

Cancer Caregiving: From Research to Policy

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Agenda

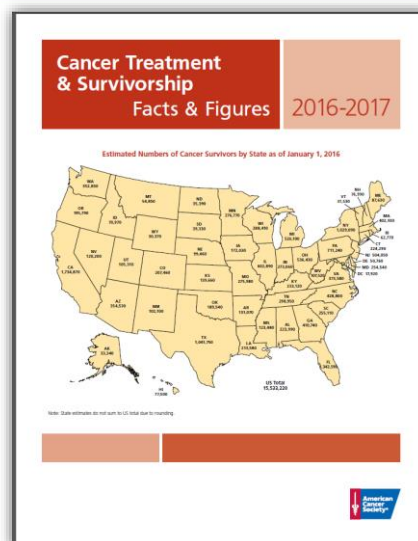
- Definition and prevalence of cancer survivorship
- Definition of a cancer caregiver
- Orientation to caregiver research at ACS
- Description of and findings from the National Quality of Life Survey for Caregivers
- Caregiver programs and services at ACS
- National reports and funding opportunities
- Caregiver-related Policy
- Q&A

Who is a Cancer Survivor?



Cancer Tx and Survivorship Facts & Figures

- > 15.5 million cancer survivors
- Includes concerns of caregivers and families
- cancer.org/statistics



Who is a Caregiver?

Unpaid loved ones who give the person with cancer physical and emotional care. They may be spouses, partners, family members, or close friends. Most often, they are not trained for the caregiver job. Many times, they may be the lifeline of the person with cancer.

(Source: American Cancer Society)



Rosalynn Carter Quote

“There are only four kinds of people in the world:

Those who have been caregivers,

Those who currently are caregivers,

Those who will be caregivers,

And those who will need caregivers.”



Caregiving in the U.S. 2015

- 44 million people in U.S.
- ~7% for cancer survivors
- 60% female
- 62% married
- 59% employed
- 66% have HS education



National Alliance for Caregiving and AARP Study
caregiving.org/caregiving2015

What do Caregivers do?

- Assume shared responsibilities for medical decisions/problem solving
- Monitor/manage symptoms, side effects, and late effects
- Provide physical, emotional, financial support
- Instrumental support (cooking, transportation)
- Serve as health advocates for the survivor
- Seek ways to return to “new normal”
- Maintain family cohesiveness

The Caregiver Profile

- Cancer impacts the entire family, including close friends
 - Emotional distress (especially guilt)
 - Physical demands
 - Activity restrictions
 - Altered job responsibilities and financial hardships
- Poorer caregiver quality of life associated with
 - Female gender
 - Younger age
 - Caring for a parent
 - Caring for the survivor as well as small children
- Positive effects
 - Post-traumatic growth/benefit-finding
 - Improved self-esteem and self-worth
 - Satisfaction with life

ACS Caregiver Research



Survivorship + Caregiver Dyadic Research

Study of Cancer Survivors-I (SCS-I)

- Longitudinal design: follows a single cohort of cancer survivors 1.5-, 2.5-, and 9-years post diagnosis
- Monitor patterns of quality of life and change over time
- Over 6,300 cancer survivors completed the baseline survey

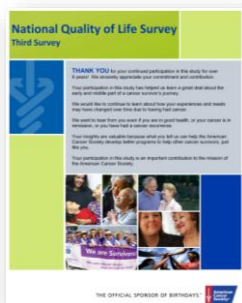


National Quality of Life Survey: Caregivers

- Longitudinal design assessing quality of life and adjustment over time
- Over 1,600 survivor-matched caregivers completed the baseline survey

Survivor + Caregiver Dyads

	Qx1	Qx2	Qx3
Survivors	6,306	5,228	3,138
Caregivers	1,635	1,108	720



Caregiver Study Demographics (n=1,635)

