

# Basic Ethical Principles and Guidelines for Utilization

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# Applying Ethical Principles to Decision-Making

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# Objectives

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- Demonstrate an awareness of ethical principles and the guidelines for their application when working with **autonomous individuals** and those with **diminished autonomy**.
- Consider decisions, actions and consequences as these pertain to **principles of ethics**.
- Consider the potentially complicated interface between ethics and the law.
- Demonstrate respect for client and caregiver perspectives.
- Observe client confidentiality except in specific circumstances, e.g., ***duty to warn***.

# Additional Objectives

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- Explore the importance of ethics in modern medicine in today's diverse health care environments.
- Consider how ethical perspectives may differ among racial and cultural groups and impact decision-making.

# Ethics- A General Definition

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- The *branch of philosophy* concerned with the **distinction of right from wrong** on the basis of a body of knowledge rather than on individual opinions.
- Ethics looks at human behavior from the vantage points of ***what is right or wrong***, ***what should we be doing or not doing***, and what should ***our priorities*** be?



# Bioethics

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- The *application of ethical principles to health care.*
- A field of study concerned with the **ethical and philosophical implications** of certain biological and medical procedures, technologies, and treatments such as organ transplantations, the freezing of embryos, and genetic engineering.
- **Decision-making at end of life.**

# Assistance with Decision Making

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- Those in the helping professions may be called upon to help others to make decisions.
- Health professionals have varying levels of comfort with this role.
- Social workers are likely to be a beneficial resource particularly if they see clients in their homes.
- Such decisions may be complicated because **there is often not a quick, easy, or correct answer.**
- Most health systems have a **medical ethicist** who is able to provide guidance and to determine what is important to the client/family.

# Examples of Ethical Decisions

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- Can and should Mrs. X be discharged to home?
- Is Mr. Y able to manage his medications safely?
- How frequently should the nurse or case manager visit Mrs. P who is partially sighted and lives on her own?
- Should Mrs. S have the right to deny her child immunizations?
- Is this the time to initiate hospice care for Mrs. N even though her family is ambivalent about this decision?
- Does Mrs. N's family possess an adequate understanding of the hospice concept?



# Why are Ethics an Increasingly Important Issue in Health Care?

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- We reside in an increasingly technological society with complicated issues that never before needed to be considered.
- Ethical debates are changing the fabric of society, particularly in terms of how we describe family structures.
- Health care has become an increasingly consumer-driven system rather than the prior model largely based upon paternalism.
- Today's consumers make their preferences known even though they may lack adequate knowledge of other options.

# Ethical Codes

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- **Codes that direct or govern actions.** For example, the American Nurses Association's ***Code of Ethics for Nurses*** with interpretive standards.
- Similar documents are published by the ***National Association of Social Workers as well as by the American Medical Association.***
- Most contain a **set of core values** that commonly include a **commitment** to those who are vulnerable, oppressed, living in poverty, and underserved.

# Learning from the Past

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- Many of the ethical concerns of today stemmed from prior historical episodes in which the **rights of others were clearly violated.**
- Most often we learned of these ***ex post facto.***

# Historical Events- Nuremberg Trials

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- In 1946, 23 defendants, 20 of them physicians, were tried for war crimes and crimes against humanity.
- Sixteen of the defendants were found guilty. Seven were hanged, and 9 were sentenced to prison terms ranging from ten years to life.
- Nurses were among those tried at Nuremberg.
- These nurses unsuccessfully tried to evoke the doctrine of *respondeat superior*.

# Judgment at Nuremberg

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# The Nuremberg Code of Research Ethics

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- Researchers are responsible for obtaining voluntary informed consent from their subjects. **They should not delegate this responsibility to others.**
- Experiments should be designed to **benefit society** and not be random or unnecessary.
- It is mandatory to precede human research with **animal experiments and studies on the natural history of disease** whenever this is possible.
- In other words, do the ends justify the means?

# Tuskegee Syphilis Studies

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- Took place in Macon County, Alabama between 1932 and 1946.
- The research objective was to record the natural history of syphilis.
- This was not explained to the participants who were told that they were being treated for “bad blood”.
- Six hundred men were enrolled...399 were in the experimental group and 201 in the control group.

# Incentives

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- Medical Care
- Survivor Insurance Benefits
- It is interesting that penicillin became widely available during this time period and could have effectively treated the illness.
- However, there is no record that penicillin was ever offered to subjects.
- During the study, hundreds of spouses and children became infected typically resulting in severe neurological damage.

