Ethical Issues in the Care of Dementia Patients

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DISCLAIMER
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Agenda
- Review the prevalence and characteristics of dementia
- Distinguish between ethical and legal issues
- Identify the unique ethical issues that arise in the care of end-stage dementia patients
- Present an ethical decision-making model for use in hospice/palliative-care settings
Prevalence of Dementia

- 5.3 million Americans currently have Alzheimer’s
  - 47% of population over 85 has dementia
- By 2050, more than 13 million people will have dementia
- Among people 55 or older now, 1 in 8 will get Alzheimer’s and 1 in 6 will get some type of dementia

(Zarnesty, 2010; Silverado Senior Living, 2006; Elliott, Gessert, and Peden-Mckhine, 2009; Roan, 2010)

Characteristics of Advanced Dementia that Lead to Ethical Dilemmas

- Inability to care for self and live alone
- Inability to make medical decisions
- Incapacity is not always permanent
  - Capacity may be transitory and may vary based on:
    - Time of day
    - Surrounding location and environment
    - Medications
    - Support or aggravation systems
    - Effects of temporary, treatable illnesses

(Kapp, 2001)

Ethical Questions Affecting the Interdisciplinary Team

- Who makes health care decisions when the patient cannot make decisions?
- What happens when family members, caregivers, and Interdisciplinary Team (IDT) members disagree with each other or with patient’s previously stated desires?
  - Family members may be in constant state of grief due to continual decline of patient
  - May have differences in spiritual or cultural beliefs
- What happens when different professions represented on the IDT have different ethical or legal guidelines?
Common Ethical Values

- **Autonomy**: The right to be free to make our own decisions and behave as we desire
- **Beneficence**: Do good
- **Non-maleficence**: Do no harm
- **Fidelity**: Be faithful, loyal, and keep promises
- **Justice**: Act fairly

Focus will be on Autonomy, Beneficence, and Non-maleficence

(Ethical and Legal Dilemmas

- Ethical dilemmas develop when:
  - We must choose between two or more relevant but competing ethical values OR
  - No matter the choice, the result will be undesirable
- Laws are the mechanisms that society uses to enforce collective ethical values
  - Implementation of ethical concepts may be optional
  - Laws are enforceable
  - Interpretation of laws may be subject to debate

(Autonomy versus Beneficence

- Medical care: Autonomy is ethical value
  - Four Principles of Informed Consent (law)
    - Medical information to be given clearly
    - Ensure that patient understands information well
    - Freedom to decide without coercion
    - Capacity to make decision
  - California Probate Code §4009 defines capacity as a person’s ability to:
    - Understand the nature and consequences of a decision
    - Make and communicate a decision
    - In the case of proposed health care, understand its significant benefits, risks, and alternatives

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(Kapp, 2001; Beauchamp & Childress as cited in Defanti, 2007; Woods & Pratt, 2005)
Dementia’s Effect on Autonomy

- Dementia results in the progressive loss of capacities on which autonomy and informed consent are based
- Ethical principles of beneficence and non-maleficence begin to slowly outweigh the ethical principle of autonomy
  - Legal principle of parens patriae comes into play
    - Protect people who are not able to protect themselves
  - Legal system developed mechanisms for intervening in lives of non-autonomous people without their current consent
    - Legal determinations of incompetence/Conservatorships
    - Self-planning: Durable powers of attorney, Living Trusts, etc.

(Defanti, et al., 2007; Woods and Pratt, 2005; Kapp, 2001)

Autonomy versus Non-maleficence

- Competency is not the same as capacity
  - Person may not be legally competent to make decisions but may have transitory capacity
  - Families and professionals may erroneously assume that dementia patients have no capacity at given time
- Constant tension between not causing distress for person (non-maleficence) and giving person as much control as possible (autonomy)

(Woods and Pratt, 2005)

Case Study: John Smith

- 85-year-old male with end-stage dementia living at assisted living facility
  - Periods of intense agitation not easily controlled
    - Two daughters disagree about treatment
    - One wants agitation to be aggressively treated with meds
    - Other is afraid that meds will make patient a “zombie”
    - One day, in a moment of apparent lucidity, patient says to one daughter, “Let me die”
  - What does the Interdisciplinary Team do?
Case Study: Jane Doe

- 90-year-old female with end-stage dementia
  - Lives with her daughter, who leaves her alone for several hours at a time during the day
  - Patient is weak and her hands tremble when she holds things
    - Patient is a chain smoker and smokes cigarettes while home alone
  - What does the Interdisciplinary Team do?

