

Ethics in Dementia and Memory Care

Dementia care in all its interactions and care situations is deeply intertwined with ethical issues.

Daniel Strech, British Journal of Psychiatry, 2018

Purpose

- The purpose of this course is to examine common practices of care and services in dementia and memory care which may present ethical and moral dilemmas.

Description

- Ethics in Dementia and Memory Care is a 90-minute presentation that takes a look at some of the day-to-day practices in memory care which may present ethical problems and moral distress for caregivers.

- Some areas that do cross an ethical line in dementia and memory care include electronic tracking, use of antipsychotic medications, constraints within the physical structure and environment and characteristics of resident's autonomy and quality of life.

Learning Objectives

1. Explore ethical frameworks to examine issues and dilemmas in dementia and memory care
2. Identify specific day-to-day practices which present ethical dilemmas

3. Discuss solutions, ideas and new ways to approach ethical and moral issues in dementia and memory care which can improve resident quality of life

Introduction

- Can we have a conversation about Alzheimer's disease and other types of dementia, residents and staff working and living within a physical space called “memory care” and some of the most glaring ethical dilemmas and issues that need our attention?

- Despite healthcare professionals and caregivers doing their best to deliver top quality care and services and try to make each day a good one, the presence of ethical and moral problems is ever present.

- What's wrong with electronically tracking seniors who wander, or using antipsychotic medications off-label, therapeutic lying, institutional constraints, and the physical environment itself?

- There is no lack of ethical dilemmas, issues and problems in dementia and memory care. Some present moral distress for healthcare professionals, caregivers and family members.

- So, let's talk ethics, frame our discussion, tackle some ethical problems seen in daily care, services and life within memory care, and then offer some solutions and new ideas that can make memory care the last, best place your residents will experience.

Learning Objective 1

Explore ethical frameworks to examine issues and dilemmas in dementia and memory care

- I'm presenting this backwards on purpose, so that we can use various lenses or frameworks to make better decisions about ethical dilemmas in memory care

The 3 C's of Ethical Decision Making

Ethical Decision Making by Logan L.
Watts, PhD, 2021

1. Compliance - a decision is ethical if and when it complies with explicit rules or regulations
2. Consensus – a decision is ethical if and when the majority of leadership and caregivers view it as an ethical decision

3. Consequences – a decision is ethical if and when it maximizes benefits while minimizing harm to the resident and others (caregivers, family and other residents)

- When an ethical question arises and all three components are met, we can be confident that we are making an ethical decision for our residents in memory care

Nuffield Council on Bioethics

Dementia: Ethical Issues, A Guide to the Report, 2009

- This is from our friends from across The Pond
- It stems from a very person-centered approach to making solid ethical decisions for memory- and cognitively-impaired people

Components to Ethical Decision Making

1. A “care-based” approach to ethical decisions that identifies facts, applies ethical values to those facts, and compares the issue with similar issues to find ethically relevant similarities or differences

2. A belief about the nature of dementia – dementia is a brain disease and is very harmful to the person
3. A belief about quality of life with dementia – with good care they can have quality throughout the course of their illness

4. Promoting the interests of the person with dementia and his or her caregivers – this involves autonomy, well-being as well as the interests of the caregiver

5. Acting in accordance with solidarity – since we are all dependent on someone, we have a responsibility to support our residents and their families

A Tad Bit More from Nuffield Council on Bioethics

- We should provide support to our residents to help them take part in decision making as much as possible
- This may involve making joint decisions with trusted family or friends

- We should also take into account the resident's past and current wishes and feelings
- This can be tricky, because sometimes their past and present wishes can be very different

A Sensible Approach to Decision Making

Identify the Ethical Problem

- Is it potentially damaging to the resident, is it a choice between good and bad, or two bads? Is it about something solely legal, moral, ethical or most efficient?

Get Every Fact Possible

- What is known and unknown?
- Who is at risk of the decision – the resident or other residents?
- What are our options to come to a conclusive decision?

Evaluate Alternative Actions

- Which option best respects the rights of the resident and others involved?
- Which treats the resident and others fairly, giving them what they are due?
- Which produces the most good and least harm?

- Which serves the community as a whole?
- Which option takes into account the relationships, concerns, and feelings of the resident, family and others?

Choose an Option for Action and Test It

- After evaluating your options to make a good ethical decision for the resident, which one best addresses the ethical problem or concern?
- If you told the media this was the right thing to do, how would they react?

Implement Your Decision and Closely Observe the Outcomes

- How did the decision turn out?
- Have you and your team learned a good lesson from this action and situation?
- Are there others actions that need to be taken?

