No Easy Answers: Ethical Considerations in the Care of Patients with Dementia

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Financial Disclosures: None

Aim: Think through ethical issues of caring for patients with dementia

Outline

- Dementia: Definitions
- Dementia: Epidemiology
- Ethics: Abbreviated Primer
- Ethical Issues Related to Dementia
- Specific Issues and Case-based Learning

Dementia: Definitions

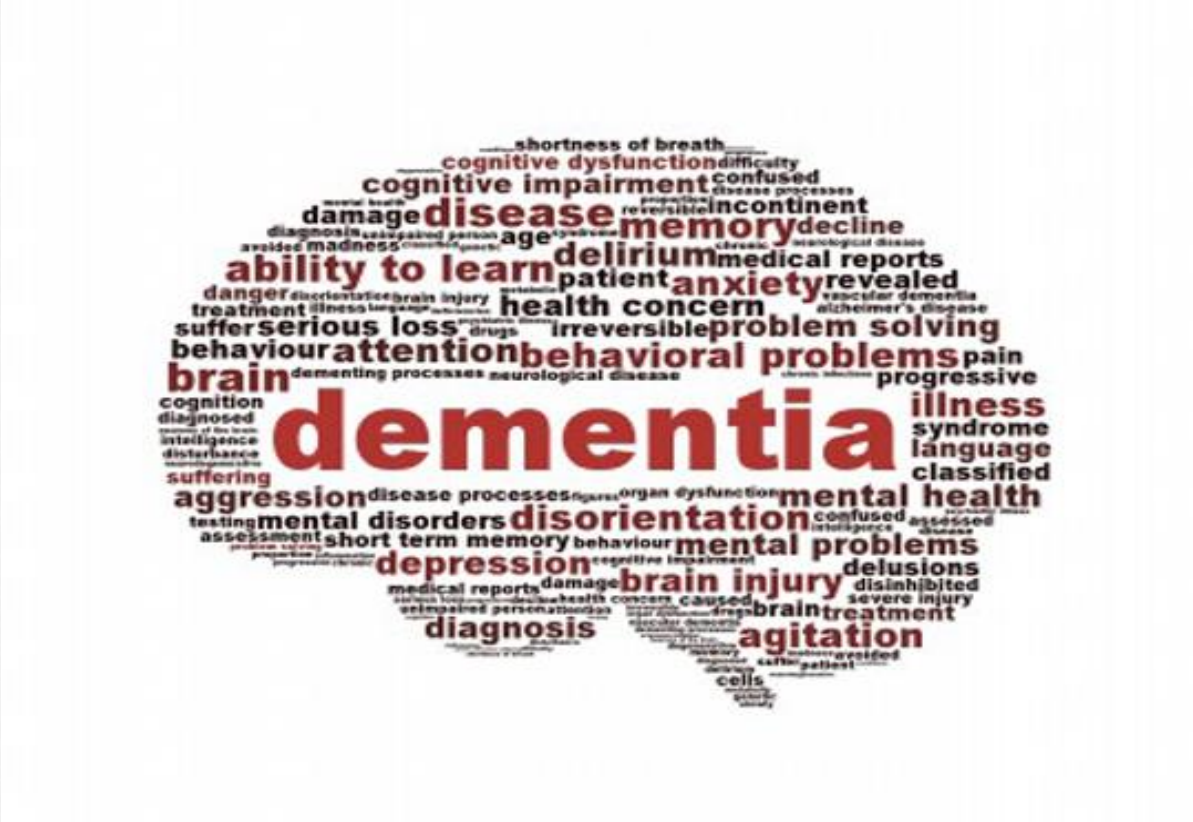
Dementia: Definitions

- Derived from the Latin word: demens (without mind) – “madness or insanity.”
- Originally referred to an acquired, longstanding cognitive/emotional syndrome that deteriorates with time.
  - Originally a general term for mental illness or insanity
  - Dementia praecox vs. Dementia senilis

Dementia: Definitions

- Today: ‘Dementia’ describes a collection of signs and symptoms such as memory and communication problems, changes in mood and behavior, and the gradual loss of control of physical functions which, taken together, are an indication of damage to the brain as a result of the progressive degeneration of nerve cells.
- This can be caused by a variety of different diseases
  - Alzheimer’s disease is the most common (~2/3 of cases)
  - Others include vascular dementia, Lewy body dementia, dementia related to Parkinson’s disease, frontotemporal dementia, alcohol-related dementias and prion diseases

Dementia: Epidemiology



Dementia: Epidemiology

- World Health Organization: ~47 million people have dementia,
- ~10 million new cases per year
- About 5-8% of general population over 60 has some form of dementia.