Types of Ethical Issues

- Family dynamics
- Behavioral challenges
- Decisions about medical care
- Elder/Dependent adult abuse

Progressive Surrogacy: Autonomy to Beneficence

- When person loses capacity to make own decisions, family gradually takes over
  - Start with autonomous elder
  - Family starts to make decisions as cognitive impairment increases
  - First decisions are made in line with elder’s autonomous wishes
  - As impairment worsens, family begins to make decisions that encroach on autonomy of elder, based on best interests of elder (beneficence)
  - Final phase - beneficence is key: preserve dignity, alleviate suffering, decline aggressive or intrusive medical care

(Elliott, Gesser, and Polen-McAlpine, 2009)
Progression of Family Involvement

- Typically, 3 ways role-change occurs (outside of court):
  - Assumption of role (occurs most often): Family reaches decision when it can no longer be avoided and simply assumes new decision-making role
  - Delegated role (easiest situation): Elder appoints person before elder becomes dependent
  - Self-appointed role (most challenging family dynamics): One person appoints self to role, which may lead to open family conflict

(Elliott, Giesert, and Peden-McAlpine, 2009)

How Do Families Make Decisions?

- Use family history as a resource
  - Make decisions based on wants, needs, and wishes of elder as they were known through their personal and family identity
- Families may make different choices than patients have chosen for themselves
  - Prior verbal and written preferences of patient appear to have a limited effect on eventual care decisions
  - Several startling studies have documented that patients prefer to defer to others (family, physicians) rather than have their own wishes followed

(Elliott, et al., 2009)

3 Ways Families Justify Decisions

- Decision-making on a continuum
  - Giving precedence to elder’s requests and life story
  - Family member’s needs and story take precedence
  - Balancing everyone’s interests, given all the circumstances

(Elliott, et al., 2009)
### Placement of Dementia Patients

- Family members report that the most difficult decisions they have to make involve changing their loved one’s living setting, often against the elder’s will
  - Signals significant transition in roles of family members to making more significant decisions
  - Occurs when dementia progresses to point where patient can no longer live independently
  - Most family members reported that the decision was reached when it could no longer be avoided
- Is lack of placement or availability of 24 hour caregiver when needed neglect or abandonment?  
  (Elliott, et. al, 2009)

### Behavioral Challenges

- 90% of dementia patients ultimately have behavioral and psychological symptoms, which may increase with the progression of the disease
  - Verbal and physical outbursts
  - Sadness/crying
  - Agitation
  - Suicidality
- Methods of controlling behavior that raise ethical issues:
  - Telling lies
  - Restraints
  - Psychoactive medications
  (Defanti, et al., 2007)

### Startling Truth-Telling Research

- People with dementia are less often told the diagnosis
  - People with dementia are given euphemisms (memory loss)
- Family members often prefer the person not be told, despite agreeing they would want to know if they were in that situation
  - Family members feel person will be distressed by the information and will not understand anyway
- BUT: People with early dementia who have been told the diagnosis generally feel this is preferable, even though they may find it upsetting
  - People with dementia have described distress, confusion, and harm caused by not knowing the diagnosis
  (Woods and Pratt, 2005)
Research on Lying to Control Behavior

- Lies may be seen as being less important in people who have dementia
- Survey for staff members in elderly care settings: Out of 112 participants, 4 said they never lied
- Percentage of respondents who lied:
  - To ease residents distress: 90%
  - To ease caregiver distress: 75%
  - To promote treatment compliance: 59%
  - To benefit staff (save time): 32%
- 93% thought lying could be beneficial; 89% recognized it could be problematic

(Boods and Pratt, 2005; James, et al., 2006)

Benefits and Problems with Lying

- Benefits:
  - Reduce resident distress when ask to:
    - see absent/deceased spouse/friend/pet
    - leave care setting to go home or to work
  - Improve compliance with care needs or medication
- Problems:
  - Increase confusion due to lack of consistency of lies
  - Cause mistrust between residents and staff
  - Cause tension and confusion with family members

(James, et al., 2006)

Recommendations about Lying from Survey Participants

- Lies should only be told if they are in the best interest of resident (ease distress)
  - Should not lead to disrespect of resident
- Develop general policies and provide training
  - When lies should be told and when not
- Develop individualized policies for specific resident issues such as medication compliance or aggressive behavior
  - Consider ability of resident to retain the truth
  - Communicate with family members, get consent, and document

(James, et al., 2006)
Use of Restraints

- Definition of Restraints: Anything that restrains freedom of movement
- In 1987, Congress passed Federal Nursing Home Reform Act (OBRA 87)
  - Restraints can be used if there are documented medical reasons to do so
  - Restraints may not be used for discipline or convenience
- Number of nursing home residents who are restrained dropped by more than 50% between 1999 and 2007
  - Number of residents restrained was 11% in 1999 and 5% in 2007
  (Defanti, et al., 2007; Appleby and Gilliam, 2009; Brooks, 2010)

