



THE HEART OF CARE: Navigating Challenges & Triumphs of Caregiving

Jean Wactawski-Wende, PhD

Mike LaMonte, PhD

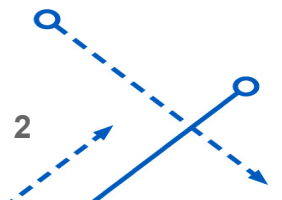
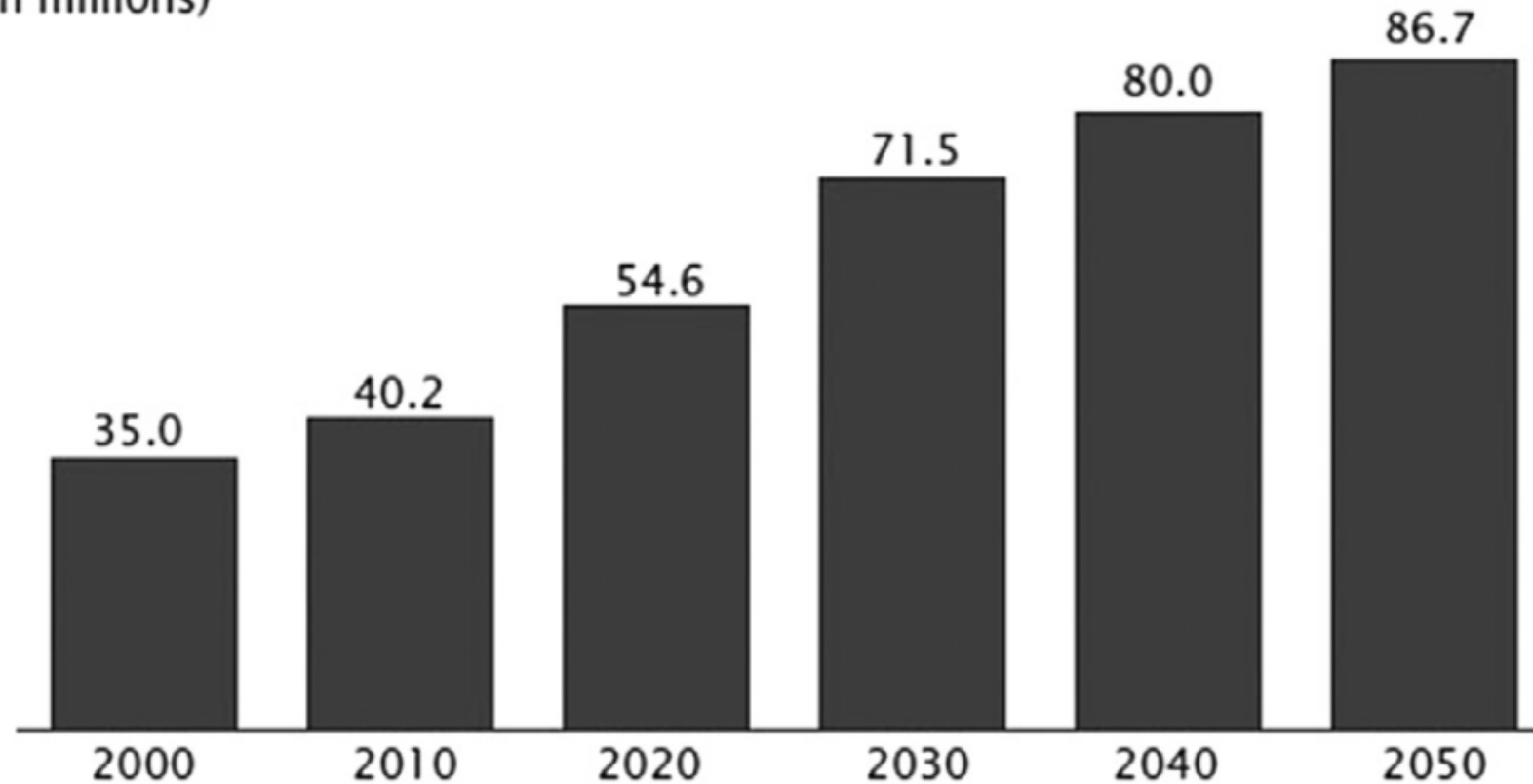
Department of Epidemiology and Environmental Health
School of Public Health and Health Professions



