Paying (Attention To) Unpaid Caregivers

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Disclosures

- I have grants from the National Institute on Aging and the Greenwall Foundation. The content is solely the responsibility of the author and does not necessarily represent the official views of the National Institutes of Health or Greenwall Foundation.

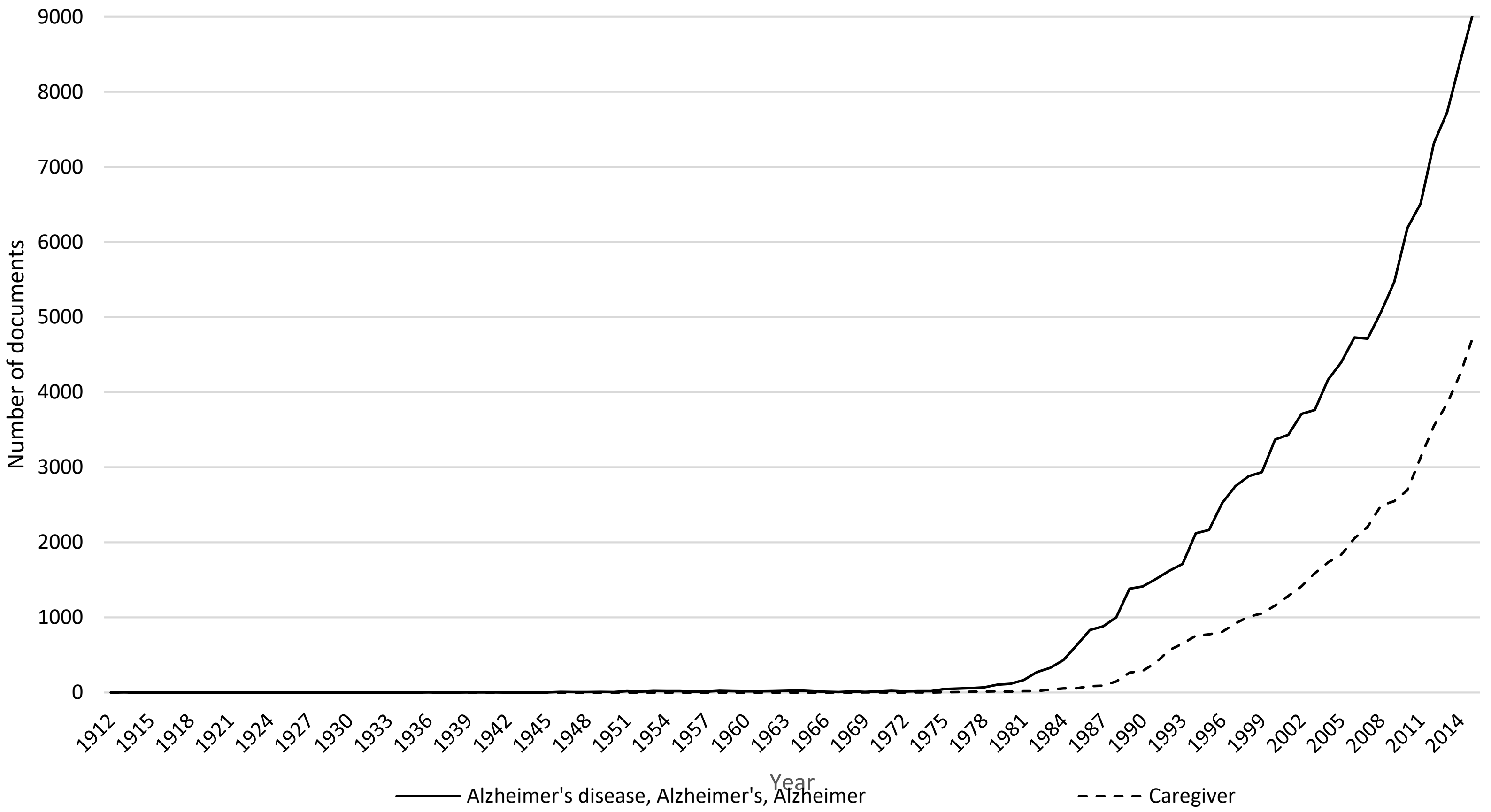

Figure 1.
The plot shows the number of documents published per year that contain terms “Alzheimer’s disease,” “Alzheimer’s,” or “Alzheimer” and “caregiver” as found in database PubMed. Similar results were found in Scopus, Web of Science, and in Google texts.
SOURCE: PubMed [online]. Available at: http://www.ncbi.nlm.nih.gov/pubmed. Accessed 5/16/16.

“Ruth Swearing to Naomi,” Jan Vikers, 1653.

Dementia care is often managed, provided, and financed by family members, and people facing dementia regularly worry about burdening their families.

National Overreliance on Unpaid Caregivers

- 11 million + Americans provide unpaid care for people with AD/ADRD.
  - Provided an estimated 16 billion hours of informal assistance in 2021, valued at $271.6 billion.[1]
  - The total lifetime cost of care for a person living with dementia is $377,621; 70% of that is borne by family caregivers.[1]
- The provide care for community-dwelling people with AD/ADRD but are also an “invisible workforce” in LTC settings.[2]
- Unpaid caregivers are not just custodians of the body; they are extensions of the mind.

[1] Alzheimer’s Association, 2022 Alzheimer's Disease Facts and Figures

[2] Coe and Werner, https://doi.org/10.1377/hlthaff.2021.01239

Caring for the Caregiver

- COVID-19: a natural experiment in what happens when care is compromised.
- Caregivers can experience *role strain* and *role gain*.
  - Independently associated with caregiver wellbeing.[1]
  - Affect the wellbeing of the person with AD/ADRD.
- Thus, it is important to:
  - Mitigate the objective demands of the caregiving role.
  - Help caregivers positively frame their interpretation of these demands and of their abilities to meet them.

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[1] Rapp & Chao, https://doi.org/10.1080/13607860050008664

Payment Mechanisms Can Help

- It’s a failure of moral imagination to perceive needs arising from dementia as problems for unlucky families to solve independently.
- What would it look like to organize health care around the dyad? A few ideas:
    - Clear documentation of who the caregiver is (will help with research, too!)
    - Time and space for triadic communication within clinic visits
    - Counseling and coaching for unpaid caregivers to equip caregivers with skills and strategies to maintain a PLWD at home
    - Interventions delivered by social workers like advance care planning, psychosocial support
    - Increased access to respite care
    - Collaborative dementia care models, dementia “navigators”

Unbefriended

- PLWD who are unbefriended and, therefore, particularly vulnerable to poor care and poor outcomes. For example, having no visitors is associated with worse care quality for nursing home residents with advanced dementia.[1]
- More research is needed to understand how to care for those who lack natural supports.

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[1] Grabowski & Mitchell, 10.1097/MLR.0b013e318195fce7

It is essential to develop policies and interventions that center care structures and supports on the person with AD/ADRD and caregiver dyad to maintain the wellbeing of the person with dementia and to promote the wellbeing of the caregiver.