

## Family Caregivers Providing Complex Chronic Care to Their Spouses

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**Family caregiving today is largely considered to be an issue affecting mainly adult children and their parents. This focus reflects the demographics of an aging population, but it misses a significant group—spouses who are caregivers. A recent national survey of family caregivers of adults conducted by the AARP Public Policy Institute and the United Hospital Fund found that 1 in 5 family caregivers is a spouse.**

**Spousal caregivers are particularly vulnerable because they are older, have lower educational levels and less income, and are less likely to be employed than nonspousal caregivers. Spousal caregivers are more likely than nonspousal caregivers to provide assistance with medical/nursing tasks such as medication management and wound care. Yet they are less likely to receive support from family and friends and are far less likely to have home visits from health care professionals and aides. Efforts to reduce isolation and stress, as well as targeted training and support, are needed to protect the health and well-being of both partners.**

All family caregivers are alike in some fundamental ways. They are committed to providing or managing the care of someone close to them, and they need training and support from health care and social service professionals, as well as others in their families and communities. Older spousal caregivers may have fewer competing responsibilities than spousal caregivers with young or teenage children at home. But this apparent advantage is often offset by financial, health, and other limitations and by the stresses of constant caregiving.

### Methodology

This *Insight on the Issues* takes a closer look at spousal caregivers who perform complex medical/nursing tasks. It compares data on spouses and nonspouses who participated in the December 2011 AARP Public Policy Institute (AARP PPI)–United Hospital Fund (UHF) survey, reported in *Home Alone: Family Caregivers Providing Complex Chronic Care*.<sup>1</sup> That survey of family caregivers of adults asked all respondents about their responsibility for activities of daily living (ADLs), instrumental activities of daily

## Family Caregivers Providing Complex Chronic Care to Their Spouses

living (IADLs), and medical/nursing tasks such as medication management and wound care. For some questions that focused only on family caregivers providing medical/nursing tasks, this paper highlights comparisons between spouses and nonspouses. The full *Home Alone* report and methodology can be found at <http://www.aarp.org/homealone> and at <http://www.uhfnyc.org/publications/880853>.

A companion AARP PPI/UHF *Insight on the Issues*, comparing employed and not employed caregivers in the Home Alone survey, is available at <http://www.aarp.org/home-family/caregiving/info-11-2013/employed-family-caregivers-providing-complex-chronic-care-AARP-ppi-health.html> and <http://www.uhfnyc.org/publications/880949>.

### Do Spousal Caregivers Face Greater Challenges?

Of the 1,677 family caregivers of adults whom AARP PPI/UHF surveyed, 20 percent (336) identified themselves as spouses or partners. The survey did not distinguish between those who described themselves as spouses or as partners; in this *Insight on the Issues*, we refer to all as “spousal caregivers.”

Table 1 presents some demographic comparisons between all spousal and all nonspousal caregivers, 81 percent of whom were an adult child or other relative. One-half of spousal caregivers were women, compared to 60 percent of nonspousal caregivers. One-half (49 percent) of spousal caregivers were over age 65, compared to 20 percent of nonspousal caregivers. Spousal caregivers were a full decade older than nonspousal caregivers—median age of 64 compared to 54.

Spousal caregivers had fewer resources to draw on for support:

- Nearly one-half (45 percent) had only a high school education or less, compared to 38 percent of nonspousal caregivers.
- Less than one-third (32 percent) were employed, compared to more than one-half (51 percent) of nonspousal caregivers.
- More than one-half (56 percent) had incomes less than \$50,000, compared to 46 percent of nonspousal caregivers, and only 13 percent had incomes greater than \$100,000, compared to 21 percent of nonspousal caregivers.

Both spouses and nonspouses tended to be long-term caregivers. One-half (49 percent) of spousal caregivers had been providing care for 3 or more years, as had 43 percent of nonspousal caregivers. Of long-term caregivers, 29 percent of spousal caregivers and 23 percent of nonspousal caregivers had been providing care for more than 5 years.

### How Do Care Recipients Differ?

Consistent with the typical media portrayal, nonspousal caregivers were likely to be caring for a woman—most likely a mother or grandmother. However, among spouses, the pattern was different; 51 percent of the spousal care recipients were male, compared to 31 percent of the nonspousal care recipients.

