

HOME ALONE:

*Family Caregivers Providing
Complex Chronic Care*



Susan C. Reinhard, RN, PhD
*Senior Vice President and Director,
AARP Public Policy Institute*

Carol Levine, MA
*Director, Families and Health Care Project,
United Hospital Fund*

Sarah Samis, MPA
*Senior Health Policy Analyst,
United Hospital Fund*



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Information, Philanthropy, Policy*

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AARP Public Policy Institute

601 E Street, NW, Washington, DC 20049

<http://www.aarp.org/ppi>

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We especially want to thank the family caregivers who responded to this survey for sharing their experiences in ways that can help us all better understand the work they do so we can advance solutions to help them.

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EXECUTIVE SUMMARY

This study 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.

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.

To document this major shift, the AARP Public Policy Institute and the United Hospital Fund undertook the first nationally representative population-based online survey of 1,677 family caregivers to determine what medical/nursing tasks they perform. Both organizations contributed to this report. We present a brief overview in this executive summary, followed by more detailed key findings and the full research report.

Highlights of Survey Results

- ▶ **Almost half (46 percent) of family caregivers performed medical/nursing tasks for care recipients with multiple chronic physical and cognitive conditions.** These tasks include managing multiple medications, helping with assistive devices for mobility, preparing food for special diets, providing wound care, using monitors, managing incontinence, and operating specialized medical equipment.
- ▶ **Many family caregivers managed many different kinds of medications.** Three out of four (78 percent) family caregivers who provided 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 care professionals.
- ▶ **Caregivers found wound care very challenging, and many wanted more training.** More than a third (35 percent) of family caregivers who provided medical/nursing tasks reported doing wound care. 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. More than a third (38 percent) would like more training.
- ▶ **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 personal care.

- ▶ **Family caregivers performing medical/nursing tasks reported both positive and negative effects on their quality of life.** Family caregivers who performed five or more medical/nursing tasks were most likely to believe they were making an important contribution, primarily preventing nursing home placement. Compared with those who performed one to four tasks, they were also most likely to report feeling stressed and worried about making a mistake. More than half reported feeling down, depressed, or hopeless in the last two weeks, and more than a third reported fair or poor health
- ▶ **More than half of family caregivers performing medical/nursing tasks said they did not feel they had a choice because there was no one else to do it or insurance wouldn't cover a professional's help.**
A small percentage (12 percent) reported pressure from the care recipient.
- ▶ **Family caregivers reported very few home visits by health care professionals.** Sixty-nine percent of the care recipients did not have any home visits by health care professionals. Of those who did have home visits, roughly seven in ten were visited by a nurse.
- ▶ **Most family caregivers who provided help with five or more medical/nursing tasks believed they were helping their family member avoid institutionalization.**
Those who provided these tasks and reported they had training were more likely to say they were able to help their family member avoid nursing home placement. These significant relationships are important on both the individual and public policy levels.

Major Recommendations

- ▶ **A consensus-building body should revisit measures of activities of daily living (ADLs) and instrumental activities of daily living (IADLs).**
The measures commonly used for a half-century no longer adequately capture what family caregivers do. 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 must 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 provider organizations (hospitals, rehabilitation centers, home care agencies, nursing homes, and hospices) must support health care professionals in their efforts through adequate resources and strong leadership.**
Every provider should have clear expectations, protocols, and support for clinicians who interact with family caregivers, especially caregivers who are taking on complex medical/nursing tasks. Payment policies should be structured to make this happen.
- ▶ **Professional organizations should lead and support professionals in their efforts to improve communication and training for family caregivers.** Some organizations have already begun this process. But much more needs to be done.

- ▶ **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.** The Joint Commission accredits and certifies more than 19,000 health care organizations and programs in the United States and has criteria for assessing patient and family participation in decision making and other aspects of quality care. But these criteria are not generally given high priority in ratings, and many institutions see them only as ideals. The Joint Commission should ensure that surveyors are trained to assess family caregiver training and support. The National Quality Forum, which endorses national consensus standards for measuring and publicly reporting on performance, should specifically define and promote standards that include the role of family caregivers.
- ▶ **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, 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.
- ▶ **Academic and government researchers should conduct further studies to understand medical/nursing tasks performed by different types of family caregivers and their needs for training and support.** Further research is needed in diverse populations, particularly ethnic minorities, family caregivers whose primary language is not English, and other groups whose experiences may differ from a national sample. More research is also needed on training methods and interactions between professionals and family caregivers. Foundations should support these studies.

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KEY FINDINGS

It is well known that family caregivers perform activities of daily living (ADLs) like bathing and dressing, as well as instrumental activities of daily living (IADLs), such as shopping, cooking, and preparing meals. But little is known about the complex health-related activities they perform. This report focuses on family caregivers' responsibility for "medical/nursing tasks" that can "make nursing students tremble."^{1 2} The AARP Public Policy Institute and the United Hospital Fund collaborated on the first national survey devoted specifically to medical/nursing tasks to further explore the complexity of the "new normal" that family caregivers face.³ We present detailed key findings here, followed by the full research report.

The findings are derived from an online survey of a nationally representative sample of 1,677 caregivers who provided unpaid care to a relative or friend age 18 or older in the preceding 12 months. Overall, the demographic characteristics of caregivers and care recipients are comparable to those of other national surveys and described in detail in the report. Most of the care recipients had multiple chronic conditions and had frequent visits to emergency departments (EDs) and overnight hospital stays. The key findings outlined here focus on the medical/nursing tasks that family caregivers performed and the general lack of training and support they received.

Almost half of family caregivers performed "medical" or "nursing" tasks for care recipients with multiple physical and chronic conditions.

In this survey, 777 of the 1,677 family caregivers (46 percent) performed medical/nursing tasks. They reported performing a variety of activities that some call "nursing," others call "medical," and still others call "health-related." Here we call them "medical/nursing tasks," which include the following:

- Managing medications, including injections and intravenous therapy (78 percent)
- Helping with assistive devices (canes and walkers) for mobility (43 percent)
- Preparing food for special diets (41 percent)

¹ S. C. Reinhard, *Caregiving and Loss: Family Needs, Professional Responses: Nursing's Role in Family Caregiver Support* (Hospice Foundation of America, Washington DC 2001).

² We decided to use the term "medical/nursing tasks" for several reasons. We wanted to use a term that survey respondents would relate to, not what professionals understand by the term. Other terms, such as "health-related," suggest activities related to food and exercise rather than the kinds of interventions we were targeting. Some terms, such as "complex medical care," have more currency in the medical world than among family caregivers. Family caregivers respond to "medical tasks" as a broader term than "nursing tasks," which they think of as something that only a licensed professional nurse can do. We chose the combined term "medical/nursing" to give survey respondents the broadest understanding of what we were asking of them. Consensus on language that captures this crucial family caregiving work would be helpful for future research and policy development.

³ L. Feinberg, S. C. Reinhard, A. Houser, and R. Choula, *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving* (Washington, DC: AARP Public Policy Institute, 2011).

- Doing wound care, such as ostomy care, treatment of pressure sores, and application of ointments and prescription drugs and bandages for skin care (35 percent)
- Using meters or monitors, including glucometers to test blood sugar levels, oxygen and blood pressure monitors, test kits, and telehealth equipment (32 percent)
- Administering enemas and managing incontinence equipment and supplies (25 percent)
- Operating durable medical equipment, such as lifts to get people out of bed, hospital beds, and geri-chairs (21 percent)
- Operating medical equipment, including mechanical ventilators, tube feeding equipment, home dialysis, and suctioning (14 percent)

Almost all (more than 96 percent) of these family caregivers also provided ADL or IADL assistance.

Family caregivers found some tasks more difficult than others, with some surprises for health care professionals.

When asked to select two medical/nursing tasks that are “hard to do,” family caregivers reported a range of tasks, including some that are conventionally not thought of as difficult. Two out of three (67 percent) of those who performed incontinence support found this very hard to do. This kind of task involves more than “help with toileting,” which is measured as an ADL, and it often involves intimacy with a parent or other family member in ways that would ordinarily be proscribed. Similarly, more than half (53 percent) of those who prepared food for special diets found this work hard to do because it involves more than “help with meals,” typically classified as an IADL.

“The constant monitoring of blood sugar levels and the need to balance diet to match blood sugar levels”...affects my quality of life.

It is less surprising that half (49 percent) of family caregivers who needed to operate mechanical equipment, such as mechanical ventilators, feeding tubes, or home dialysis equipment, found this work hard to do. And one in three (36 percent) of those who used meters, monitors, or durable medical equipment reported these activities as difficult.

Managing medications was very challenging and little training was reported.

More than three out of four (78 percent) family caregivers who provided medical/nursing tasks managed medications, including administering intravenous fluids and

injections. Almost all of these family caregivers also helped with ADLs, IADLs, or both. And the majority (81 percent) provided at least one additional medical/nursing service.

These family caregivers were not just helping with a pill or two a day, which may have been the case decades ago when IADL measures included “help with medications.” Almost half (46 percent) helped chronically ill people who took between five and nine medications a day. Close to one in five (18 percent) family caregivers helped care recipients who took ten or more prescription medications daily; seven in ten (69 percent) care recipients also took between one and four over-the-counter medications or supplements.

“I constantly monitor drugs.”

More than 60 percent of family caregivers asked a health care professional (doctor, nurse, or pharmacist) questions about the care recipient’s medication or looked up information on the Internet about the medication’s risks and benefits. Close to a third (31 percent) actively monitored their care recipient for potential side effects of medication, a task that requires caregivers to be knowledgeable about the medications.

Almost two-thirds (61 percent) of the family caregivers who found medication management difficult cited the following main reasons:

- Forty-two percent cited the time and inconvenience; 18 percent reported having to administer medications several times a day or night and 38 percent daily.
- Twenty-nine percent reported being afraid of making a mistake and harming their family member.
- Twenty-four percent reported that the care recipient was resistant and did not cooperate.

The majority of these medication caregivers (more than 60 percent) learned how to manage at least some of the medications on their own:

- Close to half (47 percent) said they never received training from any source.
- Thirty-two percent received training in an outpatient setting from a doctor or nurse.
- Sixteen percent received training from a hospital nurse or doctor.

When asked what would help them in medication management, many family caregivers commented, “Fewer medications.” Almost a third (29 percent) said another person to help would be good. One in four (24 percent) would appreciate more training, and 22 percent said they would like more cooperation from the care recipient.

Performing wound care was also very challenging, and many family caregivers received training.

More than a third (35 percent) of medical/nursing caregivers reported doing wound care, and almost all (92 percent) of these family caregivers performed other medical/nursing tasks in addition to wound care. While fewer family caregivers performed wound care tasks than medication management, a higher percentage of them (66 percent) identified it as hard.

Of these family caregivers, close to half (47 percent) felt that wound care was challenging because they were afraid of making a mistake and/or harming their family member. Other reasons included the following:

- Takes time or is inconvenient (34 percent)
- Emotionally difficult for caregiver (33 percent)
- Family member resists or has cognitive or behavioral problems (14 percent)

Family caregivers who deemed wound care difficult received more training from health professionals than did caregivers doing medication management. More than a third (36 percent) were trained by a hospital nurse or physician, and a quarter received training from a home care nurse. A substantial percentage of family caregivers (38 percent) thought more training in wound care would help them, compared with 24 percent citing training in medication management as potentially helpful.

Family caregivers felt pressured to perform medical/nursing tasks, but most pressure was self-imposed.

Family caregivers reported that they often felt pressured to take on medical/nursing tasks that they considered difficult. More than half (57 percent) said they did not feel they had a choice in assuming a hard task. Many of these (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 external pressure from the care recipient (12 percent) or another family member.

Family caregivers who perform medical/nursing tasks are more likely to be care coordinators than those who perform only ADL or IADL tasks.

Most family caregivers acted as care coordinators, but those who performed medical/nursing tasks were more than twice as likely to do so as those who performed only ADL/IADL tasks (57 percent vs. 24 percent). Very few family caregivers (3–4 percent) reported working with a care manager from an insurance company or government program or hiring a private geriatric care manager.

The greater the number of medical/nursing tasks family caregivers perform, the greater the effects on their quality of life.

Family caregivers who performed five or more medical/nursing tasks were most likely to feel close to the person they are helping. They also believed that they were gaining new skills and were making an important contribution. Compared with those who performed one or two tasks, they were also most likely to report the following:

- Depression (51 percent vs. 33 percent)
- Feeling the need to constantly watch out for something to go wrong (51 percent vs. 21 percent)
- Feeling stressed about talking to many professionals (40 percent vs. 16 percent)
- Feeling worried about making a mistake (36 percent vs. 12 percent)

These highly involved family caregivers appeared to understand how important they are to the person who needs such substantial medical/nursing care, but they were stressed and depressed by their significant health management role.

