

Caregiver Specialty Registry Report 2017

What is the Caregiver Specialty Registry?

The Cancer Support Community defines a caregiver as anyone who provides physical, emotional, financial, spiritual, or even logistical support to someone affected by cancer. Many caregivers are spouses and loved ones who live with patients, others are non-family members doing paid work. Caregiving activities span a range of day-to-day and long-term tasks, depending on the patient's medical condition, including travel to doctor's appointments, help deciding on treatment options, management of finances, assistance with eating and moving about, and provision of emotional support.

Many people do not anticipate becoming caregivers, and given the immensity of the tasks required to care for a patient, find their physical and emotional health severely impacted by caregiving. The Caregiver Specialty Registry, which began accepting participants in December 2014, documents the experiences of a cross-section of people who are caring for people affected by cancer. The Caregiver Advisory Council—made up of health care providers, behavioral scientists, patient advocates, industry representatives, and caregivers—supports the efforts of the Registry by providing continued support and guidance on outreach, research, and the dissemination of findings (see a list of Advisory Council members at www.CancerSupportCommunity.org/RegistryIndexReport2017).



KEY FINDINGS

THIS REPORT CONTAINS NUMEROUS INSIGHTS INTO THE CAREGIVER EXPERIENCE. KEY FINDINGS INCLUDE:



QUALITY OF LIFE

42%

SAID THEIR HEALTH WAS SOMEWHAT TO MUCH WORSE THAN BEFORE THEY BEGAN THEIR CAREGIVER ROLE

36%

FATIGUE IS A CONSIDERABLE PROBLEM FOR OVER ONE-THIRD OF CAREGIVERS

47%

REPORT SUBSTANTIALLY WORSE ANXIETY THAN THE NATIONAL AVERAGE



TREATMENT DECISION-MAKING

47%

OF CAREGIVERS MADE DECISIONS TOGETHER WITH THE PATIENT

73%

OF CAREGIVERS ARE HEAVILY INVOLVED IN PATIENTS' TREATMENT DECISIONS



26%

OF CAREGIVERS REPORTED THAT PATIENTS MAKE DECISIONS AFTER CONSULTING WITH THEM



CAREGIVER ROLES

20%

OF CAREGIVERS REPORTED HAVING FORMAL TRAINING AS A CAREGIVER

19%

SPEND MORE THAN 100 HOURS PER WEEK ON CAREGIVING

44%

WISH THEY HAD MORE FORMAL TRAINING THAN THEY RECEIVED



CAREGIVER NEEDS

72%



WANT HELP WITH UNDERSTANDING THE PATIENT'S MEDICAL CONDITION AND TREATMENT

64%

WANT HELP WITH ACCESS TO FINANCIAL AND EMOTIONAL SUPPORT RESOURCES

49%

REPORT EXPERIENCING A SENSE OF LOSS OF CONTROL OVER THEIR OWN LIFE

Who is in the Registry?

This 2017 report presents analysis from 220 caregivers who reside in the United States and completed survey questions from the opening of the Registry in December 2014 to December 31, 2016 (in the tables below, number of responses is 220 unless otherwise noted).

<i>FIGURE 1</i> CAREGIVER REGISTRY SURVEY DEMOGRAPHICS		
	NUMBER OF PARTICIPANTS (n)	PERCENT
AGE (n = 220)		
Mean age	52.3 years, SD = 13.3	Range: 18 to 85
18-44	51	23%
45-64	130	59%
>=65	39	18%
GENDER (n = 220)		
Male	49	22%
Female	171	78%
RACE (n = 220)		
White	187	85%
NON-HISPANIC ETHNICITY (n = 220)		
	195	89%
EDUCATION (n = 220)		
High school or less	22	10%
Associate degree or some college	75	34%
Bachelor degree	55	25%
Graduate degree	64	29%
REGION (n = 185)		
Urban	37	20%
Suburban	106	57%
Rural	36	20%
EMPLOYMENT STATUS (n = 215)		
Full-time	112	52%
Part-time	23	11%
Retired	40	19%
Not employed due to disability	7	3%
Not employed (reason not specified)	33	15%
ANNUAL INCOME (n = 212)		
<\$40K	38	18%
\$40-59.9K	20	9%
\$60-79.9K	26	12%
\$80-99.9K	21	10%
\$100K+	57	27%
Prefer not to share	50	24%

