CAREGIVERS

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Objectives

- To provide an overview of dementia caregiving in the U.S.
    - The Alzheimer's Association (2022). *2022 Alzheimer's Disease Facts and Figures*. The Alzheimer's Association: Chicago, IL. Available: https://www.alz.org/media/documents/alzheimers-facts-and-figures.pdf
- To consider whether dementia caregiving is a public health concern
- To review opportunities for engagement with the BOLD Public Health Center of Excellence on Dementia Caregiving (PHCOE-DC)

The Scope of Dementia Caregiving

- 83% of all help provide to older people in the U.S. comes from family members or other unpaid individuals
- Nearly half of all caregivers (48%) provide help to someone with ADRD
- More than 11 million dementia caregivers in U.S.
- 16 billion hours of dementia care = **$271.6 billion**

Why?

- A desire to keep a family member or friend at home (65%)
- Proximity to the person with dementia (48%)
- Perceived obligation to the person with dementia (38%)
  - Sense of love and duty

Who are dementia caregivers?

2/3 are women	30% are 65+	60% married/long-term partnership
Over half providing care to parent/PiL	2/3 White, 10% Black, 8% Hispanic, 5% Asian American	41% have a household income of <$50,000
2/3 live with the care recipient	¼ are “sandwich” generation caregivers	57% have provided care for 4+ years
Of those who provide >40 hours/week of care, 73% are women	Black caregivers are 69% less likely to use respite services	More Black caregivers provide >40 hours of care per week (54.3% versus 38.6%) than White caregivers .

What do dementia caregivers do?

Help the person with instrumental activities of daily living (IADLs)

Help the person take medications correctly

Help the person adhere to treatment recommendations for dementia or other medical conditions

Assist with personal activities of daily living (ADLs)

Manage behavioral symptoms of the disease

Find and use support services

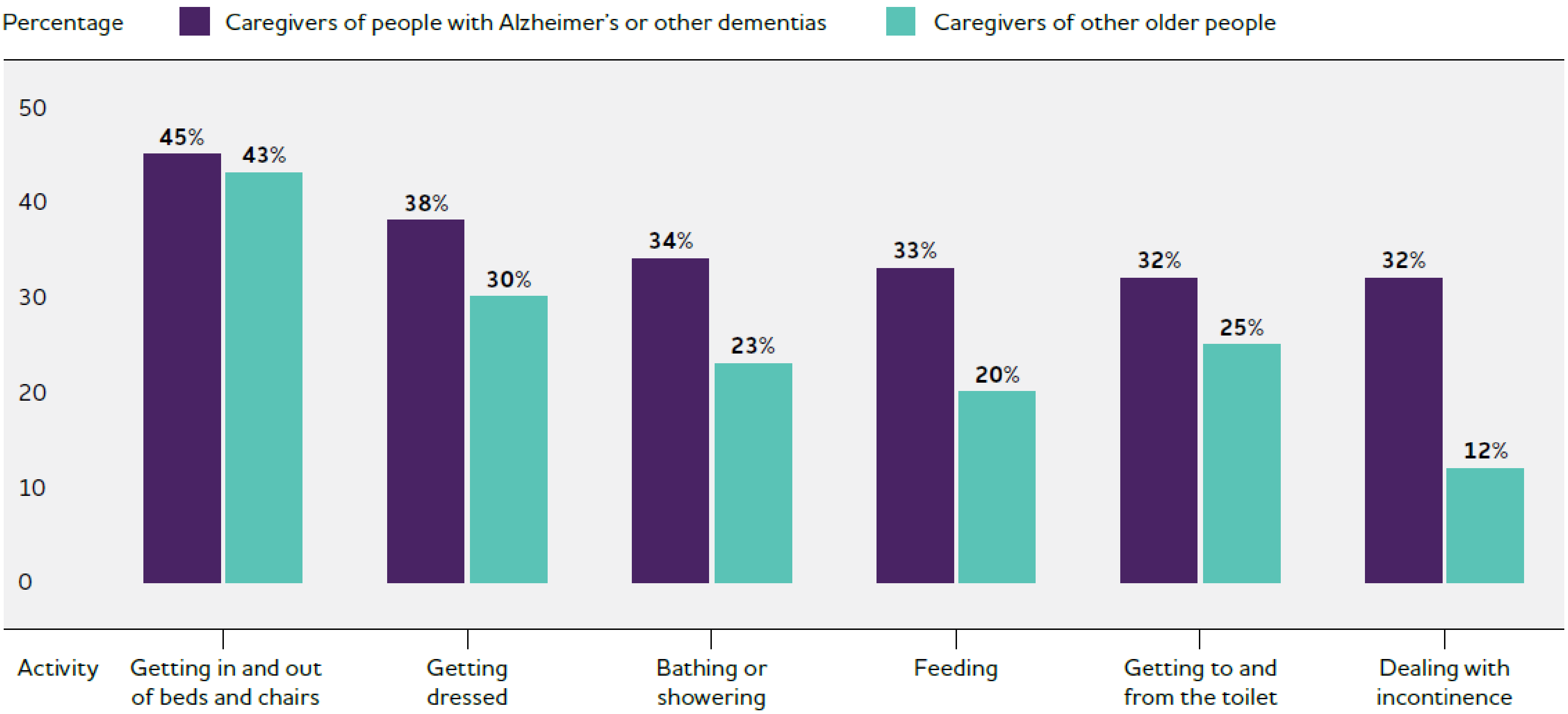
Make arrangements for paid in-home, nursing home or assisted living care

