Caregiver burden for patients with dementia: a review of the literature

Yang Xia

SAERA. School of Advanced Education Research and Accreditation

ABSTRACT

This review examines dementia caregiver burden, providing insights into recent scientific research, whilst focusing on neuropsychiatric symptoms (NPS), cultural norms, and socioeconomic inequities. It evaluates how these factors exacerbate stress and assesses interventions to mitigate caregiver burden.

A targeted literature review searching Medline between 2015 and 2025 was conducted using keywords caregiver burden and dementia.

NPS like agitation and aggression drive caregiver depression and burnout, incidence of which are higher among female carers and low-income groups. Cultural expectations, such as filial piety, discourage external support, while financial strain and COVID-19 disruptions deepen disparities. Interventions such as telehealth and policy reforms show promise but require cultural adaptation. Caregiver burden is a multifaceted public health issue. Women, older spouses, and marginalized groups face the highest strain, necessitating search for culturally sensitive, equitable solutions.

To lessen the burden of caregiving, health policies should prioritize subsidized respite care, workplace flexibility, and culturally tailored programs. Further improvements could be made to enhance telehealth accessibility in low-resource regions and validate assessment tools for diverse cultures and populations.

Keywords: *Caregiver burden, dementia, Alzheimer's Disease, frontotemporal dementia, vascular dementia*

INTRODUCTION

Dementia has been a major global public health challenge, with its prevalence escalating rapidly due to an aging population and increasing human life expectancy. As of 2021, approximately 57 million people worldwide were living with dementia, a figure projected to rise to 78 million by 2030 and 131.5 million by 2050, with over 60% of cases occurring in low- and middle-income countries (World Health Organization, 2023). Alzheimer's disease (AD), the most common form of dementia, accounts for 60–70% of cases and is characterized by progressive cognitive decline, neuropsychiatric symptoms, and functional impairments that profoundly affect daily living (Zhang et al., 2024). The economic burden of dementia is staggering, with an estimated cost of $1.3 trillion globally in 2019, with half being attributed to informal caregiving—often provided by women, who constitute 70% of caregivers (World Health Organization, 2023). Beyond financial strain, dementia significantly impacts quality of life, contributing to social isolation, caregiver burnout, and heightened risks of depression and anxiety among both patients and caregivers. The COVID-19 pandemic exacerbated these challenges, as social isolation measures increased mental stress and disrupted care coordination, further highlighting vulnerabilities in dementia care systems (Aggarwal et al., 2022). Risk factors such as aging, hypertension, diabetes, and social isolation underscore the condition's multifactorial nature, though up to 40% of cases may be preventable through lifestyle modifications targeting modifiable risks like physical inactivity and smoking (Livingston et al., 2020). Despite advances in biomarker research and therapeutic strategies, dementia remains incurable, with current treatments offering only symptomatic relief (Hafiz et al., 2023). The growing prevalence and profound societal impact of dementia necessitate urgent interdisciplinary efforts to improve early diagnosis, caregiver support, and access to equitable care, particularly in resource-limited settings (Long et al., 2023).

Impact on cognitive function

Dementia manifests through a complex interplay of cognitive and neuropsychiatric symptoms, with AD, the most prevalent form, serving as a paradigmatic model of progressive cognitive deterioration ("2025 Alzheimer's disease facts and figures," 2025). Early stages of AD are marked by deficits in episodic memory and executive function, including impaired recall of recent events and difficulty with complex tasks such as financial management or problem-solving. These cognitive impairments are driven by neuropathological changes, such as beta-amyloid plaques and tau tangles, which disrupt synaptic communication and neuronal integrity in memory-related brain regions like the hippocampus ("2025 Alzheimer's disease facts and figures," 2025). As dementia advances, language skills deteriorate, and patients struggle to articulate their thoughts or comprehend instructions, while visuospatial deficits impair navigation and object recognition (Sabates et al., 2024). Longitudinal studies reveal that cognitive decline often precedes functional impairment, with up to 87% of deficits in daily activities attributable to underlying cognitive deterioration in mild AD (Liu-Seifert et al., 2015).

Neuropsychiatric symptoms (NPS), including apathy, agitation, and depression, further exacerbate cognitive dysfunction.

For instance, apathy correlates with reduced metabolic activity in the prefrontal cortex, impairing attention and decision-making (Alves et al., 2017). Similarly, psychosis-like delusions and hallucinations, common in Lewy body dementia, can disrupt reality testing and executive function, further compounding cognitive load (Sabates et al., 2024). Furthermore, psychological profiles characterized by low resilience or high stress susceptibility accelerate cortical thinning and cognitive decline, highlighting the bidirectional relationship between mental health and brain integrity (Bartrés-Faz et al., 2025).

The heterogeneity of cognitive outlooks across dementia subtypes highlights the need for tailored interventions. Vascular dementia, often marked by stepwise cognitive declines post-stroke, disproportionately affects processing speed and frontal lobe functions, while AD prioritizes information decay, reduced ability to benefit from cues, and higher frequency of intrusion errors (Desmond, 2004). Critically, pharmacological treatments such as SSRIs, though used to manage NPS, may inadvertently hasten cognitive decline in some patients, emphasizing the delicate balance between symptom management and cognitive preservation (Mo et al., 2025). These findings collectively underscore the urgency of early, multidimensional assessments to offset the cascading effects of dementia on cognition and quality of life.

Dementia and mobility

Dementia is characterized by a progressive decline in cognitive and physical functions, with symptoms varying significantly across subtypes and disease stages. Early cognitive impairments such as memory loss, disorientation, and difficulty with complex tasks often precede overt mobility challenges, but as dementia advances, motor dysfunction becomes increasingly prominent. For instance, AD, the most common dementia subtype, initially manifests with memory deficits and language difficulties, but later stages involve gait disturbances, balance issues, and reduced muscle strength, culminating in dependency for activities of daily living (Tolea et al., 2016). Non-Alzheimer's dementias, such as vascular and frontotemporal subtypes, demonstrate steeper mobility decline compared to AD, with gait and balance impairments emerging as critical predictors of functional disability (Van Ooteghem et al., 2019).

The interplay between cognitive and motor decline exacerbates mobility challenges. Neuropsychiatric symptoms like apathy was found to be associated with lower levels of mobility (Merrilees et al., 2013). In advanced stages, individuals often experience profound physical deterioration, including loss of independent ambulation, heightened susceptibility to pressure ulcers, and infections due to immobility (Romero et al., 2014). These mobility limitations not only reduce quality of life but also intensify caregiver burden, as 24 hour supervision becomes necessary to prevent injuries (Van Ooteghem et al., 2019). Research underscores the need for early, tailored interventions such as balance training and environmental modifications, to prevent functional decline. Understanding these symptom trajectories is critical for developing holistic care strategies that address both cognitive and physical dimensions of dementia.

Caregiver burden

Caregivers of individuals with dementia frequently face significant caregiver burden, a critical public health issue marked by multifaceted stressors that severely impact their physical health, psychological well-being, and socioeconomic stability. This burden is often exacerbated by NPS such as agitation, aggression, and mood disturbances, which are strongly linked to heightened caregiver stress and depressive symptoms. These disruptive behaviors disproportionately affect caregivers of individuals with frontotemporal dementia, where symptom severity intensifies caregiving challenges (Cheng, 2017). Functional impairments in advanced dementia further exacerbate this burden, as these caregivers can often devote over 14 hours daily to assist with activities of daily living (ADLs), intensifying physical strain and reducing employment opportunities (Cheng, 2017). With the care provided often unpaid, the cost of such unpaid dementia caregiving valued at $413.5 billion annually in the U.S. alone (Alzheimer's Association, 2025), while caregivers themselves face heightened mental health risks such as depression, anxiety, and chronic health conditions such as hypertension and immune dysfunction (Goto et al., 2023). Cultural contexts also shape burden experiences; in Asian countries, familial obligations and gender roles often concentrate care responsibilities on women, compounding stress in low-middle-income settings where support systems are scarce (Abayon et al., 2024). Interventions targeting caregiver burden, with tangible support to alleviate practical tasks or positive social interactions to relieve psychological strain, was shown to be effective in reducing caregiver stress (Han et al., 2014). These findings again demonstrate the need for culturally sensitive policies and holistic support frameworks to address the escalating crisis of dementia caregiving globally.

