Online Ethics Center
FOR ENGINEERING AND SCIENCE

The Alzheimer's Caregiver Study

Author(s)

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2000

Description

A scenario meant to stimulate discussion about the ethical issues that arise when researchers propose to do research on persons with Alzheimer's Disease and their caregivers.

Body

You are the principal investigator for a study of the most effective form of respite or short term day care services for caregivers of persons with Alzheimer's Disease (AD). The study involves use of three groups -- two treatment and one control.

One treatment group will consist of 4 hours of "day care" for the AD person, five days per week. The second treatment group consists of three 8-hour "day care" sessions per week for the AD person, plus a support group for the caregiver. The control group will not have access to either respite service, but will simply be interviewed every month for the 3 month period to measure stress and coping. Part of the data collection also involves some baseline assessment of the AD person, using mental status tests and obtaining information from medical records.

Questions:

1. The AD patients themselves are part of the research group, since they are receiving an intervention and data is being collected from them. What concern is there, if any, about using AD patients as subjects when they may receive no benefit and may even be harmed (although minimally) by the "treatment"?
2. What are the potential problems with allowing the caregiver of the AD person to give permission for the involvement of the AD person, since the caregiver may be motivated by the hope of gaining personal benefit (relief from burdens of caregiving for the duration of the study)? What could you do to eliminate those problems?
3. Given the special vulnerabilities of the AD population, are there any additional restrictions or concerns about offering incentives to participate?
4. What additional protections, if any, should be put in place for studies like this that involve subjects unable to protect themselves?

Notes

Caroline Whitbeck introduced methods and modules for discussing numerous issues in responsible conduct of research at a Sigma Xi Forum in 2000. Partial funding for the development of this material came from an NIH grant.

You can find the entire sequence on the OEC at Scenarios for Ethics Modules in the Responsible Conduct of Research. Some information in these historical modules may be out-of-date; for instance, there may be a new edition of the professional society's code that is referred to in an item. If you have suggestions for updates, please contact the OEC.

Contributor(s)

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Resource Type

Case Study / Scenario

Parent Collection

Scenarios for Ethics Modules in the Responsible Conduct of Research

Topics

Human Subjects Research
Informed Consent
Vulnerable Populations

Discipline(s)

Life and Environmental Sciences
Research Ethics
Social and Behavioral Sciences

Publisher

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