November Medical Ethics Newsletter

Vol. 33

Written and Edited by: Kaitlynn Esemaya, Alexis Thompson, Annique McLune, and Anamaria Ancheta

Family Caregiver Disparities

Cultural and social factors significantly shape the experiences, burdens, and outcomes of family caregivers, often contributing to continued disparities in access, support, and health. Healthcare providers can learn from these factors to address inequities by adopting culturally sensitive, family-centered, and socially aware approaches. Cultural factors, including familism, expectations, and cultural duty, are some of the underlying factors driving caregivers' motivations, perceived obligations, and coping strategies. For example, for caregivers with African American, Hispanic, and Asian backgrounds, there are documented higher levels of familism, which at times offers some protection against perceived burden and depression, leading to the underuse of formal support services with the assumption that the family systems will provide the needed care. Furthermore, social factors, including social support, socioeconomic status, gender, age, and living arrangements, impact caregiver burden, mental health, and life satisfaction. Factors like lower income, unemployment, and smaller living spaces lead to greater physical and psychological burdens. Understanding and integrating cultural and social factors into caregiver support and healthcare delivery is essential for reducing disparities and improving outcomes for family caregivers.

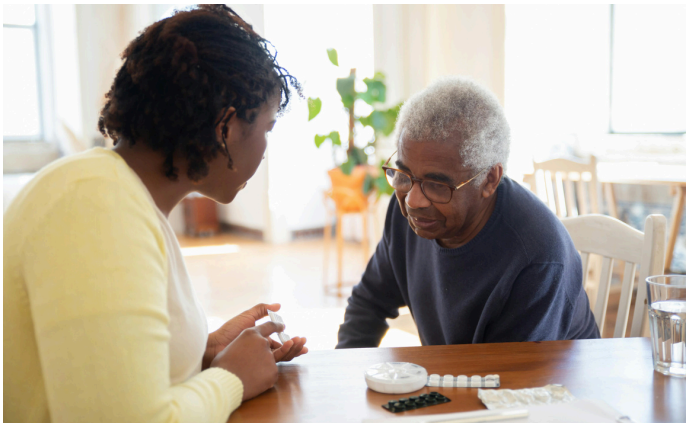
Within many cultures, it is common practice that family members remain the caregivers for their relatives. Not only do these family members act as caregivers, but they also offer support, advocate for the patient, serve as a messenger, and, at times, become the surrogate decision maker. Cultural values and beliefs play a significant role in familial caregiving. Research studies suggest that the concept of familism, which is a cultural value centered around family attachment and collectivism, consists of the perception of support received from an individual's family, familial obligations, and viewing relatives as references regarding behaviors and attitudes. Familialism introduces a buffer for the negative emotions/effects caregivers may experience. Caregivers with a higher level of familialism tend to find comfort in maintaining spiritual beliefs, leading to gaining more fulfillment and meaning in their role as caregivers, easing the caregivers' distress or burden.

Although familism can be seen as a benefit in many ways, it can also lead to false perceptions of medical conditions, in turn leading to delayed treatment, underutilization of services, and poor health outcomes. Compared to White Americans, African Americans tend to have greater familism, while Hispanics show lower familism when they have been within the United States for a longer length of time, suggesting that there is a link between acculturation and familism. Intervention such as family-based therapy and support groups reduce caregiver stress and burden, but to effectively do so, the incorporation of cultural beliefs and attitudes is crucial.

.

Family caregivers provide most of the long-term care for older adults in the United States, and their experiences are shaped by a range of social factors. Income, education level, employment status, and geographic location all influence caregiving responsibilities and outcomes. Women make up the majority of caregivers, and while most are non-Hispanic White with some college education, an increasing number come from diverse social and economic backgrounds. Financial strain is one of the most significant social factors affecting family caregivers. Many caregivers reduce work hours, decline promotions, or leave the workforce altogether to provide care, which results in loss of income, reduced savings, and lower retirement security. This financial pressure is compounded when caregivers must also cover out-of-pocket expenses for medications, medical equipment, home modifications, or transportation. Rural caregivers face additional challenges, as limited access to healthcare facilities, respite care, and transportation can increase both caregiving demands and personal health risks. By contrast, caregivers in urban and Southern regions often report higher caregiving intensity, with longer hours spent providing care, which can interfere with employment and social engagement. Social isolation is also a pervasive issue, affecting more than one quarter of caregivers, particularly those who are unmarried, in poor health, or caring for someone with dementia. This isolation can lead to emotional distress, reduced community connection, and worsening physical health. Limited access to formal support services is frequently linked to time constraints, inadequate outreach, and logistical barriers, leaving many caregivers to navigate complex responsibilities alone. Together, these social factors intensify caregiver burden, diminishing both the quality of care provided and caregivers' overall health and well-being.

