Caregiver Roles, Unmet Support Needs, and Well-Being in an Evolving Cancer Care Landscape

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Research and Training Institute, Cancer Support Community
APOS 20th Annual Meeting
March 15, 2023
Cancer Experience Registry

An online research study that aims to understand the emotional, physical, practical, and financial impact of cancer and identify unmet needs among patients, survivors, and caregivers.
Disclosures

Dr. Miller:
Institutional Research Funding: Astellas Pharma, BeiGene, Bristol-Myers Squibb, Genentech (a member of the Roche Group), Geron, Gilead Sciences, GlaxoSmithKline, Janssen Pharmaceuticals, Merck, Novartis, Pfizer, SeaGen, Taiho Oncology, and Takeda Pharmaceutical

Dr. Zaleta:
Institutional Research Funding: Astellas Pharma, Boston Scientific Foundation, Gilead Sciences, Novartis, Pfizer Oncology, SeaGen

Dr. Rogers: No disclosures

Cancer Experience Registry Caregiver funding provided by:
Genentech
Novartis
GSK
Takeda
Our Mission

To ensure that all people impacted by cancer are empowered by knowledge, strengthened by action, and sustained by community.
What We Do

Patient and Caregiver Services, Research, and Advocacy

Direct Services
• The largest network of psychosocial oncology care in North America
• All programs are free of charge to anyone affected by cancer
• 500,000 visits annually by patients and loved ones to 175 locations
• 40,000 Cancer Support Helpline inquiries (calls, email, chat) annually

Research & Training
• Elevate patient and caregiver voices through research to understand the cancer experience and its impact
• Develop new measures to better capture patient experiences
• Disseminate findings to improve cancer care and health care policy
• Over 15,000 patients and caregivers engaged

Policy & Advocacy
• Engage patient advocates and their loved ones to play a central role in legislative, regulatory, and executive policymaking
• Leverage data to advocate for access to high-quality cancer care
• Grassroots network has thousands of patients and supporters
Our Reach

CSC and Gilda’s Club centers as well as hospital partnerships in the U.S. and around the world.

NATIONAL
CSC ARIZONA
CSC SOUTH BAY
CSC PASADENA
CSC LOS ANGELES
CSC CALIFORNIA CENTRAL COAST
CSC SAN FRANCISCO BAY AREA
CSC VALLEY/VENTURA/SANTA BARBARA
CSC DELAWARE
GC SOUTH FLORIDA
CSC ATLANTA
GC CHICAGO
CSC INDIANA
GC QUAD CITIES
GC KENTUCKIANA
CSC GREATER ANN ARBOR
GC GRAND RAPIDS
GC METRO DETROIT
GC TWIN CITIES
CSC GREATER ST. LOUIS
GC KANSAS CITY
CSC MONTANA
CSC NEW JERSEY
CSC ROCHESTER
GC WESTCHESTER
CSC GREATER CINCINNATI-NORTHERN KENTUCKY
CSC CENTRAL OHIO
CSC GREATER LEHIGH VALLEY
CSC GREATER PHILADELPHIA
GC MIDDLE TENNESSEE
CSC EAST TENNESSEE
CSC NORTH TEXAS
GC MADISON

HEALTH CARE PARTNERS
CSC AT TUBA CITY REGIONAL HEALTH CARE
CSC AT ROCKY MOUNTAIN CANCER CENTERS
CSC AT WHITMAN-WALKER HEALTH
CSC AT ORLANDO HEALTH CANCER INSTITUTE
CSC AT KONA COMMUNITY HOSPITAL
CSC AT MOSAIC LIFE CARE
CSC AT HOLY NAME MEDICAL CENTER
CSC AT PRISMA HEALTH CANCER INSTITUTE

INTERNATIONAL
GC GREATER TORONTO
GC SIMCOE MUSKOKA
CSC JAPAN
TWC TEL-AVIV
TWC BAGHDAD

OPENED IN 2021
CSC AT IFHC (INDIAN FAMILY HEALTH CLINIC)
CSC AT UNIVERSITY OF GEORGIA
CSC WASHINGTON D.C.