Hire and supervise others who provide care

And much more…

figure **9**

Proportion of Caregivers of People with Alzheimer's or Other Dementias Versus Caregivers of Other Older People Who Provide Help with Specific Activities of Daily Living, United States, 2015



Created from data from the National Alliance for Caregiving in Partnership with the Alzheimer's Association.[398]

Duration of caregiving

- A desire to keep a family member or friend at home (65%)
- Proximity to the person with dementia (48%)
- Perceived obligation to the person with dementia (38%)
  - Sense of love and duty

Minnesota vs. Tennessee Compariso

State	Number of caregivers (in thousands)	Hours of unpaid care (in millions)	Value of unpaid care (in millions)
Minnesota	171	156	3,358
Tennessee	361	489	6,901

What are the effects of caregiving?

Twice as many dementia CGs indicate emotional, financial, and physical difficulties that non-dementia CGs	Spousal dementia care is associated with a 30% increase in depressive symptoms compared with non-dementia CGs	Dementia CGs are twice as likely as non-dementai CGs to report difficulty when completing medical/nursing related tasks (22% vs. 11%)
41% of dementia caregivers provide help alone	In the year before the death of the person living with dementia 59% of caregivers felt they were "on duty" 24 hours a day	45% indicated dementia care as very rewarding

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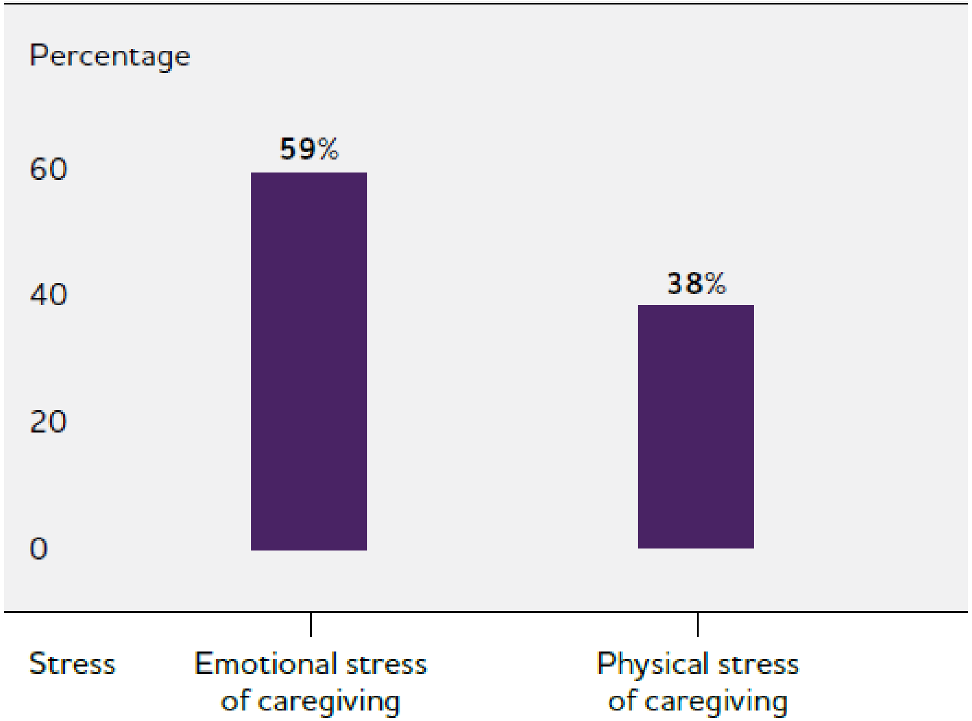
What are the effects of caregiving?

figure **10**

Percentage of Caregivers Who Report High to Very High Stress Due to Caregiving



Created from data from the Alzheimer's Association.[A9]

What are the effects of caregiving?

