

# CANCER CAREGIVING IN THE U.S.

*An Intense, Episodic, and Challenging Care Experience*



## ACKNOWLEDGEMENTS

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IN PARTNERSHIP WITH



# **Cancer Caregiving in the U.S.**

## **An Intense, Episodic, and Challenging Care Experience**

National Alliance for Caregiving,  
in partnership with the National Cancer Institute and the Cancer Support Community

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## Executive Summary

As medical technology and therapies have improved, more people than ever before are surviving cancer, and mortality rates from cancer over the last two decades have been in decline. Despite these advances, cancer itself and treatments can have a substantial adverse physical, emotional, and quality of life impact on individuals with cancer throughout the cancer trajectory, with some effects lasting into survivorship.<sup>1</sup> Cancer continues to pose challenges for millions of families; in fact, more than 1.6 million Americans are expected to receive a new cancer diagnosis in 2016 alone.

Though the effects of cancer most directly affect the individual with cancer, its impact extends to the relatives or friends who care for the person with cancer. Family and friends are often central in providing care or assistance in both the immediate and long-term management of cancer. Furthermore, as a result of advances in treatment and health care changes, much of cancer care is offered on an outpatient basis and is performed at home by caregivers.<sup>2</sup> Research indicates that caregiving can be both demanding and burdensome – physically, emotionally, and financially – for many cancer caregivers.<sup>3,4,5</sup>

This report analyzes the experiences of providing unpaid, informal care<sup>6</sup> in the United States to a relative or friend diagnosed with cancer, with the goal of identifying targeted and diverse approaches (programmatic and policy) to enhance the lives of cancer caregivers and, ultimately, the lives of their care recipients.

Our analyses are drawn from the nationally representative study *Caregiving in the U.S. 2015*,<sup>7</sup> and examine caregivers who indicate that cancer was the main problem or

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<sup>1</sup> The National Cancer Institute considers an individual a cancer survivor from the time of diagnosis through the balance of his/her life. Cancer survivorship is considered the time period post treatment until the end of life (<http://cancercontrol.cancer.gov/ocs/statistics/definitions.html>).

<sup>2</sup> Brédart, A., Kop, J. L., Beaudreau, A., Brito, T., Dolbeault, S., Aaronson, N., & EORTC Quality of Life Group. (2014). Quality of care in the oncology outpatient setting from patients' perspective: A systematic review of questionnaires' content and psychometric performance. *Psycho-Oncology*, 24 (4), 382 – 394.

<sup>3</sup> Northouse, L. L., Katapodi, M.C., Song, L., Zhang, L., & Mood, D.W. (2010). Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA: A Cancer Journal for Clinicians*, 60, 317 – 339.

<sup>4</sup> Kim, Y., & Schulz, R. (2008). Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health*, 20, 483 – 503.

<sup>5</sup> Romito, F., Goldzweig, G., Cormio, C., Hagedoorn, M., & Andersen, B. L. (2013). Informal caregiving for cancer patients. *Cancer*, 119, 2160 – 2169.

<sup>6</sup> Hereafter referred to as informal care. In order to qualify for this study, caregivers had to self-identify as providing unpaid care to a family member or friend. Those who were paid in some way to provide care were ineligible to complete this study.

<sup>7</sup> *Caregiving in the U.S. 2015* is a nationally-representative study of adults, conducted online in late 2014, sponsored by the National Alliance for Caregiving and AARP Public Policy Institute.

illness underlying why their family member or friend needed care.<sup>8</sup> This paper describes the experiences of these cancer caregivers (n=111) and compares these experiences to those of caregivers who provided care for some other primary reason (n=1,164).

## Key Findings

Cancer caregivers have diverse backgrounds and characteristics. Cancer caregivers tend to be women (58%), and most have less than a college degree (60%). They are 53 years old on average (4 years older than non-cancer caregivers). Most cancer caregivers provide care to a relative (88%); six out of ten cancer caregivers provide care to someone age 65 or older.

Providing care to a loved one with cancer is an episodic and intense experience. Cancer caregivers tend to provide care on a relatively short-term basis compared with non-cancer caregivers; approximately two years on average – possibly due to the care recipient passing away or their cancer going into remission and no longer needing care. Despite the shorter duration of cancer caregiving, the burden of caring for someone with cancer is high: 62% of cancer caregivers are in a high burden situation.<sup>9</sup> Cancer caregivers spend an average of 32.9 hours a week caring for their loved one, with 32% providing 41 or more hours of care weekly, the equivalent of a full-time job. Cancer caregivers more often help with Activities of Daily Living (ADLs, such as bathing, eating, toileting), Instrumental Activities of Daily Living (IADLs, such as shopping, driving, managing finances), and medical/nursing tasks than non-cancer caregivers. Alarming, 43% perform complex medical/nursing tasks without *any* prior preparation.

A majority of cancer caregivers (80%) report their care recipient had been hospitalized at least once in the past year. Most interact with various providers, agencies, and care professionals on behalf of their loved one: 82% communicate with their recipient's health providers; 76% monitor the severity of their loved one's condition; and 62% advocate on behalf of the cancer patient.

Despite this involvement, many cancer caregivers have not had conversations with care providers about their needs: just 54% have discussed their loved one's care needs with a provider, while only 29% discussed their own self-care needs. Only 15% of cancer caregivers report using respite services, even though 35% feel respite services could be

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<sup>8</sup> Cancer was selected by the caregiver as the main reason their family member or friend needed care.

<sup>9</sup> Burden of care is an index, combining hours of care and care tasks provided. For detail on calculation of burden of care index, see *Caregiving in the U.S. 2015 Full Report* ([www.caregiving.org/caregiving2015](http://www.caregiving.org/caregiving2015)).

helpful. Four in ten cancer caregivers want more help with or information about making end-of-life decisions.

Caring for a loved one with cancer has substantial emotional and financial implications. Half of cancer caregivers feel high levels of emotional stress. Four in ten cancer caregivers want more help to manage their own emotional and physical stress. In addition, 25% report high levels of financial strain as a result of their caregiving responsibilities. Employed cancer caregivers report the need for work accommodations, such as coming in late, leaving early, or taking time off to provide care (48%); going from full-time to part-time work or otherwise cutting back hours (24%); or taking a leave of absence to provide care (19%).

### **Policy Implications**

These findings suggest a need for a multifaceted approach to assist caregivers and improve health and functional outcomes that include programming, as well as policy initiatives. In particular, more work should be done to address the following gaps in the health care system and social services for family caregivers.

#### ***Health Care System Reform***

- Develop and provide training materials for caregivers, centered on conducting ADLs and managing the key IADLs that are more commonly a part of cancer caregiving.
- Develop and test evidence-based tools to provide clinicians with best practices for training caregivers on performing medical/nursing tasks, while ensuring the dual goals of enhancing 1) caregiver comprehension of complex medical/nursing tasks and 2) clinician understanding of cancer caregivers' barriers and limitations to assisting the patient with medication management, symptom monitoring, and side effects of treatment.
- Train physicians and other healthcare providers to engage with and encourage patients and their families to participate actively in shared-decision making.
- Expand investment in research on the impact of care management conducted by the caregiver, including medication management and role comprehension on patient outcomes and health care costs.
- Examine patient-caregiver-provider dynamics in the knowledge of palliative care, creating advanced directives, and decision-making about end-of-life care through research and practice.
- Implement hospital discharge rules that support family caregivers, such as the state-based C.A.R.E. (Caregiver Advise Record Enable) Act, to include ongoing engagement of the caregiver across care settings and during care transitions.