The greater the number of medical/nursing tasks family caregivers performed, the more likely they were to report that they were helping the care recipient avoid nursing home placement.

Three out of four family caregivers who provided help with five or more medical/nursing tasks believed they were helping their family member avoid institutionalization. The same was true of family caregivers who were caring for people with five or more chronic conditions. Two out of three caregivers who helped with medical/nursing tasks for family members with five or more chronic conditions reported that this support helped avoid nursing home placement. Family caregivers who provided medical/nursing tasks and reported they had training were more likely to say they were able to help their family member avoid nursing home placement. These significant relationships are important on both the individual and public policy levels.

“How has doing these medical/nursing tasks affected your own quality of life?”

One caregiver’s answer:

“What life?”

Another family caregiver’s answer:

“In the last year and a half I have developed high blood pressure, diabetes, and weight gain so now I have sleep apnea.”

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INTRODUCTION

In recognition of the crucial role of family caregivers as the foundation of long-term care, a national panel of experts recently identified family caregiving as one of five key dimensions in a high-performing system of long-term services and supports.⁴ Many studies have repeatedly cited family caregivers as the “backbone,” “bulwark,” or “mainstay” of care of older people and adults with disabilities.

Despite this recognition, the family caregiver’s role in primary, acute, and chronic care is typically invisible. Family caregivers are the main care coordinators, trying to tie together the fragmented pieces of their family member’s care with several different clinicians, hospitals stays, and transitions between settings, as well as dealing with social service agencies and other community services. Recent efforts to reduce hospital readmissions and improve transitional care have to varying degrees included family caregivers as critical partners,⁵ but the models are still focused mainly on the patient, or at best, the patient/family.

The United Hospital Fund’s Next Step in Care campaign is the only effort specifically addressing the needs of family caregivers during care transitions. In its Transitions in Care-Quality Improvement Collaborative (TC-QuIC), none of the 37 participating hospitals, home care agencies, rehabilitation programs, or hospices had a systematic way of identifying the actual (rather than the assumed) family caregiver. Even in the vast literature on family caregiving, there is scant attention to the complex medical/nursing tasks that caregivers are expected to take on to help people with multiple chronic conditions.

Donelan and colleagues⁶ at the Harvard School of Public Health, United Hospital Fund, and the Visiting Nurse Service of New York explored this issue more than a decade ago. Family caregivers reported receiving little training in how to manage wound care, pumps and machines at the bedside, and medications, although survey limitations did not permit more detailed analysis of their experiences in performing these medical/nursing tasks. Other studies have looked at these tasks in the context of specific populations. To our knowledge, only two books have been devoted to this subject: *Bringing the Hospital Home: Ethical and Social Implications of High-Tech Home Care*,⁷ which focuses on pediatric and human immunodeficiency virus (HIV) care, and *Family Caregivers on the Job: Moving Beyond ADLs and IADLs*.⁸

⁴ S. C. Reinhard, E. Kassner, and A. Houser, “How the Affordable Care Act Can Help Move States Toward a High-Performing System of Long-Term Services and Supports,” *Health Affairs* 30, no. 3 (2011): 447–53.

⁵ Mary Jo Gibson, Kathleen Kelly, and Alan K. Kaplan, “Family Caregiving and Transitional Care: A Critical Review,” www.caregiver.org; C. Levine and L. Feinberg, “Transitions in Care: Are They Patient- and Family-Centered?” *Generations* (Winter 2012–13), forthcoming.

⁶ K. Donelan, C. A. Hill, C. Hoffman, K. Scoles, P. Hollander Feldman, C. Levine, and D. Gould, “Challenged to Care: Information Caregivers in a Changing Health System,” *Health Affairs* (2002): 222–31.

⁷ John D. Arras, *Bringing the Hospital Home: Ethical and Social Implications of High-Tech Home Care* (Baltimore, MD: Johns Hopkins University Press, 1995).

⁸ Levine, C., S. C. Reinhard, L. Feinberg, S. Albert, and A. Hart, *Family Caregivers on the Job: Moving Beyond ADLs and IADLs* (New York, NY: United Hospital Fund of New York, 2004).

Review of this scant literature on home care nursing and family caregiver tasks found no standard list of tasks, and often no discussion of the differences between tasks performed in institutional and home settings or between the performance of the task by a nurse or other professional and a family member. There seems to be an implicit assumption either that the formal health care system provides these medical/nursing services, or that they are so simple that any untrained family member can do them. Neither assumption is true.

Methodology

Survey questions were based on a review of other national family caregiver surveys, literature on caregiver tasks, review of tasks delegated by registered nurses to unlicensed direct care workers,⁹ and the authors' experiences interviewing family caregivers and health care professionals. Knowledge Networks (KN), a survey research firm, was engaged to field the survey. KN maintains a large, nationally representative panel of survey respondents randomly recruited through probability-based sampling. Households are provided with access to the Internet and hardware if needed. KN fielded the survey in December 2011.

The initial screening question was, "In the past 12 months, have you provided unpaid care to a relative, partner, or friend age 18 years or older to help them take care of themselves because of a chronic illness or disability?" Family caregivers of people permanently living in nursing homes were excluded. About 18 percent of the respondents answered "Yes" to this question, a response rate slightly lower than, but consistent with, other survey results. A total of 1,677 valid responses made up the full panel.

These respondents were then asked, "Beyond emotional support and companionship, caregiving may include many different types of specific help. Did you help with:

- **Personal care tasks** (such as bathing, dressing, grooming, eating, moving from bed to chair, or going to the toilet);
- **Household tasks** (such as shopping, managing personal finances, arranging for outside services, or providing transportation); or
- **Medical or nursing tasks** (such as managing medications, changing dressing on wounds, or monitoring equipment like oxygen tanks)?"

The first two types of tasks corresponded respectively to the conventional ADL and IADL scales. The third category—medical/nursing tasks—included activities that are clearly in that realm, such as wound care and monitoring of medical equipment. Because of the complexity of medication management and the number of medications, both prescription and over-the-counter (OTC) drugs, that individuals with chronic illnesses take, medication management was included in the medical/nursing category rather than in the IADL category.

For this analysis, survey respondents were divided into two groups: (1) those who did any medical/nursing task in addition to ADL or IADL tasks, or both, which included 777 people; and (2) those who provided only ADL or IADL tasks, as defined in the survey question above, which included 900 people.

⁹ S. C. Reinhard, E. Kassner, A. Houser, and R. Mollica, *Rising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers* (Washington, DC: AARP Public Policy Institute, 2011).

For all survey questions with fill-in options, written responses were analyzed and assigned to the appropriate response categories whenever possible.

All information in this report comes from family caregiver responses to survey questions. No independent verification of care recipients' chronic conditions or other factors was undertaken.

Who Are the Family Caregivers?

The general profile of family caregivers in this study is quite similar to those described by other caregiver surveys, such as those by the National Alliance for Caregiving and AARP¹⁰ and the U.S. Bureau of Labor Statistics.¹¹ Using KN's basic demographic information on survey respondents and responses to additional questions on their caregiving relationships, this study carefully examined these characteristics to see if there were any differences between the family caregivers who performed medical/nursing tasks and those who assisted only with ADL/IADLs, which could affect comparisons between the two groups.

Table 1 summarizes key sociodemographic data for the survey's 1,677 respondents. In addition to displaying the information for the full panel, it compares the 900 caregivers who provided only ADL/IADL tasks with the 777 who provided medical/nursing tasks (almost

Table 1
Characteristics of Family Caregivers
(percent)

		All N=1677	M/N Tasks N=777	ADL/ IADL N=900
Gender	Male	42	38	45
	Female	58	62	55
Age	18–34	15	14	16
	35–49	19	19	19
	50–64	40	40	40
	65–79	23	24	22
	80+	3	3	3
	Mean Age	53	54	53
	Median Age	56	57	55
Race	White	73	71	75
	Black	10	12	9
	Hispanic	9	9	9
	Other	7	8	7
Marital Status	Married	67	68	66
	Single	33	32	34
Education	< High school	9	10	8
	High school	30	32	29
	Some college	31	29	32
	BA or higher	30	29	32
Work Status	Working	47	46	49
	Not working	17	18	16
	Retired	27	27	27
	Disabled	9	9	8
Household Income	< \$25K	23	23	23
	25–49	25	26	25
	50–74	19	18	20
	75–99	13	13	12
	100–124	9	7	10
	125+	11	12	10

All- Total Caregivers

M/N Tasks- Those Performing Medical/Nursing Tasks

ADL/IADL- Those Performing Only Activities of Daily Living and/or Instrumental Activities of Daily Living

Columns may not sum to 100 percent due to rounding.

¹⁰ National Alliance for Caregiving and AARP, "Caregiving in the U.S." (Washington, DC, 2009), retrieved from http://assets.aarp.org/rgcenter/il/caregiving_09_fr.pdf.

¹¹ U.S. Bureau of Labor Statistics, "American Time Use Survey Summary" (last modified June 22, 2012), retrieved from <http://www.bls.gov/news.release/atus.nr0.htm>.

always in addition to ADL/IADL tasks). In table 1 and subsequent tables, M/N Tasks stands for medical/nursing tasks.

Consistent with other family caregiving surveys,¹² we found that a modest majority of family caregivers (55 percent) were females, although a greater proportion of the caregivers performing medical/nursing tasks were female. There is a broad age distribution, with one-third younger than age 50, 40 percent age 50–64, and more than a quarter age 65 and older. A preponderance of the panel was white (73 percent). Two-thirds were married. Almost half (47 percent) were working, and more than half (61 percent) had attended or graduated from college. Household income distribution was broad, but not skewed toward the high end, with just 20 percent over \$100,000.

There were no significant differences in any of these sociodemographic characteristics between the two groups of family caregivers.

Adult children caring for their parents were the largest group of family caregivers (38 percent) (see table 2). Another 27 percent cared for other relatives. A large number (20 percent) were spousal or partner caregivers. Spousal caregivers were almost twice as likely to be doing medical/nursing tasks; 65 percent of spousal caregivers performed medical/nursing tasks compared with 35 percent who performed only ADL/IADL tasks. The relationship of intimacy/family ties holds steady, as significantly smaller proportions of caregivers for other relatives (23 percent) and friends (12 percent) performed medical/nursing tasks.

The length of time that a family caregiver cared for the family member did not appear to differ by the type of caregiving tasks. Close to a third of all family caregivers had spent less than a year in their caregiving role, close to a quarter had spent between one and two years, and an additional quarter had spent more than five years. Survey respondents had somewhat fewer longer-term caregivers than the 2009 survey by the National Alliance for

Table 2
Relationship to Care Recipient and Duration of Caregiving
(percent)

		All	M/N Tasks	ADL/IADL
Relationship with Care Recipient	Child	38	37	38
	Other relative	27	23	31
	Spouse or partner	20	28	13
	Friend or neighbor	15	12	18
Length Providing Care	< 1 year	32	31	34
	1–2 years	24	24	23
	3–5 years	20	19	20
	> 5 years	24	26	22

Columns may not sum to 100 percent due to rounding.

¹² A 2009 national survey by the National Alliance for Caregiving and AARP (http://www.caregiving.org/pdf/research/Caregiving_in_the_US_2009_full_report.pdf) found that caregivers are predominantly female (66 percent), 48 years of age on average, with a third (36 percent) taking care of a parent. Data from the 2004 National Long-term Care Survey found that spouses and children continue to be the primary family caregivers and that gender disparities persist (<http://assets.aarp.org/rgcenter/ppi/ltc/2010-09-caregiving.pdf>). The National Health and Aging Trends Study, the successor to the National Long-term Care Survey, will release its first data in spring 2013.

Caregiving and AARP, which found that 31 percent had spent five years or more.

Who Are the Care Recipients?

Care recipients in this survey looked similar to those in other surveys.¹³ The majority (65 percent) of the care recipients were female. The mean age was 71; 88 percent were over age 50, of whom 40 percent were over age 80 (table 3). Almost all (88 percent) had some health insurance. Since this was generally an older adult population, most people had some form of Medicare coverage, and many had additional supplemental coverage. Sixteen percent of family caregivers reported that the care recipient had Medicaid coverage, suggesting that this group was not predominantly low income. There were no notable differences in these sociodemographic characteristics between the group that received medical/nursing services and the group that did not.

Table 3
Characteristics of Care Recipients
(percent)

		All	M/N Tasks	ADL/IADL
Gender	Male	35	41	30
	Female	65	59	70
Age	18–34	5	5	5
	35–49	7	6	7
	50–64	20	20	19
	65–79	29	31	28
	80+	40	38	41
	Mean Age	71	71	71
	Median Age	75	74	76
Same House	Yes	38	52	26
	No	62	48	74
Health Insurance*	Medicare	58	59	57
	Medicare Advantage	13	14	11
	ESI	23	23	22
	Medicaid	16	15	17
	Direct Pay	15	15	15
	Tricare or CHAMPVA	6	5	6
	NA	2	2	2

*Columns do not sum to 100 percent because respondents could select multiple options.