Age	55.09 (12.90): 18 ~ 90
Gender	65.4% female
Education: ≤ High School	28.4%
College	51.2%
> College	19.4%
Employed	72.2%
Ethnicity: African American	4.3%
Asian	0.7%
Caucasian	89.8%
Latino	2.0%
Household Income: < \$40,000	20.1%
\$40,000 ~ \$75,000	33.9%
> \$75,000	29.6%
Family Relationship: Spouse; Offspring	66.2%; 17.5%

Caregivers' Unmet Needs

Psycho-Oncology
 Psycho-Oncology 19: 573-582 (2010)
 Published online 6 July 2009 in Wiley InterScience (www.interscience.wiley.com). DOI: 10.1002/pon.1597

Needs assessment of family caregivers of cancer survivors: three cohorts comparison¹

Youngmee Kim^{1,2*}, Deborah A. Kashy³, Rachel L. Spillers³ and Tella V. Evans¹
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Cancer affects not only the quality of life (QOL) of individuals with the disease but also that of their family members and close friends. The impact on various aspects of the family caregivers' QOL is significant throughout the trajectory of the illness [1]. Caregivers' QOL may be maximized when the caregiver's needs in the context of cancer care are met. Therefore, determining what needs are not being satisfied for family caregivers should be the initial step in the development of programs designed to enhance caregivers' QOL.

Although many researchers have considered the importance of measuring caregivers' unmet needs, gaps in current literature and instruments still exist. First, several self-reported measures [2-13] and a couple of less-validated interviewing family members [14-16] have helped to identify needs of family caregivers and each of these questionnaires assesses a variety of dimensions of needs. None of them, however, includes all major dimensions of needs that have been identified in the literature: cognitive/

informational, financial/legal, medical, social/relationship, and spiritual needs (see Northouse [17] from 1973 to 1982 and Lammert, Yost, Berg, and Macintosh [18] from 1982 to 1992, for reviews).

Second, most of existing instruments were designed to measure caregivers' needs across the phases of cancer survivorship. Cancer survivorship has been categorized as having three phases [19]: (a) the acute or early phase referring to the diagnosis and treatment; (b) the extended or mid-term phase referring to the first couple of years following the diagnosis until approximately five years later, when the probability of recurrence is the greatest for most cancers; and (c) the permanent or long-term phase that extends from five years out, when the probability of recurrence decreases for most cancers.

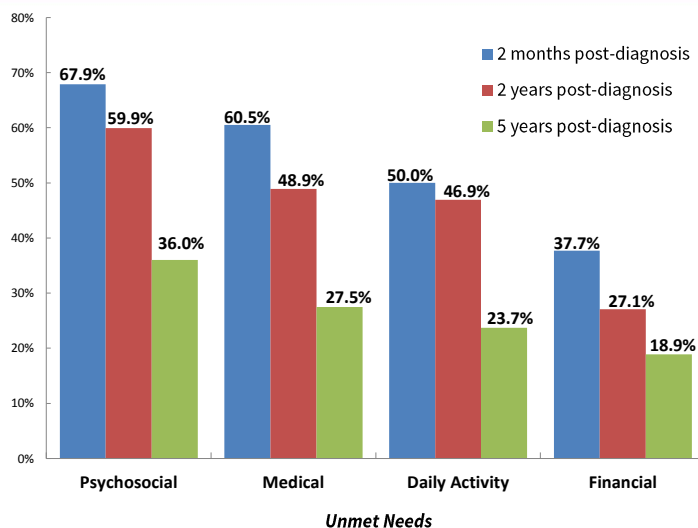
To fully understand the trajectory of caregivers' needs, these needs must be assessed using an instrument that is appropriate and comparable across the different survivorship phases.

