Welcome back. This is Unit Four of Module Three of the course, Issues in Bioethics. This lecture will focus the topic, End of Life Issues.

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End-of-life issues are arguably, the most agonizing, the most dilemmatic problems, a physician would face in his carrier. Not because, he is encountering death. But because, he is witnessing the entire process of dying. And, when I say entire process of dying, it is not just a biological process or a scientific process, but rather it also involves emotional, social, financial and several other aspects. So, death in its entirety, come into picture here. The impacts of death are also anticipated, when I say end-of-life.
In this lecture, we are actually trying to concentrate on the process of dying, where the patient is actually alive, but an inevitable death is awaiting him or her. And, the physician can almost predict, what is going to happen in the coming days. But, helplessly has to witness the whole process, cannot do anything. And occasionally, what happens is that, the patient would be undergoing severe pain and other sufferings. Physician has to witness all these things. Again, there will be a lot of other issues, that the patient’s relatives will be worried about several factors. The loss of the patient is going to have certain impacts on their life. And, several other factors like economic factors will be there involved. So, all these things are there, when you talk about death of the, end-of-life. And, the physician occasionally may have to negotiate with several people to make the situation a little better for others. So, this is what makes the crucial role of the physician in this context. And also, the end-of-life care is directly a concern of the physician.

This care has to be provided by physicians and also the hospital, other healthcare professionals. And, how can you give the patient, a quality end-of-life care is a direct concern. So, on the one hand, you have the agony of death, which involves the process of dying. And, all its emotional and other factors involved in it. On the other hand, you have a concern, you have a very practical concern to provide the patient, something which would ease the process.

So, dying patient therefore presents highly complex challenges to all physicians. And, the hardest challenge is probably to negotiate and communicate, convince, empathize with patients and other family members, because, everyone will be looking at the physician. Because, they all think that, sometimes, occasionally it happens that, people think, the physician, the patients and his or her relatives think that, the physician has an answer to all the questions, which is not the case occasionally.

Physicians may not be in a position to tell exactly, what is going to happen. But, at the same time, they know that certain things are inevitable. The point is, how to communicate this to the relatives and also the patient himself or herself. Then again, the care, which they have to provide is a very comprehensive framework has to be devised. From where, we can understand the idea
of care, to be rendered to patients at the end of their life. Which has to take into account, several factors. So, there also constant negotiations and communication are required.

So, what I mean here is, can be summarized and this one sentence. Understanding of value of life, respecting autonomy, and decision making of the individual patient, and negotiating different value systems, emotions, and human situations. Such a difficult task, occasionally, health care professionals have to undergo. The problem here is that, when you say respecting autonomy and decision making of the individual patient, which is more or less at the center of modern bioethics debates. And, we have been seeing this, the importance of autonomy.

But, on certain occasions like this, when a patient is towards the end of his life, undergoing several pains and suffering, may not be in a position to exercise his or her autonomy. So, this makes the physicians responsibilities, even harder. Because, there he has to ensure that, the patient’s wishes, the patient's aspirations and values, are given utmost importance. And, come up with a very comprehensive framework, where decisions can be taken. So, in other words, to help the patients and the family members to arrive at certain decisions, which are very difficult. (Refer Slide Time: 05:18)
Now, so we normally in this context, there are two concepts, which we discuss. One is the sanctity of life, because, we are talking about end-of-life, which implies death or of the process of dying. On the other hand, there is another very important concept called quality of life. So, you have sanctity of life and quality of life. And, these two concepts will help us to understand the whole process of dying in a better framework. Sanctity of life is a very old concept. Mostly religious and metaphysical and even today modern world also, we this concept of sanctity has its value. Even regardless of metaphysical and religious traditions, there is something called sanctity, which we associate with life.

Life has utmost value, which needs to be respected. This is something, which traditional metaphysical and religious traditions have upheld with a lot of importance. But, in today’s world, we actually put it in a different word. We do not use the word sanctity with instead, we would say that, respect for persons, which we have already seen. But here, what I mean by sanctity is more or less very closely related to the old conception of sanctity, that life is something, which is sacred or something, which cannot be taken away. It has intrinsic value and human beings have no rights to take away life.