Learning Objective 2

Identify specific day-to-day practices
which present ethical dilemmas

- Making ethical decisions in dementia and memory care, become increasingly challenging due to the introduction of new technologies, medications, and societal norms which may clash with our ethics, morals and beliefs

Snapshot of Things That Make You Go Hmmm?

- GPS Tracking
- Surveillance
- Intimacy
- Pet Robots
- Therapeutic Lying
- Antipsychotic Medications
- Physical Environment
- Wandering

GPS Tracking

- Global Positioning Systems
- Used as a result of wandering and possible elopement
- This is a safety issue

Ethical Problems with GPS Tracking

- Inherent invasion of privacy, dignity, personal autonomy and liberty
- May diminish human contact
- Can be seen as a convenience factor for staff

- According to research, families tend to favor them for safety reasons and reducing risk of harm
- Caregivers feel protecting the resident from harm is more important than issues of autonomy or privacy

Surveillance

- Used mainly for detection of resident movement or falls
- In the context of staffing shortages, this can be beneficial

- On the other hand, surveillance violates privacy and autonomy
- The principle of justice is violated because not all residents or families can afford this technology
- Stigma may exist with any use of technology for tracking

Intimacy

- This is a basic human need As well as an individual's right
- Residents have the right to live their lives reflective of their values and maintain central roles in making decisions

- The concept of consent is critical
- According to Dr. Elaine Healy, MD “By strict legal criteria, most individuals with dementia do not have capacity to consent to sexual activity because they cannot weigh the benefits and risks with sound judgment and reasoning”

- To deny residents intimacy may be injustice
- Three things must be present for an individual to have capacity for consent: comprehension of the act, ability to process it with regard to their values, and the ability to voluntarily consent

- We must also take into account abuse, rape, exploitation

Pet Robots

- These are gaining momentum in memory care as a tech-based intervention meant to support the resident's psychosocial well-being
- They can reduce agitation, improve mood and social engagement

- On the other side of the ethical coin, use of pet robots and other similar technology may be seen as deception
- It can also be said that we are infantilizing residents
- Can robots replace caregivers need for support and comfort?

Therapeutic Lying

- Should we always tell the truth?
- What answer would make the resident feel more at ease?
- Should we gently redirect conversations or say something that reassures rather than blunt honesty?

- Deception is common in dementia and memory care and its moral legitimacy is highly questionable
- When used in a specific context, it should perhaps be the last resort instead of a means of convenience

- According to researchers in the Netherlands, while lying is usually frowned upon, benevolent or “white lies” may be acceptable if the goal is to improve the resident’s quality of life and well-being

- Deception may then boil down to a matter of lying vs quality of life
- Deception also impinges on the rights of the resident to make a free and informed decision and negatively impacts autonomy

Antipsychotic Medications

- The use of antipsychotic medications, especially PRN interventions, are seen by healthcare professionals as either right or wrong because they drive approaches to behavioral management

- In senior care, we play a balancing game between resident-centered practices and regulations
- Our values, regulatory oversight and resident centeredness may not align

- Every antipsychotic drug, and all psychotropics in general, are associated with significant risks including earlier mortality
- This is why the U.S. FDA issued the black box warning on all antipsychotic medication use in older adults

- The use of such medications create numerous ethical dilemmas including the resident's autonomy, choice, dignity, independence and individuality
- We are mandated to protect our residents, so we become caught between values and safety

Physical Environment

- Many assisted living communities that have a memory care space, are wonderfully designed and have a welcoming, warm, friendly atmosphere
- So what's the ethical problem?

- Here we see another ethical balancing act between maximizing resident autonomy within an environmental context while minimizing safety concerns
- We strive to humanize care while providing a normal life for our residents

- The life of the environment involves relationships, care routines, meaningful activities, indoor and outdoor features that enable and maximize independence, and fulfill very basic human needs

- The very nature of the memory care environment, can negatively affect the resident's autonomy, choice, and dignity
- It strongly influences how the resident will spend his or her day

Wandering

- Wandering behaviors are some of the most common, important and challenging aspects of dementia
- Wandering is associated with increased risk for falls, fractures and injuries

- Wandering can cross the line and become elopement
- It's also associated with the inability to sit down for meals, malnutrition and dehydration, weight loss and fatigue
- It can also make caregiving more difficult

- Wandering can also be healthy
- Attempting to prevent wandering negatively impinges on freedom, choice, autonomy, privacy, liberty and possibly lead to isolation and the use of sedating medications

Learning Objective 3

Discuss solutions, ideas and new ways to approach ethical and moral issues in dementia and memory care which can improve resident quality of life

