Ethics and Dementia

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Basic Concepts
Family Control (2014 Review)
“I Want My Shot”

Ms. E is an 85-year-old resident who has a diagnosis of dementia but is oriented X3, lucid, able to converse on complex subjects and scored a 27 out of 29 on a recent mini-mental status exam. Ms. E recently requested an influenza inoculation and clearly indicates that she understands that this is a special injection for the current swine flu outbreak and that she will also want to receive the seasonal swine flu inoculation when the time is appropriate. Ms. E admits to no clinical contraindications for receiving the vaccine. She indicates that she has always received flu shots and secured them for her children, and that she wants this flu shot now. Ms. E’s daughter, who is listed as her responsible party but who does not carry a durable power of attorney for healthcare, does not want the facility to provide the injection on the grounds that this treatment would only prolong Ms. E’s life and that pneumonia is not a bad way to die. Ms. E insists that this decision should be hers alone and that she does not understand why her daughter would not want to her to receive the inoculation.

Diminished Capacity
Basic Assumptions

The two most important things to remember at the beginning of any interaction with a patient surrounding capacity issues are:

1) All adults should be presumed to have capacity until they are explicitly found to lack it,

2) An individual cannot be found to lack capacity simply because s/he carries a particular clinical diagnosis.
Diminished Capacity
The Definition of Capacity

In order for a patient to have diminished capacity, s/he must meet at least one of three criteria:

1) The inability to understand information about the decision that needs to be made (ARBs)

2) The inability to use the information, even if understood, to make a rational evaluation of the risks and benefits involved in the decision

3) The inability to communicate by any means

Diminished Capacity
Incapacity Determinations

There is an important difference between a clinical finding of incapacity that can be documented by the attending physician, and a legal adjudication of incompetence.

A determination that a patient has diminished capacity can apply to a particular healthcare decision, a set of healthcare decisions, or all healthcare decisions.

It is essential that a clinician making a determination that a patient has diminished capacity be able to define the scope of the finding and its basis. A note must be set forth in writing to indicate something like “This patient is unable to make decisions of type X because of deficit Y.”
**Diminished Capacity**

Important Concepts

- Capacity is task specific, so incapacity must be assessed relative to the particular decisions at hand.

- Patients can maintain capacity in certain decisional areas while simultaneously lacking it in others.

- The amount of capacity necessary to make any particular decision is relative to the complexity of the decision and the risks associated with the decision. Therefore, clinicians should be very careful when assessing the inability of patients to make complicated high-risk choices and to verify that the patient lacks a sufficient level of capacity to take responsibility for those choices.

**New Cases**
Withholding Treatment

To Treat or Not To Treat…

Mr. J is a 40-year-old patient with schizoaffective disorder, dementia NOS and has a history of poly-substance abuse. Mr. J became progressively more disoriented and is now being treated with Aricept. The Aricept is achieving marked results and has improved Mr. J’s alertness and orientation, to the point where his is able to act on his delusions. Is it ethically better to treat Mr. J with Aricept, which increases his autonomy, or to withhold Aricept so that, although clearly less oriented, Mr. J will not engage in confrontational behavior and will experience reduced agitation?

Ethics At the End of Life

“It’s Just A Little Lie”

Mr. H is an 82-year-old patient with moderate dementia who has been determined to lack capacity to make her own healthcare decisions. Ms. H suffers from a variety of health challenges, and has been determined to be terminally ill secondary to stage four lung cancer. Her family has enrolled her in hospice, but they are adamant that she not be told her diagnosis or prognosis. They demand that if Ms. H asks whether or not she is in hospice, staff should lie to her and tell her only that she is receiving home health services. How should staff handle the potential disclosure of information to an inquisitive patient with diminished capacity?
The Ethics of Intervention
“‘I Think She Has Dementia’”

Ms. A is a 60-year-old female client with multiple health concerns, including a history of prescription drug abuse. Ms. A has mobility issues and she lives alone in a townhome community. PACE staff members who have been providing in-home support have recently noticed that trash bags and boxes are stacked inside Ms. A’s foyer and there is strong odor coming from the home. The outside of Ms. A’s home is overgrown, and the house is in need of repairs. Ms. A often has her water, electric, and/or gas services cut off. Clinical personnel state that Ms. A seems to have capacity, although they note that her judgment and memory appear to be declining. Ms. A now refuses to allow anyone entry into her home and staff is concerned about her safety.

Placement Issues
“‘She Will Just Drink Again’”

Ms. D is a 70-year-old resident who was recently moved to the memory impairment unit when her ADL skills took a dramatic decline. After a couple of weeks in the unit, however, Ms. D improved greatly and it appears that many of her functional challenges were secondary to an exacerbation of her ETOH abuse. The family now reports that Ms. D had a long history of alcohol abuse. The attending psychiatrist is very concerned that if Ms. D goes back to a less supervised setting, she will re-engage in heavy drinking. On this basis, he refuses to write an order to release her from the memory impairment unit.
**Surrogate Authority**

“The Patient Isn’t The One I’m Worried About”

Mr. and Ms. P currently reside together in assisted living. Mr. P’s function has steadily deteriorated and he recently suffered a stroke. Staff believe that Mr. P needs to go to skilled care once he is released from the hospital, but the Ps have been together for a very long time and they have often indicated a desire to remain together even if that might result in increased risk. Mr. P does not have capacity to make his own healthcare decisions, but Ms. P carries a diagnosis of dementia. Ms. P insists that her husband return home, but it is not clear that she understands the intensity of his needs or that she has insight into her own ability to provide adequate support.

