



UNESCO Chair  
in Bioethics  
(Haifa)



90 Glorious Years of Healing and Humanity

# Bulletin of GSMC MUHS UNESCO Bioethics Unit

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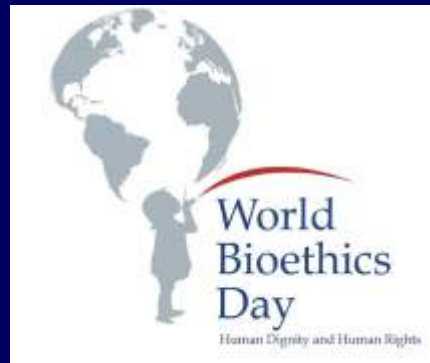
## Theme : 2016

## Human Dignity and Human Rights

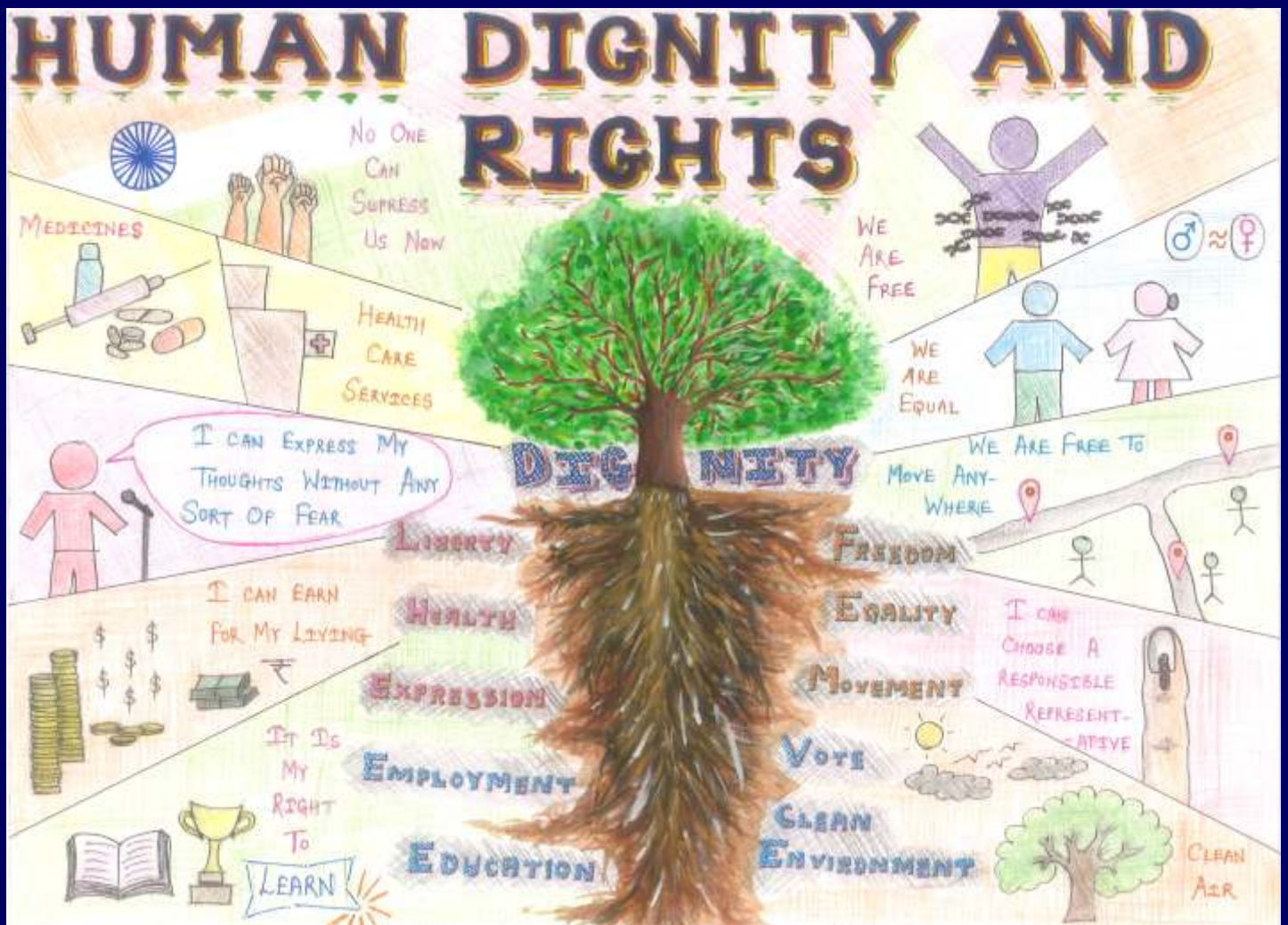
Seth G S Medical College and KEM Hospital, Parel, Mumbai -12  
[www.kem.edu](http://www.kem.edu) Email - [gmubioethics@kem.edu](mailto:gmubioethics@kem.edu)



# GSMC MUHS UNESCO Bioethics Unit



## Poster Competition on 'Human Dignity and Human Rights'



**First Prize**

**Minal Sapkal, II/I MBBS Student**





## Introduction

Advances in biomedical sciences have made ethical lens imperative for medical practitioners, researchers and society at large so that adherence to moral values of beneficence, justice, autonomy in medical practice and research are upheld.

Warren Reich's encyclopedia of Bioethics defines Bioethics as '*an area of interdisciplinary studies*' concerned with systematic study of human conduct in the area of life sciences and health care. Dr. James Drane calls the discipline paradigmatic because the dilemmas force the scholars to examine the essential life and death questions in the context of medical conditions. Scholars from diverse disciplines like philosophy, theology, sociology, law, biomedical sciences alongside medicine have contributed to development of the field. With their contributions to the development of bioethics core principles since 1960s, these streams have been instrumental in guiding medical practitioners towards rights based approach to health. So in way it is a union of the two trees of knowledge- humanities and philosophy on one side and medicine and biosciences on the other; that leads to growth of an integrated approach towards not only human but also environmental well-being and growth.

The Oxford dictionary defines the word '*Inarch*' as a plant graft created by connecting a growing branch without separating it from its parent stock. The term conveys the spirit of synergy between the two streams. Hence we chose this name for our bulletin which will bring to you articles on bioethical issues by medical faculty, students, ethicists, philosophers.

Our bulletin is intended for undergraduate, postgraduate students in medical, paramedical subjects and nursing as well as practitioners and teachers. It aims to open up discussion on ethics of practice, research, curriculum content and advances in biomedical sciences.

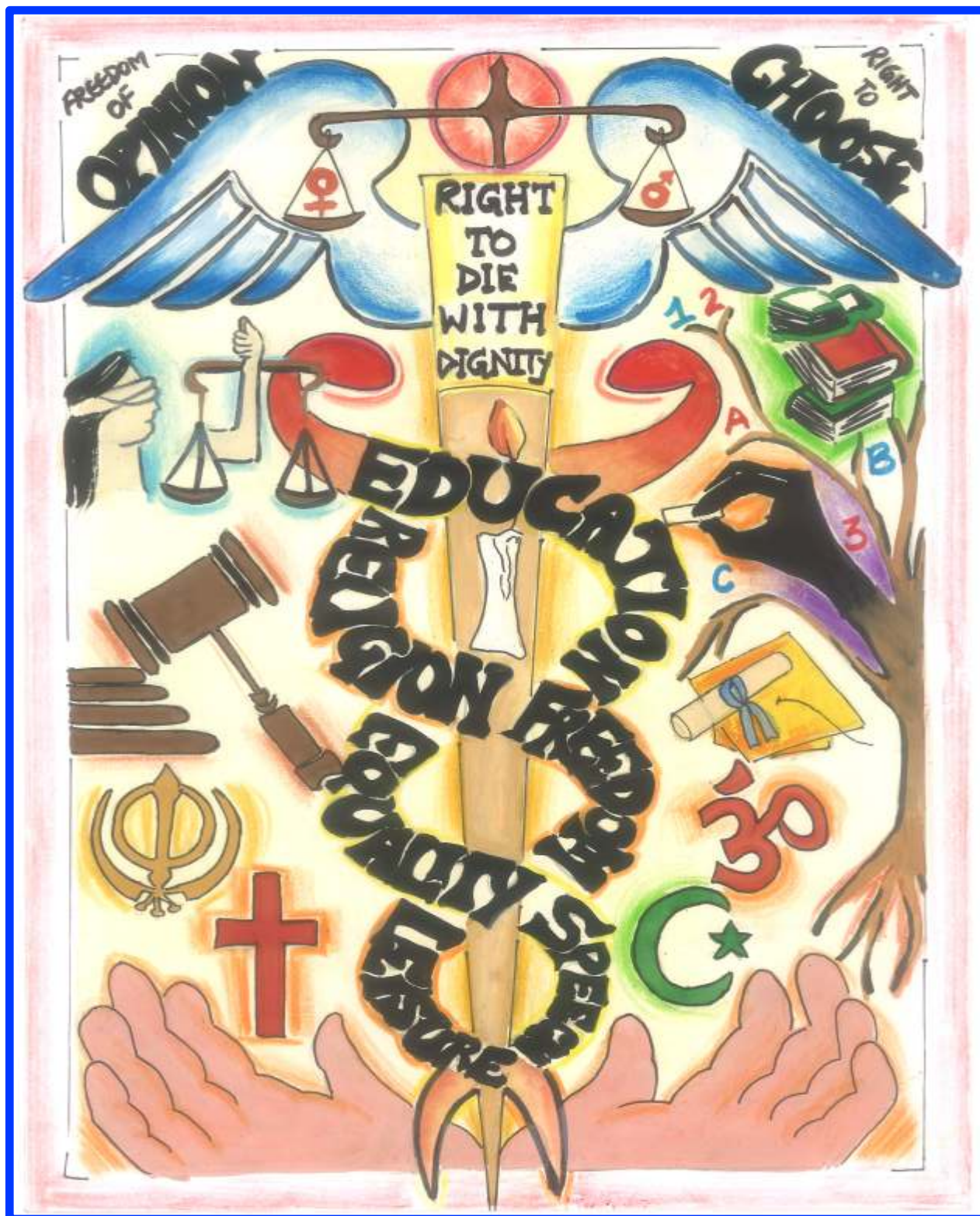






## GSMC MUHS UNESCO Bioethics Unit

### Poster Competition on 'Human Dignity and Human Rights'



### Appreciation Prize

**Nidhi Ranka**, II<sup>nd</sup> Year, Physical Therapy





# महाराष्ट्र आरोग्य विज्ञान विद्यापीठ, नाशिक

## Maharashtra University of Health Sciences, Nashik

(आय.एस.ओ. ९००१:२००८ इमागित विद्यापीठ An ISO 9001:2008 Certified University)

प्रा.डॉ. दिलीप गो. म्हैसेकर

एम.डी. (पल्मोनरी विज्ञान)

कुलगुरु

*Prof. Dr. Deelip G. Mhaisekar*

M.D. (Pulmonary Medicine)

Vice-Chancellor



### Message

It gives me immense pleasure and great joy to pen a few lines for GSMC MUHS UNESCO Bioethics Unit, Seth G S Medical College and KEM Hospital which is celebrating World Bioethics Day on 19<sup>th</sup> October 2016.

Ethics is now regarded as an essential component of medical education. I am extremely happy to note that Seth G S Medical College and KEM Hospital is planning to launch a unit bulletin – 'INARCH' during World Bioethics Day celebration. It is really praiseworthy that GSMC MUHS UNESCO Unit has chosen the most important theme Human Dignity-Human Rights and giving an opportunity to medical faculty, students, ethicists and philosophers to make their contributions through valuable articles. This University is always proud of its affiliated colleges especially those are under Municipal Corporation of Greater Mumbai. These colleges are rendering exemplary healthcare services to the masses and by doing so it not only raises the banner of the University but also makes their own progress day-by-day by leaps and bounds.

As the Vice Chancellor of Maharashtra University of Health Sciences, I consider it as my proud privilege to offer my best wishes for the success of Bulletin – INARCH team. My wholehearted compliments to the Dean, Teachers, Staff and Students on this auspicious occasion and congratulate them for all their achievements and wish them all the very best in their future endeavours.

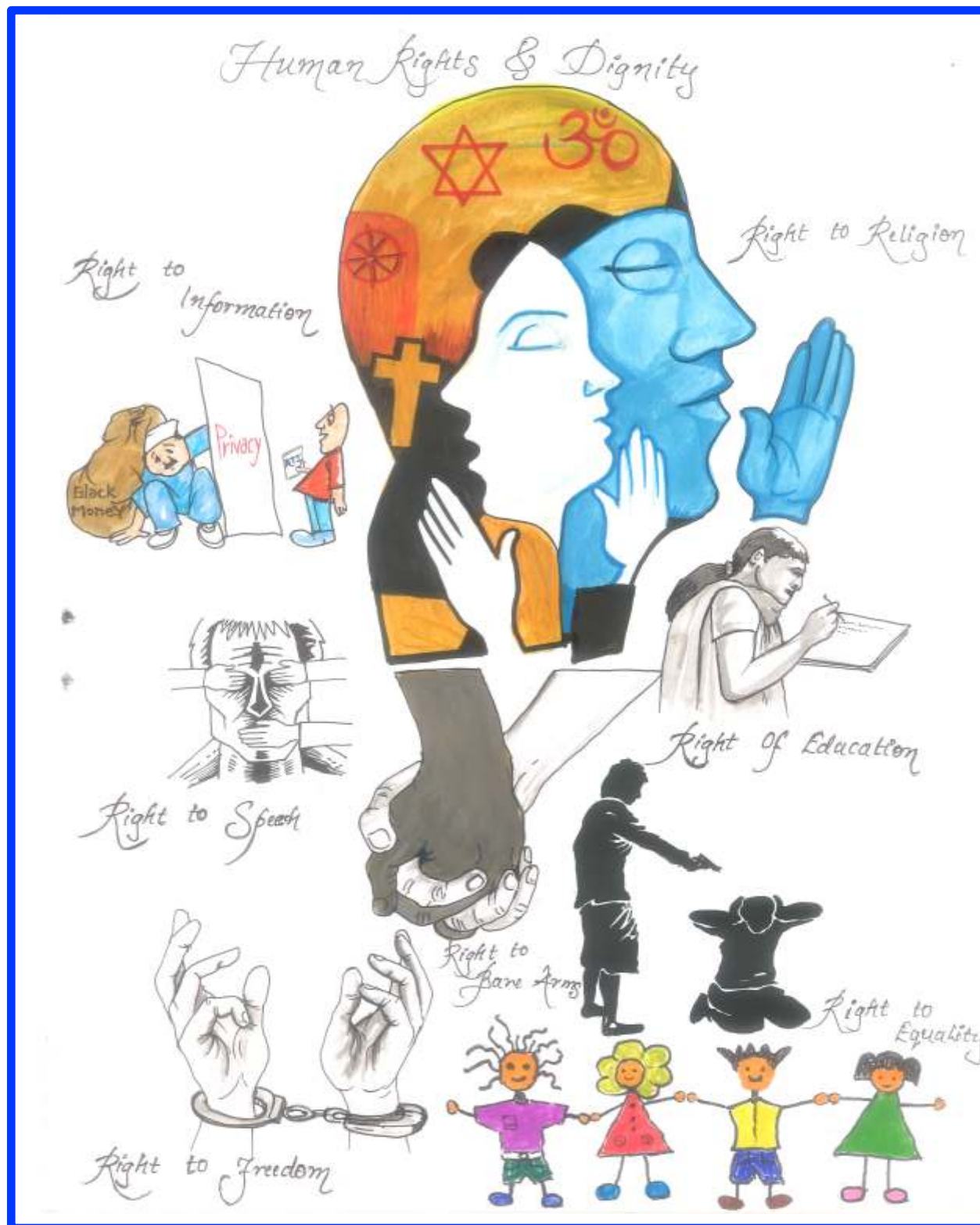
**Prof. Dr. Deelip G. Mhaisekar**





## GSMC MUHS UNESCO Bioethics Unit

### Poster Competition on 'Human Dignity and Human Rights'



### Appreciation Prize

**Hiral Sakaria**, II<sup>nd</sup> Year, Occupational Therapy





October 16<sup>th</sup>, 2016

### **Message from Prof. Amnon Carmi**

The establishment of world bioethics day is aimed as celebrating bioethical principles worldwide through an event on 19<sup>th</sup> October 2016 with the chosen theme of "Human Dignity and Human rights".

