

Family Caregivers Providing Complex Chronic Care to People with Cognitive and Behavioral Health Conditions

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Family caregiving is difficult and stressful. Providing care and support to people with cognitive or behavioral health conditions is doubly challenging. This paper reports on results from a national survey showing that caregivers of family members with challenging behaviors were more likely to perform more than one medical/nursing task, such as managing medications, and often do so with resistance from the person they are trying to help. Yet they receive little or no instruction or guidance on how to do this important work. This analysis offers recommendations for assisting family caregivers who play this dual role.

Overview

More than 5 million people in the United States are living with cognitive health issues such as Alzheimer’s disease or another form of dementia,¹ and the numbers are growing as the population ages. Behavioral health conditions are another pressing public health problem. In 2012, an estimated 9.6 million adults age 18 or older in the United States had a serious mental illness in the past year. As many as 20 percent of adults over 50 who live in the community have depression, and approximately 11 percent suffer from anxiety disorders.² Providing care for people with these conditions can be particularly challenging. Family members with cognitive or behavioral health issues may, for example, resist taking medications or reject assistance

with activities of daily life, such as bathing or eating.

A large and growing literature addresses the challenges facing family caregivers of people with cognitive or behavioral conditions. Much of it,³ however, focuses on management of the specific condition, with a nod to caregivers’ having to also take care of themselves, rather than on the special challenges of providing care for these family members.

Methodology

This *Insight on the Issues* looks broadly at the effect of cognitive impairment and behavioral health conditions on caregiving. It also examines the cumulative effect on caregivers of providing care that involves medical/nursing tasks in addition to other

caregiving responsibilities. The data are derived from a national survey of a representative sample of family caregivers conducted by the AARP Public Policy Institute and the United Hospital Fund (UHF). The full report and the methodology for the entire survey panel, *Home Alone: Family Caregivers Providing Complex Chronic Care*, can be found at <http://www.aarp.org/homealone> or at <http://www.uhfnyc.org/publications>.

In the full survey, nearly one-half (46 percent) of the 1,677 caregivers performed medical/nursing tasks (such as medication management, wound care, and monitoring of medical equipment) in addition to assisting with activities of daily living (ADLs, such as bathing and dressing) and instrumental activities of daily living (IADLs, such as shopping and transportation). Of this group, about one-half (48 percent) provided care for a family member with at least one cognitive or behavioral health condition. This analysis examines the caregiving experience of family members of people with cognitive conditions, behavioral health conditions, or both, collectively called *challenging behaviors*. The study then compares the experience of these family caregivers with that of family caregivers performing medical/nursing tasks for people without challenging behaviors.

This is the third in a series of further analyses of the *Home Alone* survey data. Two companion AARP/UHF reports compared employed and nonemployed caregivers, as well as spouses and nonspousal caregivers. These reports are available on the websites previously listed.

Key Findings

Family Caregivers of People with Challenging Behaviors

In the *Home Alone* survey, family caregivers reported whether the person

they cared for had cognitive impairments (defined as memory problems, dementia, or Alzheimer's disease) or behavioral health conditions (such as depression, anxiety, or mental illness). These caregivers were similar to caregivers of family members without challenging behaviors in age, socioeconomic status, and education level (see table 1.) For the most part, they were female (63 percent), 50 to 79 years old (63 percent), married (67 percent), and without college degrees (70 percent). One-half (51 percent) had annual incomes less than \$50,000.

Family caregivers of people with challenging behaviors were more likely to be adult children (43 percent), compared to caregivers of people without challenging behaviors (32 percent). They had also provided care for longer periods of time. About one-half (53 percent) had been caring for their family member for at least 3 years, compared to 37 percent of those caring for family members without challenging behaviors.

How Are Care Recipients with Challenging Behaviors Different?

