

Home Alone Revisited:

FAMILY CAREGIVERS PROVIDING COMPLEX CARE



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The John A. Hartford
Foundation

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Kathleen Kelly, Rita B. Choula, Jean Accius

Special Report by the Founders of the Home Alone AllianceSM

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Table of Contents

EXECUTIVE SUMMARY I

MAJOR FINDINGS I

RECOMMENDATIONS III

CONCLUSIONS..... III

BACKGROUND..... 1

METHODS 3

RESULTS 5

MAJOR FINDINGS 7

Finding #1: Today’s caregivers provide *intense and complex care*, including medical/nursing tasks and managing multiple health conditions that are often accompanied by pain..... 7

Finding #2: Today’s caregivers are *diverse* and so are their experiences. 18

Finding #3: Caregivers who are socially isolated or have no choice about caregiving are more *at risk* for experiencing difficulties with complex care. 20

Finding #4: Caregivers performing more medical/nursing tasks experience both *positive and negative impacts*..... 22

Finding #5: Many family caregivers are still on their own—health systems should do *more to prepare* these vital members of the team..... 27

RECOMMENDATIONS 32

CONCLUSIONS..... 39

APPENDIX..... 41

ENDNOTES 53

REFERENCES..... 55

EXECUTIVE SUMMARY

The AARP *Home Alone* study in 2012 was the first national look at how families, neighbors, and friends are managing medical/nursing tasks—that is, the complex care associated with administering multiple medications, changing dressings, handling medical equipment, and providing many other kinds of help that were formerly offered by trained professionals.¹ (See www.aarp.org/homealone.) Seven years later, this *Home Alone Revisited* study sought a deeper understanding of what family caregivers who perform medical/nursing tasks experience. Employing an oversampling of multicultural groups, it took a closer look at specific difficult tasks, such as managing incontinence, pain, and special diets. It also offered greater attention to resources and outcomes as well as multicultural, gender, and generational experiences.

A nationally representative, population-based, online survey of 2,089 family caregivers provided the basis for our analyses. An organizing framework, qualitative findings, and multivariate analyses provided further insights into the stories these family caregivers told us. Their voices led to our recommendations, found in these pages, for professionals, health care organizations, policy makers, and private-sector stakeholders.

Major Findings

1) **Today's caregivers provide *intense and complex care*, including performing medical/nursing tasks and managing multiple health conditions that are often accompanied by pain.**

- Half of family caregivers are performing medical/nursing tasks for individuals with challenges in physical, cognitive, and behavioral health. They carry a heavier responsibility than those who do not perform these tasks, spending more than twice as many hours per week providing care.
- Seven out of 10 family caregivers who perform medical/nursing tasks face the practical and emotional strain of managing pain.

Implications of providing intense and complex care:

- Caregivers continue to take on the responsibilities that used to be the purview of health care professionals; they are providing complex care that they often find difficult to perform.
- Caregivers report being engaged in a number of monitoring and communication activities. This health delivery trend has a direct effect on caregiver responsibilities and contributes to additional health care system expectations for their participation.
- Pain management is a major issue, and it carries an emotional as well as practical and sometimes financial strain.

2) **Today's caregivers are *diverse* and so are their experiences.**

- Caregiving is a cross-generational issue for both men and women. Different age cohorts face distinct challenges for their life stage. For example, one in four of these caregivers is a millennial, and 40 percent of millennials and younger caregivers are supporting someone with a behavioral health condition.
- Multicultural family caregivers are more likely to experience strain and worry about making a mistake, regardless of income.

Implications of the diversity of caregivers:

- Just as caregivers are diverse, interventions to meet their needs for support and guidance must be diverse and flexible.

3) Caregivers who are socially isolated or have no choice about caregiving are more *at risk* for experiencing difficulties with complex care.

- Social isolation compounds difficulties with complex care, across generations and cultural groups.
- Most family caregivers who perform medical/nursing tasks feel they have no choice.

Implications for at-risk caregivers:

- More proactive assessment and outreach is needed to identify caregivers who need additional support.
- Choice is an important issue—not all caregivers are willing or able to assume care responsibilities, yet they are often expected by other family members or professionals to take on the role. They may face unpleasant judgment by others if they do not. Understanding willingness is important as health care professionals engage caregivers.

4) Caregivers performing more medical/nursing tasks experience both *positive and negative impacts*.

- About half of caregivers who perform medical/nursing tasks are worried about making a mistake. The more complex the task, the greater the worry.
- Stress, worry, financial concerns, and feeling the need to be vigilant rise as complex care demands increase.
- The more medical/nursing tasks they perform, the more caregivers feel they are keeping their family member out of a nursing home.

Implications of performing more medical/nursing tasks:

- Caregivers are motivated by making a contribution and helping the care recipient avoid nursing home placement, but many live with the worry of making a mistake and the difficulty of performing medical/nursing tasks.
- Given that caring for a relative or friend with complex health needs requires instructions, guidance, and support, the study recognizes the emotional impact on the family caregiver of providing this kind of care.

5) Many family caregivers are still on their own—health systems should do *more to prepare these vital members of the team*.

- Caregivers are largely on their own in learning how to perform medical/nursing tasks they find difficult to perform, such as managing incontinence and preparing special diets.
- Three out of five caregivers whose family members were hospitalized in the past year report that they received instruction on how to perform medical/nursing tasks, but more work needs to be done in ensuring hospitals identify family caregivers and give them timely notification of discharge.

Implications for health professionals and health care systems:

- Caregivers remain largely alone in learning how to perform medical/nursing tasks and manage the complexity of care.

- Presently, no comprehensive multidimensional measure captures either the complexity of the care or where caregivers are in the caregiving journey.
- Health care and social service professionals are not yet fully attuned to caregiver needs for information and support and how to deliver it in ways that allay anxiety.
- The Caregiver Advise Record Enable (CARE) Act has been enacted in 41 states, yet there is more to do to ensure that the intent of the act reaches family caregivers across the nation.

Recommendations

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

Conclusions

The findings and recommendations in *Home Alone Revisited* mark a turning point in our understanding of family caregiving. The old paradigm—the uncomplicated world of “informal” caregiving—no longer applies to millions of family members, friends, and neighbors of diverse ages and cultural backgrounds providing complex care at home. In the current health care environment, it is presumed that every home is a potential hospital and every service that the person needs can be provided by an unpaid family member, with only occasional visits by a primary care provider, nurse, or therapist.

The first *Home Alone* report made it clear that family members provide technically complex care such as changing wound dressings, operating medical machinery, and administering and monitoring numerous medications. The study helped fuel strategic action and a growing body of research. This new report adds to

the understanding of this major shift in responsibility, underscoring, for example, the stress associated with managing pain—an especially timely issue given the opioid epidemic. It makes clear the emotional and time-consuming challenges of dealing with incontinence and preparing special diets, two tasks that have long been assumed to be relatively easy to do. The sum of all these tasks—activities of daily living (ADLs), instrumental activities of daily living (IADLs), medical/nursing tasks, care coordination, not to mention emotional support and companionship—takes a toll on family caregivers, leaving all too many of them isolated and with mental and physical health problems of their own.

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

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

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

BACKGROUND

Since the 1980s, when family caregiving began to be a major topic for research, the family members, neighbors, and friends supporting people who have long-term or chronic health needs were given a label. They were called *informal caregivers* because they were unpaid and untrained, in contrast to the *formal caregivers* who were part of the health care system. The label *informal* reflected the understanding of what these caregivers did—household chores and personal care activities, duties that most caregivers could readily perform.

These activities were quantified not by the types of help family members provided but by measures of the functional abilities of the person receiving care.² Measures of activities of daily living (ADLs), such as bathing, dressing, toileting, transferring, and feeding, indicated the physical functional abilities and recovery of adults with hip fractures, stroke, and other chronic illnesses. Measures of instrumental activities of daily living (IADLs), such as shopping, cooking, performing housework, doing laundry, managing money, and handling transportation, indicated earlier changes in both physical and cognitive functioning that limited a person's ability to live independently in the community. In an era when fewer and less complex medications existed, managing medications was considered an IADL.

As a result, the family caregiver's job description became "help with ADLs and IADLs." National and state policy makers even codified this construct by linking caregivers' eligibility for respite to the "ADL deficits" of the person they were helping.³

2012 Report: Family Caregivers Also Perform Complex Medical/Nursing Tasks—without Instruction

Although individual studies had described in more complete terms the roles of family caregivers, the *Home Alone* study published in 2012⁴ was the first national population-based study to challenge the

common perception of a family caregiver's job description as focusing on ADLs and IADLs alone. For the first time, the survey revealed that, in addition to helping with ADLs, IADLs, and care coordination, almost half of family caregivers also performed complex medical/nursing (M/N) tasks, once considered the responsibility of trained professionals. The research showed that family members administered multiple medications in many different ways—including injections—changed wound dressings, managed special diets and medical equipment, and performed many more M/N tasks.

Yet even though the people they helped were hospitalized frequently and saw health care providers for office visits, most family caregivers said they received little or no instruction or guidance on how to perform these complex M/N tasks. Most of those they cared for did not have a home visit from any professional. Many family caregivers said they worried about making mistakes.

Recommendations Sparked Multiple Actions

Several of the report's recommendations drove strategic action by multiple stakeholders, summarized here and detailed further below:

- ◆ Advocacy for state adoption of the Caregiver Advise, Record, Enable (CARE) Act to engage hospitals and health care professionals in rethinking and restructuring interactions with family caregivers who are expected to perform M/N tasks upon the care recipient's discharge
- ◆ Creation of the Home Alone AllianceSM (HAA) of professional organizations and others who are committed to creating resources to improve communication and guidance for family caregivers who perform complex tasks
- ◆ Establishment of the Family Caregiving Institute at the Betty Irene Moore School of Nursing at the University of California Davis

- ◆ Collaboration with the National League for Nursing (NLN) to incorporate competencies in supporting family caregivers in nursing education
- ◆ Inclusion of a focus on performance of complex tasks in the National Academies of Science, Engineering, and Medicine’s study of family caregivers⁵

CARE Act

The *Home Alone* research was rapidly translated into state policies across most of the nation.^{6,7} It sparked a passionate response from family caregivers convened by AARP state offices who advocated for the CARE Act model bill, now law in 41 states and territories and being considered in several more (appendix A1). The model statute requires hospitals to do the following:

- ◆ Ask all patients who are admitted if they want to name someone who helps with their care at home (a family caregiver).
- ◆ Include the family caregiver’s name in the electronic health record if the patient desires.
- ◆ Offer family caregivers instruction on care tasks.
- ◆ Notify the caregiver of the discharge date as soon as possible.

A CARE Act national scan of hospital implementation is underway to uncover barriers to overcome and identify promising practices to spark rapid diffusion of innovation. The LTSS State Scorecard⁸ tracks many policies that are crucial in high-performing long-term services and supports (LTSS) systems. The passage of the CARE Act is one of several indicators in this scorecard.

Home Alone AllianceSM

The AARP Public Policy Institute launched the Home Alone Alliance (appendix A2) of professional organizations, funders, and private-sector leaders committed to finding solutions that fill the gap between the complex care family caregivers are expected to provide and the guidance and support they need to deliver it. After member organizations

participated in a 2014 scan of the current landscape of instructional videos and written materials, the need for innovation was clear. Further, family caregivers told us what they need.⁹ This qualitative research led to the development of the evidence-based *No Longer Alone* series of instructional videos and tip sheets to teach family caregivers how to perform specific M/N tasks (appendix A3). The *American Journal of Nursing* is disseminating these resources as well as peer-reviewed articles on the evidence underlying the instructions.¹⁰ The videos and other resources are available at www.aarp.org/nolongeralone.

The Family Caregiving Institute

The Family Caregiving Institute (FCI) at the Betty Irene Moore School of Nursing at the University of California Davis has led several initiatives to increase capacity for both family caregivers and the health care professionals who support them. An early effort convened national experts in family caregiving to identify research priorities to advance supports. The institute conducted a series of investigations to build consensus about dimensions of family caregiving to facilitate better preparation of individuals who take on this role and another line of inquiry to develop competencies for health care professionals to ensure their preparedness to support family caregivers.

National League for Nursing

The NLN has a long-standing commitment to faculty development and the creation of learning resources for nursing students. Collaborators at the FCI and the NLN are translating the competencies into learning activities and simulations to prepare health care professionals to support family caregivers.

National Academies of Science, Engineering, and Medicine

The *Home Alone* report informed the 2016 National Academies of Science, Engineering, and Medicine report *Families Caring for an Aging America*, in which M/N tasks were discussed as an important

part of the increasingly complex roles that family caregivers play. As the report states, “Older adults’ homes have become de facto clinical care settings where caregivers are performing an array of complex care tasks once provided only by licensed or certified professionals in hospitals and nursing homes.”¹¹

Awareness Is Spreading

We are encouraged by the impact of the initial *Home Alone* research. The findings of the 2012 report enhanced awareness of the complexity of the caregiving role. The study has been cited in almost 200 publications to date, including more than 80 journal articles, 15 book chapters, and several national reports. The work has been disseminated across disciplines in prominent health policy journals, including *Generations*; *Health Affairs*; *Journal of Health Politics, Policy, and Law*; *Milbank Quarterly*; and the journals of health professionals, such as the *American Journal of Nursing*, *The Gerontologist*, *Journal of the American Geriatrics Society*, *Journal of the American Medical Association*, *Journal of the American Pharmacists Association*, and *Journal of Gerontological Social Work*.

Market Forces Continue to Increase Family Caregiving Responsibilities

The health care environment is changing rapidly, with a shift from hospital-based care to care and services in the home and community. A consequence of controlling costs through earlier discharge is the transfer of responsibility to unpaid family caregivers, often without the necessary instruction and support that these often-overwhelmed people need.

As a result, we are committed to deepening our understanding of the role of and appropriate supports for diverse caregivers. We are publishing *Home Alone Revisited: Family Caregivers Providing Complex Care* to share the varied experiences of family caregivers who perform complex care and provide recommendations that can benefit the entire community of health care stakeholders, especially those who receive care and the family members who increasingly provide that care.

METHODS

Home Alone Revisited sought a deeper understanding of what family caregivers who provide complex care experience, to guide action at the individual, organizational, and societal levels.

NEW IN THIS STUDY:

Seven years after our first look at how families, neighbors, and friends are managing M/N tasks, this study employed an oversampling of multicultural groups, a closer look at difficult tasks, and greater attention to resources and outcomes.

