

Challenges and solutions for involving persons with dementia and dementia family caregivers as members of the research team

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#DementiaCareSummit

Core principles

- A research project must have scientific validity
- A research project must have scientific value
 - some reasonable prospect of producing valuable results, a “worthwhile “ hypothesis or question
- Validity cannot be “traded-off” for value
- Logic of clinical purpose: study should reflect practice and be capable of changing that practice
 - The test of value is “will the results change practice?”

The challenges

- An essential challenge with persons living with dementia is their ability to contribute to validity
 - how persons rate their day-to-day function differs from how observers such as CG rate function
 - measures of QOL correlate best with mood and awareness of diagnosis and cognitive symptoms, not severity of disability (IADL and ADL)
- The distinction between “emic” (insider) and “etic” (outsider) understandings of a culture
 - phonemic or phonetic pronunciation or spelling of a word (“tuff” versus “tough”)

The challenges

- An essential challenge with caregivers is the variety (diversity) of their perspectives on value
 - variety reflects social, economic and family differences (gender, age, relationship, working)
 - notably, for example, most of the subjects of AD clinical trials are spousal/partner dyads
 - relationship to the person with dementia is an independent predictor of a caregiver’s willingness to have them and their relative participate in a clinical trial

Challenges with the person living with dementia



Topic **Passive**

prioritization

Given the severity of the cognitive and functional Impairments, how will they impact on validity or value?

Planning

Validity....

Implementation

What the person says is “true” (“emic”) What is “true” (“etic”)

Dissemination

Challenges with the caregiver



Topic

prioritization

Given the caregiver characteristics, how will they impact on the content of the validity or the value?

Planning

Relationship to the person: spouse vs non-spouse

Implementation

Gender: male or female

Roles other than CG: employed and other CG'ing

Dissemination

Research recommendations

- Dementia is unique among diseases because it largely affects our ability to exercise a value (autonomy) and so exercise personhood. The perspectives of cultural anthropology help to mediate this ethical fact.
- Know your subject... stakeholder... partner... researcher
 - patient input on (A) what's wrong?, or (B) how they feel about what's wrong?
 - caregiver who are also spouses or adult children or other kinds of relatives have very different experiences and perspectives

Research recommendations

- Researchers need a process to engage persons with dementia and caregivers - how to get one person (a few) to speak for many
 - elicitation interviews, surveys, review and comment periods, etc.
 - what input is needed to change practice, i.e., the value or worth of the study?