The survey showed no major demographic differences between care recipients with challenging behaviors and those without such conditions. Care recipients in both groups tended to be female (62 percent and 56 percent, respectively) and nearly half live in the same household as the caregiver (49 percent and 46 percent, respectively). The care recipients with challenging behaviors were more likely to be older than 65 (72 percent and 66 percent, respectively).

As shown in table 2, most of the care recipients with challenging behaviors (71 percent) were cognitively impaired. Twenty-eight percent had behavioral health conditions without any cognitive impairment, 46 percent had cognitive impairment without behavioral health

Table 1
Demographics of Family Caregivers (percent)

	All MN*	All Challenging Behaviors	No Challenging Behaviors
	N = 777 (% total)	N = 374 (% total)	N = 403 (% total)
Gender			
Male	38	37	39
Female	62	63	61
Age			
18–34	14	14	14
35–49	19	21	16
50–64	40	42	38
65–79	24	21	27
80+	3	2	4
Mean	54	53	55
Median	57	55	58
Race			
White	71	71	72
Black	12	12	11
Hispanic	9	3	3
Other	8	14	13
Marital Status			
Married	68	67	69
Not married	32	33	31
Employment Status			
Employed	46	44	47
Not employed	54	56	53
Education			
< High school	10	10	9
High school	32	30	33
Some college	29	30	29
Bachelor’s degree or higher	29	29	29
Household Income			
<\$25,000	23	26	20
\$25,000–\$49,000	26	25	28
\$50,000–\$74,000	18	18	18
\$75,000–\$99,000	13	12	14
\$100,000–\$124,000	7	7	7
≥ \$125,000	12	12	12

Table 1
Demographics of Family Caregivers (percent) (continued)

	All MN*	All Challenging Behaviors	No Challenging Behaviors
	N = 777 (% total)	N = 374 (% total)	N = 403 (% total)
Relationship with Care Recipient			
Child	37	43	32
Other relative	23	23	23
Spouse or partner	28	21	34
Friend or neighbor	12	13	11
Period of Time Providing Care			
< 1 year	31	21	40
1–2 years	24	26	23
3–5 years	19	23	15
> 5 years	26	30	22

Note: BH = behavioral health. Percentages may not add up to 100 because of rounding.

* All MN refers to all caregivers who performed medical/nursing tasks.

conditions, and 26 percent had both. Depression was the most common behavioral health problem, affecting 92 percent of people with behavioral health conditions. Serious mental illness, such as schizophrenia, was less common, affecting 13 percent of care recipients with behavioral health issues.

Larger differences emerged when looking at the health of the two groups: people with challenging behaviors were generally sicker than their counterparts. Nearly 9 in 10 people with challenging behaviors also had chronic physical health diagnoses, sometimes at higher rates than those without cognitive or behavioral conditions. More than one-half (55 percent) of people with challenging behaviors had a history of stroke or hypertension, compared to 34 percent of those without those behaviors. Forty-five percent had musculoskeletal problems, such as arthritis or osteoporosis, compared to 32 percent of their counterparts. Cardiac disease affected 34 percent of those with challenging behaviors, compared to 24 percent of those

without; diabetes affected 28 percent of persons with challenging behaviors versus 22 percent of those without.

Care recipients with both cognitive and behavioral health conditions had the highest burden of illness, with the highest rates of the top four chronic conditions: stroke/hypertension (68 percent), musculoskeletal (58 percent), cardiac disease (45 percent), and diabetes (32 percent). They also had the highest rates of sensory impairment: hearing problems (41 percent) and vision problems (40 percent).