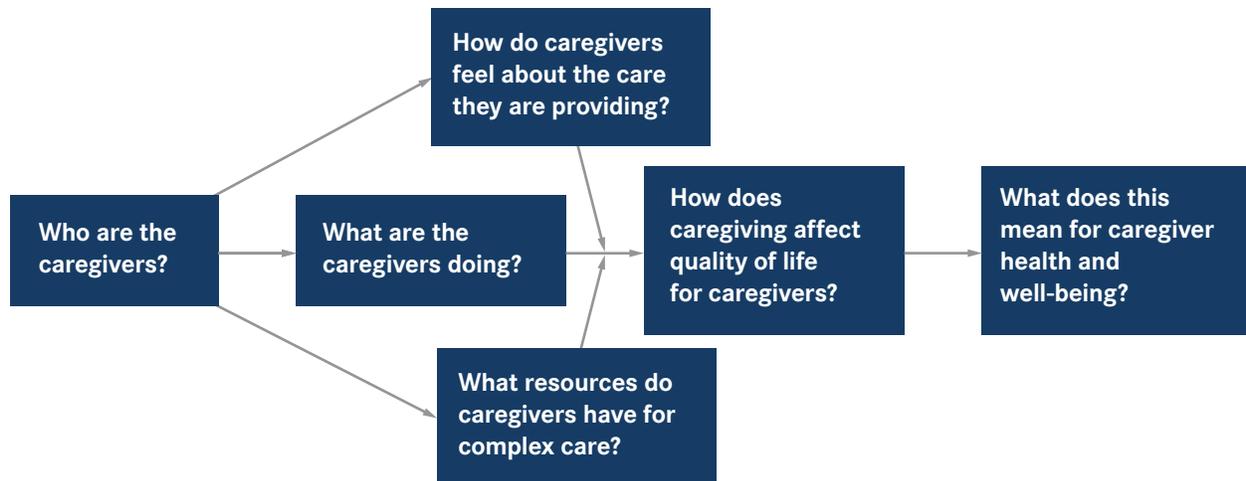
The new sampling strategy ensured multicultural representation and investigated generational differences. In addition, we explored certain topics in greater depth, including special diets, incontinence, pain, and the impact of social isolation on the caregiver. We focused on health system supports, including the requirements of the CARE Act.

An organizing framework, qualitative findings, and multivariate analyses provide further insights into the stories that these family caregivers told us.

The new cross-sectional, national, population-based survey sought to answer several important questions, summarized in the organizing framework depicted in figure 1.

We developed the current survey as a refinement and elaboration of the 2012 survey, incorporating further qualitative research among multicultural populations. Because of differences in sampling and measurement in this new study, we cannot make direct comparisons with the 2012 study (appendix A4). 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?”

Figure 1. Family Caregivers Providing Complex Care



As in the 2012 survey, we excluded family caregivers of people who permanently live in nursing homes. As a result, we based our analysis on the 2,089 respondents who responded “Yes” to the screening question. This response rate of 18.1 percent was about the same percentage as in 2012 and comparable to other national surveys of caregivers.

Respondents were then asked, “Beyond emotional support and companionship, caregiving may include many different kinds of specific help. Do 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 dressings on wounds, or monitoring equipment like oxygen tanks)?”

We then categorized respondents into two groups:

- ◆ Those who perform medical/nursing tasks (M/N caregivers)

- ◆ Those who perform only personal care tasks and household tasks (non-M/N caregivers)

The survey included questions about the caregiver’s background, the demands of the caregiving situation, caregiver perceptions about their role, their social support and social isolation (using the six-item Lubben Social Network Scale),¹² resources, caregiving strain (using the four-item Zarit Burden Screen),¹³ and the impact of caregiving on their health and well-being. All information in the survey was self-reported by the family caregiver.

Using the appropriate tests, we compared the demographic characteristics of the two groups of caregivers. We made further comparisons within the M/N group to understand gender, generational, and racial/ethnic differences in the experience of caregiving. Finally, we performed multivariate analyses to understand the contribution of background characteristics, caregiving demand, caregiver perceptions, and resources on the experience of caregiving and its impact on caregiver health and well-being.

See appendix A5 for additional information on methods.

RESULTS

Who Are the Caregivers in This Study?

Table 1 summarizes the demographic information, displayed for the total sample and for the subsamples of those caregivers who are performing M/N tasks and those who are not (non-M/N). Medical/nursing tasks are sometimes referred to as complex care in this report.

The study included 2,089 respondents from across the nation. Six out of 10 were women, and the sample ranged in age from 18 to 91 years of age, with an average age of 49. About half (50.1 percent) of family caregivers perform M/N tasks.

Table 1. Caregiver Characteristics (%)

	Total (n = 2,089)	M/N Tasks (n = 1,084)	Non-M/N (n = 1,005)
Gender: Female	57	60	53
Ethnicity: Hispanic/Latino	17	17	16
Race:			
White	63	61	64
Black/African American	12	12	12
American Indian/Alaska Native	1	1	1
Asian	7	8	5
Chinese*	1	2	1
Native Hawaiian/Pacific Islander	0	0	1
2+ races	2	2	3
Marital Status: Married/partnered	63	66	60
Employment Status: Working	62	60	63
Generation:			
Generation Z (18-21 years old)	4	3	5
Millennial (22-38)	27	26	27
Generation X (39-53)	23	24	23
Boomer (54-72)	39	39	39
Silent generation (73+)	7	8	6
Education:			
Less than high school	11	12	10
High school	30	29	30
Some college	31	31	31
Bachelor's or higher	28	28	29
Annual Income:			
Less than \$34,999	28	31	25
\$35,000 to \$74,999	29	27	31
\$75,000 to \$124,999	23	21	24
More than \$125,000	20	21	20

* Targeted over-sampling

What Is the Relationship of the Caregivers to the Person in Their Care?

The largest group of family caregivers is adult children who care for their parents, followed by one spouse who cares for the other (table 2). Half of family caregivers who perform complex care (M/N tasks) live with those they care for. More than 1 in 10 live at least two hours away. The majority of caregivers have been providing care for at least two years, while 1 in 4 has been a caregiver for more than five years.

NOTABLE IN THIS STUDY:

In the 2012 report, 35 percent of survey participants were men; in the new study, 43 percent are men.

Table 2. Relationship to Care Recipient (%)

Relationship*	M/N		
	Total (n = 2,089)	Tasks (n = 1,084)	Non-M/N (n = 1,005)
Child	45	45	44
Spouse	18	23	13
Sibling	11	7	15
Grandchild	6	5	6
Friend or neighbor	6	7	10
Parent	5	6	5

* Relationship includes biological, step, and in-law

Who Are the Care Recipients?

Care recipients have a mean age of 68, and 6 out of 10 are women. Six out of 10 are married or living

with a partner (table 3). Race and ethnicity are similar to those in the caregiving sample.

Table 3. Care Recipient Characteristics (%)

	Total (n = 2,089)	M/N Tasks (n = 1,084)	Non-M/N (n = 1,005)
Gender: Female	60	58	61
Age (years):			
0–17	2	2	1
18–49	14	15	12
50–64	20	20	21
65–74	19	21	18
75+	45	42	47
Ethnicity: Hispanic/Latino	13	14	12
Race:			
White	69	67	70
Black/African American	13	13	13
American Indian/Alaska Native	1	1	1
Asian	5	6	4
Native Hawaiian/Pacific Islander	1	0	1
Other	1	1	2
Refused	1	1	1
Veteran Status: Yes	15	16	14
Marital Status: Married/partnered	63	66	60
LGBT: Yes	2	2	2

The individuals who receive care have physical, cognitive, behavioral health, and addiction issues (table 4). Eight out of 10 caregivers are managing physical health, including conditions such as heart disease, cancer, stroke, diabetes, arthritis, and lung disease. Cognitive and behavioral health are also important reasons for providing care—approximately one-third of care recipients require assistance in each of these domains. Cognitive health includes memory problems, Alzheimer’s disease, and related dementias. Behavioral health includes mental health conditions such as depression, anxiety, bipolar disorder, and schizophrenia. Addiction includes alcoholism and prescription drug, opioid, or other substance misuse and affects 4 percent of the sample.

Table 4. Care Recipient Needs (%)

	Total (n = 2,089)	M/N Tasks (n = 1,084)	Non-M/N (n = 1,005)
Physical health	80	82	77
Cognitive health	30	32	29
Behavioral health	23	27	20
Addiction	4	4	4

Note: The table 4 total is greater than 100 percent because family caregivers could select more than one type of health issue.

NEW IN THIS STUDY:

We present caregivers by generation. Among millennial and younger adult family caregivers, 4 out of 10 care for someone with behavioral health issues. More than three-quarters indicate that managing their family member’s mental health and related behavior is very stressful.

MAJOR FINDINGS

FINDING #1: Today’s caregivers provide intense and complex care, including medical/nursing tasks and managing multiple health conditions that are often accompanied by pain.

Half of family caregivers are performing medical/nursing tasks for individuals with challenges in physical, cognitive, and behavioral health. They carry a heavier responsibility than those who do not perform these tasks, spending more than twice as many hours per week providing care.

The 2012 study found that almost half (46 percent) of family caregivers perform M/N tasks. This study found that half (50.1 percent) of all family caregivers today are performing M/N tasks for individuals with challenges in physical, cognitive, and behavioral health. More than 6 in 10 of these caregivers perform three or more M/N tasks. One-quarter perform five or more of these complex care tasks.

More than half of family caregivers who perform M/N tasks also monitor their family member’s mental health and related behavior. Of those who do, almost half find it to be stressful or extremely stressful (appendix A6).

How Do Caregivers Help?

The caregivers who perform M/N tasks carry a heavier load in several respects. In addition to assisting with IADLs, they provide more support in basic ADLs, provide more hours of care, and cared for more than one person in the past year.

Those who perform M/N tasks

- ◆ Are twice as likely to be helping with ADLs, such as bathing, dressing, and toileting;

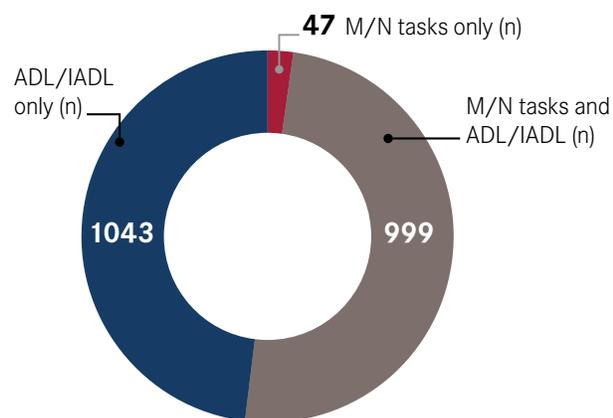
- ◆ Carry a heavier load of IADLs, such as performing household tasks, providing transportation, and managing finances;
- ◆ Are three times as likely to spend more than 20 hours per week on overall caregiving activities than those who don't perform M/N tasks; and
- ◆ Spend more than twice as many hours providing care per week on average (appendix A7). (Overall among all respondents, caregivers contribute an average of 17 hours per week.)

NEW IN THIS STUDY:

We highlight multicultural differences in caregiving. Nearly a third of Chinese caregivers indicate feeling extremely stressed managing a family member's mental health and related behavior, compared with less than 20 percent for other racial and ethnic groups (appendix A6).

Half of caregivers in the sample report performing M/N tasks, with more than 9 out of 10 providing that care in addition to helping with IADLs and more than 6 of 10 also helping with ADLs. Figure 2 shows that most of those who are performing M/N tasks are also performing ADLs and IADLs.

Figure 2. Distribution of Caregiving Tasks



NOTABLE IN THIS STUDY:

Three in 4 Blacks/African Americans who perform M/N tasks also help with personal care, compared with 6 in 10 Whites (appendix A8).

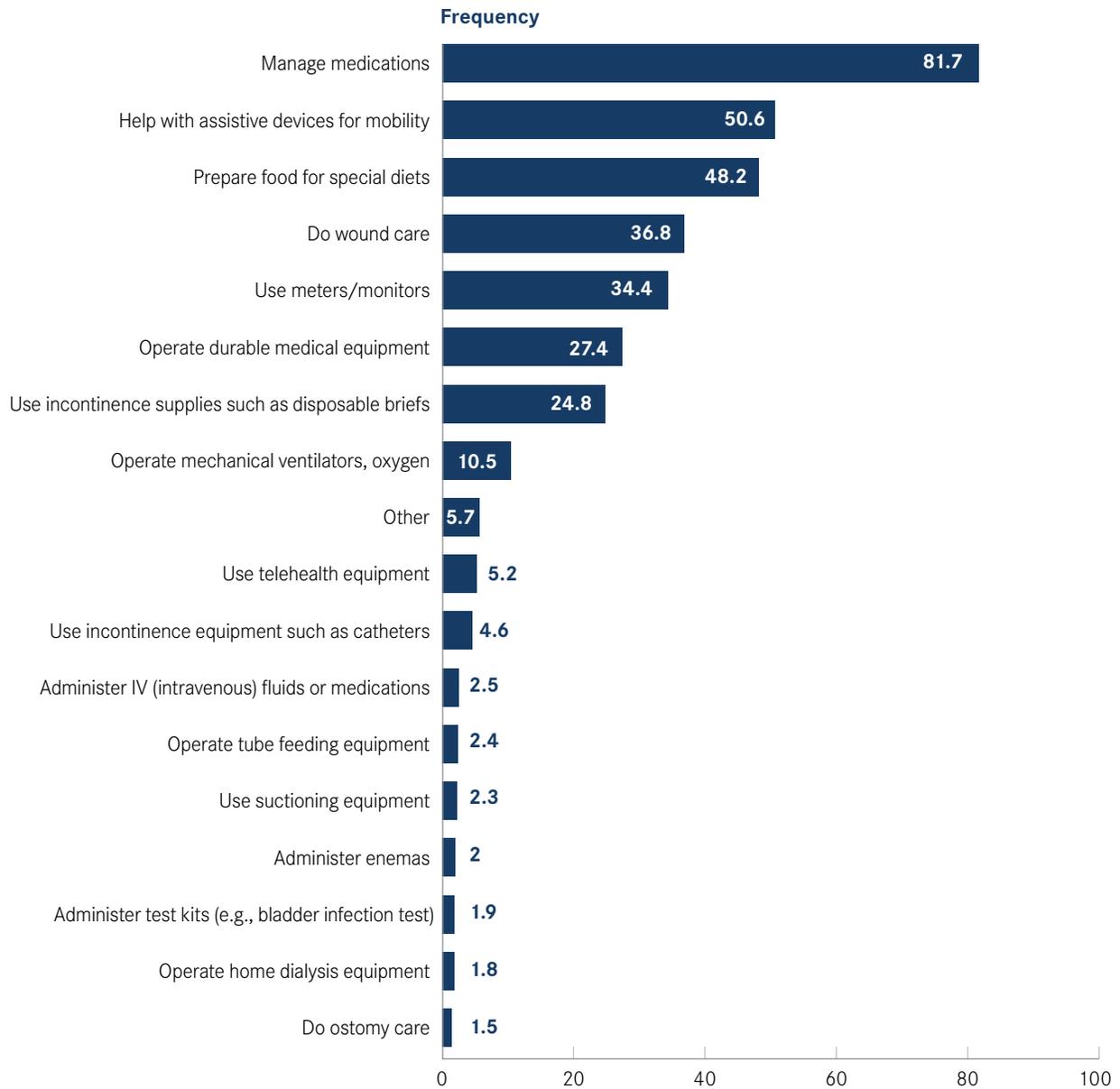
In addition to providing direct care, family plays a major role in coordinating care among health care providers and services. Most commonly, the family caregiver (44.8 percent) takes the lead, followed by the care recipient (24.6 percent) or another family member (19.4 percent). Health care professionals provide care coordination for only 7 percent of caregivers.

What Medical/Nursing Tasks Are Caregivers Performing?

Family caregivers are performing a wide range of complex M/N tasks at home. These tasks require skills previously held by health care professionals, including an understanding of the purpose of the task, the proper procedures in performing the task, what complications or side effects to look for, and when to call for help. Some of the tasks require special supplies or equipment, and all require focused attention. Figure 3 provides an overview of the M/N tasks that family caregivers perform.

