

Partnering with Caregivers



Joseph E. Gaugler, BA, MS, PhD^{a,*}, Teddie Potter, PhD, RN^b,
Lisiane Pruinelli, RN, MSN^b

KEYWORDS

- Informal long-term care • Long-term care • Burden • Stress • Caregiver intervention
- Chronic disease • Partnership-based care

KEY POINTS

- Family caregivers provide extensive long-term care to older adults in the United States; 85% of older adults in need rely on family members.
- Family caregivers indicate several unmet needs related to care provision, and are often at risk for negative health outcomes when compared to noncaregivers.
- Existing evidence suggests that caregiving interventions have moderate, positive benefits although more intensive, multicomponent models hold the most promise.
- A family-centered, partnership-based framework offers a clinical strategy that can enhance the assessment of or intervention with family caregivers.
- Family caregiving research and clinical practice must continue to evolve toward family-centered and person-centered partnership models to best meet the complex needs of families.

INTRODUCTION

There is no consistent definition of family caregiving. Some organizations such as the Alzheimer's Association define caregiving as "attending to one's health needs."^{1 (p29)} Many studies rely on family members' self-identification as a caregiver, whereas others tend to use more objective measures to define family caregiving, such as the number of activities of daily living (ADLs) that a family member helps a relative with. If the latter definitional scope is selected, it is important to acknowledge the wide range of tasks that family caregiving often encompasses: family caregiving may include not only basic or instrumental ADL tasks but also management of specific disease symptoms (eg, behavior problems caused by a relative's dementia; nausea that is a result of a relative's cancer therapy), financial help, or care coordination between health care professionals.^{2,3}

^a Center on Aging, School of Nursing, University of Minnesota, 6-153 Weaver-Densford Hall, 1331, 308 Harvard Street Southeast, Minneapolis, MN 55455, USA; ^b School of Nursing, University of Minnesota, Minneapolis, MN, USA

* Corresponding author.

E-mail address: gaug0015@umn.edu

Other approaches focus on the reasons why family members provide support; for example, Schulz and Quittner⁴ defined caregiving as “extraordinary care that exceeds the bounds of what is considered normative for others.” Family caregiving is said to occur when the support and help provided by 1 family member to another are not routine and are based on a care recipient’s health need. Use of this definition can help health care providers and practitioners better ascertain whether family caregiving is occurring, even in instances in which a family member does not consider that what they are doing is caregiving. The unwillingness of some family members to consider themselves caregivers even when extraordinary assistance is provided has led some organizations to launch public awareness campaigns for community members to become aware that “I am a caregiver” (see <http://www.whatisacaregiver.org/>).

Describing Family Caregivers

In 2009, the National Alliance of Caregiving (NAC) and the American Association of Retired Persons (AARP)⁵ conducted a telephone survey of a representative sample of family caregivers in the United States. The following points summarize statistics from this and other, similar sources that describe family caregiving as it is delivered in the United States:

- 18.9%, or 43.5 million Americans, care for someone 50 years of age or older.⁵
- 65.7 million people in the United States have provided unpaid care to an adult or child in the past 12 months.⁵
- 66% of family caregivers in the United States are women.⁵
- Family caregivers are 61 years old, on average.⁵
- 74% of caregivers live within 20 minutes of the care recipient, and more than 95% of primary family caregivers live within 30 minutes of their care recipients.^{5,6}
- The average amount of family care provided on a weekly basis is 20.4 hours.⁵
- 72% of family caregivers in the United States are white, 13% are African American, 2% are Hispanic, and 2% are Asian American. The household prevalence of caregiving across racial and ethnic groups is more evenly distributed: 30% of Hispanic households are engaged in family caregiving, 28% of African American households are caregiving, 25% white households are involved in family caregiving, and 17% of Asian American households are caregiving.⁵
- The typical family caregiver is a 46-year-old woman with some college education who provides more than 20 hours of week of help to her mother.⁷
- 85% of help provided to all older adults in the United States is from family members.⁸
- On average, care recipients are close to 80 years of age and close to 70% are women.⁶
- Close to half of care recipients are widowed, whereas approximately 40% of care recipients live alone.⁶

Much of the research available on family caregiving for older adults tends to focus on the primary family caregiver, or the 1 person who is most responsible for providing assistance to an older relative.⁹ It is possible that this focus on primary family caregivers is due to ease of analysis, because including multiple family caregivers, an entire family, or various combinations that include unpaid caregivers who are not members of the family is more complex analytically. This emphasis on primary family caregivers obscures how caregiving actually operates in US families, particularly in ethnically or racially diverse contexts. For example, older care recipients in African American families tend to rely on a more complex array of family members and

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