INSIGHT on the Issues

Employed Family Caregivers Providing Complex Chronic Care

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Juggling a job and family caregiving responsibilities can be stressful, especially for those who are performing complex tasks such as managing multiple medications, caring for wounds, preparing food for special diets, using monitors, and operating specialized medical equipment. A recent national survey shows that 45 percent of employed caregivers are performing these kinds of medical/nursing tasks for family members with multiple chronic physical, cognitive, and behavioral conditions. They are doing everything that caregivers who are not employed are doing, while also carrying job-related responsibilities during their prime working years. Policies to support them in managing this balancing act will help retain workers, promote productivity, and foster economic security for families

As reported by the National Alliance for Caregiving/AARP 2009 survey, more than half (59 percent) of all family caregivers are employed full or part time. That survey also reported that family caregivers typically spend 20 hours a week caring for a family member, broadly defined, who needs help with bathing, dressing, and other kinds of personal care, as well as household tasks such as shopping and managing finances.[1] But that is only part of the picture. Many family caregivers are also performing tasks that health care professionals do—a range of medical/nursing tasks including medication management, wound care, and more—but without the training and support those professionals receive.

This *Insight on the Issues* takes a closer look into this more complete job description, which applies to many employed family caregivers. Based on further analysis of the groundbreaking research reported in *Home Alone: Family Caregivers Providing Complex Chronic Care (Home Alone)*,[2] it explores the complexity of tasks that employed caregivers provide and what policies and practices might better support them.

KEY FINDINGS

The findings are based on an analysis of *Home Alone* data comparing family caregivers who were employed with those who were not at the time of the survey in December 2011. The full report and methodology can be found at www.aarp.org/homealone or at www.uhfnyc.org/publications/880853.

A Look at Employed Caregivers

Almost half (47 percent) of the 1,677 family caregivers who were surveyed for the *Home Alone* report were employed

(Table 1). The majority (73 percent) were in their prime working years, between the ages of 35 and 64. The gender ratio was more equal than other surveys have reported: 56 percent were women and 44 percent were men. Four out of 10 (45 percent) were caring for a parent, and a similar percentage had been providing care for 3 or more years (43 percent).

Employed family caregivers had higher levels of education and income than their not-employed counterparts. Family caregivers with a bachelor's degree or higher were more likely to be employed than those with a high school or some college education; 6 out of 10 (61 percent) family caregivers with higher education were employed. Not surprisingly, the percentage of employed caregivers who reported incomes of $75,000 or higher (44 percent) was double the percentage (22 percent) of those who were not employed.

What Kinds of Care Do Employed Caregivers Provide?

The *Home Alone* study documented that family caregivers were doing much more than researchers have been describing for the past several decades. We were not surprised to find that family caregivers were helping with activities of daily living (ADLs), such as bathing, dressing, eating, moving from bed to chair, or going to the toilet. Nor were we surprised about the help they gave with instrumental activities of daily living (IADLs), such as shopping, managing personal finances, arranging for outside services, or providing transportation. But we also found that almost half (46 percent) of all family caregivers were performing medical/nursing tasks of the kind and complexity once provided only in hospitals or rehab facilities. This is a

Table 1
Caregiver Characteristics

	ALL	
	Employed	Not Employed
	N=791	N=886
Gender		
Male	44	40
Female	56	60
Age		
18–34	17	14
35–49	28	11
50–64	46	34
65–79	10	35
80+	0	5
Mean	49	57
Median	52	62
Race		
White	73	73
Black	9	11
Hispanic	10	8
Other	8	7
Marital Status		
Married	69	65
Not Married	31	35
Education		
< High School	5	12
High School	24	36
Some College	32	30
Bachelor's Degree or Higher	39	23
Household Income		
< $25K	16	29
$25–49	20	31
$50–74	21	18
$75–99	16	9
$100–124	12	6
$125+	15	7

dramatically new job description for family caregivers, which is not captured in conventional ADL/IADL measures.

Initially, we expected that there would be a difference between the extent to which employed and not employed caregivers were performing medical/nursing tasks. But we found no significant differences, even though family caregivers who were not employed were more likely to live with the person they were assisting than employed caregivers (43 percent versus 31 percent). Forty-five percent of employed family caregivers were responsible for helping with medical/nursing tasks, the most demanding types of caregiving responsibilities.

