to inform the development of public policies, support strategies, and intervention practices that promote caregivers' quality of life and support the development of people with ASD [10, 14–16, 25]. Therefore, this study aims to analyze the scientific literature on the health of caregivers aged 50 years or older who take on the role of caring for individuals with ASD, considering the demands and challenges imposed by this role, as well as the scarcity of studies on this topic in the literature.

METHOD

Study design and eligibility criteria

This was a systematic literature review using a qualitative approach. The inclusion criteria were: (1) articles published within the previous five years (between January 2020 and September 2025); (2) publications written in Portuguese, English, and/or Spanish; (3) full-text studies available in the databases searched; (4) studies conducted with caregivers of individuals with autism spectrum disorder (ASD) whose samples included caregivers aged 50 years or older; and (5) studies addressing emotional burden among these caregivers.

The exclusion criteria were: (1) genetic or biological studies; (2) research involving pharmacological treatment; (3) duplicate articles across databases; (4) literature reviews, dissertations, theses, monographs, and letters to the editor; (5) conference abstracts; (6) studies conducted with formal caregivers; and (7) studies that did not report caregivers' ages or whose samples included only participants younger than 50 years.

Data collection procedure

The searches were conducted in September 2025 in the following databases: SciELO, the Virtual Health Library (VHL), LILACS, and PubMed. The descriptors used were obtained from Health Sciences Descriptors (DeCS) and Medical Subject Headings (MeSH) and combined using the Boolean operators AND and OR. The keywords used, in Portuguese and English, were: "Transtorno do Espectro Autista," "Autismo," "Idosos," "Envelhecimento," "Cuidador," "Sobrecarga do Cuidador," "Sobrecarga Emocional," "Autism Spectrum Disorder," "Caregiver," "Elderly," "Aging," "Burden."

Different combinations of the descriptors were used across the databases. These included: "Transtorno do Espectro Autista" AND "Idosos" AND "Sobrecarga do Cuidador"; "Autismo" AND "Idosos" AND "Cuidadores" AND "Sobrecarga emocional"; "Transtorno do Espectro Autista" AND "Cuidador" AND "Sobrecarga"; "Autism Spectrum Disorder" AND "Caregiver Burden"; "Autism Spectrum Disorder" AND "Caregiver" AND "Burden"; "Autism Spectrum Disorder" AND "Elderly" AND "Caregiver Burden." A total of 287 articles were identified.

Study selection was conducted in three stages: (1) title and abstract screening; (2) full-text review of potentially eligible studies; and (3) final selection of articles that fully met the established criteria. The entire process was conducted by three independent reviewers, and only studies for which there was reviewer agreement were included in the final analysis.

The search and selection process was conducted with the aid of Zotero®, which was used to organize, review, and store the articles. The level of evidence of the studies was analyzed considering the clarity of the rationale, study design, description of data collection, and appropriateness of the instruments used.

Ethical aspects

Ethical approval

was not required for this study because it is a systematic review of previously published literature and did not involve the collection or analysis of primary data from human participants or animals.

RESULTS

Throughout the search and study selection process, the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) recommendations were followed to ensure rigorous planning, transparency, and systematic organization of the review. The flow diagram of the article selection process is shown in Fig. 1.

Identification

Studies identified in the databases (n = 287)

Total number of duplicate studies (n = 262)

Studies selected for title and abstract screening

(n = 30)

Selection

Articles excluded after reading the title and abstract (n = 5)

Selected studies for full reading

(n = 25)

Eligibility

Studies excluded after full-text review (n = 15)

Studies included for qualitative analysis

(n = 10)

Included

Source

Author's data (2025).

The studies were carefully assessed against the inclusion and exclusion criteria, as presented in Table 1. Initially, 287 articles were identified in SciELO, VHL, LILACS, and PubMed. Of these, 262 were duplicates and were removed. Next, the titles and abstracts of the remaining 30 studies were assessed, resulting in the exclusion of 5 articles that did not meet the eligibility criteria. After this screening, 25 studies were selected for full-text review, while another 15 were excluded following full-text review. At the end of the process, 10 articles that fully met the established criteria were included in the final analysis.

Table 1
Categorization of the selected studies.

