

Ethics in Senior Living

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An Opening Case

Ethics in Long-Term Care

“Psychiatric Instability”

Mr. C is a resident in assisted living who has requested to return to independent living. Staff indicate that Mr. C was admitted to assisted living based on concern surrounding his documented suicidal ideation and a desire to closely monitor his medication management, even though he did not meet UAI criteria for assisted living. It is unclear how Mr. C scores on the UAI currently but his physical function has not deteriorated since admission. However, Mr. C does have a history of depression and there is some concern that we will be less able to monitor his mental health status in independent living. The primary ethical issue is based, therefore, on whether or not depression, without associated losses of physical function, creates a legitimate basis for ruling out an individual for living independently.

The Process of Ethics

Ethical Theory

NORMATIVE ETHICS

- Utilitarianism (J.S. Mill): Always act so as to bring about the greatest good (happiness) for the greatest number.
- Deontology (Immanuel Kant): Always treat people as ends in themselves, never as a means only.
- Virtue Theory (Aristotle): Always act consistently with the standards of the role you play in life.

CORE VALUES

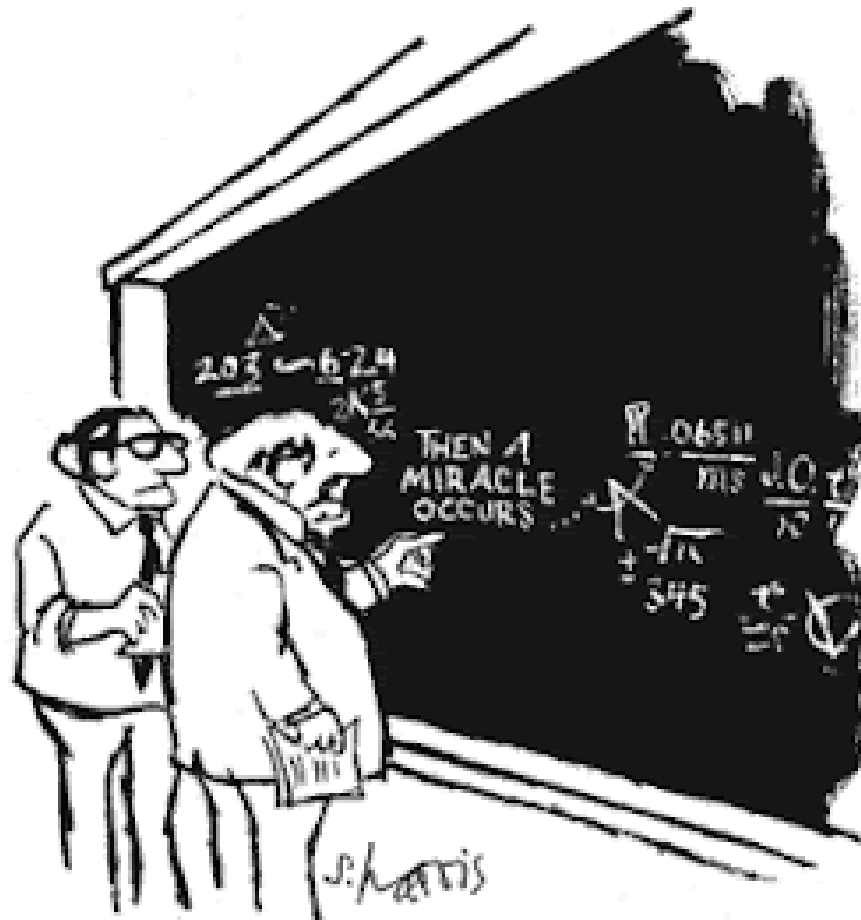
“Principles of Medical Ethics”

