Invisible Patients

The Hidden Health Costs of Caregiving

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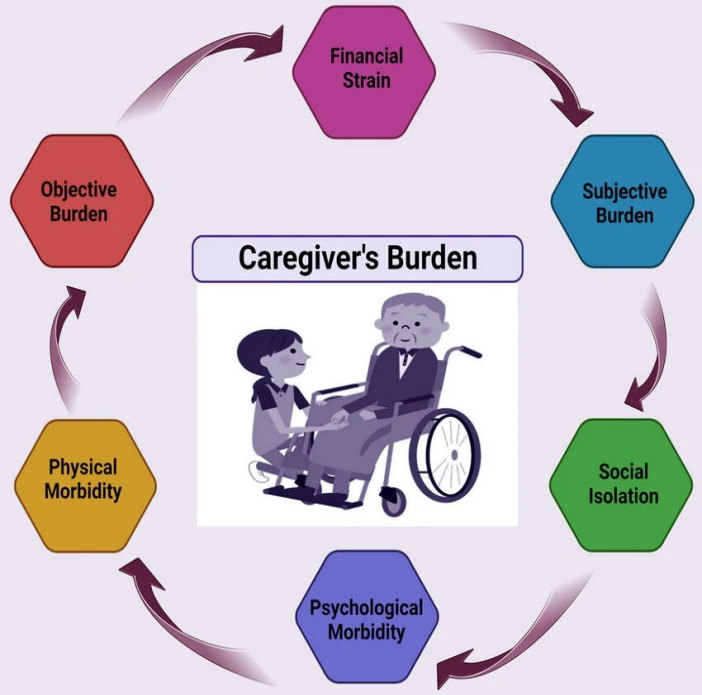


Figure courtesy of Sehar et al. (2023).

Introduction

The United States is rapidly aging—between the years 2004 and 2024, the aging population (65 and older) has increased by 5.6% (Lin & Horowitz, 2025). By 2034, this population will outgrow the population under 18 years of age (United States Census Bureau, 2018). The declining birth rate, size of the Baby Boomer generation, and heightened life expectancy have culminated in a massive need for caregivers, the majority of whom are family members. Roughly 24% of the U.S. population report fulfilling the role of a caregiver (The National Alliance for Caregiving & AARP, 2025), and caregivers often report the positive impact of caregiving on their interpersonal relationships, increased meaning in one's life, and a sense of giving back (American Psychological Association, 2011). Yet its repercussions—which include high stress, depression, and chronic inflammation (Christian, 2023)—remain invisible in the modern U.S. healthcare system.

Caregiving as a Chronic Biological Stressor

Caregiving produces biological responses comparable to other chronic stressors. Chronic stressors are defined as long-term activation of the stress response system, particularly the hypothalamic-pituitary-adrenal axis. This long-term activation results in excessive exposure to cortisol (Mayo Clinic Staff, 2023), which increases the risk of heart disease, difficulties with memory and focus, depression, accelerated aging, and increased risk of health problems such as cognitive impairments and cardiovascular disease (Luecken & Lemery, 2004). In individuals experiencing high levels of psychosocial stress, proteins involved in managing inflammation may become dysfunctional, and this stress is associated with heart failure (Bidwell & Cothran, 2021). One population in which these physiological effects are especially pronounced is caregivers.

Although a clear definition is lacking, caregiver burden is widely understood to be a multifaceted strain perceived by the caregiver arising from prolonged exposure to chronic stressors, which can lead to widespread physiological dysregulation (Liu et al., 2020). Caregivers experience allostatic load, the cumulative burden of chronic stress and life events (Guidi et al., 2021). This burden is especially severe for those providing care for family members with mental illness, Parkinson's disease, dementia, and terminal cancer (Liu et al., 2020). Furthermore, men and women who provide care to a spouse with dementia experience more frequent infectious illness episodes, poorer immune responses, an increased risk of depression, and higher rates of hypertension (Christian, 2023). One of the many health risks that can be associated with caregiving is chronic inflammation and sustained overproduction of proinflammatory cytokines, which is linked to problems associated with aging such as cardiovascular disease, osteoporosis, arthritis, and type 2 diabetes (Christian, 2023). These effects have lasting impacts: Interleukin-6, a global marker of impending health deterioration, remains at similar levels in former and current caregivers, suggesting that the immunological impact continues years beyond the caregiving experience (Christian, 2023).

Psychological Stress and the Role of Stigma

The physical demands of caregiving are not the sole factors driving the health consequences. Psychological stress, often intensified by stigma—defined as societal labeling, stereotyping, and negative judgements—plays a critical role in shaping caregiver outcomes (Andersen et al., 2022). In caregivers, the particular manifestation is called caregiver affiliate stigma, in which caregivers internalize societal biases that eventually leads to negative self-perceptions and social withdrawal (Becerra Carrillo et al., 2024). Caregiver affiliate stigma encompasses three different types of stigma: public stigma, courtesy stigma, and family stigma. Public stigma involves the negative societal reaction toward individuals the caregiver is in charge of. Courtesy stigma extends the discrimination and negative perceptions of those with conditions needing caregivers transfers onto the caregivers themselves due to their association, affecting how they see themselves. Finally, family stigma involves the negative experiences of family members connected to the relatives with stigmatized conditions.

