HAMDARD MANUAL ON CLINICAL ETHICS

April 2025

HAMDARD INSTITUTE OF MEDICAL SCIENCES AND RESEARCH & HAHC HOSPITAL, NEW DELHI-62

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Preface

Health is fundamental to a long, fulfilling life, and access to healthcare is a basic human right. For centuries, providing healthcare has been regarded as a noble endeavour, entrusted to experts. In modern times, however, healthcare has evolved into a highly complex, multidisciplinary field, governed by numerous laws, regulations, and guidelines. The integration of AI into healthcare has further added to this complexity.

Yet, whether in the past or present, ethical and moral considerations have always been central to healthcare—now more than ever. Among the many branches of bioethics, clinical ethics is particularly critical and time-sensitive, as it directly impacts human lives through prompt decisions and actions. However, determining who should make these decisions and what course of action to take is often unclear, necessitating careful ethical evaluation.

Despite rigorous medical training, clinical ethics remains underemphasized, even in postgraduate education. Moreover, many practicing clinicians lack access to an organized system for ethical guidance.

This manual on Clinical Ethics aims to bridge that gap. In its first edition, it covers fundamental ethical principles and their complex clinical applications, including end-of-life care. We hope it serves as a valuable resource, helping healthcare professionals integrate ethical concepts into their daily practice.

MESSAGE FOR CEO

Healthcare professionals are entrusted with the sacred responsibility of caring for the most vulnerable members of our society. With this privilege comes the weight of complex ethical dilemmas that can arise in the course of providing care.

The four principles of ethics that apply to clinicians and other healthcare professionals are:

1) Beneficence
2) Non-Maleficence
3) Self-determination / Autonomy
4) Informed consent

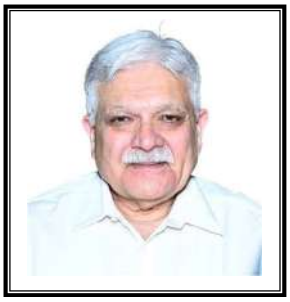
All these principal actions are fundamental determinants of the ethical conduct of medical experts at all levels.
The current workshop is expected to throw open a window of opportunity for young medical professionals to update these fundamental principles of ethics.

The clinical ethics booklet prepared for the workshop is a timely and invaluable resource for healthcare professionals navigating the intricacies of ethical decision-making. It provides a comprehensive framework for analysing and addressing the toughest ethical challenges, from informed consent and confidentiality to end-of-life care and resource allocation.

The principles and guidelines outlined in this booklet are rooted in a deep respect for the autonomy and dignity of patients, as well as a commitment to promoting their well-being and best interests. By applying these principles in practice, healthcare professionals can ensure that their decisions are guided by a strong moral compass and a dedication to upholding the highest standards of care.

I commend the authors and contributors of this booklet for their tireless efforts to provide the tools and guidance needed to navigate the complex landscape of the clinical ethics booklet.

Dr. G. N. Qazi
CEO, HIMSR & HAHC Hospital



MESSAGE FROM DEAN

It gives me great pleasure to introduce the 'Hamdard Manual on Clinical Ethics", a thoughtful and much-needed resource in today's medical landscape. As healthcare becomes more complex, with rapid advances in technology and evolving patient needs, it is vital to remember that every medical decision carries an ethical responsibility. This manual brings together essential principles of clinical ethics and explores how they apply in real-life scenarios—from informed consent and patient autonomy to mental health care and end-of-life decisions.

The contributors to this manual, with their rich experience and diverse backgrounds, have offered valuable insights that will benefit medical students, practitioners, and healthcare administrators alike. It is my hope that this compilation not only informs but also inspires a deeper commitment to ethical, compassionate, and patient-centered care.

I sincerely believe this manual will serve as a guiding light for all those involved in healing, reminding us that at the heart of medicine lies respect for human dignity.

Prof. Sunil Kohli
Dean, HIMSR & HAHC Hospital

CONFERENCE SCHEDULE

SN	Time	Session	Speakers
1	8 – 8:30 AM	Registration	
2	8:30 – 9:15 AM	**Teaching Session 1A** Theories and Principles of Bioethics	Dr. Aqsa Shaikh Chairpersons: Dr. Shridhar Dwivedi Dr. Nita Khurana
3	9:15– 10 AM	**Teaching Session 1B** Research Ethics	Dr. Sabina Khan Chairpersons: Dr. Shridhar Dwivedi Dr. Nita Khurana
4	10:00 - 10:50 AM	**Inauguration Program**	
	10:00 – 10:05 AM	Quran Recitation	Dr. Iqra Khan
	10:05 – 10:15 AM	Address by Conference Chair	Dr. Musharraf Husain
	10:15 – 10:25 AM	Address by Patron	Dr. Sunil Kohli
	10:25 – 10:40 AM	Chief Guest	Dr. Khalilullah
	10:40 – 10:50 AM	Address by Chief Patron	Dr. G N Qazi
	10:50 – 10:55 AM	Vote of Thanks	Dr. Aqsa Shaikh
	10:55 – 11:00 AM	National Anthem	
5	11:00 – 11:30 AM	Tea Break	
6	11:30 AM – 12:30 PM	**Teaching Session 2A** Autonomy & Consent Privacy & Confidentiality	Dr. Musharraf Husain Chairpersons: Dr. Keya Sircar Dr. Sunil Kohli
7	12:30 – 01:00 PM	**Teaching Session 2B** Breaking Bad News	Dr. Arun Kumar Aggarwal Chairpersons: Dr. Keya Sircar Dr. Sunil Kohli
8	01:00 – 02:00 PM	**Panel Discussion 1:** Ethics in Gender, Reproductive Health and Sexual Health including care of minors	Panelists: 1. Dr. Bhavuk Garg 2. Adv Aparna Mehrotra 3. Dr. Tamkin Khan Moderator: Dr. Aqsa Shaikh Chairperson: Dr. Dinesh Kumar
9	02:00 – 2:45 PM	Lunch	
10	02:45 – 3:45 PM	**Panel Discussion 2:** Ethics of End-of-Life care, Palliation Mental Health Ethics	Panelists: 1. Dr. Pawan Kapoor 2. Dr. R C Jiloha 3. Dr. R K Mani 4. Dr. Samiksha Khanuja Moderator: Dr. Pratibha Panjiar Chairpersons: Dr. Nimmi Jose
11	3:45 – 4:15 PM	Question and Answer	Moderated by Dr. Musharraf Husain
12	4:15 – 4:30 PM	Closing	Dr. Sonali Ohri

BIOGRAPHY OF THE RESOURCE FACULTY

Dr. Aqsa Shaikh

Dr. Aqsa Shaikh is a Professor of Community Medicine at Hamdard Institute of Medical Sciences and Research, Jamia Hamdard, Delhi. Recognized as India's first transgender woman to lead a COVID-19 vaccination center, she champions ethical healthcare inclusion. She serves as Patient Safety Nodal Officer at HAH Centenary Hospital (HAHCH) and Secretary of the Hospital Bioethics Committee, driving policies on patient care and ethical standards. Her research focuses on public health, transgender rights, and medical education reform, emphasizing empathy and equity. She is a compelling speaker who brings profound insights on ethics in medicine and marginalized communities.

Dr. Sabina Khan

Dr. Sabina Khan is a Professor and Head of Pathology at Hamdard Institute of Medical Sciences & Research, Jamia Hamdard, Delhi. With an MBBS and MD from Jawaharlal Nehru Medical College, Aligarh Muslim University, she boasts over 20 years of teaching and research experience in cytopathology and surgical oncology. She has authored over 140 peer-reviewed publications with more than 1000 citations and serves on editorial boards of national and international journals. A member of HIMSR's Institutional Ethics Committee (IEC) and Chairperson of the IEC at Jamia Millia Islamia, she shapes ethical standards in medical research. A recipient of the 2020 International Academy of Cytology membership, Dr. Khan's work emphasizes ethical diagnostic practices.

Dr. Shridhar Dwivedi

Dr. Shridhar Dwivedi is a Senior Consultant in Cardiology at the National Heart Institute (NHI), New Delhi, with an illustrious career in medicine. He served as Dean of Hamdard Institute of Medical Sciences & Research (HIMSR) and Professor of Medicine at Delhi University, shaping generations of healthcare professionals. A pioneer in preventive cardiology, he has published over 150 research papers and received prestigious honours, including FRCP (London) and FAMS. His work emphasizes ethical patient care and lifestyle interventions for heart health. Dr. Dwivedi's extensive experience and commitment to medical ethics make him a compelling speaker, offering valuable perspectives on healthcare integrity.

Dr. Nita Khurana

Dr. Nita Khurana is a Director Prof & Head, Department of Pathology, MAMC. She is also Hon. faculty member, Department of Medical education. She has over 29 years undergraduate and 26 years of postgraduate teaching experience with 300 publications in national and international pubmed indexed journals. She is recipient of "Eminent Medical and Health Education Teacher" Award by Delhi Medical Association. She is Executive member of Delhi IAPM, Member of Institutional Ethics Committee. She is a Life member Indian Association of Pathologists & Microbiologists, Life member of Delhi Chapter- IAPM, Life member Indian Society of Hematology and Blood Transfusion, Delhi Society of Hematology, Dermatopathology Society of India. Her area of expertise is Surgical Pathology and Immunohistochemistry.

Dr. Tamkin Rabbani

Dr. Tamkin Rabbani is a distinguished Professor of Obstetrics and Gynaecology at Jawaharlal Nehru Medical College, Aligarh Muslim University, with more than two decades of clinical, research, and teaching experience. Her expertise encompasses emergency obstetric care, gynaecological oncology, and medical education. She is a member of the expert committee on conformity between PC-PNDT Act, ART Act and Surrogacy Act. As a FAIMER Fellow she is keenly interested in medical humanities, medical education and medical ethics.

Dr. Musharraf Husain

Dr. Musharraf Husain is the Medical Superintendent of HAH Centenary Hospital (HAHCH) and a Professor of Surgery at Hamdard Institute of Medical Sciences & Research (HIMSR), Delhi. He graduated in medicine (MBBS) from prestigious JNMC (AMU) in 1997 and was awarded gold medal for outstanding performance during the course. He obtained his Master's in Surgery (MS) from the same institution in 2002, after which he was conferred a Diplomate from national board of examination (DNB) in 2003. Dr. Musharraf has a vast teaching experience of more than 18 years at both graduate and postgraduate level and is also the examiner for the same. He has more than 50 research publications in various national and international journals and also authored two monographs on the topic of Intra-abdominal infections. As Chairperson of the Hospital Bioethics Committee, he leads efforts to uphold ethical standards in clinical practice and patient care. With extensive experience in surgical innovation and hospital administration, he has contributed significantly to medical education and healthcare delivery.

