# Chapter 15 End-of-Life Care

# Introduction

Muslims believe that death is the departure of the soul from the body by divine decree. Death marks the transition from one state of existence to the next and the beginning of the journey in the life hereafter, which is perpetual and infinite.

It is He Who gives life and death; and when he decides upon an affair, He says to it, "Be", and it is [1].

The earth is described as a resting place for the purpose of worshipping God and doing good deeds [2]. Death is inevitable and occurs only with a command from God: "Every soul shall have a taste of death: in the end to Us shall you be brought back" [3]. It also states "Wherever you are, death will find you out, even if you are in towers built up strong and high" [4].

Death is unpredictable and can happen at any time and as such Muslims should always be prepared for the inevitable and for what is about to occur.

The time of death is predetermined by God. "When their time comes they cannot delay it for a single hour, nor can they bring it forward by a single hour" [5].

It is but a gateway from this short but mortal existence to a life of immortality in the afterlife [6].

The Prophet (PBUH) quoted saying "None of you should wish for death because of a calamity befalling him; but if he has to wish for death he should say: O Allah! Keep me alive as long as life is better for me and let me die if death is better for me" [7].

Muslims view illness as trial or a test of faith from Allah and is intended as a cleansing by Him, not as a punishment. At the same time, Allah and His Prophet clearly command that Muslims are obligated to seek treatment, and may not terminate life [8].

The purpose of medicine is to search for a cure through the application of human knowledge and scientific Endeavor, and to provide the necessary care to those afflicted with diseases. The primary obligation of a Muslim doctor is to provide care and alleviate pain. However, resorting to extraordinary means to sustain life does not in any way "prolong" life. The Qura'n states: "And for all people a term has been set. And when the end of the term approaches, they can neither delay it by a single moment, nor can they hasten it" [9].

Medical advances make it possible to restore health and sustain the life in circumstances previously regarded as hopeless. This capability brings with it considerable clinical, moral, socio-cultural, legal, and economic issues that challenge the values and goals of patients' care.

End-of-life treatment choices are increasing in intensive care units (ICUs) around the world. Many dying patients suffer prolonged and painful deaths, receiving unwarranted, expensive, and invasive care threatening their physical, psychosocial, and spiritual integrity.

The Intensive Care Unit or Critical Care Unit (CCU) is the special hospital ward within which the highest levels of continuous care and treatment are provided to patients after major surgery, with severe head injuries, life-threatening illnesses, respiratory insufficiency, coma, hemodynamic insufficiency, severe fluid imbalance, or with failure of one or more of the major organ systems.

Highly skilled specialized nursing staff mans the ICU, which is undoubtedly the most expensive and the most highly technological area of medical care [10].

Generally, patients whose conditions are expected to improve with intensive care aid are admitted to the ICU. In other words, patients are not admitted to the ICU to die. However, families of patients in the ICU are plagued with a host of dilemmas. Some of these dilemmas pertain to: (a) the justification for "prolonging" the suffering of their loved ones; (b) what extent they must outlay their financial resources in order to keep their loved ones in the ICU; (c) whether or not to give their consent to disconnect the ventilator once their loved ones are diagnosed to be brainstem dead; and (d) the validity of seeking extraordinary treatment measures for their loved ones when the prognosis is poor [11].

Although ICUs present many challenges to providing excellent end-of-life care, they also have special resources available, including a low patient-to-nurse ratio that allows better care for the dying patient. Terminally ill patients consume significant resources, including nursing care, transportation, and medications. Almost half of those who die in the hospital have been cared for in an intensive care unit (ICU) within 3 days prior to their death.

The Prophet Muhammad PBUH said: Seventy Thousands would enter paradise without being questioned. When asked who are they? He said "those who refused Ruqia (Incantation) and treatment" [12]. In another hadith he lauded the black lady who agreed not to be treated for epilepsy and said she would go directly to paradise. Many of the Sahaba (companions of the Prophet) refused to be treated in their final illness. Among them was Abubaker Al Sadiq, Abu Dardaa, Muath Ibn Jabal, etc.

Islam acknowledges that death is an inevitable phase of the life of a human being; medical management should not be given if it only prolongs the final stage of a terminal illness as opposed to treating a superimposed, life-threatening condition.

Terminally ill patients usually question the meaning of life, and the approach of death may stimulate serious spiritual questions that contribute to psychological symptoms such as anxiety, depression, hopelessness, and despair. Spiritual care is not necessarily religious, but religious care, at its best, should always be spiritual [13].