It will help foster bioethical thinking not only in health care providers and educators but also masses in general. There is also a recognized need for innovations in insemination of ethical values and virtues in the young minds.

The GSMC MUHS UNESCO Bioethics unit, under the promising leadership of Dr Avinash Supe, since solemnization, has carried out number of activities, inculcating these values using innovative tools among all the health care professionals and supportive staff.

The release of first issue of bulletin "Inarch" commemorates the growth of healthcare and bioethics with contribution from various stake holders, including ethicists and philosophers. It has channelized thoughts and emotions into words, art and games. The bulletin portrays the passion of the Steering Committee and students wing members of GSMC MUHS UNESCO Bioethics Unit through designing of the logo, articles and portray of theme through means of art.

I would like to congratulate Dr Avinash Supe, the steering committee members and students' wing of GSMC MUHS UNESCO Bioethics unit, for their success of "Inarch" and my best wishes to all for their untiring efforts in promoting bioethical spirit in the society.

Sincerely yours,

*Amnon Carmi*

**Prof. Amnon Carmi**

**Head of the UNESCO Chair in Bioethics (Haifa)**





## GSMC MUHS UNESCO Bioethics Unit

### Poster Competition on 'Human Dignity and Human Rights'



**Appreciation Prize**  
**Diksha Singh, II<sup>nd</sup> Year, M.B.B.S.**





## Asia Pacific Bioethics Division, UNESCO Chair in Bioethics, Haifa

71` Cleeland Street,  
Melbourne 3175 Australia  
Phone: + 919940515220  
Phone: + 61 (0) 3 97940045  
Fax: + 61 (0) 3 97946718



### Message

I am delighted to learn that the GSMC MUHS UNESCO Bioethics Unit is initiating the Inaugural Bulletin of the Bioethics Unit. I feel that the name of the Bulletin *Inarch* has particular meaning from beyond the reference to the concept of plant grafting, to the dynamic concept that will bring articles on Bioethical Issues from the Medical Faculty, Health Scientists, students, ethicists and philosophers.

This indeed is what might bring greater understanding and necessary skills in ethical decision-making in the clinical arena. Unit's leadership in contribution to the national bioethics program gives me confidence in this being an outstanding positive initiative.

Congratulation on the launch of the inaugural issue of *Inarch*. I also commend GSMC MUHS UNESCO Bioethics Unit on the thought process in all details including the fitting and meaningful name of the Bulletin.

I wish Dr Avinash Supe and all the members of your outstanding Unit of the UNESCO chair in Bioethics Haifa success and a very fruitful outcome to this noble initiative.

Best Wishes,

### Professor Russell D'Souza

MD(Madras),FCGP(I),MPM(Monash),DPM(Melbourne),DCTMg(Canberra),FIIOPM(USA),MRACMA,MHSMg (Monash), FACHSM (Australia),MBA (Exec)DFAPA(USA), ABDA(USA, Fellowship in International Bioethics Education

**Head -Asia Pacific Bioethics Division UNESCO Chair in Bioethics Haifa**

**Course Director -3T-IBHSc UNESCO Chair in Bioethics**

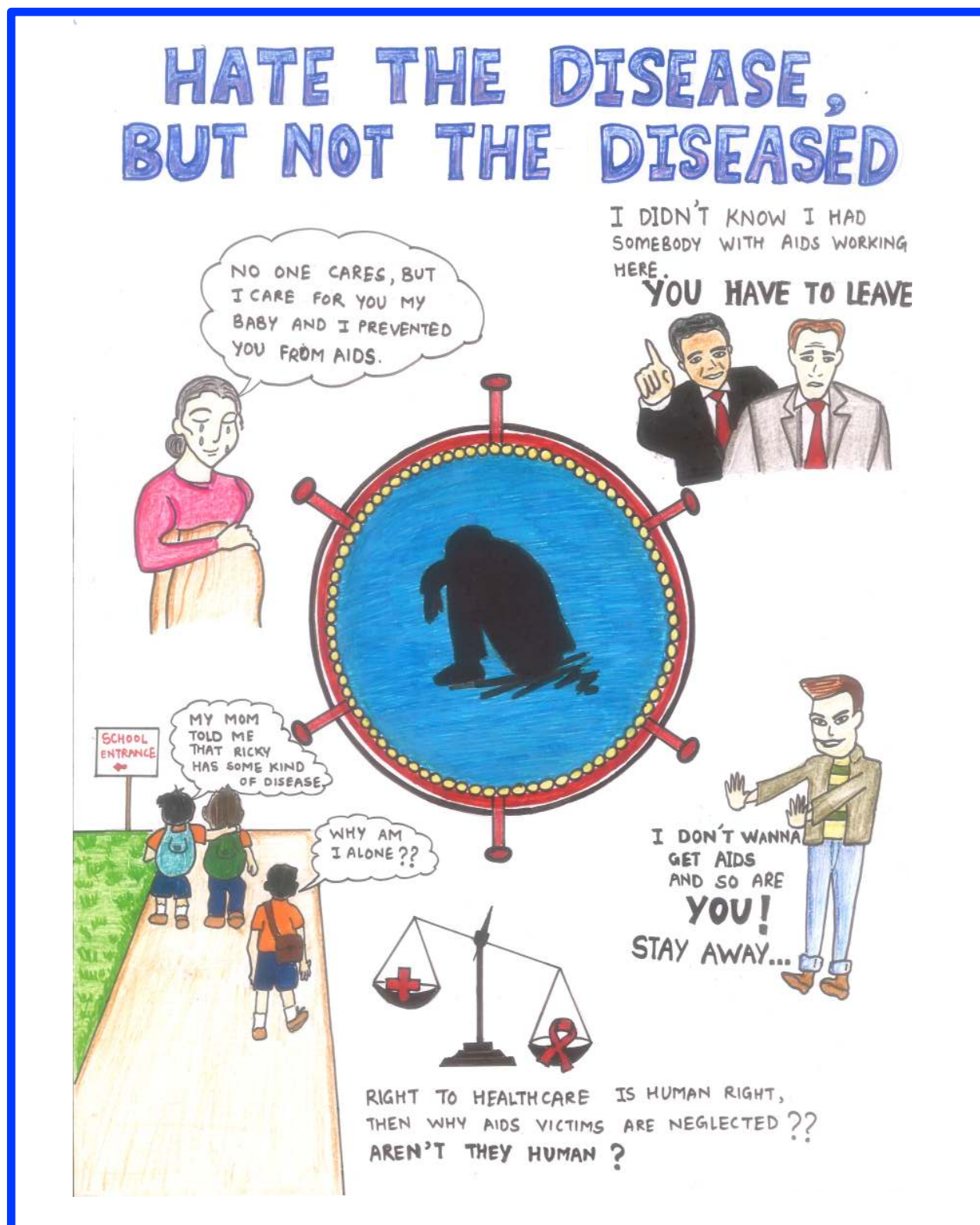
**Director - Centre for Asia Pacific Bioethics, Medical Ethics and Health Law Studies, Melbourne Australia**





## GSMC MUHS UNESCO Bioethics Unit

### Poster Competition on 'Human Dignity and Human Rights'



**Appreciation Prize**  
**Ruchita Janwade, Intern**





## Municipal Corporation of Greater Mumbai

Seth G S Medical College and K E M Hospital, Parel, Mumbai



### Message

It is my privilege to write a message for **inaugural issue of “INARCH”**, which is the official bulletin of the **UNESCO- MUHS- GSMC Bioethics unit**. Bioethics unit of our institute was established last year and over year, it has grown tremendously and has been conducting activities involving all sectors of health professions educations. In the modern era of biotechnological advances, bioethics is need of the medical specialty. Our unit has conducted various activities such as invited talks, essay competitions, debates, posters and has been spreading awareness about ethical principles amongst all students and faculty through innovations. The teamwork of core group is fantastic and discussions in the group are interesting and enlightening. On the occasion of world bioethics day, unit plans to release “INARCH” not only to promote the pursuit of ethical excellence but also to disseminate the bioethical views to the trainees, faculty and practicing professionals.

The theme of this issue is human dignity- human rights. This issue plans to cover human dignity, human rights - students’ perspectives, rights of disabled child, dignity & rights of vulnerable population, dying with dignity, and human rights in research and bioethical education in 2016. I am sure wisdom disseminated from various articles and editorial of this bulletin, will improve understanding of bioethics. This bulletin will also record excellent work carried out by our students and faculty in field of ethics. I congratulate all the contributors and the unit members for bringing out such a path-breaking bulletin.

Wishing them all the best!

#### Dr. Avinash Supe

MS FICS DNBE FCPS DHA PGDME  
MHPE (UIC)FIAGES FMAS FAIS

Director (ME & MH) and Dean,  
Chairman, GSMC MUHS UNESCO Bioethics Unit  
Professor, G I Surgery, Professor of Medical Education  
GS Medical College and KEM Hospital  
Director, GSMC FAIMER regional Institute  
President, Academy of Health Professions Education





## Poster Competition on



**Bhoomi Dalal**, I<sup>st</sup> Year, Physical Therapy





## Editorial

It is with a sense of pride and anticipation that we are embarking on our journey of exploration in this field of bioethics.

Scope of Bioethics is much wider than medicine and philosophy and the stage is much larger than medical institutes and philosophy classrooms. The subjects in bioethics range from research in human health, animal ethics, to environmental ethics.

The plight of refugees from Syria and detainees in Guantanamo bay are as much bioethical issues as political. The tragedies of survivors of atomic bombing and erosion of coral reef due to aquatic pollution are both bioethical as well as geopolitical issues. Bioethics overarches political platforms, societies and even war zones where violation of human rights is occurring every day. At the same time bodies like **Médecins Sans Frontières are healing the vulnerable people everyday**. As responsible citizens and health providers, we cannot ignore our role in making lives of these survivors tolerable.

Health care delivery is easier when there is enough budget, space and human resource. Most practitioners may argue that these scarcities are the root cause of the discontent between patients and doctors, poor health statistics and the agitation among patients. There is increasing distrust for doctors among people, Research in causes of deficiency, planning to fill the gaps and ensuring service delivery and last but not the least, advocacy for human rights are the key interventions that medical fraternity should be doing. Medical research is a critical area where justice, autonomy and nonmaleficence must be upheld and ensured.

Nursing and paramedical teaching are equally important facets of health sciences and cannot be ignored. Another area that requires to be focused on is palliative care. Nursing and paramedical health care providers have a very significant role in ensuring effective palliative care.

Current medical curriculum fails to highlight women's health issues as gender issue. There is little discussion in classrooms on the socio-political aspects of reproductive health problems, female feticide, surrogacy related issues etc. This causes perpetuation of apathy in medical graduates for the vulnerable.

Non-governmental organizations, ethicists, social workers have been on the forefront in doing sensitization interventions with medical fraternity. Maharashtra University of Health Sciences has given the mandate of training students in bioethics to medical colleges so that ethics and justice become underlying principles in teaching.

Good science cannot be based on poor ethics. So communities across medical universities should come forward to mainstream bioethics teaching in medicine.

**Dr. Padmaja Samant**



SWITCH  
LIVE CARE  
EDUCATION  
HEALTHY environment  
HEALTHY  
RECREATION  
HUMAN RIGHTS  
SEX Discrimination  
LAWLESS  
HUMAN RIGHTS  
HUMAN RIGHTS

PLEASE PRESERVE YOUR HUMANITY  
SO THAT  
WE CAN LIVE OUR  
CHILDHOOD

CHILDREN'S RIGHTS & DIGNITY





## **Integrating Bioethics in Health Professions Education – Need of the Hour**

**Dr Avinash Supe**

Dean and Director,

Medical Education and Major Hospitals MCGM

The term “bioethics” was first introduced in 1971 (Professor Van Rensselaer Potter (Wisconsin) and fellows of the Kennedy Institute in Washington, D.C.); it probably meant the merging of biology and bioscience with humanistic knowledge. However, over years bioethics now encompasses a wide range of issues, from ethical issues in complex clinical decisions to dilemmas of stem cell research, impact of cloning and newer reproductive technologies as well as broader concerns about international human subject research, public policy/legislation in healthcare and delivery of healthcare in resource scarce countries. Bioethics is multidisciplinary. It blends philosophy, theology, history, law with medicine, nursing, health policy and the medical humanities. Insights from various disciplines are brought to bear on the complex interaction of human life, science, and technology. Though these issues are present for many years, these are now covered under one umbrella termed as bioethics. Over the past few years bioethics has become an integral part of medical education worldwide.

