Clinical Medical Ethics
A Philosophy and Practice Primer
2015 TNMHO/TAPM Annual Meeting

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Purpose of this workshop

• Provide an overall introduction to clinical ethics consultation
• Engage in ethical analysis as a moral community of palliative care and hospice professionals
What Skills and Knowledge are needed for Effective Clinical Ethics Consultation?

• Although ethics consultation has been offered since the early 1980s, there is still no certification process!
  – 1st clinical ethics consult at BUMC in 1985
  – What about your organization?

• A work group from the American Society of Bioethics and Humanities proposed a combination of basic to advanced skills and knowledge that should be present at least within each ethics committee.

• At BSWH we have adapted that to the following:
BSWH Clinical Ethics Knowledge

• Moral reasoning and ethical theory as it relates to ethics consultation
• Bioethical issues and concepts that typically emerge in ethics consultation
• Health Care systems as they relate to ethics consultations
• Clinical context as it relates to ethics consultation
• Health Care institution in which the consultants work, as it relates to ethics consultation

• BSWH institutional policies relevant for ethics consultation
• Beliefs and perspectives of patient and staff population where one does ethics consultation
• Relevant codes of ethics, professional conduct and guidelines of accrediting organizations as they relate to ethics consultation
• Health law relevant to ethics consultation
BSWH Clinical Ethics Skills

• I have the skills necessary to identify the nature of the ethical uncertainty or conflict that underlies the need for ethics consultation
• I have the skills necessary to analyze the ethical uncertainty or conflict
• I have the ability to build moral consensus
• I have the ability to facilitate formal and informal meetings
• I have the ability to utilize institutional structures and resources to facilitate the implementation of the chosen option
BSWH Clinical Ethics Skills

• I have the ability to document consults and elicit feedback regarding the process of consultation so that the process can be evaluated
• I have the ability to listen well and to communicate interest, respect, support and empathy to involved parties
• I have the ability to educate involved parties regarding the ethical dimensions of the case
BSWH Clinical Ethics Skills

• I have the ability to elicit the moral views of involved parties
• I have the ability to represent the views of involved parties to others
• I have the ability to enable the involved parties to communicate effectively and be heard by other parties
• I have the ability to recognize and attend to various relational barriers to communication
Part One: Ethics 101
Learning Objectives

• Outline the evolution of contemporary medical ethics from the time of Hippocrates to the present.
• Define medical ethics and relate it to science, law, politics, and professionalism
• Examine different theories of ethics
• Recognize in yourself and explain to others our current understanding of the neurobiology of ethical decision making
Case Study: Is there a “right to die”?

- Patient ML is a 43-year-old WF, s/p MVA leaving her with a C-2 cord injury, ventilator dependence, and no other major medical problems. With ongoing ventilator treatment, she can reasonably expect to live for 10 or more years, but she can never recover. About 8 weeks after injury, while in the local rehab hospital, she requests that she be “put to sleep” and that the ventilator be withdrawn. You are asked if this is ethically acceptable and will you do this for the patient as the hospital staff is not comfortable with this request?
- Is the request ethically acceptable? Why or why not?
- How do you think the following might feel?
  - The rehab physician? The pulmonologist?
  - The bedside nurse?
  - The respiratory therapist?
  - The hospice physician or nurse?
  - The chaplain, either for the hospital or hospice?
Case Study: Is there a right to unlimited treatment?

• Mr. J is an 82-year-old nursing home patient with ESRD, CHF, and advanced dementia. For the past 2 years he has been transferring to a dialysis center by ambulance 3 times a week. He is now admitted to the acute care hospital for the 3rd time in the past 6 months with pneumonia and CHF exacerbation. His two children demand the doctors “do everything.”
• Mr. J is intubated, started on IV antibiotics and made full code. Meanwhile, the nephrologist states dialysis is no longer appropriate and the ICU staff feels the same about any attempted CPR. A SPC consult is requested.
Case Study: Is there a right to unlimited treatment?

