Review articles:

Withdrawing or Withholding Treatment

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Abstract

Muslims believe that all healing comes from God, so they have the obligation to search out medical care and right to receive appropriate medical treatment. Islam considers disease as a natural phenomenon and a type of tribulation that expiates sin. Unfortunately many elder patients with chronic illness spend their last few weeks or months in hospitals. Life support is not required if it prolongs the agony and suffering associated with final stages of a terminal illness. The decision to withhold life support from a patient in the intensive care unit (ICU) is a modern medico-legal issue. When considering end-of-life decision making, both withholding and withdrawing life support are considered to be ethically and legally equivalent. Islamic law permits withdrawal of futile treatment on the basis a clear medical decision by at least three Physicians.

Keywords: Withdrawing treatment, withholding treatment, do-not-resuscitate, medical ethics,Islam, ICD deactivation.

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Introduction

The tremendous technological advances of modern medicine have increased physicians' capability to carry out a wide spectrum of clinical interventions near the end-of-life. These new procedures have led to new "types" of living where a patient's cognitive functions are severely impaired while many physiological functions remain active. Patients, surrogate decision-makers, and physicians all struggle with decisions about what clinical interventions to pursue and when therapeutic intent should be replaced with palliative care.Some countries have an established legal framework for withholding and withdrawing treatment with widely accepted standards for both competent and incompetent patients, but many developed countries do not.[1-5]

Not only the patient who suffers in dignity will be rewarded in the hereafter, but also his family who bear with him the ordeal.[6] Muslims therefore believe that illness is a test of person's faith in God, and saving a life and caring for someone is considered one of the highest imperatives in Islam. The Quran says: "Because of that, we decreed upon the Children of Israel that whoever kills a soul - unless for a soul or for corruption done in the land - it is as if he had slain the entire mankind. And whoever saves one - it is as if he had saved the entire mankind.[7]

Death is inevitable and occurs only with a command from God. Muslims also believe that God is the ultimate healer of any physical and psychological illness. At the same time, Muslims are obligated to seek treatment, and should not terminate life.

Patient's religious affiliation constitutes a key component in medical decision making. This is particularly pertinent in issues involving end-of-life decisions such as withdrawing and withholding treatment, medical futility, nutritional feeding and do-not-resuscitate (DNR) orders. These issues affect not only the patient's values and beliefs, but also the family unit and members of the medical profession.[8]

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) (*Mobah*) , or it may be (*Makrooh*)

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i.e. not preferred or discouraged. In some situations and with certain types of treatment it may be prohibited (*Haram*).

Seeking remedy may not be preferred (*Makrooh*), when therapy is unlikely to bring benefit, where harm or even inconvenience from therapy may exceed its benefit, and in end-of-life cases. Many companions of the Prophet Muhammad ﷺrefused therapy in their last illness, as they felt it would be futile e.g. *Abubakr al-Sidiq*-the first caliph, and *Muath ibn Jabal*.6Seeking remedy is facultative (optional) or (*mobah*) where the benefit is not proved or evendoubtful 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 thetherapy may exceed its benefit.

The dominant position in the *Hanafī*, *Malikī*and *Hanbalī* schools is that seeking medical treatment ispermissible but not obligatory, while *Shafiʿī* jurists holdseeking medical treatment to be a recommended act. All ofthe four schools of Sunni law regard that leaving medicaltreatment becomes sinful under exceptional circumstancesand in the minority of cases. *Hanafī* jurists consider forgoingmedical treatment even if this non-action results indeath does not carry the weight of sin, while *Shafiʿī* and*Malikī* authorities suggest that Muslims would be consideredsinning should they not seek medical treatmentwhen the malady is treatable and will cause death if not treated.[6,9]

The Prophet Muhammad ﷺ(Peace Be upon Him) said: "Seventy Thousands would enter paradise without being questioned. When asked who are they? He said: "those who refused *Ruqia* (Incantation) and treatment" (Sahih Al-Bukhari). He also praised the lady who agreed not to be treated for epilepsy and told if she remains patient she will enter paradise (*Sahih al-Bukhari*).These two Hadiths do not contradict the Prophet hadith stating: "Verily, Allah sent down the disease and the cure, and for every disease he made a cure. Seek treatment, but do not seek treatment by the unlawful."(Sunan Abī Dāwūd 3874) for the following reasons:

1. As a general rule, if a person has an ailment, he should be treated. However, some people want to have "Rukaya" in advance, as a form of protection of possible disease in the future, which is Islamically acceptable. Others refuse to have such "Rukaya" to prevent a possible disease in future. These are the seventy thousands people mentioned in the Hadith.
2. Certain groups of people have strong belief in God, and they refuse to expose themselves to any kind of physical treatment. They consider trust in Allah (Twakkul) as a real treatment.[10]
3. At the end of life, and when treatment is considered futile, patients have the right to refuse such a futile treatment.
4. As for the lady with epilepsy, there was no available treatment for this illness at that time.

