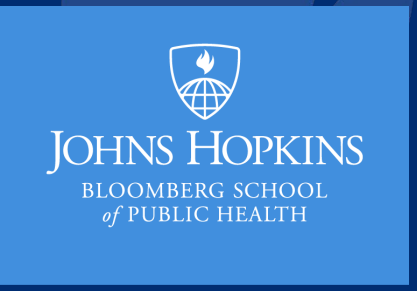

Family Caregiving for People with Cancer and Other Serious Illnesses: Research Challenges and Opportunities

Jennifer L. Wolff, PhD
Eugene and Mildred Lipitz Professor


Impact on
Caregiving
Policy & Practice
The Science of
Family Caregiving

Research Impact

Impact occurs when research generates benefits in one or more areas (health, economic, society) in addition to building the academic knowledge base

Greenhalgh et al, “Research impact: a narrative review”; *BMC Medicine*, 2016
https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4876557/

Research Impact to Address The Needs of Family Caregivers: Challenges Across the Continuum

Descriptive

Interventional

Research Impact to Address The Needs of Family Caregivers: Challenges Across the Continuum

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- Words Matter: variable nomenclature (“informal”, “family”, “caregiver”, “proxy”, “knowledgeable informant”, “care partner”; *Stall; JAGS 2019*)
- Variable definitions: by activity, population, setting
- Diffuse and far-ranging consequences – both positive and negative: for individuals, families, employers, insurers, society

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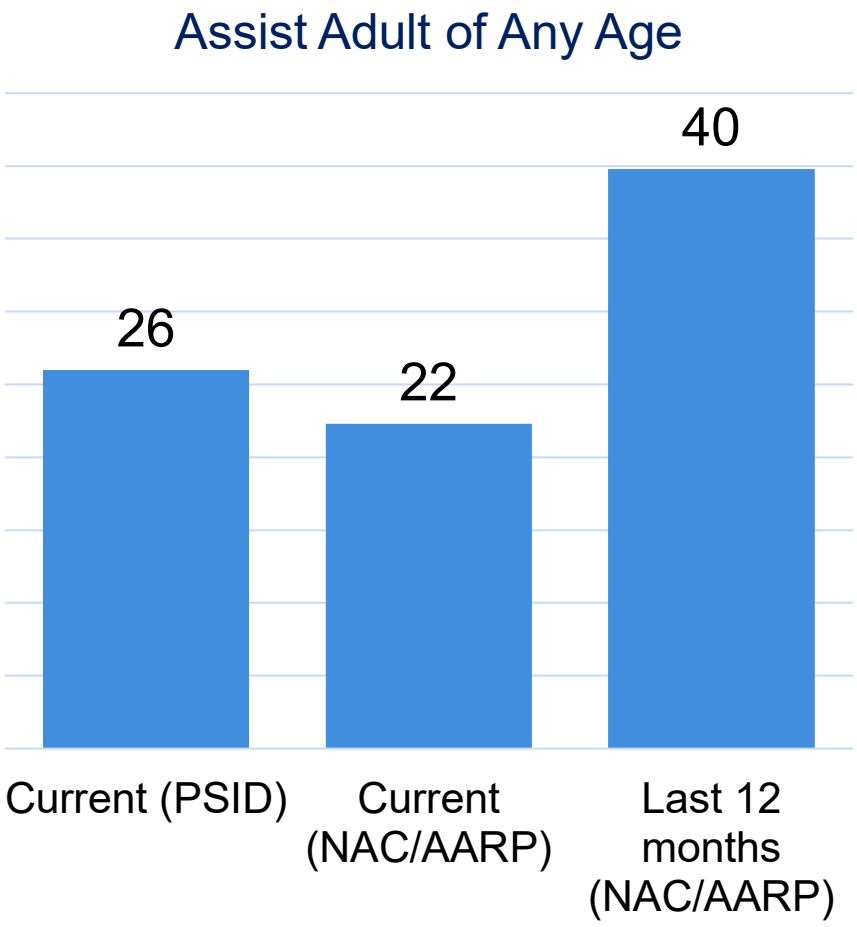
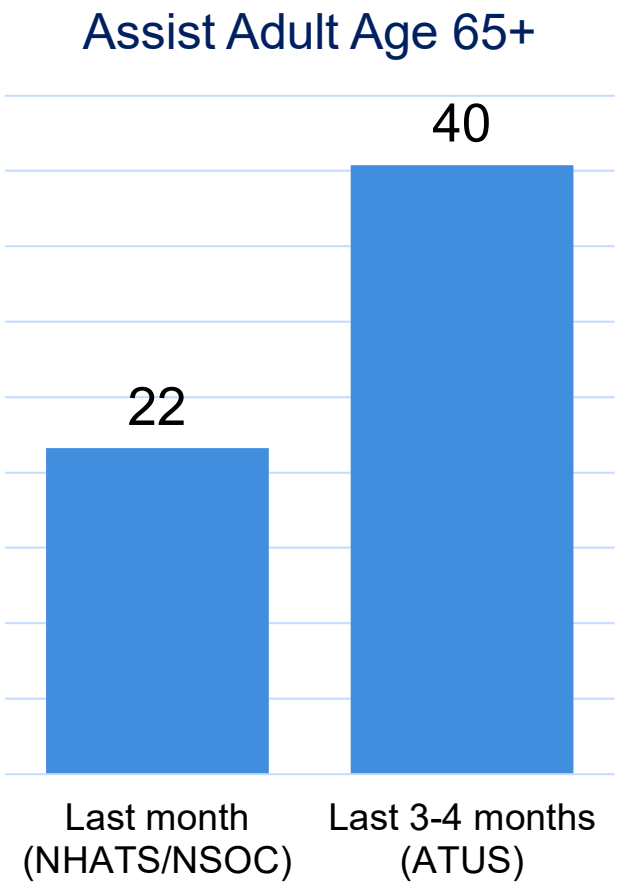
→ Weak Policy Progress

