BIOETHICS: ISSUES AND CHALLENGES

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INTRODUCTION

A man without ethics is a wild beast loosed upon this world

- Albert Camus

Bioethics concerns itself with the ethical issues faced in the healthcare, biotechnology, research related system. It raises a question regarding the intersection between law, medicine, public policy etc. As we live in an interchanging and growing world these fields have brought different changes with those changes comes the question of ethics of that particular change. On how it would affect the society in whole or what would go against the law. The professional working in this field can be people who are philosophers, person related to legal profession, scientists and Health administrators. In the process, the input of each field is given in the area of resources and methodology to help make change or alter the practices and policies that raises the doubt or question on ethical concern. It discusses in depth regarding clinical research such as organ transplant, AIDS, genetics and so on. It talks about any occurring change and when such change takes place does it cover all the points that are ethical, which is nothing that goes against the nature and law. The emergence of Bioethics or such discussion on ethics had started taking place in the late 1960's but the actual topic was raised in the year 1970, which was first proposed by a Biochemist Van Renesselaer Potter. When we talk further more on the topic then we shall get to know few challenges faced in the fields of Bioethics namely being genetics, environmental ethics and ethical treatment of animals and so on. The paper would go more around the explanation of bioethics, the history and challenges faced in different fields where there is a question raised on the ethical value of the particular change or biotechnology.

In a world where development is taking, place rapidly the growth in is also transpiring in different fields one such field is the medical field. As we keep reading or hearing about innovations or invention let, it be in research or biotechnology. When we talk about Bioethics,

it concerns itself with the study of ethical, social and legal concerns that emerge in biomedicine and bioresearch. The subject includes medical ethics that focuses on healthcare, research ethics, which focuses in the conduct of research, environmental ethics that deals with the issues pertaining to the relationship between human activities and environment, public health issues those talks about issues relating to public health. As we talk about bioethics, it is important to know about bioethicist, they are people who conduct research on issues relating to legal issues regarding ethics in the sphere of biomedicines. They usually work for academic institutions, hospitals, Medical Centre, private company, government agencies and foundationsⁱ.

The questions usually raised are how do I do? Alternatively, how should a person be treated? What are the obligations and responsibility towards an individual? What does it take to be a good doctor, nurse, or anyone relating to the medical field?

OBJECTIVE

- 1. To know the working of bioethics
- 2. To study the issues and challenges present in the field of bioethics
- 3. To know legislative measures

HYPOTHESIS

In India, with the development in all fields, one such is medical field and as changes are taking place, the question pops out whether such changes are in respect of ethics and natural law and if so what are the issues and challenges among them?

RESEARCH METHDOLOGY

This is a doctrinal form of research where secondary source of data is used rather than the primary source.

RESEARCH QUESTION

Issues and challenges in the field of Bioethics?

LITERATURE REVIEW

Ethical Challenges Related to the Novel Coronavirus (COVID-19) Outbreak

By: Ghaiath Alahmad, Hanie Richi, Ala'a BaniMustafa and Adel F. Almutairi

The article talks about the recent dangerous Corona Virus disease and it posing a serious challenge to the ability of the healthcare system and that is posing many ethical challenges both in itself and the methods used for the management. Under this paper they tend to investigate the ethical issues related to COVID-19 pandemic and that it will help address the ethical questions at individual, social and organization levels. The study that has been used in writing the paper is qualitative reseach and hence interviews of 24 healthworkers took place who specialized in treating infectious disease such as researchers and decision makers. The said paper is then divided into different themes and hence discuss various ethical issues such as theme 1 discusses about ethical challenges that took place while establishing the measures to control COVID-19. Moreover, theme 2 talks about Ethical challenges in connection to procedures and actions of certain group, while the third theme talks about ethical issues in relation to detecting the virus and maintaining confidentiality. The 4th theme discusses ethical challenges in respect of the research taken place, lastly talking about ethical duties in light of bioethical principles and states that the all this can be summarized as the offer of maximum amount of protection to the society and community while providing highest standard of healthcare to the patients following international bioethical principles.

PHYSICIAN AND PATIENT RELATIONSHIPⁱⁱ

Now when we talk about this it is the most important and a basic principle to be followed by any practitioner working in the said field. It is takes place when a physician tens to patients medical needs by the way of checkups or providing a treatment. The whole relationship is based

on trust between the doctor and the patient. It is the physician's ethical responsibility to build trust and place patient's welfare before his own interest. Usually the formulation of such relationship is consensual that is it is mutually formed and when such relation is formed between the doctor and patient then it becomes the obligation of the doctor to treat the patient fairly and with utmost care and most importantly maintain the amount of confidentiality that is required out of him.

