Ethics and End of Life Care

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Objectives:

- Review Ethical Decision Making
- How to address Goals of Care
- How to Communicate Bad News
- How to address Code Status
- Approach to the withdrawel/witholding of life sustaining treatment – ventilator withdrawel
- Withdrawel/witholding artificial nutrition/hydration

Ethical Decision Making:

- **Non-maleficence**– Do No Harm
- **Beneficence** – Your goal is to achieve a benefit which the patient can appreciate
- **Patient Autonomy** – Must be guided by patient's wishes even after the patient has lost decision making capacity (Advance Directives)
- **Distributive Justice** – Allocating limited resources in a fair manner

Translating Basic Ethical Principles to daily clinical decision making…

Based on the concept of Beneficence, we understand that the goal of medicine is to benefit the patient.

What is the benefit we are hoping to achieve, what are our goals of care??

Addressing Goals of Care:

- Cure
- Prolongation of Life
- Alleviate Suffering/Comfort Care

When Cure is no longer achievable....

- Our focus becomes prolongation of life (managing a chronic progressive disease)
- Prognostication is vital in helping the patient/family make decisions
- When does the burden of treatment outweigh any potential for benefit? Who decides?

When Prolongation of life is no longer achievable or desirable...

- We shift our goal to alleviation of suffering/comfort care
- How do we define comfort care?
  - Antibiotics?
  - Transfusions?
  - ICU?

Language with unintended consequences:

- Do you want us to do everything possible?
- Will you agree to discontinue care?
- It's time we talk about pulling back
- There is nothing more we can do

Helpful Language....

- I will focus my efforts on treating your symptoms
- I want to ensure that you receive the kind of treatment you want
- Your comfort and dignity will be my top priority

Estimation of Prognosis

- Prognostication is a tool to help us determine our goals – preservation of life vs. providing a "good death"
- Objective measures such as APACHE and MPM (Mortality Prediction Model) develop to reduce biases in predicting outcomes.

Dealing with Uncertainty

- Physician discomfort with uncertainty may be a major barrier to good end of life care
- Most common response to uncertainty is avoidance – focus on details, ignore the big picture (Rearranging chairs on the Titanic)

Communicating Bad News....

1. Proper Setting – quiet, privacy, no interruptions
2. What does the patient know?
3. How much does the patient want to know? Patients have the right not to know!

....Communicating Bad News

4. Share the information- avoid medical jargon
5. Respond to patient, family feelings
6. Plan follow-up

Adapted from Robert Buckman

When family says "don't tell" . . .

- Legal obligation to obtain informed consent from the patient

  Vs.
- Respect for family's wishes

. . . When family says "don't tell"

- Ask the family:
  - Why not tell?
  - What are you afraid I will say?
  - What are your previous experiences?
  - Is there a personal, cultural, or religious context?
- Talk to the patient together

Addressing Code Status....

- Decision regarding code status should be consistent with goals of care
- Chances of successful resuscitation should be communicated
- Option of full code should not be offered when resuscitation attempts would clearly be futile

When a terminally ill patient insists "everything be done"....

- Patient may fear being abandoned
- Patient/family may not trust physicians
- Patient/family may be hoping for a miracle
- Need to address issues of medical futility – conflict resolution process

Conflict Resolution:

- Conflict regarding patient's treatment may be between the patient/surrogate and the doctors, it may be between nursing and doctors, or between doctors.

...Conflict Resolution

- All Parties need to be heard
- If any uncertainty, may need to clarify prognosis, treatment options... seek clarification from consultants, second opinions, etc...
- Try to achieve consensus on a time limitation when the outcome is still uncertain (We can all agree that we will continue treatment for another 48 hours, then reassess)

.....Conflict Resolution

- If conflict persists, request ethics consultation
- If conflict still persists, offer the patient the option of transferring their care to another physician/hospital.

Withholding, withdrawing treatment

- Decisions should be made based on goals of care
- Withdrawing and withholding treatment is viewed to be the same, ethically and legally
- Must be familiar with your institution's policies

UCSD Policy on Limitation of Life Sustaining Treatment:

- Life sustaining treatment can be withheld/withdrawn when a competent patient/surrogate requests
- Or, when the treatment has no reasonable chance of providing benefit (medically futile)

Common concerns . . .

- Are physicians legally required to "do everything?"
- Is withdrawal or withholding treatment euthanasia?
- Can the treatment of symptoms constitute euthanasia? – concept of "double effect"

Terminal Extubation:

- Once the decision has been made to extubate a patient with the intent of allowing the patient to die, the process should proceed according to protocol, by a physician who is experienced in conducting terminal extubations

Before Extubating:

- Document discussions with patient/family
- DNAR order signed by attending
- Discuss tissue/organ donation
- Remove any unnecessary monitors/alarms
- If possible, move patient to private room

Prepare the family . . .

- Describe the procedure
- Reassure that comfort is a primary concern and medication is available
- Patient may need to sleep to be comfortable
- Describe uncertainty

Withdrawal protocol–

- Establish adequate symptom control prior to extubation
- Titrate medications
  - Opioids – dosing varies widely. Titrate up rapidly for comfort.
  - Benzodiazepines/sedatives may be added for relief of agitation.
  - MAKE SURE NO PARALYTICS ARE IN EFFECT!

Withdrawal of nutrition, hydration

- Review goals of care – will nutrition,hydration achieve these goals?
- Address misperceptions
- Potential complications from feeding, fluids
- Help family with need to give care

Caring for families:

- Allow them to be with the patient
- Allow them to be helpful
- Keep them informed of changes
- Help them understand what is being done and why
- Assure them of the patient's comfort

…Caring for families:

- Comfort them
- Allow them to express their emotions
- Assure them that their decisions were right
- Help them find meaning in the dying of their loved one
- Assure that they are fed, hydrated, and rested.

Caring for Staff:

- Direct involvement of senior MD's/Nurses in caring for the dying pt.
- Effective communication between physicians and nurses re. goals of care
- Ongoing education in end of life care.

…Caring for Staff:

- Administrative Support – providing adequate staffing to care for dying patients who need intensive palliative care.
- Minimize transfer of imminently dying patients out of the ICU.
- Allow opportunities for bereavement and debriefing after a patient dies.

After Patient's Death

- Acknowledge family/loved one's loss and grief – refer to grief support
- Send a note to family
- Consider attending memorial service
- Allow staff time off to attend memorial service

Summary:

- Ethical Decision making – always strive to "do no harm", benefit the patient, and respect patient autonomy
- Always guide treatment decisions according to the Goals of Care
- When cure/prolongation of life no longer achievable, life sustaining treatments should be limited/withdrawn

....Summary:

The final goal of care should always be to help patients achieve a peaceful death..

To achieve this, we must not equate death with failure.