It is reported that two residents of the facility, one male and the other female, spend a lot of time together. They have been seen touching each others hands in public and they spend “private” time with each other in their respective rooms.

There are strong suspicions that there private time involves sexual activity, but this has not actually been witnessed by anyone.

He is widowed and has been a resident at the facility for 3 months. She is also widowed and has been living at the facility for 2 years.
PRESENTATION OUTLINE

• Basic Principles of Bioethics
• Advance Directives (MOLST)
• Clinical Issues
  • Expression of sexuality
  • Artificial nutrition and hydration
  • Withholding health information
  • Withdrawal of medical treatment

MISSION STATEMENT

To assist healthcare providers, administrators, patients, and families by serving to develop, recommend, educate, and review broad institutional standards, policies, and procedures related to bioethical issues. The committee also fosters interdisciplinary dialogue concerning the bioethical implications of patient care and medical research through education and consultation of individual cases.
Bioethics in Long Term Care

• 83 years old
• Moderate cognitive impairment
• Minimal assistance with ADL’s
• Socially active
• Participates in most activities
• History of hypertension, CAD, anemia of chronic disease, and mild renal insufficiency.
• Has 2 daughters who both visit frequently.

Bioethics in Long Term Care

• 87 years old
• Mild cognitive impairment
• Moderate assistance with ADL’s due to a prior stroke.
• Tends to isolate himself.
• Participates in almost no activities.
• History of IDDM, CVA, Atrial fibrillation, and hypertension.
• 1 daughter that lives out of town & 1 local son.

One day, the staff walked into the day room where they found the couple in an embrace, and kissing. No one else was present in the room at the time of the episode.
PRINCIPLES OF BIOETHICS

Bioethical Issues in Long Term Care

FOUNDATION OF BIOETHICS

• Ethics
  • Ethics is about the process as well as what you do. It is about how you get there.
  • Good ethics begins with good facts.
  • There is always a range of morally acceptable actions.

• Principles of Decision Making
  • Informed consent.
  • Substituted judgment.
    • A Guardian making a decision for someone based on decisions that person has made in the past.
    • Considers the ward's value systems, religious beliefs, wants, needs, and desires.
  • Best interest.
    • The Guardian, in the absence of ability to make informed judgment, makes decisions based on what is best for the patient.
BIOETHICS COMMITTEE

• Should function as a patient care advisory committee to the facility.

• Members of the committee function by:
  • Serving as an education resource to employees, residents, and families.
  • Review and share opinions regarding facility policy governing the withholding or withdrawal of medical treatment.
  • Providing advice about issues related to life threatening conditions.
  • Providing opinions about treatment for individuals with life-threatening conditions.
  • Being aware of and abiding by all applicable laws and regulations.

Bioethics in Long Term Care

BIOETHICS COMMITTEE

• Committee Members
  • Administrator
  • Chaplain/ Pastor
  • Director of Nursing
  • Social Worker
  • Dietician
  • Medical Director
  • Nurse Manager
  • Other members if the team may vary depending on the nature of the case that is being considered

Bioethics in Long Term Care
BIOETHICS COMMITTEE

• Committee Activities
  • Case review for the purpose of making recommendations based on consensus
    • Applicable legal and ethical issues are applied to each case
    • Applying “personal values” of the resident and family to what the law has to say regarding “hard choices” that have to be made
    • Apply the experience of how similar issues have been resolved in the past
  • Review topics of interest for potential quarterly meetings
    • Advance directives
    • Ethics at the end of life
    • Research ethics
    • Rationing of care
    • Interpretation of changes in laws and regulations

ADVANCE DIRECTIVES

• Assessing patient wishes when they can’t speak for themselves
  • Cruzan 1990 – established the constitutional basis for competent patients to direct their future medical treatment through the execution of an advance directive.

• Advance Directives
  • Living Wills
  • Durable power of attorney for healthcare
  • Verbal; statements to primary care physician or family members

• PSDA 1990 – Federal law that requires states to provide education, upon entering an institution, about advance directives.
POLL QUESTION

Which of the following statements is true?

1. To perform CPR is an extraordinary measure.
2. To provide hemodialysis to a patient with acute loss of renal function is a heroic measure.
3. Both of the above statements are true.
4. Neither of the above statements are true.