Differences between the two groups are probably related to spousal caregiving. Care recipients receiving medical/nursing services were far more likely to be men (41 percent of men vs. 30 percent of women). They were also twice as likely to be living with the family caregiver; half (52 percent) of all medical/nursing recipients lived with their family caregiver, compared with one in four (26 percent) receiving ADL/IADL assistance only.

What Are Care Recipients' Health Problems?

As suggested by their frequent use of acute care, care recipients in this survey had multiple health problems (table 4). Almost all family caregivers (85 percent) reported that recipients had chronic physical health conditions such as stroke/hypertension, musculoskeletal conditions (arthritis, osteoporosis), cardiac conditions, and others. Some family caregivers (10 percent) reported “old age” as a problem.

¹³ In the National Alliance for Caregiving and AARP survey (http://www.caregiving.org/pdf/research/Caregiving_in_the_US_2009_full_report.pdf), the typical care recipient was female (62 percent), and 70 percent of the caregivers cared for someone 50 years of age or older.

Table 4
Care Recipient Chronic Conditions
(percent)

		All	M/N Tasks	ADL/IADL
Physical Health	Stroke, hypertension	38	44	33
	Musculoskeletal (arthritis, osteoporosis, etc.)	38	38	37
	Cardiac disease (heart attack, angina, congestive heart failure, etc.)	25	29	21
	Diabetes	22	25	20
	Cancer	14	15	12
	Lung disease	12	16	9
	Kidney disease	8	9	6
	Movement disorder (Parkinsons, etc.)	4	4	3
	Trauma	3	3	3
	Neurological disorders (ALS, epilepsy, Epstein Barr, etc.)	2	2	2
	Congenital conditions (CP, autism, Downs, etc.)	2	2	2
	Traumatic brain injury	2	2	2
	Gastro-intestinal problems	2	2	2
	Paralysis	2	3	1
	Multiple sclerosis	1	2	1
	Transplant (kindey, liver, stem cell)	1	1	1
HIV/AIDS	<1	<1	<1	
Cognitive	Memory problems, including dementia or Alzheimer's	30	34	27
Behavioral Health	Depression	22	25	19
	Mental Illness	4	4	4
Sensory	Hearing problems	20	22	18
	Vision problems	20	22	18
No Specific Condition, Just Old Age		10	7	13
Other		<1	3	3

Columns do not sum to 100 percent because respondents could select multiple options.

What Conditions Complicate the Performance of Medical/Nursing Tasks?

The survey also explored the incidence of other conditions that would likely complicate the provision of services by grouping health conditions into four domains: physical health conditions; cognitive conditions such as dementia, memory problems, and Alzheimer's; sensory impairments such as vision and hearing and behavioral conditions such as depression and mental illness. There was a notable incidence of confounding domain conditions for both groups; close to a quarter had at least one behavioral health condition, and 30 percent had at least one cognitive condition (table 5). For all four domains, care recipients whose family caregivers performed medical/nursing

Table 5
Chronic Conditions by Domain
(percent)

	All	M/N Tasks	ADL/IADL
Physical Health	85	89	80
Cognitive	30	34	27
Sensory	30	33	27
Behavioral	23	26	20

Care recipients can have more than one condition per domain.

Columns do not sum to 100 percent because respondents could select multiple options.

tasks were more likely than recipients with only ADL/IADL assistance to have health conditions in each domain.

While the presence of any of these confounding conditions can complicate caregiving, the presence of conditions in more than one domain can be especially burdensome for family caregivers. Table 6 displays a “piling on” effect where recipients with physical health conditions have co-occurring conditions across multiple domains. Recipients of medical/nursing services are more likely to present confounding conditions in at least one additional domain; more than half (55 percent) of medical/nursing recipients with physical health condition(s) suffer from at least one condition in a confounding domain, compared with fewer than half (43 percent) of ADL/IADL only recipients .

Table 6
Overlap in Chronic Conditions for Those Who Have Physical Conditions
(percent)

	M/N Tasks N=702	ADL/IADL N=803
Physical + Cognitive + Behavioral + Sensory	7	4
Physical + two other domains	15	11
Physical + one other domain	33	28
Physical only	45	57

N includes only care recipients with physical health conditions.
Columns may not sum to 100 percent due to rounding.

Care Recipients’ Use of Acute Care Services

Consistent with other findings about recipients of long-term services and supports with serious chronic conditions, care recipients in the survey were heavy users of acute care services. According to family caregivers, more than 30 percent of the care recipients used an ambulatory care surgery setting in the past year; 63 percent went to an ED at least once in the past year. More than half (56 percent) had at least one overnight hospital stay (table 7). Care recipients who received medical/nursing services were also more likely to have had two or more

Table 7
Care Recipients’ Health Service Use within the Past 12 Months
(percent)

		All N=1,677	M/N Tasks N=777	ADL/IADL N=900
Ambulatory Surgery	None	70	66	72
	1	19	21	17
	2	8	8	8
	3+	3	4	3
ED	None	36	31	41
	1	25	25	25
	2	20	22	19
	3+	17	21	14
	No response	1	1	1
Inpatient	None	43	39	47
	1	25	24	26
	2	17	19	14
	3+	15	18	12
	No response	1	1	1

Columns may not sum to 100 percent due to rounding.

overnight hospital stays than those who received only ADL/IADL services (37 percent vs. 26 percent).

Who Coordinates Care?

Most care coordination was performed by family caregivers, care recipients, and/or their family members (table 8), which means that these family caregivers had an additional responsibility on top of their other caregiving activities. Considering that care recipients have a high incidence of multiple chronic conditions and heavy acute care use, care coordination may be challenging for family caregivers. Family caregivers who performed medical/nursing tasks were more than twice as likely to be the primary care coordinator (53 percent) as those who provided only ADL or IADL care (24 percent). Primary care doctors were less likely to be coordinating care for care recipients who received medical/nursing assistance than for those who received only ADL or IADL care (16 percent vs. 29 percent).

Table 8
Care Coordinators
(percent)

	All	M/N Tasks	ADL/IADL
Caregiver	37	53	24
Care Recipient or Other Family Member of the Caregiver or the Care Recipient	23	16	29
Primary Care Doctor	23	16	29
Specialist Physician	5	5	5
Care Manager (geriatric, or from private insurance or government program)	3	3	4
Physician's Assistant, Nurse, or Assistant in Doctor's Office	3	3	2
Care Recipient + Caregiver/Other Family Member	1	2	1
Other	2	1	3
No Response	2	2	2

Columns may sum to 100 percent due to rounding.

Who Helps at Home—Professionals and Others

To examine additional support provided at home, family caregivers were asked whether health care professionals conducted home visits and whether they had other assistance with their caregiving activities. Most care recipients (69 percent) did not have home visits by health care professionals (table 9). For the 31 percent (521) of care recipients who did have home visits, roughly seven in ten were visited by a nurse (table 10). Medical/nursing care recipients who had home visits by professionals were more likely to have nurse visits than those receiving only

Table 9
Care Recipients with Home Visits by Health Care Professionals
(percent)

	All	M/N Tasks	ADL/IADL
Received a Home Visit	31	36	26
No Home Visits	69	64	73
No Response	<1	<1	<1

*Columns may not sum to 100 percent due to rounding.

ADL or IADL care (74 percent vs. 66 percent). For the whole panel, about a third of care recipients with home visits had physical therapist visits, and close to 30 percent had visits by social workers. These rates were similar for both of the care groups.

Family caregivers were also asked whether anyone helped them to provide regular care for the care recipient at home. More than one in four (27 percent) did not have any additional assistance with caregiving (table 11). Of those who reported additional help, the most common source was from another family member; more than half of the entire panel was supported in this fashion, although family caregivers who performed medical/nursing tasks were less likely to have help from another family member (49 percent vs. 58 percent for caregivers performing only ADL or IADL tasks). Overall, about one in five households (19 percent) had a home care aide. Family caregivers performing medical/nursing tasks were more likely (23 percent) to have assistance from a home care aide than those who provided only ADL or IADL assistance (16 percent). This may be related to the former group’s more frequent use of acute care services, because Medicare covers postdischarge aide service if a skilled nursing need is also identified. Because family caregivers could indicate more than one source of payment, it is not clear which payers were primary payers.

Looking at these statistics in a broader, more humanistic way, we see a population of mostly middle-aged family members taking care of a group of older relatives with many physical and cognitive problems, with very little help from health care and social service professionals. The care recipients live at home but are frequent users of acute care services, such as hospital EDs and inpatient units. Their care is generally ongoing rather than intermittent, as is the contribution of family members. This is the face of long-term services and supports in the “new normal.”¹⁴

Table 10
Type of Health Care Providers Making Home Visits
(percent)

	All N=521	M/N Tasks N=282	ADL/ IADL N=239
Nurse	70	74	66
Physical Therapist	33	34	31
Licensed Social Worker	28	28	27
Occupation Therapy	14	16	11
Doctor	13	16	11
Respiratory Therapist	6	8	4
Other	2	2	3

*Columns do not sum to 100 percent because respondents could select multiple options.

Table 11
Additional Help at Home
(percent)

	All N=1677	M/N Tasks N=777	ADL/ IADL N=900
Additional Family Member	54	49	58
Home Care Aide	19	23	16
Friend	12	11	13
Other	1	1	1
No Additional Assistance	27	30	25
No Response	20	21	19

*Columns do not sum to 100 percent because respondents could select multiple options.

¹⁴ Feinberg L, Reinhard SC, Houser A and Choula R. “Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving.” AARP Public Policy Institute (2011) Washington, D.C.

What Medical/Nursing Tasks Do Family Caregivers Perform?

Nearly half of family caregivers in the panel (46 percent, or 777) performed medical/nursing tasks. Almost all medical/nursing caregivers, more than 96 percent (747), also provided ADL or IADL supports, or both. Notably, of these family caregivers providing medical and nonmedical support, close to two-thirds (501) did all three types of tasks: medical/nursing, ADL, and IADL. Of the nonmedical family caregivers, two-thirds (605) provided only IADL assistance. Figure 1 shows the overlap in types of caregiving tasks and the number of family caregivers in each segment.

Some tasks were more obvious candidates for the medical/nursing category than others. Recent journal articles have included medication management as a medical/nursing task.¹⁵ Wound care and operating medical equipment like feeding tubes are clearly in the medical/nursing realm. Using assistive mobility devices like walkers was included because use of these devices by people with multiple chronic conditions is far more complicated than what is generally considered “help with walking.” Likewise, we included preparation of food for special diets, which can include not only meal planning and cooking but also complicated shopping for food that fits the diet, precise measurements, and careful feeding, such as for people with swallowing difficulties.

The survey presented a list of 18 possible medical/nursing tasks, which were condensed into seven categories (figure 2). The most commonly performed medical 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).

Which Medical/Nursing Tasks Were Hard to Do?

Family caregivers who performed medical/nursing tasks were asked to choose which two they found “hardest to do” (table 12) and asked further questions about why these tasks were difficult. If caregivers performed only one or two medical/nursing tasks, they were automatically asked the follow-up questions. When these respondents were given the opportunity to comment on whether they found these tasks difficult, the majority affirmed that these tasks were indeed difficult for them, and we have included their responses in table 12. The results were revealing and are consistent with our decision to include some tasks typically considered ADLs, as well as the more obvious clinical tasks, in the medical/nursing category.

¹⁵ E. R. Giovanetti, J. L. Wolff, Q. L. Xue, C. O. Weiss, B. Leff, C. Boulton, T. Hughes, and C. M. Boyd constructed an eight-item health care task difficulty scale for caregivers taking care of older adults, of which difficulties managing medication accounted for four of the eight items (“Difficulty Assisting with Health Care Tasks Among Caregivers of Multimorbid Older Adults,” *Journal of General Internal Medicine* 2011 27, no. 1: 37–44). Similarly, in a cohort of cancer caregivers, Van Ryn M, Sanders S, Kahn K, Van Houtven C, Griffin JM, Martin M, Atienza AA, Phelan S, Finstad D and Rowland J. “Objective Burden, Resources, and Other Stressors Among Informal Cancer Caregivers: A Hidden Quality Issue?” *Psycho-Oncology* 20 (2011): (1) 44-52. found that more than half administered medications and decided whether medication was needed, in addition to performing ADL tasks (“Objective burden, resources, and other stressor among informal cancer caregivers: a hidden quality issue,” *Psycho-Oncology* 20 (2011) : 44–52.) A study of caregivers in the Cash and Counseling demonstration projects specifically included a list of tasks as “nursing care,” including “giving or taking medicine” and “caring for pressure sores and other wounds” (Sara M. Moorman and Cameron Macdonald, “Medically Complex Home Care and Caregiver Strain,” *The Gerontologist*, <http://gerontologist.oxfordjournals.org/content/early/2012/05/04/geront.gns067.full.pdf>).