• The SPC team finds a semi-fetal position advanced dementia patient displaying multiple non-verbal criteria for pain. The family expresses strong beliefs that the patient is not in pain and refuse all pain meds. They state that “dad wants to live” and refuse to even discuss hospice stating, “hospice just kills people.” The care coordination department recommends repeat nursing home placement, but the nephrologist and pulmonary medicine specialist note that the patient is now too ill to be cared for in that setting and the nursing home also declines to take the patient back. An ethics consult is requested.
  – What ethical questions are at stake in this case?
  – What advice might you give and why?
Case Study: Truth-telling and culture

• Mr. T is a 58-year-old. SE Asian man with ESLD and recurrent variceal bleeding. He has severe dyspnea and pain, is clinically unstable and is full code. He is not a liver transplant candidate.

• His attending wishes to engage him in EOL care planning, but his daughters insist that he not be told the truth, stating it is against their cultural beliefs. There are orders for opioids for pain, but at doses lower than appear effective and some nurses appear to be withholding opioids out of fear the patient will require intubation. They also object to CPR noting his terminal liver disease.

• The attending calls for an ethics consult saying, “I need a Laotian Bubba who can help this family understand. They won’t even let me talk to him and I’m his doctor! Also, the nurses are frustrated.”
  – What ethics questions might you formulate in this case?
Historical Background

• Medicine has always had a moral purpose!
• The original Hippocratic goals of medicine: cure, relief of suffering, and refusing to treat those overmastered by illness.
• These goals were supported by physician defined beneficence and non-maleficence until ...
• The medical technology revolution:
  – Changed when, what, where, and how we die
  – Created therapeutic options
  – Undermined the Hippocratic notion of disease “overmastering” the patient
Historical Background

• Paternalistic beneficence/non-maleficence gives way to anti-paternalistic patient autonomy (self governance).

• New rights, not imagined by Hippocrates, are asserted:
  – Patient’s rights
  – Informed consent
  – Right to die
Historical Background

- *Quinlan*, 1976, acknowledges conflict between physician defined beneficence and patient autonomy
- Court finds that autonomy is a trump card if the patient has a grim prognosis
- Court proposes an “ethics committee” to help make decisions
- Evolution of ethics committees in the 1980s-90s.
Medical ethics is the discipline that deals with what we believe to be good or bad, right or wrong about the ends of Medicine and the means used to achieve those ends. It is not about what we can do in a given set of circumstances. It is about what we should do in those circumstances.
Medical Ethics as it relates to:

- Science and technology
- Law
- Politics
- Professionalism
Question: Is Einstein’s monumental insight into the relationship of energy and mass, $e=mc^2$, good or bad?
Medical Ethics and Science

• Science is ethically neutral, neither good nor bad.
  – $e = mc^2$ is neither good or bad,
  – nor are the laws of gas exchange good or bad,
  – nor is the science of inserting a gene into a cell.
Medical Ethics and Technology

- Technology (applied science) takes on ethical value only when it is applied towards some particular end or goal.
  - bombs vs. power generation
  - short term mechanical ventilation vs. long term life on a ventilator
  - eliminating Cystic Fibrosis through genetic engineering vs. vanity genetic engineering
Law reflects the politically agreed upon standard of ethical acceptability, not necessarily the highest standard nor necessarily the correct “ethical” standard.

- Slavery was legal, but was it moral?
- Active euthanasia is illegal, but is it always immoral?

Plato: Ethics belongs to the body polis.
Medical Ethics and Professionalism

• Essential attributes of the professional as opposed to the technician includes:
  – A publicly professed code of behavior and purpose.
  – Using one’s knowledge and skill first for the good of others.
  – What do you profess?
  – What should we profess as an institution?
Ethical Content vs. Conflict

• Every clinical encounter has ethical content. Most of this content is rarely recognized by the parties involved. There are no competing values, goods, or harms.

