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Ethical Dilemmas at the End of Life: Islamic Perspective

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Abstract Many Muslim patients and families are often reluctant to accept fatal diagnoses and prognoses. Not infrequently, aggressive therapy is sought by the patient or his/her family, to prolong the life of the patient at all costs. A series of searches were conducted of Medline databases published in English between January 2000 and January 2015 with the following Keywords: End-of-life, Ethics and Islam. Islamic law permits the withdrawal of futile treatment, including all kinds of life support, from terminally ill patients leaving death to take its natural course. However, such decision should only take place when the physicians are confident that death is inevitable. All interventions ensuring patient's comfort and dignity should be maintained. This topic is quite challenging for the health care providers of Muslim patients in the Western World.

Keywords End of life · Ethics · Islam · Do not resuscitate · Withholding or withdrawing treatment

Introduction

Muslims make up the world's second-largest religious group with a population of 1.57 billion Muslims, accounting for over 23 % of the world population. The total number of Muslims in the European Union and the USA exceeds 25 million. The number of Muslim physicians is growing in both the UK and the USA with an estimated number of 50,000 in

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the USA alone (Abu-Ras et al. 2012). Physicians treating Muslim patients are often ethically challenged in making decisions at the end-of-life cases, and they seriously search for religious guidance in these matters. This review is intended to discuss the most challenging dilemmas facing health care providers in such scenarios.

Islam considers disease as a natural phenomenon and a type of suffering that expiates patient's sins. Not only the patient who suffers will be rewarded in the hereafter, but also his family who bear with him the ordeal; hence, saving a life and caring for someone is considered one of the highest obligations in Islam. Muslims strongly believe that God is the ultimate healer of any physical and psychological illness. At the same time, Muslims are obligated to seek treatment whenever possible and should not terminate life (Albar 2007).

Until quite recently, families in most Muslim communities used to live together, and their children take care of their parents till they die. With increasing employment of both men and women, family members may live in different locations, and the time devoted to looking after their parents, particularly those with disabilities or chronic illness, is becoming much less. Nowadays, many elderly patients with chronic debilitating illnesses spend their last few weeks or months in hospitals (Al-Bar and Chamsi-Pasha 2015).

The following ethical issues will be discussed in this review:

1. Seeking remedy
2. The concept of futility
3. Do not resuscitate
4. Withholding of life-sustaining treatments

   Deactivation of cardiac devices in terminally ill patients
5. Nutrition at end of life
6. Advance directives
7. Truth telling

Seeking Remedy

Seeking remedy in Islamic jurisprudence may be obligatory (mandatory) in certain life-saving situations or may be preferred or encouraged (*mandoob*) in other situations. It may be facultative or optional and may be (*makrooh*), that is, discouraged, and in some situations or a certain type of treatment it may be (*haram*), that is, not allowed. Seeking remedy is facultative (optional) or (mobah) where the benefit is not proved or even doubtful and where ill effects of that mode of therapy are uncertain. It may be (*makrooh*) when therapy is unlikely to bring benefit and where harm or even inconvenience from the therapy may exceed its benefit. Many companions of the Prophet Muhammad (Peace Be Upon Him) (PBUH) refused therapy in their last illness, as they felt it would be futile, e.g., Abubaker Assidiq-the First Caliph and Muath ibn Jabal (Ibn Taimyiah 1997). The current medical advances made it possible to restore health and sustain the life in situations previously regarded as hopeless cases. This capability brought with it some clinical, moral, legal, cultural and economic issues that challenge the physicians at the end of life.

In general, patients with illnesses expected to improve with intensive measures are admitted to the intensive care unit (ICU). Patients are not admitted to the ICU to die there. However, families of patients in the ICU are faced with several dilemmas related to (a) the justification for "prolonging" the suffering of their loved ones; (b) to what level they

should consume their financial resources in order to keep their loved ones in the ICU; and (c) shall they give their consent to disconnect the ventilator if their patient reaches a terminal stage (Ebrahim 2006a).