Dementia: Epidemiology

- In the United States about 8.2 million people have some form of dementia – about 5.5 million people have Alzheimer's Dementia.
- In the US, about 15 million people provide unpaid care to people with dementia
- In 2016 this amounted to over 180 million hours valued at $230 billion
- Prevalence rises sharply with age, representing a significant burden on medical and mental health services, social services, and caregivers.

Prevalence of Dementia in Medicare population (2015)

Overall	8.46%
Age Groups	
65-74	2.76%
75-84	10.48%
85 and older	24.88%

Ethics: Abbreviated Primer

Ethical Issues related to Dementia

- Ethics as a view through which to view any clinical situation
  - (Rather than relegated to peripheral / extreme cases).
- Distinguish ethics from morality and the law:
  - Ethics -- social rules/guidelines provided by an external source (often based on moral principles/values
    - e.g., codes of conduct in workplaces or principles in religions.
  - Morals -- an individual's own principles regarding right and wrong
  - Laws -- rules and regulations with specific penalties and consequences when violated.

Overview of Ethical Approaches

- Consequentialist: The class of normative ethical theories holding that the consequences of one's conduct are the ultimate basis for any judgment about the rightness or wrongness of that conduct.
  - A morally right act (or omission from acting) is one that will produce a good outcome, or consequence.
- Deontological: (from Greek δέον, deon, "obligation, duty“) the normative ethical position that judges the morality of an action based on whether it is consistent with a set of rules, principles, or obligations.

Overview of Ethical Approaches

- Virtue ethics: normative ethical theories that emphasize the role of one's character and the virtues that one's character embodies for determining or evaluating ethical behavior.
- Narrative ethics: Approach that focuses on personal identity through story, and particular events in the life story of the individual or community.
  - Can form a basis for ethical reflection and learning
  - Frequenly resembles or presupposes virtue ethics.

Ethical analysis

1. The Facts?
2. The Ethical Issues?
3. The Alternative Actions/Options?
4. The Stakeholders?
5. The Ethics of the Alternatives?
6. The Practical Constraints?
7. Actions to Take?

Ethical Issues in Dementia across the Course of Illness

Ethical Issues across the course of illness

- Respect for Personhood / Dignity
- Diagnosis & Testing: How often to perform imaging tests? When should this testing start/stop? Role of genetic testing?
- Consent for medical procedures and potential treatment
- Questions of independent living and driving

Ethical Issues across the course of illness

- Clinical care of patients with dementia
  - How to manage agitation to ensure safety of patients, family, and staff
  - Is it acceptable to deceive patients (i.e. manipulate, withhold information, or lie) as part of care?
- Surrogate decision making

Ethical Issues across the course of illness

- End-of-life decisions
  - Feeding tube for nutrition?
  - When stop treating infections?
  - Advanced directives? When honor pre-morbid patient's wishes, and when not?
  - Physician-aid-in-dying
- How do we learn about dementia – questions of research ethics.

Respect for Personhood / Dignity

NEWS

Alzheimer's Sufferers Demand Cure For Pancakes

6/18/97 3:00pm • SEE MORE: HEALTH

WASHINGTON, DC—Alzheimer's sufferers from across the nation marched on random buildings throughout Washington, D.C., Washington State, and Iowa City, IA, Monday, demanding that Congress prioritize finding a cure for pancakes, the nation's third-leading breakfast food.

