

## Dying Wishes: Understanding Advance Medical Directives from the Malaysian and Islamic Law Perspectives

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### Abstract

The respect for patient autonomy is a bioethical principle that has acquired a compelling degree of prevalence in modern medical practice. While a doctor is ethically and lawfully bound to respect a patient's preference and personal values in administering the requisite treatment, the duty to do so is more intricate in end-of-life care, when most patients are unable to partake in the decision-making process. An advance medical directive thus, provides an assurance that the patient's right to make autonomous decisions is preserved and will not be defeated by any future incapacity. It also serves to alleviate the ethical dilemma faced by doctors and assist them to determine the course of treatment according to the incompetent patient's wishes. In turn, this facilitates healthcare providers to effectuate a more functional allocation of resources, which include costly life-sustaining equipment. In Malaysia, although advance care planning and advance medical directives are fairly novel concepts, there have

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been recent calls by certain sectors to increase awareness among the public and incorporate such measures into the delivery of healthcare services. This paper seeks to discuss the viability of integrating advance medical directives into the Malaysian regulatory framework on the provision of healthcare. Accordingly, this will also include a deliberation on the Islamic standpoint with regard to the subject matter, in view of Malaysia's religious demography and the position of Islam as the official religion of the country.

**Keywords:** *advance care planning, advance directives, end-of-life care, Islamic law, Malaysian law*

## **1. Introduction**

Since the turn of the 20<sup>th</sup> century, the increase in the degree of medical prevalence particularly at the end of life, has shifted the dimensionality between life and death. Medical treatment and equipment are now able to prolong the life expectancy of patients suffering from life-limiting illnesses even in the absence of any brain activity. Resultantly, patient autonomy has taken precedence over medical paternalism in medical decision-making, amidst the fears that one's dying phase would be suspended indefinitely by medical intervention. Advance medical directives were developed as a response to address this concern, providing a means for patients to preserve their right to self-determination in situations where they might lose the ability to decide on the course of their medical treatment. As an embodiment of a patient's anticipatory medical decisions, as well as his or her values in relation thereto, advance medical directives not only enhance patient autonomy, but also serve to facilitate doctors in performing their ethical obligations towards the patient at a time when the latter might not be able to participate in the decision-making process. The development of advance medical directives is seen to be more prominent in its place of origin, that is, the United States than other parts of the world. In Malaysia, particularly, the use of advance medical directives is still in its infancy, and to date, the matter has yet to be properly legislated.

## **2. The Significance of Advance Care Planning and Advance Medical Directives**

One of the main attributes in the end-of-life decision-making process is the significant and compelling deference to patient autonomy. While a doctor is lawfully bound to respect a patient's preference and personal values in administering the requisite treatment, it has been shown that this proves to be more complexed when the patient is incompetent. The conception of advance medical directives served as a means of responding to this dilemma, and to address the fear that many people have over the fact that it had become clinically possible to continuously be kept "alive" in a state where they have lost all cognitive functions and are incapable of exercising any control over how they wish to be treated. An advance medical directive operates as an assurance that the right of an individual to make autonomous

decisions will not be defeated by any future incapacity, and thus, in this respect, functions as an enhancement of patient autonomy.

An advance medical directive is a written statement made by a person while he is competent pertaining to future medical treatment, in the event he becomes incapable of decision-making when the need arises. It consists of anticipatory instructions and decisions as to the extent of treatment that 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 (Capron, 2009). 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 (Htut et al., 2007). The model for advance care planning involves a structured process where doctors engage with patients to understand the latter's needs, values, goals and thought process, as well as establish a trustworthy relationship for shared decision making (Emanuel et al., 2000). It is a continuous discussion that needs to be reviewed and reaffirmed periodically throughout the patient's clinical course and while the patient possesses the requisite mental capacity, in order to ensure that the decision documented reflects the patient's current and true wishes upon having been properly informed of the treatment options (Mullick et al., 2013).

Proper advance care planning, which includes the formulation of advance medical directives, functions to enhance patient autonomy as it entails the consequential involvement of the patient in expressing and validating his values and 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 medical directives (Andorno, 2009). The existence of a valid advance medical directive acts as a guide for doctors to determine the course of 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 the autonomy of their patients, but also promotes the biomedical principle of justice, where management of health care resources are concerned. In this respect, the implementation of advance medical directives enables a more functional allocation of expensive life-sustaining medical equipment, especially in institutions that have limited health care budgets (Astroff, 1997). From the personal viewpoint of the patient and family members, an advance medical directive provides a formal assurance that health care decisions will conform to the patients' individual wishes and interests at a time when the patient's active participation may not be possible, and help to alleviate the psychological burden experienced by not only the family members but also health care providers (Pellegrino and Thomasma, 1988).