- ◆ Medication assistance is the most frequent task, performed by 8 out of 10 caregivers.
- ◆ Half of caregivers assist with mobility devices, such as canes or walkers.
- ◆ Almost half of caregivers prepare special diets.
- ◆ Almost 4 out of 10 caregivers report performing wound or ostomy care.
- ◆ More than 1 in 3 caregivers monitor health parameters with meters/monitors or test kits.

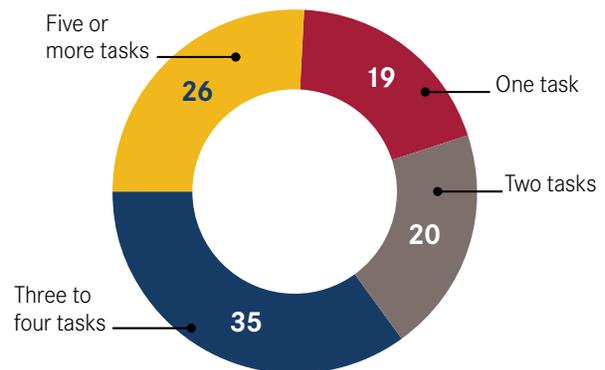
Figure 3. M/N Tasks Frequency, % (n = 1,084)



Importantly, many caregivers are performing more than one task, reflecting the complex needs of their family member. As shown in figure 4, of those caregivers performing M/N tasks,

- ◆ More than 3 out of 10 perform three to four tasks, and
- ◆ More than 2 out of 10 perform more than five tasks.

Figure 4. Performing Multiple M/N Tasks, % (n = 1,084)



Boomers, compared with other generations, are more likely to spend larger amounts of time performing M/N tasks. Boomers spend an average of 28 hours per week helping their family member, in comparison with 19 hours for generation X caregivers and 18 hours for millennials.

Also, the type of M/N task a caregiver performs differs significantly by generation (table 5):

- ◆ More than half of generation X and silent generation caregivers help with assistive devices, compared with 4 in 10 millennials and younger adults.

- ◆ About half of boomer, generation X, and millennial caregivers prepare food for special diets, compared with a third of silent generation caregivers.
- ◆ More than 4 in 10 generation X caregivers help with wound care, compared with about a third of boomers.
- ◆ Ten percent of millennials use telehealth, compared with 2 percent of boomer and silent generation caregivers.

Table 5. M/N Tasks by Generation, %

Medical/Nursing Tasks	Younger Caregiver (n = 231)	Generation X (n = 241)	Boomer (n = 499)	Silent Generation (n = 113)
Manage medications	76.5	82.9	84.6	82.8
Help with assistive devices	44.7	53.8*	51.5	58.9
Prepare food for special diets	51.3**	48.8**	48.6**	33.2
Use incontinence equipment	7.6***	5.2	2.1	5.2
Use incontinence supplies	20.7	24.1	28.1	25.1
Use meters/monitors	36.3	36.3	33.8	24.6
Wound care	29	45.2***	32.7	35.3

* Statistically significant compared with younger caregivers

** Statistically significant compared with silent generation caregivers

*** Statistically significant compared with boomers

M/N Task Difficulty by Generation, %

M/N Tasks	Younger Caregiver (n = 231)	Generation X (n = 241)	Boomer (n = 499)	Silent Generation (n = 113)
Manage medications	28*	31**	16	15
Help with assistive devices	43*	36*	20	34
Prepare food for special diets	41*	38*	20	27
Use incontinence equipment	59	42	35	33
Use incontinence supplies	66***	40	24	23
Use meters/monitors	33*	30*	17	19
Wound care	27	36	30	23

* Statistically significant compared with boomers

** Statistically significant compared with boomer and silent generation caregivers

*** Statistically significant compared with Generation X caregivers and boomers

How Frequently Are Caregivers Performing Medical/Nursing Tasks and How Difficult Are They?

M/N tasks vary both in frequency and in how difficult they are to perform. Table 6 displays the overall frequency of the task, how many caregivers report performing this task multiple times per day, and how many caregivers rate the task as difficult to perform. There are some generational differences in frequency, with boomers managing medications and preparing food for special diets multiple times per day.

Interestingly, the tasks rated as most difficult to perform are those performed less often. These include operating home dialysis equipment,

administering test kits, managing catheters, administering enemas, and performing ostomy care. These tasks all have complex steps. Those tasks involving elimination, such as tasks that include the use of incontinence supplies (e.g., disposable briefs), can be embarrassing or emotionally sensitive.

Some tasks are performed several times per day and are linked to activities of daily living, such as mobility, eating and special diets, and elimination. Others, such as administering enemas, performing wound care, and administering test kits, may be intermittent.

Table 6. Medical/Nursing Tasks, Frequency and Difficulty, % (n = 1,084)

Task	Frequency	Multiple times/day	Hard to do
Manage medications	82	44	23
Help with assistive devices for mobility	51	51	31
Prepare food for special diets	48	54	31
Do wound care	37	17	30
Use meters/monitors	34	27	25
Operate durable medical equipment	27	49	26
Use incontinence supplies such as disposable briefs	25	54	37
Operate mechanical ventilators, oxygen	11	35	32
Other	6	23	42
Use telehealth equipment	5	28	28
Use incontinence equipment such as catheters	5	40	48
Administer intravenous (IV) fluids or medications	3	31	37
Operate tube feeding equipment	2	49	29
Use suctioning equipment	2	46	24
Administer enemas	2	0	47
Administer test kits (e.g., bladder infection test)	2	15	48
Operate home dialysis equipment	2	34	64
Do ostomy care	2	41	45

NOTABLE IN THIS STUDY:

When asked why a task is difficult to perform, more than a quarter (27.5 percent) of family caregivers report they are afraid of making a mistake. The fear of making a mistake is highest for managing medications, using meters and monitors, and performing wound care.

A closer look at the issues behind perceptions of difficulty in performing the most common M/N tasks reveals some interesting patterns (table 7).

The constant attention demand is another important issue, particularly for special diets and medications. Fear of hurting the care recipient is a factor for wound

care, mobility, and the use of durable medical equipment. The most emotionally challenging issue is managing incontinence with disposable briefs, rated by almost 3 out of 10 caregivers as embarrassing for their family member and by more than 2 in 10 as emotionally difficult for the caregiver.

Table 7. Issues in Managing Most Common M/N Tasks, %

	Manage Medications (n = 213)	Help with Assistive Devices for Mobility (n = 153)	Prepare Food for Special Diets (n = 156)	Do Wound Care (n = 119)	Use Meters/ Monitors (n = 86)	Operate Durable Medical Equipment (n = 79)	Use Incontinence Supplies (n = 109)
I'm afraid of making a mistake	28	5	10	21	24	5	1
Requires my constant attention	20	13	22	12	17	8	13
Inconvenient	8	1	10	2	9	3	1
I'm afraid of hurting my family member	7	12	4	17	8	12	4
Emotionally difficult for me	7	6	3	12	2	13	23
I don't understand what to do	5	6	6	5	0	0	0
My family member resists	4	4	6	6	9	4	5
Involves lifting/ physical effort	3	26	2	6	5	31	16
Hard to find time	3	2	12	2	7	4	0
It's embarrassing for my family member	2	5	0	6	3	4	31
I'm afraid of hurting myself	1	4	1	1	0	4	0

NOTABLE IN THIS STUDY:

There is a statistically significant relationship between income and perceptions of difficulty with tasks.

- ◆ Caregivers with incomes below \$25,000 report greater difficulty with tasks than those with higher incomes. This pattern is significant for managing medications, mobility assistive devices, incontinence supplies, meters and monitors, and for operating ventilators and oxygen.
- ◆ Overall, those with incomes over \$100,000 have the lowest degree of difficulty, with the notable exceptions of use of incontinence supplies and wound care (appendix A9).

How Prepared Are Caregivers to Perform Complex Care and How Do They Receive Instructions?

Depending on the task, caregiver preparation comes from different sources (table 8). Most commonly, caregivers learn on their own. Health professional involvement is more prevalent as the technical complexity and care recipient risk increases. Physicians, nurse practitioners, nurses, physical and occupational therapists, wound care specialists, pharmacists, respiratory therapists, and medical supply experts engage with the caregiver as appropriate to the task.

Health care professionals are engaged most frequently in providing instruction for home dialysis, tube feeding, suctioning, intravenous (IV) fluids or medications, test kits, urinary catheters, ostomy care, and wound care. All of these constitute skilled nursing activities likely to be covered by Medicare home health, providing a potential mechanism for instruction in the home by health care professionals. Peer support in learning M/N tasks is minimal. Some of the M/N tasks are initiated in the hospital; in these instances, caregivers receive instruction as part of the discharge process. Hospital staff provide instruction for suctioning, tube feeding, IV fluids or medications, and ostomy care.

Table 8. How Caregivers Learn M/N Tasks, % (n = 1,084)

Task	Learned on My Own	Health Care Professional	At Hospital
Incontinence—disposable briefs	76	14	5
Special diets	71	18	7
Enemas	70	25	9
Assistive devices for mobility	60	33	13
Durable medical equipment	56	34	12
Medications	54	36	10
Meters/monitors	46	40	10
Telehealth equipment	34	52	4
Wound care	34	55	20
Test kits	30	65	17
Ostomy care	30	57	32
Mechanical ventilators, oxygen	21	67	17
Incontinence—catheters	19	62	20
IV fluids or medications	9	80	38
Tube feeding	7	88	44
Suctioning	4	87	51
Home dialysis	1	98	16

Millennials are less likely than boomers to receive instructions for M/N tasks they will perform for their family member at home. Four in 10 caregivers who perform M/N tasks are men, who are less likely than women to receive instruction. More than a third of millennial family caregivers indicate that they have not received any instruction, compared

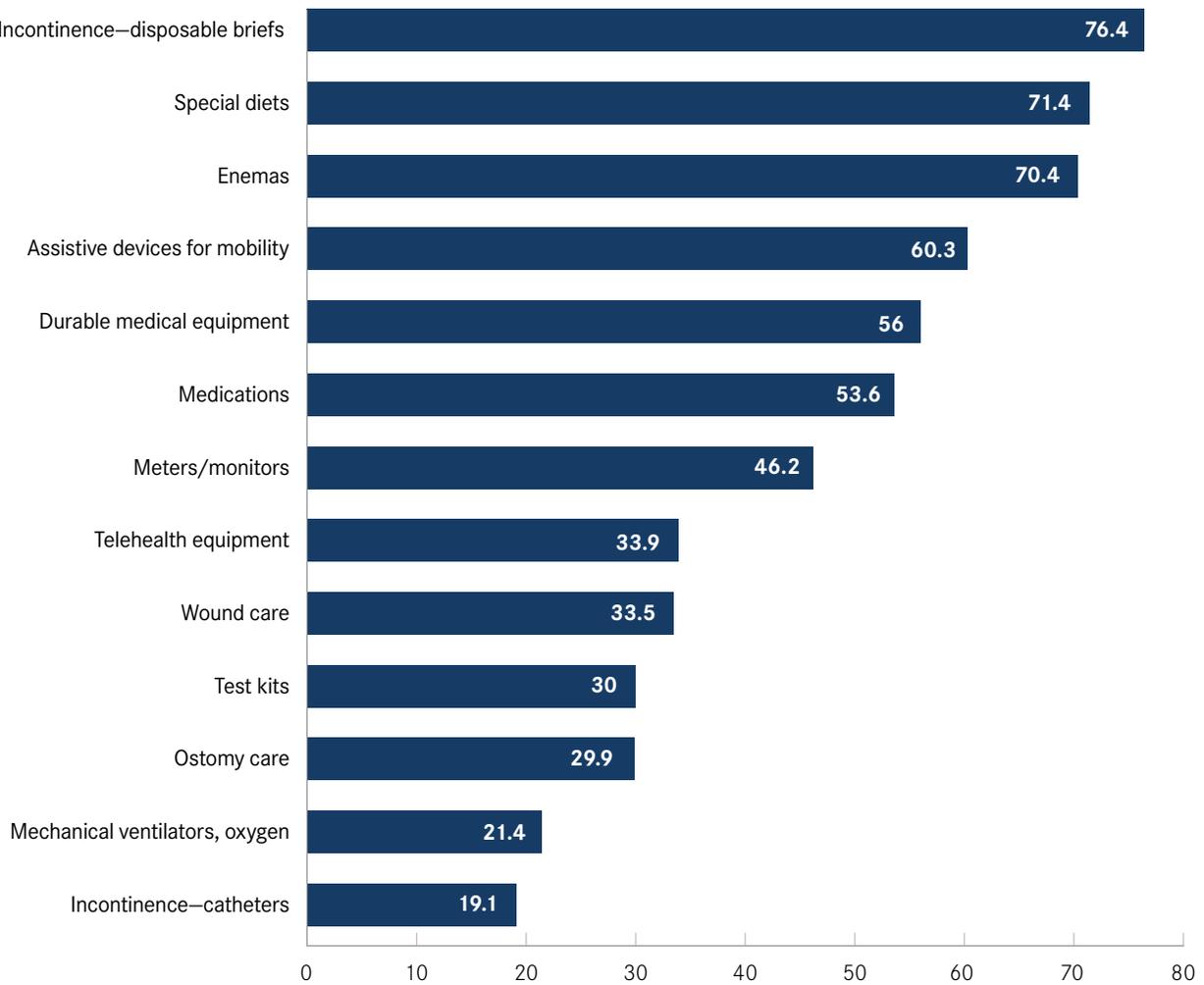
with 2 out of 10 boomers. In addition, 2 out of 10 millennials indicate that they were not given the opportunity to ask questions about the M/N tasks to be performed at home, in comparison with less than 1 in 10 boomers and 3 percent of the silent generation (appendix A10).

“I Learned on My Own”

The most common tasks that are self-taught include managing incontinence with disposable briefs, special diets, enemas, assistive devices for mobility,

durable medical equipment, and medications (figure 5).

Figure 5. M/N Tasks Learned on Own, % (n = 1,084)



We asked caregivers what would make it easier to perform M/N tasks. The most common response across all tasks is more and/or better instruction—including additional exposure to the content,

practice with supervision, written instructions, visual instruction, videos, consistent instructions, and a phone number to call with questions (table 9).

Table 9. M/N Tasks—Making It Easier, % (n = 1,084)

Task	More/Better Instruction	More Help from Others	Better Cooperation from Care Recipient	Giving Task to Someone Else
Suctioning	80	0	0	0
Mechanical ventilators, oxygen	60	7	3	6
Home dialysis	60	18	0	0
Incontinence—catheters	59	36	0	3
Meters/monitors	56	17	3	5
Telehealth equipment	54	33	0	13
Medications	52	15	9	11
Special diets	51	27	5	6
Wound care	49	20	4	10
Test kits	44	18	17	0
Assistive devices for mobility	43	29	9	6
Durable medical equipment	29	37	2	16
Ostomy care	28	13	2	35
IV fluids or medications	27	15	0	0
Incontinence—disposable briefs	27	36	10	16
Enemas	19	23	0	22
Tube feeding	17	61	6	0

Caregivers most desire further instruction for suctioning, home dialysis, mechanical ventilators/oxygen, urinary catheters, meters/monitors, telehealth equipment, and medications. They most want help from others in managing tube feeding, durable medical equipment, and incontinence (disposable briefs and catheters). Care recipient cooperation is most challenging with test kits. Despite these difficulties, most caregivers do not want to give the task to someone else. Ostomy care is the most highly cited task that caregivers would prefer to delegate.

