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## Who Cares for the Caregiver? Exploring Extension's Role in Informal Caregiving Support

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# Who Cares for the Caregiver? Exploring Extension's Role in Informal Caregiving Support

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**Abstract.** Family caregivers provide invaluable service by taking on the responsibility of caring for older adults in the United States. With a growing aging population, the need for family caregivers and demands on their time and resources will continue to increase. Although a variety of caregiving resources and support services exist, family caregivers often lack the awareness, time, transportation, or financial resources to connect to services. There is a critical need to address the barriers that prevent caregivers from accessing services. In this commentary, we highlight barriers and make recommendations for improving conversations, research, and practice to meet this growing problem.

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## INTRODUCTION

“Like many older adults, my grandparents have long been self-sufficient. They could independently complete basic and instrumental activities of daily living, such as lawn care, grocery shopping, house maintenance, and personal care. However, when my grandmother had a double knee replacement, the need for a caregiver arose. Although she could still complete much of her personal care, such as getting dressed and showering, simple chores like cooking became much more difficult. My grandfather was able to contribute but quickly became overwhelmed with these additional responsibilities while still being employed full-time. As a result, he would forget things, be unable to complete basic household tasks and repairs, and even innocently overlook the challenges my grandmother would face while she was home alone. There were growing concerns of safety and well-being, and considerable worry that the surgery would be unsuccessful due to a poor recovery. In turn, there was added reliance on family for physical support—but they, too, were stressed, overwhelmed, and facing their own life’s demands.” (Carrie the Caregiver)

This and similar lived experiences are increasingly common and, coupled with contemporary literature, highlight the opportunity for Extension to connect older adults and their caregivers with research-based information, resources, and support services.

## CAREGIVERS

The latest data reveal that more than one in five adults in the United States are informal caregivers—an estimated 53 million adults. Informal caregivers provide unpaid care and assistance to someone with short- or long-term needs due to physical (63%), mental or emotional (27%), or memory (32%) diseases, illnesses, or conditions. Ninety percent of informal caregivers are relatives, most often female and the adult child, spouse/partner, or grandchild of the individual receiving care (AARP and National Alliance for Caregiving, 2020). Although 51% of caregivers report that their responsibilities give them a sense of purpose and meaning, there is an immense concern among researchers, practitioners, and policymakers regarding caregiver stress and their plethora of unmet needs (Scommegna, 2016).

These unmet needs often include the skills necessary for complex care, self-care, and care of their own physical and mental health (Li, 2023). These and other unmet needs can ultimately affect the quality of care they provide—and as a result, the quality of life, health, and well-being of caregivers and care recipients alike (Schulz et al., 2020). For instance, 21% of caregivers report being lonely, another 21% report being in fair or poor health, and 23% indicate that serving as a caregiver has resulted in a decline in their own health and well-being.

Although caregiving roles may only be temporary, such as those due to surgery or acute illness, the majority of caregivers provide care for a minimum of six months (Centers for Disease Control and Prevention, 2019). Regardless, a caregiver's commitment requires sacrifices of time, independence, social engagement, and their own health needs. With these sacrifices comes the potential for burnout—a state of pure physical, emotional, and mental exhaustion—which can have substantial effects on a caregiver's physical health, mental health, and ability to provide excellent care (Abdi et al., 2019). Schulz and colleagues (2020) state that the “effects of caregiving are both wide ranging and highly individualized. Caregivers are potentially at increased risk for adverse effects on their well-being in virtually every aspect of their lives...” (p. 5).

Despite many caregivers having similar experiences, caregiving is a unique experience. It is, in part, crafted by the person receiving care, the intensity of care required, the degree of suffering experienced by the care recipient, culture, personality, community, financial resources, workplace support, capacity for work-life balance, geography and proximity, and other resources both internal and external (Pop et al., 2022; Yee Lam et al., 2022). It is imperative to consider these, and other contextual factors, when advocating and providing resources for caregivers to equip them with information, resources, and services that promote a positive caregiving experience, protect caregivers' health and well-being, and enhance the quality of care provided to care recipients.

