## **BIOETHICS ISSUES RELATED TO TECHNOLOGY**

Burkhardt - Chapter 10 - Practice Issues Related to Technology

#### BENEFITS AND CHALLENGES OF TECHNOLOGY

- Significant scientific advances have occurred over last 10 years
- Before technology illness and death regarded as inevitable
  - Death not always welcome but accepted as a normal outcome of many illnesses
  - Deformity often viewed as a curse
- Technology affords many changes to natural outcome of disease
  - Restart an arrested heart
  - Respirators to artificially breath (for patient unable to do so)
  - Medical correction of deformities
  - Medical treatment to deal with otherwise fatal diseases

## Technology raises significant Quality of Life issues

- Is physical existence synonymous with living?
- When should technologies when available be used? Always? Selectively?

#### **QUALITY OF LIFE ISSUES**

Issues and questions concerning quality of life

- What constitutes living?
- Is person alive where there is only physical function without consciousness?
- Differing perspectives re Quality of Life
  - One view holds that biologic life must be preserved regardless of effect on individual
  - Another view holds that living implies a quality of life that goes beyond physical existence
- QoL is subjective appraisal different meanings to different individuals
  - Factors which make life worth living
  - Factors which contribute to a positive experience of living
- Difficult to find clear and concise definition
  - Multi-disciplinary usage and variable cultural understanding of terminology
  - Varying sources of definitions
    - Lay vs "expert" perspectives
    - Global understanding vs focused perspective

Global example: satisfaction with life

Focused: research perspective of health or functional ability

- Common measures of quality of life
  - Fulfillment
  - Satisfaction/dissatisfaction
  - Conditions of life
  - Happiness/unhappiness
  - Experiences of life
- Other factors commonly used to measure quality of life:

- Comfort
- Functional status, socioecconomic status
- Independence
- Environmental conditions
- Problems occur in deciding what weight to give different parameters
  - Which is more important: happiness or functional status (self-care, etc.)?
  - Plans/goals must consider patient's perspective/values re: Q of L
  - Q of L is personal perspective determined by each individual
  - Should not judge another's life based on own value system
  - Discrimination/injustice follows judgements based on subjective factors
    - Contribution to society (subjective)
    - Age, mental capacity, ability to function, etc (subjective)

Example: one person with debilitation may rate high Q of L where another could not tolerate same limitation

- Role of health care provider concerning technological options
  - Assist patients and families clarify issues when faced with decisions
  - Address not only how life extended but Q of L with various options

### PRINCIPLES OF BENEFICENCE AND NON-MALEFICENCE

- Principles of beneficence and non-maleficence may be in conflict
- Technology implemented with good intentions (beneficence) may cause suffering
- Inducing suffering is contrary to maxim of non-maleficence (do no harm)
- Some suffering acceptable
  - Acceptable where there is reasonable expectation of recovery
  - Acceptable where there is <u>expectation of resultant greater health</u> Examples:
    - Pain associated with surgery
    - Side effects of chemotherapy
- What <u>role for technology where little/no expectation of recovery/improved functioning</u>?
  Does <u>harm outweigh</u> the good intended by its use?
- Suffering related to technology can be multi-dimensional
  - Physical, spiritual, emotional elements
  - Involve both patient and family
- Relief of suffering is a fundamental and historic goal of all healing
- Technology must be addressed in light of inducing or relieving suffering

**CURRENT TECHNOLOGY ISSUES AND DILEMMAS** 

- "Hot" issues: fraught with dilemmas
  - Organ and tissue transplantation
  - Genetic engineering
  - Assisted reproduction
  - Sustaining life
- Nurses typically have role of care-giver after these decisions have been made by others
- Nursing role is to help patients and families deal with issues:
  - Purposes/goals of technology in question
  - Benefits/limitations of technologies

## TREATING PATIENTS: WHEN TO INTERVENE AND TO WHAT END

Highly controversial issue concerns withholding/withdrawing life sustaining treatments

- Typically concerns withholding/withdrawing treatments where prognosis is poor
- Decisions usually via physicians in consultation with patients and family

