

Recent Updates on the Health Effects of Family Caregiving Stress

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Caregiving Questions

Are you currently providing care on an on-going basis to a family member, friend, or neighbor with a chronic illness or a disability?

“Care” would include any kind of regular help with basic activities such as dressing, bathing, grooming this person, managing bills, arranging for medical care, watching or supervising this person, or providing transportation.

If yes, how much of a mental or emotional strain is it on you to provide this care? Would you say ...

no strain, some strain, or a lot of strain?

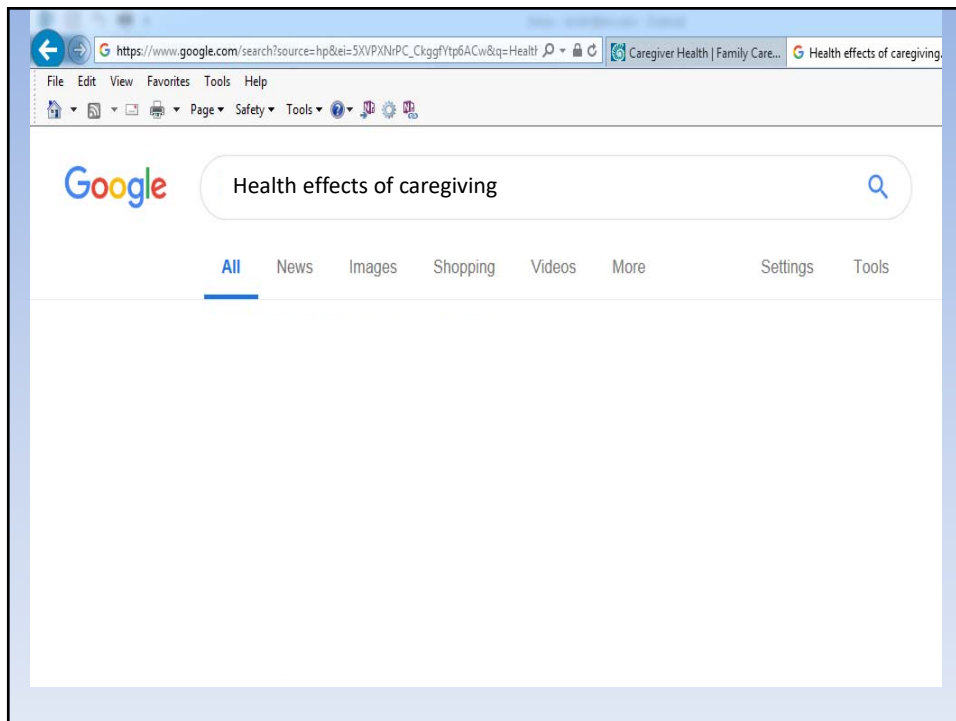



Facts about Informal (Family) Caregivers

- Depending on how caregiving is defined, there are between **18 million** (Schulz & Eden, 2016) and **41 million** (Bureau of Labor Statistics, 2016) Americans who provide regular, unpaid care for the health needs of an older adult family member or friend.
- The AARP estimates that economic value of these services exceeds **\$500 billion** per year.
- Caregiving can be stressful. About **20%** of caregivers report **high caregiving strain**.
- The increasing size of the older adult population, smaller and more dispersed families, and increasing emphasis on home-based care are converging into a **supply-and-demand crisis** for informal care.



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Impact of Caregiving on Caregiver Physical Health

High rates of depressive symptoms and mental health problems among caregivers, compounded with the physical strain of caring for someone who cannot perform activities of daily living (ADLs), such as bathing, grooming and other personal care activities, put many caregivers at serious risk for poor physical health outcomes. Indeed, the impact of providing care can lead to increased health care needs for the caregiver.

Caregivers are in worse health.

- About one in ten (11%) caregivers report that caregiving has caused their physical health to get worse.⁴⁰

⋮

Caregivers pay the ultimate price for providing care—increased mortality.

- Elderly spousal caregivers (aged 66-96) who experience caregiving-related stress have a 63% higher mortality rate than noncaregivers of the same age.⁷²
- In 2006, hospitalization of an elderly spouse was found to be associated with an increased risk of caregiver death.⁷³

Summary Statements on Caregiving and Health

“Caregivers suffer a mortality rate that is 63% higher than non-caregivers.” (US Administration on Aging, based on Schulz & Beach, 1999)

“Family caregivers experiencing extreme stress have been shown to age prematurely. This level of stress can take as much as 10 years off of a family caregiver’s life.” (Caregiver Action Network, based on Epel et al., 2004)

“It is clear that the chronic stress of caregiving has widespread effects on immunity.” (Gallagher et al., 2008)