Autonomy

Nonmaleficence

Beneficence

Justice



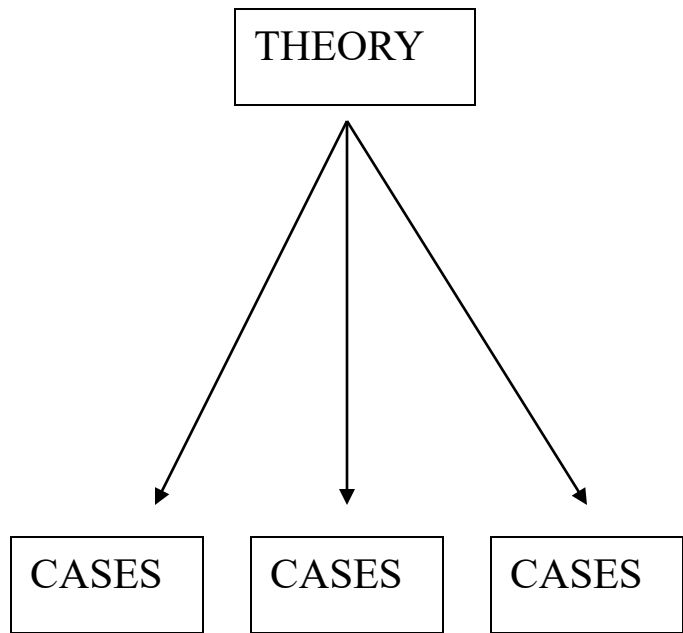
"I THINK YOU SHOULD BE MORE EXPLICIT HERE IN STEP TWO."

Methods of Doing Ethics

“Theory and Casuistry”

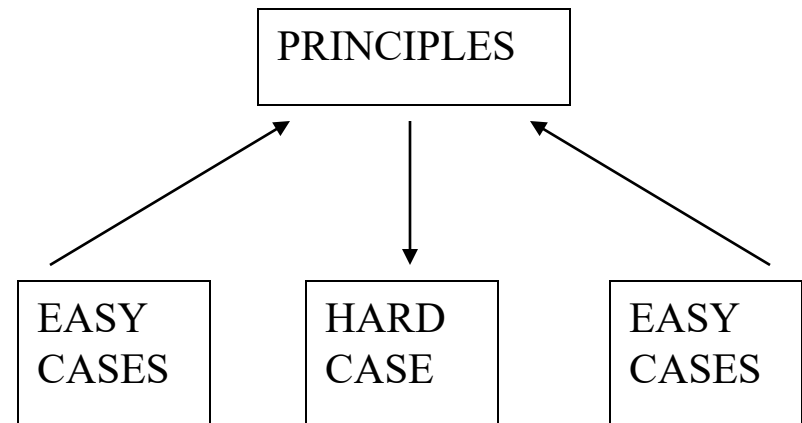
Theory

Top-Down



Casuistry

Bottom-Middle-Down



The Structure of Ethical Argument

The Process of Moral Reasoning

The Default Assumption

The Burden of Proof

Casuistic Exploration

Application to the Current Case

Individual Choice

Basic Assumptions

1) What is the default assumption regarding an adult individual's right to direct his/her own healthcare?

2) Where does the burden of proof rest? Does the patient have to justify control, or do those who would intervene have to justify wresting control away from the individual?

3) What would it take to satisfy the burden of proof?

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 on the basis of only two classes of argument: prevention of harm to self (paternalism) and prevention of harm to others (distributive justice).

The First Paradigm: Paternalism

Paternalism

An intervention is ‘paternalistic’ whenever the justification for the restriction of an individual’s freedom is calculated to be in their own best interest.

Ethics in Long-Term Care

“Psychiatric Instability”

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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.



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.

“Psychiatric Instability”

Conclusions

- 1) If Mr. D meets the requirements for paternalism, then he needs a dedicated mental health intervention.
- 2) If Mr. D does not meet the requirements for paternalism, then he must be allowed to return to independent living.
- 3) In neither event was assisted living an appropriate response because it implied an area of expertise that the facility does not possess and is not licensed to provide.