### ***Supports for Caregivers***

- Develop and test new mobile technologies, such as caregiving digital platforms and mobile applications, to help caregivers with tasks such as coordinating support and managing finances.
- Develop distress screening/assessments for caregivers with appropriate referrals to resources.
- Identify and develop respite and other evidence-based supports for caregivers that would reduce stress, such as distress screening and referral and retreats or supports, and expand access to these programs.
- Utilize and expand community-based solutions that are easily accessible and culturally adaptive.
- Identify strategies that could include public policy solutions such as Social Security credits for caregiving and tax credits for financial expenditures related to caregiving as the impact of cancer caregiving on work may have implications for the caregivers' career and ability to save for retirement.
- Collaborate with employers to increase the availability of strategies to enhance work flexibility, including paid family and medical leave, telework, and other flexible leave programs to support caregivers.

Caring for a friend or relative with cancer can be intense, episodic, and challenging. Health care reformers, medical providers, policymakers, and researchers should continue to examine ways to support cancer caregivers as a means to reduce the national burden of cancer.

## Full Report

### Introduction

Cancer remains a primary and devastating threat to the health of Americans. The lifetime probability of developing invasive cancer is estimated at 42% for men and 38% for women.<sup>10</sup> Due in large part to population growth and increased life expectancy, cancer prevalence is rising. For 2016, an estimated 1,685,210 Americans will receive a new cancer diagnosis.<sup>11</sup> Importantly, more people than ever are surviving cancer as death rates from cancer over the last two decades have been in decline. This decline in cancer mortality is reflective of increasing early detection, treatment advances, and improvements in health behaviors at the population level.<sup>12</sup>

Cancer itself and cancer treatments can cause substantial physical, emotional and quality of life effects on survivors throughout the cancer trajectory, with some effects lasting well into survivorship. Sometimes late side effects emerge months or even years after treatment concludes. The course of cancer varies as well, depending upon cancer type and stage at diagnosis. As such, some individuals with a cancer diagnosis might experience a rapid deterioration over a short period of time while for others the disease may require chronic or long-term monitoring and/or treatment. Cancer survivors also might experience a recurrence of cancer or secondary cancer in the future, or might live with the fear of a future diagnosis.<sup>13</sup>

In light of these potentially acute and chronic physical and emotional effects, relatives and friends of cancer survivors are often central in providing care or assistance in both the immediate and long-term. Furthermore, as a result of advances in treatment and health care changes, more care is offered on an outpatient basis in cancer as well as performed at home.<sup>14</sup> A growing body of literature shows that caregiving can be demanding and burdensome – physically, emotionally, and financially – for many cancer

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<sup>10</sup> Siegel, R. L., Miller, K. D., & Jemal, A. (2016). Cancer statistics, 2016. *CA: A Cancer Journal for Clinicians*, 66 (1), 7 – 30.

<sup>11</sup> American Cancer Society. (2016). *Cancer Facts & Figures 2016*. Atlanta: American Cancer Society

<sup>12</sup> Siegel, R. L., Miller, K. D., & Jemal, A. (2016). Cancer statistics, 2016. *CA: A Cancer Journal for Clinicians*, 66 (1), 7 – 30.

<sup>13</sup> Mariotto, A. B., Rowland, J. H., Ries, L. A., Scopa, S., & Feuer, E. J. (2007). Multiple cancer prevalence: a growing challenge in long-term survivorship. *Cancer Epidemiology Biomarkers and Prevention*, 16 (3), 566 – 571.

<sup>14</sup> Brédart, A., Kop, J. L., Beaudeau, A., Brito, T., Dolbeault, S., Aaronson, N., & EORTC Quality of Life Group. (2014). Quality of care in the oncology outpatient setting from patients' perspective: A systematic review of questionnaires' content and psychometric performance. *Psycho-Oncology*, 24 (4), 382 – 394.

caregivers.<sup>15,16,17</sup> Obtaining national level data on the experiences of those caring for persons diagnosed with cancer is a necessary first step toward efforts to develop targeted and diverse approaches (programmatic and policy) to enhance the lives of cancer caregivers and, ultimately, those of the recipients of their care.

This report reviews the experiences of providing unpaid, informal care<sup>18</sup> in the United States to a relative or friend diagnosed with cancer. Our analyses come from the study *Caregiving in the U.S. 2015* and examine caregivers who indicated that cancer as the main problem or illness underlying why their family member or friend needed care.<sup>19</sup> This paper describes the experiences of these cancer caregivers and compares these experiences to those of caregivers who provide care for some other primary reason.

## Methodology

*Caregiving in the U.S. 2015* is a nationally representative study of adults, age 18 or older, conducted in late 2014 using GfK's probability-based online KnowledgePanel®. *Caregiving in the U.S. 2015* aimed to achieve two goals for the National Alliance for Caregiving and AARP Public Policy Institute. First: estimate the prevalence of caregiving for someone of any age within both the U.S. population and households. Second: describe the characteristics, roles, and needs among caregivers who provide care to an adult age 18 or older.<sup>20</sup>

In order to qualify for the study, respondents must have self-identified as an unpaid caregiver of an adult either currently or at some point in the twelve months prior to the survey. Self-identified caregivers had to also report providing help with at least one Activity of Daily Living (ADL), Instrumental Activity of Daily Living (IADL), or medical/nursing task. Surveys were conducted between September 18 and November

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<sup>15</sup> Northouse, L. L., Katapodi, M.C., Song, L., Zhang, L., & Mood, D.W. (2010). Interventions with family caregivers of cancer patients: meta-analysis of randomized trials. *CA: A Cancer Journal for Clinicians*, 60, 317 – 339.

<sup>16</sup> Kim, Y., & Schulz, R. (2008). Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health*, 20, 483 – 503.

<sup>17</sup> Romito, F., Goldzweig, G., Cormio, C., Hagedoorn, M., & Andersen, B. L. (2013). Informal caregiving for cancer patients. *Cancer*, 119, 2160 – 2169.

<sup>18</sup> Hereafter referred to as informal care. In order to qualify for this study, caregivers had to self-identify as providing unpaid care to a family member or friend. Those who were paid in some way to provide care were ineligible to complete this study.

<sup>19</sup> Cancer was selected by the caregiver as the main reason their family member or friend needed care.

<sup>20</sup> To see complete study results, questionnaires, or detailed study methodology, please reference *Caregiving in the U.S. 2015* full report and Appendices A and B ([www.caregiving.org/caregiving2015](http://www.caregiving.org/caregiving2015)).

5, 2014, and averaged 24 minutes to complete (23.8 minutes online; 24.7 minutes on the phone).

This paper examines the responses of 111 caregivers who indicated that cancer was the main problem or illness underlying why their family member or friend needed care,<sup>21</sup> hereafter referred to as cancer caregivers. In this paper, we compare cancer caregivers' characteristics, experiences, and needs with those of non-cancer caregivers (those who reported providing care to an adult family member or friend for a primary reason other than cancer).<sup>22</sup> The top four primary reasons for providing care among the comparison group were: "old age"/aging/frailty (15%), Alzheimer's or dementia (9%), surgery/wounds (9%), and mobility problems (8%).

*Caregiving in the U.S. 2015* used a complex, six-part sampling design. Custom population weights were designed in order to analyze data from all 111 cancer caregivers present in all six samples of the *Caregiving in the U.S. 2015* study. Understanding the demographic characteristics of cancer caregivers in the general population is a challenge, as there are no standard population-based studies to draw upon for benchmarking data. To circumvent the lack of weighting targets, we drew upon the knowledge present in the *Caregiving in the U.S. 2015* study and developed a multi-step weighting process.

First, in order to produce targets for weighting – that is, a description of what cancer caregivers look like in the general population – a demographic profile of the 84 cancer caregivers from the base study samples was developed.<sup>23</sup> The age, race/ethnicity, and gender distributions of the sample of 84 cancer caregivers was used to create a profile of a typical caregiver of an adult whose primary need for care was cancer. Second, responses from cancer caregivers across all samples (n=111) were examined unweighted for their comparable demographic composition.<sup>24</sup> Third, responses from these 111 cancer caregivers were then weighted in a stepwise fashion (first age, then race/ethnicity, finally gender) to match the population-weighted profile of cancer

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<sup>21</sup> Cancer was selected by the caregiver as the main reason their family member or friend needed care.

