Dementia: Challenges of Care, Stress, and Psychological Impact on Nurses and Informal Caregivers – A Review Article

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Article received: 20. 08. 2025.

Article accepted: 09. 12. 2025.

DOI: 10.24141/2/10/1/14

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Keywords: dementia, Alzheimer's disease, caregiving, caregivers, stress, psychological health, support

Abstract

Introduction. Dementia is a chronic and progressive syndrome in which cognitive function (i.e., the ability to process thoughts) deteriorates beyond what is expected from normal aging. There are several types of dementia, most of which are progressive neurodegenerative disorders that significantly affect the quality of life of individuals living with the condition, as well as their families and caregivers.

Aim. This review article analyzes recent scientific literature with a particular focus on the challenges of long-term care and the stress experienced by caregivers including nurses. It explores the psychological, physical, and social aspects of caregiving, as well as potential interventions aimed at reducing caregiver burden. The article highlights the need for an integrated approach that includes education, support, and institutional change.

Methods. A literature review was conducted using PubMed, Scopus, and Web of Science and includes studies published between 2015 and 2025. The review included systematic reviews and quantitative and qualitative studies investigating the effects of dementia care on caregivers, particularly nurses. The analysis addressed psychological, social, physical, and organizational aspects of caregiving, as well as the effectiveness of interventions such as mindfulness training, educational programs, and professional supervision.

Results. Dementia caregiving is linked to high levels of stress, depression, anxiety, and emotional exhaustion. Prolonged exposure to stress and insufficient support increase burnout risk, while organizational support, ongoing education, and psychological interventions serve as protective factors. Mindfulness and cognitive-behavioral approaches significantly reduce stress and burnout, and supervision and peer support enhance job satisfaction.

Conclusion. Integrating psychological support and educational programs into nursing practice is essential for maintaining caregivers' mental health and care quality. Regular stress monitoring and preventive measures—such as mindfulness, supervision, and dementia-specific education—help prevent burnout and strengthen professional resilience among nurses.

Introduction

Dementia represents one of the greatest public health challenges of the 21st century. According to the World Health Organization, more than 55 million people worldwide are living with dementia, and this number continues to grow (1).

Dementias are neurodegenerative disorders characterized by progressive cognitive decline that interferes with daily functioning. The prevalence of dementia increases with age, and the most common type is Alzheimer's disease.

As the disease progresses, the need for continuous care becomes more pronounced, placing the burden of care on family members or professional caregivers such as nurses. Because the disease significantly impairs patients' functional abilities, the vast majority of individuals with dementia depend on daily assistance from both formal and informal caregivers—most often family members. This raises concerns about the long-term impact of caregiving on the mental and physical health of caregivers.

The most common types of dementia are Alzheimer's disease (accounting for 60–70% of cases), followed by vascular dementia, which is associated with cerebrovascular damage. Early symptoms include forgetfulness, speech and orientation difficulties, and changes in personality and behavior. As the disease advances, more intensive care and supervision are required.

Other forms include Lewy body dementia, characterized by visual hallucinations and fluctuations in alertness, and frontotemporal dementia, which typically occurs at a younger age and is marked by behavioral and speech changes (1,2,3).

Neuropsychiatric Symptoms and the Global Impact of Dementia

The occurrence of psychiatric symptoms in individuals with Alzheimer's disease and other forms of dementia presents one of the major challenges in their care. Conditions such as depression, psychotic episodes, or delirium occurring alongside pre-existing dementia can significantly impair cognitive abilities, accelerate cognitive decline, and negatively affect daily functioning and the level of independence in patients (4).

Epidemiological Trends, Gender Differences, and Risk Factors in Dementia

Furthermore, the study by Beam and colleagues (2018) highlights significant differences in the incidence of dementia and Alzheimer's disease between men and women. Findings show that women, especially in older age groups, are more susceptible to developing Alzheimer's disease. These differences cannot be fully explained by women's longer life expectancy, but rather point to possible biological and sociocultural factors. The study underscores the importance of developing gender-sensitive preventive and therapeutic strategies in dementia care (5).