Seven out of 10 family caregivers who perform medical/nursing tasks face the practical and emotional strain of managing pain.

A source of considerable stress for caregivers is managing pain and discomfort. Of the family caregivers who perform M/N tasks, 69.8 percent are managing pain or discomfort. A number of aspects of managing pain (figure 6) can exist concurrently, exacerbating the level of stress involved for the caregiver.

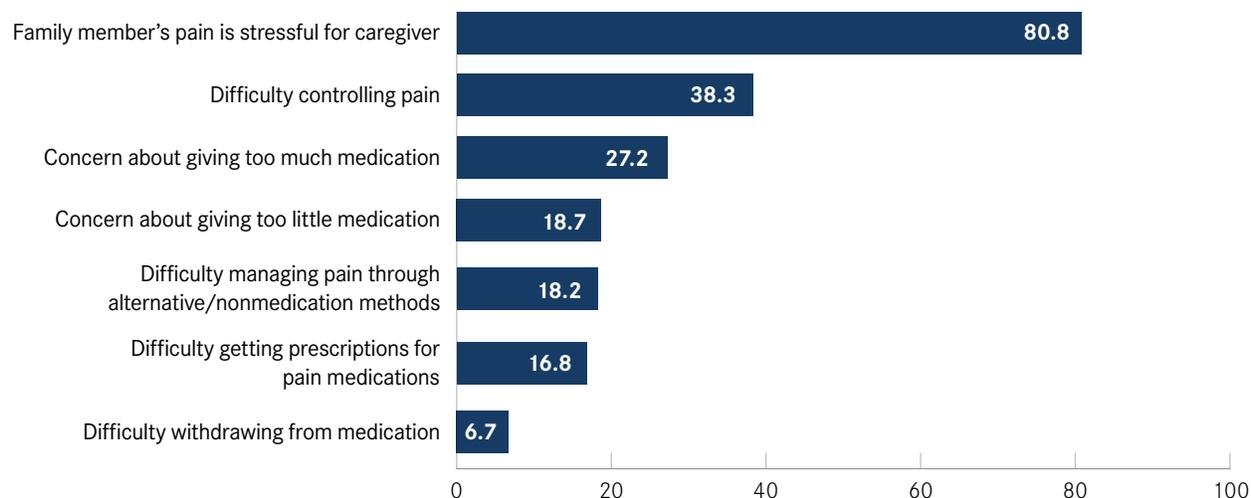
- ◆ Nearly 7 in 10 caregivers who perform M/N tasks help their family member manage pain and/or discomfort.
- ◆ Eight in 10 rate pain management as stressful.
- ◆ About 4 out of 10 face difficulties with controlling pain, and more than 4 of 10 express concerns about giving the optimal dose.

“Pain medication has to be monitored because it may not be working and needs to be adjusted to another form.”¹⁴

The study also highlights differences in pain management between male and female family caregivers. More men reported difficulties and worry relative to pain medications.

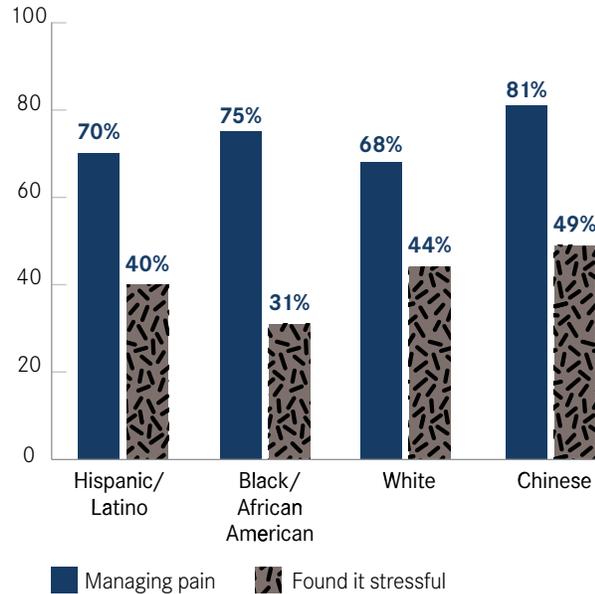
- ◆ Twenty-one percent of men and 14 percent of women experience difficulty getting prescriptions for pain medications.
- ◆ Twenty-two percent of men and 16 percent of women worry about giving a family member too little medication.
- ◆ Thirty-one percent of men and 25 percent of women worry about giving too much medication.

Figure 6. Managing Pain and Discomfort, % (n = 751)



Family caregivers across all racial and ethnic groups report helping family members manage pain, and many find it to be stressful (figure 7).

Figure 7. Managing Pain and Stress by Racial and Ethnic Group, % (n = 1,077)



Differences among generations also exist. Overall, nearly half of millennial, younger adult, and generation X caregivers combined indicate that the experience of managing their family member’s pain is very stressful, compared with about a third of boomers and a quarter of the silent generation. More than 2 in 10 millennial caregivers and younger adults and almost 2 in 10 generation X caregivers experience difficulty getting prescriptions for pain medications, compared with less than 1 in 10 of the silent generation. More than a quarter of millennial caregivers and younger adults experience difficulty managing pain through alternative/nonmedication methods compared with boomers (appendix A11).

“Just seeing my father go from being a tough man to being weak is hard to see.”

Implications of providing intense and complex care:

- ◆ Caregivers continue to take on the responsibilities that used to be the purview of health care professionals; they are providing complex care that they often find difficult to perform. More than half the caregivers who perform M/N tasks are performing three or more of them. They provide this care in the context of multiple health conditions, serious illness, and palliative care. The context matters for understanding the experience of family caregivers and tailoring appropriate support.
- ◆ Caregivers report being engaged in a number of monitoring and communication activities, including using meters and monitors, administering test kits, and using telehealth equipment. These activities are consistent with efforts to increase self-management of chronic conditions and reflect increasing attention to quality indicators in primary care and monitoring health outcomes for chronic conditions.¹⁵ This health delivery trend has a direct effect on caregiver responsibilities and contributes to additional health care system expectations for their participation.
- ◆ Pain management is a major issue, and it carries an emotional as well as practical and sometimes financial strain. Witnessing the suffering of a family member is stressful. In addition to the heartbreak of often being unable to ease pain, caregivers sometimes need to cause further pain to help—by giving injections, removing bandages from wounds, or performing other invasive procedures.

Identifying and easing the cause of pain can be a difficult process. The result is family caregivers coping with the additional strain of watching prolonged suffering. Caregivers also worry that their family member may not be forthcoming about the level of pain in an effort to protect the caregiver, which can cause caregivers to worry even more. Pain medication requires constant

monitoring and frequent adjustments, making pain an ongoing unpleasant focus and adding to the stressful feeling of the loss of control for both the person being cared for and the family caregiver. Further, the current concern about the overprescription of opioids has led to difficulties in obtaining adequate pain relief, particularly for people whose chronic pain has been managed with high levels of opioids.

FINDING #2: Today's caregivers are diverse and so are their experiences.

Caregiving is a cross-generational issue for both men and women. Different age cohorts face distinct challenges for their life stage. For example, one in four of these caregivers is a millennial, and 40 percent of millennials and younger caregivers are supporting someone with a behavioral health condition.

This study reveals that both women and men provide complex care, yet there are gender differences in the experience. Men report that they struggle more with certain tasks, such as managing pain, helping with incontinence, and preparing special diets, and are more likely to indicate that receiving additional instruction at home would help them. Significantly, when their family member is hospitalized, they are less likely to receive instruction on how to perform complex tasks after discharge. On the other hand, women (32 percent) are more likely compared with men (25 percent) to indicate that they felt down, depressed, or hopeless on several days in the past two weeks.

This research highlights that caregiving is an important issue for each generation. With the aging of the different cohorts, caregiving is becoming a more common experience. Boomers are now more commonly caring for spouses or partners, while generation X caregivers more commonly support aging parents.

Notable Generational Differences Exist in Relation to Behavioral Health

However, there are significant differences regarding the impact of performing M/N tasks across generations. For example, a substantial number of millennial and younger adult family caregivers are supporting someone with a behavioral health condition. Millennial and younger adult family caregivers report difficulty with performing several of the M/N tasks, that they were less likely to have received instructions or been given the opportunity to ask questions about the M/N tasks, and were more likely to be worried and experience stress in performing these activities.

Differences in the experiences of caregivers of different generations may result from cohort effects (e.g., the millennial caregiver experience is fundamentally different from older generations owing to sociocultural factors) or lifespan effects (e.g., these differences are because millennials are engaged in different activities based on their developmental stage), or a combination of both. With the exception of a few differences that are obviously driven by lifespan effects, such as that boomers now more commonly care for spouses or partners while generation X caregivers more commonly support aging parents, it is not possible in this study to distinguish between these types of effects.

This study finds that, in 2018, the experiences of caregivers differed in the following ways: More millennial and generation X family caregivers than boomers consider managing medications, helping with assistive devices, preparing food for special diets, and using meters and monitors hard to do. Millennial caregivers who assist with incontinence supplies are more likely than boomers to indicate this is difficult to do.

NOTABLE IN THIS STUDY:

Performing M/N tasks has a greater negative impact on younger generations of caregivers. Similarly, millennials are twice as likely as boomers to note that some M/N tasks are difficult to perform.

Table 10 summarizes the generational differences in reporting difficulty with M/N tasks.

Table 10. Task Difficulty by Generation, %

Medical/Nursing Tasks	Younger Caregiver (n = 221)	Generation X (n = 241)	Boomer (n = 499)	Silent Generation (n = 113)
Manage medications (n = 855)	28*	31**	16	15
Help with assistive devices (n = 529)	43*	36*	20	34*
Prepare food for special diets (n = 504)	41*	38*	20	27
Use incontinence supplies (n = 259)	66***	40	24	23
Use meters/monitors (n = 360)	33*	30*	17	19

* Statistically significant compared with boomers

** Statistically significant compared with boomers and silent generation caregivers

*** Statistically significant compared with generation X and boomer caregivers

Negative Effects of Caregiving Differ by Generation

Family members indicate that, in some cases, performing M/N tasks has a negative impact on their quality of life (appendix A12). Millennials and generation X caregivers are more likely than older generations to worry about making a mistake in the care they are providing or worry about paying for care, and they feel an added level of stress from having to talk to so many health care professionals or suppliers. Millennials and generation X caregivers are more likely than boomers to note that performing these M/N tasks causes problems in their relationship with their family member and makes the home feel less safe because of the equipment and supplies.

“And this now happening with my mom has just really complicated my life. With the way our aging population is going, we’re going to triple our aging population in the not too distant future. I know when I get to be my mom’s age, there isn’t going to be anybody to take care of me.”

Positive Effects of Caregiving Differ by Generation, Too

Performing M/N tasks also has a positive effect on the quality of life of family caregivers. Boomers (72 percent) are more likely than generation X (63 percent) to feel that performing M/N tasks eases their worries about their family member's condition. More boomers (79 percent) and generation X caregivers (81 percent) than millennials (65 percent) feel they are making an important contribution. Millennials and generation X caregivers combined (62 percent) are more likely than the silent generation (47 percent) to feel that performing these M/N tasks offers them new skills they can apply to other areas of their life.

“Taking care of her was the most difficult but the most rewarding thing I have ever done.”

Multicultural family caregivers are more likely to experience strain and worry about making a mistake, regardless of income.

Multicultural family caregivers are performing M/N tasks at rates similar to Whites. However, this study finds that the amount of income can influence the level of strain and worry about making a mistake. The impact of income and experience with strain and worry differs quite strikingly by racial and ethnic group. For Whites, the level of strain and worry about making a mistake decreases as their income increases. In contrast, multicultural family caregivers are more likely to experience strain and worry about making a mistake, regardless of their income level (appendix A13).

“It’s a matter of what’s next. You know the worry is what are you facing the next day.”

Implications of the diversity of caregivers:

- ◆ The face of family caregiving is diverse and multigenerational. Family caregiving is an issue for all racial/ethnic groups and across the lifespan. Millennials and younger adult caregivers are already making major contributions to family care in the United States. Both women and men are caregivers. Just as caregivers are diverse, interventions to meet their needs for support and guidance must reflect that diversity.
- ◆ While this study focuses primarily on M/N tasks, it also identifies that many caregivers are dealing with diverse cognitive, mental, and behavioral issues as well. These conditions can complicate physical health problems and the ability of family caregivers to manage care. They also pose challenges of their own and, with the focus on physical health issues, may remain invisible.

FINDING #3: Caregivers who are socially isolated or have no choice about caregiving are more *at risk* for experiencing difficulties with complex care.

Social isolation compounds difficulties with complex care, across generations and cultural groups.

The majority of caregivers report having either a relative or friend available for social contact, confiding in about private matters, and being available to help. However, 9 percent of caregivers have no one to talk to about private matters, and 20 percent have no one to call for help. These

caregivers would be at higher risk for strain and depression. Caregivers who perform M/N tasks score an average of 14.0 (standard deviation 6.4) on the Lubben scale, indicating moderate social engagement. Those with a score of less than 12 are considered at risk for social isolation. When asked about satisfaction with social relationships, 8 in 10 reported feeling very or somewhat satisfied.

NOTABLE IN THIS STUDY:

Millennial caregivers are more likely than other generations to be disconnected from friends. In fact, nearly 2 in 10 report that they do not see any of their friends in a given month.

Multicultural Family Caregivers Have Fewer Social Connections Compared with Whites

Of all the groups, Blacks/African Americans are most at risk of being socially isolated and less satisfied with the quality of their social relationships.

Boomers and silent generation caregivers are more satisfied with the quality of their social relationships compared with millennials and generation X caregivers. In fact, 27 percent of millennials indicate they are not satisfied with the quality of their social relationships, compared with 12 percent of boomers and 8 percent of silent generation caregivers. About 23 percent of millennial and younger adult family caregivers indicate that they see or hear from one friend at least once a month. On the other hand, 33 percent of boomers and 32 percent of family caregivers in the silent generation hear from three or four friends at least once a month.

Multivariate analysis reveals that family caregivers with fewer social connections and lower satisfaction with their social supports are at higher risk in a number of ways (appendix A14). They experience more stress in coordinating with health care professionals; are more likely to feel the pressure of

constantly watching; are more likely to feel they have no choice in taking on caregiving duties; are more likely to perceive the tasks as difficult; worry more about making a mistake; and experience more strain, depression, sleep disturbance, and poor health. Those with more social connections and higher satisfaction with social supports are more likely to cite a cultural or religious influence in their choice to become a caregiver and are more likely to have received professional instruction on performing the tasks.

Importantly, fewer social connections and lower satisfaction with social supports significantly predict depressive symptoms, particularly for women. These factors are more important than the number and difficulty of tasks performed (appendix A14).

Most family caregivers who perform medical/nursing tasks feel they have no choice.

This finding aligns with the shifting of care responsibility from health systems to family caregivers. The majority of family caregivers feel they do not have a choice in taking on M/N tasks. About one-third feel pressured by various sources—including their own personal feelings, the care recipient, another family member, and a physician or nurse—to take on these responsibilities.