FIGURE 2 CANCER STAGE, TIME SINCE DIAGNOSIS AND CANCER STATUS OF SURVEY PARTICIPANTS

	NUMBER OF PARTICIPANTS (n)	PERCENT
STAGE AT DIAGNOSIS	(n = 175)	
Stage I	3	2%
Stage II	19	11%
Stage III	22	13%
Stage IV	76	43%
I don't know	14	8%
RECURRENCE	(n = 170)	
	159	94%

What are we learning?

CAREGIVER ROLES

Some caregivers find it difficult to identify themselves as such, particularly if they are unpaid family members who live with the patient. The survey asked caregivers whether they met the Registry's definition of caregiving and 88% strongly believed they did; 75% reported that they were currently a caregiver for a person with a cancer diagnosis. Just over three-quarters (77%) lived with the person under their care. A majority of patients receiving care were male (57%); care recipients ranged in age from 5 to 89 years (average age = 57 years).

Sixty percent of caregiver respondents were caring for a spouse and 21% for a parent, for an average duration of 3.7 years (some as long as 35 years).

Significantly, 71% of caregiver respondents reported they had no choice in becoming a caregiver. Only 20% of respondents reported they had any formal training as a caregiver; of these, the largest portion (35%) received over 40 hours of formal training, mostly (57%) from a nurse; 9% received their training from a social worker. Eighty-two percent reported that their training was quite a bit or very helpful and 44% wished they had more formal training than they received.

Caregiving can encompass help with eating, drinking, and bathing; coordinating and transporting to numerous medical appointments; financial planning; and emotional support. Figure 3 shows the degree to which respondents were involved in a wide variety of tasks.

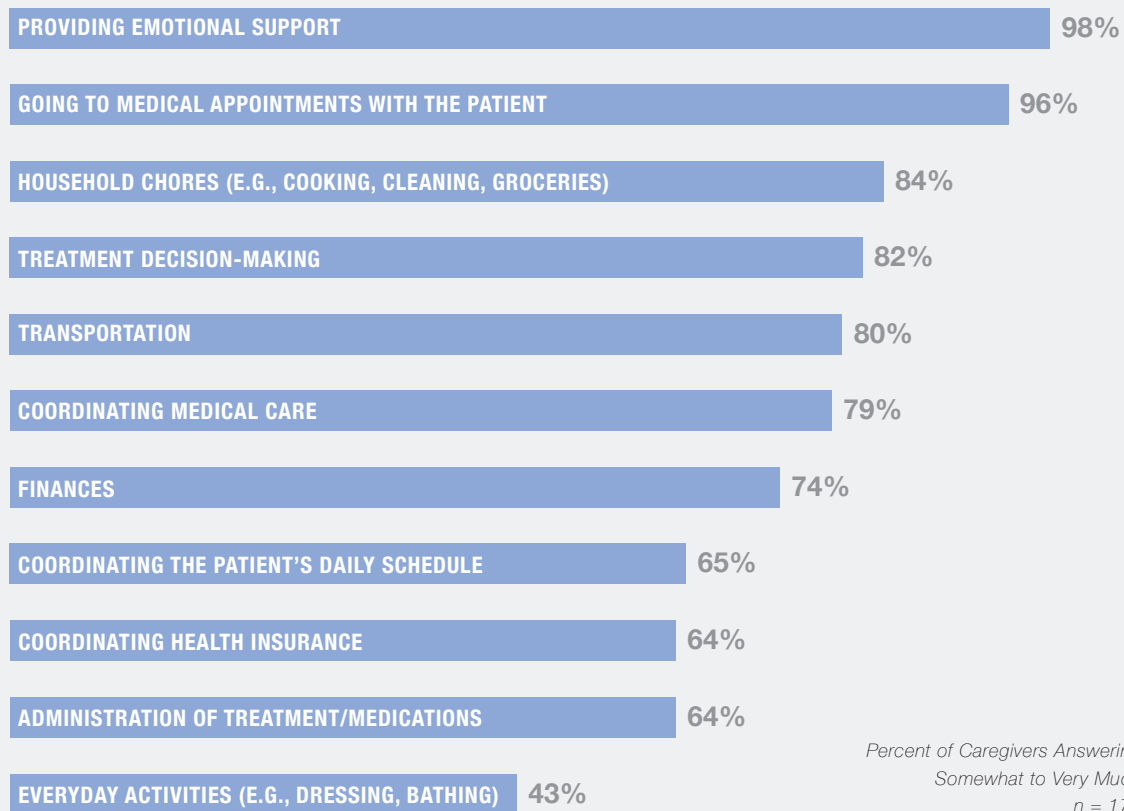
In the survey, 23% of caregivers reported spending 10 hours or less per week on caregiving, 17% spent 11-20 hours, and 20% spent between 21-40 hours. Close to one in five (19%) revealed they spent more than 100 hours per week on caregiving. It is easy to see why some caregivers get assistance to supplement their own caregiving. In fact, of respondents who answered the question, 94% said they received 10 hours or less per week of paid caregiving help and 82% reported 10 hours or less of unpaid help—mostly from family, friends, and volunteers (7% received over 40 hours per week of unpaid help). Any amount of assistance can reduce stress and allow caregivers to focus on their lives and their own self-care. While 50% reported being satisfied or very satisfied with the caregiving assistance, 18% were dissatisfied.