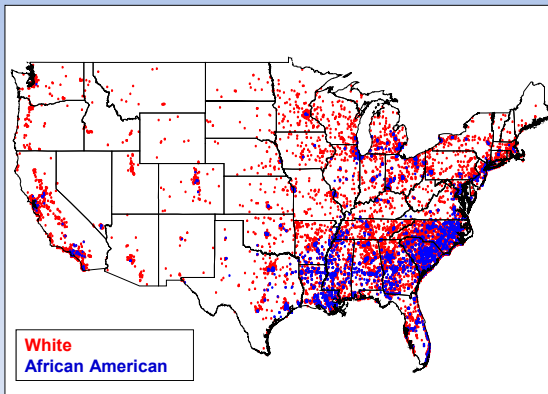
“Findings consistently revealed dysregulation of cellular and humoral immune markers in elderly, spousal caregivers.” (Lovell & Wetherell, 2011)

Caution: Cigarette Smoking May Be Hazardous to Your Health.



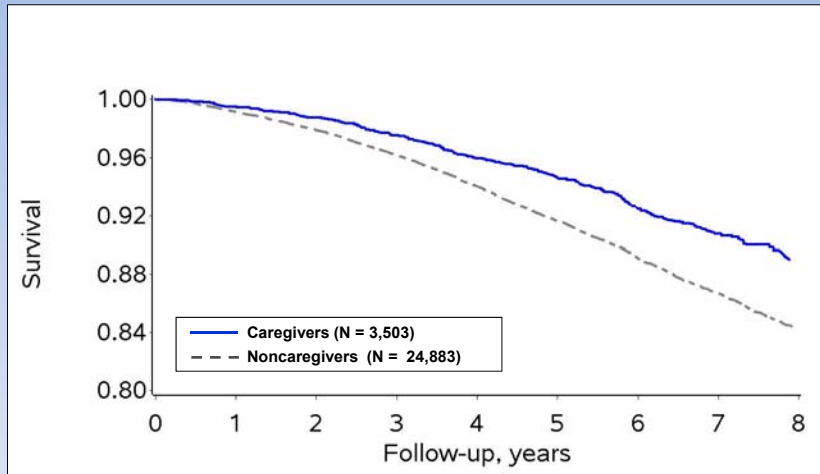
Caution: Informal Caregiving May Be Hazardous to Your Health.

The REasons for Geographic and Racial Differences in Stroke (REGARDS) Project:



- N = 30,239
- Enrolled 2003-2007
- 45+ years of age at enrollment
- Oversampling in the South (55%)
- 47% African American
- 57% Women
- ***12% were caregivers at the time of enrollment***

Caregiving and All-Cause Mortality in the REGARDS Project



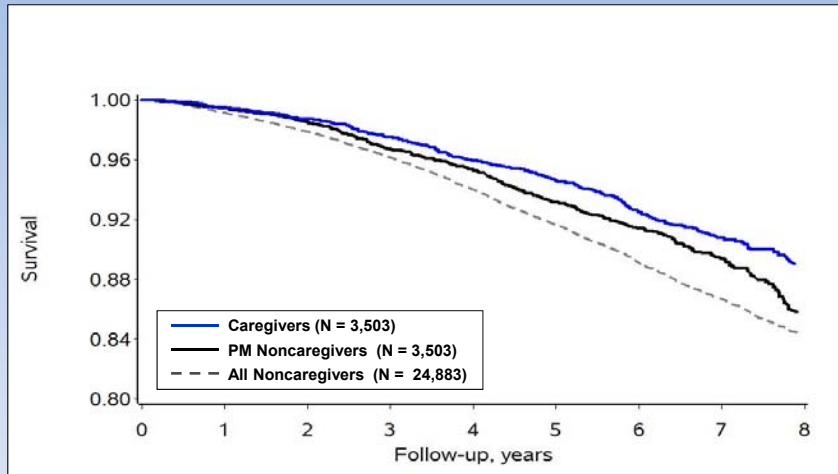
Source: Roth et al. (2013). *American Journal of Epidemiology*, 178, 1571-1578.