**Proxy Decision Makers**

“Surrogates With Diminished Capacity”

- A properly identified surrogate is innocent until proven guilty.
- The burden of proof rests on the party that seeks to subvert surrogate authority and can be satisfied by evidence of abuse, neglect or demand for substandard care.
- Surrogates are not patients and cannot be compelled to undergo psychiatric evaluation.
- Surrogates can fail in their duty, but they cannot be found to have diminished capacity.
Old Cases

Autonomy and Safety
“Ah, The Joy Of The Open Road”

Mr. R is a 77-year-old gentleman who carries a diagnosis of Alzheimer’s Dementia and exhibits poor safety awareness. Mr. R requires assistance in transitioning from sitting to lying positions and he recently recovered from an ankle fracture that was caused by operating his mobility scooter too close to a wall. Mr. R has been observed using his scooter in a dangerous manner, specifically by operating it on the road in traffic. Mr. R’s children, who carry his POA, want the community to restrict access to the scooter in order to protect their father from harm. Mr. R insists that he is safe, however, and demands that he be allowed to operate his mobility scooter without restriction.
**Confidentiality**

“She Needs To Know”

Mr. V is a 90-year-old resident who suffers dementia and often becomes agitated by another specific individual in the community, Ms. W. On one recent occasion, Mr. V and Ms. W had a verbal altercation in which Mr. V stated that Ms. W was in her way and would not move. Both residents have mobility problems and they were attempting to move through a doorway at the same time. Although the altercation began with nothing more than a verbal exchange, Mr. V eventually grabbed Ms. W’s arm and caused her a minor injury (a superficial laceration). Ms. W now wants to press charges against Mr. V but staff believe that she would not do so if she knew of Mr. V’s dementia. Should staff members disclose information about Mr. V’s mental status to Ms. W?

**Clinical Ethics for Non-Clinicians**

“Control”

Ms. O is a patient in skilled care who very much enjoys visits from her grandson. Every time he visits, however, he ends up leaving with a check. Ms. O’s children are very upset by the imposition that their child places on their mother, but they are not able to police the situation all of the time. They have asked staff to notify them whenever the grandson attempts to visit, and to prevent the visit if they are not available.
Ethics in Long-Term Care

“She Knows What She Wants”

Ms. M is an 88-year-old resident who has been diagnosed with dysphagia by MBS and a recommendation has been made that she receive only a mechanical soft diet and thickened liquids. Ms. M adamantly opposes the restriction to thickened liquids and desires to drink water and ginger ale. She is capable of voicing her desire, and she is also able to ambulate and secure liquids for herself. Ms. M has been determined to have diminished capacity to make health care decisions regarding her diet. Her diagnosis is senile dementia with delusions. Ms. M does not have a written advance directive, as she indicated no need to complete one since she wanted her son to make all decisions in the event that she lost capacity, and he is the next of kin. Ms. M’s son has been made aware of the health risks associated with allowing his mother access to thin liquids and he has requested that she be allowed such access. Given the fact that Ms. M is deteriorating secondary to advanced age and an irreversible disease, the son wishes that her quality of life be maximized by allowing her to eat and drink as she pleases.
An Interesting Final Issue

Ethics in Long Term Care
“She Doesn’t Like It”

Ms. M is an 82-year-old white female resident in skilled care who suffers from moderate dementia. The facility in which Ms. M resides has a racially mixed staff and it maintains a policy that prohibits discrimination on the basis of race, among other factors. Based on discussions with Ms. M and her children, it becomes clear that Ms. M and her entire family hold deeply racist views towards African Americans. Ms. M clearly indicates that she does not trust providers of color, and she now demands that she be cared for only by white providers. How should the facility respond?
Ethics in Long Term Care
“She Wouldn’t Like It”

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Ethics in Long Term Care
“She Doesn’t Know What She Likes”

Ms. M is an 82-year-old white female resident in skilled care who suffers from advanced dementia. The facility in which Ms. M resides has a racially mixed staff and it maintains a policy that prohibits discrimination on the basis of race, among other factors. Based on discussions with Ms. M’s children, it becomes clear that Ms. M and her entire family have always worked hard to overcome racial bias and that Ms. M herself worked tirelessly to advance civil rights issues and to support the desegregation of public schools. However, secondary to her dementia, Ms. M now makes rude and racist comments whenever an African American care giver is in her room. Some staff members of color have complained and requested to be relieved of having to provide services to Ms. M. How should the facility respond?
Supporting Material

**Individual Choice**

The Burden of Proof

1) All other things being equal, individuals have an autonomy right to control their own care.

2) The burden of proof rests on the party that would restrict an individual’s autonomy right.

3) The burden of proof can be satisfied in on the basis of only two classes of argument: prevention of harm to self (paternalism) and prevention of harm to others (distributive justice).
Requirements For Paternalism

Paternalistic interferences with clients’ liberty of action are justified only when:

• The client lacks the capacity for autonomous choice regarding the relevant issue
• There is a clearly demonstrated clinical indication for the treatment or restriction under consideration
• The treatment or restriction under consideration is the least restrictive alternative that is reasonably available and capable of meeting the client’s needs
• The benefits of the treatment under consideration outweigh the harms of the interference itself

*Paternalistic interventions must attempt to advance the values of the individual whose freedom is restricted.*

Requirements For Justice

Justice-based interferences with clients’ liberty of action are justified only when:

• The client behaves in some manner that places others at risk
  and
• Those placed at risk have not provided valid consent to be placed at risk (either by choice or incapacity)
  and either
• The risk of harm to others is more significant than the harm generated by restricting the client’s freedom and is not protected by an identified right (deterrence)
  or
• The client forfeits his/her right to liberty by transgressing a clearly defined social expectation (punishment)