Figure 1
Distribution of 1,677 Caregivers by Task: Medical/Nursing, ADL, IADL

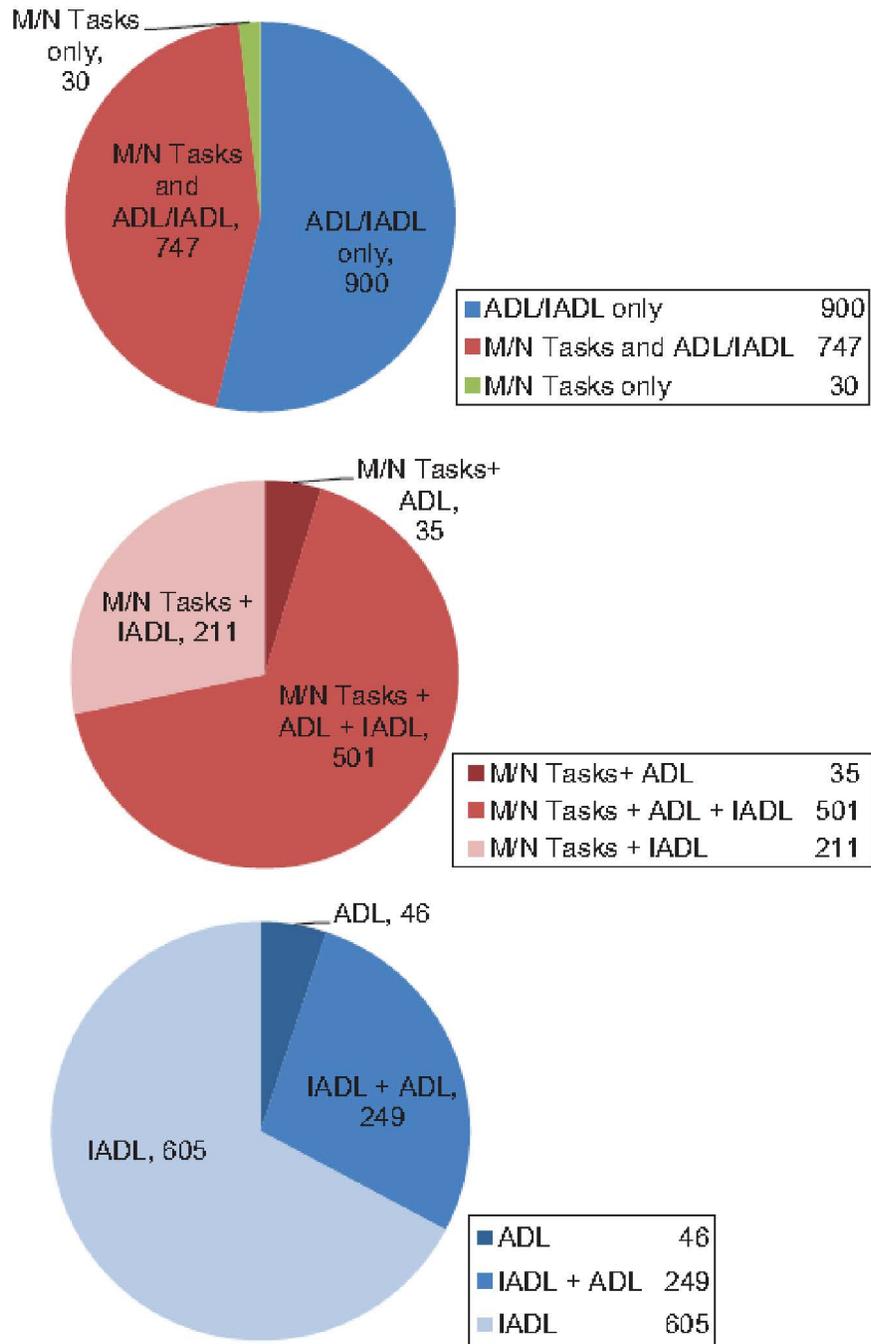
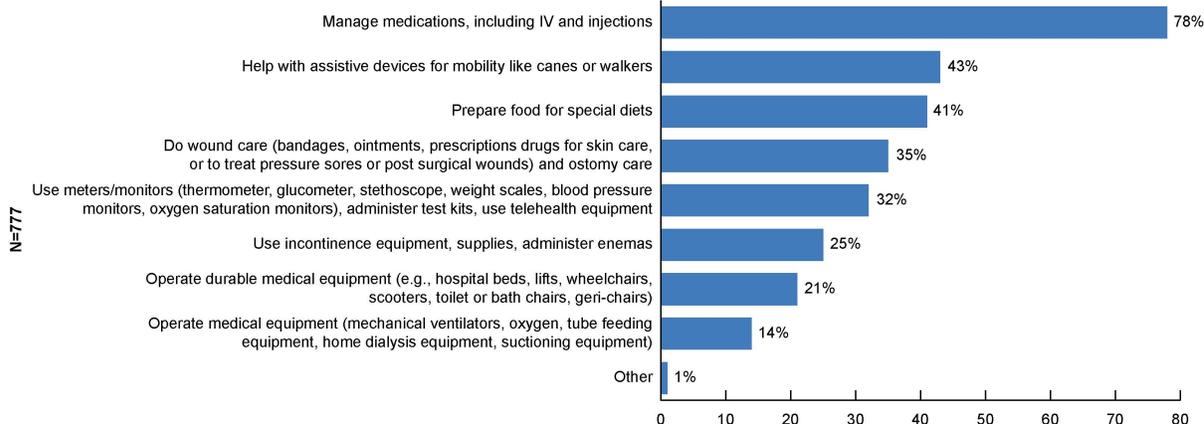


Figure 2
Medical/Nursing Tasks



Columns do not sum to 100 percent because respondents could select multiple options.

Table 12
Difficult Medical/Nursing Tasks

	# Performing Task	# Reported Hard Task	% Reported Hard Task
Use incontinence equipment, supplies, administer enemas	194	130	67
Do wound care (bandages, ointments, prescription drugs for skin care, or to treat pressure sores or post-surgical wounds) and ostomy care	275	181	66
Manage medications, including IV and injections	607	373	61
Prepare food for special diets	319	170	53
Operate medical equipment (mechanical ventilators, oxygen, tube feeding equipment, home dialysis equipment, suctioning equipment)	111	54	49
Help with assistive devices for mobility like canes or walkers	333	129	39
Use meters/monitors (thermometer, glucometer, stethoscope, weight scales, blood pressure monitors, oxygen saturation monitors), administer test kits, use telehealth equipment	275	100	36
Operate durable medical equipment (hospital beds, lifts, wheelchairs, scooters, toilet or bath chairs, geri-chairs, for example)	162	58	36
Other	7	5	71

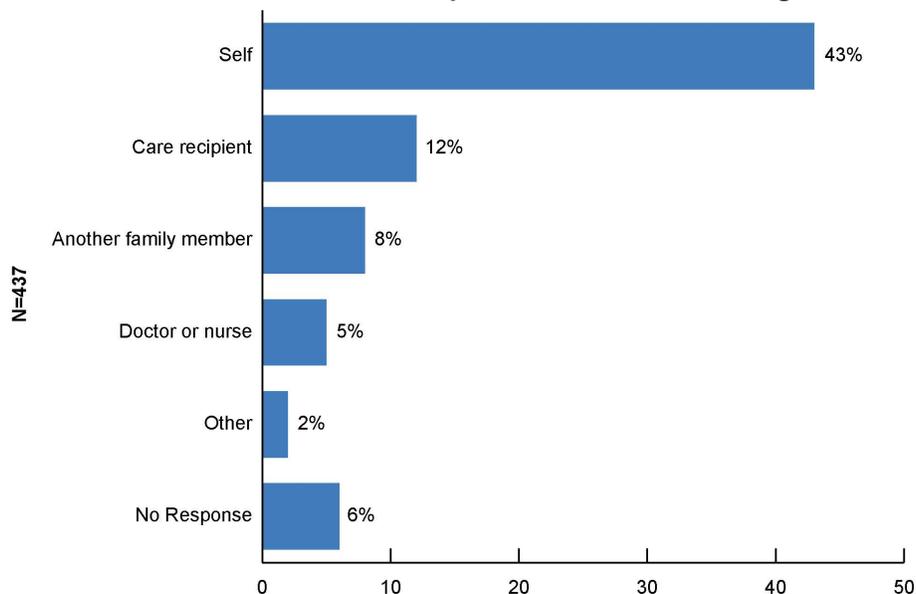
MacDonald¹⁶ classified “medically complex care tasks” along four dimensions: operation of technological equipment, sophisticated diagnostic skills, exposure to bodily fluids, and substantial risk to care recipients. The results confirm that family caregivers perceived tasks with these characteristics as difficult. Two-thirds of family caregivers engaged in wound care found it difficult, and more than 60 percent who managed medications said that this was emotionally difficult and frightening. 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 that in the recent past would have been done only in hospitals or nursing homes.

Some tasks that health care professionals might not consider hard are seen differently by family caregivers. For example, two out of three (67 percent) family caregivers reported that managing incontinence, which is different from the ADL of “helping someone go to the toilet,” is hard to do. Managing incontinence involves adult diapers and an intimate level of personal care for someone with whom the family caregiver has a long-standing personal relationship and for whom this task may impinge on familial or societal norms. Similarly, “preparing food for special diets,” as already noted, involves more than making a tuna sandwich for lunch. The degree of difficulty differs by situation and person, but all tasks can be challenging for some family caregivers.

Did Family Caregivers Feel They Had a Choice in Taking on These Tasks?

Family caregivers who did difficult tasks (N = 770) were asked whether they felt they had a choice in taking on these tasks (figure 3) More than half (57 percent) reported that they did not have a choice, but most of this pressure was self-imposed. For

Figure 3
Sources of Pressure for Those Who Reported No Choice in Taking on M/N Tasks



¹⁶ C. MacDonald, “High-Tech Home Care: Family Caregivers and Consequences.” Plenary Session Meeting of American Sociological Association, Boston, MA, 2008. <http://gerontologist.oxfordjournals.org/content/early/2012/05/04/geront.gns067.full.pdf+h>

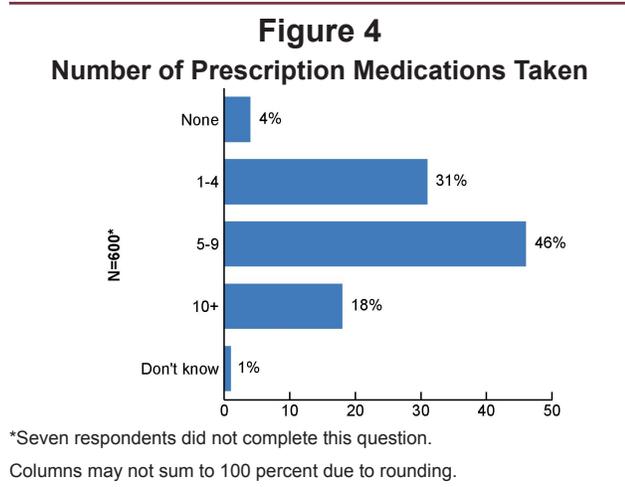
these family caregivers, the most frequently cited reason (43 percent) was feelings of personal responsibility (no one else to do it, insurance would not cover payment for a professional), while 12 percent said that the pressure came from the care recipient, and 8 percent said it came from another family member.

Medication Management: Further Analysis

Further analysis focused on two tasks that in today’s world most clearly fit into the medical/nursing category: medication management and wound care. These are two of the four tasks most commonly reported by family caregivers in the survey and are clearly in the medical/nursing realm. In addition, large majorities of family caregivers doing medication management and wound care called these tasks difficult. Finally, these tasks merit a closer look because they can require specialized training, and they have been linked to preventable health care spending, such the costs of inpatient admissions due to medication errors and infections.¹⁷ Performing these tasks incorrectly can have adverse impacts on the care recipient’s health status and quality of life.

More than three-quarters (78 percent) of medical/nursing family caregivers managed medications, including administering intravenous fluids and injections. Because medication management is such an important element in managing care at home and preventing hospital readmissions, several additional questions were asked about this task.