Even though Medical Council of India has for years stipulated that medical ethics be taught in medical colleges in our curriculum, bioethics is not being taught regularly in our formal medical curricula. Bioethicists can provide a more objective and balanced view of complex ethical issues in health care settings. In other words, bioethicists can often provide an outside perspective on medical care.

### **Ethics Education – Need of the Hour**

In Indian culture, moral & ethical values get inculcated since birth. Over years when students come for medical college, basic values are already

assumed to be entrenched in them. However, when medical students encounter patients and face hospital scenarios, their basic values get challenged. This is right time where teachers along with peers can rebuild ethical values in them. In an US study involving medical students regarding perceptions regarding ethical values, it was found that students exposed to unethical situations within clinical environment may feel encouraged to maintain two separate codes of ethics, one personal and one as a physician. Many students felt that ethical values may decline as you face real world while establishing private practice. Witnessing unethical behavior predictably leads to an erosion of the noble ideals that young men and women entering medical college bring with them as they begin their training. There is a traumatic deidealization of graduates when they face real world. It is therefore very important to introduce bioethics, which prepares students to face real environment more ably. Inclusion of bioethics into medical curricula is an attempt to stem this decay and salvage the sanctity of this profession.

As the objective of teaching surgery or obstetrics at the undergraduate level is not to create specialist surgeons or obstetricians but to produce a mature medical graduate who is adequately equipped to recognize a variety of medical problems and treat them within limits of his expertise and refer those beyond his capacity of intervention to appropriate healthcare facilities. Similarly the objective of teaching bioethics is not to create bioethicists but to equip the graduate with adequate reasoning skills to be able to identify ethical dilemmas as they occur in his practice and attempt judicious resolution using the



knowledge and experience imparted to him/her during the training years. One who maximally benefits by introducing ethics education is patient. When a young student learns importance of bioethical issues during clinical training, his/ her patients do not suffer needless pain, their legal rights of self-determination are protected and their experience of health care is optimal.

A significant part of ethics education occurs passively through observation of faculty and peer influence during college days. To strengthen this informal mode of imbibing ethical values, more formal methods need to be applied; for example, formal didactic lectures, small group discussions, narrative essays, standardized patients, ethics rounds, movies and so on. It is generally agreed that actual case scenario based discussions are the best way of imparting bioethics education. A small group discussion with faculty guidance is the best method to achieve this.

For long-term acceptability and effectiveness, ethics education has to be seamlessly integrated into the existing medical curriculum. Bioethics must be taught by variety of faculty consisting of interdisciplinary groups rather than only medical teachers. There is an urgent need for including

bioethics in graduate medical education and other health professions curricula. However there is a need to create a culturally and regionally relevant bioethics curriculum. In India, bioethics became part of health Profession education under aegis of UNESCO. **UNESCO- MUHS- Bioethics** units have initiated these activities but system should adopt it over period of time to inculcate these values in our graduates and practicing physicians.

***Most of bioethics curricula are only on paper but are not actually delivered.*** Though many accrediting organizations require institutions to address ethics issues to some extent, the compliance bar is set fairly low for this purpose. Institutions therefore work with minimum requirement rather than adequate attention to ensure ethical patient care. Institutions should prioritize this, and also create separate funding for effective implementation of this curriculum.

In summary, ***bioethics education should be mandatory for all health professions students and practicing physicians. It should be integrated with existing curricula and thoughtfully delivered to prepare our graduates for facing real world more efficiently.***



**“Educating the mind without educating the heart is no education at all”**

**- Aristotle**



## Human Rights in Research –Journey So Far

*Guest Author*

**Dr. Sangita Sukumaran**

Prof. & Head, Pharmacology

Terna Medical College

***Protecting the health and welfare*** of those who volunteer to participate in clinical trials is the key tenet of ethical conduct of clinical research. Research participants should be treated with dignity, their well-being /rights preserved and safety protected. Scientific discoveries have alleviated the suffering caused by disease and disability. Nonetheless, the prospect of gaining valuable scientific knowledge need not and should not be pursued at the expense of human rights or dignity. History has demonstrated that researchers sometimes did not treat participants as persons but as mere objects of study. Though a number of ethical guidelines have been developed to improve ethical conduct of research, they are not being adequately followed.

Going back to history, the 1960s and 1970s saw many instances of unethical research reported where vulnerable groups like children, women, mentally challenged, prisoners of war, sick and elderly with diminished capacity to give consent were treated with disrespect and exposed to significant harm. The experiments had no scientific basis and rationale, consent was not taken and deception was used to enrol patients.

### **LANDMARK EXPERIMENTS OF HUMAN RIGHTS EXPLOITATION**

#### ***Nazi Experiments, 1947***<sup>1</sup>

In 1947 there were a horrendous set of experiments called Nuremberg trials conducted by the Nazis on the prisoners of World War II. After the war ended, many Nazi doctors and scientists were tried for the murder of concentration camp inmates who were used as research subjects.

#### ***Tuskegee syphilis Study (1932-1972)***<sup>2</sup>

Tuskegee syphilis study was conducted between 1932- 1972 by the US Public Health Service and examined the natural course of untreated syphilis in Afro-American sharecroppers from Alabama who were unknowingly participants in the study. They were not told they had syphilis and they were not offered treatment even after Penicillin was available as a cure in 1947. The outcome of the study was 28 deaths, 100 cases of disabilities, 19 cases of congenital syphilis.

#### ***Willowbrook Hepatitis Study (1956)***<sup>3</sup>

In 1956, mentally retarded children at an institution for in Staten Island, New York were deliberately infected with a mild form of hepatitis so that natural history of viral hepatitis and effectiveness of gamma globulin could be tested. The possible hazards involved in the study was not fully informed to the parents.

#### ***Brooklyn Jewish Chronic Disease Study (1963)***<sup>4</sup>

In 1963 live cancer cells were injected into senile patients without their knowledge as part of a study of immunity to cancer. Apparently the investigators believed that the cells would be rejected, and so did not seek consent from the participants because they did not want to frighten them.

#### ***Beecher's Landmark Article (1966)***<sup>5</sup>

In 1966 Henry Beecher an anesthesiologist published in the New England Journal Of Medicine, 22 cases of controversial research conducted by reputed physicians of United States and published in top journals.. He highlighted instances of dangerous research done, lack of informed consent and undue coercion. The risks were found to outweigh the



benefits and were not disclosed to the subjects.

### **Controversial Clinical Trials conducted in India**

#### ***John Hopkins-RCC Clinical trials***<sup>6</sup>

Reports of unethical conduct of clinical trials in India include John Hopkins and Regional Cancer Center, Trivandrum collaborative study. They enrolled 25 patients of oral cancer and tested an experimental anticancer drug.<sup>6</sup> The patients believed the injections given were part of treatment. The trial was conducted without taking informed consent and without regulatory approvals. The study led to worsening of the patients' condition and even death of two patients.

#### ***HPV Vaccine trials***<sup>7</sup>

The HPV vaccine study in Andhra Pradesh where tribal girls between 10-14 years from a hostel were administered HPV vaccine that resulted in four deaths. On enquiry, it was found that the parents who consented were made to believe the vaccine was part of public immunisation program. Consent forms were "incomplete and inaccurate", comprehensive information to the participants' parents/guardians on various aspects of the vaccination was not given, there were directions by the state (Andhra Pradesh) to hostel wardens to sign the consent forms on the parents' or guardians' behalf.<sup>7</sup> The study was not reviewed by an Ethics Committee.

Ensuring protection of rights of the vulnerable subjects involved in research is jointly the responsibility of researcher, ethics committees and sponsor. Obtaining a well informed consent from research participants is a challenge in India. Investigators must make appropriate disclosures and ensure that participants have understood the information, their rights and choices, at enrolment, and also throughout the research.

### **CODES AND GUIDELINES TO PROTECT HUMAN RESEARCH SUBJECTS**

The ethical guidelines in various parts of the world were formulated as a reaction to inhumane behavior with participants during research experiments.

#### **Nuremberg Code 1948**<sup>8</sup>

Nuremberg Code was developed after the Nuremberg trials. The Nuremberg code is considered the basis for sound scientific research protocol and consent. The code has 10 standards to which research scientists must adhere. The code emphasised that all participation in clinical research should be entirely voluntary, all experiments must be supported by strong scientific rationale, physical and mental damage to volunteers is not permissible and every subject has the right to withdraw from any clinical research.

#### **WMA-Declaration of Helsinki, 1964-2013**<sup>9</sup>

In 1964, the declaration of Helsinki was adopted by the World Medical Association. The Declaration of Helsinki is accepted as an international standard for biomedical research. This was the foundation for clinical research and has undergone 7 revisions, the latest revision in 2013. It emphasises the need for a clear experimental protocol that should be submitted for consideration, comment, guidance, and, approval to a specially appointed ethical review committee, which must be independent of the investigator, the sponsor or any other kind of undue influence. The latest version of the Declaration of Helsinki has addressed many of the important issues relevant to conducting research in developing countries, such as the need to include under-represented groups in research, the importance of effective research ethics committees, post-trial access to care, use of unproven interventions, and improving informed consent.

#### **Belmont report**<sup>10</sup>

As a reaction to Tuskegee syphilis study, in 1974 US Congress authorized the formation of the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research to identify basic principles of ethics for conduct of human research. The National Commission in 1979 published the Belmont Report. It recommended for the first time, oversight of research by an "Institutional Review Board".<sup>10</sup>



The Belmont report identifies three fundamental principles that underlie all research in human subjects: respect for persons, beneficence, and justice.

Respect for Persons requires individuals to be treated as autonomous beings and not as a means to an end. This includes special protection to vulnerable subjects. The principle of respect for persons requires obtaining informed consent and respecting the privacy and confidentiality of research subjects. Subjects if capable must be given opportunity to choose what shall or shall not happen to them in the research process. They must be provided adequate information, made to understand the implications of research and need to volunteer to participate. Research should allow subjects to withdraw from the study. Beneficence requires use of best possible study design, researchers must be able to perform the procedures and handle the risks. Researchers should evaluate the social and scientific value of the study. The principle of justice requires to treat people fairly and to design research so that its burdens and benefits are shared equitably. There should be no exploitation of vulnerable populations.

Each of the three principles should have equal moral force. This means that in some situations, the three principles might be in conflict with one another.

#### **CIOMS/WHO International Ethical Guidelines For Biomedical Research Involving Human Subjects(1993)<sup>11</sup>**

With the increasing interest of pharmaceutical industries in carrying out research experiments in the developing and the under developed countries, in 1982, the Council for International Organizations of Medical Sciences (CIOMS) in association with World Health Organization (WHO) developed 'International Ethical Guidelines for Biomedical Research Involving Human Subjects', revised in 1993 and updated in 2002. They stress upon ethical issues in less developed countries like investigator's duties

regarding consent, appropriate compensation, special/vulnerable populations, therapeutic misconceptions and post-trial access.

#### **International Conference on Harmonization Guidelines for Good Clinical Practice(ICH/GCP) (1996)<sup>12</sup>**

Harmonised Tripartite Guidelines (ICH-GCP) is the product of an ambitious international partnership between USA, Japan and Europe promulgated in 1996. It details standards for ethics review committees, describes responsibilities of investigators and sponsors and is formulated specifically for research on drugs and devices for regulatory approval.

#### **INDIAN GUIDELINES**

##### **The ICMR Ethical Guidelines for Biomedical Research on Human Participants 2006**

In 1980, the Indian Council of Medical Research(ICMR) developed "Policy Statement on Ethical Considerations Involved in Research on Human Subjects"<sup>13</sup>, revised in 2000 and amended in 2006. These guidelines elaborate twelve general principles for conduct of research

1. Essentiality
2. Principle of voluntariness, informed consent and community agreement
3. Principle of non-exploitation
4. Principle of privacy and confidentiality
5. Principle of precaution and risk minimisation
6. Principle of professional competence
7. Principle of accountability and transparency
8. Principle of maximisation of public interest and distributive justice
9. Principle of institutional arrangements
10. Principle of public domain
11. Principle of totality of responsibility and
12. Principle of compliance.

The 2006 amendments elaborated on five specific areas such as clinical trials, epidemiological research, human genetics research, organ transplantation and assisted reproductive technologies. With further new debatable issues cropping up in the global scenario like stem cell research, bio-banking, herbal remedies



etc. guidelines were updated in 2006 guidelines. The ICMR released the *National Guidelines for Stem Cell Research* in 2013.

Recently the draft version of third edition of the ICMR guidelines has been released for public comments.<sup>14</sup> Efforts are on to legislate the ICMR guidelines to make them mandatory for all biomedical researchers.

### **Schedule Y Drugs and Cosmetics Rules**

Although not a law, the ICMR guidelines have been put into force through Revised Schedule Y 2005 of Drugs and Cosmetics Rules 1945<sup>15</sup>. The Schedule Y is the law to be followed for conduct of clinical trials in India. It was amended in 2013. Rules for compensation, permission for clinical trial, ethics committee registration and audiovisual recording of informed consent process in clinical trials have also been released. An online clinical trial registry has been initiated by the Indian Council of Medical Research.

All the existing documents mentioned above provide an ethical framework that is largely consistent and have been formulated to ensure protection of research participants. They are still evolving in detail, especially concerning international research and research involving vulnerable populations.

Today, after having several guidelines in place, the mechanism for their interpretation, application and enforcement, still continues to be an outstanding challenge in the area of research ethics.

### **The Way Forward**

A comprehensive and effective oversight system is essential to uniformly protect the rights and welfare of participants while permitting ethically and scientifically responsible research. Quality implementation of ethics by independent review of risk and potential benefit, educating researchers and Ethics Committees on Good Clinical Practices, effectively monitoring ongoing research and legislating the existing ethical guidelines will ensure

protection of human rights of research subjects.

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## Human dignity and Human rights

**Kunal Marathe**  
(III/I MBBS Student)

We humans think, analyse, reason, emotionally relate and act! That's why each one of us have their own self respect –“Dignity” = the state or quality of being worthy of honour or respect – no matter what our position or achievements be like! Human dignity involves mutual respect and compromise among the different people of any society. Don't we feel humiliated when somebody insults us? Do we not feel bad when someone bullies us and others laugh? Isn't it desirable to live in a world where everyone has equal access to resources and equal rights to live, prosper and die the way one prefers! But then why it doesn't happen that way? It's an evolutionary trait to compete and suppress the other living beings and try to be better than everyone else and reach the phylogenetic epitome that the human species has achieved....but then are we same as the other animals who struggle to survive by competition?

