

Ethics and Patient Advocacy

Kathleen W McNicholas

MD, FACS, FACC, FCCP

JD, LLM, PTCA, CABG

CHC, CCEP, LVOTO

BCPA

Ethics

- *“The Activity of Man directed to secure the inner perfection of his own personality.”*
-Albert Schweitzer
- *“Knowing the difference between what you have the right to do and what is right to do.”*
- Potter Stewart

Ethics Lessons

- “Do the Right thing.”
- “Tell the Truth”
- “Be respectful”
- “Follow the Golden Rule”

Then came “BUT”:

”Be Truthful... BUT... Loyal.”

Mother Sylvester MSJA 1965

Honest: Same Latin root as “Honor”

- An inner-directed ideal: “X is honest” requires no object
- To be honest is to be true to one’s own moral sense.
- Uprightness of disposition and conduct.
- Truthfulness, straightforwardness.
- Honesty means being true to oneself.
- INTEGRITY.

Loyal

- Outer-directed: “X is Loyal” is incomplete until explain to whom, or what.
- Describes a relationship.
- Loyal means being true to others and subordinating what you believe is right.

Ethics

Study and practice of Ethics:

- Medicine
- Surgery
- Law
- Compliance
- Patient Safety
- Patient Advocacy

Medical Ethics- High Principles and Ideals

- Code Of Hammurabi- 2000 BC
- Hippocrates and Maimonides- Oaths codifying the practice of Medicine
- Sacred Trust of physicians to protect and care for the patient
- Set of Values for physicians
- Primacy of benefiting the sick according to one's ability and judgement

“To treat the ill according to the best of one's ability, to preserve a patient's privacy, to teach the secrets of medicine to the next generation...”

Classic Version of the Hippocratic Oath

- **Ethics**

- “What I may see or hear in course of treatment or even outside of the treatment or in regard to the life of men, which on no account one must spread abroad, I will keep to myself, holding such things shameful to be spoken about.

- **Compliance**

- “If I fulfill this oath and do not violate it, may it be granted to me to enjoy life and art, being honored with fame among all men for all time to come; if I transgress it and swear falsely, may the opposite of all this be my lot.”

Principles of Bioethics

Autonomy- The patient has the right to refuse or choose their treatment

Beneficence- A practitioner should act in the best interest of the patient

Nonmaleficence- To cause no harm

Justice- Fair and equal treatment

Truthful... AND... Loyal

- Values Aligned
- Truthful, Honest, and Ethical with Patients and Colleagues
- Respect and Loyalty- Patients and profession

Medical Ethics and Professional Ethics

- Manchester Infirmary Rules and Thomas Percival 1800s
 - Complexity of medical environment in hospitals
 - Concept of shared professional responsibilities
 - Profession's compact with society
- Added:
 - Veracity-Truth-telling
 - Role fidelity- Follow job description; work within credentials
 - Fidelity- Faithfulness to a person, cause , or belief, demonstrated by continuing loyalty and support.
 - LOYALTY, ALLEGIANCE, and OBEDIENCE

Truthful.....LOYAL

Codes of Medical Ethics

- **1847- First National Code of Ethics for any profession**

- Defined obligations to : patients, colleagues, and community

- **2001- AMA Code of Medical Ethics**

IV. A Physician shall respect the rights of patients, colleagues, and other healthcare professionals, and shall safeguard patient confidences and privacy within the constraints of the law.

III. A Physician shall respect the law and also recognize a responsibility to seek changes in those requirements which are contrary to the best interests of the patient

HIPAA (1996)

Surgical Ethics

- Vulnerability of patients
- Special degree of Intimacy
- Distinctive aspects of surgical procedures
- Absence of complete information and immediate decisions needed
- Requirement of special and advanced skills

Surgical Ethics

- Personal responsibility and accountability
- “The difference between surgeons and internists is that surgeons practice Ethics, while internists mainly talk about it.”
- Internist’s patients die because they were very sick or old.
- When surgical patients die others ask: “What went wrong?”
“What did or didn’t you do?”

