Issues in Bioethics

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Module No #04
Lecture No #17
The Challenges Posed by Genetic Engineering & Gene therapy

Hi, welcome to this course, Issues in Bioethics. Module Four and Unit Two. In continuation with the previous lecture, where we discuss, some challenges posed by, some technological advancements in medicine. This unit will also focus on some of them. This unit will focus on the Challenges Posed by Genetic Engineering and Gene therapy.

So, when it comes to Genetic Engineering and Gene therapy or the domain of genetics, we are actually touching upon a very sensitive area. Because, this is something, which tells us about, what we have inherited, and what our children are going to inherit from us. And, we are going to tamper that, or we are going to manipulate, we are going to make changes, modifications in that very crucial information, which is hidden in all of us, the domain of genes.

And, Genetic Engineering is a something, which scientists have been practicing very successfully among plants, and to some extent, animals as well. But, their application in the human world is much limited. Of course, people still do that. Doctors, Physicians still do that. But, there are lot of controversies and ethical issues, they raise. And, Gene therapy also raises several issues, several ethical concerns. And, we are going to address, some of these issues in this lecture.

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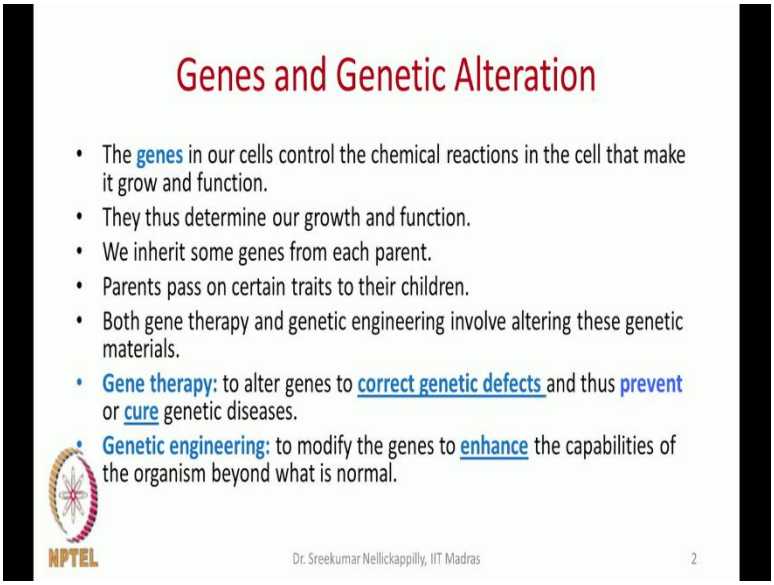
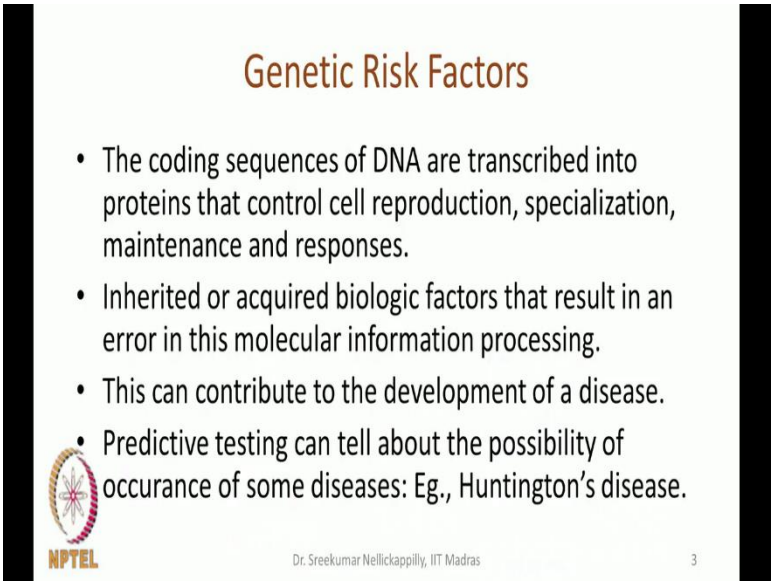


So, the Genes. Before, we get into the real issues, let us try to have a primary understanding about, some of the terms used. The genes in our cells, control the chemical reactions in the cell, that make it grow and function. In one sense, we can say that, the genes are the most important constituents of our organism. And, they are very crucial. And, when Gene therapy is trying to address them, trying to modify them, we are entering into a very new domain of medicine or medical technology.

They, thus determine, our growth and function. The genes determine, our growth and function. And, we inherit some of these genes from, each of our parents. And then, parents pass on certain traits to their children. Many of the things, many of the and even some, according to some scientists, many diseases, which we have, which we are prone to, are because of the genes, which we inherit. There are many important diseases. Say for example, certain types of cancers. Certain people are more prone to that, because they genetically inherit the kind of gene, which is responsible for that.