The Dignity of Risk

The Dignity of Risk

“Why Risk Matters”

- Intrinsic Value: The Thrill of Taking Chances
- Instrumental Value: The Ends Justify the Means

The Dignity of Risk

“Risky Choices”

- Respect for Personal Autonomy
 - Person Centered Planning
 - Recovery Principles

Dealing With Dementia

Family Control

“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.

Ethics and Dementia

“We Want to Live Together”

The T's are a married couple who resided in Independent Living when they were first admitted to the facility. When their need for assistance increased, the Ts then moved together into Assisted Living. Mr. T's health has continued to deteriorate, however, and he has been transferred to Skilled Care. Mrs. T has been diagnosed with moderate to severe multi-infarct dementia. Mrs. T is capable of living in Assisted Living but has forcefully expressed a desire that she be allowed to share a room with her husband. The T's children oppose placing their parents together, because they believe that their mother places too many demands on their father. Staff are unsure how to proceed in the face of Mrs. T's repeated requests for a change in placement. Mr. T seems agreeable to sharing a room, but his capacity is limited.



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.

Ethics And Dementia

“She Just Wants To Have Fun, And It’s Fine With Me”

A client who lives in an assisted living facility has been enjoying afternoon trysts with her boyfriend who also lives in the facility. The client has dementia; the boyfriend does not. The assisted living facility would like APS to get involved as they do not believe the client has capacity to consent to sex. However, when they asked the client’s daughter, who is her Power of Attorney, to sign an agreement that the client and her boyfriend would not be allowed to be alone behind closed doors, the daughter refused. She said she saw no harm whatsoever in her mother enjoying the last years of her life in whatever manner she sees fit. She accused the facility of violating her mother’s human rights, and she called APS as well.

Sexuality in the Institutional Setting

“Competing Goals”

1. We want to provide as full, complete and healthy a lifestyle as possible for the clients whom we serve.
2. We want to protect our clients from harm and exploitation.

Sexuality in the Institutional Setting

“Possible Approaches”

1. Ignore sexual activity entirely.
2. Assume capacity, allow freedom of action, then deal with inappropriate situations as they arise.
3. Assume incapacity, restrict activity, then ease restrictions as capacities are clearly demonstrated.
4. Restrict all sexual activity in the facility, refuse to consider sexual activity outside of the facility.

Sexuality in the Geriatric Setting

Policy Considerations

- When will capacity be questioned? What are the circumstances under which an incident report should be filed?
- How will capacity be determined?
- How will privacy be insured once capacity is verified, without creating the impression of direct support or negligence?
- Who will provide educational supports?
- When will families be notified?
- How should we respond to family objections?
- When will adult protective services or the police be notified?
- How should we intervene in suspected sexual abuse between married individuals?
- How should we handle sexuality issues other than those involving interpersonal relationships?
- What types of documentation should exist concerning these issues?

The Second Paradigm: Distributive Justice

Distributive Justice

An intervention is justice-based whenever the justification for the restriction of an individual's freedom is that it is calculated to protect a victim of the individual's action other than him/herself.

Ethics in Long-Term Care

“He Smells”

Mr. B is a 92-year-old resident who has a history of hypertension, atrial flutter, macular degeneration, irritable bowel syndrome, back pain and constipation. Mr. B has difficulty with several ADLs including dressing and toileting. Mr. B has incontinence of bowel and on several occasions he has entered public areas with feces on his clothing. Mr. B wishes to remain in his independent living apartment and is willing to hire a private duty sitter for the maximum eight hours per day that is allowed by facility policy, and to sign a release of liability indemnifying the facility in the event that he has a poor outcome. Even with these supports, Mr. B often shows up at the dining room disheveled and odorous. Other residents have complained that he needs to be restricted from the dining room at the very least and also moved to assisted living.