# Haven't We Learned a Lesson ?

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- On a smaller scale, the story of Henrietta Lacks parallels the Tuskegee story.
- Without the permission of the patient, her husband, or other family, cells taken from her cervical tumor were harvested, cultured, and shipped all over the world in the name of cancer research as HeLa cells.

# The Ethical Principle of Informed Consent

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- Cells taken from Mrs. Lacks, without discussion or permission, were harvested, grown out in culture, and shipped around the world for use in biomedical research.
- These were subsequently used to develop vaccines, in cloning, in gene mapping, and in *in vitro* fertilization.
- Henrietta died at age 31.



# The Belmont Report

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- While this landmark report, published in 1976, predominantly focused on research ethics, it also specified the duty to obtain **informed consent** prior to any intervention.
- Discussions related to **risks and benefits** of a medical or surgical procedure were also mandated.
- **Most ethical principles in use today were grounded in the Belmont Report.**

# Ethical Principles

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- ***Autonomy*** - Respect for **individual liberty** and decision making.
- ***Respect for Persons***- An individual should be treated as an **autonomous agent**.
- ***Persons with Diminished Autonomy***- These are individuals **entitled to special protections**.
- ***Justice*** - The **equitable distribution** of potential benefits and risks.

# Additional Ethical Principles

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- ***Fidelity*** - The duty to do what one has promised.
- ***Nonmaleficence*** - The obligation to do or cause no harm to another- **FIRST DO NO HARM.**
- ***Beneficence*** - The duty to do good to others
- ***Veracity*** - The obligation to tell the truth

# Who is an Autonomous Person?

- An individual who is ***capable of understanding*** the information being shared and can participate in ***making a decision***.
- One who has received information and an assessment has been made indicating that the ***client understands the options available and their probable outcomes***.
- The individual demonstrates ***understanding of benefits and risks*** as related to their health and personal goals.

# Consent vs. Assent

- An individual with an intellectual disability may be unable to fully or adequately understand a treatment or procedure.
- In other words, she or he cannot give consent; however, in most instances the physician responsible for the client prefers that she or he give **assent**.
- A explanation of what will occur is provided in language the client understands.
- The goal is to minimize fear or other emotional trauma to the client related to not understanding the treatment plan. **It also satisfies the requirement of respect for persons.**



# Ethical Theories- A Basis for Decision-Making

## Immanuel Kant

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- ***Teleology Theory* also known as *Kantian Theory* –**
  - Here the ethical focus is on application of the *classical virtues* of **courage, justice, and wisdom**.
  - The good man or woman possesses the *theological virtues* of **faith, hope, and love**.
  - Combined with classical virtues, these provide a basis for ethical decision making.
  - **This ethical stance results in decisions that emphasize the wisdom underlying an ethical decision and the courage to speak out if unjust decisions are being made.**

# Utilitarian Theories- Thomas Hobbes

## Selected Ethical Goals

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- “To provide the greatest happiness for the greatest number.”
- **“The ends justify the means”**. Yes or No?
- Good acts may have unforeseen consequences.
- **Acting rightly may result in the need to break the rules.**

# A Liberal Viewpoint: John Stuart Mill

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- There are limits to the power society can exercise over an individual.
- Mill was a liberal who wrote that **individuals should be able to do what they want so long as they are not infringing upon the rights of others.**
- **An unethical act can involve either commission or omission.**

# Caring- Based Ethics

- Originated with **Carol Gilligan**, a clinical psychologist educated at Swarthmore and Harvard, who suggested that men and women differ in their ethics and ethical behaviors.
- As a feminist, she focuses on the **emotions, feelings, and attitudes manifested by the participants in a situation where an ethical decision must be made.**
- **Individuals or families may agonize over “acting rightly”.**

# More on Gilligan

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- **Acting rightly focuses on achieving consensus related to making a decision with which most involved parties are comfortable.**
- For a family, **conflict and blame typically diminish over time.** But this is not always the outcome.



# Core Beliefs of Caring Based Ethics

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- Persons are understood to have *varying degrees* of dependence and interdependence.
- Individuals who are particularly **vulnerable** deserve extra consideration when choices must be made.
- It is essential to pay attention to details and preferences in order to **safeguard the specific interests of vulnerable persons**.

