SCHOLARLY REVIEW

SCHOLARLY REVIEW JOURNAL

E-ISSN: 2996-8380
Published by Leadership & Innovation Lab

FALL 2025

Caring for the Caregivers: Addressing the Health, Financial, and Systemic Challenges of Alzheimer's Disease

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ABSTRACT

Unpaid caregivers (spouses and adult children) provide the majority of care to Americans with Alzheimer's disease, a progressive condition that demands intensive, long-term support. This review examines the challenges confronting these caregivers and evaluates emerging policy solutions to address the growing crisis. It identifies three primary areas of concern: significant physical and mental health deterioration among unpaid caregivers, substantial financial burdens that disproportionately affect lower-income households, and limited access to reliable and affordable institutional services. It then assesses several recent policy proposals, including a new care delivery and payment model, a tax credit for unpaid caregivers, and regulatory measures aimed at private equity-owned nursing homes. The review concludes that although these initiatives mark meaningful progress, they fall short of alleviating the severe burdens faced by Alzheimer's caregivers.

Keywords: Alzheimer's Disease, Dementia, Long-Term Care, Unpaid Caregivers, Caregiver Burden, Nursing Homes, Private Equity, Health Policy

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INTRODUCTION

According to the Alzheimer's Association, an estimated 6.9 million Americans were living with Alzheimer's disease in 2024—a figure projected to double by 2060 barring medical breakthroughs (Alzheimer's Association, 2024). Alzheimer's falls under the umbrella of dementia, which is a general term describing cognitive decline severe enough to interfere with daily life. Despite its prevalence, scientists still lack a complete understanding of what causes Alzheimer's due to the disease's complexity and the extended timeframe over which it develops. At the time of writing, the most advanced drugs can only moderately slow cognitive decline during the early stages of Alzheimer's.

Even though Alzheimer's is a progressive and terminal condition, patients typically live an average of 4 to 8 years after diagnosis, spending much of that time in a state of severe dependence (Larson et al., 2004). This prolonged period of decline is grueling for both patients and their caregivers, as the demands of caregiving eventually extend to every aspect of daily life. Thus, Alzheimer's places a heavy burden on caregivers across society. Although some care is provided by paid professionals, studies consistently show that unpaid caregivers, particularly spouses and adult children, provide the vast majority of care. For example, research in *Health Affairs* found that informal caregivers account for 83% of total care hours received by older adults (Friedman et al., 2015). America's reliance on informal caregivers is driven by deep-rooted social norms, the high cost of long-term care insurance, and inconsistent care quality resulting from low wages and high staff turnover in the professional caregiving sector.

Currently, these vital unpaid caregivers struggle with physical and mental health challenges, face substantial financial burdens, and have limited access to reliable institutional or home-based care services. Considering the rapidly aging population, targeted measures to support informal caregivers are essential to prevent the disease from exerting further pressure on this already vulnerable group. Such measures should not only protect the physical, mental, and financial well-being of informal caregivers but also improve the quality and affordability of paid care.

PHYSICAL AND MENTAL HEALTH STRUGGLES

In 2023, more than 11 million unpaid caregivers provided approximately 18.4 billion hours of care to individuals with Alzheimer's or other dementias, reflecting a decrease in the number of caregivers but an increase in care hours per caregiver compared to the previous decade (Alzheimer's Association, 2024). On average, Alzheimer's caregivers provide 27 hours more care per month than caregivers of other conditions (Kasper et al., 2016).

The prolonged caregiving hours directly impact caregivers' health, with 74% of unpaid Alzheimer's caregivers reporting concerns about maintaining their own well-being (Alzheimer's Association, 2024). This worry is not unfounded, as numerous clinical studies have substantiated these adverse health outcomes. To start, researchers from the University of California at San Diego identified increased risks of hypertension and

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coronary heart disease among Alzheimer's caregivers as a result of elevated levels of stress hormones (Shaw et al., 1999). Moreover, Alzheimer's caregivers' sleep quality—a key indicator of health and well-being—is often compromised by the disruptive nighttime behaviors of care recipients. One study revealed that caregivers typically lose 2.42 to 3.50 hours of sleep weekly compared to non-caregivers (Gao et al., 2019). Due to high stress and poor sleep quality, informal caregivers become markedly more susceptible to diseases and health complications.