However, there are certain times when such mutual or consent is not necessary between the doctor and the patient such as:

- 1. At the times of emergency that is at the request of the patient's treating physician.
- 2. Or when the physician provides medical care to a prisoner under court order
- 3. When a physician examines a patient in the context of independent medical examination

In all the above stated it is always important for the physician in action to do and act what is ethically correct.

But if there is a starting of any relationship there is always an end to such a relationship in the same manner when there is an end of physician and patients relationship then it's the responsibility of the physician that he notifies the patient long enough in advance to permit the patient to ensure for another physician and to facilitate transfer of care whenever necessary.

The next important thing to keep in mind is the conscience of a physician that is they are expected to sustain the ethical norms of their professional practice as they are expected to provide their services and oblige the decisions of the patients they are treating even when the decision made by few patients are against their beliefs such as their option to refuse life-sustaining treatment.

Nevertheless, it is in some cases they might be able to act in respect to their conscience without going against their professional obligations. For example in cases where they have a long lasting relation with the patient where they are in a position to give different suggestion in respect to the decision given by the individual where he can give the person a chance to rethink his decision by giving out different options. On the other hand, if the physician makes it clear

before getting into the doctor patient relationship that he would not do anything against his deeply believed beliefs or something that would go against his conscience.

GENETIC TESTINGⁱⁱⁱ

Then comes another ethical issue in the field of biomedicine is known as 'Genetic testing' before discussing the ethics in the testing we shall look forward to know what is genetic testing. Now, it is something that looks for changes or mutations in one's DNA and is known to be very useful due to its nature of providing a diagnosis of any genetic condition present in an individual that may lead to any significant or consequential disease. There are many ways that the said test is done by way of blood or spit sample. The reason behind the test to be done is to know that the disease runs genetically and in females the current chance of pregnancy would be effected with such genetic disease and finally to cure the diagnosed disease.

Now when we have gained some knowledge regarding what a gene test is then there are some important things that raise a question which are Is it important to do a gene test? Alternatively, if the test is so done should the reports be released to any third person and many more.

Four ethical principles that are to be kept in mind if a person is doing or conducting such a test are as confidentiality, autonomy, privacy and lastly equity. When we talk about confidentiality, it can act as one of the main ethical principle of not only gene test but in any field of medical care. If there is no clause of confidentiality, automatically a person's privacy will be invaded and which would not only result in loss of trust on the medical care but also prevent people who are in urgent need of treatment to avoid such care with the thought that their personal information would not be protected or remained confidential. However, in some case the information is not supposed to be kept confidential under the law such as in the matter of reporting wounds due to guns or something that could cause serious harm to others in case of gene test if a person knows that such disease can cause harm to a lot of people then such shall be communicated or can break the clause of confidentiality. In addition, sometimes there can be a breach in confidentiality due to lack of care by the individual in charge.

When we talk about equity, as soon as we hear the word equity we are reminded of fairness or issues relating to justice. Above all, it talks about the discrimination that might take place while

gene test also known as genetic discrimination in cases of health insurance or employment. The argument here lies that the society being the question of a person acquiring decent heath care and a surety to be taken care of when any such health crises takes place. Not only this but another issue is regarding depriving an individual of being fairly treated with any other individual and providing equal opportunity for them any such facility that is given to others without drawing a line between them.

Although when we look at the legislations regarding genetic testing then in India there are no specific laws that regarding the same as there are not many labs that provide or tackle genetic diseases. Hence, no strong laws have been formulated but looking at other countries such as the Council of Europe are influenced by International Documents such as Convention on Human rights and biomedicine. In addition another document is the Additional Protocol on Genetic testing for Health purposes which was the first International binding document inscribing the Genetic testing, it looks upon the clinical utility, medical supervision and genetic counselling^{iv}.

When we talked about genetic discrimination then the legislation that covers such issue is the Genetic Information Nondiscrimination Act 2000 (GINA) that talks about prohibiting the discrimination and The Affordable Care Act 2010 talks about antidiscrimination including the measures taken where the health insurers depriving them the coverage^v.