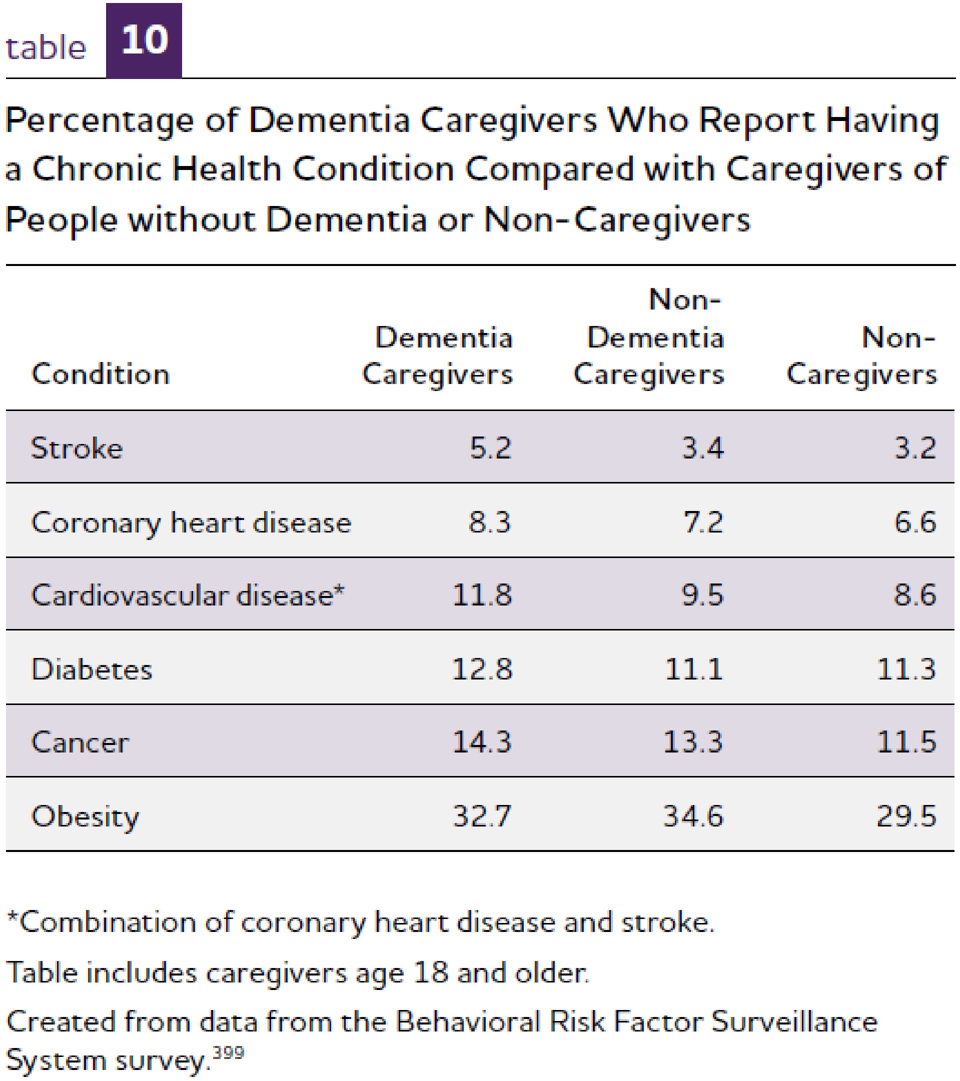


table **10**

Percentage of Dementia Caregivers Who Report Having a Chronic Health Condition Compared with Caregivers of People without Dementia or Non-Caregivers

Condition	Dementia Caregivers	Non-Dementia Caregivers	Non-Caregivers
Stroke	5.2	3.4	3.2
Coronary heart disease	8.3	7.2	6.6
Cardiovascular disease*	11.8	9.5	8.6
Diabetes	12.8	11.1	11.3
Cancer	14.3	13.3	11.5
Obesity	32.7	34.6	29.5

*Combination of coronary heart disease and stroke.

Table includes caregivers age 18 and older.