• Some clinical encounters have an ethical conflict in which there are competing values. This is usually recognized, though not always. These conflicts demand answers, they will not go away, and they demand answers that we can feel good about!
How do I know I am right?

• Appeals to authority: law, codes, traditions
  – state/federal law, Hippocratic oath, Ten Commandments/other religious teachings

• Consensus Hominum: general consensus
  – works better in less diverse societies and often driven by appeal to authority

• Intuition: it just feels right
  – there appears to be a biological substrate for this

• Socratic Q & A: careful questioning
  – application of various theories, principles, or virtues
Classical Theories of Ethical Reasoning

• Deontological - duty based ethic. An action is right or wrong regardless of the consequences.
  – Think Ten Commandments
  – Think Immanuel Kant and the categorical imperative.

• Consequentialist - an outcome based ethic. An action is right or wrong based upon the end result.
  – Think Jeremy Bentham, J. S. Mill and Utilitarianism.
  – But also think Niccolo Machiavelli.
  – Science teaches empiric utility.
Other Theories of Ethical Reasoning

• Casuistry - Case by case approach where the active case is compared against an earlier similar case of moral consensus.
  – Think case law and precedence.
• Narrative - The story and the relationships embedded in it are most important. Feeling perhaps more than thinking/logic.
  – Probably biologic basis for this.
  – Often associated with virtue and/or feminist ethics.
Trolleyology

With respect to Phillipa Foot, Professor of Philosophy, UCLA, d. 10/3/2010
There is a biological substrate to notions of ethics

- Brain areas implicated in moral cognition:
  1. medial frontal gyrus; 2. posterior cingulate, precuneus, retrosplenial cortex;
  3. superior temporal sulcus, inferior parietal lobe; 4. orbitofrontal, ventromedial frontal cortex; 5. temporal pole; 6. Amygdala; 7. dorsolateral prefrontal cortex; 8. parietal lobe.

- “Gut feelings” and intuition may be more important than philosophy in moral decision making.

- We decide, then we justify.
How do I know if I am right?

Ich vays nit: I don’t know. Admitting a lack of knowledge, admitting we don’t know, is the beginning of true wisdom.
How do I know if I am wrong?

Would I feel bad, embarrassed, or unable to justify myself if my decisions or actions were published on the front page of the local newspaper?
How do we commonly “Do Ethics”?

• Principle Based Approach
  – Apply Prima Facie Principles as an action template to each circumstance, asking: “What action does this principle demand of me in this circumstance?”

• Virtue Based Approach
  – Apply Cardinal Virtues as a behavior template to each circumstance, asking: “What virtues should I display in this case?”

• These Principles and Virtues may not only guide action and behavior in a particular case, but they may guide institutional policy and procedure for a set of circumstances.
Prima Facie Principles

• These “first face” principles are generally accepted as ethically good.

• When prima facie principles come into conflict with each other, then we have an ethical dilemma.

• A prima facie principle should only be abandoned with adequate justification, that is when another principle or group of principles outweighs it in our moral scale.
Ethical Principles: Definition and Derivation

• Respect for persons
  – Treat others the way you wish to be treated as a moral being. Respect their moral agency as you wish yours respected.
    • “Love thy neighbor as thyself” - Biblical tradition

• Beneficence and Nonmaleficence
  – Promote good and avoid harm
    • “I will go to the house of the sick for the benefit of the sick” and “First do no harm” - Hippocratic tradition

• Autonomy
  – Self governance
    • “Inalienable right to life, liberty, and the pursuit of happiness” - Secular legal tradition
Ethical Principles: Definition and Derivation

• Justice
  – Distributive versus Retributive. We should be most concerned in health care about a just of fair distribution of resources and avoid the inclination that some have towards blaming and punishing the patient,
    • “Justice, justice you shall pursue” - Biblical and Secular/Legal