The U.S. Population Is Aging Rapidly

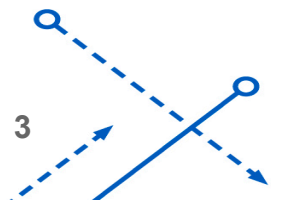
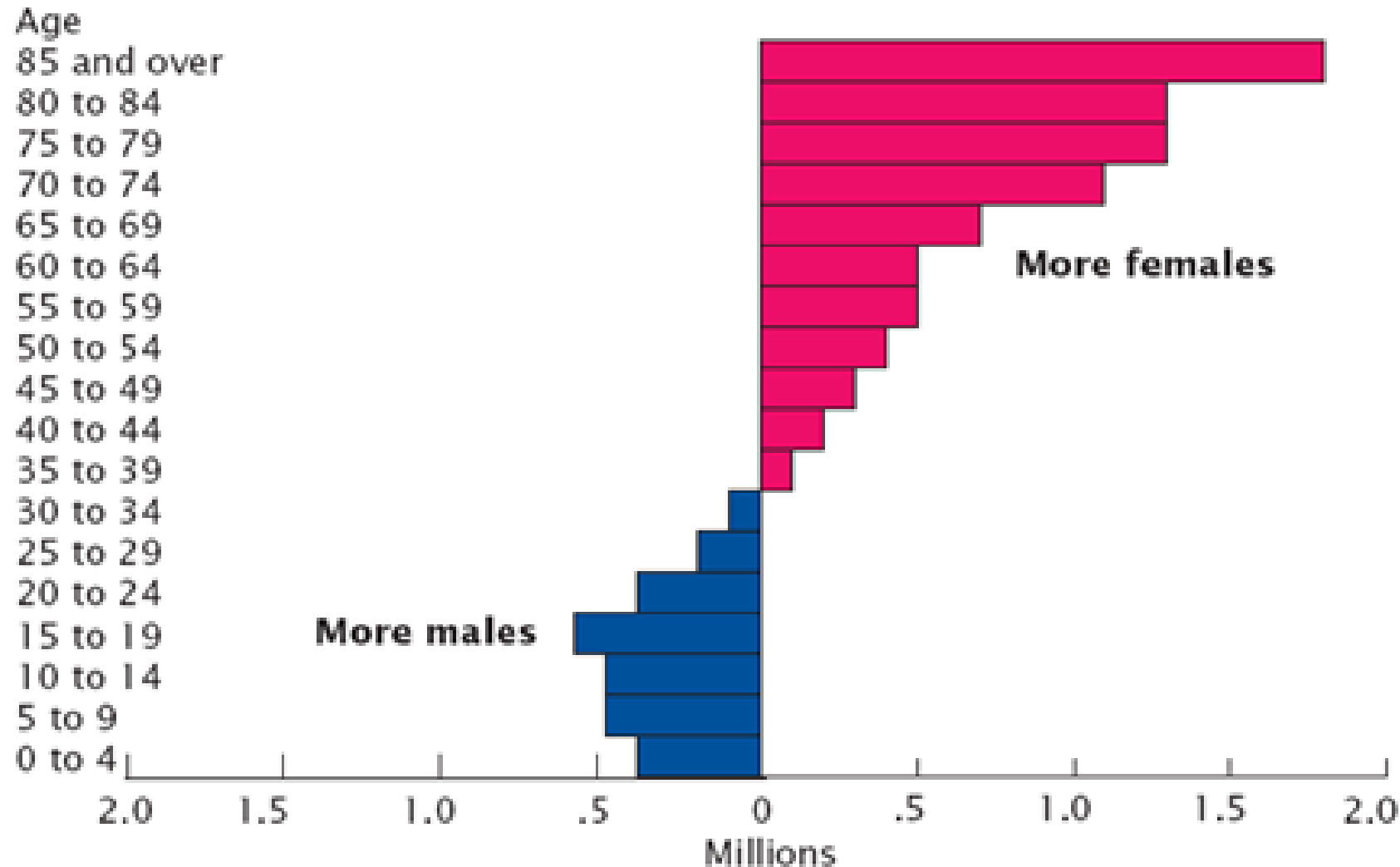
Population Aged 65 and Over: 2000 to 2050