Figure 4 demonstrates caregivers' views about how much help was required by patients with basic self-care tasks (activities of daily living or ADLs).

PERCEPTIONS OF HEALTH

Caregiving places enormous physical and emotional demands on people who have assumed a caregiver role for a cancer patient. In order to fulfill their role effectively, caregivers need to pay attention to their own health. Self-care is essential, and a majority of caregiver respondents (61%) perceived their health to be fair to poor, and 50% perceived their health as

FIGURE 3 CAREGIVERS' ROLES IN SUPPORTING PATIENTS



worse than others (Figures 5 and 6). Twenty-three percent rated their health as either somewhat worse or much worse than a year prior to completing the survey, and 42% believed their health was somewhat to much worse than before they began their caregiver role.

QUALITY OF LIFE

As the lives of patients across the cancer spectrum become extended, more and more caregivers are contending with caregiving and its impact on quality of life.

The Caregiver Specialty Registry incorporates the PROMIS-29, which compares how respondents describe their quality of life to other U.S. population groups across different areas of life.¹ As Figure 7 illustrates, many caregivers report substantially

worse quality of life than the national average for anxiety (47% of respondents), fatigue (36%), depression (31%), social functioning (17%), and sleep disturbance (16%).

TREATMENT DECISION-MAKING AND PLANNING

One of the primary roles caregivers perform for patients is assisting with decisions about their treatment. Indeed, 73% of respondents to the caregiver survey reported either quite a bit or a lot of involvement with treatment decision-making.

Respondents also described a high degree of shared decision-making: 47% of caregivers made decisions together with the patient, 26% reported that patients make decisions after consulting with their caregiver, and only 5% indicated that patients leave all final decisions to their caregiver.