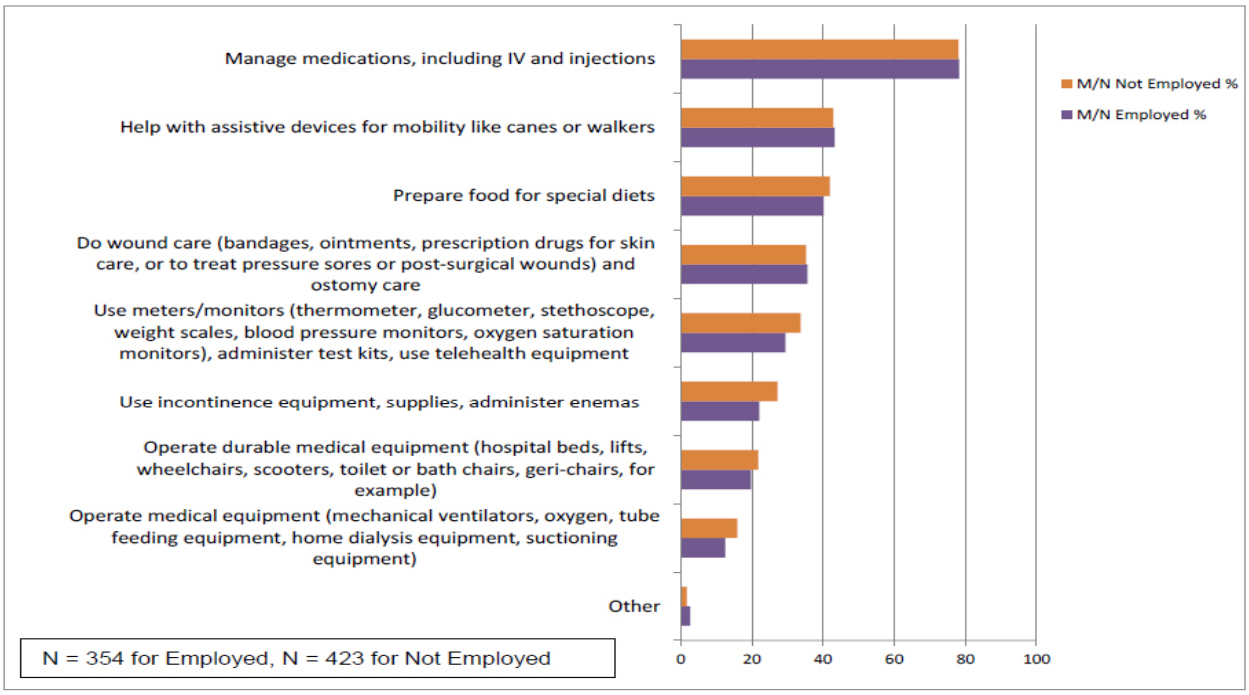
Figure 1 summarizes the categories of medical/nursing tasks and compares what employed and not employed family

Table 1 Continued

	ALL	
	Employed	Not Employed
	N=791	N=886
Relationship with Care Recipient		
Child	45	32
Other Relative	29	25
Spouse or Partner	14	26
Friend or Neighbor	13	17
Residing in Same House		
Yes	31	43
No	68	56
Length Providing Care		
< 1 year	34	31
1–2 years	24	24
3–5 years	19	21
> 5 years	24	24

Note: Numbers in this table are percentages and columns may not sum to 100 percent due to rounding.

Figure 1
Percent of Family Caregivers Performing Medical/Nursing Tasks



caregivers were providing. The patterns are quite similar. Whether employed or not, 8 out of 10 family caregivers who provided assistance with medical nursing tasks were helping with medications, including injections. Four out of 10 were helping with special diets and assistive devices for mobility. And more than a third were helping with wound care, including post-surgical wounds, pressure sores, and colostomies.

What Medical/Nursing Tasks Did Employed Family Caregivers Find Hard to Do?

Family caregivers find that some medical/nursing tasks are more difficult to do than others. When asked which two medical/nursing tasks they found the hardest to do, employed and not employed family caregivers gave similar answers. Table 2 summarizes the findings. Both groups most commonly reported that managing incontinence, performing wound care, and managing medications were difficult. Although only a small number of employed family caregivers reported operating medical equipment, such as ventilators, oxygen, tube feedings, suctioning, or dialysis, 61 percent reported that it was difficult to do, compared to 40 percent of caregivers who were not employed. The time it takes to learn this task and perform it correctly may account for this difference.

