



# Medium and Long-Term Consequences of Increased Caregiving for Older Adults

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## Overview

**1** – Setting the Stage: Socioeconomic and Demographic Disparities in Caregiving among Older Adults

**2** – Emerging Research on Impacts of COVID-19 in Caregiving among Older Adults

**3** – Implications for Studies Investigating Mid- and Long-Term Consequences

# Setting the Stage: Unequal Distribution of Caregiving Burden

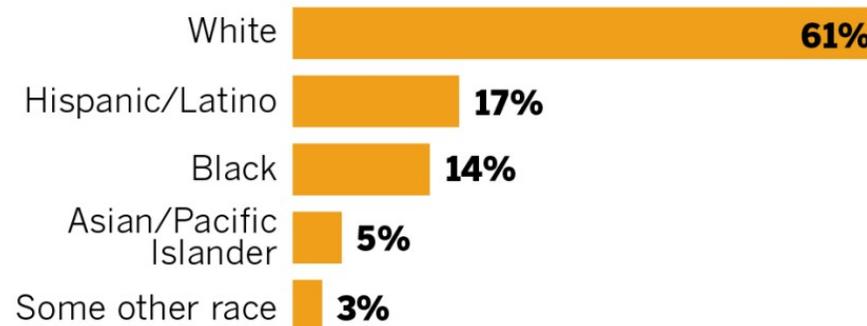
## Demographic Trends

- Median age **51 years**, about 34% are over age 65
- Estimated **66% are women**
- 24% caring for more than one care recipient (women 27%, men 20%)
- **~36% (15 million) provide care to someone with ADRD**
- **LGBTQ people become caregivers at slightly higher rate than non LGBTQ peers**

## Emerging Trends— Millennial Caregivers

- 1 in 4 millennial caregivers most diverse group of caregivers
  - 44% white
  - 27% Hispanic/Latino
  - 18% African American/Black
  - 8% AAPI
  - 3% other

### Race/ethnicity



Source: AARP and National Alliance for Caregiving

# Setting the Stage: Unequal Distribution of Caregiving Burden

## Sub-group Reported Prevalence of Caregiving and Average Age

- Hispanic 21% | 42.7 years
- African American 20.3% | 44.2 years
- Asian American 19.7% | 46.6 years
- White 16.9% | 52.2 years

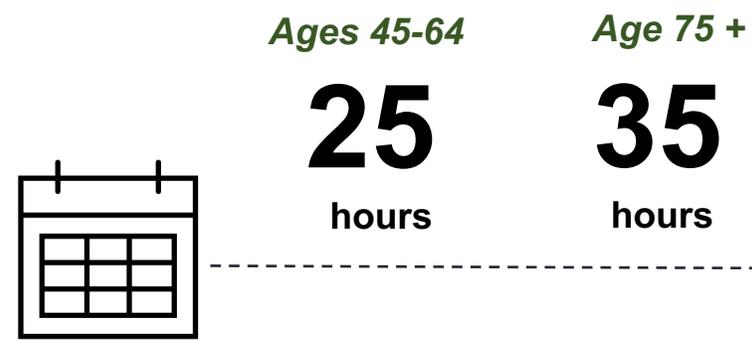
## Caregiving Responsibilities and Burden

### Prevalence of High-Intensity Caregiving

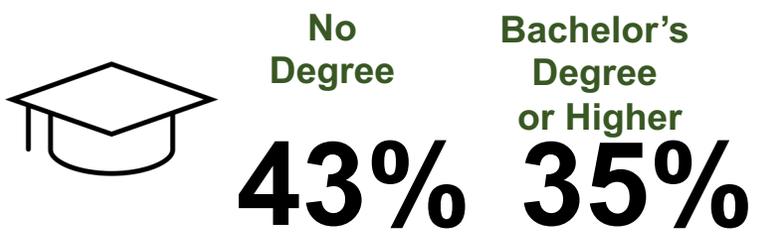
#### Race/Ethnicity



### Average Time Caregiving Per Week



#### Education



#### Household Income



Women spend more time engaged in caregiving activities, and perform more intensive activities