• Fidelity
  – Faithfulness, both in telling the truth and being true.
    • “Am I my brother’s keeper?” - Biblical, but also Hippocratic as well as Secular/Legal if one sees Fidelity as the source of fiduciary duties
Derivative Values and Behaviors

• Respect for persons
  – Attention to customs, beliefs, & vulnerabilities of the patient
    • Cultivate the virtue of giving time, attention, and common courtesy to the sick in particular, for illness creates vulnerability

• Beneficence
  – It is good to relieve suffering, cure a patient, save a life
    • Paternalism/Maternalism - Parentalism

• Nonmaleficence
  – It is good not to harm, cause suffering or prolong dying
    • Paternalism/Maternalism - Parentalism

• Autonomy
  – Informed Consent, Patient’s Rights, Privacy, Confidentiality
    • Anti-paternalism
Derivative Values and Behaviors

• Fidelity
  – Faithfulness to the patient first - being true or being there for the patient when they are most vulnerable
  – Telling the truth
    • Demonstrating compassion and empathy

• Justice
  – Fairness, equity
    • Equanimity (even handedness or balance)
A Partial List of Virtues in Medicine

- Competency (technical)
- Competency (behavioral, ethical, spiritual)
- Compassion
- Empathy
- Courage
- Honesty

- Attentiveness
- Patience
- Courtesy
- Instructive (to be a good doctor is to be a good teacher)
- Gentleness
- Equanimity
Miscellaneous Concepts in Ethics

• Rights
  – Negative Rights - the right to be left alone. No obligation accompanies a negative right.
  – Positive Rights - a right to something. Positive rights impose an obligation on someone else.
  – Natural rights - a right that is found in Nature or Divinely given
  – Legal rights - a right specifically found in either statutory or case law
Miscellaneous Concepts in Ethics

• The Slippery Slope (An argument used against certain actions)
  – If you make an exception to a rule, even if the exception is justified, it will lead to other exceptions that are harmful and not justified.
    • So, how well do you ski?
• The Principle of Double Effect (An argument used in favor of certain actions)
  – If an action has both a good and bad effect, it is permissible to perform the act if:
    • you intend only the good effect
    • your action was the only way to achieve the good effect
    • the good effect morally outweighs the bad effect
Miscellaneous Concepts in Ethics

• The Clinical Encounter and Crossed Aspect Decision Making or “there’s more to clinical ethics than ethics!”
  – The clinical encounter between patient and health care provider has multiple elements or aspects including medical science, human behavior, spirituality, health law, and ethics.
  – At any given time, one or two of these aspects may take relative priority over the others.
  – There are no medical science answers to ethical problems, ethical answers to legal problems, legal answers to problems of the spirit and so on.
  – The discipline of clinical ethics deals with all of these areas and tries to keep all parties focused on defining the problem at hand, keeping the aspects clear, and achieving the best outcome possible. Clinical ethics is PRAGMATIC!
Questions?
Clinical Ethics Consultation Practice
Learning Objectives

• Define clinical ethics consultation (as opposed to medical ethics)
• Recognize issues of authority, formal and informal consultation
• Outline a general process and format for clinical ethics consultation
Clinical Ethics Consultation

• Calls upon knowledge and skills in medicine, human behavior, health law, spirituality, and ethics
• Is primarily facilitative
• Is run on a “medical consultation” model
• Is usually multidisciplinary
• Has legal standing in Texas
Clinical Ethics Consultation (CEC)

Access

• “Open access” across BSWH - any member of the treatment team (including admin and legal), the patient, or the family may request input.
  – Physician may not block.
  – Patient/family may not block – they’ve signed general consent on admission for other hospital personnel to discuss patient treatment and plan of care.
CEC Documentation

• “Formal” consults are documented in the chart, where as “informal” consults may involve only a brief conversation.
CEC Authority