Spousal care recipients were more than a decade younger (median age 65) than nonspousal care recipients (median age 78). They were, as might be expected, about the same age as their caregivers. Only 12 percent of spousal care recipients were age 80 or older, compared to almost one-half (47 percent) of nonspousal care recipients.

Nearly all (98 percent) of the spouses lived in the same household.

**Table 1**  
**Characteristics of Spouse and Nonspouse Family Caregivers (percent)**

	Spouse N = 336	Nonspouse N = 1,339
<b>Gender</b>		
Male	50	40
Female	50	60
<b>Age</b>		
18–34	6	18
35–49	13	21
50–64	32	42
65–79	40	19
80+	9	1
Mean	62	51
Median	64	54
<b>Race</b>		
White	82	71
Black	6	11
Hispanic	7	3
Other	4	14
<b>Education</b>		
< High school	8	9
High school	37	29
Some college	31	31
Bachelor’s degree or higher	25	32

	Spouse N = 336	Nonspouse N = 1,339
<b>Employment Status</b>		
Employed	32	51
Unemployed	68	49
<b>Household Income</b>		
<\$25,000	22	23
\$25,000–\$49,000	34	23
\$50,000–\$74,000	20	19
\$75,000–\$99,000	11	13
\$100,000–\$124,000	6	9
≥ \$125,000	7	12
<b>Relationship with Care Recipient</b>		
Child	0	47
Other relative	0	34
Spouse or partner	100	0
Friend or neighbor	0	19
<b>Period of Time Providing Care</b>		
< 1 year	31	32
1–2 years	19	25
3–5 years	20	20
> 5 years	29	23

Note: Two people did not respond to the survey question about the relationship between the caregiver and the care recipient.

Overall, spouses and nonspouses were caring for persons with similar patterns of serious chronic illness and disability. The most common physical health conditions were stroke and hypertension, musculoskeletal diseases (such as arthritis), heart disease, diabetes, cancer, and lung disease. Reported rates of depression and mental illness among care recipients were also similar.

There were differences, however, in the rates of cognitive and sensory conditions. Spousal caregivers reported that their care recipients had lower incidences of cognitive issues (19 percent versus 33 percent for nonspousal care recipients), as well as fewer hearing and vision problems (14 percent versus 21 percent). One explanation for this difference may be that because spousal

## Family Caregivers Providing Complex Chronic Care to Their Spouses

care recipients were younger than those receiving care from nonspouses, they had not yet developed serious problems in these areas. However, spousal caregivers may have been less attuned to changes in cognitive status and sensory deficits because they spent so much time with the care recipient, whereas most nonspousal caregivers (77 percent) did not live with their family member. Also, spousal caregivers may have been reluctant to acknowledge these changes.

### What Types of Care Do Spouses Provide?

*Home Alone* documented that the family caregiver's job description was much more complex than researchers and practitioners had acknowledged for decades. We expected to see family caregivers reporting their help with ADLs, such as bathing, dressing, eating, moving from bed to chair, or going to the toilet. We also expected they would report helping with IADLs, such as shopping, managing personal finances, arranging for outside services, or providing transportation. But we documented that almost one-half (46 percent) of family caregivers performed complex medical/nursing tasks that were traditionally conducted by highly skilled professionals only in hospitals or rehabilitation facilities. These medical/nursing tasks are not captured in conventional family caregiving measures. Our findings shed light on largely hidden responsibilities and provided a much more complete job description for family caregivers.

Strikingly, spousal caregivers were much more likely to be performing medical/nursing tasks; 65 percent performed medical/nursing tasks compared to 42 percent of nonspousal caregivers. Nearly one-half (43 percent) of spousal caregivers performed all three types of care—ADLs, IADLs, and medical/

nursing tasks—compared to 27 percent of nonspousal caregivers.

Figure 1 summarizes the categories of medical/nursing tasks and shows that spouses and nonspouses were performing specific medical/nursing tasks at similar rates. Regardless of relationship status, 8 of 10 family caregivers who provided assistance with medical/nursing tasks were helping with medications, which included injections. Four of 10 were helping with assistive devices for mobility and special diet. More than one-third were helping with wound care, including pressure sores, colostomies, and postsurgical wounds.

