

In Brief

Home Alone Revisited: At a Glance

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Across genders, generations, and cultures, half of family caregivers perform complex medical/nursing tasks for people with multiple chronic conditions. Their needs for instruction have become part of the conversation in the professional and research literature but have not been translated into assessment measures that can determine their level of involvement in complex care and guide evidence-based interventions. Much work remains to fully integrate family caregivers into the practices and policies of an evolving health care system.

The *Home Alone* study in 2012 was the first national look at how families, neighbors, and friends manage medical/nursing tasks, the complex care associated with administering multiple medications, changing dressings, handling medical equipment, and providing many other kinds of help that were formerly offered by trained professionals.¹ Seven years later, this *Home Alone Revisited* study sought a deeper understanding of what family caregivers who perform medical/nursing tasks experience.

This new study affirmed many of those findings and took a closer look at specific difficult tasks, such as managing incontinence, pain, and special diets. It also offered greater attention to resources and outcomes as well as family caregiver experiences by gender, generation, and culture.

A nationally representative, population-based, online survey of 2,089 family caregivers provided the basis for our analyses. Because the two *Home Alone* studies were cross-sectional samples, it was

not possible to draw conclusions about trends. Instead, we can report on the current prevalence of caregiving issues and the perceptions of caregivers at this time. It would not be appropriate to interpret the findings in terms of increases or decreases since 2012.

In this new study, an organizing framework, qualitative findings, and multivariate analyses provided further insights into the stories these family caregivers told us. Their voices led to our recommendations for professionals, health care organizations, public policies, and private-sector stakeholders.

This **In Brief** is a synopsis of the research report, *Home Alone Revisited: Family Caregivers Providing Complex Care 2019-03*. To view the full report, visit <http://www.aarp.org/homealone>.



Family Caregiving™

This *In Brief* highlights the survey findings, implications, and recommendations that are addressed comprehensively in the research report *Home Alone Revisited: Family Caregivers Providing Complex Care* released by the AARP Public Policy Institute in April 2019. This research was supported by The John A. Hartford Foundation and the AARP Foundation. Major Findings and Implications

MAJOR FINDINGS AND IMPLICATIONS

1. **Today's caregivers provide *intense and complex care*, including medical/nursing tasks and managing multiple health conditions that are often accompanied by pain.**
Implications
 - Caregivers continue to take on the responsibilities that used to be the purview of health care professionals; they are providing complex care that they often find difficult to perform.
 - Caregivers report being engaged in a number of monitoring and communication activities. This health delivery trend has a direct effect on caregiver responsibilities and contributes to additional health care system expectations for their participation.
 - Pain management is a major issue, and it carries an emotional as well as practical and sometimes financial strain.
2. **Today's caregivers are *diverse* and so are their experiences.**
Implications
 - Interventions to meet caregivers' needs for support and guidance must reflect the diversity of the caregiver themselves.
3. **Caregivers who are socially isolated or have no choice about caregiving are more *at risk* for experiencing difficulties with complex care.**
Implications
 - More proactive assessment and outreach are needed to identify caregivers who need additional support.
4. **Caregivers performing more medical/nursing tasks experience both *positive and negative impacts*.**
Implications
 - Choice is an important issue—not every caregiver is willing or able to assume care responsibilities, yet caregivers are often expected by other family members or professionals to take on the role, facing unpleasant judgment by others if they do not. Understanding willingness is important as health care professionals engage caregivers.
 - Caregivers are motivated by making a contribution and helping the care recipient avoid nursing home placement, but many live with the worry of making a mistake and the difficulty of performing medical/nursing tasks.
 - Caring for a relative or friend with complex health needs requires instructions, guidance, and support, but the study also recognizes the emotional impact on the family caregiver for providing this care.
5. **Many family caregivers are still on their own—health systems should do *more to prepare these vital members of the team*.**
Implications
 - It is largely up to caregivers to learn how to perform medical/nursing tasks and manage the complexity of care.
 - Presently, no comprehensive multidimensional measure captures the complexity of the care or where caregivers are in the caregiving journey.
 - Health care and social service professionals are not yet fully attuned to caregiver needs for information and support and how to deliver them in ways that allay anxiety.
 - The CARE Act has been enacted in 40 states, yet there is more to do to ensure that the intent of the act reaches family caregivers across the nation.

MAJOR RECOMMENDATIONS

1. Increase awareness of the current realities for family caregivers among the general public, health care professionals, health care delivery systems, and policy makers.
2. Update assessment tools for family caregivers to include medical/nursing tasks and capture the complexity and trajectory of care.
3. Public programs should include assessments of family caregivers who are providing complex care for consumers who identify these caregivers in the person-centered plan of care.
4. Health care and social service professionals must elicit and respond to the worries of family caregivers providing complex care.
5. Health care systems and professionals must make stronger efforts to recognize family caregivers and offer them instruction on and support for complex care.
6. Health care and social service professionals must recognize that family caregivers are diverse in many ways and need proactive outreach to help them manage complex care.
7. Health care and social service professional education must include preparation to support family caregivers who provide complex care.
8. The private sector—employers and industry—can help recognize and support family caregivers who provide complex care.
9. Community-based organizations should include in their programs and services targeted resources that address the needs of all family caregivers, particularly those engaged in complex care.
10. Further research could advance understanding of the experiences of family caregivers providing complex care and generate evidence-based solutions for them.

CONCLUSIONS

The findings and recommendations in *Home Alone Revisited* mark a turning point in the understanding of family caregiving. The old paradigm—the uncomplicated world of “informal”

caregiving—no longer applies to millions of family members, friends, and neighbors of diverse ages and cultural backgrounds who provide complex care at home. In the current health care environment, it is presumed that every home is a potential hospital and every service that a person needs can be provided by an unpaid family member, with occasional visits with a doctor, nurse, or therapist.

The first *Home Alone* report made it clear that family members perform technically complex tasks such as caring for wounds, operating medical machinery, and administering and monitoring numerous medications. The study helped fuel strategic action and a growing body of research. This new report adds to this major shift in responsibility by underscoring the stress associated with managing pain, especially timely given the current opioid epidemic. It makes clear the emotional and time-consuming challenges of dealing with incontinence and preparing special diets, two tasks that have long been assumed to be relatively easy to perform. The sum of all these tasks—activities of daily living (ADLs) and instrumental activities of daily living (IADLs), medical/nursing tasks, and care coordination, not to mention emotional support and companionship—takes a toll on family caregivers, leaving all too many isolated and with mental and physical health problems.

America’s caregivers deserve to be seen as valuable members of the health care team. They should be included in decision making, given opportunities to voice their concerns, and provided appropriate instruction. They should not be taken for granted—or worse, criticized for their perceived failures and inadequacies.

The responsibility for meeting the challenges of the new paradigm falls on all sectors of society, but health care and social service professionals and the systems in which they work bear a special duty to bring about a culture change as well as implement new practices and policies that make a difference for family caregivers. Public policies and funding should be tailored to support these practices in diverse communities.

The recommendations in this report are a good place to start. We cannot go back to the “good old days”—if they even existed. The future is our only path to justice and a caring society.

¹ S. C. Reinhard, C. Levine, and S. Samis, *Home Alone: Family Caregivers Providing Complex Care* (Washington, DC: AARP Public Policy Institute, 2012), <https://www.aarp.org/ppi/issues/caregiving/>.



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