So, life needs to be protected at any cost. And, there is also the right to life. Every creature has the right to life. Particularly, when it comes to human beings, the right to life has to be underlined. And, it is morally wrong to fail to serve, preserve and lengthen life. If there is a possibility to save life, we have to do that. Nobody would argue against this view. But, when you say that, there is a moral responsibility to preserve and lengthen life at any cost. There are certain doubts about it, because, nowadays with the help of medical devices and medical technologies, we can preserve life to a great extent.

But, to what extent, we should do this, because, on many such occasions, what happens is that, preserving life might end up with a direct clash with the quality of life. So, there is something called quality. We talk about, based on the idea of value of life. Life can be understood in different ways. There is a qualitatively higher life, where a person is able to perform all his duties, fulfill all his requirements, without the help of other people and reasonably exhibit autonomy and do things on his own or her own.
So, such a life, we consider as valuable. But, on the other hand, there is a life, which is extended or preserved with the help of medical devices. But, the person or the patient lives definitely, life is there. But, what about the quality of that person? He or she is not able to do things in the normal way. And, definitely the concept of quality is very important. To say that, life of all forms has value is questionable in the modern world.

And again, virtue of being a living thing, does not make something valuable. Just because, something is living does not make it valuable. So, one has to recognize the quality dimension, which also says that, life on certain occasions can be valueless. And, on such occasions, death is more preferable than life. Just preservation of life has no value on certain occasions. So, the quality dimension would help us to appreciate these aspects. (Refer Slide Time: 09:11)

The complexity of the situation because, the end of life situation is a highly complex situation, as I already mentioned. Because, it involves several factors and interest of several people come into picture. Not just one person, a patient, individual patient, but so many others come into picture. Most of the problems, which we have discussed, so far in this course, you can see, resource allocation for example, in the previous lecture, we have discussed it. Resource allocation also comes into picture, when we discuss end-of-life care.
Because, certain care needs to be provided with certain resources. And, this care is scarce, there is severe shortage for these facilities available. And, you are providing these facilities, extending them to a patient, who is, whose death is imminent, who is going to die in another few days. So, what is a point in using these facilities for a person, while others, more deserving people are waiting outside? Such problems are quite normal, when we discuss about end-of-life issues. So, complexity of the situation makes many issues difficult to comprehend.

There are several concepts, that sound hard to understand. Even the concept of death itself needs to be understood properly. Because, nowadays modern science has come to a conclusion, a kind of unanimous agreement among physicians that, death is equated with the brain death, which is not the case earlier. Equating death with brain death has got several advantages. Because, it helps doctors to harvest organs from the people, who are dying.

Which will be helpful for those, who are in need of them. But, at the same time, several traditions do not accept this idea of death. And they might encounter severe clashes with their traditional values. And, the physicians end up negotiating with these values. So, there should be a lot of awareness created among the public about concepts. And again, several other factors, which physicians themselves encounter in such situations.

And, physicians again on a typical end-of-life situation, might encounter a situation. where he or she might find himself between two extreme situations. Like either he or she might have to treat at all cost. He or she might be knowing, the physician might be knowing that, there is no point in extending the treatment. It is going to be all futile. But, still has to provide the concerned care and extend the treatment, as the family members of the physician or the physician himself or herself might be wanting this to continue with the hope that, there will be an imminent recovery in future.

But, the physicians are quite sure that, this is not going to happen. But, they have no choice. Sometimes, they will have to continue with that. On the other hand, there is another patient, whom they know that, he or she would definitely recover with proper medication. But then, there is a strong request from the patient himself or herself saying that, I do not want the treatment to
be continued. So, refusal of treatment, which might lead to the death of the patient. So they, they find themselves occasionally between these two extremes. And, that again actually contributes to their professional agony.