Healthcare providers need to identify and share resources available to patients and their caregivers. One beneficial resource that often helps alleviate the physical and mental burden placed on caregivers is respite care. Respite care provides primary caregivers with a short-term relief period from their caregiving duties, allowing them to care for themselves, attend to personal matters, and, most importantly, rest. Patients and caregivers can identify available local respite care services at the Access to Respite Care and Help (ARCH) National Respite Network. Other services designed to support patients with dementia and their caregivers include the Program of All-Inclusive Care for the Elderly (PACE). PACE is a program designed for patients with dementia who require nursing facility-level care but wish to remain at home. Funded by Medicare and Medicaid, this program provides healthcare services to patients who would otherwise require placement in a skilled nursing facility. This allows patients to continue living at home while still receiving the care they need. The program covers the cost of social services and medical care from an interdisciplinary healthcare team, including occupational therapists, dieticians, speech therapists, physicians, and physical therapists. Enrolled patients can receive in-home medical care and also utilize adult day centers that provide fresh meals, activities, laboratory services, dentistry services, vision appointments, and medical visits. Offering respite services to caregivers may stir emotions of judgment and guilt. Healthcare providers must approach respite care conversations gently and frame the services as both beneficial to the caregiver and patient in receiving the best quality care.



Reflection Questions

- What are some ways in which healthcare providers can help alleviate the burden that familial caregivers experience?
- What are some cultural factors that impact the family caregiver burden?
- In what ways might geographic location shape both the availability of support services and the caregiver's overall well-being?

Helpful Links

- Medicare | PACE
- ARCH | National Respite Locator
- WellSpouse Organization | Resources
- National PACE Association | Program Locator
- Caregiver Action Network
- Alzheimer's Association | Respite Care
- Family Caregiver Alliance | Family Caregiver Services by State
- National Council of Aging | Caregiver Support
- NAMI | Family Members and Caregivers
- NIH | Caregiving

References

Choi, Hyojin, et al. "Conceptualizing family caregivers' use of Community Support Services: A scoping review." The Gerontologist, vol. 64, no. 5, 6 Apr. 2023, https://doi.org/10.1093/geront/gnad039.

Falzarano, Francesca et al. "Family Matters: Cross-Cultural Differences in Familism and Caregiving Outcomes." The journals of gerontology. Series B, Psychological sciences and social sciences vol. 77,7 (2022): 1269-1279. doi:10.1093/geronb/gbab160

Gazaway, Shena et al. "Cultural Values Influence on Rural Family Caregivers' Decision-Making for Ill Older Adult Loved Ones." Journal of pain and symptom management vol. 68,1 (2024): 86-95. doi:10.1016/j.jpainsymman.2024.04.012

Kampus Production. Man in Blue Sweater Sitting Near a Woman in Yellow Sweater. Pexels, https://www.pexels.com/photo/man-in-blue-sweater-sitting-near-a-woman-in-yellow-sweater-7551650/. Accessed 25 Oct. 2025.

Kaplan, Daniel. "Family Caregiving for Older Adults - Geriatrics." MSD Manual Professional Edition, Jan. 2025, www.msdmanuals.com/professional/geriatrics/social-issues-in-older-adults/family-caregiving-for-older-adults.

Karpovich, Vlada. Woman Taking the Blood Pressure of a Man in Blue Sweater. Pexels, 4 Nov. 2020, https://www.pexels.com/photo/woman-taking-the-blood-pressure-of-a-man-in-blue-sweater-5790820/. Accessed 25 Oct. 2025

Maximiano-Barreto, Madson Alan et al. "Cultural factors associated with burden in unpaid caregivers of older adults: A systematic review." Health & social care in the community vol. 30,6 (2022): e3629-e3642. doi:10.1111/hsc.14003

Oquendo, Caleb. Caring Interaction Between Nurse and Elderly Patient. Pexels, https://www.pexels.com/photo/caring-interaction-between-nurse-and-elderly-patient-34328480/. Accessed 25 Oct. 2025.

Prihodko, Danik. Mother and Daughter Sitting at the Table and Holding Hands. Pexels, https://www.pexels.com/photo/mother-and-daughter-sitting-at-the-table-and-holding-hands-17066496/. Accessed 25 Oct. 2025.

RDNE Stock project. A Man Pushing an Elderly on a Wheelchair. Pexels, 30 Jan. 2021, https://www.pexels.com/photo/a-man-pushing-an-elderly-on-a-wheelchair-6646773/. Accessed 25 Oct. 2025.

Tran, Jessica T., et al. "Cultural diversity impacts caregiving experiences: a comprehensive exploration of differences in caregiver burdens, needs, and outcomes." Cureus 15.10 (2023).

What Is Respite Care?" National Institute on Aging, 12 Oct. 2023, https://www.nia.nih.gov/health/caregiving/what-respite-care.....