<sup>22</sup> This includes 1,164 caregivers of adults who indicate that their family member or friend's main problem or illness for which he/she required care was something other than cancer. For the purposes of this paper, we refer to the comparison caregivers as non-cancer caregivers.

<sup>23</sup> Base study samples from *Caregiving in the U.S. 2015* included samples 1 through 4: 1) A general population sample; 2) An African-American targeted sample; 3) A Hispanic targeted sample; and 4) An Asian-American targeted sample. These four samples were weighted together to produce the full nationally-representative base-study results as reported throughout *Caregiving in the U.S. 2015* reporting (n=1,248 caregivers of adults).

<sup>24</sup> The three additional samples from which cancer caregivers were pulled include: 5) Targeted online sample of caregivers age 65-74; 6) Targeted online sample of caregivers age 75 or older; and 7) A targeted telephone (landline and cell phone) sample of Asian-American caregivers.

caregivers developed from the *Caregiving in the U.S. 2015* base study results. All results shown for cancer caregivers in this paper are adjusted by these custom weights.

The comparison group of non-cancer caregivers (n=1,164) is drawn from the remaining sample of participants of *Caregiving in the U.S. 2015*, and analyses of the non-cancer population utilize the population weight provided from the base study results. This includes the 1,248 base study caregivers, minus the 84 cancer caregivers present in the base study, for a total of 1,164 non-cancer caregivers.

## Reading this Report

All demographic information about the caregiver is in reference to their current situation if currently caregiving, or in reference to when they last provided care if not currently serving as a caregiver.

All figures have been weighted and rounded. In addition, "don't know" or "refused" responses are not always presented in charts and tables. For these reasons, some charts and tables will not add to 100%. The results for multiple response questions may also add to greater than 100%.

The sample sizes (*n*) shown in each table or graphic represent the unweighted number of respondents who answered each question. All results were tested for statistical significance at the 95% confidence level using the appropriate test depending on the result presented.<sup>25</sup> We only present significant differences between cancer caregivers and non-cancer caregivers in this paper. In all tables and graphs, a notation of \* shown on a result indicates the value being significantly higher than the comparison group.

## Detailed Findings

### Prevalence of Cancer Caregiving

From *Caregiving in the U.S. 2015*, it is estimated that 39.8 million Americans provide care to an adult for any reason. Approximately 7% of caregivers indicate cancer as the primary reason for providing care. This indicates that at least 2.8 million Americans were providing care to an adult family member or friend because of a primary diagnosis of cancer over the prior 12 months from the survey. Importantly, because of the increasing commonality of co-morbidity among care recipients<sup>26</sup>, the percentage of

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<sup>25</sup> Statistical testing applied to comparison of cancer caregivers and non-cancer caregivers were: Independent T-Test for Means with assumption of equal variances and Independent Z-Test for Percentages with assumption of unpooled proportions.

<sup>26</sup>Edwards, B. K., Noone, A.-M., Mariotto, A. B., Simard, E. P., Boscoe, F. P., et al. (2014). Annual report to the Nation on the status of cancer 1975-2010, featuring prevalence of comorbidity and impact on survival among persons with lung, colorectal, breast, or prostate cancer. *Cancer*, 120 (9), 1290 – 1314.

Americans providing care to individuals with cancer may be even higher if cancer was considered a secondary condition.

### Who are Cancer Caregivers?

Cancer caregivers tend to be women (58%). They are 53.1 years old, on average, about 4 years older than non-cancer caregivers (49 years old). About two in three are white non-Hispanic, six in ten have less than a college degree, and most (64%) report less than \$75,000 in household income.<sup>27</sup> Most cancer caregivers provide care to a relative (88%), commonly a parent/parent-in-law (44%), spouse or partner (16%), or sibling/sibling-in-law (14%).

Their care recipients also tend to be women (70%), with an average age of 68. It is important to consider caregiving in the cancer context for those age 65 or older given the projected increase in the US older adult population.<sup>28</sup> Indeed, cancer caregivers are significantly more likely to be caring for someone age 65 to 74 (28% vs. 18% of non-cancer caregivers), while six out of ten cancer caregivers are providing care to a recipient age 65 or older (62%).

**Figure 1: Age of Care Recipient**

	Cancer Caregiver (n=111)	Non-Cancer Caregiver (n=1,164)
18 to 49	12%	14%
50 to 64	26%	20%
65 to 74	28%*	18%
75 or older	34%	48%*
Average age	68.0	69.5
Median age	69.0	73.0
Range	38 – 94	18 – 107

When asked about their care recipient’s living situation, nearly four in ten cancer caregivers (39%) report living together with family member or friend in the same home; 45% say their loved one lives in his or her own home (and not in the same home as the cancer caregiver), 10% report the care recipient lives in someone else’s home, and the

<sup>27</sup>For full demographic profile of cancer caregivers included in this analysis, including a comparison to non-cancer caregivers, see Respondent Profile tables (Figure 14) at the end of the report.

<sup>28</sup>Parry, C., Kent, E. E., Mariotto, A. B., Alfano, C. M., Rowland, J. H. (2011). Cancer survivors: a booming population. *Cancer Epidemiology Biomarkers and Prevention*, 20 (10), 1996 – 2005.

remaining 6% report their family member or friend with cancer lives elsewhere.<sup>29</sup> Among cancer caregivers not living in the same household as their loved one, 79% visit once a week or more often.

### Cancer Caregiving: A Team Approach

Cancer caregivers often report having other ‘helpers’ around. Nearly eight in ten cancer caregivers report that their care recipient lives with some other person (78%), significantly more frequently than non-cancer caregivers (68%). Seven in ten cancer caregivers say others help provide unpaid care (69%), a significantly greater proportion than non-cancer caregivers (52%). Just 31% of cancer caregivers report being the sole caregiver – whereas 48% of non-cancer caregivers are the only unpaid caregiver.

**Figure 2: Primary Caregiver Status**

	<b>Cancer Caregiver (n=111)</b>	<b>Non-Cancer Caregiver (n=1,164)</b>
Primary caregiver	47%	64%*
Sole caregiver	31%	48%*
Provides most unpaid care among the unpaid caregivers	16%	16%
Non-primary caregiver	53%*	35%
Other caregiver provides most of the unpaid care	31%	24%
Caregiving shared equally	22%*	11%

Four in ten cancer caregivers report their loved one received some sort of paid help from aides, housekeepers, or other paid helpers (41%).

### Cancer Caregiving: Episodic and Intense

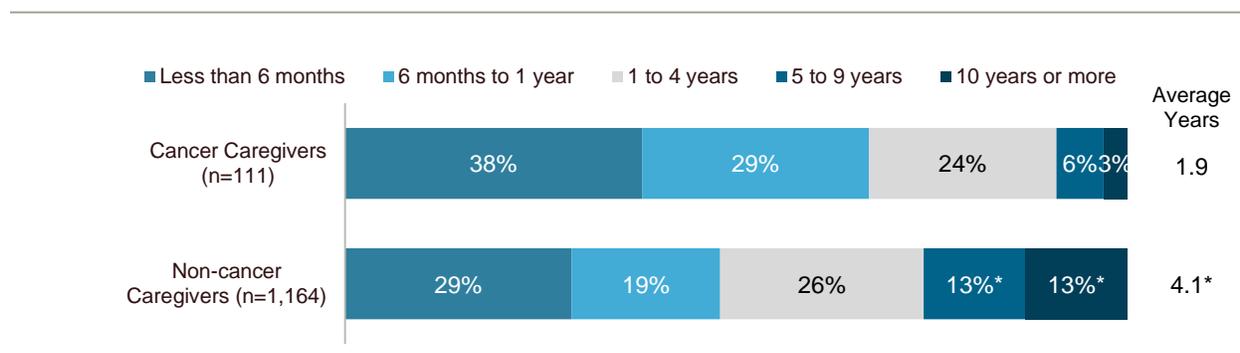
Our findings suggest that compared to non-cancer caregivers, caring for someone with cancer lasts for a shorter time (though still years-long) period, but is more intense in terms of the number of hours and tasks.

