The American Cancer Society
National Quality of Life Survey for Caregivers

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Atlanta, GA
• 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
• Q&A
Who is a Cancer Survivor?
• > 15.5 million cancer survivors in Jan 2016

• Includes concerns of caregivers and families

• cancer.org/research/cancerfactsstatistics
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)
“There are only four kinds of people in the world:

Those who have been caregivers,

Those who are currently 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
Overview of Caregiver Research

• 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

<table>
<thead>
<tr>
<th></th>
<th>Qx1</th>
<th>Qx2</th>
<th>Qx3</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Survivors</strong></td>
<td>6,306</td>
<td>5,228</td>
<td>3,138</td>
</tr>
<tr>
<td><strong>Caregivers</strong></td>
<td>1,635</td>
<td>1,108</td>
<td>720</td>
</tr>
</tbody>
</table>

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**National Quality of Life Survey**

**Third Survey**

Thank you for your continued participation in this study for over 15 years. We sincerely appreciate your commitment and contribution.

Your participation in this study has helped us learn a great deal about the daily and helpful part of a cancer survivor's journey.

- We would like to continue to learn about how your experiences and needs may have changed over time due to your cancer.
- We want to hear from you even if you are in good health, or your cancer is in remission, or you have had a cancer recurrence.

Your insights are valuable because what you tell us can help the American Cancer Society develop better programs to help other cancer survivors, just like you.

Your participation in this study is an important contribution to the mission of the American Cancer Society.

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**National Quality Of Life Survey: Caregivers**

Thank you for taking the time to complete this survey. The information you provide will be used to help families and friends of cancer survivors.

This survey asks about your experiences helping an individual with cancer. Please be as accurate as you can be throughout, and try to honestly reflect how you feel at any one time. It may influence your answer to any other item. A number of questions ask how you are feeling or doing at a particular time. Even if you complete the questionnaire over several days, you do not need to go back to change the answers you gave earlier.

Your answers are very important to us and are completely confidential. Here are some tips in completing this survey:

1. Please print clearly using blue or black ink pen. Do NOT use pencil or markers.
2. Completely darken your answers, that is, fill the circles.
3. If you wish to change an answer, please go back to the question and cross out the circle.
4. Written responses must stay within the boxes provided.
5. Please answer **EVERY** question unless you are asked to skip it.
   - Please fill out and return the survey as soon as possible in the enclosed postage paid envelope.
   - If you have any problems or questions, please call 1-800-783-0227.

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**The Official Sponsor of Birthdays**

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**American Cancer Society**

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## Caregiver Study Demographics (n=1,635)

<table>
<thead>
<tr>
<th>Age</th>
<th>55.09 (12.90): 18 ~ 90</th>
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</thead>
<tbody>
<tr>
<td>Gender</td>
<td>65.4% female</td>
</tr>
<tr>
<td><strong>Education:</strong></td>
<td>≤ High School</td>
</tr>
<tr>
<td></td>
<td>College</td>
</tr>
<tr>
<td></td>
<td>&gt; College</td>
</tr>
<tr>
<td></td>
<td>51.2%</td>
</tr>
<tr>
<td></td>
<td>19.4%</td>
</tr>
<tr>
<td>Employed</td>
<td>72.2%</td>
</tr>
<tr>
<td><strong>Ethnicity:</strong></td>
<td>African American</td>
</tr>
<tr>
<td></td>
<td>Asian</td>
</tr>
<tr>
<td></td>
<td>Caucasian</td>
</tr>
<tr>
<td></td>
<td>Latino</td>
</tr>
<tr>
<td><strong>Household Income:</strong></td>
<td>&lt; $40,000</td>
</tr>
<tr>
<td></td>
<td>$40,000 ~ $75,000</td>
</tr>
<tr>
<td></td>
<td>&gt; $75,000</td>
</tr>
<tr>
<td></td>
<td>29.6%</td>
</tr>
<tr>
<td><strong>Family Relationship:</strong></td>
<td>Spouse; Offspring</td>
</tr>
<tr>
<td></td>
<td>66.2%; 17.5%</td>
</tr>
</tbody>
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Caregivers’ Unmet Needs

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

Caregiver Unmet Needs Across Trajectory

Caregivers’ Top 5 Unmet Needs

Helping the survivor with his/her emotional distress (i.e., anger, anxiety, depression, fear, etc.)
- 2 mo: 21.4%
- 2 yr: 38.4%
- 5 yr: 47.5%

Dealing with your emotional distress (e.g., anger, anxiety, depression, fear, resentment, etc.)
- 2 mo: 11.8%
- 2 yr: 30.8%
- 5 yr: 29.6%

Dealing with lifestyle changes
- 2 mo: 10.7%
- 2 yr: 26.5%
- 5 yr: 29.6%

Getting information about the cancer he/she was diagnosed with (e.g., prognosis, treatment, etc.)
- 2 mo: 10%
- 2 yr: 26.5%
- 5 yr: 46.3%

Talking to the survivor about his/her concerns
- 2 mo: 7.1%
- 2 yr: 25.6%
- 5 yr: 31.5%

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

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

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

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.

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

Long-Term Physical Impairments

- Arthritis
- Back Pain
- Heart Disease

<table>
<thead>
<tr>
<th>Time</th>
<th>Arthritis</th>
<th>Back Pain</th>
<th>Heart Disease</th>
</tr>
</thead>
<tbody>
<tr>
<td>2 Years</td>
<td>21%</td>
<td>17%</td>
<td>14%</td>
</tr>
<tr>
<td>5 Years</td>
<td>28%</td>
<td>32%</td>
<td>15%</td>
</tr>
<tr>
<td>8 Years</td>
<td>35%</td>
<td>32%</td>
<td>16%</td>
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ACS Programs and Services for Caregivers
ACS Programs and Services

Chat with an Information Specialist
Monday - Friday
8am - 6:30pm CST

or call
1-800-227-2345

CHAT LIVE »

HOPE LODGE® AND HOTEL PARTNERS PROGRAM
LODGING ASSISTANCE FOR CANCER PATIENTS AND CAREGIVERS

Having cancer is hard.
Finding a ride to treatment shouldn’t be.

American Cancer Society
Road To Recovery®
cancer.org/roadtorecovery
• 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
COMING SOON!

- Cancer Caregiving
- Caregiver Self-Care
- Cancer Information
- Cancer Treatment/Side Effects
- Communication
- Coping
- Patient Nutrition
- Financial/Employment Issues
- Caregiver Resources
National Caregiver Reports and Funding Opportunities
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
Intervening with Cancer Caregivers to Improve Patient Health Outcomes and Optimize Health Care Utilization

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

Interventions supported by this FOA are intended to provide caregivers of adult cancer patients with care training, promote coping skills, and ultimately help them manage care.

Outcomes of such interventions are expected to (1) optimize patient health care utilization, (2) improve caregiver well-being, and (3) improve patient physical health and psychosocial outcomes.

grants.nih.gov
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
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.