

Decision Making and Dementia

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WHY: Patients have the right to participate in decisions about their care, e.g., diagnostic and treatment interventions, diet, ambulation, daily care, and end-of-life care. Consent to (or refusal of) diagnostic and treatment interventions requires that the patient demonstrate their ability to consider the benefits, burdens and risks of the decision. Whether or not an individual has the capacity to understand, make a decision and take responsibility for the consequences of the decision is a clinical determination; it is not a question of legal competence. Persons with mild-to-moderate dementia can have the capacity to make some, but not all, decisions. They may be able to participate in decision making but impaired memory recall might preclude their ability to demonstrate that they understand the treatment options (Moye, et al, 2004). Ethically, legally, and clinically it is always better to try to ascertain the patient's authentic wishes, goals, values, and preferences rather than to immediately default to a family member or other surrogate decision maker.

BEST PRACTICES: Patients whose cognitive status is unclear or fluctuates need protection from two types of mistakes: first, mistakenly preventing capacitated patients from directing the course of their healthcare; second, failing to protect incapacitated patients from the harmful effects of their decisions. There is no gold standard for capacity determination. A Folstein Mini-Mental Status Examination score below 19 or above 23 is one proposed means to differentiate those with capacity from those who lack capacity for healthcare decision making (Karlavish, et al, 2005). The patient's ability to appreciate the consequences of a decision is a highly valued standard of decision making (Volicer & Ganzini, 2003). Clinicians need to guard against assuming that certain categories of patients, for example patients with depression and overlaying mild dementia, lack decisional capacity.

TARGET POPULATION: All hospitalized patients and those in long-term care diagnosed with Alzheimer's Disease/dementia. For patients previously declared legally incompetent, their legally appointed guardian will make decisions for them if the guardianship includes healthcare decision making. All patients not adjudicated as incompetent should be assessed for capacity to make health care decisions. Adults with mild to moderate dementia and mild-to-moderate mental retardation have been shown to be able to make treatment decisions, provide a rationale, and evaluate the risks and benefits of treatment options (Cea & Fisher, 2003).

GUIDING CONCEPTS

1. Capacity is not an all-or-nothing "on-off" switch.
2. "Decision-specific capacity" assumes the presence or absence of capacity for a particular decision at a particular time and under a particular set of circumstances.
3. A patient may be able to make, or indicate, some but not all decisions; e.g. state (or indicate) a preference related to daily care but not make a complex treatment choice.
4. Even a patient with advanced dementia may have the capacity to appoint a health care proxy but not complete a living will (Mezey, et al, 2002).
5. The more serious the risks or consequences of a decision, the clearer the patient's decisional capacity needs to be. For decisions about high-risk or burden interventions and/or low potential benefit, and which require signed consent, a patient with dementia needs to demonstrate a fairly high degree of understanding to process information. Decision-making capacity presumes the retention of personal values and goals.
6. A patient should be encouraged to participate in the discussion even if another person will be making the actual decision.
7. A patient's "bad" decision from the perspective of the healthcare professionals and/or family caregivers is not necessarily a prime indicator of lack of capacity or incompetence.
8. Periodically, re-assess a patient's understanding and reasoning with regard to diagnostic and treatment intervention decision making.

Guidelines for evaluating decision-making capacity

Evaluation Guidelines: Elements that a patient must demonstrate in order for the nurse to have confidence that the patient has decisional capacity:

1. “Appreciation” and understanding that s/he has the right to make a choice/decision.
2. Understanding that s/he is being asked to make a specific decision (e.g., daily care preferences, diagnostic work-up, treatment).
3. Application of a set of personal values to the decision.
4. Communication of the decision including explaining, in his/her own words, why a particular decision was made (e.g., the burden, benefits and risks taken into consideration).
5. Stability and consistency of the decision over time (e.g., 24 hours).

Process Guidelines

1. Information should be presented in short, simple sentences.
2. After each “input” of information, ask the patient to tell you in his/her own words what was just said. Listen for accuracy in the patient’s rephrasing of the recalled information; the patient does not have to use medical “jargon” or speak a word-for-word replay.
3. Assist the patient in considering what s/he thinks will be the benefit, burden and risk of each diagnostic/treatment/care option (or refusal).
 - What would proceeding with the test/intervention likely do to further their personal goals, interests, life style, comfort, longevity, anxiety reduction, etc?
 - What kinds of decisions have they made in the past that were of similar significance /magnitude/importance to them?
4. Do not rush the process for capacity determination. Most healthcare decisions are not made individually; they are made with family involvement. When at all possible, the person with dementia’s authentic wishes should be respected and not over-ruled in the interests of what family or staff feel is best for them.

Decisions made by Others

Health Care Proxy (HCP): The Durable Power of Attorney for Health Care authorizes someone, e.g., the health care proxy or agent, to make health care decisions if the individual loses the ability to make or communicate decisions. State laws differ about who is assumed to be the surrogate decision-maker for a person who cannot make decisions for him/herself and does not have a designated HCP. State laws also differ on who is included and the order of preference in selecting a surrogate decision-maker. Contact the American Bar Association Commission for Legal Problems and the Elderly at <http://www.abanet.org/aging/> for state-specific information. When a decision must be made by another person, ask that person:

- If (the patient) could join this discussion, what would s/he say?
- Faced with similar situations in the past, how did the patient decide?

MORE ON THE TOPIC:

Best practice information on care of older adults: www.ConsultGeriRN.org. See Treatment Decision Making.

Cea, C.D., & Fisher, C.B. (2003). Health care decision making by adults with mental retardation. *Mental Retardation*, 41(2), 78-87. Evidence Level IV: Non-experimental study.

Karlawish, J.H., Casarett, D.J., James, B.D., Xie, S.X., & Kim, S.Y. (2005). The ability of persons with Alzheimer’s Disease (AD) to make a decision about taking an AD treatment. *Neurology*, 64(9), 1514-1519. Evidence Level IV: Non-experimental study.

Mezey, M., Teresi, J., Ramsey, G., Mitty, E., & Bobrowitz, T. (2002). Determining a resident’s capacity to execute a health care proxy. In M. Mezey, N. N. Dubler, & E. Mitty (Eds.), *Voices of decisions in nursing homes: Respecting residents’ preferences for end-of-life care* (pp. 3-26). New York: United Hospital Fund. Evidence Level IV: Non-experimental study.

Mitty, E., & Ramsey G. Advance Directives: Protecting Patient’s Rights and Mitty, E. & Post, L.F. (2007). Healthcare Decision Making. In D. Zwicker, M.D. Mezey, E. Capezuti, & T. Fulmer (Eds.) and D. Gray-Miceli (Associate Ed.), *Geriatric nursing protocols for best practice* (3rd ed.). New York: Springer Publishing Company, Inc. Evidence Level V and VI: Review of the Literature; Expert opinion.

Moye, J., Karel, M.J., Azar, A.R., & Gurrera, R.J. (2004). Capacity to consent to treatment: Empirical comparison of three instruments in older adults with and without dementia. *Gerontologist*, 44(2), 166-175. Evidence Level IV: Non-experimental study.

Volicer, L., & Ganzini, L. (2003). Health professionals; views on standards for decision-making capacity regarding refusal of medical treatment in mild Alzheimer’s Disease. *JAGS*, 51(5), 1270-1274. Evidence Level IV: Non-experimental study.