

Advance Healthcare Directives: The Emerging Global Trends and *Shari'ah* Perspectives

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Abstract: Advance Healthcare Directives emerged due to the enhancement of patient autonomy which ideals have been firmly embedded in the development of modern medical decision making. An advance healthcare directive is a document that seeks to preserve the patient's right of self-determination by representing his values and wishes in the event he becomes incapacitated and no longer able to fully partake in the decision-making process. Particularly, when life sustaining measures are required in making end of life decisions, clear instructions embodied in the advance healthcare directives will serve as guidance to healthcare providers in respecting patient's wishes, managing healthcare resources and reducing the likelihood of disputes with patient's family members. Subsequently, the growth and popularity of these directives has led to the enactment of legislations by many countries in clarifying the legitimacy of such directives when employed in healthcare settings. The legal development of advance healthcare directives is seen to be more prominent in the United States, Australia and parts of Europe while countries in other jurisdictions may not specifically address the legal status of such directives in their legislations but treat them as being legally persuasive. Nevertheless, for Muslim patients, the use of advance healthcare directives to determine their health destiny must abide by the *Shari'ah* as the right and ability to make their own choices and decisions about medical care and treatment must be within the defined limitations of the *Shari'ah*. This paper seeks to discuss the legal development of advance healthcare directives in selected countries around the globe and the legitimacy of these directives from the *Shari'ah* perspectives.

Key words: Advance Healthcare Directives • Legal Development • Global Trends • *Shari'ah*

INTRODUCTION

Advance healthcare directives arose as a means for individuals to have greater control over all aspects of their care and treatment particularly, those related to end of life decisions. An advance healthcare directive seeks to preserve a patient's right of self-determination and acts as a guide for doctors to determine medical treatment that represents the patient's values and wishes when he is unable to partake in the decision-making process. It not only fulfils the ethical obligation of doctors in respecting patient autonomy, but also facilitates the application of the principle of justice in terms of managing health care resources and helps to alleviate the psychological burden experienced by family members and health care providers. However, the validity of advance healthcare directives has often been challenged and doctors are constantly in a dilemma on whether to execute the instructions contained in

advance directives. This has led to the growth of legislative framework governing advance healthcare directives to be proposed and implemented in various jurisdictions around the globe to ensure the legitimacy of such directives in terms of its recognition and enforcement. Regulating advance healthcare directives through legislation is seen to be important particularly, in terms of drawing up the limitations in the use of such directives. For instance, advance healthcare directives should not be executed if the stipulated contents contravene the existing laws of the particular country, such as instructing the doctor to commit acts of active euthanasia that may be equivalent to murder or culpable homicide under the Malaysian law (section 299, Malaysian Penal Code [Act 574]).

MATERIALS AND METHODS

Qualitative Research – Content Analysis

RESULT AND DISCUSSION

Advance healthcare directives are documents containing statements made by persons while they are competent, pertaining to their desired medical treatment in the future in the event that they are incapable of participating in the decision-making process at the relevant time. They consist of anticipatory instructions and decisions as to the extent of treatment in which a person agrees or refuses to receive, the circumstances in which treatment may or may not be provided and may also include the appointment of a proxy who is authorised to make health care decisions on the person's behalf [1]. Advance care planning is the discussion process between doctor and patient, which may also include family members, to develop and document a valid projection of the patient's wishes with regard to the type of medical care in situations where he becomes unable to communicate [2]. Proper advanced care planning, which includes the formulation of advance healthcare directives, serve to enhance patient autonomy as it entails the consequential involvement of the patient in expressing and validating his values as well as wishes in anticipation of a situation where he might lose his decision-making capacity. It stems from the theoretical rationale that if patients have the right to refuse treatment even when such refusal might endanger their lives, then they should be entitled to exercise the same right when they become incompetent, which is facilitated by the use of advance healthcare directives [3].