Historical perspective sheds light

- Hippocrates era: physicians taught that goals of medicine to reduce suffering
  - Directly reducing suffering
  - Reduce effects of disease by lending support to natural processes
  - Medicine not intended for situations where body overpowered by disease
  - Discouraged interventions which prolonged suffering
  - Accepted ethical stance recognized limitations of medicine
  - Encouraged withholding treatments which held little potential for healing
- Scientific era fostered change in previous perspectives
  - Changes began emerging in 17th C
  - Conquering and dominating nature becomes goal (vs working with nature)
  - 19th century saw medicine align more with science
    - Biologic causes of diseases were increasingly discovered
    - Goal became conquest of disease exercise power over nature
  - Technology in spite of poor quality of life is outgrowth of scientific tradition \*
  - "...are the outgrowth of a scientific tradition whose mission is to control and dominate, whose proving ground is nature, and whose means is an unfailing faith in the scientific method (Jecker, p. 144) \*
    - \* Jecker N.S. (1995) Knowing when to stop: The limits of medicine. In J. H. Howell and W. F. Sale, eds, Life Choices: A Hastings Center introduction to bioethics (pp. 139-148). Washington, DC Georgetown University Press
  - Focus on curing may neglect issues of personal Q of L and/or suffering
  - Nurses play key role in calling attention beyond narrow focus of curing

## ISSUES OF LIFE, DEATH AND DYING

- Need to address questions re: what constitutes life?
  - When does life begin?
  - When does life end?
  - How can we be sure someone has died?
  - Who decides?
- Technology has stretched the boundaries and clouded the issues
- Perspectives on life/death vary many different views
  - One view holds that life begins at conception
  - Contrasting view: life begins when infant can survive outside womb
- Questions brought forth by technology
  - What happens when conception cannot occur "naturally?"
  - In vivo/vitro artificial processes: "Is the laboratory embryo a life?"
- Technology fosters survival of infants who would not have survived in prior eras
  - Low birth weight or deformed infants can survive with technology
  - Machinery which supports life, medications, surgical procedures
  - Some babies kept alive only to die after months of expensive treatment
  - Some infants survive to face chronic health problems
  - Financial, emotional, physical strains on family and health care system
  - Cannot predict which infants will have problems as they grow and develop
  - Dilemmas concern how much effort to invest in "saving" few infants
    - Infants with high probability of living only a short time
    - Infants with significant health problems
- Death in our society has evolved into an unnatural event
  - Hospitals, institutions, tubes, machinery, heroic efforts
  - Determining when life ends has become critical issue re: technology
- Death often viewed as "the enemy" by select healthcare providers
  - "Enemy" to be kept at bay or overcome as long as possible <u>regardless of age</u>, health, etc.
  - · Death may be viewed as failure on part of health care provider
  - Providers commonly have difficulty in accepting death as a possible outcome
- Death and related discussions may be emotionally-charged topic
  - Force persons (including providers) to face issues of own mortality
  - · Questions re: what is the meaning of life?
  - Issues re anxieties, fears
- Lack of discussion may lead families to unreasonable expectations and false hopes
- Misunderstandings may result when families have unrealistic perceptions
  - Demands for inappropriate interventions
  - Accusations that not enough was done for the patient
- Patients/families need support to face death and associated issues
- Cultural differences concerning view of death -

- Many cultures view death as part of life cycle approach will reflect views
  - Health care directed toward curing where appropriate or hope of benefit
  - Sometimes it is appropriate to let go facilitate transition thru dying process
- Some cultures dying commonly occurs at home surround by family friends
- Knowledge of attitudes re death will facilitate professional care
  - Awareness of own attitudes concerning death/dying
  - Awareness of attitudes of beliefs/expectations of patients, family, other providers
  - Will alert to situations where conflicting attitudes between parties involved

<u>Example</u>: patient may express wish to die peacefully at home while physician or family is advocating additional surgery with limited prognosis of success