Matching Caregivers with Non-Caregivers in the REGARDS project using a Greedy Matching Algorithm on Propensity Scores

Variable	p before matching (3,503 vs. 24,863)	p after matching (3,503 vs. 3,503)
Age	<.0001	.14
Gender	<.0001	.42
Race	.001	.75
Region	<.0001	.96
Education	.0023	.98
Income	.0395	.47
Marital status	<.0001	.72
Health Insurance	<.0001	.80
Smoking	<.0001	.83
Alcohol Use	.008	.49
Cognitive Screener	<.0001	.72
Self-Rated Health	.29	.71
Hypertension	.62	.35
Diabetes	.15	.86
Heart Disease	<.0001	.95

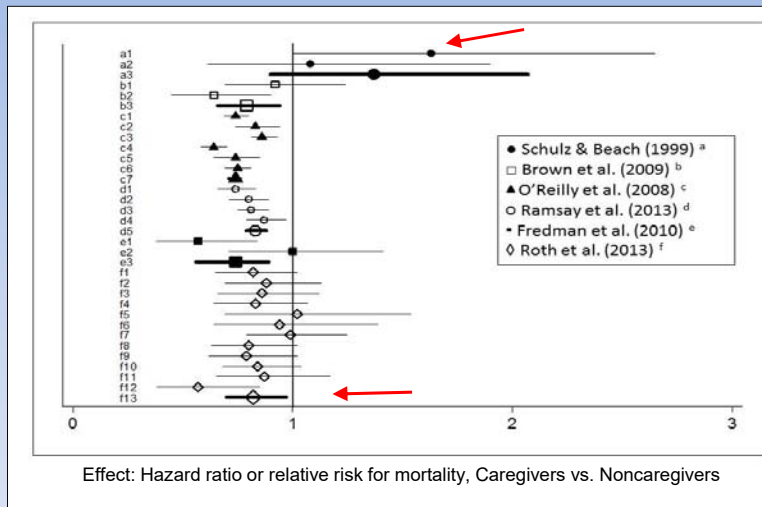
Source: Roth et al. (2013). *American Journal of Epidemiology*, 178, 1571-1578.

Caregiving and All-Cause Mortality in the REGARDS Project



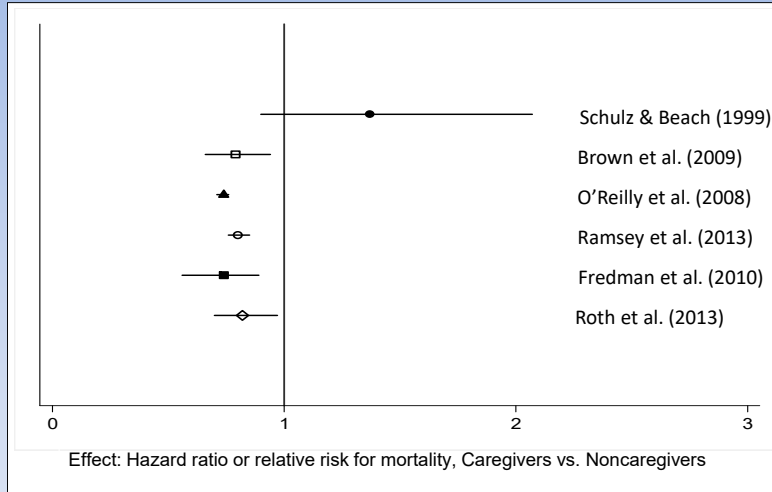
Source: Roth et al. (2013). *American Journal of Epidemiology*, 178, 1571-1578.

Effects of Caregiving on Caregiver Mortality



Source: Roth, Fredman, & Haley (2015). *The Gerontologist*, 55, 309-319.

Effects of Caregiving on Caregiver Mortality



Source: Roth, Fredman, & Haley (2015). *The Gerontologist*, 55, 309-319.

Important Update on Caregiving and Mortality

- Common claim:** Family caregivers suffer a mortality rate that is 63% higher than non-caregivers.

 - very popular on caregiving and aging websites, based on Schulz & Beach (1999)
- Update:** In fact, no study has ever found that family caregivers (as a general group) have significantly higher mortality rates than comparable non-caregivers. At least 8 population-based studies from 3 continents have found the opposite pattern -- that caregivers experience a significant longevity benefit (*a 16% to 26% **lower mortality rate***) than non-caregivers.