Given this high burden of illness, care recipients with both cognitive and behavioral health conditions were the most likely to use acute care services. Among those with challenging behaviors, this subgroup was the most likely to use ambulatory surgery services, to visit an emergency department, and to be admitted as an inpatient in the previous year (see table 3). Those with behavioral conditions but no cognitive impairment also had high rates of acute care use; 26 percent had at

Table 2
Care Recipients' Chronic Conditions (percent)

		All Challenging Behaviors	No Challenging Behaviors	Cognitive	BH	Cognitive + BH
		N = 374 (% total)	N = 403 (% total)	N = 171 (% total)	N = 107 (% total)	N = 96 (% total)
Physical Health	Stroke, hypertension	55	34	51	50	68
	Musculoskeletal (arthritis, osteoporosis, etc.)	45	32	40	40	58
	Cardiac disease (heart attack, angina, congestive heart failure, etc.)	34	24	29	34	45
	Diabetes	28	22	25	31	32
	Cancer	9	22	9	7	10
	Lung disease	19	13	11	20	33
	Kidney disease	9	9	9	7	11
	Movement disorder (Parkinson's, etc.)	6	3	7	4	6
	Trauma	1	4	0	3	1
	Neurological disorders (ALS, epilepsy, Epstein-Barr, etc.)	2	3	1	4	1
	Congenital conditions (CP, autism, Down, etc.)	1	2	0	3	1
	Traumatic brain injury	3	1	1	3	5
	Gastrointestinal problems	1	3	0	2	3
	Paralysis	3	2	2	6	2
	Multiple sclerosis	1	2	1	2	1
Transplant (kidney, liver, stem cell)	0	1	0	0	0	
HIV/AIDS	1	0	0	2	0	
Cognitive	Memory problems, including dementia or Alzheimer's	71	0	100	0	100
Behavioral Health	Depression or anxiety	52	0	0	92	99
	Mental illness	8	0	0	13	17
Sensory	Hearing problems	32	14	34	20	41
	Vision problems	29	15	25	28	40

Note: ALS = amyotrophic lateral sclerosis (Lou Gehrig's Disease), BH = behavioral health, CP = cerebral palsy, HIV/AIDS = human immunodeficiency virus/acquired immune deficiency syndrome.

least three emergency department visits in the previous year, a rate similar to that of care recipients with both cognitive and behavioral health conditions (27 percent). These findings are consistent with previous research showing that adults with behavioral health conditions have greater emergency department use than adults without these conditions.⁴

What Kinds of Care Do Family Caregivers Provide?

Almost all caregivers of family members with challenging behaviors—more than 96 percent—provided both medical/nursing and nonmedical support. Nearly two-thirds of these caregivers did all three types of tasks: medical/nursing,

ADLs, and IADLs. Moreover, 57 percent of these caregivers were the primary care coordinator for their family member.

Caregivers of people with challenging behaviors performed the same range of medical/nursing tasks as the full *Home Alone* survey panel, with medication management, help with assistive mobility devices, and preparation of food for special diets being the three most commonly performed. Although caregivers were more likely to assist with medication management, they were somewhat less likely to perform wound care than caregivers of those without cognitive or behavioral conditions (see table 4).

Table 3
Care Recipients' Health Service Use within the Past 12 Months (percent)

	All Challenging Behaviors N = 374 (% total)	No Challenging Behaviors N = 403 (% total)	Cognitive N = 171 (% total)	BH N = 107 (% total)	Cognitive + BH N = 96 (% total)
Ambulatory Surgery					
None	72	61	78	71	65
1	18	24	15	18	23
2	6	10	4	8	8
3+	3	5	3	3	4
Emergency Department					
None	31	30	40	26	21
1	23	27	22	19	31
2	25	21	25	28	21
3+	21	21	14	26	27
No response	0	1	0	1	0
Inpatient					
None	43	35	49	37	38
1	22	25	17	25	27
2	19	19	22	17	16
3+	16	20	12	20	20
No response	1	1	1	1	0

Note: BH = behavioral health. Percentages may not add up to 100 because of rounding.