- Nurses should act to <u>facilitate communication</u> between parties involved or communicate wishes to family/providers
- Dying may be viewed as a spiritual process (not simply a medical occurrence)
  - Touches individual, family and community
  - Medical intervention can serve to separate dying from families
    - Physical barriers, institutionalization
    - Technology can prolong suffering via prolonging dying process

### **MEDICAL FUTILITY**

- -Initiating-discontinuing life-sustaining technologies based on relative benefits/burdens patient
- Not instituting treatment vs discontinuing treatment in progress
  - Many health care professionals feel reluctant to d/c treatment
  - Philosophical and legal commentators do not always distinguish between the two
- Withholding futile treatment is to allow death from natural progression of illness Futile treatment: where burden or harm deemed to outweigh benefits

Euthanasia: causing painless death to end/prevent suffering

- Euthanasia is an active process differs from withholding treatment
- Withholding treatment allows disease itself to cause death

Medical futility: situations where interventions have no medical benefit or low success rate

- Major factor in deliberations re: initiating, withholding or d/c life-sustaining measures
- Futility often discussed relative to CPR
- Applies to interventions which preserve patients in persistent vegetative state
- Patients where life dependent on technology of tertiary care settings
- Problem: no set definition of the concept only suggested parameters which vary greatly
- Lo (1995) suggests strict definitions of futility that would justify unilateral decisions \*
  - Interventions that have no pathophysiologic rational
  - Interventions which have already failed in the patient
  - Interventions which will not achieve the goal of care
  - Situations where maximal treatment is failing
  - \* Lo B. (1995) resolving ethical dilemmas: A guide for clinicians. Baltimore: Williams and Wilkins

## Strict vs loose definitions of futility

# Strict definitions of futility

- Determination of futility is based on objective data and judgements
- Physicians have no ethical duty to provide interventions which are futile
- Ethical obligation not to provide futile interventions even if requested

### Contrast to loose, value-laden definitions of concept do not justify unilateral decisions

- Loose definitions: situations that prompt variable interpretations thus more confusing
- Examples of loose definitions
  - Liklihood of success is very small
  - No worthwhile goals of care can be achieved
  - Patient quality of life is unacceptable
  - Prospective benefit is not worth resources required
- Meaning of futility must consider perceptions of patient, family, healthcare team
- These less-clear situations require more skillful nursing care
- Decisions draw on personal understandings and resources shaped by beliefs and cultural values
- Differing persons may have differing views re benefit and burden
- Difficulty to define and develop clear guidelines
- Focus is less on concept of futility and more on explaining concepts to patients
  - Explain medical circumstances fully
  - Assist parties to negotiate care in the best interest of patient

## Parties involved may have differing perspectives

### **EXAMPLES**

- Patient or family may cling to 5% success while healthcare provider views it as futile
- 72 year old quadriplegic on home ventilator deteriorating
  - Physician suggests DNR
  - Daughter wants every effort made
- Heath care professionals view treatment as prolonging suffering while family views it as buying time opportunity to say goodbye

## DNR - do not recessitate

### **Economics and Medical Futility**

- Economics factors into discussions of futility
- Scarce resource view discourages futile treatment
  - Resources are better directed toward another patient who can make better use of the resource
- Economics of medicine prompt providers and hospitals to look closely at futile treatments
- Prospective payment systems delegated responsibility to limit futile treatment to physicians
  - Social mandate social responsibility
  - Perspective is consistent with utilitarian ethics
  - Government commonly uses utilitarian ethics in deciding distribution of goods/services

#### DO NOT RESUSCITATE ORDERS

- Nurses have active role in initiating or withholding CPR
- Initiation requires consideration of professional, ethical, legal and institutional considerations
  - Autonomy
  - Self-determination
  - Non-maleficence
  - · Respect for persons
- General practice re CPR must be initiated unless one of the following
  - · It would be clearly futile to do so
  - · Practitioner has specific instructions not to do so