The combination of these stigmas results in increased caregiver burden and stress. For instance, it was found that caregiving for those with neurodegenerative disorders was associated with substantial psychological stress that exceeded physical strain (Becerra Carrillo et al., 2024). In addition to that, higher levels of affiliated stigma results in caregivers perceiving higher burden (Kaggwa et al., 2023). Essentially, the stigma tied to caregiving

and associated conditions intensifies stress, worsening mental and physical health, negative self-perception, and caregiver burden. For example, men who strongly identify with traditional male roles can feel judged for caregiving, tending to isolate themselves more, limiting emotional expression and support-seeking behaviors (Bhatt et al., 2022). In many cases, caregivers experience enacted stigma, such as staring and social exclusion, that pushes them to self-isolate as well (Sommers-Spijkerman et al., 2023). Altogether, these intersecting forms of stigma intensify caregiver burden by compounding psychological distress, ultimately exacerbating both mental and physiological health outcomes.

Structural Invisibility of Caregivers

Despite the substantial evidence of physiological and psychological risk, caregiving remains structurally invisible within healthcare and policy systems. Informal caregivers dedicate significant time and energy to work that is physically, socially, and emotionally demanding, yet their needs are rarely formally addressed in clinical care. They are often treated as secondary to patients, with limited institutional support or recognition of their health risks. In a national study, it was reported that only 16% percent of healthcare providers asked caregivers what resources they need for their own health and quality of life. This is in comparison to the 33% of caregivers that reported that they were asked what was needed to provide quality care to the care recipient (Barnhart, 2020). This invisibility persists despite evidence that the psychological burden associated with caregiving—particularly in the context of cancer—can exceed that of the patients themselves (Applebaum, 2015). This raises the question of why such a high-burden role remains consistently underrecognized.

One key explanation lies in cultural norms that frame caregiving as an expected moral obligation rather than a form of labor requiring support. In many communities, particularly among minority populations within the United States, caregiving is framed as a moral and spiritual responsibility, and an expression of intergenerational respect (Okigbo et al., 2025). The cultural emphasis on familism in Hispanic populations, for instance, drives caregivers to neglect their own health (Falzarano et al., 2021). This normalization contributes to the systematic overlooking of caregiver wellbeing. In conjunction with this, caregiving is often viewed as a natural, gendered duty, allowing others to overlook the wellbeing of caregivers. For example, in Japan, family caregiving is seen to be a common and expected part of relationships, particularly for women (Zarzycki et al., 2022).

Gender also plays a significant role in shaping concerns about caregiver health, with women accounting for roughly two-thirds of family caregivers (Barzallo et al., 2024). Despite a trend of more men taking on caregiving duties, female caregivers report a higher caregiver burden (Applebaum, 2015). Societal expectations often place women in the category of being selfless providers with roles centered on the home and family obligation. In contrast, there is a societal expectation that men be competitive, independent, and avoid weakness, shaping caregiving approaches that are more managerial (Barzallo et al., 2024). This expectation for men in caregiver roles leaves no room for emotion, further forcing male caregivers and the healthcare system to ignore their psychological needs. These different expectations contribute to a system where caregiver health is deprioritized and result in unequal burdens and lack of support.

Conclusion

Chronic illness diffuses across relationships, and therefore care must consider both the person being cared for and the person's caregivers. Despite the essential work caregivers do, most health care delivery models focus primarily on patients, failing to engage, educate, or support informal care providers (McHugh et al., 2025). The lack of internal resources, including coping behaviors, and external resources—such as financial support, help from other family members and formal care—result in caregivers experiencing high levels of stress (Roth et al., 2015). If caregiving constitutes a health risk exposure, then public health systems bear the responsibility of implementing policies that mitigate its physiological and psychological consequences. Evidence shows that caregiver interventions are effective, with 23 out of 26 reviews reporting reduction in caregiver depression and 9 out of 16 reviews showing decreased caregiver burden (McHugh et al., 2025). However, the persistence of caregiver burden despite these findings suggests that existing interventions are not being implemented at the required scale or integrated into standard care.

This gap highlights a critical opportunity for health systems to move towards structural reform. Accordingly, efforts should focus on better preparing caregivers, reducing stress and guilt of failing through education, and improving dissemination of information to healthcare providers to increase awareness of caregiver health (Roth et al., 2015). External factors, such as finances, have been found to be an added stress to caregivers. Therefore, some have suggested economic support resources, such as travel reimbursement, primary caregiver compensation by insurers, and the development of more accommodating policies that support family leaves of absences, are also needed (Roth et al., 2015). Furthermore, caregivers' health should be incorporated into the care plan and documented in health records to reduce their invisibility. Such efforts address the economical and emotional needs of caregivers, targeting the root of the stress that makes caregiving a health risk. Making caregivers visible is not simply an ethical imperative, but a necessary step towards improving population health as the aging community continues to grow.

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