Approximately 55 million people worldwide are currently living with dementia, with over 60% residing in low- and middle-income countries. Moreover, it is projected that the number of people diagnosed with dementia will reach 78 million by 2030, and 139 million by 2050, as the proportion of older individuals increases in nearly every country (6). Women exhibit a higher prevalence of dementia, primarily due to their longer average life expectancy (7). In Croatia, it is estimated that over 100,000 individuals are living with some form of dementia (8).

Risk factors include age and genetics (e.g., the presence of the APOE $\varepsilon4$ allele), as well as hypertension, diabetes, depression, low educational attainment, social isolation, and physical inactivity (9,10).

The diagnostic process involves clinical evaluation (e.g., MMSE, MoCA, ADAS-Cog), laboratory testing, neuroimaging (MRI, CT, PET), and increasingly the use of biomarkers such as CSF tau and beta-amyloid (11).

The Impact of Dementia on Female Caregivers: Professional and Informal Roles

The impact of dementia has been analyzed in relation to women who provide professional care—such as nurses—as well as those who assume the role of informal caregivers within the family setting. Dementia is known to disproportionately affect women worldwide. In many societies, there is a prevailing expectation that care for older family members, including those with dementia, should occur within the family unit. This responsibility is often automatically assigned to women, leading to additional physical, emotional, and social burdens.

This issue is particularly challenging in low-income countries, where the availability of community-based support services is critical—especially for women with limited access to education or low levels of formal schooling (12). Women constitute the majority of informal dementia caregivers—approximately two-thirds—with even higher proportions in low- and middle-income countries. As a result, the burden of caregiving, including health, emotional, and financial consequences, is especially pronounced for women in these regions.

Furthermore, women dominate the formal care sector, providing most of the health and social care services in community settings, hospitals, and long-term care facilities (12). Specialized competencies are required among healthcare and caregiving professionals to adequately care for people with dementia, who often present with complex needs and multiple comorbidities (12).

Caring for a person with Alzheimer's disease (AD) is associated with significant mental health challenges, such as depression, anxiety, and difficulties in social, family, and occupational functioning (13).

The concept of "caregiver burden," introduced in the 1980s, refers to the emotional, financial, social, and physical strain experienced by individuals caring for someone with a chronic illness. The intensity of caregiving is directly linked to the magnitude of its health impacts. Feelings of anxiety and depression can negatively affect the physical health of caregivers. Elevated rates of depression and stress, along with decreased subjective well-being, are associated with the care recipient's behavioral disturbances, cognitive impairments, and functional limitations, as well as the duration of caregiving and the age of the caregiver (13).

Aim

The aim of this review is to present and analyze current knowledge on psychological burden and stress among formal and informal caregivers of individuals with dementia, with particular emphasis on nurses, and to identify effective interventions that contribute to reducing caregiver burden and preventing burnout.

Methods

A narrative literature review was conducted by searching the PubMed, Scopus, and Web of Science databases. The review included studies published between 2015 and 2025, a time frame selected to capture the most recent scientific evidence on caregiver burden and to reflect contemporary clinical practices and recent developments in psychological and educational interventions in dementia care. This period also aligns with a significant rise in global dementia prevalence, prompting an increase in caregiver-focused research.

The search strategy used a combination of controlled vocabulary (e.g., MeSH terms) and free-text keywords. The following keywords and their combinations were used: *dementia, Alzheimer's disease, caregiving, caregiver burden, informal caregivers, nurses, stress, burnout, psychological health, psychological outcomes, quality of life, mental health, mindfulness, cognitive-behavioral interventions, education programs, psychological support, organizational support, long-term care, caregiver interventions*.

The included studies examined stress, burnout, quality of life, psychological and physical outcomes among caregivers, as well as the effects of educational programs, psychological support, mindfulness-based interventions, and organizational measures.

