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REVIEW ARTICLE

Advance medical directives: a proposed new approach and terminology from an Islamic perspective

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Abstract Advance directives are specific competent consumers' wishes about future medical plans in the event that they become incompetent. Awareness of a patient's autonomy particularly, in relation to their right to refuse or withdraw treatment, a right for the patient to die from natural causes and interest in end of life issues were among the main reasons for developing and legalizing advance medical directives in developed countries. However, in many circumstances cultural and religious aspects are among many factors that can hamper implementation of advance directives. Islam and Muslims in general have a good understanding of death and dying. Islam allows the withholding or withdrawal of treatments in some cases where the intervention is considered futile. However, there is lack of literature and debate about such issues from an Islamic point of view. This article provides the Islamic perspective with regards to advance medical directive with the hope that it will generate more thoughts and evoke further discussion on this important topic.

Keywords Living will · Advance medical directives · Muslims · Islam

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Introduction

Medical advances and availability of mechanical ventilation in early 1960s created ethical dilemmas of keeping many patients with chronic incurable diseases alive, who otherwise would die at home or in hospital. These patients would be attached to artificial machines in the ICU for a long time with all the anticipated secondary complications and cost. Furthermore, by 1960s cardiopulmonary resuscitation (CPR) was spearheaded by the American Heart Association in many parts of the USA and globally and considered as the standard of care when a patient had no pulse or respiration (Association Ah 2009). But the health care providers soon realized that CPR was not appropriate for every patient leading to the subsequent emergence of Do Not Resuscitate (DNR) policy to identify patients who would not benefit from CPR (Brown 2003). Decisions on CPR and DNR were often initiated by physicians without inputs from the patient or his or her family (Brown 2003).

Awareness and emphasis of patient autonomy particularly, in relation to their right to refuse or withdraw treatment, a right to die from natural causes and interest in end of life issues also began at the same time (Brown 2003). The combination of all these factors raised concerns that many patients were being kept alive indefinitely through unwanted or futile medical treatment and with concomitant rising concerns about patients and family emotional and financial burdens. On the basis of respect for a patient's

autonomy, a law professor, Luis Kutner, proposed in 1969 to use a living will which is a legal document made by an individual determining the course of medical treatment in case he or she becomes unable to make a decision on his or her own (Levine 2004).

In 1976, Karen Ann Quinlan became an important person in the history of the right to die controversy in the United States. She was left in a permanent unconsciousness after CPR. Her parents requested the removal of the ventilator and after a lengthy court battle the request was finally granted. In 1976, following the Quinlan case, California enacted the nation's first law approving the use of living wills and soon thereafter nearly every state in the United States followed this precedent (Levine 2004). This also created problem in at least two areas namely that it was difficult to anticipate all possible future medical crises and in some cases the directive was unrealistic or ambiguous. This led to the President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research in 1983 to recommend an alternative approach. Rather than signing a document that specified certain treatments that should be forgone, patients were encouraged to name a person who would make health care decisions on their behalf (Levine 2004). Another landmark case from USA involved Ms. Nancy Cruzan, who was in a persistent vegetative status. In 1983, Ms. Cruzan's family wanted her feeding tube to be withdrawn, but the court refused the request because Ms Cruzan did not have any form of advance directive. However, in 1990, after witnesses provided evidence of Ms Cruzan's previously expressed healthcare preferences, the court ordered that her feeding tube be removed and she died. In response to concerns raised during these court cases, the United States Congress enacted the Patient Self Determination Act (PSDA) in 1991. The PSDA requires "hospitals and all other healthcare organizations receiving federal funding to inform patients, upon their admission, of their right under state law to make decisions about their medical care, including drawing up an advance directive" (Bioethics TIcf 2007). This important federal law confirms the right of each individual to indicate what kind of care he or she wishes at the end of life or to appoint a spokesperson to make health care decisions when and if the patient looses the capacity to make a decision (Brown 2003; Bioethics TIcf 2007). Similar specific legislations for advance directives were implemented in other developed countries (Bioethics TIcf 2007; Mental Capacity Act 2005 2010; Association BM 2009).