Ethical Use of Restraints

- Guidelines:
  - Only use when alternative or less restrictive methods fail
  - Use no longer than necessary; Check appropriateness periodically
  - Do not use to compensate for lack of personnel or environment
  - Never use as measure of control or punishment
  - Use only when patient’s behavior creates danger to self/others
  - Adopt with involvement of family
  - Respect patient’s dignity and well-being
  - Must be in patient’s best interest
  (Defanti, et al., 2007)

Use of Psychoactive Drugs

- Use of psychoactive drugs may raise particular ethical concerns because drugs are often administered without patient’s consent and against wishes
  - Often requires deceit: Hiding administration of drug or saying it has a different purpose
  - Ethical dilemma: Treating patient against his/her will in a way that both law and public sentiment have banned from other areas of medicine
  (Defanti, et al., 2007)
Recent California Nursing Home Criminal Case

- On September 8, 2009, Attorney General Ed Brown charged Kern Valley administrator, Director of Nursing, pharmacist, and medical director of elder abuse
  - Alzheimer's and other dementia patients given high doses of psychotropic drugs to make them more tranquil and easy to control
  - Drugs were given to patients who argued with the Director of Nursing, were noisy, or were otherwise disruptive
  - 2 patients were held down and forcibly given injections
  - Alleged that 3 patients died and one suffered great bodily injury as a result
  - Charges stated that patients were given the drugs for staff convenience, not in their best interests
  (Brown, 2009)

Recommendations

- Best means for controlling behavior of dementia patients appear to be environmental
  - Provide creative activities that preserve patient’s autonomy and self-esteem
  - Alzheimer Gardens: allowing free wandering
  - Training healthcare personnel to use techniques of verbal and nonverbal communication to calm patients

Suicidality

- Suicidality often increases with the undertreatment of pain
- CA Evidence Code 1024
  - Breach of confidentiality legally permitted but not legally mandated
  - Reasonable cause to believe that patient is in such a mental or emotional state as to be dangerous to himself or to the person or property of another and disclosure is necessary to prevent threatened danger
- Must take reasonable steps to prevent suicide of client
  - WIC 5150 is one action that may be taken when danger is a result of a mental disorder
  (Delanis, 2007; Association for Advanced Training in the Behavioral Sciences, 2010)
Caregiver Threat to Kill Patient to “Put Them out of Their Misery”

- Tarasoff v. Regents of UC: Duty to Warn
  - When client has communicated to a “psychotherapist” (social worker, MFT):
    - a serious threat of physical violence
    - against a reasonably identifiable, foreseeable victim or victims
  - The “therapist” must make reasonable efforts to communicate the threat to:
    - the victim
    - a law enforcement agency
- More recent California case: Ewing v. Goldstein
  - Duty to warn applies when “therapist” learns of danger to identifiable victim from a family member of the client

Decisions about Health Care

- California Health Care Decisions Act (Cal Prob Code §4600-4806) defines health care decision as:
  - a decision made by patient or patient’s agent, conservator, or surrogate regarding health care, including:
    - Selection and discharge of health care providers
    - Approval or disapproval of tests, procedures, and medications
    - Directions to provide, withhold, or withdraw artificial nutrition and hydration and all other forms of health care, including cardiopulmonary resuscitation

Duties of Conservators, Agents and Surrogates (Cal Prob Code §§2355, 4684, 4714)

- Conservator, agent or surrogate shall make a health care decision in accordance with:
  - patient’s individual health care instructions, if any
  - and other wishes to the extent known to the conservator, agent, or surrogate
- Otherwise, conservator, agent or surrogate shall make the decision in accordance with determination of the patient’s best interest
  - In determining patient’s best interest, agent or surrogate shall consider the patient’s personal values to the extent known to the conservator, agent or surrogate
Conservatorship of Wendland

- Landmark 2001 California Supreme Court case
  - Case focused on how much proof is necessary to know a patient's wishes about artificial nutrition and hydration when the patient is incompetent but conscious
  - Court held that law requires "clear and convincing evidence" of patient's wishes when:
    - conservator requests withdrawal of life-sustaining treatment
    - from a conscious, incompetent patient
    - who has not left legal instructions for health care or appointed an agent or surrogate for health care decisions
  - "Clear and convincing" means explicit and unequivocal

(Eisenberg and Kelso, 2002)

Implications of Wendland

- Patient made statement to wife-conservator prior to incompetence that he "would not want to be a vegetable" or to be "kept alive with tubes"
  - Court said that is not clear and convincing evidence of patient's wishes
- Court requires only "preponderance of evidence" (more likely than not) when:
  - Patient is permanently unconscious OR
  - Patient has executed an advance directive or designated a surrogate OR
  - Has a conservator, is conscious, and health care decision is not intended to result in death

