Preventing and Managing Caregiver Burnout

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Introduction

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Learning Objectives

01 Describe the health effects of spousal caregiving in later life

02 Describe self-care strategies to optimize health and wellbeing for older family caregivers

03 Describe bereavement after caregiving
1. Health Effects of Family Caregiving

WHAT ARE THE EMOTIONAL AND PHYSICAL EFFECTS OF CAREGIVING IN LATE-LIFE?
1 in 5 adults (53 million people) in the US are providing unpaid care to a family member with health or functional needs.

More family caregivers (26%) have difficulty coordinating care up from 19% in 2015.

More Americans (26%) are caring for someone with Alzheimer’s disease or dementia up from 22% in 2015.

More Americans (23%) say caregiving has made their own health worse up from 17% in 2015.

Family caregiving spans across all generations, including Boomers, Gen-X, Gen-Z, Millennials, and Silent.

61% of family caregivers are also working.  

AARP Public Policy Institute
Caregiver statistics

Typical caregivers are middle-aged adult children and older spouses who care for a parent or spouse with functional limitations.

Economic value: The value of services provided by caregivers has steadily increased over the last decade, with an estimated economic value of $470 billion in 2013, up from $450 billion in 2009.
Caregiving Tasks

• On average, caregivers spend:
  • 13 days each month on tasks such as shopping, food preparation, housekeeping, laundry, transportation, and giving medication;
  • 6 days per month on feeding, dressing, grooming, walking, bathing, and assistance toileting;
  • 13 hours per month researching care services or information on disease, coordinating physician visits or managing financial matters.

• On average, caregivers perform 2 of 6 ADLs, most commonly getting in and out of beds and chairs (43%).

• On average, caregivers perform 4.2 of 7 IADLs, most commonly transportation (78%), grocery or other shopping (76%), and housework (72%).

• 57% of caregivers report that they do not have a choice about performing clinical tasks, and that this lack of choice is self-imposed.
  • 43% feel that these tasks are their personal responsibility because no one else can do it or because insurance will not pay for a professional caregiver.
  • 12% report that they are pressured to perform these tasks by the care receiver.
  • 8% report that they are pressured to perform these tasks by another family member.

National Alliance for Caregiving and AARP. (2015). Caregiving in the U.S.
Number of Hours Dedicated to Caregiving by Age of Family Caregiver
Caregiver Gender and Care Tasks

Gender: approximately 75% of all caregivers are female, and may spend as much as 50% more time providing care than males.

Males may be sharing in caregiving tasks more than in the past, but females still shoulder the major burden of care: (21.9 vs. 17.4 hours per week).

Among spousal pairs aged 74+ years, males and females spend equal among of time providing care.

36% of female caregivers handle the most difficult caregiving tasks (bathing, toileting, and dressing) when compared with 24% of males, who are more likely to help with finances, arrangement of care, and other less burdensome tasks.
Caregiving is a risk factor for mortality

(Schulz & Beach, 1999, JAMA)

Most of the early research in caregiving focused on the negative health effects of family caregiving.

Caring for an elderly individual with disability is burdensome and stressful to many family members and contributes to psychiatric morbidity.

Being a caregiver who experiences mental or emotional strain was an independent risk factor for mortality.
Positive Aspects of Family Caregiving

Many family caregivers (>80%) report positive experiences including

- a sense of giving back to someone who has cared for them
- the satisfaction of knowing that their loved one is getting excellent care
- personal growth
- increased meaning and purpose in one’s life

Caregivers who perceive more benefits from caregiving report lower levels of depression.

Caregivers may experience both emotional distress and psychological satisfaction and growth.
2. Self-care Strategies for Family Caregivers
Self-care for Caregivers

Taking care of oneself is one of the most important things caregivers can do.

Many times, caregivers can forget to take care of themselves simply because they are feeling stressed or overwhelmed with their caregiving responsibilities.

Some signs of caregiver stress include not getting enough sleep, gaining or losing weight, losing interest in activities you used to enjoy, and having frequent headaches or other physical problems.
Self-care Tips from Caregivers Themselves

01 Find ways to exercise, especially in the morning
02 Focus on sleep
03 Socialize and spend time with others
04 Join a caregiver support group
05 Seek professional help from a counselor or therapist
How Can we Encourage Caregivers to engage in self-care?

Include the care recipient: Alice, (72 years) started including her husband in her yoga/stretching routine and she loved that it got her husband “out of his chair” and it felt like they were doing something “together, as a couple.”

Opportunity to vent: Most caregivers want to feel validated and heard and need a space (support group, therapist, group exercise class) to talk.
Emerging Strategies to Optimize Caregivers’ Health and Wellbeing

- Focusing on morning activity
  - May reduce caregiver distress like depression and anxiety

- MyRhythm App to monitor the 24-hr sleep and activity
  - May help caregivers increase their sleep drive and promote a strong circadian rhythm
3. Bereavement after Caregiving
What does bereavement do to your body?

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<thead>
<tr>
<th>Emotional reactions</th>
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<td>Cognitive difficulties</td>
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<td>Physical ailments</td>
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<td>Immune and endocrine changes</td>
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<td>Circadian rhythm changes</td>
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Does caregiving prior to death impact adjustment post-death?

- Cancer caregiving
- Dementia caregiving
Bereavement after cancer caregiving

Loss due to cancer can be particularly challenging
- Exhausting caregiving situation
- Witnessing and managing depression symptoms
- Being socially isolated while providing care

Persons bereaved by cancer more susceptible to negative outcomes compared to those bereaved by other causes of death
- Depression
- Anxiety
- Complicated Grief
- Loneliness
Bereavement after cancer caregiving

It is possible that cancer caregivers have better bereavement outcomes because they
- Are prepared for the death
- Experience anticipatory grief
Bereavement outcomes by cause of death

Compared to those bereaved by other causes of death, those who lost their spouses/partner to cancer
  ◦ more depressed
  ◦ more grief
Bereavement outcomes by cause of death and death expectedness

Does death expectedness lessen depression and grief symptoms?

- Yes, but for non-cancer deaths only
- Why? Treatment is often described as “battle.” Death may signify a “battle lost” which takes a toll on survivors, despite the death being expected.
Bereavement after dementia caregiving

After an extended period of caregiving, the death of a family member with dementia can provide a sense of relief to individuals because caregiving has ended and their loved one is no longer suffering.

- Feelings of relief are common
- Is caregiver relief associated with adjustment post-loss?
What predicts feelings of caregiver relief?

It depends on the stage of dementia

Mild-to moderate dementia
- Preparedness prior to death is the greatest predictor of caregiver relief

Severe dementia
- Care recipient suffering is the strongest predictor of caregiver relief
Caregiver relief promotes adjustment

Caregiver relief is associated with fewer symptoms of complicated grief, especially among those caregivers of patients with severe dementia.

From a clinical perspective, we need to reassure individuals that feelings of relief after a loved one’s death are common and warranted following their role as a family caregiver.
Caregiving has both positive and negative effects overall health.

Self-care is important for the health and well-being of the caregiver, and it may impact the quality of care received by the care recipient.

Individuals’ caregiving experience impacts their adjustment to bereavement.
Thank you

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