The new technological context of course, presents a lot of confusion. Because, there is a direct conflict with some of the value systems, which people come up with. Patients of course, come with different value systems. And, sometimes you know the possibilities, which technological context offer or impossibilities again, possibilities as well as impossibilities and also certain situations, which this technological context create.

They might generate, a lot of confusions in the minds of patients as well as physicians. And, they particularly, when they try to negotiate with patients. When you deal with end-of-life issues or situations, the physician find themselves between life and death. Because, the patient is still alive, technically alive. And, at the same time is undergoing a process of death, an imminent death almost comparable to death.

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So, it is a domain, which presents many ethical confusions and dilemmas. And, there is something called persistent vegetative state. This is what, has happened to the Aruna case, which we have discussed in some lectures, in this lecture series. The famous Aruna Shanbaug
case, which supreme court has stated its verdict. Where Aruna was in a vegetative state, but still the court was not ready to come up with the judgement, which would ultimately lead to the euthanasia, the passive euthanasia or active, whatever of Aruna. Because, the court believed that, the close friend of Aruna are the nurses, who was taking care of Aruna.

So, the close friends of Aruna did not want her to die. They were ready to look after her, because they have been looking after her for several decades. So, ultimately the physicians have to comply with that decision, because that was a court decision. And, allow this lady to continue to live, though she was in a persistent vegetative state. Again, a coma is another situation, which needs to be distinguished from vegetative state. Because, a person in a coma is in a state of complete unresponsiveness to stimuli although, there may be brain stem reflexes.

So, there is a possibility that, this person might come back to life and lead a very normal life. So, one should be very careful. Recently, there was a news that, a person who went to coma several years back, 2004 or so, woke up the other day. And, the first thing he asked, one of the first things he asked, was about Roger Federer, the famous tennis player, who was his famous, who was his favourite player.

So, it was almost 10 years, this patient was under kind of unconscious state. So, this state of unconscious state should not be, confused with persistent vegetative state, where recovery is almost ruled out. But, this, there are cases, where there are examples, where patients have woke up from a state of coma, complete coma, where there is complete unresponsiveness to stimuli, after several years and even after decades. So, such people have almost complete life. Only thing is that, they are unconscious. So, there is, but a possibility of recovery after sometime.

Again, there are situations like this, which are called Stupor or Obtundation, where states of reduced consciousness in which meaningful responses are possible if the patient receive enough stimulation. So, physicians often try to give the patient, stimulations, which will bring back the patient to normal life, under such situations. Again, Locked in Syndrome is another condition, where one is paralyzed and cannot speak, but is completely awake. And, such people can move
their eyelids, and also look up and down, and express their wishes with others. So, even communication is possible because their minds are working, they are able to communicate with other people.

So, such people also should not be treated as dead or brain dead or persistently vegetative state or anything. So, none of these cases, none of these examples, which I have cited here are examples of brain death. They are all people, who live, have life in the technical sense of the term. Brain death is a process. It is a technical situation, where a person’s brain stops working. But the heart will be beating. And, that is an ideal situation, where physicians will harvest his heart from his body and various other organs. Because, there is technically life. Blood circulation will be there, and other organs will be functioning, the only issue is with the brain. (Refer Slide Time: 17:18)

Now, there are several other issues, which are, which have got social dimension, very strong social dimensions or rather, more direct social implications. See for example, modern medicine has enabled people to increase their lifespan with new medicines and other things. So, there is increasing number of age people in some societies, and there are quality of life issues. So, technically speaking, many of them can also be understood, can also be treated as people, who are in the process of dying. Some of them have critical illness but this continue to live with the help of medicines.
So, the situation varies. Some people manage without much of medication, and much of difficulties, they carry out almost all their daily routines, without much of dependence on others. But, on many occasions, some people completely depend on others. So, quality-of-life issues figure in under such circumstances.

And then, the sharp contrast to this situation, certain other countries, particularly in some developing countries, we find that, there are many young people, who are suffering from AIDS and die at a very young age. And, people who die with aids also have a very long process, sometimes of painful death. So, physicians have to actually witness both the situations.