And both, Gene therapy and Genetic Engineering involved, altering these genetic materials. And, Gene therapy is, it consists of altering genes to correct genetic defects. And thus, prevent or cure genetic diseases. So, it is a major-medical intervention, and a very crucial, and an important medical intervention, which new advances in medicine have introduced. And in that sense, it is going to be a, definitely a great boon to humanity. No doubt in that.

And on the other hand, Genetic Engineering is to modify the genes, to enhance the capabilities of the organism, beyond what is normal. Genetic Engineering on the other hand, insert, modifying the genes, to enhance the capabilities of the organism, beyond what is said to be normal. So, in that sense, the scope of Genetic Engineering is slightly different, and also beyond medicine, we can say. Because, it tries to even enhance the capabilities of the organism. So, there are certain, these two advancements in modern medicine, have definitely introduce certain risk factors. (Refer Slide Time: 04:22)



Now, let us try to understand, what is the rid cause of genetic risk factors, which these two modern therapies or modern therapeutic measures, are trying to address the genetic risk factors. The coding sequences of DNA are transcribed into proteins, that control cell reproduction, specialization, maintenance, and responses. So, this is what the DNA does. They are transcribed into proteins. The coding sequences are transcribed into proteins, which are responsible for various activities, that happen to us. And, we this inherited or acquired biologic factors, that result in an error in this molecular information processing, can result in fatal consequences. This can contribute to the development of diseases.

And, this is what, Genetic therapy or Genetic Engineering and Gene therapy are trying to address. So, predictive testing can tell about the possibility of occurrence of some diseases. For

example, Huntington's disease. This is a very famous example. That, this particular disease is a genetically inherited disease, whose appearance can be predicted well in advance, if a proper testing is done. And, Gene therapy aims at trying to find solutions to many such problems. As I mentioned earlier, certain cancers and many other diseases have their roots in the genes. And, if we can think of, if we can identify this, we can think of proper measures to prevent them, and also to cure them.

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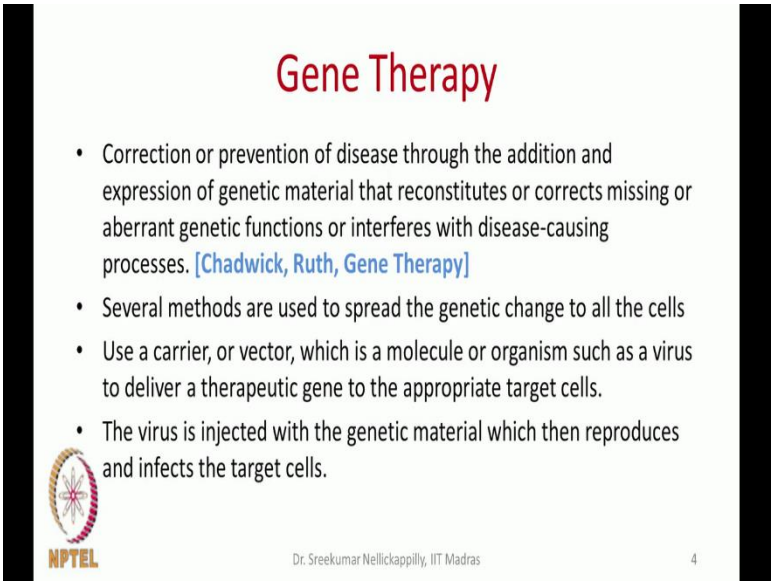

So, Gene therapy. So, let us try to understand, what is it. So here, this is a very broad introduction. So, this is trying not to define Gene therapy, but it is also trying to give an account of, what Gene therapy is, by Ruth, Chadwick's book, Ruth, Chadwick's article, Gene therapy. It says that, it is a correction, or prevention of disease, through the addition and expression of genetic material, that reconstitutes, or corrects, missing or aberrant genetic functions, or interferes with disease-causing processes. So, this account is trying to give a comprehensive picture about, what Gene therapy is, and several methods are used to spread the genetic change in all the cells.

Because for instance, it is very difficult to change all the cells, taking them one by one. Scientists cannot do that. So, what they normally do is that, they use a carrier, a vector, which is a molecule, or an organism, such as a virus, to deliver a therapeutic gene, to the appropriate target

cells. See for example, if there are certain cells, which are cancer cells, which were, which we are trying to modify needs to, we need to, we are planning to modify, we are trying to make some changes in those areas. Say for example, in the liver or in the heart for example. Certain other problem in the heart, we are trying to make certain changes.

So, these changes have to be made only in that particular organ, not anywhere else. So, what doctors do is that, they inject the virus with the genetic material. Which then, reproduces and infects the target cells and then, do the needful, the desirable. So, this is how, Gene therapy is normally done, or rather the idea of Gene therapy.