Specifically, cancer caregivers provide care on average for 1.9 years whereas non-cancer caregivers provide care for an average of 4.1 years (see Figure 3, next page).

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<sup>29</sup> Includes independent living or retirement community, assisted living facility, or nursing care or long-term care facility.

**Figure 3: Duration of Care**



Reasons for ceasing care are not examined by the survey, but one factor may be differential survival rates of care recipients with differing medical conditions. Survival rates for individuals with cancer differ widely according to cancer type and stage at diagnosis. It is plausible that care duration differs from conditions requiring longer term care, such as dementia, for a number of reasons: (1) the care recipient with cancer had more advanced disease, resulting in a shorter duration of care; (2) the care recipient survived cancer and is free from debilitating symptoms and/or treatment side effects that would otherwise require ongoing care; or (3) the caregiver may not self-identify as providing “active” care but the care recipient has moved into a maintenance/survivorship phase of cancer.

Indeed, most cancer caregivers report they have provided care in the past year but are no longer doing so (64%),<sup>30</sup> while 36% are currently providing care. Non-cancer caregivers, in contrast, have a near-opposite profile: 57% are current caregivers and 43% have provided care in the past year but are no longer doing so. This finding further reinforces the importance of considering the context of the trajectory of care. It also might indicate more role fluidity and change among cancer caregivers as compared to non-cancer caregivers, which includes survivorship-related caregiving as survivors enter a “new normal” or also possibly the phase of bereavement.

Compared to non-cancer caregivers, cancer caregivers often provide care just to the individual with cancer. Nearly all cancer caregivers provide care to just one care recipient (95%), whereas non-cancer caregivers are significantly more likely to report providing care for multiple people (81% care for one person; 19% care for two or more).

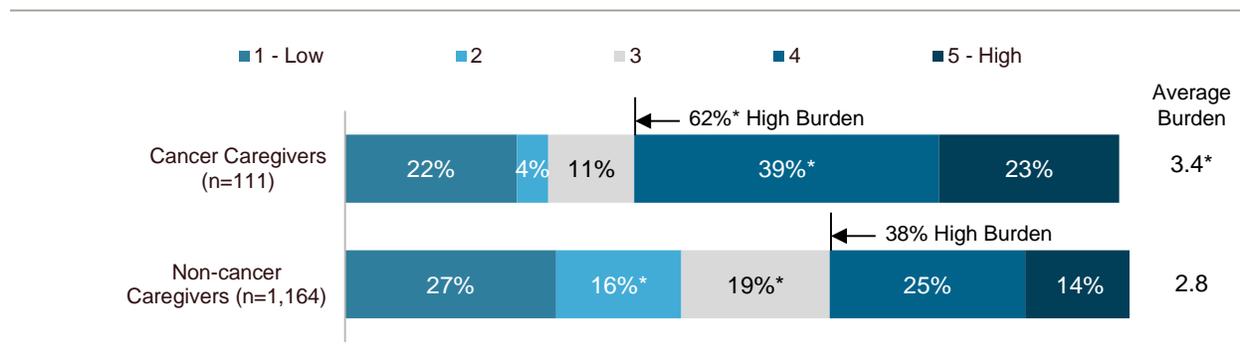
In addition to care being focused on one individual, findings also indicate that the burden of care is extremely high in the cancer context. A majority of cancer caregivers

<sup>30</sup> In the past year refers to the time period of the 12 months prior to the time of survey. Survey was administered in fall 2014.

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are in high burden situations (62%).<sup>31</sup> On average, the burden of care is significantly higher among cancer caregivers (3.4) than non-cancer caregivers (2.8).

**Figure 4: Burden of Care Index**



Cancer caregivers spend an average of 32.9 hours<sup>32</sup> a week providing care to their loved one, significantly more than non-cancer caregivers (23.9 hours). One-third (32%) of cancer caregivers provide 41 or more hours of care weekly, the equivalent of a full-time job. A significantly lower proportion of cancer caregivers also reports low hours of care (fewer than 9 hours) compared to non-cancer caregivers, which further suggests

<sup>31</sup> “Burden of care” is an index which is based on the number of hours of care provided by the caregiver, the number of Activities of Daily Living performed, and the number of Instrumental Activities of Daily Living. Points are assigned for each of these, and ultimately, these points are consolidated into three burden categories: low (values 1-2), medium (3), and high (values 4-5). See *Caregiving in the U.S. 2015* Appendix B, Detailed Methodology for the details of creating the index.

<sup>32</sup> Any caregiver who typed in hours of care in excess of 98 hours per week is capped at this level, equivalent to 14 hours per day. Caregivers who selected constant care were capped at 77 hours per week, the mean hours of care derived from an imputation model predicting hours of care provided. For more details on mean imputation, see *Caregiving in the U.S. 2015* Appendix B, Detailed Methodology.

that cancer caregiving is often intensive and, possibly, that care may not be readily replaceable by more formal or paid care, such as a direct care worker.

**Figure 5: Hours of Care per Week**

	Cancer Caregiver (n=111)	Non-Cancer Caregiver (n=1,164)
Fewer than 9 hours	32%	47%*
9 to 20 hours	24%	21%
21 to 40 hours	13%	19%
41 or more hours	32%	22%
<i>Average hours of care provided per week</i>	<b>32.9*</b>	23.9

### Activities of Care: Many and Varied

Cancer caregivers are helping their loved one with a wide variety of activities, and assisting in a significantly greater number of ways for their care recipient than non-cancer caregivers. Tasks vary from the very intimate or personal such as feeding and dressing someone, to tasks of care coordination and advocacy, to skilled tasks of administering medications and performing medical/nursing tasks.

Cancer caregivers help with more ADLs than non-cancer caregivers, which replicates findings from the Caregiving in the U.S. 2004 study.<sup>33</sup> On average, cancer caregivers help their care recipient with 2.4 ADLs out of 6 ADLs, nearly an entire task more than non-cancer caregivers help with (1.6 ADLs on average, detailed tasks presented in Figure 6). Half of cancer caregivers perform 3 or more ADLs (49% vs. 30% of non-cancer caregivers). Cancer caregivers are significantly more likely to help their loved

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<sup>33</sup> Kim, Y., Schulz, R. (2008). Family caregivers' strains: comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health*, 20, 483 – 503.

one get dressed, in and out of beds and chairs, and to and from the toilet, as well as feeding their care recipient.

**Figure 6: Help with Activities of Daily Living (ADLs)**

	Cancer Caregiver (n=111)	Non-Cancer Caregiver (n=1,164)
Get in and out of beds and chairs	57%*	42%
Get to and from the toilet	46%*	26%
Get dressed	42%*	31%
By feeding him or her	39%*	22%
Bathe or shower	35%	25%
By dealing with incontinence/diapers	24%	16%

This assistance with ADLs may be due to the often taxing/difficult nature of cancer and cancer treatment on survivors as mentioned earlier in this report. Depending upon many factors, including cancer type, disease progression or stage, and treatment type(s), survivors experience common side effects such as pain, fatigue, and mental confusion or memory loss, as well as appetite loss, all of which might adversely impact daily functioning and lead the recipient to require greater assistance.<sup>34,35,36</sup>

In addition, cancer caregivers help with 4.6 IADLs out of 7 IADLs on average, significantly more than non-cancer caregivers (4.2, see Figure 7 for detailed breakout of task performance). Cancer caregivers are significantly more likely to report giving medicines, pills, or injections, as well as arranging outside services, such as nurses,

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<sup>34</sup> Deshields, T. L., Potter, P., Olsen, S., Liu, J., & Dye, L. (2011). Documenting the symptom experience of cancer patients. *Journal of Support Oncology*, 9 (6), 216 – 223.