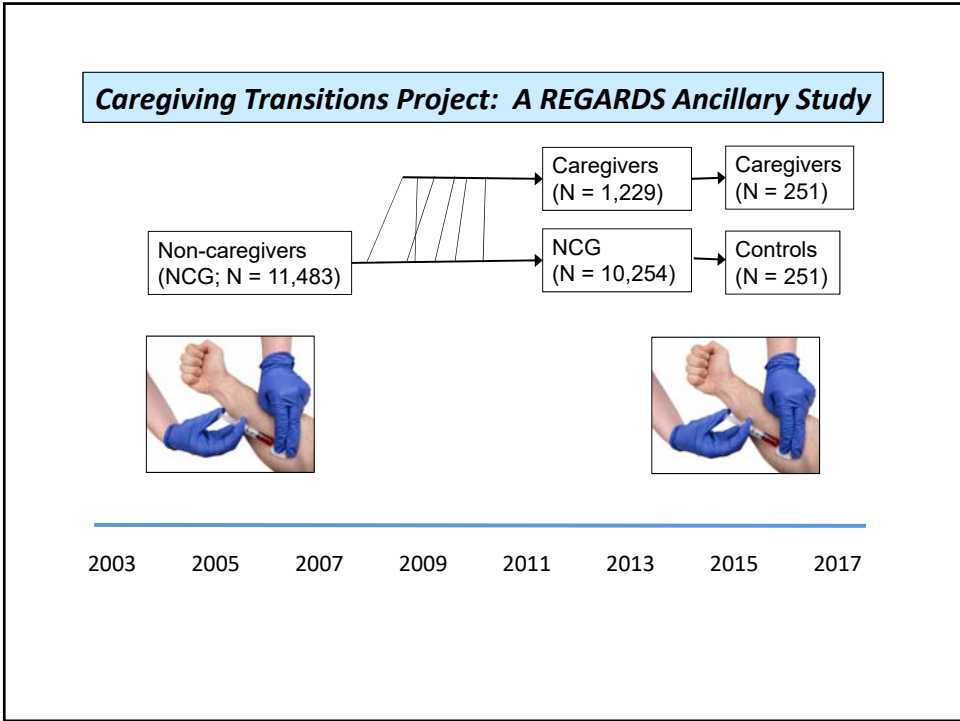
 - see Roth et al. (2015)

Why Might Caregivers Enjoy a Reduced Risk of Mortality (and other Health Benefits)?

- Selection factors: The Healthy Caregiver Hypothesis
 1. Healthier individuals may be more likely to take on caregiving roles.
 2. This may be especially true for non-spouse caregivers.
- Caregiving as a prosocial activity. Helping others might lead to...
 1. Increased social engagement
 2. Increased health awareness
 3. Increased physical activity from performing caregiving tasks
 4. Increased purpose in life (Marino et al., 2017)
 5. Biologically-based (e.g., oxytocin, inflammatory pathways) stress-buffering benefits of prosocial helping behaviors (including family caregiving; Brown & Brown, 2015; Roth et al., 2018).

What about Caregiving and Biomarkers?



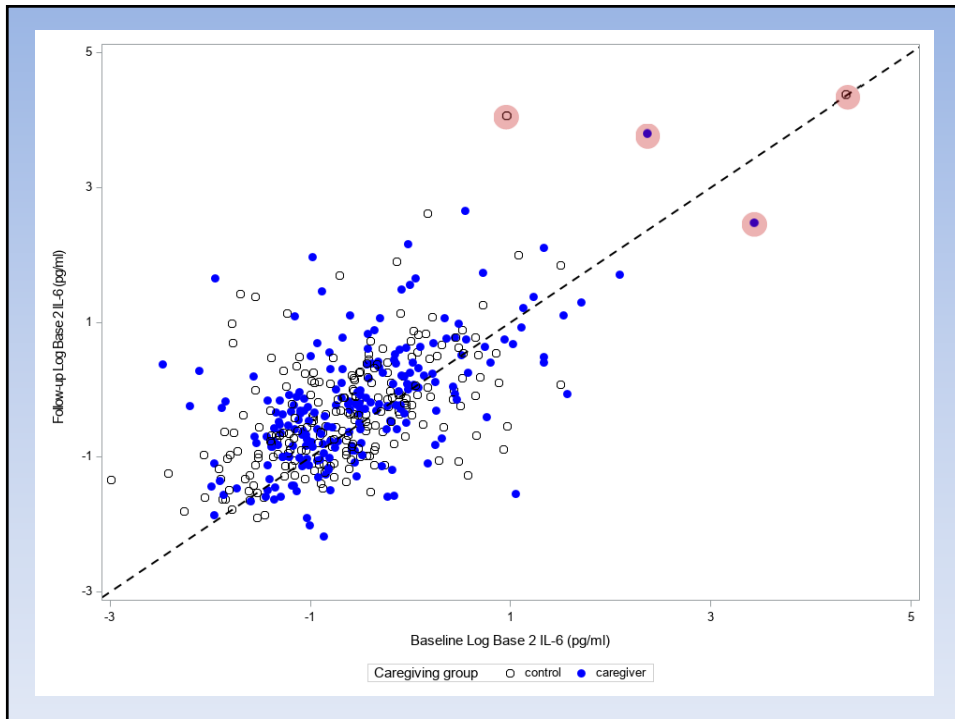


Caregiving Transitions Project: Descriptive Information

<ul style="list-style-type: none"> • Caregivers (N = 251) 163 women (65%) 90 African Americans (36%) 69.3 years of age (SD = 8.0) 190 married (76%) 	<ul style="list-style-type: none"> • Controls (N = 251) 163 women (65%) 90 African Americans (36%) 68.9 years of age (SD = 7.5) 190 married (76%)
<ul style="list-style-type: none"> 63 adult child caregivers (25%) 117 dementia caregivers (47%) hours of care per week = 43.3 (SD = 29.2; range = 5 to 84.0) duration of caregiving before 2nd blood sample = 3.4 years (SD = 2.4; range = 0.25 to 9.9 years) 	