### **Persistent Vegetative State**

The persistent vegetative state (PVS), a chronic neurological disorder of consciousness characterized by wakefulness without awareness, is a tragic and ironic artifact of modern medical technology. Patients reach a PVS after suffering a pathological process that has produced widespread damage to cerebral cortical neurons, thalamic neurons, or the white matter connections between the cortex and thalamus, but that largely spares the brain stem and hypothalamic neurons. Common etiologies of acute PVS are traumatic brain injury, stroke, and neuronal hypoxia and ischemia suffered during cardiopulmonary arrest [14].

The diagnosis and prognosis of PVS have reached public attention through several landmark high court rulings involving termination of life-sustaining treatment, most notably the cases of Karen Ann Quinlan in the 1970s, Nancy Beth Cruzan in the late 1980s, and the case of Terri Schiavo in 2005.

Karen Ann-Quinlane was the first case of PVS brought to courts in 1975. The ventilator was stopped in 1976, but she lived for 9 years and finally died of pneumonia. She was kept alive with artificial nutrition and hydration.

Thousands of cases have been recognized all over the world annually. Nancy Cruzan (1990) was another PVS whose family requested to stop hydration and nutrition after 4 years of loss of her cognitive functions, as she expressed her wishes previously.

# The Case of Terri Schiavo

On March 31, 2005, a 41-year-old patient, Terri Schiavo died 2 weeks after her feeding tube was removed in a Florida, USA nursing home.

The saga of Mrs. Schiavo started in 1990 when she developed cardiac arrest of undetermined etiology; she was resuscitated, but never regained consciousness. A percutaneous endoscopic gastrostomy (PEG) tube was introduced for feeding and hydration.

Neurological evaluation established the diagnosis of PVS.

In August 1992 Michael Schiavo, her husband, received \$250,000 in an out-ofcourt settlement with a physician and he later received \$300,000 for loss of consortium.

In May 1998 Michael Schiavo filed a petition in Court to have the PEG tube removed, because she had no chance of improvement.

On April 24, 2001 the PEG tube was removed. From that point on, a major conflict started, and became the focus of heated and prolonged medical, legal, religious, ethical, social, and political controversy. Several contradicting court or administrative orders were issued to remove or maintain the tube, or to reinstate it after its removal! During that period, there were active movements by ethical and human rights groups to defend Terri's right to live, and others to defend her right to withdraw Life-Sustaining Treatment (LST) and die.

After prolonged trials, litigations, and accusations the High Court agreed to remove the PEG tube of Terri Schiavo on March 18, 2005. She died on March 30, 2005 by starving to death. It would have been less traumatic if she had an injection that put her agony to end in a few minutes.

On January 26, 2006 Michael Schiavo married his girlfriend with whom he has two children.

The practical questions that must be answered in Terri's case, as well as many other similar cases, could be summarized in the following points:

- Is it ethically and legally permissible to withdraw or withhold life-sustaining treatment?
- Who speaks for the patient when he/she cannot speak?
- What are the duties of a surrogate decision maker or proxy?
- Surrogate or proxy decision makers are persons appointed to speak and make decisions for the unconscious patient.
- What should be done when it is suspected that a surrogate may not be acting in the best interests of the patient?
- Is artificially supplied fluid and nutrition considered a medical treatment or a mandatory comfort care? [15]. People rarely execute living wills or advance directives, to help in delineation of their wishes regarding medical interventions when they face end-of-life stages, or when they become unconscious. Physicians rarely discuss such issues with patients and families when they face terminal illnesses. And if they do so they do not usually document patients' and families' opinions and wishes in the medical records.

### **Concepts Involving End-of-Life Care**

Full Resuscitation: Aggressive ICU management up to and including full resuscitative attempts.

Withholding Resuscitation: Aggressive ICU management up to, but not including Cardio-Pulmonary Resuscitation (CPR).

Withholding Life Support: Decision not to institute a medically appropriate and potentially beneficial therapy, with the understanding that the patient will probably die without the therapy in question.

Withdrawing Life Support: Cessation and removal of an ongoing therapy with the explicit intent not to substitute an equivalent alternative treatment. Palliative Care: Prevention or treatment of suffering, including the administration of drugs such as narcotics and sedatives.

Do Not Resuscitate (DNR) order: An order stating that in case of cardiac arrest or respiratory arrest, cardiopulmonary resuscitation will not be undertaken by any means.