## RESOURCES

A review of caregiving research identifies several approaches for meeting the needs of family caregivers. For example, research shows that group-based programs are effective at meeting caregiver's emotional needs by teaching relaxation tools and promoting social support through connecting with other caregivers (Kim, 2017). One program frequently offered by Extension professionals is *Powerful Tools for Caregivers*, a six-week course that provides caregivers with the tools to reduce stress, manage emotions, build self-confidence, and connect with community resources (Powerful Tools for Caregivers, 2022). Complementary approaches work to connect caregivers with community-based support services such as wellness programs; nutritional support; educational programs about health and aging; counseling services; and general assistance with housing, finances, and home safety (Siegler et al., 2015, p. 1). Extension is well-known for providing research- and evidence-based health promotion programs that aim to improve and manage overall health and well-being; although many programs may not be specifically designed for caregivers, they are undeniably advantageous. No matter the method of implementation or a program's specific focus, the literature demands that interventions and resources focus both on the emotional toll of caregiving and the practical aspects of caregiving to be truly impactful and effective (Schulz et al., 2022).

Because Extension is deeply rooted in and familiar with local resources and providers, Extension professionals themselves can be the crux of connecting caregivers with helpful and necessary resources and assisting with the dissemination and utilization of services. However, as many Extension professionals know, those resources and services do not always exist—and even if they do, they may not be accessible to all who need them. Many caregivers report difficulty or reluctance in seeking help (Musich et al., 2017), a lack of awareness of services, and an inability to access services due to availability or affordability. In addition, there is often siloing of providers, resources, and services that prohibits some from knowing what services even exist (Siegler et al., 2015). Therein lies the problem: a glaring gap between the existence of services and their availability, affordability, visibility, and utilization. Arguably, solutions to this problem begin with raising awareness of existing challenges and identifying steps to overcome them.

One such challenge is the impact of rurality on the accessibility of services; there are considerable resource and service constraints in rural areas compared to more suburban and urban locales. A few barriers and social determinants of health that can contribute to the inadequacy of accessibility include limited or a lack of health care coverage, a lack of health care providers, affordability, eligibility for support or respite services, cultural and language barriers, geographic proximity to providers and services, and a lack of transportation.

## Caring for the Caregiver

This is where Extension can come into play. Extension professionals are staunch advocates in their communities. Extension can and should utilize their professionals to support caregivers, particularly those in rural areas. This support could include the following.

- Providing educational programs about chronic disease management, self-care, end-of-life considerations, age-friendly homes, awareness and prevention of elder abuse and neglect, Medicare and Medicaid, and the financial considerations of caregiving. Research shows that informal caregivers “are likely to benefit from enhanced knowledge about the disease, the caregiving role, and resources available to them” along with tools like intervention and problem-solving skills (Schulz et al., 2020).
- Connecting informal caregivers to resources that can assist them in providing exceptional informal care, such as the identification of medical and other support services, insurance benefits, respite services, support groups, financial support, nutrition resources, and food security assistance (Centers for Disease Control and Prevention, 2019).
- Advocating for and actively pursuing policy, systems, and environmental changes that support and enhance the informal caregiving experience. This could include advocating for the development of local respite services, coordinating with others to create and host a caregiver support group, identifying and promoting financial assistance and tax benefits for caregivers, and working to create a centralized resource hub for caregivers.

Extension is a critical link that can help bridge the gap that exists between caregiver needs and caregiver resources. This bridge is paramount as the older adult population, and the number of informal caregivers, continues to increase. Extension can disseminate valuable information, provide educational programs, and connect individuals with much-needed services and support—particularly those in under-resourced rural communities.

### CONCLUSION

By understanding the value and needs of informal caregivers, identifying the barriers to support, and offering solutions, Extension professionals can improve the well-being of caregivers and care receivers. We encourage all Extension professionals to ask questions about the responsibilities of caregiving, work to understand the challenges and needs of those in your community, connect caregivers with vital education and resources, and continue conversations about caregiving with relevant changemakers. By bringing awareness to the challenges associated with caregiving and the ways communities can support one another, we can improve the health, well-being, and quality of life of caregivers.

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