Article	Author(s) (No.), year, and country	Title, journal, and database
A1	**Dantas, K. O. et al. (2024), Brazil.**	Author(s) (No.), year, and country: DANTAS, K. O. et al. (2024), Brazil. Title: The influence of paternal involvement on the quality of life of mothers of children with disabilities. **Journal: Saúde e Sociedade.** Database: PubMed. Caregiver age: 22 and 66 years.
A2	**Shorey, S., et al. (2021), Portugal.**	Author(s) (No.), year, and country: SHOREY et al. (2021), Singapore. Title: Brief report: caregivers' wellbeing in families with neurodevelopmental disorders members during COVID-19: implications for family therapy. Journal of Family Therapy. **Journal: Journal of Pediatric Psychology (Oxford University Press).** Database: PubMed. Caregiver age: 26–63 years.
A3	**Rizzo et al. (2024), Italy.**	Author(s), year, and country: RIZZO et al. (2024), Italy. Title: Caregivers of Children with Autism Spectrum Disorders: The Role of Guilt Sensitivity and Support. **Journal: Journal of Clinical Medicine.** Database: PubMed. Caregiver age: 26–62 years.
A4	**Marsack-Topolewski, C. N., & Wang, F. (2022), United States**	Author(s) (No.), year, and country: Marsack-Topolewski, C. N., Wang, F. (2022), United States. Title: Dimensions of Caregiver Burden between Compound and Noncompound Caregivers of Adults with Autism. **Journal: Journal of Gerontological Social.** Database: PubMed. Caregiver age: 50 years or older.
A5	**Hüsna Kaan, S. et al., (2025), Türkiye.**	Author(s) (No.), year, and country: Hüsna Kaan; Seda Erbilgin; Alper Alnak; Murat Coskun (2025), Turqua. Title: Exploring Parental Motivations for and Consequences of Having a Subsequent Child After an Autism Diagnosis in Türkiye. **Journal: Journal of Autism and Developmental Disorders.** Database: PubMed. Caregiver age: 60 years.
A6	**Hulood Mohammed AL Mansoor (2025), Saudi Arabia.**	Author(s) (No.), year, and country: hulood Mohammed Al Mansoor (2025), Saudi Arabia. Title: The association between intolerance of uncertainty and psychological burden among caregivers of children with autism and the impact on their

Article	Author(s) (No.), year, and country	Title, journal, and database
		quality of life. **Journal: Frontiers in Psychiatry, Autism section.** Database: PubMed. Caregiver age: 18–64 years.
A7	**Duckert et al (2023), Germany.**	Author(s) (No.), year, and country: Dückert, S. et al. (2023), Germany. Title: Health-related quality of life in family caregivers of autistic, adults. **Journal: Frontiers in Psychiatry (Frontiers Media S.A.).** Database: PubMed. Caregiver age: 20–65 years.
A8	**Falquetti, B. B. et al. (2023), Brazil.**	Author(s) (No.), year, and country: FALQUETTI, B. B. et al. (2023), Brazil. Title: Impact of the burden of caregivers of children with ASD on oral health. **Journal: Revista de Odontologia da UNESP (Universidade Estadual Paulista).** Database: PubMed. Caregiver age: > 60 years.
A9	**Dhiman, S. et al. (2020), India.**	Author(s) (No.), year, and country: DHIMAN, S. et al. (2020), India. Title: Impact of COVID-19 outbreak on mental health and perceived strain among caregivers tending children with special needs. **Journal: Research in Developmental Disabilities.** Database: PubMed. Caregiver age: > 60 years.
A10	**Falquetti, B. B. et al. (2023), Brazil.**	Author(s) (No.), year, and country: FALQUETTI, B. B. et al. (2023), Brazil. Title: Self-efficacy of caregivers of children with autism spectrum disorder. **Journal: Revista Psicopedagogia.** Database: VHL. Caregiver age: Up to 62 years.

The analysis of the ten selected articles shows that recent literature has focused on understanding the emotional experiences of caregivers of people with ASD, with particular attention to caregivers aged 50 years or older. The samples ranged in age from 18 to 66 years, and approximately 36% of the studies included only older caregivers, demonstrating the relevance of investigating aging as it relates to caregiving demands.

Geographically, the studies were conducted in different countries, particularly Brazil and India (18% each), with the remaining studies distributed across Italy, Germany, Portugal/Singapore, Türkiye, and Saudi Arabia (approximately 10% each), reflecting the global scope of the issue and cultural diversity in caregiving experiences.

From a methodological perspective, the vast majority of studies (90%) used quantitative study designs, with standardized questionnaires and psychological scales to assess variables such as emotional burden, quality of life, self-efficacy, mental

health, and social support. Only one study used a qualitative approach with semistructured interviews, providing an in-depth perspective on subjective aspects of caregiving.