Caregiving Transitions Project: Selective Outcomes

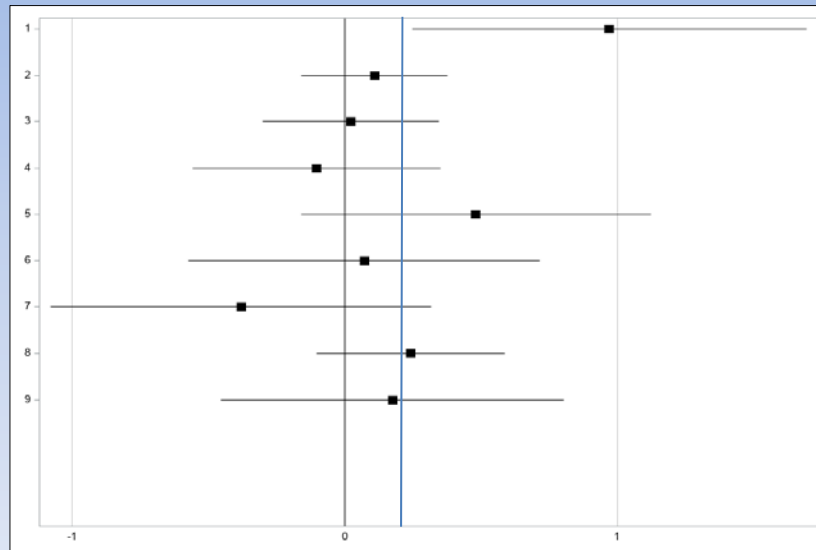
<u>Variables</u>	<u>Participants</u>	<u>Assessments</u>
Biomarkers:		
CRP	All	T ₁ and T ₂
IL-6	All	T ₁ and T ₂
TNFR1	All	T ₁ and T ₂
Ddimer	All	T ₁ and T ₂
IL-2, IL-10	All	T ₁ and T ₂
Leukocyte Telomere Length	All	T ₁ and T ₂
Interview Measures:		
CES-D (10-item)	All	T ₁ and T ₂
Perceived Stress	All	T ₁ and T ₂
SF-12	All	T ₁ and T ₂
ADL, IADL, Mem and Beh Problems	Caregivers	T ₂ only
Positive Aspects of Caregiving	Caregivers	T ₂ only



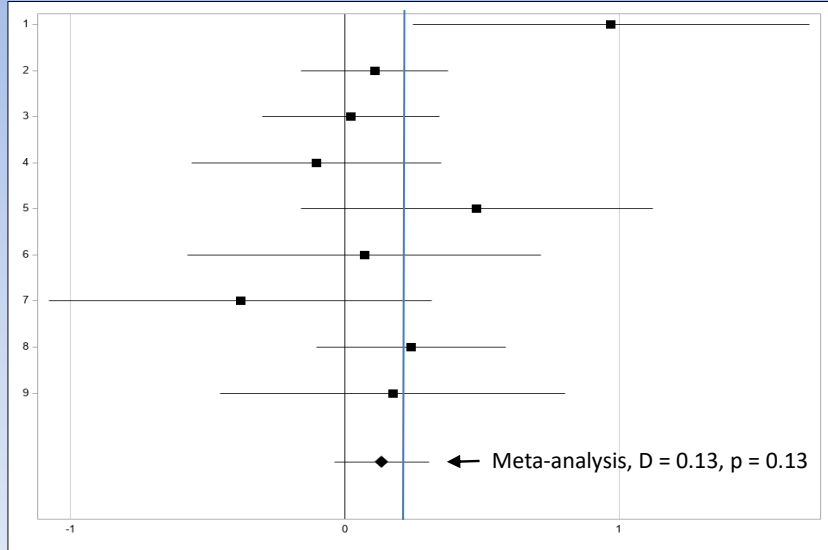
Inflammatory Biomarker Analysis Methods

- Inflammatory biomarkers in blood are highly skewed. A log (base 2) transformation was used.
- Even after transformation, a few extreme outliers were evident. Tukey's (1977) outer fences (3 IQR above the 75th percentile, or 3 IQR below the 25th percentile) were used to identify outliers and recode as missing.
- Change over time: $\Delta = \text{Log}_2(T_2) - \text{Log}_2(T_1) = \text{Log}_2(T_2/T_1)$. This results in a scaling of "doubling over time."
- Δ was modeled as a function of caregiver vs. control, with sex, race, age at T_1 , and the biomarker level at T_1 as covariates.

