

Preventing and Managing Caregiver Burnout

SARAH T. STAHL, PHD

ASSOCIATE PROFESSOR AND PSYCHIATRY AND CLINICAL & TRANSLATIONAL SCIENCE

UNIVERSITY OF PITTSBURGH

Introduction



Funding: supported in part by R01
MH118270, MH132114 and CTSI
UL1TR000005



Clinical Trials ID: NCT04016896



No conflicts to disclose

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

WHAT ARE THE
EMOTIONAL AND
PHYSICAL EFFECTS
OF CAREGIVING IN
LATE-LIFE?

1. Health Effects of Family Caregiving

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.

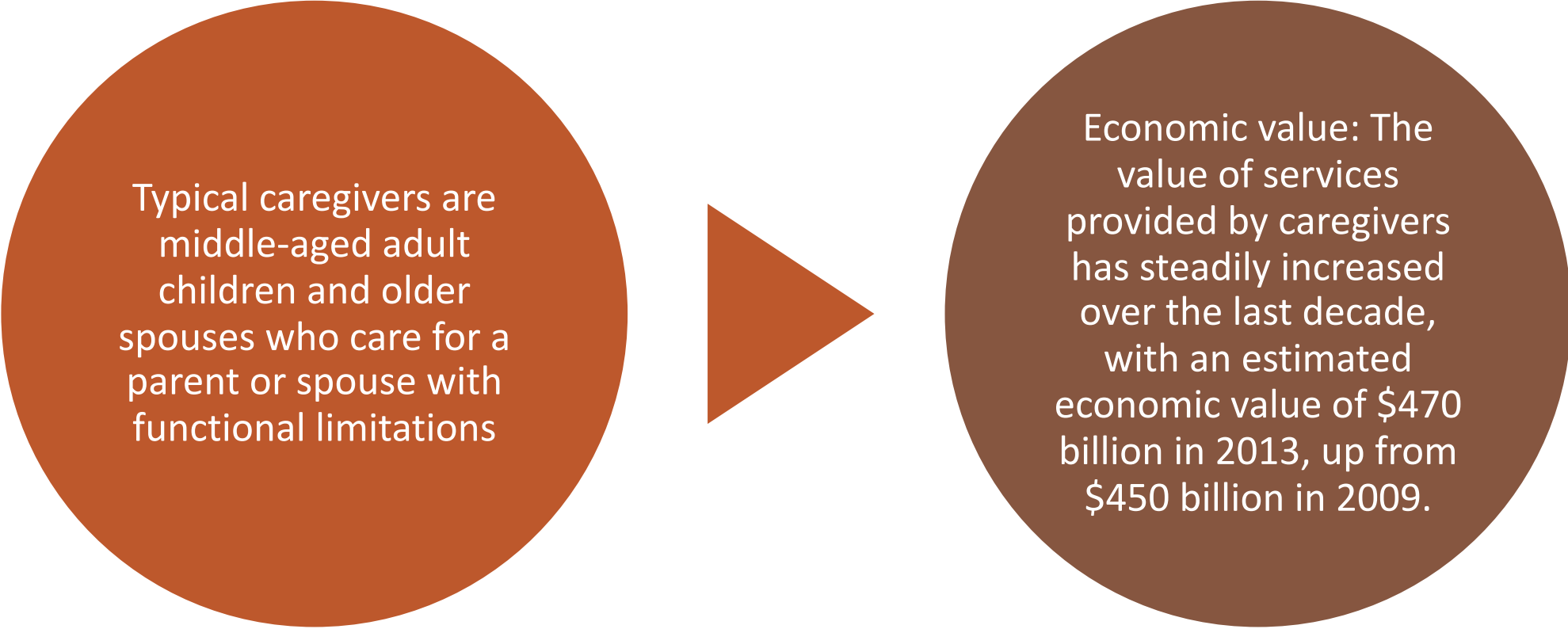
Family caregiving spans across all generations, including Boomers, Gen-X, Gen-Z, Millennials, and Silent.

61% of family caregivers are also working.