<sup>35</sup> Kent, E. E., Mitchell, S. A., Oakley-Girvan, I., Arora, N. K. (2014). The importance of symptom surveillance during follow-up care of leukemia, bladder, and colorectal cancer survivors. *Support Care Cancer*, 22 (1), 163 – 72.

<sup>36</sup> Burkett, V. S., Cleeland, C. S. (2007). Symptom burden in cancer survivorship. *Journal of Cancer Survival*, 1 (2), 167 – 175.

home care aides, or meals-on-wheels. Prior research has shown an increase in the number of prescription medications taken by cancer survivors.<sup>37</sup>

**Figure 7: Help with Instrumental Activities of Daily Living (IADLs)**

	<b>Cancer Caregiver (n=111)</b>	<b>Non-Cancer Caregiver (n=1,164)</b>
Transportation	<b>81%</b>	77%
Housework	<b>75%</b>	72%
Grocery or other shopping	<b>70%</b>	76%
Preparing meals	<b>68%</b>	61%
Giving medicines, pills, or injections	<b>61%*</b>	45%
Managing finances	<b>59%</b>	53%
Arranging outside services	<b>43%*</b>	30%

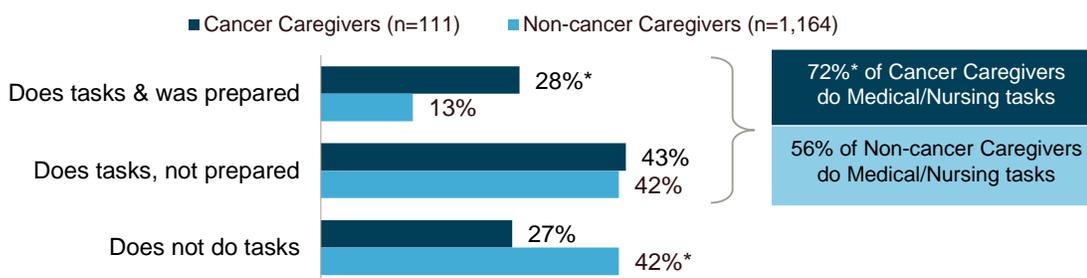
Cancer caregivers are often responsible for tasks that nurses or other medical professionals typically perform.<sup>38</sup> Our findings further support the demanding nursing or direct care tasks assumed by those providing care to persons with cancer. These "medical/nursing tasks" as they are called, include skilled activities such as administering injections, tube feedings, catheter and colostomy care, and many other complex medical responsibilities. Seven in ten cancer caregivers assist with medical/nursing tasks (72%), significantly more so than non-cancer caregivers (56%).

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<sup>37</sup> Shih, Y.-C., T., Smieliauskas, F., Geynisman, D. M., Kelly, R. J., & Smith, T. J. (2015). Trends in the cost and use of target cancer therapies for the privately insured nonelderly: 2001 to 2011. *American Society of Clinical Oncology*, 33, 2190 – 2196.

<sup>38</sup> Reinhard, S. C., Levine, C., & Samis, S. (2012) "Home Alone: Family Caregivers Providing Complex Chronic Care" AARP Public Policy Institute & United Hospital Fund.

**Figure 8: Performance of and Preparation for Doing Medical/Nursing Tasks**



While cancer caregivers are significantly more likely to report having received some sort of preparation for medical/nursing tasks than non-cancer caregivers, still many are doing so without preparation. More than four in ten (43%) are performing these complex medical/nursing tasks without *any* prior preparation. Moreover, despite cancer caregivers being significantly more likely to have received training to do medical/nursing tasks, they are no different from non-cancer caregivers in finding it difficult to do these kinds of tasks for their loved one. Among cancer caregivers who perform medical/nursing tasks, 17% find it difficult to do so (rated 4 or 5 on a 5-point scale where 5 is very difficult), similar to non-cancer caregivers (14%).

Among the few cancer caregivers who were prepared to perform these tasks, most report getting preparation from medical staff such as doctors, nurses, and counselors (80%), significantly more so than non-cancer caregivers (57%). Cancer caregivers were also prepared to do medical/nursing tasks by family or friends (27%), their own prior medical training or background (8%), a formal course or training in caregiving (6%), and prior caregiving for other people (4%).

A primary role of cancer caregivers compared to non-cancer caregivers involves interacting with various providers, agencies, and professionals on behalf of their loved one; 82% communicate with health care professionals on behalf of their care recipient, 76% monitor the severity of their loved one’s condition in order to adjust care accordingly, and 62% advocate for their recipient with health care providers, community services, and government agencies.

**Figure 9: Help with Key Activities**

	Cancer Caregiver (n=111)	Non-Cancer Caregiver (n=1,164)
Communicating with healthcare professionals (doctors, nurses, social workers) about his/her care	82%*	62%
Monitoring severity of recipient's condition to adjust care accordingly	76%*	66%
Advocating for him/her with health care providers, community services, government agencies	62%*	49%

Taken together, these findings highlight the prominent and unique role that caregivers play for cancer patients and the myriad tasks they perform: providing home and logistical support, performing medical/nursing tasks with better training, communicating with health care providers, monitoring their patient's health status, and advocating for their care.

### Caregivers and Care Transitions

Though much of cancer care is provided on an outpatient basis, cancer patients also often require hospitalization due to surgery.<sup>39,40</sup> Patients and survivors are also hospitalized for other common (and sometimes preventable) reasons, including high and insufficiently managed symptom burden.<sup>41</sup> In 2009, there were 4.7 million cancer-related hospitalizations among adults in the U.S.<sup>42</sup>

A high majority of cancer caregivers (80%) report that the care recipient has been hospitalized at least once in the past year, an event that is significantly less common among non-cancer caregivers (52%). Many cancer caregivers report being involved in care discussions during hospital stays and are significantly more likely to say they were included in all discussions with health care workers about their friend or family member's care during his/her hospitalization (73% vs. 61% non-cancer caregivers).

Yet, only 54% of cancer caregivers report having ever been asked by a health care professional what they needed to help care for the care recipient – meaning nearly half

<sup>39</sup> Brédart, A., Kop, J. L., Beaudou, A., Brito, T., Dolbeault, S., Aaronson, N., & EORTC Quality of Life Group. (2014). Quality of care in the oncology outpatient setting from patients' perspective: A systematic review of questionnaires' content and psychometric performance. *Psycho-Oncology*, 24 (4), 382 – 394.

<sup>40</sup> Siegel, R., DeSantis, C., Virgo, K., Stein, K., Mariotto, A., et al. (2012). Cancer treatment and survivorship statistics, 2012. *CA: A Cancer Journal for Clinicians*, 62 (4), 220 – 241.

<sup>41</sup> Meisenberg, B. R., Hahn, E., Binner, M., & Weng, D. (2016). ReCAP: insights into the potential preventability of oncology readmissions. *Journal of Oncology Practice*, 12 (2), 153 – 154.

<sup>42</sup> Price, R. A., Stranges, E., Elixhauser, A. (2012). *Cancer hospitalizations for adults, 2009*. HCUP Statistical Brief #125. Agency for Healthcare Research and Quality, Rockville, MD.

of cancer caregivers have not been asked about this topic, core to care decisions and support. Furthermore, very few (29%) of cancer caregivers' own self-care needs are being addressed in conversations with providers.