(In millions)





Sex Differences in Population Aging (2050 Projected)



Caregiving is a Major Public Health Issue of the 21st Century



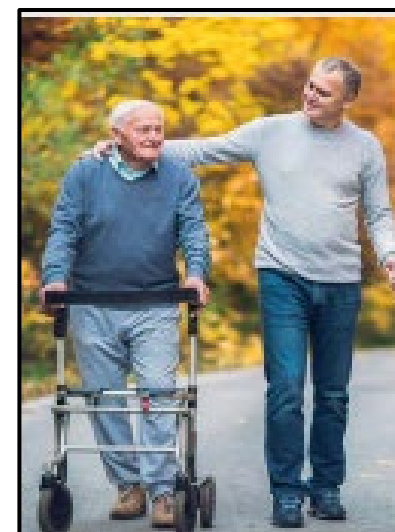
Caregiving for Family and Friends — A Public Health Issue

Caregiving is an important public health issue that affects the quality of life for millions of individuals. Caregivers provide assistance with another person's social or health needs. Caregiving may include help with one or more activities important for daily living such as bathing and dressing, paying bills, shopping and providing transportation. It also may involve emotional support and help with managing a chronic disease or disability. Caregiving responsibilities can increase and change as the recipient's needs increase, which may result in additional strain on the caregiver.^{1,2,3}

Caregivers can be unpaid family members or friends or paid caregivers.^{1,2} Informal or unpaid caregivers are the backbone of long-term care provided in people's homes. In particular, middle-aged and older adults provide a substantial portion of this care in the US, as they care for children, parents or spouses.^{2,3} These informal caregivers are the focus of this brief.^{2,3}