Created from data from the Behavioral Risk Factor Surveillance System survey.[399]

Minnesota vs. Tennessee Compariso

State	Percentage of Caregivers Reporting at Least One Chronic Condition	Percentage of Caregivers Reporting Depression	Percentage of Caregivers Reporting Frequent Poor Physical Health
Minnesota	55.3	29.9	14.4
Tennessee	66.7	29.8	17.0

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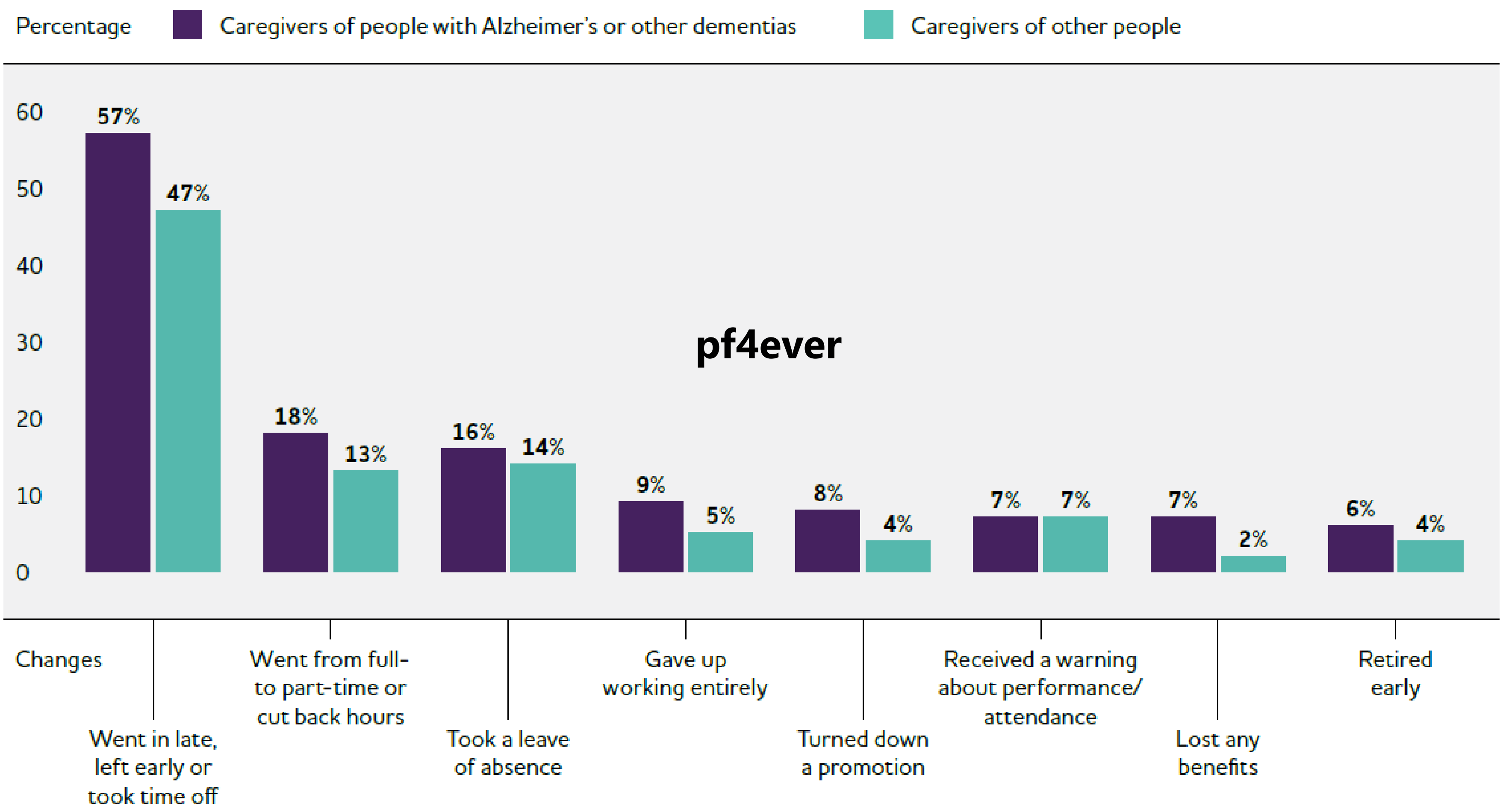
figure **11**

Work-Related Changes Among Caregivers of People with Alzheimer's or Other Dementias Who Had Been Employed at Any Time Since They Began Caregiving



Created from data from the National Alliance for Caregiving in Partnership with the Alzheimer's Association.[398]