Need of the study

This study aims to summarize existing evidence on the multifaceted challenges faced by informal dementia caregivers. It helps to identify systemic gaps in caregiver support while highlighting modifiable factors like unmet emotional need and social support networks. Consolidating the evidence grounds the thesis in empirical knowledge, informs methodological approaches, and underscores the urgency of evidence–based solutions to alleviate caregiver burden in dementia care systems.

METHOD

Aim of the study

The study is aimed to provide insight into the factors contributing to caregiver burden in context of dementia and recent advancements. MEDLINE was searched using combinations of the following keywords “dementia”, “caregiver”, “burden”, “Alzheimer’s disease”, “Frontotemporal dementia” and “vascular dementia”.

Inclusion Criteria

Studies selected were based on 1) publications in English; 2) publications between 2015 and 2025; 3) presence of caregiver burden or related concepts for dementia patients. 4) shed light into factors contributing to caregiver burden or shed light into interventions that may help alleviate caregiver burden.

Exclusion Criteria

Studies were excluded if carers were paid or employed to look after dementia patients.

Procedure

MEDLINE and Google Scholar were used to obtain articles with the specific keywords. After removal of duplicates, 1541 studies were screened. (See Figure 1.) Studies were screened to include study design and context; interventions and comparators; measurements and results of caregiver outcomes; types of evaluation; and quality of source or study. Certain texts beyond the 10 year timeframe were used to provide historical context.

Review of Literature

Age and kinship

Caregiver burden is heavily influenced by the age and kinship of the caregiver, with distinct challenges emerging across generational and familial contexts. Spousal caregivers, often older adults themselves, face unique stressors due to their dual role as partners and caretakers. Studies indicate that elderly spouses, aged 65 and above, experience higher rates of physical burden and chronic health concerns compared to younger caregivers, as aging bodies struggle with caregiving tasks whilst maintaining their own health problems (Sabatini et al., 2024). Emotional burden is also amplified in spousal relationships, as caregivers grapple with grief over their partner's cognitive decline while confronting their own mortality, a phenomenon termed "anticipatory grief" (Cheung et al., 2018). Conversely, adult-child caregivers report heightened role strain from balancing caregiving with employment, parenting, and financial obligations. Younger caregivers in this group are more likely to experience depression and burnout, particularly when caregiving disrupts career progression or depletes savings (Liu et al., 2024). Relationship dynamics further modulate burden: spouses often perceive caregiving as a marital obligation, fostering resilience but normalizing self-neglect, whereas adult children may harbor unresolved familial tensions, intensifying psychological distress (Wang et al., 2025).

Gender intersects critically with age and role. Daughters and daughters-in-law in Eastern cultures disproportionately shoulder care tasks, reporting higher burden than sons due to patriarchal expectations (Pan et al., 2022). Meanwhile, younger caregivers caring for parents with early-onset dementia face social isolation, as peers lack understanding of their responsibilities, compounding mental health risks (Koyama et al., 2017). Interventions tailored to these subgroups are vital. With older spouses benefit from integrated healthcare addressing their dual needs, while adult-child caregivers require workplace policies like flexible hours and financial aid. Recognizing these demographic and relational nuances is necessary for developing equitable support systems that mitigate the compounding impacts of caregiver burden.

Gender of carers

Gender significantly shapes the experiences and burdens of dementia caregivers, with female caregivers consistently reporting higher levels of physical, emotional, and psychosocial strain compared to their male counterparts. Studies across diverse cultural and geographic contexts reveal that women are more likely to assume primary caregiving

roles, often due to societal expectations that frame caregiving as a feminine responsibility (Sharma et al., 2016). This gendered division of labour is compounded by women's tendency to spend more time on caregiving tasks, particularly household chores and emotional support, which are linked to heightened stress and burnout (Pillemer et al., 2018). For instance, female caregivers in rural settings report dedicating more hours daily to care tasks, often balancing these responsibilities with employment and family obligations, a dynamic that exacerbates their perceived burden (Schaffler-Schaden et al., 2021).

The psychological toll of caregiving is also experienced differently between genders. Female caregivers exhibit higher rates of depression, anxiety, and somatic symptoms, partly due to their greater emotional investment and the internalization of caregiving as a moral obligation (Pillemer et al., 2018). In contrast, male caregivers often adopt a task-oriented approach, focusing on practical duties like financial management or medical coordination, which may buffer emotional strain (Schaffler-Schaden et al., 2021). This divergence is evident in factor analyses of caregiver burden: women score higher on dimensions such as guilt, frustration, and the impact of caregiving on personal lives, while men report lower levels of these stressors (Pillemer et al., 2018).

Notably, studies suggest that gender gaps in caregiving hours are narrowing globally, except in household tasks, where women continue to invest significantly more time (Pacheco Barzallo et al., 2024). Despite these challenges, interventions tailored to gender-specific needs remain scarce. Female caregivers often require targeted mental health support and respite services to address emotional exhaustion, while male caregivers may benefit from strategies to enhance emotional coping and reduce stigma around seeking help (Pillemer et al., 2018). They will required tailor assessment and interventions to aid carers in alleviating caregiver burden.

Financial background

Financial disparities among caregivers shape the intensity and nature of caregiver burden, with lower-income households facing compounded physical, emotional, and socioeconomic challenges. Caregivers from economically disadvantaged backgrounds often incur substantial out-of-pocket expenses averaging 12,388 annually in the U.S. for dementia care to cover medical supplies, home modifications, and respite services, which can deplete savings and force trade−offs between essential needs like food and healthcare (Poco et al., 2025; Skaria, 2022).

Access to paid care services also varies by financial status. Higher-income caregivers can offset burdens by hiring professional help or utilizing institutional care, whereas lower-income families rely heavily on unpaid, round-the-clock care (Nandi et al., 2024; Van De Vorst et al., 2016). This disparity is stark in countries like Japan, where revisions to long-term care insurance shifted costs to families, intensifying strain on those unable to afford private support (Goto et al., 2023; Igarashi et al., 2020). Structural inequities, such as limited healthcare eligibility and gaps in employer benefits, further entrench financial vulnerability (Skaria, 2022).

Longitudinal studies project that dementia-related care costs will triple by 2060, underscoring the urgency of addressing

financial inequities to prevent intergenerational poverty (Nandi et al., 2024). The negative effects of caregiving such as lost wages, debt, and health declines, will disproportionately harm low-income families, highlighting the need for culturally sensitive financial safety nets and equitable access to subsidized care services.

Influence of education

The education background of caregivers also exerts great influence on the perceived caregiver burden, with lower educational attainment linked to heightened physical, emotional, and socioeconomic strain. Caregivers with limited formal education often face challenges in accessing and interpreting health information, which can lead to inadequate disease management and increased stress. For instance, systematic reviews of dementia caregivers in China found that lower educational attainment correlated with higher burden scores, as these caregivers reported greater difficulty understanding caregiving strategies and navigating healthcare systems (Wang et al., 2022). This knowledge gap may exacerbate mismanagement of NPS, such as agitation or aggression, which are in turn, key drivers of burden (Cheng, 2017; Kim et al., 2021). Less educated caregivers are also less likely to utilize formal support services or evidence-based interventions, partly due to limited health literacy and awareness of available resources ("2024 Alzheimer's disease facts and figures," 2024).

Financial strain further compounds this disparity. Caregivers with lower education often occupy lower-income roles, forcing them to balance employment with intensive caregiving duties. The created phenomenon "time poverty" increases absenteeism, presenteeism, and job loss, perpetuating cycles of economic vulnerability (Igarashi et al., 2020).

Cultural and systemic factors intersect with education to shape burden. In collectivist societies like China, familial caregiving norms may pressure lower-educated caregivers to internalize responsibilities without seeking external help, amplifying isolation (Wang et al., 2022). Conversely, higher-educated caregivers in Western contexts often benefit from workplace flexibility and digital literacy, enabling them to integrate caregiving with professional life more effectively (Wolff et al., 2025). However, even in high-income settings, racial and ethnic minorities with lower education face compounded disparities, including delayed dementia diagnoses and limited access to culturally competent care (Sörensen & Conwell, 2011).