### Withdrawal of Life-Sustaining Treatments

Withholding or withdrawing life support, however, is still an area of controversy. Its applicability is weighed with benefits and risks and how futile the treatment is for the terminally ill patients.

Withdrawing and withholding treatment can be "voluntary," where the conscious patient authorizes it, or if unconscious, the patient had communicated to his next of kin that he would prefer not to be kept alive on life support. It can also be "nonvoluntary," where the decision to withdraw life support is made by the family of the patient, [16] or by the treating physicians.

At the end of life, the chronic heart patient, for example, often becomes increasingly symptomatic, and may have other life-limiting comorbidities as well. A clear mortality benefit with the use of implantable cardioverter defibrillators (ICDs) has been shown in patients with poor left ventricle and ventricular arrhythmia. However, patients who have an ICD may be denied the chance of a sudden cardiac death, and instead are committed to a slower terminal decline, with frequent electrical shocks that can be painful and decrease the quality of life, greatly contributing to their distress and that of their families during this period.

Deactivating an ICD or not performing a generator change is both legal and ethical, and is supported by guidelines from both sides of the Atlantic. Patient autonomy is paramount, and no patient is committed to any therapy that they no longer wish to receive [17].

Terminally ill Muslim patients are permitted to have life-sustaining treatments withheld or withdrawn when the physicians are certain about the inevitability of death and the treatment is futile, does not improve the patient's condition or quality of life, involves great complications, delays the dying process, or involves suffering. However, it should be a collective decision acquired on the basis of informed consent after consultation with the patient's family and all individuals involved in providing care. In these situations, death is allowed to take its natural course [18, 19].

The definition of **futility** is elusive and has been widely debated. The American Thoracic Society states that a treatment should be considered futile if it is highly unlikely that it will result in "meaningful survival" for the patient.

Resource utilization and outcomes in gravely ill patients must be observed. Futile treatments and medical interventions must be considered in light of outcomes. If the treating physicians find a certain modality of treatment useless or going to increase the suffering of the patient, that modality of treatment should not be enforced from the start. The Prophet Muhammad (PBUH) says "above all do no harm" and this rule of non-maleficence is the cornerstone of all medical ethics. The intention must never be to hasten death, only to abstain from overzealous treatment [20].

Issues arising from withdrawal and withholding treatment have not reached total consensus among Muslim jurists. However, Article 63 of the Islamic code of medical ethics can be regarded as a clarion call on Muslim medical personnel. The article states that, "the treatment of a patient can be terminated if a team of medical experts or a medical committee involved in the management of such patient are satisfied that the continuation of treatment would be futile or useless." It further states that "treatment of patients whose condition has been confirmed to be useless by the medical committee should not be commenced" [21].

The following Fatwa is a landmark in regulating resuscitative measures, stopping of machines in cases thought to be not suitable for resuscitative measures. The decision should be based on medical criteria and decided by at least three competent physicians. The family should be approached and the facts discussed fully with them [22].

The Permanent Committee for Research and Fatwa, Fatwa No. 12086 on 28/3/ 1409 (1989). Question from Military Hospital (N.W. region) on using resuscitative measure on the following cases:

- Q. 1. If a person who arrives to the hospital is already dead?
- A. 1. There is no need to use any resuscitative measures in such a case.
- Q. 2. If the medical file of the patient is already stamped: "Do not resuscitate," according to the patient's or his proxy's will and the patient is unsuitable for resuscitation.
- A. 2. If three competent specialized physicians agree that he is unsuitable for resuscitation, then there is no need to do any resuscitative measures.
- Q. 3. If three physicians have decided that it is inappropriate to resuscitate a patient who is suffering from a serious irremediable disease and that his death is almost certain.
- A. 3. If the disease is irremediable and his death is almost certain, as witnessed by three competent physicians, there is no need to use resuscitative measures.
- Q. 4. If the patient is mentally or physically incapacitated and is also suffering from stroke or late stage cancer or having severe cardiopulmonary disease or already had several cardiac arrests.
- A. 4. If the condition of the patient is as described and the decision not to resuscitate has been reached by three competent specialist physicians, then it is permissible not to resuscitate.
- Q. 5. If the patient had irremediable brain damage after a cardiac arrest?
- A. 5. If the condition is authenticated by three competent specialist physicians, then there is no need for resuscitative measures as they will be useless.

