

Elder Abuse & Neglect: Ethical Consideration in Research & Care

Jason Karlawish, MD

University of Pennsylvania; Departments of
Medicine, Medical Ethics and Health Policy

Alzheimers Disease Center

Penn Neurodegenerative Disease Ethics and
Policy Program

Jasonkarlawish@gmail.com

Ethical considerations in research & care

A 85-year-old woman is hospitalized for pneumonia and is now ready for discharge. Her friend and neighbor returns from the patient's apartment. She's discovered two mispaid bills, a ledger with cash transfers to her daughter, and two full bottles of medications.

The patient's daughter says that everything is ok – “I'm looking after my mother fine” – and the patient should go home to her apartment.

The case manager asks you. “Can we send her home?”

Ethical considerations in research & care

You ask the patient whether she'd like a nurse to come over to assist with her medicines and review how things are going at home.

The patient replies, "No. I don't like that compared to what I do. I don't like people coming over to my private place, and I don't want my daughter bothered."

Ethical considerations in research & care

| | <u>Able to perform IADL?</u> | | |
|---|------------------------------|-------------------------|----|
| | | YES | NO |
| <u>Able to decide how to manage IADL impairment</u> | YES | living independently | |
| | NO | | |

Ethical considerations in research & care

| | <u>Able to perform IADL?</u> | | |
|---|------------------------------|----------------------|------------------|
| | | YES | NO |
| <u>Able to decide how to manage IADL impairment</u> | YES | living independently | dependent and ok |
| | NO | NA | |

Ethical considerations in research & care

| | <u>Able to perform IADL?</u> | | |
|---|------------------------------|----------------------|----------------------|
| | | YES | NO |
| <u>Able to decide how to manage IADL impairment</u> | YES | living independently | dependent and ok |
| | NO | NA | dependent and not OK |

Ethical considerations in research & care

We are poised to achieve...

- Clear and coherent and consistent communication about the concepts of capacity and competency
- Ethically and scientifically sensible research review and approval

Ethical considerations in research & care

- The theory and practice of capacity assessment has made substantial progress in arriving at a coherent set of concepts and practices that are legally and ethically acceptable
 - Measures of overall cognition are not measures of capacity
 - They are measures of the risk of the loss of capacity

Ethical considerations in research & care

- Capacity and competency
 - Capacity is the continuum of decision making abilities
 - “Being competent” or “having adequate capacity” is a judgment of a person’s decision making abilities
- The decision making abilities
 - choice, understanding, appreciation, reasoning
- Assessments of capacity are used to make *judgments* of competency

Ethical considerations in research & care

- Instruments exist, and new ones can be developed, that can structure how we decide someone can make a decision
 - They focus us on ability, not status, or “reasonableness,” or cognition
 - They specify the abilities we ought to care about
 - They demonstrate where there are impairments

Ethical considerations in research & care

- Instruments exist, and new ones can be developed, that can structure how we decide someone can make a decision
 - They explain the clinical significance of overall cognitive impairment and neuropsychiatric impairment
 - They provide us a coherent language to talk about the IADL of decisionmaking
 - They put assessment into our ethics

Ethical considerations in research & care

- Financial “capacity” -- the ability to manage money and financial assets in ways that meet a person’s needs and which are consistent with his/her values and self-interest. (Marson In: *Forensic Neuropsychology* 2011).

Ethical considerations in research & care

- Financial capacity is multidimensional
 - Basic monetary skills
 - Carrying out cash transactions
 - Managing a checkbook and bank statement
 - Exercising financial judgment
- A person may be able to carry out some financial transactions but not others
- Financial capacity is in a sense an instrumental activity of daily living (IADL)

- Decisional capacity – the decision about how to manage an IADL impairment
 - Assessment for the Capacity for Everyday Decisionmaking (ACED)
 - a measure of the ability to decide how to manage an IADL impairment
 - in older adults with mild to moderate dementia, we see (a) decent ability to choose and reason, and (b) impaired abilities to understand and appreciate information

Ethical considerations in research & care

- Lai J.M., Karlawish J.H.: Assessing the Capacity to Make Everyday Decisions: A Guide for Clinicians and an Agenda for Future Research. *Am J Geriatr Psych* 2007;15: 101-11.
- Copies of ACED and SPACED:
jasonkarlawish@gmail.com
- *Generations: Journal of the American Society on Aging*. Vol 36(2); Summer 2012
 - An excellent review of financial capacity

Ethical considerations in research & care

- The ethics of research that involves persons with disorders that may impair their decisionmaking capacity is reasonably well worked out
- In elder abuse and neglect, there may be some concern over who can serve as a surrogate, *if the research requires a surrogate*
 - In our case, would the daughter be an appropriate surrogate?