No we are not! We are the most intelligent beings ever created. (at least we think we are). That's why we discuss the topics like ethics and rights of other human beings and not just our own!

History abounds with accounts of the mightier oppressing the weak, the stories of discrimination on the basis of colour, caste or creed or religion. Each time philosophers and thinkers came forward, laid down moral principles, tried to reform the society. Humans have the natural instinct to work hard to grow, become powerful and rich; and with great power comes great responsibility to respect the dignity of the weak, at which most rulers and kingdoms failed. That also has been the reason of most revolutions, wars or killings. The way to prevent the catastrophe is tolerance...and for tolerance, it is

necessary to identify what we must do as our responsibilities and what we must get as rights!

Human rights are moral principles or norms, which describe certain standards of human behaviour, and are regularly protected as legal rights in municipal and international law. A person is entitled to these simply because he or she is a human being. They are universal and applicable everywhere at any time.

The idea of need for human rights movement was sown in the post second world war era after the killing of 6 million Jews by the Nazis (also known as the holocaust). This led to the birth of the **universal declaration of human rights in 1948**. Later, there were many bodies across the globe, which made policies with regards to the human rights. The rights as described by the universal declaration are:<sup>(1)</sup>

- ☐ Right to life
- ☐ Freedom from torture
- ☐ Freedom from slavery
- ☐ Right to a fair trial
- ☐ Freedom of speech
- ☐ Freedom of thought conscience and religion
- ☐ Freedom of movement

But these rights as mentioned in the declaration are a matter of debate too. The right to life itself is debated in cases like abortion, euthanasia etc.

For a working purpose we define what is a fundamental right. “Fundamental rights are a generally regarded set of legal protections in the context of a legal system”, where such system is itself based upon this same set of basic, fundamental, or inalienable rights. Such rights thus belong without presumption or cost of privilege to all human beings under such jurisdiction.



There are seven important fundamental rights in Indian constitution .<sup>(2)</sup>

1. Right to equality
2. Right to freedom of speech and expression
3. Right to freedom of religion
4. Right against exploitation
5. Cultural and educational rights
6. Right to constitutional remedies

Newly implemented 7th Fundamental right in India is

7. Right to education (It was added in the constitution after the 86th amendment in the year 2002 under article 21A. It is the most recently implemented fundamental right. RTE Act enabled this right in the year 2010.

Every human being has the basic right of respect both of himself and by his fellow man. Every person has the right to freedom and to express his moral beliefs through words and actions that will help him grow as he uses his talents to help others. People have the right to be free of fear. They have the right to find peace in the understanding and acceptance of who they are, but only to the extent that their rights do not intrude on the rights and beliefs of others. Each person's rights end where the dignity of others begins. People come from different families, different countries, different religions, different political systems, and different races. Their beliefs make up different systems of morals. Respect of these morals or human dignity will determine how society works.

So far we know that we are entitled to human rights by birth, and they do not change with time and place. Then why do the laws and regulations of different countries have these differences of opinion? We need to consider firstly that these fundamental rights are under jurisdiction while the basic rights do not have any jurisdiction. E.g. right to religion is special in our country which hosts so many different religions and might not fit in the laws of a monoreligious country. But that doesn't change the basic right of a person to get equal treatment and

dignity.

Let's keep in mind that “the human rights that do not apply to everyone are not human rights at all!”

Human rights are universal in the sense that they affect all of us – doctors and biologists, politicians and lawmakers, journalists, priests, and society in general.

The important thing is not for the rights to be mentioned in the law books and constitutions or in the moral codes.... there is an indispensable need for them to be incorporated into actions by people and they must know their own rights as well as those of others around them. This is the most essential ingredient in development of a harmonious community. Also equally important for the oppressed is to control their hatred towards the vultures of the past. Martin Luther king jr. Said, “In the struggle for human rights and injustice, Negros will make mistake if they become bitter and indulge in hate campaigns.”

All this said and done-we already studied Civics way back in our school days...then why now? And why relate it to bioethics?

Bioethics is one of the hottest topics today. We are all aware of the tremendous advances in medical technology and concerned about the implementation of those advances in our world. While much hope is kindled among us in light of the potential for good, we are rightly scared of its negative potentials.

There is an increasing awareness of the need to adequately address the bioethical issues with respect of the dignity and rights of every human individual. UNESCO adopted the universal declaration on bioethics and human rights quite recently in 2005.<sup>(3)</sup> It addresses ethical issues related to medicine. It says “The interests and welfare of the individual should have priority over the sole interest of science or society”

Thus it is clearly apparent that every step of medical decision making and research activities is closely related to respecting the human rights of



autonomy and equality. The principles of ethics are not much different from what the rights are meant to convey. Nelson Mandela said “To deny people of their human rights is to challenge their very humanity.” Thus violating the rights of human beings in the humanitarian field of medical services is contradicting principles of medicine.

It becomes particularly important for the medicos to understand and respect the rights of patients (and also of their colleagues, staff personnel etc.) The autonomy of persons to make decisions, while taking responsibility for those decisions and respecting the autonomy of others, is to be respected. For persons who are not capable of exercising autonomy, special measures are to be taken to protect their rights and interests.

After answering ‘*Why bioethics in human rights?*’ the question that still remains to be explored is “*Why now?*”

Today the society is in an enormous developmental log phase. Telecommunications and social media developing at the speed of light after the

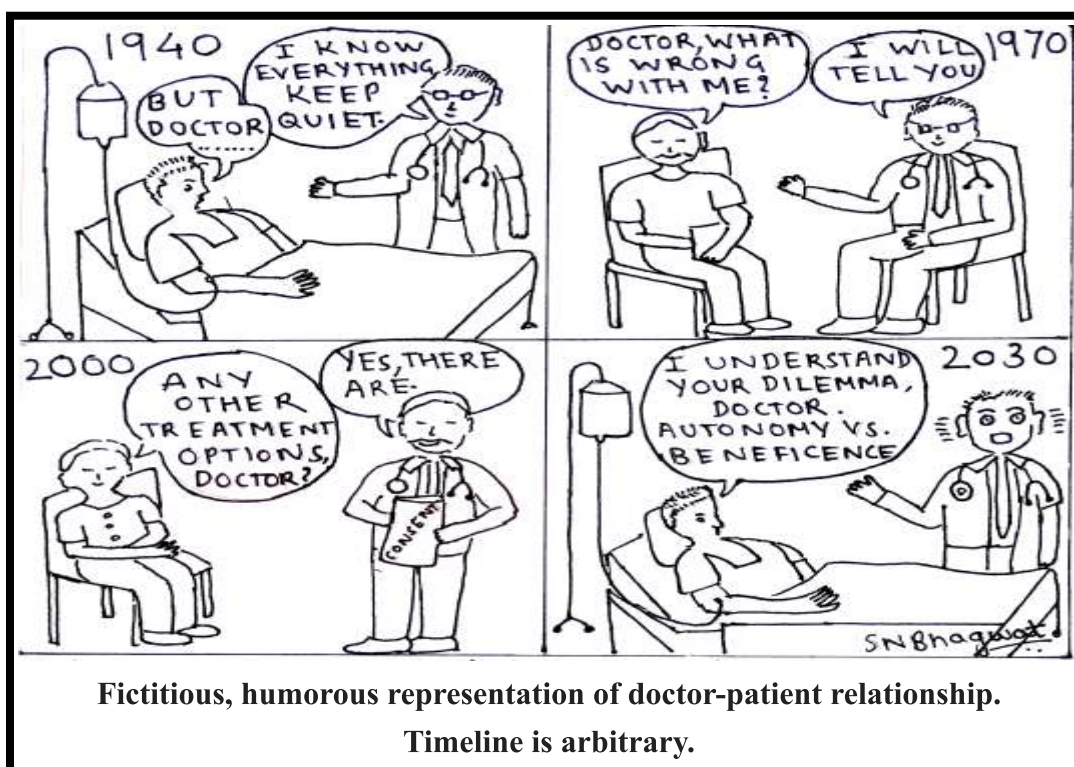
advent of fiberoptics and wireless have transformed the already competitive world into a furnace of greed and selfish motives. The Charybdis of greed for power rises again and again in the exploding population and “there is more fruit in a rich man's shampoo than in a poor man's plate”. With more differences comes less equality and that is why protecting rights of individuals in an era of competition becomes a necessity.

No matter what our job, no matter what our height ; we all deserve to be treated right and equal.

The time is not yet lost. Because Time is always right to do what is right! At the same time, there is a need to engage these questions in a creative manner, anticipating and addressing the issues proactively rather than reactively.

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## Reflections

**Dr. Raivat Bagadia**

Ex Students' wing Member

Being a part of our vibrant bioethics committee has been a eye-opening experience that helped me to acquire and disperse the skills that I could never have learnt in classroom. The controlled environment of group successfully enabled me to explore my values, beliefs and attitudes towards features of professionalism without feeling my personal integrity being threatened. The main thing I learned is to question and reason everything objectively.

As new modalities of treatment continue to be researched, new ethical dilemmas seems to keep cropping up. A healthcare provider is now placed at a juncture of many opinions. Opposing opinions about a course of action to be taken are backed by different ethical principles. Ethical principles are in turned shaped by varied experiences which leads one to feel some principle as morally significant. As medical students we are formally exposed to brute scientific knowledge and trained in logical application of that knowledge, yet the understanding of the implications of certain procedures, technologies and attitudes are for us to be explored and grasped. The bioethics journey lifted the veil between clinical management and holistic management of patients.

After Dr. Eric Subba's lecture, I have now started to scrutinize methodology and outcomes of each clinical trial under oil immersion microscopy before accepting its results as reliable in clinical management. It was surprising to hear questions arising on validity of outcomes and ethical motives of some important clinical trials that led to formation of gold standards in patient management decade ago.

I realised that a bioethicist should have a balanced mind-set. Too much of moral conversation can lead to serious red-tapes around research work, while too much of laxity can cause societal constructs of morality being ignored by researchers.

The experience of ethical debating on the topics which concerns the well-being of many individuals and global population at large is bittersweet . We learn that in dialoging about such topics we may contribute to finding answers that can lead to promoting justice of individuals , but even while having the best intentions possible , we may never be able to assure that we are not putting someone in a position where they may be more disadvantaged.

The activities are fun and gives you a way to learn teamwork , its a valuable preparation for future . Because of the activities, I have become a much better speaker, writer, coordinator and more importantly I have met many great friends and role models among the team members and teaching faculty.

I feel more confident to deal with treatment related adverse events, rookie mistakes, workload burnout and more equipped to tackle ethical dilemmas in real life scenario like physician assisted death and voluntary sale of human organs.

I think the experiences I had with the bioethics team has increased my interest in ethics immensely. I now look forward to continue pursuit of my career in medicine while looking for ways to utilize my interest in bioethics.





## Dignity and Human Rights of Children with Special Needs

Dr. Padmaja Samant

'I am no bird, and no net ensnares me....'- Charlotte Bronte says in Jane Eyre. This is dignity! Dignity is personified in Kate, a cancer survivor child in 'My sister's keeper', getting ready for a date with her cancer survivor boyfriend; it is witnessed in a rape survivor testifying in the court, in Aruna Shanbaug in her bed with her colleagues rallying around her.' For ordinary people like us, it is easy to maintain dignity; but when challenges tower over you, destiny plots against you, if you still maintain the free spirit and discover self; you defeat the idea of Defeat. That is the real dignity.

In ethical, legal, and medical context, dignity implies the idea that every living being has the right to be valued, respected and receive ethical treatment. Shouldn't respect be maintained at and after death too? And nowhere is this right to dignified living more threatened than in a child with a challenge. We call them children with special needs, disabled children, handicapped children, differently able children and so on. Though 'special or differently able children' is a more humane term, the term 'disabled children' conveys the physical gravity. Parents of these children lose hope while fighting a tough battle giving their darlings a life with dignity and normality.

There is an inspiring TED talk by a mother where she narrates how she gave her anencephalic baby's organs for research and the impact he could make on research. It is overwhelming to say the least. The belief and reasoning of a mother transforms a nature's mistake into something beautiful and proud. It makes one realize that rights and concept of dignity evolves with evolution and maturity of societies.

World Health Organization considers disability as an overarching term that includes physical impairments, which limit a one's activity and restricts one participation in day to day social

interactions denying a chance to achieve one's full growth potential.<sup>1</sup> In socioeconomic context a disabled person suffers injustice due to insurmountable barriers to acquisition of the highest standard of physical, mental, socioeconomic well being. Tragically societies reinforce the barriers. **This makes it obligatory for you and I to jointly work to remove these barriers.**

Developmental disabilities are a group of conditions due to a problem in physical, cognition, language, or behavior domains. About one in six children in the U.S. have one or more developmental disabilities or other developmental delays. In developing countries lack of detection is a major problem. That means inequity and unpreparedness on the part of health services.

About one in every 33 babies is born with a birth defect. Due to poverty, inability to access appropriate medical interventions, parental neglect and associated co-morbidities, these babies may succumb much earlier in life. With advent of ultrasonography, many babies with birth defects are aborted. Whether this can be called injustice to the unborn is open to debate where we do not want to tread. But if there are grave consequences, it is torturous for the child and the parents to go through the agony of day-to-day struggle. The much publicized Nikita Mehta case highlighted the issue. The courts have recently taken a more liberal stance in abortion for a rape case survivor.

That brings us to the debate on euthanasia for children. In some countries it is legalized. In the Netherlands, euthanasia for children over 12 years was legalised in 2002.<sup>2</sup> But do children know what they are asking for if they say no to therapy? First Belgian child euthanasia case was in 2014.<sup>3</sup> Even more questionable is euthanasia in children with



severe mental disability. In our country where even adult euthanasia is not legal, the question in disabled children is yet too far to contemplate. Focus should be on is how lack of inclusive treatment of the disabled children and lack of empathy in socio-political environment can be addressed.

Numerous international conventions and instruments are in place for safeguarding interests of children in general as well as the disabled children.

- Geneva Declaration of the Rights of the Child of 1924
- Declaration of the Rights of the Child UN General Assembly in 1959
- United Nations Standard Minimum Rules for the Administration of Juvenile Justice 1985
- Declaration on the Protection of Women and Children in Emergency and Armed Conflict.