OPENING IN 2022- 2023
GC AT METHODIST CANCER INSTITUTE
CSC AT BRECKINRIDGE HEALTH, INC.
GC NEW HAMPSHIRE
CSC SW COLORADO
CSC MASSACHUSETTS
GC NORTHEAST ARKANSAS
CSC AT NORTHERN ARIZONA UNIVERSITY
GC AT ST. AMBROSE UNIVERSITY
Background
More than 1 in 5 Americans are caregivers, totaling 53 million adults in the U.S.

Caregivers provide $470 billion in unpaid care in the U.S.

In 2022, nearly 2 million Americans will be diagnosed with a new cancer requiring treatment and support.

Inclusion of caregivers in the health care delivery process lacks recognition, coordination, and standardization.

(AARP, 2021; National Alliance for Caregiving, 2020; Siegel et al, 2022; Stephenson et al., 2022)
Background

Caregivers are a National Resource

“Supporting family caregivers is an issue that will touch every one of us in some way. At some point in our lives, most of us will either be a family caregiver or need one.

Many of us will experience both.”
# Background

## Caregiver Roles, Unmet Support Needs, & Well-Being

### Timeframe
- Cancer therapies are advancing rapidly; cancer diagnosed earlier
- Cancer continues to evolve into more of a chronic disease
- Cancer caregiving is becoming longer-term; sometimes even lifelong

### History Effects
- The COVID-19 pandemic exacerbated healthcare barriers and psychosocial distress
- Policy changes (healthcare, insurance, retirement age, etc.)
- Technological advancements

### Evolving Expectations
- “Today’s family caregivers are often expected to perform highly complex tasks, including medical tasks, care coordination, administration, and technological support – activities that extend well beyond the help with activities of daily living that were the hallmark of family caregiving in years gone by” (p.19)

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2022 National Strategy to Support Family Caregivers; Truskinovsky, Finlay, & Kobayashi, 2022; Rosalynn Carter Institute, 2020; AARP and National Alliance for Caregiving, 2020.
Yet, understanding and support of cancer caregivers’ unmet needs is not keeping pace with this evolving landscape.

**Goal 5:** Expand data, research, and evidence-based practices to support family caregivers
Cancer Experience Registry
A Three-Pronged Approach for Examining Caregiver Roles, Unmet Support Needs, & Well-Being

- Cross-sectional data
- Longitudinal data
- Dyadic/Paired data
Aims
Caregiver Roles, Unmet Support Needs, & Well-Being

The **objective** was to characterize:

1) caregiver role engagement across diverse areas of support
2) support needed vs. received by caregivers
3) caregiver well-being impacts

**313 present and former caregivers** completed the Cancer Experience Registry between Oct 2021 and Nov 2022
Results
Participants
Caregiver Characteristics

➢ Age
  ➢ Mean: **56 years** (SD=15)
  ➢ Range: 21-86 years

➢ Gender Identity
  ➢ Women: 79%
  ➢ Men: 19%
  ➢ Non-binary: 0.6%
  ➢ Other/Prefer not to share/Unsure: 1%

➢ Race & Ethnicity

- Hispanic, Latino, or Spanish: 4%
- NH Asian: 2%
- NH Black/African American: 8%
- NH White: 82%
- NH other race: 1%
- NH, 2 or more races selected: 1%
- Not reported: 3%

$n = 313$
Participants
Caregiver Characteristics

➢ Relationship to Care Recipient

- Caring for spouse: 58%
- Caring for parent/in-law: 23%
- Caring for child: 12%
- Caring for sibling: 2%
- Caring for grandparent: 2%
- Other: 3%

➢ Hours of Care Provided Weekly

- ≤20 hours: 25%
- 21-80 hours: 34%
- >80 hours: 34%
- Not reported: 7%

n = 313
Participants
Caregiver Characteristics

➢ Years Providing Care

- <1: 26%
- 1: 17%
- 2: 18%
- 3-4: 19%
- 5+: 20%

➢ Caregiver / Care Recipient Status

- Current / On Treatment: 35%
- Current / No Treatment: 42%
- Former / Alive: 14%
- Former / Deceased: 9%

n = 313
Participants
Care Recipient Characteristics

- Care Recipient Age When Caring Began
  - Mean: **59 years** (SD=18)
  - Range: <1-92 years

- Primary Cancer Diagnosis
  - *Only diagnoses with ≥7 participants are displayed*