On the one hand, you have people, aged people, who face quality-of-life problems. Here also, you have very young people facing quality-of-life problems, because of the kind of diseases they have, for which there is no effective medication. And, you have also children dying from malnutrition in particularly in developing countries. And, these are typically developing world concerns, of course. But, still that is another problem, which physicians have to negotiate, when it comes to the discussion of end-of-life issues and the problem of the terminally ill people.

So, in this context, we are looking for, what should be the, what ought to be the approach of physicians. What approach would help patients to have a more meaningful death, if not life. Or rather, the process of dying in their entire process of dying, which is of course a suffering. No doubt about it. But, at the same time, the interventions of physicians might help patients to have a smooth journey ahead, till they end their lives. So, there is an idea of empowering the patient. And, this idea is nowadays advocated by many ethicists. Understanding of death in the light of technological possibilities is very important here.

And, the possibility of a dignified death can be thought about under such circumstances. So, we can also think about planning death. Because, there are certain patients, who know that, they are going to die with some critical illness. And, they know that, towards the end of their life, they are going to undergo several difficulties. They can anticipate it with the help of the physician. They can and the available scientific knowledge. You know that, this particular condition is going to
take you to a situation, where you will be having, you will eventually will have to undergo several difficult situations in your life.

So, how are you going to tackle those situations. So, you can plan it in advance. So, under certain extremes severe situations, you can even tell your physicians, express your wish for euthanasia, that please end my life, if I reach that particular stage, where I am incapable of taking any decision, where that capacity is not there. So, please end my life. So, with the help of the physicians, the patient can plan their death in advance. So, this possibility is also there in several countries in today’s world. Of course, not there in many countries.

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So, the problem of the terminally ill is very specific. It is a condition, where a disease or disease process, that will result eventually in a person’s death, no matter, what treatment is given. What care is available for them is the most important question. So, if there is no recovery possible then, whatever time this patient is going to be alive, as much as possible, we should enable that person to have a meaningful, valuable life. So, what can we do for that? Care is the only solution. So, what kind of care, we can give. What care is available? Then, the question is who treat them, and how and where they have to be treated?

So, can they be taken to the hospitals or care should be given at home? Many patients prefer to die at home. So, for such patients, whether we can take them home. And, can the physicians
ensure that, the family members can be reasonably educated to take care of situations, where there is eventualities. And, also the proper care can be, can we ensure proper care at such situations? So, all these questions have to be addressed in such context.

How costly and who will pay? This is another very important issue. Because, financial aspect of treatment is a major burden in today’s world. In many countries, people die not because there is no proper medication or treatment available. But, because people have no money to get and buy treatment. So, that is the reason for people dying. So, that is the unfortunate agony or rather irony of today’s world.

Who takes decision. That is another extremely important thing. Who is going to take decision? Because normally, when a person is terminally ill, he or she, on several circumstances, will not be in a position to take decision. So, who is going to take decision? The physician might find himself or herself in a very difficult situation here.

The family members will also sometimes say that; they are also not; they also may not have any clue. And on several occasions, there is a need for a collective decision taken by the family members and the physicians. And occasionally, the patient as well.

The need for pain management is another extremely vital aspect of the situation. Because, if there is no proper medication available for a particular disease. The only thing, you can do is Palliative care, provide care to alleviate pain. Reduce the pain, which the patient is undergoing. So, which is, which amounts to the reduction of sufferings. Where do people die? Home, Hospital wards, ICU’s, these are another set of questions.

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Now, I have mentioned about the idea of empowering the patient. So, there are different ways in which a patient can be empowered. And of course, physicians play a very crucial role here, along with others, along with the family members, friends and various other people, who are involved in the context. So, empowering patient probably helps to ease the situation in a very significantly positive manner. Enable the individual to control the dying process by refusing life-extending intervention. So, I mentioned this earlier that, the patient definitely has the right to refuse medical interventions.

