Alzheimer's Association: Ethical Dilemmas and End-of-Life Care

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Objectives:

1. Learn from a case which can highlight some ethical challenges
2. Learn about non-beneficial treatment and the ethics around offering treatment based on symptoms alone
3. Dementia and behaviors
4. Learn about the surprise question

Case 1

- Lucy is a 72-year-old woman who has advanced early onset Alzheimer's dementia. She was diagnosed at age 58 and has progressed to the point where now she no longer recognizes her family. She thinks her husband is her father. She is mostly non-verbal now although she remains quite mobile. She has eloped on multiple occasions from her home and her husband has had to install locks on the top of the doors, which she cannot reach. She has lost 30 lbs over the last 2 years, 15 in the last 6 months, and paces a great deal. She is known in the neighborhood as she has walks avidly and used to walk around the community for hours daily. She is a retired teacher and taught 1st grade until age 60 when she had to retire due to her disease.
- She gets admitted to the hospital due to severe agitation as well as a fall with head strike when she attempted to go for a walk and could not exit the house. Her husband is also in the ED as he fell trying to stop her from getting hurt and he hit his head on the table.

Determine the Cause of Delirium

- Does the patient have a history of pain?
- Could this be withdrawal from medications she has stopped?
- Infection (We over-test and treat UTI)?
- Does the patient have a history of psychosis?

Hospitalization

-Admitted due to acute delirium

-Found to have COVID and history from husband notes recent gathering with family, 28 in attendance to celebrate Lucy's birthday.

- Patient is asymptomatic other than the delirium
- Multiple bruises and healing skin tears noted suggesting frequent falls at home.
- Husband shares that she never wanted to live this long when she found out she had her disease. She has always prided herself on being physically fit and social. She now struggles to walk safely and does not recognize or interact with family or friends. She has had increased agitation and anxiety, especially at night and standard medications have not improved her symptoms

Updates

- The patient completed an Advanced Directive 8 years ago and named her husband and daughter as her decision makers. She wrote on the form that she does not want to be in a nursing home but does check that her family can make those decisions.
- Documented in wishes: She never wants anything that will prolong her dying process. If she cannot care for her personal needs, let her go!

Coping with Challenging Behaviors

- As dementia progresses, a person can no longer convey their thoughts, needs and emotions. Your interactions may be frustrating—for both you and them. You may begin to see new behavior, such as:
  - refusing care,
  - wandering,
  - agitation, and
  - repetition.
- If you think something triggered the behavior, think about what happened right before it started. Triggers can be physical, emotional, social or environmental. If you can identify the trigger, how can you avoid it in the future?

- Finding the source of the problem: Behaviors are usually caused by either an unmet need or a trigger. You can start by asking:
  - Is the person hungry/thirsty?
  - Do they need to use the bathroom?
  - Do they have uncontrolled pain?
  - Is an infection causing discomfort?
  - Are they tired?
  - What happened right before the behavior started?

- Treat with dignity: When you greet a person with dementia, call them only by their preferred name.
  Preview your actions: Tell and show what you are going to do, step by step. This might include miming the actions, such as sitting down or taking off shoes.
  (Adapted from Teepa Snow, Positive Approach to Care)
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Approach to the patient with dementia

- Before providing any care, take a deep, relaxing breath to calm yourself, then gently get the person's attention.
- Approach from the front: As dementia progresses, a person's vision and hearing may fail. It is best to approach from the front to prevent startling or upsetting them.
- Slow down your physical approach: It may take longer for a person with dementia to recognize you. Slow down and pause in their presence for 5 to 10 seconds before you start a task.
- Take a side stance: Standing directly in front of a person with dementia can be intimidating and make them feel trapped. After you approach from the front, move to side of the person, which lets them feel that they are able to leave the interaction.
- Meet at their level: If a person with dementia is seated or in bed, crouch down to meet them at their level; this can help them feel comfortable and in control.

What happens next for Lucy?

- The delirium is determined to be both due to her infection, possibly her medications for her dementia and pain from falls at home.
- She continues to have some behaviors which include anxiety, some paranoia and hallucinations although decreasing her medication burden and scheduling acetaminophen has helped.

demonstrating side approach

Behaviors

Day 14 in hospital

- Patient is up walking in her hospital room and falls. The fall is witnessed, and she is attended to immediately.
- Lucy is crying in pain and unable to get up. Her right leg is shortened and internally rotated. She has a hip fracture.
- Orthopedics offers surgery although they share, they are worried about how she will do. Palliative consult is requested.

Goals of Care discussion with family

Daughter and Husband attended with hospital care team.

- Goals of patient: to be, independent, live at home and to be comfortable. Do not prolong her dying process
- Goals of family/POA: for Lucy to not suffer and to have her die at home.

Surgery or no surgery?

- Is it beneficial?
- What is the long-term goal?
- What is the alternative?

The Four Principles of Biomedical Ethics

- Autonomy: Informed consent. Is there are role for medical expert recommendations in autonomy? Difference between guidance and paternalism?
- Non-maleficence: Do No Harm (intentional and unintentional)
- Beneficence: Do the treatment benefits outweigh the risks?
- Justice: Healthcare equity, access and appropriate distribution of resources (COVID)

Surgery or no surgery?

- Is it beneficial? *It will medically not change her outcome (1/3 of all patients die within a month of surgery for hip fracture, 2/3 of patients with dementia die with in a month)*
- What is the long-term goal?

What is the alternative?