Despite these considerable challenges, many caregivers report positive aspects of the experience, such as finding meaning in their lives and feeling needed. However, these anecdotes may reflect participation bias more than they reflect the broader psychological reality of caregiving. According to a meta-analysis conducted by researchers from the University of Adelaide's Faculty of Health and Medical Sciences, dementia caregivers experience significantly higher rates of depression and anxiety than non-caregivers (Ma et al., 2017). These psychological challenges are compounded by social isolation, as dementia caregivers consistently report greater reductions in their social networks compared to those caring for individuals with other conditions (Liu et al., 2020). The combination of mental burden and diminished social support carries serious consequences, as demonstrated by Richard Schulz's highly cited cohort study, which identified emotional strain from caregiving as an independent mortality risk factor, with caregivers facing a 63% higher risk of death within four years compared to non-caregivers (Schulz & Beach, 1999).

FINANCIAL CHALLENGES

Based on an evidence-based mathematical model developed by Dr. Jutkowitz, the lifetime cost of care for an individual with Alzheimer's approached $400,000 in 2023, with families bearing 70% of the burden through unpaid caregiving and out-of-pocket expenses (Jutkowitz et al., 2017). Importantly, Medicare—the federal health insurance program for U.S. adults aged 65 and older—does not cover long-term custodial care, which constitutes the majority of caregiving needs for Alzheimer's patients. In addition, the significant time commitment required for dementia care results in 9% of dementia caregivers leaving the workforce entirely, nearly twice the rate of caregivers for other conditions (Alzheimer's Association, 2024). Consequently, the Alzheimer's Association estimates that 48% of informal caregivers reduce general spending and 43% cut savings to meet caregiving obligations (Alzheimer's Association, 2024). Sadly, Alzheimer's caregiving disproportionately impacts lower-income households, as 41% of caregivers report annual incomes of $50,000 or less (Alzheimer's Association, 2024). Most caregivers in this income bracket cannot afford to quit their jobs and often struggle to manage overwhelming stress and hectic schedules alone, resulting in a decline in both physical and mental health.

LACK OF AFFORDABLE AND HIGH-QUALITY PAID CARE

As established above, most caregivers lack the financial means to stop working and concentrate on providing care for a family member with Alzheimer's. Additionally, approximately a quarter of U.S. dementia caregivers simultaneously care for an aging parent and at least one child (Lei et al., 2022). In these circumstances,

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caregivers must often choose between memory care facilities, nursing homes, or hiring a home health aide. However, these services have become increasingly scarce and unaffordable, and their quality remains generally poor and inconsistent.

According to the American Health Care Association, there were 62,567 fewer nursing home beds in 2024 compared to 2020. Additionally, at least 774 nursing homes closed, and 20% reduced operational capacity over this four-year period (American Health Care Association, 2024). Meanwhile, over the past two years, the cost of in-home care increased by 13%, while the cost of a private nursing home room rose by 15% (Genworth, 2024). Other than the contribution of inflation, the increased presence of private equity in this sector is a major factor. From 2010 to 2020, private equity deals in US healthcare totaled $750 billion (Scheffler et al., 2023). Private equity firms finance acquisitions with a significant amount of debt for amplified returns and tax benefits. As a result, private equity firms have typically raised prices and reduced costs in acquired facilities, most commonly by cutting staff. To compensate for reduced staffing, private equity-owned nursing homes administer antipsychotics at rates 50% higher than those of non-private equity-owned facilities, leading to substantially higher mortality rates (Gupta et al., 2020). Furthermore, when private equity firms acquire nursing home chains, they often close underperforming facilities and sell off real estate assets to raise immediate capital for debt repayment, contributing to the decline in the number of nursing homes.

In addition to private equity involvement, an unstable care workforce is another key driver of nursing home closures. A study examining nursing staff turnover from 2017 to 2018 found a mean annual turnover rate of 128%, indicating that many nursing homes had to replace their entire staff in less than a year (Gandhi et al., 2021). The high turnover rates among professional caregivers can be attributed to persistently low wages and difficult working conditions. According to a report by the Paraprofessional Healthcare Institute, the median hourly wage for direct care workers was just $15.43 in 2022 (Paraprofessional Healthcare Institute, 2023). At the same time, nursing home workers were eight times more likely than the average U.S. worker to experience workplace injuries in 2020 (Bureau of Labor Statistics, 2020).