- When trying to make ethically sound decisions with or for residents, remember the following:
- Autonomy, justice, beneficence, nonmaleficence, and fidelity

Autonomy

- Respect for independence, self-determination; freedom of choice and action
- Help residents to understand how their decisions and values will impact them and others

Justice

- “...treating equals equally and unequals unequally but in proportion to their relevant differences” (Kitchener, 1984)
- In more basic terms, it refers to fairness

Beneficence

- To do good, to be proactive, and to prevent harm
- Do what contributes to the well-being of each resident

Nonmaleficence

- Not causing harm to the resident
- Not inflicting intentional harm
- Not engaging in actions that risk harming others
- Weighing potential harm against potential benefits

Fidelity

- Loyalty, faithfulness and honoring commitments to residents and families
- We should not threaten relationships or leave obligations unfulfilled

Ethical Solutions for GPS

- Always protect the resident against misuse of this technology
- Ideally, the use of GPS should be made within the family at the time of diagnosis and may now go into a living will

- Any decision to use GPS without consent of the resident should be made in their best interests
- Maintain balance between safety and autonomy

- Advance directives, durable power of attorney for health and social care of appointment of a designated proxy seem to be the best solutions for dealing with issues of informed consent when the resident is unable to give informed consent

- The proxy decision should be based on the resident's and family's prior attitudes and values as well as their current ones when possible
- Devices should be lightweight, small and comfortable to wear and use

Ethical Solutions for Surveillance

- Risks, safety and positive benefits must be taken into consideration
- Does the resident lose considerable autonomy, justice and privacy?

- Do the systems provide for better resident well-being?
- Is the data and security kept safe and confidential?
- Did the resident, family and care team come to a consensus on this issue?

Ethical Solutions for Intimate Relationships

- Consider the resident's rights, values and choices
- Intimacy impacts well-being, autonomy and quality of life
- What is in their best interests?

- Shared decisions can be made between all parties involved
- Honor wishes while they still can make decisions
- Do a benefits/risk analysis

- Does having intimate relationships violate beneficence, nonmaleficence, autonomy or justice?

Ethical Solutions for Pet Robots

- Did the resident have a history of being a pet lover?
- Are they isolated and lonely?
- Does the pet robot cause problems (disrupt daily caregiving, etc.)

- Is there a cross-contamination issue?
- Are other residents frightened?
- Does the pet robot pose a risk for falls?
- Are we infantilizing residents?
- Does the pet help connect the resident to others?

- Does the pet assist with bathing, eating, and other ADLs?
- Does the pet provide companionship?
- Does it reduce negative behaviors?
- Are we lying when the resident believes the pet is real?

- Can all families or residents afford pet robots (social justice)?
- Are the psychosocial impacts far better than any negatives?

Ethical Solutions for Therapeutic Lying

- Is telling a little white lie worse than prioritizing the resident's emotional well-being?
- Is it morally defensible to deceive a resident to protect their best interests?

- Is it ok to use as a last resort when other interventions fail?
- We should never deceive out of staff convenience
- What is more important, the resident's quality of life or deceiving?

- Making ethical decisions on therapeutic lying must be viewed in specific context or situations
- Remember, lying does impinge on the resident's rights, make decisions and choices and their autonomy

Ethical Solutions for Use of Antipsychotic Medications

- Base the decision on the resident's, family's and care staff's attitudes and beliefs about psychotropic drugs

- Do the majority have negative, positive or neutral attitudes about it?
- Does the resident respond well to non-pharmacological interventions?
- Is staff following the care plan?

- Can we justify using meds because they actually promote the resident's comfort and quality of life?
- Would they be worse without them?
- Remember, we are using a chemical restraint that comes with potentially negative side effects

- Such medications should be used as a last resort
- We must balance the good and the bad
- Be cautious of over-medicating
- Is staff well-trained to watch for changes in condition?

Ethical Solutions for the Physical Environment

- Does the environment promote autonomy, justice, fidelity, beneficence, and nonmaleficence?
- Does staff negotiate risk and autonomy?

- Are there meaningful activities to choose from?
- Are the resident's lives normalized by the environment?
- Does it maximize independence?
- Does it fulfill everyday needs?

Ethical Solutions for Wandering

- Can staff tell differences between health wandering and stressful wandering?
- Are staff well-trained on risk factors and causes of wandering?

- Does wandering relieve stress and anxiety for the resident?
- Is it a means of coping?
- Is it done to prevent loneliness?
- How does the family feel about this issue?

- Is wandering better than using sedatives?
- Should tracking devices be employed?
- Remember, discouraging wandering can be viewed as a violation of the resident's autonomy, liberty, privacy and best interests



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