DNR/POLST Forms (Cal Prob §4781.2)

- The legally recognized health care decisionmaker of an individual without capacity shall consult with the physician who is, at that time, the individual's treating physician prior to making a request to modify that individual's POLST form
Elder/Dependent Adult Abuse

- All care custodians are legally mandated reporters, including
  - all health practitioners
  - chaplains (as clergy)
- Elder is person age 65 or older
- Dependent adult is person between 18 and 64 with physical or mental limitations restricting ability to carry out normal activities or protect rights
  - Developmental disabilities
  - Individuals whose physical or mental abilities have diminished because of age
  - Individuals who have been admitted as inpatients to 24 hour health facility

When Report Must Be Made

- Report known or suspected elder or dependent adult abuse when you:
  - are in your professional capacity or scope of employment
  - have observed or have knowledge of incident that reasonably appears to be abuse
  - are told by an elder or dependent adult that he/she has experienced abuse
  - Exception: Patient has dementia and no other evidence indicates abuse
  - reasonably suspect abuse

Types of Elder Abuse that Must Be Reported

- Physical abuse: Assault, sexual assault, unreasonable physical restraint, or chemical restraint for punishment or for period beyond time for which med was ordered
- Neglect: Failing to meet a person’s basic needs of food, water, and shelter, including self-neglect
- Abandonment: Desertion of person by anyone having care of that person in which a reasonable person would continue to provide care and custody
- Financial Abuse: Misuse or theft of patient’s real or personal property
- Isolation: Deliberately preventing patient from receiving mail, phone calls, or visitors
How to Report

- Must report by telephone as soon as practically possible and in writing within two working days
- Generally report to Adult Protective Services or law enforcement
  - Long-term care facility – report to ombudsman
- Failure to report: Misdemeanor – up to 6 months in county jail and/or fine up to $1000
- Immunity – not criminally or civilly liable for report as long as report is not made falsely

Other Reports

- Optional reports: Mandated reporters may report forms of abuse for which report is not mandated or when person’s emotional well-being is threatened in any other way
  - Rule of thumb: Call Adult Protective Services for consultation and/or speak to an attorney if in doubt
- Remember we are also mandated reports for child abuse
  - Witness or learn of it through contact with patient
  - Adult reports being victim of childhood abuse and have reasonable suspicion that abuser may be victimizing other children

Ethical Decision-Making Process

- Four elements (Cottone & Claus, 2000, p. 276):
  - To interpret the situation in terms of how one’s actions affect the welfare of others
  - To formulate what a moral course of action would be
  - To select among competing value outcomes of ideals, the one to act on
  - To execute and implement what one intends to do
- Short-Hand (Gamino & Ritter, as cited in Bradley et al., 2010):
  - A person with a challenging ethical problem in a particular contextual place applies appropriate ethical principles in a deliberate decision-making process.
Focus on the Particular Decision to Be Made

- Remember that dementia patient’s capacity may be transitory
- Maximize patient’s capacity for making (or contributing to) the decision at hand
  - Remove barriers to decision-making in particular circumstances
    - Organic (timing of medications, etc.), environmental, allowing extra time
  - Try to see the situation from the patient’s worldview and values
    - Explore fears
    - Be honest when you are uncertain about what to do
    - Agree to disagree but not to abandon patient or family

(Delanis, 2007)

Ethics Committees

- Tend to be multidisciplinary with primary purpose to protect rights of patients
- Widespread in hospitals but much less common in hospices
  - 31% of hospices have ethics committees within the agency
  - 42% had access to a hospital ethics committee
  - 54% of survey respondents believed that ethics committee is needed at their agency
- Interdisciplinary Team Meetings become critical for discussing ethical dilemmas where no formal ethics committee exists

(Csikai, 2004)

Ethical Decision-Making Model for the Care of Dementia Patients

I. What is the Problem?___________________________________________________

II. What are the legal, ethical, and agency obligations?
   - Legal (Statutes, cases, regulations):________________________________
   - Ethical (Ethical codes):__________________________________________
   - Agency/Organizational policies:___________________________________

III. What are the possible courses of action?
   1.____________________________________________________________________
   2.____________________________________________________________________
   3.____________________________________________________________________

IV. Which is the best course of action (see next page)?___________________________

V. How will this course of action be implemented?______________________________

VI. What was the result of this course of action?________________________________

VII. What policies or practices need to be updated?______________________________

(Adapted from Rae, Fournier, and Roberts, as cited in Cottone and Claus, 2000)
Selecting the Best Course of Action

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(Adapted from Brodbeck, 2007)

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