The most important belief crosscutting all these instruments is that safety, health interventions, inclusive environment, education, nutrition are the entitlements of all children regardless of their physical and mental ability or disability. India is estimated to have more than 12 million children living with disabilities. Malnutrition, other preventable communicable diseases will take toll on these persons' lives and 80% of them will die before reaching 40 years of life.<sup>4</sup>

With this magnitude in mind, there has to be inclusive social milieu to remove social stigma on disabilities. Political will and intervention is required to make all possible provisions for easy access to services. There must be legal safeguards and mandates to the institutions like schools and hospitals so that there are no physical and environmental barriers. The personnel involved in care of children and the disabled children in particular must have the necessary empathy, knowledge and skills in dealing with the unique issues of these young people. Organizations like UNICEF have been tirelessly working on advocacy and aid in ensuring equitable opportunities and world-class services to the disabled children all over the world. Article 23 of UNCRC of

1990 recognizes the rights of the disabled children to full, self reliant life with skilled care and assistance. They must get access to education, vocational training, health & rehabilitation services, and recreation opportunities. The key word in the document is 'Social Integration'.<sup>5</sup>

#### **Barriers at individual and social level:**

Though we may sympathize with the disabled, the faint hint of condescension in our tone, glance or gesture reminds the person that he/she is different. The terms like differently able, special, divyang are all good but not enough. In health care, the discrimination during service provision is enormous. At a personal level, It may be unintentional but the caution and silence around the disabled children also stifles them. No one wants sympathy or special treatment. Everyone wants respect and equitable treatment.

A disabled person is stripped of his or her dignity when the service is given with pity or disdain. It is crucial to remember that we have capacity to boost or break someone's spirit.

There are common health needs shared by special children with general public; for example-immunization. They face barriers in accessing the health and rehabilitation services they need in many settings. There are hidden costs of travel to specialized centres and in getting personal assistance. Wages lost by parents in accompanying these children for school or therapy push the families into poverty. As these children grow, they are vulnerable to secondary conditions like injuries and malnutrition related diseases. They also experience social exclusion.

The environmental barriers to health care: Prohibitive costs of special treatments and regular therapies are beyond capacity for most families. 32-33% of non-disabled people cannot afford health care whereas for 51-53% of people with disabilities health care is unaffordable.

The special services for the disabled are not available in all setups. The health centres are many



times constructed without taking into account the needs of the disabled.

**Medical misconceptions and treatment of the disabled:** It is an exercise worth doing for anyone to acquire a disability certificate. It really is a herculean task to go through all barriers for the needful. Junior doctors are generally not well informed, hospital OPDs and counters are not disabled friendly, there is no assistance. Certification itself requires many visits. All this is due to lack of coordination.

Disabled children, especially physically challenged girls are very vulnerable to sexual abuse. Even attainment of physical maturity with menstruation becomes a nightmare for the parents. They approach doctors for hysterectomy. There have been discussions in civil society about the same for some while now.<sup>6</sup>

Extirpation of the uterus is not likely to avoid sexual abuse. Menses are at least not as messy as defecation is. So why subject them to the unnecessary and increased risk of surgery and anesthesia? Sexual exploitation and its prevention is more a social and judicial issue and a strong deterrent in terms of definitive conviction is the answer.

**Policy issues :** There are numerous provisions in the law for free aid to the disabled but the hidden costs are too high<sup>7</sup>. Free treatment and health insurance has to be ensured. Physical modification of the existing infrastructure of hospitals and schools, use of Braille for communication and training of providers in facilitation must be implemented. Most important is the opinion and active participation of the people with disabilities in policy making and programme implementation. Policy makers have to take into account dangerous child labour that poses risks of disability. Lastly, there is unmet need of research on the disability issues, access barriers, and results of inequity with regards to the disabled children.

#### **Efforts that are making a difference**

One cannot but mention here the work done by

institutions like the spastics society of India, now called ADAPT (Able disabled all people together) (8). It offers para-medical, educational, vocational and community services for disabled children and adolescents. Resource material is generated by the organization for inclusive socio-political and educational effort for the disabled.

Indian government passed the Persons with Disabilities Act 1995 in January 1996. Chapter V of the act mandates the government to facilitate free education, integration of disabled children into special schools, establishing more special schools.

The Right of Persons with Disabilities Bill, 2014, is in the parliament and will replace the Persons with Disabilities Act, 1995.<sup>9</sup> It makes accessibility mandatory under the law. Soon a web-based unique disability identification (UDID) card will be rolled out. It is expected to make certification and carrying certificate hassle-free.

Recent step taken by the government to make public spaces more disabled friendly is a welcome gesture. It is important that the momentum is maintained and the services are more rights based, and uphold dignity and rights of the disabled children.

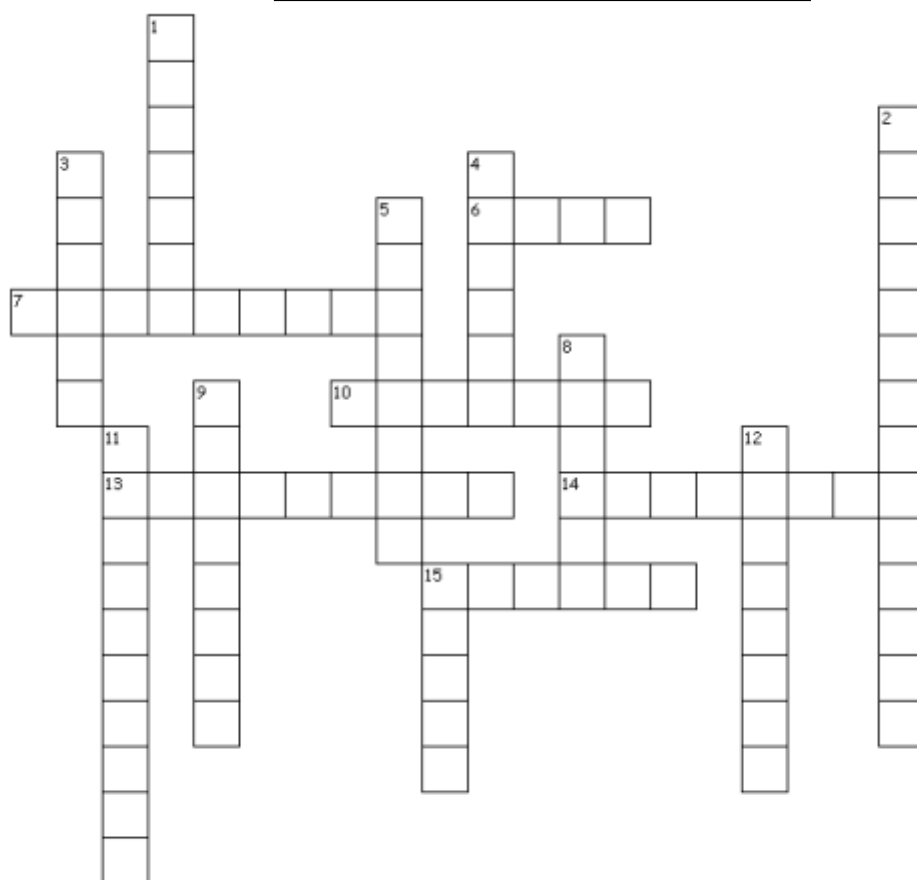
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## Let's Play Bioethics



### Clues:

#### Across:

- 6) National authority in India which has formulated detailed ethical guidelines for biomedical research on human participants (abbrv) (4)
- 7) The study of ethical and moral implications of developments in the area of biological sciences (9)
- 10) Beneficence means providing a “\_\_\_\_\_” (7)
- 13) This code (1947) of research ethics emphasized the need for voluntary consent in medical research (9)
- 14) This Declaration (1964) is a statement of ethical principles for medical research on human subjects by World Medical Association (8)
- 15) A specialized agency of the United Nations involved in Bioethics (Acronym) (6)

#### Down:

- 1) Fairness in treatment (7)
- 2) Bioethical principle – “Do no harm” (14)
- 3) Application of fairness, which may require unequal treatment giving extra considerations to the disadvantaged (6)
- 4) A quality in person especially in character and behavior (6)
- 5) Infamous syphilis experiment known by this name (8)
- 8) Human Dignity and Human \_\_\_\_\_ usually go hand in hand (6)
- 9) Ethical principle of telling the truth (8)
- 11) Lacking the freedom to make authentic decisions because of an inability to make such decisions even when given the opportunity (10)
- 12) Ethical principle of keeping a promise or commitment (8)
- 15) The United Nations Convention on the Rights of the Child (abbrv) (5)

**Created by Dr. Swarupa Bhagwat**

*(Answer Key on page 48)*



## Dying With Dignity

**Mrs. Mariya Jiandani**

**Dr. Santosh Salagre**

### **Aruna - the paricharika**

Aruna Shanbaug was a staff nurse working at the King Edward Memorial Hospital, Parel, Mumbai. On 27<sup>th</sup> November 1973, she was attacked and strangled with a chain by a sweeper of the hospital in the basement of hospital building, where she had gone to change her duty uniform. The hypoxia left her in a vegetative state ever since. She was treated at KEM hospital since the incident. Her nutrition was by feeding tube and the nursing care she received from two generations of nursing staff is a remarkable example of dedication and humanity. Pinki Virani, a social activist, filed a petition in the Supreme Court on behalf of Aruna arguing that the "continued existence of Aruna is in violation of her right to live with dignity". The Supreme Court in its decision on the 7th March 2011, rejected the plea to discontinue Aruna's life support. However it issued a set of broad guidelines legalizing passive euthanasia in India. The Supreme Court's decision was based on the fact that the hospital staff that treated and took care of her did not support euthanizing her. She died on 18<sup>th</sup> May 2015 due to pneumonia, after being in a vegetative state for 42 years. Her final rituals were performed by the Dean of KEM Hospital, Dr Avinash Supe in presence of her relatives and thousands of hospital nurses and employees.

### **Euthanasia: Definition and Types**

Generally, the word euthanasia is defined as the act or practice of putting to death painlessly or withdrawing treatment from a person suffering an incurable disease. Euthanasia is intentionally killing another person to relieve his or her suffering. Euthanasia is one of the most perplexing issues which the courts and legislatures all over the world are

facing today. The topic has religious and moral overtones. If the life of a person becomes painful, fruitless and full of sufferings, should the person get rid of their life? A solution for such a problem is not just legalizing the mercy killing. It is not desirable or workable as each case has to be judged individually.

There are two types of euthanasia: passive euthanasia and active euthanasia. **Active euthanasia** is defined as taking an immediate action such as using lethal injection to painlessly put a terminally-ill patient to death. **Passive euthanasia** is withdrawing treatment while the life of the patient is still dependent on it and when it is believed that treatment is more burdensome than beneficial. Passive euthanasia allows the patient to die naturally and is often considered more acceptable.

### **Outcome of Aruna's case**

While rejecting Pinki Virani's plea for Aruna Shanbaug's euthanasia, the court laid out guidelines for passive euthanasia. According to these guidelines, passive euthanasia involves the withdrawing of treatment or food that would allow the patient to live. Forms of active euthanasia, including the administration of lethal compounds, legal in a number of nations and jurisdictions including Luxemburg, Belgium and the Netherlands, as well as the US states of Washington and Oregon, are still illegal in India. As India had no law about euthanasia, the Supreme Court's guidelines are law until and unless Parliament passes legislation.

The following guidelines were laid down:

1. A decision has to be taken to discontinue life support either by the parents or the spouse or other close relatives, or in the absence of any of them, such a decision can be taken even by



a person or a body of persons acting as a next friend. It can also be taken by the doctors attending the patient. However, the decision should be taken bona fide in the best interest of the patient.

2. Even if a decision is taken by the near relatives or doctors or next friend to withdraw life support, such a decision requires approval from the High Court concerned.
3. When such an application is filled the Chief Justice of the High Court should forthwith constitute a Bench of at least two Judges who should decide to grant approval or not. A committee of three reputed doctors to be nominated by the Bench, who will give report regarding the condition of the patient. Before giving the verdict a notice regarding the report should be given to the close relatives and the State. After hearing the parties, the High Court can give its verdict.

### **Death, Dignity and Religion**

India is a country of diverse religions and each one has its own faith and belief. Indians believe illness and death are related to karma. Most religions disapprove euthanasia, autopsy and organ donation. There is a belief amongst the Hindus and Muslims that such procedures disturb the soul and inhibit it from moving ahead. It is believed that if such procedures are done, a part of the body lives on. It interferes with reincarnation and onward journey. Conversations around death are considered taboo in India and silence prevails.

Hindu philosophy believes in rebirth and accepts end of life. Buddhism believes in nirvana and discourages the use of narcotics. Christianity believes that illness and death are punishment where the body and soul separates temporarily. As per Islamic belief, submission to suffering is submission to god. It allows the use of narcotics for relief of pain but not to hasten death in the terminally ill. The patient's ability to

participate in prayers and rituals in the final moments of life is maintained.

### **Dying with dignity – different perspectives**

The million dollar question remains “Does dying with dignity mean euthanasia?” where the phrase is used interchangeably. Death is the end of very existence and dignity is the state or quality of being worthy of respect or honour. Dying with dignity is the process, the period leading to death where transition occurs from living to non- living being. Death of a soldier on the battlefield is considered as a dignified death and perhaps also of the malformed unborn when medically terminated. Death as suggested by Coope can occur in undignified circumstances (e.g. gruesome murders). According to him dying with dignity is whatever the dying person thinks it is. It is a personal subjective feeling hence if someone thinks to die in a confused state, incontinent or dependent on others is undignified, then it is.

As suggested by Allmark “Indignity” conveys an idea of affront. This generally occurs when we fail to acknowledge the ability of an individual to reason or rationalize. Failure to inform terminal diagnosis, minimize pain, discomfort and suffering and jeering at incontinent individual are some affronts caused by health care professionals. The health care professionals' plays a twin role. On one hand they try to maintain the right of the patient to reason and make active decisions for one's self and on the other hand, try to minimize the indignities of painful incurable diseases or incapacitating physical impairments or psychological factors such as depression, feeling of being a burden or dependent in order to give a dignified death.

A patient in a state of unconsciousness has his or her modesty ripped when attended for self-care without privacy with a loss of personal identity. So also is unbearable pain and suffering of a person with terminal cancer or the one struggling for each breath in end stage lung disease. When there is no cure and



death is awaited by minutes, hours and days suffering needs to be mitigated with care and compassion to assist the process of dying.