Dr. Arun Kumar Agarwal

Dr. Arun Kumar Agarwal is a distinguished medical educator and former Dean of Maulana Azad Medical College (MAMC), New Delhi, where he shaped healthcare training for over three decades. Currently, he serves as Chairperson of the Institutional Ethics Committee (IEC) at Hamdard Institute of Medical Sciences & Research (HIMSR), ensuring rigorous ethical oversight in research and clinical practice. With expertise in otolaryngology and public health, he has published widely and influenced national health policies. Dr. Agarwal's leadership in medical ethics and education, combined with his commitment to patient rights, positions him as a key speaker, offering profound insights into ethical challenges in modern medicine.

Dr. Sunil Kohli

Dr. Sunil Kohli is the Dean of Hamdard Institute of Medical Sciences & Research (HIMSR), Jamia Hamdard, Delhi, and a Professor of Medicine with a distinguished career in medical education and clinical practice. Specializing in internal medicine, he has guided HIMSR's academic and research initiatives, fostering a culture of ethical healthcare delivery. With numerous publications and years of teaching experience, Dr. Kohli emphasizes patient-centered care and the ethical responsibilities of physicians. As Dean, he has spearheaded initiatives to modernize HIMSR's curriculum and infrastructure, emphasizing evidence-based practice and compassionate care. Dr. Kohli also serves on various academic boards, shaping the future of medical training in India.

Dr. Keya Sircar

Dr. Keya Sircar is the Dean of the Faculty of Dentistry at Jamia Millia Islamia (JMI), New Delhi, and a Professor of Oral Pathology. With an MDS from a premier institution, she has over two decades of experience in dental education and research, specializing in salivary diagnostics and precancerous lesions. She serves as Member Secretary of the Institutional Ethics Committee (IEC)

at JMI, ensuring ethical integrity in research. Dr. Sircar has published extensively, with over 700 citations, and is recognized for her contributions to oral health equity. Her leadership has elevated JMI's dental faculty to a top-tier institution, ranking 10th in NIRF 2023.

Dr. Bhavuk Garg

Dr. Bhavuk Garg is an Associate Professor of Psychiatry at Lady Hardinge Medical College (LHMC), New Delhi, and a key contributor to the Mental Health Division, Directorate General of Health Services (DGHS). Holding an MBBS from Maulana Azad Medical College, an MD in Psychiatry from IHBAS, Delhi, and a DNB, he specializes in child and addiction psychiatry. With over a decade of experience, he has published extensively on topics like etizolam dependence and chronic mental illness in youth. Dr. Garg is a member of the Indian Psychiatric Society and has received the Appreciation Award from IHBAS for his impactful work in mental health.

Dr. Dinesh Kumar

Dr. Dinesh Kumar is a Director Professor of Anatomy and Head of the Department of Medical Education at Maulana Azad Medical College (MAMC), New Delhi. With an MBBS and MS from prestigious institutions, he has over 25 years of experience in anatomical sciences and medical pedagogy. Renowned for his expertise in clinical anatomy and embryology, he has published extensively and trained thousands of medical students. Dr. Kumar has pioneered innovative teaching methods, integrating technology into medical education, and serves on national curriculum committees. His leadership at MAMC has elevated its educational standards, earning him accolades from the Medical Council of India.

Adv. Aparna Mehrotra

Adv. Aparna Mehrotra is a Senior Litigation Associate at the Centre for Law and Policy Research, Bengaluru, and an advocate at the Supreme Court of India. She holds a BA (Hons) in Political Science from Delhi University and an LLM in Transnational Law from King's College London. With extensive experience, she served as a Law Clerk at the Supreme Court (2019-2021) and as a researcher on the Sundarbans Climate Justice at King's College London and West Bengal National University of Juridical Sciences. Aparna also works with Justice Adda, a legal design start-up to research and develop projects on overcoming informational barriers to justice. Her litigation spans High Courts and the Supreme Court, addressing the rights of vulnerable communities. Her research and practice interests include constitutional and criminal law, gender and sexuality law, and environmental law. As a litigation fellow, Aparna is involved with CLPR's strategic litigation across High Courts and the Supreme Court.

Dr. Pratibha Panjiar

Dr. Pratibha Panjiar is a Professor of Anaesthesia and Pain Medicine at Hamdard Institute of Medical Sciences & Research (HIMSR), Jamia Hamdard, Delhi. With an MBBS and MD in Anaesthesiology from reputed institutions, she has over 20 years of experience in perioperative care and pain management. She serves as a member of the Hospital Bioethics Committee at HIMSR and HAH Centenary Hospital (HAHCH), contributing to ethical guidelines in clinical practice. Dr. Panjiar has published research on pain relief techniques and patient safety, earning recognition for her work in critical care. She also trains medical students and residents, emphasizing compassionate and evidence-based anaesthesia practices.

Dr. R C Jiloha

Dr. R C Jiloha is a Senior Consultant Psychiatrist with over four decades of expertise in mental health. He served as Professor and Head of Psychiatry at Delhi University and later at Hamdard Institute of Medical Sciences & Research (HIMSR), Jamia Hamdard, Delhi. Holding an MD from PGIMER Chandigarh, he has authored over 100 research papers on addiction, schizophrenia, and cultural psychiatry. Dr. Jiloha has trained generations of psychiatrists and contributed to national mental health policies as a member of the Indian Psychiatric Society. His work bridges clinical practice and academic research, earning him widespread respect in the field.

Dr. Samiksha Khanooja

Dr. Samiksha Khanooja is a Professor of Anaesthesia at the Government Institute of Medical Sciences, Greater Noida, Uttar Pradesh. With an MBBS and MD, she brings extensive experience in anaesthesia and critical care, previously serving as an Associate Professor at HIMSR, Delhi. Her research, cited over 10 times, includes studies on pain management and intraocular pressure during intubation. Dr. Khanooja has co-supervised postgraduate theses and contributed to patient care in operating rooms, ICUs, and pain clinics. She has organized CMEs, including the 2022 HIMSR Anaesthesia and Pain Update, and excels in teaching, research, and clinical practice.

Dr. Nimmi Jose

Dr. Nimmi Jose is a Professor of Psychiatry at Hamdard Institute of Medical Sciences & Research (HIMSR), Jamia Hamdard, Delhi, with extensive expertise in mental health care. She serves as a member of the Hospital Bioethics Committee and Chairperson of the Equal Opportunity Cell at HIMSR and HAH Centenary Hospital (HAHCH), advocating for inclusivity and ethical practices. Holding an MD in Psychiatry, she has published research on psychological well-being and patient rights. Dr. Jose has trained numerous students and clinicians, emphasizing compassionate care. Her leadership in promoting equity and ethical standards in healthcare has earned her recognition within academic and medical communities.

Dr. Pawan Kapoor

Air Marshal (Dr.) Pawan Kapoor, AVSM, VSM (Retd.), is Vice Chairman of Rus Education and Chairman of the Technical Committee at the National Accreditation Board for Hospitals (NABH). A former Director General of Medical Services (Indian Air Force), he retired in 2017 after 38 years of distinguished service. An alumnus of Armed Forces Medical College, he holds advanced degrees in hospital administration from AIIMS and beyond. Honoured with the Lifetime Achievement Award at the 2024 FICCI Healthcare Excellence Awards, Dr. Kapoor has shaped healthcare quality standards globally, serving as an ISQua analyzer and mentoring medical education initiatives.

Dr. R K Mani

Dr. R K Mani is Chairman of Critical Care and Pulmonology at Yashoda Super Speciality Hospital, Ghaziabad, and a pioneer in these fields with over 40 years of experience. A former President of the Indian Society of Critical Care Medicine, he has held leadership roles at Apollo Hospitals, Fortis, and Nayati Medicity, where he was Group CEO. Trained in India and the UK, he developed non-invasive ventilation and sleep medicine in India. Dr. Mani has authored numerous papers on critical care ethics and end-of-life care, earning the FCCP (USA) and a Delhi Medical Association award for distinguished service.

Chapter 1: Theories of Ethics

Dr. Aqsa Shaikh
Professor, Department of Community Medicine
Hamdard Institute of Medical Sciences and Research

Clinical ethics is a practical discipline that helps healthcare professionals navigate ethical dilemmas in clinical practice. It provides a structured approach to identify, analyze, and resolve ethical issues that arise during patient care. These issues often involve conflicts of values, such as balancing patient autonomy with beneficence or addressing cultural and social attitudes that influence medical decisions.

For example, clinical ethics might come into play when deciding on end-of-life care, handling informed consent, or resolving disagreements between patients and healthcare providers. It ensures that decisions are made transparently and in the best interest of patients while respecting the values of all parties involved.

The **Trolley Problem** is a famous ethical thought experiment in moral philosophy, often used to explore **utilitarianism, deontology, and virtue ethics**. It presents a moral dilemma about making difficult choices that affect human lives.

The Classic Scenario:

A runaway trolley is heading toward **five people** tied to the tracks. You are standing next to a lever that can divert the trolley onto another track, where **one person** is tied.

Your choices:

1. **Do nothing** – The trolley continues on its path and kills five people.
2. **Pull the lever** – The trolley is redirected, killing one person instead of five.

Ethical Interpretations:

- **Utilitarianism**: Pulling the lever is the right choice because it minimizes overall harm (one death instead of five).
- **Deontology**: It may be wrong to pull the lever because it involves actively choosing to harm an innocent person, violating moral duties.
- **Virtue Ethics**: The decision depends on the character and intentions of the person making it rather than just the consequences.
- **Variations of the Trolley Problem:**
- **Fat Man Variant**: Instead of a lever, you must push a large man off a bridge to stop the trolley and save the five. This raises further moral concerns about direct harm.

Loop Variant: The trolley will loop back and still kill five unless diverted, but the one person on the other track would stop it either way.

Normative Ethics

Normative ethics is a branch of ethics that focuses on establishing moral standards and principles to determine what is right and wrong. It seeks to provide guidelines for how individuals ought to act in various situations. Major approaches within normative ethics include **utilitarianism/consequentialism** (judging actions based on their outcomes), **deontology** (emphasizing duties and rules), and **virtue ethics** (focusing on moral character). This field helps shape moral decision-making in personal, professional, and societal contexts.

Deontology:

Deontology is an ethical theory that emphasizes duty, rules, and obligations in determining the morality of actions. It argues that certain actions are inherently right or wrong, regardless of their consequences. The most well-known deontological approach comes from **Immanuel Kant**, who proposed the **categorical imperative**, a principle that requires individuals to act according to **universal moral laws.** Deontology contrasts with consequentialist theories, which judge actions based on their outcomes, and instead focuses on adhering to moral duties and principles.

The **Categorical Imperative** is a central concept in **Immanuel Kant's** deontological ethics. It is a moral principle that dictates that one should act only according to rules that could be universally applied. In other words, an action is morally right if it can be consistently followed by everyone without contradiction.