### 3. Legislating Advance Medical Directives: The UK and Australian Experience

It is imperative that doctors respect and abide by a patient's advance medical directive. By doing so, doctors would not only be acting ethically in terms of respecting the patient's right to self-determination, but it would also operate to absolve them from legal liability. It is an established principle in common law that it is unlawful for doctors to administer treatment to a competent adult unless the latter has validly consented to such treatment. A doctor who proceeds to do so without the consent of an adult of sound mind would be committing battery (*Wilson v Pringle*, 1986). The patient's right to choose is accordingly "not limited to decisions which others might regard as sensible. It exists notwithstanding that the reasons for making the choice are rational, irrational, unknown or even non-existent." (*Re T (adult: refusal of medical treatment)*, 1992) Likewise, this principle covers refusals to treatment; a competent patient has the right, either for rational or irrational reasons or for no reason at all, to refuse any medical intervention, even though the consequence of such decision may lead to his death (*Re MB (an adult: medical treatment)*, 1997).

The importance of a regulatory framework on end-of-life care, including that of advance care planning and advance medical directives can be seen from the experiences of the UK and Australia, two common law jurisdictions, in which the provision of end-of-life care has been fully integrated into their respective mainstream health care services (Lynch et al., 2013). The 2015 Quality of Death Index reports that the UK and Australia occupy the first and second topmost ranking above 80 countries across the world (The Economic Intelligence Unit, 2015). One of the key findings of the report is that the leading countries share a common feature: "a strong and effectively implemented national palliative care policy framework", where aspects such as advance medical directives have been legislated.

Under English common law, whether the patient has given a valid consent or refusal to medical treatment essentially rests on whether he did so upon being properly informed (Kassim, 2007), that it was done voluntarily (*Re T (adult: refusal of medical treatment)*, 1992), and whether he possessed the capacity to make the decision at the time when it was made. In *Re T (adult: refusal of treatment)*(1992), the test of competency as laid down by the House of Lords necessitated the following conditions to be fulfilled: at the time when the decision was made, (1) the patient must have had the legal capacity and possessed the requisite competence to consent or refuse treatment. In other words, the patient must be an adult and must not suffer from any impairment that may undermine his ability to make up his own mind. It is important to note that a person with reduced capacity does not however *ipso facto* render him incapable of making a decision as to the treatment in question. Doctors must consider whether the patient had a capacity which was commensurable to the gravity of the decision which he purported to make; (2) the patient must have been aware and intended for the scope and basis of his consent to be applicable in that particular situation. In *Airedale NHS Trust v Bland* (1993), the court drew attention to the need for special care in ensuring that a prior anticipatory refusal could still be regarded as relevant to the situation at hand; and (3) the

patient must have known the nature, purpose and effect of the treatment to which he is consenting. This third element was further clarified in *Re C (adult: refusal of medical treatment)*(1994); in order to determine whether the patient has sufficient understanding, it must first be proven that he understood and is able to retain the information given pertaining to the treatment, secondly, that the patient believes it, and thirdly, that the patient is able to internalise and weigh such information by balancing the need for such treatment with the risks that may be involved, before making a choice.

The conditions of a valid consent as set out above are therefore applicable in determining the legitimacy of an advance medical directive i.e. whether the person making the advance medical directive was provided the necessary information and was indeed competent at the time when he expressed his preferences. In the event that the person does not satisfy the aforementioned criteria for competency as set out in *Re T (adult: refusal of treatment)*(1992), his advance medical directive will not be valid and therefore any act or decision pertaining to the person's medical treatment during his period of incapacity must be made in his best interests.

The aforementioned common law principles were adopted and incorporated in the first formal move to recommend the use of advance medical directives in the form of the 1993 report produced by the UK Law Commission (The Law Commission, 1993), and the House of Lords Select Committee on Medical Ethics in 1994, which proposed a code of practice as a guide for health care professionals in the use of advance medical directives (Select Committee on Medical Ethics, 1994). These developments eventually led to the passing of the Mental Capacity Act 2005 ("MCA"), which came into effect on 1 October 2007. This piece of legislation is to be read together with the MCA Code of Practice, which supports the legal framework provided by the MCA and acts as a guidance as to how the provisions of the latter are to be implemented.