When asked, “From whom did you feel pressure to take on the medical/nursing tasks you perform?” one family caregiver replied, “The whole medical system. Hospitals, doctors, state resources. . . .”

For almost half of these caregivers, their culture or religion influenced their decision. Women are more likely than men to indicate they feel pressure from other family members to perform these tasks (appendix A15).

There are some racial and ethnic differences in feelings related to choice. Chinese caregivers are more likely to indicate that they feel they have no choice and feel pressure, particularly from their families, to take on M/N tasks. Blacks/African Americans and Hispanics/Latinos are more likely to indicate that culture or religion influenced their decision (appendix A16).

The Older the Caregivers, the Less They Feel They Have a Choice

While every generation performs M/N tasks, more than 7 in 10 family caregivers in the silent generation and 6 in 10 boomers indicate they have no choice in taking on these tasks, compared with almost 5 in 10 millennials (table 11). However, for millennials who do perform these M/N tasks, 4 in 10 feel pressure to do so, compared with about 2 in 10 of the silent generation.

Table 11. No Choice by Generation, % (n = 1,040)

Generation	%
Generation Z (n = 19)	50
Millennial (n = 207)	47
Generation X (n = 240)	58
Boomer (n = 498)	60*
Silent generation (n = 113)	73**

*Statistically significant compared with millennials

**Statistically significant compared with boomers, generation X caregivers, and millennials

Implications for at-risk caregivers:

- ◆ More proactive assessment and outreach is needed to identify caregivers who need additional support.
- ◆ Choice is an important issue—not all caregivers are willing or able to assume care responsibilities, yet they are often expected by other family

members or professionals to take on the role. They may face unpleasant judgment by others if they do not. Understanding willingness is important as health care professionals engage caregivers.

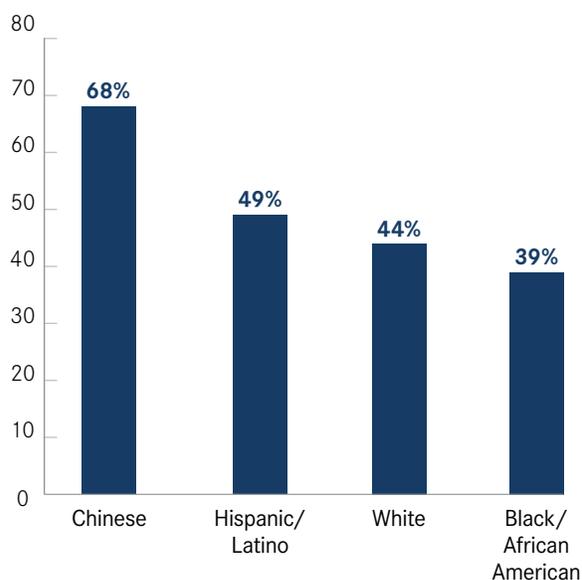
FINDING #4: Caregivers performing more medical/nursing tasks experience both positive and negative impacts.

About half of caregivers who perform medical/nursing tasks are worried about making a mistake. The more complex the task, the greater the worry.

Worry is a significant source of strain for family caregivers and has multiple facets for the population that performs M/N tasks.

Almost half of family caregivers who perform complex care are afraid of making a mistake in their family member’s care, and some groups are markedly more worried than others. It is a particularly notable concern for Chinese caregivers (figure 8).

Figure 8. Worry about Making a Mistake by Racial and Ethnic Group, % (n = 1,077)



Using multivariate analysis, we found that family caregivers who worry the most about making a mistake also worry about a number of other aspects of caregiving. They report the following (appendix A14):

- ◆ They have to constantly watch out for something to go wrong.
- ◆ They find the caregiving tasks more difficult.
- ◆ Their worry is greater in situations in which they have more instruction from health care professionals.
- ◆ Talking to multiple professionals and suppliers is associated with greater stress.

More younger caregivers (76 percent) than older (66 percent), and more of those caring for a parent or grandparent (73 percent) than not (64 percent), have greater worry. Additionally, Asian caregivers (84 percent) worry more than non-Asian caregivers (67 percent).

Stress, worry, financial concerns, and feeling the need to be vigilant rise as the demands of providing complex care increase.

Although most family caregivers rate their overall health as good, it is a very common experience for them to feel down, depressed, or hopeless at least several times per week. Almost half of M/N caregivers feel down, depressed, or hopeless (41.8 percent), compared with a third of caregivers who do not perform M/N tasks and 26 percent of the general population of older adults.¹⁶ Sleep disturbances affect approximately 6 in 10 caregivers.

Overall, family caregivers are experiencing a moderate amount of strain. In multivariate analysis (appendix A14), higher caregiver strain is associated with the following:

- ◆ Being younger
- ◆ Being female
- ◆ Providing care to a parent or grandparent
- ◆ Caring for an individual who has multiple conditions
- ◆ Communicating with multiple health care professionals
- ◆ Feeling that one
 - Has to be constantly watching,

- Does not have a choice, or
- Has pressure from other sources to take on the role

- ◆ Rating tasks as difficult to perform

Caregiver depressed mood is also related to both demographic factors and aspects of the caregiving situation. Younger caregivers, women, those with lower incomes, and those caring for a partner are more likely to report a depressed mood. Depressed mood is more common with more care recipient conditions, the stress of communicating with multiple health care providers, feeling on constant alert, finding the tasks difficult, and having less social support.

Overall, family caregivers report good health, but some are experiencing poor health and are at particular risk. Caregivers who report poorer health tend to

- ◆ Be older,
- ◆ Have lower incomes,
- ◆ Provide care to a partner,
- ◆ Deal with multiple conditions,
- ◆ Coordinate care with multiple health care professionals,
- ◆ Be on constant alert, and
- ◆ Have less social support

Caregivers Note Positive and Negative Effects on Quality of Life

Caregivers report a variety of ways that performing M/N tasks affects their quality of life, and that the effects differ by number of tasks, number of conditions, and whether the caregiver receives instruction (appendix A17). In general, caregivers note more positive effects than negative effects. Positive effects are greatest for caregivers who perform three to four tasks compared with those who perform fewer than three tasks or more than five tasks.

NOTABLE IN THIS STUDY:

Negative effects are significantly worse as the number of tasks increases. Similarly, there is a significant pattern of experiencing more negative effects with a greater number of conditions.

Caregivers Feel They Make an Important Contribution

The strongest positive effects are the caregiver feeling that he or she is making an important contribution and feels closer to the care recipient. The majority of respondents feel that performing these tasks also eases worry and gives the caregiver new skills.

Stress, Worry, and Financial Concerns Rise with More Conditions and Tasks

Negative aspects of the experience are added stress, worry about making a mistake, and feeling the need to be vigilant. Financial effects include worry about paying for care and negative effects on employment. These concerns increase with the number of tasks.

Instruction Generates both Positive and Negative Effects

Receiving instruction is associated with feelings of making a contribution, closeness to the family member, and gaining new skills. Instruction is also associated with greater worry about making a mistake and reporting poorer health.

Cultural Differences Vary

Almost three-quarters of Hispanic/Latino, Black/African American, and Chinese family caregivers and slightly more than half of White family caregivers indicate that performing these M/N tasks gives them new skills they can apply in other areas of their life.

About half of Hispanic/Latino and Black/African American caregivers and 3 in 10 White and Chinese caregivers strongly agree that they are making an important contribution to the care of their family member or friend.

Chinese family caregivers face more challenges to their quality of life:

- ◆ Two-thirds report that they worry about paying for care, making a mistake in providing care, and feeling that they have to constantly watch out for something to go wrong.
- ◆ About 6 in 10 report that performing these M/N tasks adds to their level of stress because they have to talk to so many health care professionals or suppliers.
- ◆ They are twice as likely to say that performing these M/N tasks causes problems in their relationship with the family member.

Generational Differences Are Both Positive and Negative

In some cases, performing M/N tasks has a positive effect on the quality of life of family caregivers. Boomers, compared with generation X caregivers, are more likely to indicate that performing M/N task eases their worries about their family member's condition (72 percent v. 63 percent, respectively). Both boomers (79 percent) and generation X caregivers (81 percent) who perform M/N tasks feel they are making an important contribution, more so than millennials (65 percent). Generation X and millennials are similarly more likely than the silent generation (62 percent v. 47 percent, respectively) to indicate that performing these M/N tasks offers them new skills that they can apply to other areas of their life.

However, in other cases, family members indicate that performing these M/N tasks has a negative impact on their quality of life (appendix A12). Millennials, generation X, and boomers are more likely than the silent generation to say that performing these M/N tasks affects their employment negatively. Millennials and generation X caregivers worry more than older generations about making a mistake in the care they are providing and worry more about paying for care;

they also feel an added level of stress from having to talk to so many health care professionals or suppliers. Millennials and generation X are more likely than boomers to note that performing these M/N tasks causes problems in their relationship with the family member and makes the home feel less safe because of the equipment and supplies.

Care Recipient Quality of Life Is Affected by M/N Tasks

Caregivers also reflect on how performing these tasks affects the care recipients' quality of life (appendix A18). Clearly, caregivers see the benefits of the help they are providing in terms of promoting comfort, permitting greater participation with family and outside activities, allowing more independence, and avoiding nursing home placement. The most positive effects occur when caregivers perform three to four tasks. On the flip side, caregivers see the care recipient experiencing limited activity; having constant reminders of illness or disability; and suffering from pain, discomfort, and embarrassment.

In terms of quality of life for care recipients, millennials and generation X caregivers are more likely than older generations to say that medication side effects or a treatment schedule limits the care recipient's activities. Also, more millennials than boomers (46 percent v. 33 percent, respectively) note that the M/N tasks involve pain, discomfort, and embarrassment.

Caregiver Strain Has Multiple Dimensions

Given the array of M/N tasks that caregivers perform and the demands in terms of time and commitment, we explored their perceptions of strain. Table 12 shows caregiver ratings of strain along several dimensions. Approximately 75 percent of caregivers experience aspects of strain sometimes or more frequently, including not having enough time for themselves, feeling stressed about managing caregiving and other responsibilities, feeling strained around the care recipient, and being uncertain about what to do.

Table 12. Caregiver Strain, % (n = 1,084)

	Nearly Always	Quite Frequently	Sometimes	Rarely	Never
Not enough time for myself	6	12	32	25	25
Stressed between care and other responsibilities	7	13	35	21	23
Strained when around family member	5	8	25	25	36
Uncertain about what to do	6	10	26	24	33

Balancing caregiving with work and life responsibilities can be difficult for anyone. However, the study highlights that the stress of caregiving differs for men and women. Women (23 percent) are more likely than men (16 percent) to indicate that they nearly always or quite frequently feel stressed because they are caring for a relative or friend while at the same time trying to meet other responsibilities, such as working or tending to the rest of the family.

We asked caregivers about their own health and well-being, including their ratings of their overall health, whether they feel down or depressed, and how they are sleeping. As shown in table 13, the majority of caregivers rate their health as either excellent or very good, with a higher proportion of better health among caregivers who are not engaged in M/N tasks.

Table 13. Caregiver Health and Well-Being, %

Health Indicator	Total (n = 2,089)	M/N tasks (n = 1,084)	Non-M/N (n = 1,005)
Overall health (excellent/very good)	65	62	68
Sleep disturbances (at least several days/week)	58	59	58
Feeling down, depressed, hopeless in last two weeks (at least several days per week)	39	42	35

Almost half of M/N caregivers feel down, depressed, or hopeless (41.8 percent), compared with a third of caregivers who are not performing M/N tasks. Finally, sleep disturbances affect well over half of caregivers.

“It is a trial taking care of her as I have numerous health issues of my own.”

The data suggest that performing M/N tasks has a stronger impact on younger generations. In comparison with boomers, millennials and generation X caregivers (36 percent) are more likely to indicate that they have felt bothered, depressed, or hopeless for several days in the past two weeks (36 percent v. 25 percent, respectively). Millennials and generation X caregivers feel strained around relatives or friends (18 percent and 17 percent, respectively, compared with 8 percent for boomers) or uncertain about what to do with their relative or friend (24 percent and 17 percent, respectively, compared with 10 percent for boomers). In comparison with the silent generation (12 percent), millennials (24 percent) and generation X caregivers (25 percent) are twice as likely to indicate that they frequently or always feel stressed between caring for their relative or friend and trying to meet work and family responsibilities.

The more medical/nursing tasks they perform, the more caregivers feel they are keeping their family member out of a nursing home.

Family caregivers who care for individuals with the most complex health needs state they are avoiding nursing home placement for the care recipient.

There is a strong relationship between the number of tasks the caregiver performs and their awareness that they are avoiding nursing home care for the care recipient. Similarly, the more conditions the care recipient has, the more likely it is that caregivers recognize their role in keeping the care recipient at home.

Multivariate analysis sheds further light on this important finding. Family caregivers who perform a higher number of M/N tasks, experience the stress of communicating with multiple health care professionals or suppliers, and feel they are constantly watching for something to go wrong are more likely to feel they are preventing the care recipient’s admission to a nursing home. Women and those motivated by cultural or religious influences to provide care are more likely to feel they are preventing nursing home admission for the care recipient. Along with the complex care these caregivers are providing, they are also more likely to have had a home visit from a health care professional (appendix A14).

Implications of performing more medical/nursing tasks:

- ◆ Caregivers are motivated by making a contribution and helping the care recipient avoid nursing home placement, but many live with the worry of making a mistake and the difficulty of performing M/N tasks. The emotional strain of caregiving is even greater for certain at-risk groups and may go unrecognized by health care professionals.
- ◆ Caring for a relative or friend with complex health needs requires instructions, guidance, and support, but the study also recognizes the

emotional impact on the family caregiver for providing this care. While discharge instruction can be viewed as a “task,” it also carries meaning for caregivers in terms of both worry about performing the task and the implications for their daily routine.

FINDING #5: Many family caregivers are still on their own—health systems should do more to prepare these vital members of the team.

Caregivers are largely on their own in learning how to perform medical/nursing tasks they find difficult to perform, such as managing incontinence and preparing special diets.

Incontinence

Incontinence is considered an M/N task because it often relates to medical conditions, may require special equipment, and is more demanding than the *help with toileting* task envisioned in the ADL framework. Managing incontinence is rarely discussed with caregivers. They find this task to be more difficult than managing medications, helping with assistive devices, performing wound care, and many other complex tasks (table 6). Yet this is the number one area in which caregivers learn on their own, with three-quarters of family caregivers who manage incontinence tackling this task without help (figure 5).

This task is handled multiple times a day by more than half of the caregivers who manage it, and more than a third of them find it hard to perform (table 6); more than half would have liked more instruction on using catheters; more than one in four would have found this task easier to perform after more or better instruction; and more than one in four would appreciate having another person to help with this unrelenting task. Incontinence care can be embarrassing or uncomfortable for both caregivers and care recipients (table 7), with almost 40 percent of men and almost 25 percent of women reporting that the issue is embarrassing for their family member.

“He wants huge supplies of pads . . . he’s worried about the money . . . he’ll get a little rash and oh my gosh.”

Preparing Special Diets

Preparing food for special diets is more complex than simply preparing meals because it often involves precise measurements, specific guidelines, constant monitoring, and special equipment for preparation or feeding. More than 3 in 10 family caregivers find preparing special diets hard to manage, and almost three-quarters of caregivers learn to do this on their own. Fewer than 2 in 10 receive instruction from health care professionals.