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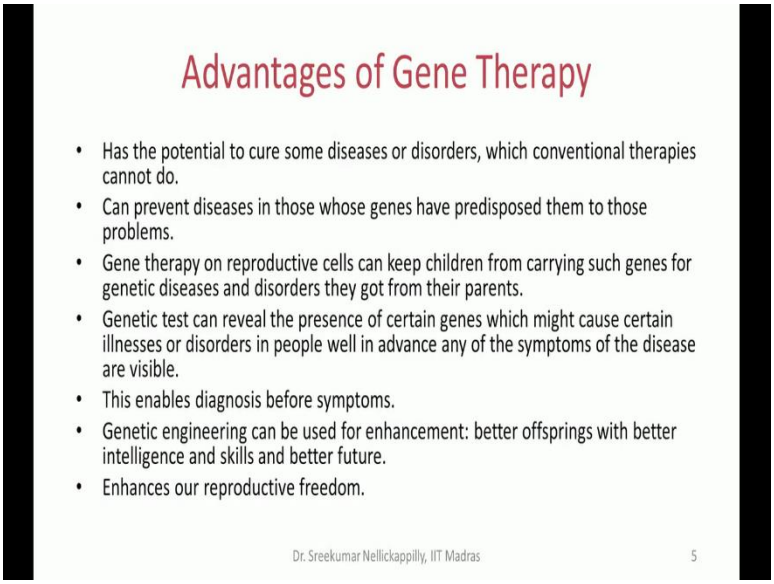

Now, there are several advantages of adopting Gene therapy. It has the potential to cure some diseases or disorders, which conventional therapies cannot do. And, a scientist expects that in future, once Gene therapy advances more and more than, what it is today. We would be able to resolve many problems with the help of Gene therapy.

And, Gene therapy is expected to have less side effects than taking, consuming medicines, drugs, which are chemicals. Because many drugs, some of the problems, which drugs have is that, though they might be very effective, for the kind of diseases for which, we consume them. But, most of the drugs will have side effects. So, often what happens is that, patients will have to choose, between bad and worse. Worse is the disease and bad is the side effects, which are due to

consuming the medicine for the disease. But, these things can be avoided, if you can identify the problem area and target it with the help of Gene therapy. You can probably resolve the problem without taking drugs.

It can prevent diseases in those, whose genes have predisposed them to those problems. So, you can identify, which gene could cause certain diseases in future. And, tackle them and try to solve the problem, much in advance, much before the disease actually manifest itself. So, Gene therapy on reproductive cells, which is another area, which we are going to discuss. There are two types of Gene therapies, which will be discussing very shortly. But, the Gene therapy of reproductive cells can keep children from carrying, such genes for genetic diseases and disorders, they got from their parents. See for example, down syndrome is a major problem, which children face the, so this can be.

So, this is another genetic disorder. Very serious genetic disorder, which can be identified much in advance. And parents, can resolve this problem, by effective Gene therapy on reproductive cells. Genetic test can reveal the presence of certain genes, which might cause certain illnesses or disorders in people well in advance. So, this is the advantage of Gene therapy. Genetic Testing, if you conduct Genetic Testing, Genetic test can reveal the presence of certain genes. Which might cause, certain illnesses or disorders, in people well in advance, any of the symptoms of the disease are visible.

Symptoms are visible much before the patient, the so-called patient has, having start much before the so-called patient, starts having troubles from the disease. The presence of the disease can be identified and physicians can start treatment for that. And, this enables diagnosis before symptoms. That is the greatest advantage of this new technologies. For that, we have to, of course have genetic scanning or genetic test, for which, we have facilities today. Or, we may have need more and more facilities for tomorrows generation. Genetic Engineering can be used for enhancement, better offspring with better intelligence and skills, and better future.

So, this is another very interesting and very controversial possibility of Genetic Engineering, that it can think of having better off springs. Whole idea of better offspring is very extremely

controversy. What do you mean by better? So, these are issues, which we naturally have to grapple with. We will discuss it, slightly later. And, enhances our reproductive freedom. No doubt in that. The reproductive freedom and autonomy are increased. It enhanced with these new technologies. Because, these new technologies provide us new possibilities, which we can think of and employ