Finally, family caregivers may have important needs that are not directly related to caring for

- **Aim:** Assess caregivers' needs at various time-points throughout the cancer trajectory

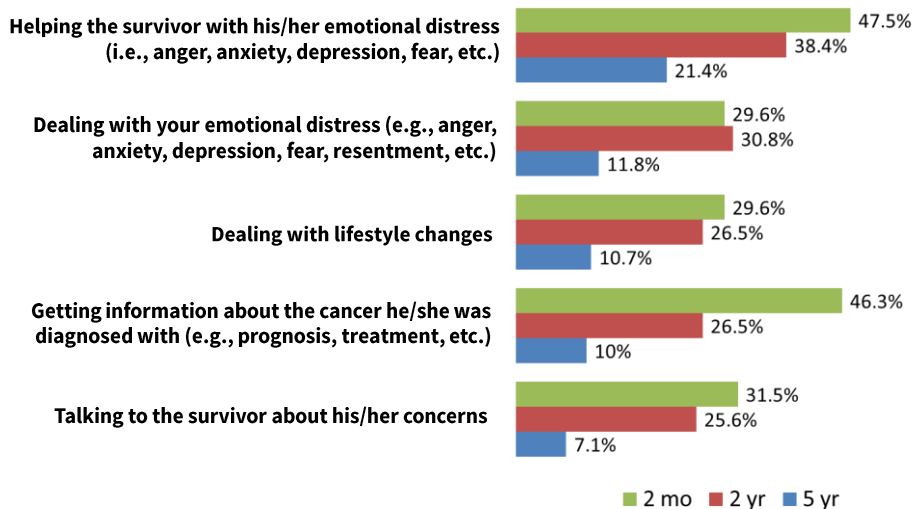
Kim, Y., Kashy, D.A., Spillers, R.L., & Evans, T.V. (2010). Needs assessment of family caregivers of cancer survivors: Three cohorts comparison. *Psycho-Oncology*, 19, 573-582.

Caregiver Unmet Needs Across Trajectory



Kim, Y., Kashy, D.A., Spillers, R.L., & Evans, T.V. (2010). Needs assessment of family caregivers of cancer survivors: Three cohorts comparison. *Psycho-Oncology*, 19, 573-582.

Caregivers' Top 5 Unmet Needs



Kim, Y., Kashy, D.A., Spillers, R.L., & Evans, T.V. (2009). Needs assessment of family caregivers of cancer survivors: Three cohorts comparison. *Psycho-Oncology*, 19, 573-582.

Predictors of Unmet Needs and QOL

- Younger age was related to various domains of unmet needs across all caregiver phases
- Ethnicity: Caucasians report higher unmet needs in the early phase and lower unmet need in the long-term phase of caregiving
- Greater psychological unmet needs consistently related to various aspects of QOL after controlling for demographic factors
- Greater financial unmet needs was related to:
 - poor physical health in the early phase of caregiving
 - poor mental and physical in the mid-phase of caregiving
 - poor mental health in the long-term phase of caregiving

Comparison of Caregivers Across Diseases

Family Caregivers' Strains

Comparative Analysis of Cancer Caregiving With Dementia, Diabetes, and Frail Elderly Caregiving

Youngmee Kim, PhD
American Cancer Society
 Richard Schulz, PhD
University of Pittsburgh

Objectives: This study aimed to investigate the impact of cancer from family caregivers' perspective, based on a comparative analysis of caregiving burden and distress, among four types of caregivers. **Methods:** The sample included caregivers of persons with cancer, dementia, diabetes, or frail elderly from a nationally representative sample of 606 caregivers. **Results:** Although the four different types of caregivers were comparable in most sociodemographic characteristics, caregiving involvement and caregiving outcomes differed among the caregiving groups. Both cancer and dementia caregivers reported greater levels of physical burden and psychological distress than other caregivers, after controlling for sociodemographic and caregiving involvement (i.e., level of burden and caregiving duration) factors. **Discussion:** The comparative analysis provided a systematic review of cancer caregiving in the context of three other types of caregiving. Given the high levels of burden and distress, greater emphasis should be placed on developing social service policy and practice for cancer caregivers.

