Chapter 3.1.2: Relevant study material block 3.1

Ethics of Dealing with Life-threatening and Incurable Diseases

Life-threatening incurable diseases are those diseases that have no known effective treatment and are characterized by continuous deterioration in the condition of the patient finally leading to the death of the patient by the determination of Allah (SWT) within a period of time that may shorten or lengthen. Among these examples is cancer, if it does not respond to any available medical treatment and multi-organ failure like heart, lung, kidney or liver when it becomes severe enough and enters a phase of progressive deterioration that cannot be stopped using medical procedures. It also includes some of the diseases that affect the nervous system and deteriorate steadily until causing death, like motor neuron disease or severe dementia.

It is required by the Muslim faith to believe that illness and its cure are in the hands of Allah (SWT) and it is not permissible to lose hope in the mercy of Allah (SWT). So the reference to being ‘incurable’ refers to the doctors’ estimation based on their expertise and the available resources to them at the present time.

During managing these conditions, the following should be considered:

1. The main duty of the healthcare practitioner is preservation of human health and life, and he/she has to do his/her best to achieve that.

2. The medical team should observe the following when making a decision about classifying the patient’s condition as life-threatening and incurable.
   a. The decision (of classification) should be made by three consultants, whose specialties are the most relevant to the case of the patient.
   b. One or more of the specialist consultants in each of the specialties related to the management of the patient should be involved in the decision making, so that the total number of consultants deciding on such a case is not less than three.
   c. Document the decision (of classifying the disease) in the patient’s record and specify the reasons for taking such a decision, doing their best to make the decision crystal clear to all members of the healthcare team, and whoever else needs to be aware of this decision outside the team.

3. The decision that a disease is life-threatening and incurable should never affect the quality of healthcare that a patient receives; rather the patient’s management plan
should be modified in accordance with the decisions taken while maintaining the highest possible care.

4. The treating doctor should strive to determine the best approach to tell the patient and his/her family what the medical team’s decision, as stated in this book on breaking bad news.

5. The healthcare team, in general, and the treating doctor in particular should emphasise to the patient and his/her family their full determination to do whatever they could to continually care for the patient, even if their ability to treat him/her diminishes or disappears, through alleviation of pain and other symptoms, and work on providing the highest possible level of comfort to the patient physically, psychologically, socially, and spiritually.

6. The patient should not be deprived of any medical intervention if, according to medical standards, considered useful to the patient. Similarly, the patient should not be exposed to any intervention that would be probably more harmful than useful to the patient or community. In these conditions, the decision should be made by three consultants or more, whenever possible. It is also important to have these decisions explained to the patient and his/her family whenever possible.

7. The medical team should respect the patient, however their patient deteriorates, and provide the appropriate medical care suitable for the condition without exaggeration or negligence. The feeling of hopelessness of a cure should not decrease the frequency of visits to the patient, or reduce the care provided. There should be continuous care of the patient’s cleanliness, proper nursing, and provision of suitable feeding even if it would require less usual routes for nutrition.

8. The healthcare team should communicate with the patient’s family, whenever possible, and allow them access to the patient to the greatest possible extent, and always observe the effect of any life-threatening disease on the patient’s family psychologically, socially, and spiritually. They [the healthcare team] should also do their best in caring for them and allowing them to be debriefed of what they are suffering because of the condition of their relative. Help should be sought from whosoever can help in that communication, for example the religious guide, the psychologist, or social worker.

9. The healthcare team should instruct the patient to continue performing their prayers, even if it may be difficult for them to have the full cleanliness(Tahara)\(^1\), and remind them of that, whenever needed.
10. It is a right for the patient or his/her guardian, if the patient is incompetent, to take decisions to ask for having his/her treating doctor changed, and the health institution should do its best to meet this request whenever this is possible.

11. It is strictly prohibited for any member of the healthcare team to help a patient take his/her own life by being given high doses of any drug, or teach the patient how to administer it, which is known as physician-assisted suicide, or to participate in euthanasia, through injecting a lethal drug or otherwise, regardless of the pain and suffering of the patient.

12. It is permissible to use powerful analgesics like opioids and pain-relieving drugs, even if they sometimes have side-effects on the intellect.

(A) Does the Patient Have the Right to Refuse Treatment in Incurable Conditions?