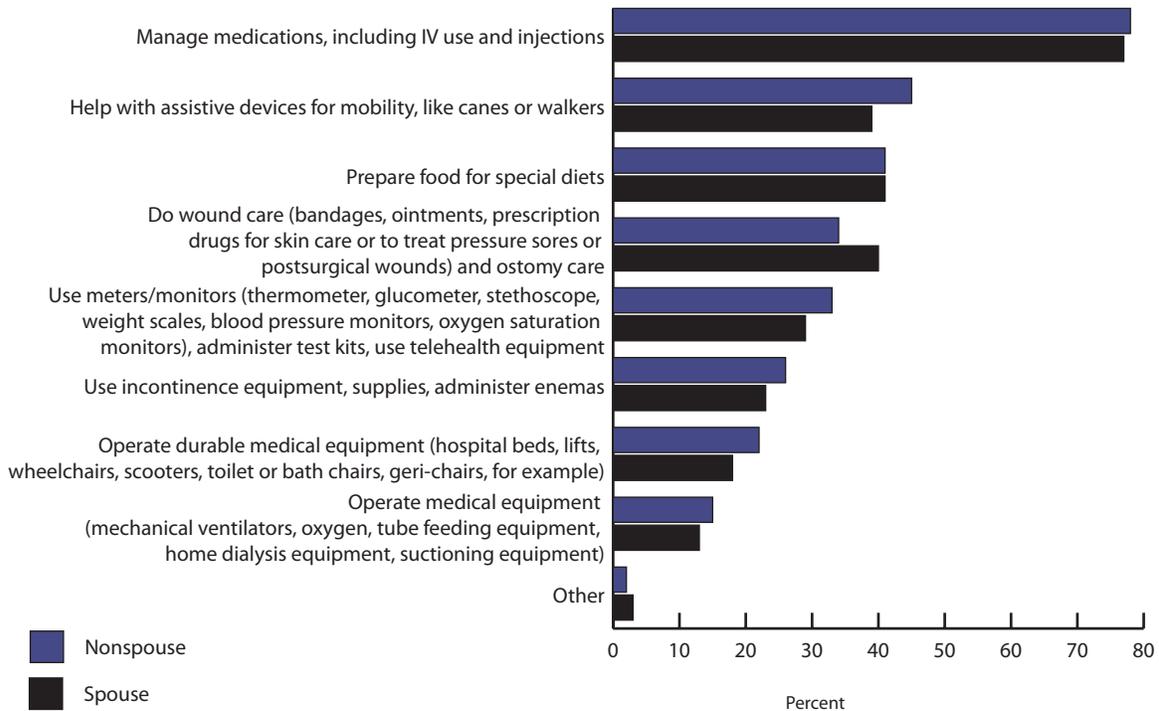
### What Medical/Nursing Tasks Do Spouses Find Difficult?

Some medical/nursing tasks are more difficult than others, according to the family caregiver respondents. But spousal and nonspousal family caregivers gave similar answers when asked which two tasks they found the most difficult. Table 2 summarizes the findings.

### Spouses and Complex Medication Management

Although medications are a major and common issue for all family caregivers, medications may be more complicated for spousal caregivers. More spousal care recipients took five or more medications (73 percent compared to 60 percent of nonspousal care recipients) and required nonpill forms of drugs (e.g., injections, inhalers, eye and ear drops, and infusion pumps) than did nonspousal care recipients (39 percent versus 26 percent). In addition, managing medications was time consuming: 73 percent of spouses who said that medication management was one of their two most difficult medical/nursing tasks performed this

**Figure 1**  
**Percentage of Family Caregivers Performing Medical/Nursing Tasks, for Spouses and Nonspouses**



Spouses (N = 217) and Nonspouses (N = 559)

task at least daily, compared to 48 percent of nonspousal caregivers.

When family caregivers, both spouses and nonspouses, were asked who prepared them to manage medications, about 6 of 10 (61 percent) caregivers who found this task challenging reported learning how to perform at least some of this task on their own. However, some of these caregivers also indicated that they had some instruction from other sources, most commonly a doctor’s office or other outpatient setting (37 percent of spousal caregivers and 30 percent of nonspousal caregivers). This finding demonstrates family caregivers’ striking lack of

preparation to manage these difficult tasks.