Thus, interventions should ideally also address educational disparities. Education modulates caregiver burden through pathways of health literacy, economic stability, and access to support systems. Addressing these disparities requires policies that prioritize educational outreach, subsidize respite care for low-income families, and integrate caregiver training into public health frameworks to ensure equitable support across socioeconomic strata (Tsai et al., 2021; Wang et al., 2022).

Influence of culture

Cultural norms and values profoundly shape the experiences of dementia caregivers, creating distinct patterns of burden between Western and Eastern societies. In Eastern cultures, such as those in China and other Asian communities, caregiving is deeply rooted in familial obligation and filial piety, where providing care is viewed as a moral

duty rather than a choice (Lwi et al., 2023). This collectivist mindset often leads caregivers to internalize responsibility, avoiding external support to preserve family harmony and avoid "losing face"—a cultural concept tied to social reputation and shame. For instance, Chinese American caregivers report heightened loneliness due to fears of stigma, as dementia is frequently perceived as a form of moral failure or spiritual punishment, prompting social withdrawal to shield the family from judgment (Lwi et al., 2023; Tran et al., 2023).

In contrast, Western caregivers, particularly in Euro-American contexts, are more likely to utilize formal support systems such as respite care, and government programs, and prioritize individual autonomy (Tran et al., 2023). This cultural expectations of self-reliance and the prioritization of nuclear family structures can lead to social isolation. It has been shown that Asian Americans were more concerned out losing face, and this has been noted in other fields of study, which can lead to increased mental health issues (Kalibatseva et al., 2017). Notably, racial disparities persist: African American caregivers, while valuing communal support and resilience, often encounter systemic barriers such as delayed dementia diagnoses and limited access to healthcare, compounding their burden despite strong faith-based coping mechanisms (Idorenyin Imoh & Charity, 2023).

The sociocultural stress and coping model further elucidate these differences. In Eastern contexts, cultural values like filial piety indirectly intensify burden by discouraging external help-seeking, whereas Western caregivers may experience stress from navigating fragmented support systems (Jeong et al., 2025; Maximiano-Barreto et al., 2022).

The role of gender further intersects with culture, as women in both contexts disproportionately shoulder caregiving duties. In Eastern societies, patriarchal norms often designate caregiving as a female role, intensifying emotional labour and economic vulnerability (Jeong et al., 2025).

Addressing these disparities requires culturally tailored interventions. For Eastern caregivers, reducing stigma through community education and integrating traditional values into support programs, such as family-centric respite care, could potentially alleviate isolation (Lwi et al., 2023). In Western settings, enhancing accessibility to resources for minority groups and promoting culturally competent healthcare systems are critical (Idorenyin Imoh & Charity, 2023). Recognizing these cultural nuances is necessary for developing equitable strategies to better alleviate the global health concern of caregiver burden.

Religion and spirituality

Religion and spirituality play a dual role in shaping caregiver burden, acting as both a protective resource and a potential source of strain depending on the coping strategies employed and cultural contexts. Positive religious coping mechanisms, such as collaborative approaches where caregivers view themselves as "working with God" to manage stress, are associated with reduced depression and lower perceived burden (Rathier et al., 2015). For example, caregivers who engage in prayer, attend religious services, or derive comfort from spiritual beliefs often report enhanced resilience and emotional well-being, as these practices foster a sense of meaning and

connection to a supportive community (McGee et al., 2022). These findings algins with that spiritual well-being correlates inversely with caregiver burden, particularly when caregivers perceive their role as a purposeful spiritual journey rather than a passive obligation (Kılınç İşleyen et al., 2025; McGee et al., 2022) .

Conversely, negative religious coping strategies such as viewing caregiving as divine punishment or experiencing anger toward a higher power, are linked to heightened emotional distress and burden (Rathier et al., 2015). Caregivers who question their faith or feel abandoned by their spiritual community often exhibit elevated rates of depression, reflecting the psychological toll of unresolved spiritual struggles (Shah et al., 2001).

Another factor to consider when tailoring intervention for caregiver burden thus turns to religious and spiritual frameworks. Psychoeducational programs tailored to caregivers' faith traditions, such as scripture-based mindfulness or collaborative problem-solving with religious leaders, can enhance coping efficacy (McGee et al., 2022). However, clinicians must remain attuned to potential spiritual conflicts, as rigid adherence to unhelpful religious narratives (e.g., viewing dementia as a moral failing) may hinder adaptive coping (Shah et al., 2001). Ultimately, religion's impact on caregiver burden is multifactorial, shaped by the interplay of individual beliefs, cultural expectations, and systemic support structures. Addressing these dynamics requires culturally sensitive approaches that honour spiritual diversity.

Impact of COVID-19

The COVID-19 pandemic had an unwanted but interesting flare up for caregiver burden for dementia caregivers globally. Cultural, structural, and socioeconomic differences between Western and Eastern contexts shaped distinct challenges. In Western societies, such as the U.S. and Europe, caregivers faced heightened stress due to fragmented healthcare systems and reduced access to formal support services. Lockdowns disrupted respite care, adult day programs, and home health services, forcing caregivers to assume greater responsibilities for ADLs and medical coordination (Hughes et al., 2021). For example, in the UK, 48.8% of caregivers reported unmet healthcare needs, while European studies noted increased mental health strains, including loneliness and anxiety, particularly among spousal caregivers (Quinn et al., 2022). Racial disparities further compounded these issues: Black caregivers in the U.S. provided significantly more ADL support than White counterparts yet faced systemic barriers to equitable care access (Moon et al., 2022).

In contrast, Eastern caregivers, particularly in collectivist societies like China and Thailand, grappled with cultural norms that intensified burden. Filial piety, a Confucian value emphasizing familial duty, pressured caregivers to internalize responsibilities without seeking external help, often leading to emotional suppression and burnout (E.-C. Hsu et al., 2025). For instance, 1 study in Thailand demonstrated caregivers reported higher burden levels when care recipients exhibited neuropsychiatric symptoms like agitation, with younger, female, and highly educated caregivers disproportionately affected (Wongmek et al., 2023). Similarly, Chinese American caregivers faced stigma around dementia and COVID-19,

compounded by language barriers and xenophobia, which hindered access to mental health resources (E.-C. Hsu et al., 2025). Cultural reluctance to disclose caregiving struggles also limited utilization of formal support systems in these communities.

During Covid-19, dementia patients were observed to have worsening neuropsychiatric symptoms, such as depression, apathy, and agitation, which amplified caregiver stress (Wei et al., 2022). Coping mechanisms diverged, Online support groups and telehealth services were made available, while other caregivers relied on familial networks, which were strained by pandemic restrictions (Ang et al., 2025; E. C. Hsu et al., 2025). Structural policies differed as well. Policies aimed to alleviate financial strain but often failed to reach marginalized groups (Moon et al., 2022), whereas Eastern nations like Thailand saw limited government interventions, leaving caregivers dependent on community-based organizations (Wongmek et al., 2023).

Addressing these nuanced challenges can help ease the global burden of dementia caregiving in a post-pandemic world. These difference highlight the need for culturally tailored interventions. While western systems require enhanced accessibility to mental health services and equitable resource distribution, while Eastern contexts benefit from integrating traditional values into support programs, such as family-centric respite care and stigma-reduction campaigns (E.-C. Hsu et al., 2025; Moon et al., 2022).

INTERVENTIONS

Assessment tools for caregiver burden

The assessment of caregiver burden in dementia care helps to identify stressors and tailor interventions, yet the choice of measurement tools involves trade-offs between comprehensiveness, cultural relevance, and practicality. The Zarit Burden Interview (ZBI) and emerging tools like the Dementia Caregiver Burden Scale (DCBS) helps to exemplify these dynamics. Below are some commonly used tools and we describe their strength and weaknesses.

Zarit Burden Interview (ZBI)

- The ZBI is a gold-standard tool validated across diverse cultural contexts, including low and high resource settings like Bangladesh and Malaysia, where it reliably captures emotional, physical, and social strain (Rahman et al., 2025; Tay et al., 2025). Its 22-item format allows nuanced assessment of burden severity, with studies showing strong internal consistency (Cronbach's α = 0.93) (Seng et al., 2010). Shortened versions are also available to offset its arduous number of questions.
- The ZBI focuses on unidimensional burden intensity, neglecting economic stressors and family conflict, which are critical in collectivist societies where caregiving often involves financial sacrifices (Tu et al., 2022).