When asked what would make this task easier, more than half of caregivers indicated more and better instruction—specifically more details, more practice with supervision, and video-based instruction. Because of this task’s time demands, more than a quarter of caregivers report that help from another person would make managing the task easier for them.

NOTABLE IN THIS STUDY:

Chinese family caregivers are almost twice as likely as Blacks/African Americans and Whites to indicate that preparing food for special diets is difficult (appendix A19).

Special diets pose particular challenges for caregivers, as restrictions may

- ◆ Require adjustments to the routine of the household;
- ◆ Have implications for costs of food when preparing additional or modified meals;
- ◆ Involve extra effort;
- ◆ Consist of complex guidelines; and

- ◆ Require regular attention, with almost 7 in 10 caregivers reporting they perform this task at least daily (more than half perform it multiple times per day) (table 6).

The challenges associated with managing special diets center primarily on the constant and time-consuming nature of the issue (appendix A19):

- ◆ More than 2 in 10 caregivers feel this task demands constant attention.
- ◆ Almost 2 in 10 have difficulty finding time to do this work.
- ◆ One in 10 reports inconvenience.
- ◆ Fear of making a mistake is a challenge for more than 1 in 10.

Help with preparing special foods is hard because “I am not sure how to prepare the food.”

Special diets also pose specific challenges for men, 12 percent of whom note that the main reason they find preparing food for special diets to be difficult is because they do not understand what to do, compared with 1 percent of women. Fifteen percent of men indicate that receiving more instruction at home would make this task easier to perform, and 10 percent of women give the same response (appendix A19).

Three out of five caregivers whose family members were hospitalized in the past year report that they received instruction on how to perform medical/nursing tasks, but more work needs to be done in identifying family caregivers and giving them timely notification of hospital discharge.

How Much Do Care Recipients Use Health Care Services?

Almost half of family caregivers (48 percent) care for a family member who has been hospitalized in the past 12 months. Visits to the emergency department are even more common, with almost two-thirds having had at least one visit. The rate of hospitalization for the care recipients noted in this sample (21.6 percent)¹⁷ is more than double that of the general population of older adults.

It is also evident that these consumers and their family caregivers have multiple encounters with the health care system—encounters that offer both changes in the necessary M/N tasks and the opportunity to teach the consumer and caregiver how to perform them. Family caregivers who perform M/N tasks are more likely than non-M/N caregivers to have a family member who has used telehealth (14 percent v. 8 percent) and are more likely to have been involved in the telehealth visit (64 percent v. 29 percent). More Black/African American and White caregivers (43 percent and 44 percent, respectively) than Hispanic/Latino and Chinese caregivers (19 percent and 17 percent, respectively) receive information about home health care or an agency contact and have their family member receive care as a result.

Is the CARE Act Making a Difference in Identifying and Instructing Caregivers?

The CARE Act is now law across most of the country, and hospital officials say they are recognizing and instructing family caregivers on how to perform complex care before discharge. However, the data from this study demonstrate that many family caregivers still need help.

For family caregivers who report at least one admission to the hospital for their care recipient, we asked questions consistent with the provisions of the CARE Act. In particular, we asked whether their family member had the opportunity to

identify a family caregiver, whether instructions for care tasks were provided to the family caregiver, and how far in advance they were notified of impending discharge (table 14).

Table 14. CARE Act Checklist % Positive

	Total Sample (n = 1,007)	M/N Tasks (n = 565)	Non-M/N Tasks (n = 442)	Male (n = 394)	Female (n = 613)
Family caregiver received instruction for M/N tasks	58	66	47	49	64
Asked to identify family caregiver	49	56	39	46	50
If asked, decided to identify family caregiver	53	62	42	49	57
Given at least 24 hours' notice of discharge	20	20	20	20	19

There is evidence that some CARE Act provisions are more widely adopted than others.

First, identification of the family caregiver is almost a matter of chance—there is just over a 50/50 likelihood that hospital staff will ask the patient to identify a family caregiver.

Second, at the other end of the hospitalization, family caregivers have **less than a 20 percent chance of receiving at least 24 hours' notice of discharge** (see figure 10). This means that fewer than one in five caregivers gets more than 24 hours' notice about discharge.

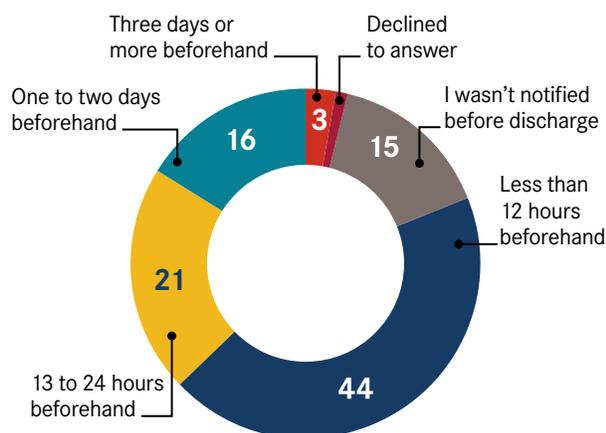
To express this finding in another way, more than 8 in 10 caregivers receive less than 24 hours' notice of discharge from the hospital.

More than half of caregivers are given either no notice (15 percent) or less than 12 hours' notice (43.6 percent).

- ◆ An additional 21.2 percent report between 13 and 24 hours' notice.
- ◆ A quarter of millennial family caregivers and younger adults who had a family member hospitalized report that they received no notification before their family member was discharged, compared with 10 percent of boomers and 6 percent of silent generation caregivers.

Timely notification is a key feature of the CARE Act, and a timeframe of less than 24 hours is not adequate for many caregivers to prepare at home or make arrangements to accommodate the discharge. Family caregivers report they have had little time to prepare for the transition home.

Figure 10: Notification about Hospital Discharge, % (n = 1,007)



“In the beginning, the scariest thing was when he came home...he had to be suctioned.”

Third, there is mixed evidence that family caregivers are receiving the instruction they need to perform M/N tasks once they get home. Three out of five report receiving complex care instruction prior to discharge. But gender differences are evident—men are less likely than women to receive any instruction. More than half of male family caregivers report they received no instruction for the M/N tasks they would perform at home; only one-third of women indicate they did not receive instruction (appendix A10).

For those who have received instruction, written materials (72 percent) and live demonstration (55 percent) are the most common types of support, with 3 percent receiving video instruction. One in three caregivers who have not received instruction indicate they would have appreciated this support through demonstrations (19.6 percent), more complete written instructions (17.9 percent), and video instruction (10.6 percent).

Postdischarge services are available to some families, including home health (44.1 percent), nursing home (16.9 percent), and assisted living

(2.9 percent) arrangements. Among family caregivers whose care recipient was discharged to a nursing home for rehabilitation, about half received instruction at that nursing home on M/N tasks to be performed at home.

About one-third of caregivers take their family member home without home health support (30.9 percent). Some caregivers report help at home after discharge—42.2 percent receive a visit from a health care professional, 18.9 percent have help from a home health care aide, and 63.6 percent receive assistance from another family member or friend.

Implications for health professionals and health care systems:

- ◆ Although the first *Home Alone* study helped fuel a growing body of research on M/N tasks performed by family caregivers, there is no consensus on assessment measures that could be used in the health care system and in the community. In addition, this study finds a high prevalence of assistance with ADLs and IADLs with the presence of M/N tasks, indicating that complex care is increasingly common. Our findings about the caregiver experience of providing care shed light on the diversity of experience. Presently, no comprehensive multidimensional measure captures the complexity of the care or where caregivers are in the caregiving journey.
- ◆ Caregivers remain largely alone in learning how to perform M/N tasks and manage the complexity of care. Caregivers report that instruction on M/N tasks involving the use of home medical equipment for high-risk conditions, such as suctioning and home dialysis, is usually provided by health care professionals—but other, more frequently performed tasks, such as medication management, incontinence, and special diets, are not. Although it is not clear whether caregivers are asked about difficulties in the more frequently performed medical tasks, responses of “learned it on my own” warrant greater awareness of the potential that caregivers require additional instruction and support across health care settings.

- ◆ Health care professionals are not yet fully attuned to caregiver needs for information and support and how to deliver it in ways that allay anxiety. In some cases, health care professional instruction is associated with greater worry and stress. This might be because health professionals are more involved with care that is more complex and skilled in nature—care that carries greater risk. It also might mean that the health care system has not yet perfected the best way to teach and support caregivers as they manage complexity. The finding that caregivers would like additional instruction reinforces the importance of checking after the initial instruction to see if they have additional questions or concerns.
- ◆ The CARE Act has been enacted in 41 states, yet there is more to do to ensure that the intent of the act reaches family caregivers across the nation. Even in hospitals, family caregivers have about a 50/50 chance of being recognized. The CARE Act does not yet reach other settings, such as primary care or rehabilitation settings, where new M/N tasks may emerge with changes in the care regimen. Furthermore, family caregivers may need additional instruction as they gain experience with the M/N tasks and have further questions beyond the hospital stay. Ideally, health care providers in all settings include family caregivers as part of the team and provide the necessary support and instruction.

RECOMMENDATIONS

1) Increase awareness of the current realities for family caregivers among the general public, health care professionals, health care delivery systems, and policy makers.

We are at the dawn of a new day for family caregivers. A recent article in *Annals of Internal Medicine* called better training for caregivers “the new frontier.”¹⁸ M/N tasks have become part of the conversation in the professional and research literature, but practice has far to go. Much work remains to be done to fully integrate family caregivers into the practices and policies of an evolving health care system.

As the 2012 *Home Alone* survey report demonstrated, and *Home Alone Revisited* confirms, the ADL and IADL measures commonly used to describe family caregiving activities fail to capture the increasingly complex and demanding M/N tasks that half of all family caregivers are performing. As health care moves from institutional settings into the community, which largely means homes, the demands on family caregivers will increase.

As a start, researchers, policy makers, and the media should use the label *informal caregivers* only in a historical context. To call a person who changes postsurgical wound dressings, operates medical equipment, and gives injections an *informal caregiver* devalues the requisite skill and commitment. The face of caregiving is changing, and it crosses generations and communities. This report begins to elevate awareness, but further work is needed to ensure that the important contributions and needs of family caregivers are recognized in the workplace, in policy, and in health systems.

Specifically, we recommend that the Centers for Disease Control and Prevention update the optional Caregiver Module in its Behavioral Risk Factor Surveillance System.¹⁹ Currently, only 24 states opt to field this module. The questionnaire was updated in 2015, but it still includes only ADLs and IADLs and focuses mainly on caregivers of people with Alzheimer’s disease. Medications are grouped in the ADL category. Recognition by the leading federal public health agency of the many complex tasks assumed by family caregivers would strengthen the importance of caregiving as a public health issue. It would give state departments of health an impetus to field this module and obtain more comprehensive information about caregivers. This would also allow the comparison of findings across states. The current questionnaire is available at <https://www.cdc.gov/aging/pdf/2015-caregiving-module.pdf>.

2) Update assessment tools for family caregivers to include medical/nursing tasks and capture the complexity and trajectory of care.

Existing measures that assess family caregivers primarily focus on ADL and IADL tasks, managing problem behaviors in the context of dementia, and caregiver strain. This study highlights the multiple relevant dimensions of the caregiving experience, including the following elements that should be included in comprehensive, multidimensional assessment tools:

- a) The prevalence of M/N tasks
- b) The difficulties and challenges caregivers have with these tasks
- c) The preparation to perform the tasks (experience, instructional needs, emotional readiness)
- d) The context and goals of care—whether the focus is rehabilitation, complex serious illness, or palliative care
- e) The trajectory of the caregiving journey

Scoring of the instruments should facilitate identification of caregivers at risk and the nature of supports that could be useful. Such elements would improve the ability to tailor supports for family caregivers.

These multidimensional measures could be integrated into assessments of personal care and assistance (ADLs and IADLs) of family caregivers at the community and health systems levels.

Who should lead this effort? The National Academy of Medicine's 2016 report *Families Caring for an Aging America*²⁰ included a comprehensive discussion of the increasingly complex tasks family caregivers perform, which could be the basis for the new measures. That report looked only at caregivers of people over 65; the review should include a wider age range. The National Academies could advance this work further.

Another possibility is the creation of a specific group of experts, including family caregivers and representatives of leading organizations, for this purpose. A report from such a group would go a long way toward bringing an understanding of family caregivers' responsibilities into the present and provide tools for agencies to identify and prioritize supports.

3) Public programs should include assessments of family caregivers who are providing complex care for consumers who identify these caregivers in the person-centered plan of care.

For the first time, the federal government included such language in the 1915(i) state plan option for people on Medicaid who choose to live in the community to receive long-term services and supports. That option requires an assessment of family caregivers' needs when their care is part of a person-centered service plan.²¹

Specifically, the regulation requires the program to "include in the assessment the individual's physical, cognitive, and behavioral health care and support needs, strengths and preferences, available service and housing options, and if unpaid caregivers will be relied upon to implement any elements of the person-centered service plan, a caregiver assessment."

The assessment should include M/N tasks. And this provision should be extended to other Medicaid home and community-based waivers. It should also serve as a model for Medicare and private insurance for home health care services.

If caregiver assessments that include the caregiver's capabilities and limitations for performing M/N tasks should be essential elements of a care plan, discharge planners and community advisers as well as policy makers must acknowledge that not all caregivers have the necessary physical, emotional, or financial resources to do the job expected of them. These situations are challenging, as are those in which there is no family or friend to take on the role. As health care moves from hospitals and other facilities to the home, and as family members are taking on more complex and demanding types of care, there is a tendency on the part of policy makers, health care professionals, and payers to assume that all families should be willing and able. Those who fail this test are often judged harshly. This survey shows that 57 percent of participants feel they have no choice in taking on the role, largely because of their own sense of responsibility. But they also feel pressure from others, including health care professionals. Relying on family may be the first and legitimate response, but it should not be the only one. The assessment can be a guide to finding additional sources of ongoing support in the community. Leaving family caregivers to find help on their own is a failure of professional responsibility.

4) Health care and social service professionals must elicit and respond to the worries of these family caregivers.

We need to deepen our understanding of caregivers worrying about making a mistake. It would appear to be actionable across settings. Those who do receive instruction on performing M/N tasks say they are making an important contribution to their family member's care. But instruction by a professional does not always appear to lessen worries about making a mistake. Caregivers are more likely to receive instruction for highly technical tasks, like intravenous medications, ostomy care, suctioning, and tube feedings, and are likely to worry about making a mistake. The origin of the worry is not clear—whether the instruction increases anxiety or whether the worry about making a mistake relates to the technical nature of these tasks.

Caregivers are highly aware of the weight of their responsibility. The greater the complexity of the task, the more worried caregivers are about making a mistake. Instructions can be complicated and may not be delivered at a time or in a way that is most helpful and useful for family caregivers. It is vital to acknowledge that worry is a common experience and to provide opportunity for caregivers to verbalize their concerns and ask questions. Anticipatory guidance is key—recognizing what kinds of questions the caregiver might have so they can be raised, because caregivers often are not aware of what they do not know. The pacing of instruction is also important, so that skill and confidence can build with experience and caregivers are not overwhelmed by extraneous information before gaining basic skills.

5) Health care systems and professionals must make stronger efforts to recognize family caregivers and offer them instruction on and support for complex care.