Then another legislation is the American with Disability Act, 1990 (ADA) that protects an individual from discrimination based on their disability in the worksite, this act does not specifically focuses on the genetic disease but does provide protection to some extent on genetic based disability. Whereas, Health Insurance Portability and accountability act, 199 (HIPAA) the only act that deals directly with genetic prejudice in the area of health insurance on employer based and HIPAA National standards to protect patients personal medical records, 2002 which dealt with the privacy of an individual's medical records by the medical institutions^{vi}.

GENETIC ENGINEERING^{vii}

Next, when we look at "Genetic Engineering" the term means alteration of characteristics of genetic material of an organism. In an more specific way it is when a person usually who are in the medical field purposefully or consciously modifies any traits or qualities of an entity by altering its genetic material for giving out a new form of result or species. The question here is where such an alteration is always ethical or not? The answer to this question is slightly complex because some genetic engineering can result in good and some can raise different queries. This can be done with different things, which includes foods, plants and animals, but here we will majorly discuss regarding genetic altering in animals. Now, briefly to say such alteration in animals done by manipulating its DNA by way of adding the parent gene with gene of another. Here, the Canadian Council on Animal Care (CCAN) gave in a new definition of genetically engineered animals as "an animal that has had change in its nuclear or mitochondrial DNA by means of addition, deletion or substitution of some part with any foreign DNA that is attained by a deliberate human technological intervention". Moreover, such animals have gone through mutations or are cloned animals are to be called genetically engineered animals.

When this takes place the there are some ethical issues that has been stated by the World Organization of Animal Healthcare regarding the state of the animal, or how is it coping up with the environment it is living in. The others are that kind or how the procedure is taking place, large number of animals or the thin line that is drawn while doing such manipulation. On the discussion of large numbers of animals being used in such process they could be of different kinds such as companion, wild, farm and research animals these are the animals, which are genetically altered like in case of farm animals the example could be transgenic pigs and sheep.

While, focusing on the main topic being the ethical issue then for the change to take place some form of incision or any surgical method used can result into the inducing of the animal to take in anesthesia or euthanize the female in such procedure leading to the different repercussion which in some cases might not be on a positive side. The surgical procedure can leave the animal in pain and suffering or result in permanent damage. While the question arises as to why is it done then the answer to such question is the many things that might cover production

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of altogether a new species and the second being the benefit or profit that an individual gains out of such genetically modified animal. When we talk about the second reason then the example can be sellers selling genetically modified animals that are excess in meat and hence leading to profit and upto an extent used for irradiating the hunger. But with this in mind is it really ethical to change the actual nature of the animal merely such benefits, and when such modification takes place are these animals provided with proper environment and food supply for recovering from such modification. Being clouded with the advantages we often forget to acknowledge the effect on the animals such as increase susceptibility to stress, genetic abnormalities and lameness.

Now the question is can it take place in humans as well? To answer this question a scientist in the year 2018 in China claimed to have modified a gene in two human embryos and embedded them in the mother's womb resulting to the birth of genetically altered twins. Which caused an International scandal and month later scientist were called for global moratorium on gene editing embryos. This is one example of such modification as there is not much progress in this area but as the rapid advancement in technology is taking place it will not be long enough that we see designer babies in coming future. Now to know what is designer baby it means that putting in those or modifying those genes that are ideal for the baby by the parents as fancy and attractive it sounds to have the ideal baby as one wants is it ethically correct? Is it fair to disturb the natural course of a person's genes? Even if in future this modification takes place then it will come in with challenges of its own. It would build a whole line between the natural born baby and a designer baby as in terms of intelligence, growth and other features, both would be treated differently and hence it being ethically wrong as there would be no equality between them.

Genetic engineering also involves the topic of one form of genetically engineered viruses, which means that the creating and modifying virus that can cause mass destruction like the Ebola virus that was widely spread across the nation. These viruses have the chance of being used as a weapon as spreading of such virus can affect the world as whole and the some viruses are created in such a way that they are immune to any kind of antibiotic and by the time the antidote of the virus manufactured it has already done a lot of damage. Earlier at the time of World War II, there was usage of such virus and was injected to the opponent side, as the results of these viruses can be lethal leaving very less survival rates. For taking an example of

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the recent days now almost two years that the whole world is suffering due to the spread of corona virus which when started was showing various symptoms and was resilient to any antibiotic and hence was giving out less survival chances and causing huge increase in the death mortality rate all over the world. Now, this virus has the chance of being used a as a bio weapon due to its deadly nature and non-reactant to the medications and it is continuously mutating itself and resulting into formation of new variants. Any of these viruses can be used by the terrorists to form or lead to a lot of damage to the world, which is both ethically and morally wrong.