SOLUTIONS

On July 1, 2024, the Centers for Medicare & Medicaid Services (CMS) launched the Guiding an Improved Dementia Experience (GUIDE) model. Under the model, participating organizations are required to provide unpaid caregivers with access to a 24/7 support line, respite services, and a care navigator for each patient. Given that these requirements are met, CMS would disburse a per-beneficiary per-month payment to the participating organization. In addition, CMS covers up to $2,500 in annual respite care costs per beneficiary. The support line and respite service alleviate pressure on unpaid caregivers, while the care navigator helps coordinate and guide families to available support and resources. Furthermore, the per-beneficiary per-month payment framework stands in contrast to the traditional fee-for-service framework that incentivized providing excessive services and discouraged effective care coordination. The novel payment methodology aims to foster a collaborative approach to caregiving, resulting in better outcomes and lower expenditures (Centers for Medicare & Medicaid Services, 2024).

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The GUIDE model eases the financial burden on unpaid caregivers by providing a respite care allowance and improving the cost-effectiveness of paid care, whereas the Credit for Caring Act of 2025 aims to provide direct financial support through a tax credit. Introduced in March 2025, the latest version of the Credit for Caring Act proposes a nonrefundable tax credit equal to 30% of annual caregiving expenses that exceed a $2,000 threshold, up to a maximum of $5,000 (Carey, 2025). At the time of writing, the bill awaits consideration in the tax-writing committees. Given the significant cuts to Medicaid and Medicare, along with the substantial increase in the projected budget deficit following the recent passage of the One Big Beautiful Bill Act, the Credit for Caring Act is unlikely to make meaningful legislative progress in the near future. However, there is overwhelming bipartisan support for policies that help unpaid caregivers. In a poll of over 4,000 voters, which included nearly equal numbers of Democrats and Republicans, 82% expressed support for providing tax credits to unpaid caregivers (Long, 2024). Additionally, the poll found that 82% of voters support a paid leave program for informal caregivers, indicating a clear future direction for legislators (Long, 2024). Ultimately, the success of these policy solutions will depend largely on how they are incorporated into a broader legislative vehicle alongside other priorities.

Finally, the crisis in paid care demands a multi-pronged policy response. In January 2024, the Biden Administration implemented a rule requiring all Medicare and Medicaid-participating nursing homes to disclose their ownership information to CMS (Edelman, 2023). Currently, CMS is collecting data and updating its forms to more clearly identify private equity in complex structures. Progressive lawmakers have introduced legislative proposals to impose stricter regulations on private equity, most notably the Stop Wall Street Looting Act. Last reintroduced in November 2024, the act limits the use of debt in acquisitions, prohibits private equity firms from liquidating assets to raise cash, and establishes criminal liability for private equity owners in cases of patient harm or death (Warren, 2023). The act currently lacks Republican support and is unlikely to pass without Democratic control of all three branches of government. However, key provisions of the act should be considered by CMS, the Department of Justice, and the Department of Health and Human Services when developing regulations in response to ownership data and high-profile cases of financial distress within the industry. For all Medicare and Medicaid-participating nursing homes, CMS has begun linking payment to quality and enforcing minimum staffing ratios. These measures are expected not only to improve the quality of care but also to reduce injuries among nursing home workers, thereby contributing to a more stable care workforce. In light of the current political environment, efforts to raise the minimum wage for care workers at the federal level are likely to face significant opposition. The most feasible short-term strategy is to pursue the extension of union wage bargaining rights for care workers.

CONCLUSION

The convergence of severe health impacts, financial pressures, and systemic care shortages has created an unsustainable situation for the millions of Americans caring for family members with Alzheimer's disease. While the GUIDE model and proposed legislation such as the Credit for Caring Act represent promising first steps, addressing this crisis requires a combination of solutions encompassing structural support programs, targeted

financial relief, regulatory reform of private equity practices in nursing homes, and workforce investment to improve wages and working conditions.

The urgency of these reforms cannot be overstated. An aging population is expanding the pool of individuals at risk for Alzheimer's disease, and reduced workforce participation by caregivers will slow economic growth, shrink tax revenues, and strain funding for public programs such as Medicare and Medicaid.

By implementing and advancing the policies reviewed in this article, the United States can develop a more sustainable approach to Alzheimer's care that supports and safeguards a vulnerable population.

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