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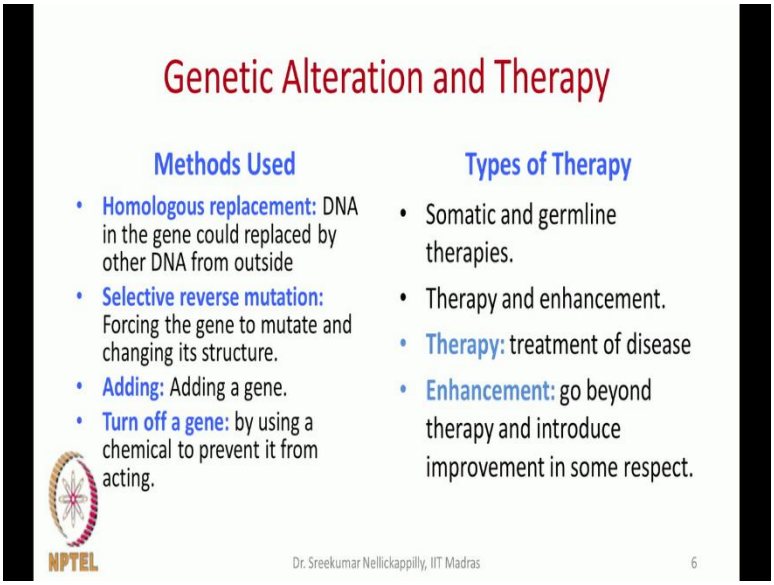

Now, when we talk about genetic alteration and therapy, there are certain methods used by scientists all over the world. For example, there is something called homologous replacement, where DNA in the gene could replace by other DNA from outside. Another method is selective reverse mutation, where we force the gene to mutate and change its structure. The third one is adding, where you add a new gene. The fourth one is turn off a gene, by using a chemical to prevent a particular gene from getting activated or acting, functioning. So, these are the common methods and many other, a few other methods also, people are trying now.

So, these are some of the important methods, scientist used for genetic alteration and therapy. And, the types of therapies are, we can generally classify that, there are two types of therapies. Somatic and Germline Therapies. Somatic is a therapy, which tries to, which targets body cells. And Germline therapies are therapies, which target the genes in the reproductive cells. Therapy and enhancement, these are two possibilities. On the one hand, these new technologies aim at

solving problems. They are uses directly therapeutic. But on the other hand, there is also the possibility of enhancement. And, therapy is treatment of diseases, as all of us know. And, enhancement is to go beyond therapy and introduced improvement in some respect.

So, this is, what I mentioned. When you talk about improvement, what do you mean by improvement. Improvement in intelligence, in height, in complexion, these are all controversial issues. And now, since I mentioned about the two types of cells, the Somatic cells, which I said are the body cells, and the Reproductive cells.

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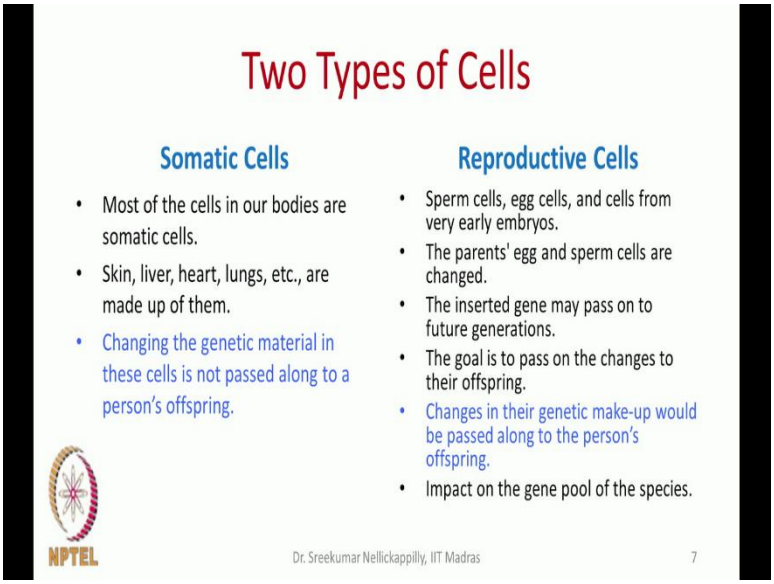

Let us have a little more detailed explanation of these two. Somatic cells are, most of the cells in our bodies are somatic cells. Like our skin, our heart, liver. All these cells are somatic cells. Skin, liver, heart, lungs, etc. And then, changing the genetic material in these cells is not passed along to the person's offspring. So, whatever treatment a person undertakes, will be confined to that particular person. This will not be passed on to the next generation. Because, that is basically done at the body level.

But on the other hand, reproductive cells are these, sperm cells, egg cells and cells from very early embryos. So, these cells are the parent's egg and sperm cells are changed, and they inserted gene, may pass on to the future generations. So, whatever modifications, therapeutic interventions, we are trying to do here, will have an impact on future generations as well. So, that

is what makes the Germline therapies or the reproductive cells therapy, a little more crucial and more vulnerable or more prone for ethical issues or violations.

So, one of the advantages of this therapies, of course, we can avoid the birth of children, with the deformities and other major inherited diseases. On the other hand, there are certain interesting ethical issues, which it would trace. Because, we are already proposing and executing treatment for people, who are yet to be born. So, without their consent, can we do that. These are some of the issues. So, changes in their genetic make-up would be passed along the person's offspring and impact on the gene pool of the species. So, that is what makes this reproductive cell therapy or Germline therapy more serious. Now, when we concentrate on risk, as far as the somatic therapy is concerned.