### **Death & indignity- can we do better?**

The focus point is the change in relationship between patient and health care providers not just in those known to survive but also in those known to die. The health care provider needs to empathize the distress of the patient, to relieve it at all times to the best extent possible governing the ethical principles of “First do no harm” (non-maleficence) and “Do good “at all times (beneficence). The definition of dignity in dying identifies not only an intrinsic, unconditional quality of human worth, but also the external qualities of physical comfort, autonomy, meaningfulness, usefulness, preparedness, and interpersonal connection. Respect should be fostered by being mindful of the “ABCDs” of dignity-conserving care (Attitudes, Behaviours, Compassion, and Dialogue). The responsibility of health care professional towards the patient at the end of life is to care such that it respects their values when they are most vulnerable. One needs to preserve the patients' dignity and resolve conflicts if any applying the principle of non-maleficence. Death is a process, rather than a moment in time, resting on a need for balance between the scientific advances and spirituality. Palliative care or collaborated care has now emerged as a speciality with various protocols to deal with various physical and emotional vicissitudes encountered in terminally ill. It is a support provided in the transition from life to death. It allows the process of dying to take its natural course with less suffering. Palliative care patients seek solace in the use of spiritual and religious coping methods. The WHO definition of palliative care stresses on improving the quality of life of patients and their families by providing relief from the pain and suffering that includes the psycho-social and spiritual needs as well.

Dying with dignity campaigns for the greater choice, control and access to a full range of medical and palliative services at the end-of-life and providing terminally ill adults with the option of a painless, assisted death, within strict legal safeguards. A detailed discussion with relatives and close friends helps in making decisions. Death is a unique experience for one, there being a tremendous societal pressure on a dying person to be a “good patient” while trying to experience the “good death.” These pressures influence the decision making for end of life situations in the patient, caregiver and family. One needs to understand that to heal is more important than to cure and what the notion of dignity means to people and how it needs to be translated into health care settings in Indian context. We need to reflect on apathy within the system which is at odds at the very foundational principles of bioethics – Empathy and Humanity.

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## Human Rights and Vulnerability

**Dr. Padmaja Marathe**

**Dr. Nayana Ingole**

### Introduction

“A class IX, local zilla parishad high school boy from Telangana was allegedly ordered by the school teacher to fetch fodder for his cattle. He injured his foot while collecting grass, developed infection in the wound and was admitted to a private hospital with septicaemia. The incident came to light after a children's rights body took up the issue with local authorities”- A news report.<sup>1</sup>

Census 2011 shows decline of girl population as a percentage to total population under the age of seven with an approximately eight million female fetuses aborted in the past decade. The situation has not improved in the last 10 years and female feticide continues despite the PCPNDT act. Literacy for females stands at 65.46%, compared to 82.14% for males. Indian women on an average earn 64% of what their male counterparts earn for the same occupation and level of qualification<sup>2,3</sup>.

Human rights apply universally to all, however we find that a large section of society in India is not leading a life of dignity and freedom. Vulnerable individuals/ groups lack full enjoyment of a wide range of human rights, including the basic needs related to health, education and well-being. They find it hard to survive and lack development opportunities due to being at a relative disadvantage in the economic, cultural, physical, intellectual, and other situations. The Oxford dictionary defines **Vulnerability** as “The quality or state of being exposed to the possibility of being attacked or harmed, either physically or emotionally”. (<https://en.oxforddictionaries.com/definition/vulnerability>). Vulnerability is a concern in bioethics as vulnerable individuals and groups are subject to exploitation, and exploitation is morally wrong.<sup>4</sup>

### Assessment of Vulnerability

The concept of vulnerability is relative and dynamic. People differ in their exposure to risk as a result of their social group, gender, ethnic or other identity, age and other factors. Also, people have variable capacity (physical or material resources) to cope with a threat or to resist the impact of a hazard. Hence, though different groups within a society may have the same level of exposure to a natural/ man-made hazard, it may have a varying consequence for them.

To assess vulnerability, there is a need to understand the conditions that lead to vulnerability.<sup>5,6</sup>

1. Attitudes held by the general population towards certain groups regarding their reputation and status have led to biased social evaluation, discrimination and rejection contributing to their vulnerable status. Eg. scheduled Castes (SC), Scheduled Tribes (ST), Children, Aged, Sexual Minorities.- gay, lesbian, transgender, bisexual, kothi and hijra, orphans and widowed, old people who are living alone, etc.

2. Poverty is a major contributor to vulnerability. Poor, unemployed and /or illiterate people are more likely to live and work in areas exposed to potential hazards, while they are less likely to have the resources to cope when a disaster strikes. Eg. Farmers from Maharashtra committing suicide, mine workers, etc. In richer countries, because of secured livelihoods and higher incomes, people usually have a greater capacity to resist the impact of a hazard. Eg. Japan recovered fast from destruction caused by Tsunami.

3. Health conditions, including both the physical and mental health have an impact on their social position. Eg. People living with HIV/AIDS, Leprosy



patients, mentally challenged, people with physical disability, etc

4. The cultural construct of Indian society reinforces gender bias against women leading to violation of human rights.<sup>7</sup> Eg. lack of equitable access to healthcare, female feticide, higher rates of female illiteracy, lower pay scales to women, etc.

5. Situations of substantial limitation or deprivation of personal liberty lead to a vulnerable status. e.g. prisoners, prisoners of war, asylum seekers, etc

6. Hierarchical relations often make the junior person vulnerable to exploitation. e.g. students, employees, members of the armed forces or the police, etc

7. Displaced populations who leave their habitual residence in collectives, usually due to a sudden disaster, or who leave or flee their habitual residence to go to new places, usually abroad to seek better and safer perspectives, are in a vulnerable position. Eg. People flocking to metro cities, etc

8. Natural hazards like earthquakes, hurricanes or tsunamis or man-made disaster can contribute to vulnerability. Eg. People afflicted during Bhopal gas tragedy, Earthquake in Bhuj, Gujarat.

To summarise, for determining people's vulnerability, two questions should be answered:

- **To what threat or hazard are they vulnerable?**
- **What makes them vulnerable** to that threat or hazard?

It is also important to distinguish between vulnerability and susceptibility which also marks the difference between being intact but fragile--vulnerable--and being injured and predisposed to compound additional harm--susceptible.<sup>7</sup>

#### **Protection of the Rights of Vulnerable**<sup>6,8</sup>

Existence of the vulnerable groups and their problems cannot be mitigated. However, it is possible to take steps at various levels- individual, community and government for protecting the basic rights of

vulnerable groups.

1. To reduce the impact of the hazard itself, where possible building capacities to withstand and cope with hazards;(through mitigation, prediction and warning, preparedness);

2. To identify disadvantaged/marginalized groups; their health status and needs in different situations.

3. To review the health information and services that are available to protect the health of the poor, vulnerable, or otherwise disadvantaged groups, including their quality, accessibility, affordability and acceptability. It is important to find out whether they are allowed freedom in the choice of treatment; whether their full, free and informed consent is obtained during specific interventions; and whether confidentiality is maintained where necessary.

4. To identify barriers to the implementation of relevant laws, obligations and commitments;

5. To have Government policies and laws in place. The government should take the main responsibility to strengthen and improve the political and legal protection for vulnerable groups. This will enable the vulnerable groups to enjoy equal opportunities and civil rights. There are a few provisions made by Indian Government which favours vulnerable sections to promote their development and protect their dignity for eg- Free school education and 33% girls quota in government schools and colleges, reservations for scheduled castes and scheduled tribes, laws against child labour, dowry etc. The implementation of the law is a big issue and much more needs to be done by the Government on this front. More opportunities should be created for education, employment and to improve the standard of living of marginalized sections of the society.

Also measures such as provision of pension, living allowance, disability living allowance, and a variety of temporary relief funds by Government



authorities may serve to protect vulnerable sections.

6. To build strong social support systems- Government efforts alone are far from enough to protect the rights of vulnerable groups. Vulnerable groups are mainly resulted from a country's social, political and institutional factors. The phenomenon of vulnerable groups is a derivative of social development. Biased social evaluation, discrimination and rejection from the general population all contribute to the existence of vulnerable groups. We should strive to develop community services and build social support networks. There needs to be increased public awareness on the right to health of the vulnerable groups. Vulnerable groups should be provided services and support related to law, education, medical care and mental health.

7. To create self-help groups – Self-help groups within the vulnerable population should be encouraged as sole dependence on external support from the community and government can only solve short-term problems but not the fundamental problems.

8. To promote capacity-building among health professionals to ensure conformity with the right to health in service delivery. The curricula of medical and other health professional training schools should be examined and health and human rights of vulnerable groups to be included as part of education.

We can dream of achieving a harmonious society through coordinated efforts of various stakeholders. There is a provision in the Universal Declaration on Bioethics and Human Rights on “Respect for human vulnerability and personal integrity” as a bioethical value of universal concern to the Member States of UNESCO(2005)<sup>9</sup>. The Article 8 of this declaration states that in applying and advancing scientific knowledge, medical practice and associated technologies, individuals and groups of special vulnerability should be protected and the

personal integrity of such individuals respected.

### **Research on Vulnerable Population<sup>10,11</sup>**

Despite of availability of a number of ethical guidelines and law in many countries for regulating research practices, the exploitation of vulnerable participants in research continues even today. In the first few decades of this century, there were numerous instances wherein marginalized sections of society were subjected to unethical research causing disability, death and life long suffering. The Nazi experiments on the prisoners of World War II, **Tuskegee syphilis Study** on Afro-American men, **Willowbrook Hepatitis Study** on institutionalized mentally retarded children in New York are some of the notorious examples. India also has a long history of unethical research. John Hopkins-RCC Clinical trial in which research on patients of oral cancer was conducted without their consent, unjustified research done on Bhopal gas tragedy victims, HPV Vaccine trials in Andhra Pradesh on tribal minor girls are a few examples from the recent past. The research in vulnerable population is not prohibited by law or ethical guidelines. Principle of justice requires that the vulnerable individuals should also get equal opportunity to participate in research and to derive benefit from results of research. However, while planning the research study in vulnerable population, the following safeguards need to be exercised as stated in the ICMR guidelines. “Persons who are economically or socially disadvantaged should not be used to benefit those who are better off than them. Rights and welfare of mentally challenged and mentally differently able persons who are incapable of giving informed consent or those with behavioral disorders must be protected. . Adequate justification is required for the involvement of subjects such as prisoners, students, subordinates, employees, service personnel etc. who have reduced autonomy as research subjects”. The research question posed should be important and relevant to the health and



well-being of the vulnerable population and the design should be appropriate and due measures should be taken to prevent undue coercion or influence on them. The responsibility lies with all stakeholders in research- investigators, sponsor, ethics committee and regulatory authority.

### Conclusion

We cannot eradicate vulnerability entirely, given that it is a feature of the human condition. We can and should provide every human being with the best available means to ensure that they do not find themselves in a position of special vulnerability, regardless of age, gender, educational level, financial situation, health status and life experiences. The stronger have a duty not to exploit the vulnerable. Securing the protection of individuals with vulnerability, can be done by addressing the context and causes that give rise to it and it requires strong resolve and capacity to do so.

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**‘The right to health does not mean the right to be healthy, nor does it mean that poor governments must put in place expensive health services for which they have no resources. But it does require governments and public authorities to put in place policies and action plans which will lead to available and accessible health care for all in the shortest possible time. To ensure it happens is the challenge facing the human rights community and public health professionals.’**

**- Mary Robinson, Former UN High Commissioner for Human Rights**





**“First, Do No Harm”**  
**Summary of Panel Discussion - 19th July 2016**

**Dr Swarupa N. Bhagwat**  
**Dr Yuvaraj B Chavan**

### Introduction

The importance of upholding high ethical standards in medical practice has been emphasized upon for centuries as reflected in the Hippocratic Oath. However, the ever-increasing complexities of medical advancements, work pressure and changing human needs in the recent times have been perceived to have shifted the focus of health professional from compassion to mere competence without considerations of ethical principles. Training of medical students and other healthcare providers in clinical skills would be incomplete without awareness of the fundamental bioethical principles and moral behavior. The key bioethical principle of nonmaleficence is embodied by the phrase “First, Do No Harm”. Another way to state it is that, "given an existing problem, it may be better not to do something, or even to do nothing, than to risk causing more harm than good."

Bearing this in mind, the **GSMC MUHS UNESCO Bioethics Unit** had organized a panel discussion, “*First, Do No Harm*” on July 19<sup>th</sup>, 2016. This scientific program, on the auspicious day of Guru Pournima, was graced by the presence and participation of senior teachers, “teachers of teachers”, as panelists. Dr Farokh Udwadia, Professor Emeritus of Medicine, Grant Medical College; Dr Sunil Pandya, ex-Professor and Head, Neurosurgery, KEM Hospital; Dr Yeshwant Amdekar, Medical Director, BJ Wadia Hospital for Children; and Dr Urmila Thatte, Professor and Head, Clinical Pharmacology, Seth GS Medical College participated as panelists. Dr Aniruddha Malpani, IVF specialist and information therapist, moderated the discussion. The panel discussion was preceded by

release of the book “**Patient Safety – protect yourself from medical errors**” authored by Dr Malpani. The audience included more than 300 practitioners, healthcare professionals, undergraduate and postgraduate students. We present here the essence of this panel discussion

### Discussion

The discussion began with an important issue that the patients frequently perceive apathy on the part of the treating clinician. The panelists expressed a serious concern that the deep regard, not only for doctors, but for the entire medical profession has declined. The single most important reason is that people perceive dearth of humanity and lack of communication from the doctors. Furthermore, doctors' domain of work has become compartmentalized due to the specializations in the medical education and healthcare. They take care of individual organ systems rather than the whole patient. It was appealingly highlighted that the science, but not the art, of medicine is taught in medical colleges. The art needs to be imbibed by ourselves.

The theme of the panel discussion was centered on “medical errors” and the reasons for their consequences. A medical error is a preventable adverse effect of care, whether or not it is evident or harmful to the patient. An error frequently leads to feeling of anger and upsurge among the patients and the relatives. All the panelists concurred that the most critical reason behind these incidences is breakdown in the doctor-patient relationship.

To elaborate this point further, an effective communication between the doctor and the patient right from the beginning prevents patient



dissatisfaction. It is necessary to explain to the patient the probable diagnosis, rationale behind the prescribed diagnostic tests and the therapy. It is equally important to document so that there is accountability and responsibility. If truth is told, patients become ally or else become antagonists. Doctors need to have a balanced decision. The resentment from patient and the relatives is uncommon when they observe the doctor doing his duty with concern and conscience.