Table 4
Family Caregivers Performing Medical/Nursing Tasks
by Cognitive and Behavioral Conditions (percent)

	All Challenging Behaviors	No Challenging Behaviors	Cognitive	BH	Cognitive + BH
	N = 374 (% total)	N = 403 (% total)	N = 171 (% total)	N = 107 (% total)	N = 96 (% total)
Manage medications, including IV and injections	84	72	86	81	85
Help with assistive devices for mobility like canes or walkers	41	44	44	29	50
Prepare food for special diets	42	40	35	45	51
Do wound care (bandages, ointments, prescription drugs for skin care, or to treat pressure sores or post-surgical wounds) and ostomy care	32	39	29	35	33
Use meters/monitors (thermometer, glucometer, stethoscope, weight scales, blood pressure monitors, oxygen saturation monitors), administer test kits, use telehealth equipment	37	27	32	30	52
Use incontinence equipment, supplies, administer enemas	29	21	31	16	41
Operate durable medical equipment (hospital beds, lifts, wheelchairs, scooters, toilet or bath chairs, geri-chairs, for example)	21	21	21	15	26
Operate medical equipment (mechanical ventilators, oxygen, tube feeding equipment, home dialysis equipment, suctioning equipment)	14	15	10	15	20

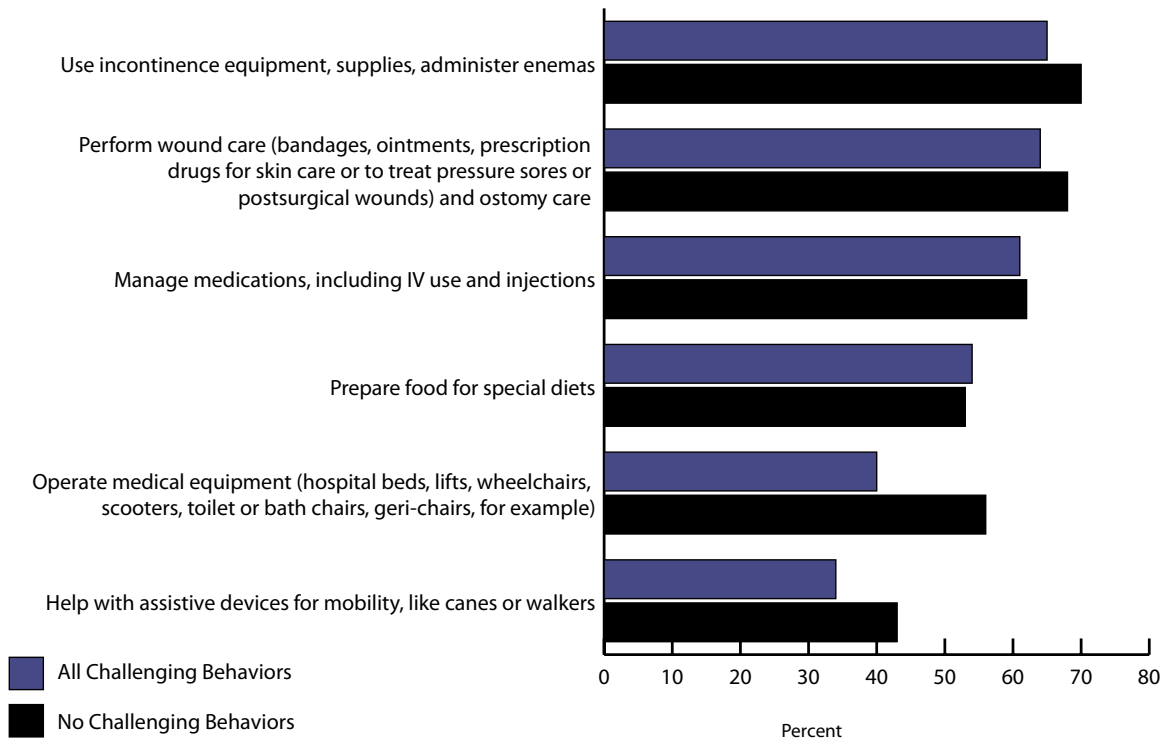
Note: BH = behavioral health.