AARP Public Policy Institute

Family Caregiving Statistics

Caregiver statistics



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

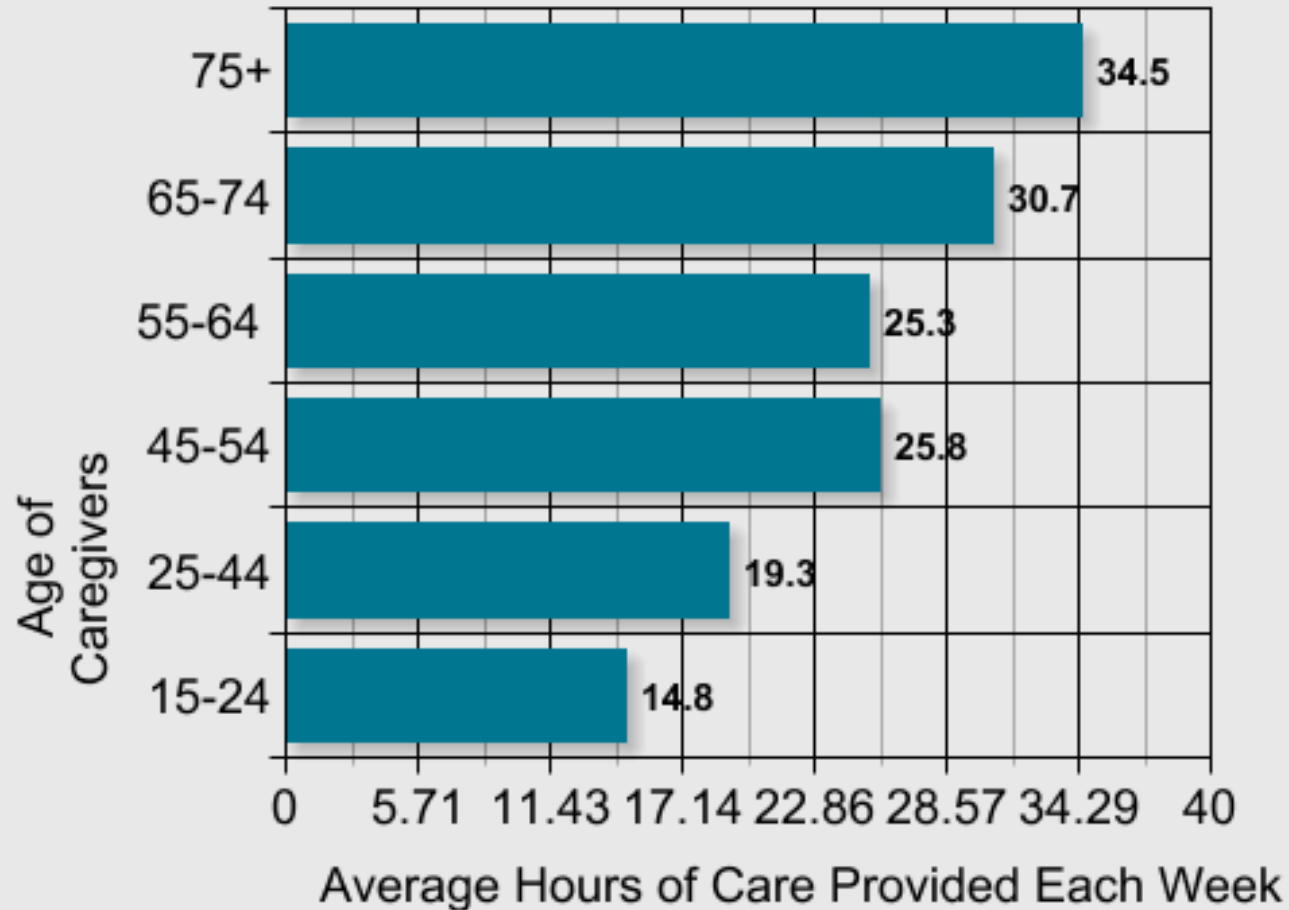
Economic value: The value of services provided by caregivers has steadily increased over the last decade, with an estimated economic value of \$470 billion in 2013, up from \$450 billion in 2009.

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.]

