Cancer Caregiving: From Research to Policy

Rachel S. Cannady
Strategic Director, Cancer Caregiver Support
Atlanta, GA

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-1 (SCS-1)**
- 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>
Caregiver Study Demographics (n=1,635)

<table>
<thead>
<tr>
<th>Category</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Age</strong></td>
<td>55.09 (12.90): 18 ~ 90</td>
</tr>
<tr>
<td><strong>Gender</strong></td>
<td>65.4% female</td>
</tr>
<tr>
<td><strong>Education</strong></td>
<td></td>
</tr>
<tr>
<td>≤ High School</td>
<td>28.4%</td>
</tr>
<tr>
<td>College</td>
<td>51.2%</td>
</tr>
<tr>
<td>&gt; College</td>
<td>19.4%</td>
</tr>
<tr>
<td><strong>Employed</strong></td>
<td>72.2%</td>
</tr>
<tr>
<td><strong>Ethnicity</strong></td>
<td></td>
</tr>
<tr>
<td>African American</td>
<td>4.3%</td>
</tr>
<tr>
<td>Asian</td>
<td>0.7%</td>
</tr>
<tr>
<td>Caucasian</td>
<td>89.8%</td>
</tr>
<tr>
<td>Latino</td>
<td>2.0%</td>
</tr>
<tr>
<td><strong>Household Income</strong></td>
<td></td>
</tr>
<tr>
<td>&lt;$40,000</td>
<td>20.1%</td>
</tr>
<tr>
<td>$40,000 ~ $75,000</td>
<td>33.9%</td>
</tr>
<tr>
<td>&gt; $75,000</td>
<td>29.6%</td>
</tr>
<tr>
<td><strong>Family Relationship</strong></td>
<td>Spouse; Offspring 66.2%; 17.5%</td>
</tr>
</tbody>
</table>

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

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

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

Caregiver Comparison

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


Caregiver Time Costs

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

Value of Caregiver Time 2-yrs 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.

Long-term Physical Impairments

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

Long-Term Physical Impairments

Programs and Services for Caregivers
ACS Programs and Services

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

Road To Recovery cancer.org/readto recovery

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

caregiving.org/cancer

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

CONTACT:
ellie.daniels@cancer.org
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

CONTACT: erin.kent@nih.gov

---

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

CONTACT: erin.kent@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.

pcori.org
The Caregiver Advise, Record, Enable (CARE) Act

- **Provision #1: Designation**
  - Give hospital inpatients the chance to name a caregiver and have their information put in the record

- **Provision #2: Notification**
  - Contact the caregiver prior to discharging the patient

- **Provision #3: Instruction**
  - Consult with the caregiver and provide a demonstration and a chance to ask questions about the tasks the caregiver will need to carry out at home

---

The CARE Act is a commonsense solution that supports family caregivers when their loved ones go into the hospital, and provides for instruction on the medical tasks they will need to perform when their loved one returns home.

CARE Act goes into effect:
- Arkansas, 1/1/14; Colorado, 9/1/14; New Jersey, 5/12/15; West Virginia, 5/9/15; New Mexico, 6/11/15; Mississippi, 7/1/15; Virginia, 7/1/15; Arkansas, 7/22/15; Connecticut, 10/1/15; Nevada, 1/1/15; Maine, 1/1/15; Puerto Rico, 12/31/15; California, 1/1/16; Indiana, 1/1/16; New Hampshire, 1/1/16; Oregon, 1/1/16; Illinois, 1/27/2016; Utah, 1/1/16; Rhode Island, 1/1/16; Nebraska, 3/2/16; Virgin Islands, 3/2/16; New York, 4/23/16; Washington, 5/1/16; Wyoming, 7/1/16; Washington D.C., 7/1/16; Michigan, 7/1/16; Louisiana, 5/1/16; Maryland, 1/1/16; Alaska, 1/1/17; Delaware, 1/1/17; Minnesota, 1/1/17; Pennsylvania, 4/25/17; Hawaii, 7/1/17; Massachusetts, TBD; Ohio, TBD

**Updated on 12/31/2016**
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.

cancer.org | 800.227.2345