ADVANCE DIRECTIVES

- Potential Issues
  - Vague language – “heroic,” “extraordinary”
    - Heroic: Legally defined as artificial or emergency healthcare measures with or without the use of machinery, designed to revive an individual who but for those measures, would in all probability die.
    - Extraordinary: Medical procedures to temporarily replace or supplement failing and essential bodily functions.
  - Difficult to anticipate future medical scenarios
  - Keeping records of wishes current as the patient may change their mind
    - What if the proxy changes their mind regarding an issue after the patient has lost capacity and the proxy has been activated
  - Portability
**HISTORY OF MOLST**

- Project initiated in 2001
- Community pilot was launched in 2005
- Governor Paterson signed bill in 2008 making MOLST permanent and statewide
- HEAL 5 grant in 2008 included eMOLST
- DOH-5003 NYSDOH MOLST form introduced in 2010.

**ETHICS AT THE END OF LIFE**

- What is the conceptual difference between killing and letting someone die?
- Is foregoing life sustaining treatment sometimes a form of killing, and if so, can it be considered a form of suicide or homicide?
- Under what conditions, if any, is it permissible for patients, healthcare professionals, or surrogates to forgo treatment and allow the patient to die, to arrange for assisted suicide, or to arrange for some other cause of death?
ETHICS AT THE END OF LIFE

• Forms of Euthanasia
  • Active
    • Lethal intervention
  • Passive
    • Withdrawal of care such as artificial nutrition and hydration
    • Withholding care
  • Assisted (Physician Assisted Suicide)
    • Supreme Court 1997 Washington v. Glucksberg
      • Individuals do not have a constitutional right to secure assistance of a physician to actively hasten their own deaths, and states may continue to make a physician’s assistance in such cases criminal offense. Courts lefty open the possibility that states could decriminalize Physician Assisted Suicide if they choose to do so (Oregon has done so)

RESEARCH ETHICS

• Informed consent for care
  • Competence to give informed consent
  • Competent patients have the right to refuse treatment
  • Ethical dilemma of caring for incompetent, dying patient
  • Making treatment / consent decisions for incapacitated older adults without advanced directives
HEALTH CARE RATIONING

• Callahan: Setting Limits
  • Rationing is already happening
  • It is common to withhold expensive medical technology after the age of 80

• Daniels
  • Proposes creation of a national policy on rationing care

• Veatch
  • A policy should be established where claims are filed to receive care (a cap would be in place for how many procedures could be done per period of time) and the allowance of these claims would be given based on a system of “inverse proportion to chronological age”

Bioethics in Long Term Care

The team informed both families of the incident that occurred between the two residents, but as they did this they wondered if they had waited too long to inform the families of what had been happening.

Fundamental Concerns
1. Both residents have some level of cognitive impairment, but does that exclude them from giving informed consent for participation in a relationship whether sexual or non-sexual?
2. How would the families react?
3. Should this relationship be promoted or discouraged?
Ethical Issues
1. Is demonstration of mutual sexuality a “treatment”, and if it isn’t was it necessary for the team to have to promote or oppose the activity?
2. How to promote autonomy while maintaining dignity.
3. How do you protect both residents and keep them safe?
4. How do you address the various needs of both residents?
   1. Physical
   2. Emotional
   3. Cognitive
   4. Religious & Spiritual
   5. Sexual

FAMILY REACTION
FAMILY REACTION

STAFF INTERVENTION

• Promote or Discourage?
POLL QUESTION

As a voting member of the ethics committee, considering all of the information you have been given, your decision regarding this case is (may choose more than one option):

1. Prepare a care plan that promotes the relationship.
2. Prepare a care plan that discourages the relationship.
3. Have the physician do a medical assessment of each resident.
4. Order a psychiatric consultation.
5. Need more information to make a decision.
CASE STUDY #2
Artificial Nutrition & Hydration

UNDERSTANDING PEG’S

- 60% one year mortality
- Aspiration occurs in up to 50%
- Has not been found to prolong life in patients with dementia
- Have not been proven to be effective in providing adequate nutrition in patients with end state dementia.
THE FEEDING TUBE DEATH SPIRAL