When the terminally ill patient is deemed to lack the capacity for decision making, he/she loses the right to autonomy. A substitute decision maker will have to make the necessary decisions. This decision maker might have been designated previously by the patient. If no substitute decision maker has been previously designated, a member of the family could be the decision maker. An intriguing problem arises when there are several family members with different points of view. In principle, the doctors should not be involved in family disputes; the family should be told to discuss among themselves and come back with one unanimous decision. If family consensus fails, some order of precedence among family members can be used based on their respective strengths as inheritors. For example, the decision of the son takes precedence over the decision of the brother. (Hussein et al. 2015).

Futility

The futility of end-of-life treatment can be difficult to define due to several factors such as the effect on the quality and length of life, financial costs, emotional costs and chances of success (Rodriguez and Young 2006). The American Thoracic Society states that treatment should be considered futile if it is highly unlikely that it will result in "meaningful survival" for the patient.

Clinicians have little difficulty in estimating prognosis, although they mostly overestimate survival and are not always accurate about the date of death. Some Muslims strongly believe in God's miraculous cures even if the physicians believe the case is futile or hopeless (Al-Jahdali et al. 2013).

In Saudi Arabia, for example, futile treatment is often requested by relatives (Mobeireek et al. 2008). This is a subject of great dispute, even among Islamic scholars. Many scholars do not advocate treatment if it is to prolong merely the final stages of life. Delaying death with futile or hopeless treatment is unacceptable in Islam.

Fortunately, Muslims believe all healing comes ultimately from God and that no cure is possible without God's will. For Muslims, denying the possibility of a miracle is a sin and may be attributed as an expression of disbelief in God's power. However, this should not obligate Muslims to demand treatment if an expert physician has deemed it of no benefit (Alibhai and Gordon 2004).

Damghi et al. studied 177 patients who died in emergency room in a Moroccan hospital. Withholding and withdrawing life-sustaining treatment was applied to 30.5 % of patients who died. Life-sustaining treatment was withheld or withdrawn from elderly patients with the underlying advanced cardiovascular disease or metastatic cancer or patients with acute stroke. Religious beliefs and the lack of guidelines or official Moroccan law could explain the ethical difficulties faced in the decision-making process in this study (Damghi et al. 2011).

Futile treatments and medical interventions should be considered in light of patients' outcome, and resource utilization in end-stage patients must be carefully observed. For Muslims, treatment can be withheld in the case of a terminal illness such as widespread metastatic cancer. However, reversible illnesses should be normally treated (e.g., pneumonia), whereas terminal manifestations of illness should not (Albar 2007).

A well-known example of futile cases from the USA is the case of a baby, widely referred to as "baby K" who was born in Virginia on October 30, 1992, and had been diagnosed prenatally as having anencephaly. The mother insisted that life support is continued. The physicians believed that ventilatory support was not warranted as the baby would never recover consciousness, and sought legal authority in the federal court to forgo it. "Baby K" continued to receive high-quality medical care and survived for two and a half years before succumbing to an infection (Veatch 2013).

Do Not Resuscitate

Cardiopulmonary resuscitation (CPR) is now routinely performed on any hospitalized patient suffering cardiac or respiratory arrest. The frequent performance of CPR on patients who are terminally ill or who have a remote chance of surviving has raised concerns that these resuscitations were often utilized inappropriately. This lead to the emergence of do not resuscitate (DNR) policy to identify patients who would not benefit from CPR.

Concerns were raised that many patients were kept alive through futile medical therapy. This contributed to further worries about the emotional and financial burdens imposed on the patients and their families. It is evident that these invasive measures may sustain life for a while, but may not confer any genuine benefits to the patient (Jan 2011). Therefore, DNR may be withheld if, in the opinion of the treating team, an attempt to resuscitate the patient would be futile.