Keywords: caregivers; cancer; dementia; diabetes; national survey; strains

The family's involvement in medical care continues to expand in response to the raising number of older individuals with chronic illness and disabilities, and changes in health care delivery such as early discharge of hospitalized patients (Edwards et al., 2002). This trend is particularly evident among family members involved in cancer care because the number of people who develop cancer each year has increased since 1973 (Ries et al., 2006), and cancer continues to be one of the leading causes of death in the United States. Close to a million and a half new cancer cases are diagnosed annually, and approximately 10.8 million Americans with a history of cancer

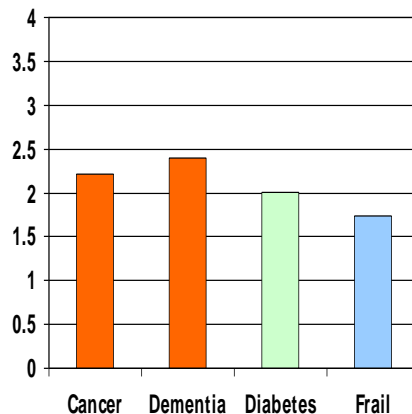
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- **Aim:** Compare burden and distress among caregivers of patients who are frail or have cancer, dementia, or diabetes

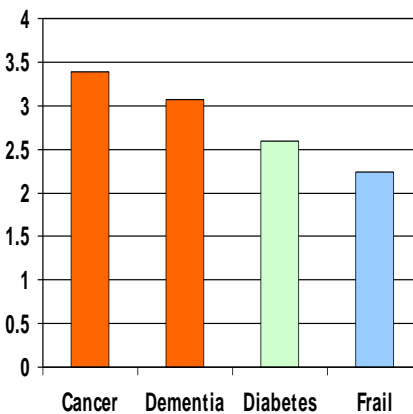
Kim, Y., & Schulz, R. (2008). Family caregivers' strains: Comparative analysis of cancer caregiving with dementia, diabetes, and frail elderly caregiving. *Journal of Aging and Health*, 20, 483-503.

Caregiver Comparison

Physical Strain



Emotional Distress



Controlling for caregiver's socio-demographic and caregiving factors.

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.

Caregiver Time Costs

Original Article

Time Costs Associated With Informal Caregiving for Cancer Survivors*

K. Robin Yabroff, PhD¹ and Youngmee Kim, PhD^{2,3}

BACKGROUND: To the authors' knowledge, little work has been done to estimate the time costs associated with informal caregiving for cancer survivors. **METHODS:** Data from a national survey of caregivers of cancer patients in 2003 to 2006 were used to estimate the time associated with informal caregiving in the 2 years after patient diagnosis with bladder, breast, colorectal, kidney, lung, melanoma of the skin, esophagus, prostate, or uterine cancer, or non-Hodgkin lymphoma (NHL). Caregivers reported the duration and daily intensity of caregiving as well as the types and frequency of support provided. The median wage rate in 2005 (\$16.26) was used to value caregiver time, and other methods to value time were evaluated with sensitivity analyses. **RESULTS:** On average, caregivers provided care for 8.3 hours per day for 15.7 months. The number of months and daily hours spent caregiving were the highest for cancer survivors diagnosed with distant disease compared with survivors with regional or localized disease ($P < .05$). Approximately half of caregivers provided emotional, instrumental, tangible, or medical support, although the frequency varied dramatically. Informal caregiver time costs over the 2-year period after diagnosis were the highest for caregivers of patients diagnosed with lung (\$72,702; 95% confidence interval [95% CI], \$56,654-\$88,530) and ovarian (\$66,290; 95% CI, \$40,790-\$99,670) cancers and NHL (\$59,635; 95% CI, \$43,423-\$75,803) and the lowest for caregivers of patients with breast cancer (\$38,354; 95% CI, \$35,442-\$45,226). **CONCLUSIONS:** Time spent by informal caregivers was substantial and was an important component of the burden of cancer care. Incorporation of the value of informal caregiver time will be important when evaluating the costs and benefits of cancer control interventions. *Cancer* 2009;115(18 suppl):4362-73. © 2009 American Cancer Society.