Results

A total of 48 articles were identified through the literature search, and all of them met the predefined inclusion criteria, as the search strategy was focused on the most recent evidence (2015–2025) and on clearly specified keywords related to dementia caregiving, caregiver burden, stress, burnout, and interventions.

The Role, Burden, and Health Consequences of Dementia Caregiving

Providing long-term care for individuals with Alzheimer's disease is largely the responsibility of both formal and informal caregivers. Care is a dynamic process between the caregiver and the patient. Informal care is rooted in family structures (e.g., family members, friends, neighbors), whereas formal care refers to services delivered by professional caregivers employed within public or private care systems (13).

A study examining 100 caregivers—50 formal and 50 informal—of patients with Alzheimer's disease used several tools to assess personal resources and mental health: the Social Support Questionnaire (SSQ), the General Self-Efficacy Scale (GSES), the Sense of Coherence Questionnaire (SCQ), the Depression Assessment Questionnaire (DAQ), and the General Health Questionnaire (GHQ).

The results indicated no significant differences between formal and informal caregivers in terms of psychological variables such as sense of coherence, social support, self-efficacy, or mental health problems. However, distinct predictors of mental health problems were identified in each group (13).

There is a notable increase in stress, depression, and fatigue, often manifesting as a sense of helplessness. Higher levels of depressive symptoms and stress caused by patients' challenging behaviors have been shown to predict the onset of cardiovascular diseases in caregivers within 18 months of starting caregiving. The duration of caregiving has also been linked to immune system dysregulation, which may persist for up to four years after the death of the care recipient. Caregivers are more likely to develop respiratory infections, suffer from obesity, and exhibit elevated serum lipid levels, contributing to increased cardiovascular risk (13).

The financial implications of caregiving are substantial. In a systematic review, authors found that most caregivers experienced increased care-related expenses, while family income decreased due to time and resources devoted to caregiving. Due to the progressive nature of dementia, resource use and family expenses increase over time, a trend observed even in both high- and lower-middle-income Asian countries.

Caregivers were found to utilize more healthcare resources, regardless of financial capacity, as reflected in frequent emergency room visits and use of other medical services (14).

Compared to caregivers of individuals with other chronic conditions, those caring for people with dementia are more likely to experience depression, elevated stress, and poorer overall health (15). Both formal caregivers, such as nurses, and informal caregivers often feel unprepared and insufficiently trained to provide dementia care. Due to unpredictable symptoms such as aggression or wandering, along with persistent stress and high care demands, caregivers are vulnerable to psychological difficulties, including depression, anxiety, insomnia, irritability, exhaustion, loneliness, guilt, helplessness, and chronic stress (16).

A clinical cross-sectional study conducted in Zagreb demonstrated that neuropsychiatric symptoms measured by the NPI-Q were significantly associated with poorer quality of life and higher caregiver burden according to the ZBI scale (17). The validation of the Croatian version of the ZBI confirmed key burden dimensions, including emotional strain, frustration, guilt, and social limitations among dementia caregivers (18). A symptom-specific analysis in the same cohort found that agitation/aggression and apathy/inactivity were the strongest predictors of increased caregiver burden (18). A systematic review of longitudinal studies showed that caregiver burden progressively increases as neuropsychiatric symptoms worsen and activities of daily living decline (19). A meta-analysis of 39 randomized controlled trials revealed that individual therapy and nurse-delivered workshops significantly reduced caregiver burden, with an effect size of approximately 0.48 (20). A review of psychoeducational interventions concluded that programs combining education, psychological support, and social resources are the most effective in reducing caregiver burden (21). A study examining the use of wearable devices and AI-based predictive analytics demonstrated that early detection of BPSD is feasible, enabling timelier intervention (22). A randomized controlled trial of an eight-week mindfulness-based health care (MBHC) program showed significant reductions in caregiver burden (ZBI) and improvements in activity balance (23). Research on organizational support for nurses found that structured supervision combined with education significantly reduced burnout and improved job satisfaction (23). Table 1 summarizes the studies outlined above, focusing on caregiver burden and evidence-based interventions designed to reduce stress and burnout among formal and informal caregivers, including nursing professionals.