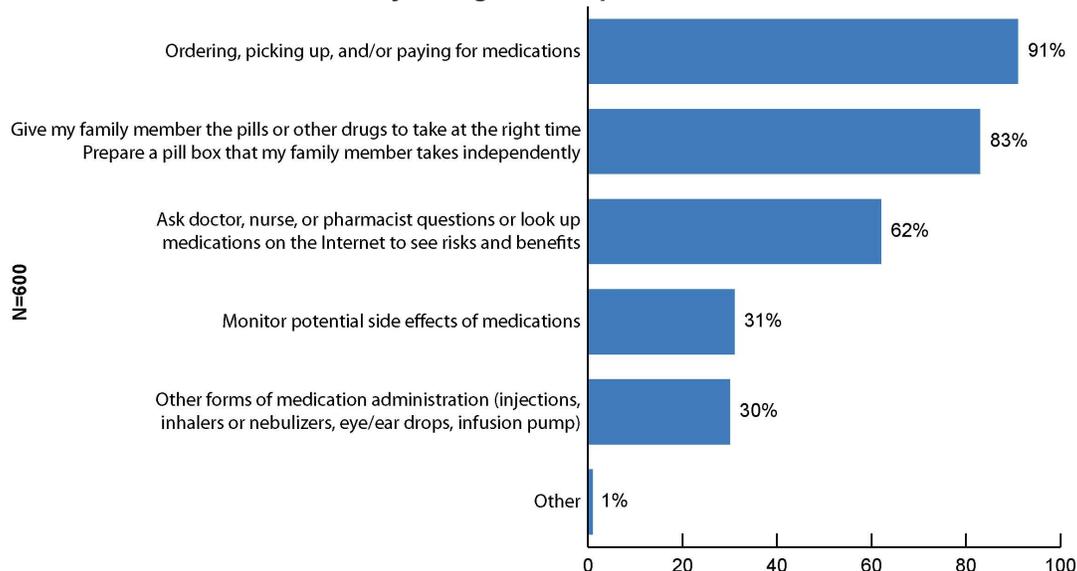
Most care recipients took several medications: 46 percent took between five and nine different prescription medications; close to one in five (18 percent) took ten or more prescription medications (figure 4). In addition to multiple prescription medications, care recipients also took OTC medications and supplements; more than three-quarters of caregivers reported that the person they cared for took one or more OTC medications or supplements.



Family caregivers helped with medications in a variety of ways (figure 5). More than 90 percent ordered, picked up, and/or paid for the care recipient’s medication. More than 80 percent of family caregivers helped care recipients take oral medications—either by giving pills or other drugs at the right time or by preparing a pillbox for recipients to take the pills independently. Thirty percent of family caregivers performed other forms of medication administration, including injections, inhalers or nebulizers, eye/ear drops, and using an infusion pump.

¹⁷ D. C. Classen, L. Jaser, and D. S. Budnitz, “Adverse Drug Events Among Hospitalized Medicare Patients: Epidemiology and National Estimates,” *Joint Commission Journal of Quality and Patient Safety* 36, no. 1 (2010): 12–21; G. Piazza, T. N. Nguyen, D. Cios, M. Labreche, B. Hohlfelder, J. Fanikos, K. Fiumara, and S. Z. Goldhaber, “Anticoagulation-Associated Adverse Drug Events,” *The American Journal of Medicine* 124 (2011): 1136–42.

Figure 5
How Family Caregivers Help with Medication



*Seven respondents did not complete this question.

Columns do not sum to 100 percent because respondents could select multiple options.

These “medication managers” also gathered information and became familiar with possible adverse effects of the medications. More than 60 percent of family caregivers asked a health care professional (doctor, nurse, or pharmacist) questions about the care recipient’s medication or looked up information on the Internet about the medication’s risks and benefits. Close to a third of family caregivers (31 percent) actively monitored their care recipient for potential side effects of medication, a task that requires them to have considerable knowledge about the medications.

These “medication managers” also were responsible for a significant number of other caregiving tasks. Fully four in five (81 percent) provided at least one additional medical/nursing service, and almost all (97 percent) also provided ADL or IADL supports, or all three to their care recipients.

Why Was Medication Management Hard to Do?

Medication management is often a difficult and time-consuming task. Family caregivers who considered it hard to do (N = 373) most frequently cited the time and inconvenience required (42 percent) (table 13). More than half of family caregivers (56 percent) who cited medication management as hard reported that they engaged in this activity at least once a day, if not several times a day or night. Other notable reasons were fear of making a mistake and causing harm (29 percent), which may be related to the number of medications being taken or the different ways in which they had to be administered (e.g., with food or on an empty stomach). Close to 60 percent of family caregivers (223) who identified medication management as hard reported that their care recipient took five or more medications. Lack of cooperation by care recipients (24 percent) was another common reason, and a repeated refrain in the comments. Many care recipients refused to take their medications as prescribed, or at all, adding to the family caregivers’ stress and frustration.

Some family caregivers who completed this section of the survey describing the difficulties of performing the selected tasks nevertheless commented that “this is my mother,” or “we have been married 51 years,” as if simply stating that this relationship superseded the difficulties. It is an important reminder of the reason family caregivers take on this role.

Table 13
Reasons Why Medication Management Was Hard

N=373	#	%
Takes Time and/or Is Inconvenient	157	42
Afraid of Making Mistake and/or Causing Harm	110	29
My Family Member Resists or Has Cognitive or Behavioral Problems	89	24
Emotionally Difficult for Caregiver	59	16
Other	10	3
I Don't Understand What to Do	7	2
Involves Lifting or Other Physical Effort	6	2
No Response	49	13

Columns do not sum to 100 percent because respondents could select multiple options.

The survey asked about difficulties in medication management in different ways, and with different results. When all family caregivers who responded that they managed medication were asked early in the survey whether they “understood” the reason medications were prescribed, why they should be taken at specific times, and whom to call with questions, 95 percent said that they understood these factors. Almost as many (93 percent) said that they understood what adverse reaction symptoms to look for in their care recipient. Only 3 percent said they had made a medication error that resulted in a hospitalization. These findings differ from those of other surveys and anecdotal reports, in which medication mishaps are a leading cause of rehospitalization.¹⁸

Despite their high reported confidence in managing medications, 61 percent of the family caregivers considered it a hard task. (As noted earlier, some may have responded in this way because they only performed one or two types of task, although most confirmed that it was difficult.) There are several possible reasons for this discrepancy. The family caregivers in the survey were not in the midst of a transition or crisis; they may have learned how to manage medications, although they still find it hard. They may distinguish between “understanding” what the medication regimen should be and what to look out for, and actually fitting it into a busy schedule, especially when the care recipient is uncooperative. Or it may simply be that these family caregivers, when asked a general question about “understanding,” gave what they considered to be the responsible answer.

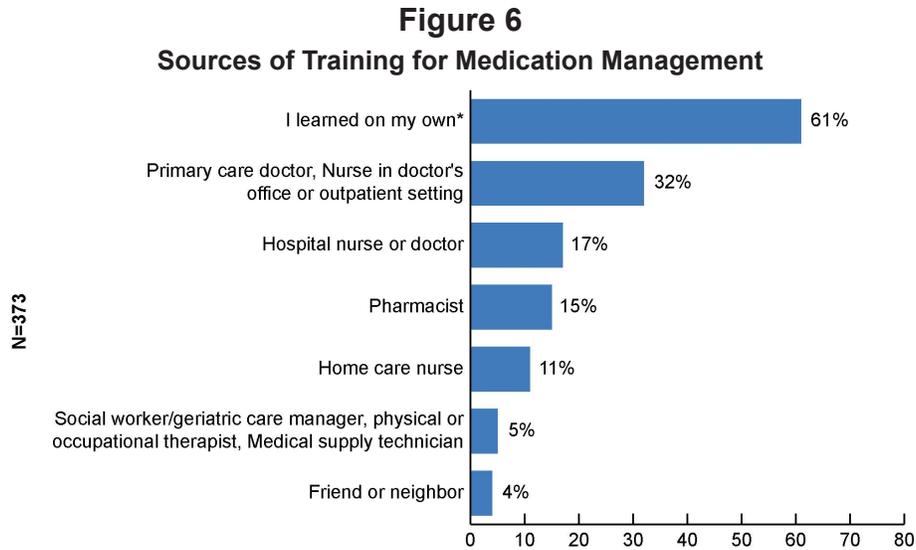
Who Trains Family Caregivers to Manage Medications?

Given the multiple chronic health conditions of care recipients and their frequent use of acute care services, it is notable that the majority of these family caregivers (more than 60 percent) learned at least some part of how to manage on their own, and close to half (47 percent, 176) said they have never received training from any source (figure 6).

The fact that some family caregivers who responded that they learned on their own also reported that they received training from other sources may indicate that their formal

¹⁸ Institute of Medicine- Committee on Identifying and Preventing Medication Errors. *Preventing Medication Errors: Quality Chasm Series*. Washington, DC: The National Academies Press, 2007.

A. J. Forster, H. J. Murff, F. Peterson, T. K. Gandhi, and D. W. Bates, “The Incidence and Severity of Adverse Events Among Medical Patients After Discharge from the Hospital,” *Annals of Internal Medicine* 138 (2003): 317–23.



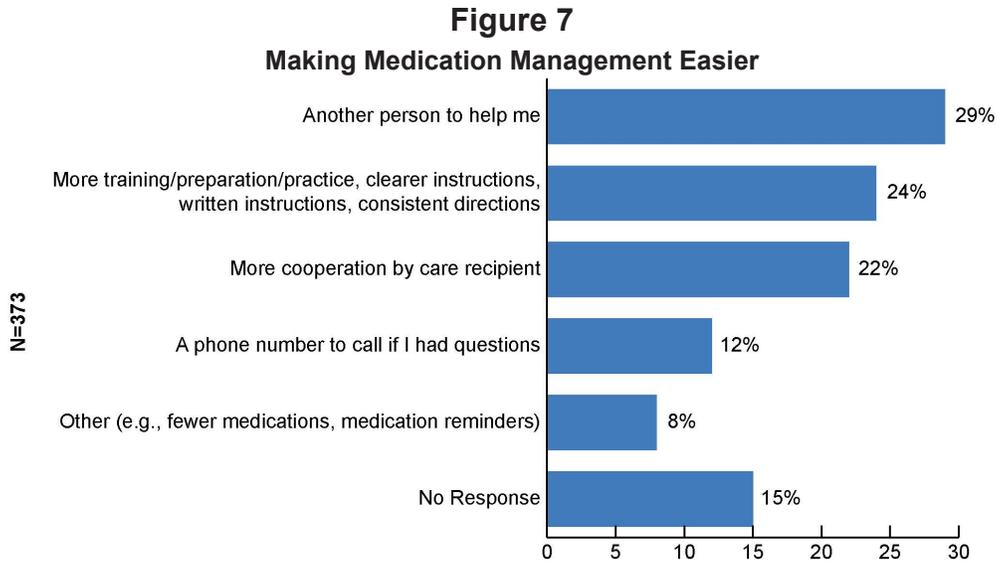
*Some people who selected “I learned on my own” also selected other sources of training.
Columns do not sum to 100 percent because respondents could select multiple options.

training was inadequate. While more than half (58 percent, 213) of medical/nursing caregivers who found medication management difficult reported that their care recipient was hospitalized overnight at least once in the past 12 months, only one in five of those caregivers (21 percent, 45) received training from hospital staff. Similarly, about one in five (22 percent) of medical/nursing caregivers who identified medication management as hard had a home care aide helping them to provide care. Yet fewer than a third of these family caregivers (30 percent) received training from a home care nurse.

If family caregivers received training from a health care professional—a doctor or nurse—it was most likely in an outpatient community setting. Family caregivers who learned on their own, but who also had some outside training, received it from an outpatient provider. Since most care recipients in the study were taking five or more medications, it is striking that pharmacists are not a more common resource; only 15 percent report receiving training from a pharmacist.

Looking at a group of family caregivers with significant medication responsibilities—multiple medications, often resistant care recipients, likelihood of hospitalizations, and spotty training from the formal care system—it is notable that only a quarter (24 percent) thought that more training and preparation would ease their burden (figure 7). Two other possible responses—having another person or family member help with medication management and better cooperation by the care recipient—received roughly comparable positive answers (29 percent and 22 percent, respectively). No response was considered helpful by a large percentage of family caregivers.

Many of the written comments suggest that it would help if the care recipient took fewer medications. This may seem like a facetious comment, but it is well known that older people are often overprescribed medications, in addition to the OTC substances that they take on their own. In these personal responses, family caregivers have identified a more general problem in geriatric care.



Columns do not sum to 100 percent because respondents could select multiple options.

One in four responded that more training would help. This relatively low response may reflect family caregivers’ dissatisfaction with the training that they did receive, either in the hospital or in the community, as indicated in their responses to “I learned on my own” and “I received some training.” Better training might well be a source of support. When staff in hospitals, nursing homes, and home care agencies participating in the United Hospital Fund’s TC-QuIC were surveyed about their own performance in communicating with and training family caregivers, they were generally quite positive. By contrast, family caregivers who had recently been through a discharge in these settings had very negative responses about the same items. Clearly, the training that is being provided—usually hastily and at the last minute—is not satisfying family caregivers’ needs.