• Best authority is the power of moral persuasion.
• Recommendations are voluntary unless it is a matter of hospital policy or law.
• In 166.046 process, ethics committees may affirm or refuse to affirm treating physician decisions about medically appropriate treatment.
Primary Issues at Consultation

- “Level of Treatment” concerns ranging from patient/family request to withdraw treatment (right to die) to physician request (medical futility).
- Other values conflicts, for example truth telling.
- Decisional capacity, surrogacy concerns, informed consent issues.
- Institutional allocation of resource issues.
- Institutional values setting.
- Communication problems and behavior management.
- Legal liability concerns.
Consult Process: CEC Request

• Who is requesting?
  – Open access but should tell the attending physician.

• Is there a specific ethical question?
  – A “should” or “what is the good or right” question.

• No identifiable ethical question?
  – Help identify one or refer to other departments including SW, pastoral care, law, CMO, or CNO.
  – If serious illness consider SPC service
Consult Process: Question Identified

• Assign to approved ethics consultant for the local committee.
  – May be chaplain, nurse, social worker – especially if only clarifying policy.
  – Often needs the “authority of the physician”

• If this touches on a particular policy, review policy if not already familiar.
  – May want to place excerpt from policy on chart or copy into your note.
Consult Process: Initial Consult

- Review chart, speak with all relevant parties including patient/family when possible, members of core team (physician, nurse, social work, pastoral care), and other relevant parties.
- Document consult using the Ethics Consult format in the EMR. Follow paper chart ethics consult form if EMR not available.
- Verbally follow up with requesting party when possible.
- Determine appropriate further ethics involvement.
- If ongoing disagreement, note potential resolution under Texas law.
Consult Process: Ongoing Disagreement?

- Is this a "right to die" or "medical futility" dispute that might be handled under chapter 166.046 of Texas Health and Safety Code?
- Has dialogue by ethics team for at least 72 hours failed to resolve case or is patient actively suffering?
  - If suffering, recommend SPC or Pain Management consult if not already present.
- Confirm treating physicians have documented terminal or irreversible condition as defined in law and treating physicians wish to further explore using 046 process.
Consult Process: 166.046 Process

- Notify BHCS Office of CE &PC and BHCS Law Department.
- Assign a hospital liaison.
- Unless otherwise guided by Office of CE&PC or Law Department, give surrogate written disclosure information about process, *but explain we have not further entered that process yet.*
- Further guidance at this point will come on a case by case basis from Office of CE&PC and Law Department.
Ethics Consult Template

- What is the ethical question?
  - What other questions might there be?
  - Who is asking and why?
- What are the relevant clinical/medical facts?
- What are the relevant emotional/social/cultural/spiritual issues?
- What ethical principles might be at stake?
- What ethical virtues might be useful?
- Are there any relevant policy issues?
- Are there any relevant legal issues?
- What is the range of ethically acceptable answers?
- What is your final recommendation?
- What are your follow up plans?
References

• The Principles of Biomedical Ethics, Beauchamp and Childress.
• The Virtues in Medical Practice, Pellegrino.
• The Physicians Covenant, May.
• Clinical Ethics: A Practical Approach to Ethical Decisions in Clinical Medicine, Jonsen, Siegler, and Winslade.
• Fine RL. Institutional Ethics Committees: The Ten Year Experience at Baylor. BUMC Proceedings, Volume 9, Number 1, 1996.
Questions?
Learning Objectives

• Attendees will be able to
  – Articulate the difference in competency and capacity
  – Assess basic decision making capacity
  – Utilize the basic elements of Informed Consent
  – Explain the difference in Substituted Judgment and Best Interest standards for surrogates
Competency

• Competency is a legal term that establishes if a patient has the ability to make her or his own health care decisions.
  – Ultimately a judge can find someone incompetent
• Capacity is a medical judgment (physician).
• Terms are often used interchangeably.
Informed Consent

• Grounded in basic ethical principles, but especially
  – Respect for Persons, Autonomy, Non-maleficence.