Ethical issues with advance directives and patient preferences

Advance care planning reflects respect for patient consent regarding preferred medical intervention when the patient becomes sick and is no longer able to discuss their treatment options with physicians. It also reflects respect for the patient's self determination and autonomy. Respect of the patient's self determination and autonomy also extends to the patient's respect of his/her religious belief principles and practices. The patient's advance care planning also preserves the patient's dignity and what he or she believes to be in his/her best interest while still mentally competent.

In order to enable the patient to make the right and the appropriate decision he or she should be informed fully, honestly and openly by the treating medical team. The team should balance the benefits and the harms of such information at the same time (Bioethics TIcf 2007). Some argue that respecting autonomy is so important in advance directives that the health care provider should abide by the patient's wishes in all circumstances (Levi and Green 2010). However, this argument is not always valid; especially if the patient or his or her surrogate requests a procedure or a therapeutic intervention which, to the best clinical judgment is futile or even harmful (Levi and Green 2010; Dawson and Wrigley 2010). It is very important for health care professional to know when to say "enough is enough" in some cases of end-of-life treatment. It is very important to understand that advance directives do not equate to legal imposition on health professional to follow a special treatment option or decision. However, they should be regarded as important and relevant guides about the patient's background and values that should be respected as long as it did not interfere with the physician's best clinical judgments (Dawson and Wrigley 2010). Hospitals should have policy in place to solve any conflict between physician and patients' families. Such policy should take into account prevailing, societal, religious and cultural beliefs and attitudes.

Implementation of advance directive in practice

The majority of patients suffering from chronic diseases or serious medical conditions prefer to decide and express in advance their preferred medical interventions and their views about the use of life-sustaining care interventions (Emanuel et al. 1991; Edinger and Smucker 1992; Gates et al. 1993; Kelner et al. 1993). Studies from USA and Europe revealed that patients usually prefer to discuss advance directives early in the patient-physician relationship. Such discussions are to be introduced in the outpatient clinics though; this varies according to background ethnicity and culture (Edinger and Smucker 1992; Kelner et al. 1993; Finucane et al. 1988; Johnston et al. 1995; Gamble et al. 1991; Pfeifer et al. 1994; Shmerling et al. 1988; Hines et al. 1999; Emanuel et al. 2004).

Decision to withhold or withdraw life-support in cases with limited therapeutic intervention and futility occurred in approximately 65–90% of the cases (Prendergast et al. 1998; Vincent 2001; Prendergast and Luce 1997). Contrary to common beliefs by physicians, it is very well documented by numerous studies that patients often discuss end of life issues with their families but rarely with their treating health care professionals (Hines et al. 1999; Bradley et al. 2010; Morrison et al. 1994; Davidson et al. 1989; Pollack et al. 2010; Go et al. 2007). Several studies reported that discussions of physicians with hospitalized patients about CPR and ICU admission preferences occur infrequently or late and have variable content (Finucane et al. 1988; Johnston et al. 1995; Shmerling et al. 1988; Weiner and Roth 2006; Blackhall et al. 1989).

In practice it also true that many physicians avoid bringing issues of advance directive or seeking patients' opinion about what they want from their physician to do or what are their preferred medical interventions in case they become seriously sick. Physicians may find discussions about death, dying, or advance directives with patients or their families stressful for them and for the patients. Some believe that such discussions might lower the patient's self esteem or eliminate patient's hopes (Emanuel et al. 2004). Another problem is that treating physicians may have inadequate determination of the overall prognosis of the patients which may hinder end of life discussions (Weiner and Roth 2006). Moreover, some families consider the discussion about the seriousness of an illness or the patients preference regarding dying or death as disrespectful and may feel that this may induce hopelessness and provoke depression or anxiety (Searight and Gafford 2005). However, it has been shown also that using structured interviews on these topics is rarely stressful and frequently very helpful (Emanuel et al. 2004; Winzelberg et al. 2005). One of the limitations of advance directives is that some people may not be able to predict or envisage what are the exact medical problems they may encounter or what the exact medical decision is that they have to make in the future. In fact most ordinary people do not have a good understanding or the skills to make decision about end of life medical care (Levi and Green 2010; Dawson and Wrigley 2010). Other practical limitations with implementation of advance directive are proper communication, content of advance directives, and agreement of health care professionals or family members about the exact meaning or understanding of special requests or wishes (Levi and Green 2010). Although there are unresolved controversies and problems with implementation of advance directives, what is important to bear in mind is that advance directives should be viewed as simple aids to the health care professionals and proxies to formulate best interests judgment for end of life care to an incapacitated patient (Dawson and Wrigley 2010).