Overall, family caregivers’ primary complaints regarding medication management pertained to the time-consuming and complex nature of simultaneously administering several prescription medications to a vulnerable person.

Wound Care: Further Analysis

The analysis of wound care performed by family caregivers illustrates how different medical/nursing caregiving tasks present discrete challenges for caregivers. When family caregivers perform multiple tasks simultaneously, they face numerous stresses that may amplify each other.

Like medication management, wound care is a diverse set of tasks that includes preparation and application of bandages, ointments, and prescription drugs for skin care, or treating pressure sores or postsurgical wounds, including colostomy (after removal of part of the colon) and urostomy (after removal of the bladder) care. Family caregivers almost always performed other medical/nursing tasks in addition to wound care; 92 percent of family caregivers engaged in wound care were responsible for additional medical/nursing tasks. As with medication management, almost all family caregivers who found wound care to be hard (96 percent) also provided ADL or IADL supports, or all three.

While fewer family caregivers performed wound care tasks than medication management, a higher percentage of them (66 percent) identified it as hard (table 14). Wound care is so specialized that in hospitals and home care agencies it is often assigned to a wound care nurse.

For these family caregivers (N = 181), close to half (47 percent) felt that wound care was challenging because they were afraid of making a mistake and harming their family member. While the time and inconvenience associated with wound care were also top reasons, a third of these family caregivers cited emotional difficulties on their part, twice the rate that said this about medication management. Comments provided by family caregivers cited the “ick” factor of dealing with wounds. These results are in keeping with the fact that wound care requires more intimate physical contact and personal risk than many medication management activities.

Wound care was performed less frequently than medication management, although a significant share of family caregivers reported engaging in wound care daily (table 15). Two-thirds (64 percent) of family caregivers who said wound care was challenging performed the activity less than once each day; roughly one-third (27 percent) completed wound care activities daily or more frequently.

Table 14
Reasons Why Wound Care Was Hard

N=181	#	%
Afraid of Making Mistake and/or Causing Harm	84	47
Takes Time and/or Is Inconvenient	60	34
Emotionally Difficult for Caregiver	59	33
My Family Member Resists or has Cognitive or Behavioral Problems	25	14
Involves Lifting or Other Physical Effort	21	12
Other	15	8
I Don't Understand What to Do	3	2
No Response	16	9

Columns do not sum to 100 percent because respondents could select multiple options.

Table 15
Frequency of Wound Care

N=181	#	%
Several Times a Day or Night	12	7
Daily	49	27
Frequently	42	23
Occasionally	74	41
No Response	2	1

Columns may not sum to 100 percent due to rounding.

Who Trains Family Caregivers to Do Wound Care?

Given the intimate physical nature of wound care and the fact that many family caregivers may not be familiar with the skills required to perform this task, wound care is a medical/nursing task that requires training. Family caregivers who deemed wound care difficult received more training from health professionals than did caregivers doing medication management (table 16). More than a third (36 percent) were trained by a hospital nurse or physician, and a quarter received training from a home care nurse. Roughly a quarter learned from an outpatient health provider. As with medication management, many family caregivers (42 percent) taught themselves how to care for wounds, although about half of these family caregivers also received training from other sources (47 percent).

What Would Make Wound Care Easier?

A larger share of family caregivers (37 percent vs. 24 percent for medication management) thought that having more training could ease their burden with wound care

(table 17). Similar to medication management, family caregivers experiencing difficulty with wound care reported that having another person or family member to help would make the task easier, as would better cooperation by the care recipient. Notably, family caregivers felt more strongly that assistance with wound care would be beneficial; larger shares of caregivers said that something could be done to make wound care easier than said so with regard to medication management.

What Is the Effect on Quality of Life for Family Caregivers Who Perform Medical/Nursing Tasks?

Recognizing the complexity of the medical/nursing tasks they are performing, we sought to explore the effect of performing these medical/nursing tasks on family caregivers’ quality of life. The analysis considered the effects of caregiving on the family caregiver’s physical and mental health, as well as other possible effects. These potential effects were drawn from the broad caregiving literature and the expertise of the research team.

To the question “How has doing these medical/nursing tasks affected your own quality of life?” family caregivers responded in several ways, as summarized in table 18.

In terms of positive response, almost half (44 percent) indicated that providing this care eased their worries about their family member’s condition. The same was true for feeling closer to the person (44 percent). Some family caregivers (24 percent) felt they had gained new skills they could apply in other areas of their life, and more than half (57 percent) felt they were making an important contribution.

With regard to negative effects, 14 percent said that performing these tasks had affected their employment, for example, by making it necessary for them to take time off from work. Almost one in four (23 percent) felt that these responsibilities added stress because they had to talk to so many professionals and suppliers. This source of stress is seldom recognized. And almost one in five (19 percent) worried about making a mistake. Nearly one-third (32 percent) felt that performing these tasks made them feel they had to be constantly watching out for something to go wrong.

Table 16
Sources of Training for Wound Care

N=181	#	%
I Learned on My Own*	76	42
Hospital Nurse or Doctor	64	36
Home Care Nurse	45	25
Primary Care Doctor, Nurse in Doctor’s Office or Outpatient Setting	41	23
Friend or Neighbor	11	6
Social Worker/Geriatric Care Manager, Physical or Occupational Therapist, Medical Supply Technician	8	4
No Response	3	2

*Some people who selected “I learned on my own” also selected other sources of training.

Columns do not sum to 100 percent because respondents could select multiple options.

Table 17
Responses to Making Wound Care Easier

N=181	#	%
More Training/Preparation/Practice, Clearer Instructions, Written Instructions, Consistent Directions	66	37
Another Person to Help Me	62	35
More Cooperation by Care Recipient	34	19
Other	20	11
A Phone Number to Call if I Had Questions	20	11
No Response	21	12

Columns do not sum to 100 percent because respondents could select multiple options.

Table 18
Positive and Negative Effects on Quality of Life for Family Caregivers Who Perform Medical/Nursing Tasks

N=777		#	%
Positive Effects	Eased/less worry	342	44
	Feeling closer	344	44
	Gaining new skills	190	24
	Making important contribution	440	57
Negative Effects	Employment/taking time off	110	14
	Dealing with many suppliers/professionals	179	23
	Making a mistake	146	19
	Constantly watching for something to go wrong	245	32
Physical and Mental Health	Fair or poor physical health	245	32
	Feeling down depressed or hopeless	349	40

Columns do not sum to 100 percent because respondents could select multiple options.

In terms of health status, nearly a third of family caregivers (32 percent) reported fair or poor physical health. Perhaps most concerning, 40 percent of the caregivers performing medical/nursing tasks reported feeling down, depressed, or hopeless in the last two weeks. While it is not possible to link these findings directly to caregiving, they suggest that family caregivers performing medical/nursing tasks are a vulnerable group at risk for serious physical and mental health consequences.

Tables 18, 19, and 20 summarize significant relationships between these effects on family caregivers' quality of life and three important aspects of their experience: the number of medical/nursing tasks performed, the number of chronic conditions the care recipient has, and whether the family caregiver received training from anyone other than a neighbor or friend. Training included any training other than that provided by a neighbor or a friend.

Table 19
Relationship between Number of Medical/Nursing Tasks Performed and Effects on Quality of Life for Family Caregivers

Effects		Number of Tasks		
		1–2 (N=366)	3–4 (N=237)	5+ (N=172)
Positive	Less worry	43%	46%	42%
	Feeling closer*	40%	46%	51%
	Gaining new skills**	20%	25%	34%
	Making important contribution**	48%	65%	65%
Negative	Employment**	9%	14%	26%
	Stress of talking to many**	16%	22%	40%
	Worry about making mistakes**	12%	17%	36%
	Constantly watching**	21%	34%	51%
Physical and Mental Health	Fair/poor health	31%	30%	35%
	Depressed in last 2 weeks**	33%	42%	51%

Columns do not sum to 100 percent because respondents could select multiple options

* Statistically significant differences between groups, at $p < 0.05$.

** Statistically significant differences between groups, at $p < 0.01$.

First, the more medical/nursing tasks the family caregiver performed, the greater the effects in all areas, except for reports of less worrying and poor physical health (table 19). Family caregivers who performed five or more medical/nursing tasks were more likely to feel closer to the person they were helping. They were also more likely to feel they were gaining skills and making an important contribution. On the other hand, the more tasks family caregivers were responsible for performing, the more negative the responses. Those who performed five or more tasks were more likely to report depression (51 percent) than those who performed one or two tasks (33 percent). The same was true for feeling the need to constantly watch out for something to go wrong (51 percent vs. 21 percent), feeling stressed about talking to many professionals (40 percent vs. 16 percent), and worrying about making a mistake (36 percent vs. 12 percent). These family caregivers appear to value the role they have taken on to provide such substantial medical/nursing care, but they experience high stress and depression

Second, the more chronic conditions the care recipient had, the greater the negative effects on quality of life for family caregivers in all areas, particularly physical and mental health (table 20). More than half (54 percent) of family caregivers providing medical/nursing tasks for family members with five or more chronic conditions reported depression, and 44 percent reported fair/poor health. Although there is a relationship between chronic conditions and feeling closer to the family member, family caregivers of people with five or more chronic conditions reported the least close relationship.

Finally, family caregivers who had reported they had received training¹⁹ were also more likely to feel that they were gaining new skills and making an important contribution than those who reported no training (table 21). Those receiving training

Table 20
Relationship between Number of Chronic Conditions and
Quality of Life for the Family Caregiver

		0 (N=80)	Number of Chronic Conditions		
			1 (N=151)	2-4 (N=367)	5+ (N=179)
Positive	Less worry	46%	45%	43%	44%
	Feeling closer*	43%	54%	44%	39%
	Gaining new skills	24%	26%	24%	25%
	Making important contribution	43%	58%	59%	58%
Negative	Employment**	8%	11%	13%	23%
	Stress of talking to many**	9%	13%	23%	37%
	Worry about making mistakes**	10%	13%	20%	25%
	Constantly watching**	18%	21%	32%	45%
Physical and Mental Health	Fair/poor health**	27%	28%	28%	44%
	Depressed in last 2 weeks**	33%	29%	39%	54%

Columns do not sum to 100 percent because respondents could select multiple options

* Statistically significant differences between groups, at $p < 0.05$.

** Statistically significant differences between groups, at $p < 0.01$.

¹⁹ For the purpose of this report, “training” is defined as receiving training from a professional (e.g., doctor, nurse, technician, social worker) for either of the two most difficult tasks performed by the caregiver. It is possible that some caregivers performing multiple medical/nursing tasks classified as “not having training” received some training for tasks other than the two most difficult.

Table 21
Relationship between Training and Quality of Life for the Family Caregiver

		Training	
		No (N=320)	Yes (N=457)
Positive	Less worry	42%	45%
	Feeling closer	41%	47%
	Gaining new skills**	16%	30%
	Making important contribution*	52%	60%
Negative	Employment	12%	16%
	Stress of talking to many**	18%	27%
	Worry about making mistakes*	15%	21%
	Constantly watching*	27%	35%
Physical and Mental Health	Fair/poor health	35%	30%
	Depressed in last 2 weeks	40%	40%

Columns do not sum to 100 percent because respondents could select multiple options

* Statistically significant differences between groups, at $p < 0.05$.

** Statistically significant differences between groups, at $p < 0.01$.

were also more likely to report negative consequences—feeling stressed about talking to many professionals, worrying about making a mistake, and constantly watching out for something to go wrong. It is unlikely that these were a consequence of training; the results may suggest that caregivers seek out training in response to these impacts.

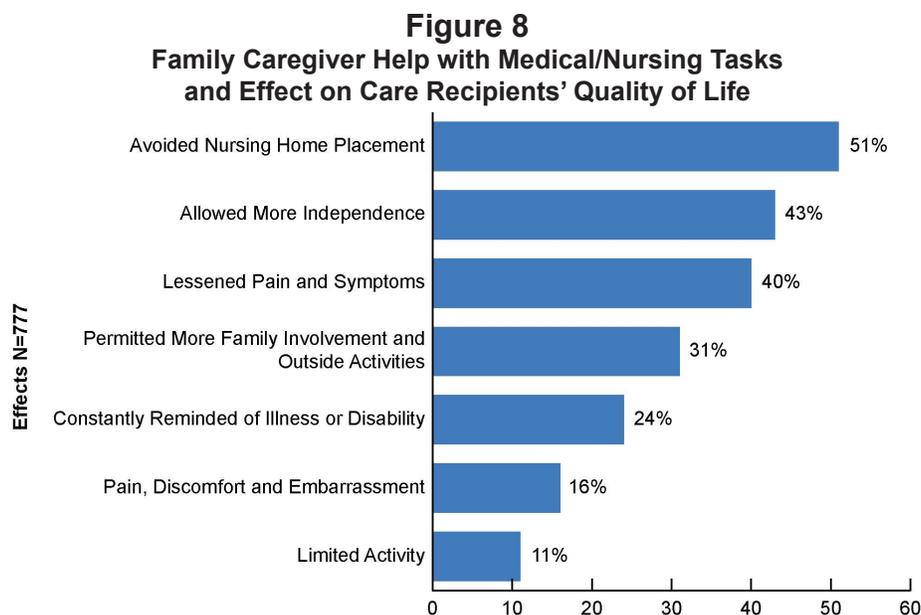
What Is the Effect on the Care Recipient of Family Caregiver Help with Medical/Nursing Tasks?