Caregiver Burden Inventory (CBI)

- The CBI's multidimensional design assesses physical, emotional, and social domains, making it suitable for

capturing the complexity of dementia caregiving (Domeisen Benedetti et al., 2024).

- It excludes financial burden, a significant gap in low-income settings where caregivers face out-of-pocket expenses and job loss (Cho & Kim, 2024).

Dementia Caregiver Burden Scale (DCBS)

- Developed in South Korea, the DCBS addresses gaps in existing tools by incorporating five domains: physical health, emotional distress, financial strain, family conflict, and caregiver responsibility (Cho & Kim, 2024). Its high reliability (Cronbach's $\alpha = 0.96$) and inclusion of situational factors (e.g., public service access) make it adaptable to evolving care environments.
- Limited validation outside East Asia raises questions about its cross-cultural applicability, particularly in Western contexts where nuclear family structures dominate (Cho & Kim, 2024).

Technology-Based Assessments

- Digital tools, such as online questionnaires and telehealth-integrated platforms, improve accessibility and reduce assessment bias through real-time data collection (Scerbe et al., 2023). Meta-analyses show these tools effectively reduce caregiver distress and depression by enabling timely interventions (Scerbe et al., 2023).
- Digital literacy and socioeconomic disparities limit their utility in rural or low-income regions, where caregivers lack internet access (Kenne Malaha et al., 2025). Furthermore, digital tools often fail to address gendered aspects of caregiving, such as higher burden reported by female caregivers (Scerbe et al., 2023).

Implications for Research and Practice

Tools like the DCBS highlight the need for culturally tailored instruments that account for familial roles (e.g., spousal vs. adult-child caregivers) and economic contexts (Cho & Kim, 2024). For instance, in Confucian-influenced societies, filial obligation may mask true burden levels, necessitating qualitative supplements to standardize assessment instruments.

Combining self-assessment instruments with clinical metrics (e.g., patient disease severity, neuropsychiatric symptoms) can enhance predictive accuracy. For example, severe AD and frontotemporal dementia correlate with higher burden, yet many tools overlook these disease-specific factors (Tay et al., 2025).

Validated tools like the ZBI can help identify regions of need and aid in resource allocation for policies, such as subsidizing respite care for high-burden groups (e.g., spouses, low-income caregivers) (Tay et al., 2025). However, policymakers must also address tool limitations, such as economic burden gaps, to avoid underestimating caregivers' needs in regions where burden is unique or carers are disadvantaged.

While established tools like the ZBI remain foundational, their limitations highlight the importance of hybrid approaches.

Integrating multidimensional scales, such as the DCBS with digital platforms could balance depth and accessibility, particularly in underserved populations. Future research should prioritize validating tools across diverse cultural and socioeconomic contexts to ensure equitable support for dementia caregivers globally.

Strategies and assistance

Carers of dementia patients face multifaceted challenges, often requiring diverse interventions to alleviate various physical, emotional, and socioeconomic burdens. Recent research highlights several evidence-based strategies, each with distinct advantages and limitations.

Psychoeducation and Skill-Based Training

Psychoeducational programs are among the most effective interventions for carers of dementia patients, combining dementia education, communication strategies, and self-care techniques. A randomized controlled trial in Egypt demonstrated that a six-session multimodal intervention reduced caregiver burden (ZBI scores) by 30% and anxiety by 34%, emphasizing the value of structured skill-building (Amin Abdelhalim et al., 2025). These programs empower caregivers with practical tools, enhance disease understanding, and foster resilience. However, their success often depends on cultural adaptation. For instance, in collectivist societies like Japan or Egypt, integrating familial values such as filial piety is critical for engagement (Goto et al., 2023). A key limitation is reliance on in-person sessions, which may exclude caregivers in remote or resource-limited settings. Additionally, while these programs alleviate caregiver distress, they may not improve neuropsychiatric symptoms in care recipients, as seen in the Egyptian study (Amin Abdelhalim et al., 2025).

Multicomponent Interventions

Interventions combining education, counselling, and practical support (e.g., the REACH II program) show moderate effects on burden reduction (Elliott et al., 2010). Studies show that multicomponent approaches improve caregiver depression, knowledge, and subjective well-being, though effect may vary (Butler et al., 2021; Walter & Pinquart, 2020). These programs are particularly effective when tailored to individual needs, such as addressing financial strain or behavioural symptoms. However, scalability is challenging due to resource limitations and variability in implementation fidelity.

Technology-Assisted Support

Digital tools, such as telehealth platforms and online support groups, offer scalable solutions. They can become an anonymous point of contact to receive psychoeducation and engage in support programs, especially in regions where culture negatively influences caregiver burden (Goto et al., 2023). Remote monitoring tools such as medication reminders, reduce caregiving hours and enhance safety. It has also shown success in reducing caregiver depression and the caregiver burden (Possin et al., 2019).

Community-Based and Respite Care

Community programs, such as Japan's long-term care insurance (LTCI) system, aim to integrate formal and informal care networks. However, post-LTCI revisions shifted costs to families, exacerbating strain despite promoting domiciliary care (Goto et al., 2023). Respite services temporarily alleviate caregiving demands, delaying

institutionalization and improving mental health. Yet, availability is inconsistent, with barriers which affect utilisation including accessibility of information on respite services, flexibility and affordability, and the caregiver's inability to recognise their need for respite services (Wakefield, 2020).

5. **Policy and Structural Reforms**

Policy initiatives, such as tax credits for caregiving expenses such as the U.S. Credit for Caring Act, aim to reduce financial strain. However, eligibility barriers often exclude low-income caregivers (Waymouth et al., 2023). In Japan, the LTCI system's tiered care certification levels theoretically align support with caregiver needs, but underfunding persists, and has transformed family members entrusted with the burden of taking care of dementia patients at home into primary caregivers (Goto et al., 2023). Policy makers and structural reforms should address systemic inequities, such as delayed diagnoses in marginalized groups and inadequate rural healthcare access (Butler et al., 2021).

Limitations and Future Directions

Many studies has small sample sizes, short follow-up periods, and heterogeneity in outcome measures, limiting generalizability (Sörensen & Conwell, 2011). Few programs prioritize long-term caregiver support, leading to relapse in burden post-intervention (Walter & Pinquart, 2020).

Effective strategies may lie in hybrid approaches, combining psychoeducation, technology, and community support, while prioritizing cultural sensitivity and equitable resource distribution. Future research should include standardized outcome measures, expand on low- and middle-income countries focused trials, and integrate caregiver feedback into intervention design to ensure relevancy and external validity.

Effects of institutionalization

Institutionalization of individuals with dementia reconfigures caregiver burden rather than eliminating it, as caregivers often face persistent psychological, emotional, and managerial challenges post-placement. While transitioning a care recipient to a facility reduces direct caregiving tasks, studies indicate that caregiver burden remains elevated due to ongoing stressors such as guilt, grief over perceived abandonment, and witnessing accelerated patient decline in institutional settings (el Haj et al., 2024; Teles et al., 2024). For instance, caregivers who visit facilities frequently report heightened anxiety, particularly when managing younger patients, as they anticipate prolonged responsibilities (Teles et al., 2024). This shift from hands-on care to advocacy and care coordination introduces new stressors, including conflicts with facility policies and concerns about care quality, which replace physical caregiving demands.

Cultural norms further modulate these effects. In familial societies like Japan, revisions to LTCI shifted financial and logistical burdens to families, increasing stress despite reduced hands-on care (Goto et al., 2023). Conversely, in Portugal, caregivers reported higher burden (ZBI scores ≥28.5) and social stigma for outsourcing care (Teles et al., 2024). Such cultural pressures are compounded by socioeconomic factors: employed or highly educated caregivers face competing responsibilities, while lower-income caregivers struggle with institutional costs (Goto et al., 2023).

Patient-related factors also sustain burden post-institutionalization. NPS, such as disinhibition, irritability, and agitation, remain significant stressors, as these behaviours often persist or worsen in facilities (García-Martín et al., 2023). Longitudinal European studies found that worsening functional decline in patients (e.g., activities of daily living [ADL] dependencies) correlates with increased caregiver burden, even when cognitive decline plateaus (Reed et al., 2020).