"Until Budenheimer's is cured, there will never be enough bread in the laundry," said a spokesperson for the group, who identified himself variously as Dr. James Lustig, Brian Boitano, Mr. Jet Captain and Socko the Happy-Turtle. "Until we are all properly rotated and serviced, none of us can ever truly be plaid."

Lustig's comments were echoed by fellow marchers, who warned that unless a cure for pancakes is found by 2000,

Respect for Personhood / Dignity

- Stigma, exclusion, and lack of access
- Public spaces and public discourse rarely accommodate people with dementia.
- People with dementia are at best excluded, and at worst neglected or ridiculed
- People fear a diagnosis of dementia.
  - A large part is not the illness itself, but the ‘social demise’ that often predates the physical one.

Dignity and the Power of Language

- ‘Being’ ill vs ‘having’ illness.
- “She’s demented” vs. “She has dementia”
- Patients identified as illness vs. having one.
- Once you are a ‘thing’ there’s nothing to be done
- However, if you have a thing, then you are whole with a problem to be addressed.

Ethics of Notification and Testing

Ethics of Notification and Testing

- Individual or community
  - Confidentiality / Autonomy vs. Beneficence
  - Broaden autonomy
  - When involve spouse? Adult children?
  - Sliding scale of autonomy as cognition declines?
- “Timely diagnosis” – When cognitive issues begin to affect lives of people around them.
- Testing: How often to perform imaging tests? When should this testing start/stop? Role of genetic testing? Who consents?

Cases for Discussion

Case 1: Dementia and Driving

Mr. A is a 72-year-old retired bus driver who lives with his wife in their home of 30 years. He has become increasingly frustrated with difficulties in finding his way around the house and gets lost at times in the neighborhood. He and his wife present to a neurologist, Dr. Lien, who diagnoses him with moderately advanced vascular dementia, characterized by considerable impairment of short-term and long-term memory. Mr. A insists that his memory is intact.

Dr. Lien asks the patient if he drives a car. Mr. Avila says that he does, and defensively asserts, “I’m a very good driver – far better than the young lunatics on the road!” At this point Mrs. A quietly interrupts to remind her husband that he recently has caused two small car accidents. Mr. A adamantly denies this. And he refuses to consider Dr. Lien’s suggestion to stop driving.

Case 1: Dementia and Driving

Before they leave, Mrs. Avila pulls Dr. Lien aside to say she worries about her husband's driving. She has even tried to hide the keys, but he found them and was very angry with her. "I know he shouldn't be driving, but I can't bear it when he's mad at me."

What should Dr. Lien do?

What should Dr. Lien do?

- What are the ethical concerns Dr. Lien is facing?
- Who is he responsible for? Is he accountable for public risk Mr. A poses?
- Should Dr. Lien intervene in any way?
- If so, what options (if any) does Dr. Lien have to intervene?

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Case 2: The Wandering Patient

Mrs. C is a 79-year-old widow who lived alone in her home on a farm with her family living close by. In winter she worked hard to keep heaters burning. She had to chop wood and risked slipping on an icy path when she carried wood from the shed. Grocery shopping and eating nutritious meals were an additional problem, and her family frequently found her refrigerator and cupboards empty, or only stocked with canned beans. Her family thought it would be better for her to move to a supported housing complex with electrical heating.

They provided her with information, arranged for her to see her new housing situation. Mrs. C made an autonomous decision to move, signed the necessary papers and moved in. The professional caregivers saw to it that she got up in the morning, ate her meals and attended the day care center. They tied colored scarves on the stairs as cues to lead her to her own front door as she sometimes was unable to find her way in the large housing complex.

Case 2: The Wandering Patient

Mrs. C was on her own most afternoons and evenings, and did little but sit and watch television. After some weeks, she changed her mind and wanted to return home, phoning her family frequently to say she was anxious, afraid of being alone, and that she no longer saw any reason for living.

On several occasions she was found outside the complex wearing only her nightclothes. On one occasion she walked many miles back to the farm and was found by the police. Her daughter-in-law was very worried and without informing Mrs. C, decided to apply for placement in a dementia unit of a nursing home. When she heard about this, Mrs. C was infuriated and stopped returning her daughter-in-law's calls.