But, on several occasions, patients are not in a position to take this decision. That is because, they have no power to do that. They are not empowered to do that. So, the physicians can empower the patients to come up with the right decision. So, they will take the decision for their life. And the idea is to help them, to have better control over the process, which they are undergoing.

The process, which they are undergoing is unfortunately, the dying process. And to decide, whether to continue life or to die, that is another very important possibility, which we have today, euthanasia. Euthanasia was a possibility even earlier days also. But in todays, medical world with all new medicines and other equipment, we have better facilities for that. Preparation of advance directives with, which are again the policy, the law come in to picture.

The government, the policy and the law come into picture here, where you can help the patient to come up with advance directives, preparing a will, a living will. And, he or she can express his decisions about, under what conditions, they prefer euthanasia? Under what conditions, they prefer passive euthanasia, active euthanasia? All these things can be expressed, when they are in a normal condition, when they are able to take decisions.

So, they know that, eventually they are going to die. Eventually they are going to a situation, where they will not be able to express their wishes. They might become unconscious or they might become immovable. So, on such circumstances, what should be done. Physicians and relatives, what should they do.
The physician, the patients can express all these things in advance. There are certain countries, where this such advance directives are possible, where people can write and endorse it with signatures and all that.

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Now, since I mentioned about euthanasia, which is one of the most controversial topics in modern bioethics. I thought, I can mention a little bit more about it, before I wind up the discussion of this topic. Euthanasia is a word, which is derived from a Greek word, eu for good, and thanatos for death.

So, it means good or gentle death. So, it actually raises several questions. Can death be good? But, of course you understand, what I mean by good or gentle death. This is a death, which involves less pain, less suffering and suffering in all the senses, not just in the physical sense, but on all psychological and social senses of the term.

And there are two types of euthanasia. There is this active euthanasia, where overt, deliberate killing of the patient is involved where the physicians play a very key role. They participate in the process of killing, by injecting an overdose of some medicines. And, which will stop their heart or affect their bodily constitution and eventually leading to death. So, this is called active
euthanasia, which is not allowed in many countries. Most of the countries in the world do not have sanctions for active euthanasia.

Passive euthanasia in comparison to active euthanasia, is more or less acceptable in many countries, which actually means, withdrawing or withholding of treatment, which is more or less happening in many countries today. Then, killing and letting die. So, we can see the difference between active and passive euthanasia, as killing and letting die. The first one is almost killing. Of course, killing happens with the consent of the person, who is getting killed, either the person or his relatives.

In the second case, killing, it is the process of letting die, though we can reasonably extend the life of the patient for sometimes in certain occasions, for several more years. Still you allow the person to die. Because, the person or the patient, because the patient will have a more dignified death.

While patient has right to refuse medicine, he or she has no right for active euthanasia. So, this is a very interesting thing, one has to keep in mind that in many countries, as I mentioned, euthanasia is a legal process, it is allowed legally. But, even in such countries, it is not that under all circumstances, a patient can demand for euthanasia. He has no right for euthanasia. He can request for euthanasia, but the decision is not taken by the patient. The patient only gives consent under extreme circumstances where in such, under what circumstances, euthanasia is, can be allowed is not decided by the patient, it is decided by a medical team. So, based on the medical condition, the physician can recommend, whether a situation can require or whether euthanasia can be performed or not. That is the only thing, they can do. But, the consent has to come from the patient. The patient or the substitute, the decision maker has to give the consent. But, in whatever case, the patient cannot demand for euthanasia. It is based on a decision made by the physicians. (Refer Slide Time: 30:32)
Now, let us have a broad picture of euthanasia. This entire thing will give you a broad understanding of euthanasia. Euthanasia is two types, on the left-hand side, you can see. There is active euthanasia, which is more or less equated with killing. And, there is passive euthanasia, which is letting die, which I have already discussed. Now, on the right-hand side, you can see that, there are three categories of euthanasia, which is voluntary, non-voluntary and involuntary.