KEY WORDS: informal caregiving, cancer, burden of illness, time cost, economic.

In 2005, approximately 10.7 million individuals in the United States were alive with a history of cancer.¹ An additional 1.4 million cancer were diagnosed in 2006,² and the number of new cancer patients is expected to increase over time due to population changes in the United States. As a result, a large prevalence of cancer survivorship is expected in the future.^{3,4} These cancer survivors will receive medical care throughout the trajectory of their cancer experience, including the initial period after diagnosis, long-term

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The research is dedicated to the memory of Dorothy Yabroff and Haejung Kim.

Presented at the Fourth National Cancer Survivorship Research Conference entitled "Cancer Survivorship Research: Mapping the New Challenges," Atlanta, Georgia, June 10-12, 2008.

*Cancer Survivorship Research: Mapping the New Challenges, Atlanta, Georgia, September to October

Received January 15, 2009; Received April 6, 2009; Accepted May 5, 2009

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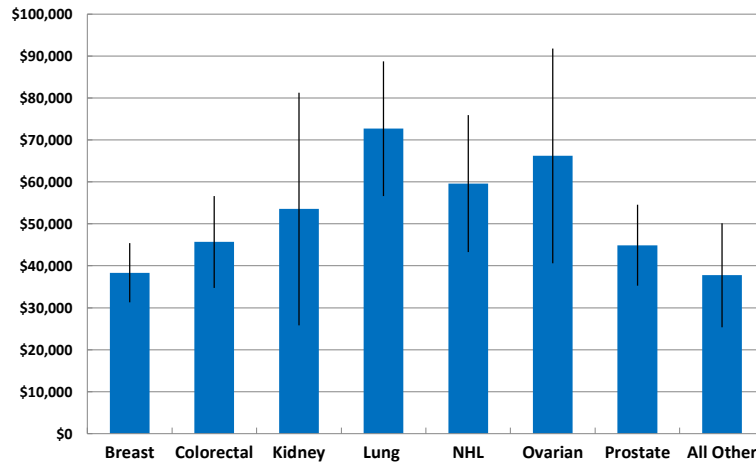
DOI: 10.1002/cncr.24039; www.interscience.wiley.com

CANCER September 15, 2009

- **Aim:** Estimate time costs separately for informal caregivers of patients diagnosed with 1 of 10 most common cancers

Yabroff, K. R., & Kim, Y. (2009). Time costs associated with informal caregiving for cancer patients. *Cancer*, 115 (18 suppl), 4362-4373.

Value of Caregiver Time 2-ys Post-Dx



NHL: Non-Hodgkin lymphoma. All Other includes survivors with bladder, melanoma of the skin, and uterine cancers.
Bars represent cost estimates and lines represent 95% confidence intervals.

Yabroff, K. R., & Kim, Y. (2009). Time costs associated with informal caregiving for cancer patients. *Cancer*, 115 (18 suppl), 4362-4373.

Long-term Physical Impairments

Original Article

Cancer Caregiving Predicts Physical Impairments: Roles of Earlier Caregiving Stress and Being a Spousal Caregiver

Yongmei Kim, PhD¹; Charles S. Carver, PhD²; Kelly M. Shaffer, PhD³; Ted Gansler, MD, MBA, MPH⁴; and Rachel S. Cannady, PhD⁵