One of the cases that came before the English courts in relation to advance medical directives was *W v M and others* (2011). The case concerned M, who suffered from extensive and irreparable brain damage as a result of viral encephalitis and had, since 2003, been in a minimally conscious state ("MCS"). M's family accordingly sought a declaration from the court for life-sustaining treatment including artificial nutrition and hydration to be withheld and withdrawn. They based their request on the contention that prior to M's collapse in 2003, she had expressed her wish to not live a life that was dependent on others and that she "wanted to go quickly". It was not disputed that M no longer had the capacity to decide due to her present state. In determining whether M's previous statements made at the time she was competent amounted to a valid advance medical directive, the court examined it against the requirements specified under common law, which were now imbued and further refined in the MCA. Accordingly, the court held that it could not attach significant weight to such statements due to the fact that there was no evidence that M had specifically intended those wishes to represent her preference with regard to the withdrawal of artificial nutrition and hydration, or

that it had been articulated in anticipation of a situation resembling that of MCS. Under the common law and the MCA, among the conditions for an advance refusal to be valid was that it must unequivocally refer to the scope of treatment and circumstances in which it is to operate. It was ruled that since this requirement had not been fulfilled, the statements in question did not constitute an advance medical directive and therefore the application by M's family members was dismissed. Further, upon considering all the relevant factors involved, the court held that it was not in the best interests of M to have the artificial nutrition and hydration withdrawn.

In Australia, legislation on advance care planning is available in all states and territories, except for New South Wales and Tasmania, in which case reference is made to the rules of common law (Fountain et al., 2018). Advance medical directives in the different regions are accordingly governed by the following statutes: The Medical Treatment (Health Directions) Act 2006 of the Australian Capital Territory, the Advance Personal Planning Act of the Northern Territory, the Powers of Attorney Act 1998 of Queensland, the Guardianship and Administration Act 1990 of Western Australia, the Advanced Care Directives Act 2013 of South Australia and the recent Medical Treatment Planning and Decisions Act 2016.

#### **4. The Current Position on Advance Medical Directives in Malaysia**

The use of advance directives in medical care is a relatively novel concept in Malaysia. This could be primarily attributable to the cultural conditions and lack of exposure on the subject matter. The level of awareness, both on the concept of palliative care in general and specifically on advance medical directives, has been documented by local studies. In a 2007 survey conducted by Htut, Shahrul and Poi, it was found that none of the respondents had heard of advance medical directives or advance care planning (Htut et al., 2007). The majority were also hesitant to decide on issues relating to future medical care due to religious reasons and were of the view it was premature or unnecessary to formally decide on related matters. A recent report issued by Hospis Malaysia in 2016 revealed that out of the 600 respondents interviewed, 24.7% answered that they were aware that there existed a provision of services "to relieve the suffering and improve the quality of life for patients and their families living with or dying from a chronic illness", and only 17.2% correctly identified it as hospice or palliative care (Sekhar et al., 2016). Further, a study carried out on Malaysian palliative nurses indicated that there was still a lack of knowledge with regard to end-of-life care and poor perception of end-of-life issues among them (Subramanian and Chinna, 2013). In terms of advance care planning, statistics in a study conducted in the same year to evaluate the attitudes of older Malaysians towards advance care planning (Siew et al., 2016) indicated that out of the 234 respondents, the majority (77.8%) were receptive to the concept. Those who were opposed to it primarily justified their response on the basis that they did not have sufficient information on advance care planning and would prefer their family members to make end-of-life decisions on their behalf when it became necessary. Religious beliefs were also cited as a

significant reason for their refusal to participate in advance care planning, as they felt that it was a matter best left to God to decide, a factor which is found to be consistent with the findings of the 2007 survey conducted among elderly Malaysians around the same age group, although the latter was conducted in a smaller cohort (Htut et al., 2007). Despite not being exhaustive findings, it is submitted that the analyses on advance medical directives help to provide insight into the perceptions of Malaysians on the subject.