The Permanent Committee for Research and Fatwa in Saudi Arabia issued Fatwa (Decree) No. 12086 on 28/3/1409 (1989) based on questions raised on using resuscitative measures:

1. "If a person arrives at the hospital is already dead, there is no need to use any resuscitative measures in such a case.
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, as agreed by three competent specialized physicians, and then there is no need to do any resuscitative measures.
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, there is no need to use resuscitative measures.
4. If the patient is mentally or physically incapacitated and is also suffering from stroke or late stage cancer or having the severe cardiopulmonary disease and already had several cardiac arrests, and the decision not to resuscitate has been reached by three competent specialist physicians, then it is permissible not to resuscitate.
5. If the patient had irremediable brain damage after a cardiac arrest and the condition is authenticated by three competent specialist physicians, then there is no need for the resuscitative measures as they will be useless.
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" (Permanent Committee for Scholarly Research and Ifta 1989).

The medical practice in Saudi Arabia involves the guardians and families in the discussion of DNR. When discussing not using cardiopulmonary resuscitation, 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 health care, 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 health care team members (Code of Ethics for Healthcare Practitioners 2014).

The DNR Form is valid only under when it is signed by three qualified physicians (mainly two consultants and one staff physician) and only acceptable within the hospital during the patient's admission.

The "Fatwa" should be explained to the family. If the family still insists on doing everything possible, then they should be offered the option of transferring their patient to whichever hospital agrees to accept the patient. A clear policy regarding DNR, brain death and end-of-life issues is needed for all health care providers dealing with Muslim patients.

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 other ongoing medical treatments can be continued. IMANA does not believe in prolonging misery on mechanical life support in a patient in a vegetative state, when a team of physicians, including critical care specialists, have determined that no further 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. No attempt should be made to enhance the dying process in patients on life support (IMANA 2005).

Furthermore, the article 63 of the Islamic code of medical ethics issued by the Islamic Organization for Medical Sciences stated 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" (The Islamic Code of Medical Ethics 2004; Kassim and Adeniyi 2010).

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

Physicians' religiosity may affect their approach to end-of-life care beliefs. Saeed et al studied the religious aspects of end-of-life care among 461 Muslim physicians in the US and other countries. Only 66.8 % of the respondents believed that DNR is allowed in Islam. Muslim physicians' beliefs on end-of-life issues were affected more by the place of practice, country of origin and previous experience in talking about this type of care than the religious beliefs (Saeed et al. 2015).

Ur Rahman et al. designed a questionnaire that was sent to members of the Pan Arab Society of Critical Care. The majority of responders were trained in western countries. Admission of DNR patients to the ICU was acceptable for 47.7 % of respondents. DNR was considered equivalent to comfort care by 39.5 %. They concluded that neither the training background nor the level of seniority affects the opinion on most of end-of-life issues in terminally ill patients (Ur Rahman et al. 2013). The need for educating the public at large is an essential part of DNR practice. Poor explanation to the family has often led to family dissatisfaction in most of the cases.

Withholding of Life-Sustaining Treatments

Withholding medical therapy in terminally ill patients has been widely accepted around the world on medical, legal and ethical grounds. Health care providers have to base their judgments on scientific data and to restrict treatment options in case of medical futility (Ur Rahman et al. 2013).

In most Muslims cultures, illness is considered as a family affair, and it is not unusual to see family members requesting not to tell their loved ones about a life-threatening diagnosis or prognosis. They may even want to be the decision makers regarding end-of-life medical decisions and may often request heroic measures for their patients. Unfortunately, this may subject the patients to medical interventions that may be contrary to their wishes and beliefs (Ebrahim 2006a).

The Saudi Ulema 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 (Albar 2007).

Terminally ill Muslim patients are permitted to have life-sustaining treatments withheld or withdrawn when the treatment is deemed by the expert physicians to be futile, does not lead to any improvement in the quality of life, involves significant complications and prolongs the dying process and suffering.

Delaying the inevitable death of a patient is neither in his interest nor in the interest of public's resources. Yazigi et al. from Lebanon expressed concerns that the shift to palliative care was excessively delayed in the course of the patients' illness (Yazigi et al. 2005).

The basic human rights of the patient, including food, water, nursing and painkillers, should be maintained, and this can be done at home or hospice. The patient should be allowed to die peacefully and comfortably. The role of social workers and religious affairs personnel at such stage cannot be overemphasized.