Patient's mindset also makes a difference to the outcome. Communication with the patient and the relatives improves the doctor-patient bond and trust which are important aspects of healing.

It is equally important for the doctors to introspect, retrospect and communicate with themselves. It helps them to get on the right track in the patient treatment.

Doctors are second victims of medical errors. If error is committed, doctors also undergo emotional turmoils. While discussing the source of errors, Dr Udwardia stated that judgmental error is human. Clinical judgment is something a person is born with and may be improved upon with experience. Dr Amdekar reiterated that it is important to find the genesis of the mistake. Most of the times, it is an error of judgment. If medical error is committed by junior doctor then the seniors should talk to him and advice about rectification. Conscience and sense of duty need to be instilled in juniors. Documented standard operating procedures can serve as a guideline to the resident doctors.

Another vital issue discussed was the communication amongst different specialists treating the same patient. One of the clinicians should take the overall command and give right perspective to the patient. An adverse drug reaction in patient is not due to negligence. However, these incidents should be reported to the Pharmacovigilance Program of Government of India

The perception that medicine has become commercialized is based on a number of observations. Dr Pandya expressed the concern that the issue of commercialization has been extrapolated to the entire medical profession. Doctors are frequently reluctant to disclose that they are unable to reach a particular diagnosis, and hence a number of diagnostic tests are ordered. Additionally, the patient may be referred to another doctor for opinion. It is very important to be communicative and honest. If a doctor explains the rationale behind ordering particular test or a referral, the feeling of being cheated would be alleviated. This gives the patients an added confidence that you are honest and are doing your best.

It should be realized that teamwork is of utmost importance in healthcare. We always function as a team with each having a role to play. The final responsibility and decision and authority lies with one person. The panelists beautifully recounted their experiences how they had learnt from the other members of a team while working as resident physicians. Dr. Amdekar emphasized the valuable roles the nursing staff and the mothers of pediatric patients play in child healthcare. We should respect everyone in the team and not err by equating illiteracy with lack of intelligence

There was discourse regarding various views about clinical research in India. Clinical research is an essential component of advances in healthcare. However, the way the entire clinical research is looked upon at, especially in India, is discouraging. There have been reports that the research participants from lower socioeconomic strata are treated as guinea pigs. They are not given adequate care and hence they face problems. Dr Thatte appreciated that there is good clinical research going on in India. Still, the general lack of awareness among doctors about the research principles is one of the obstacles to clinical research in India. It is to be understood that there is



reversal of roles when a clinician works as an investigator. The investigator gains from patient while clinician has his own expertise.

In addition, we need to acknowledge that patients are partners in clinical research. According to the Declaration of Helsinki (2013 version), patients have right to be a part of research. Research is beneficial for the society as well as for the patient. The Ethics Committee and Informed Consent Documents do not make the research participant feel like guinea pigs any more. Communication between participant and investigator is very important.

The issue of complains from the patients was also discussed. Patients are reluctant to talk to doctors because they fear vengeance. A suggestion box or patient redressal fora would be helpful for these purpose.

The take-home messages given by the esteemed speakers are precious pearls of wisdom to be cherished especially by the budding healthcare professionals. Dr Thatte laid emphasis on research for

progress of science and wellbeing of the community. Dr Pandya restated that every step should be towards the betterment of the patient. If we put ourselves in the shoes of the patients, errors will be minimized. Dr Amdekar underlined the importance of being responsible and answerable to one's own conscience. Dr Udwadia concluded by advising the medical students to be reasonably knowledgeable, honest, upright, ethical, communicative and humane. The “four C”s : **communication, care, concern and compassion** form the cornerstones of ethical healthcare.

The deliberations in the discussion were highly appreciated by everyone. Different facets of ethics in healthcare and research were unfolded. It was an enlightening and thought provoking experience particularly against the backdrop of the currently perceived depreciation of ethical values in healthcare.

To summarize, honesty, integrity and effective communication form a triad that leads us to the fundamental bioethical principle “First, Do No Harm”.



**Laws and Principles are not for the times when there is no temptation:  
They are for such moments as this,  
when body and soul rise in mutiny against their rigour...  
if at my convenience I might break them, what would be their worth?**

- Charlotte Bronte - Jane Eyre



GSMC MUHS UNESCO Bioethics Unit.  
Seth G. S. Medical College and K. E. M. Hospital, Mumbai, Maharashtra, India



**NURTURING ETHICAL VALUES.....**

**ENRICHING MEDICAL EDUCATION.**

**Vision :** Establishing highest level of ethical and professional standards in health professionals education, practice and research.

**Mission :** To inculcate the basic ethical, professional and humanitarian values in medical students right from the first day of training in order to make them not only expert clinicians but also compassionate human beings.

**Background :** The 'GSMC-MUHS UNESCO (GMU) Bioethics Unit' was conceived in August 2015 and solemnized under the MCGM Nodal Bioethics Unit and affiliation with UNESCO, Chair in Bioethics Haifa Australia on 9th November 2015 at a grand event held in Topiwala National Medical College auditorium.

Mr Sanjay Deshmukh, Hon. Addl. Municipal Commissioner and Dr Suhasini Nagda , Director (ME& MH) received the UNESCO Charter and writ for the establishment of the MCGM MUHS UNESCO Nodal Centre for Medical and Dental institutions by Professor Russell D'Souza Head, Asia Pacific Bioethics Program of UNESCO Chair in Bioethics, Haifa. Dr Avinash Supe, Dean Seth G S Medical College received the writ for GSMC MUHS UNESCO Bioethics Unit and so did the respected Deans of other municipal medical colleges of Mumbai.

The objective of GMU bioethics unit is to integrate and upgrade the MUHS approved UNESCO Bioethics curriculum into the medical, nursing ,Occupational & Physiotherapy syllabus, to collaborate and facilitate research in bioethics and also to train the faculty in effective implementation of the same. It also aims to increase interest and respect to values involved in health care delivery and raising awareness for competing interests, introducing various non-medical facets of medicine like sociology, economics, and public administration to students.



Steering committee of GSMC-MUHS UNESCO Bioethics Unit (GMU Bioethics Unit) is composed of 15 members from various disciplines and preclinical, paraclinical and clinical departments, with Dr Santosh Salagre as the head of the unit and Dr Padmaja Marathe as the head of steering committee.

The students wing members were selected from the winners of the essay competition in bioethics from medical, nursing ,Occupational and physiotherapy courses and was formulated on 21<sup>st</sup> January 2016.





GSMC MUHS UNESCO Bioethics Unit.  
Seth G. S. Medical College and K. E. M. Hospital, Mumbai.

- Students' Wing -



**Rucha Gadgil**

Intern - Physical Therapy

**Ekta Patil**

IV<sup>th</sup> year Physical Therapy

**Prajakta Kulkarni**

IV<sup>th</sup> year Occupational Therapy

**Kunal Marathe**

III<sup>rd</sup> year MBBS

**Sayli Kalzunkar**

III<sup>rd</sup> year Occupational Therapy

**Hema Joshi**

III<sup>rd</sup> year Nursing

**Namrata Pakhare**

III<sup>rd</sup> year Nursing

**Vaishnavi Maske**

II<sup>nd</sup> year MBBS

**Priyashree Desai**

II<sup>nd</sup> year MBBS

**Tanisha Apate**

II<sup>nd</sup> year Physical Therapy

**Sneha Ghogale**

II<sup>nd</sup> year Nursing

**Radhika Rane**

II<sup>nd</sup> year Nursing



**GSMC MUHS UNESCO Bioethics Unit.  
Seth G. S. Medical College and K. E. M. Hospital, Mumbai.**

**Steering Committee**



**- Office Bearers -**

|                     |                         |                      |
|---------------------|-------------------------|----------------------|
| Dr Avinash Supe     | Chairman                | Dean and Director    |
| Dr Santosh Salagre  | Head of Unit            | Internal Medicine    |
| Dr Padmaja Marathe  | Head Steering Committee | Pharmacology         |
| Dr Nayana Ingole    | Secretary               | Microbiology         |
| Mrs Mariya Jiandani | Treasurer               | Physical Therapy     |
| Dr Padmaja Samant   | Editor 'Inarch'         | Obst. & Gynaecology  |
| Mrs Karuna Nadkarni | Co- editor              | Occupational Therapy |

**- Committee Members -**

|                       |                      |
|-----------------------|----------------------|
| Mrs Pradnya Nachankar | Nursing              |
| Dr Swarupa Bhagwat    | Transfusion Medicine |
| Dr Anjali Telang      | Anatomy              |
| Dr Yuvaraj Chavan     | Community Medicine   |
| Dr Monty Khajanchi    | Surgery              |
| Dr Sachin Patil       | Forensic Medicine    |
| Dr Kinjalka Ghosh     | Biochemistry         |
| Dr Venkatesh Rathod   | Physiology           |
| Dr Kanchan Kothari    | Pathology            |





## Introductory Workshop for First Year Students 2<sup>nd</sup> October 2015



**An Introductory workshop on Bioethics for I<sup>st</sup> MBBS & Physiotherapy students** : was held on 2nd October 2015 and was attended by 220 students. Expert bioethicists Dr. Sunil Pandya and Dr. Amar Jesani spoke on evolution and principles of bioethics. GMU bioethics unit members facilitated the understanding of bioethical principles and doctor-patient relationship.

## Bioethics Grand Rounds for Postgraduate Students 5<sup>th</sup> December 2015



**Bioethics Grand rounds** was organized for postgraduate students and Staff members of Anaesthesia and Surgery Departments on 5th December 2015 and was attended by 30 postgraduates. Bioethical dilemmas in Surgery and Anaesthesia practice were presented. The event was conducted by Dr. Padmaja Samant (OBGY) and Dr. Monty Khajanchi (Surgery). Mrs Neha Madhiwala, external faculty moderated the discussion. There was intense discussion on each case. Dr. Sunil Pandya, Consultant Neurosurgeon, Jaslok Hospital and Ex- Head of Neurosurgery, KEM Hospital gave conclusive remarks on each case.



## Essay Competition 14<sup>th</sup> October 2015



An essay competition for MBBS, Occupational Therapy, Physiotherapy and Nursing students : was organized on 14th October 2015. 221 students wrote essays on the pre - announced topics in a language of expression as English, hindi or Marathi . The essay were evaluated by two independent judges ,an internal judge member of GMU bioethics Unit and External from field of literature and Philosophy. Winners were felicitated on foundation day and they constituted the First student's wing of GMU bioethics unit .Topics for essay were as under.

### Topics for Essay

| Patient as a Human Being                       | रुग्ण- एक माणूस                            | मरीज- एक मनुष्य                          |
|--|--|--|
| Movies and Medicine                            | चित्रपट आणि वैद्यकशास्त्र                  | सिनेमा और आयुर्विज्ञान                   |
| Why I chose Health Care as a Profession?       | मी आरोग्यसेवाक्षेत्र का निवडले ?           | मैंने स्वास्थ्यसेवा क्षेत्र क्यों चुना ? |
| My first Experience in Anatomy Dissection Hall | Anatomy डिसेक्शन हॉल मधील माझा पहिला अनुभव | Anatomy डिसेक्शन हॉल में मेरा पहला अनुभव |





### Introductory workshop for nursing students 14<sup>th</sup> December 2015



**Introductory workshop for nursing students :** was organized on 14th December 2015. Total of 250 nursing students and 16 nursing faculty participated in this workshop. The event highlighted the importance of Bioethics in nursing and how it directly affects patient care. Students were introduced to the concept of bioethics, their principles and applications, nursing code of bioethics and Nursing advocacy and accountability especially in vulnerable patients. They were also introduced to basics in communication skills.

### Introductory workshop for first year PT and OT Students 10<sup>th</sup> February 2016



**Introductory workshop for first year Physiotherapy and occupational therapy students** was held on Wednesday 10th February 2016. The workshop was attended by 70 students. They were introduced to bioethics principles, cultural diversities and its importance in health care. Concepts of cultural competences, cultural incapacities, cultural destructiveness and cultural blindness were explained. They were introduced to the basics of effective communication skills and Professionalism.



## Guest Lecture on Research Ethics 4<sup>th</sup> February 2016



### GSMC-MUHS-UNESCO BIOETHICS UNIT



Presents

Guest Lecture on

### Ethics in Medical Research

### 8<sup>th</sup> K. R. Memorial Lecture Entitled

### ‘The Golden Rule : A Remedy for Decadence in Global Health’ by

### Dr. Eric Suba<sup>(M.D.)</sup>,

Director of Clinical Laboratories, Kaiser Permanente Medical Center, San Francisco, California, USA

**Thursday, 4th February, 2016 (2.00 pm to 4.00 pm)**

**Venue : Sen Kinare Hall, 3rd Floor, CVTS Building, KEM Hospital, Parel, Mumbai**

Collaborators :



**Ethics in medical Research:** The GMU unit hosted the 8<sup>th</sup> Krishna Raj Memorial Lecture in collaboration with Anusandhan trust CEHAT, MASUM(Pune), TISS, SNDT and Mumbai University with the theme of “Ethics in Medical Research” on 4<sup>th</sup> Feb 2016 at Sen Kinare hall, CVTC. The lecture was attended by approximately 200 participants which included social workers, researchers and health care practitioners.

"The Golden Rule: A Remedy for Decadence in Global Health" was delivered by Dr Eric Suba, Director of clinical laboratories, Kaiser Permanent Medical Centre San Francisco California, a visiting Scholar at the National Center for Bioethics at Tuskegee University in Tuskegee. The lecture focused on trials conducted for detection of cervical cancer in women from developing countries including India. The session was chaired by Dr Sanjay Nagral, Dr Rajendra Badwe and Dr Amar Jesani. A number of questions from the audience on the trials lead to a very healthy interactive discussion. The points emerged out of the discussion were based on research practices with respecting the right of individual, non maleficence and beneficence principle.





## Panel discussion “First , do no harm”& Book release function 19<sup>th</sup> July 2016

**Panel Discussion “First Do No Harm” and Book release : “Patient Safety – protect yourself from medical errors”, Author – Dr.AniruddhaMalpani .** The event was organized on Guru-Purnima, 19th July 2016 and was attended by more than 300 practitioners, health care professionals, undergraduate and post graduate students. The Panel discussion by eminent teachers, - clinicians and researchers Dr Farokh Udwadia, Dr Y Amdekar, Dr S Pandya and Dr Urmila thatte brought out key messages like The 4 Cs : communication, care, concern and compassion , reporting of adverse events and importance of research.