In recent years however, issues regarding its importance and calls by the medical community for increased awareness as well as the wider implementation of advance care planning made local newspaper headlines. Malaysian doctors have voiced the need for advance medical directives to assist them in managing their patients in a more effective manner, especially in dealing with disputes among family members as to what would be the best course of action for the patient (Mageswari, 2014). There is also concern among the religious groups in Malaysia that proper guidelines be issued in respect of advance medical directives and the right of family members to decide on a patient's behalf (The Star Online, 2014). To this end, some effort has been initiated to discuss the issue among the relevant sectors, which has recognised the evident need for a comprehensive regulatory framework to be developed, taking into account the different religious and cultural views (Yusof, 2015).

Currently there is no regulatory instrument that specifically addresses the issue of advance care planning or advance medical directives in Malaysia. 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 WMA Declaration of Venice on Terminal Illness, which is referred to in Appendix IV of the CME for example, recognizes the right of patients to develop advance medical 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 medical directive (World Medical Association, n.d). It also highlights the importance of advance care planning, particularly with respect to life-sustaining treatment and palliative measures that might hasten death.

It is clear from the CME that doctors must give precedence to advance medical directives, which are an embodiment of the patient's right to self-determination, in deciding whether a particular medical treatment is to be administered during the patient's incapacitated state. The obligation to abide by a patient's wishes and preferences is accordingly subject to the condition that the advance medical directive in question must be valid, which necessitates determination of the patient's competency. This is reflected in clause 18 of the Consent for Treatment of Patients by Registered Medical Practitioners issued by the Malaysian Medical Council ("Consent Guideline"). The provision highlights the duty of doctors to give precedence to advance medical directives, in deciding whether a particular medical treatment

is to be administered during the patient's incapacitated state. The relevant details can be summarised as follows:

- (a) A doctor must comply with an unequivocal refusal to treatment in a patient's written directive in the circumstances specified therein;
- (b) A doctor must not comply with an advance directive that contains instructions that are unlawful such as euthanasia or the termination of pregnancy;
- (c) A doctor should determine the validity of an advance directive by considering the following factors:
  - (i) whether it is sufficiently clear and specific to apply to the clinical circumstances which have arisen;
  - (ii) 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
  - (iii) 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;
- (d) 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;
- (e) 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.

Although the instrument has been mentioned in the CME and the Consent Guideline, there has yet to be proper guidance with respect to advance care planning and its execution as a whole. The Consent Guideline for instance, does not address all relevant aspects pertaining to advance medical directives such as the considerations in ascertaining the patient's competency and best interests. Further, only a "written directive" is referred to by the Consent Guideline, whereas it is both the legal and ethical norm that a verbal refusal communicated to the doctor by a competent patient would equally bind the doctor. It is accordingly unclear how these guidelines can be effectively carried out in practice by Malaysian doctors in terms of seeking legal advice as to the validity of an advance directive, having regard to the paucity of clear, precise and enforceable legal standards on the matter.



In the case of persons suffering from mental illness, section 77(1) of the Mental Health Act 2001 (“MHA”) recognises the right of a mentally disordered person to consent to surgery, electroconvulsive therapy or clinical trials unless he is assessed by a psychiatrist to be incapable of doing so, in which case such consent may be given by the guardian or relative of the mentally disordered person. Thus, being mentally ill does not of itself render the person incapable of consenting to his own medical treatment, which is representative of one of principles enunciated in *Re T (adult: refusal of treatment)* (1992). In order to determine whether the mentally disordered person is capable of forming his own decision, section 77(5) of the MHA applies the common law test of competency whereby the following considerations are listed: (a) the condition for which the treatment is proposed; (b) the nature and purpose of the treatment; (c) the risks involved in undergoing the treatment; (d) the risks involved in not undergoing the treatment; and (e) whether or not the person’s ability to consent is affected by his condition.

Several observations can be made on the MHA. Firstly, the MHA does not cover all instances of incapacity and its application is restricted to those who suffer from “mental disorder” as defined under section 2(1). This refers to “any mental illness, arrested or incomplete development of the mind, psychiatric disorder or any other disorder or disability of the mind however acquired.” A person is however not to be considered as mentally disordered “by reason only of his promiscuity or other immoral conduct, sexual deviancy, consumption of alcohol or drug, or where he expresses or refuses or fails to express a particular political or religious opinion or belief, or of his antisocial personality” under section 2(2) of the MHA. It is submitted that although the phrase “any other disorder or disability of mind” is generic, the statute is not meant to cover situations in which a person temporarily loses consciousness or where his cognitive functions are impaired due to medical conditions other than mental illness. The purport of the MHA is reflective from the provisions; it was enacted to regulate, among others, the proper treatment and care for those who require psychiatric help.