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)

Ethics in Long-Term Care

“Refusing Mood Stabilizers”

Mr. D is a 78-year-old gentleman who recently moved into assisted living directly from his own home. Although Mr. D initially seemed to adjust well to the move, he has now been reported as bothering other residents. He is awake for most of the hours of the day and night, and often engages other residents in conversations with an aggressive and pressured speech pattern. Discussions with Mr. D about his behaviors have not resulted in any modification to his behavior, and Mr. D’s children indicate that this is often how he behaves. They explain that Mr. D has an old diagnosis of Bi-polar Affective Disorder, but that after a short and successful experience on Lithium, Mr. D complained that he did not like how the medications made him feel, and he refused any further attempt to manage his manic symptoms with medications. Mr. D’s behaviors appear to be worsening and complaints from other residents are increasing. Nevertheless, while Mr. D admits to having a mood disorder, he refuses all interventions.



Privacy and Pathology

“I’m a Collector”

Ms. L and her husband have lived in Assisted Living for the past two years and during that time concerns have repeatedly been raised regarding Ms. L's excessive hoarding behavior.

Difficulties regarding hoarding became so pronounced that the Ethics Committee was asked to prepare a general policy level discussion of the issue. Subsequent to the completion of the policy work on hoarding, staff worked diligently with Ms. L and they were able to help her clean out her apartment significantly and to satisfy health and safety concerns. However, Ms. L's hoarding behavior has continued and the progress made previously has now been reversed. Staff are concerned that the hoarding behavior creates an unsafe living environment that must be mitigated, that it is significant of a mental illness that would benefit from treatment, and that inappropriate amounts of nursing staff time are now being expended on housekeeping tasks. Since efforts to refer Ms. L to counseling and to assist in maintaining a clean apartment have failed, this ethics consult was requested to identify and examine the ethical implications further intervention.



Dealing With Dementia In The Community

Ethics And Dementia

“How Do You Define OK?”

A concerned citizen called APS to report a concern about his neighbor, Ms. L, who is in her 80s, lives alone, is extremely thin, may not have sufficient food, has had her electricity and telephone shut off, and has not paid her HOA fees for several months. It is August and she has no air conditioning. Ms. L is described as disoriented and confused and does not appear to have bathed in some time. The caller believes that Ms. L might have dementia and he is worried that she is still driving. Ms. L has no involved family members and at times she knocks on neighbors doors asking for rides to the store. An APS worker went to the home and was invited in. Many of the issues reported are true—there is no electricity, the home is stifling, the phone is not working, and Ms. L is unkempt. She is pleasant and friendly, denying that she needs any assistance. She states she states that she drives to the store to get food when she needs it, pays her bills on time, and hasn't seen a doctor in years because she is very healthy. How should staff respond?



Ethics And Dementia

“How Hard Should We Push?”

Sarah’s 89-year-old mother, Ms. M, has been diagnosed with advancing dementia. The doctor stated that it was no longer safe for her to remain home alone. She did not want to leave her apartment, but reluctantly agreed to move in with Sarah when she suggested assisted living might be the only other option. Sarah works full time. She hired caregivers to be with her mother during the day, but Ms. M is refusing to cooperate with them. She states that she is perfectly able to take care of herself as she has been for 89 years. She verbally abuses the caregivers until they leave the home or she locks herself in her room. Ms. M refuses to go to the Adult Day Center. Sarah is not able to work from home and has exhausted all her available leave. Is it negligent for Sarah to allow her mother to stay with her under these circumstances?