Family caregivers who provided help with medical/nursing tasks experienced significant consequences, but what about the consequences for the care recipients? To explore this question, family caregivers who provided medical/nursing tasks were asked, “How have these medical/nursing tasks affected your family member’s quality of life?” Several potential responses were offered, again based on the literature and research team’s expertise: Lessened pain and symptoms; permitted more involvement in family and outside activities; allowed more independence; allowed him/her to avoid nursing home placement; limited activity because of medication side effects or treatment schedule; been a constant reminder of illness or disability; and involved pain, discomfort, and embarrassment.

Figure 8 reports overall findings on care recipient effects. Most notable are family caregiver reports that the help they provided with medical/nursing tasks lessened their family member’s pain and symptoms (40 percent), allowed more independence (43 percent), and avoided nursing home placement (51 percent).

Tables 22–24 summarize significant relationships between several effects on care recipients’ quality of life and three factors: the number of medical/nursing tasks the family caregiver performed, the number of chronic conditions the care recipient had, and whether or not the family caregiver received training from anyone other than a neighbor or friend.

Several significant relationships are observed. For example, helping care recipients with up to four tasks allowed that family member more independence, but helping with five or more tasks is significantly related to less independence. The same pattern is shown



in the relationship between help with tasks and care recipients' limited activity. Most likely, once people reach the level of need for help with five or more specialized tasks, they are more dependent for help in ADLs. There are significant relationships between the number of medical/nursing tasks the family caregiver performed and reports that the care recipient had more pain, discomfort, and embarrassment. And having the family caregiver perform many tasks was likely to constantly remind the care recipient of his/her illness or disability.

The most important finding, which has direct implications for both family caregivers and public policy, is that the more tasks family caregivers performed, the more likely they were to report that these efforts allowed the care recipient to avoid nursing home

Table 22
Relationship between the Number of Tasks Family Caregivers Performed and Care Recipient's Quality of Life

Effect on Family Member	Number of Tasks		
	1–2 (N=366)	3–4 (N=237)	5+ (N=172)
Lessened Pain	37%	41%	43%
More Involvement in Family	28%	34%	31%
More Independence*	45%	48%	34%
Avoid Nursing Home**	35%	59%	73%
Limited Activity**	7%	12%	16%
Constant Reminder**	17%	24%	40%
Pain, Discomfort, Embarrassment**	10%	16%	30%

Columns do not sum to 100 percent because respondents could select multiple options

* Statistically significant differences between groups, at $p < 0.05$.

** Statistically significant differences between groups, at $p < 0.01$.

placement. Three out of four family caregivers who provided assistance with five or more medical/nursing tasks reported that they were helping their family member avoid institutionalization. The same was true for family caregivers who were caring for people with five or more chronic conditions (table 23). Two out of three caregivers who helped with medical/nursing tasks for family members with five or more chronic conditions reported that this support helped avoid nursing home placement.

Table 23
Relationship between the Number of Chronic Conditions and Effect on Care Recipients' Quality of Life

Effect on Family Member	Number of Chronic Conditions			
	0 (N=80)	1 (N=151)	2-4 (N=367)	5+ (N=179)
Lessened Pain	40%	37%	37%	47%
More Involvement in Family	26%	25%	32%	37%
More Independence	45%	36%	47%	40%
Avoid Nursing Home**	24%	36%	56%	66%
Limited Activity	9%	9%	11%	12%
Constant Reminder*	13%	25%	24%	30%
Pain, Discomfort, Embarrassment	13%	13%	17%	17%

Columns do not sum to 100 percent because respondents could select multiple options.

* Statistically significant differences between groups, at $p < 0.05$.

** Statistically significant differences between groups, at $p < 0.01$.

Finally, table 24 summarizes the relationship between whether the family caregiver received training and several consequences for the care recipient. Family caregivers who provided medical/nursing tasks and had some training were more likely to say they were able to help their family member avoid nursing home placement.

Table 24
Relationship between the Family Caregiver's Training and Effects on the Care Recipient

Effect on Family Member	Training	
	No (N=390)	Yes (N=387)
Lessened Pain	38%	41%
More Involvement in Family	29%	33%
More Independence	42%	44%
Avoid Nursing Home*	47%	55%
Limited Activity*	8%	13%
Constant Reminder	24%	25%
Pain, Discomfort, Embarrassment	17%	16%

Columns do not sum to 100 percent because respondents could select multiple options.

* Statistically significant differences between groups, at $p < 0.05$.

** Statistically significant differences between groups, at $p < 0.01$.

CONCLUSION AND RECOMMENDATIONS

This report describes the hidden world of family caregivers who perform medical/nursing tasks, such as medication management and wound care for adults with multiple chronic conditions. Almost half of family caregivers take on these tasks, in addition to doing personal care and household management. The report reveals the complexity and difficulty of specific tasks, the lack of support and training family caregivers receive, and the effects on their quality of life.

In a fragmented health care system, it is often difficult to pinpoint individual or institutional responsibility for action. As a result, people with chronic conditions and their family caregivers too often move from the care of one professional to another or from one care setting to another without a clear sense of who is in charge. All too often, no one is in charge. Expecting family caregivers to perform the medical/nursing tasks described in this report without substantial professional involvement is unrealistic and unacceptable. There are all sorts of explanations for this situation but no justification. A health care system that relies on untrained and unpaid family members to perform skilled medical/nursing tasks, but does not train and support them, has lost sight of its primary mission of providing humane and compassionate care to sick people and their families.

The report findings highlight an urgent need for both individual and collective action. No single profession or health care provider is solely responsible for ensuring that family caregivers who take on these daunting responsibilities are trained and supported. This effort 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 so firmly entrenched in the current system. Yet collective action will not be effective without individual commitment.

Based on the findings in this report, we offer 10 recommendations for action.

1. A consensus-building body should revisit ADL and IADL measures.

As this report has shown, the ADL and IADL measures developed and commonly used for a half-century no longer capture what family caregivers do as they provide a range of services and supports to people with chronic illness and disabilities.²⁰ As a result, family caregiving is typically mismeasured and misunderstood by health care professionals and policymakers as a fairly simple, easily learned set of responsibilities.

In order to identify, assess, and support family caregivers, we need to know who they are, what they are doing (or are expected to do), and what training and support they need. Therefore, we recommend a full review of existing measures, and the construction of a new measure that encompasses the kinds of tasks described in this report. The review should also look at the existing ADL and IADL measures in terms of their complexity, timing, and duration. The first challenge will be to arrive at a consensus about terminology. As we have noted, different researchers have used different terms to describe the same set of tasks. The terms should be clear to all (including family caregivers), appropriate for both research and practice settings, and useful in following trends.

²⁰ 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*, 181–83 (New York, NY: United Hospital Fund of New York, 2004).

Who should be responsible for this review? Although several existing bodies might take on the responsibility, we suggest that the Institute of Medicine (IOM) is particularly well suited to this kind of consensus-building effort. The IOM has already issued two reports that touch on family caregiving: Its report *Retooling for an Aging America: Building the Health Care Workforce*²¹ included family caregivers as part of the workforce but did not provide in-depth discussion of what practices and policies are needed to support them. In 2010 the National Research Council of the National Academy of Sciences, the parent organization to the IOM, published a Workshop Summary on *The Role of Human Factors in Home Health Care*.²² While this report focused on professional roles, its descriptions of the home care environment and the kinds of equipment and tasks mirror those family caregivers in our report performed

2. Individual health care professionals must fundamentally rethink and restructure the way they interact with family caregivers in daily practice.

Every health care clinician and social service professional must feel personally responsible for ensuring that the patients and families in their care understand how to perform the challenging tasks outlined in this report, as well as others not mentioned. Physicians, nurses, social workers, pharmacists, rehabilitation therapists, and others must encourage family caregivers to ask questions, and give them information for additional help. Professionals must embrace this responsibility and institute protocols to ensure that it is met. This responsibility can be shared with other professionals through teamwork and through collaboration with other health care and social service agencies, but there must be a clear system of accountability. One compelling demand for this kind of teamwork is addressing the numbers of medications prescribed and the complexity of the medication routine. Concerted efforts can reduce the likelihood of serious adverse reactions and costly hospitalizations, as well as ease the workload for family caregivers.

3. Health care provider organizations (hospitals, rehabilitation centers, home care agencies, nursing homes, and hospices) must support health care professionals in their efforts through adequate resources and strong leadership.

Individual health care professionals and interprofessional teams cannot do this work alone. They need support and resources from their provider organizations across all settings. This is not just an issue for acute care hospitals or for family caregivers coping with a transition from one setting to another, although these are sentinel events that demand sustained attention. Chronic care is by its nature long term, and the training and supports for family caregivers must be of similar duration. The need does not end with discharge from any formal service, but extends to the community, where health care clinicians and social service professionals will need to address the challenge of assessment, instruction, and support, which must become integral to routine practice. And payers must recognize the need for this crucial support of family caregivers by providing financial incentives to help make it happen.

²¹ Institute of Medicine, *Retooling for an Aging America: Building the Health Care Workforce: Consensus Report* (Washington, DC: National Academies Press, 2008).

²² National Research Council of the National Academy of Sciences, *The Role of Human Factors in Home Health Care* (Washington, DC: National Academies Press, 2010).

4. Professional organizations should lead and support professionals in their efforts to improve communication and training for family caregivers.

Some organizations have already begun this process, but much more needs to be done. Supported by The John A. Hartford Foundation and the Jacob and Valeria Langeloth Foundation, a broad panel of experts has identified the urgent need for health care professionals to better support family caregivers through evidenced-based information and tailored support.²³ In response, the National Association of Social Workers created the first *Standards for Social Work Practice with Family Caregivers of Older Adults*.²⁴ To reach practicing nurses, the New York University/Hartford Institute for Geriatric Nursing is leading a pilot with nurses in five hospitals to incorporate better communication, support, practical tools, and training for family caregivers. The goal is to expand this work with more than 300 hospitals nationwide that participate in NICHE (Nurses Improving Care of HealthSystem Elders).²⁵ A group of physician organizations (American College of Physicians, Society of General Internal Medicine, American Geriatrics Society, American College of Emergency Physicians, and Society of Academic Emergency Physicians) issued a transitions of care consensus policy statement that suggested specific elements that include family caregivers.²⁶ These organizations should follow up with their membership to see how well their recommendations are being implemented.

5. Leaders in medical, nursing, social work, and allied health professional training and continuing education should examine their curricula to determine where and how the importance of family caregivers and their ongoing needs for training and support can be added or strengthened.

Recognizing the need to train and support is an essential first step in education. But training is too often provided on the professional's schedule, not the family caregiver's, and in a manner that does not meet the family caregiver's learning style or health care knowledge. Professionals often forget that family caregivers are learning to do something that is difficult, embarrassing, or painful for the care recipient, with whom they have a long-standing, intimate relationship. Evidence on the best methods for training should be reviewed for applicability to family caregivers, and new approaches should be developed that blend technical and communication skills training. Good training is not a hurried demonstration on the day of discharge or a reassuring comment that "I explained everything to your mother." Training must be repeated and reinforced to be responsive to changes in the patient's condition or the family caregiver's own needs and capabilities.

²³ S. C. Reinhard, A. Brooks-Danso, and K. Kelly, "State of the Science: Professional Partners Supporting Family Caregivers," *American Journal of Nursing* 108 (2008): 9.

²⁴ National Association of Social Workers, "NASW Standards for Social Work Practice with Family Caregivers of Older Adults" (Washington, DC, 2010), Retrieved from <http://www.socialworkers.org/practice/standards/NASWFamilyCaregiverStandards.pdf>.

²⁵ E. Capezuti, M. Boltz, D. Cline, V. Vaughn Dickenson, M. Rosenberg, L. Wagner, J. Shulk, and C. Nigolian, "Nurses Improving Care for Healthsystem Elders—A Model for Optimizing the Geriatric Nursing Practice Environment," *Journal of Clinical Nursing* (2012).

