

Home Alone: Family Caregivers Providing Complex Chronic Care

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In a recent national survey, almost half (46 percent) of family caregivers reported performing medical/nursing tasks for care recipients with multiple chronic physical and cognitive conditions. These tasks include managing multiple medications, providing wound care, preparing food for special diets, using monitors, and operating specialized medical equipment. These tasks were in addition to assisting with activities of daily living (ADLs) and instrumental activities of daily living (IADLs). Most caregivers said that they received little or no training to perform these medical/nursing tasks.

Family caregivers have traditionally provided assistance with bathing, dressing, eating, and household tasks such as shopping and managing finances. While these remain critically important to the well-being of care recipients, the role of family caregivers has dramatically expanded to include performing medical/nursing tasks of the kind and complexity once provided only in hospitals and nursing homes and by home care professionals. This change has occurred because of the prevalence of chronic conditions in an aging population, economic pressures to reduce hospital stays, and the growth of in-home technology. Formal home care services are short-term and limited.

To document and analyze this major shift, PPI and the United Hospital Fund (UHF) undertook the first nationally representative population-based online survey of 1,677 family caregivers. Caregiver age, socioeconomic status, and education were similar to demographics reported in other national surveys. The care recipients were older (average age 75), mostly female, and mostly Medicare beneficiaries.

This *In Brief* provides highlights of the survey results and recommendations that are fully addressed in the Research Report, *Home Alone: Family Caregivers Providing Complex Chronic Care*, released by PPI and UHF in October 2012. The report explores the complexity of tasks that caregivers provide and challenges the common perception of family caregiving as a set of personal care and household chores that most adults already do or can easily master.

KEY FINDINGS

Family Caregivers Perform Complicated Medical/Nursing Tasks

The most commonly performed medical/nursing tasks were medication management (78 percent), help with assistive mobility devices (43 percent), preparing food for special diets (41 percent), and wound care (35 percent).

Even though the number of family caregivers saying that they operate medical equipment, such as mechanical ventilators and tube feeding systems, was small (14 percent), 49 percent reported it as hard to do. These family caregivers are performing tasks in a home environment that would challenge even seasoned professionals.

Caregivers Are Responsible for Complex Medication Management

Many family caregivers managed many different kinds of medications. Three out of four (78 percent) family caregivers who performed medical/nursing tasks were managing medications, including administering intravenous fluids and injections.

Almost half were administering five to nine prescription medications a day. Medication management was reported to be difficult because it took so much time, it created anxieties about making a mistake, and some care recipients were uncooperative.

Most family caregivers learned how to manage at least some of the medications on their own. Despite frequent emergency department visits and overnight hospital stays, few family caregivers reported receiving assistance and training from health professionals.

Training Is Limited for Often Challenging Wound Care

More than a third (35 percent) of family caregivers who provided medical/nursing tasks reported doing wound care such as ostomy care and postsurgical dressing changes. While fewer caregivers performed wound care tasks than medication management, a higher percentage of them (66 percent) identified it as difficult because of fear of making a mistake and discomfort with the level of bodily intrusiveness required.

Family caregivers who deemed wound care difficult received more training from health professionals than did caregivers doing medication management. About a third reported some training by a hospital nurse or physician, and a quarter received training from a home care nurse, but most did not get any training to perform these tasks. Four out of ten family caregivers performing wound care thought more training would help them.

Family Caregivers Feel They Have No Choice

More than half (57 percent) of family caregivers who reported that they felt pressured to take on medical/nursing tasks said they did not feel they had a choice. Of these, many (43 percent) felt they had a personal responsibility (there was no one else to do it, or insurance would not cover it). And some cited pressure from the care recipient (12 percent) or another family member.

Most Care Recipients Do Not Receive Home Visits by Health Professionals

Most care recipients (69 percent) did not have home visits by a health care professional. Of those who did have home visits, roughly seven in ten were visited by a nurse. Twenty-seven percent of caregivers reported no additional help at home.

Family Caregivers Often Serve as Primary Care Coordinators

Family caregivers of chronically ill persons frequently served as care coordinators. More than half (53 percent) of family caregivers who performed medical/nursing tasks coordinated care—twice the rate of those who mainly provided ADL or IADL care.