Kant formulated the Categorical Imperative in different ways, but two key formulations are:

1. **Universalizability Principle** – "Act only according to that maxim whereby you can at the same time will that it should become a universal law." This means before acting, one should ask: *What if everyone did this?* If the action leads to a contradiction or an undesirable world, it is morally wrong.
2. **Humanity Principle** – "Act in such a way that you treat humanity, whether in your own person or in the person of any other, always at the same time as an end, never merely as a means." This emphasizes respect for human dignity and forbids using people purely for one's own benefit.

The Categorical Imperative serves as a foundation for moral duty, independent of personal desires or consequences.

Utilitarianism is a moral theory that evaluates actions based on their consequences, aiming to maximize overall happiness or well-being. It is a form of **consequentialism**, meaning that the morality of an action is determined solely by its outcomes.

Key Principles of Utilitarianism:

1. **Greatest Happiness Principle** – The right action is the one that produces the greatest happiness (or least suffering) for the greatest number of people.
2. **Impartiality** – Everyone's happiness counts equally; no one's well-being is prioritized over another's.
3. **Hedonism (in Classical Utilitarianism)** – Happiness and pleasure are the only intrinsic goods, while pain and suffering are the only intrinsic evils.

Types of Utilitarianism:

- **Act Utilitarianism** – Evaluates the morality of each individual action based on whether it maximizes happiness.
- **Rule Utilitarianism** – Focuses on following rules that generally lead to the greatest happiness when followed consistently.

Utilitarianism is widely applied in ethical decision-making, especially in public policy, economics, and healthcare, but it is also criticized for potentially justifying morally questionable actions if they lead to greater overall happiness.

Virtue ethics is a moral theory that focuses on the character and virtues of a person rather than rules (deontology) or consequences (utilitarianism). It emphasizes **moral character** and the development of good habits that lead to a flourishing life (**eudaimonia**).

Key Principles of Virtue Ethics:

1. **Moral Character** – A good person is someone who possesses and cultivates virtues such as courage, honesty, and kindness.
2. **Eudaimonia** – The ultimate goal of human life is to achieve **flourishing** or **well-being**, not just temporary pleasure.
3. **The Golden Mean** – Virtues lie between two extremes (vices):
    - Example: **Courage** is the balance between **recklessness** and **cowardice**.
4. **Moral Education** – Virtue is developed through **practice**, **habit**, and **role models** rather than simply following rules.

Virtue ethics is often applied in **personal development, leadership, and education**, though critics argue it lacks clear guidelines for resolving ethical dilemmas.

Heinz's Dilemma is a moral thought experiment used by **Lawrence Kohlberg** to study moral development. It presents an ethical dilemma about breaking the law to save a life and is used to assess how individuals reason about right and wrong.

The Scenario:

Heinz's wife is seriously ill and will die without a special drug. A pharmacist has developed the drug but is selling it for **ten times** its production cost, making it unaffordable for Heinz. Heinz **pleads for a discount**, but the pharmacist refuses. Desperate, Heinz **considers stealing the drug** to save his wife.

The Dilemma:

Should Heinz **steal the drug** to save his wife, or should he **obey the law** and let her die?

Key Takeaway:

Heinz's Dilemma doesn't have a "right" answer; rather, it examines *how* people justify their decisions. It is widely used in psychology, ethics, and education to explore moral reasoning.

Kohlberg's Stages of Moral Development:

Kohlberg used responses to this dilemma to classify people into different **moral reasoning stages**:

1. **Preconventional Level** (Self-interest)
    - *Stage 1*: Avoiding punishment (*"Stealing is wrong because he'll go to jail."*)
    - *Stage 2*: Personal gain (*"He should steal it because saving his wife is more important."*)
2. **Conventional Level** (Social norms)
    - *Stage 3*: Seeking approval (*"A good husband would steal the drug."*)
    - *Stage 4*: Law and order (*"Stealing is wrong because laws must be followed."*)
3. **Postconventional Level** (Ethical principles)
    - *Stage 5*: Social contract (*"Laws exist for fairness, but saving a life is more important."*)
    - *Stage 6*: Universal ethics (*"Human life has supreme value, and moral duty justifies breaking an unjust law."*)

Chapter 2: Principles of Medical Ethics

Dr. Aqsa Shaikh
Professor, Department of Community Medicine
Hamdard Institute of Medical Sciences and Research

The **Four Principles of Ethics** are a widely used framework in **bioethics and medical ethics**, introduced by **Beauchamp and Childress**. These principles help guide ethical decision-making in healthcare, research, and other fields.

1. Autonomy (Respect for Individuals)

- People have the right to make their own choices and decisions, as long as they do not harm others.
- In healthcare, this means **informed consent**—patients must understand and voluntarily agree to treatments.

2. Beneficence (Do Good)

- Actions should promote **well-being** and benefit others.
- Healthcare professionals should strive to **maximize positive outcomes** for patients.

3. Non-Maleficence (Do No Harm)

- Avoid causing harm or unnecessary suffering.
- In medicine, this means weighing risks and benefits carefully (e.g., avoiding harmful treatments).

4. Justice (Fairness)

- Ethical decisions should be **fair and equitable**.
- This includes **fair distribution of resources**, equal treatment of patients, and ensuring no one is unfairly disadvantaged.

These principles help resolve ethical dilemmas by balancing individual rights, societal needs, and professional responsibilities.

Autonomy in Clinical Ethics

Autonomy in clinical ethics refers to a patient's right to make their own healthcare decisions, based on their values, beliefs, and preferences. It is grounded in the idea that individuals have the ability to make rational choices about their own bodies and medical treatments. **Informed consent** is a key aspect of autonomy, ensuring that patients understand their options before making a decision.

Examples of Autonomy in Clinical Ethics:

1. Informed Consent

A doctor must explain the risks, benefits, and alternatives of a medical procedure before a patient agrees to it.

✅ *Example:* A patient with cancer is given information about chemotherapy, radiation, and palliative care. They choose palliative care instead of aggressive treatment, and their choice must be respected.

2. Right to Refuse Treatment

Patients have the right to decline medical interventions, even if it may result in harm or death.
✅ *Example:* A Jehovah's Witness patient refuses a blood transfusion due to religious beliefs, despite the doctor's recommendation. The doctor must respect this decision.

3. Advance Directives & Living Wills

Patients can document their medical preferences in advance in case they become unable to communicate.
✅ *Example:* A patient with a **do-not-resuscitate (DNR) order** cannot be given CPR if their heart stops, even if family members want to override their decision.

4. Psychiatric and Mental Health Cases

Autonomy may be limited if a patient lacks the capacity to make rational decisions (e.g., severe psychosis).
✅ *Example:* A patient with **schizophrenia refusing medication** may be treated involuntarily if they pose a danger to themselves or others. However, every effort should be made to respect their autonomy when possible.

Beneficence in Clinical Ethics

Beneficence in the clinical context refers to actions taken by healthcare professionals to actively promote the well-being of patients. It goes beyond avoiding harm (non-maleficence) and focuses on doing good for the patient. Here are some examples:

1. **Preventive Care**: Recommending vaccines or regular health screenings to prevent diseases aligns with beneficence. For instance, advising a patient to get a flu shot to reduce their risk of severe illness demonstrates this principle.
2. **Palliative Care**: When a cure is no longer possible, beneficence guides practitioners to focus on comfort and quality of life. For example, providing pain relief and emotional support to terminally ill patients reflects beneficence.
3. **Emergency Interventions**: In critical situations, beneficence might involve making decisions that prioritize saving a patient's life. For instance, performing CPR on a patient in cardiac arrest is a direct application of beneficence.
4. **Holistic Care**: Beneficence also includes considering the patient's individual circumstances and preferences. For example, tailoring treatment plans to align with a patient's cultural beliefs or personal values demonstrates beneficence.

Non-Maleficence in Clinical Ethics

Non-maleficence is an ethical principle in healthcare that emphasizes the duty to avoid causing harm to patients. It is derived from the Latin phrase *"primum non nocere,"* meaning "first, do no harm." This principle guides healthcare professionals to carefully weigh the risks and benefits of

their actions, ensuring that any intervention minimizes harm while promoting the patient's well-being.

Examples in Clinical Practice:

1. **Avoiding Harmful Treatments**: If a medication has severe side effects that outweigh its benefits, non-maleficence would guide the clinician to avoid prescribing it.
2. **Safe Surgical Practices**: Surgeons must ensure that procedures are performed under sterile conditions to prevent infections, adhering to non-maleficence.
3. **Informed Consent**: Before any medical intervention, patients are informed about potential risks and benefits, allowing them to make decisions that align with their values and minimize harm.

Justice in Clinical Ethics

The ethical principle of **justice** in healthcare emphasizes fairness and equality in the distribution of resources, treatments, and opportunities. It ensures that all patients are treated equitably, regardless of their background, socioeconomic status, or other factors. Justice can be applied in various clinical scenarios:

1. **Resource Allocation**: In situations where resources are limited, such as ICU beds or organ transplants, justice ensures that decisions are made based on medical need and ethical criteria rather than personal biases or social status.
2. **Access to Care**: Justice is reflected in policies that provide equal access to healthcare services. For example, ensuring that rural and underserved populations have access to vaccinations or primary care aligns with this principle.
3. **Triage**: In emergency departments, triage systems are used to prioritize patients based on the severity of their condition, ensuring that those in critical need receive immediate attention.
4. **Equity**: Justice involves actively working to reduce health disparities. For instance, offering free or subsidized treatment for low-income patients or marginalized communities demonstrates a commitment to fairness.
5. **Clinical Trials**: When conducting research, justice ensures that participants are selected fairly and that vulnerable populations are not exploited. It also means that the benefits of the research are shared equitably.

Chapter 3: Development of Modern Clinical Ethics

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Edward Jenner's vaccination experiments in the late 18th century marked a groundbreaking moment in medical history, but they also raise ethical questions when viewed through a modern lens.

Jenner's Experiment:

In 1796, Jenner inoculated an 8-year-old boy, James Phipps, with material from a cowpox sore taken from a milkmaid. Jenner hypothesized that exposure to cowpox would protect against smallpox. Later, he deliberately exposed Phipps to smallpox to test his theory, and the boy did not develop the disease. This experiment laid the foundation for the development of vaccines and eventually led to the eradication of smallpox.

Ethical Reflections:

1. **Lack of Informed Consent**: By today's standards, Jenner's experiment would be considered unethical because James Phipps, a child, could not provide informed consent, and there is no evidence that his parents were fully informed of the risks.
2. **Risk to Participants**: Deliberately exposing someone to smallpox, a deadly disease, posed significant risks, even though Jenner believed the cowpox inoculation would be protective.
3. **Historical Context**: At the time, smallpox was a devastating disease with high mortality rates, and variolation (a riskier method of inducing immunity) was already in practice. Jenner's work was seen as a safer alternative and a public health necessity.

While Jenner's methods would not meet modern ethical standards, his work was revolutionary and ultimately saved countless lives. It also highlights the importance of ethical oversight in medical research today.