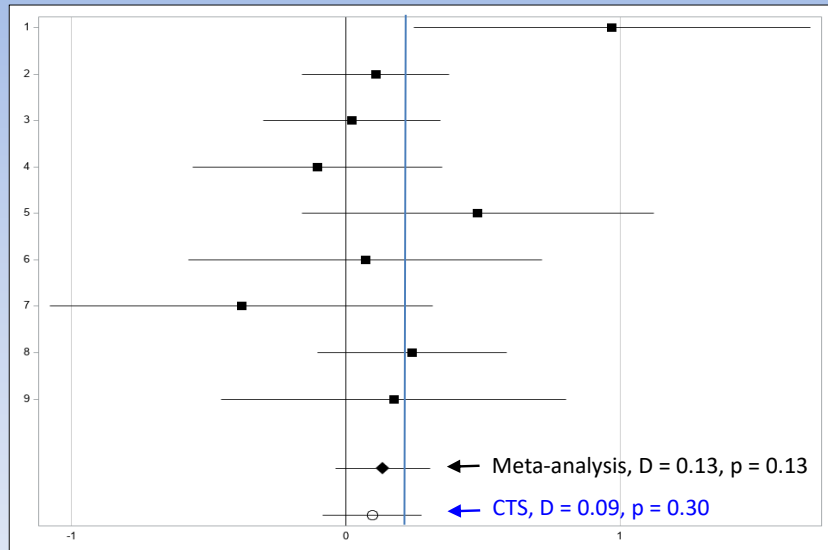
Caregiving vs. Control on IL-6



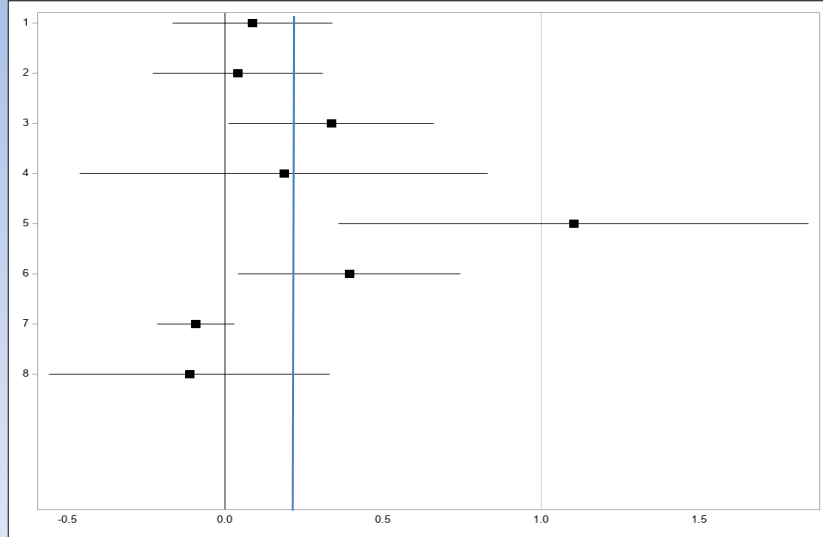
Caregiving vs. Control on IL-6



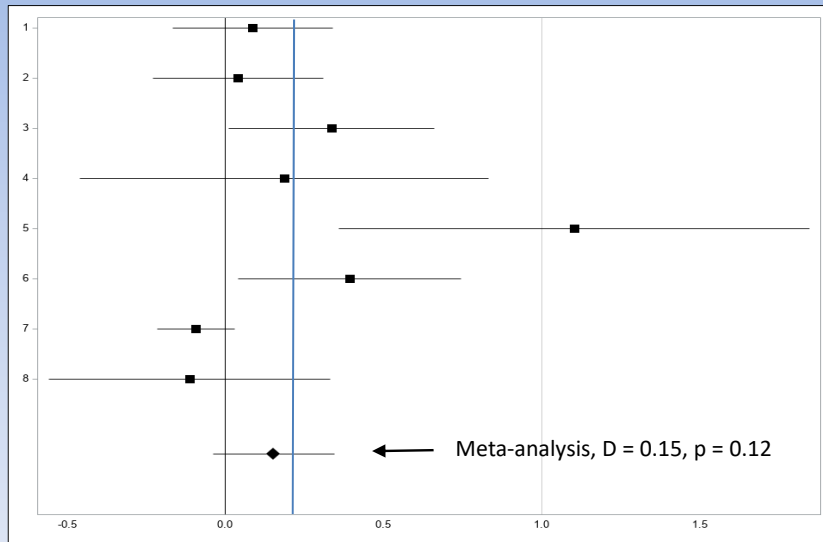
Caregiving vs. Control on IL-6



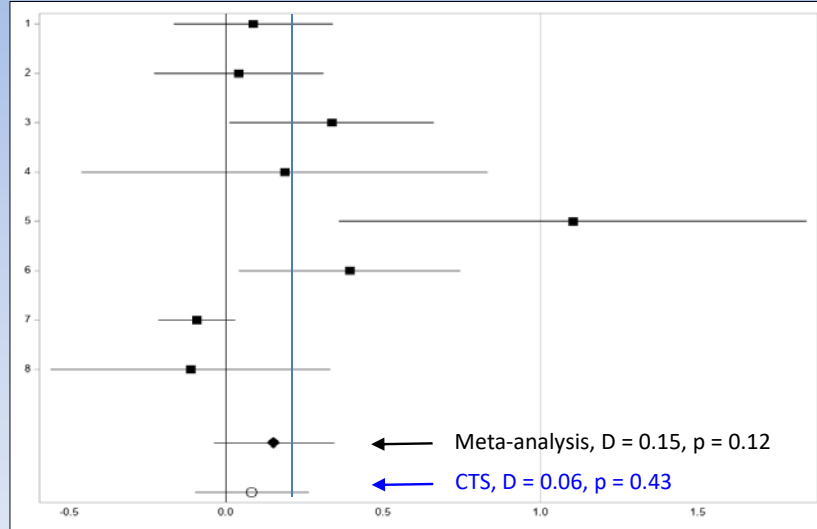
Caregiving vs. Control on CRP



Caregiving vs. Control on CRP



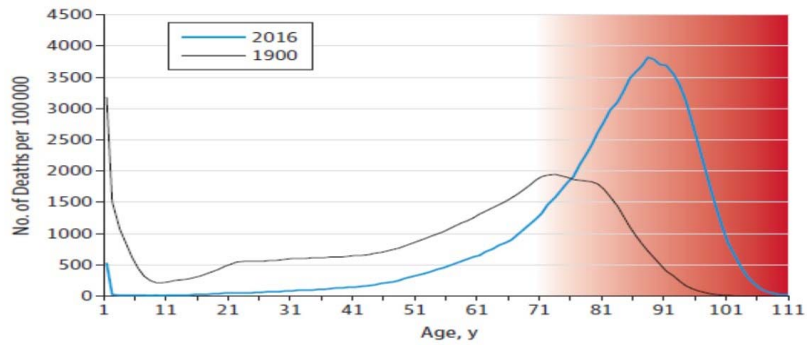
Caregiving vs. Control on CRP



*Summary of Biomarker Findings
(Roth et al., under review)*

