WHO GIVES CARE TO THE CAREGIVER?

Allison J. Applebaum, PhD
Director, Caregivers Clinic
Assistant Attending Psychologist
Department of Psychiatry and Behavioral Sciences
Memorial Sloan Kettering Counseling Center
New York, NY

DISCLOSURES
Who Gives Care to the Caregiver?

Allison J. Applebaum, PhD, has no disclosures.
Who Gives Care to the Caregiver
The Leukemia & Lymphoma Society

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Director, Caregivers Clinic
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Who are Caregivers?

- Formal caregivers
- Informal caregivers (ICs)

World Health Organization (WHO) estimates that ~8% of the global population is dependent on others for care:

- 1/3 US households in 2017 had an IC
- 65.7 million Americans, 4.6 million of whom provide care to patients with cancer
- ICs are predominantly female and providing care to a parent, and over 1/3 provide care to two or more people
What Do Caregivers Do?

- Instrumental support
  - Activities of daily living (ADL)
- Emotional support
- On average, ICs provide care for 8.3 hours/day, for 13.7 months
- 1/3 ICs provide care for 5+ years
- Annual economic value of caregiving in the U.S. was recently estimated at $375 billion

Caregiver Experience in Cancer Care

Figure 3: Duration of Care

<table>
<thead>
<tr>
<th>Duration of Care</th>
<th>Cancer Caregivers (n=111)</th>
<th>Non-cancer Caregivers (n=1,164)</th>
<th>Average Years</th>
</tr>
</thead>
<tbody>
<tr>
<td>Less than 6 months</td>
<td>38%</td>
<td>20%</td>
<td>1.9</td>
</tr>
<tr>
<td>6 months to 1 year</td>
<td>20%</td>
<td>19%</td>
<td></td>
</tr>
<tr>
<td>1 to 4 years</td>
<td>24%</td>
<td>28%</td>
<td></td>
</tr>
<tr>
<td>5 to 9 years</td>
<td>6%</td>
<td>13%*</td>
<td></td>
</tr>
<tr>
<td>10 years or more</td>
<td>3%</td>
<td>13%*</td>
<td></td>
</tr>
</tbody>
</table>

Caregiving in the U.S., 2016; www.caregiving.org
Caregiver Experience in Cancer Care

Figure 5: Hours of Care per Week

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

*Caregiving in the U.S., 2016; www.caregiving.org

Caregiver Experience in Cancer Care

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

- Does tasks & was prepared: 13% Cancer Caregivers, 28%* Non-cancer Caregivers
- Does tasks, not prepared: 43% Cancer Caregivers, 42% Non-cancer Caregivers
- Does not do tasks: 27% Cancer Caregivers, 42%* Non-cancer Caregivers

72% of Cancer Caregivers do Medical/Nursing tasks
50% of Non-cancer Caregivers do Medical/Nursing tasks

*Caregiving in the U.S., 2016; www.caregiving.org
Demands exceed resources

Caregiver Burden

- Multi-dimensional
  - Psychological
    - Anxiety
    - Depression
  - Physical/Medical
    - Cardiovascular disease
    - Poor immune functioning
    - Fatigue/sleep difficulties
    - Higher rates mortality
- Financial
- Temporal
- Existential
Existential Distress

- Multi-dimensional
  - Hopelessness
  - Powerlessness
  - Questions about identity
  - Feeling like a burden to others
  - Decreased sense of meaning and purpose
  - Guilt
  - Death anxiety

Distress Across the Caregiving Trajectory

Diagnosis → Treatment → Survivorship → Recurrence → Disease Progression → Hospice → Bereavement
Cancer Caregivers are Cancer Survivors

• NCI (2013) definition of Cancer Survivor:

“An individual is considered a cancer survivor from the time of diagnosis, through the balance of his or her life. Family members, friends, and caregivers are also impacted by the survivorship experience and are therefore included in this definition.”