These caregivers also were more likely to assist with more than one medical/nursing task. Close to two-thirds (65 percent) performed more than two medical/nursing tasks, compared to slightly more than one-half (53 percent) of caregivers for family members without cognitive or behavioral health conditions. And they were more likely to use meters, monitors, or telehealth equipment; and to manage incontinence. These findings are consistent with the higher rates of chronic illness and the greatest use of acute care services among care recipients with challenging behaviors.

What Medical/Nursing Tasks Did Family Caregivers Find Hard?

Family caregivers found some medical/nursing tasks harder to perform than others. When asked which two tasks they found hardest, caregivers of family members with challenging behaviors identified tasks at similar rates as caregivers of people without these conditions. More than one-half said the hardest things they did were helping with incontinence, wound care, and medications and preparing food for special diets (see figure 1).

Figure 1
Medical/Nursing Tasks That Family Caregivers Find Hard to Do

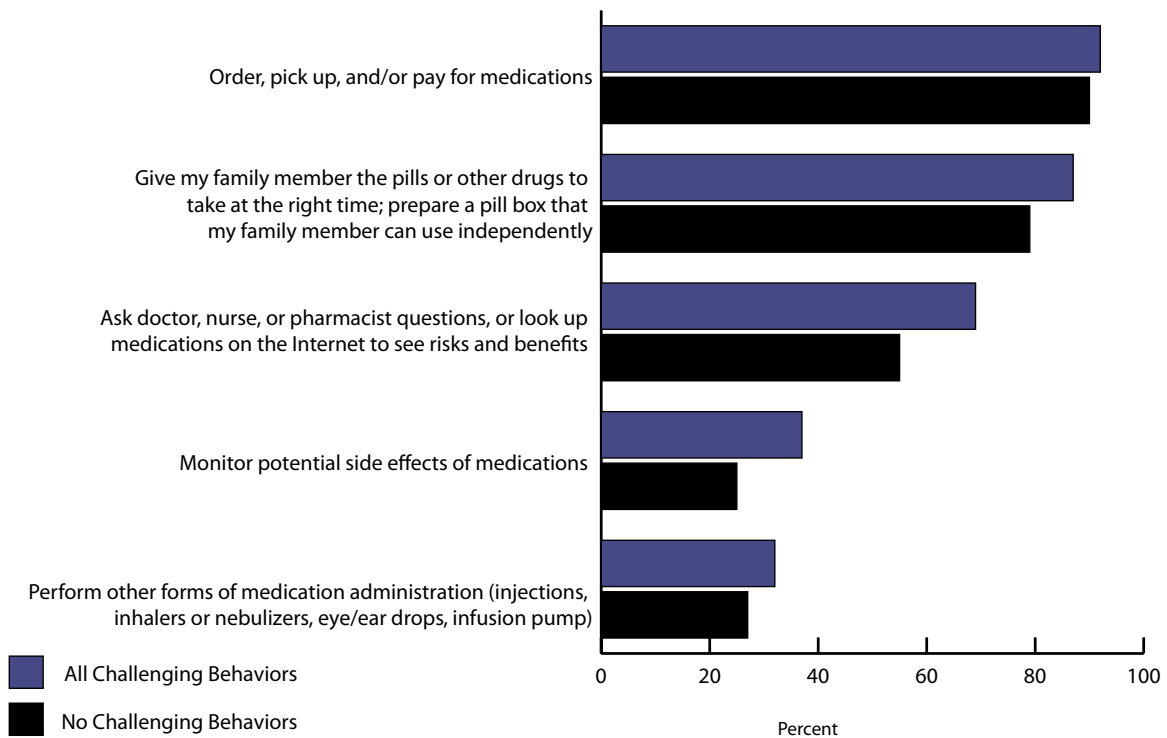


Medication Management: A Common but Difficult Task

The vast majority (84 percent) of caregivers of family members with challenging behaviors assisted with medication management, a task that may have been more challenging for them than for other caregivers, in part because it was more likely to involve administering non-pill forms of medications. These caregivers were also more likely to ask questions or look up information and to monitor their family member for potential drug side effects (see figure 2).