- Colorectal: 47
- Breast: 40
- Lung: 29
- MDS: 7
- Brain/Spinal Cord: 7
- Multiple Myeloma: 7
- Pancreatic: 12
- Prostate: 13
- Bladder: 26
- Liver: 29
- Non-Hodgkins Lymphoma: 40

n = 313
Participants
Care Recipient Characteristics

➢ Time Since Diagnosis
  ➢ Median: 2 years
  ➢ Range: <1-66 years

<table>
<thead>
<tr>
<th>Time Since Diagnosis</th>
<th>n</th>
<th>%</th>
</tr>
</thead>
<tbody>
<tr>
<td>&lt;1 year</td>
<td>27</td>
<td>17%</td>
</tr>
<tr>
<td>1-2 years</td>
<td>54</td>
<td>34%</td>
</tr>
<tr>
<td>3-4 years</td>
<td>34</td>
<td>12%</td>
</tr>
<tr>
<td>5+ years</td>
<td>13</td>
<td>26%</td>
</tr>
<tr>
<td>Not reported</td>
<td>17</td>
<td>11%</td>
</tr>
</tbody>
</table>

Among current caregivers; n = 160

➢ Current Cancer Status

- Localized disease: 19%
- Metastatic/Stage IV: 11%
- Remission/NED: 15%
- Don't know: 8%
- Not reported: 11%
- Not reported: 8%
- Not reported: 19%
### Caregiver Roles

#### Support Provided

<table>
<thead>
<tr>
<th>Caregiver Role</th>
<th>% Quite a bit to Very much involved</th>
</tr>
</thead>
<tbody>
<tr>
<td>Providing emotional support</td>
<td>95%</td>
</tr>
<tr>
<td>Talking with patients about cancer/prognosis</td>
<td>90%</td>
</tr>
<tr>
<td>Talking with patients about treatment goals/preferences</td>
<td>88%</td>
</tr>
<tr>
<td>Managing symptoms/side effects</td>
<td>82%</td>
</tr>
<tr>
<td>Household chores</td>
<td>78%</td>
</tr>
<tr>
<td>Transportation</td>
<td>77%</td>
</tr>
<tr>
<td>Coordinating family support</td>
<td>69%</td>
</tr>
<tr>
<td>Facilitating patient social activities</td>
<td>65%</td>
</tr>
<tr>
<td>Coordinating medical visits</td>
<td>61%</td>
</tr>
<tr>
<td>Providing medical care</td>
<td>59%</td>
</tr>
<tr>
<td>Managing health insurance/benefits</td>
<td>56%</td>
</tr>
<tr>
<td>Talking with patient about EOL planning</td>
<td>55%</td>
</tr>
<tr>
<td>Managing patient finances</td>
<td>54%</td>
</tr>
<tr>
<td>Finding/coordinating support services</td>
<td>48%</td>
</tr>
<tr>
<td>Setting up legal resources for patient</td>
<td>46%</td>
</tr>
<tr>
<td>Providing personal care</td>
<td>46%</td>
</tr>
<tr>
<td>Finding financial resources</td>
<td>44%</td>
</tr>
</tbody>
</table>