The thematic analysis revealed that emotional burden was the most frequently reported phenomenon, present in 60% of the studies (A4, A6, A7, A8, A9, and A10). This distress manifested as stress, anxiety, fatigue, and feelings of guilt, frequently associated with a lack of institutional support and overlapping family responsibilities. Quality of life was addressed in 50% of the studies, indicating that caregivers with greater burden tend to have poorer physical, psychological, and social well-being. Self-efficacy and coping strategies, in turn, were addressed in 20% of the articles, demonstrating their protective role in reducing emotional burden. In addition, the impacts of the COVID-19 pandemic were examined in 20% of the studies, showing that external factors, such as public health crises, may substantially exacerbate caregiver stress. Family and social support was identified as a mitigating factor in approximately 30% of the studies, emerging as an essential resource for preserving mental health and emotional balance.

The results consistently indicate that social support, family engagement, and perceived self-efficacy function as protective factors, supporting better quality of life and greater psychological balance. On the other hand, the lack of structured public policies, combined with age-related physical and emotional strain, substantially increases these caregivers' vulnerability.

In summary, the analysis of the studies supports the conclusion that aging among caregivers of people with ASD is a complex, multifactorial, and emotionally challenging process. Emotional burden, present in most of the studies, emerges as the main consequence of long-term caregiving, while protective factors—social support, family engagement, and self-efficacy—help mitigate the negative impacts. These findings reinforce the need for structured interventions and intersectoral public policies aimed at mental health promotion, recognition of caregivers, and mitigation of emotional burden, especially for those facing the challenge of caregiving in later life.

Table 2 presents a synthesis of the ten selected studies investigating emotional and psychosocial aspects among caregivers of people with autism spectrum disorder (ASD). It organizes each article into seven main categories: Article, Objective, Study design, Sample, Variables, Instruments, and Results. This structure provides a quick overview of the focus, methodology, and main findings of each study.

Table 2
Characteristics of the included studies.

Article	Objective	Study design	Sample	Variables	Instruments	Results
A1 – Dantas et al., 2024 (Brazil)	Assess the influence of paternal involvement on the quality of life of mothers of children with disabilities	Quantitative	Caregivers aged 22–66 years	Quality of life, paternal involvement	Standardized questionnaires	Greater paternal involvement was associated with better quality of life among mothers
A2 – Shorey et al., 2021 (Portugal/Singapore)	Assess caregiver well-being during COVID-19	Quantitative	Caregivers aged 26–63 years	Mental health, stress	Well-being scales	The pandemic increased stress and reduced family well-being
A3 – Rizzo et al., 2024 (Italy)	Explore guilt and support in the lives of caregivers of children with ASD	Quantitative	Caregivers aged 26–62 years	Guilt, social support, stress	Standardized questionnaires	Social support mitigated feelings of guilt and caregiver burden
A4 – Marsack-Topolewski & Wang, 2022 (U.S.)	Compare caregiver burden among caregivers of adults with ASD	Quantitative	Caregivers aged 50 years or older	Caregiver burden, stress, quality of life	Caregiver burden scales	Older caregivers experienced greater emotional burden
A5 – Hüsna Kaan et al., 2025 (Türkyie)	Explore parental motivation and the emotional consequences of having a child after an ASD diagnosis	Qualitative	Caregivers aged 60 years	Parental emotions, reproductive decision-making	Semistructured interviews	A previous ASD diagnosis influenced emotional and family decisions
A6 – Hülod Mohammed Al Mansoor, 2025 (Saudi Arabia)	Examine the relationship between intolerance of uncertainty and psychological burden	Quantitative	Caregivers aged 18–64 years	Anxiety, caregiver burden, quality of life	Psychological scales	Intolerance of uncertainty was correlated with greater caregiver burden and lower quality of life
A7 – Dückert et al., 2023 (Germany)	Assess health-related quality of life among caregivers of adults with ASD	Quantitative	Caregivers aged 20–65 years	Quality of life, mental health	Standardized questionnaires	Greater caregiver burden was associated with lower quality of life

Article	Objective	Study design	Sample	Variables	Instruments	Results
A8 – Falquetti et al., 2023 (Brazil)	Investigate the impact of caregiver burden on caregivers' oral health	Quantitative	Caregivers aged > 60 years	Caregiver burden, oral health	Scales and clinical examinations	Higher caregiver burden was associated with poorer oral health
A9 – Dhiman et al., 2020 (India)	Assess the impact of COVID-19 on mental health and perceived burden	Quantitative	Caregivers aged > 60 years	Stress, anxiety, perceived burden	Standardized questionnaires	Social isolation increased stress and perceived burden
A10 – Falquetti et al., 2023 (Brazil)	Assess self-efficacy among caregivers of children with ASD	Quantitative	Caregivers aged up to 62 years	Self-efficacy, caregiver burden	Standardized questionnaires	Greater self-efficacy was associated with lower emotional burden