Types of Advance Healthcare Directives: There are two types of advance healthcare directives:

Living Will: Advance healthcare directives usually take the form of a living will. A living will, also described as an "anticipatory decision" [4], is a list of preferences and instructions expressed by a person in respect of the type of treatment that should or should not be provided to him in different circumstances [5]. It allows people to indicate and document their wishes in advance as to how they would want their medical care to be carried out, in the event that they lack the competency to decide in the future. For example, a person may express his refusal to receive cardiopulmonary resuscitation or blood transfusion, or request for life-sustaining treatment such as a respiratory ventilator to be withheld or withdrawn.

Lasting Power of Attorney: A lasting or continuing power of attorney, also referred to as a "durable power of

attorney for health care" [1], "health-care proxy", or "medical treatment attorney" is an instrument that allows a person to appoint a surrogate or proxy who is authorised to decide on his behalf on health care matters should he lose the ability to do so [3]. This legal document takes effect only when the person appointing, that is, the donor becomes incompetent and no longer has the capacity to decide for himself [1]. Due to the scope and nature of such an appointment, it is important that the person appointed, that is, the health care proxy to be someone who is very familiar with the values and wishes of the donor [5].

The difference between a living will and a lasting power of attorney is that while the former is an expression of the patient's wishes and preferences, a lasting power of attorney allows the appointed health care proxy to replace the incapacitated donor in the medical decision-making process. Thus, it is suggested that an effective way to ensure that an advance healthcare directive serves a two-fold purpose is by integrating a lasting power of attorney into the living will.

Circumstances in Which Advance Directives Are Applicable: Since advance healthcare directives are the embodiment and extension of a patient's autonomous choices when he is unable to make decisions pertaining to his medical care, the circumstances in which advance healthcare directives are operative are very much related to the issue of capacity. Doctors may have recourse to an advance healthcare directive in determining the course of medical treatment for a patient who does not have the capacity to consent or refuse. This may include situations where the patient's ability to decide is impaired by a temporary loss of consciousness (Re C (Adult: Refusal of Medical Treatment) [1994] 1 All ER 819), or when the patient becomes insensate or is in a vegetative state due to a severe injury or terminal illness (Airedale NHS Trust v Bland [1993] 1 All ER 821). Some experts contend that the full measure of autonomy is also compromised in patients with serious illness although they may still possess basic decision-making capacity [6]. Factors such as pain, systemic weakness, delirium, depression and anxiety could distort the cognitive function of terminally ill patients and impair their ability and perception to make autonomous decisions [7]. An advance healthcare directive may also be applicable in cases where the patient suffers from mental disorders such as dementia [8] and schizophrenia (Heart of England NHS Foundation Trust v JB [2014] 137 BMLR 232).

The Global Trends: Historically, the first advance healthcare directive or “living will” as it was first termed, was proposed and drafted by Luis Kutner, an American lawyer in 1967 [9]. It was meant to allow a competent person to leave instructions about their medical treatment in the final stages of their lives, when they were no longer able to express their wishes [1]. The issue of advance healthcare directives however, did not garner much attention from the public until almost a decade later, when the *Quinlan* case was decided in 1976 (Re Quinlan 355 A.2d 647 (N.J. 1976)). The case highlighted the importance of a living will to be formally recognised as a means of conveying the wishes of a patient while they were still competent. Subsequently, California became the first state in the United States to pass a law which was intended to give legal validity to advance directives [10]. The California Natural Death Act 1976 declared that a competent adult had the right to make decisions regarding life-sustaining treatment, which could include a written instruction to withhold or withdraw such treatment if the patient developed a terminal condition [11]. Subsequently, other states began to develop their own legislations to govern advance healthcare directives and in 1983, Pennsylvania became the first state to establish legislation for durable powers of attorney for health care [12]. By 1992, all the fifty states in the United States of America had enacted some form of legislative framework to govern advance healthcare directives [13]. Eventually in 1991, a federal statute, the Patient Self-Determination Act (PDSA) of 1990, came into force. The PDSA 1990 requires all health care providers to inform patients in writing regarding their rights under state law to make decisions concerning their medical care, which includes the right to make advance healthcare directives. Furthermore, PDSA legislates for community and staff education relating to advance healthcare directives and ensures that the presence or absence of advance healthcare directives does not influence the provision of care [12].