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 he 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 And Dementia

“The Criteria Are Clear”

Mr. I is a fiercely independent man in his 80s who was diagnosed with dementia and lives alone in hoarding conditions. His daughter, who lives in another state, is his power of attorney. Mr. I was recently in a rehab facility for post-surgical care, after which his daughter was planning to move him into assisted living in her state. However, he refused to go with his daughter and insisted on being discharged home. Mr. I appears to be unable to manage his twenty prescribed medications which include Aricept and Namenda, and it is unclear how he is addressing hygiene and nutrition as he can no longer go up the stairs in his home or drive. Home health was prescribed but he won't answer the door. Prior to his rehab stay, Mr. I would at least speak to his daughter on the phone daily. Now he does not answer the phone. A few weeks after discharge, he called the police stating that there were intruders in his home. The police came and found no one in the home. They recommend that he go to the hospital, and Mr. I agreed. Once medically cleared the Mental Health evaluator stated that since Mr. I's issues are dementia-related, he cannot be hospitalized psychiatrically. Where should Mr. I go?

Ethics And Dementia

“She Is Nice, But Impaired”

The property manager for an upscale senior community called APS to report that a tenant who recently had her driver's license suspended after being found driving down the wrong side of Route 28 is continuing to drive. The property manager states that the client has a dementia diagnosis, but the family is refusing to intervene because every time they try to help, the client accuses them of stealing from her. The client has come to the manager's office 3 times in the past month because she has locked herself out of her apartment and can't find her keys. She also left the gas on one day, which eventually was noticed by one of the neighbors who had to call the Fire Department. The client is a lovely 85-year-old woman who states that her favorite thing to do every day is drive to Wegmans to pick up groceries, then cook her dinner. She refuses all offers of help, insisting that she will continue to drive, shop, and cook for herself until the day she dies. The neighbors have put together a petition stating that the client is endangering everyone in their building, not to mention everyone on the road, and they are demanding that the property manager do something.

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.



Provider-Family Conflicts

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?

Ethics At the End of Life

“We Have To Preserve Hope”

Ms. G is an 82-year-old patient who has never been determined to lack capacity to make her own healthcare decisions. She was recently evaluated for epi-gastric pain and it was determined that she is terminally ill with advanced pancreatic cancer. Prior to doing the biopsy, however, Ms. G’s son asked the doctor to communicate directly with him regarding the results. He is concerned that if Ms. G is given bad news, it would rob her of all hope and quality of life for the time that she has left. They are concerned that she will “freak out” if she hears the “C-word”. The son tells the doctor not to tell Ms. G about her diagnosis or prognosis. The family intends to tell Ms. G that she is suffering from gastric issues that should resolve in time, and they will provide pain relieving medications which they will represent as effective treatment for their mother’s illness. Should Ms. G be told of her diagnosis, prognosis and treatment options?

Pain and the Standard of Care

“I Don’t Want to Knock Her Out”

Ms. F is an 84-year-old hospice participant who carries a diagnosis of dementia and is being treated for an unstable femur fracture. Ms. F is in the end-stage of a deteriorating condition and the family has decided not to provide aggressive life-prolonging care. She exhibits significant signs of physical discomfort and the attending prescribed morphine to cover her pain. Ms. F’s son, who carries durable power of attorney for healthcare, refuses to allow the use of morphine because he is concerned that it will cause a substantial sedating effect.

Family Authority

Parental authority over minor children is powerful, *but not absolute* :

- The burden of proof rests with those seeking to overrule parental authority.
- Parental authority does not empower a parent to be negligent in the care of a child.
- Parental authority does not empower a parent to be abusive in the care of a child.
- Parental authority does not empower a parent to demand that care providers offer sub-standard care.

Three Responses to Conflict Between Providers and Families

1. If it can not be shown that the family's choice is abusive, negligent, or inconsistent with the standard of care, the care must be provided.
2. If it can be shown that the family's choice is inconsistent with the standard of care, but not abusive or negligent, then care can be refused but transfer must be allowed.
3. If it can be shown that the family's choice is abusive or negligent, judicial relief is appropriate.