Table 2
Medical Nursing Tasks That Employed and Not Employed Family Caregivers Find Hard to Do

	Employed			Not Employed		
	# Performing Task	# Reported Hard Task	% Reported Hard Task	# Performing Task	# Reported Hard Task	% Reported Hard Task
Use incontinence equipment, supplies, administer enemas	78	51	65	115	79	69
Do wound care (bandages, ointments, prescription drugs for skin care, or to treat pressure sores or post surgical wounds) and ostomy care	126	82	65	149	99	66
Manage medications, including IV and injections	277	176	64	330	197	60
Prepare food for special diets	142	80	56	177	90	51
Operate medical equipment (mechanical ventilators, oxygen, tube feeding equipment, home dialysis equipment, suctioning equipment)	44	27	61	67	27	40
Help with assistive devices for mobility like canes or walkers	153	52	34	181	77	43
Use meters/monitors (thermometer, glucometer, stethoscope, weight scales, blood pressure monitors, oxygen saturation monitors), administer test kits, use telehealth equipment	104	43	41	142	57	40

Employed Caregivers and Complex Medication Management

Most employed caregivers who performed medical/nursing tasks managed medications (78 percent), including injections and intravenous infusions. They were managing medications for family members who take many medications. Close to two-thirds of their family members took five or more prescription medications, and 70 percent took between one and four over-the-counter drugs or supplements.

Helping to manage all of these medications can be time-consuming, a special burden for an employed caregiver. Of those who found this task to be difficult, almost half (47 percent) were managing medications at least daily. Each prescription medication may require doses several times a day, each has side effects that need to be monitored, and potential drug interactions demand careful attention. These complicated and demanding medication regimens can make balancing work and caregiving difficult. Four in 10 employed family caregivers who managed medications said that medication management was one of their two hardest medical/nursing tasks because it took too much time or was inconvenient, or both. Given that their time is limited, it is not surprising that 31 percent of employed caregivers said that having another person to help would make managing this task easier.

How prepared were these employed family caregivers for this part of their job description? Like their non-employed counterparts, most (61 percent) employed caregivers who assumed the responsibility to help with medication management learned about at least some of the medications on their own.

Wound Care Can Be Time-Consuming and Emotionally Difficult

Wound care is another complex task performed by more than a third (36 percent) of employed caregivers involved in helping with medical/nursing care. Wound care encompasses bandages, ointments, prescription drugs for skin care or to treat pressure sores or post-surgical wounds, and ostomy care. Most employed caregivers (65 percent) doing wound care found this task hard to do. Significant from both the caregiver and health care delivery viewpoints, almost half of these caregivers (46 percent) said it was difficult because they were afraid of making a mistake or causing harm.

In addition to worrying about making a mistake, close to a third of these caregivers (30 percent) found wound care hard because it was emotionally difficult. Many found it hard because, like medication management, it takes time and is inconvenient—a third reported doing wound care on a daily basis or several times a day. This impact was more pronounced for employed caregivers (39 percent) than for those who were not employed (28 percent), which is consistent with employed caregivers having less time to devote to their caregiving tasks.

Given their worries about making mistakes, it is particularly important to note that 4 out of 10 (43 percent) of employed caregivers performing wound care who found it difficult had to learn

how to do it on their own. More than a third (35 percent) reported that more training, preparation, and practice would have made wound care easier. They were also more likely than those who were not employed to say that having another person to help with wound care would ease their burden (40 percent compared to 29 percent, respectively).

Providing Complex Chronic Care is Often Not a Choice and is Stressful

When asked if they felt that they had a choice in performing difficult medical/nursing tasks, 6 out of 10 employed caregivers (57 percent) felt that they did not. Of these employed caregivers who felt they had no choice, most (67 percent) reported that they had a personal responsibility to care for their family member.

Half (50 percent) of employed caregivers performing medical/nursing tasks said they were the primary care coordinators, a critical and time-consuming function. This role was particularly challenging because their family members had multiple chronic conditions and frequently used ambulatory, emergency room, and overnight hospital care.

Employed family caregivers who performed medical/nursing tasks were more likely than those who were not employed to report that juggling the demands of caregiving with their other responsibilities caused them stress (61 percent versus 49 percent, respectively, as seen in Table 3). Indeed, those who

Table 3
Relationship between the Number of Chronic Conditions/Tasks and Quality of Life for the Employed Family Caregiver

			Employed Caregivers Only					
Variable	**Employed**		**Number of Tasks**			**# of Chronic Conditions**		
	Yes	No	1–2	3–4	5+	0–1	2–4	5+
Negative Impact								
Employment	19% **	10% **	12% **	18% **	35% **	10% **	20% **	32% **
Stress of Talking to Many	25%	21%	14% **	27% **	47% **	16% **	27% **	37% **
Worry about Making Mistakes	21%	17%	13% **	20% **	40% **	14%	23%	26%
Constantly Watching	32%	31%	19% **	41% **	53% **	24% *	35% *	41% *
Fair/Poor Health	22% **	39% **	22%	23%	22%	21%	20%	31%
Depressed in Last 2 Weeks	39%	41%	32% **	40% **	52% **	31% *	38% *	54% *
Sometimes to Always								
Feel Have No Time to Self	52%	47%	42% **	53% **	70% **	41% **	51% **	73% **
Stressed between Care and Other Responsibilities	61% **	49% **	55% **	59% **	75% **	56% *	59% *	75% *
Feel Strained	37%	32%	35%	34%	46%	24% **	38% **	59% **
Feel Uncertain	39%	37%	36%	42%	43%	38%	36%	52%