This new survey is the first time caregivers have been asked questions that probe into the implementation of the CARE Act, providing baseline data regarding implementation efforts across the nation.

Versions of the CARE Act are law across most of the country, but implementation lags. Caregivers need a better than 50 percent chance that they will be recognized and included in the care team if the patient agrees. Two out of five report they did not receive instruction, and those who did say they could use more. Instruction is more common for highly technical tasks like home dialysis and intravenous medications. But caregivers want help with more common but difficult tasks like incontinence care and special diets.

Performing M/N tasks occurs over time, and caregivers may need reinforcement or further instruction as they gain experience and encounter challenges in performing the task. To consider instruction a one-time event is not sufficient; rather, this responsibility should be viewed as requiring ongoing assessment and support for the family caregiver. Likewise, to assume that instruction will be provided in another setting is not sufficient. Ideally, health care professionals recognize and provide instruction and support to family caregivers, wherever in their care journey they may be.

Discharge notification is a serious problem. Eight out of 10 caregivers receive less than 24 hours' notice that their family member is coming home. People need as much notice as possible to prepare the home and themselves for aftercare.

Improved guidance and support may be important for certain tasks. For example, finding #5 notes that family caregivers are on their own when learning how to perform difficult tasks. In particular,

incontinence care is both time-consuming and emotionally taxing for both the family caregiver and the care recipient. The vast majority of caregivers learn to manage this common issue alone. Several strategies might mitigate the difficulty for caregivers:

- a) Health care professionals could be more proactive in asking about whether incontinence is a problem because it may be embarrassing for a family caregiver to raise the issue.
- b) Incontinence can arise and escalate without full evaluation of a root cause and instruction about prevention. Appropriate referrals for both evaluation and treatment could offset the need to provide incontinence care.
- c) Guidance could be developed and disseminated about product selection to ensure appropriate supplies to manage the particular issue.

6) Health care and social service professionals must recognize that family caregivers are diverse in many ways and need proactive outreach to help them manage complex care.

While ethnicity and culture play key roles in complex care, it should be recognized that each family is unique in its approach to provision of care and decision making. Cultural expectations are but one of many issues—emotionality about the level of care needed, financial issues, social support, family dynamics—that must be considered when working with diverse family caregivers and systems. The study finds that the emotional impact can be greater within multicultural families and should be considered in practice and in the development of training and interventions for complex care situations. While pride in cultural customs and expectations are positive attributes for diverse populations, it would be erroneous for health and social service professionals to assume that those caregivers do not need instruction or emotional support.

Family caregivers from racially and ethnically diverse communities have unique needs related to health care and social supports. In addition to other aspects of complex care, these family caregivers are increasingly expected to perform M/N tasks. It is imperative that health care and social service providers begin to identify and address existing barriers that impede communication, instruction, and support in these communities.

- ◆ Language is a major barrier to communication for diverse family caregivers when English is not their preferred language. Instruction on M/N tasks—both written and verbal—as well as resources should be offered in multiple languages. This should occur through transcreation instead of rote translation. Simple translation is often not culturally appropriate or tailored to local language variations; this can create more confusion or potentially adverse effects for both the family caregiver and the person receiving care.
- ◆ An initiative designed to raise awareness and address the challenges diverse family caregivers face when providing complex care should be created. The goal of this initiative should be to drive the development and promotion of tools and resources to educate health and social service providers on providing culturally competent support to diverse caregivers. This initiative should include a diverse coalition of health professional associations, community-based organizations, and national organizations that represent multicultural communities.
- ◆ Meeting the needs of multicultural family caregivers who provide complex care requires organizational support. Health care systems, hospital associations, and national health care professional associations should recognize and address the unique challenges that multicultural

family caregivers who provide complex care often face when interacting with the health care system and professionals who are not cognizant of how to address these challenges. These entities must seek opportunities to dispel existing cultural stereotypes that prevent effective communication and must enhance the cultural competency of their members through education, replication of promising practices, and partnership with existing organizations rooted in these communities.

- ◆ There is an opportunity to change public policy to address the unmet needs of multicultural family caregivers who provide complex care. State and federal policy makers should incorporate a culturally competent assessment of caregivers' needs in all publicly supported programs. Once assessed, resources and tools should be available to support the reported needs.

7) Health care and social service professional education must include preparation to support family caregivers who provide complex care.

Health care curricula should address both the emotional context for caregivers and the practical skills to prepare health care professionals to be more effective in working with family caregivers. Content should include how to assess family caregivers for their preparedness, strain, resources, and worries and how to provide instruction in an effective, culturally and generationally appropriate manner. Relevant domains for understanding family caregiving include the context; caregiver perception of health and functional status of the care recipient; values and preferences; caregiver well-being; consequences of caregiving; the skills, abilities, and knowledge needed to provide care; and potential resources for the caregiver.²² Health care curricula should address both generational and multicultural considerations.

The Family Caregiving Institute at the University of California Davis recently released *Interprofessional Family Caregiving Competencies*, developed through a consensus process with national experts.²³ These competencies provide a framework for preparing health care professionals to support family caregivers and address the nature and context of caregiving, family caregiver identification and assessment, and providing family-centered care. The National League for Nursing is incorporating these competencies in learning resources. We recommend that educators take advantage of these resources to enhance curricular offerings that address the needs of family caregivers.

The lack of adequate preparation of health care professionals in managing pain is already a major focus because of the opioid crisis.²⁴ This applies to family caregivers as well. Health care curricula should address the collaboration with family caregivers in assessing and managing pain, while recognizing the emotional toll that this issue takes on the family.

8) The private sector—employers and industry—can help to better recognize and support employees who are family caregivers.

EMPLOYERS

Three in five caregivers who perform M/N tasks are working, and a third are engaged in care for more than 20 hours per week. These caregivers are juggling work responsibilities with complex family care. Proactive employers recognize this dynamic in their workforce and develop policies to support their employees. Family-friendly policies can benefit both the caregiver and employer when they enable greater work-home balance, thus reducing unplanned absenteeism and lower productivity. AARP and

the Northeast Business Group on Health²⁵ identify several strategies to support caregivers, including leave policies that allow employees to use sick days for family care, designated paid caregiver leave, employee counseling and support to help with care navigation and coping, and sponsored or facilitated access to external resources such as discounted respite care.

FOOD INDUSTRY

The findings about special diets have several implications for the food industry. The first is about convenience. Caregivers report that one of the challenges of special diets is the unrelenting demand, several times a day. Another is the expertise required to prepare a varied menu that meets prescribed dietary guidelines. This can be particularly difficult when preparing different meals for other members of the family. Affordable and healthy choices for special diets are limited, yet the need for appealing, nutritious choices is growing. Given the increasing number of older adults who require special diets, and the number of caregivers who are challenged by this important task, there is an opportunity for further innovation in the food industry.

INCONTINENCE PRODUCT INDUSTRY

Developers of incontinence products could enhance both the acceptability and the comfort of disposable briefs and provide more guidance to consumers about product selection. Input from family caregivers could provide valuable insights to industry in design considerations.

9) Community-based organizations should include in their programs and services targeted resources that address the needs of all family caregivers, particularly those engaged in complex care.

These programs and services should target resources that address the needs of family caregivers who have taken on the triple challenge of personal care, household chores, and M/N tasks.

As health care moves from institutions into the community, social service agencies, faith-based organizations, advocacy groups, employers, and the private sector should recognize the growing complexity of tasks family caregivers are performing and target resources to address their complicated lives.

They should also develop outreach strategies that reflect the various needs of men, younger caregivers, and multicultural caregivers who may not be familiar with the organizations' services. These caregivers should be encouraged to participate in various activities and programs that connect them with their peers and be offered access to additional services. This does not mean "medicalizing" the experience of caregivers; it simply recognizes that being well prepared and informed about the M/N needs of the person they are providing care for is an essential prerequisite to dealing with their emotional and spiritual needs. Hospitals, provider offices, and other health care sites should collaborate with community agencies, employers, and private-sector organizations to build training programs and to establish means of regular communication.

10) Further research could advance understanding of the experiences of these family caregivers and generate evidence-based solutions for them.

More research is needed about how best to support family caregivers, particularly as they face challenges that cause them to worry. While being aware of risk is likely to lead to better quality in providing care, it can also make the task even more stressful than it already is. Research could explore more about caregiver perceptions about their experience and how health care professionals could be

most helpful, as well as the appropriate resources for instruction, reinforcement, and ongoing problem solving. This research is necessary across settings, where caregivers need guidance and support.

Current evidence-based or best practice family caregiver interventions should be reviewed for use with caregivers who are caring for adults with complex care needs that would likely include performing M/N tasks. It would be important to include whether these interventions are effective for caregivers at a complex care stage and across health conditions, and whether they have been tested on diverse populations.

We also need to better understand the needs of family caregivers who provide support to family members with mental and behavioral health issues as well as addiction. The separation of mind and body that occurs with specialty care can leave serious mental health issues unrecognized and family caregivers unsupported. Further research could identify the needs and challenges these families experience and explore which strategies can help. The finding of the higher prevalence of mental health supports from millennial caregivers demands further exploration to understand the underlying trend and to tailor supports for this at-risk group.

CONCLUSIONS

This study affirmed many of the findings of the 2012 study and added new information about targeted issues. Because we made modifications in our sampling strategy and in our measurement to enhance our understanding of the findings from the 2012 study, it is not possible to draw conclusions about trends—instead, we can report on the current prevalence of caregiving tasks and the responses of caregivers to their responsibilities at this time. It would not be appropriate to interpret the findings in terms of increases or decreases since 2012. All generations are cohorts that are seven years older than they were in the 2012 study. The findings and recommendations in *Home Alone Revisited* mark a turning point in our understanding of family caregiving. The old paradigm—the uncomplicated world of “informal” caregiving—no longer applies to millions of family members, friends, and neighbors of diverse ages and cultural backgrounds who provide complex care at home. In the current health care environment, it is presumed that every home is a potential hospital and every service that the person needs can be provided by an unpaid family member, with occasional visits by a primary care provider, nurse, or therapist.

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

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

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

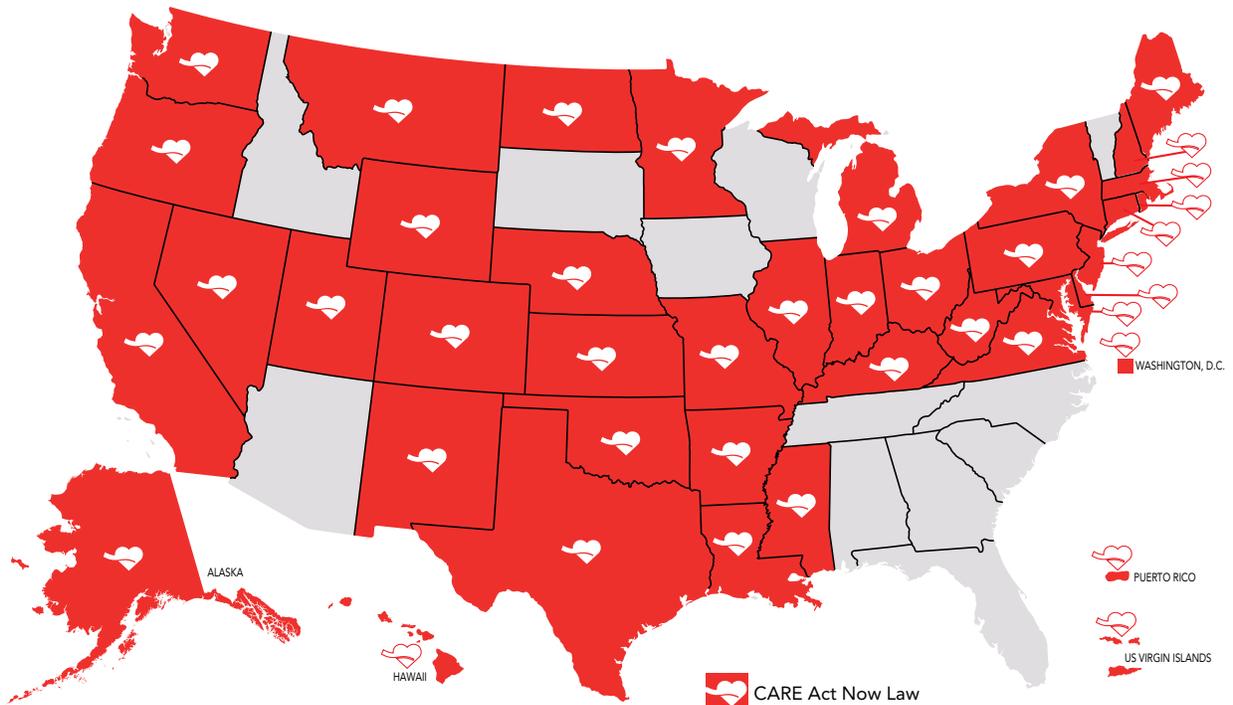
The recommendations in this report are a good place to start. We cannot go back to the “good old days”—if they even existed. The future is our only path to justice and a caring society.

APPENDIX

Appendix A1

The Caregiver Advise, Record, Enable (CARE) Act

The CARE Act is a commonsense solution that supports family caregivers when their loved ones go into the hospital, and provides for instruction on the medical tasks they will need to perform when their loved ones return home.