## Orientation of Interns to principles of bioethics 29<sup>th</sup> February 2016 & 3<sup>rd</sup> August 2016



**Interns orientation workshop** was held on 29th Feb 2016 by bioethics unit members. It was attended by 170 Interns of 2016 batch. The principles of bioethics and an approach to decision making during ethical dilemmas were dealt using real life case scenarios. Legal aspects relevant to the case scenarios were also explained and emphasized along with importance of effective communication.

Interns orientation workshop for second batch was held on 3<sup>rd</sup> August 2016. The interns were made aware of the Ethical Dilemmas and Conflicts of various bioethical principles through the daily encountered examples.

## Module 2 for First MBBS students 2<sup>nd</sup> March 2016



**Module 2 of bioethics curriculum for First MBBS students** was held on 2<sup>nd</sup> March 2016. It was attended by 146 students. Basics of bioethics discussed during the first contact session were recapitulated. The principles of Autonomy and Dignity; 'Assessment of Capacity' and 'Medical Parentalism' were discussed. Module 2 also dealt with the importance of Informed consent and Assent, indications for taking written consent and violations of informed consent process in a setting of a clinical research study. The principle and concept of justice incorporating equality and equity was discussed to demonstrate how it may be at stake and how to deal with it.



## Students' wing Activities

### Ebate : Debate on ethical issues 16<sup>th</sup> September 2016

**E-bate :** An ethical debate was organized on 16<sup>th</sup> Sept 2016 as a part of World Bioethics Day celebrations. The event was attended by more than 200 students. A total of 12 teams (each team comprising of two students) from M.B.B.S., Occupational Therapy and Physiotherapy participated with great enthusiasm and fervor taking a stand on ethical dilemmas in the medical world. The arguments put forward by all the teams certainly challenged the ethical beliefs of all present, compelling them to put their thinking hats on but stressing upon the motto of the E-bate- 'Raise your arguments not your voice.' In the end after a mind boggling discussion the judges declared Ms Poorva Dige and Ms Vaishnavi Hazare as winners and Mr Preet Shah and Mr. Sushmit Ashya as runner-ups. The best speaker was Mr Preet Shah. The esteemed judges Dr Anuradha Kanhere, Veena Johari and Dr Sandhya Kamat gave their valuable inputs at the end of each debate.





## Guest Lecture on “Doctors Without Borders” - MSF 19<sup>th</sup> September 2016

**“Doctors without borders”:** a guest lecture “Doctors without Borders” by Dr **Bharat Kelkar** on 19<sup>th</sup> September 2016, an alumnus of GSMC, an orthopaedic surgeon and MSF volunteer. It was an awareness raising session where he shared his experiences while volunteering with **MSF** –a medical humanitarian organization. The event was attended by more than 300 undergraduate students (MBBS, occupational therapy, physiotherapy and nursing), postgraduate students and faculty. Dr Kelkar gave an inspiring account of his experience while serving on Jordan-Syria border as an MSF Volunteer. He described different injuries inflicted in the war by bomb blasts, mines, bullets, torchers. The situation was “many nations, one mission” with doctors, nurses and support staff from different countries working in a resource limited environment. Ms Akansha Arora the human relation officer of MSF Doctors without Borders/Médecins Sans Frontières (MSF) introduced the objective and working of the international organization.





## Poster Competition Human Dignity and Human Rights

**Poster competition :** Blending with the theme of world bioethics day - Human Rights and Human dignity the GSMC MUHS UNESCO Bioethics unit held poster competition where creativity through art was used as a medium to express the theme. Total of 76 participants submitted posters. The posters were judged by Mrs. Vrunda Bhagwat, Dr. Nirmala Rege and Ms. Neha Madhiwalla.

As a part of celebrations of World Bioethics Day(19<sup>th</sup> October)  
GSMC-MUHS-UNESCO Bioethics Unit announces

### **Poster Making Competition on “Human Dignity & Human Rights”** Theme for the year 2016

**Last Date for submission of poster (a hard copy) - 10<sup>th</sup> October 2016**

**Last date for Registration - 30<sup>th</sup> September 2016**  
(Prior registration compulsory)

#### **Instructions for participants**

- Competition is **open for all** Undergraduate - Medical, OT, PT, Nursing Students, Interns(all disciplines), Postgraduate students (all disciplines), Faculty & SGSMC & KEMH employees.
- Please mention your **full name, course/year, department, mobile number & email ID** while registering for the competition and also mention it on the **BACK-SIDE** of your poster.
- Poster has to be based on the WBD theme of “**Human Dignity & Human Rights**”.
- Poster should be **hand made** on A3 size poster paper. Participants can use any medium of their choice while drawing/ colouring the poster.
- Participants are encouraged to make their poster in English, however use of Marathi or Hindi will be accepted.
- **Electronic – Copy pasted versions/ posters NOT of A3 size and posters NOT reflecting the theme will be rejected.**
- Each participant can submit **ONLY ONE** poster.
- Best posters in each category will be awarded. Selected posters will be displayed in the exhibition on World Bioethics Day, i.e. 19<sup>th</sup> October 2016. The BEST poster/s will be sent to UNESCO headquarters.
- **Submitted posters will NOT be returned.** Poster may be displayed at various relevant places in our institution in future. Participants will have to sign declaration related to same.

**Dr Avinash Supe**  
Director & Convenor

**Steering Committee**  
GSMC MUHS UNESCO Bioethics Unit



## Let's Play Bioethics

### Answer key for Crossword

#### Across:

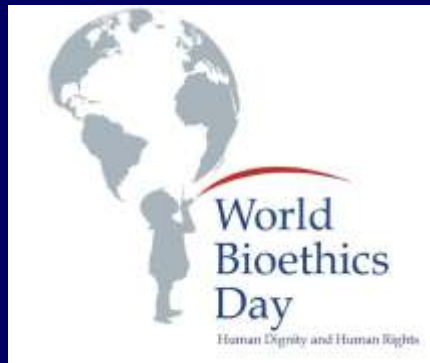
- 1) ICMR
- 2) BIOETHICS
- 10) BENEFIT
- 13) NUREMBERG
- 14) HELSINKI
- 15) UNESCO

#### Down:

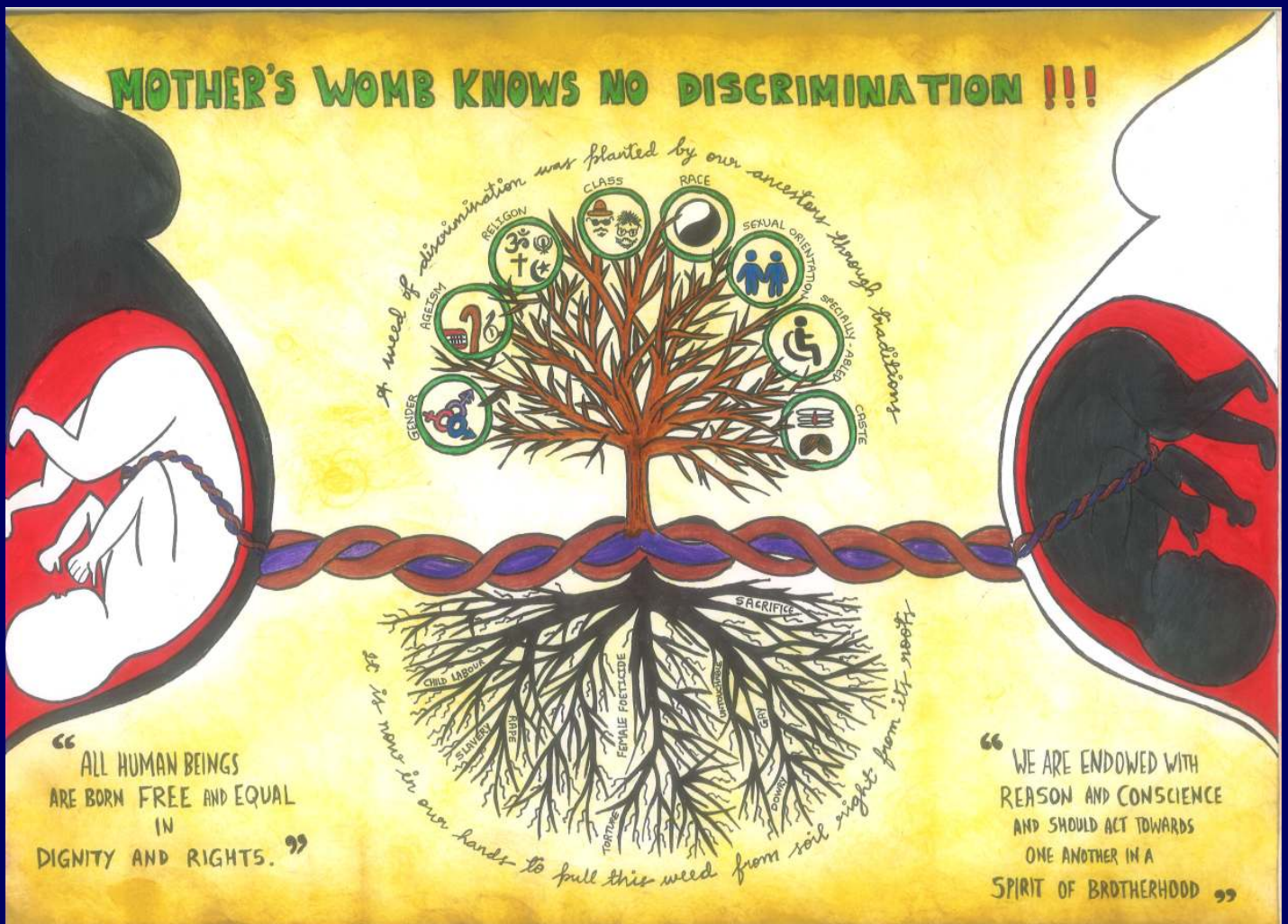
- 1) JUSTICE
- 2) NONMALEFICENCE
- 3) EQUITY
- 4) VIRTUE
- 5) TUSKEGEE
- 8) RIGHTS
- 9) VERACITY
- 11) INCAPACITY
- 12) FIDELITY
- 15) UNROC



# GSMC MUHS UNESCO Bioethics Unit



## Poster Competition on 'Human Dignity and Human Rights'



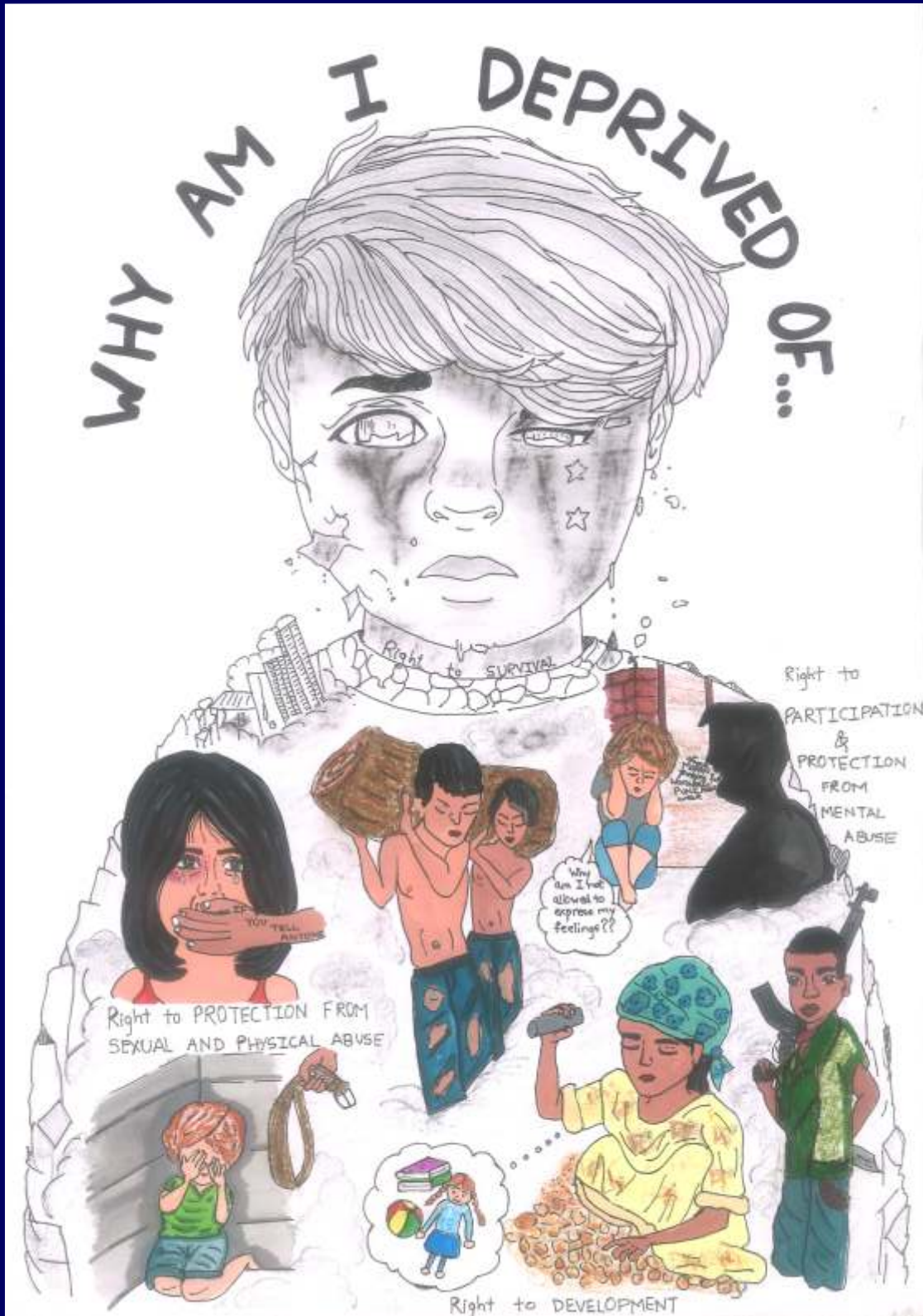
**Third Prize**

**Dr. Hiranmayee Bagwe, Physical Therapy PG Student**



**GSMC MUHS UNESCO Bioethics Unit**

## Poster Competition on 'Human Dignity and Human Rights'



## Second Prize

**Neha Shetty**, Intern, Physical Therapy