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

Generally, patients whose conditions are expected to improve with intensive care measures are admitted to the intensive care unit (ICU). In other words, patients are not admitted to the ICU to die. However, families of patients in the ICU are agonized with several dilemmas. Some of these dilemmas related to: (a) the justification for "prolonging" the suffering of their loved ones; (b) to what extent they should exhaust 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 patient is diagnosed to be brain dead; and (d) the validity for seeking extraordinary therapeutic measures for their patient when the prognosis is poor.[11] Terminally ill patients may consume significant resources, including nursing care, and medications. Spiritual care is not necessarily religious, but religious care should always be spiritual.

The Family Role

Until recently, families in Muslim countries used to live together, children taking care of their parents until they die. Now, in affluent Muslims countries and with increasing employment of men and women, family members may live in different cities, or different locations and the time devoted to take care of parents particularly with disabilities or chronic illness is less. Increasingly and unfortunately many elder patients with chronic illness spend their last few weeks or months in hospitals.[12]In most of Muslims cultures, illness is considered as awhole-family affair, and it is not unusual that the familymembers prefer that their patient is not informedabout a life threatening diagnosis or prognosis. They mayeven demand to be the decision makers regarding end of life medical decisions, intubation and ventilation, cardiopulmonary resuscitation (CPR), admission

to ICU and may often request heroic measures for their patients. Unfortunately, this may subjectthe patients to medical interventions and procedures that may be contrary totheir wishes or preferences.[12]

The ethics of a number of Asian and Eastern countries require that any fatal diagnosis or prognosis to first be disclosed to a family member. Following discussion with the treating physician, the family judge whether communicating the truth is in the best interests of the patient. The truth is often concealed for fear that it will extinguish the patient's hopes, leading to desperation, physical suffering, anxiety and a hastened death.Most families then tend to withhold crucial information that—in their best of knowledge—might lead to psychological suffering of their loved ones. It is narrated by Ibn Majah that the prophet PBUH said: "When you enter upon one who is sick, cheer him up and give him hope of a long life, for that does not change anything (of the Divine Decree), but it will cheer the heart of the one who is sick."

It is acceptable in Islam that the physician can withhold information from the patient if he has good reason that divulging the information to that patient is going to cause great harm, 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).[5]

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 thenecessary decisions. This decision maker might have been designated previously by thepatient. If no substitute decision maker has been previously designated, a member of thefamily (next of kin) could be the decision maker. An intriguing problem arises when there are severalfamily members with different points of view. In principle, the doctors should not beinvolved in family disputes; the family should be told to discuss among themselves andcome 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.[2] This is agreed upon by Muslim Jurists in the Islamic Jurisprudence as"Rules of Guardians" (أحكام الولايةوالوصاية)

Withdrawal of life-sustaining treatments

Withholding medical therapy in terminallyill patients is now been widely accepted around the world on medical, legal, ethical, and moral grounds. Critical care physicians and other health care providers have to base their recommendations on scientific data and to limit treatment in case of medical futility.[13]A Questionnaire study conducted on 847 ICU physicians in 10 low-middle-income countries and 618 physicians from ICUs in six high-income countries showed that physicians from low-middle-income countries were less likely to limit cardiopulmonary resuscitation, mechanical ventilation, vasopressors and inotropes, tracheostomy and hemodialysis than those from high-income countries. They were more likely to involve families in end-of-life care discussions and to perceive legal risks with limitation of life-sustaining treatments and DNR orders.[14]

Withholding or withdrawing life support is still an area of controversy. Its applicability is weighed with benefits and risks and how futile the treatment is for the terminally ill patient.Withdrawing and withholding treatment can be "voluntary", where the conscious patient authorizes it, or if unconscious, the patient had expressed to his next of kin that he would prefer not to be kept alive on life support. It can also be "non-voluntary", where the decision to withdraw life support is made by the family of the patient, provided that it is suggested by the treating team.

Issues arising from the withdrawal and withholding treatment have not reached total consensus amongst the Muslim jurists. However, the article 62 of the Islamic code of medical ethics (Code of Conduct1981) 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 stated that "treatment of patients whose condition has been confirmed to be useless by the medical committee should not be commenced."[15]

The Saudi *Ulema's 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.[5,16]

Terminally ill Muslim patients are permitted to have life-sustaining treatments withheld or

withdrawn when 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 .[16]In Saudi Arabia, for example, futile treatment is often requested by relatives.[17]A study from Lebanon, looking at withholding and withdrawal of treatment in an intensive care unit, highlighted concerns that the shift of focus to palliative care was taking place inappropriately late in the course of the patients' illnesses.[18]Delaying the inevitable death of a patient is neither in the patient's nor in the public's limited resources best interests. Western trained physicians have more exposure to medico-legal aspects and interpretation of these different medical terms to limit therapy. Further awareness and education is needed among Middle Eastern trained physicians to clarify the difference between of DNR/no code and comfort care.

The basic human rights of the patient, which include food, water, 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. Social workers and religious affairs personnel will be needed for the social and religious requirements of the patient and his family.[5,16]

Health-care professionals need to be clear about the law and ethics of death and dying, as well as practice standards developed by their local regulatory body to prevent potential errors.