#### **DNR** orders

- legal definition is NOT to initiate CPR in event of cardiac or pulmonary arrest
- Written directives placed in patient's chart (medical record)
- DNR orders in medical record should contain the following
  - Reason order was written
  - · Who gave consent and who involved in discussion
  - · Whether patient was competent to give consent
  - · Who was authorized to do so
  - · Time frame for DNR
- Lo (p.5) suggests that with medical futility CPR need not be offered as an option
- Nurses role is ideally suited to working with families/patients to decide re DNR
- DNR requires open and explicit communication w patient, family, surrogate, etc.
  - Lay persons often overestimate power of CPR
  - Persons do not understand that CPR is not always medically indicated
  - Media/TV perpetuates mis-perceptions re CPR survival much higher in TV dramas
  - People rarely appreciate that <u>CPR is harsh/traumatic procedure</u>
    CPR performed on persons with multiple, severe, chronic health problems rarely survive to discharge
- Decisions re CPR or DNR must flow from values of patient or patient surrogate
- Competent persons have right to refuse CPR becomes issue of autonomy
- Good communication is the key

### - DNR orders apply only to resuscitation

- Fact that CPR is futile does not imply that other life-sustaining treatments are futile
- Other treatments may be appropriate and should be continued
- Healthcare providers sometimes do not make distinction resulting in confusion
- Many institutions require specific instructions re what to do or not do for patient
  - Treatment of physiologic abnormalities (fever, cardiac arrhythmia)
  - Nutrition
  - Mechanical ventilation and CPR
- Goal of care must be clear particularly when DNR in effect or under consideration
- No reduction in care to patient or family is appropriate (aside from DNR)
- Some DNR patients recover and return home

- DNR raises philosophical aspects of death and dying
  - Death which was once matter of fate now takes on some aspect of choice
  - Integrate death and related decisions into "legitimating values of our moral universe" \*
  - \* Scofield G.R. (1995) Guidelines on foregoing life-sustaining medical treatment. *Pediatric Nursing* 20, 517-521
- Nursing implications related to DNR orders
  - Physicians write such orders but nurses need to be aware of parameters of such orders
  - Orders must be clearly documented in chart
  - Nurses to be aware of which patients have DNR orders errors have serious implications
  - Order to be reviewed periodically as patient's condition changes
  - A <u>new request for DNR</u> (patient or surrogate) should be documented and brought to immediate attention of physician
  - Orders should specify which interventions to be withheld and circumstances to withhold
  - All persons involved in care of patients need to know orders
  - Nurse's attitudes re DNR will affect approach to patients must have awareness
    - Awareness of own attitude toward withholding interventions
    - Awareness in general and as it applies to particular patients

### **ARTIFICIAL SOURCES OF NUTRITION**

- Maintaining nutrition is natural life-sustaining measure common part of nursing role
- Decisions re artificial nutrition relevant once patient has difficulty with eating
  - Difficulty chewing
  - Not conscious enough to eat
- Ethical dilemma arise re whether to classify interventions as feeding or medical treatment
- Whether to classify feeding as ordinary or extraordinary measures
- ANA has policy on Forgoing Nutrition and Hydration
  - Stress importance of determining whether food/fluid are more beneficial or harmful to patient
  - Artificially-provided nutrition and hydration may not be ethically justified
- Problematic with persistent vegetative state or end-stage dying processes
  - Nutrition may maintain life
  - Withholding nutrition will eventually lead to starvation and death

### - Is withholding nutrition ethical?

- Starvation/withhold food under ordinary circumstances considered unethical
- Considered appropriate when not benefitting patient or are contrary to patient wishes
- Issues in withholding
  - Decision must consider wishes of patient or surrogate
  - Quality of life is important factor
  - Principle of **non-malfeasance** applies if interventions contribute to suffering
    - Applies where intervention contributes more to suffering than relieving it
    - Non-malfeasance may sway toward decision to withhold or d/c life-sustaining treatment

- Evidence concerning withholding feeding in dementia or multi-system illness
  - Tube feeding does not improve outcomes
  - Has substantial risks in some patients