FIGURE 4 HELP NEEDED BY PATIENT WITH DAILY ACTIVITIES

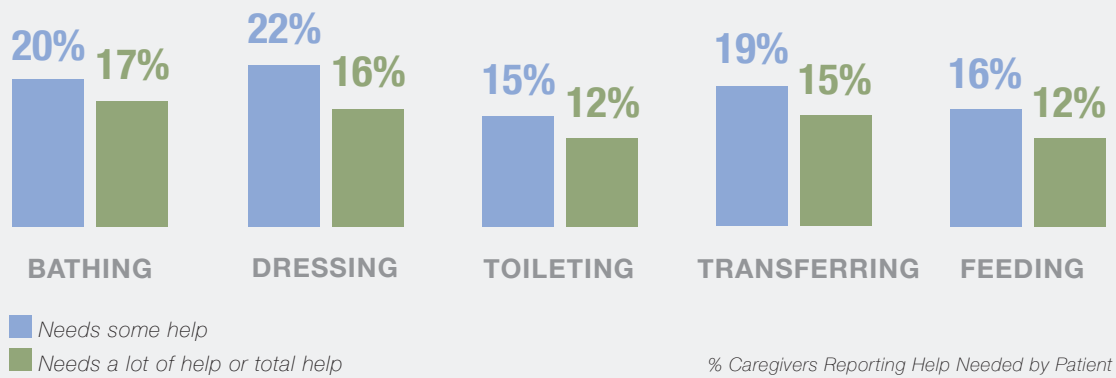
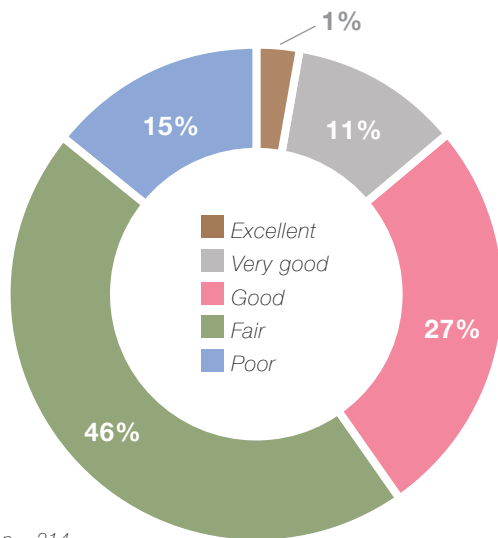


Figure 4 demonstrates caregivers' views about how much help was required by patients with basic self-care tasks (activities of daily living, or ADLs).