What can we do? Interventions

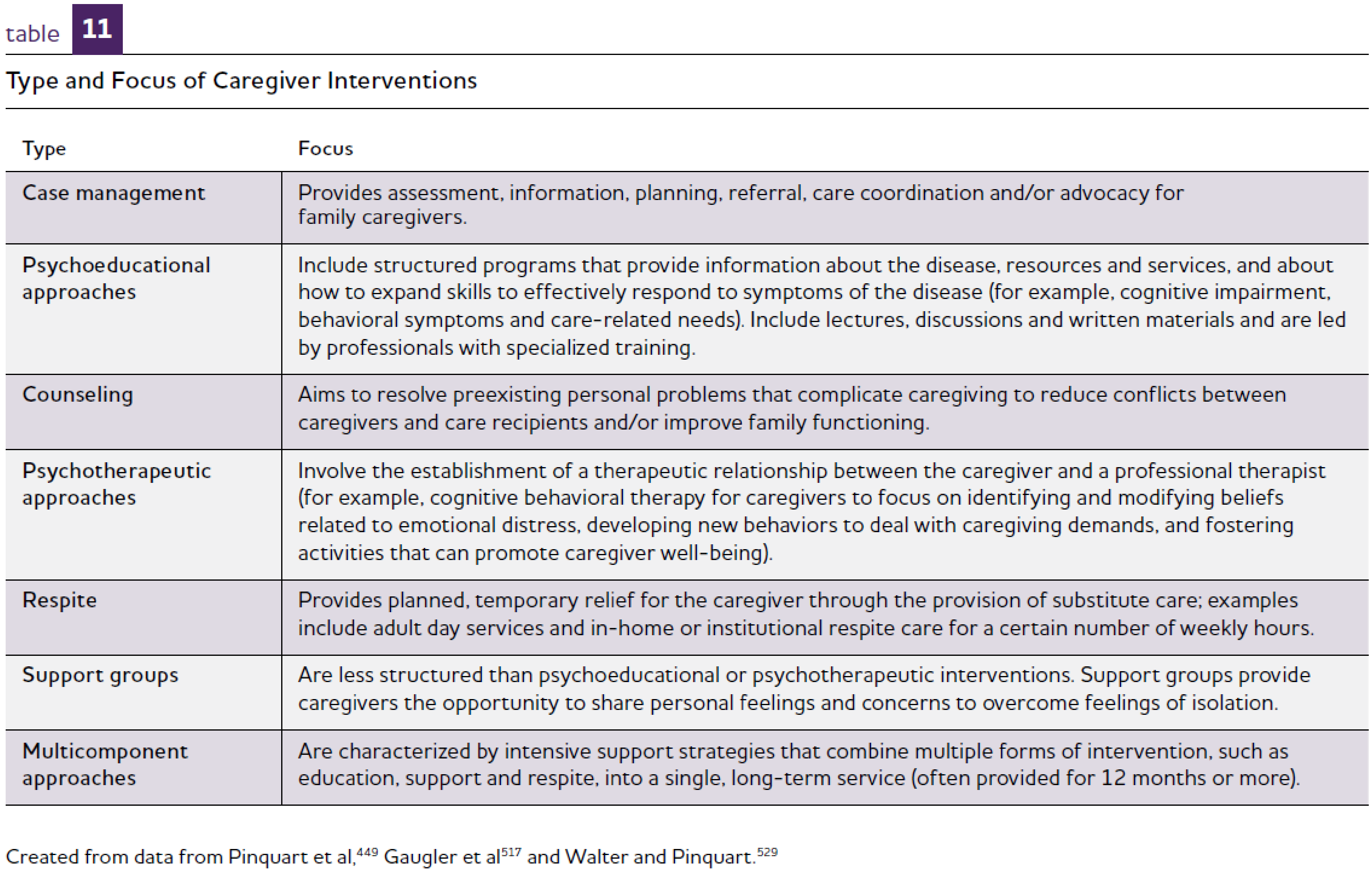


table **11**

Type and Focus of Caregiver Interventions

Type	Focus
Case management	Provides assessment, information, planning, referral, care coordination and/or advocacy for family caregivers.
Psychoeducational approaches	Include structured programs that provide information about the disease, resources and services, and about how to expand skills to effectively respond to symptoms of the disease (for example, cognitive impairment, behavioral symptoms and care-related needs). Include lectures, discussions and written materials and are led by professionals with specialized training.
Counseling	Aims to resolve preexisting personal problems that complicate caregiving to reduce conflicts between caregivers and care recipients and/or improve family functioning.
Psychotherapeutic approaches	Involve the establishment of a therapeutic relationship between the caregiver and a professional therapist (for example, cognitive behavioral therapy for caregivers to focus on identifying and modifying beliefs related to emotional distress, developing new behaviors to deal with caregiving demands, and fostering activities that can promote caregiver well-being).
Respite	Provides planned, temporary relief for the caregiver through the provision of substitute care; examples include adult day services and in-home or institutional respite care for a certain number of weekly hours.
Support groups	Are less structured than psychoeducational or psychotherapeutic interventions. Support groups provide caregivers the opportunity to share personal feelings and concerns to overcome feelings of isolation.
Multicomponent approaches	Are characterized by intensive support strategies that combine multiple forms of intervention, such as education, support and respite, into a single, long-term service (often provided for 12 months or more).

Created from data from Pinquart et al,[449] Gaugler et al[517] and Walter and Pinquart.[529]

Why is Dementia Caregiving an Important Public Health Priority? (Bouldin et a 2021)

- It affects the health of the population—including both caregivers and care recipients
- The effects may be unequally borne by some members of that population