Principles and Practice of Surgical Ethics

- ***VIRTUES*** Fiduciary relevant to the case;
- ***CONSEQUENCES*** Beneficence and nonmaleficence relevant to the case;
- ***RIGHTS*** Respect for autonomy;
- ***JUSTICE AND EQUALITY***- Allocation of limited financial, material, and human resources in care of patients

Appeals together- Implications consider surgeon's clinical judgement, decision making, and behavior.

Truthful (Ethical) AND Loyal (to patient and profession)

Practice of Medicine (Surgeons practice Ethics, Internists talk about Ethics)

- The “Creative Destruction of Medicine”
- Industrial-Medical Complex
- Corporate Practice of Medicine
- “Providers” not Physicians. Employees.
- Policies, Protocols, Pathways, Guidelines, Regulations, Oversight, etc.
- All are ”Team Members” BUT “Who is in charge?”
- M.D., FACS, FACC, FCCP → Law Student

Legal Ethics

- ABA Model Rules of Professional Conduct
- Long lineage going back nearly 200 years
- Virtually no earlier regulation of legal profession
- David Hoffman, founder of University of Maryland School of Law
- 50 “Resolutions in Regard to Professional Department.”
- 1854 Judge George Sharswood- “ A Compendium of Lectures on the Aims and Duties of the Profession of Law.”

Professional Standards- Models of the Law Governing Lawyers

- Canons of Professional Ethics 1908
- Model Code of Professional Ethics 1969
- Model Rules of Professional Conduct 1983
- 60 rules covering 8 subject areas.

“Legal Ethics in a Nutshell” 5th Edition Ronald d Rotunda. 547 pages

Legal Ethics

- “The minimum standards of appropriate conduct within the legal profession. It is the behavioral norms and morals which govern judges and lawyers. It involves duties that the members owe one another, their clients, and the courts.”

Approach to Legal Ethics

- Determine what kind of legal problems a situation involves;
- Apply traditional legal skills to the fact situation;
- Evaluate how the rules deal with the problem.
- The Model Rules prescribe what a lawyer **MUST** or **MUST NOT** do.
 - Rule may be vague or involve bad policy.
- “What a law ought to be is always relevant.”
- The “ought” influences the “is”

Approach to Legal Ethics

The *LAW* sets minimum standards of behavior while *ETHICS* sets Maximum standards.

TruthfulAND.....Loyal
It Depends

Ethical Practice of Medicine and Surgery

- Surgeons must disclose ALL material risks.
- The first day I worried about myself was the last day (overnight) I operated.



Compliance and Ethics

- Conforming conduct to statutory and regulatory rules
- Line-drawing- lawful and unlawful
- Divining the shades of grey in between

Compliance

- Kicks in where law leaves off.

Ethics

- Emphasis on values and doing the right thing.

LAW permitted Morton Thiokol management to decide to approve the Challenger launch.

COMPLIANCE (engineering ethics) argued to scrub the launch.

“Separating Compliance and Legal...” Compliance Today, February, 2020

Ethical Culture

“The shared values, attitudes, standards, and beliefs that characterize members of an organization and define its nature.”

“Corporate culture is rooted in an organization’s goals, strategies, structure, and approaches to labor, customers, investors, and the greater community.”

Inc.com

Challenge to Compliance Professionals

- Lack of Broad-based commitment to compliance with the law.
 - Values and Standards not clearly defined and understood by members.
- Noncompliant offenders:
 - Unethicality
 - The “Should self” vs The “Want self”
 - Bounded Ethicality

Noncompliant Offenders

- Trouble recognizing own unethicity (lacking moral principles)
- Unwilling to adhere with the standards of a profession. Act wrongly not because they are willing to pay some internal or external price but because they have a biased assessment of what they are doing.

“Unconscious Bias and Psychological Safety: How They Affect Compliance”

-Michael Bret Hood CEP Magazine March, 2020

What We Do, NOT What We Want to Do

- Inner Conflicts with what you desire and what you perceive.
- The “should self”- Normally recognize the implications of various compliance decisions and make correct decisions.
- The “want self”- Failure to recognize that stress and pressures can affect decision-making processes.
- When deciding, one may be dominated by thoughts of how we want to behave while thoughts of how we should behave disappear.