Did her daughter-in-law do the right thing? What would be the ethical next step to take in this case?

Capacity to consent for medical procedures and treatment

Determining Capacity

- Competency: Degree of mental soundness necessary to make decisions about a specific issue or to carry out a specific act.
- Distinct from competency – a legal determination
- All adults presumed to have capacity unless determined otherwise.
- Any physician can determine – but psychiatrists frequently called to make determination

Determining Capacity

- Components of capacity
  - Free choice
  - Reliability
  - Comprehension
    - Understand the situation as it relates to his specific condition
    - Understand the consequences of his decisions
    - Demonstrate rational manipulation of information
- Dementia does not mean lacks capacity per se…
- How much capacity is enough? …it depends…

Risk/Benefit Ratio of Treatment

	Favorable	Unfavorable/ Questionable
Consent	Low level of competency	High Level of competency
Refusal	High Level of competency	Low level of competency

Dementia: Who gets to say?

- Spectrum of capacity over time.
  - Sliding scale of capacity depending on circumstances
  - Sometimes make own decisions, sometimes cannot.
- Decisions never in isolation.
- Autonomy and beneficence in tension with each other.

Case 3: The Boxer – Who decides what's best?

Mr. P is a 68-year-old married man who had been a semi-professional boxer in his youth. He now has been diagnosed with dementia associated with Parkinson's Disease, as well as dementia pugilistica (a form of chronic traumatic encephalopathy associated with multiple head traumas).

While at home he is generally calm, but has bursts of irritability and impulsivity -- lashing out verbally and even physically at his adult son and wife. He has punched and elbowed both of them.

He was admitted to the hospital for a urinary tract infection, which has now cleared. He has refused to take any medications for his behavior issues, and is generally well-behaved. However, on occasion he will lash out without warning and strike nursing and other staff.

Case 3: The Boxer – Who decides what's best?

He is ready for discharge and the staff is eager to have him leave the hospital. They worry about his potential for harming his wife in particular, and suggest that he be placed in a nursing home where his behavior could be better managed.

Both the son and wife say they want him to return home – as does the patient. The son and wife, insist that they "know him", can handle his behavior, and plead with the medical staff not to involve elder services. They simply ask that Mr. P be prescribed a medication that they can "sneak into his food" when they worry he might get irritable.

The nursing staff requests an ethics consultation to assist in thinking through the patient's disposition. As the ethics consultant, what do you recommend?

When medical teams and families disagree

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Case 4: Whose wishes do we honor?

Mrs. R had been a successful lawyer. She had owned her own practice and was known for her composure and dignity by friends and family. While healthy, she executed a valid advance directive ordering that only palliative care be given should she become mentally incompetent to the point where she could neither recognize his family nor store new memories.

Mrs. R is now 87 years old, and demented enough to meet those conditions, but she is cheerful, peaceful, and appears to take pleasure in the moment. Her adult children and grandchildren enjoy spending time with her, and she appears to take pleasure in their company.

Case 4: Whose wishes do we honor?

Mrs. R was recently diagnosed with a cancer that has a 75-80% survival rate if treated with chemotherapy and surgery. Her son and daughter understand their mother's wishes, but want her treated, arguing that his quality of life is far better than he could have imagined when he signed the Advance Directive.

How would you advise the medical team?

(Also, what if, instead of cancer, she was diagnosed with pneumonia that is easily treatable with oral antibiotics? Does that change your ethical analysis of the situation?)

What do we honor? Past or Present?

- How balance past and present?
  - Can relate to both as expressions of person's autonomy.
- Balance autonomy and wellbeing of person with dementia
  - Wellbeing factors (e.g. happiness) against autonomy (past expression of wishes) being respected.

What do we honor? Past or Present? Factors to consider:

- How important is the issue?
- How much distress or pleasure is it causing?
- Have the underlying beliefs or values on which earlier preferences were based genuinely changed or can they be interpreted in new light?
- Do apparent changes in preference/values result from psychosocial factors (e.g. fear) or dementia (sexual disinhibition behavior) or linked with genuine pleasure in doing things differently?

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Question and Discussion