- There are effective prevention strategies that could be employed to reduce these negative impacts.
- **What can public health do to help dementia caregivers?**

What Can Public Health Do? (Bouldin et al., 2021)

- Public health has a role in measuring the number of caregivers and documenting their experiences and health status
- Educate caregivers about health risks they might be facing, providing them information about effective programs to reduce stress or their financial burden, and giving them skills to support the care recipient
- Develop health-related awareness and education campaigns

What Can Public Health Do? (Bouldin et al., 2021) (cont.)

- Support community meetings and activities related to health advocacy
- Draft or provide input on ordinances, policies, and laws all fall under possible public health activities
- Assure that people have access to information and effective programs
  - Evidence-based interventions that reduce caregiver burden
  - Provide caregivers with training to complete medical tasks or manage difficult behaviors
    - Both may involve linking people to healthcare or service organizations or offering programs through entities like local public health departments.

Public Health and Dementia Caregiv
What Next? (Splaine, 2022)

- Group 1: “I Don’t See Dementia Caregiving as a Public Health Issue”
  - Continue with data. Build some message visuals about caregiver health.
  - Tweak the message “Caregiver health”
  - Pull in KOL’s from NASEM report and Richard Schulz
  - Highlight in public health e news.
  - Point to BOLD center.
  - Stimulate new review articles/contest/AAIC/special journal issue.
  - Find testimonials (NY, AZ)
  - Address state public health associations.
  - Assess our academic public health curriculum for update or offering programs through entities like local public health departments.

Public Health and Dementia Caregiv
What Next? (Splaine, 2022)

- Group 2: "I Get It. What Do You Want Me to Do About It?"
  - More state specific BRFSS analysis with cross tabs.
  - Promote identification of caregivers in health systems.
  - A young (30-55 year old) caregivers town hall meeting
  - 99483 campaigns and capacity building on care planning.
  - Engage the consumer voice in policy process.