In most of Muslims cultures, illness is considered as a whole-family affair and it is not unusual that the family members prefer that the patient is not directly informed about a life threatening diagnosis or prognosis. They may even demand to be the decision makers regarding end of life medical decisions, intubation and ventilation, cardiopulmonary resuscitation (CPR), admission to intensive care units (ICU) and often request heroic interventions on behalf of their loved ones. This, unfortunately, may subject the patients to medical measures that may be contrary to their wishes or preferences.

Islamic perspective regarding death, dying and seeking remedy

Muslims believe in "Qadar" or fate as determined by God. Koran confirms that all suffering and death is determined by the will of God.

"مَا أَصَابَ مِن مُّصِيبَةٍ فِي الْأَرْضِ وَلَا فِي أَنفُسِكُمْ إِلَّا فِي كِتَابٍ مِّن قَبْلِ أَن نَّبْرَأَهَا ۚ إِنَّ ذَٰلِكَ عَلَى اللَّـهِ يَسِيرٌ "

> No calamity befalls on the earth or in your selves but it is inscribed in the Book of Decrees before We bring it into existence. Verily, that is easy for Allâh (God) (Koran 57.22).

Muslims, therefore accept sickness as God's will and they believe this is to test their fortitude and favorable reception of the will of God.

"وَلَنَبْلُوَنَّكُم بِشَيْءٍ مِّنَ الْخَوْفِ وَالْجُوعِ وَنَقْصٍ مِّنَ الْأَمْوَالِ وَالْأَنفُسِ وَالثَّمَرَاتِ ۗ وَبَشِّرِ الصَّابِرِينَ (155)الَّذِينَ إِذَا أَصَابَتْهُم مُّصِيبَةٌ قَالُوا إِنَّا لِلَّـهِ وَإِنَّا إِلَيْهِ رَاجِعُونَ) سورة البقره"(156)

> And certainly, We shall test you with something of fear, hunger, loss of wealth, lives and fruits, but give glad tidings to the patient (Koran 2.155).
> Who, when afflicted with calamity, say: "Truly! To Allâh (God) we belong and truly, to Him we shall return" (Koran 2.156).

However, at the same time, Islam teaches Muslims that they should seek remedies for their illnesses. In a Hadith narrated by Abu Huraira—the Prophet's companion, the Prophet said: "There is no disease that Allah has created, except that He also has created its treatment" (Translation of Sahih Bukhari. medicine 2011)

Islamic jurisprudence divides the issue of seeking remedy into three categories (Albar 2007):

Obligatory "mandatory" seeking of therapy. This would include having a treatable and curable disease, life saving conditions and communicable disease that may be harmful to others. Examples of such conditions are acute gastrointestinal bleeding, acute infection, diabetes, hypertension,

or pulmonary tuberculosis. In these situations seeking remedy is mandatory.

Optional "facultative" seeking of therapy when it is up to the patient to seek or not seek treatment. This would include situations in which the overall benefit is not very proven, experimental or may extend life at the cost of quality for example some neuromuscular diseases or muscular dystrophy or Alzheimer disease.