1. Primary illness (example: urosepsis) in the setting of advanced dementia.
2. Inability to swallow documented with or without aspiration and/or weight loss
3. Swallow evaluation with recommendation for NPO order
4. Feeding tube placed followed by increasing agitation and dislodged tube
5. Re-insertion of tube with consideration for a restraint
6. Aspiration pneumonia
7. Intravenous antibiotics and pulse oximetry
8. Repeat steps 4 – 6 two or more times
9. Family conference
10. Death

POLL QUESTION

Case #2A

An 89 year old resident who has had a CVA now has dysphagia with silent aspiration and has inadequate caloric intake with documented significant weight loss. The speech pathologist recommends that she have an NPO order. A feeding tube can be inserted to provide nutrition and fluids but the resident does not have capacity to give consent and has not assigned a healthcare proxy. The attending physician feels that it would be medically futile to insert a feeding tube and has made the resident’s son aware of her condition and prognosis. He is not the proxy but is acting as surrogate and decides he will not give consent for a feeding tube because he does not feel the tube would be in his mother’s best interest.

Based on the steps presented, can artificial feeding be withheld as the next step?

A. Yes
B. No
Case #28

A 73 year old male with advanced MS, right hemiplegia and hemiparesis, and chronic dysphagia has been admitted to your sub-acute unit following a hospitalization for septicemia secondary to Proteus Mirabilis ESBL. He is able to communicate and make needs known, however, his wife often speaks on his behalf. He has been eating a pureed diet with poor intake and since admission, pulled out his PICC line prior to completion of IV antibiotics. He has not been losing weight and his nutritional parameters are normal, however, the speech pathologist has recommended he be NPO and have an assessment for insertion of a feeding tube. His wife states that he is going to be discharged home when his rehab is finished and does not want to pursue a feeding at this time because he will get better.

Should this case be referred to the ethics committee?

A. Yes
B. No

NEW YORK STATE LAW

- For patients who can make decisions for themselves
  - The usual standards of informed consent apply.
    - Physicians will discuss the pros & cons of a feeding tube.
    - If the patient chooses at one point in time to have the tube, they can choose to have it withdrawn at any subsequent point that they feel it no longer meets their goals or needs provided they maintain capacity to make decisions.
    - If the patient chooses not to have a feeding tube, food and fluids will be offered as tolerated using careful hand feeding.
NEW YORK STATE LAW

• For patients who cannot make decisions for themselves
  • If they have a completed health care proxy form
    • The chosen agent is required to make a decision that
      represents what is known about the patient’s wishes.
    • If the patient’s wishes are not known, the decision should
      be made according to the patient’s best interest.
    • The agent can make all end of life decisions on the
      patient’s behalf, but the decisions must be based on
      reasonable knowledge of the patient’s wishes in the case of
      withdrawing or withholding of tube feeding.
    • This is best accomplished by including a statement on the
      proxy form saying that conversations have occurred
      between the patient and the healthcare agent about
      artificial hydration and nutrition tube feeding.

NEW YORK STATE LAW

• For patients who cannot make decisions for themselves
  • If they do not have a completed health care proxy form;
    • The legal standard for withholding or withdrawing a feeding
      tube is different depending upon the site of care.
    • As of September 2011, if such a person is in a hospital or
      nursing home, NYS law allows for surrogate decision makers
      to make decisions about feeding tubes based upon
      substituted judgment (what is known about the patient’s
      wishes, or if not known, based on the patient’s best interest.
    • Decision-maker order of priority: Authorized guardian,
      Spouse (if not legally separated) or domestic partner, Son
      or daughter if over the age of 18, Parent, Sibling if over the
      age of 18, Close friend (must complete a signed statement
      as a close friend).
NEW YORK STATE LAW

• For patients who cannot make decisions for themselves
  • If they do not have a completed health care proxy form and a decision is being made by a surrogate decision-maker as outlined on prior slide;
    • Additionally, under this circumstance, two physicians must concur that either;
      • The patient has an illness or injury expected to cause death within 6 months, or
      • The patient is permanently unconscious, or
      • Treatment is inhumane or extraordinarily burdensome and the patient has an irreversible or incurable condition.
  • If the attending MD does not agree with the decision to withhold or withdraw nutrition, an ethics committee should review the case.