Hours Dedicated to Caregiving



Number of Hours Dedicated to Caregiving by Age of Family Caregiver

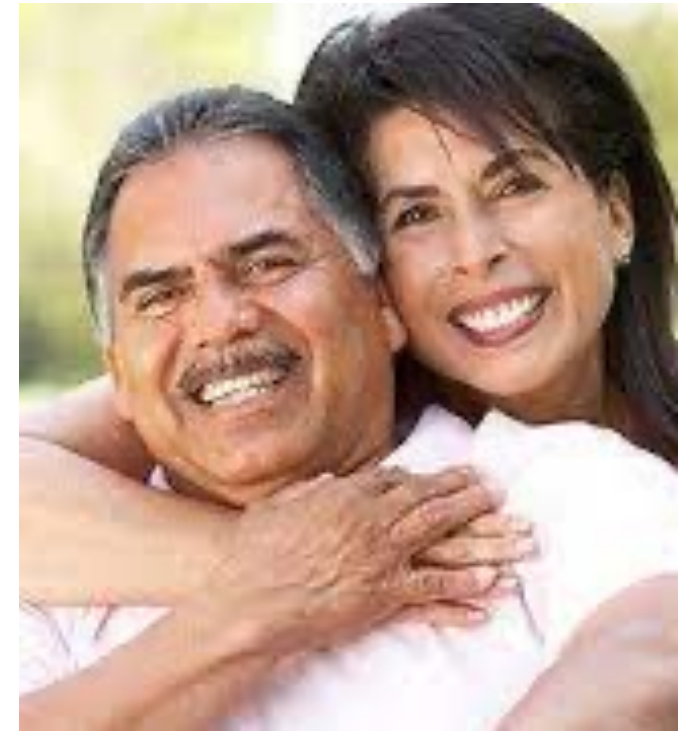
Caregiver Gender and Care Tasks

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 amount 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



Health Effects of Family Caregiving

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



Caregiving is a risk factor for mortality

(Schulz & Beach, 1999, JAMA)

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

Being a caregivers 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.

HOW CAN WE
OPTIMIZE HEALTH
AND WELLBEING IN
FAMILY
CAREGIVERS?

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

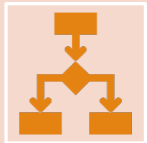
05

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.”

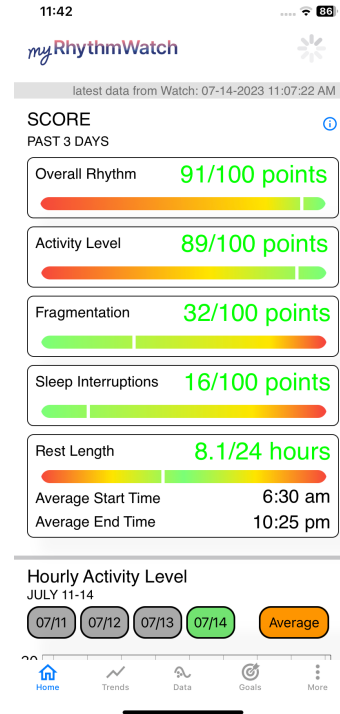
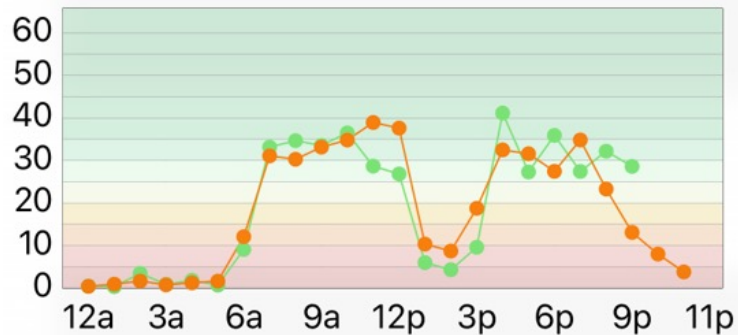


Opportunity to vent: Most caregivers want to feel validated and heard and need a space (support group, therapist, group exercise class) to talk.

Emerging Strategies to Optimize Caregivers' Health and Wellbeing

Hourly Activity Level

JULY 12-15



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

DOES THE TYPE OF
CAREGIVING
MATTER IN TERMS
OF BEREAVEMENT
OUTCOMES?

3. Bereavement after Caregiving

What does bereavement do to your body?