Those who cared for people with challenging behaviors and found medication management difficult were more than 2.5 times as likely to say that it was hard because of their family member’s lack of cooperation (34 percent, versus 13 percent for caregivers of family members without these conditions). Caregivers of people with challenging behaviors also found medication management difficult because it was time-consuming (44 percent) and because they were afraid of making a mistake or causing harm (30 percent).

**Figure 2
Caregiver Medication Tasks**



When asked what would make managing medications easier, caregivers of people with challenging behaviors were more likely to say that “more cooperation by their family member” (31 percent) or “having another person to assist” (34 percent) would be helpful, compared to caregivers of family members without these conditions (13 percent and 24 percent, respectively). Two-thirds (66 percent) of these caregivers reported that they had little or no training and learned how to administer at least some medications on their own.

Little Help at Home

Most care recipients with challenging behaviors (65 percent) did not receive home visits by health care professionals, and nearly a third (29 percent) of their caregivers did not receive any additional help from nonmedical professionals in caring for their family member at home.

Caregivers of family members with challenging behaviors were more likely to have help from a home care aide (28 percent) than those caring for family members without these conditions (19 percent). Within this group, caregivers of family members with cognitive conditions got help from home care aides at higher rates than those caring for people with only behavioral health conditions. The advanced age of care recipients with cognitive impairment may partially explain their greater use of home care aides.

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

Most caregivers of family members with challenging behaviors (60 percent) did not feel that they had a choice in performing medical/nursing tasks for their family member. These caregivers were more likely to report pressure from other family members (17 percent, compared to 9 percent for caregivers of family members without challenging

behaviors). A higher percentage of these caregivers are an adult child of the care recipient, which may mean they have more interactions with siblings and other relatives.

Caregivers of family members with challenging behaviors who performed medical/nursing tasks almost always reported higher levels of stress than caregivers of people without such behaviors who also performed medical/nursing tasks. Sixty-one percent said they “sometimes to always” felt stressed, between their caregiving responsibilities and trying to meet other work or family obligations (see figure 3). Nearly one-half (47 percent) reported feeling depressed within the past two weeks, compared to one-third (34 percent) of their counterparts (figure 4). Forty-five percent said they felt strained when around their family member, while only one-quarter of their counterparts said they felt this way. These results suggest some of the challenges of caring for a family member who may behave unpredictably or resist their caregiver’s help.

But Family Caregiving Helps People Avoid Nursing Homes

On a positive note, many family caregivers taking care of people with cognitive or behavioral health conditions reported that they believed that their efforts were valuable. Sixty percent of people caring for family members with challenging behaviors who performed medical/nursing tasks believed that their caregiving allowed their family member to avoid nursing home placement, compared to 43 percent of medical/nursing caregivers of people without these conditions. Moreover, caregivers who performed multiple medical/nursing tasks or whose family members had several chronic conditions were even more likely to say that their family caregiving activities helped keep their family member from moving to a

Figure 3
Family Caregivers' Reported Levels of Stress (percent feeling that way "sometimes to always")