²⁶ V. Snow, D. Beck, T. Budnitz, D. Miller, J. Potter, R. Wears, K. Weiss, and M. Williams, "Transitions of Care Consensus Policy Statement American College of Physicians-Society of General Internal Medicine-Society of Hospital Medicine-American Geriatrics Society- American College of Emergency Physicians-Society of Academic Emergency Medicine," *US National Library of Medicine, National Institutes of Health* 24, no. 8 (2009): 971–76.

Hospital residency training is a particularly important area for enhanced attention. A recent study found that there is no formal curriculum or organized teaching about how to develop competency to perform a high-quality discharge. Resident physicians said that they learned by default, leading to substantial variation.²⁷ The Accreditation Council for Graduate Medical Education should review its training requirements to include discharge planning that assists family caregivers. The new Medicare Graduate Nurse Education Demonstration pilot that will for the first time invest \$200 million in Medicare funding to train more advanced practice registered nurses should mandate a strong focus on interventions to support family caregivers.

6. 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.

The Joint Commission has many criteria for assessing patient and family participation in decision making and other important aspects of quality care. But these criteria are not generally given high priority in ratings, and many institutions see them as ideals, not standards on which they will be judged. The Joint Commission should ensure that surveyors are trained to assess family caregiver training and support. In setting standards for the delivery of high-quality health care, the National Quality Forum could specifically address the need to define and promote standards that include the role of family caregivers to follow up on its goal statement: “Healthcare should guide patients and families through their healthcare experience, while respecting patient choice, offering physical and psychological supports, and encouraging strong relationships among patients and the healthcare professionals accountable for their care....” Broad statements like these need to be followed by specific measures and tools.

7. Federal policymakers should proactively consider family caregivers in developing new models of care that focus on coordination and quality improvement.

As the United States aggressively develops new financing and care delivery models focusing on the integration and coordination of care—such as patient-centered medical homes, bundled payments, accountable care organizations, and managed care programs for people dually eligible for Medicare and Medicaid—it is essential to recognize that for many chronically ill people, *family caregivers are the primary care coordinators*. They cannot be expected to do more, and to play an integral role in these new models, with too little training and support. Without creatively addressing these needs, new systems of care and financing run serious risk of failure.

Now is a time ripe with opportunity. Overwhelming concerns with costs and quality of care—shared across the political spectrum—point directly to family caregivers, especially those taking on medical/nursing tasks. The federal Center for Medicare & Medicaid Innovation has the funding and visibility to stimulate new ways to assess and address the needs of family caregivers, who must be critical partners with health care professionals and provider organizations. Including family caregivers explicitly in federal requirements for funding new models of care is an essential first step. Proposals

²⁷ S. R. Greyson, D. Schilla, L. Curry, E. H. Bradley, and L. I. Horwitz, “Learning by Doing: Resident Perspectives on Developing Competency in High-Quality Discharge Care,” *Journal of General Internal Medicine* 27, no. 9 (2012): 1188–94.

for funding for Community Care Transitions Programs and programs for dually eligible beneficiaries are two immediate targets. Innovator organizations will need technical and financial assistance because very few existing organizations have developed adequate capacity to identify family caregivers, assess their needs, and provide training and support.

8. State policymakers should proactively consider family caregivers in funding and policy development.

The federal government leads and sets standards, but state governments set local policies and fund long-term services and supports. These efforts should incorporate family caregiver assessments in publicly funded programs,²⁸ including the new demonstrations for people who are eligible for both Medicare and Medicaid. States should also ensure that their state nurse practice acts and regulations permit registered nurses to delegate medical/nursing care tasks to direct care workers who demonstrate competence to perform these tasks for specific individuals in their homes. Whether paid to provide care to individuals through public funds or private payers, these workers can also relieve the demands on family caregivers who would otherwise have to perform tasks such as medication management, often leaving their job sites to do so. The State Scorecard on Long Term Services and Supports²⁹ will monitor progress in both caregiver assessment and nurse delegation by 2014.

9. 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. Caregiver organizations have drawn attention to the needs of family caregivers whose family members have Alzheimer’s disease or other dementias. As this report shows, many of these individuals also have concurrent medical/nursing needs, and the combination presents particular difficulties for family caregivers. Understanding the full spectrum of family caregiver needs is essential for future program development.

10. Academic and government researchers should conduct further studies to understand medical/nursing tasks performed by different types of family caregivers and their needs for training and support.

One of the strengths of this survey is its national scope and its portrayal of a representative group of family caregivers. However, that representativeness also limited its ability to document and explore the experiences of specific subgroups and specific tasks. We encourage further research in these areas:

²⁸ L. Feinberg and A. Houser, *Assessing Family Caregiver Needs: Policy and Practice Considerations* (Washington, DC: AARP Public Policy Institute, 2012).

²⁹ Reinhard Kassner E, Houser A and Mollica R. “Rising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers.” AARP Public Policy Institute (2011) Washington, D.C.

- Diverse populations, particularly ethnic minorities, family caregivers whose primary language is not English, and other groups whose experiences may differ from a national sample
- Spousal caregivers, who are likely to be of the same age as the care recipient and at risk for chronic health conditions
- Family caregivers of people with cognitive or behavioral conditions that may make performing medical/nursing tasks more difficult

More qualitative research is also needed about, for example, the interactions between family caregivers performing medical/nursing tasks and health care professionals in different settings.

Many academic and other research organizations can take on parts of this agenda. Foundations that have supported family caregiving in the past can sponsor a valuable new series of projects. Other foundations can provide new leadership. At the federal level, the Agency for Healthcare Research and Development, which already has consumer issues on its agenda, could focus specifically on family caregivers.

Summary

At a time when federal and state health policy is driving changes to reduce hospitalizations and nursing home admissions, it is critical to consider who will care for people with multiple chronic conditions who need substantial help with tasks that are often considered “nursing” or “medical” care. The default is the family, ready or not. Family caregivers agree to what has been called an “invisible contract”³⁰ when they take on the complex care of a person with multiple chronic conditions. It is time to change the terms of the contract to clearly spell out the respective responsibilities of health care providers, payers, and family caregivers with transparency and accountability.

³⁰ Dow B, McDonald J. “The Invisible Contract: Shifting Care from the Hospital to the Home.” *Australian Health Review*. 2007. 31 (2): 193-202.

REFERENCES

- Arras, John D. *Bringing the Hospital Home: Ethical and Social Implications of High-Tech Home Care*. Baltimore, MD: Johns Hopkins University Press, 1995.
- Capezuti, E., M. Boltz, D. Cline, V. Vaughn Dickenson, M. Rosenberg, L. Wagner, J. Shulk, and C. Nigolian. "Nurses Improving Care for Healthsystem Elders— A Model for Optimizing the Geriatric Nursing Practice Environment." *Journal of Clinical Nursing* (2012).
- Classen, D. C., L. Jaser, and D. S. Budnitz. "Adverse Drug Events Among Hospitalized Medicare Patients: Epidemiology and National Estimates." *Joint Commission Journal of Quality and Patient Safety* 36, no. 1 (2010): 12–21.
- Donelan, K., C. H. Hill, C. Hoffman, K. Scoles, P. Hollander Feldman, C. Levine, and D. Gould. "Challenged to Care: Information Caregivers in a Changing Health System." *Health Affairs* (2002): 222–31.
- Feinberg, L., and A. Houser. *Assessing Family Caregiver Needs: Policy and Practice Considerations*. Washington, DC: AARP Public Policy Institute, 2012.
- Feinberg, L., S. C. Reinhard, A. Houser, and R. Choula. *Valuing the Invaluable: 2011 Update, The Growing Contributions and Costs of Family Caregiving*. Washington, DC: AARP Public Policy Institute, 2011.
- Forster, A. J., H. J. Murff, F. Peterson, T. K. Gandhi, and D. W. Bates. "The Incidence and Severity of Adverse Events Among Medical Patients After Discharge from the Hospital." *Annals of Internal Medicine* 138 (2003): 317–323.
- Gibson, M. J., K. Kelly, and A. K. Kaplan. "Family Caregiving and Transitional Care: A Critical Review." 2012. www.caregiver.org.
- Giovanetti, E.R., J. L. Wolff, Q. L. Xue, C. O. Weiss, B. Leff, C. Boulton, T. Hughes, and C. M. Boyd. "Difficulty Assisting with Health Care Tasks Among Caregivers of Multimorbid Older Adults." *Journal of General Internal Medicine* 27, no. 1 (2011): 37–44.
- Greyson, S. R., D. Schilla, L. Curry, E. H. Bradley, and L. I. Horwitz. "Learning by Doing: Resident Perspectives on Developing Competency in High-Quality Discharge Care." *Journal of General Internal Medicine* 27, no. 9 (2012): 1188–94.
- Institute of Medicine. *Retooling for an Aging America: Building the Health Care Workforce: Consensus Report*. Washington, DC: National Academies Press, 2008.
- Institute of Medicine, Committee on Identifying and Preventing Medication Errors. *Preventing Medication Errors: Quality Chasm Series*. Washington, DC: The National Academies Press, 2007.
- Levine, C., and L. Feinberg. "Transitions in Care: Are They Patient- and Family-Centered?" *Generations* (Winter 2012–13), forthcoming.
- Levine, C., S. C. Reinhard, L. Feinberg, S. Albert, and A. Hart. *Family Caregivers on the Job: Moving beyond ADLs and IADLs*. New York, NY: United Hospital Fund of New York, 2004.
- MacDonald, C. "High-Tech Home Care: Family Caregivers and Consequences." Plenary Session Meeting of American Sociological Association. Boston, MA, 2008.
- Moorman, S. M., and C. MacDonald C. "Medically Complex Home Care and Caregiver Strain." *The Gerontologist* (2012).

- National Alliance for Caregiving and AARP. "Caregiving in the U.S." Washington, DC, 2009. http://assets.aarp.org/rgcenter/il/caregiving_09_fr.pdf.
- National Association of Social Workers. "NASW Standards for Social Work Practice with Family Caregivers of Older Adults." Washington, DC, 2010. <http://www.socialworkers.org/practice/standards/NASWFamilyCaregiverStandards.pdf>.
- National Research Council of the National Academy of Sciences. *The Role of Human Factors in Home Health Care*. Washington, DC: National Academies Press, 2010.
- Piazza, G., T. N. Nguyen, D. Cios, M. Labreche, D. Hohlfelder, J. Fanikos, K. Fiumara, and S. Z. Goldhaber. "Anticoagulation-Associated Adverse Drug Events." *The American Journal of Medicine* 124 (2011): 1136–42.
- Reinhard, S. C. *Caregiving and Loss: Family Needs, professional Responses: Nursing's Role in Family Caregiver Support*. Washington, DC: K.J. Doka and J.D. Davidson, 2001.
- Reinhard, S. C. "The Work of Caregiving: What Do ADLs and IADLs Tell Us?" In *Family Caregivers on the Job: Moving Beyond ADLs and IADLs*, 181–83. New York, NY: United Hospital Fund of New York, 2004.
- Reinhard, S. C., A. Brooks-Danso, and K. Kelly. "State of the Science: Professional Partners Supporting Family Caregivers." *American Journal of Nursing* 108 (2008): 9.
- Reinhard, S. C., E. Kassner, and A. Houser. "How the Affordable Care Act can Help Move States Toward a High-Performing System of Long-Term Services and Supports." *Health Affairs* 30, no. 3 (2011): 447–53.
- Reinhard, S. C., E. Kassner, A. Houser, and R. Mollica. *Rising Expectations: A State Scorecard on Long Term Services and Supports for Older Adults, People with Physical Disabilities, and Family Caregivers*. Washington, DC: AARP Public Policy Institute, 2011.
- Snow, V., D. Beck, T. Budnitz, D. Miller, J. Potter, R. Wears, K. Weiss, and M. Williams. "Transitions of Care Consensus Policy Statement American College of Physicians-Society of General Internal Medicine-Society of Hospital Medicine-American Geriatrics Society-American College of Emergency Physicians-Society of Academic Emergency Medicine." *US National Library of Medicine, National Institutes of Health* 24, no. 8 (2009): 971–76.
- U.S. Bureau of Labor Statistics. "American Time Use Survey Summary." Last modified June 22, 2012. <http://www.bls.gov/news.release/atus.nr0.htm>.
- Van Ryn, M., S. Sanders, K. Kahn, C. Van Houtven, J. M. Griffin, M. Martin, A. A. Atienza, S. Phelan, D. Finstad, and J. Rowland. "Objective Burden, Resources, and Other Stressors Among Informal Cancer Caregivers: A Hidden Quality Issue?" *Psycho-Oncology* 20, no. 1 (2011): 44–52.