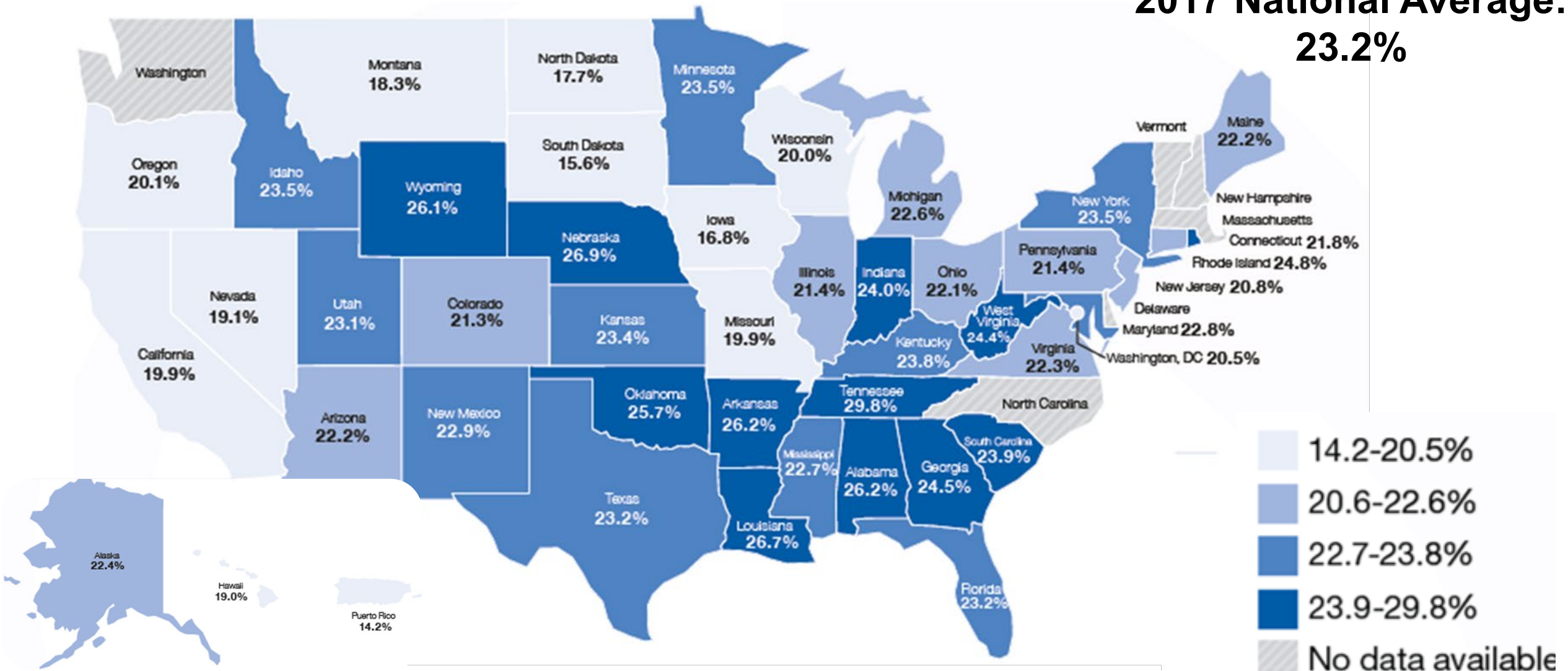
Caregiving can affect the caregiver's life in a myriad of ways including his/her ability to work, engage in social interactions and relationships, and maintain good physical and mental health.¹ Caregiving also can bring great satisfaction and strengthen relationships, thus enhancing the caregivers' quality of life. As the population ages and disability worsens, it is critical to understand the physical and mental health burden on caregivers, the range of tasks caregivers may perform, and the societal and economic impacts of long-term chronic diseases or disability.² Gathering information on these topics enables us to plan for public health approaches to assist individuals as well as their communities and maintain the health of caregivers and care recipients.¹

Informal caregivers provide regular care or assistance to a friend or family member who has a health problem or disability.^{2,4}