BACKGROUND: The objective of this study was to investigate associations between earlier caregiving experience and the development of physical impairments over the subsequent 8 years among family caregivers of patients with cancer. **DESIGN:** Family caregivers of cancer survivors participated in a nationwide survey 2 years after their relative's cancer diagnosis (T1; N=107) with follow-up at 5 years (T2) and 8 years (T3) postdiagnosis. Caregivers self-reported their demographics and levels of caregiving stress at T1. Caregiving stress ("stress" for those whose patient was deceased, "burden" for those whose patient had died, and "strain" for those whose patient was alive) was measured at T1 through T3. **RESULTS:** Caregiving stress was significantly related to concurrent presence of the 3 impairment markers at T1. Physical impairments were more likely to develop later in time, and caregiver stress was more likely than other variables to predict physical impairments at T3. **CONCLUSIONS:** The current findings suggest that earlier caregiving experience at T1 and T2, these effects were independent of age, sex, education, and income at T1, and they were also independent of caregiving stress at each assessment. **CONCLUSIONS:** The current findings suggest that earlier caregiving experience at T1 and T2, these effects were independent of age, sex, education, and income at T1, and they were also independent of caregiving stress at each assessment. **CONCLUSIONS:** The current findings suggest that earlier caregiving experience at T1 and T2, these effects were independent of age, sex, education, and income at T1, and they were also independent of caregiving stress at each assessment. **KEYWORDS:** cancer caregivers, caregiving stress, arthritis, chronic back pain, heart diseases, longitudinal study.

INTRODUCTION

Providing informal care to relatives with chronic illnesses has been linked to poor physical health. Compared with age-matched and sex-matched noncaregivers, caregivers report more physical distress and infectious illness episodes, exhibit slower healing for small and/or deep wounds, and are at greater risk for coronary heart disease.¹⁻³ All-cause mortality of caregivers, compared with noncaregivers, was higher in 2 studies,^{4,5} although it was lower in another.⁶ Caregiving strain, however, has been consistently related to poor physical health, including elevated risk for stroke⁷ and higher mortality.^{8,9}

These findings come mainly from spousal caregivers of individuals with dementia or cardiovascular disorder. Unknown is the generalizability of these findings to caregivers of patients with cancer, which is a large and fast-growing population, because approximately 13.7 million Americans with a history of cancer are alive today^{10,11} and, as this number continues to rise, more family members will become cancer caregivers.¹²⁻¹⁵ Cancer caregiving differs from other caregiving because it is more yet intensive.¹⁶ For example, approximately 60% of cancer caregivers provide care for less than 1 year, whereas dementia caregivers typically do so for 4 years. However, both cancer and dementia caregivers provide approximately 30 hours per week when they are engaged in caregiving.¹⁷ Whether such unique stress characteristics of cancer caregiving—more yet intense—have a substantial impact on caregivers' physical health warrants investigation.

Cancer caregivers' increased risk of poor physical health has recently been recognized by a large epidemiological study using Swedish registries. The study demonstrated that spouses of patients with cancer, compared with unaffected spouses, were more vulnerable to poor cardiovascular health, including risks of coronary heart disease (13% increased) and stroke (26% increased), up to 20 years after their spouse's cancer diagnosis.¹⁸ Unknown, however, is the role in caregiver health outcomes of the caregiver's subjective experience of the caregiving situation versus the role of being a spouse of the

- **Aim:** Among spousal caregivers, assess the long-term physical health consequences of caregiving

Kim, Y., Carver, C.S., Shaffer, K.M., Gansler, T., & Cannady, R.S. (2015). Cancer caregiving predicts physical impairments: Roles of earlier caregiving stress and being a spousal caregiver. *Cancer*, 121(2), 302-310.