Secondly, the MHA does not contain reference to the applicability of advance medical directives in situations where the mentally disordered person is incapable of giving consent. If a person had clearly expressed his wishes regarding the purported treatment prior to his mental illness and/or inability to decide and this amounts to a valid advance directive, would it then be operative when the occasion arises during the person’s incapacity? If the answer is in the negative, would that not then amount to a violation of the person’s inherent right to self-determination? Further, if the advance directive includes the appointment of a health care proxy, who is then authorised to consent on the incapacitated person’s behalf, the health care proxy or the person’s guardian or relatives as stated in section 77(1)(b)? Currently, it would seem that the consent of a guardian/relative authorised under the relevant provision would prevail over the decision of a health care proxy under an advance directive since Malaysia does not have a statute legislating the use of lasting power of attorneys. The existing Powers of Attorney Act 1949 regulates the execution of normal power of attorneys that are revocable upon the death, unsoundness of mind or bankruptcy of the donor. Further, the provisions

dealing with an irrevocable power of attorney under the Act are relevant to property transactions and are incompatible with the nature of a lasting power of attorney in respect of health care matters.

Although there has yet to be a case on advance medical directives presented to the Malaysian courts for resolution, the development of local case law pertaining to consent to medical treatment have largely relied on principles of common law. However, legal standards on advance medical directives must take into account the values and perspectives of the different communities which make up Malaysia's racial and religious demography. Accordingly, this not only constitutes a requirement of legality, but corresponds with the importance of value and social considerations that significantly influence a patient's wishes in forming medical decisions (Htut et al., 2007). The inclusion of measures of religiosity and spirituality into the medical framework will facilitate doctors towards a better understanding of patients' beliefs, values, expectations and needs, and at the same time facilitate a dynamic interaction between patients, family members and healthcare professionals (Padela, 2006). Cultural competence, which is the acquisition of the knowledge and skills that enhance the organisation of culturally effective care in a clinical environment is therefore essential.

In Malaysia, Islam as the principal and official religion (as stated under article 3 of the Federal Constitution) accounts for 61.3%, Buddhism constitutes the second largest religion with 19.8%, while Christianity and Hinduism comprise 9.2% and 6.3%, respectively (see Figure 1). Accordingly, religious stances have always been an important and influential factor in the advancement of policy and regulatory frameworks in Malaysia (Mat Karim et al., 2012). It has been suggested that although the provisions of the Malaysian Federal Constitution do not explicitly require that legislation must be in conformity with any set of religious principles, the constitutional guarantee and protection accorded to religious practices and the influence of religious ideals in the law-making process in Malaysia are evidence of the impact that religion has on the country's legal development (Abdul Aziz, 2009). Islamic influence, in particular, has played a significant role in the construction of the social and political affairs of the country (Wu, 2005; Abdul Aziz, 2009).