Percentage of Adults Ages >45 Years Providing Caregiving in Past 30 Days

**2017 National Average:
23.2%**

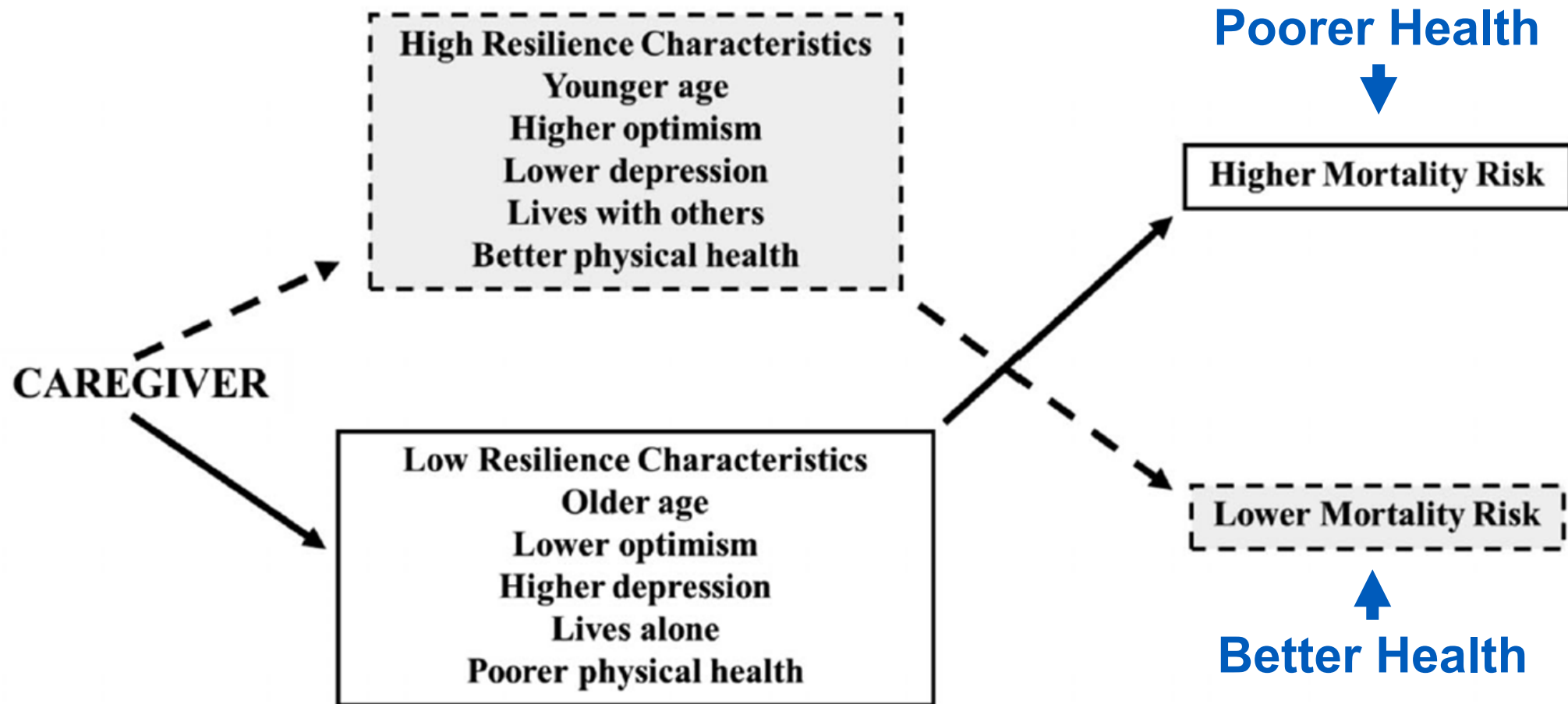


Who are the Caregivers and Why is this Important?



- 53 million unpaid caregivers in 2020
- Majority of recipients are 50 or older
- 60% of Caregivers are women
- Huge societal benefit – valued at \$470 billion
- Primary reason for care recipients to enter assisted living is caregiver health decline

Impacts on Caregiver's Health is Unclear

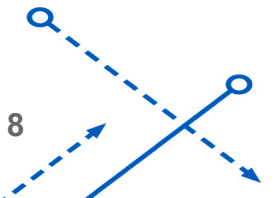


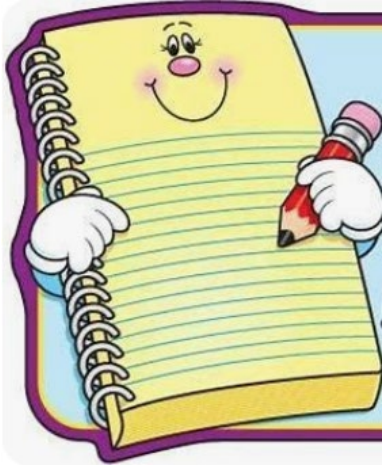
Caregiving and all-cause mortality in postmenopausal women: Findings from the Women's Health Initiative

Journal of American Geriatrics Society, 2024

“Are you now helping at least one sick, limited, or frail family member or friend on a regular basis?” [Yes, No]

- ✓ 158,987 women ages 50-79 years responded at WHI enrollment
- ✓ 40.7% reported being a caregiver
- ✓ Compared mortality in caregivers vs noncaregivers 17 years later
- **Statistically significant 9% lower mortality in caregivers**

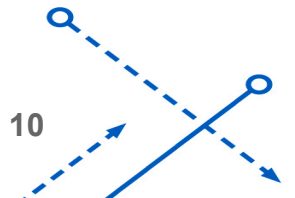




We are interested in learning more about caregiving and its impact on caregiver health because our WHI participants have asked about it.

First, we would like to learn more from you!

ONLY for WHI Participants ... please answer the following:



Question 1:

Have you helped at least one sick, limited, or frail family member or friend in the past year?