Nazi Human Experiments

Nazi human experimentation during World War II was a horrifying chapter in medical history, marked by extreme cruelty and disregard for ethical principles. These experiments were conducted on prisoners in concentration camps, including Jews, Romani people, disabled individuals, and others deemed "undesirable" by the Nazi regime.

Key Features of the Experiments:

1. **Lack of Consent**: Victims were forced into participation without any form of consent, violating their autonomy and dignity.
2. **Inhumane Methods**: Experiments included exposure to extreme temperatures, infectious diseases, and chemical substances, often resulting in death, permanent injury, or severe trauma.
3. **Pseudoscientific Goals**: Many experiments aimed to support Nazi racial ideology or military objectives, rather than genuine scientific advancement.

Ethical Legacy:

The atrocities committed led to the establishment of the **Nuremberg Code**, a set of ethical guidelines for human research, emphasizing informed consent, risk minimization, and the necessity of scientific merit.

These experiments serve as a stark reminder of the importance of ethical oversight in research.

The Nuremberg Code of Ethics

It is a foundational document in the field of medical ethics, established in 1947 during the Nuremberg Trials. It was created in response to the unethical human experimentation conducted by Nazi doctors during World War II. The code outlines ten principles to ensure the ethical conduct of medical research involving human subjects.

Key principles include:

1. **Voluntary Consent:** Participants must give informed and voluntary consent without coercion.
2. **Beneficial Results:** Research must aim to produce results that benefit society and cannot be obtained by other means.
3. **Risk Minimization:** Experiments should avoid unnecessary physical or mental suffering and injury.
4. **Qualified Researchers:** Only scientifically qualified individuals should conduct experiments.
5. **Right to Withdraw:** Participants have the right to withdraw from the study at any time.

The Nuremberg Code remains a cornerstone of ethical guidelines in medical research, influencing documents like the Declaration of Helsinki and modern Institutional Review Board (IRB) standards. It emphasizes the importance of respecting human dignity and autonomy in scientific endeavors.

Tuskegee Syphilis Trials

The Tuskegee Syphilis Study (1932–1972) was an unethical medical experiment conducted by the U.S. Public Health Service. It involved 600 African American men, 399 of whom had syphilis, in Macon County, Alabama. The men were misled into believing they were receiving treatment for "bad blood," but in reality, they were denied proper care, even after penicillin became the standard treatment for syphilis in 1947.

The study aimed to observe the natural progression of untreated syphilis, but it resulted in severe harm, including deaths, transmission to spouses, and congenital syphilis in children. The experiment violated ethical principles such as informed consent and non-maleficence.

The Belmont Report

The **Belmont Report**, published in 1979, is a foundational document in research ethics. It was created by the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research in response to unethical studies like the Tuskegee Syphilis Study. The report outlines ethical principles and guidelines for conducting research involving human subjects.

Core Ethical Principles:

1. **Respect for Persons**: Recognizes the autonomy of individuals and requires informed consent for participation in research.
2. **Beneficence**: Ensures that research maximizes benefits while minimizing harm to participants.
3. **Justice**: Promotes fairness in the selection of research subjects and the distribution of risks and benefits.

Applications:

The Belmont Report serves as the basis for regulations governing human research, including the establishment of Institutional Review Boards (IRBs) to oversee ethical compliance.

The Beecher Paper

The *Ethics and Clinical Research*, was a groundbreaking article published by Dr. Henry K. Beecher in the *New England Journal of Medicine* in 1966. This paper highlighted unethical practices in medical research, particularly focusing on the lack of informed consent and the exploitation of vulnerable populations in clinical studies.

Dr. Beecher reviewed 22 published studies and revealed that many of them involved unethical experimentation on human subjects without their knowledge or proper consent. His work emphasized the need for ethical oversight in research and called for greater accountability among researchers and institutions.

The Beecher Paper played a pivotal role in shaping modern research ethics. It contributed to the development of stricter guidelines for human experimentation, including the establishment of Institutional Review Boards (IRBs) and the reinforcement of informed consent as a fundamental principle in clinical research.

The Stanford Prison Experiments

The Stanford Prison Experiment, conducted in 1971 by psychologist Philip Zimbardo, is one of the most well-known studies in social psychology. It aimed to explore how situational factors influence human behavior, particularly in a prison-like environment.

In the study, 24 male college students were randomly assigned roles as either "prisoners" or "guards" in a simulated prison set up in the basement of Stanford University's psychology building. The experiment was intended to last two weeks but was terminated after just six days due to the extreme and unethical behavior that emerged. The "guards" became increasingly abusive, while the "prisoners" exhibited signs of severe stress and helplessness.

The study revealed how quickly individuals could conform to roles and how power dynamics could lead to dehumanizing behavior. However, it has been widely criticized for ethical issues, including the lack of informed consent and the psychological harm caused to participants. It also faced scrutiny for methodological flaws, such as the influence of Zimbardo's own role as the "prison superintendent."

Despite its controversies, the experiment remains a significant reference point in discussions about ethics in research and the impact of situational factors on behavior.

Chapter 4: Research Ethics

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"In research- one should not injure one person regardless of the benefits that might come to others"
Claude Bernard

Research ethics are set of ethical guidelines that oversee conduct of scientific research. The four core principles of medical ethics are autonomy, non-maleficence (do no harm), beneficence (do good), and justice. Research ethics involves application of these fundamental ethical principles for planning, conducting and publishing scientific research.

Research ethics in medical education is crucial for training future healthcare professionals to conduct ethical research and practice medicine responsibly, ensuring patient well-being and upholding scientific integrity.

A number of treaties and declarations have been reported in the literature, which addressed fundamental principles of ethical conduct in biomedical research: the Nuremberg Code, the Declaration of Helsinki, EU Convention on Human Rights and Biomedicine. The main aim of these is to protect research participants from harm, maximize benefits and minimize risks.

ICMR in 2017 published **National Ethical guidelines** for biomedical and health research involving human participants. This document is considered as a gold standard for the ethical conduct of research and is important for researchers, ethics committees, institutions and sponsors engaged in biomedical research across the country.

Key Elements of Research ethics

a) Informed consent
b) Patient information sheet
c) Confidentiality
d) Privileged communication
e) Respect and responsibility
f) Conflict of interest
g) Publication ethics

a) **Informed Consent**:

Informed consent refers to an ethical and legal doctrine based on the understanding that all interventions in the medical field should only be performed after a participant has been informed about the purpose, nature, consequences of the intervention. Participants in research must be fully informed about the risks and benefits of participating and have the right to withdraw at any time.

The primary focus of consent should be on informing and protecting research subjects, through disclosure and discussion of relevant information, and by ensuring that decisions to participate, or to continue participating, are always made voluntarily.

b) Patient information sheet:

Once informed consent is obtained, the research subject is given a patient information sheet , detailing the following aspects of the study:

1. Title of the research project
2. Invitation to participate in the research
3. Purpose and significance of research
4. Time commitments
5. Termination of participation, indication voluntary contribution
6. Risks involved
7. Costs and compensation
8. Anonymity and confidentiality

c) Confidentiality and Privacy:

Protecting the privacy and confidentiality of research participants is a fundamental ethical obligation. The concept of confidentiality implies that the information regarding their personal information and identities is protected, their data is handled securely and used only for the intended research purposes.

There are some exceptions to the principle of confidentiality eg/ when researcher is legally bound to report certain information.

d) Privileged communication:

Privileged communication has been identified as an important ethical principle in healthcare. It refers to specific types of confidential exchanges that are protected from disclosure in legal proceedings.

e) **Responsible conduct of research**:

It is dependent on integrity of researchers who are expected to maintain high standards to uphold the fundamental values of research. Researchers must ensure the scientific validity and rigor of their work, avoiding bias or manipulation of data.

f) **Conflict of interest:**

A conflict of interest exists when professional judgement concerning a primary interest (such as patients' welfare or the validity of research) may be influenced by a secondary interest (such as financial gain). Perceptions of conflict of interest are as important as actual conflicts of interest.

g) **Publication Ethics:**

These are the ethical standards, policies and guidelines to be followed while publishing results of scientific research. Transparency in funding, authorship, and reporting research findings are crucial for maintaining the credibility of medical research.

The International Committee of Medical Journal Editors (ICMJE) has developed criteria for authorship that can be used by all journals. Authors should follow these ICMJE guidelines on authorship which review best practice and ethical standards in the conduct and reporting of research.

Who Is an Author?

The ICMJE recommends that authorship be based on the following 4 criteria:

1. Substantial contributions to the conception or de sign of the work; or the acquisition, analysis, or interpretation of data for the work; AND
2. Drafting the work or revising it critically for important intellectual content; AND

3. Final approval of the version to be published; AND
4. Agreement to be accountable for all aspects of the work in ensuring that questions related to the accuracy or integrity of any part of the work are appropriately investigated and resolved.

All those designated as authors should meet all four criteria for authorship, and all who meet the four criteria should be identified as authors. Those who do not meet all four criteria should be acknowledged.

Scientific misconduct

When doing scientific research, it is very important to know what constitutes scientific misconduct. It involves fabrication, falsification and plagiarism

Fabrication- intentional act of making up data results and reporting them

Falsification- manipulating research processes, changing or omitting data without scientific justification

Plagiarism- act of presenting another's work or ideas as your own without giving due credit

Inappropiate authorship (**Ghost authorship/gift authorship**) should be avoided at any cost

When scientific misconduct is alleged, or concerns are otherwise raised about the conduct or integrity of work described in submitted or published papers, the editor should initiate appropriate procedures detailed by committees such as the Committee on Publication Ethics (COPE)

Institutional Review Boards (IRBs)/ Research Ethics Committees:

IRBs or Research Ethics Committees review research proposals to ensure ethical compliance and safeguard the welfare, dignity, and safety of the participants, ensures that ethically approved research is conducted in line with the approved protocol, and promotes public confidence in the conduct of human research.

It is mandatory that all proposals on biomedical and health research involving human participants should be reviewed by Institutional Ethics committee before it is conducted. The committee should perform its function through competent initial and continuing review of all scientific, ethical, medical and social aspects of research proposals received by it .

Chapter 5: Autonomy and Confidentiality in Healthcare

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Confidentiality in Patient Care

Confidentiality is a fundamental principle of medical ethics that obligates healthcare providers to protect patient privacy. It ensures that personal, medical, and treatment-related details remain secure and are not disclosed to unauthorized individuals without the patient's consent. Maintaining confidentiality is both a legal requirement and an essential component of ethical medical practice.

Importance of Confidentiality

1. **Trust and Relationship Building:** Patients are more likely to seek care, disclose sensitive information, and follow medical advice when they trust that their information remains private. This trust forms the foundation of the provider-patient relationship.
2. **Respect for Autonomy:** Maintaining confidentiality upholds a patient's right to control access to their personal information.
3. **Legal and Ethical Duty:** Healthcare professionals are bound by legal and ethical obligations to safeguard patient information. Breaching confidentiality can lead to legal consequences and loss of professional credibility.