- Q. 6. If the treating physicians decided that resuscitation will be useless in a certain patient, is it permissible not to resuscitate even though the patient or his relatives asked for resuscitative measures to be carried on.
- A. 6. If resuscitative measures are deemed useless and inappropriate for a certain patient in the opinion of three competent specialist physicians, then there is no need for resuscitative measures to be carried out. The opinion of the patient or his relatives should not be considered, both in withholding or withdrawing resuscitative measures and machines, as it is a medical decision and it is not in their capacity to reach such a decision" [23].

Islamic law permits withdrawal of futile and disproportionate treatment on the basis of the consent of the immediate family members who act on the professional advice of the physician in charge of the case or, as the Saudi Fatwa implies, it should be a clear medical decision by the treating physicians (at least 3).

Muslim jurists recognize, as a legal competent, the patient's informed refusal of treatment or a living will, which allows a person to die under circumstances in which there are no medical reasons to continue treatment [24]. The Prophet (PBUH) himself lauded those who refused treatment and many of the Sahaba (companions) refused to be treated in their final illness.

The basic human rights of the patient, which include being provided with food, drink, nursing, and painkillers, must still be provided and this can be done at home or hospice. The patient should be allowed to die peacefully and comfortably [25]. Thus, the removal of such basic necessities of life such as food and water will amount to actively killing the patient.

Social workers and religious affairs personnel will be needed for both the social and religious and spiritual needs of the patient and his family.

Supportive care is compassionate, humane, integrated, and responsive to the patient and family's physical, psychological, and spiritual needs at the end of life.

### **Do Not Resuscitate**

Resuscitation is a medical procedure which seeks to restore cardiac and/or respiratory function to individuals who have sustained a cardiac and/or respiratory arrest. Cardiopulmonary resuscitation (CPR) is now routinely performed on any hospitalized patient who suffers cardiac or respiratory arrest. The frequent performance of CPR on patients who are terminally ill or who have little chance of surviving has prompted concern that resuscitation efforts may be employed too broadly. Advanced invasive procedures and treatments that may promote and sustain life may not confer any foreseeable benefit, and in fact may cause further suffering to the patient and the family [26].

Therefore, CPR may be withheld if, in the judgment of the treating team, an attempt to resuscitate the patient would be futile.

Do Not Resuscitate ("DNR") is a medical order to provide no resuscitation to individuals for whom resuscitation is not warranted.

The Islamic Medical Association of North America (IMANA) believes that when death becomes inevitable, as determined by physicians taking care of terminally ill patients, the patient should be allowed to die without unnecessary procedures. While the patient is still alive, all ongoing medical treatments can be continued. IMANA does not believe in prolonging misery on mechanical life support in a vegetative state. All of the procedures of mechanical life support are temporary measures. When a team of physicians, including critical care specialists, have determined, no further or new attempt should be made to sustain artificial support. Even in this state, the patient should be treated with full respect, comfort measures, and pain control. The patient should be allowed to die peacefully and comfortably. No attempt should be made to enhance the dying process in patients on life support [27]. Hydration and feeding should continue and no attempt should be made to withhold nutrition and hydration. Otherwise, it will be considered by Islamic Law (Shari'ah) as a murder case. If hydration and feeding is stopped the patient does not die peacefully and comfortably. He suffers dehydration and hunger for 10-14 days. It would be more humane to inject him and let him die in seconds or a few minutes rather than torturing him for 2 weeks, but this is considered as Euthanasia which is emphatically prohibited by Islamic jurists.

If the patient is competent enough; it should be discussed with him. He should be ensured of being given all necessary care and medication to alleviate pain and distressing symptoms.

If the patient is not competent enough, DNR should be discussed with the family members, especially the most appreciative and comprehending person.

The Fatwa of the high council of ulama of Saudi Arabica should be explained and given to the family. If the family still insists on doing everything possible, then they should be offered the possibility of transferring their patient to whichever hospital they wish.

A clear policy from the ministry of health regarding DNR, brain death, and endof-life issues is urgently needed for all hospitals and health providers in most (if not all) Muslim and Arab countries.

A DNR is acceptable in Islamic law in certain situations [28]. In Saudi Arabia, for example, DNR policies that are practiced are mainly used in the hospital arena and are not valid outside the hospitals.

According to the fatwa, families and guardians cannot decide on the application or removal of resuscitation measures or procedures, as they are not considered qualified under the Fatwa. This is an important difference from the practice in the United States. The DNR Form in Saudi Arabia, for example, is valid only on the condition that it is signed by three qualified physicians (mainly 2 consultants, and 1 staff physician), and only acceptable within the hospital during the patient's admission. When signed, the form is kept in the patient's record, and it has to be reviewed by the physicians according to the institution's policies.