• Basic functions of IC
  – Promotion of patient autonomy
  – Protection of patients (includes avoidance of fraud)
  – Protection of practitioners
  – Encouragement of self scrutiny by the professional
  – Promotion of rational decisions
When to use Informed Consent?

- Intrusive or invasive treatments or procedures.
- Benefit or purpose of treatment is unclear.
- Significant risks or burdens.
  - Risks, burdens and benefits must be assessed from the patient’s perspective.
  - Secondary consideration of family and treatment team concerns.
  - Some patients more concerned about burdens than obvious risks.
  - Burdens may be physical, emotional, financial.
  - Risks and burdens should be proportional to the reasonable or hoped for benefit.
  - The greater the risks or burden, the more attention given to IC.
Practical Standards for IC

- Threshold element - Is IC even necessary?
- Decision making capacity - Sliding scale?
- Disclosure element - How much?
- Authorization - Voluntariness?
- Documentation – Notes, forms, or both?
Threshold Element

• Is IC even necessary?
  – General consent to discuss care of patient is given by patient/surrogate on admission.
    • This covers consent for Clinical Ethics Consultation
  – Implied consent within the doctor/patient relationship for basic testing and treatment.
  – Specific consent for invasive procedures or any risk.
  – Emergency circumstances suspend normal consent procedures.
Decision Making Capacity

• Sliding Scale: The more significant the decision, the more decisional capacity needed.
• Patient’s educational and cultural background.
• Can the patient communicate reliably.
  – Don’t assume intubated or poorly responsive patients can’t communicate.
  – Use yes/no questions with care.
  – Nonsense questions can help.
• Can patient demonstrate understanding?
• Is there values constancy?
• Is there adequate disclosure of diagnosis, prognosis, treatment options, benefits, burdens, and risks?
  – What would the reasonable person want to know?
Authorization and Documentation

• **Authorization** - Is it voluntary and non-coerced?
  – Paternalism/Parentalism, guiding the patient to what is best for them is not coercion!

• **Documentation** - If you do not document it, you did not do it. Remember that IC is a process and your best ethical behavior is what most protects you.
  – Progress note
  – Specific consent documents
Surrogates and Informed Consent

- Texas surrogate hierarchy when patients lack capacity:
  - Court appointed guardian or MPA
  - Spouse
  - Adult child having consent of all other qualified adult children
  - Majority of the patient’s reasonably available adult children
  - Patient’s parents
  - An individual clearly identified by the patient as surrogate
  - Patient’s nearest living relative
  - A member of the clergy (Chaplains at Baylor)
  - EOL situations: a physician member of ethics committee
Surrogates and Informed Consent

• The most important issue related to surrogates is the standard of judgment they use.
  – “Substituted judgment.” The decision the patient would make if the patient could. This can usually be deduced from the patient’s prior statements, advance directives, or delving into the patient’s values and beliefs.
    • **Surrogates are messengers for the patient!**
    • **MPAs should follow the patient’s advance directive or known wishes.**
  – “Best interests.” For minors, or adults from whom one can not deduce a substituted judgment (for example, an adult patient with life long mental incapacity or an adult patient one knows absolutely nothing about), the standard of judgment is known as “best interest”.

Cultural Competency for Ethics Committees

Inadvertently, Roy dooms the entire earth to annihilation when, in an attempt to be friendly, he seizes their leader by the head and shakes vigorously.
Learning Objectives

• Attendees will be able to
  – Define culture
  – Articulate the impact of culture on health care delivery
  – Utilize Kleinman’s explanatory model across cultures
  – Outline basic rules for using interpreters in end of life settings
Culture

• Socially transmitted behavior patterns defining an expected normative way of life for a particular society (and its members), including manners, dress, language, religion, rituals, laws, ethical constructs, art, and more.