Exceptions to Confidentiality: Confidentiality may be overridden in certain circumstances:

- **Patient Consent:** If the patient explicitly agrees to share their information with another party, such as a specialist, insurer, or family member.
- **Legal Requirements:** Healthcare providers may be required to disclose information in cases such as reporting communicable diseases (e.g., tuberculosis, HIV) or when a patient poses a threat to themselves or others.
- **Court Orders:** A legal directive may mandate the release of medical records.
- **Public Health Concerns:** In cases of public health threats (e.g., a contagious disease outbreak), confidentiality may be overridden to protect others.

Challenges to Maintaining Confidentiality

- **Electronic Health Records (EHRs):** Digital records improve efficiency but also pose risks of unauthorized access and data breaches.
- **Workplace Discussions:** Healthcare professionals must avoid discussing patient details in public areas.
- **Third-Party Involvement:** Family members or caregivers may be involved in patient care, requiring explicit consent for sharing information.

Privacy in Healthcare

Protecting patient privacy is essential for maintaining trust in healthcare systems and ensuring individuals receive care without fear of discrimination or misuse of medical data.

Key Principles of Patient Privacy

- **Confidentiality:** Patient information must be kept private unless explicit consent is given or disclosure is legally mandated.
- **Informed Consent:** Patients must be aware of how their data will be used and provide consent before disclosure.
- **Data Security:** Healthcare institutions must implement robust security measures to protect patient records.
- **Compliance with Legal Standards:** Healthcare professionals must adhere to legal regulations governing health data management.
- **Limited Access:** Only authorized personnel should access patient records to minimize privacy violations.
- **Patient Control:** Patients should have the right to access, correct, or restrict their medical records.
- **Preventing Harm:** Breaches of privacy can lead to stigma, discrimination, or emotional distress. Ethical medical practice prioritizes safeguarding patient data.

Autonomy in Clinical Ethics

Autonomy in clinical ethics refers to a patient's right to make informed decisions regarding their healthcare. It is one of the fundamental principles of medical ethics, along with beneficence, non-maleficence, and justice.

Key Aspects of Autonomy

- **Informed Consent:** Patients must receive clear, comprehensive information about their diagnosis, treatment options, risks, and benefits.
- **Decision-Making Capacity:** Patients must be mentally competent to make healthcare decisions. If they lack capacity, a surrogate decision-maker (e.g., family member or legal representative) may act on their behalf.
- **Voluntariness:** Decisions should be made freely, without coercion or undue influence.
- **Right to Refuse Treatment:** Patients can decline medical interventions, even if their decision may result in harm or death.
- **Advance Directives:** Patients can document their healthcare preferences for future situations where they may be unable to communicate their wishes.

Challenges to Autonomy

- **Cognitive Impairment:** Conditions like dementia or severe mental illness may hinder informed decision-making.
- **Cultural and Religious Beliefs:** Some cultures emphasize collective decision-making over individual autonomy.
- **Medical Paternalism:** Healthcare providers may override patient choices in an attempt to act in their best interest.

Informed Consent for Medical and Surgical Procedures

Informed consent ensures that patients understand and voluntarily agree to a proposed medical or surgical intervention.

Key Components of Informed Consent

1. **Disclosure of Information:**
   - **Diagnosis:** Explanation of the medical condition.
   - **Nature of the Procedure:** Detailed description of the recommended treatment or surgery.
   - **Purpose:** Intended benefits and expected outcomes.
   - **Risks and Complications:** Potential side effects and rare but serious risks.
   - **Alternatives:** Other treatment options, including non-surgical approaches.
   - **Consequences of Refusal:** Possible outcomes if the patient declines treatment.
2. **Comprehension:**
   - Healthcare providers should use clear, non-technical language and confirm understanding by asking patients to restate key points.
3. **Voluntariness:**
   - The decision must be made freely, without coercion from medical staff, family, or others.
4. **Capacity to Decide:**
   - The patient must have the mental capacity to make informed decisions. If they lack capacity, a surrogate or healthcare proxy may provide consent.
5. **Documentation:**
   - The consent process must be documented, typically with a signed form outlining the discussion.
   - In emergencies, when consent cannot be obtained, healthcare providers may proceed under the principle of **implied consent**.

Consent for Medical Procedures in Children

Minors generally lack the legal capacity to provide full informed consent, so parents or legal guardians must typically consent on their behalf.

Key Considerations

1. **Parental/Guardian Consent:**
   - Parents or legal guardians usually provide consent for medical procedures on behalf of a child.
   - Informed consent requires that guardians understand the risks, benefits, and alternatives.
   - Custody agreements may determine which parent has the authority to consent.
2. **Assent from the Child:**
   - While legal consent comes from the guardian, children should be involved in decisions about their healthcare whenever possible.
   - **Assent** refers to the child's willingness to undergo a procedure after it has been explained in an age-appropriate manner.
3. **Exceptions Allowing Minors to Consent:**
   - **Mature Minor Doctrine:** Some jurisdictions allow competent minors (e.g., 16 or 17 years old) to consent to medical treatment.
   - **Emancipated Minors:** If legally emancipated (married, in the military, or financially independent), they can consent to their own medical care.
   - **Specific Medical Situations:** Minors may self-consent for reproductive health services, mental health treatment, STI testing, and substance abuse treatment.

Surrogate Consent

Surrogate consent allows a designated individual to make healthcare decisions for a patient who lacks decision-making capacity.

Key Aspects of Surrogate Consent

1. **When It Is Needed:**

    - Patients who are unconscious, in a coma, or severely ill.
    - Individuals with cognitive impairments such as advanced dementia.
    - Patients with severe mental health conditions affecting decision-making ability.

2. **Who Can Act as a Surrogate?**

    - A legally appointed healthcare proxy or power of attorney.
    - A court-appointed guardian.
    - A close family member (spouse, parent, adult child, or sibling) in the absence of legal documentation.

3. **Ethical and Legal Considerations:**

    - The surrogate should prioritize **substituted judgment** (what the patient would have wanted) over personal beliefs.
    - If the patient's preferences are unknown, decisions should be made based on the **best interest standard**.

Challenges in Surrogate Decision-Making

- Family disagreements over care decisions.
- Uncertainty about the patient's true wishes.
- Ethical conflicts between surrogates and medical recommendations.

Surrogate consent is vital for preserving patient dignity and ensuring ethical care when individuals cannot advocate for themselves.

Chapter 6: Consents in Pre-, Intra-, and Post-op Disclosure: A Comprehensive Overview

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In the medical field, obtaining informed consent is a fundamental ethical and legal requirement that ensures patients are fully aware of the risks, benefits, and alternatives associated with any medical procedure. This serves as a critical component in patient autonomy and shared decision-making, which are essential principles of the modern healthcare systems. This process is particularly vital in the context of surgical interventions, where the stakes are often high and the risk for complications is significant. Informed consent is not a one-time event but a continuous interaction that spans the pre-operative (pre-op), intra-operative (intra-op), and post-operative (post-op) phases of care. Each phase has its importance and presents its unique challenges and considerations.

Pre-operative Consent: The Foundation of Patient Autonomy

The pre-operative phase is where the foundation of informed consent is laid. During this stage, the surgeon or healthcare professional is responsible for explaining the nature of the proposed surgery, including its purpose, expected outcomes, potential risks, and any available alternatives. This discussion must be tailored to the patient's level of understanding, ensuring that they can make an informed decision about their care.

1. **Disclosure of Information**: The surgeon must disclose all relevant information about the procedure, including the diagnosis, the nature of the surgery, the likelihood of success, and the potential risks and complications. This information should be presented in a clear and understandable manner, avoiding medical jargon that could confuse the patient. Enforcing a pre-planned format of obtaining consent with a standardised checklist ensures uniformity, reduces the risk of missing critical information, and helps facilitate clear communication between healthcare professionals and patients, ultimately improving informed decision-making and patient trust.

2. **Understanding and Voluntariness**: It is not enough to simply provide information; the patient must also understand it. Patients frequently experience anxiety and uncertainty as they try to understand and cope with the complexities of their medical conditions. Keeping this in mind, healthcare professionals should assess the patient's comprehension and address any questions or concerns they may have. It is essential to tailor the method of informed consent, taking into account factors like age, educational background and cultural differences. Additionally, the consent must be given voluntarily, without any coercion or undue influence from the healthcare professionals or others.

3. **Documentation**: Once the patient has been adequately informed and has agreed to the procedure, their consent must be documented in writing. This documentation serves as a legal record that the patient was informed and agreed to the surgery. It typically includes a description of the procedure, a discussion of the possible complications, and the patient's signature.

4. **Special Considerations**: In some cases, additional considerations may be necessary. For example, if the patient is a minor, consent must be obtained from a parent or legal guardian. Similarly, if the patient is unable to provide consent due to cognitive impairment or unconsciousness, a surrogate decision-maker may be required. In emergency procedures, when immediate intervention is required to save a patient's life or prevent serious harm, obtaining informed consent may not always be feasible. If a surrogate decision-maker is unavailable and the urgency of the situation demands swift action, surgeons may proceed with treatment under the presumption of implied consent to act in the patient's best interest.

Intra-operative Consent: Adapting to Unforeseen Circumstances

The intra-operative phase presents unique challenges for obtaining consent, as the patient is typically under anesthesia and unable to participate in decision-making. However, there are situations where immediate decisions must be made intraoperatively, potentially without the opportunity for prior consent. This raises ethical dilemmas regarding patient autonomy and the necessity of obtaining consent in real-time. Surgeons can navigate these challenges by maintaining transparency and open communication with patients whenever feasible. This fosters a relationship of trust and confidence while respecting patient autonomy.

1. **Unanticipated Findings**: During surgery, the surgeon may encounter unexpected findings that were not anticipated during the pre-operative discussions. For example, the surgeon may discover a previously undiagnosed condition or a complication that requires immediate intervention. In such cases, the surgeon must decide whether to proceed with additional procedures or to delay further action until the patient can be informed and provide consent.

2. **Emergency Situations**: In life-threatening situations where immediate action is required to save the patient's life or prevent serious harm, the surgeon may proceed without obtaining additional consent. This is based on the principle of implied consent, which assumes that the patient would consent to life-saving measures if they were able to do so.

3. **Documentation of Intra-operative Decisions**: Any decisions made during the intra-operative phase must be thoroughly documented in the patient's medical record. This includes the nature of the unforeseen circumstances, the actions taken, and the rationale for those actions. This documentation is essential for maintaining transparency and accountability.

The ethical implications of obtaining consent under duress or urgency must be carefully considered, and guidelines should be established to aid surgeons in these circumstances.

Post-operative Consent: Ensuring Continued Understanding and Agreement

The post-operative phase is often overlooked in discussions of informed consent, but it is a critical component of the overall process. Patients should receive detailed information about their surgical experience, including potential risks and complications that may arise postoperatively. This phase is critical for reinforcing the patient's understanding of the procedure and for setting realistic expectations for recovery. Providing follow-up consultations and clear written instructions enhances the patient's postoperative experience and promotes adherence to recovery protocols.