Table 1. **Key studies from 2015-2025 on caregiver burden and interventions to reduce caregiver stress, including among nurses**

No.	Study & Sample	Intervention/Focus	Key Findings	Author
1	Clinical cross-sectional study, 131 patients in Zagreb	Burden measurement (ZBI), neuropsychiatric symptoms	NPIQ associated with poorer SF-36; higher burden predicted worse physical/mental health	Lucijanić et al., 2021 (17)
2	Validation of ZBI (NeDEM project), Croatian caregivers	Instrument validation	Confirmed burden dimensions: burden, frustration, guilt, social limitations	Lucijanić et al., 2020 (18)
4	Systematic review	Caregiver burden over time in dementia and its risk factors	Increasing caregiver burden	Van den Kieboom R, Snaphaan L, Mark R, Bongers I, et al (19)
5	Meta-analysis of 39 RCTs, n = 4,715	Individual therapy & nurse workshops	Reduced burden (~0.48 effect size)	Rodríguez-Alcázar, et al., 2024 (20)
6	Review of psychoeducational interventions	Education + psychological + social support	Most effective when combined	Walter & Pinquart, 2020 (21)
7	Wearables + AI to predict BPSD	Predictive analytics	Earlier intervention possible	Hsu et al., 2024 (22)
8	RCT, 66 informal caregivers, 8-week MBHC	Mindfulness program	Reduced ZBI ($\beta = -7$, $p = 0.026$), improved activity balance	Prieto-Botella et al., 2025 (23)

Discussion

Depression among caregivers, including nurses

Depression (melancholia) is an emotional response to chronic frustration and disappointment. In psychopathology, it is classified as an affective and emotional disorder (24). Depression is a common and serious health condition that differs from usual mood fluctuations and short-term emotional reactions to everyday challenges. It can cause significant suffering and impair functioning at work, in school, and within the family. According to the World Health Organization, approximately 332 million people globally suffer from depressive disorder, making it one of the leading causes of disability (25). The prevalence of depression among dementia caregivers is even higher than in the general population. As dementia patients experience cognitive decline and loss of ability to perform daily activities (such as bathing, eating, etc.), the quality of caregiving is crucial. Caregivers often spend several hours per day with the patient—or live in the same household. Numerous studies have shown that behavioral and psychological symptoms of dementia (BPSD) affect caregiver performance and, in turn, negatively impact their own physical and mental health (26).

Depression can lead to various psychological and physical health problems, including increased risk of suicide among caregivers. It undermines caregivers' physical well-being, reduces their quality of life, and has been shown to be associated with earlier institutionalization of dementia patients. Caregiver depression may also negatively influence the cognitive status of the person with dementia and has been linked to faster cognitive decline in patients (26).

Mild forms of depressive mood are often difficult to distinguish from normal experiences of disappointment or grief. However, depression is a common, recurrent, and debilitating condition that may lead to suicidal behavior, interpersonal conflict, unemployment, and psychosocial dysfunction.

Demographic characteristics of caregivers (such as age, gender, employment status, and relationship to the patient) are known to influence the stress process at multiple levels—shaping the types of stress, the perception of stressors, and outcomes such as caregiver burden and depression (26). On the other hand, caregivers who report a sense of purpose, stronger emotional closeness to the patient, and higher caregiving competence are more likely to derive positive meaning from the caregiving experience and experience fewer negative outcomes in such a challenging context (27).

Burnout among caregivers and nurses caring for individuals with dementia

Burnout among caregivers and nurses who care for individuals with dementia represents a significant public health concern. This syndrome is most commonly manifested through emotional exhaustion, depersonalization, and a reduced sense of professional accomplishment.