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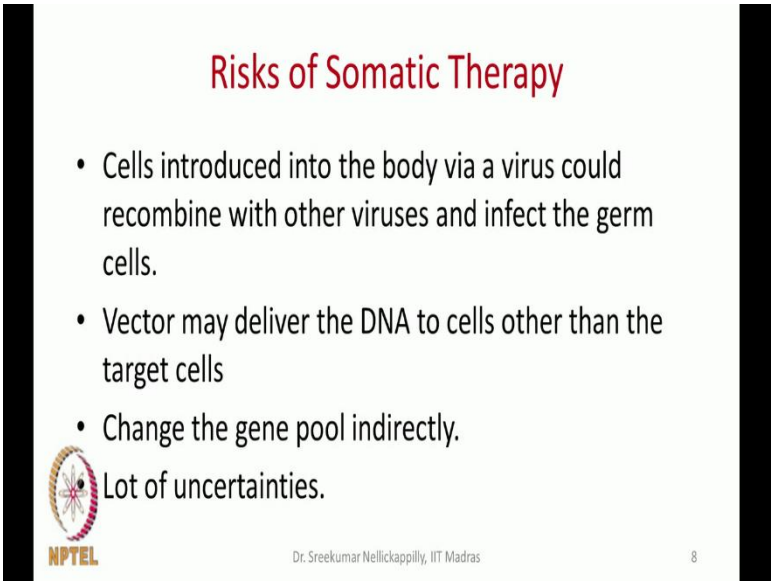

The cells introduced into the body via a virus, which I have already mentioned. A vector is needed and quite often, a virus is injected with the gene. And this virus, there is a possibility that, this virus could recombine with other viruses and infect the germ cells. So, there is a possibility that, it might not do the desired consequences or it might bring more than, what is decided. Sometimes, even adverse consequences. Sometimes, even unexpected adverse consequences, so in that way, there are certain uncertainties, which are yet to be solved.

Again, vector may deliver the DNA to cells other than the target cells. This is again a serious problem. Because, we of course, as I mentioned, some time back, taking the example of heart or liver. The target cells are in the heart. And, we are trying to, we, what we desire is that, the required changes have to be made by Gene therapy in the heart. And, we injected through a virus. But, it may deliver the DNA to cells, other than the heart and many other places, which might bring us very undesirable and unexpected consequences. And, this might also have certain indirect changes. This might also affect, some indirect changes in the gene pool, though directly it may not do that. And lot of uncertainties. No doubt in that

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And, when you come to the Germline or reproductive cells therapy, it will affect the future generations, who have not consented to it. This is what, I mentioned. That, we are also, we are in effect interesting, we are proposing, or we are executing treatment for people, who are yet to be born to the next generation. And, one of the fundamental principles of medical ethics is that, we have to take consent, before we actually execute a treatment. But, we are not doing it here. But, this is again, not a very valid kind of an argument, we can point out.

Because, in the case of our children, when we take decisions, medical decisions, on most occasions, what happens is that, the parents who take decisions for the children. Because, children we believe are not mature enough to consent for medical therapeutic intervention. So,

parents take the decision. Here also, the parents are taking the decision. So, there is not much of a significant difference from parents taking decisions for infants. And in this case, when you take decisions, decisions for the future generations. Now again, questions raised by the idea of reproductive autonomy and freedom. Decisions about, what kind of children to have.

So, this is another possibility of Germline therapy, Gene therapy. Because, we have a lot of reproductive autonomy and freedom with this new technology. Because, we can decide. We can know, whether children are going to have any genetic disorders. If there are any serious genetic disorders, parents can opt for abortion, or even treatment in advance. Certain diseases can be treated well in advance. And, this could be done. So, that possibility is there, because of the new technology. And again, can we allow people to choose, have children, who do suffer from a genetic disorder. This is a very interesting serious concern.

But at the same time, a possible concern. Because, it is quite possible that, some of the parents, say for example, both the parents are deaf, and they might desire, their offspring also to be deaf. This is not a very common phenomenon, but this is not impossible. Sometimes, parents may desire so. So, they are opting for a deaf child. Which is in one sense, we can say, consciously making the child deaf, a disability. So, can we allow this to happen. If you allow, if you are talking about reproductive autonomy and reproductive freedom, then you will have to allow this as well. So, these are some of the contradictions involved in the issue.

This therapy is at the moment, extremely uncertain. The consequences are uncertain. There are a lot of uncertainties. So, failure in the treatment is possible. And gene failing to be ended, the gene failing to be introduced to being activated. The resulting child may suffer more than otherwise. So, that possibility is also there. So, these are some of the factors, again errors in gene insertion, may be severe and might affect generations. Because, Germline Gene therapy are reproductive cells therapy, will have bearing upon the next generations and also the gene pool. Changing future generations and not just one individual is involved in this case.