Deactivation of Cardiac Devices in Terminally Ill Patients

At the end of life, most chronic heart failure patients become increasingly symptomatic and may have other life-limiting comorbidities as well. Implantable cardioverter defibrillator (ICD) is the treatment of choice for patients with poor left ventricular function who are at risk of sudden cardiac death due to ventricular arrhythmias. However, patients who have an ICD often denied the chance of sudden cardiac death and instead are exposed to a slower terminal decline, with frequent DC shocks that can be painful, resulting in major distress for the patient and family (Chamsi-Pasha et al. 2014).

When a patient with an ICD approaches the end-of-life stage, discussion concerning the termination of ICD treatment may be indicated. Deactivating an ICD or not performing a generator change is both legal and ethical and is supported by both American and European guidelines. Whether the futile terminal illness is cardiac or noncardiac and the battery reaches its end of life, then it may not be changed, in accordance with The Saudi Ulema Fatwa (Fatwa No. 12086) already mentioned. The patient has the right to refuse any treatment or to withdraw a previous consent to treatment if it no longer satisfies his/her health care goals (Chamsi-Pasha et al. 2014).However, there is disagreement within the medical community on deactivation. Rady et al. consider such an act either patient-assisted

suicide or euthanasia (Rady and Verheijde 2011). In Islam, seeking a remedy is facultative (optional) where the benefit is not proved or even doubtful and where ill effects of that mode of therapy are uncertain. The patient should dictate his/her decision, whether to accept or refuse that modality of treatment (Chamsi-Pasha and Albar 2013).

Nutrition at End of Life

Little data are found in the literature about the religious ethics of withholding and withdrawing nutrition and hydration at the end of life, apart from Jewish and Catholic perspectives (Alsolamy 2014).

The Prophet Muhammad (PBUH) discouraged forcing the sick to take food or drink. However, Muslim families tend to express major concern when the nutritional intake of their patient has deteriorated. Some families may demand a kind of intervention to compensate for this decrease in nutritional intake. Referring them to the teachings of the Prophet (PBUH) on this matter may alleviate their concerns.

In Islam, nutritional support is considered basic care and not medical treatment; hence, it is a duty to feed people who are no longer capable of feeding themselves. Islamic law, therefore, does not allow the withholding or withdrawal of basic nutrition because this would lead to death by starvation, which is a crime in Islamic teachings (Alibhai 2008).

The IMANA states that: When death becomes inevitable, as determined by a team of physicians, the patient should be allowed to die without unnecessary procedures. However, no attempt should be made to withhold nutrition and hydration (IMANA 2005).

Advance Directives

There are two types of advance directives: a living will (Advance directive) and a durable or medical power of attorney. Advance directives are legal documents which dictate future health care choices and inform both the health care professionals and family members about an individual's wishes and the type of care to receive in case they cannot express themselves. This document helps the attending physician to withhold or withdraw certain medical procedures and allow the patient to die naturally. Living will cannot form part of the (wasiyyah) since what is incorporated in the (wasiyyah) will be executed only after one's demise.

In the durable power of attorney, patients unable to make health care decisions can call upon an authorized representative to express his or her wishes, and thus make treatment decisions on behalf of their best interest (Babgi 2009).

The concept of advance directives is very well known and even practiced by the Prophet Muhammad (PBUH) himself. As narrated by Al-Bukhari, the Prophet, in his terminal illness, used a certain notion that would conform to the concept of advance directive. He asked his wives, when he was terminally ill, not to pour medicament in the side of his mouth (Ladood), should he become unconscious, but his wives did. When he came around, he scorned them and asked them to do the same for themselves (AlBukhari 1958). This Hadith points out to the following issues: (a) that the Muslims are allowed not to take treatment, particularly when they have an incurable illness, (b) individuals taking care of the patient are not permitted to force him to take certain treatment, particularly if expressed

his wish regarding this type of therapy, and (c) these people are accountable for their action (Al-Jahdali et al. 2013).

A very few studies were published about the prevalence of using advance directives by Muslim patients. Tayeb et al. found that the majority of participants interviewed (284 Muslims), including health care providers, were not aware of such concept. However, when the concept was explained to them, the majority of participants advocated the issue of advance directives (Tayeb et al. 2010).