The Ethics of Patient Refusal

“The Limits of Provider Support”

Optimal Care

Sub-Optimal/Super-Standard Care

Sub-Standard Care

Staff never have an obligation to commit malpractice



Provider Rights

Nursing Ethics

Unsafe Working Conditions

Ms. D is a 61-year-old patient who carries a diagnosis of Type II diabetes. She suffers from urinary incontinence and has a Foley Catheter. At present, Ms. D lives at home and receives once monthly visits from Home Health to provide catheter care. The trailer in which Ms. D lives is poorly kept and extremely dirty. On a recent visit to the trailer, the home health nurse fell through the floor and injured her back. The dangerousness of the environment has been well documented and multiple attempts have been made to arrange for fixing the floor. Home Health staff members have even gone so far as to locate alternate housing, but Ms. D refuses to move to a safer environment. Staff are now concerned that visiting Ms. D in her present living arrangement is too risky. This ethics case consultation was requested to help staff consider the ethical implications of withdrawing on-site support from Ms. D in order to protect the safety of the home health practitioner.

Ethics in Long Term Care

“It Does Fit A Pattern”

Mr. E is a 92-year-old resident in long term care who repeatedly pinches female providers on the buttocks and makes lewd comments to them. Staff believe that this behavior is long standing and that it has gone unreported because of the Mr. E’s position of authority in the community. Mr. E now suffers from dementia and his behaviors have gotten worse. On one occasion, he pulled a provider on top of him in bed and attempted to hold her down and fondle her. When confronted, Mr. E claims he was just joking, and he refrains from similar actions for a day or so until the pattern repeats. Staff has indicated a desire to avoid providing close supports to Mr. E, but his family complains that since this is all just a function of his dementia, providers should be more forgiving and more supportive. How should the facility manage Mr. E’s care?

Ethics in Long Term Care

“Black Lives Matter”

Over the past year, we have seen significant unrest in this country as we consider the systemic racism that lingers in our society. Tension has increased as some have made an effort to highlight their concerns that individuals and communities of color have been unfairly targeted by violent police tactics. Others have countered that the “protesters” are “rioters” and that they are influenced by anarchist agitators.

How should the facility respond if white residents make overt comments to African-American staff members denigrating the Black Lives Matter agenda when those comments make the provider feel threatened or offended?



Workplace Harassment

Definitions

Harassment is a form of employment discrimination that violates Title VII of the Civil Rights Act of 1964, the Age Discrimination in Employment Act of 1967, (ADEA), and the Americans with Disabilities Act of 1990, (ADA).

Harassment is unwelcome conduct that is based on race, color, religion, sex (including pregnancy), national origin, age (40 or older), disability or genetic information. Harassment becomes unlawful where 1) enduring the offensive conduct becomes a condition of continued employment, or 2) the conduct is severe or pervasive enough to create a work environment that a reasonable person would consider intimidating, hostile, or abusive. Anti-discrimination laws also prohibit harassment against individuals in retaliation for filing a discrimination charge, testifying, or participating in any way in an investigation, proceeding, or lawsuit under these laws; or opposing employment practices that they reasonably believe discriminate against individuals, in violation of these laws.

Workplace Harassment

Definitions

Petty slights, annoyances, and isolated incidents (unless extremely serious) will not rise to the level of illegality. To be unlawful, the conduct must create a work environment that would be intimidating, hostile, or offensive to reasonable people.

<https://www.eeoc.gov/laws/types/harassment.cfm>



Workplace Harassment

Definitions

Offensive conduct may include, but is not limited to, offensive jokes, slurs, epithets or name calling, physical assaults or threats, intimidation, ridicule or mockery, insults or put-downs, offensive objects or pictures, and interference with work performance. Harassment can occur in a variety of circumstances, including, but not limited to, the following:

- The harasser can be the victim's supervisor, a supervisor in another area, an agent of the employer, a co-worker, or a non-employee.
- The victim does not have to be the person harassed, but can be anyone affected by the offensive conduct.
- Unlawful harassment may occur without economic injury to, or discharge of, the victim.

<https://www.eeoc.gov/laws/types/harassment.cfm>