• Responses to life events are passed on via learned culture.
Culture and Religion Often Linked
American Religious Identification Survey (ARIS) 2008

- 54,461 English or Spanish language respondents
  - 76% report belief in God.
    - 12% Deist
  - 50.9% Non-Catholic Christian
  - 25.1% Catholic
  - 15% Non-theist / Atheist / No religion (8.2% in 1990)
  - 5.2% Don’t know, refused
  - 1.4% Mormon, 1.2% Jewish, 0.9% Eastern Religions, 0.6% Muslim

Cultural Differences Impact Values

• Values - the things we each hold as true, meaningful, and important, differ by culture:
  – Autonomy and locus of control for decision making
    • Individual vs. family unit
  – Beneficence: vitalistic vs. qualitative values
  – Purpose of life and meaning of suffering
  – World view assumptions about reality
    • Western scientific view vs. magic
  – Relationship to nature: harmony vs. exploitation
Cultural Differences Impact Behavior

- Behaviors – the actions we display to the world differ by culture:
  - Personal space
  - Eye contact
  - Modesty and gender roles
  - Self-control vs. emotional expressiveness
  - Social organization – the nature of the family or the tribe
Stereotyping vs. Generalization

• Stereotypes are end points based upon appearance and language.
  – No attempt to learn whether the individual in question fits the statement.
  – Leads to *isms*: racism, sexism, nativism, faithism, etc.
  – Stereotyping causes poor interactions and misunderstanding.

• Generalizations are starting points, also based upon appearance and language.
  – The “generalizer” seeks more information to the unique characteristics of the particular individual.

• Differences between individuals within any group!
Cultural Competency Required!

• Cultural knowledge: data about cultures beyond one’s own.
  – Internet, books, colleague diversity
• Personal attitude awareness: self awareness of personal attributes including prejudices, adaptability, and acceptance of the different.
  – Introspection
• Communication skill: verbal and nonverbal, interpretation, mediation.
  – Internet, books, courses, practical experience
Cultural differences are like an iceberg.
The Cultural Iceberg

It is the unseen part below the water that sinks our ship!
Cultural Differences Impacting Health Care Delivery

• Gender and Authority
  – Dominant gender varies by cultural group.
    • Ex: Female (Native American) vs. Male (Middle Eastern).
    • Should this influence choice of ethics consultant?

• Modesty
  – Patients in some cultures may demand same sex health care professionals.
Cultural Differences Impacting Health Care Delivery

• Eye Contact
  – Uninterested and not listening vs. disrespect
  – Endangering one’s spirit vs. respect for hierarchy

• Pain
  – “Expressive” patients often come from Hispanic, Middle Eastern, and Mediterranean backgrounds.
  – “Stoic” patients often come from Northern European and Asian backgrounds.
Cultural Differences Impacting Health Care Delivery

• Social Organization
  – Friend, family, tribe
    • Where is the locus of control?
    • When one member of a group is ill, the entire group is ill.

• Dietary Practices
  – The body is kept in balance by the foods one eats.
    • Dietary practice as religious obligation: Jews, Muslims
  – Sharing food as an offer of trust/respect.
    • Accepting/tasting food when offered
Cultural Differences Impacting Health Care Delivery

• Time
  – Viewing of time in the present, past, or future varies among different cultural groups.
    • Future orientated: long-range goals, preventive health care.
    • Present oriented: less concerned about being on time and may have trouble conceptualizing changes in the future.
    • Past oriented: things that happened in the past control our present and predetermine our future.
Arthur Kleinman’s Patient/Family Explanatory Model

1. What do you call the problem?
2. What do you think has caused the problem?
3. Why do you think it started when it did?
4. What do you think the sickness does? How does it work?
5. How severe is the sickness? Will it have a short or long course?
6. What kind of treatment do you think the patient should receive?
7. What are the chief problems the sickness has caused?
8. What do you fear most about the sickness?
Communication across Cultures
Communication with Interpreters at EOL