Bioethics in Long Term Care

NEW YORK STATE LAW

• For patients who cannot make decisions for themselves
  • If they do not have a completed health care proxy form and there is no eligible candidate to serve as surrogate;
    • Decisions about withholding or withdrawing tube feeding can be made if two physicians agree that
      • Life sustaining treatment offers no medical benefit and the patient will die imminently even if treatment is provided, AND
      • The provision of life sustaining treatment would violate accepted medical standards
NEW YORK STATE LAW

- For patients who cannot make decisions for themselves
- If they do not have a completed health care proxy form and there is no eligible candidate to serve as surrogate – and they are not in a Hospital or Nursing Home:
  - The legal standard to withhold or withdraw artificial nutrition is “clear and convincing evidence” of the patient’s wishes.
  - A prior written statement about feeding tubes or artificial nutrition in a Living Will
  - Completion of a MOLST
  - Clear oral statements by the patient about their wishes

MOLST: SECTIONS E&F

SECTION E
Orders For Other Life-Sustaining Treatment and Future Hospitalization
When the Patient has a Pulse and the Patient is Breathing

Bioethics in Long Term Care
EMOLST
Advanced Planning

WELCOME TO eMOLST

Please enter your username and password.

User name: lorem1.exceius
Password: ***************

Log On  Forgot password? Need an account?

eMOLST is a web-based version of the current paper-based New York State Department of Health-5003 MOLST form and is made available through the Rochester RHIO’s Health Information Exchange. By moving the MOLST form to a readily accessible electronic format, health care providers, including EMS, can have access to MOLST forms at all sites of care including hospitals, nursing homes and the community.

Learn How to Use eMOLST
Watch video tutorials to learn how to complete and manage patient MOLST forms with the eMOLST application.
Create Patient Profile

Fill in all of the remaining fields below and click the Create Patient button to create a Profile for this patient.

**First Name:** John

**Middle Name:** Joe

**Last Name:** Doe

**Gender:** Male

**Date of Birth:** 01/01/1901

**Street Address:** 165 Court Street

**City:** Rochester

**State:** New York

**Zip:** 14647

Create Patient Go Back
If there is no health care proxy, assess capacity to complete a health care proxy

Discuss values and beliefs with the person who will make the decision

Disclose goals for care with the person who will make the decision

Document where the eMOLST form is being completed. Location is based on where the patient is receiving care when the MOLST discussion is held and eMOLST is completed. Check one:

The appropriate legal requirements checklist is automatically selected based on the patient information entered in the eMOLST Discussion Section, above.

Bioethics in Long Term Care

Bioethics in Long Term Care
DISCUSSING THE ISSUES

- Focus on the Patient’s own values, preferences, and beliefs
  - Discuss the underlying disease that has caused the loss of appetite.
  - Discuss the role of palliative care.
  - Proactively discuss concerns regarding starvation.
  - Recognize concerns regarding hastening death.
  - Clarify that withholding or withdrawing artificial nutrition and hydration is NOT the same as denying food or drink. Remind all concerned that oral food and drink will still be offered if the individual can eat and/or drink.
DISCUSSING THE ISSUES

• Learn about and understand cultural and religious values.
  • Most cultures recognize death as a normal part of life.
  • Explore religious values that may influence decisions regarding artificial nutrition and hydration.
  • When not familiar with the culture, seek consultation with a chaplain or spiritual leader from the involved tradition.
  • Recognize that there are variations within each culture.
    • Applicable variations are most effectively managed if the decision-maker is interviewed about applicable values and beliefs.
  • Recognize how your own values may interfere with your ability to be effective in the process.

CASE #2C

RS is an 85-year-old resident of your facility who has had an 8-year history of Alzheimer’s Dementia and has resided on the dementia unit for 5 years.

Her daughter, who she no longer recognizes, visits almost every day and usually assists with feeding her mother lunch.

RS is now non-ambulatory and has had steady weight loss despite supplements, appetite stimulants, antidepressants, and careful hand feeding.
CASE #2C

She has just been readmitted from the hospital where she was treated for aspiration pneumonia. It was her second episode of aspiration pneumonia in 8 weeks.

Since returning for the hospital she has needed more frequent cues and she now holds food in her mouth more frequently.