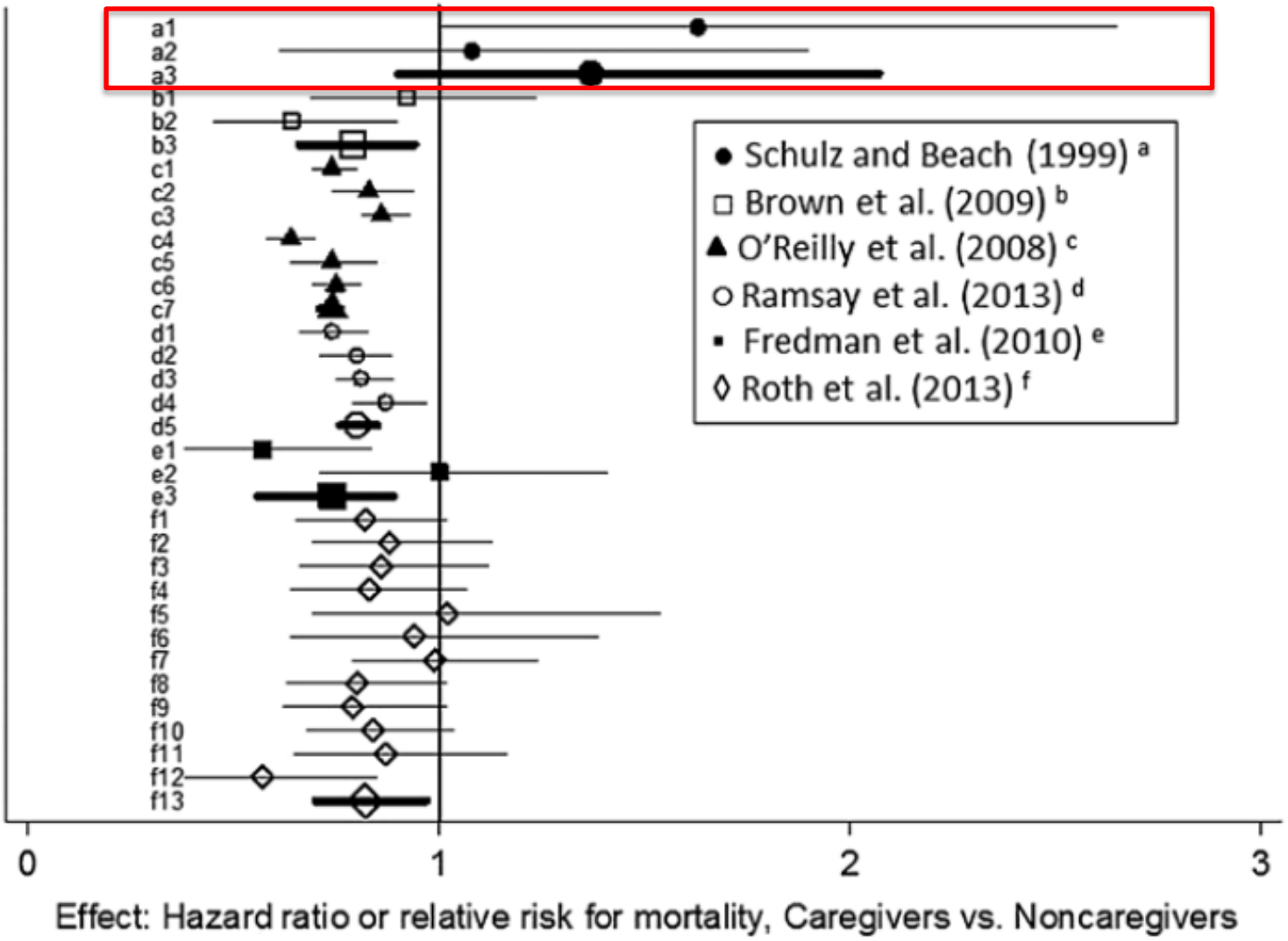
Interventional

Range of Family Caregiving Estimates, 2015-2017 (in millions)