DISCUSSION

The analysis of the selected studies shows that caregivers of people with autism spectrum disorder (ASD) have varied profiles, with ages ranging from 18 to 66 years, while a substantial proportion of the samples included caregivers aged 50 years or older. This finding reinforces the relevance of examining caregiving from the perspective of aging, considering the additional physical and emotional challenges that arise as caregivers age, such as chronic fatigue and mobility limitations [9, 10].

A predominance of women among caregivers, especially mothers, is also observed, reflecting cultural and social patterns in which women traditionally assume most family caregiving responsibilities [1, 3].

Among the psychosocial challenges faced by these caregivers are financial difficulties resulting from an ASD diagnosis, including high costs associated with therapies, specialized interventions, and home adaptations, as well as loss of income due to reduced working hours or leaving employment to devote themselves to caregiving. Studies indicate that these factors contribute to increased financial stress and socioeconomic vulnerability, affecting caregivers' quality of life and, consequently, the effectiveness of the support provided to people with ASD [2, 6–7].

These challenges are exacerbated in contexts of overall burden, such as the COVID-19 pandemic, when mental well-being and perceived strain increase, reflecting indirect economic implications [9, 8].

Studies emphasize that caring for people with ASD involves complex and ongoing demands, including support for basic needs, therapeutic follow-up, management of challenging behaviors, and adaptation of daily routines. These demands have a direct impact on emotional health, reflected in high levels of stress, anxiety, fatigue, and feelings of guilt, frequently associated with caregivers' perception that they are not fully meeting the needs of the person receiving care [13, 19–20, 23, 25, 31].

The literature also indicates that caregivers frequently experience a reduced social life and limitations in personal activities, as intensive caregiving requires constant availability, affecting family and social relationships [2, 7].

Another relevant aspect addressed in the articles is perceived self-efficacy and resilience. Caregivers who reported greater confidence in their ability to manage the challenges of caregiving have lower levels of emotional burden and greater

satisfaction with the caregiving experience. On the other hand, the lack of institutional and social support substantially increases these individuals' vulnerability, intensifying emotional and physical burden [5, 8].

The studies also reinforce the importance of support networks, including family members, friends, support groups, and health care professionals, as essential elements in reducing burden and promoting well-being. Despite this, many caregivers report feeling isolated and overburdened, revealing gaps in public policies, support programs, and intersectoral services intended for this group [1, 10].

Finally, the articles discuss concerns about caregiver aging and its impact on caregiving capacity. Older caregivers face greater physical challenges, a higher risk of chronic diseases, and concerns about their own health and longevity, which increase the stress associated with long-term caregiving. This finding highlights the need for structured interventions, ongoing psychological support, institutional support, and strategies to prevent caregiver burden, ensuring that caregivers can maintain their physical, emotional, and social health over time [9, 8].

In summary, being a caregiver for a person with ASD is a multifaceted experience, marked by emotional, physical, and social challenges, but also encompassing learning, skill development, and, in some cases, a sense of fulfillment and emotional connection. The literature reinforces the need for public policies, family and community support, and health promotion strategies that consider the specific needs of this population, especially in the context of aging [3, 5].

CONCLUSION

This systematic review made it possible to synthesize the available knowledge on the emotional aspects of caregivers aged 50 years or older who care for people with ASD, showing that few studies have addressed the topic. This is a highly relevant issue today because of both population aging and the increase in ASD diagnoses.

The results indicate that long-term caregiving represents a substantial challenge to caregivers' physical and emotional health, highlighting the need for targeted interventions. In addition, the findings provide important information to inform the development of public policies and intersectoral strategies aimed at promoting the well-being and quality of life of family caregivers. It is also noteworthy that the included studies involved professionals from various health fields, demonstrating the interdisciplinarity needed to understand and meet the needs of this population. Despite the limited number of studies available, this review highlights the importance of investing in future research to deepen understanding of the challenges, demands, and support strategies for caregivers of people with ASD, particularly those in later life.

This discussion is aligned with the Sustainable Development Goals (SDGs), particularly SDG 3: Good Health and Well-Being, which aims to ensure healthy lives and promote well-being for all at all ages, and SDG 10: Reduced Inequalities, which aims to promote social inclusion and equitable access to health care services, especially for populations in vulnerable situations, such as older caregivers of individuals with ASD.