When we look into the legislations that govern genetic engineering or genetically modified organisms (GMO) are under the supervision of "Rules for the manufacture, use, import, export and storage of hazardous microorganisms, genetically engineered organisms or cells", 1989, which are incorporated under the Environment Protection Act, 1986. The said rules were executed by the Ministry of Environment and Department of Biotechnology. So, the Rules, 1989 comprise of six competent authority under which there is Review Committee on Genetic Manipulation (RCGM) where, its functions are to monitor the safety in connection with the ongoing research projects and activity relating to the genetically engineered organisms. It also mandates manuals of guidelines specifying procedures; the second competent authority is Genetic Engineering Committee Appraisal (GEAC), the committee compromises representative from ministries, agencies and experts. The Rules, 1989 talks about approvals, supervisions and penalties. In case of any intervention, the individual who is responsible for such damage would be liable to compensate for such damageviii.

ENVIRONMENTAL ETHICS^{ix}

The next or one of the important issues is the environment and its ethical issues or environmental ethics. It focuses on the moral and ethical obligation of human beings towards the environment; this topic is not new it has been a topic of debate from a long time. Now this issue did not come up until the 1970's only after then did the emergence of this issue when the population started to grow rapidly which in return began to influence the environment. As it is said that every things has its pros and cons just like two sides of the coin one being the positive

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and other negative, in the same way the growth lead to development which brought many changes which were both in nature. The changes leading to water and air pollution, depletion of natural resources, loss of biodiversity, climate change or interference in ecosystem let it be any one these things it is ethically and moral responsibility of human being to take care of the environment they are living in. the question here lies as to what can be done? The answer to this is as globalization is taking place the industrialization is growing rapidly not only in cities now but also making its way to the villages, which is resulting in cutting down of mountains not only this but destruction of forest, extinction of species or over using of natural resources being available to us. All this is nothing but a step forward in shrinking of the environment, in olden days air was more pure, natural resources were unlimited but now that is not the case. Recently, a whole lot of discussion took place regarding the exhausting of coal, which resulted in problems with the electricity. This is a sign of the environment shrinking and the only possible solution to this is to make efforts in conserving the said resources and spreading education about the same to people who do not have knowledge about this. If not now then, when will we understand our ethical duty to save where we are living, it is important to not only save natural resources but also other things. The biggest example of water pollution being the river Ganga which is being polluted so badly that recently we could observe white foam forming in the water of Ganga. It is only ethical to save and provide our future generations with some security so that they can have a peaceful existence.

IONIZING RADIATION^x

Another is the ethical consideration in protecting environment from the effect of ionizing radiation. When we talk about radiation then natural, radiation has been present since the beginning of life although it varied in its levels in the same way the humans evolved now it has effects on both the biotic and abiotic. In case of biotic then the effects can be observed when the radiation doses are considerably above that the usual such an increase can lead to health risk by damaging the tissue as it has sufficient energy to affect the atoms in living cells. When we talk about plants then in such case the soil can become compact and lose the nutrients that are in need for the growth of the plant which will result in the depletion of the plant and leading to its death^{xi}. In cases of animals the biological radiation are generally common to man and

animals but studies on Drosophila have shown that the mutation rates were increased enormously due to radiation, even small amount of radionuclides lead to such increase and they enter into the metabolic cycle making its way to the DNA and hence resulting into genetic damage^{xii}.

In the ethical view, philosophers came up with number of concepts to draw basic difference between moralities as well as pronouncement of minimum environmental concerns, by the suggesting of two theories that are ethics of end and ethics of duty. Where the ethics of end is based on the utilitarian thought and states that any activity that is based on the general happiness of human beings on a larger extent is morally correct and hence making it difficult to make space for human anatomy and dignity with the thought of utilitarianism. However, when we talk about the ethics of duty basing on the thought that gives importance to the human anatomy and dignity than the utilitarian thought, that means nothing is held important that the life of the nature and binds the human to fulfil its moral and ethical duty in respect of reserving the same.