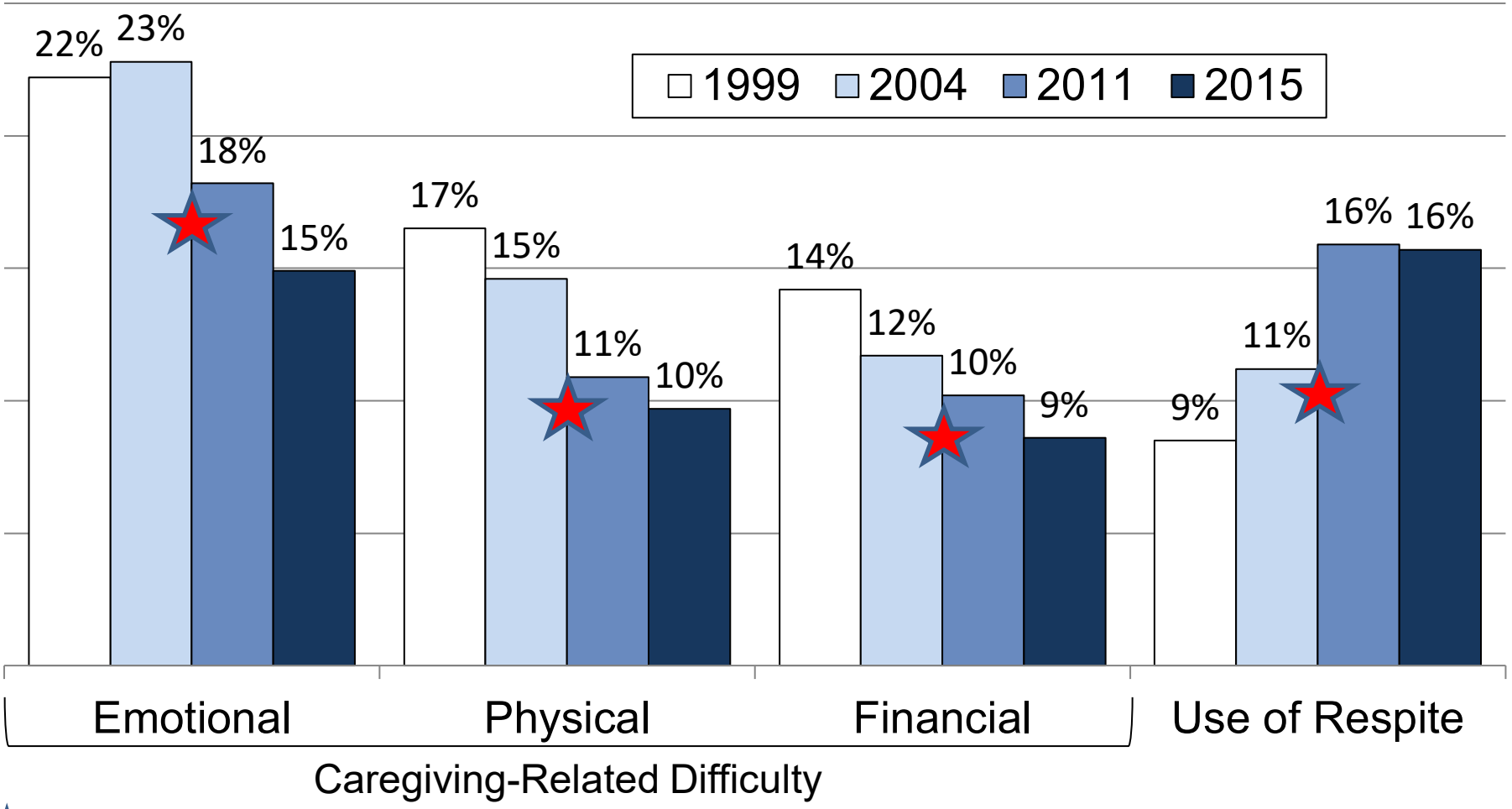


Freedman & Wolff, AEI-Brookings Conference on Paid Family Leave. November 2019.



Roth et al, "Informal caregiving and its impact on health: A reappraisal";
The Gerontologist, 2015

Fewer Caregivers with Substantial Caregiving-Related Difficulty, More Using Respite



Statistically significant difference, 1999, 2004, and 2011 vs. 2015

JL Wolff, J Mulcahy, J Huang, DL Roth, K Covinsky, JD Kasper, The Gerontologist, 2018.

1999 & 2004 National Long-Term Care Survey & its Linked Informal Caregiver Surveys and the 2011 & 2015 National Health & Aging Trends Survey & Linked National Study of Caregivers

The Landscape of Policy Impact

Economic Value of Contributions
$63 – 642 billion
(Mudrazija & Johnson 2020)

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$1,575-$16,050 per caregiver, (assuming 40 million caregivers)

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$150 million
(No increase since inception)

The Landscape of Policy Impact

Economic Value of Contributions
$63 – 642 billion
(Mudrazija & Johnson 2020)

$1,575-$16,050 per caregiver, (assuming 40 million caregivers)

National Family Caregiver Support Program
$150 million
(No increase since inception)

~$4 of support per caregiver (assuming 40 million caregivers)

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→ **Weak Policy Progress**

Interventional

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→ **Weak Policy Progress**

Interventional

- Studies not conducted in real-world settings,
- Interventions too complex, disconnected from care delivery
- Lack of alignment in outcomes of central interest to stakeholders with decisional authority related to adoption/diffusion

Adapted from Table 5.2, NASEM 2016 *Families Caring for an Aging America* report.

Research Impact to Address The Needs of Family Caregivers: Challenges Across the Continuum

