

Evolving knowledge about the health effects of caregiving to persons with dementia and other conditions

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#DementiaCareSummit

Evolving research on health effects of caregiving

Early studies:

- Guided by stress theory (1)
- Small, select samples of caregivers and non-caregivers
- Often spouse caregivers and married non-caregiver volunteers
- Cross-sectional, or short (1-2 yrs) follow-up periods
- Caregivers- more stressed, neglected health more, elevated levels of some biomarkers (2)
- Inconsistent findings re. physical health outcomes

Recent studies:

- Guided by stress theory
- Population-based samples
- Often connected to large, prospective epidemiologic studies
- Long follow-up periods (4-12 yrs)
- Caregivers- more stressed
- Overall, caregivers better health outcomes than non-caregivers: lower mortality, less decline in physical and cognitive functioning (3)
- Poorer outcomes in some subgroups: stressed, metabolic syndrome, spouses, caregivers to persons w. dementia (4,5)

Why these disparate findings?

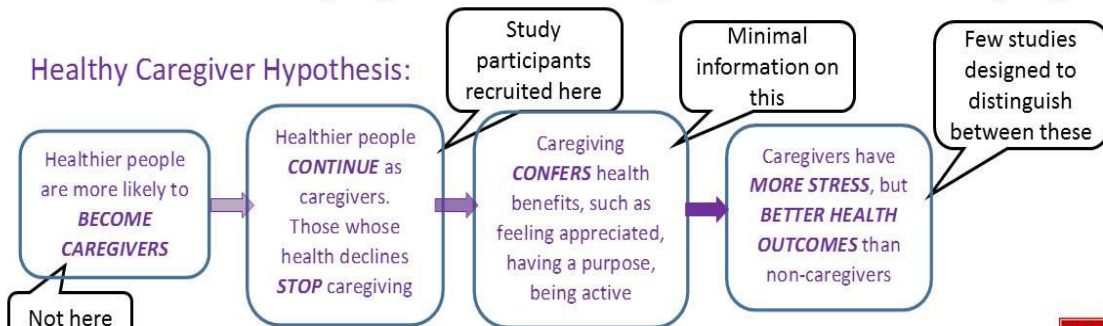


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Disparate findings may reflect disconnect between research designs, and factors that determine who becomes a caregiver and remains a caregiver (6)

- Research designs: identify and recruit **current** caregivers and non-caregivers
- Determine caregiver status at baseline only
- Ignore changes in caregiver status over the follow-up period
- Health influences caregiving transitions → findings on health effects of caregiving

Healthy Caregiver Hypothesis:



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Effects of community-based services:

- Recent review of 53 randomized and non-randomized controlled trials (7) found positive health effects of:
 - Psychoeducational interventions
 - Cognitive behavioral therapy (CBT)
 - Respite care
 - Occupational therapy
 - Interventions targeted to caregiver
- Caveats: generally psychological, not physical health outcomes; short follow-up periods; wait-list control groups
- Small beneficial effects may be because caregivers who use community-based services have better mental health and social support than those who do not (8)
- Daily assessments (e.g., DaSH study of caregivers to Adult Day Service users) show proximal and long-term effects of service use on caregiver health (9, 10)

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What is needed to better understand health effects of caregiving to persons with dementia

- Longitudinal studies that follow persons from before they start caregiving to after caregiving ends
- Longitudinal assessment of caregiver status to better document caregiving transitions
- Longitudinal measurement of self-reported stress in caregivers and non-caregivers
- Examine impact of health, relationship dynamics, life course issues on caregiving transitions, and on short- and long-term health effects of caregiving
- Biomarkers as indicators of the pathways and mediators of the effects of caregiving on health
- Integrate with models of aging, life course development, resilience
- Caregiver's assessment of caregiving-related benefits, as well as stressors
- Innovative study designs, not just RCTs, to evaluate effects of community-based services (9)

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Recommendations to better understand health effects of caregiving to persons with dementia and other conditions

"There are four types of people in the world.
Those who have been caregivers.
Those who are currently caregivers.
Those who will be caregivers.
And those who will need a caregiver."



Former First Lady, Rosalynn Carter

Current caregivers:

- Link to on-going prospective epidemiologic studies, ex: Caregiver-SOF, Caregiver Health Effects study
- Add information on caregiver status to health records
- Apply epidemiologic methods to studies of dementia caregivers: attention to comparison groups, assessment and re-assessment of caregiver status, approaches to reduce potential bias

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Recommendations to better understand health effects of caregiving to persons with dementia and other conditions

Current caregivers, continued:

- Expand from studying caregiving dyads to caregiving families and groups
- Examine caregiver's assessment of caregiving-related benefits, as well as stressors
- Studies of interventions/community services: use non-RCT designs, and link to prospective epidemiologic studies to create observational comparison group

Former caregivers:

- Evaluate short- and long-term health outcomes after persons stop caregiving
- Connect recipient's end-of-life care/experience with short- and long-term outcomes in the caregivers

Future caregivers and those who will need a caregiver:

- Study impact of a priori discussion of caregiving preferences on caregivers' health, along the lines of The Conversation Project for End-of-Life care

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