## Setting the Stage: Unequal Access to Supports

### Caregiving Networks – sole unpaid caregiver

- African American caregivers (55%), Hispanic (52%) White (44%), Asian American (43%)
- Women 67% vs 59% for men
- LGBTQ caregivers 78% vs. 63% persons who do not identify as LGBTQ
- Spousal caregiver 80% vs. 44% parent

### Use of Paid Supports

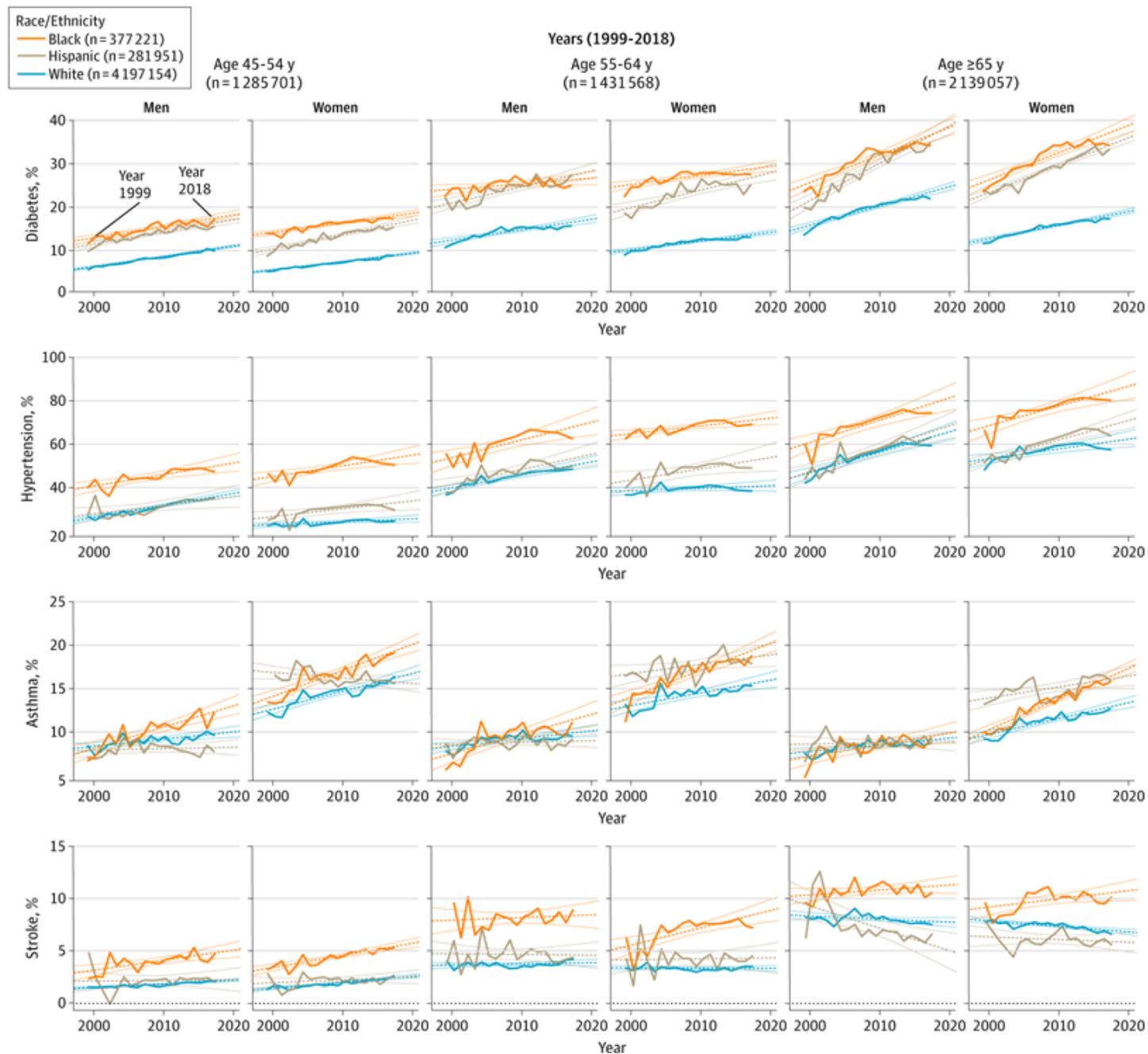
- Low socio-economic status, Black and Hispanic caregivers report lower rates of use