The general rule is that the patient has the right to make any decision whether to accept or refuse therapeutic interventions proposed by a doctor, in part or in whole. The doctor does not have the right to force the patient to accept treatment, except in rare cases where the patient or his/her guardians are legally required to seek treatment, like some infectious diseases from which there is fear of spread. It is conditional for the patient who refuses treatment that he/she has fully understood the medical information related to his/her condition, and the consequences of such refusal, benefits of the treatment, and risks associated with his/her decisions (to refuse the treatment). This should be in the presence of two independent witnesses and these actions and witness names should be clearly documented in the patient’s medical record. However, in cases that the patient cannot make appropriate decisions him/herself because of his/her health condition or loss of legal competence, the issue comes in accordance with the patient’s guardian’s decision and the healthcare team following the same rules previously stated for decision making.

(B) Should Medical Treatment Be Stopped?

In incurable conditions, with the use of advanced equipment, in situations that are futile and with no expected benefit, it is permissible not to initiate the use of this equipment from the beginning, or to stop using them in treatment if they are found to be of no use (to the patient); following the previously stated principles in decision making, and also abiding by specific regulations for such procedures in the hospital concerned. In such cases, the patient’s family should be made aware of that decision, unless it is not possible to inform them for objective reasons.
In the case of disagreement between the patient or his/her guardian on one side, and the healthcare practitioner on the other, about the use of this equipment, there should be a thorough discussion between the two sides. If no agreement is reached, the general rule is that the patient has the right to choose his/her treating doctor, and the patient can be transferred to the care of another doctor who accepts to treat him/her, and if this is not possible, then the case must be resolved by the concerned authority in the hospital.

Generally, there is no difference between a specific medical intervention (like assisted ventilation), and not to initiate that intervention, if there are three specialized consultants who have decided that this intervention is futile.

However, it is better to take more care before stopping the medical intervention compared not to initiating the intervention.

**(C) Cardiopulmonary Resuscitation**

Cardiopulmonary resuscitation is among the interventions that are related to patients with incurable conditions. This intervention is attached to a number of principles and ethical behaviour that the healthcare practitioner should know and observe for these conditions. They are as follow:

1. This intervention is characterized by the its urgency when needed, so it is better to study its use and the extent of its benefit in this medical condition, and to discuss it with the patient or his/her proxy decision makers in sufficient time before it is expected to be needed. This is to make the decision about it, taken in enough time and as objectively as possible.

2. It may not be useful to do cardiopulmonary resuscitation in cases of incurable late-stage disease, thus it has no purpose, and it is most probably of no benefit to the patient in this condition.

3. If it is carried out for a long enough period of time, as per recognized medical standards, and then becomes obvious that the heart or lungs cannot be restored to normal function, it is permissible to stop any further continuation of the intervention.

4. In case of the insistence of the patient or his/her family to continue the cardiopulmonary resuscitation under all conditions and circumstances, while the treating doctor(s) has a different opinion; then the doctor should explain his/her opinion supported by adequate information, with observance of the patient’s ability to understand and appreciate his/her explanations. If the patient or his/her guardian is still not convinced, then the doctor should report his/her opinion to the medical management, and write his/her opinion clearly in the patient’s medical record, and make the patient
and or his/her guardian aware of that. In any case, the doctor should consider making use of all available means to demonstrate the facts, and to overcome the psychological barriers that may prevent acceptance of medical opinion that includes the futility of the medical intervention or the futility of its continuation.

5. When discussing not using cardiopulmonary resuscitation before it is needed, it should be clarified to the patient or his/her guardian that this does not mean totally abandoning the treatment in the meantime, and that this does not affect the patient’s status receiving suitable healthcare, and to secure all the nursing requirements, and to take care of him/her, and respect his/her dignity at all times. This should be known, recommended, and shared among all the healthcare team members.

(D) Conditions of Prolonged or Terminal Coma due to Cerebral Cortical Damage

The patient may be suffering from an irreversible coma secondary to damage of the cerebral cortex, while the brain stem remains functioning. This kind of patient does not feel what is surrounding him/her, but he/she can react to stimuli around him/her, and yet he/she is not classified as a fatal condition, as his/her life in this state of coma may last for many months or even years.

This patient is treated like the incompetent patient, and not treated as a patient suffering from a fatal condition, as defined earlier in this chapter. From a scientific point of view, the patient whose cortical damage is untreatable; he/she should be treated without the use of complicated equipment like assisted ventilation and haemodialysis, and so on, especially if the treatment with this equipment would deny other patients from using them. However, some patients’ guardians (family) may provide their patients with such equipment to help them breathing or renal dialysis on an individual basis that does not affect other patients. In these conditions, the healthcare practitioner should perform the duty of the required medication and care.

Reference and Further Reading