Question 2: *if you said “Yes” to being a caregiver ...*

What is your relationship with the person you provide care for?

Question 3: *if you said “Yes” to being a caregiver ...*

How many hours per week do you provide care to this person?

WHI Caregiving Pilot Study (Fall 2024)

New: WHI Caregiving Questionnaire & Pilot Study

Women's Health Initiative Caregiving Survey



This is a study that the **Women's Health Initiative (WHI)** is conducting to better understand the degree to which you are, or have been, **involved in caregiving**.

This survey will take about 20 minutes if you are a caregiver, and about 10 minutes if you are not.

Your responses are important to us. Please consider completing this survey regardless of your recent caregiving status.

By completing this survey, you agree to share this data with the WHI and interested investigators. Your personal identity will not be used in any publication or shared in any way. We may contact you again in the future for clarification, updates and/or future research studies related to caregiving.

Please indicate your willingness/unwillingness to participate.

- ☐ I am willing to participate in this survey.
☐ I am not willing to participate in this survey.

1. Have you helped at least one sick, limited, or frail family member or friend in the past 20 years? Mark all that apply.
☐ No ☐ 5 years ago ☐ 5-10 years ago ☐ 10-20 years ago

2. Have you helped at least one sick, limited, or frail family member or friend in the past year?

☐ Yes ☐ No If Yes, go to the next question; If No, go to question 37.

2.1 If yes, did you in the last 4 weeks, help at least one sick, limited, or frail family member or friend? ☐ Yes ☐ No

The following questions will ask you to describe the individual for whom you primarily perform caregiving tasks in the past year. If you give care for more than one person, you must select a primary care recipient, or the one person for whom you spend/spent the most time, energy and/or effort caring for and answer the questions accordingly. Later in the questionnaire we will ask about other people you may care for.

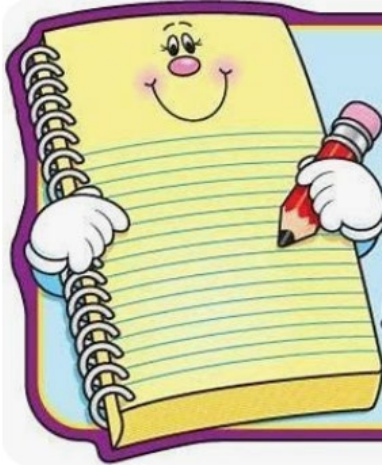
3. In your best estimate, when did you begin to help this individual? Mark one.

- ☐ Less than one year ago ☐ 1 – 2 years ago ☐ 2 – 3 years ago
☐ 3 – 5 years ago ☐ 5 -10 years ago ☐ more than 10 years ago

- ✓ Experts from within & outside WHI
- ✓ Developed new questions to fill in gaps

Final version:

- 61 items
- 20 minutes to complete
- Paper (postal mail) or Redcap (email)

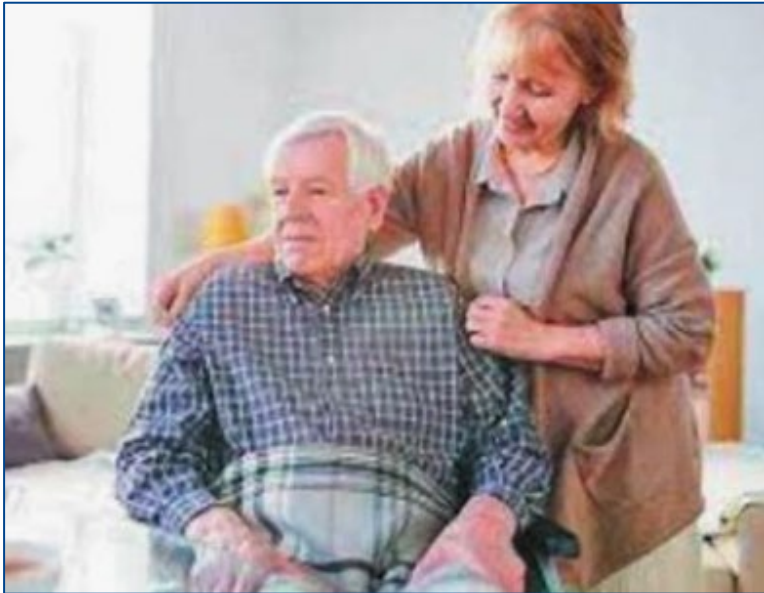


WHI Caregiving Pilot Study Results

- 264 questionnaires sent (Northeast Region)
- 67% response (same for postal mail or Email)
- **25% reported being a caregiver in the past year (same for mail or Email)**