### Supportive Services and Interventions

- Supportive services designed largely around role appraisal, coping processes, social norms of white caregivers
- Differential effectiveness of support interventions rarely reported by race/ethnicity or gender and some evidence of unequal effectiveness

# Backdrop: Disparities in Chronic Diseases of Aging

- Unequal distribution of chronic disease
- Prevalence and incidence of ADRD



## Consequences of Caregiving

### Occupational, Financial

- 70% experience work-related impacts
- Disparities in access to paid leave
- Greater burden experienced by women (occupational gender inequality)
- **African American caregivers of those with ADRD bear 1/3 total costs of ADRD**

### Physical health impacts

- Associates with caregiving duration, level of burden, ADRD status
- Poorer physical health impacts among millennials

### Emotional, Psychological, and Relational Impacts

- 40-70% clinically significant depressive symptoms; rates higher ADRD caregivers
- Burden, strain, stress – may be less useful outcome measures among minoritized groups

## Persistent Research Gaps

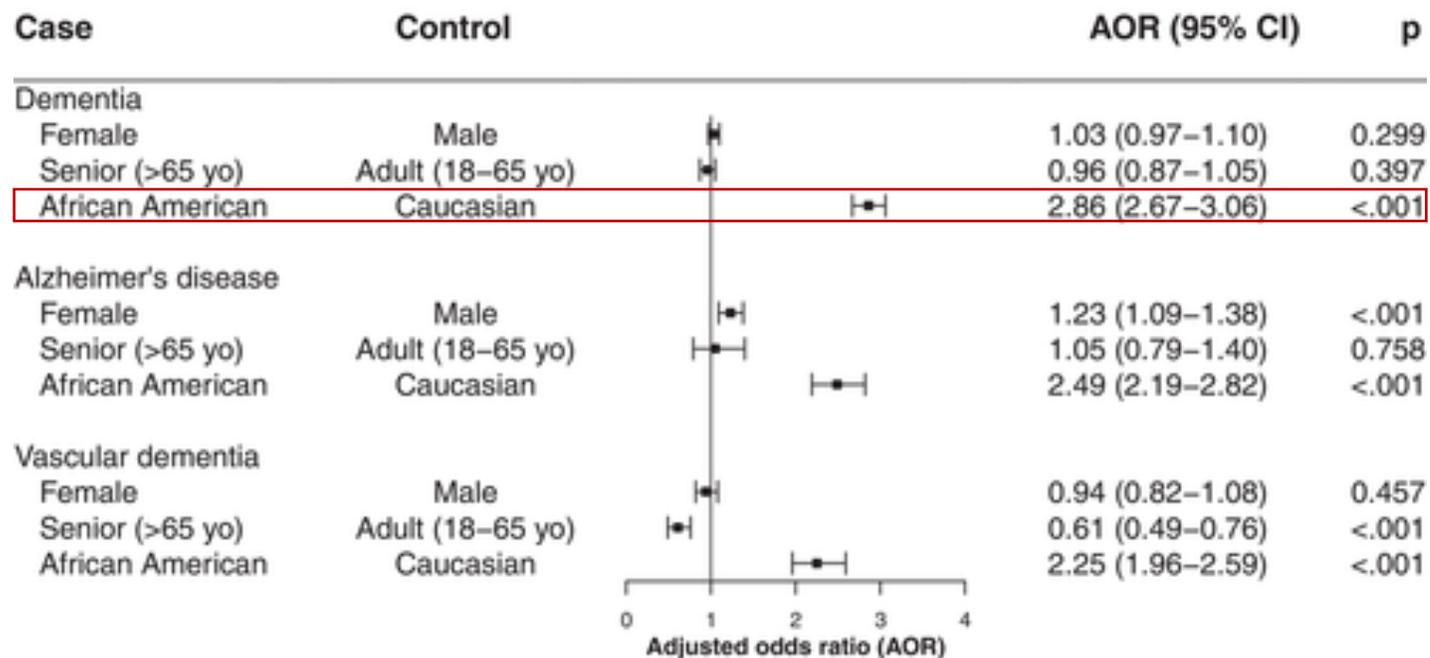
- **Under-inclusion, under-identification, and under-reporting in caregiving research**
  - ✓ Historically excluded and minoritized populations, including LGBTQ persons and those experiencing individual and contextual socioeconomic disadvantage
- **Intersectional assessments of salient exposures, burden, access to and use of supports**
  - Lower SES more likely to be caregivers
  - Women more likely care for 2+ individuals, more intensive care greater occupational/financial impacts
  - Caregiving demands increase significantly with caregiver **age** and **presence of ADRD**
  - Continuation of racially-patterned differences in occupational protections and social capital
- **Disparities in working conditions**
  - Women, minoritized and immigrant populations more likely to have poorer working conditions, less flexibility, less access to paid leave