**Figure 10: Conversations with Care Professional**

<i>In your experience as a caregiver, have you ever had a doctor, nurse, or social worker ask you what you need/needed...</i>	<b>Cancer Caregiver (n=111)</b>	<b>Non-Cancer Caregiver (n=1,164)</b>
To help care for your recipient	<b>54%*</b>	31%
To take care of yourself	<b>29%*</b>	16%

Cancer caregivers do see value in these kinds of conversations: 41% would find it helpful to discuss needs for their care recipient, while 31% want to talk about their own self-care needs.

Additionally, cancer caregivers were asked how helpful several policy proposals might have been to their caregiving experience. The most popular policy proposals among cancer caregivers reflect a desire for clear communication and inclusion in the care team. More than half of cancer caregivers say it would be helpful to require health care providers to include their name on their care recipients' chart (55%), and 46% say it would help if hospitals or facilities were required to instruct or demonstrate how to perform medical/nursing tasks. Four in ten cancer caregivers want hospitals to inform them about major decisions, like transferring or discharging (40%).

### **The Cancer Caregiver's Well-Being**

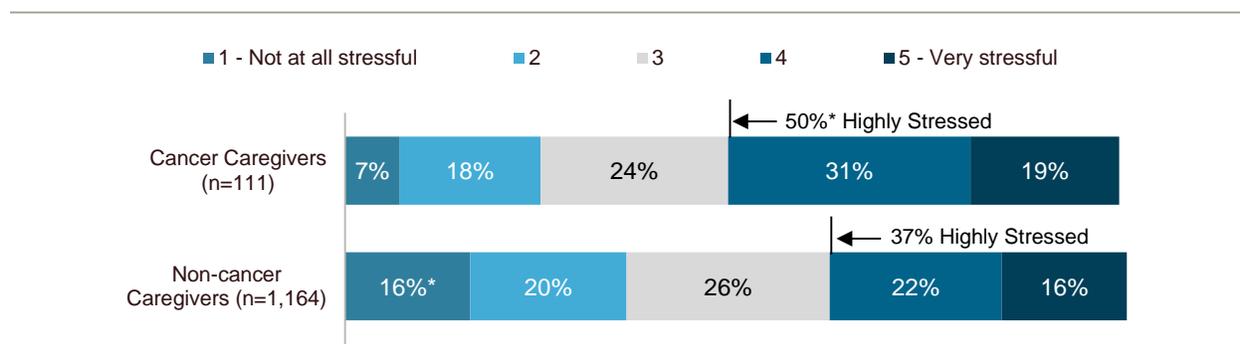
Due to the intense and demanding nature of cancer caregiving, many cancer caregivers report elevated emotional stress as a result of providing care. Half of cancer caregivers say they experience high levels of emotional stress (50% rating it 4 or 5), while non-cancer caregivers are significantly less likely to say that providing care is highly emotionally stressful (37%, see Figure 11 next page). This finding is especially important given the previous finding that only 29% report being asked about their own self-care needs. There is growing evidence that the emotional responses of cancer caregivers might have important implications for survivor outcomes, including the survivor's own emotional response.<sup>43</sup> Longitudinal findings from other work show that

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<sup>43</sup> Litzelman, K., Yabroff, K. R. (2015). How are spousal depressed mood, distress, and quality of life associated with risk of depressed mood in cancer survivors? Longitudinal findings from a national sample. *Cancer Epidemiology, Biomarkers and Prevention*, 24, 969 – 977.

spousal distress is associated with heightened risk of distress among cancer survivors.<sup>44</sup>

**Figure 11: Emotional Stress of Caregiving**



In addition to the emotional stress of caring for a loved one with cancer, a quarter of cancer caregivers report high levels of financial strain as a result of their caregiving responsibilities (25% rating 4 or 5 on a 5-point scale), comparable to non-cancer caregivers (17% high financial strain). The financial toxicity of cancer care is being increasingly recognized as survivors note strain related to the cost of cancer care.<sup>45</sup>

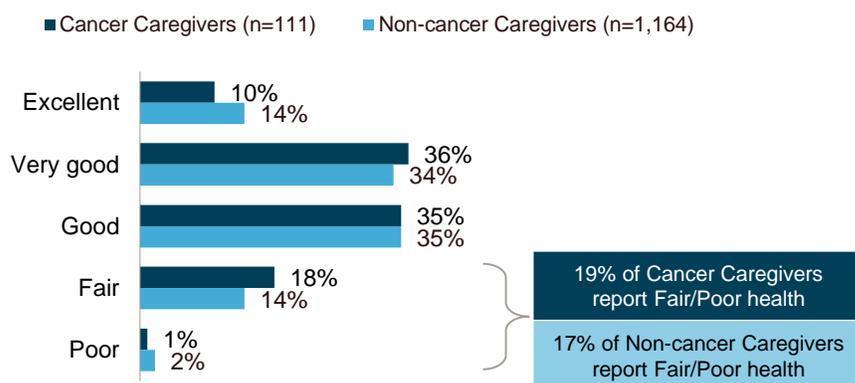
Although more than four in ten cancer caregivers consider their health *excellent* or *very good* (46%), 19% say their health is *fair* or *poor*, in line with non-cancer caregivers.<sup>46</sup>

<sup>44</sup> Milbury, K., Badr, H., Fossella, F., Pisters, K. M., & Carmack, C. L. (2013). Longitudinal associations between caregiver burden and patient and spouse distress in couples coping with lung cancer. *Supportive Care in Cancer*, 21 (9), 2371 – 2379.

<sup>45</sup> Zafar, S. Y. (2015). Financial toxicity of cancer care: it’s time to intervene. *Journal of the National Cancer Institute*, 108 (5).

<sup>46</sup> Prior research (see *Caregiving in the U.S. 2015*) has shown that caregivers, as a whole, have worse health than the general U.S. adult population. Only 10% of the U.S. adult population reports their health as fair/poor (CDC/NCHS, National Health Interview Survey, January–June 2014, Family Core component).

**Figure 12: Caregiver Health Status**



Roughly one in five feels caring for their loved one with cancer has made their own health worse (22%), although 76% say their health has not been affected. Very few cancer caregivers say their own health has improved as a result of providing care (2%), significantly fewer than the 6% of non-cancer caregivers who feel caregiving has made their health better.

About half of cancer caregivers find their caregiving tasks difficult or physically taxing. Among cancer caregivers who perform ADLs, 29% find it difficult and 22% find it moderately difficult.<sup>47</sup> Similarly, 21% of cancer caregivers report high levels of physical strain as a result of providing care (rating 4 or 5 on a 5-point scale) and 23% report moderate physical strain. A little over half (52%) of cancer caregivers said they had no choice in taking on their caregiving responsibility. Prior research has shown that caregivers’ perception of having no choice in taking on their caregiving role is related to increased levels of caregiver stress and strain.<sup>48</sup>

### Caregiver Outreach, Services, and Support

Most cancer caregivers indicate they need more help or information about at least one caregiving-related topic (84%). Perhaps not surprising, given their high levels of emotional stress (see earlier Figure 11), the top need among cancer caregivers is managing their own emotional and physical stress (43%). Cancer caregivers are significantly more likely to want to help with making end-of-life decisions (40%) than

<sup>47</sup> Cancer caregivers rated helping their care recipient with ADLs a 4 or 5 on a scale where 1 is “not at all difficult” and 5 is “very difficult”.

<sup>48</sup> Caregiving in the U.S. 2015.

non-cancer caregivers (21%). One out of three cancer caregivers would also like help keeping their loved one safe at home (33%).