In voluntary euthanasia, where the patient request for euthanasia. The patient approaches the physician and request that, please perform euthanasia on me, I do not want to stand this pain. Now, the physician has to take a decision based on several medical conditions. Non-voluntary is where the incompetent patient, the patient has become already incompetent to take a decision, where the family has to request.

So here, we are not very sure about the voluntariness of the patient to undergo euthanasia. The patient is not in a position to do that. So, here we listen to the family request and accordingly, the physicians will have to take a call. The third one is involuntary, where the patient is competent, and there is no request from the part of the patient. But still it is done. (Refer Slide Time: 31:55)
So, as far as the, from an ethical perspective, if you examine the idea of euthanasia, such differences according to many philosophers and ethicist are not very important. They are irrelevant. Because, what euthanasia involves is the idea of killing or letting die. And, it also involves questions about the value of life, the sacredness of life and many other issues. As far as, religious traditions are concerned, they vehemently oppose euthanasia.

For them, killing or taking life is, under all circumstances, wrong. But, modern sensibilities have a different view about it. They would say that, the patient has the right to decide about his life, whether to end it or not to end it. So, there are of course, extreme views about it. And, there are people, who argue for euthanasia. The distinctions between different types are irrelevant. Consistent with the rights of the patient to make autonomous choices. So, under certain circumstances, under extreme circumstances of course, the patient is taking a choice, which is his autonomous choice. It is not suicide.

So, that you know, without any provocation, the patient or the person is committing suicide. Here there is a reason for that. There is a very strong reason for that, which can be endorsed by the scientific facts. Based on those facts, the state or the authorities can take a decision and allow, whether euthanasia needs to be performed. So, with by allowing this, we are actually respecting, recognizing and respecting, the autonomous choices of the patient. And, it is relieving the suffering of many patients. And, in that way a great advantage, which patients have.
And people, who argue against euthanasia, the physician who performs euthanasia as death of patient, as his objective, which is against all medical moralities. Because, most of the medical moralities would assert that, physician’s objective or physician’s primary duty is not to, is to help people to save life, not to take it.

Under no circumstances, physician should take life. That is an integral part of most of the traditional moralities. Individual autonomy has its limits. So, we cannot say that, by allowing people to choose euthanasia, you are respecting and recognizing their autonomy. It has got its limits. And, there is also a possibility of misuse.

So, all these things, which people, who oppose euthanasia point out. Now. I will try to wind up with my discussions on end of life, by emphasizing, the importance of the idea of care. (Refer Slide Time: 34:33)

Because, that is the only thing meaningfully, we can do now. Care, provide care for the people, who are in the unfortunate process of dying. (Refer Slide Time: 34:43) Because, you know the agony of dying is incomprehensible, incomparable, nobody can understand it, unless you undergo that. So, you have to, you can never compare it with any other agony.
So, in that way, the only thing you can do, physicians and other people in the society can do, is to help the patient to face a situation in a more dignified manner, by providing him or her, the required care. Others can only do that. Should start much before the process has originally begun. So, in this context, we can think of advance directives. Patients can, all of us actually can do this, can provide advance directives, about the kind of care needs to be given to us, in case if you require it. A proper understanding of situations about death, and also about life and death, is extremely important here.

Because, many people have a lot of misconceptions about life and death, particularly death. Now, since I mentioned earlier, that death is almost equated with brain death. People needs to have awareness, proper awareness about, what this brain death is. And, approaching the patient and family from diverse perspective is very important. And, the importance of arriving at, what is a patient-centered decision is, so central to our concern. So, I will wind up my lecture here.

We have discussed, one of the very important concerns of modern bioethics, the whole idea of dying. The process of dying is as difficult and as painful as it used to be earlier. But, with modern technology, we have different options. And, people can explore different way-outs to solve the problems. But, after all it is a set of emotions. It is a set of aspirations.

It is a set of goals and values; we will have to tackle with. And, when you try to tackle with these values and emotions and passions and interest, you have to be extremely sensitive to different factors, physician's responsibility to do that. It is very important in today’s world. I will wind up my lecture here. Thank You.