Emotional reactions

Cognitive difficulties

Physical ailments

Behavioral changes

Immune and endocrine changes

Circadian rhythm changes



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

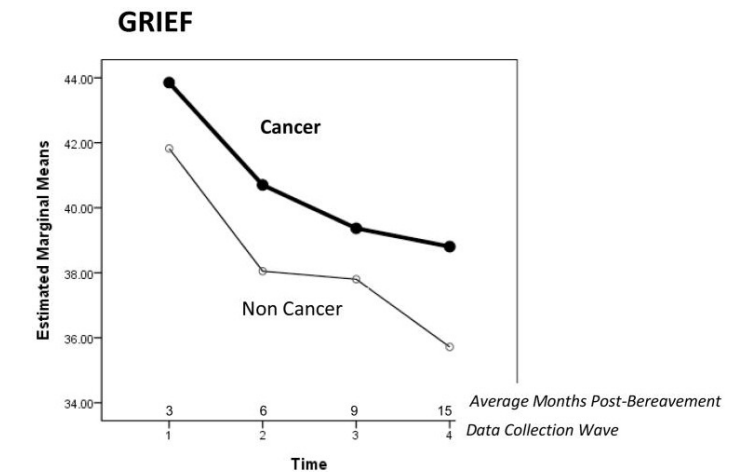
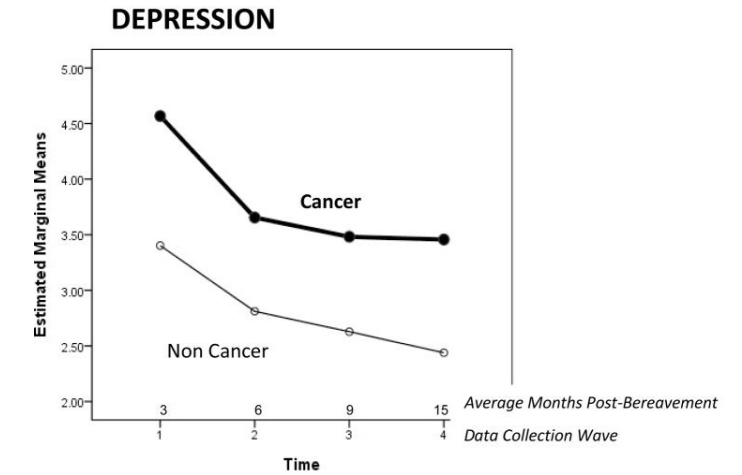
- Are prepared for the death
- Experience anticipatory grief



Bereavement outcomes by cause of death

Compared to those bereaved by other causes of death, those who lost their spouses/partner to cancer

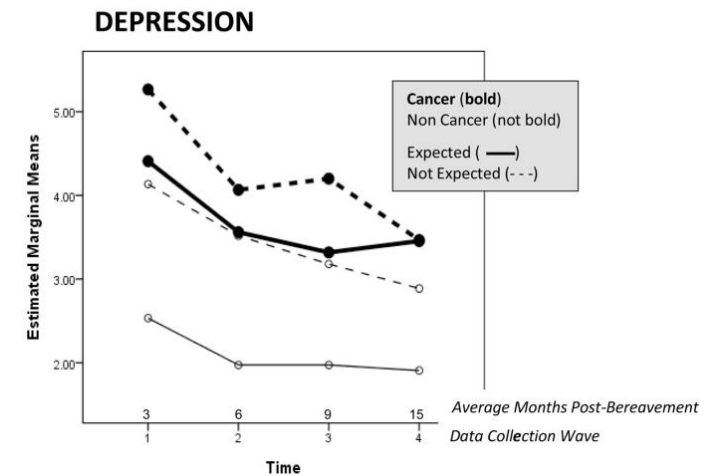
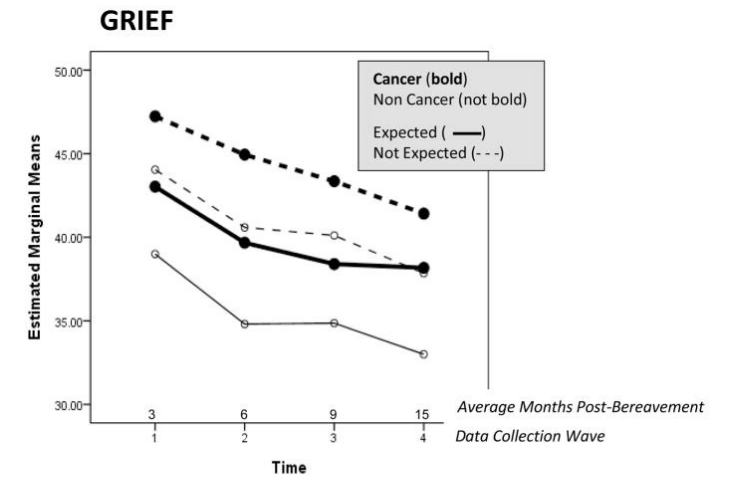
- more depressed
- more grief



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

01

Caregiving has both positive and negative effects overall health.

02

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.

03

Individuals' caregiving experience impacts their adjustment to bereavement.

Summary