**Figure 13: Caregivers Need More Help and Information**

<i>As a caregiver, on which of the following do you feel you need more help or information...</i>	<b>Cancer Caregiver (n=111)</b>	<b>Non-Cancer Caregiver (n=1,164)</b>
Managing your emotional and physical stress	<b>43%</b>	42%
Making end-of-life decisions	<b>40%*</b>	21%
Keeping care recipient safe at home	<b>33%</b>	42%
Managing his/her incontinence or toileting problems	<b>15%</b>	11%
Managing his/her challenging behaviors, such as wandering	<b>10%</b>	13%
Finding non-English language educational materials	<b>5%</b>	5%

Some cancer caregivers have sought out changes or services to help their loved one. One in three cancer caregivers has made modifications to the place where their family member or friend lives (35%). One in four have requested information about how to get financial help for their loved one (28%), and this is consistent with the finding that one in four cancer caregivers are reporting high levels of financial strain.

However, fewer than one in five cancer caregivers report having used an outside transportation service (17%) or respite service (15%). Despite very few having used respite services, 35% of cancer caregivers feel respite services might be helpful.

Cost may be a barrier to using particular services. About one in four cancer caregivers say it is difficult to get affordable services for their care recipient in their local area or community (23% rating 4 or 5 on a 5-point scale). The most popular financial support policies<sup>49</sup> among cancer caregivers are paid-care programs (28%) or income tax credits (21%). Some would like relief from the dual burden of employment and caregiving: 17% prefer a partially paid leave of absence from work. A third of cancer caregivers, however, were unsure which financial support policy they would find most helpful (34%).

Many cancer caregivers indicate a lack of long-range planning. Less than half of cancer caregivers indicate their care recipient has or had future care plans in place to handle decisions on things like living arrangements, health care decisions, or financial matters

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<sup>49</sup> Financial support policies described as: 1) a program where caregivers could be paid for at least some of the hours they provide care; 2) an income tax credit to caregivers, to help offset the cost of care; 3) a partially paid leave of absence from work, for caregivers who are employed.

(47%). Even fewer cancer caregivers have their own long-range plans in place to handle these kinds of decisions (44%).

### Caregivers in the Workplace

For the most part, cancer caregivers and non-cancer caregivers do not vary in terms of employment: they are employed at similar rates, they have similar workplace benefits, and experience similar need to make workplace accommodations. However, it seems workplace awareness of caregiving responsibilities is more common among cancer caregivers, which may follow general declines in cancer stigma over the last century.<sup>50</sup>

Half of cancer caregivers were employed at some point in the past year while providing care (50%). Employed cancer caregivers work 35.2 hours a week, on average, with 47% working part-time and 53% working full-time. One in four employed cancer caregivers is self-employed (25%).<sup>51</sup>

Cancer caregivers report similar levels of assistance and workplace benefits as non-cancer caregivers; most commonly, flexible work hours (57%) and paid sick days (48%). Caregiving responsibilities can often impact work: 63% of cancer caregivers report having to make a workplace accommodation as a result of caregiving. The most common accommodations that cancer caregivers have made include: coming in late, leaving early, or taking time off to provide care (48%); going from full-time to part-time work or otherwise cutting back hours (24%); or taking a leave of absence (19%).

Among those working for an employer, 73% of cancer caregivers say their supervisor knew of their caregiving responsibilities, significantly higher than the 55% of non-cancer caregivers who report the same. In addition, 74% of cancer caregivers favor banning workplace discrimination against workers who have caregiving responsibilities.

### Summary and Next Steps

This report profiles both the similar and unique features of caregiving for cancer patients as compared with caregiving for adults with other health problems. These findings suggest a need for a multifaceted approach to assist caregivers and improve outcomes that include programming, as well as policy initiatives. Of particular note is the intensity

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<sup>50</sup> Rowland, J. H., Kent, E. E., Forsythe, L. P., Loge, J. H., Hjorth, L., Glaser, A., Mattioli, V., & Foss, S. D. (2013). Cancer survivorship research in Europe and the United States: where have we been, where are we going, and what can we learn from each other? *Cancer*, 119, 2094 – 2108.

<sup>51</sup> In comparison, 9.4% of all U.S. workers report being self-employed. Current Population Survey, Annual Social and Economic Supplement, 2012 data, presented in Bureau of Labor Statistics Monthly Labor Review article “Female self-employment in the United States: an update to 2012” (October 2014). *Caregiving in the U.S. 2015* found higher rates of self-employment among caregivers of adults generally, so this does not seem to be an employment arrangement unique to cancer caregiving.

of cancer caregiving in terms of time and tasks, namely medical/nursing related tasks. The high stress expressed by cancer caregivers also suggest the need to provide sufficient support for these caregivers, and continue to explore how best to do this.

Key findings related to the specific characteristics, experiences, and challenges faced by cancer caregivers, along with recommendations to improve caregiving experiences linked to research, practice, and policy, are provided below.

### **Who are Cancer Caregivers?**

<b>Key Findings</b>	<b>Next Steps</b>
42% of cancer caregivers are male. 62% provide care to cancer patients age 65 and older.	Recognize the diversity of caregiver background and perspectives. Explore cultural influences on caregiving as well as differences in caring for older adults with cancer.
44% care for a parent or parent-in-law; 16% care for spouse or partner.	Understand the influence of caregiver relationship to care recipient and the competing demands of other needs (e.g., child rearing) on caregivers.

### **Caregiving Burden**

<b>Key Findings</b>	<b>Next Steps</b>
64% cared in the past year but are not currently doing so.	Study the fluidity of the cancer trajectory and explore needs and experiences throughout, including survivorship and bereavement.
62% of cancer caregivers are in high burden situations, based on the number of tasks they manage and hours of caregiving they provided	Facilitate the dissemination and implementation of evidence-based support interventions for caregivers who experience high burden and ways to prevent caregiver burnout.
Average hours of care provided weekly is 32.9 hours, with 32% providing 41 or more hours of care weekly.	Explore the implications of caregiving demand on caregivers, including impact on work, family and daily life.

### Activities of Care: Many and Varied

Key Findings	Next Steps
49% perform 3 or more ADLs. They help with 4.6 IADLs, on average.	Develop training materials and provide caregivers with instructions on how to conduct ADLs and cancer-related medical/nursing tasks. Identify the impact of new technologies (such as caregiver apps) in improving the coordination of care, management of finances, and other IADLs.
Cancer caregivers are more likely to give medicines, pills, or injections.	Understand cancer caregivers' barriers and limitations to promoting recipients' adherence to medications. Understand the caregivers' ability to monitor symptoms and side effects for treatment. Study the impact of caregiver mismanagement and/or misunderstanding of medication management in terms of care recipient outcomes and health care delivery related costs.
72% help with medical/nursing tasks. 43% do complex medical/nursing tasks without prior preparation.	Develop and test evidence-based training tools for providing caregiver information to assist with medical/nursing tasks. Explore best practices to ensure comprehension.
82% communicate with health care professionals; 76% monitor the severity of their loved one's condition; 62% advocate for their recipient.	Develop and provide training for clinicians, including physicians, nurses, oncologists, and others to engage patients and their families in care and encourage the patient and caregiver to participate in shared-decision making. Understand health system limitations for including caregivers, and explore strategies to resolve limitations.

### Care Transitions

Key Findings	Next Steps
80% say the cancer patient has been hospitalized at least once in the past year.	Explore implementation of policies like the C.A.R.E. Act and other incentives to better prepare and involve caregivers post-discharge.
54% discussed care needs for the recipient, but only 29% of discussed their own self-care needs.	Develop and test needs/distress assessment of the caregiver and appropriate referral.