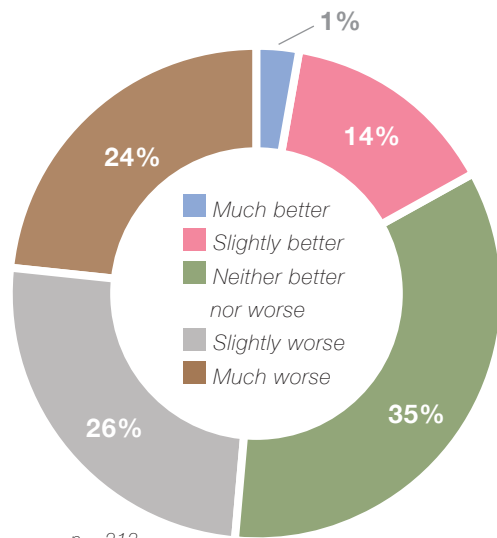
n = 172

FIGURE 5 PERCEPTIONS OF OVERALL HEALTH



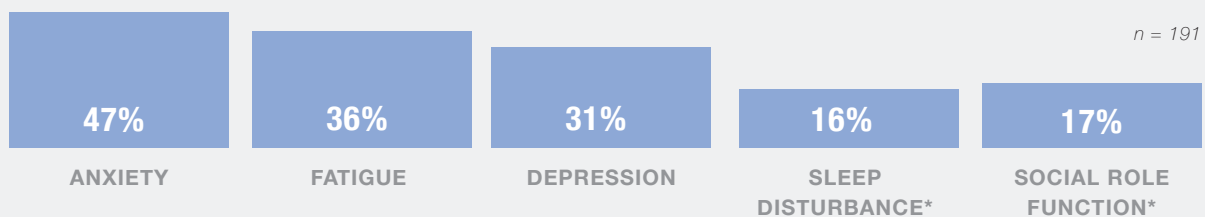
n = 214

FIGURE 6 CAREGIVER PERCEIVED HEALTH AS COMPARED TO OTHERS



n = 213

FIGURE 7 PERCENT OF CAREGIVERS REPORTING WORSE QUALITY OF LIFE



n = 191

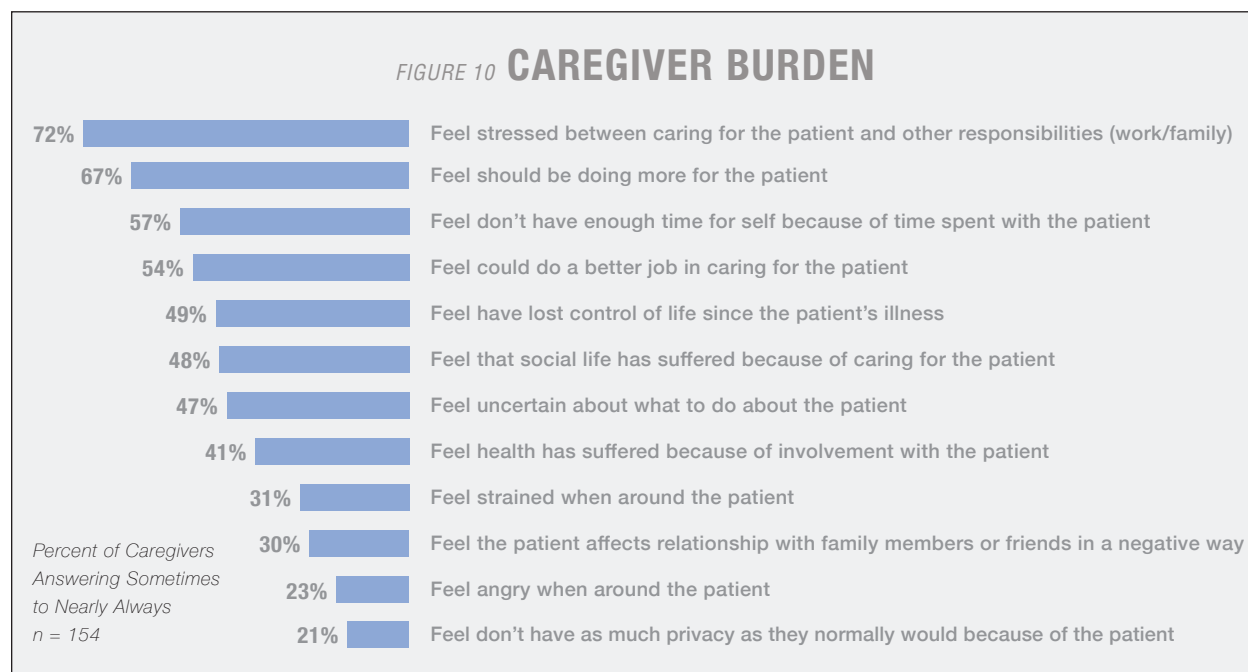
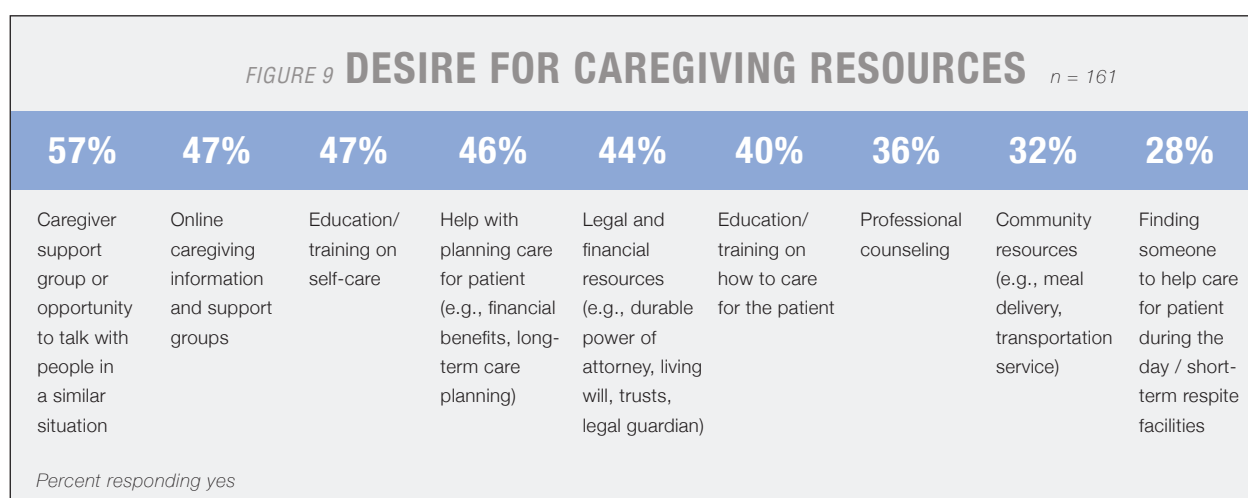
Note: All comparisons are vs. general U.S. population, except where * denotes comparison to U.S. population group balanced to include more people with chronic illness. Worse quality of life is defined as having a score that is at least 1 standard deviation poorer than the respective comparison group.