### Health Care Service Use

Because spousal and nonspousal care recipients had comparable health conditions, similar use of acute health care services might be expected. Both spousal and nonspousal care recipients had similar emergency department and hospital use. Sixty percent of spousal care recipients had at least one emergency department visit in the previous year, as did 64 percent of nonspousal care recipients. More than one-half (54 percent of spouses and 57 percent of nonspouses) reported

**Table 2**  
**Medical/Nursing Tasks That Spouse and Nonspouse Family Caregivers Find Difficult**

	Spouse		Nonspouse	
	Number Performing Task	Percentage Who Reported Task as Difficult	Number Performing Task	Percentage Who Reported Task as Difficult
Use incontinence equipment, supplies, administer enemas	49	71	144	66
Do wound care (bandages, ointments, prescription drugs for skin care or to treat pressure sores or postsurgical wounds) and ostomy care	87	62	188	68
Manage medications, including IV use and injections	168	62	438	61
Prepare food for special diets	90	59	229	51
Operate medical equipment (mechanical ventilators, oxygen, tube feeding equipment, home dialysis equipment, suctioning equipment)	28	39	83	52
Help with assistive devices for mobility, like canes or walkers	85	40	249	38
Use meters/monitors (thermometer, glucometer, stethoscope, weight scales, blood pressure monitors, oxygen saturation monitors), administer test kits, use telehealth equipment	63	32	182	43
Operate durable medical equipment (hospital beds, lifts, wheelchairs, scooters, toilet or bath chairs, geri-chairs, for example)	40	38	122	35

## Family Caregivers Providing Complex Chronic Care to Their Spouses

that the care recipient had at least one hospital stay in the previous year.

Spousal care recipients, however, visited more health care providers on a regular basis: 20 percent (one in five) saw four or more professionals compared to 12 percent of nonspousal care recipients.

### Lack of Help at Home

In general, all family caregivers reported that care recipients received very few home visits from health care professionals. Spouses fared worse than nonspouses: 84 percent of spousal care recipients received no home visits, compared to 65 percent of nonspousal care recipients.

Nor did these spousal caregivers receive much help from family or friends or home care aides: more than one-half (58 percent) of the spouses reported no additional help from others, compared to one in five (20 percent) of nonspouses who lacked any additional help at home. Sixty percent of nonspouses reported that they had help from another family member, whereas only 28 percent of spouses reported this kind of assistance. Similarly, nonspouses were also more likely to have a home care aide (22 percent) than were spouses (7 percent).

Not surprisingly, given the lack of external support, more than one-half (53 percent) of spousal caregivers were the primary care coordinators compared to one-third (33 percent) of nonspousal caregivers.

The reasons that spousal caregivers received so much less help than did nonspousal caregivers are unknown. The spouses may have chosen to provide care alone, or others' may have assumed that no outside help was needed. This issue needs further exploration because the lack of outside help is likely to increase caregiver isolation and stress.

### Providing Complex Chronic Care Is a Stressor and Often Not a Choice

Spousal caregivers were less likely than nonspousal caregivers to perceive that they had a choice in taking on difficult medical/nursing tasks: 70 percent reported feeling that they had no choice, compared to 52 percent of nonspousal caregivers. Spouses were far less likely to report pressure from other family members (4 percent compared to 18 percent for nonspouses). These results again suggest that spousal caregivers might be more disposed to shoulder their responsibilities alone and not easily ask for help.

Despite the differences in age and caregiving situation, in general spousal and nonspousal caregivers reported similar levels of stress and strain. For example, 47 percent of spouses reported feeling that they had no time for themselves, as did 50 percent of nonspouses. About one-third of both groups reported fair or poor health, and 44 percent of spouses and 39 percent of nonspouses reported feeling depressed in the past 2 weeks. However, 49 percent of spouses felt stressed between care and other responsibilities, whereas 57 percent of nonspouses felt this effect. As noted earlier, nonspouses were more likely to be employed, which may be contributing to this stress.