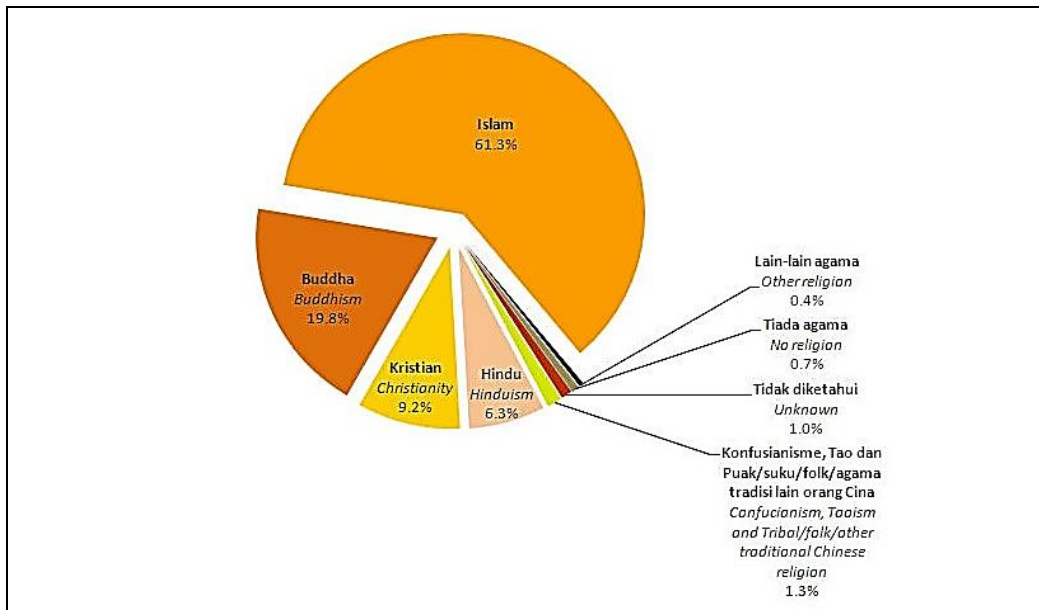


Figure 1 Percentage distribution of the Malaysian population by religion (Department of Statistics Malaysia, 2010)

## 5. The Validity of Advance Medical Directives in Islam

According to Al-<sup>◦</sup>Iz ibn <sup>◦</sup>Abdilsalam, a renowned Muslim jurist in the 7th century of *Hijrah*, in his book, *Qawa'id Al-Ahkam* (Basics of Rulings), the preservation of health serves as the primary goal of medicine, which involves restoring one's health, curing illnesses and reducing its effects to a person's well-being (<sup>◦</sup>Abdilsalam, 2000). There is a transcendental element to the concept of illness from the Islamic perspective; to practice patience when afflicted with pain or difficulty is a means of purification to absolve one's wrongdoings and elevate his or her position in gaining the pleasure of God and attaining Paradise. Several verses in the *Qur'an* attest to this, among others, in *Al-Baqarah*: 155-157: "...And We will surely test you with something of fear and hunger and a loss of wealth and lives and fruits, but give good tidings to the patient, who, when disaster strikes them, say, "Indeed we belong to Allah, and indeed to Him we will return. Those are the ones upon whom are blessings from their Lord and mercy. And it is those who are the [rightly] guided."

The above is substantiated by the following *hadith* of the Prophet (peace and blessings be upon him): It is narrated by <sup>◦</sup>Abdullah bin Mas<sup>◦</sup>ud that, "I visited the Prophet (peace and blessings be upon him) while he was suffering from a high fever. I touched him with my hand and said, "O Prophet! You have a high fever." The Prophet (peace be upon him) said, "Yes, I have as much fever as two men of you have." I said, "Is it because you will get a double reward?" The Prophet (peace and blessings be upon him) said, "Yes, no Muslim is afflicted

with harm because of sickness or some other inconvenience, but that Allah will remove his sins for him as a tree sheds its leaves." (*Sahih al-Bukhariyy*, vol. 7, Book 70, Hadith 550).

Although Muslims are encouraged to face illness with patience and perseverance, this does not denote that they are forbidden to seek treatment in order to alleviate the suffering. This precept is substantiated by verses in the *Qur'an* and *hadith* of the Prophet (peace and blessings be upon him) that encourage Muslims to remove harm and difficulty: "Allah intends for you ease and does not intend for you hardship" (Al-Baqarah: 185); and "Allah does not intend to make difficulty for you, but He intends to purify you and complete His favor upon you that you may be grateful" (Al-Ma'idah: 6). In a *hadith* of the Prophet (peace and blessings be upon him), narrated by Abu Hurairah, the Islamic position that Muslims should avail themselves of assistance to relieve their burdens is further elucidated: It is reported that the Prophet (peace and blessings be upon him) said: "Religion is very easy and whoever overburdens himself in his religion will not be able to continue in that way. So you should not be extremists, but try to be near to perfection and receive the good tidings that you will be rewarded; and gain strength by worshipping in the mornings, the nights." (*Sahih al-Bukhariyy*, vol. 1, Book 2, Hadith 32)