When we discuss about the environmental ethics then according to the philosophers it has largely evolved from the already subsisting human or fabricated theories that at ties raise the question on the moral standing in the world. now, there are different views that are existing such as anthropocentrism and non-anthropocentrism where an individual who believes in the first concept contemplate that human experience and life are given of the utmost important position and that the shielding of the environment is only important till it satisfies the needs of human. Whereas, the people who are of the latter view deny the proclamation that moral value can be derived only on the terms of human interest but rather suggest other ways of ethical outlook. When we look into the legal aspects or the measure taken for such deprivation then it has started from earlier years itself for example UN General Assembly's World Charter for Nature in the year 1982, in the said charter there was a mention of recognition of ecosystems as a life support system. Then the concern for nature segmenting in the Stockholm Declaration of the United Nation Conference on the Human Environment, 1972, but it was the Rio Declaration on Environment and Development in the year 1992 that made sure of all the countries agreeing on the norms relating to international environmental protection. Another important aspect that has to be looked at was the climate change, which was also covered under the Rio Declaration, 1992. Nevertheless, also other legislations talk about the change in climate

such as The Kyoto Protocol to the United Nation framework convention on climate change in the year 2001 under which they address the topic of sustainable utilization.

CLINICAL RESEARCH

As we move forward, we look into the topic of clinical research, as we discuss this it is important to know that clinical research plays a pivotal role in the field of the healthcare system as through this process only there are introduction of new treatments. Now the definition of clinical research given by the National Institute of Health (NIH) as medical research that tests new treatments and therapies on people and determine the effect of such intervention on health related outcomes that includes both biomedical and behavioral^{xiii}.

The goal of such research is to expand the knowledge of an individual or group of individuals and help in improving patient care and the research can involve different kinds such as medical research, treatment research, and prevention, diagnostic and genetic^{xiv}. When we talk about its importance then with the recent times of COVID-19 the most important places have been the clinical research centers due to the formation of the vaccination and then testing on people to see its success rates and have played a major role in the reduction and safety of the people all over the world and hence being an example and explaining the importance of such research centers. Now to get on the topic of ethics there are three ethical principles that were introduced by the Belmont Report in the year 1979 which are respect for a person, it should be beneficial to the person and has to be done with non-malaise intension and lastly giving out proper justice. Now, when we talk about the first ethical principle then the anonymity of the person who has given his name for such research should be maintained and case the name has somehow exposed then such person must be provided proper amount of protection in any case possible. When we talk about the second mentioned principle that indicates that whoever has been in such process of the research or part of the same must gain some amount of benefit for example while the testing of vaccines for COVID-19 virus, secondly the said procedure should be conducted with no malaise or wrongful intention such as only for the profit of the person doing so. In this case there should be benefit that would be divided equally to both the sides and accomplish the greater benefit of the public that is the widespread of knowledge. Thirdly and

the last that talks about providing proper justice that is no discrimination must take place while regulating such course of action and that the person should be treated equally^{xv}.

There are requirements for conducting an ethical research are that they should be socially viable that is the said research should either be beneficial in areas of health as well distribute knowledge to the people. Secondly it should access risk fairly that is the research that is being in action should minimize the risk or level of danger on the said subject taking into the aspect of the subject's vulnerability or keeping in mind the effects that would take place after the research has been concluded. Lastly respect for the subject that is the part of the research which means looking into the proper amount of confidentiality of the subject and that there no harassment that takes place in the course of action or till it is the part of the research and looking to provide it with utmost protection. In cases of any injury or damage caused during the plan of action then compensate for such appropriately, and always keep in mind for the acknowledgement of the consent of the subject, it should not be forced or under any undue influence for carrying out such research^{xvi}.

LAWS^{xvii}

Looking into the guiding power for conducting the clinical research then the World Health Organization (WHO) states that any research so conducted according in the steps of the approved protocol and all the applicable regulatory requirements. In addition, that the records documenting the study shall undergo strict verification for making sure that the study is taking place according to the said protocol (Principle 11). It also mentions about the safety that any procedure taking place the researcher has to make sure they are carried out with utmost safety and that the clinical investigatory will hold primary responsibility for any damage of any nature. The point of monitoring under this usually the sponsor would make sure that he regularly visits the site and provide or give in his reviews. It also states under WHO principles that if any research involves any human beings then they should be fully consensual and of sound in nature, not being under any kind of influence (Principle 7). Whereas Principle 9 talks about the qualified and duly licensed medical personnel who will be responsible regarding the medical care during the trial of the subject or any decision that has to made during the process. Similarly principle 10 talks about whoever is involved in the trial should be qualified by

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ISSN 2582 6921 Volume 2 Issue 2 [June - July 2021] © 2015-2021 All Rights Reserved by <u>The Law Brigade Publishers</u> education, training and experience for performing or conducting such trial, principle 13 discusses about the investigational products which should be manufactured, handled and stored according to the instruction of Good Manufactured Products (GMP).