So, in that case, we have to approach, Germline Gene therapy with extreme caution. And, we have to be extremely careful here. Now, there are certain general concerns. Because, since I have been talking about desirable consequences, improvements and many other words, I have used here. So, there are some, very general concerns, which are applicable for all kinds of genetic interventions.

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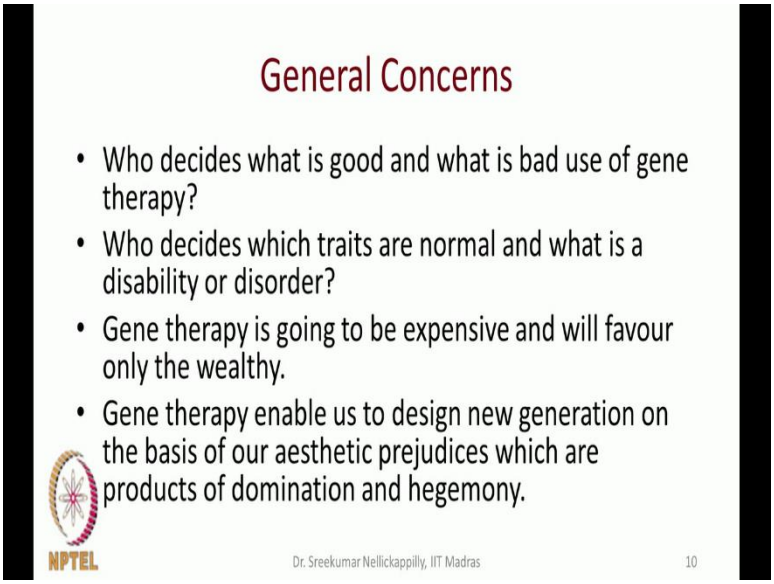

The question is, who decides, what is good, and what is bad, use of Gene therapy. Because, we are talking about the, we have given the example of that, deaf parents wishing to have a deaf child. Or parents coming to know, about the kind of disability of their child, and decide to abort the child. So, all these are very crucial decisions, which parents take for the next generation, for the immediate offspring, and on certain occasions for the coming generation, in total.

So, who decide, who has the right to decide this. On what basis, you know that, certain decisions are good, and certain decisions are bad. Who decides, which traits are normal, and what is a disability or disorder. There are a lot of disagreements on this. Again, the whole idea of normal is an extremely controversial notion. What is normal is yet to be decided. Gene therapy is going to be expensive and will favor only the wealthy. This is another serious problem, which our world is going to face, with more popular with Gene therapy, becoming more and more popular.

Because, it is definitely going to be more expensive than conventional therapies. And, Gene therapy enable us to design new generation on the basis of our aesthetic prejudices, which are products of domination and hegemony. So, sometime back, I mentioned. This is particularly more relevant, when it comes to Genetic Engineering, where we can literally design babies, decide what are the features, the future generation is going to have. So, when you design this, on most occasions what happens is that, we are prejudiced by our aesthetic sensibilities, which may not be a very politically right or ethically right.

Because, we are quite often influenced by certain forms of domination and hegemony. See for example, many people think that, it is good to have white skin, white complexion, which is actually, for which there is no basis. It is a prejudice. But unfortunately, because of certain historical cultural and social factors. This is the way many people think. So, this is a clear discrimination against people, who have dark skin. A huge majority of people, who have dark skin in the world are being, there is a possibility that people will be, such people will be looked upon by prejudices.

So, in that sense, these new technological possibilities are probably, we can argue, encouraging such prejudices to spread, and people practicing them in their own lives. Now, I mentioned that, Genetic Engineering is one possibility, where enhancement is one of the direct concerns. And this happens, the case of plants, and plants this is being used. In the case of plants, this is being used by scientists quite successively.

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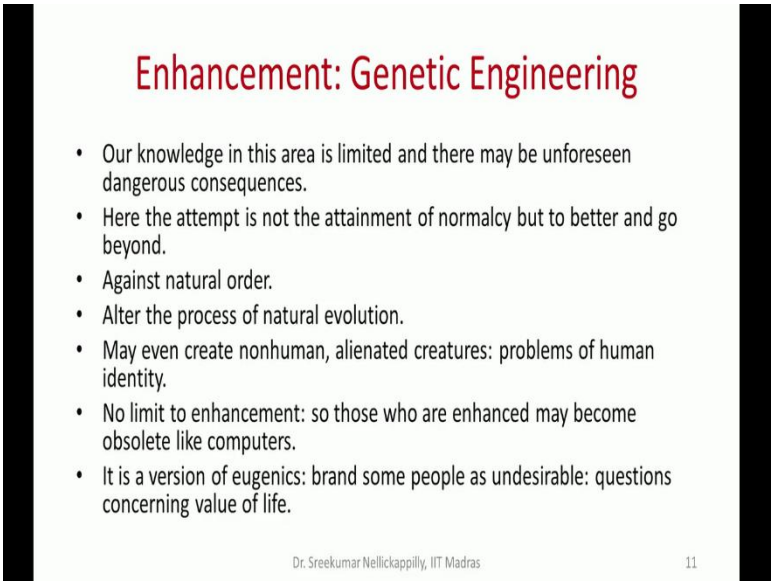