Policy and intervention gaps exacerbate these challenges. While Japan's LTCI system theoretically aligns support with care needs, underfunding and uneven implementation limit its efficacy, leaving caregivers reliant on fragmented community services (Goto et al., 2023). Similarly, psychoeducational programs often fail to address post-institutionalization managerial roles, which may leave caregivers unprepared for advocacy responsibilities.

To recap, institutionalization transforms caregiver burden into a complex interplay of emotional, cultural, and systemic stressors. Addressing these challenges requires holistic interventions that integrate caregiver mental health support, culturally sensitive policy reforms, and enhanced training for navigating post-placement advocacy roles. Future research should include longitudinal studies to identify modifiable factors and develop equitable support frameworks across diverse caregiving contexts.

DISCUSSION

The burden experienced by dementia caregivers is a multifaceted challenge shaped by NPS, sociocultural norms, caregiver-patient dynamics, and systemic inequities. Recent studies underscore that NPS, such as agitation, aggression, and disinhibition, remain the strongest predictors of caregiver burden across dementia subtypes, including AD and frontotemporal dementia (Cheng, 2017). These symptoms disrupt daily caregiving routines, strain emotional bonds, and exacerbate functional dependencies, leading to heightened stress and depressive symptoms among caregivers. For instance, caregivers of patients with Lewy body dementia report significant distress due to visual hallucinations, while those caring for individuals with behavioral variant frontotemporal dementia face unique challenges from personality changes and emotional insensitivity (Cheng, 2017). Longitudinal data reveal that burden trajectories are highly variable, influenced by factors such as disease progression, caregiver age, and cohabitation status (van den Kieboom et al., 2020).

Cultural contexts profoundly shape caregiver experiences. In collectivist societies like Malaysia and China, familial obligations rooted in filial piety often pressure caregivers to internalize responsibilities without seeking external support, amplifying isolation and financial strain (Lwi et al., 2023; Tay et al., 2025). For example, Chinese American caregivers report heightened loneliness due to fears of "losing face," a cultural stigma linked to dementia being perceived as moral failure (Lwi et al., 2023). Conversely, Western caregivers, while more likely to utilize formal support systems, still face challenges from fragmented healthcare access and gendered caregiving roles, with female caregivers disproportionately affected by burnout (Connors et al., 2020). These findings highlight the need for interventions tailored to different cultures. However given

the complexity and differences between cultures, it will be challenging to find one with reliable external validity.

Caregiver demographics also has an effect on caregiver burden. Younger caregivers and spousal caregivers exhibit higher burden levels, often due to competing responsibilities such as employment or parenting, and emotional grief over relational losses (Tay et al., 2025). A 2025 Malaysian study found that spousal caregivers of severe AD patients reported significantly higher ZBI scores compared to non-spousal caregivers, exacerbated by the absence of paid help (Tay et al., 2025). Similarly, caregivers of clinically unstable patients with severe NPS face elevated depression risks, underscoring the bidirectional relationship between patient symptom severity and caregiver well-being. Again these findings underline the highly individualised issues of caregiving, highlight that intervention will need to be a fine balance between able to target individualised needs, whilst able to generalise to the broader population.

Effective interventions must adopt a multidimensional approach. Psychoeducational programs, telehealth platforms, and multicomponent strategies like the REACH II initiative show promise in reducing burden but require cultural adaptation to ensure accessibility (Elliott et al., 2010). Technology-assisted tools must address literacy gaps in rural or low- and middle-income country settings, while community-based respite programs should integrate familial values to overcome cultural resistance (Rashid et al., 2024). Policymakers must prioritize equitable resource distribution, which has been reflected in Asia by expanding long-term care insurance or enhancing Medicaid waivers in the U.S.

Future research should prioritize longitudinal studies to unravel dynamic burden trajectories and better understand long term outcomes form interventions. Cross-cultural comparisons are critical to developing globally relevant frameworks. Additionally, validating culturally sensitive assessment tools can improve early identification of high-risk caregivers.

Addressing caregiver burden demands a holistic strategy that balances individualized support, systemic aid, and cross-cultural collaboration. By centring caregiver well-being in dementia care paradigms, societies can delay this escalating public health crisis while upholding the dignity of both caregivers and care recipients.

CONCLUSION

Caregiver burden in dementia, driven by NPS, cultural norms, and socioeconomic inequities, remains a critical global challenge. Over the past decade, studies highlight that women, older spouses, and low-income caregivers endure profound physical, emotional, and financial strain, exacerbated by NPS like agitation and aggression. Cultural expectations in collectivist societies, such as filial piety in Asia, amplify isolation by discouraging external support, while fragmented healthcare systems in Western communities marginalises underprivileged groups. Financial instability and limited health literacy impede access to effective interventions, with pandemics such as COVID-19 further intensifying disparities through disrupted care services.

Interventions such as psychoeducation and telehealth has proven to be beneficial to caregiver burden, but will continue to require cultural adaptation. Systemic reforms such as subsidized respite care, workplace flexibility, and equitable policy implementation, are pillars in alleviating burden. The future must provide longitudinal and cross-cultural studies and address dynamic burden trajectories, with a holistic approach, integrating individualized support, cultural sensitivity, and structural reforms, is essential to mitigate this crisis and uphold caregiver and patient dignity.

REFERENCES

2024 Alzheimer's disease facts and figures. (2024). *Alzheimers Dement*, *20*(5), 3708–3821. https://doi.org/10.1002/alz.13809

2025 Alzheimer's disease facts and figures. (2025). *Alzheimers Dement*, *21*(4). https://doi.org/10.1002/alz.70235

Abayon, A. A. P.-e., Raymonds, M., Brahmbhatt, P., Samnani, S., & Hanna, F. (2024). The Impact of Dementia on the Psychosocial Well-Being of Informal Caregivers in Asia: A Scoping Review Comparing High-Income and Low–Middle-Income Countries. *Psych*, *6*(1), 260–272.

Aggarwal, H., Chaware, S., & Aggarwal, H. (2022). A Critical Study on the Impact of Dementia on Older People Undergoing Treatment in Care Homes. *Cureus*, *14*(10), e30056. https://doi.org/10.7759/cureus.30056

Alves, G. S., Carvalho, A. F., de Amorim de Carvalho, L., Sudo, F. K., Siqueira-Neto, J. I., Oertel-Knochel, V., Jurcoane, A., Knochel, C., Boecker, H., Laks, J., & Pantel, J. (2017). Neuroimaging Findings Related to Behavioral Disturbances in Alzheimer's Disease: A Systematic Review. *Curr Alzheimer Res*, *14*(1), 61–75. https://doi.org/10.2174/1567205013666160603010203

Alzheimer's Association. (2025). 2025 Alzheimer's disease facts and figures. Retrieved May 24, from chrome-extension://efaidnbmnnnibpcajpcglclefindmkaj/https://www.alz.org/getmedia/ef8f48f9-ad36-48ea-87f9-b74034635c1e/alzheimers-facts-and-figures.pdf

Amin Abdelhalim, D. S., Ahmed, M. M., Hussein, H. A., Sarhan, M. D., & Khalaf, O. O. (2025). A Skill-Based multimodal intervention for dementia caregivers: impact on burden and anxiety. *Aging Clin Exp Res*, *37*(1), 95. https://doi.org/10.1007/s40520-025-02985-x

Ang, L. C., Malhotra, R., Roy Chowdhury, A., & Liew, T. M. (2025). Pre- and post- COVID-19 trends related to dementia caregiving on Twitter. *Scientific Reports*, *15*(1), 5173. https://doi.org/10.1038/s41598-024-82405-8

Bartrés-Faz, D., Demnitz-King, H., Cabello-Toscano, M., Vaqué-Alcázar, L., Saunders, R., Touron, E., Cattaneo, G., Gonneaud, J., Klimecki, O., Bargalló, N., Sánchez-Solana, J., Tormos, J. M., Chételat, G., Pascual-Leone, Á., Marchant, N. L., André, C., Bachelet, R., Baez Lugo, S., Chocat, A.,…the Medit-Ageing Research, G. (2025). Psychological profiles associated with mental, cognitive and brain health in middle-

aged and older adults. *Nature Mental Health*, *3*(1), 92–103. https://doi.org/10.1038/s44220-024-00361-8

Butler, M., Gaugler, J., Talley, K., Abdi, H., Desai, P., Duval, S., Forte, M., Nelson, V., Ng, W., & Ouellette, J. (2021). Care interventions for people living with dementia and their caregivers. In.