Abstinence from seeking therapy; when it is preferred not to seek therapy. This would include situations in which therapy is futile and may be even harmful as in terminal cancer cases or multi-organ failures (Albar 2007). Abstaining is, holding therapy or not to offer therapy in terminal cases or when judged by experiences physicians that the remedy is futile. This is the preferred option by Islamic law.

Islamic teachings permit the physician to withhold treatment or if the treatment is believed to be futile, useless or harmful. Prophet–peace be upon him (PBUH) said "There is no injury nor return of injury." (Muwatta ToMs 2011) Meaning "above all do no harm" (Albar 2007).

Despite these clear Islamic teachings some Muslims believe in the reward they would be getting from being forbearing of the disease and suffering. They consider being patient with their illness as being an atonement which expiates sins. In these circumstances they may request from the physician to continue treatment even in futile cases. Some Muslims strongly believe in God's miraculous cures and that it is within God's power (hands) to heal and cure even if the medical professions believe the case is futile or hopeless.

There are limited studies about the concept of advance directives and the prevalence of using advance directives by Muslim patients and the factors which influence their decisions. Recently Tayeb et al. published a study about Muslims perspective of a good death. They found that the majority of participants interviewed, including health care providers, are not aware of the advance directive concept. However, when the concept is explained as "the right to refuse any therapeutic intervention", the majority of the participants preferred to issue advance directives and plans of "good death" (Tayeb et al. 2010). In Tayeb et al. study, the majority of the patient wanted to have control on the timing and place of their deaths, control over what is happening, need for privacy, dignity and spiritual and emotional support. They prefer to be able to say goodbye to the loved ones (Tayeb et al. 2010). This study supports the idea that although health care professionals and health care systems do not discus or encourage advance directives on cultural and religious grounds, the patients, on the other hand, would be willing to get involved in such discussions around advanced directives. Another study about advance care planning preferences among dialysis patients and factors influencing their decisions revealed that the majority of the patients with advance medical conditions want to be involved in making their own decisions regarding their preferred medical interventions or life sustaining measures when the time comes (Al-Jahdali et al. 2009; Baharoon et al. 2010).

Islamic perspective of advance directives and definition of the will and living will

A living will as defined in the literature is: "the expression living will indicates a declaration made by a person in possession of his mental faculties, in which he or she specifies the limits which he or she wants to be treated within in the event of being in an extremely critical condition without possible recovery" (Atighetchi 2007). However, a will in Islamic law is different.

"Al-wasiyah" (**the will**) is well known term in Islam that indicates the last wishes of the person before his death. All Muslims are strongly encouraged to document their living will "al wasiyah" before death. The will gives detailed instruction on inheritance, guardianship and burial issues. The will becomes effective only after death of the testate. The regulation of wills or "al-wasiyah" is present in the Koran and "Sunnah".

"كُتِبَ عَلَيْكُمْ إِذَا حَضَرَ أَحَدَكُمُ الْمَوْتُ إِنْ تَرَكَ خَيْرًا الْوَصِيَّةُ لِلْوَالِدَيْنِ وَالأَقْرَبِينَ حَقًّا عَلَى الْمُتَّقِينَ" .صورة البقره اية 180 صفحة

> If one of you facing death can leave a legacy, he should bequeath "leave" it to his parents and relatives, according to the law. This is the duty of the pious (Koran 2.180).

قال رسول الله صلى الله عليه وسلم: ما حق امرى مسلم له شي يوصي فيه يبيت ليلتين الا ووصيته مكتوبة عنده (.البخاري)

> The Prophet (PBUH) said: "It is not permissible for any Muslim who has something to will to stay for two nights without having his last will and testament written and kept ready with him (Translation of Sahih Bukhari. Wills and Testaments 2012)".