Finucane, T.E., Christmas C. and Travis, K. (1999) Tube feeding in Patients with Advanced Dementia JAMA 282(14) 1365-70

McCann, R. (1999) Lack of evidence about tube feedings. Food for thoughtr. JAMA 282(14), 1381 Moss, A. H. (2001) What's new? Progress in palliative care, CPR and advance directives. Seminar at Raleigh general Hospital, beckley WV January 18, 2001

- Unethical to withhold food from person willing/able to eat in an effort to quicken death
  - Withholding in such circumstances unethical even if patient is suffering/death inevitable
- Highly sophisticated means of artificial feeding may be withdrawn in certain conditions
  - Condition of living is intolerable and death is inevitable
  - Feeding is not in patient's best interest and represents pointless prolongation of suffering
- Withdrawing feeding
  - Once artificial feeding is implemented it is psychologically more difficult to withdraw it
  - Continued as long as sentient life is reasonable
  - May be appropriately terminated when reliable prediction of permanent unconsciousness
  - Ask whether use is prolonging living or prolonging dying
- Nursing responsibilities when competent person refuses food/fluid
  - Nurse to honor request
  - Nurse to assist family/caretakers that dying persons often have decline in appetite Involved persons may have different perspectives or understanding
  - Comfort care to dying may not necessarily include maintaining nutrition

# **LEGAL ISSUES RELATED TO TECHNOLOGY**

- Ethical decision may not be upheld as a legal action
- Courts have intervened re withholding/withdrawing life support where disagreement of parties
- Legal precedence regarding issues set in the process of legal intervention

#### **EXAMPLES PRECEDENCE ISSUES**

- What constitutes clear evidence of patient's wishes related to treatments?
- What is considered standard practice?
- Advanced directives key role in issues of healthcare dilemmas
  - AD are instructions indicating one's wishes regarding health care
  - Individual can designate surrogate to make health-related decisions if patient is incapacitated Individual selected for AD need not be same person who has been chosen for durable power of attorney in financial realm or executor of estate for will.
- Guardian ad litem appointed by court when individual cannot make decisions
  - Responsible for person (body/medical context) vs property (vs property)
  - Prominent cases where life support/guardian ad litem issues gained public attention
    - Karen Ann Quinlan 1975
    - Nancy Cruzan 1983

#### **PALLIATIVE CARE**

- Two obligations owed to people who are dying: comfort and company
- Palliative care becomes focus when life-sustaining interventions no longer appropriate
- Focus is directed toward comfort and support patients and families
- Palliative care is comprehensive, interdisciplinary and total care
- Indicated when illness is chronic and not responsive to curative treatment
- Provide best quality of life for patients and family
  - Meticulous control of pain and other symptoms
  - Efforts directed toward optimizing quality of life as defined by patient and family
  - Includes spiritual and psychological care
- Coordinated and continuous services in home, hospice, nursing home, hospital
- Services to include support in bereavement
- Nurses play key role in providing care and coordinating team
  Team may include nurses, physicians, spiritual support persons, pharmacists, social services, mental health services, pain services
- Effective communication is crucial when family members disagreement re interventions
  - Nurse's ability to communicate with and facilitate same with family is key
- Time is important element
  - Families need time to understanding patient's illness and intervention outcomes
  - Nurses to take as much time as need and as often as needed to explain facts/decisions
- Palliative care conference is a useful technique for coordinating palliative care

### REPRODUCTIVE TECHNOLOGIES

- Examples: artificial donor insemination, in vitro fertilization, surrogate embryo transfer
- Ethicists raise issues related to reproductive technologies

Surrogacy: Is the mother the woman who donates ovum or woman who carries baby? Who has custody of frozen embryos? Do embryos have rights? Have women become exploited or liberated by technologies?

Who should pay for the expensive technologies? For whom should they be available?