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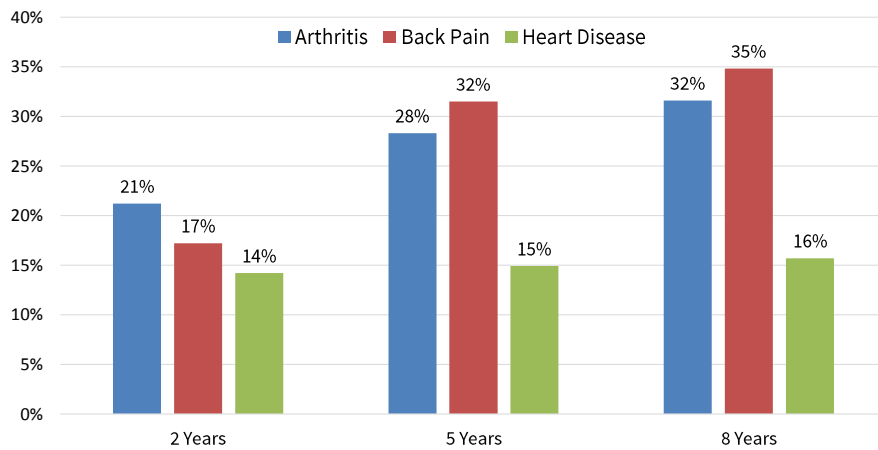
We extend our appreciation to all of the families who participated in this investigation. Dr. Rita Dubler assisted in the research of the manuscript.

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Cancer January 16, 2015

Long-Term Physical Impairments



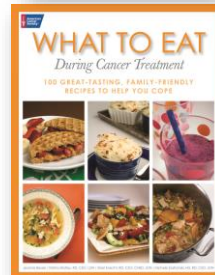
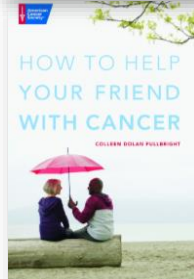
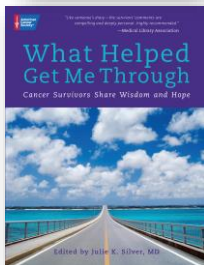
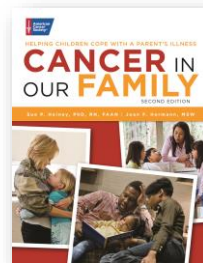
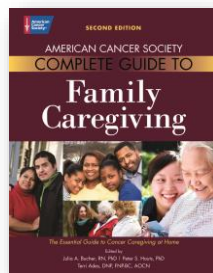
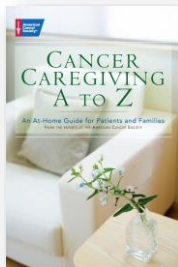
Programs and Services for Caregivers



ACS Programs and Services

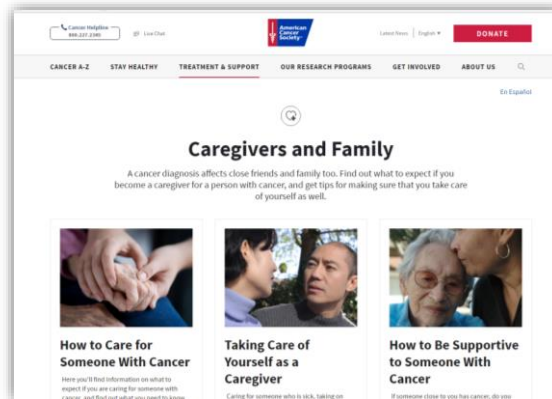


cancer.org/bookstore (15% off: ACS15)



cancer.org/caregivers

- What it takes to be a caregiver
- Distress Checklist
- Assisting survivors' in the management of long-term and late effects of cancer and its treatment
- Tips on coordinating care
- How to care for someone at the end of life
- Caring for a child with cancer



Online Environments for Caregivers

Cancer Survivors Network

• csn.cancer.org

MyLifeLine

• acs.mylifeline.org

Connection

Friendship

Empowerment

Community

ACS Caregiver Resource Guide



COMING SOON!