It can be seen that the legal development of advance directives is rather prominent in the United States of America, Europe and Australia. In Europe, countries such as the United Kingdom, the Netherlands, Belgium, Finland, Spain and Austria have sought to legislate laws pertaining to advance directives [3]. In the United Kingdom, the Mental Capacity Act 2005 of England and Wales, which came into effect on 1 October 2007, currently regulates the validity and implementation of advance healthcare directives. The objective of the 2005 Act was to clarify the legal uncertainties and amend

existing law on substitute and assisted decision-making on behalf of individuals with incapacity (Mental Capacity Act 2005, Chapter 9). Advance healthcare directives have also been made legal in Spain since 14 November 2002. The Spanish Basic Law 41/2002 regulating the Autonomy of the Patient and Rights and Duties related to Clinical Information and Documentation permits persons to state their wishes with regard to medical treatment while they still have the capacity to do so [14]. Specific legislations relating to advance healthcare directives have also been in place in countries such as Finland (Act on the Status and Rights of Patients 1992) [15], Denmark (Law on Patients' Legal Status 1998) and Netherlands (Medical Treatment Contracts Act (WGBO) 1994) [16]. Regulation 8 of the Finland's Act on the Status and Rights of Patients 1992 stated that in cases of emergency, doctors cannot give treatment to a person who is unconscious or unable to express their will if such treatment would be against that person's will, as expressed steadfastly and competently at some point in the past. Article 450 of the Netherlands Medical Treatment Contracts Act (WGBO) 1994 stated that if a patient aged 16 or over cannot be deemed capable of reasonably assessing his/her interests with regard to care, the care provider shall comply with the apparent opinion of the patient expressed in writing while he/she was still capable of reasonable assessment [14]. In Australia, legislation governing advance healthcare directives has been enacted in six Australian jurisdictions, namely, South Australia, Queensland, Australian Capital Territory, Victoria, Western Australia and Northern Territory. South Australia was the first Australian jurisdiction to enact a legislation known as the Natural Death Act 1983, which allowed a competent adult to complete a document that refused treatment in advance. In 2006, the Australian Capital Territory enacted the Medical Treatment (Health Directions) Act with the objective of protecting the right of patients to refuse unwanted medical treatment. The Western Australia Parliament had also enacted the Acts Amendment (Consent to Medical Treatment) Act in 2006 to provide a formal legislative framework to ensure wishes of individuals would be carried out [17].

In Malaysia, there is no legislation specifically addressing the issue of advance healthcare directives. General mention is made under Clause 5 of Section II of the Code of Medical Ethics of the Malaysian Medical Association (“CME”), which states that in the case of a dying patient, “[o]ne should always take into consideration any advance directives and the wishes of the family in this regard.” The CME also makes reference

to numerous declarations and statements made by international bodies such as the World Medical Association (WMA), the World Psychiatry Association and the United Nations in Appendix IV. The WMA Declaration of Venice on Terminal Illness for example, recognizes the right of patients to develop advance directives that describe their preferences regarding medical care in the event that they are unable to communicate and the designation of a substitute decision-maker to make decisions that are not expressed in the advance healthcare directive [18]. Further, the guideline on “Consent for Treatment of Patients by Registered Medical Practitioners” issued by the Malaysian Medical Council has relevant provisions pertaining to advance healthcare directives (MMC, 2013). Clause 17 on Advance Care Directives (or Living Wills) of the Consent Guideline can be summarised as follows:

- A doctor must comply with an unequivocal refusal to treatment in a patient’s written directive in the circumstances specified therein;
- A doctor must not comply with an advance directive that contains instructions that are unlawful such as euthanasia or the termination of pregnancy;
- A doctor should determine the validity of an advance directive by considering the following factors:
- whether it is sufficiently clear and specific to apply to the clinical circumstances which have arisen;
- whether it can be said to have been made in contemplation of the current circumstances (for example, whether the directive was made before or after the diagnosis of the current illness); and
- whether there is any reason to doubt the patient’s competence at the time that the directive was made, or whether there was any undue pressure on the patient to make the directive;
- If the doctor is in doubt about the validity of an advance directive, he should consult the patient’s spouse or next of kin and the doctor should also consider the need to seek legal advice and to discuss the issue with his or other clinicians involved in the patient’s care;
- In emergency cases, the doctor can treat the patient in accordance with his professional judgment of the patient’s best interests until legal advice can be obtained on the validity or scope of the patient’s advance directives [19].

However, these guidelines do not address all relevant aspects pertaining to advance healthcare directives such

as the considerations in ascertaining the patient’s competency and best interests. Nevertheless, there is a need for a comprehensive regulatory framework governing advance healthcare directives in Malaysia as there is certainly increased awareness amongst the Malaysian community on the existence and the use of these directives to protect their right of self-determination in healthcare matters [20].

The *Shari’ah* Perspectives: For Muslim patients, even though the importance of patient autonomy is duly recognized in Islamic law, the advancement of this concept is not without its limitations as it has to evolve within the perimeters of the religion. The right and ability to make their own choices and decisions about medical care and treatment for Muslims must be within the defined limitations of the *Shari’ah*. A Muslim patient cannot refuse medical treatment if it is done voluntarily to cause death. The Holy Qur’an is clear in prohibiting a person from committing suicide. In Surah al-Nisa’, it is stated to the effect: “Do not kill yourselves as God has been to you very Merciful” (The Holy Qur’an, 4:29) [21]. These authorities from the Holy Qur’an and Hadith illustrate the sanctity of human life, prohibition of killing a human being with no justification and prohibition of killing oneself. Killing a person to ease his suffering even though it is at the request of the person is therefore inconsistent with Islamic law. A person in such a situation should persevere patiently with the available medical treatment as the reward for such patience in the Hereafter is tremendous, as promised in Surah al-Zumar: “And those who patiently persevere will truly receive a reward without measure” (The Holy Qur’an, 39:10) [21]. Muslims believe that pain and illness are a natural process of life and more importantly, tests from God to confirm a believer’s level of faith. The Qur’an states, “O all you who believe, seek your help in patience and prayer; surely God is with the patient” Surely We will try you with something of fear and hunger and diminution of goods and lives and fruits; yet give thou good tidings unto the patient who, when they are visited by an affliction, say, ‘Surely we belong to God and to Him we return’; upon those rest blessings and mercy from their Lord and those - they are the truly guided.” (The Holy Qur’an, Surah al-Baqarah, 2:153-157) [21]. This however does not mean that Muslims are required to endure suffering without searching for a cure. On the contrary, Islam directs those who are sick to conscientiously and patiently seek medical treatment: “And who despairs of the mercy of his Lord, but those who are misguided.” (The Holy Qur’an, Surah al-Hijr,

15:56) [21]. In a Hadith, it is narrated that Prophet Muhammad (pbuh) said, "There is no disease that Allah has sent down except that He has also sent down its treatment." (Sahih al-Bukhaari, Book 76, Hadith 1) [22].

In making anticipatory refusal through advance healthcare directives, some jurists contend that this is allowed and consistent with Islamic teachings and was actually practised even in the time of the Prophet Muhammad (pbuh). When the Prophet (pbuh) became terminally ill, there were times in which he would lose consciousness. In one such occasion, his companions tried to force feed him medicine, pursuant to which the Prophet (pbuh) indicated his disapproval by waving his hand at them. When the Prophet (pbuh) came to his senses, he reproached the companions and voiced his displeasure at their actions. The following principles can be derived from this Hadith: (a) A patient's right of autonomy must be respected; (b) It is permitted for a patient to refuse treatment particularly at the end of life and when such treatment would be futile; and (c) Islam recognises the effect of an anticipatory refusal and doctors should give effect to the patient's wishes [23]. Accordingly, the issuance of advance healthcare directives is incorporated in the recommendations made by IMANA for the health care of Muslim patients [24]. The IMANA Ethics Committee also endorses the appointment of a case manager to assist doctors in clarifying and carrying out the wishes of patients who are unable to partake in the decision-making process relating to their care [24]. Further, consistent with the limitations of patient autonomy, the purport and content of an advance healthcare directive cannot be antithetical to Islamic principles.