1. **Disclosure of Outcomes**: After the surgery, the operating surgeon should inform the patient of the outcomes, including whether the procedure was successful, any complications, any unexpected findings and the rationale behind decisions made during the procedure.. This information should be provided in a timely manner and in a way that the patient can understand.
2. **Follow-up Treatments**: In some cases, additional treatments or procedures may be necessary following the surgery. For example, the patient may require physical therapy, medication, or even additional surgery. Healthcare professionals must obtain consent for these follow-up treatments, just as they did for the initial procedure.
3. **Addressing Complications**: If complications arise during the post-operative period, the surgeon must inform the patient and discuss the options for managing those complications. This may involve obtaining additional consent for further interventions or treatments.
4. **Patient Feedback and Questions**: The post-operative period is also an opportunity for the patient to ask questions and provide feedback about their experience. Healthcare professionals should encourage open communication and address any concerns the patient may have. Encouraging patients to express concerns or ask questions during follow-up visits can foster a collaborative relationship between patients and healthcare professionals.

Ethical and Legal Considerations

The process of obtaining consent in the pre-op, intra-op, and post-op phases is guided by both ethical principles and legal requirements. Ethically, informed consent is rooted in the principle of respect for patient autonomy, which holds that patients have the right to make decisions about their own bodies and medical care. This principle is enshrined in various ethical codes, including the Hippocratic Oath and the Declaration of Helsinki.

From a legal perspective, informed consent is a requirement in most jurisdictions. Failure to obtain proper consent can result in legal liability for healthcare professionals, including claims of negligence or battery. In some cases, the lack of informed consent can lead to significant financial penalties, loss of medical licensure, or even criminal charges.

To mitigate these risks, healthcare professionals must ensure that they follow best practices for obtaining and documenting consent at every stage of the surgical process. This includes providing clear and comprehensive information, assessing the patient's understanding, and documenting all discussions and decisions in the patient's medical record.

Challenges and Recommendations

Despite the recognized importance of informed consent, several challenges persist across all phases. Time constraints, high patient volumes, and varying levels of health literacy can hinder effective communication. To address these issues, healthcare institutions should invest in training programs focused on communication skills for surgical teams. Implementing standardized consent protocols, leveraging technology for educational purposes, and allocating adequate time for discussions can also improve the consent process.

Additionally, involving interdisciplinary teams, including nurses and patient advocates, can enhance the quality of consent discussions. These team members can provide additional support and resources, ensuring that patients feel informed and empowered to make well-informed decisions about their care while also offering emotional support and clarity throughout the process.

Conclusion

Informed consent in the surgical context is a dynamic process that extends beyond a single signature on a form. It encompasses a continuum of communication that begins in the preoperative phase and continues through to postoperative care.. Each phase presents unique challenges and considerations, but the underlying principles remain the same: patients must be fully informed, understand the risks and benefits of their treatment, and have the opportunity to make decisions about their care.

By adhering to these principles, healthcare professionals can ensure that they respect patient autonomy, minimize legal risks, and provide the highest standard of care. Ultimately, the goal of informed consent is to empower patients to make decisions that are in their best interests while also fostering a trusting and collaborative relationship between patients and the healthcare professionals.

Chapter 7: Breaking Bad News to Patients: An Empathetic Approach

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Breaking bad news to patients is one of the most challenging tasks for healthcare professionals. When it comes time to giving bad news like a serious diagnosis or one that's really unlikely to improve or to saying someone isn't responding to treatment, it's important to strike a good balance of empathy, frankness and clarity. Patients and their immediate families really carry these last moments with them for a long, long time. It is vitally important for the doctors and nurses to approach that conversation sensitively and professionally, as it is incredibly significant. This article explores the best practices, strategies, and ethical considerations involved in breaking bad news effectively.

Understanding the Importance of Compassionate Communication:

Bad news in a medical context refers to any information that negatively alters a patient's view of their future. This could range from a cancer diagnosis to the progression of a chronic disease or even the death of a loved one. The way this news is delivered can significantly impact a patient's emotional and psychological well-being. Poor communication can lead to confusion, distress, and loss of trust in the healthcare system, whereas a well-conducted conversation can foster understanding, acceptance, and a better coping mechanism.

The SPIKES Protocol: A Structured Approach:

One of the most common ways to give people the bad news that others don't like hearing is by following this SPIKES plan. These six steps help doctors and nurses show empathy and organise their focus to nail these conversations.

1. Setting Up the Interview (S):

Let's start by getting the physical space ready—put in some effort here—and also create a really cozy feeling, ready for the work that's ahead. This includes:

- Choosing a private, quiet, and comfortable space.
- Ensuring there is enough time to have the conversation without interruptions.
- Having a support person, such as a family member, present if the patient wishes.

2. Assessing the Patient's Perception (P):

Before delivering the news, it is crucial to understand what the patient already knows or suspects. Asking open-ended questions like, "What do you understand about your condition so far? can help gauge their awareness and readiness to receive the information.

3. Obtaining the Patient's Invitation (I):

Some folks don't like to get every gory detail all at once when they find out they aren't feeling right away. Some prefer gradual disclosure. Asking, "Would you like me to explain everything, or would you prefer to hear the key points first? Allows the patient to control the flow of information.

4. Giving the Knowledge and Information (K):

Use simple, non-technical language to explain the diagnosis and prognosis.

- Deliver the news in small, digestible chunks.
- Be truthful but also compassionate. Instead of saying, "You have terminal cancer and have only a few months to live, a more sensitive approach would be, "Your test results show that the cancer has advanced significantly. You know there are treatments that can help manage the symptoms, but we also need to talk about what that means for you next.

5. Addressing Emotions with Empathy (E):

Patients react differently to bad news—some may cry, others may become angry or withdrawn. Acknowledging their emotions and responding with empathy is crucial. Statements like "you really know this is really tough right now" or even the simple act of gently sitting there with them can be incredible ways of providing support.

6. Strategy and Summary (S):

Once the news has been delivered, the next step is to discuss the way forward. This includes treatment options, palliative care, support groups, and involving family members in decision-making. Summarising the discussion and ensuring the patient understands their options is essential for a smooth transition into the next phase of care.

The Role of Empathy and Emotional Intelligence:

Empathy is the cornerstone of effective communication in healthcare. It involves not only understanding a patient's feelings but also responding in a way that provides comfort and reassurance. Emotional intelligence is super important for doctors and nurses because it helps them keep their cool and keep showing that warm and caring side, even when things are terribly stressful and tricky to talk about.

Some key aspects of empathetic communication include:

• Active Listening: Paying full attention, nodding, maintaining eye contact, and allowing the patient to speak without interruption.

• Validating Feelings: Phrases like "It totally makes sense to feel that way" are really important because they make patients feel really listened to. Giving that kind of feedback really lets them know their feelings are understood and accepted.

• Nonverbal Cues: A gentle touch on the shoulder, a warm tone of voice, and open body language can convey support and compassion.

Common Challenges and How to Overcome Them

1. Dealing with Emotional Reactions

Patients may react with shock, denial, anger, or deep sadness. It's really important to give people time to simmer things down and not to rush through the conversation. Offering follow-up meetings and psychological support could really help them deal with things better.

2. Handling Family Dynamics

In many different cultures, family members play a central role in making decisions about health matters. Some families might ask not to tell their loved ones the full story. In such cases, ethical considerations come into play, and a balance must be struck between respecting cultural norms and maintaining patient autonomy.

3. Managing One's Own Emotions

It can really take an emotional toll on health providers when they have to deliver bad news. Regular debriefing with colleagues, seeking support from mentors, and practicing self-care are essential for maintaining emotional resilience.

Ethical Considerations in Breaking Bad News: Ethical principles such as autonomy, beneficence, non-maleficence, and justice play a crucial role in delivering difficult news.

- Autonomy: People deserve to know what's going on with their health and get to make smart decisions about it too.
- Beneficence: Healthcare providers must act in the patient's best interest, ensuring they receive compassionate care.
- Non-Maleficence: Certainly, part of the principle of doing no harm means that getting bad news to someone is very important to do it in a way that avoids causing too much psychological hurt.
- Justice: All patients deserve straight talk and respect from medical folks, no matter what background they come from or where their wealth is at.
-

The Importance of Follow-Up

Bad news doesn't end with one conversation. Follow-up appointments allow providers to monitor emotional well-being, clarify doubts, and adjust plans. This ongoing support shows commitment to the patient's journey.

Example: A week after a diagnosis, the provider checks in: "How are you feeling about everything? Any new questions?"

Breaking bad news to patients is a complex and emotionally charged process that requires skill, empathy, and ethical sensitivity. Using structured approaches like the SPIKES protocol, practicing active listening, and being mindful of emotional responses can help healthcare providers navigate these difficult conversations effectively. By fostering trust and understanding, they can support patients and their families through some of life's most challenging moments with dignity and care.

Chapter 8: Caring for Minors According to Medical Ethics

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Introduction

Caring for minors within the framework of medical ethics involves a delicate balance between respecting the rights of children, ensuring their well-being, and navigating the roles of parents or legal guardians.
Ethical considerations in paediatric care require a focus on autonomy, beneficence, non-maleficence, and justice while ensuring that minors receive the best possible medical care. This paper explores the key ethical principles governing medical care for minors, including consent, confidentiality, best interests, and the role of parents and healthcare providers in decision-making.

Ethical Principles in Paediatric Care

1. **Autonomy and Assent**
    - Autonomy refers to an individual's right to make informed decisions about their own healthcare. In paediatric care, full autonomy is often limited due to the minor's age and developmental stage.
    - Assent is the agreement of a minor to receive medical treatment. While minors may not have full legal capacity to consent, they should be involved in decision-making as much as possible based on their maturity level.
    - The American Academy of Paediatrics (AAP) encourages physicians to seek assent from minors when they have the capacity to understand their medical condition and treatment options.
2. **Beneficence and Non-Maleficence**
    - Beneficence requires that healthcare providers act in the best interests of the child, ensuring that medical decisions promote health and well-being.
    - Non-maleficence obligates healthcare professionals to avoid harm. This principle requires balancing risks and benefits of treatments while minimizing potential negative consequences for minors.
    - Healthcare providers must evaluate whether a proposed treatment aligns with the child's best interests and seek alternative options if necessary.
3. **Justice and Equity in Care**
    - Justice involves fairness in the distribution of healthcare resources and access to medical services for all minors, regardless of socioeconomic background.
    - Equity ensures that all children receive appropriate medical care tailored to their needs, with particular attention to vulnerable populations, such as those in foster care or with disabilities.