Multiple studies confirm that emotional stress, challenging patient behaviors, lack of organizational support, and insufficient dementia-related education are key contributing factors to burnout. A meta-analysis by Aguayo et al. (2018), which included 17 studies, found that caregivers in nursing homes—particularly those caring for individuals with dementia—demonstrate moderate to high levels of emotional exhaustion, most often associated with aggressive patient behaviors and staff shortages (27).

A study involving 436 nurses and caregivers from nursing homes in Croatia and Slovenia found that nearly half of the participants exhibited high levels of professional burnout. Although demographic variables such as age, years of experience, and educational background were examined, none were statistically significant predictors of burnout levels. The results suggest that nurses and caregivers in both countries are exposed to similar o ccupational stressors, which increase the risk of emotional exhaustion and depersonalization. The authors emphasize the need for systematic psychological support and preventive interventions within institutional care settings (28).

Uzun et al. (2019) point out that formal caregivers, especially nurses caring for individuals with Alzheimer's disease, often experience significant emotional stress, including anxiety, depression, and insomnia. They highlight the importance of early recognition of stress symptoms and the implementation of psychological support and education to prevent the deterioration of both mental and physical health in caregivers (29).

Kozumplik et al. (2019) warn that psychotic symptoms—such as delusions in individuals with dementia—further increase the emotional and cognitive burden on formal caregivers and nurses. They propose the implementation of educational programs and clear protocols for the identification and management of these symptoms, in order to reduce the workload and psychological distress of caregiving staff (30).

The COVID-19 pandemic further exacerbated the situation. A meta-analysis by Ghasemi Kooktapeh et al. (2023) revealed a notable increase in emotional exhaustion among nurses caring for dementia patients during the pandemic, with burnout prevalence reaching nearly 3% (31).

Regarding informal caregivers (i.e., family members), a study by Brownie et al. (2014) found that burnout among family caregivers correlated with higher levels of depression and lower quality of life (32).

A combination of support and interventions to maintain caregiver well-being

Organizational Support and Interventions for Preventing Burnout Among Dementia Care Professionals

Organizational support reduces the risk of burnout among dementia care professionals. A study by Maslach and Leiter (2016) highlights that a lack of organizational support—such as poor communication with management, imbalance between effort and reward, and unclear expectations—directly increases the risk of emotional exhaustion and depersonalization among healthcare workers. The authors conclude that a structured and consistent organizational support system acts as a protective factor against burnout syndrome (33).

Supervision and peer support are key to preserving professionals' mental health. A study by Edwards et al. (2006) showed that regular supervision and peer support groups enable aged care professionals to express emotional challenges, share experiences, and find collective solutions. Such structured support systems are associated with lower stress levels and higher job satisfaction, ultimately reducing the risk of burnout (34).

There is a clear association between the lack of organizational support and an increased risk of emotional exhaustion, as highlighted in the study by Maslach and Leiter, which established that a dysfunctional work environment significantly contributes to the development of burnout among healthcare professionals (33).

Conclusion

Burnout among caregivers and nurses working with people affected by dementia is a complex psychosocial phenomenon requiring a systematic, multifaceted response. Studies indicate that the combination of organizational support, continuous education, structured psychological interventions, and supervision represents the most effective approach for preventing and alleviating burnout. Implementing such measures benefits not only the mental health of professionals but also the quality of care they provide.

Author contributions

Conceptualization (TL, MH); Data Curation (TL, MH), Formal Analysis (TL, MH); Investigation and Project Administration (TL, MH); Writing – Original Draft (SU), Writing – Review & Editing (SU). All authors reviewed and approved the final version of the manuscript.

Conflict of interest

The authors declare no conflicts of interest.

Acknowledgments

The authors would like to thank all researchers and clinicians whose work contributed to the development of this review article. Special appreciation is extended to colleagues from the University Hospital Sveti Duh and the University Psychiatric Hospital Vrapče for their professional support and academic environment that facilitated the preparation of this manuscript.

Funding

This research did not receive any specific grant from funding agencies in the public, commercial or not for-profit sectors.

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