*Statistically significant differences between groups, at p< 0.05

**Statistically significant difference between groups, at p<0.01

performed five or more tasks were significantly more likely to report:

- feeling stressed from juggling caregiving and other responsibilities (75 percent);
- having no time to themselves (70 percent);
- feeling they were on constant watch (53 percent);
- being depressed in the past 2 weeks (52 percent);
- feeling stressed from talking to too many providers (47 percent); and
- worrying that they would make a mistake (40 percent).

A similar pattern emerged for employed family caregivers who are helping a family member with five or more chronic conditions. The greater the number of chronic conditions, the greater the impact on the caregiver's quality of life.

On the positive side, family caregivers who performed complex medical/nursing tasks for family members recognized the value they brought in doing this job. Half of the employed caregivers (50 percent) felt that they were helping their family member avoid nursing home placement, and an even larger share of caregivers whose family members had multiple chronic conditions reported that they helped their family member to remain at home (66 percent of employed caregivers whose family members had five or more chronic conditions).

CAREGIVING AND WORK

Employed family caregivers who performed medical/nursing tasks were twice as likely to report that their caregiving responsibilities had a negative impact on their employment. One in five employed family caregivers (19 percent) reported negative impacts, including time off from work, missed professional opportunities, and financial losses. This negative impact on employment was magnified when employed caregivers performed multiple medical nursing tasks or when they cared for family members with multiple chronic conditions. While only 12 percent of employed caregivers who performed one or two medical/nursing tasks reported a negative impact of their employment, more than a third (35 percent) of caregivers doing five or more medical/nursing tasks experienced this negative impact. Similarly, 32 percent of employed caregivers helping a family member with five or more chronic conditions reported negative employment impacts, compared to only 10 percent of caregivers whose family members had fewer chronic conditions.

This *Insight on the Issues* highlights an urgent need for employers to recognize that many of their employees are family caregivers who manage complex responsibilities at home and on the job. They are doing medical/nursing tasks at rates comparable to caregivers who are not employed. And they need support to manage both jobs.

When employed caregivers find it too difficult to balance work and family caregiving responsibilities, some make changes in their employment status that can affect their long-term economic security, especially if they feel compelled to reduce their hours or responsibilities or leave the workforce.[3]

The impact of these personal decisions can affect the economy as a whole. The *Home Alone* national survey shows that

employed family caregivers are in their prime working years, are more highly educated, and have higher incomes than family caregivers who are not employed. Replacing these experienced workers, should they leave the workforce to devote all of their time to provide complex care, would be costly to employers and damaging to the economy.

What Can Employers Do to Help?

Policies and practices are essential to help employed caregivers to continue to contribute to the workplace productively as they fulfill what they perceive as their family obligations. It is vitally important that these caregivers—many of whom are in their peak earning years—do not lose their jobs due to stereotypes that they will be less productive because of caregiving and are protected from discrimination in the workplace.[4] Offering employed caregivers flexible hours, paid sick time, and family leave can enhance employee productivity, lower absenteeism, reduce costs, and positively affect profits.[5,6] Examples of promising employer practices include educating and training supervisors and managers on the needs of caregiving employees, on-site support groups, referral to community-based caregiver resources, and discounted backup home care for emergencies.[7]

The National Alliance for Caregiving study of *Best Practices in Workplace Eldercare* identifies current trends and innovations in workplace policies and practices that support employees with eldercare responsibilities.[8] Seventeen companies are featured, including key program elements, utilization rates, evaluations, and the benefits to the employer. The findings and recommendations are helpful guides for employers seeking opportunities to better support their employees who are also family caregivers.

Employers looking for a community of similar companies who share in their interest for supporting the working caregiver can learn more about a coalition that began in 2010 known as ReACT (Respect A Caregiver's Time). This coalition is composed of corporations and organizations dedicated to addressing the challenges faced by employed caregivers.

Currently, AARP and the United Hospital Fund are seeking ways to develop more resources for family caregivers to access the training and support necessary to provide complex chronic care. Family caregivers need multimedia options, as well as hands-on training, scheduled at convenient times. As payers of health care benefits, many employers are in a position to exert influence on health care providers to play an active role in supporting family caregivers' needs for information and training on the complex tasks they are expected to perform. Exerting this influence could go a long way in helping caregivers stay on the job as productive and valued employees.

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Endnotes

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