- Would seem more available to white women than women of color
- Issues of social justice and societal attitudes regarding assisted reproduction

## GENETIC DIAGNOSIS, ENGINEERING AND SCREENING

- Advances in molecular biology, genetics and Human Genome Project
  - Resulted in benefits related to possible remedies for genetic diseases
  - Raises ethical, legal, social justice issues

### · Genetic diagnosis

- Usually done within an in vitro fertilization program biopsy embryo
- Determines presence of genetic flaws, gender prior to implantation
- Aimed at couples with high risk of genetic disorders
- Intent that embryo free of genetic flaws would be implanted

## · Genetic engineering

- Ability to alter organisms genetically for variety of purposes
- Currently used to develop more disease resistant fruits and vegetables
- Proposed that future use will involve developing healthier fetus and baby

## · Genetic screening

- Possible to determine presence of genetically impaired fetus
- Distinction has been made between therapeutic use and use to modify human characteristics
  - Use to eliminate disease/abnormalities vs use to produce "desired" traits in offspring
  - Use to produce 'desired" qualities and discarding "undesirable" traits
- · Eugenics meaning "good birth"
  - Eugenics movement of 20<sup>th</sup> century
  - Goal to promote traits proponents viewed as desirable while weeding out "undesirable" traits
  - Sought to discourage procreation among people viewed as "socially inferior"
  - Compulsory sterilization of those who were poor, prisoners, or in mental institutions

# · Other issues related to genetic technologies

- Technologies may impose skewed/harmful definition of what is normal/abnormal human traits
- Serious transcultural implications (societies tend to impose standards/values on others)
- Abuses and exploitations easy to imagine Slippery slope concept
  One decision based on relaxing of standards leads to a slide into accepting lower standards as ethical guidelines
- Common potential concerns re genetic technologies
  - · Genetic engineering can produce harmful organisms
  - <u>Employers or insurers</u> who acquire info could use it to bar persons from employment or insurance
  - · Forbidding persons with certain traits to procreate
  - Insurance companies refusing to cover expenses for birth of genetically-impaired infants
  - · Prohibiting birth of babies with genetic features deemed undesirable by those in power
  - · Who pays for procedures? Who determines guidelines?
  - For whom technologies made available?

#### ORGAN AND TISSUE PROCUREMENT AND TRANSPLANTATION

- Transplantation overview
  - No longer considered extraordinary or uncommon healthcare event
  - Becomes more common and available as techniques become more refined
  - Demand for organs greater than supply dilemmas emerge
  - Issues of eligibility arise
  - May involve organs from dead or living human donors or animals (pig valves)
  - Procedure must occur soon after death to insure well-nourished organs
  - Criteria for determining death becomes imperative

# Allocation of resources - eligibility issues

- How shall decisions be based?
  - Recipient's potential to survive?
  - Ability to pay for procedure?
  - Power and prestige?
  - Combination of above factors?

# Criteria for determining death

- <u>CPR</u> irreversible <u>cessation of CPR</u> one criteria but entails problems
  - Requires that CPR be attempted which in turn may damage organs if attempted
  - When and how aggressively to initiate CPR becomes an issue esp for prospective donors
- · Brain death is most likely criteria esp if person on life-support technologies
  - Current criteria: all functions of entire brain must cease
  - Some suggest that current criteria are more stringent than necessary
    - Irreversible cessation of higher brain e.g. persistent vegetative state may suffice
    - Persistent vegetative state equals permanent coma
    - More liberal criteria would open possibility of organ harvest for vegetive states

# Issues involving living donors

- Long waiting list for organs raises questions of ethics
- Would scarcity encourage prematurely declaring persons as brain dead?
- What constitutes voluntary informed consent? (see below re buying and selling organs)
- Issues of **buying and selling organs** (practice occurs in some parts of globe)
  - Involuntary harvesting of organs from prisoners or indigent people
  - Organs so obtained sold to procurement centers in affluent countries
  - Desperate straits prompted some individuals to sell organs for personal/family needs
  - Is there true voluntary consent in cases of desperation?
- Families giving consent in sudden accidental death of loved one
  - Is there true voluntary informed consent given crisis and shock
  - Urgency for a decision can lead to issues of coercion as a faction
  - Nurses may be asked to approach families for donation
    - Nurse must have awareness of own feelings regarding procurement
    - More often task of approaching families is delegated to specialized team
  - Family needs must take precedence over time constraints in organ harvesting