### Do not resuscitate in pediatric practice

The ethical issues that attend the implementation of DNR orders to elderly patients are obviously different from those that are relevant to the neonatal or pediatric patient, who has just begun their life [29].

Children with irreversible or progressive terminal illness may benefit temporarily from CPR, only to deteriorate later. Painful and invasive procedures may be performed unnecessarily, and the child could be left in a poorer condition. A DNR order indicates that the treating team has decided not to have CPR attempted in the event of cardiac or pulmonary arrest.

Optimal ethical decision making requires open and timely communication between members of the pediatric team and the family, respecting their values, beliefs, and the fundamental principles of ethics [30].

It is never permissible to withdraw procedures designed to alleviate pain or promote comfort. For example, withholding hydration or antibiotics to treat transient infections is not justifiable. These infections may cause distress and pain, and treating them represents an important element of good palliative care.

### Discussion of end-of-life issues in Neonatal Intensive Care Unit (NICU)

The subject of withholding or withdrawing treatment thus needs to be broached with considerable sensitivity and awareness, as not only is this an emotionally challenging time for parents, but there may also be important ethico-religious imperatives that parents will need to consider and sometimes seek advice on. Generally, parents and relatives are reluctant to make life-and-death decisions themselves, but are willing to transfer authority for such decisions to professionals who they trust will work in the interests of their baby while at the same time respecting the principles of their faith [31].

The decision of DNR is always a medical decision taken by the treating physicians (at least 3) and should be fully discussed with the family.

### Breaking news of babies death

Telling parents that their baby has died using the words (your baby is now in the loving care of the Lord) or the Qur'anic expression "To Allah we belong and to Allah is our return" [32] can provide comfort. We also remind parents of Prophet Muhammad's (PBUH) reassurances that those who bear this loss with patience their babies, who are pure, will be their forerunners into Paradise [33].

# Palliative Care at End-of-Life

The World Health Organization (WHO) defines palliative care as an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through prevention and relief of suffering by means of physical, psychosocial, and spiritual means. The WHO has gone so far as to assert: "A palliative care program cannot exist unless it is based on a rational drug policy including...ready access of suffering patients to opioids."

Palliative care involves much more than the alleviation of physical pain but rather encompasses "total pain" including emotional, psychological, social, and spiritual pain [34].

Based either on assessment of available palliative care services or on the consumption of opioid analgesics, it is clear that palliative care is severely lacking in Muslim-majority countries (MMCs). This is true not only in the low- and middleincome MMCs (e.g., Pakistan, Bangladesh, and the MMCs of Africa) but also in the higher income countries of the Arab Gulf [35].

Ideally, these services would encompass consultative services within each hospital, dedicated beds for a palliative care unit, stand-alone hospices, and home-care palliative care and hospice services.

Issues regarding spirituality, religious beliefs, and practices can come to the forefront in patients' advanced illnesses [36]. Many patients may wish to discuss their beliefs with their healthcare providers [37] and it would appear obvious that for these discussions to be optimally useful, healthcare providers should possess cultural and religious knowledge and sensitivity relevant to the patients being treated. Healthcare providers should involve religious or spiritual persons in dealing with such patients and their families.

Historically, care for the dying has been seen as a family responsibility and death has been generally managed at home [38]. However, the lack of home-care services in most MMCs can lead to return trips to the hospital and/or extended stays and death in a hospital.

The core principles for end-of-life care are: (a) Respect the dignity of both the patient and the care giver. (b) Be sensitive to the patient's and family wishes (as far as possible). (c) Management of pain or other symptom. (d) Offer any therapy or measure that can improve quality of life. (e) Assess and manage psychological, social, spiritual needs of the patient and his family (as far as possible). (f) Respect the physicians' decisions to limit their intervention or forgo any specific treatment which they think to be of no use and probably harmful. (g) Hospice and home-care services should be the benchmark and bedrock of end-of-life care. (h) There is ample evidence that hospice and homecare provide better end-of-life care, with dignity. It is remarkably inexpensive compared to hospital care.

### Relieving pain and suffering

True, there is pain and suffering at the terminal end of an illness, but Muslims believe there is immeasurable reward from God for those who patiently persevere in suffering. "Those who patiently persevere will truly receive a reward without measure" [39].