# Values

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- Ethical principles are much like rules or guidelines.
- Values are different from principles in that they contribute to or influence the development of our beliefs and attitudes.
- They directly or indirectly influence our decisions.

# Value Systems

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- An individual's personal collection of inner beliefs that guide the way that person acts.
- These help influence or determine the choices we make for ourselves or for others.
- Often our value system is linked to our spiritual perspective.

# Value Clarification

- Taking another look at one's values.
- The process of analyzing one's own values to better understand which **things are truly important in life.**
- Individuals **may differ** significantly in their understanding of what is truly important.
- This is the **basis of the conflict** frequently occurring when ethical decisions must be made.

# Value Clarification

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- It **takes time** to come to an understanding of those **things that are truly important** in the life of a client with diminished autonomy.
- In many situations an ethical decision must be made within a rather short time frame.
- The client's perspective may differ from those of other family members or health providers.



# Self-Reflection

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- Because ethics and values are so closely associated, care providers must explore their own values in order to acknowledge and understand the value systems of their clients.
- This explains why some client/caregiver dyads are a success and others are simply not a good fit for one another.

# Additional Safeguards: The Patient Self-Determination Act

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- A document designed to guarantee ethical care of clients in terms of **their decision making about treatment choices** and other aspects of their care.
- This has gradually replaced the long held principle of paternalism- ***the doctor knows best.***
- Paternalism is **not always wrong.** For example, if a client lacks decisional capacity, following the physician's recommendation may truly reduce the risk of harm.

# HIPPA- An Additional Safeguard

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- The Health Insurance Portability and Accountability Act- 1996/2003.
- Ensures privacy and confidentiality of medical records.
- Healthcare providers are mandated to educate all personnel to be knowledgeable of HIPPA in terms of privacy and security of medical records.

# Ethical Dilemma

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- A conflict between two or more ethical principles.
- This occurs most of the time!!
- In an ethical dilemma, there may be no absolutely “correct” decision.
- The goal is to reach a decision with which most or all can be at peace.

# Ethics Committees/IRBs

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- Most likely to be found in health care facilities and academic institutions.
- 12 to 15 members
- Function to review standards of care, institutional policies, procedures, and guidelines.
- Structure is specified by federal guidelines.



# Composition of Ethics Committees/IRBs

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- Medical Director
- Director of Nursing
- One member of the Board of Trustees.
- One staff nurse and one physician.
- Clergyman from the vicinity
- One social worker
- An attorney
- An ethicist
- Members from the area community.

# Implementing an Ethic of Caring

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- **Attentiveness:** Recognition of the needs of others.
- **Responsibility:** A sense of obligation towards clients.
- **Competence:** Skillfully implementing the actions required to meet care requirements.
- **Responsiveness:** Outcomes experienced by the recipient of care.

# Major Types of Ethical Dilemmas

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- Active and Passive Euthanasia
- Patient sustained actual harm.
  - Medical or Surgical Error
- Refusal of Treatment.
- Failure to Document.
- Scarcity of Resources.

# Euthanasia

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- Intentional action or lack of action that causes the merciful death of someone suffering from a terminal illness or incurable condition.
- The Principle of Double Effect.

# Refusal of Treatment

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- Based on the principle of autonomy.
- Links back to a living will or durable power of attorney.
- A client's rights to refuse treatment and to die often challenge the values of his or her health care providers or significant others.



# Scarcity of Resources

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- The allocation of scarce resources (e.g. organs, transplant teams, hospice beds) is emerging as a major medical dilemma.
- Fortunately, the availability of cord blood banking has increased access to stem cells which have the capacity to become any other type of cell.
- Scarce resources do not always need to be medical in nature.
- For example, poor staff retention.

# Case Consultation

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- This involves the provision of information about ethical principles relevant to a case.
- The goal is to help clarify what occurred.
- Review relevant policies of the facility.
- Provide a recommendation which is advisory in nature.

# Client Advocacy

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- When case managers, nurses, home health staff, and social workers act as **client advocates**, the first step is develop an **open relationship** with the client.
- It is a poor idea to bombard the client and family with options if the ground work regarding options has not been adequate.
- The care provider is then able to discuss options with the client and caregiver based on the strength of the relationship.

# Care Provider as Whistleblower

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- ***Whistleblowing*** refers to calling attention to unethical, illegal, or incompetent actions of others.
- Whistleblowing is based on the ethical principles of veracity and non-maleficence.
- Federal and state laws (to varying degrees) provide protection, such as privacy, to whistleblowers.