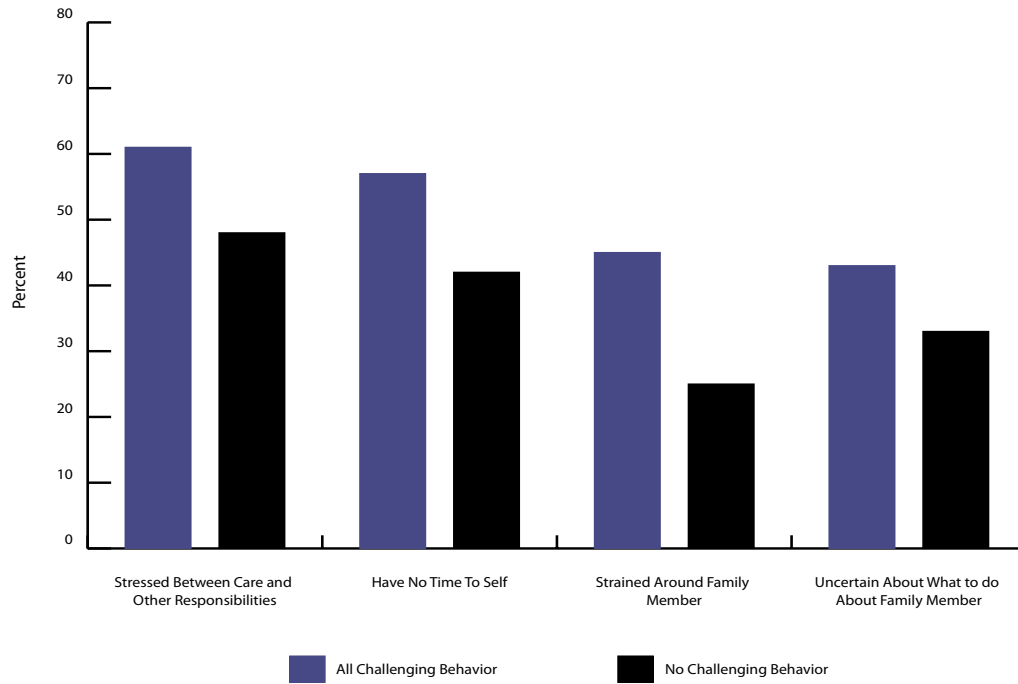
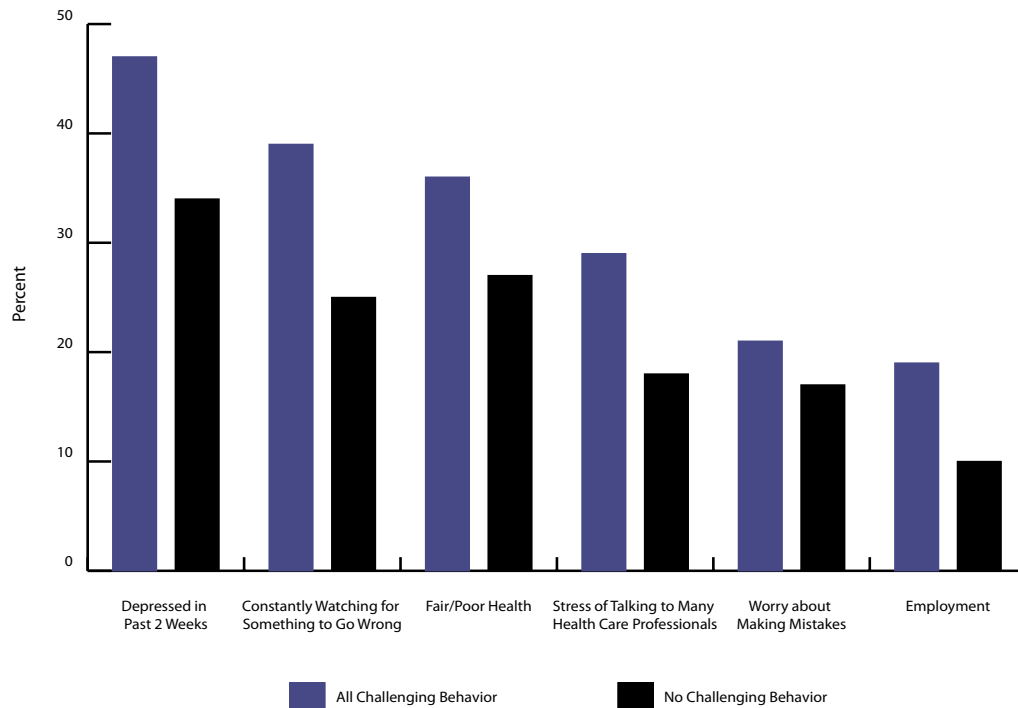


Figure 4
Negative Impacts on Family Caregivers' Quality of Life



nursing home. Nearly 8 in 10 caregivers who performed five or more medical/nursing tasks gave this response, as did nearly 7 in 10 caregivers whose family members had five or more chronic conditions.