Advance directives are permitted for Muslims provided that none of the clauses contradict the broad teaching of the Qur'an and the Sunnah (Ebrahim 2006b). This may also include instruction (wakalah) of appointing an attorney (wakeel) to make a decision in case he or she is not able to do so.

A prototype of an Islamic living will has been developed by the Ethics Committee of the Islamic Medical Association of North America (IMANA 2005). In fact, an advance directive should not only be limited to elderly patients, but should be also advocated among patients with chronic disabling disease irrespective of their age, social, cultural or economic status.

It is mandatory for hospitals to create policy to solve any conflict between physicians and patients' families. Such policy should take into account the prevailing religious, societal, and cultural beliefs and attitudes of the patients.

Truth Telling

One of the ethical dilemmas clinicians face concerns informing patients about their terminal illness or an incurable disease that is reasonably expected to result in death within a relatively short period. Disclosure of such information to the patient can be considered harmful by the physician and/or patient's family. On the other hand, not telling the patient the truth or revealing it to the family without his/her permission infringes on patient's rights of autonomy and confidentiality (de Pentheny O'Kelly et al. 2011).

Although truth telling is a principal rule in Western medicine, it is not a globally shared moral attitude. In many cultures, hiding the truth is common practice, and the family may become the focus of decision-making process. Consequently, the physicians would respect the "autonomy of the family as a unit" (Chamsi-Pasha and Albar 2013; Chattopadhyay and Simon 2008). Following the discussion with the treating physician, the family usually decides whether telling the truth to their patient is in his best interests or not. Occasionally, both the patient and his/her family know that the patient is dying, but each pretends that the other does not know the real facts (Zahedi 2011).

The truth is often hidden because of the fear that it will put an end to the patient's hopes, leading to despondency, mental torment, physical suffering and possibly an accelerated death (Mobeireek et al. 2008). In some instances, discussing the likelihood of death is considered disrespectful to their religion and their belief in God's power.

Some Islamic authorities state that if the doctor finds that the patient has cancer, for example, the doctor should tell the patient the truth and should not lie. If the doctor believes that the patient will be harmed by telling the truth, then he/she may tell the close relatives to choose the right approach to disclose the diagnosis. If they were unable to do that, they might ask the patient about his/her debts, and other obligations, and encourage him/her to do good deeds or charity (Al-Shangeeti 1994).

There is no contradiction between reassuring the patient and telling him/her about his/her condition, even if it is serious and fatal. It is the right of the patient to know his/her health condition, illness, symptoms and prognosis in general terms. If the patient requires more details, he/she should be answered with that [request]. Informing the patient is the duty of the treating doctor and should not be left to doctors more junior to him/her, especially if these doctors do not have sufficient experience (Code of Ethics for Healthcare Practitioners 2014).

Patients and their families, who favor concealment of the truth, often demand futile heroic treatment. This may create a dilemma for the physician who has to decide between respecting the patient's (or their family's) autonomy, not inflicting harm caused by the side effects of the treatment, and the justice of fair distribution of the limited resources (de Pentheny O'Kelly et al. 2011).

Abdulhameed studied the codes of medical ethics regarding disclosure of terminal illness in 14 Islamic countries. In general, the codes were more for a paternalistic/utilitarian, family-centered approach than an autonomous, patient-centered approach. The codes were remarkably different among these countries. Five codes were silent concerning informing the patient; seven permitted concealment; one prohibited disclosure; and one made truth telling mandatory. Five codes were also silent concerning informing the family, four permitted disclosure, and five recommended or mandated disclosure to the patient's family (Abdulhameed et al. 2011).

Conclusion

Many dying Muslim patients suffer protracted and painful deaths, receiving unnecessary, invasive and costly care, which may create a strong impact on their physical, psychosocial and spiritual integrity. In Islam, the sanctity of human life is extremely valued, but life support is not required if it prolongs the agony and suffering associated with final stages of a terminal illness. Islamic law permits withdrawal of futile treatment and considers it a clear medical decision by at least three physicians. The removal of basic necessities of life such as food and water will amount to actively killing the patient.

Compliance with Ethical Standards

Conflict of interest None.

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