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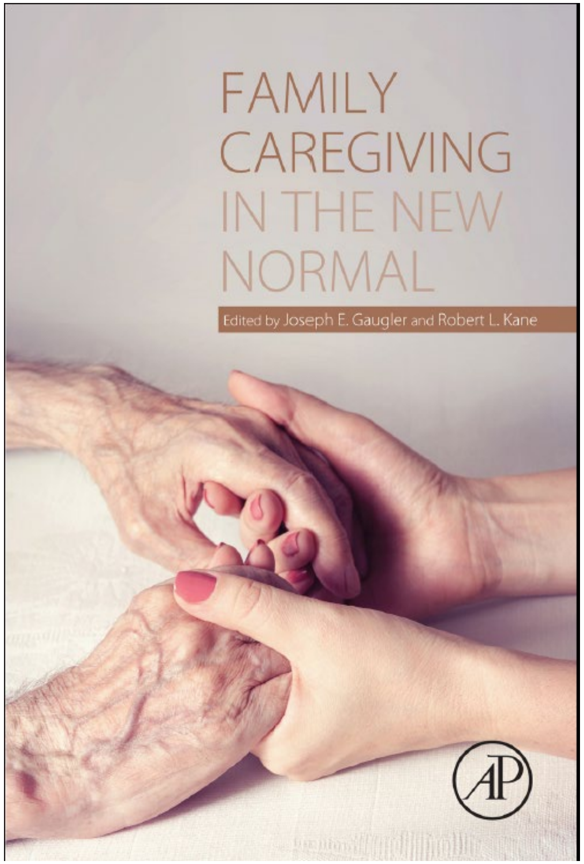
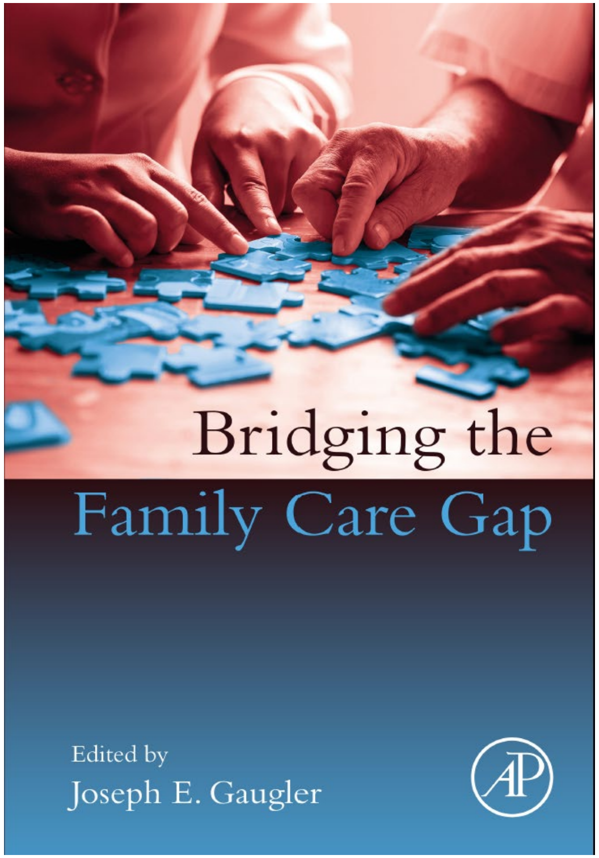
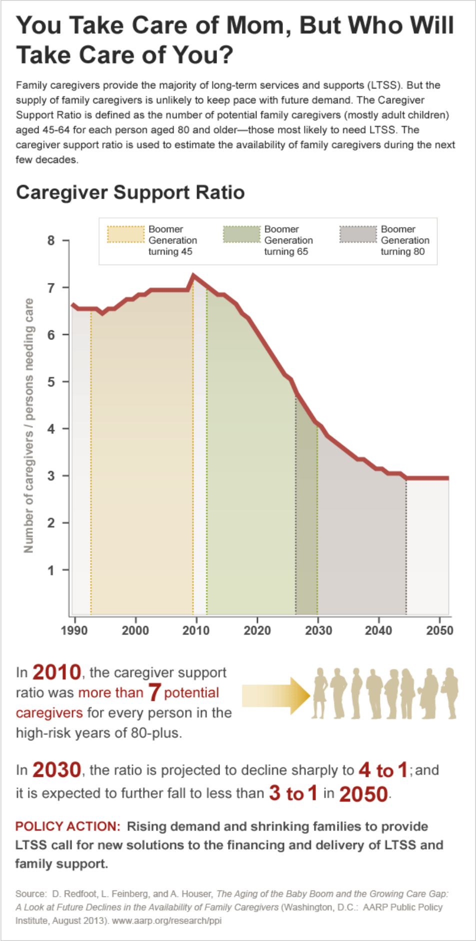




-Gaugler, J. E., & Kane, R. L. (Eds.). (2015). *Family caregiving in the new normal*. San Diego, CA: Academic Press.
-Gaugler, J. E. (Editor) (2021). *Bridging the family care gap*. San Diego, CA: Academic Press.

Is Our Reliance on Family Caregivin Sustainable?



You Take Care of Mom, But Who Will Take Care of You?

Family caregivers provide the majority of long-term services and supports (LTSS). But the supply of family caregivers is unlikely to keep pace with future demand. The Caregiver Support Ratio is defined as the number of potential family caregivers (mostly adult children) aged 45-64 for each person aged 80 and older—those most likely to need LTSS. The caregiver support ratio is used to estimate the availability of family caregivers during the next few decades.

Caregiver Support Ratio

In **2010**, the caregiver support ratio was more than **7** potential caregivers for every person in the high-risk years of 80-plus.

In **2030**, the ratio is projected to decline sharply to **4 to 1**; and it is expected to further fall to less than **3 to 1** in **2050**.

POLICY ACTION: Rising demand and shrinking families to provide LTSS call for new solutions to the financing and delivery of LTSS and family support.