Consent and Decision-Making

1. **Parental Consent**
   - In most jurisdictions, parents or legal guardians must provide informed consent for a minor's medical treatment.
   - Exceptions exist where minors can consent on their own, such as for emergency medical treatment, reproductive health services, mental health care, or substance abuse treatment in some regions.
2. **Mature Minor Doctrine**
   - Some legal systems recognize the "mature minor doctrine," allowing minors who demonstrate sufficient maturity to make their own medical decisions without parental consent.
   - Courts and medical professionals assess maturity based on factors such as age, intelligence, experience, and ability to understand consequences.
3. **Emancipated Minors**
   - Minors who are legally emancipated (through marriage, military service, or court order) have the right to make independent healthcare decisions without parental involvement.
4. **Emergencies and Life-Threatening Conditions**
   - In emergencies, healthcare providers can administer life-saving treatment to minors without parental consent if delaying care would result in significant harm or death.

Confidentiality and Privacy

1. **Protecting Minor's Confidentiality**
   - Confidentiality is essential in building trust between minors and healthcare providers.
   - Physicians should ensure that minors feel safe discussing sensitive issues such as sexual health, mental health, and substance use.
2. **Limits of Confidentiality**
   - While confidentiality is important, it is not absolute. Healthcare providers must break confidentiality in cases where minors are at risk of harm, such as abuse, suicidal ideation, or risk to others.
   - Mandatory reporting laws require healthcare providers to report suspected abuse or neglect to appropriate authorities.

Ethical Dilemmas in Paediatric Care

1. **Refusal of Treatment by Minors or Parents**
   - A minor's refusal of treatment, such as a blood transfusion, may be overridden if the treatment is necessary to save their life.
   - If parents refuse life-saving treatment for their child due to religious beliefs, courts may intervene to protect the child's welfare.
2. **End-of-Life Decisions**
   - Ethical challenges arise when minors suffer from terminal illnesses and must decide on palliative care, do-not-resuscitate (DNR) orders, or withdrawal of life-sustaining treatment.

- In cases where minors have expressed their preferences, healthcare providers must consider their voices while ensuring legal and ethical compliance.

3.GENETIC TESTING AND RESEARCH

The advances in technology and expanded access to genetic testing resulted in more minor patients receiving genetic tests for diagnostic or prognostic purposes.

It is important that the genetics and ethics committees work together on specific case-based guidelines to maximize the benefit for paediatric care, while preventing harmful situations.

Genome sequencing is nowadays becoming increasingly faster and affordable, with significant impact on scientific research and clinical practice.

The utility of genetic testing in paediatrics is growing significantly, and it is believed that it will help discover undiagnosed and rare genetic diseases.

Besides the benefits of genomic sequencing in paediatric practice, the literature has also underlined a number of important ethical dilemmas including minor's future autonomy, parental permission and autonomy, the best interests of the patient and his/her family

4.Vaccination and Public Health

- Parents who refuse vaccinations for their children pose an ethical dilemma, as their decision may endanger public health.
- Some jurisdictions allow minors to consent to vaccinations without parental approval to protect community health.

Role of Healthcare Providers

1. **Advocacy for the Child's Best Interests**
    - Paediatricians and other healthcare professionals serve as advocates for their young patients, ensuring that medical decisions prioritize the child's welfare.
2. **Communication with Families**
    - Transparent and compassionate communication is essential when discussing diagnoses, treatment options, and potential outcomes with both minors and their guardians.
    - Providers should educate parents and children about medical conditions in a way that is age-appropriate and understandable.
3. **Ethics Committees and Legal Guidance**
    - In complex cases, healthcare providers may seek guidance from hospital ethics committees or legal experts to resolve ethical conflicts.

Insights from "Involving Minors in Medical Decision Making"

- **Understanding Assent and Refusal:** Lang and Paquette (2021) discuss the ethical complexities of pediatric assent and refusal. They emphasize that while minors should be involved in decision-making, their refusal of treatment must be carefully assessed, considering their cognitive development and emotional state.

- **Parental and Provider Roles:** The article highlights the role of parents and providers in ensuring decisions align with the child's best interests while respecting the minor's developing autonomy.
- **Legal and Ethical Frameworks:** It underscores the importance of balancing legal obligations with ethical considerations when minors refuse treatment, particularly in cases involving chronic illnesses or end-of-life care.

Relevant Indian Legislations

1. **The Indian Medical Council Act, 1956**
   Governs medical practice in India and establishes ethical guidelines for doctors, including treatment of minors.
2. **The Protection of Children from Sexual Offences (POCSO) Act, 2012**
   Ensures confidentiality and special provisions for the medical care of minor victims of sexual offenses.
3. **The Juvenile Justice (Care and Protection of Children) Act, 2015**
   Provides legal provisions for the care and protection of minors, including their rights in medical decision-making.
4. **The Medical Termination of Pregnancy (MTP) Act, 1971 (Amended in 2021)**
   Allows minors to seek abortion with the consent of a guardian, ensuring access to reproductive health services while protecting their rights.
5. **The Right to Education Act, 2009**
   Indirectly impacts healthcare by emphasizing the need for health and nutrition in school-aged children.
6. **The Drugs and Cosmetics Act, 1940**
   Regulates access to medications, including those prescribed to minors, ensuring safe medical practices.
7. **The Mental Healthcare Act, 2017**
   Grants rights to minors regarding mental health care and establishes guidelines for their treatment and consent in psychiatric care.

Conclusion

Caring for minors in medical practice requires navigating complex ethical principles, balancing parental authority with the child's rights, and ensuring that medical decisions align with the best interests of the minor. By upholding principles of autonomy, beneficence, non-maleficence, and justice, healthcare providers can offer ethical and compassionate care to minors while addressing ethical dilemmas with sensitivity and professionalism.

Chapter 9: Ethics of mental healthcare

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Ethical principles provide the foundation of professional practice in mental healthcare. Autonomy, beneficence, non-maleficence, and fairness are the fundamental ethical principles of mental health care. Each of these values is essential for guiding the conduct of mental health practitioners and ensuring that patients receive treatment that respects their rights and dignity.

Psychiatry is distinct from other branches of medicine due to the nature of its practice, which involves treating patients with mental disorders where the lines between health and illness, reality and delusion, and autonomy and incapacity can be blurry. Unlike other medical fields, psychiatric practice often involves subjective assessments of patients; thoughts, emotions, and behaviors, which introduce significant ethical dilemmas regarding patient rights and treatment.

Relevance of Ethics in Psychiatry

- The line of demarcation between normal and abnormal is hazy
- Validity of diagnosis and treatment can be questioned
- Psychiatric treatment can be used for vested interests
- A close relationship between therapist & the patient can lead to intense transference, which could be wrongly utilised
- Poor insight may affect a patient's decision making
- Confidence reposed in the therapist may be exploited

In 1989, the Indian Psychiatric Society (IPS) adopted a code of ethics for psychiatrists in India, emphasizing principles like responsibility, competence, benevolence, moral standards, patient welfare, and confidentiality, drawing from the World Psychiatric Association (WPA) code.

Some key areas in which ethics plays a crucial role in psychiatry:

a) Patient Autonomy and Informed Consent:

Autonomy: Respecting a patient's autonomy, or their right to make decisions about their treatment, is a cornerstone of medical ethics. However, in psychiatry, patients may not always be in a position to make fully informed decisions due to the nature of their mental illness (e.g., in cases of psychosis or severe depression).

Informed Consent: Psychiatrists face ethical challenges when patients with mental health disorders refuse treatment or are incapable of understanding their medical options.

b) Involuntary Treatment:

A unique ethical dilemma in psychiatry is when treatment needs to be administered involuntarily, often in cases where a patient is deemed a danger to themselves or others. The decision to impose

treatment against a patient's will is fraught with ethical questions about autonomy, beneficence (doing good), and non-maleficence (avoiding harm).

c) Confidentiality and Privacy:

Confidentiality is another critical aspect of medical ethics, particularly in psychiatry, where patients often reveal deeply personal and sensitive information. The challenge of balancing confidentiality with the need to share information in certain circumstances, such as when a patient poses a risk to themselves or others. Psychiatrists must carefully navigate these boundaries, ensuring that they protect patient privacy while also safeguarding the well-being of patients and others.

d) Stigma and Discrimination:

Stigma surrounding mental illness remains a significant ethical issue in psychiatry, often leading to discrimination and marginalisation of patients. It is the responsibility of psychiatrists to combat stigma, both within the healthcare system and society at large, and to treat patients with respect and dignity

e) Cultural Sensitivity:

Psychiatry must also take into account cultural beliefs and values, as these can influence both the presentation of mental illness and how patients perceive and respond to treatment. Psychiatrists need to be culturally competent and sensitive to the diverse backgrounds of their patients to provide ethical and effective care.

f) The Right to Refuse Treatment:

Psychiatrists often face situations where patients refuse treatment, either because they don't believe they need it or due to concerns about the medications. Respecting a patient's right to refuse treatment while also ensuring they receive appropriate care is a difficult ethical dilemma. In some cases, a psychiatrist may have to determine if the patient's decision is influenced by their illness (e.g., lack of insight in conditions like schizophrenia) and if treatment should be imposed for their safety.

g) End-of-Life Decisions:

In psychiatry, patients with severe mental health conditions may sometimes make decisions about end-of-life care, such as requesting euthanasia or assisted suicide. Psychiatry intersects with debates about euthanasia, assisted suicide, and palliative care in cases of chronic, severe mental illness. Psychiatrists must navigate these issues while balancing the rights of the patient and the legal and ethical frameworks in place.

h) Psychiatric Research:

Ethical principles hold particular significance in psychiatric research, especially when involving vulnerable populations, such as those with severe mental disorders. In psychiatric studies, obtaining informed consent from participants is essential, particularly when working with patients who may have impaired decision-making abilities due to their mental health conditions.

It is crucial to ensure that participants fully understand the purpose of the research, as well as its potential risks and benefits. Research involving individuals with mental illness must take extra precautions to protect their rights and safety, minimizing risks of exploitation.

i) Therapeutic Relationship*:*

A psychiatrist's relationship with the patient should be trust-based and focused on patient-centered care. Ethical principles emphasize that psychiatrists should maintain appropriate boundaries, avoid dual relationships (e.g., treating friends or family members), and prioritize the patient's well-being. Psychiatrists should involve patients in the treatment process, collaborating with them to understand their goals, preferences, and concerns.

j) Ethical Guidelines and Professionalism:

Psychiatrists must adhere to established ethical guidelines provided by professional bodies like the Indian Psychiatric Society or international organisations like the World Psychiatric Association. Maintaining professional ethics and integrity in clinical practice, education, and research ensures high standards of care and protects the rights of patients.

Evolution of mental healthcare in India

India's mental healthcare system has evolved from early asylum-based custodial care to a more holistic approach, marked by key milestones including the Indian Lunacy Act of 1912, the Mental Health Act of 1987, and the Mental Healthcare Act of 2017, which emphasises on rights and access to care.