Very few family caregivers (3 percent) reported working with a care manager from an insurance company or government program or hiring a private geriatric care manager.

Performing Medical/Nursing Tasks May Prevent Nursing Home Placement

Family caregivers who performed medical/nursing tasks were most likely to believe they were making an important contribution, primarily preventing nursing home placement (51 percent). The more medical/nursing tasks they performed, the more likely they were to report this positive effect.

Quality of Life Is Affected

Family caregivers performing medical/nursing tasks were most likely to report feeling stressed and worried about making a mistake. They were also more likely to report talking to so many health care professionals and suppliers as a source of stress. More than half reported feeling down, depressed, or hopeless in the last two weeks, and more than a third reported fair or poor health. These negative impacts increased with the number of the care recipients' chronic conditions.

MAJOR RECOMMENDATIONS

The report highlights an urgent need for both individual and collective action to help family caregivers better cope with handling medical/nursing tasks at home. If adopted, these recommendations should result in consistently improved home care and fewer hospitalizations.

The report notes that no single profession or health care provider is solely responsible for ensuring that family caregivers are trained and supported. This challenge requires the coordinated efforts of all sectors—hospitals, home care agencies, community agencies, nursing homes, hospices, and physician and other clinician practices—and a level of teamwork that challenges attitudes and behaviors firmly entrenched in the current system.

Based on the survey findings, the report recommends the following:

- Because health care professionals' and policymakers' understanding of family caregiving and eligibility of care recipients is typically based on measures of ADLs and IADLs, a consensus-building body should revisit these measures to acknowledge the types of tasks described in this report. The measures commonly used for a half-century no longer adequately capture what family caregivers do.¹ The Institute of Medicine is particularly well suited to this kind of consensus-building effort.
- Individual health care professionals must fundamentally reassess and restructure the way they interact with family caregivers in daily practice. Every health care clinician and social service professional should feel personally responsible for ensuring that patients and families in their care understand how to perform the challenging tasks outlined in this report.
- Health care organizations should support individual professionals and provide resources to ensure that family caregivers' needs for training and support are met.

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- Professional organizations should lead and support professionals in their efforts to improve communication with and training for family caregivers.
- Leaders in medical, nursing, social work, allied health professional training, and continuing education should examine their curricula to determine where and how the importance of acknowledging, supporting, and training family caregivers can be added or strengthened. New approaches are needed that blend technical and communication skills. Training must be adapted to respond to changes in the family member's condition or the family caregiver's needs and capabilities.
- Accrediting and standard-setting organizations must take seriously their evaluation of how well institutions incorporate family caregiver needs and require corrective steps to address deficiencies.
- Federal policymakers should proactively consider family caregivers in developing new models of care that focus on coordination and quality improvement. Explicitly including family caregivers in federal funding requirements for new models of care focused on care coordination and quality improvement is an essential first step.
- State policymakers should proactively consider family caregivers in funding and policy development. State governments should incorporate family caregiver assessments in publicly funded programs,² including the new demonstrations for people eligible for both Medicare and Medicaid. States should enable registered nurses to delegate medical/nursing care tasks to qualified direct care workers who serve people in their homes.
- Caregiver advocacy and support organizations should include in their service and policy agendas resources that address the needs of family caregivers who have taken on the triple burden of personal care, household chores, and medical/nursing tasks. Caregiver organizations have used ADLs and IADLs in describing their constituents and in advocating for funding and services. They, like their health care professional colleagues, must expand their view to include the special needs of family caregivers who perform medical/nursing tasks.
- Further research is needed around subpopulations of family caregivers performing medical/nursing tasks, such as ethnic or cultural minorities.

Family caregivers are the default providers for the complex care of people with multiple chronic conditions. It is time to clearly spell out the respective responsibilities of health care providers, payers, and family caregivers with transparency and accountability.

Endnotes

¹ S. C. Reinhard, "The Work of Caregiving: What Do ADLs and IADLs Tell Us?" in *Family Caregivers on the Job: Moving Beyond ADLs and IADLs*, ed. Carol Levine (New York, NY: United Hospital Fund of New York, 2004), 181–83.

² L. Feinberg and A. Houser, *Assessing Family Caregiver Needs: Policy and Practice Considerations* (Washington, DC: AARP Public Policy Institute, 2012).

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