1. The transition to caregiving had little to no impact on IL-6, CRP, and other common measures of systemic inflammation. Caregiver vs. control effects for IL-6 and CRP were less than 1/10th of a standard deviation unit and not statistically significant.
2. The lack of significant differences remained even when analyses were restricted to key subgroups (e.g., caregivers of persons with dementia, high strain caregivers, spouse caregivers)

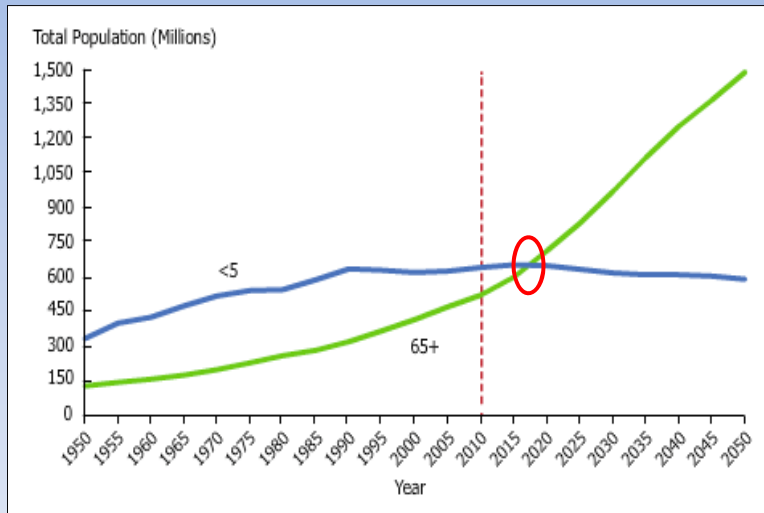
Figure. Age Distribution of Life Table Deaths for Women in the United States, per 100 000 People, 1900 and 2016