UNMET NEEDS

Many caregivers are thrust into their role unexpectedly, with little to prepare them, and feel overwhelmed at the level of assistance they need to provide to the patient. Eighty-seven percent of survey respondents believed they were somewhat to very much knowledgeable about the patient's cancer. However, the prospect of performing many caregiving tasks alone can be daunting. As Figure 8 illustrates, caregiver respondents desired support across a variety of physical, emotional, and practical aspects of life.

In particular, self-care, time management, financial matters, and understanding the patient's disease were identified as areas of elevated need for support.

In addition, Figure 9 shows how many caregiver respondents expressed a desire for support in other broad-based caregiving areas. The top requested resources included support groups where caregivers can share experiences (57%), online information and support groups (47%), training on caregiver self-care (47%), and long-term care planning and financial support (46%).



CAREGIVER BURDEN AND PREPAREDNESS

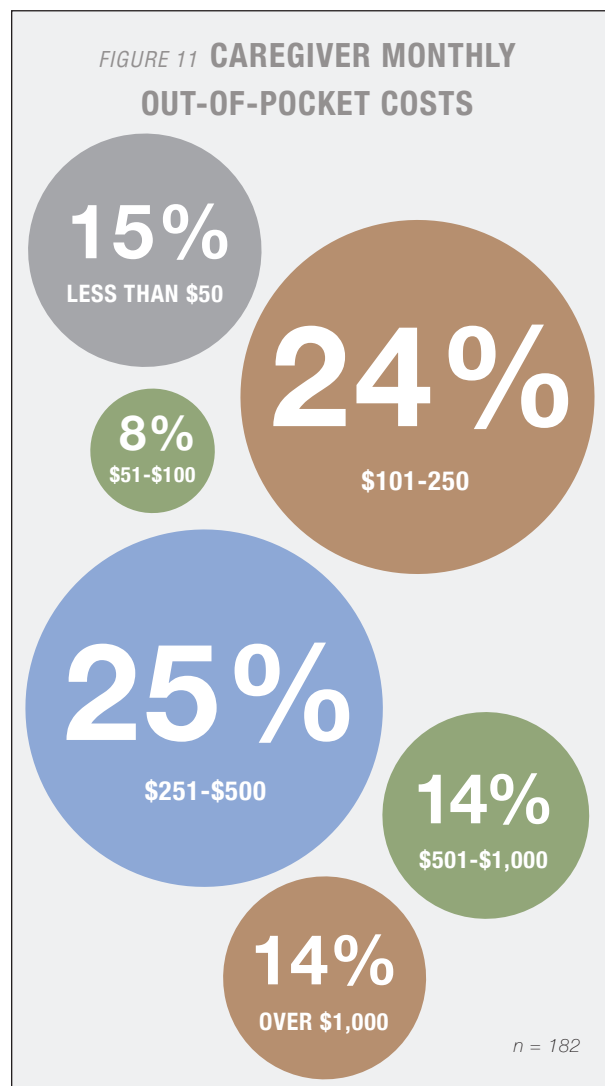
Caring for cancer patients is associated with high degrees of stress and negatively impacts the caregiver's own health, leading to poor outcomes for the entire care experience (Bevans & Sternberg, *JAMA*, 2012). Caregiver registrants reported their views about the burden associated with caregiving using the Zarit Burden Interview.² Many caregivers expressed signs of excess stress and strong feelings of inadequacy about their caregiving (Figure 10). Seventy-two percent sometimes, frequently, or nearly always felt stressed juggling their caregiving duties with other day-to-day activities. Forty-nine percent of respondents report at least sometimes experiencing a sense of loss of control over their own life. Sixty-seven percent felt at least