On March 27, 2017, Lok Sabha unanimously passed the **Mental Healthcare Act 2017** and was approved by the Honorable President of India in April 2017. In MHCA 2017, the legal and ethical aspects related to admission, discharge, consent to treatment, the capacity to consent, and role of the nominated representative (NR) are clearly set forward.

The Mental Healthcare Act, 2017 gives legal recognition to advance directives and nominated representatives, aligning with the UN Convention on the Rights of Persons with Disabilities (UNCRPD). It allows patients with mental health conditions to make binding decisions about their future care, including appointing a nominated representative who can make decisions on their behalf when needed. The Act aims to protect individuals rights while ensuring that their treatment preferences are respected.

Advance directives

Advance directives are legal documents that allow adults (or legal guardians in case of minors) to express their preferences for treatment in case they lose the capacity to make decisions about their own care in the future, especially during a psychiatric crisis.

The individual wishing to make advance treatment decisions must write out on paper his/her prescriptions and/or proscriptions for future care and treatment.

He/she may also additionally nominate a surrogate decision-maker referred to in the MHCA as nominated representative (NR).

Such a document must be submitted then to the Mental Health Review Boards (MHRB), where it must be registered. Every Board shall maintain an online register of all advance directives registered with it and make them available to the concerned mental health professionals as and when required.

An advance directive may be made by a person irrespective of his past mental illness or treatment for the same.

An advance directive shall be invoked only when such a person ceases to have the capacity to make mental health care or treatment decisions and shall remain effective until such a person regains the capacity to make mental health care or treatment decisions.

Any decision made by a person while he has the capacity to make mental health care and treatment decisions shall override any previously written advance directive by such person.

An advance directive may be revoked, amended or cancelled by the person who made it at any time.

The advance directive shall not apply to the emergency treatment given under section 103 (MHCA) to a person who made the advance directive.

It shall be the duty of every medical officer in charge of a mental health establishment and the psychiatrist in charge of a person's treatment to propose or give treatment to a person with mental illness, in accordance with his valid advance directive

Power to review, alter, modify or cancel advance directive

Where a mental health professional or a relative or a care-giver of a person desires not to follow an advance directive while treating a person with mental illness, such mental health professional or the relative or the care-giver of the person shall make an application to the concerned Board to review, alter, modify or cancel the advance directive. Upon receipt of the application, the Board shall, after giving an opportunity of hearing to all concerned parties (including the person whose advance directive is in question),either uphold, modify, alter or cancel the advance directive after taking into consideration the following, namely:

(a) whether the advance directive was made by the person out of his own free will and free

from force, undue influence or coercion; or

(b) whether the person intended the advance directive to apply to the present circumstances,

which may be different from those anticipated; or

(c) whether the person was sufficiently well informed to make the decision; or

(d) whether the person had capacity to make decisions relating to his mental health care or treatment when such advanced directive was made; or

(e) whether the content of the advance directive is contrary to other laws or constitutional provisions.

The person writing the advance directive and his nominated representative shall have a duty to ensure that the medical officer in charge of a mental health establishment or a medical practitioner or a mental health professional, as the case may be, has access to the advance directive when required.

A medical practitioner or a mental health professional shall not be held liable for any unforeseen consequences on following a valid advance directive. He/ she shall not be held liable for not following a valid advance directive, if he has not been given a copy of the valid advance directive.

Recommendations for Improvement:

Training and Awareness: There is a need for better education and training for healthcare professionals, patients, and families about advance directives and the role of nominated representatives to ensure these mechanisms are used effectively.

Clearer Legal Framework: There is a need for clearer guidelines regarding how advance directives and nominated representatives are to be implemented, particularly in cases where there is ambiguity or conflict about the patient's preferences.

Support Systems: Supportive systems need to be created to help individuals make advance directives, such as counseling services that can guide patients through the process of understanding and expressing their preferences.

Chapter 10: End of Life and Palliative Care

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End of life care means the provision of care to a patient suffering terminal illness that shifts the focus of care to symptom control, comfort, dignity, palliative care, quality of life and quality of dying rather than treatments aimed at cure or prolongation of life and includes care provided after the withholding or withdrawing of life sustaining treatment.

Palliative care is an approach that improves the quality of life of patients and their families' facing problems associated with life-threatening illness, through the prevention and relief of suffering via early identification and impeccable assessment and treatment of pain and other problems, whether physical, psychosocial, or spiritual.

Withdrawal (WD): A considered decision in a patient's best interests, to stop or discontinue ongoing life support in a terminally ill disease that is no longer likely to benefit the patient or is likely to harm in terms of causing suffering and loss of dignity.

Withholding (WH): A considered decision in a patient's best interests, to not start a life supporting measure in a terminally ill patient, that is unlikely to benefit the patient and is likely to harm in terms of suffering and loss of dignity. The same above three conditions must apply.

Do-Not-Attempt-Resuscitation (DNAR): A considered decision not to perform cardio pulmonary resuscitation (CPR) in the event of anticipated cardiac arrest if there is no realistic possibility of survival or meaningful recovery.

WD, WH and DNAR are collectively termed Foregoing of Life Support (**FLST**)

Life sustaining treatment (LST) means any medical treatment that artificially supports or replaces a body function essential to the life of the person and includes but is not limited to cardiopulmonary resuscitation, endotracheal intubation, extra-corporeal membrane oxygenation, mechanical ventilation, vasopressor therapy, left ventricular assist devices, parenteral or artificial enteral nutrition, dialysis, blood products, antibiotics, intravenous fluids.

Ethical principles in EOLC

Autonomy: Patients have the right to agree to or refuse any life sustaining treatment. Moreover, patients without decision-making capacity, autonomy is protected by the instrument called Advance Medical Directive (AMD), or patients' wishes can be expressed by family, or legally authorized proxy.

Beneficence: For terminally ill patients where death is inevitable, treating physician should neither hasten or delay the dying process, should avoid unwanted treatment and unjustifiable financial burdens, and provide timely emotional support.

Nonmaleficence: Decision of WH and WD of life sustaining treatment for terminally ill patients should always be taken in the best interest of the patient. At all times potential benefits must outweigh potential harms.

Distributive justice: Physician should prioritize the allocation of resources to a potentially curable patient over patient with terminal illness who needs comfort care rather curative care.

Triggers to identify patients potentially in need of end-of-life care/palliative care

1. Catastrophic brain injury (traumatic brain injury, massive acute ischemic stroke, intracranial hemorrhage, brain infections, demyelinating diseases, septic encephalopathy) with coma (other than brain death) with poor prospects for meaningful neurological recovery.

2. Critical illness on a background of irreversible severe neurological disability such traumatic quadriplegia or end stage muscular dystrophies.

3. Critical illness on a background of chronic irreversible disorders of consciousness such as advanced dementia/minimally conscious state/ permanent vegetative state.

4. Postcardiac arrest anoxic-ischemic injury with Glasgow Motor Score M≤2 and neurophysiological markers of poor prognosis >3 days after return of spontaneous circulation (ROSC) having excluded confounding factors.

5. Advanced or metastatic malignancy with short median survival rates if treatment options are exhausted are declined by the patient

6. Advanced age with declining functional status and frailty or multiple co morbidities where interventions have a low probability of success or are declined by the patient.

7. Acute decompensation of chronic end stage organ failure such as pulmonary, cardiac, renal, or hepatic with low life expectancy and no option of organ transplantation; >/= 3 hospitalizations in the last 12 months.

8. Worsening multiorgan failure (e.g., SOFA >15) due to acute conditions refractory to a reasonable trial of organ support.

9. Any patient who expresses a desire against aggressive care or a patient without decision-making capacity with previously executed valid AMD declining such care.

10. Any other clinical scenario where the answer to the question "would you be surprised if the patient is alive at the end of 6 months–1 year" is "yes".

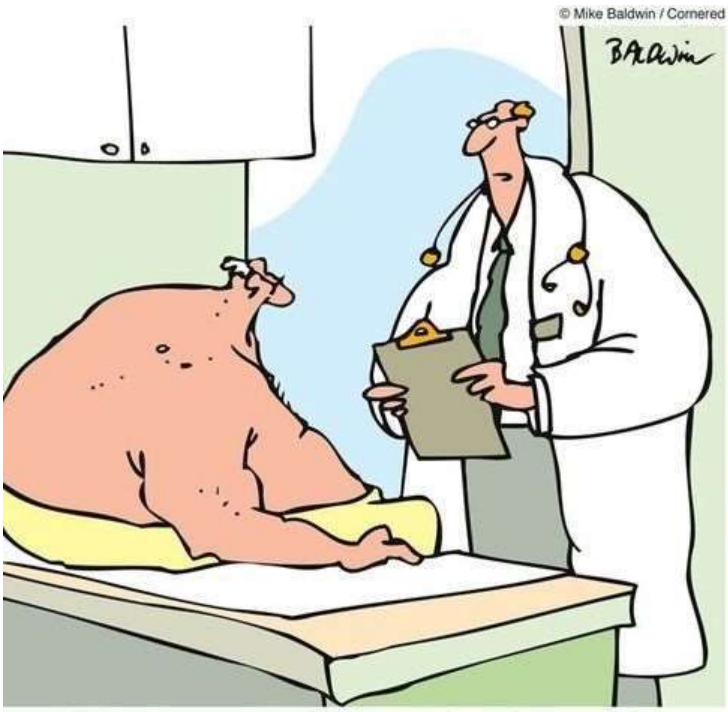
Legal standing of EOLC

- An adult patient capable of taking healthcare decisions may refuse LST even if it results in death.
- LST may be withheld or withdrawn lawfully under certain conditions from persons who no longer retain decision-making capacity.
- AMD that meets specified requirements is a legally valid document.
- Active Euthanasia is not lawful.

EOLC Clinical Pathway (Flowchart 1)

- For a patient without capacity, FLST proposals should be made by consensus among a group of at least 3 physicians who form the Primary Medical Board (PMB).
- The Primary Medical Board is constituted by the hospital/institution for each case, consisting of the primary physician and at least 2 subject experts with >/= 5 years' experience. Members of the PMB may be from the multidisciplinary treating team.
- The PMB must explain the illness, the medical treatment available, alternative forms of treatment, and the consequences of remaining treated and untreated to fully inform the surrogate.

- A Secondary Medical Board (SMB) of 3 physicians with one appointee by the Chief Medical Officer (CMO) of the district must validate the decision by the PMB.
- The Secondary Medical Board (SMB) constituted by the hospital/institution, consists of one Registered Medical Practitioner (RMP) nominated by the CMO and at least 2 subject experts >/= 5 years' experience.
- The PMB and SMB shall have to give an opinion in 48 hours.
- The doctor nominated by the district CMO may be from the same hospital.
- There is no bar on all doctors, in both Boards, being from the same hospital.
- A member of the PMB cannot form part of the SMB.
- The hospital should notify the decision of FLST by SMD to judicial magistrate of first class. Approval is not required.

Suggested reading

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