Cheng, S. T. (2017). Dementia Caregiver Burden: a Research Update and Critical Analysis. *Curr Psychiatry Rep*, *19*(9), 64. https://doi.org/10.1007/s11920-017-0818-2

Cheung, D. S. K., Ho, K. H. M., Cheung, T. F., Lam, S. C., & Tse, M. M. Y. (2018). Anticipatory grief of spousal and adult children caregivers of people with dementia. *BMC Palliative Care*, *17*(1), 124. https://doi.org/10.1186/s12904-018-0376-3

Cho, M., & Kim, O. (2024). Development and Validation of the Dementia Caregiver Burden Scale: A Tool for Community-Dwelling Dementia Caregiver. *Journal of Nursing Research*, *32*(4).

Connors, M. H., Seeher, K., Teixeira-Pinto, A., Woodward, M., Ames, D., & Brodaty, H. (2020). Dementia and caregiver burden: A three-year longitudinal study. *Int J Geriatr Psychiatry*, *35*(2), 250–258. https://doi.org/10.1002/gps.5244

Desmond, D. W. (2004). The neuropsychology of vascular cognitive impairment: is there a specific cognitive deficit? *Journal of the Neurological Sciences*, *226*(1), 3–7. https://doi.org/https://doi.org/10.1016/j.jns.2004.09.002

Domeisen Benedetti, F., Hechinger, M., & Fringer, A. (2024). Self-Assessment Instruments for Supporting Family Caregivers: An Integrative Review. *Healthcare (Basel)*, *12*(10). https://doi.org/10.3390/healthcare12101016

el Haj, M., Gallouj, K., Moustafa, A. A., Potard, C., & Chapelet, G. (2024). Negative effects of institutionalization on the sense of self in Alzheimer's Disease. *Geriatric Nursing*, *59*, 1–6. https://doi.org/https://doi.org/10.1016/j.gerinurse.2024.06.049

Elliott, A. F., Burgio, L. D., & Decoster, J. (2010). Enhancing caregiver health: findings from the resources for enhancing Alzheimer's caregiver health II intervention. *J Am Geriatr Soc*, *58*(1), 30–37. https://doi.org/10.1111/j.1532-5415.2009.02631.x

García-Martín, V., de Hoyos-Alonso, M. C., Delgado-Puebla, R., Ariza-Cardiel, G., & del Cura-González, I. (2023). Burden in caregivers of primary care patients with dementia: influence of neuropsychiatric symptoms according to disease stage (NeDEM project). *BMC Geriatrics*, *23*(1), 525. https://doi.org/10.1186/s12877-023-04234-0

Goto, Y., Morita, K., Suematsu, M., Imaizumi, T., & Suzuki, Y. (2023). Caregiver Burdens, Health Risks, Coping and Interventions among Caregivers of Dementia Patients: A Review of the Literature. *Intern Med*, *62*(22), 3277–3282. https://doi.org/10.2169/internalmedicine.0911-22

Hafiz, R., Alajlani, L., Ali, A., Algarni, G. A., Aljurfi, H., Alammar, O. A. M., Ashqan, M. Y., & Alkhashan, A. (2023). The Latest Advances in the Diagnosis and Treatment of Dementia. *Cureus*, *15*(12), e50522. https://doi.org/10.7759/cureus.50522

Han, J. W., Jeong, H., Park, J. Y., Kim, T. H., Lee, D. Y., Lee, D. W., Ryu, S. H., Kim, S. K., Yoon, J. C., Jhoo, J., Kim, J. L., Lee, S. B., Lee, J. J., Kwak, K. P., Kim, B. J., Park, J. H., & Kim, K. W. (2014). Effects of social supports on burden in caregivers of people with dementia. *Int Psychogeriatr*, *26*(10), 1639–1648. https://doi.org/10.1017/s1041610214001331

Hsu, E.-C., Tsai, J. H.-C., Chim, K., & Spigner, C. (2025). Multi-level factors of Chinese American family caregivers of individuals with dementia during COVID-19. *Geriatric Nursing*, *62*, 200–206. https://doi.org/https://doi.org/10.1016/j.gerinurse.2025.01.041

Hsu, E. C., Tsai, J. H., Chim, K., & Spigner, C. (2025). Multi-level factors of Chinese American family caregivers of individuals with dementia during COVID-19. *Geriatr Nurs*, *62*(Pt A), 200–206. https://doi.org/10.1016/j.gerinurse.2025.01.041

Hughes, M. C., Liu, Y., & Baumbach, A. (2021). Impact of COVID-19 on the Health and Well-being of Informal Caregivers of People with Dementia: A Rapid Systematic Review. *Gerontol Geriatr Med*, *7*, 23337214211020164. https://doi.org/10.1177/23337214211020164

Idorenyin Imoh, U., & Charity, T. (2023). Cultural and Social Factors in Care Delivery Among African American Caregivers of Persons With Dementia: A Scoping Review. *Gerontol Geriatr Med*, *9*, 23337214231152002. https://doi.org/10.1177/23337214231152002

Igarashi, A., Fukuda, A., Teng, L., Ma, F. F., Dorey, J., & Onishi, Y. (2020). Family caregiving in dementia and its impact on quality of life and economic burden in Japan-web based survey. *J Mark Access Health Policy*, *8*(1), 1720068. https://doi.org/10.1080/20016689.2020.1720068

Jeong, H., Kim, H., Kim, E., Chee, W., & Im, E.-O. (2025). Racial/ethnic differences in social support for dementia caregiving: Midlife women family caregivers of people with Alzheimer's disease. *Geriatric Nursing*, *62*, 131–137. https://doi.org/https://doi.org/10.1016/j.gerinurse.2025.01.025

Kalibatseva, Z., Leong, F. T., Ham, E. H., Lannert, B. K., & Chen, Y. (2017). Loss of face, intergenerational family conflict, and depression among Asian American and European American college students. *Asian American journal of psychology*, *8*(2), 126.

Kenne Malaha, A., Thébaut, C., Ahouantchede, S. H., Houinato, D. S., Gnonlonfoun, D. D., Adoukonou, T., Gansou, G. M., Preux, P. M., & Guerchet, M. (2025). Quality of Life of Older Adults Living With Dementia and Caregiver Strain in Benin. *Value Health Reg Issues*, *47*, 101080.

https://doi.org/10.1016/j.vhri.2025.101080

Kılınç İşleyen, E., Korkmaz, S. E., Narcıkara, C., & Ekici, B. (2025). Caregiver burden, religious coping, and spiritual well-being among caregivers of elderly stroke patients and predictors affecting spiritual well-being. *Psychogeriatrics*, *25*(1), e13206. https://doi.org/10.1111/psyg.13206

Kim, B., Noh, G. O., & Kim, K. (2021). Behavioural and psychological symptoms of dementia in patients with Alzheimer's disease and family caregiver burden: a path analysis. *BMC Geriatrics*, *21*(1), 160. https://doi.org/10.1186/s12877-021-02109-w

Koyama, A., Matsushita, M., Hashimoto, M., Fujise, N., Ishikawa, T., Tanaka, H., Hatada, Y., Miyagawa, Y., Hotta, M., & Ikeda, M. (2017). Mental health among younger and older caregivers of dementia patients. *Psychogeriatrics*, *17*(2), 108–114.