During survivorship, caregivers are at greater risk for distress than patients

• Caregivers of long term cancer survivors report significant health problems, including heart disease, hypertension and arthritis.

• Caregivers report lower QOL and receiving less social support than do patients.

• Fear of recurrence is equal if not greater among caregivers than patients.

• Navigating return to full-time employment and shifting family roles requires negotiation.

Kim et al., 2010, 2012; Lambert et al., 2012; Papastavrou et al., 2009.
During survivorship, caregivers are at greater risk for psychopathology than patients

- Baseline levels of anxiety and depression higher among caregivers than patients.

- Symptoms remained stable over 2 year survivorship period (4 groups modeled).

- Levels of anxiety and depression remained constant across time points from 6 months to 5 years post diagnosis.

Institute of Medicine (IOM, 2008)
“Retooling for an Aging America: Building the Health Care Workforce”

Highlighted the responsibility of health care professionals to prepare caregivers for their role and the need to establish programs to assist them with managing their own stress that results from providing care.
How to Get Help

• Recognize signs and symptoms of burden

• Activate support networks
  – Challenge yourself to ask for help
  – Support may come from unlikely sources

• Recognize what is meant by self-care
  – Guilt is a red flag
  – Self-care includes expressing emotions

Professional Support
Professional Support

• Many cancer centers have licensed clinical psychologists, social workers, and mental health professionals who specialize in supporting families facing cancer. Just ask!

• Phenomenal resources through organizations such as:
  – American Cancer Society
  – Cancer Support Community
  – CancerCare
  – The Leukemia & Lymphoma Society

Most frequent presenting complaints:
  – Difficulty communicating with patients and/or healthcare professionals
    • Advanced Care Planning
    • Networks of silence
  – Generalized Anxiety Disorder
  – Insomnia and related distress
  – Maintaining a balance between caregiving and self-care
  – Guilt
  – Existential distress, Death anxiety
• Titles/abstracts of 2,199 articles reviewed, N=49 interventions included:
  • 13 psychoeducation
  • 10 supportive tx
  • 10 problem-solving/skills building
  • 8 family/couples tx
  • 4 CBT/IPT
  • 4 CAM/Sleep/Relaxation/Massage.

• 88% delivered in person, 6% over the phone, 6% combined in-person and telephone sessions.

• 61% delivered to caregiver/patient dyad or family, 37% to individuals, 14% groups of caregivers.
  • **Desire for caregiver-specific interventions**

• Successful interventions were time limited, flexibly administered, and integrative.
  • No interventions focused on existential distress, despite N=9 identifying this as an area that is critical for further study.

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**Caregiver-Specific Interventions (2018)**

• Cognitive Behavioral Therapy for Insomnia (CBT-I)

• Problem-Solving Therapy

• Meaning-Centered Psychotherapy for Cancer Caregivers (MCP-C)

• Emotion Regulation Therapy for Cancer Caregivers (ERT-C)

• Communication skills training programs
Self-Care

What is Self-Care?

• Self-care is about being deliberate in taking time for yourself for the betterment of your mind, body and soul.

• Self-care is NOT about being selfish. It is about replenishing and refreshing your spirit in different ways.
When is Self-Care Needed?

• ALWAYS.

• When burden is high:
  – No longer able to carry out responsibilities
  – Increased anger
  – More frequent medical problems
  – Poor health-related behaviors
  – Direct communication of depressive symptoms/suicidal ideation

Self-Care Tips

• Schedule self-care as you would a medical appointment or work meeting
• Integrate one self-care activity into every day, more on stressful days
• Take an honest look at your current coping strategies
• Think SMALL
• Make sure self-care activities are in line with good sleep hygiene
Autogenic Relaxation Instructions

This exercise lowers physiological stress, increases blood flow, and decreases muscle tension through the repetition of simple words and phrases. The script below is one example of many variations. The script may be memorized or recorded on tape:

My right arm is warm and heavy. My right arm is warm and heavy.
My left arm is warm and heavy. My left arm is warm and heavy.
My right arm and my left arm are warm and heavy. My right arm and my left arm are warm and heavy.
My forehead is calm and relaxed. My forehead is calm and relaxed.
My face is calm and relaxed. My entire head is calm and relaxed.
My chest is warm and heavy. My chest is warm and heavy.
My stomach is calm and relaxed. My entire upper body is warm and heavy, calm and relaxed.
My right thigh is warm and heavy. My right thigh is warm and heavy.
My right lower leg is calm and relaxed. My right lower leg is calm and relaxed.
My left thigh is warm and heavy. My left leg is warm and heavy.
My left lower leg is calm and relaxed. My entire right leg and my entire left leg are warm and heavy, calm and relaxed.
My entire body is warm and heavy, calm and relaxed. My entire body is warm and heavy, calm and relaxed.
Caregiving and Sleep Disturbance
Shaffer, 2017

What is Insomnia?
• Rule of 3s:
  – > 30 minutes: fall asleep, waking in night, before alarm
  – >3 nights per week
  – >3 months

… despite adequate opportunity

… & distress / impairment
Insomnia Treatment

<table>
<thead>
<tr>
<th>Question</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>What time did you go to bed?</td>
<td>10:15 PM</td>
</tr>
<tr>
<td>What time did you try to go to sleep?</td>
<td>11:50 PM</td>
</tr>
<tr>
<td>How long did it take you to fall asleep?</td>
<td>55 mins</td>
</tr>
<tr>
<td>How many times did you wake up not counting your final awakening?</td>
<td>3</td>
</tr>
<tr>
<td>In total, how long did these awakenings last?</td>
<td>1 hour 10 mins</td>
</tr>
<tr>
<td>What time was your final awakening?</td>
<td>6:55 AM</td>
</tr>
<tr>
<td>What time did you get out of bed for the day?</td>
<td>7:20 AM</td>
</tr>
</tbody>
</table>

8. How would you rate the quality of your sleep?  
- Very poor
- Poor
- Fair
- Good
- Very good

The Benefits of Being a Caregiver
Challenges Faced by Informal Caregivers

Applebaum et al., 2013

Providing Care to a Loved one with Cancer

Applebaum et al., 2013
“Marriage is just as effective as chemotherapy.”
- Rebecca Johnson, M.D.

Cancer caregivers are the next generation of cancer patients.
Thank You!

QUESTION & ANSWER SESSION
LLS EDUCATION & SUPPORT RESOURCES

- Information Specialists
  Master’s level oncology professionals, available to help cancer survivors navigate the best route from diagnosis through treatment, clinical trials and survivorship.
  - EMAIL: infocenter@LLS.org
  - TOLL-FREE PHONE: 1-800-955-4572

- Free Education Booklets:
  - www.LLS.org/booklets

- Free Telephone/Web Programs:
  - www.LLS.org/programs

- Live, weekly Online Chats:
  - www.LLS.org/chat

LLS EDUCATION & SUPPORT RESOURCES

- LLS Podcast, The Bloodline with LLS
  Listen in as experts and patients guide listeners in understanding diagnosis, treatment, and resources available to blood cancer patients: www.thebloodline.org

- Education Videos
  Free education videos about survivorship, treatment, disease updates and other topics: www.LLS.org/educationvideos

- Patti Robinson Kaufmann First Connection Program
  Peer-to-peer program that matches newly diagnosed patients and their families: www.LLS.org/firstconnection

- Free Nutrition Consults
  Telephone and email consultations with a Registered Dietitian: www.LLS.org/nutrition

- What to Ask
  Questions to ask your treatment team: www.LLS.org/whattoask

- LLS Community
  Join the community of blood cancer patients, survivors and caregivers: www.LLS.org/community

- Other Support Resources
  Blogs, support groups, financial assistance and more: www.LLS.org/support
THANK YOU

We have one goal: A world without blood cancers