And also, in agriculture, Genetic Engineering is used to prevent, certain very important problems like, with the new Genetic Engineering technologies, scientists could bring down, the usage of pesticides and other things. They can develop, pest resistant, you know varieties, they can develop pest resistant weeds, which will yield more than the conventional ones. But, when you apply them in the human world, it definitely invites a lot of problem. Our knowledge in this area is limited. And then, there may be unforeseen dangerous consequences, when you try to apply this in the case of man. Again, here the attempt is not to attain normalcy, but to better and go beyond.

See on the one hand, normalcy itself is a very controversial notion. What do you mean by normal? But here, the idea is that, Genetic Engineering technologies are used to go beyond that, to better, to go beyond, what is normal. And, it is in that sense, we can say that, against natural order. And, many theologians and religious people criticize the application of genetic technologies, precisely on the ground of this, precisely on this ground that, they tries to go against the natural order, which is created by god according to them. Whether it is created by god or not, there is a natural order and Genetic Engineering is a forceful intervention in that natural order. There is no doubt about that.

It is in one sense, people argue that, there are certain people, who argue that, it alters the process of natural evolution. Everything in this world is evolving, that is a scientific view. But, there is a

course of natural evolution. And, with the introduction of Genetic Engineering technologies, you are making forceful changes, which is some sort of a revolutionary change, which have happened not as a result of natural changes, not as a result of a response to, what is happening to the natural environment, but something, which scientist have decided to bring about. And, they brought it about with the use of technologies. So, in that that way, we can say that, it is absolutely artificial. May even create non-human, alienated creatures, problems of human identity.

See, there is another very important problem, which ethicist imagine here. People, who have been born, out of usage of this technologies, of course with "so-called" improved qualities and characteristic features. The problem is that, since they have born out of non-natural methods, they constitute a kind of species, within the human kind. Within the human species, they constitute another species, a special species with very different characteristic features. So, they might alienate themselves, with their features, as a result of their "so-called" improved features. This might cause very severe problems of human identity and alienation. And, no limit to enhancement. That is another problem.

Enhance the capabilities. What is your limit. Of course, we all know that, many of our capacities and qualities have certain limits. But, when there is a possibility of improving them, what is our limit. So, those who are enhanced may become obsolete like computers. This is another problem. It is a fact that, we all enhance our computers to, when the new operating system comes in the market. We enhance our computer, and its performance goes up. So, the older one will become obsolete. The telephones, the mobile phones, which we have used five years back, have become completely obsolete now. We are now, after new models of mobile phones.

Now it is smart phone, tomorrow there will be another model. So, every day, there is an improvement. And these people, who have born out of Genetic Engineering, with improved characteristic features, will repeatedly get obsolete, with the new addition of improvements in the next generation. So, they will become like smart phones and computers, their identities, not like human beings. It is a version of eugenics: brand some people as undesirable: question concerning value of life. So, this actually had Genetic Engineering, and the whole idea of enhancement can create is the eugenics, the possibility of eugenics.

And, we have seen the historical version. We have seen in human history, the ways in which can be really undesirable. So, it reminds us the idea of eugenics, actually reminds us the Nazi, Germany. Where certain people, were treated as worse than animals, not as human beings. And again, people who are unable to produce, people whose productivity is, people without productivity like old people, and all that. So, they were all treated inhumanly and the Nazi regime. So, here also, there is a possibility that, we might brand some people as undesirable, which raises very serious concerns about the values of life.

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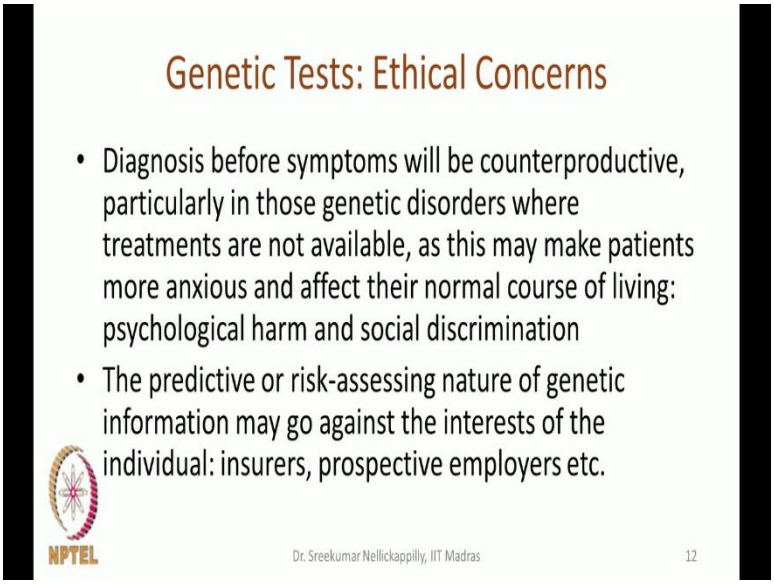