Bounded Ethicality

- Systematic and predictable ways people engage in unethical acts without awareness that they are doing anything wrong.
- Idea that our ability to make choices is often limited or restricted because of internal or external pressures.
- People value their positive self-image and will tend to distort ethics in a way that presents themselves in a positive light.
- Outside pressures such as a tendency to conform to actions of those around or internal biases may cause some to favor selves at expense of others.
- Rationalize behavior and make it seem that not only was the noncompliance reasonable, but it was the right thing to do

EVERYONE IS ETHICALLY BOUNDED

-
- Cognitive biases;
 - Convictions;
 - Organizational Pressures;
Social Pressures;
 - Other priorities;
 - Conflicting Loyalties, Divided Loyalties;
 - Owes duty or is influenced by an affiliation with an entity involved.
 - Bounded Loyalty

BUT... LOYAL

MAKATO (Japanese Principal)

- Places harmony and obedience over everything else.
- Valued over even honesty and truthfulness.
- Blind adherence to positional power can lead to transgressions.
- Authority figures may not accurately see proper perspectives.

Makato (not Truthful) BUT ... LOYAL

Roles Following CT Surgery



Truthful..... Loyalty

Cognitive Dissonance

The state of having inconsistent thoughts, beliefs, or attitudes, especially relating to behavioral decisions and attitude change.

Truthful.....Loyal

TRUTHFUL.....LOYAL

Mind the GAP

- “Moral Injury”- Phrase used to describe inner struggles of Healthcare Professionals.
- Term initially used to explain why military veterans were not responsive to standard treatment of PTSD.
- Emotional, Physical, and spiritual harm people feel after perpetrating, failing to prevent, or witnessing acts that transgress deeply held moral beliefs and expectations.

Truthful.....Loyal *The Gap*

“When providers know how best to care for their patients, but were blocked from doing so by systemic barriers related to the business side of health care.”

-“How ‘Moral injury’ is harming doctors.”

Melissa Bailey, Kaiser Health News, The Philadelphia Inquire, March 1, 2020

BARRIERS in Healthcare

- Speed and efficiency valued at cost of high-quality care.
- Priority of speed and money not patient care.
- Insurance Preauthorization.
- Patient referrals. Nuisance Electronic Health Records. “Cut and Paste”.
- Hallway Medicine – Boarders.
- Mid-Level Providers.
- Limited physician patient contact or “relationship”.
- Fragmented care. Multiple “Providers” but Limited accountability.
- Complex systems.

Moral Injury

Truthful.....Loyal

- Identifies problem which lies with the system.
- “It’s grinding us. It’s grinding good docs and providers out of existence.”
- “It’s not that I don’t like the job, it’s just that I don’t like what the job has become.”
- “I didn’t leave medicine, medicine left me.”

Compassion fatigue and Burn out

There's No Such Thing As "Honest Loyalty"

Peter Beinart The Atlantic June 8, 2017

- Worried that Trump was trying to "create some sort of patronage relationship", Comey made a point of saying that he will not be politically "reliable" but will always tell Trump the truth.
- Trump responded: "I need loyalty. I expect loyalty." Comey responded: "You will always get honesty from me."
- Trump demanded "Honest Loyalty"

We know how that ended !!!

LVOTO

Back to Ethics

*Honest (Truthful) to oneself...BUT...Loyal
(SUBORDINATE what you believe is right)*

Ethical Theories: Ethics 101

- *Consequentialism*- Judge quality of act solely by end it achieves.
- *Deontological*- Judge morality on grounds other than the results produced.
- *Kantianism*- Measures morality of an act by whether it arises from “good will”.
- *Natural Law*- Intent is to do good or avoid bad effect.
 - The good done must outweigh the bad effect.
- *Humanism*-Values human beings as rational and transcendent with innate understanding of right principles and values.