Pilot Study Results

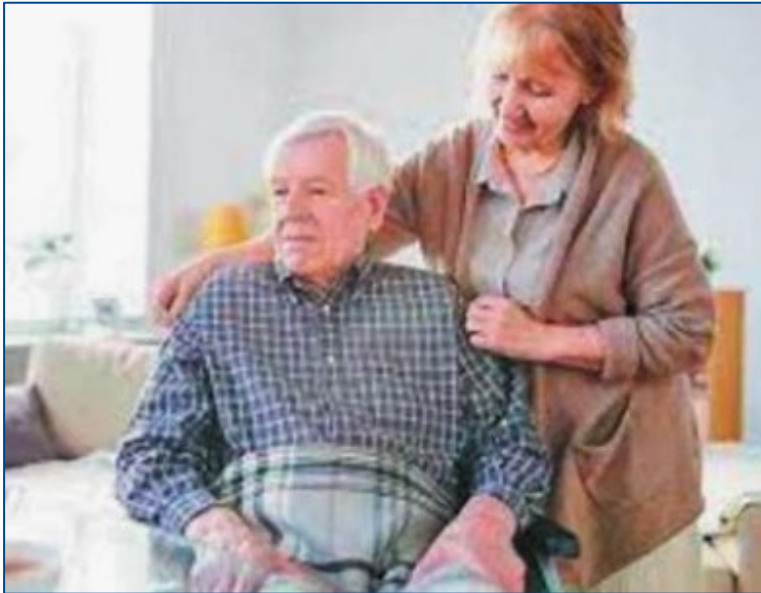
What is your relationship with the person you provide care for?



- ✓ **55% of caregivers provided care for their husband/partner**

Pilot Study Results

What is your relationship with the person you provide care for?



- ✓ **55% of caregivers provided care for their husband/partner**
- ✓ **12% provided care for their Daughter**
- ✓ **7% provided care for their Mother/Mother-in-law**
- ✓ **2.4% provided care for their Brother/Sister**

Pilot Study Results

How many hours a week do you spend on Caregiving?



- ✓ **54% provide care <10 hours/wk**
- ✓ **18% provide care 10-20 hours/wk**
- ✓ **8% provide care 21-40 hours/wk**
- ✓ **20% provide care >40 hours/wk**

Pilot Study Results

What health condition(s) does recipient have?



- ✓ **54% Physical disability**
- ✓ **39% Vision or Hearing disability**
- ✓ **34% Heart disease**
- ✓ **27% Alzheimer's/dementia**
- ✓ **25% Cancer**
- ✓ **20% Stroke**

Pilot Study Results

What services do you provide?



- ✓ **61% Transportation**
- ✓ **61% Shopping**
- ✓ **59% Attend medical appointments**
- ✓ **47% Laundry**
- ✓ **45% Prepare meals**
- ✓ **43% Medication management**

Our Next Plans in WHI

- **Submit a grant in June or October 2025 to National Institutes of Health (NIH) for funding**

Our Proposed Plan:

- **Administer Caregiver Survey to 10,000 participants <90 years old**
- **Also collect information on physical & mental health status**
- **Repeat health status survey two years later in a subset of women**
 - ✓ **Characterize older women caregivers and noncaregivers**
 - ✓ **Compare their physical and mental health status**
 - ✓ **Follow to assess impact on health outcomes and compare**



*With Gratitude for
all you have done
for WHI, and
continue to do...*

Thank you !

Questions?