- **She is not a good candidate for surgery as she will not understand the surgical pain post-op, will have delirium and will not remember she cannot walk unassisted**
- **Her goal is to live independently, or she does not want to live. She would likely need nursing home care post operatively.**
- **What is non-beneficial treatment? Treatment that does not meet a person's goals or may cause more harm than benefit.**

Pain and terminal delirium

- Care team addressed the acute pain and noted worsening of her delirium with the new injury although it did slightly improve with the pain being treated
- Palliative medicine team recommended hospice

Who Qualifies for Hospice?

- The surprise question: Would you be surprised if this person died in the next 6 months? If you answer, "no" then they likely qualify.
- What diseases qualify for hospice care? Any progressive malignancy (curable but untreated or incurable), Heart Failure, COPD, Chronic Kidney Disease, Chronic Liver Disease, Dementias, Movement Disorders (Parkinson's, MS, ALS, Huntington's), Stroke with disability, unhealable wounds, severe malnutrition, severe functional decline.
- Are they opting to no longer pursue aggressive treatment?
- Do their goals align with hospice care?

Treating delirium at the end of life

- Non-pharmacologic approaches first: quiet room, minimal light, soothing music if patient prefers, sleep hygiene orders, is the patient a night-owl? (Nurses are a great example)
- How do we choose medication to treat delirium?
  - Literature support, Research, Access to the medication
  - Drugs we use in hospice are easily titratable, accessible, easily administered and have the support of research and standards of care
    - Haldol: low doses it is low risk, effective and also helps nausea and constipation, easily titratable, easily administered and accessible.
    - Olanzapine: low doses are low risk, effective and helps with nausea, more difficult to titrate but accessible and easily administered.
    - Risperidone: similar to Haldol, less often used, access can be a problem at times.

How did we treat Lucy?

- Hallucinations were still present: started on low dose Haldol every afternoon and at bedtime scheduled with as needed dosing.
- After 4 days, patient improved, stable doses and no PRNs required so discontinued

Another ethical dilemma

- Patient is finally comfortable
- Current medications are allowing her quality of life, meaningful interactions with his daughter
- Kidney and liver function are deteriorating with patient not eating or drinking much. The patient has a life expectancy of weeks, not months
- Is it ethical to withdraw care which is beneficial?
  - What is the alternative?

Options

- Patient is comfortable
- Withdrawal of a medication might lead to a crisis
- Trial dose reduction first
- Prolonging hospitalization also poses risks of hospital acquired infections, overstimulation and fall
- Discuss with facility plan for managing the medication, stop PRNs, monitor, reassess

Challenges of antipsychotics in facilities

- Chemical restraints
- Monitoring
- Regulatory Concerns
- Hospice can support education and goals

- You must have informed consent to treat in WI
- Psychotropics require a patient to be seen every 14 days **if prescribed on an as needed (PRN) basis**, if scheduled and care plan supports treatment and gradual dose reductions are attempted then the 14 day requirement does not apply.

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Circle of Care

Members of the Hospice Care Team

Is she safe for discharge now?

- On stable medication regimen
- Goals discussed with patient, activated POA, hospice referral made
- Plan of care agreed upon by all parties
- Referrals made to SNFs

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Transitions in Care

- Patient continued a gradual decline.
- Husband and family want to take her home but worry she is now too difficult to manage with hip fracture. Facilities are reviewing although there are concerns about the Haldol.
- PRN antipsychotics stopped but scheduled Haldol continued.
- Patient discharged to SNF with hospice to admit that day and agreement to not change current comfort medications.

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Lucy's Outcome

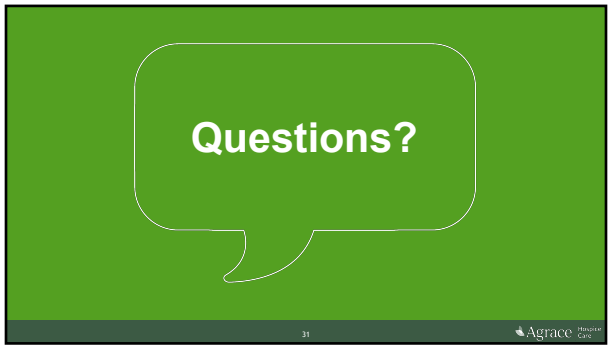
- She had good pain control with continued support from hospice and her SNF care team collaborating. Priority was given to management of pain during cares and position changes.
- Patient did have a fall in week 5 when she attempted to get out of bed unassisted although it was a slide from bed.
- Education had been provided at admission and reiterated and, thankfully, the facility called hospice first.
- Patient started having some increased delirium which likely contributed to her fall, Haldol dose adjusted, and she was comfortable, she showed signs of transitioning to end of life and died at week 7 on hospice.

Don't Call 911, Call Hospice

- When a person transitions to hospice, they do better when they stay out of the emergency department/hospital
- Patients and families prefer to not have their loved ones transferred by ambulance as it is uncomfortable and can cause anxiety
- Hospice will make PRN visits, and we can manage symptoms in the "home."
- If we cannot manage symptoms in home, we will guide the care in a hospital where we can provide inpatient level hospice care while respecting a patient's wishes, advocating for their care and while avoiding non-beneficial testing and treatments.

Bereavement

- Lucy's husband struggled with not having Lucy die at home. A safe place for him to share these concerns was given with bereavement and grief support. His daughter and he realized that they still honored Lucy's wishes as they had kept her home through most of her journey and when she needed specialized care to keep her comfortable, they made this happen which also honored her goal of dying in comfort.


Questions?
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