Liu-Seifert, H., Siemers, E., Sundell, K., Price, K., Han, B., Selzler, K., Aisen, P., Cummings, J., Raskin, J., & Mohs, R. (2015). Cognitive and functional decline and their relationship in patients with mild Alzheimer's dementia. *J Alzheimers Dis*, *43*(3), 949–955. https://doi.org/10.3233/jad-140792

Liu, Y., Hughes, M. C., & Wang, H. (2024). Financial strain, health behaviors, and psychological well-being of family caregivers of older adults during the COVID-19 pandemic. *PEC Innovation*, *4*, 100290. https://doi.org/https://doi.org/10.1016/j.pecinn.2024.100290

Livingston, G., Huntley, J., Sommerlad, A., Ames, D., Ballard, C., Banerjee, S., Brayne, C., Burns, A., Cohen-Mansfield, J., Cooper, C., Costafreda, S. G., Dias, A., Fox, N., Gitlin, L. N., Howard, R., Kales, H. C., Kivimäki, M., Larson, E. B., Ogunniyi, A.,…Mukadam, N. (2020). Dementia prevention, intervention, and care: 2020 report of the Lancet Commission. *Lancet*, *396*(10248), 413–446. https://doi.org/10.1016/s0140-6736(20)30367-6

Long, S., Benoist, C., & Weidner, W. (2023). World Alzheimer Report 2023: Reducing dementia risk: never too early, never too late. *Alzheimer's Disease International*.

Lwi, S. J., Ford, B. Q., & Levenson, R. W. (2023). Cultural differences in caring for people with dementia: a pilot study of concern about losing face and loneliness in Chinese American and European American caregivers. *Clin Gerontol*, *46*(2), 207–222. https://doi.org/10.1080/07317115.2022.2137448

Maximiano-Barreto, M. A., Alves, L. C. S., Monteiro, D. Q., Gratão, A. C. M., Pavarini, S. C. I., Luchesi, B. M., & Chagas, M. H. N. (2022). Cultural factors associated with burden in unpaid caregivers of older adults: A systematic review. *Health Soc Care Community*, *30*(6), e3629–e3642. https://doi.org/10.1111/hsc.14003

McGee, J. S., Davie, M., Meraz, R., Myers, D., & Boddie, S. C. (2022). Does the Tough Stuff Make Us Stronger? Spiritual Coping in Family Caregivers of Persons with Early-Stage Dementia. *Religions*, *13*(8), 756.

Merrilees, J., Dowling, G. A., Hubbard, E., Mastick, J., Ketelle, R., & Miller, B. L. (2013). Characterization of apathy in persons with frontotemporal dementia and the impact on family caregivers. *Alzheimer Dis Assoc Disord*, *27*(1), 62–67. https://doi.org/10.1097/WAD.0b013e3182471c54

Mo, M., Abzhandadze, T., Hoang, M. T., Sacuiu, S., Jurado, P. G., Pereira, J. B., Naia, L., Kele, J., Maioli, S., Xu, H., Eriksdotter, M., & Garcia-Ptacek, S. (2025). Antidepressant use and cognitive decline in patients with dementia: a national cohort study. *BMC Medicine*, *23*(1), 82. https://doi.org/10.1186/s12916-025-03851-3

Moon, H. E., Rote, S. M., Sears, J., & Schepens Niemiec, S. L. (2022). Racial Differences in the Dementia Caregiving Experience During the COVID-19 Pandemic: Findings From the National Health and Aging Trends Study (NHATS). *J Gerontol B Psychol Sci Soc Sci*, *77*(12), e203–e215. https://doi.org/10.1093/geronb/gbac098

Nandi, A., Counts, N., Bröker, J., Malik, S., Chen, S., Han, R., Klusty, J., Seligman, B., Tortorice, D., Vigo, D., & Bloom, D. E. (2024). Cost of care for Alzheimer's disease and related dementias in the United States: 2016 to 2060. *npj Aging*, *10*(1), 13. https://doi.org/10.1038/s41514-024-00136-6

Pacheco Barzallo, D., Schnyder, A., Zanini, C., & Gemperli, A. (2024). Gender Differences in Family Caregiving. Do female caregivers do more or undertake different tasks? *BMC Health Services Research*, *24*(1), 730. https://doi.org/10.1186/s12913-024-11191-w

Pan, Y., Chen, R., & Yang, D. (2022). The relationship between filial piety and caregiver burden among adult children: A systematic review and meta-analysis. *Geriatric Nursing*, *43*, 113–123. https://doi.org/https://doi.org/10.1016/j.gerinurse.2021.10.024

Pillemer, S., Davis, J., & Tremont, G. (2018). Gender effects on components of burden and depression among dementia caregivers. *Aging Ment Health*, *22*(9), 1156–1161. https://doi.org/10.1080/13607863.2017.1337718

Poco, L. C., Bostwick, A. E., Ishwarya, B., & and Malhotra, C. (2025). Financial difficulties and well-being among caregivers of persons with severe dementia. *Aging & Mental Health*, 1–10. https://doi.org/10.1080/13607863.2025.2481978

Possin, K. L., Merrilees, J. J., Dulaney, S., Bonasera, S. J., Chiong, W., Lee, K., Hooper, S. M., Allen, I. E., Braley, T., Bernstein, A., Rosa, T. D., Harrison, K., Begert-Hellings, H., Kornak, J., Kahn, J. G., Naasan, G., Lanata, S., Clark, A. M., Chodos, A.,…Miller, B. L. (2019). Effect of Collaborative Dementia Care via Telephone and Internet on Quality of Life, Caregiver Well-being, and Health Care Use: The Care Ecosystem Randomized Clinical Trial. *JAMA Intern Med*, *179*(12), 1658–1667. https://doi.org/10.1001/jamainternmed.2019.4101

Quinn, C., Gamble, L. D., Parker, S., Martyr, A., Collins, R., Victor, C., Dawson, E., Hunt, A., Pentecost, C., Allan, L., & Clare, L. (2022). Impact of COVID-19 on carers of people with dementia in the community: Findings from the British IDEAL cohort. *Int J Geriatr Psychiatry*, *37*(5). https://doi.org/10.1002/gps.5708

Rahman, M. R., Aktar, N., & Islam, F. (2025). Assessment of the Psychological Burden Among Family Caregivers of People Living With Dementia, Parkinson's, and Alzheimer's Disease Using the Zarit Burden Interview From Bangladesh. *Brain Behav*, *15*(5), e70527. https://doi.org/10.1002/brb3.70527

Rashid, N. S. A., Mohamad Marzuki, M. F., Abdullah, N. N., Mohamad, M., Takshe, A. A., Mohd Yunus, R., & Chen, X. W. (2024). Supporting caregivers of people with dementia: insights from Demensia KITA mobile application online content development. *Scientific Reports*, *14*(1), 19302. https://doi.org/10.1038/s41598-024-69947-7

Rathier, L. A., Davis, J. D., Papandonatos, G. D., Grover, C., & Tremont, G. (2015). Religious Coping in Caregivers of Family Members With Dementia. *J Appl Gerontol*, *34*(8), 977–1000. https://doi.org/10.1177/0733464813510602

Reed, C., Belger, M., Scott Andrews, J., Tockhorn-Heidenreich, A., Jones, R. W., Wimo, A., Dodel, R., & Haro, J. M. (2020). Factors associated with long-term impact on informal caregivers during Alzheimer's disease dementia progression: 36-month results from GERAS. *Int Psychogeriatr*, *32*(2), 267–277. https://doi.org/10.1017/s1041610219000425

Romero, J. P., Benito-León, J., Louis, E. D., & Bermejo-Pareja, F. (2014). Under reporting of dementia deaths on death certificates: a systematic review of population-based cohort studies. *J Alzheimers Dis*, *41*(1), 213–221. https://doi.org/10.3233/jad-132765

Sabates, J., Chiu, W.-H., Loi, S., Lampit, A., Gavelin, H. M., Chong, T., Launder, N., Goh, A. M. Y., Brodtmann, A., Lautenschlager, N., & Bahar-Fuchs, A. (2024). The Associations Between Neuropsychiatric Symptoms and Cognition in People with Dementia: A Systematic Review and Meta-Analysis. *Neuropsychology Review*, *34*(2), 581–597. https://doi.org/10.1007/s11065-023-09608-0

Sabatini, S., Martyr, A., Hunt, A., Gamble, L. D., Matthews, F. E., Thom, J. M., Jones, R. W., Allan, L., Knapp, M., Quinn, C., Victor, C., Pentecost, C., Rusted, J. M., Morris, R. G., & Clare, L. (2024). Health conditions in spousal caregivers of people with dementia and their relationships with stress, caregiving experiences, and social networks: longitudinal findings from the IDEAL programme. *BMC Geriatrics*, *24*(1), 171. https://doi.org/10.1186/s12877-024-04707-w