some of the time that they should be doing more for the patient and 53% felt they could be doing a better job at providing care.

Feelings of inadequacy can be related to a sense of unpreparedness that many caregivers experience—in terms of providing physical support, relieving stress, and accessing information. Although 74% felt they were at least somewhat prepared to take care of the patient's physical needs, and 83% at least somewhat prepared to handle emergencies, sizable portions were ill-prepared for the emotional issues of caregiving. Over one-quarter (27%) felt minimally or not at all prepared to meet the emotional needs of the patient, and over one-third (35%) felt minimally or not at all prepared about their ability to manage their own stress levels. Relatedly, 69% felt quite or very confident in their ability to provide overall care; 13% had little to no confidence in their ability to meet the patient's emotional needs.

COST OF CANCER AND CAREGIVING

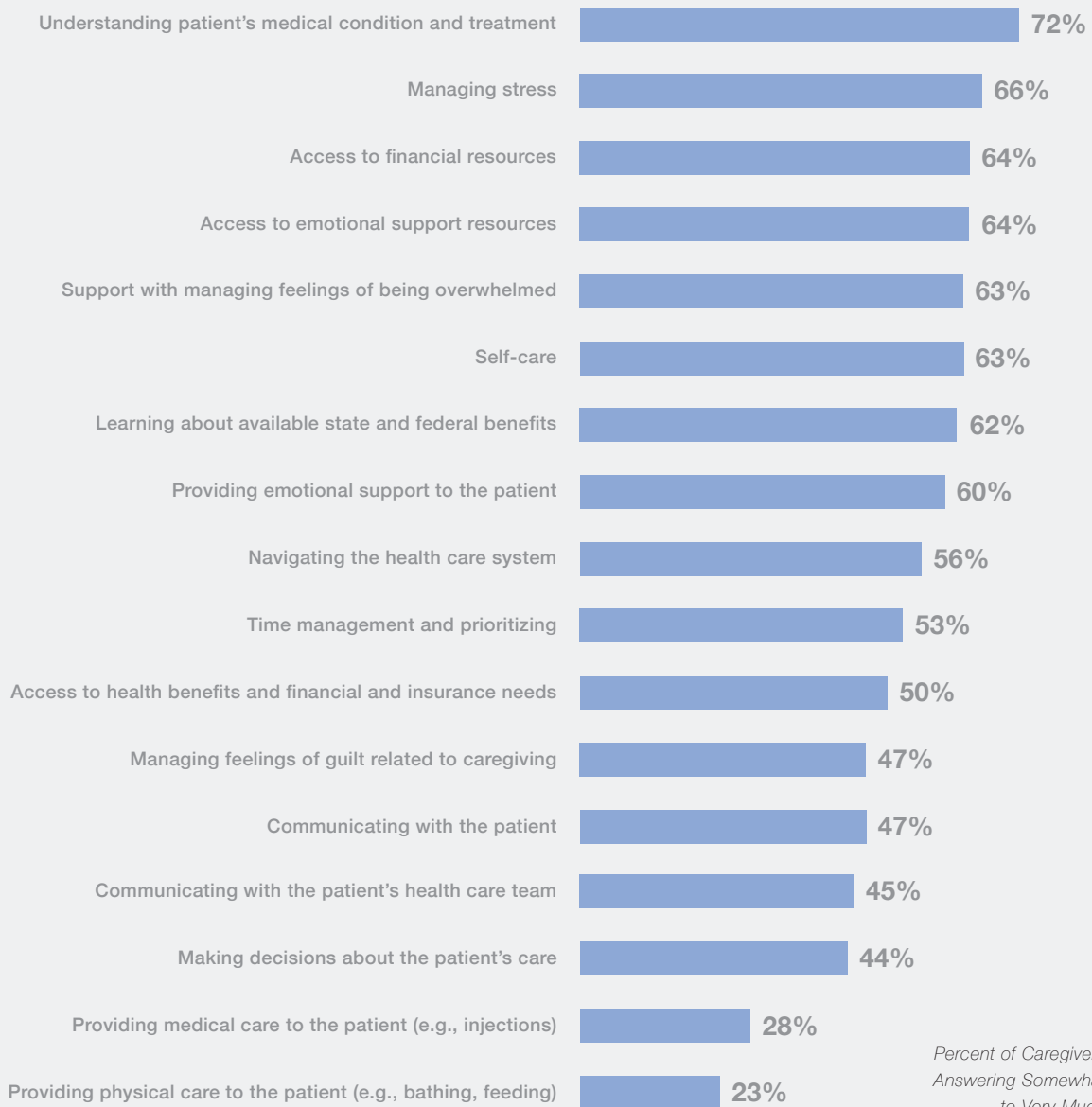
Slightly under half (41%) indicated their income had decreased or was otherwise negatively affected by their role as caregiver. Importantly, they have to allot a sizable portion of their household spending to out-of-pocket costs for co-pays for prescribed drugs, gas to transport patients to medical appointments, and other relevant caregiving expenses (Figure 11).