The clinical team suggests consideration of jejunostomy insertion because it has a lower aspiration risk than that found with gastrostomy tubes.
CASE #2C

• Pertinent Facts
  • Dementia patients often reach a point where they lose ability to handle food.
  • Dementia is the 5th leading cause of death in the US.
  • 30% of feeding tubes are placed in patients with dementia.
  • Common complications of dementia include dysphagia, apraxia, recurrent aspiration, pneumonia, and weight loss.
  • These “common complications” signal the final stages of the disease and most patients will only have months to a year of remaining life.
  • These facts should be clearly explained to those making healthcare decisions.

• Potential Benefits of a Feeding Tube
  • May prolong life in certain situations (example – in cases of ALS), but this has not been found in systematic literature review regarding patients with dementia.

• Potential Negative Consequences
  • Use has not been found to prolong survival or improve quality of life.
  • Aspiration pneumonia (not from feeding but from continued oral secretions).
  • Has not been shown to reduce the risk of acquiring a pressure sore or improve the healing rates of existing pressure sores.
  • Studies have demonstrated that jejunostomy use, despite previous perception, was not associated with a lower risk than gastrostomy.
  • Complications: leaking around tubes, tubes pulled out, increased need for ER visits to manage blocked or displaced tubes.
CASE #2C

- Presenting Alternative Interventions
  - Background: We all love food and even use food to show love. To allow one to go without food is usually viewed as starving them and allowing them to waste away while imposing suffering.
  - Trial of hand feeding where it is safe to provide a modified diet.
  - If the person cannot tolerate oral food you must carefully explain what is known about the experience of dying without food or water.
  - The patient will die of dehydration.
  - This will involve drifting off into a coma.
  - The evidence indicates that the majority of symptoms are not severe.
  - 75% of terminally ill patients retain some ability to report hunger and thirst. These feelings can be managed with comfort feeding (small amounts of food, ice chips, sips of liquids, or mouth swabs).

Bioethics in Long Term Care
CASE STUDY #3
Withholding Information

MJ is an 83-year-old male with a history of coronary artery disease, hypertension, BPH, and mild renal insufficiency. He has been complaining of excruciating lower pain that has not been relieved by potent analgesic medication. He has been followed by a urologist and his daughter accompanied him to an appointment with his urologist today.

When they return, she informs the nurse manager that the urologist did testing that confirms the reason for her father’s back pain is metastatic adenocarcinoma of the prostate involving the LS spine.

She states that the doctor explained his findings to her and that her father, who is fully alert and oriented, does not know anything about the diagnosis or prognosis. She further states that she and the urologist agree that no curative interventions will be attempted.

She is requesting that her father not be informed of his diagnosis or prognosis.
The daughter of MJ, who is his appointed healthcare proxy, states that she doesn’t want her father to know about his condition because the stress would have negative impact on the quality of life that he has left and will cause him to “withdraw and throw in the towel.”

1. The facility should care plan to ensure that the daughter’s wishes are followed.
2. MJ should be informed of his condition and prognosis.
3. Cultural aspects of the case should be investigated before the team makes a decision regarding the request.
4. If the information will be devastating, as his daughter fears, it should be withheld.

CULTURAL IMPLICATIONS

- The issue of Human Rights widely held in the US
  - Telling the truth to competent patients is the cardinal rule
  - For many patients, recognizing the end of life
    - facilitates meaningful advance care planning discussions.
    - Enables strengthening of relationships with loved ones.
    - Allows you to have a higher level of control over your illness.
  - Failure to disclose denies patients the right to exercise their autonomy and places limits on their choices concerning treatment.
CULTURAL IMPLICATIONS

• Great Britain has an end-of-life strategy that promotes telling competent patients the truth as a way of enhancing independence, individualism, autonomy, reduction of fear, and promoting avoidance of efforts toward sustaining poor quality of life.

CULTURAL IMPLICATIONS

• There are regions where it is felt that withholding medical information is more humane and ethical
  • Many Southern and Eastern European Countries
  • Large portions of Asia
  • Much of the Middle East
• In Ethiopian culture there are fears that the shock of bad news will hasten death.
• Certain ancient cultures recognize the value of “merciful lies” and will use them to maintain hope.
• An Iranian position paper stated that, “without any doubt, the right of patients to autonomy and truth regarding prognosis is imperative, but that the patient should be able to tolerate the truth with minimal psychological and somatic damage.”
ETHICAL ISSUES

• The most important rule is that respect is held for the autonomy of the individual.
  • This does not automatically open the door for “truth dumping”.
  • The rule should be upheld in a way that promotes maintenance or development of a trusting relationship between patient, family, and caregiver.
• A patient who does not know his or her diagnosis may not be able to assess the risks and benefits of a treatment decision, including decisions to withhold treatment.