Spousal caregivers were more likely to report negative effects for their care recipient. This may be a result of the spousal caregiver living with the care recipient and being involved in daily caregiving. More than one-third (35 percent) reported that their caregiving was a constant reminder of illness for their care recipient, compared to 20 percent of nonspousal caregivers. Spousal caregivers were twice as likely (17 percent) as nonspousal caregivers (8 percent) to report that their caregiving

**Table 3**  
**Effects on Spousal Caregivers by Number of Tasks and Chronic Conditions**

Variable	Spouse Caregivers Only							
	Spouse		Number of Tasks			Number of Chronic Conditions		
	Yes	No	1-2	3-4	5+	0-1	2-4	5+
<b>Negative Impact</b>								
Employment	12%	15%	8%*	11%*	26%*	5%*	15%*	20%*
Stress of talking to many	21%	24%	15%**	17%**	40%**	10%*	24%*	33%*
Worry about making mistakes	20%	18%	14%**	12%**	47%**	8%**	27%**	25%**
Constantly watching	38%*	29%*	26%**	36%**	72%**	22%**	41%**	63%**
Fair/poor health	33%	31%	35%	26%	42%	23%*	36%*	45%*
Depressed in last 2 weeks	44%	39%	36%**	39%**	67%**	35%**	42%**	65%**
<b>Sometimes to Always (% of respondents)</b>								
Feel have no time for self	47%	50%	38%**	45%**	72%**	23%**	53%**	80%**
Feel stressed between care and other responsibilities	49%	57%	38%**	53%**	65%**	34%**	54%**	65%**
Feel strained	29%	36%	25%	28%	40%	10%**	33%**	55%**
Feel uncertain	38%	38%	34%	36%	47%	21%**	40%**	63%**

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

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

limited their spouses' activity because of medication side effects or treatment schedule. And more spousal caregivers (20 percent) reported that the medical/nursing tasks they performed involved pain, discomfort, and embarrassment for the care recipient than did nonspousal caregivers (14 percent).

Both positive and negative effects on spousal and nonspousal caregivers increased as the number of tasks and chronic conditions increased. Table 3 shows that nearly three-fourths (72 percent) of the spouses performing

five or more tasks reported feeling that they had no time for themselves, whereas 38 percent of those who did one or two tasks felt the same. The same pattern prevailed in terms of number of conditions: 80 percent of spouses who cared for someone with five or more conditions reported having no time for themselves, compared to 23 percent of those caring for someone with one or two conditions.

Spousal caregivers were less likely (41 percent) than nonspousal caregivers (55 percent) to report that their

## Family Caregivers Providing Complex Chronic Care to Their Spouses

caregiving avoided nursing home placement. Spouses may have been less likely to entertain that option in the first place, which would contribute to a lower rate of effect. However, the percentage reporting that they felt that they were keeping a spouse out of a nursing home increased with the number of tasks; 70 percent of spousal caregivers who performed five or more tasks gave this response, compared to 23 percent of spousal caregivers who performed one or two tasks. This pattern was also true for spouses caring for spouses with multiple chronic conditions: 60 percent of spousal caregivers whose spouse had five or more chronic conditions reported that their caregiving helped avoid nursing home placement, compared to 22 percent of those caring for spouses with fewer chronic conditions.

### Spouses and Caregiving

Spouses taking care of one another during illness seems a natural part of an intimate relationship. This analysis suggests that spouses are in fact assuming this responsibility over long periods of time and with little or no help from professionals or other family members. Yet “taking care of one another” in an era of complicated medication regimens, wound care, and tasks associated with complex chronic care is a challenge that no one should have to face alone.

Much more attention needs to be paid to spousal caregivers. Why are they “home alone”? Is it choice? Lack of awareness of sources of help? Finances? Fear of losing independence? A better understanding of how spousal relationships in caregiving differ from those of adult children or other family relationships would help tailor interventions that support but do not supplant the primary bond.

Finally, what can be done to build a family and community support network that respects the preferences and values of spouses, but offers them the training and assistance that they need to maintain the caregiving situation? One spouse may be ill, but both are at risk.

Policy makers should proactively consider spousal family caregivers in developing new models of care that focus on chronic care coordination and transitions between care settings. They should not assume that spouses have the knowledge, skills, and resources to perform all tasks. Spouses may know their partner, but they are not trained to be nurses or social workers. Development, funding, and execution of innovative care and coordination models should have a strong, explicit focus on supporting family caregivers who are assuming ever more complex responsibilities. And spousal caregivers need special attention, not assumptions that they are somehow better prepared to do the job.

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### Endnote

<sup>1</sup> Susan C. Reinhard, Carol Levine, and Sarah Samis, Home Alone: Family Caregivers Providing Complex Chronic Care (Washington, DC: AARP Public Policy Institute, 2012).

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