When we talk about instances where there was unethical behviour during such trials or research are as follows^{xviii}:

Plutonium Trials: under this trial being the part of the Manhattan project, the researchers had a greater understanding of the effects of Plutonium on the human body and to further gain knowledge about it more they conducted a research involving many people who were then injected by the plutonium injections. It was then revealed through the documents that the people who were acting as test subjects were not completely informed about the risk of the plutonium that was injected due to which the subjects suffering long term health complications.

Tuskegee Syphilis Study: in the year of 1932, the Tuskegee Institute recruited a number of around 600 black men and offered on participation for a new research on the transmission of syphilis. The researchers misguided the men and gained consent for getting into the trial, which was not known, to the Government at that time of the trial. Later, the said fact disclosed on the report given by the Centre for disease control and prevention (CDC).

Willow broke Hepatitis Experiments: in the year of 1950, the outbreak of Hepatitis considered common and so researchers for conducting the trial fed live hepatitis virus to 60 healthy children. The opposing of public then brought down this trial.

These were few instances where the professionals did not follow the ethical principle for clinical research.

RESOURCE ALLOCATION^{xix}

Moving on to another area is the point of resource allocation, the definition it is understood as the distribution or dispensation of the resources to the competing organization and can be provided by the Government at different stages of healthcare. It occurs when there is decline or stable in the total resources. The said topic becomes or gets included in ethical areas is because it solely the matter of fairness and justice, as it is based on fair allocation of resources

to the organization in need which automatically becomes the ethical duty of the person who is in the position of providing such resources. It mostly follows the path of equity and distributive justice where one ethical theory that takes in consideration of equity, fairness rather than looking into the overall benefit is the "Theory of Justice" which was propounded by John Rawls and was incorporated by Norman Daniels in the system of health care. With this application in talks about the sense of providing allocation of resources to the poorest health and greatest need.

Now to provide such an example to demonstrate the allocation of resource is the recent times of COVID-19 where such a pandemic took place it took a huge toll on the healthcare system all over the world as the demand increased more than usual in the aspect of machinery or beds or any other form of resource that was needed. In such a case the government who provides such resource or the monetary value has given that much amount for the organization to function and provide proper care for the patients coming in. but, even then in some situations we could see the wastage of such allocation and hence resulting in denying the care in some areas.

In this we can notice that the government was fair and just in providing funds to each and every organization who was in need and was helping with the pandemic situation plus also giving resource to the people who gave in places as COVID accommodation. Not only that but also providing funds for the vaccination and to the research centers. Hence, all this is the proper example of Theory of Justice, which talks about fair and just while allocating resources.

When we discuss about law and its relation with resource allocation then it plays a major role as it can be implemented to resolution for various issues that occur in the field of allocating resources. There are two leading principles under which these issues can be elevated in litigation, first being when the services of healthcare and not being provided to the patient in need and based on the action the suitable area of offence selected. Alternatively, have caused any negligence in the course of such care by the system. Legal action concerning individual patients affected by such resource allocation considered rare where Pulllinger v Medical Benefits Fund is the clear example of such a legal action. In the said case, Pullinger was an eight-year-old kid with the disease called Smith-Lemli-Optiz syndrome, which includes intellectual and physical disabilities with other issues such as epilepsy, several nutritional

problem as well as cordial blindness. Which would require utmost care and physical therapy, so that issue that arose in case of allocating resource was that the point of providing allocation of resource if they are never going to show prospects of improvement could continue to receive such expensive treatment in private hospital or whether such care to be transferred in public hospital. Now here she received the certificate of "Acute care" which was then reviewed by the acute care adversary committee to be known as false and that she need to shift to another accommodation from the one she was staying in. It was stated that the acute care certificate was only provided to people who have chances of even slight improvement, which was not the situation in her case. Secondly, the point of negligence is when a medical practitioner takes an account of resources limitations in treating a patient a risk of tort liability may arise, if the patient shows that the damage has suffered due to the decision raising a doubt on the care that is being provided. Where such issues can arise at any level of the process in case of institutional process then an intensive care unit or failure to provide a new and beneficial drug to patients because of its expense and hence create potential problems. Later coming to the liability of the hospital it is to mention that the cases concerned whether the care so provided was actually of an adequate standard and it is seen that the duty of the hospital goes way beyond rather than just looking at the staff. It is the hospital's non-delegable duty towards its patients that the primary liability and not merely vicariously liable for negligence within it. But it cannot deny or ignore it's moral and ethical duty to appoint proper number of staffs as if the hospital goes understaff then the chances of liability for negligence can increase which can also be in a way of not addressing the patient in need. Cases raised directly to increase health care costs in the UK and US have often been unsuccessful. "In England a group of patients from an orthopaedic hospital has filed a complaint with the court. Unreasonable delay in treatment due to lack of equipment It arises in part from the decision not to build a new hospital building. Foundations of Value.