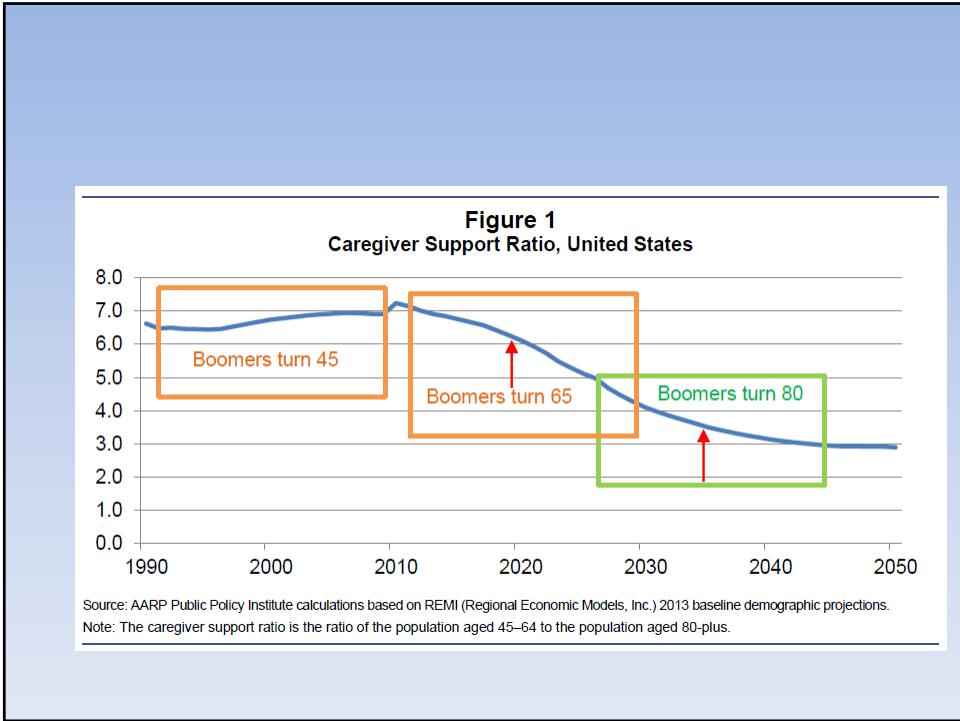
The red zone represents a period in life when the risk of frailty and disability begins to increase rapidly. The goal of aging science is to delay and compress the red zone, which may extend healthy life. Sources: 1900 data from Bell and Miller¹; 2016 data from Human Mortality Database.²

Source: Olshansky SJ. From Lifespan to Healthspan. *JAMA*. Published online September 17, 2018. doi:10.1001/jama.2018.12621

World Population, Age 65+ and Age <5



Source: Population Reference Bureau



The Demand for Informal Caregiving

- The size of the older adult population is exploding and will approximately double in the next 15 years.
- Baby Boomers, because of lower birth rates and lower marriage rates, will have roughly ½ of the family members who have traditionally taken on family caregiving roles available to them as they age over the next 15 years.

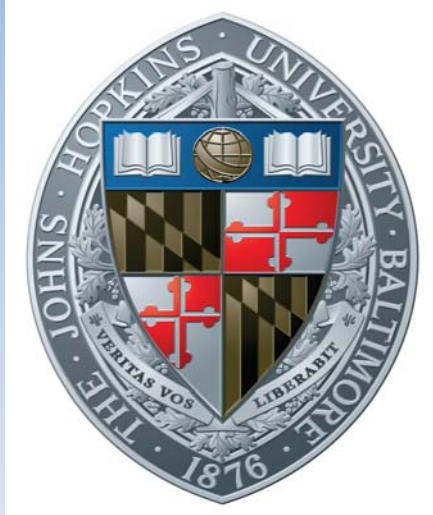


Should We Study Caregivers, or Caregiving?

- “**Caregiving**” is the act of providing assistance to a person with a disability.
- “**Caregivers**” provide caregiving. However, some caregiving is done by persons who are not regular or primary caregivers. Care can also be provided to older adults who do not have a clear disability, but who might still benefit from certain types of assistance or companionship (e.g., accompanying an older person to a medical appointment).
- Studies of **caregivers** usually focus on their problems (e.g., stress) or on interventions designed to address those problems.
- Studies that focus on other aspects of **caregiving** – the act of providing care, and the benefits of that care for both the carers and the care recipients, are less common, but greatly needed.

Should We Study Caregivers or Caregiving?

- ***Caregiving vs. Volunteering.*** Many studies have documented the health benefits of volunteerism. Caregiving is also a prosocial (altruistic) behavior. It can be seen as volunteerism within one’s own family or social network.
- Giving care to older adults should be ***encouraged, celebrated, and supported*** on many *levels*. In fact, it must be, if community- and home-based innovative care plans for older adults have any chance at all for success at a population impact level.



Thank you!