Declarations

Consent for publication

Not applicable.

Competing interests

The authors declare that they have no competing interests.

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Author contributions

Ynara Amaral dos Santos contributed to the conceptualization, methodology, data curation, formal analysis and writing of the original draft.

João Vitor Arnosti de Castro contributed to the methodology, investigation and writing – review and editing.

Thays Fontineles de Freitas contributed to the methodology, investigation and writing – review and editing.

Gabriela Martins-Cavichioli contributed to the methodology, investigation and writing – review and editing.

Ana Julia de Souza Caparrol contributed to the methodology, investigation and writing – review and editing.

Denise Caroline Feitosa contributed to the methodology, investigation and writing – review and editing.

Aline Cristina Martins Gratão contributed to the supervision, project administration and writing – review and editing.

All authors read and approved the final manuscript.

Data availability

Not applicable.

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Figures

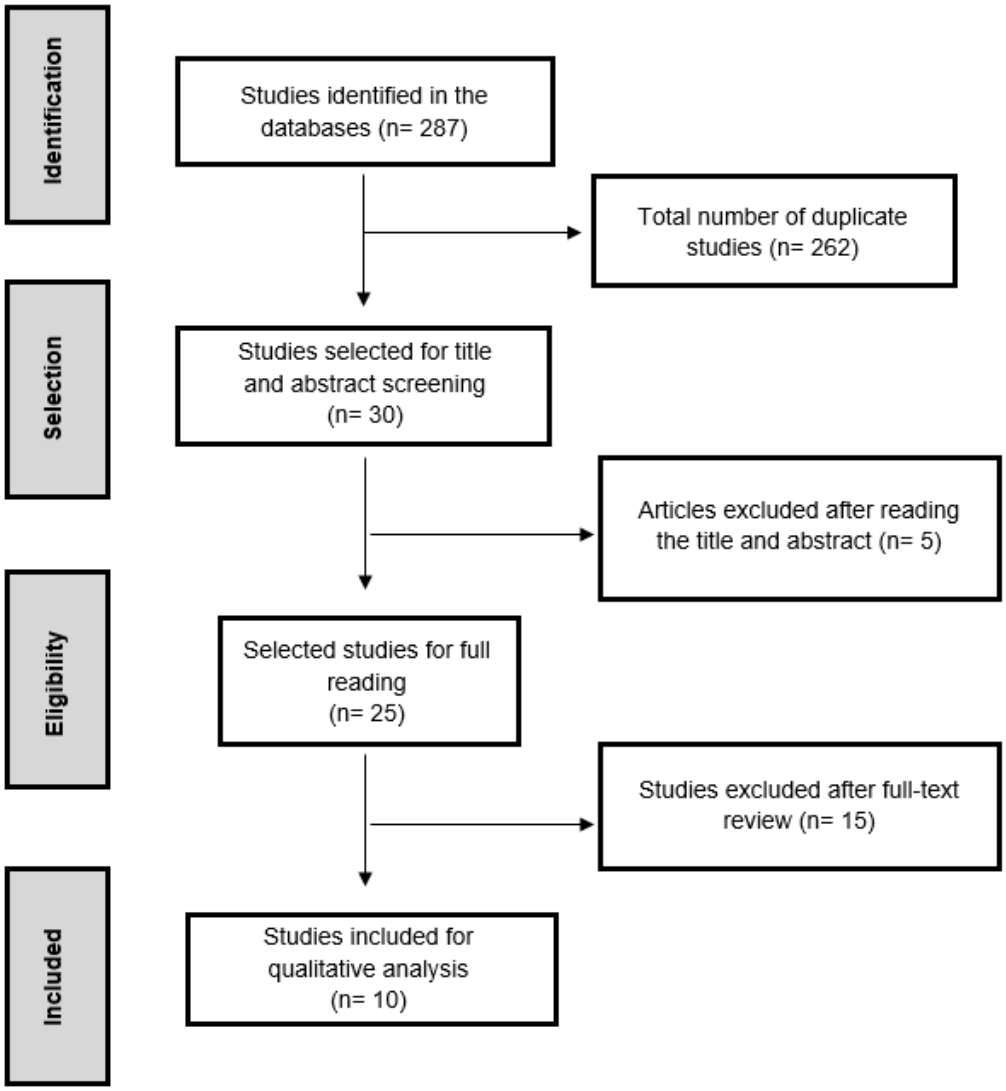


Figure 1

PRISMA flow diagram of study selection.