# Questions for Whistleblowers

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- Whose problem is this?
- Must I do anything about it?
- Is it in any way my fault?
- Who am I to judge?
- Do I have the facts straight?



# Predicting Future Care Needs of Adults with Intellectual Disability

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- Meeting an ethical challenge!
- As global aging becomes a recognized event, it is critical to focus attention on the aging of clients with intellectual disabilities.
- This is considered a somewhat new phenomenon as in prior decades clients with intellectual disability generally predeceased their parents.

# Preferences for Future Care

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- Taggart, Truesdale-Kennedy, Ryan, and McConkey interviewed 112 parent caregivers.
- Most were lone caregivers, primarily mothers.
- Most caregivers reported high anxiety.
- Their future care preference was for their child to remain at home with either family or paid staff.

# Living Arrangements

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- A subsequent study of 12,500 persons with intellectual disability documented that only 20% of adult clients were living with a relative other than their parent(s).
- Future planning was a highly emotional topic.
- Caregiver denial of own mortality was common.

# Sources of Support

“I worry constantly about this.”

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- Family Support- 74%
- Parental caregiver still in good health- 67.9%
- Help from church or religious group- 18.8%
- Day care- 65.2%
- Respite Care- 13.4%
- Support Group- 5.4%
- Conclusion- Having a plan did not reduce fears about the future.

# Relocation Concerns

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- A minority of caregivers anticipated that, after their death, their child would reside with a sibling.
- Very few wanted their child to move into a residential or nursing facility. Essentially, they did not trust in the facility's ability to provide quality care.
- When the concept of future planning was introduced, several themes emerged.



# Responding to Needs for Advocacy

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- “I **always assumed** my daughter would take X. But now that she has a husband, children, and a job, I have that awful fear about X fitting into her lifestyle.”
- “We need advice from **someone who deals with these things.**”
- Many who **said they had a plan actually did not.** They never “got around to it”.
- “I need to make a plan **before this becomes a crisis.** Making a plan is part of **letting go.**”

# Perceptions of Caregivers

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- Unremitting apprehension when thinking about the future
- Avoidance of dealing with the issue.
- Based on the ages of caregivers, the future was conceptualized as an aging mother child dyad.
- When questioned by the interviewer, most were unaware of the time required to secure an adequate placement.

# Generating Solutions to Facilitate Planning

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- Parents often “won’t look toward the future”. They *need help* to do so.
- Enhance recognition of the need to seek legal and/or financial help in *planning*.
- Instill the idea that *early preparation minimizes trauma* to the care recipient.
- Sewing seeds for the future is a way of *continuing one’s commitment* to one’s child or other dependent loved one .

# Policies for the Un-befriended

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- The Un-befriended comprise approximately 4% of the older adult population.
- Medical decision making for patients without surrogates is considered one of the biggest yet permanently neglected topics in clinical bioethics (NYC Health and Hospitals Corporation, 2016)
- The term “un-befriended” describes those persons, regardless of age, who reach end of life with neither decision-making capacity nor surrogates.

# Legislative Action

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- The initial goal is to convey compassion and offer protection for the client.
- Next are efforts to locate family.
- Twenty-four states and the District of Columbia have passed legislation regarding un-befriended individuals by adding “close friend” to the list of surrogate decision makers”.



# Alternatives When No Kin Can Be Located

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- As an exemplar, The Cleveland Clinic requires the collaborative agreement of two physicians and the medical ethicist in determining a treatment plan for an unbefriended client.
- Colorado has developed a program to train volunteers to serve as court-appointed guardians for the unbefriended.

# What Information Can Inform A Care Plan for the Un-befriended?

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- Evidence of previous encounters of the individual with a health care system
- Long standing religious preferences
- History of past rejections and acceptances of medical interventions.
- “We need to look for anything that enables us to best execute substitute judgment”. (*Society for Post-Acute and Long-term Care Management, 2016*)

# Not All Un-befriended Clients Are Elders

- Infant abandonment has increased by 46% since 1991.
- Three cities have been determined to account for most abandonments (New York, Chicago, and Los Angeles).
- Substance abuse continues to be the most common factor in abandonment.
- Many mothers who opt for abandonment made no birth plans and sporadically engaged in pre-natal care.