*n = 311-313*
# Caregiver Support Needs

<table>
<thead>
<tr>
<th>Wanted and DID NOT receive help</th>
<th>Wanted and DID receive help</th>
<th>Did not want help</th>
</tr>
</thead>
<tbody>
<tr>
<td>Understanding patient’s cancer/prognosis</td>
<td>14%</td>
<td>76%</td>
</tr>
<tr>
<td>Managing symptoms/side effects</td>
<td>14%</td>
<td>67%</td>
</tr>
<tr>
<td>Providing medical care</td>
<td>8%</td>
<td>64%</td>
</tr>
<tr>
<td>Providing emotional support</td>
<td>23%</td>
<td>47%</td>
</tr>
<tr>
<td>Talking with patients about cancer/prognosis</td>
<td>14%</td>
<td>50%</td>
</tr>
<tr>
<td>Managing negative feelings (e.g., guilt, anger, stress)</td>
<td>29%</td>
<td>34%</td>
</tr>
<tr>
<td>Taking care of own mental health</td>
<td>24%</td>
<td>37%</td>
</tr>
<tr>
<td>Balancing work/life/family/caregiving demands</td>
<td>31%</td>
<td>29%</td>
</tr>
<tr>
<td>Coordinating family care roles</td>
<td>20%</td>
<td>39%</td>
</tr>
<tr>
<td>Talking with patients about treatment goals/preferences</td>
<td>13%</td>
<td>46%</td>
</tr>
<tr>
<td>Finding/coordinating support services</td>
<td>18%</td>
<td>46%</td>
</tr>
<tr>
<td>Household chores</td>
<td>23%</td>
<td>29%</td>
</tr>
<tr>
<td>Facilitating patient social activities</td>
<td>15%</td>
<td>33%</td>
</tr>
<tr>
<td>Taking care of own physical health</td>
<td>23%</td>
<td>24%</td>
</tr>
<tr>
<td>Providing personal care</td>
<td>12%</td>
<td>34%</td>
</tr>
<tr>
<td>Talking with patients about EOL planning</td>
<td>15%</td>
<td>31%</td>
</tr>
<tr>
<td>Coordinating medical visits</td>
<td>8%</td>
<td>35%</td>
</tr>
<tr>
<td>Setting up patient legal resources</td>
<td>9%</td>
<td>32%</td>
</tr>
<tr>
<td>Finding financial resources</td>
<td>17%</td>
<td>23%</td>
</tr>
<tr>
<td>Providing transportation</td>
<td>12%</td>
<td>24%</td>
</tr>
<tr>
<td>Managing patient health insurance and benefits</td>
<td>12%</td>
<td>21%</td>
</tr>
<tr>
<td>Managing patient finances</td>
<td>10%</td>
<td>14%</td>
</tr>
</tbody>
</table>

*n = 285-290*
Caregiver Support Needs

- **Wanted help**
- **Did not want help**

- Understanding patient’s cancer/prognosis: 90% (Wanted), 10% (Did not want)
- Managing symptoms/side effects: 81% (Wanted), 19% (Did not want)
- Providing medical care: 72% (Wanted), 28% (Did not want)
- Providing emotional support: 71% (Wanted), 29% (Did not want)
- Talking with patients about cancer/prognosis: 64% (Wanted), 36% (Did not want)
- Managing negative feelings (e.g., guilt, anger, stress): 63% (Wanted), 37% (Did not want)
- Taking care of own mental health: 61% (Wanted), 39% (Did not want)
- Balancing work/life/family/caregiving demands: 61% (Wanted), 39% (Did not want)
- Coordinating family care roles: 59% (Wanted), 41% (Did not want)
- Talking with patients about treatment goals/preferences: 59% (Wanted), 41% (Did not want)
- Finding/coordinating support services: 52% (Wanted), 48% (Did not want)
- Household chores: 51% (Wanted), 49% (Did not want)
- Facilitating patient social activities: 48% (Wanted), 52% (Did not want)
- Taking care of own physical health: 47% (Wanted), 53% (Did not want)
- Providing personal care: 47% (Wanted), 53% (Did not want)
- Talking with patients about EOL planning: 46% (Wanted), 54% (Did not want)
- Coordinating medical visits: 44% (Wanted), 56% (Did not want)
- Setting up patient legal resources: 41% (Wanted), 59% (Did not want)
- Finding financial resources: 40% (Wanted), 60% (Did not want)
- Providing transportation: 35% (Wanted), 65% (Did not want)
- Managing patient health insurance and benefits: 32% (Wanted), 68% (Did not want)
- Managing patient finances: 24% (Wanted), 76% (Did not want)

*n = 285-290*
Caregiver Support Needs

Top Met Needs

- Understanding patient’s cancer/prognosis: 76%
- Managing symptoms/side effects: 67%
- Providing medical care: 64%
- Talking with patients about cancer/prognosis: 50%
- Providing emotional support: 47%
- Talking about treatment goals/preferences: 46%
- Coordinating family care roles: 39%
- Taking care of own mental health: 37%
- Coordinating medical visits: 35%
- Finding/coordinating support services: 35%

$n = 285-290$
Caregiver Support Needs

## Top Unmet Needs

- Balancing work/life/family/caregiving demands: 31%
- Managing negative feelings (e.g., guilt, anger, stress): 29%
- Taking care of own mental health: 24%
- Taking care of own physical health: 23%
- Providing emotional support: 23%
- Household chores: 23%
- Coordinating family care roles: 20%
- Finding/coordinating support services: 18%
- Finding financial resources: 17%
- Facilitating patient social activities: 15%