SILVER LININGS

On occasion, caregivers find, amidst the physical and emotional stress, positive aspects of caregiving. Ninety-two percent of respondents at least sometimes felt they were growing closer to the patient, 74% felt that they were growing closer to their family, and 92% expressed pride, at least sometimes, in caring for someone in need.

FIGURE 8 CAREGIVERS WANT HELP WITH...



Percent of Caregivers
Answering Somewhat
to Very Much
n = 164

Financial matters were a significant area of concern: 64% were hoping for at least some support in understanding the resources available to them, 62% wanted help understanding state and local benefits, and 50% needed at least some assistance managing benefits.

Learn More

For more information and to see our other specialty reports please visit:
www.cancersupportcommunity.org/RegistryIndexReport2017

- Breast Cancer Specialty Registry Report
- Chronic Lymphocytic Leukemia (CLL) Specialty Registry Report
- Chronic Myeloid Leukemia (CML) Specialty Registry Report
- General Registry Report
- Lung Cancer Specialty Registry Report
- Melanoma Specialty Registry Report
- Metastatic Breast Cancer Specialty Registry Report
- Multiple Myeloma Specialty Registry Report
- Prostate Cancer Specialty Registry Report
- Stomach Cancer Specialty Registry Report



1. Cella, D., Riley, W., Stone, A., Rothrock, N., Reeve, B., Yount, S.,...Hays, R. D. on behalf of the PROMIS Cooperative Group. (2010). Initial item banks and first wave testing of the Patient-Reported Outcomes Measurement Information System (PROMIS) network: 2005-2008. *Journal of Clinical Epidemiology*, 63(11), 1179-94.

2. Zarit, S. H., Reever, K. E., Back-Peterson, J. (1980). Relatives of the impaired elderly: correlates of feelings of burden. *The Gerontologist*, 20, 649-655

ACKNOWLEDGMENTS: The Cancer Experience Registry: Caregivers is made possible thanks to the support of Amgen Oncology (inaugural sponsor), Lilly Oncology, and Takeda Oncology.

Designed by Yolanda Cuomo Design, NYC; Photographs © Ed Cunicelli