Deactivation of Cardiac Devices

At the end of life, the chronic heart failure patient often becomes 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 may be denied the chance of a sudden cardiac death, andinstead are committed to a slower terminal decline, with frequent DC shocks that can be painful and reduce the quality of life of the patients , contributing to major distress for the patient and family.

When a patient with an ICD approaches the end of life, discussion with regard to ending ICD treatment may be indicated. ICDs can create an extra burden for patients, particularly from inappropriate discharges and prevention of a rapid death.

Deactivating an ICD or not performing a generator change is both legal and ethical, and is supported by both American and European guidelines. The respect for autonomy and individual personhood support a patient's right to dictate decisions about their treatment, and detailed informed consent to a procedure is a fundamental right. The patient has the right to refuse any treatment or to withdraw a previous consent to a treatment if it no longer satisfies his health care goals or if the perceived hardship of such treatment outweighs its perceived benefits.[19]

There is disagreement within the medical community with respect to deactivation.[20]*Rady* et al. consider such an act either patient-assisted suicide or euthanasia.[20]The American Heart Rhythm Society clearly affirms that "carrying out a request to withdraw life-sustaining treatment is neither physician-assisted suicide (PAS) nor euthanasia" and that "the right to refuse or request the withdrawal of a treatment is a personal right of the patient and does not depend on the type of the treatment."

Management of ICDs and Cardiac Resynchronization Therapy-Defibrillator (CRT-D) as patients near the end of their lives creates ethical dilemmas. Decisions about deactivation of implantable cardioverter defibrillators (ICDs) are complicated. Unilateral DNR orders (against patient/family wishes) have been ethically justified in cases of medical futility. Unilateral deactivation of ICDs may be seen as a logical extension of a unilateral DNR order. Few patients consider device deactivation at end-of-life, although a large majority believes that unilateral deactivation is not ethical/moral, even in the setting of medical futility. Advance care planning for these patients should address device deactivation.[21]

Left ventricular assist devices (LVADs) were initially used as bridge in patients awaiting heart transplantation, but they are currently implanted as destination therapy (DT) in patients with end-stage heart failure, who have failed to respond to optimal medical therapy, and who are ineligiblefor cardiac transplantation.

For heart failure patients at the end of their lives, continued circulatory support by an LVAD may become undesirable. Consensus is being developed within the transplant ethics community that deactivation of a LVAD is appropriate. Grounds for ethical permissibility are usually based on the well-established ethical and legal consensus that competent, informed patients (or their surrogates) have the right to request the withdrawal of any life-sustaining intervention they perceive as

excessively onerous relative to benefits.[22]Some ethicists, however, remain opposed to device deactivation in many circumstances.[23]

End-of-life care practice and decision making should be grounded in clinically trustworthy guidelines rather than opinions that are short of scientific validation and potentially cause more harm than benefit to LVAD patients.Although the technical, emotional, and psychological aspects of turning off or removing these devices are challenging, these aspects of care should not confuse the ethical considerations for how best to manage these devices at the end of life.[5]

In Islam, seeking remedy is facultative (optional) where benefit is not proved or even doubtful and where ill effects of that mode of therapy are uncertain. The person should have autonomy and decide for himself, whether to accept or refuse that modality of treatment.[6]

Conclusion

Although Muslims believe that all healing comes ultimately from God, they have a duty to seek out medical attention when ill and a right to receive appropriate medical care. The patients'and their families' trust in God may therefore deter some of themfrom making decisions about withdrawal of life-sustaining therapy. Many dying patients suffer prolonged and painful deaths, receiving unwarranted, invasive and expensive care, which affects their physical, psychosocial and spiritual integrity. In Islam, the sanctity of human life is paramount, but life support is not required if it prolongs the final stages of a terminal illness. Islamic law permits withdrawal of futile treatment on the basis of the consent of the immediate family members who act upon the professional advice of the physician in charge or, as the Saudi *Fatwa* implies, it should be a clear medical decision by at least three Physicians. Muslim jurists also recognize the patient's right of refusal of futile treatment.The removal of basic necessities of life such as food and water will amount to actively killing the patient. The 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 a medical intervention to compensate for this decreased nutritional intake. Reference to the teachings of the Prophet (PBUH) on this matter may alleviate the concerns of families. Ibn Qayyim al-Jawziyya in his book of "Tibi Nabawi" states that forcing a patient to have feeding is sometimes mandatory, particularly in cases of mental disturbances, confusion or unconsciousness.[24] (For further details, please refer to our chapter "Artificial nutrition and hydration")

Anything short of aggressive resuscitative measures will be applied to ease pain and relieve symptoms.

Explaining the truth about diagnosis, prognosis and treatment options generates the basis for freedom of the individual's choice. However, in serious illness, Muslim family members are usually closely connected, and the family often decide whether and how much to tell the patient.

Many believe medically, legally, morally, and ethically there is no difference between withholding and withdrawing life-sustaining treatment. Withholding a treatment may seem more acceptable to healthcare professionals, patients, and their families.

There is a need for the medical profession to be guided on the ethical obligations, legal demands and religious expectations prior to handling difficult end-of-life decisions. The development of comprehensive ethical codes in congruence with developing legal standards may offer clear guidance to the medical profession in making sound medical decisions.

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