The Qur'an states that "Allah does not tax any soul beyond that which he can bear" and pain and suffering is not a punishment, but rather a "kaffarah" (expiation) for one's sins. But relieving pain or providing a sedative drug with the aim of pain relief is still allowed even if death is hastened (double effect), provided death was definitely not the intention of the physician [40]. The major disadvantage of controlling pain with morphine and its derivatives, especially in patients where their respiratory centers are depressed or they are suffering from chronic obstructive lung disease, is further depression of the respiratory center and hence shortening the end of life.

Recently, cannabis and its derivatives have been introduced with good results in AIDS patients and other near-end-of-life cases. It reduces the sense of pain, gives some euphoria, and does not affect the respiratory center. The objection is by law and religion. Muslims prefer to be around until almost the very end, to make shahada and remember Allah. Opioids, cannabis, and other drugs may obscure consciousness. Alleviation of pain can also be done with nerve injection or other minor surgical procedures.

In the Islamic perspective, medication-related sedation could be looked at from two different angles. On the one hand, alleviation of the suffering of a human being is considered righteous. On the other hand, maintaining a level of consciousness as close to normal as possible is of great importance to allow for observance of the worship rites for the longest period possible before death. In terminally ill patients, it may be difficult to maintain a state of equilibrium allowing for optimal symptom control and a normal level of consciousness. In these situations, the pros and cons should be clarified to the patient and family, who may prefer to endure a slightly higher degree of symptoms in order to maintain a better level of consciousness [41].

### **End-of-Life Practices**

Terminally ill patients should be entitled to the respect and dignity of a good death according to Islamic tradition. Tayeb et al. described three important domains in the end-of-life care of dying Muslim patients. The first domain of religious preferences at the time of dying includes: the presence of someone to prompt the dying person to say the "Shahadah (bearing witness that there is no true God but Allah and Muhammad is verily His Servant and His Messenger) as a final statement of faith"; the presence of someone at the bedside to recite chapters from the Holy Qur'an during the dying process; and positioning the dying patient to face the Kaaba at the Holy Mosque in Mecca. The second domain on self-esteem and image is preserving the bodily dignity in death, maintaining cleanliness of the body and clothing from bodily fluids (e.g., urine, stool, vomit), the eyes and mouth of the deceased should be closed, and ensuring normal appearance of the body after death (e.g., removing external medical devices, catheters, and indwelling tubes) and the limbs straightened.

When Muslims are sick, their friends and relatives tend to visit and sometimes in rather large numbers for rather extended visits. Western trained healthcare workers may find this somewhat unusual, but consideration should be given to the point where the visitors are not in some way impeding the delivery of care [42].

When death of the patient occurs, it is important to assist the family in preparation for burial which is to be performed as quickly as possible. Autopsy is not generally done except for legal or possible public health reasons.

The third domain is the wellbeing of surviving relatives, whereby the dying person feels secure that surviving family members will not be burdened with psychosocial and/or financial difficulties after one's death [43].

The Muslim person is required to make A "Wasyiah," will, testament especially if he has financial deals, debts, or commitments to others. The physician, the social worker, or the religious adviser should remind the competent patient of this religious and social duty. The treating physician should offer the family home care if they wish and arrange for home visits if needed.

He should recognize the special needs of the patient, e.g.: A family member can stay with the patient all the time. Food and comfort measures should be allowed to be brought from home. Support to the patient and family psychologically, socially, and spiritually is extremely important. Spiritual care and pastoral service for non-Muslims should be arranged, if requested through their embassies/consulates.

#### Disclosure

Some families may not wish their dying relative to be fully informed regarding his/ her illness. While this is certainly not unique to Islam, it is perhaps somewhat more common in Muslim families than in Western families today. In some instances, the patients and relatives may be engaging in what has been termed "mutual pretense" i.e., both the patient and his/her family know that the patient is dying but the topic is avoided with each pretending that the other does not know the real situation [44].

The physician can withhold information from the patient if he has good reason that divulging the information to the patient is going to cause harm or impair management or cause distress. The physician should document this fact in the patient's file and should get the consent of the substitute decision maker (legal representative).

### Nutrition at end of life

Prophet Muhammad (PBUH) discouraged forcing the sick to take food or drink. However, Muslim families tend to express great concern when the nutritional intake of a patient is jeopardized. Some Muslim families may demand for medical intervention to compensate for this decreased nutritional intake. Reference to the teachings of the Prophet (PBUH) on this matter helps to address the concerns of families and to facilitate their understanding of the anorexia/cachexia syndrome associated with malignancy. However, in patients who are slowly deteriorating, one should maintain the minimal amount of nutrition and hydration until the last moments of life. The reason for this approach is to prevent the potential feelings of guilt and sorrow that could be experienced by the family if nutritional or hydration support was withdrawn or withheld completely.