CARE Act goes into effect:
Alaska, 1/1/17; Arkansas, 7/22/15; California, 1/1/16; Colorado, 5/8/15; Connecticut, 10/1/15; Delaware, 1/1/17; Hawaii, 7/1/17; Illinois, 1/27/16; Indiana, 1/1/16; Kansas, 7/1/18; Kentucky, 6/29/17; Louisiana, 8/1/16; Maine, 10/15/15; Maryland, 10/1/16; Massachusetts, 11/8/17; Michigan, 7/12/16; Minnesota, 1/1/17; Mississippi, 7/1/15; Missouri, 8/28/18; Montana, 10/1/17; Nebraska, 3/30/16; Nevada, 10/1/15; New Hampshire, 1/1/16; New Jersey, 5/12/15; New Mexico, 6/17/15; New York, 4/23/16; North Dakota, 8/1/19; Ohio, 3/21/17; Oklahoma, 11/5/14; Oregon, 1/1/16; Pennsylvania, 4/20/17; Puerto Rico, 12/31/15; Rhode Island, 3/14/17; Texas, 5/26/17; Utah, 2/10/16; Virgin Islands, 3/30/16; Virginia, 7/1/15; Washington, 6/9/16; Washington, DC, 7/6/16; West Virginia, 6/8/15; Wyoming, 7/1/16

Updated on 3/26/19

I ♥ Caregivers **AARP** Real Possibilities

Appendix A2. Home Alone Alliance Members

AARP*	Betty Irene Moore School of Nursing, University of California, Davis*	United Hospital Fund*	Family Caregiver Alliance*	<i>American Journal of Nursing</i>
The John A. Hartford Foundation**	African American Alzheimer's and Wellness Association	Nurses Improving Care for Healthsystem Elders	Center to Advance Palliative Care	Ralph C. Wilson, Jr. Foundation**
Coalition to Transform Advanced Care	Home Alone AllianceSM Members			CENTENE Charitable Foundation**
EMD Serono Inc.	Home Instead Senior Care Inc.	National League for Nursing	Retirement Research Foundation**	National Alliance for Caregiving
The Lindsay Institute on Caregiving/Virginia Navigator	Rosalynn Carter Institute for Caregiving	Pfizer Inc.**	Rush University Medical Center	New York University Rory Meyers College of Nursing
ElevatingHOME/Visiting Nurses Association of America	Hartford Institute for Geriatric Nursing	Atlas of Caregiving	US Department of Veterans Affairs	*indicates HAA founding partner **indicates HAA funder

Appendix A3. How-To Videos to Date

Medication Management:	Mobility:	Wound Care:	Managing Incontinence:	Preparing Special Diets:
Beyond Pills: Eye Drops, Patches & Suppositories	Preparing Your Home for Safe Mobility*	Treatment of Skin Tears	How Family Caregivers Can Help*	Nutrition Basics*
Dealing with Dementia-Related Resistance	Getting from a Car to a Wheelchair*	Pressure Ulcers: Prevention and Skin Care	Managing Incontinence at Home	Preparing Reduced Sodium Meals
Giving Insulin Injections	What to Do When Someone Falls*	Caring for and Maintaining Ostomy Bags	Helping Someone to the Toilet	Modifying Food Textures
Hospital Discharge Planning*	Using a Walker or Cane and Navigating Stairs*	Diabetic Foot Care: Treatment and Prevention*	Seeking Emotional Support	Managing Low Appetite
Organizing and Administering Pills	Moving from a Walker to Shower or Bed*	General Principles of Wound Care*	How to Talk with Someone about Incontinence*	Caring for Someone with Dementia: Feeding Challenges
		Caring for Lower Extremity Wounds and Cellulitis	Selecting Incontinence Products*	"G-Tube" Feeding Guidelines
			Managing Incontinence for Those with Difficulty Getting Out of Bed*	

* Videos available in Spanish

Appendix A4. Comparison of Caregiver Characteristics, %

	2012 (n = 1,677)	2018 (n = 2,089)
Gender: Female	58	57
Age (mean years)	53	49
Ethnicity: Hispanic/Latino	9	17
Race:		
White	73	77
Black/African American	10	13
Other	7	10
Marital Status: Married	67	63
Employment Status: Working	47	62
Education:		
Less than high school	9	11
High school	30	30
Some college	31	31
Bachelor's or higher	30	28
Relationship to Care Recipient:		
Child	38	45
Spouse/partner	20	18
Other relative	27	16
Friend	11	15
Performing M/N tasks	46	50

Appendix A5. Methods

We developed the current survey as a refinement and elaboration of the 2012 study, incorporating further qualitative research with multicultural populations conducted in 2017 and 2018, by Alan Newman Research.

Ipsos, a survey research firm, fielded the online 2018 Caregiver Home Alone Survey in June–July 2018.²⁶ Ipsos recruited participants from its

KnowledgePanel, a large, nationally representative group made up of respondents invited to participate through probability-based sampling. If necessary, participants were given a computer and Internet access. They were offered a variety of surveys and were paid a small fee for each completed survey for which they were eligible and may have also earned other rewards.

The sampling strategy ensured multicultural representation, including at least 200 Black/African American caregivers, 300 Hispanic/Latino caregivers, and 150 Chinese caregivers, all of whom were performing M/N tasks. For Hispanic/Latino caregivers, the survey was conducted in their preferred language. While the Black/African American and Hispanic/Latino participants were selected from the probability-based sample, 23 Chinese panelists (1.1 percent of surveyed caregivers) were added to the sample from outside the KnowledgePanel to increase the sample size. These panelists were weighted against the population and blended into the probability-based panel.

We analyzed data using SPSS version 24, generating descriptive statistics for all survey items. Using the appropriate parametric or nonparametric tests, we compared the demographic characteristics of these two groups. We made further comparisons within the group that performs complex care to understand gender, generational, and racial/ethnic differences in the experience of caregiving. Finally, we performed a step-wise linear regression to understand the contribution of background characteristics, caregiving demand, caregiver perceptions, and resources on the experience of caregiving and its impact on caregiver health and well-being.

Appendix A6. Manage Mental Health, % (*n* = 1,084)

	Yes
Manage and/or monitor family member's mental health and related behavior	55

Find Mental Health/Behavior Monitoring Stressful

	Extremely Stressful	Stressful	Somewhat Stressful	Not at all stressful
Hispanic/Latino (<i>n</i> = 88)	14	32	37	16
Black/African American (<i>n</i> = 65)	11	20	46	23
White (<i>n</i> = 352)	20	32	35	14
Asian (<i>n</i> = 71)	33	19	37	11
Chinese (<i>n</i> = 55)	30	27	36	7
Non-Hispanic other (<i>n</i> = 76)	32	20	33	15
2+ races (<i>n</i> = 55)	7	44	48	1

Appendix A7. Help Caregivers Provide, %

Type of Help	Total (<i>n</i> = 2,089)	M/N Tasks (<i>n</i> = 1,084)	Non-M/N (<i>n</i> = 1,005)
Household care—instrumental activities of daily living (IADLs)	92	92	92
Personal care—basic activities of daily living (ADLs)	48	64	32
Help to more than one person	21	23	19
More than 20 hours per week	18	29	8

Appendix A8. Multicultural ADLs and IADLs in Addition to M/N Tasks

	Personal Care Tasks	Household Care Tasks
Hispanic/Latino (<i>n</i> = 165)	64	87
Black/African American (<i>n</i> = 114)	75*	96**
White (<i>n</i> = 631)	61	94**
Asian (<i>n</i> = 122)	68	91
Chinese (<i>n</i> = 95)	66	92
Non-Hispanic other (<i>n</i> = 132)	69	91
2+ races (<i>n</i> = 42)	66	87

* statistically significant compared with White/Non-Hispanics

** statistically significant compared with Hispanics

Appendix A9. Relationship of Income to Task Difficulty

	Pearson Chi-Square	Fisher's Exact Test (2-Sided)	Direction of Association
Manage medications	14.57	0.000	Positive
Assistive devices for mobility	17.41	0.000	Positive
Incontinence—disposable briefs	4.67	0.033	Positive
Do ostomy care	5.66	0.034	Negative
Use meters/monitors	7.35	0.010	Positive
Operate mechanical ventilators, oxygen	9.10	0.004	Positive

Appendix A10: Differences in Instruction by Gender and Generation, %

Received Instruction

	Yes	No
Generation:		
Generation Z (<i>n</i> = 13)	69	19
Millennial (<i>n</i> = 169)	55	37
Generation X (<i>n</i> = 202)	69	28
Boomer (<i>n</i> = 424)	72	22
Silent generation (<i>n</i> = 92)	64	26
Gender:		
Female (<i>n</i> = 561)	71	23
Male (<i>n</i> = 339)	59	36

Opportunity to Ask Questions

Generation:	Yes	No	Not Sure
Generation Z (<i>n</i> = 13)	81	7	12
Millennial (<i>n</i> = 169)	73	20	7
Generation X (<i>n</i> = 202)	84	10	6
Boomer (<i>n</i> = 424)	84	7	8
Silent generation (<i>n</i> = 92)	90	3	7

Appendix A11. Managing Pain by Generation, %

Finding Pain Management Stressful

Pain Management	Generation Z (n = 14)	Millennial (n = 158)	Generation X (n = 166)	Boomer (n = 338)	Silent Generation (n = 75)
Very stressful	1	22	21	8	9
Stressful	29	29	28	28	16
Somewhat stressful	46	33	33	42	56
Not stressful	24	16	18	22	20

	Generation Z (n = 14)	Millennial (n = 158)	Generation X (n = 166)	Boomer (n = 338)	Silent Generation (n = 75)
Difficulty getting prescriptions	33	20	19	14	6
Difficulty managing pain through alternative methods	7	27	16	15	15

Appendix A12. Effect on Caregiver Quality of Life by Generation, % (Strongly Agree/Agree) (n = 1,084)

	Younger Caregiver	Generation X	Boomer	Silent Generation
Eased worries about your family member's condition	65	63	72****	68
Affected employment negatively	43*	33*	23**	12
Made you feel that you are making an important contribution	70	81*****	79*****	77
Added to level of stress because you have to talk to so many health care professionals or suppliers	57*	51**	44	34
Made you worry about paying for care	48*	45*	31	25
Made you worry about making a mistake in your family member's care	55*	55*	39	36
Caused problems in your relationship with your family member	43***	28*	17	15
Given you new skills	65**	61**	55	47
Made you feel closer to your family member	67	74	74	74

* Statistically significant compared with boomers and silent generation caregivers

** Statistically significant compared with silent generation caregivers

*** Statistically significant compared with generation X, boomer, and silent generation caregivers

**** Statistically significant compared with boomers

***** Statistically significant compared with younger caregivers

Appendix A13. Relationship of Income and Race/Ethnicity to Caregiver Outcomes

	R2	Income* White v. Non-White
Worry about mistakes? (agreement increases)	0.49	-.03*
Gain new skills? (disagreement increases)	0.21	n.s
Makes contribution? (disagreement increases)	0.23	n.s
Avoids nursing home? (agreement increases)	0.16	n.s
Health (excellent to poor)	0.18	n.s
Strain (low to high)	0.46	-.05*
Depressive symptoms (low to high)	0.33	n.s
Sleep (rare to frequent disturbances)	0.24	n.s

*= Attains significance

n.s. = Not significant

Appendix A14. Multivariate Analysis: Predictive Models

	Worry about Mistakes?	Avoid Nursing Home Admission	Strain	Depressive Symptoms
R²	0.49	0.16	0.46	0.33
F	40	8.32	30.47	18.15
(d.f.) and Significance	(24; 1,015)***	(24; 1,015)***	(28; 1011)***	(28; 1011)***
Background				
Age				
Female			.108*	.114***
Lives with care recipient	-.059*	-.080*		
Recipient is older relative		.087**		-.084
Race (ref = White/Non-Hispanic)				
Black/African American			-.052*	
Hispanic/Latino		-.126***		
Asian				
Work (ref= not working)				
Employed				-.074
Caregiving Demands				
Number of types of recipient needs			.068**	.101***
Sum of M/N tasks		.165***		
Communicating with multiple health care providers	.177***	.136**	.189***	
Constantly watching	.372***	.142***	.101**	.117**
% of tasks done on daily basis				
Caregiver Appraisal				
Had no choice?		-.073*	.083**	
Tasks hard to do?	.053***	-.240***	.287***	
Felt cultural pressure?			.056*	
% MN tasks deemed difficult			.079**	
Resources				
Income				-.083**
Lubben scale				-.062*
Social satisfaction			-.23***	-.347***
% tasks got professional instruction	.928**		-.11***	
CARE resources/instruction				
Professional Visits?				
		.091**		

* $p < .05$

** $p < .01$

*** $p < .001$

Appendix A15. Choice and Pressure by Gender, %

Choice in taking on medical/nursing tasks	Female (<i>n</i> = 669)	Male (<i>n</i> = 408)
Yes	41	44
No	58	56

Felt pressure to take on medical/nursing tasks	Female (<i>n</i> = 669)	Male (<i>n</i> = 408)
Yes	35	33
No	65	66

Appendix A16. Choice by Race and Ethnicity (%)

	Yes	No
Hispanic/Latino (<i>n</i> = 164)	47	50
Black/African American (<i>n</i> = 113)	56	43
White (<i>n</i> = 627)	39	61
Asian (<i>n</i> = 121)	42	59
Chinese (<i>n</i> = 95)	37	63
Non-Hispanic other (<i>n</i> = 131)	38	62
2+ races (<i>n</i> = 42)	50	50

Felt Pressure to Take on the Medical/Nursing Tasks

	Yes	No
Hispanic/Latino (<i>n</i> = 164)	35	64
Black/African American (<i>n</i> = 113)	23	77
White (<i>n</i> = 627)	36	63
Asian (<i>n</i> = 121)	26	74
Chinese (<i>n</i> = 95)	48	51
Non-Hispanic other (<i>n</i> = 131)	29	71
2+ races (<i>n</i> = 42)	39	61

Appendix A17. Effect on Caregiver Quality of Life, % (Strongly Agree/Agree) (n = 1,084)

Positive Effects	Number of Tasks			Number of Conditions			Training	
	1-2	3-5	5+	1	2	3+	No	Yes
Made me feel I am making an important contribution	74	81	77	76	79	77	72**	82**
Made me feel closer to family member	67**	78**	72**	72	74	70	67**	77**
Eased worries about family member's condition	68**	76**	58**	72*	68*	64*	65	71
Given me new skills I can apply in other areas of life	56	62	61	60	59	59	49**	67**
Negative Effects								
Added to my level of stress because I have to talk to so many health care professionals or suppliers	45**	45**	58**	37**	47**	64**	47	50
Made me worry about making a mistake in care	44	46	53	40**	47**	55**	42**	51**
Made me feel I have to constantly watch out for something to go wrong	40**	44**	55**	35**	44**	59**	44	46
Made me worry about paying for care	45**	45**	58**	37**	47**	64**	47	50
Affected my employment negatively	25*	33*	35*	24**	32**	37**	28	33
Self-reported fair/poor health	34**	34**	48**	34**	35**	45**	33**	41**
Depressed in last two weeks	39	39	47	36**	38**	52**	38	44

* = $p < .05$

** = $p < .01$

Appendix A18. Effect on Care Recipient Quality of Life, % (Strongly Agree/Agree) (n = 1,084)

Positive Effects	Number of Tasks			Number of Conditions			Training	
	1-2	3-5	5+	1	2	3+	No	Yes
Lessened pain and symptoms	65**	78**	68**	75*	67*	69*	68	73
Avoided nursing home placement	62**	81**	83**	67**	76**	81**	72	76
Permitted more involvement in family/outside activities	64*	71*	63*	69	65	65	65	67
Allowed more independence	63**	74**	56**	71**	65**	58**	61*	68*
Negative Effects								
Been a constant reminder of illness/disability	45*	39*	48*	42	41	49	44	43
Limited activity because of medication side effects or treatment schedule	38*	38*	47*	40	36	45	38	42
Involved pain, discomfort, or embarrassment	38	35	43	38**	33**	46**	38	39

* = $p < .05$

** = $p < .01$

**Appendix A19. Issues with Special Diets by Race/
Ethnicity and Gender, %**

	Prepare Food for Special Diets
Hispanic/Latino (<i>n</i> = 148)	37
Black/African American (<i>n</i> = 107)	25
White (<i>n</i> = 516)	28
Asian (<i>n</i> = 58)	43
Chinese (<i>n</i> = 11)	43
Non-Hispanic other (<i>n</i> = 71)	48
2+ races (<i>n</i> = 13)	28

Task Difficulty (Preparing Food) by Gender

	Female (<i>n</i> = 99)	Male (<i>n</i> = 57)
I didn't understand what to do	1	12
I'm afraid of making a mistake	14	5
I'm afraid of hurting my family member	3	6
I'm afraid of hurting myself	-	2
Involves lifting	2	1
It's emotionally difficult for me	2	5
Requires my constant attention	25	18
Hard to find time	14	8
Inconvenient	7	15
My family member resists	8	3
It's embarrassing for my family member	0	0

**What Would Make Preparing Food for Special Diets
Easier?**

	Female (<i>n</i> = 99)	Male (<i>n</i> = 57)
More instruction/preparation	14	14
More instruction/ preparation at home	10	15
More practice with supervision	8	2
Clearer written instructions	5	5
Video-based instructions	3	14
Another person to help me	15	16

ENDNOTES

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