In cases of incompetent patients i.e. those who are unable to provide consent for medical treatment, the consent of their next of kin or legal guardian is an imperative consideration in Islam. This is based on the concept of *wali* (guardian) in Islam, which is mentioned in the following verse of the Holy Qur'an: "And test the orphans [in their abilities] until they reach marriageable age. Then if you perceive in them sound judgement, release their property to them. And do not consume it excessively and quickly, [anticipating] that they will grow up. And whoever, [when acting as guardian], is self-sufficient should refrain [from taking a fee]; and whoever is poor - let him take according to what is acceptable. Then when you release their property to them, bring witnesses upon them. And sufficient is Allah as Accountant." The Holy Qur'an, Surah an-Nisa', 4:6) [21]. The ruling in the verse concerning the guardianship of a

child's property is equally applicable to medical treatment and other cases involving patients who are incapable of partaking in decision making. Accordingly, at the 23rd session of the Council of Senior Scholars in Riyadh, it was unanimously decided that "it is not permissible to operate on a patient without his or her permission provided the patient is pubescent and sane, whether the patient is male or female. If the patient is not of age or insane, the permission of their *wali* (guardian) must be obtained" [25]. It is incumbent upon a *wali* to carry out his or her responsibilities in the best interests of his or her ward. In this respect, the opinion and recommendation of doctors are of paramount importance in determining what would be in the best interests of an incompetent patient and thus there is an evident need for medical experts to be consulted in each situation [26]. If the *wali* refuses to consent to medical treatment and such refusal is detrimental to the latter, then the *wali*'s decision shall not be taken into account. In such a case, the right of permission will be transferred to the next *wali* and ultimately to the ruler of the Islamic state [27]. Thus, it can be seen that the validity of any pre-emptive refusal to treatment is subject to the approval of the patient's *wali* upon obtaining the opinion and advice of doctors [28]. Proponents of this view based this on the role of the *wali* expounded in the Holy Qur'an; they accordingly argue that during a period of incapacity, the *wali* is conferred the right to decide on behalf of the patient and this cannot be overridden by the issuance of an advance healthcare directive. It is nevertheless submitted that this does not negate the importance of an advance healthcare directive in helping doctors to respect the patient's wishes and decide on the most viable medical course of action. The appointment of a patient's *wali* as the case manager in the preparation and implementation of the patient's advance healthcare directives fulfils both the Islamic role and responsibility to be undertaken by a *wali* on behalf of his incompetent ward, as well as the obligation to respect the patient's wishes regarding his medical treatment. Further, Islam does not give unqualified power to a *wali* as a *wali* is duty-bound to act in the best interests of the patient and this is achieved through consultation and a mutual decision-making process with medical experts.

CONCLUSION

Accordingly, there is an apparent need to establish legal standards and proper rules of conduct in order to address the various issues pertaining to advance

healthcare directives. It is submitted that this is best addressed by means of statutory reform, supported by other regulatory instruments such as practice guidelines. This will accord proper direction to both doctors and patients in formulating advance healthcare directives and guide doctors in its proper implementation. A comprehensive regulatory framework governing advance healthcare directives, in terms of its recognition and enforcement, will ultimately, provide assurance to the doctors that their actions in executing the directives are ethically and legally valid as well as safeguarding the preservation of a patient's autonomous rights and best interests in modern healthcare settings.

ACKNOWLEDGMENT

This study has been funded by the Ministry of Higher Education (MOHE) in Malaysia.

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