PRACTICAL APPROACHES

• Step 1: Try to fully understand the point of view of the family member who requests withholding the information.
  • Demonstrate respect for the family’s perspective. Doing this will reduce the risk of starting an adversarial confrontation.
  • Understand that the family has genuine concern for the patient.
  • Address the family’s concern and anxiety.
  • Get a clear understanding of what they think will happen with disclosure of the diagnosis and prognosis.
• If the physician feels that the family member requests is not consistent with his/her moral obligation, he/she must remember that the primary responsibility is to the patient.
PRACTICAL APPROACHES

• Step 2: Understand the patient’s true preferences for receiving information.
  • Ask the patient whether and how they would like to receive information about the results of tests that have been performed.
  • Options
    • The patient may want to have all discussions directly with the physician.
    • The patient may want family included in all meetings at which test results are discussed and treatment decisions are made.
    • The patient may want to hear all important news from family members.

PRACTICAL APPROACHES

• Step 3: Try to resolve the request for nondisclosure gradually over a period of time.
  • Gradually share information about the test results and their implications.
  • Try to explain to the family what may happen symptomatically and how the patient may feel as these changes occur with no explanation as to why they are happening.
  • Give the family time to adjust to the changing clinical situation and understand how they can best meet cultural obligations while allowing professional obligations to be met.
PRACTICAL APPROACHES

• Step 4: Continue to work with the family and keep them included at key points of change in condition.
  • These will be difficult times for everyone involved, including the family.
  • Understand that one of the ways the family will cope with the situation will be to rely on cultural tradition as a mechanism of support.
  • The physician will be able to provide a higher level of comfort for the family if respect is shown for cultural traditions.
  • Higher levels of comfort translate to higher levels of trust.

CASE STUDY #4
Request to Discontinue Medical Treatment
DW is a 66-year-old female who has been a resident of the facility for almost 3 years.

Her medical history is significant for
1. End stage renal disease/ Dialysis dependent
2. Early onset vascular dementia
3. Depression & Co-morbid Anxiety
4. Congestive Heart Failure
5. Type II Diabetes Mellitus
6. CVA with left sided hemiparesis/ Ongoing TIA’s
7. Hypertension with history of IWI
8. Dysphagia

She is expressing a desire to discontinue dialysis because she is “tired and has had enough”.

She currently attends dialysis at the local dialysis center three times per week on Tuesday, Thursday, and Saturday mornings.

Current Medications
Risperdal 0.5 mg BID for anxiety
Zoloft 100 mg daily for depression
Klonopin sublingual for anxiety given TID just prior to going to dialysis

The attending spoke with the resident and placed the resident on “palliative care” with and additional order to discontinue dialysis.
POLL QUESTION

The attending physician

1. Should have ordered a psychiatric consultation to confirm capacity
2. Was correct in stopping dialysis as requested
3. Should have ordered a psychiatric consultation to assess depression
4. All of the above
5. None of the above

Bioethics in Long Term Care

Concerns

1. Can a resident with history of dementia refuse medical treatment?
2. Is her request a symptom of undertreated depression/ anxiety?
3. What is the significance of her needing Klonopin TID prior to dialysis?
4. What is the significance of the off-label use of Risperdal?
10 ETHICAL PRINCIPLES OF CARE

- Do right by the patient
- Avoid harm
- Treatment should be consistent with patient goals
- Maintain confidentiality
- A therapeutic alliance should be maintained between patient and physician
- Autonomy/Informed consent
- Physicians have a duty to tell the truth and be honest
- Be objective and avoid emotional or subjective processes
- Uphold the principle of fidelity (non-abandonment)
- Realize there are limited healthcare resources, allocate them objectively

CLINICAL PEARLS

- Bioethics serves to respect the moral, religious, and cultural beliefs of everyone.
- Our primary goal as caregiver is to promote good patient care and protect from harm.
- A basic understanding of law and ethics can help protect against lawsuits.
- Laws are often reactive and lag behind the moral standard.
- Decision making models should be established and used by ethics committees in making recommendations.
Thank You
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