

Caregiving for Alzheimers Disease and Related Dementias: Enhancing the National Study of Caregiving (NSOC)

<https://www.neurodegenerationresearch.eu/survey/caregiving-for-alzheimers-disease-and-related-dementias-enhancing-the-national-study-of-caregiving-nsoc/>

Principal Investigators

KASPER, JUDITH

Institution

JOHNS HOPKINS UNIVERSITY

Contact information of lead PI Country

USA

Title of project or programme

Caregiving for Alzheimers Disease and Related Dementias: Enhancing the National Study of Caregiving (NSOC)

Source of funding information

NIH (NIA)

Total sum awarded (Euro)

€ 4,087,622.94

Start date of award

15/09/2016

Total duration of award in years

1

The project/programme is most relevant to:

Alzheimer's disease & other dementias

Keywords

Acquired Cognitive Impairment... Aging... Alzheimer's Disease... Alzheimer's Disease including Alzheimer's Disease Related Dementias (AD/ADRD)... Behavioral and Social Science... Brain

Disorders... Caregiving Research... Clinical Research... Clinical Research - Extramural...
Dementia... Health Services... Neurodegenerative... Neurosciences

Research Abstract

PROJECT SUMMARY: There is widespread agreement that growth in the number of people living into their 80s and 90s, when risks of Alzheimer's disease and related dementias (ADRD) are substantial, will dramatically increase the number of people living with dementia over the next few decades. Caregiving to people with ADRD is most often provided by family members and while the National Plan to Address Alzheimer's Disease has among its goals enhancing the care quality for persons with ADRD and expanding supports for family caregivers there are critical gaps in knowledge about how to proceed. This project enhances understanding of caregiving to older adults with Alzheimer's disease and related dementia through new national longitudinal data that builds upon the National Health and Aging Trends Study (NHATS) and its companion National Study of Caregiving (NSOC). The unique NSOC study design and new content proposed for NSOC III will permit contrasts between caregivers to older adults with and without ADRD for a nationally representative sample of caregivers who help older adult participants in the NHATS. Begun in 2011, NHATS collects detailed information annually about the disability and care needs for a nationally representative panel of over 8,000 adults 65 and older. By collecting, disseminating, and analyzing a new round of NSOC, the proposed project will allow researchers to study a range of innovative questions about ADRD caregiving and its consequences from the perspective of both the care recipient and the caregiver. Aims are : 1. Re-interview caregivers who participated in the 2015 NSOC and new caregivers of older adults in the 2017 NHATS. In addition to core NSOC content, administer a new module on involvement in medical care and two time diary interviews to capture activities and experienced wellbeing on the previous day. Altogether, we expect a nationally representative sample of about 2700 caregivers to older adults, including about 900 caring for older adults with Alzheimer's disease and related dementias. 2. Disseminate the data widely by creating a set of easy-to-use linked longitudinal files; holding user workshops at scientific meetings; and hosting an early results workshop focused on ADRD caregiving; and, 3. Conduct analyses to: 1) identify salient ADRD informal care and caregiving trajectories from both recipient and caregiver perspectives; 2) provide the first national profile of informal ADRD caregivers' health system interactions; and 3) investigate the wellbeing of informal ADRD caregivers and the role of care activities. For each topic, we will provide contrasts with caregivers to older adults without ADRD. The NHATS and NSOC are the only national, population-based surveys that provide insight regarding a well characterized population of older adults as well as the informal caregivers who assist them for health and functioning reasons. These data provide a strong platform for research to inform planning and policies to meet the impending demand for ADRD care and to support ADRD caregivers.

Lay Summary

NARRATIVE This project enhances understanding of caregiving to older adults with Alzheimer's disease and related dementias (ADRD) through new national longitudinal data that provides both care recipient and caregiver perspectives to inform planning and policies to meet demands for ADRD care and support ADRD caregivers.

Further information available at:

Types:

Investments > €500k

Member States:

United States of America

Diseases:

Alzheimer's disease & other dementias

Years:

2016

Database Categories:

N/A

Database Tags:

N/A