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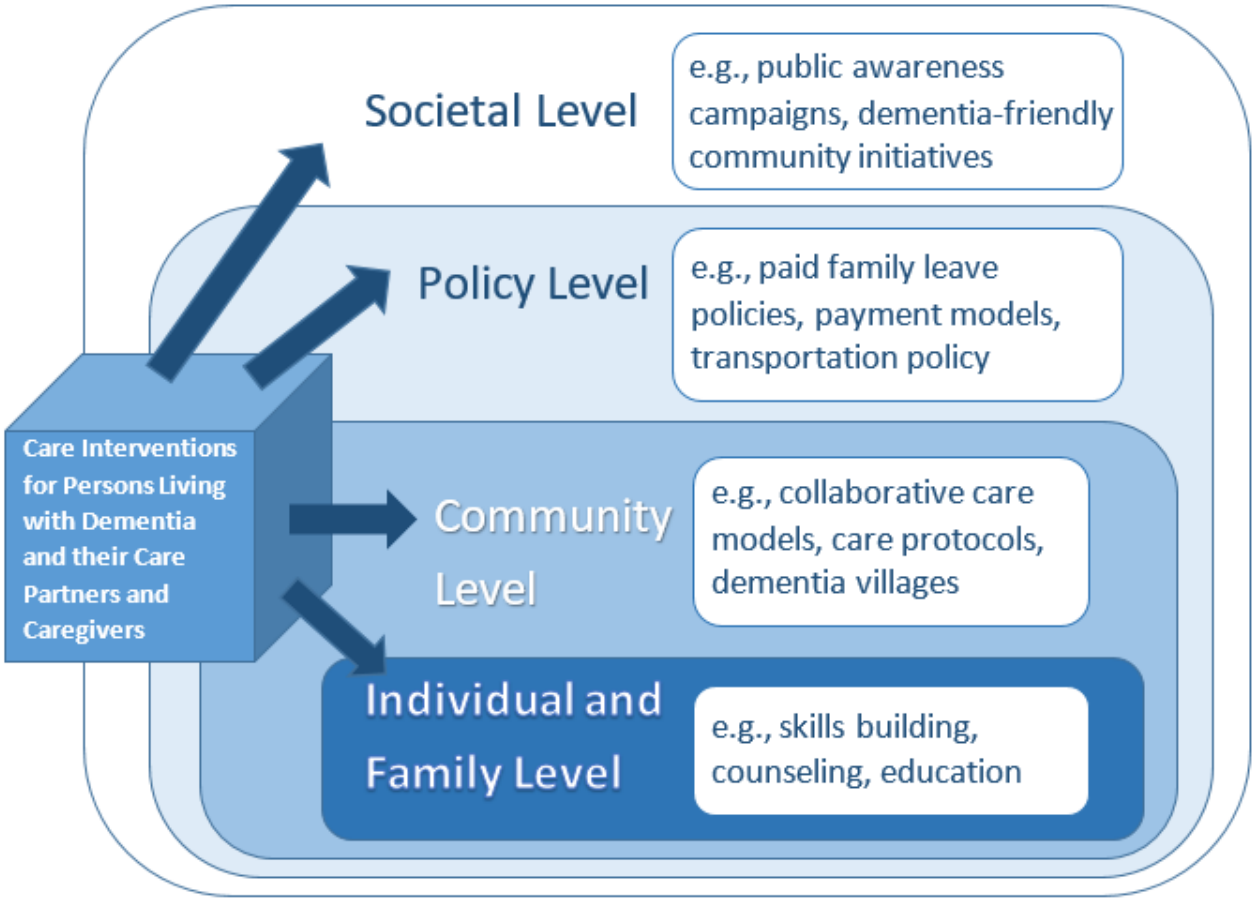
→ Few Caregivers Benefit

Figure 3-1 NASEM Report: MEETING THE CHALLENGE OF CARING FOR PERSONS LIVING WITH DEMENTIA AND THEIR CARE PARTNERS AND CAREGIVERS
A WAY FORWARD

Organizing Framework for Care Interventions



The National Academies of SCIENCES ENGINEERING MEDICINE

Designing for Impact –

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Standards of reporting: Internal consistency of analyses (nomenclature, definition, cited estimates)

Designing for Impact -

Standards of reporting: Internal consistency of analyses (nomenclature, definition, cited estimates)

Critical review: Assess the existing research infrastructure: strengths, weaknesses, and plan for coordinated action

RAISE Council Recommendation 5.1: Establish a national infrastructure using standardized data, questions, and definitions for obtaining, analyzing, and disseminating information about caregivers and their experiences.

Designing for Impact -

Standards of reporting: Internal consistency of analyses (nomenclature, definition, cited estimates)

Critical review: Assess the existing research infrastructure: strengths, weaknesses, and plan for coordinated action

Transformational Change: Building the capacity for embedded interventional research and trials within systems (health care, long-term services and supports, employer organizations, communities)

RAISE Council Goal 2: Family caregivers are recognized, engaged, and supported as key partners with providers of health care and long-term services and supports.

Designing for Impact -

Standards of reporting: Internal consistency of analyses (nomenclature, definition, cited estimates)

Critical review: Assess the existing research infrastructure: strengths, weaknesses, and plan for coordinated action

Transformational Change: Building the capacity for embedded interventional research and trials within systems (health care, long-term services and supports, employer organizations, communities)

Observational studies: Investing in national survey infrastructure that affords linkages to care delivery system (e.g., NIA-funded National Health and Aging Trends Study and National Study of Caregiving)

Designing for Impact -

Standards of reporting: Internal consistency of analyses (nomenclature, definition, cited estimates)

Critical review: Assess the existing research infrastructure: strengths, weaknesses, and plan for coordinated action

Transformational Change: Building the capacity for embedded interventional research and trials within systems (health care, long-term services and supports, employer organizations, communities)

Interventional studies: Embedded studies in partnership with organizational stakeholders with decisional authority for subsequent diffusion (e.g., NIA-funded Impact Collaboratory; JAHF Age-Friendly Health System)

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Commonwealth Fund
John A. Hartford Foundation
Ralph C. Wilson Foundation
National Institute on Aging

Thanks!

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