Traditionally, most Muslims would wish to die at home (Sheikh 1998). They prefer to be surrounded by their families and loved one, wish to be reminded to say "shahadah" (testimony of faith). The phrase "there is no God but one God (Allah), and Mohammad is his messenger" to face Makah at the time of death if possible, and to get spiritual comfort from hearing the Quran recited (Tayeb et al. 2010). However, recently this practice has changed in most affluent Islamic countries, where most of the patients now die in the hospitals. In most of the cases when a patient is admitted to the hospital, he or she would be

restricted to limited visiting hours by the relatives and he or she may need to be admitted to intensive care and even rendered unconscious to allow for intubation and ventilation thus depriving him or her from end of life needs described above. The practice of advance medical directives as implemented in the West is not adopted or followed by Muslims except possibly by those living in western countries.

The concept of a life not worth living is unacceptable concept in Muslims beliefs; suicide and euthanasia are strictly forbidden by Islamic law. God said

"وَلَا تَقْتُلُوا النَّفْسَ الَّتِي حَرَّمَ اللَّـهُ إِلَّا بِالْحَقِّ"

"Do not kill the soul which Allah prevented except in righteous situation" (Koran 17:33) Also God said:

مِنْ أَجْلِ ذَٰلِكَ كَتَبْنَا عَلَىٰ بَنِي إِسْرَائِيلَ أَنَّهُ مَن قَتَلَ نَفْسًا بِغَيْرِ نَفْسٍ أَوْ فَسَادٍ فِي الْأَرْضِ فَكَأَنَّمَا قَتَلَ النَّاسَ جَمِيعًا وَمَنْ أَحْيَاهَا فَكَأَنَّمَا أَحْيَا النَّاسَ جَمِيعًا"

> For that we have ordained to children of Israel; that whoever slains a person, without being soul (life) for soul (life) or corruption on earth, it is as if he slained the whole of humanity; and that who saves a life, he is as he saved the whole of humanity (Koran 5.32).

Similar to Christian and Jewish beliefs, Muslims believe that death is only the end of an existing earthly life and the start of a future life (Sheikh 1998; Sarhill et al. 2001). Muslim jurists consider that in terminal cases and when the quality of life is poor and where the medical intervention is futile, the prolongation of life by using supportive machines is unacceptable (Dept of Religious Sciences RaF, Riyadh 1989). Some believe that advance directives are not allowed because God (Allah) is the only one who may decide the future and life and death of a person while others believe that Muslims may be reluctant to issue advanced directives because they may believe that life and death are entirely in the hands of God, and only God can decide how long each person lives or when he or she dies. Thus patient should be left to "live" as long as God wills, not according to their own wills (Miklancie 2007; Gatrad 1994). We believe that there are no contradictions between believing in these concepts and in planning future medical therapy particularly in relationship with end of life issues. We also believe that the concept of advance directives is very well known and even practiced by the Prophet Mohammad (PBUH) himself. The Prophet, in his terminal illness, used a certain notion that would conform to the concept of advance directive. He asked not to be given medications during his illness in view of the fact that his death was imminent and that the treatment was futile. In one of the episodes when he became temporarily unconscious in his final illness the companions, out of love for the Prophet, tried to force feed the medicines. When the Prophet regained consciousness, he was not happy about this and reprimanded the persons responsible for this act. In fact in order to emphasize his instruction for not being fed the medications and that how unpleasant it was, he asked them that they should try to take the medicines themselves.

ـ حديث روته عائشه و ابن عباس, أن أبا بكر رضي الله عنه قبل النبي صلى الله عليه وسلم وهو ميت ، قال : وقالت عائشة : لددناه في مرضه فجعل يشير إلينا : أن لا تلدوني ، فقلنا : كراهية المريض للدواء ، فلما أفاق قال : (ألم أنهكم أن تلدوني) . قلنا : كراهية المريض للدواء ، فقال : (لا يبقى في البيت أحد إلا لد وأنا أنظر إلا العباس ، فإنه لم يشهدكم) .