DEATH AND DYING OF PATIENT^{xx}

Another issue relating to ethics in the field of health care is the treatment of the dying patient which when kept forward pose a huge dilemma on the ethical and moral duty of an individual.

Now, when a person has to decide on ending a treatment of an individual let it be a person treating or he is the close one to the person in care it is always a decision of puzzling.

When the issue of ethics is raised then there are different scenarios one must decide to end of his life care where one of them is lack of access to Hospice care, studies show that lot of American's decide to end their life care due to non-availability of Hospice care. Now, before moving on we need to know what Hospice care is. The answer to that is the care that is provided to the patients or a special hospital for the patients who are dying where they deal with the practical and emotional care of the person. Second is the Medicare which provides or support through monetary value for the patients of Hospice Care, it requires that the patient have prognosis of six months or less before entering the hospice care. These limits, as required by Medicare, are a requirement for a patient to have a prognosis. Six months or less, paid per day - may be disruptive for some patients Imposing financial restrictions on some hospice programs, from hospitalization to hospice. Then comes, Prognosis so before anyone enters Medicare Hospice Benefit they have get the prognosis done by the physician showing that the person has six or less than six months to live. The ethicality under Prognosis are accuracy, which means giving out proper diagnosis to the patient, and other two are six month limitation and third is the communicating the same with the patient. Then comes the pain management now after a person gets to know the prognosis of the disease the pain due to the said disease may at times be unbearable and intensify at times it is the ethical duty of the doctor to give proper medication for reducing the pain. Where antibiotics comes into the scene now the concern in this is the overdosing of the medicine that after a period of time the person becomes immune to the given antibiotics.

Then comes Medical Futility where the ethical questions that are posed are first, those who are curious How to determine medical nonsense and prevent it? It is the doctor's decision. Second, there are concerns about treatment. May appear less beneficial or ineffective to the healthcare professional, but the patient finds it useful^{xxi}. Finally, the biggest problem is the treatment needed to save money. This problem is a problem for some elderly people, people with disabilities, and socio-economically disadvantaged part of the population^{xxii}. Nevertheless, advocates who want to limit unnecessary health care, argue:^{xxiii}

• Metrics, including forecasts and estimates, can be used to determine obsolescence. Recoverability and functional status.

• Not all treatments are beneficial.

• Health care providers do not consider beneficial treatments useless.

• Waste disposal is expensive and uses resources inefficiently.

• Addressing the medical valuelessness issue allows patients to receive care that is more appropriate. For other programs such as hospice.

CONCLUSION

With the above material, we understand the meaning and importance of Bioethics, which is the ethical issues that is dealt in the field of biomedical as well as biotechnology. The people who deal with it are known as Bioethicists and are accessible in different institutions, research centres and so on. The importance of Bioethics emerged in the year 1970, as there was an understanding that as the world is progressing there are introduction of different technologies. In the advancement of people and with so many changes and usage of those changes even in the field of medicine will raise different ethical question and every change can be of two side positive as well as negative.

In the existing field of medicine there are different ethical issues such as the relationship between the doctor and the patient under which it is determined where the duty of a doctor starts and when does it end. In the similar way the ethical concerns raised in the field of genetic testing under which it is the ethical duty of the person or the institute who is conducting such test to follow the rules of confidentiality and establishing non-discrimination of any kind. It also talks about the duties of the companies under which such person is working and the insurance companies making sure they provide basic health care to the person and being fair and just. But when we look into the topic of Genetic engineering we get a proper definition of it that states that modifying the gene of the DNA of an organism to create something new is to be termed as genetic engineering and the ethical issues that arise under that cover the protection and well-being of the subject that is genetically engineering. Here, under the paper I have

mentioned genetic engineering done on animals and stated how they are effected due to such modification. Later have also mentioned regarding the emerging of designer babies due to the method of such modification and focusing the future ethical issues that would be raised due to such emergence and how ethical would it be. Then coming down to Clinical research and resource allocation explaining the importance of it as they are the source of spreading knowledge and giving out new treatments with the example of recent pandemic of COVID-19 and the expertise work that has been done by these two field.