Basic nutrition should not be discontinued because such an action would starve a patient to death—a crime in the Islamic faith [45].

# **Advance Directives**

Death is an inevitable phenomenon which strikes at any time during a person's infancy, youth, or old age. But, one cannot overlook the fact that before the inevitable (i.e., death) does take place a person may become a victim of a terminal illness, or may lapse into irreversible coma, or (PVS) [46]. The contemporary sophisticated medical care of terminally ill patients increasingly utilizes life support technologies and procedures that many individuals prefer to avoid when they reach that stage [47].

The Living Will (Advance Medical Directive) is a document in which a healthy person explains in writing which medical treatment he/she would accept or refuse at that critical juncture when he/she may not be in a position to express his/her wishes in case of emergencies, terminal illnesses, and situations where they may be incapable of making decisions. In other words, this document assists the attending physician to withhold or withdraw certain medical procedures and allow the patient to die naturally.

There are two types of advance directives: a living will and a durable or medical power of attorney.

Living wills and advance directives, which are legal documents in the United States, are used to make decisions regarding the person's type of care to receive in situations in which they cannot speak for themselves.

A durable power of attorney of health care is acceptable for Muslim patients. Patients not capable of making healthcare decisions can call upon an authorized representative to express his or her wishes and make treatment decisions on behalf of their best interests [48].

The question that arises here is whether it is permissible for a Muslim to include an advance medical directive in his his/her wasiyyah? Attention should be drawn here to the fact that the Living Will cannot form part of the wasiyyah, since what is incorporated in the wasiyyah will be executed only after one's demise.

Prophet Muhammad (PBUH) asked his wives, when he was ill, not to pour medicament in the side of his mouth (Ladood), if he would become unconscious, but his wives did. When he came around, he scorned them and asked them to do the same for themselves.

The following may be incorporated into the living will:

• Request to discontinue treatment

A terminally ill Muslim patient can request that treatment be discontinued if the treatment would not in any way improve his/her condition or quality of life based on the Islamic juridical principle of *la darar wa la dirar* (no harm and no harassment). The intention here is not to hasten death, but the refusal of "overzealous" treatment. However, "palliative" care in the sense of maintaining personal hygiene and basic nutrition should not be discontinued.

• Instruction to switch off the life-support equipment

A healthy Muslim may instruct that should he/she, as a result of a terminal illness or massive head injury, be diagnosed as brain dead, then the life-support equipment should be switched off. In this regard the International Islamic Fiqh Academy of the Organization of the Islamic Conference, during its third session held in Amman–Jordan from 8 to 13 Safar 1407 Hijri/11–16 October 1986, resolved that a person whose brain activity has ceased and the physicians confirm that such a cessation is irreversible and that the brain has entered the state of decomposition, under such circumstances the ventilator could be stopped even though some organs of his body, like the heart, continue to function artificially with the help of life-support equipment [49]. Other Fatwas on this issue allowed stopping the ventilators whenever brain death was diagnosed. They have been discussed in the Chap. 14.

• Inclusion of organ donation (Please refer to chapter on Organ transplantation).

• <u>Power of attorney (wakalah)</u>

In the alternative Living Will it would be prudent on the part of a Muslim to entrust someone with the power of attorney and mention that person by name in his/her Living Will. This would safeguard that should he/she become noncompetent, then his/her wishes as stated in the Living Will would be expressed by his/her wakil [50] (authorized representative) to family members and the attending physicians. The document should be dated and signed by the person giving the advanced medical directive, his/her wakil, and that of two witnesses. Muslims may draw up an alternative Living Will and include in it instructions pertaining to the cessation of treatment, switching off the life-support equipment, and organ donation. The wakil (authorized representative) would be morally bound to express and convey the wishes of the person concerned to members of the family and the attending physicians. If none of the clauses of the Living Will contradicts the broad teachings of the Qur'an and Sunnah of Prophet Muhammad (PBUH) there would be no justification to ignore the directives given therein [51].

A prototype of an Islamic Living Will has been developed by the Ethics Committee of the Islamic Medical Association of North America (IMANA). It was published in The Journal of the Islamic Medical Association of North America, Volume 37, Number 1, July 2005. p. 37.

# Euthanasia

Euthanasia is a Greek word composed of two syllables: EU means Good or Easy, Thanatos means Death [52]. Thus, the meaning becomes good death or easy death, and nowadays proponents like to call it "mercy killing."