### NURSING PRACTICE IN THE MIDST OF TECHNOLOGY

- New technologies introduce associated nursing issues of concerns
- Key issues: attitudes and values, communication, maintaining human focus of care

### **ATTITUDES AND VALUES**

- Attention to personal values become critical when dealing with issues related to technology
- Nurse must distinguish personal values from values of patients and families
- Important nursing issues re technology
  - Quality of life
  - Living
  - Dying
  - Medical futility
- Individuals may judge technologic benefits from varying perspectives
- Self-determination and autonomy are key issues for nursing and technology
  - Assist patients to foster good communication
  - Encourage others to make own decisions
  - Avoid personal-value judgements re rightness/wrongness of an activity
  - Accepting decisions even if vary from nurse's preference
- Facilitating discussion important nursing role
  - May serve to clarify nurse's own perspective
  - Alert to situations where patient, family, physician may hold different values
  - Timely communication may avert major dilemma or facilitate more effective solution
- Nurse must remove self from situation if cannot reconcile personal values with situation
  - Avoids compromise of patient care
  - Avoids compromise of personal integrity
  - Must avoid abandonment ensure that others are available to provide needed care

#### IMPORTANCE OF COMMUNICATION - WHO DECIDES?

- Nurse to determine key persons in decision-making
- Determine where how nurse fits into scenario
- Be aware of institutional policies and protocols re technologies
  - Approaches to decision-making
  - Ways of dealing with conflicts
  - Protection of patient rights
  - Description of roles of those ind decision-making process
  - Documentation of decision in patient's chart
- Patient or surrogate has ultimate authority to decide (use or withdraw technology)
- Nurses typically perceived as more available/approachable than physicians
  - Patients/families may seek nurse: discuss concerns -request advise
  - Must be aware of what patients have already been told by physician
  - Determine patient/family level of understanding
  - Determine if parties have <u>necessary information</u> for informed decision
     Risks, discomfort, side effects, potential benefits, likelihood of success, treatment
     alternatives, estimated costs

- Serving as patient advocate expectation re nursing
  - Facilitate communication with physician
  - Facilitate communication with other key people
    - Family, clergy, etc.
    - Patient representative
    - Members of ethics committee
- Nurses in a key position to facilitate decision-making
  - Conversations with patients and families to discover areas of confusion
  - Elicit information re patient's wishes regarding intervention
- Nurse may serve important role as a listener
  - People may need to talk and sort through concerns
  - Conflicting messages may emerge from intellect and emotions
  - Venting emotions, speak fears, clarify concerns
- Nurse as advocate may facilitate communication
  - Provide non-rushed environment
  - Terms and language understood by other persons
  - Allowing time for and encouraging questions
  - Practice attentive listening
  - Offering caring presence

### **CARING: THE HUMAN FOCUS**

- Benefit from technology but must always remember human focus if care
- Nursing care in fullest meaning is essential when medical treatment is futile
- Nursing role in palliative care
- In midst of technology (machines, noises, etc.) nurse can foster relationships
  - Encourage family and loved ones to talk
  - Encourage touch and empathy with patient
- Assist patients/families to become more comfortable with machines/equipment
- Assist parties to interpret large amounts of clinical data
- Nursing care provides opportunity for perspective
  - Observe patient in both good and bad moments
  - Realistic view of patient's condition
- Encourage family to share in patient's care and experience
  - Shutting out family promotes anxiety and mistrust
  - Provides family with more experiences on which to base hard decisions
- Key points to compassionate care
  - Explain as many times as necessary purpose and problems of interventions
  - See experience from another's point of view
  - Address questions, fears, concerns, frustrations appropriately
  - Support/encourage parties to choose behaviors compatible with patient/family's beliefs
  - Develop proficiency in technical skills with intent on doing what is best for patient
  - Be with and wait with persons who struggle through difficult situations