# Emerging Data on Impacts of SARS-COV-2

## Exposure risk

- Occupational exposure
- Families and intergenerational relationships common to caregiving situations

**Demographic disparities of COVID-19 infection in patients with dementia  
(adjusted for known COVID-19 risk factors)**



## Emerging Data on Impacts of SARS-COV-2

### Immediate Health Impacts – Documented

- Heightened physical impacts, depression/anxiety, burden
- Increase caregiving intensity
- Exacerbation of behavioral, psychiatric symptoms
- **Race/Ethnicity not reported**

*Altieri & Santangelo, 2021 American Journal Geriatric Psychiatry; Cohen et al. Gerontology & Geriatric Medicine*

- Fatigue, sleep disturbance, reduced social participation, increased food insecurity & financial worries
- COVID-19 related stressors and disruptions associated with more adverse outcomes
- Impacts worse among female, younger, lower SES
- **87% Non-Hispanic White sample**

*Beach et al. 2021; The Gerontologist*



*Image: STAT News used under Commons License*

## Medium-Range Consequences

### Disruptions, Access, and Compounded Bereavement

- Shifts in caregiving workforce availability/support systems
- Utilization: Disproportionate access to protective benefits of technology-based disparities in access to telehealth, supportive services and interventions
- Elder abuse
- Complicated grief and bereavement
- Workforce re-entry and economic impacts on women
- **Equitable paid leave policies**

## Long-Term Consequences

### Individual, Dyadic, Network-Based

- Disease progression and clinical deterioration
- Chronic disease burden
- Use of long-term services and supports
- Lasting impacts on trust and distrust
- Distal impacts on cognition
  - ✓ HTN risk and management, isolation, stress
- Generational wealth and links to social/health opportunities



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# Data Gaps and Needs

## Sampling Considerations

- Technology-based surveying, accessibility considerations and limitations
- Depth of assessments within under-studied caregiving populations → mechanism
- Differential attrition in longitudinal studies → sampling bias
- Impact of unknown exposure on ongoing studies; approaches to measurement including self-report/triangulation

## Conceptual, Methodological Considerations

- Incorporation of workforce, economic, and social exposure data into longitudinal and cohort studies
- Beyond dyadic assessment of caregiving
- Limitations of stress and coping models for minoritized communities
- Inclusion and Reporting