الراوي:عبدالله بن عباس و عائشةالمحدث:البخاري - المصدر:صحيح البخاري- الصفحة أو الرقم:5709 خلاصة حكم المحدث:[صحيح]

> This Hadith Narrated Ibn 'Abbas and 'Aisha: Abu Bakr kissed (the forehead of) the Prophet when he was dead. 'Aisha added: We put medicine in one side of his mouth but he started waving us not to insert the medicine into his mouth. We said, "He dislikes the medicine as a patient usually does." But when he came to his senses he said, "Did I not forbid you to put medicine (by force) in the side of my mouth?" We said, "We thought it was just because a patient usually dislikes medicine." He said, "All of those who are in the house will be forced to take medicine in the side of their mouth while I am watching, except for Al-'Abbas, for he had not witnessed your deed" (Translation of Sahih Bukhari. medicine 2012).

This Hadith contain three very important elements relevant to the issue we are discussing. (a) That the Muslims are permitted not to take treatment especially when they have incurable disease. (b) That it is not allowed for other individuals taking care to force the patients to take certain therapy especially when they knew that the patient did not wish this. (c) This Hadith makes them also accountable for their action.

Muslims living in Western countries are more familiar with the concept of a living will as it is a commonly practiced there. The Islamic Medical Association of North America (IMANA) recommends that all Muslims living in North America sign a living will or advance directive. They recommend that the will should specifically state "in the event of fatal illness or injury where the doctor certifies in writing that the use of life prolonging procedures only artificially prolongs the agony. The patients ask that such procedures be withheld or withdrawn (Atighetchi 2007; Perspective IECIMETI 2011). Ebrahim (2000) , in his paper "The living will (Wasiyat Al-Hayy): a study of its legality in the light of Islamic jurisprudence", recommend that living will should include the followings:

Request to suspend treatment if this does not improve the quality of life according to the principle "لاضرر ولاضرار"

Instruction to switch off life supporting equipment after brain stem death has been diagnosed. Inclusion of the wish to donate organs fulfilling the principle of public benefit (المصالح العامةMasalaha). Appointing an attorney (wakalah or wakeelالوكاله او الوكيل). Requests contained in the living will that do not contradict the teaching of Sharia law (Islamic jurisprudence) should be followed and not ignored.

Living will must be signed by the author or by his legal representative (wakeel) and by two witnesses.

Proposed definition for advance medical directives

The Islamic concept of "alwasiyah" which is usually written during the life of the testate, is used only as instruction that should be respected following the death of testate. We believe that the terms proposed by Ebrahim (2000) "The living will (wasiyat al-hayy)" to descript the advance directive is a confusion and is not accurate. The living will (wasiyat al-hayy) cannot be included in the will (alwassiyah) as it refers to what to do in the phase *preceding* death and is considered without legal value (57, 58) some refer to it as "al wassiyah alMubaha" " admissible document of wishes".

To avoid such confusion we proposed to use the exact translation of the English term (advance medical directive التوجيهات الطبيه المسبقه). This definition is very specific to directive that is made in advance by the patient to give specific or general instruction about what will be his wishes regarding future management, intervention in case he is not able to make decision and even organ donation. This may also include instruction (wakalah الوكاله) of appointing an attorney (wakeel الوكيل) to make decision in case he or she is not able to do so.

Conclusion

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. This subjects them to limited visiting hour's policy and a feeling of loneliness. Finding an alternative solution such as strong palliative care, hospices, and universal home health care programs to address the patient medical need and provide appropriate palliative care without the need to be transferred them to the hospital is crucial for the success of advance directives. It is very important to emphasize that the advance directive should not only be limited or encouraged among elder patients but also among patients with chronic and disabling disease regardless of their age, social or economic status. In most of poor Islamic countries this issue of advance directive is a not a major concern where most of the patients with chronic disease die at home. However, we believe increase awareness of health care professionals and patients taken care of patients about the Islamic view in permitting and encouraging advance directives particularly for incurable and chronic disease is very useful even in such poor countries. This would happen by alleviating the anxieties and reducing misgivings felt by many Moslems through informing them that it is permissible by the religion to refuse or abstain from treatment in certain special medical circumstances. This should also include discussions by the health care provider with the patient and their relatives well in advance if they believe with conviction in the futility of medical intervention and emphasize palliative approaches instead.

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