Recommendations

Family caregivers work hard to ensure that their family members maintain dignity and independence. This analysis demonstrates that caring for a person with cognitive or behavioral health problems, or both, is especially challenging because these conditions increase the difficulty of doing not only the ordinary tasks of caregiving but also the complex medical/nursing tasks that often are required. These are tasks that all caregivers, even those whose family members do not have cognitive or behavioral health conditions, find difficult. The analysis also reveals that people with cognitive or behavioral health conditions (especially those with both) also suffer from a range of physical ailments that add to the burden of care. In addition, the findings show that caregivers of people with challenging behavioral conditions are more likely to suffer from stress.

Much more has to be done for family caregivers in these particularly difficult situations. Here are five recommendations:

- Behavioral health programs must be better integrated with medical care so that care is truly person- and family-centered.
- Programs supporting caregivers whose family members have cognitive or behavioral health conditions should include assessments that examine the impact of these conditions on the full spectrum of caregiving activities, including any medical/nursing tasks

required, as well as the health care needs of the caregivers.

- Special efforts are needed to set up respite and adult day care programs for caregivers whose family members have both complex chronic illnesses and cognitive and behavioral conditions. The programs should be tailored to the specific needs of these caregivers who may be most in need of a break but reluctant to leave their family member in the care of others.
- Family caregivers can benefit from evidence-based training that helps them understand what the sources of challenging behaviors are, how to respond to challenges appropriately, and how to maintain their own health and well-being.
- Health care providers can benefit from training in recognizing signs of cognitive impairment and behavioral conditions and guidance on working collaboratively with family caregivers when the care recipient is hospitalized.⁵
- Policy makers should ensure that educational and supportive programs related to Alzheimer's disease, behavioral health conditions, or mental illness include support and training for family caregivers on managing care of the whole person, not just the specific condition.

All caregivers need training and support; caregivers who are responsible for people with challenging behaviors are among those most in need of assistance.

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Supporting Family Caregivers, which seeks a better understanding of what family caregivers are expected to do and how health care professionals can better support them in their work.

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Endnotes

- ¹ See <http://www.cdc.gov/features/alzheimers> for more information.
- ² “Mental and Behavioral Health of Older Americans,” American Psychological Association, 2014, <https://www.apa.org/about/gr/issues/aging/mental-health.aspx>.
- ³ “Alzheimer’s Disease Facts and Figures,” Alzheimer’s Association, 2014, http://www.alz.org/downloads/Facts_Figures_2014.pdf; T. Aboulafla-Brakha, D. Suchecki, F. Gouveia-Paulino, R. Nitri, and R. Ptak, “Cognitive-Behavioural Group Therapy Improves a Psychophysiological Marker of Stress in Caregivers of Patients with Alzheimer’s Disease,” *Aging and Mental Health*, no. 18 (6): 801–08.
- ⁴ National Survey on Drug Use and Health, “Physical Health Conditions among Adults with Mental Illness,” news release, April 5, 2012, <http://www.samhsa.gov/data/2k12/NSDUH103/SR103AdultsAMI2012.pdf>.
- ⁵ See “Reducing the Stress of Hospitalization for Patients with Dementia and Their Family Caregivers: A Provider’s Guide,” Next Step in Care, http://www.nextstepincare.org/Provider_Home/Hospitalization_and_Dementia.

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