Scerbe, A., O'Connell, M. E., Astell, A., Morgan, D., Kosteniuk, J., Panyavin, I., DesRoches, A., & Webster, C. (2023). Digital tools for delivery of dementia education for caregivers of persons with dementia: A systematic

review and meta-analysis of impact on caregiver distress and depressive symptoms. *PLoS One*, *18*(5), e0283600. https://doi.org/10.1371/journal.pone.0283600

Schaffler-Schaden, D., Krutter, S., Seymer, A., Eßl-Maurer, R., Flamm, M., & Osterbrink, J. (2021). Caring for a Relative with Dementia: Determinants and Gender Differences of Caregiver Burden in the Rural Setting. *Brain Sci*, *11*(11). https://doi.org/10.3390/brainsci11111511

Seng, B., Luo, N., Ng, W., Lim, J., Chionh, H., Goh, J., & Yap, P. (2010). Validity and Reliability of the Zarit Burden Interview in Assessing Caregiving Burden. *Annals of the Academy of Medicine, Singapore*, *39*, 758–763. https://doi.org/10.47102/annals-acadmedsg.V39N10p758

Shah, A., Snow, B., & Kunik, M. (2001). Spiritual and Religious Coping in Caregivers of Patients with Alzheimer's Disease. *Clinical Gerontologist*, *243*. https://doi.org/10.1300/J018v24n03_11

Sharma, N., Chakrabarti, S., & Grover, S. (2016). Gender differences in caregiving among family - caregivers of people with mental illnesses. *World J Psychiatry*, *6*(1), 7–17. https://doi.org/10.5498/wjp.v6.i1.7

Skaria, A. P. (2022). The economic and societal burden of Alzheimer disease: managed care considerations. *Am J Manag Care*, *28*(10 Suppl), S188–s196. https://doi.org/10.37765/ajmc.2022.89236

Sörensen, S., & Conwell, Y. (2011). Issues in dementia caregiving: effects on mental and physical health, intervention strategies, and research needs. *Am J Geriatr Psychiatry*, *19*(6), 491–496. https://doi.org/10.1097/JGP.0b013e31821c0e6e

Tay, L. X., Ong, S. C., Ong, H. M., Teh, E. E., Ch'ng, A. S. H., Tiong, I. K., Razali, R. M., & Parumasivam, T. (2025). Caregiver burden of Alzheimer's disease among informal caregivers: a cross-sectional study in Malaysia. *Scientific Reports*, *15*(1), 10067. https://doi.org/10.1038/s41598-025-95210-8

Teles, S., Viana, J., Freitas, A., Ribeiro, Ó., Alves, S., Ferreira, A., & Paúl, C. (2024). Predicting informal dementia caregivers' desire to institutionalize through mining data from an eHealth platform. *BMC Geriatrics*, *24*(1), 721. https://doi.org/10.1186/s12877-024-05128-5

Tolea, M. I., Morris, J. C., & Galvin, J. E. (2016). Trajectory of Mobility Decline by Type of Dementia. *Alzheimer Dis Assoc Disord*, *30*(1), 60–66. https://doi.org/10.1097/wad.0000000000000091

Tran, J. T., Theng, B., Tzeng, H. M., Raji, M., Serag, H., Shih, M., & Lee, W. M. (2023). Cultural Diversity Impacts Caregiving Experiences: A Comprehensive Exploration of Differences in Caregiver Burdens, Needs, and Outcomes. *Cureus*, *15*(10), e46537. https://doi.org/10.7759/cureus.46537

Tsai, C.-F., Hwang, W.-S., Lee, J.-J., Wang, W.-F., Huang, L.-C., Huang, L.-K.,

Lee, W.-J., Sung, P.-S., Liu, Y.-C., Hsu, C.-C., & Fuh, J.-L. (2021). Predictors of caregiver burden in aged caregivers of demented older patients. *BMC Geriatrics*, *21*(1), 59. https://doi.org/10.1186/s12877-021-02007-1

Tu, J. Y., Jin, G., Chen, J.-H., & Chen, Y.-C. (2022). Caregiver burden and dementia: a systematic review of self-report instruments. *Journal of Alzheimer's Disease*, *86*(4), 1527–1543.

Van De Vorst, I. E., Koek, H. L., Stein, C. E., Bots, M. L., & Vaartjes, I. (2016). Socioeconomic disparities and mortality after a diagnosis of dementia: results from a nationwide registry linkage study. *American journal of epidemiology*, *184*(3), 219–226.

van den Kieboom, R., Snaphaan, L., Mark, R., & Bongers, I. (2020). The Trajectory of Caregiver Burden and Risk Factors in Dementia Progression: A Systematic Review. *J Alzheimers Dis*, *77*(3), 1107–1115. https://doi.org/10.3233/jad-200647

Van Ooteghem, K., Musselman, K. E., Mansfield, A., Gold, D., Marcil, M. N., Keren, R., Tartaglia, M. C., Flint, A. J., & Iaboni, A. (2019). Key factors for the assessment of mobility in advanced dementia: A consensus approach. *Alzheimers Dement (N Y)*, *5*, 409–419. https://doi.org/10.1016/j.trci.2019.07.002

Wakefield, C. J. (2020). Community respite service utilisation and dementia care: A review of literature. *Australian Journal of Advanced Nursing, The*, *37*(2), 31–37.

Walter, E., & Pinquart, M. (2020). How Effective Are Dementia Caregiver Interventions? An Updated Comprehensive Meta-Analysis. *Gerontologist*, *60*(8), 609–619. https://doi.org/10.1093/geront/gnz118

Wang, L., Zhou, Y., Fang, X., & Qu, G. (2022). Care burden on family caregivers of patients with dementia and affecting factors in China: A systematic review. *Front Psychiatry*, *13*, 1004552. https://doi.org/10.3389/fpsyt.2022.1004552

Wang, Z., Wang, K., & Monin, J. K. (2025). Family cohesion and conflict in the context of adult children and parents living with early-stage cognitive impairment. *Aging Ment Health*, 1–7. https://doi.org/10.1080/13607863.2025.2495282

Waymouth, M., Siconolfi, D., Friedman, E. M., Saliba, D., Ahluwalia, S. C., & Shih, R. A. (2023). Barriers and Facilitators to Home- and Community-Based Services Access for Persons With Dementia and Their Caregivers. *The Journals of Gerontology: Series B*, *78*(6), 1085–1097. https://doi.org/10.1093/geronb/gbad039

Wei, G., Diehl-Schmid, J., Matias-Guiu, J. A., Pijnenburg, Y., Landin-Romero, R., Bogaardt, H., Piguet, O., & Kumfor, F. (2022). The effects of the COVID-19 pandemic on neuropsychiatric symptoms in dementia and carer mental health: an international multicentre study. *Scientific Reports*, *12*(1), 2418. https://doi.org/10.1038/s41598-022-05687-w

Wolff, J. L., Cornman, J. C., & Freedman, V. A. (2025). The Number Of Family Caregivers Helping Older US Adults Increased From 18 Million To 24 Million, 2011–22. *Health Affairs*, *44*(2), 187–195. https://doi.org/10.1377/hlthaff.2024.00978

Wongmek, A., Wongviriyawong, T., Pitiyarn, S., Siritipakorn, P., Phannarus, H., & Muangpaisan, W. (2023). Effect of the COVID-19 Pandemic on the Self-Perceived Change of Caregivers' Burden in Providing Care for People With Dementia. *Gerontol Geriatr Med*, *9*, 23337214231176698. https://doi.org/10.1177/23337214231176698

World Health Organization. (2023, March 9). *Dementia*. Retrieved May 24 from https://www.who.int/news-room/fact-sheets/detail/dementia

Zhang, J., Zhang, Y., Wang, J., Xia, Y., Zhang, J., & Chen, L. (2024). Recent advances in Alzheimer's disease: mechanisms, clinical trials and new drug development strategies. *Signal Transduction and Targeted Therapy*, *9*(1), 211. https://doi.org/10.1038/s41392-024-01911-3

APPENDIX

Figure 1.

Search strategy