Now, when you talk about the genetic test again. Diagnosis before symptoms is one of the attractive features of the genetic test, which I have mentioned, sometime back. This can be really counter-productive. Because, it particularly in those genetic disorders, where treatments are not available. As this may make patient more anxious and affect their normal course of living. Psychological harm, great psychological harm will be done, in under such circumstances. And, social discrimination could happen to such kind of people. This is another problem.

Because, on many occasions, what happens is that, the Genetic Testing is available, scanning is available. But, you identify a problem, a serious medical problem for which, you have no medicine. And, patients have to be told about, they have the right. So, true telling, disclosure that is a major, that is one of the primary obligations, from the part of the physician. So, now the

patients have all information about their diseases, for which, there are no medicines available. This might cause, severe psychological harm to the patients. And, the predictive or risk assessment nature of genetic information may go against the interest of the individual.

In the sense, that this information might land, this might go to the hands of the insurers. Insurance companies might refuse to insure the individuals. Because, they come to know that, this person is prone to certain very severe diseases. Then again, employees might know that, this person is going to have such a disease. So, they decide not to hire him. So, there are several such issues, which might affect the confidentiality issues, privacy issues, which might raise, very serious issues, with the relation with confidentiality and privacy.

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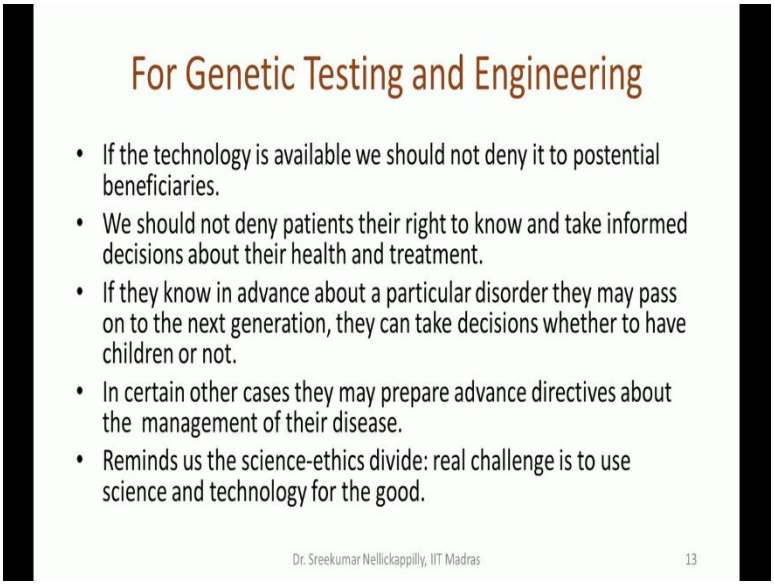

In spite of all such worries, all such inhibitions and concerns, Genetic Testing and Genetic Engineering and of course Gene therapy, there are all new possibilities, which can actually bring a lot of benefit to the entire humanity. No doubt in that. We should know, how to use them. We should have the right policy, how to use them. So, if the technology is available, we should not deny it to potential beneficiaries. We have no right to do that. It is a knowledge, scientific knowledge, which is available with humanity. And, humanity has the right to benefit out of this. We should not deny patients, their right to know and take informed decisions about their health and treatment. So here, what happens is that, the one of the greatest advantage is this.

If you know in advance, about a particular disorder. This, which may pass into the next generation. We can take advance decisions, actions to prevent this from happening. Which in one way, will be a great help for the next generation, for our children. So, in one sense, this is going to be a great boon for all of us. And in certain other cases, they may prepare advance directives about the management of these diseases. You can plan well in advance. If you know that, you are likely to have a particular disease. What to do by that time. And this actually, the problem here is, not the problem with scientific knowledge or technological know-how.

The problem is with humanities management of this knowledge and technologies. Humanity has always mismanaged it. As always, mismanaged science and technology. And, naturally this might happened in the world of medicine, as well. But, that does not mean that, we should not use technology at all, we should not progress technologically and scientifically. We should use them with caution and with ethics. So, this actually reminds us the original division between science and ethics, ethics and technology, ethics and science.

So, the problem is the challenge. The real challenge is to use, science and technology for the good of humanity. And once we do that, many of these great technological advancements can turn, can make human life, better and better in this world. I will conclude this lecturer at this point. Thank you.