Guardianship and Medical Decision Making for the Unbefriended Elderly

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Contact information of lead PI
Country

USA

Title of project or programme

Guardianship and Medical Decision Making for the Unbefriended Elderly

Source of funding information

NIH (NIA)

Total sum awarded (Euro)

€ 230,504.59

Start date of award

15/08/2016

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... Palliative Care

Research Abstract

PROJECT SUMMARY As the Baby Boom generation ages, the convergence of long-term socio-demographic trends with the growth in Alzheimer's disease will lead to a dramatic increase in the number of older Americans who have diminished capacity to make decisions about their medical care, no legally appointed health care proxy, and no close relatives or friends to make decisions for them. For such individuals, who are said to be "unbefriended," guardianship is currently the default mechanism for identifying a surrogate decision maker. In this process, the court appoints an official, known as a professional guardian, who is paid to represent the impaired individual. Case reports have repeatedly called attention to potential problems with medical decision making by guardians, particularly when choices must be made about end-of-life care. Concerns have also been raised about guardians' oversight as well as conflicting and underdetermined ethical standards. Nevertheless, even though between 0.5 and 1.5 million Americans are under guardianship, no empirical research has been done on medical decision making by guardians because it has not previously been possible to identify patients with guardians in existing datasets. The candidate has developed a reliable method to identify individuals with professional guardians using data from the Veterans Health Administration. In Specific Aim 1, this method will be used to determine whether nursing home residents with advanced dementia who are represented by guardians receive higher intensity end-of-life care than those who have family members available. Specific Aim 2 involves a complementary qualitative study, involving interviews with probate court judges and professional guardians to examine guardians' appointment and oversight, their relationships with the persons they represent, and how complex decisions about treatment are made for patients with serious illness. The proposed work will move our knowledge from case reports to population-level analysis. It will generate data that are essential to advance our understanding of what the current system gets right and wrong about making the best possible decisions for unbefriended patients. The findings will serve as the first step towards the candidate's long-term objective, which is to develop evidence-based interventions to ensure that unbefriended patients receive care that respects their dignity and priorities without imposing undue burdens on clinical staff, health systems, or courts. During the award period, the candidate, who is a geriatrician, will acquire skills in large database analysis and qualitative research methods, as well as additional training and mentorship in areas outside geriatrics that are of key relevance to this work, including medical ethics and law.

Lay Summary

PROJECT NARRATIVE The aging of the Baby Boom generation will bring a dramatic increase in the number of "unbefriended" older Americans, who have prolonged decision making incapacity, no legally appointed health care proxy, and no family members or friends available to make medical decisions for them. Little is known about decision making by the court-appointed surrogates who represent such individuals — paid officials known as professional guardians. The objective of this proposal is to evaluate medical decision making by professional guardians, with special attention to determining whether unbefriended individuals with guardians receive high intensity end-of-life care that may be inappropriate and to elucidating the key factors influencing guardians' decisions.

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