- Cancer Caregiving
- Caregiver Self-Care
- Communication
- Cancer Information
- Cancer Treatment
- Patient Nutrition
- Coping
- Caregiver Resources

General Caregiver Resources

- **National Alliance for Caregiving**
 - caregiving.org
- **Family Caregiver Alliance/National Center on Caregiving**
 - caregiver.org
- **Caregiver Action Network**
 - caregiveraction.org
- **National Family Caregiver Support Program**
 - aoa.acl.gov/AoA_Programs/HCLTC/Caregiver/

National Caregiver Reports and Funding Opportunities

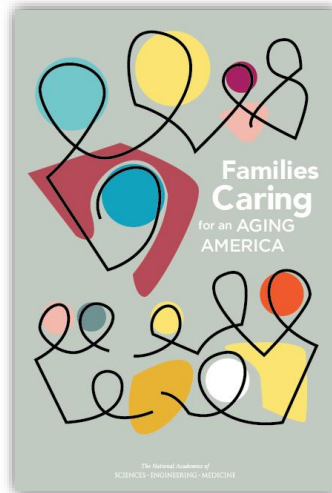


Cancer Caregiving in the U.S.



caregiving.org/cancer

Families Caring for an Aging America



nationalacademies.org

American Cancer Society

- Postdoctoral Fellowships
- Mentored Research Scholar Grants
- Research Scholar Grants

RFA: Pilot and Exploratory Projects in Palliative Care of Cancer Patients and Their Families

Provides funding for investigators performing pilot and exploratory research studies whose purpose is to test interventions, develop research methodologies, and explore novel areas of research in palliative care of cancer patients and their families.

[**cancer.org/research**](http://cancer.org/research)

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National Cancer Institute (NCI)

PAR-16-317 (R01), PAR-16-318 (R21)

- Fund interventions that support the success of informal cancer caregivers for adult cancer patients, as measured by the following outcomes:

1. Improved patient health:

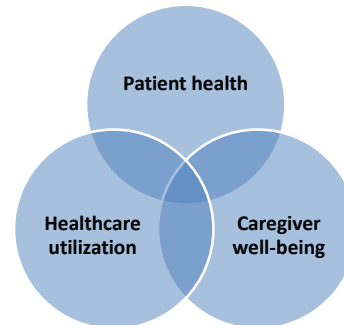
Physical and psychosocial outcomes, quality of life

2. Improved caregiver well-being:

Lower burden, higher capacity and quality of life

3. Optimized healthcare utilization:

Improved oral medication adherence; reduced emergency room visits, hospitalization and hospital readmissions; lower rates of infection; timely medication refills; better adherence; use of supportive/palliative care service; primary care visits



grants.nih.gov

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National Institute of Nursing Research & NCI

Palliative Care Needs of Individuals with Rare Advanced Diseases and Their Family Caregivers

PA-17-018 (R01), PA-17-017 (R21)

This FOA seeks to expand knowledge and increase the evidence base for palliative care in advanced rare diseases, including rare cancers, and to improve physical and psychosocial well-being and quality of life among seriously ill individuals and their family caregivers.

grants.nih.gov

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Patient-Centered Outcomes Research Institute

Community-based Palliative Care Delivery for Adult Patients with Advanced Illnesses and their Caregivers

The overarching goal of this PFA is to generate needed comparative effective research (CER) evidence to:

- a) support care planning over time that is consistent with the goals and preferences of adult patients with advanced illnesses and their caregivers, and
- b) support the delivery of coordinated, community-based palliative care that effectively implements those care plans. PCORI seeks to fund multiple, large, multi-site, community-based CER studies to generate evidence in support of this goal.

pcori.org

Policy



RAISE Family Caregivers Act

Recognize, Assist, Include, Support, and Engage (RAISE) Family Caregivers Act

- Directs the Department of Health and Human Services (HHS) to develop, maintain, and periodically update a National Family Caregiving Strategy.
- HHS would then convene a Family Caregiving Advisory Council to advise it on recognizing and supporting family caregivers.
- Federal departments and agencies must share with HHS any data needed to prepare recommended strategies.



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