#### Types of euthanasia:

Voluntary euthanasia is defined as: "The intentional administration of lethal drugs in order to painlessly terminate the life of a patient suffering from an incurable condition deemed unbearable by the patient, at this patient's request," while Assisted suicide is defined as: "intentionally assisting a person, at this person's request, to terminate his or her life."

Nonvoluntary euthanasia is defined as: "The intentional administration of lethal drugs in order to painlessly terminate the life of a patient suffering from an incurable condition deemed unbearable, not at this patient's request" [53].

### Islam and Euthanasia

A subject of great importance is the subject of life. Life is given by God and cannot be taken away except by Him or with His permission. Preservation of life is one of the five basic purposes of the sacred law [54].

Human beings are considered to be responsible stewards of their bodies, which are viewed as gifts from God. The sanctity of human life is affirmed in the Qur'an. One cannot take the life of another: "Do not take life which God has made sacred except in the course of Justice" [55].

Thus, the person who intentionally ends his life will be punished because of his disobedience to Allah, and for denying His mercy, on judgment day. The Sunnah, a teaching of Prophet Muhammad (Hadith) describes one such instance. He (PBUH) said in one of the Hadith: "Whoever kills himself with an iron instrument will be carrying it forever in hell. Whoever takes poison and kills himself will forever keep sipping that poison in hell. Whoever jumps off a mountain and kills himself will forever keep falling down in the depths of hell" [12].

Life saving is a duty and the unjustifiable taking of life is considered a grave sin.

Islam and the Islamic law clearly prohibit euthanasia in all circumstances. However, the wishes of patient not to have his dying prolonged artificially in the presence of hopeless prognosis are well preserved. Such wishes may be declared in accepted standing Do Not Resuscitate (DNR) orders in certain hopeless medical conditions [56].

The Holy Qur'an says: "...One who has killed a person except in lieu of murder or mischief on earth; it would be as he slew the whole mankind and whoever saves the life of a human being, it is as if he has saved the life of all mankind ... ." [39].

One cannot also take one's own life: "Do not kill yourselves, for verily God has been to you most merciful." [57].

God says in the Qur'an: "It is He who created death and life, that He may try which of you is best in deed  $\dots$ ." [58].

He also says: "... Nor can they control death nor life nor resurrection." [59].

The physician therefore has no right to terminate any human life under his care. This also applies to the unborn baby since clear evidence indicates that human life starts at the time of ensoulment (120 days from fertilization). Taking away life should be the domain of the One Who gives life. The Qur'an emphasizes that "it is the sole prerogative of Allah to bestow life and to cause death," and therefore euthanasia is never allowed [24].

These sources from the Qur'an and hadith illustrate the sanctity of human life, prohibition of killing a human being with no justification, and prohibition of killing oneself. Thus, killing a person to ease his suffering even though it is at the request of the person will be inconsistent with Islamic law, regardless of the different names given to the procedure, such as, active voluntary euthanasia, assisted suicide, or mercy killing. A person in such situation is expected to persevere patiently with the available medical treatment as reward for such patience in the Hereafter is tremendous as promised in Qur'an, in which Allah (swt) stated to the effect: "And those who patiently persevere will timely receive a reward without measure" [60].

The Islamic World League held in Jeddah [61] in May 1992 declared a strong rejection against so-called euthanasia under all circumstances. And those terminally ill patients should receive the appropriate palliative medication, utilizing all measures provided by God in this universe, and that in no way should one despair from Allah's mercy, and that doctors should do their best to support their patients morally and physically, irrespective of whether these measures are curative or not [62].

The Islamic Medical Association of North America (IMANA) is absolutely opposed to euthanasia and assisted suicide in terminally ill patients by healthcare providers or patients' relatives [27].

All the Fatwas refuse euthanasia and considered it a crime punishable both in this world and the Hereafter. The Laws in Islamic and Arab Countries criminalize euthanasia and the physician participating in it is punished. The consent of the deceased or the action on his repeated plea to end his life reduces the punishment from capital punishment to imprisonment and abrogation of the license of Practice of Medicine [63].

In summary, no one is authorized deliberately to end life, whether one's own or that of another human being. Saving life is encouraged, and reducing suffering with analgesia is however acceptable, even if, in the process, death is hastened. This rule is based on the central teaching that "actions are to be judged by their intentions." Withdrawal of food and drink to hasten death is therefore not allowed and is considered as a murder crime [64, 65].

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