### Cancer Caregiver's Well-Being

Key Findings	Next Steps
50% experience high emotional stress.	Identify, disseminate, and implement evidence-based supports for caregivers to reduce stress, including but not limited to the impact of retreats, and in-person or online support groups for cancer caregivers. Also, utilize and expand community-based solutions that are easily accessible and culturally adaptive.
25% report high financial strain as a result of caregiving.	Identify strategies to help caregivers guard against financial insecurity related to caregiving, including public policy solutions such as Social Security credits for caregiving and tax credits for financial expenditures related to caregiving.

### Caregiver Outreach, Services, and Support

Key Findings	Next Steps
15% have used respite services, but 35% say these might be helpful.	Explore respite care and approaches that would be appropriate in the cancer context.
40% want more help or information on making end-of-life decisions.	Study patient-caregiver-provider dynamics on the knowledge of and role in seeking palliative care, creating advanced directives, and decision-making about end-of-life care.
47% of care recipients have long-term plans in place, and fewer cancer caregivers have their own plans (44%).	Identify existing resources to get cancer caregivers and care recipients discussing and planning for their future care, finances, and living arrangements. Leverage existing resources available to families in advance care planning and encourage additional supports for caregivers during advanced illnesses.

### Caregivers in the Workplace

Key Findings	Next Steps
Many make workplace adjustments: coming in late, leaving early, or taking time off to provide care (48%); going from full-time to part-time work or otherwise cutting back hours (24%); or taking a leave of absence (19%).	Study the implications of work impacts particularly among subsets of caregivers and what it means for financial stability in the immediate and long-term. This includes identifying the impact of caregiving on the caregiver's retirement security and career. Explore work policies such as Family Medical Leave Act (FMLA) that can provide assistance to caregivers.

## Appendix: Respondent Profile

Figure 14 (multiple pages) provides sociodemographic characteristics of cancer and non-cancer caregivers. Most characteristics are not significantly different between cancer and non-cancer caregivers, with the exception of the care recipient and caregiver age, marital status, and education. Cancer caregivers are 53 years old, on average. About two-thirds of cancer caregivers are white non-Hispanic, 16% are Hispanic, and 11% are African-American non-Hispanic.

**Figure 14: Demographic Summary by Caregiver Type**

	<b>Cancer Caregivers (n=111)</b>	<b>Non-Cancer Caregivers (n=1,164)</b>
<b>Caregiver Gender</b>		
Male	<b>42%</b>	40%
Female	<b>58%</b>	60%
<b>Age of Caregiver</b>		
18 to 34	<b>8%</b>	25%*
35 to 49	<b>36%*</b>	23%
50 to 64	<b>31%</b>	34%
65 to 74	<b>13%</b>	12%
75 or older	<b>12%</b>	7%
<i>Mean age</i>	<b>53.1</b>	49.0
<i>Median age</i>	<b>52.0</b>	51.0
Range	<b>18 – 88</b>	18 – 90
<b>Race/Ethnicity of Caregiver</b>		
White non-Hispanic	<b>65%</b>	61%
Hispanic	<b>16%</b>	17%
African-American non-Hispanic	<b>11%</b>	13%
Asian American <sup>52</sup>	<b>8%</b>	6%
Other	<b>--</b>	3%*

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<sup>52</sup> Asian American is inclusive of those caregivers who are of Asian origin, background, or descent, including the regions of the Indian subcontinent, Far East, Southeast Asia, or Pacific Islands.

CANCER CAREGIVING IN THE U.S.

Four in ten cancer caregivers have a college or graduate degree (40%). Cancer caregivers have a median household income of \$55,500, comparable to \$53,046 for the U.S. overall.<sup>53</sup> Most are married or living with a partner, and a little over a quarter have a child or grandchild under the age of 18 living in their household.

**Demographic Summary (continued)**

	<b>Cancer Caregivers (n=111)</b>	<b>Non-Cancer Caregivers (n=1,164)</b>
<b>Caregiver Marital Status</b>		
Married	<b>62%</b>	56%
Living with a partner	<b>2%</b>	8%*
Widowed	<b>5%</b>	5%
Separated	<b>--</b>	2%*
Divorced	<b>11%</b>	8%
Single, never married	<b>17%</b>	19%
<b>Caregiver Education</b>		
Less than high school	<b>4%</b>	8%*
High school graduate	<b>33%</b>	28%
Some college	<b>17%</b>	22%
Technical school	<b>6%</b>	8%
College graduate	<b>23%</b>	20%
Graduate school	<b>17%</b>	14%
<b>Caregiver Household Income</b>		
Less than \$50,000 (net)	<b>46%</b>	47%
Less than \$15,000	<b>10%</b>	12%
\$15,000 to \$29,999	<b>12%</b>	16%
\$30,000 to \$49,999	<b>23%</b>	18%
\$50,000 or more (net)	<b>54%</b>	53%
\$50,000 to \$74,999	<b>18%</b>	18%
\$75,000 to \$99,999	<b>13%</b>	13%
\$100,000 or more	<b>23%</b>	23%
<i>Median Household Income</i>	<b>\$55,500</b>	\$54,800
<b>Children/Grandchildren in Caregiver's Household</b>		
Yes	<b>26%</b>	29%
No	<b>73%</b>	70%

<sup>53</sup> U. S. Census Bureau, American Community Survey, 2013.

CANCER CAREGIVING IN THE U.S.

Half of cancer caregivers were employed while providing care and most live in an urban/suburban setting. 11% have served on active duty in the Armed Forces and 5% self-identify as lesbian, gay, bisexual, and/or transgender.<sup>54</sup>

**Demographic Summary (continued)**

	<b>Cancer Caregivers (n=111)</b>	<b>Non-Cancer Caregivers (n=1,164)</b>
<b>Care Recipient Living Location</b>		
Urban/Suburban	<b>77%</b>	71%
Rural	<b>21%</b>	28%
<b>Caregiver Living Location</b>		
Urban/Suburban	<b>85%</b>	84%
Rural	<b>15%</b>	16%
<b>Caregiver Employment Status</b>		
Employed in past year while caregiving	<b>50%</b>	60%
Not employed	<b>50%</b>	40%
<b>Caregiver Service in Armed Forces</b>		
Ever served on active duty	<b>11%</b>	11%
Did not ever serve	<b>89%</b>	89%
<b>Care Recipient Service in Armed Forces</b>		
Ever served on active duty	<b>14%</b>	14%
Did not ever serve	<b>84%</b>	84%
<b>Caregiver LGBT status</b>		
Yes	<b>5%</b>	9%
No	<b>95%</b>	91%

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<sup>54</sup> Nationally, Gallup estimates 5.6% of Americans are LGBT. Gates, G.J. (2014) "LGBT Demographics: Comparisons among population based surveys," The Williams Institute, October.



## ABOUT THE NATIONAL ALLIANCE FOR CAREGIVING

*Established in 1996, the National Alliance for Caregiving is a non-profit coalition of national organizations focusing on advancing family caregiving through research, innovation, and advocacy. The Alliance conducts research, does policy analysis, develops national best-practice programs, and works to increase public awareness of family caregiving issues. Recognizing that family caregivers provide important societal and financial contributions toward maintaining the well-being of those they care for, the Alliance supports a network of more than 80 state and local caregiving coalitions and serves as Secretariat for the International Alliance of Carer Organizations (IACO). Learn more at [www.caregiving.org](http://www.caregiving.org).*

## ABOUT CANCER SUPPORT COMMUNITY

*As the largest professionally led nonprofit network of cancer support worldwide, the Cancer Support Community (CSC) is dedicated to ensuring that all people impacted by cancer are empowered by knowledge, strengthened by action and sustained by community. CSC achieves its mission through three areas: direct service delivery, research and advocacy. The organization includes an international network of Affiliates that offer the highest quality social and emotional support for people impacted by cancer, as well as a community of support available online and over the phone. For more information, please call the toll-free cancer support helpline at 888-793-9355, or visit [www.CancerSupportCommunity.org](http://www.CancerSupportCommunity.org).*