Relativists Ask

- *What Cultural norms shape views of right and wrong ?*
- *Does self-interest shape ethical choices ?*
- *Do providers risk imposing ethical views on specific cultures ?*

But Which:

- **Rules**- most easily defensible or justifiable
- **Action**- Hope for outcome that best optimizes human welfare
- **Consequences**- Problems with range of effects.
- **Virtue**- Little agreement on which virtues are most important for happiness or excellence.

Utilitarian Approach

- Judging alternative solutions to an ethical issue by focusing on Outcomes.
 - Justification of act lies only in consequences
- ACT Utilitarianism- Consequences of each individual act
- RULE Utilitarianism- Consequences of rules that guide conduct.

Ethics and Patient Advocacy

- Patient Protection and Affordable Care Act of 2010 as amended by Congress
- Healthcare professionals and “consumers” ultimately decide who get served and with what benefits and services even if high-level policies shape choices.
- Take initiatives to correct ill-advised healthcare choices and policies.

Ethical Providers

- Honor Patient rights to self-determination;
- Provide accurate and timely information;
- Provide intelligent information;
- Understand informed consent.

Power differential

- Patients with adverse diagnosis are susceptible to unethical behavior;
- Fear may lead patients to accept without full understanding.

Patient Advocates

- The healthcare system is a policy and regulatory thicket requiring ethical conduct

Patient advocates:

- Must understand major elements of health care;
- Must inform themselves of consumer's ethical rights;
- Act as effective advocates when rights are violated.
- Have knowledge of Multiple Regulations and laws.

Ethical Standards for a Board Certified Patient Advocate

- The Role of an Advocate;
- Transparency and Honest Disclosure;
- Protecting Confidentiality and Privacy;
- Fostering Autonomy;
- Provision of Competent Services;
- Avoidance of Impropriety and Conflicts of interest;
- Avoidance of Discriminatory Practices;
- Necessity of Continuing Education and Professional Development.

Role of an Advocate

- Guidance and Assistance in decisions related to healthcare needs;
- Commitment to helping clients and client communities make informed choices and access resources.

Advocates do not:

- Make decisions about specific treatment choices;
- Provide clinical opinions;
- Perform medical care of any type, even with clinical credentials.

Transparency and Disclosure

- Honesty
 - Clear expectations
 - Scope of practice
 - Assure patients fully aware of all Conflicts of interest related to employment.
- Disclosure
 - Fees
 - Training
 - Education
 - Experience
 - Credentials
 - Contractual relationships.

Confidentiality and Privacy

- Respect patient's right to privacy
- Abide by all relevant laws and regulations pertaining to records and personal identifiable information
- Safeguard and protect confidentiality of all medical records and communications
- Respect decisions concerning disclosure to others (family and friends) including a guarantor if not the patient
- Inform patient about advocate's records retention policy.

Fostering Autonomy

- Treat patients with compassion and respect;
- Honor personal values regarding care and right to be involved in all decisions affecting care;
- Uphold statutory rights;
- Honor Rights of disenfranchised people and communities;
- Provide fair and equal treatment.

Autonomy

- Client's right to exercise autonomous decision making;
- Meaningful informed consent;
- Ensure patients are fully aware of and understand care and treatment options including potential risks, benefits, and alternatives;
- Provide information to facilitate informed decision making, respect dignity and freedom to make decisions grounded in individual's cultural, spiritual, and ethical context;
- Ensure patient's wishes are guiding force for decisions affecting care and the withholding or withdrawing of treatment while maintaining care;
- Recognize and work with legally designated surrogate.

Justice

- Rights of disenfranchised persons
- Fair and equitable treatment.

Provision of Competent Services

- Must inform patient of advocate's specific areas of proficiency;
- Only assist in areas with demonstrated expertise;
- Obligated to refer to appropriate system or resource if assistance is needed;
- Have adequate referral systems in place.

Avoidance of Impropriety and Conflicts of Interest

- Advocates may not accept remuneration for making referrals or steer clients for products or services from which advocates will profit financially or earn a commission
- Shall not accept advertising for products or other service providers.

Conflicts of Interest

- A substantial risk that services will be materially limited by advocate's personal or professional interests;
- Services may be provided when COI exists when both: a) the advocate will be able to provide competent and diligent services AND b) the client gives informed consent in writing;
- May accept gifts not substantial in value
 - Value greater than \$75 is presumed to be substantial (single or more).