Source: D. Redfoot, L. Feinberg, and A. Houser, *The Aging of the Baby Boom and the Growing Care Gap: A Look at Future Declines in the Availability of Family Caregivers* (Washington, D.C.: AARP Public Policy Institute, August 2013). www.aarp.org/research/ppi

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Factors Driving/Contributing to the Family Care Gap (Spillman, 2020; Stone, 201

- Rising educational attainment
- Longer time spent in the workforce
- Women more likely to participate in the workforce
- More complex family structures
- Diversity
- Geographic dispersion of families
- Changes in the how long-term care is financed/delivered
- The aging of/shortage of the geriatric workforce

How Can We Bridge the Family Care Gap? (Gaugler, 2021)

- Develop a national family caregiving strategy
- Achieve “family-centered” care, or approaches that more effectively incorporate family caregivers into healthcare delivery
- Advocate for the widespread dissemination and implementation of evidence-based supports and services for family caregivers
- Develop and/or support policies and programs that have a public health impact (Plichta, 2018)

National Strategy: The RAISE Family Council

- The RAISE Family Caregivers Act became law on Jan. 22, 2018.
  - It directs the Secretary of Health and Human Services to develop a national family caregiving strategy
- The RAISE (Recognize, Assist, Include, Support, and Engage) Advisory Council included national experts as well as family caregivers
- 26 recommendations across five goals were delivered to Congress in Fall of 2021 following a 2-year information gathering effort
- Five priority areas:
  - **Increased awareness of family caregiving**
  - **Increased emphasis on integrating the caregiver. into processes and systems from which they have been traditionally excluded**
  - **Increased access to services and supports to assist family caregivers**
  - **Increased financial and workplace protections for caregivers**
  - **Better and more consistent research and data collection**

Supporting Policies That Have a Pub Health Impact

- Relatively flat funding for the National Family Caregiver Support Program since its inception in 2000 until around 2013 or so
  - Only reaches about 700,000 caregivers
- Policy Paying family caregivers
- innovations: Refinancing long-term services and supports
  - Public-private models
  - Washington’s Long-Term Services and Supports Trust Act
  - Universal Family Care

The Urgent Need for Dissemination and Implementation

- Best Practice Caregiving
  - https://bpc.caregiver.org/

best practice caregiving | *Guiding organizations to dementia programs for family caregivers*

A partnership between
Benjamin Rose Institute on Aging and Family Caregiver Alliance

Program Snapshot SAVVY CAREGIVER

WHAT IT IS

Savvy Caregiver is a dementia caregiving program that offers six online or in-person group education and skills-training sessions for caregivers of those living with any type of dementia.

HELPS CAREGIVERS WITH

- Coping with stress
- Improving caregiving knowledge & skills
- Encouraging persons living with dementia to participate in daily tasks & activities

EASY DELIVERY & SERVES DIVERSE CAREGIVERS

Can be delivered by a lay leader, professional or paraprofessional Offered in English & Spanish.

REMOTE-FRIENDLY, FREE & READY TO ADOPT

Savvy Caregiver is proven, vetted and ready for implementation by organizations that support and serve caregivers and their care recipients. Program can be delivered to caregivers remotely.

Training provided? YES

Cost to implement? $0

Learn More

Savvy Caregiver is one of more than 40 dementia caregiving programs found in Best Practice Caregiving (**bpc.caregiver.org**), a free, online database that helps organizations identify, compare and adopt best-fit programs for their clients and community.

DIRECT LINK: bpc.caregiver.org/#programDetails/savvy-caregiver

https://www.caregiver.org/news/at-a-glance-savvy-caregiver/

PHCOE on Dementia Caregiving

Our mission is to assist state, tribal and local public health agencies nationwide in developing their dementia caregiving-focused programs and initiatives.

- We achieve our mission by:
  - Providing expert technical assistance to public health agencies for selecting their caregiving-related goals.
  - Improving access to & use of evidence-based programs, tools, materials and best-practices in dementia caregiving.
  - Facilitating connections and collaboration between public health agencies and a wide network of providers and organizations serving dementia caregivers.

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Engage with Us!

- Visit us regularly at bolddementiacaregiving.org for events, resources & more
- Email us at phcoe-dc@umn.edu
- Follow us on Twitter @PHCOE_DC
- Request free technical assistance at https://bolddementiacaregiving.org/technical-assistance/

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Citations

- Bouldin, E. D., Andresen, E. M., Edwards, V. J., Kearley, J. P., Reed, N., & McGuire, L. C. (2021). Public health perspectives on the family care gap. In J. E. Gaugler (Ed.), *Bridging the family care gap* (pp. 3–42). Academic Press.
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Transition Slide

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