$n = 285-290$

% Wanted and DID NOT receive help
### Caregiver Well-Being

#### Health-Related Quality of Life Changes Due to Caregiving

<table>
<thead>
<tr>
<th>Category</th>
<th>Much or somewhat worse</th>
<th>About the same</th>
<th>Somewhat or much better</th>
</tr>
</thead>
<tbody>
<tr>
<td>Emotional/mental health</td>
<td>67%</td>
<td>26%</td>
<td>7%</td>
</tr>
<tr>
<td>Sleep</td>
<td>62%</td>
<td>33%</td>
<td>5%</td>
</tr>
<tr>
<td>Energy level</td>
<td>58%</td>
<td>37%</td>
<td>6%</td>
</tr>
<tr>
<td>Romantic relationship(s)/intimacy</td>
<td>53%</td>
<td>38%</td>
<td>9%</td>
</tr>
<tr>
<td>Diet and nutrition</td>
<td>44%</td>
<td>44%</td>
<td>12%</td>
</tr>
<tr>
<td>Physical health</td>
<td>43%</td>
<td>48%</td>
<td>9%</td>
</tr>
<tr>
<td>Friendships and social life</td>
<td>38%</td>
<td>47%</td>
<td>15%</td>
</tr>
<tr>
<td>Financial security</td>
<td>35%</td>
<td>58%</td>
<td>8%</td>
</tr>
<tr>
<td>Family life</td>
<td>28%</td>
<td>50%</td>
<td>22%</td>
</tr>
<tr>
<td>Spirituality/faith/religion</td>
<td>21%</td>
<td>55%</td>
<td>24%</td>
</tr>
<tr>
<td>Relationship with the patient</td>
<td>12%</td>
<td>44%</td>
<td>44%</td>
</tr>
</tbody>
</table>

*n = 311-313*
Quality of Life
PROMIS-29 Symptom Burden

Mean PROMIS-29 Symptom Burden Scores

* Denotes clinically meaningful (Tdiff ≥ 3 points) difference

- Anxiety
- Depression
- Fatigue
- Sleep Disturbance
- Pain Interference

General U.S. Population
U.S. Cancer Patient Population
CER, Former Caregiver
CER, Current Caregiver

n = 149-153
n = 156-160
Quality of Life
PROMIS-29 Function

Mean PROMIS-29 Functioning Scores

<table>
<thead>
<tr>
<th></th>
<th>General U.S. Population</th>
<th>U.S. Cancer Patient Population</th>
<th>CER, Former Caregiver</th>
<th>CER, Current Caregiver</th>
</tr>
</thead>
<tbody>
<tr>
<td>Physical Function</td>
<td>50.0</td>
<td>44.8</td>
<td>50.8</td>
<td>50.2</td>
</tr>
<tr>
<td>Social Function</td>
<td>50.0</td>
<td>50.3</td>
<td>49.9</td>
<td>46.2</td>
</tr>
<tr>
<td>Cognitive Function</td>
<td>50.0</td>
<td>52.1</td>
<td>49.6</td>
<td>49.4</td>
</tr>
</tbody>
</table>

* Denotes clinically meaningful ($T$ diff $\geq$ 3 points) difference

$n = 149-153$ for CER, Former Caregiver
$n = 156-160$ for CER, Current Caregiver
Conclusions
Conclusions & Implications

Continued Need for Caregiver Support and Research

There is a growing public awareness of the importance of caregiving.

Cancer caregivers continue to experience substantial quality of life impacts.

Caregivers still do not receive needed support, especially for their own psychosocial needs and those of patients.

Critical need for ongoing, updated data collection to keep tabs on the ever-changing landscape of caregiving.

Integrated, whole-person caregiver care is needed to address support barriers.

Systemic distress screening and referral programs for caregivers may be key.
Join the Cancer Experience Registry!

The CER is an online research study that aims to understand the emotional, physical, practical, and financial impact of cancer and identify unmet needs among patients, survivors, and caregivers.
Thank you

CancerSupportCommunity.org/Registry