Avoidance of Discriminatory Practices

- Equal access to appropriate health care and treatment is the right of each individual;
- Equal access regarding:
 - Age
 - Race
 - Religious/ spiritual practice
 - Culture
 - Ethnicity
 - Sexual orientation

Advocates must understand preferences regarding health care.

Continuing Education and Professional Development

- Life-long learning
- Current knowledge and skill
- Hone professional expertise
- Keep current in changing healthcare environment
- Share information and resources for benefit of profession and public
- Participate in development of other advocates

Applied Ethics- Principlism

- Core Principles: *Truth-telling, autonomy, Beneficence, non-maleficence and distributive justice.*
 - Provides a guide for examining issues

Challenges:

- Demands of Principles may conflict
- Criticism that analysis tends to focus too narrowly on the interests of the patient alone to the exclusion of the family or other health professionals or broader social concerns.

Easily utilized by Patient Advocates

FIRST PRINCIPLES

Four Principles:

Respect for Autonomy

Beneficence

Non-Maleficence

Justice

Common Morality;

Basic premises taken from the morality shared by members of society.

Unphilosophical common sense and tradition.

First Principle Approach

Process:



Less emphasis on medical outcome than on honoring widely accepted ethical principles

Developing an Ethical Reasoning Matrix

Case: 73 y/o woman underwent neurological and cognitive tests to determine the cause of her memory lapses. She had a FH of Alzheimer's disease. Her physician husband requested that she not be told DX which would cause distress. The diagnosis was confirmed.

1. First Ethical principle of self-determination, which requires informed consent unless patient not competent.
2. The utilitarian goal of advancing the physical and mental well-being of the patient

Ethical Reasoning Matrix

At top of table two criteria with weights (self determination 0.6 and patient's well being 0.4). Opposite axis contains options: Only tell husband; tell both together; tell wife by herself first, both if she consents.

Options	<u>Criteria</u>				Total
	self-determination (0.6)		Pts well-being (0.4)		
Only tell husband	1	0.6	1	0.4	1.0
Tell both together	6	3.6	8	3.2	6.8
Wife first, husband if consent	10	6.0	9	3.6	9.6

Principlism

- Applied Ethics approach to the examination of moral dilemmas which is based on the application of certain ethical principles.
- Side steps complex debates in moral philosophy at the theoretical level.
- Rather than engaging in debate about the best or more appropriate approach at the normative level (e.g. Virtue ethics, deontology, or consequentialist ethics) Principlism offers a practical method of dealing with real world ethical dilemmas.

Principlism

ETHICS

Truthful.....Loyal

First Principles

Provides a lens and perspective.

Allows one to judge a particular action as Right or Wrong and to choose and act upon the best among competing options. Subordinate to Ethics ONLY.

Justice Potter Stewart

- “Ethics is knowing the difference between what you have a right to do and what is right to do.” Potter Stewart
- In 1945 Justice Potter Stewart used a phrase to describe his threshold test for obscenity in *Jacobellis v. Ohio*.
 - He responded: “I know it when I see it.”

TEST for Truthful and Loyal

- Justice Stewart attempted to categorize an observable fact or event, although the category is subjective or lacks clearly defined parameters (pornography).
- This test may be used when evaluating Truthfulness and Loyalty or an “Ethical Culture” where honesty may be subordinated to Loyalty.

**The goal is to be Truthful AND Loyal
AND
YOU KNOW IT WHEN YOU SEE IT**

“Advice for New Compliance Professionals”

“ABOVE ALL ELSE, REMEMBER THAT NOTHING
MATTERS IF YOU DON’T DO IT WITH INTEGRITY.”

Rob E Foster April 2020 Compliance Today

Many Thanks

- Delaware Law School
- First Healthcare Compliance
- Julie Shephard
- Pamela Beech
- Eileen Grena
- Kathryn Travers Farrell
- Students and Practitioners of Medicine, Law, Compliance, Ethics, and to all Patient Advocates.
- And Mother Sylvester