BIBLIOGRAPHY

List of Statutes:

- 1. Genetic Information Non-discrimination Act, 2000
- 2. The Affordable Care Act, 2010
- 3. The Environment Protection Act, 1986
- 4. Rio Declaration, 1992
- 5. The Kyoto Protocol, 2001
- 6. UN General Assembly's World Charter For Nature, 1982
- 7. UN Conference on Human Environment, 1972
- 8. Rules, 1989
- 9. Convention on Human rights and biomedicine
- 10. American with Disability Act, 1990
- 11. Health Insurance Portability and Accountability Act
- 12. World Health Organization

Abbreviations:

- 1. Genetically Modified Organisms (GMO)
- 2. Genetic engineering approval committee (GEAC)
- 3. National Institute of Health (NIH)
- 4. Review committee on genetic manipulation (RCGM)

Case:

Pullinger v. Medical Benefits Fund

ENDNOTES

ⁱⁱ Code of medical ethics: Patient- physician relationships, http://www.ama-assn.org (last visited Dec 2, 2021).

^{iv} Kalokairinou, L., Howard, H.C., Slokenberga, S. *et al.* Legislation of direct-to-consumer genetic testing in Europe: a fragmented regulatory landscape. *J Community Genet* **9**, 117–132 (2018). https://doi.org/10.1007/s12687-017-0344-2

^{vi} Genetics Legislation, (2019), http://www.web.ornl.gov (last visited Dec 4, 2021).

^{vii} Elizabeth H. Ormanly, Julie Dale & Gilly Griffin, Genetic engineering of animals: ethical issues including welfare concerns (2011), http://www.ncbi.nlm.nih.gov (last visited Dec 4, 2021).

^x International Atomic energy agency, Ethical consideration in protecting the environment from effects of ionizing radiation (2002), https://www-pub.iaea.org / (last visited Dec 5, 2021).

^{xi} Diksha Kashyap, Effects of Radiation on Plants and Animals (2021), http://www.yourarticlelibrary.com (last visited Dec 5, 2021).

^{xii} IBID

xiii Wake Forest Uiniversity, Ethics in clinical research: Foundation and current issues, http://www.onlinehealth.wfu.edu (last visited Dec 6, 2021).

^{xiv} IBID

^{xv} Overview of ethics of clinical research, ethical principle and requirements, (2021), http://www.crc.gov.my (last visited Dec 5, 2021).

^{xvi} Overview of ethics of clinical research, ethical principle and requirements, http://www.crc.gov.my (last visited Dec 5, 2021).

^{xvii} World Health Organisation, Handbook for Good clinical research practice (2002), http://www.who.int (last visited Dec 5, 2021).

^{xviii} Wake Forest Uiniversity, Ethics in clinical research: Foundation and current issues, http://www.onlinehealth.wfu.edu (last visited Dec 6, 2021).

^{xix} Beth Gaze, *Resource Allocation: the legal implications*, 9 Journal of Contemporary Health law and policy (1993).

^{xx} Centre for Bioethics University of Minnesota, End of Life Care: An ethical review (2005), http://www.ahc.umn.edu (last visited Dec 7, 2021).

^{xxi} 8 Coppa S. Futile Care: Confronting the high costs of dying. Journal of Nursing Administration, 1996; 26(12):18-23.

^{xxii} Kapp MB. Economic influences on end-of-life care: empirical evidence and ethical speculation. Death Studies, 2001; 25(3):251-263.

^{xxiii} Coppa S. Futile Care: Confronting the high costs of dying. Journal of Nursing Administration, 1996; 26(12):18-23.

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Volume 2 Issue 2 [June - July 2021] © 2015-2021 All Rights Reserved by The Law Brigade Publishers

ⁱ What is Bioethics?, https://bioethicsarchive.georgetown.edu/ (last visited Dec 1, 2021).

ⁱⁱⁱ JE Holtzman, Social, Legal and ethical implications of genetic testing (1994), http://www.ncbi.nlm.nih.gov (last visited Dec 3, 2021).

^v Genetics Legislation, (2019), http://www.web.ornl.gov (last visited Dec 4, 2021).

^{viii} Ahuja V, Regulation of emerging gene technology in India (2018), http://www.bmcproc.biomedcentral.com (last visited Dec 4, 2021).

^{ix} Donald.A Brown, The Ethical dimension of global environmental issues (2001), http://www.amacad.org (last visited Dec 5, 2021).