• Work with skilled interpreters
  – Social work or guest relations can arrange
  – Ideally a trained professional interpreter
    • Outside vs. inside your institution
  – A native speaker from within your institution
  – Family
    • Be careful!
    • The more serious the conversation, the more the need to avoid family interpretation

– Telephone interpretation lines
  • Suboptimal for end of life interpretation
Communication with Interpreters

- Brief the interpreter prior to delivering bad news
- Choose strict interpretation vs. cultural brokering
- Debrief with the interpreter after the discussion
- Use nonverbal education (drawing, pictures, x-rays)
- Not all tools (such as pain scales) are universal
- Use terms that are culturally relevant
- Avoid jokes/humor – subject to misunderstanding.
Cultural Competence Resources

• Health Resources and Services Administration (HRSA)
  – http://www.hrsa.gov/culturalcompetence/curriculumguide/

• National Network of Libraries of Medicine (NN/LM)

• Diversity Rx
  – http://www.diversityrx.org/

• Ethnomed
  – http://www.ethnomed.org/
References

• Galanti, G. *Caring For Patients From Different Cultures: Case Studies from American Hospitals*. Philadelphia: U of Penn Press, 1997
Case Studies
Ethics Consult Template

• What is the ethical question?
  – What other questions might there be?
  – Who is asking and why?
• What are the relevant clinical/medical facts?
• What are the relevant emotional/social/cultural/spiritual issues?
• What ethical principles might be at stake?
• What ethical virtues might be useful?
• Are there any relevant policy issues?
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- Patient ML is a 43-year-old WF, s/p MVA leaving her with a C-2 cord injury, ventilator dependence, and no other major medical problems. With ongoing ventilator treatment, she can reasonably expect to live for 10 or more years, but she can never recover. About 8 weeks after injury, while in the local rehab hospital, she requests that she be “put to sleep” and that the ventilator be withdrawn. You are asked if this is ethically acceptable and will you do this for the patient as the hospital staff is not comfortable with this request?
Case Study: Is there a right to unlimited treatment?

- Mr. J is an 82-year-old nursing home patient with ESRD, CHF, and advanced dementia. For the past 2 years he has been transferring to a dialysis center by ambulance 3 times a week. He is now admitted to the acute care hospital for the 3rd time in the past 6 months with pneumonia and CHF exacerbation. His two children demand the doctors “do everything.”

- Mr. J is intubated, started on IV antibiotics and made full code. Meanwhile, the nephrologist states dialysis is no longer appropriate and the ICU staff feels the same about any attempted CPR. A SPC consult is requested.
Case Study: Is there a right to unlimited treatment?

• The SPC team finds a semi-fetal position advanced dementia patient displaying multiple non-verbal criteria for pain. The family expresses strong beliefs that the patient is not in pain and refuse all pain meds. They state that “dad wants to live” and refuse to even discuss hospice stating, “hospice just kills people.” The care coordination department recommends repeat nursing home placement, but the nephrologist and pulmonary medicine specialist note that the patient is now too ill to be cared for in that setting and the nursing home also declines to take the patient back. An ethics consult is requested.
Case Study: Truth-telling and culture

- Mr. T is a 58-year-old. SE Asian man with ESLD and recurrent variceal bleeding. He has severe dyspnea and pain, is clinically unstable and is full code. He is not a liver transplant candidate.
- His attending wishes to engage him in EOL care planning, but his daughters insist that he not be told the truth, stating it is against their cultural beliefs. There are orders for opioids for pain, but at doses lower than appear effective and some nurses appear to be withholding opioids out of fear the patient will require intubation. They also object to CPR noting his terminal liver disease.
- The attending calls for an ethics consult saying, “I need a Laotian Bubba who can help this family understand. They won’t even let me talk to him and I’m his doctor! Also, the nurses are frustrated.”
Case Study: Palliative sedation for existential distress and/or refractory depression?

• Details to follow