

Words Matter: The Language of Family Caregiving

Increased attention has been paid recently to the central role of language in shaping the culture of aging.¹ This includes the notable adoption of the modified American Medical Association style by the *Journal of the American Geriatrics Society*, recognizing that word choices can frame important aging issues in judgmental and counterproductive ways.^{2,3} For example, using catastrophic metaphors like “silver tsunami” and “tidal wave” to frame demographic changes may garner short-term attention but discourage long-term public engagement in creating a more age-integrated healthcare system and society.³ Elsewhere, organizations such as the Alzheimer Society of Canada have created person-centered language guidelines to reframe the historically negative and loss-based terms used to describe the experience of persons living with dementia.⁴

One area that has received less attention than it deserves is the language used to describe family caregiving. Every day, at least 43.5 million individuals in the United States assume caregiving responsibilities for a spouse, family member, or friend who needs help because of limitations in their physical, mental, or cognitive functioning.⁵⁻⁷ Although many people require care, age-related needs are the single most common problem requiring help from caregivers.⁷ To distinguish family caregivers from paid care providers such as home care workers, the term “informal caregiver” is commonly used.⁵ We argue that this term is a poor choice of words that disrespectfully frames the family caregiving role and has counterproductive consequences.

The term “informal caregiver” originated in the 1980s when caregiving became a major topic for research. It was used to reflect the understanding that family caregivers were relied on mainly for emotional support and for basic assistance with household tasks and personal care.⁸ Indeed, the term “informal” suggests “casual, unstructured, unofficial care—pleasant but not essential”; today’s caregivers would tell you they find this term invalidating and that there is absolutely nothing “informal” or unessential about the care they provide.^{5,9,10} These caregivers, most of whom are women, provide approximately 80% of direct home and community care services, an unpaid contribution valued at \$375 billion US dollars annually.⁵ On average, caregivers spend nearly 25 hours a week providing care, and about one-quarter (23%) provide 41 or more hours of care a week.⁷

The 2012 American Association of Retired Persons (AARP) *Home Alone* study was an important national population-based study of American caregivers. It challenged the

common perception that caregiving is limited to basic personal care and household chores.¹¹ *Home Alone* highlighted how the caregiving role had become increasingly complex, demanding, and stressful. With little to no training or support, caregivers are tasked with providing medical and nursing care in the home, navigating health and long-term care systems, and serving as substitute decision makers.^{6,7,11-13} AARP recently released its 2019 follow-up study, *Home Alone Revisited*, that reports the family caregiving role continues to be complex, involving tasks typically performed by nurses in hospital such as administering medications, changing dressings, managing incontinence, and assessing and treating pain.⁸ Alarming, only 7.3% of family caregivers for older adults report receiving any training related to their complex role.¹⁴

Clearly, the term “informal” is a poor descriptor of the duties performed by family caregivers. But beyond being inaccurate, framing the role in this way may form the basis of what cognitive anthropologists would describe as a “cultural model” of caregiving, “a set of tacit, pervasive, and culturally mediated assumptions about an issue that shapes people’s understanding of the world and drives their behavior within it.”^{15,16} This cultural model of caregiving may create implicit attitudes and associations that may be activated without conscious awareness or intent.¹⁷ In the context of family caregiving, clinicians, healthcare systems, and policymakers may have implicit attitudes that family caregivers need not require recognition, training, or support because the care they are providing is “informal” and consistent with tasks that most adults already do (eg, personal care and household chores) or can easily master.¹¹ Furthermore, the cultural model may reinforce gendered expectations about family caregiving because women may implicitly be expected to take on caregiving roles. Currently, women provide two-thirds of all older adult care, with wives and daughters much more likely to assume caregiving roles than husbands and sons.¹⁸

In their 2016 report, the National Academies of Sciences, Engineering, and Medicine Committee on Family Caregiving for Older Adults justifiably declared that “the need to recognize and support caregivers is among the most significant overlooked challenges facing the US population, their families, and society.”⁷ We argue that family caregivers do not receive the proper recognition and support they need when language is used that frames them as “informal” and contrasts them with paid care providers who are often referred to as “formal” and “professional” caregivers. Further, this is an issue not just for the United States but one that impacts countries around the world.

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Table 1. Terms to Use When Describing Caregiving

Caregiving role	Terms to be avoided	Less optimal terms	Preferred terms
Provide care primarily because of a <i>personal</i> relationship. They are usually next of kin (spouses, children, or other relatives) but may sometimes be friends or neighbors.	<i>“Informal caregiver”</i> Family caregivers may find this term insulting and invalidating, and it is an inaccurate description of the complex tasks performed by today’s caregivers.	<i>“Care partner”</i> or <i>“Carer”</i> In North America, these terms do not clearly distinguish family caregivers from paid care providers.	<i>“Family caregiver”</i> <i>“Family/Friend caregiver”</i> <i>“Unpaid caregiver”</i>
Provide care primarily because of a <i>financial</i> relationship. They may be licensed or unlicensed home care workers (home health aides, nursing assistants, registered nurses).	<i>“Formal caregiver”</i> By labeling paid care providers as formal, this necessarily suggests that family caregivers are informal.	<i>“Professional caregiver”</i> By contrasting family caregivers with “professional” caregivers, it may suggest that family caregivers are less competent. Certainly, paid care providers should be professional in their duties, but the compound term “professional caregiver” should be avoided.	<i>“Home care worker”</i> <i>“Professional home care worker”</i> <i>“Paid caregiver”</i> <i>“Care provider”</i> <i>“Healthcare professional”</i>

Unfortunately, there is no consensus language for describing family caregivers, and a number of different terms have been inconsistently applied across the medical and scientific literature, clinical practice, and the general press (Table 1). Further complicating matters is the inconsistent language used to describe paid care providers. Although not the focus of this editorial, this terminology is important to consider, especially when family caregivers are commonly contrasted with paid care providers. In addition to “informal caregiver,” the terms “care partner” and “carer” are commonly used, but in North America these do not clearly differentiate family caregivers from paid care providers.⁹ Other organizations including the New York City Department for the Aging have used the term “unpaid caregiver” to distinguish family caregivers from paid care providers.¹⁹

The National Academies of Sciences, Engineering, and Medicine Committee on Family Caregiving for Older Adults agreed on the term “family caregiver” while acknowledging that an increasing number of caregivers do not have a family or legally defined relationship with their care recipients.⁹ The term “family caregiver” is also used by the AARP Public Policy Institute in their studies *Home Alone* (2012) and *Home Alone Revisited* (2019).^{8,11} We too support the term family caregiver and suggest that “family/friend caregiver” could also be used to reflect the full diversity of individuals assuming caregiving roles (15% of all caregivers in the United States are not related to their care recipients).^{7,9} Table 1 describes the terms that have been applied to both family caregivers and paid care providers, and proposes more appropriate terms to use when describing caregiving.

Encouragingly, healthcare systems and society are beginning to recognize the complexity of family caregiving and the critical need to integrate caregivers as central and valuable members of the healthcare team.^{8,13,20} To promote these efforts, there is a pressing need to establish appropriate and consistent caregiving language that is both acceptable to caregivers and care recipients, and that promotes rather than hinders increased support and recognition for family and friend caregivers. Simply put, words matter.

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