Muslims also believe that for every ailment there is a remedy, based on several *hadith* of the Prophet (peace and blessings be upon him). For instance, it is narrated by Abu Hurairah that the Prophet (peace and blessings be upon him) said, "There is no disease that Allah has created, except that He also has created its treatment." (*Sahih al-Bukhariyy*, vol. 76, Hadith 1) There are differing views among both classical and modern jurists as to whether seeking remedy for an ailment falls into the category of being an obligatory or permissible act. The majority of Muslim scholars concur that seeking medical attention is not mandatory but is instead permissible and recommended, based on the Qur'anic verses and *hadith* of the Prophet (peace and blessings be upon him) on the removal of harm and difficulty, as well as the provision of medicinal remedy (Albar, 2007). Further, it has been reported in numerous *hadith* that the Prophet (peace and blessings be upon him) prescribed several substances and procedures such as honey, nigella seeds, dates, bloodletting and cupping as cure for ailments suffered by his family and Companions, and used to apply such remedies to himself (*Sahih al-Bukhariyy*, vol. 7, Book 71 (Book of Medicine); *Sunan Abi Dawud*, Book 28 (Book of Medicine); *Jami' al-Tirmidhi*, vol. 4, Book 2 (Chapters on Medicine); *Sunan Ibn Majah*, vol. 4, Book 31 (Chapters on Medicine)). Muslims may therefore choose either to pursue medical treatment for their illness or stoically forbear the pain and suffering in relation thereto; both acts are acceptable in Islam (Abu-El-Noor and Abu-El-Noor, 2014). One of the authorities upon which this precept is established is the *hadith* of the Prophet (peace and blessings be upon him) narrated by "Ata' bin Abi Rabah, who reported that, "Ibn 'Abbas said to me, "Shall I show you a woman of the people of Paradise?" I said, "Yes." He said, "This black lady came to the Prophet (peace and blessings be upon him) and said, 'I get attacks of epilepsy and my body becomes uncovered; please invoke Allah for me.' The Prophet (peace and blessings be upon him) said (to her), 'If you wish, be patient and you will have (enter) Paradise; and if you wish, I will invoke Allah to cure you.' She said, 'I will remain patient,' and

added, 'but I become uncovered, so please invoke Allah for me that I may not become uncovered.' So he invoked Allah for her." (*Sahih al-Bukhariyy*, vol. 7, Book 70, Hadith 555)

According to Ibn Taimiyyah, seeking medical treatment, might be classified as *wajib* (obligatory), *mandub* (highly recommended), *mubah* (optional), *makruh* (not preferred) and *haram* (prohibited) (Albar, 2007; Chamsi-Pasha and Albar, 2017), depending on the circumstances. Based on this view, contemporary Islamic scholars have categorised the ruling on medical treatment as follows: (a) The general rule of seeking medical treatment is that it is permissible and recommended when there is a substantial possibility that it will cure the illness and not cause harm to the patient, and the illness will hamper the individual's ability to perform his duties and obligations as a Muslim (Ebrahim, 2006). The treatment must also not involve any elements or substances which are prohibited, unless there is no alternative and it is deemed necessary in order to cure the patient of his illness; (b) It is obligatory to seek treatment when it is life-saving and there is a bigger threat or harm if this is not done, such as preventing the spread of infectious diseases by way of vaccination; (c) Seeking medical treatment is optional if the success and harm associated with such therapy is uncertain; (d) It is preferable to refrain from seeking treatment if its benefit to the patient is questionable, and the harm it may cause outweighs the benefit; (e) Medical treatment is prohibited when it involves methods and substances which are forbidden in Islam, such as talismans, intoxicants, porcine derivatives and blood, unless it is absolutely necessary in order to save one's life from grave danger and there exists no other alternative remedy. This view is similarly reflected in an edict issued by the Council of the Fiqh Academy in 1993 on medical treatment, which also emphasised on the obligation to respect the patient's autonomy, whether he decides to accept or refuse such therapy, if he is competent (Islamic Fiqh Academy, 2000).

In applying the Islamic position on medicine as discussed above, it would appear that in terms of end-of-life care, seeking treatment would therefore fall under the category of being permissible and/or optional, depending on the patient's prognosis vis-à-vis the modality of treatment, as well as his personal wishes. Nevertheless, it is important to note that even in cases where chances of recovery are considered to be dim, it is important for the doctor and patient's family to maintain and uplift the patient's morale, and continue to exert efforts to provide comfort and alleviate his pain and suffering, as it is impermissible in Islam to despair of God's mercy. This is enunciated in the *Qur'an* (*Yusuf*: 87): "Indeed, no one despairs of relief from Allah except the disbelieving people." Sachedina highlights the significance of addressing issues at the end of life from the Islamic juristic standpoint, stating that "with modern medical developments and their universal implementation, Muslim legal scholars are under pressure to respond to the moral and legal questions pertaining to health care of terminally ill patients." (Sachedina, 2005)

In the case 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 a vital consideration in Islam. This is based on the concept of *wali* (guardian) in Islam This is based on the concept of *wali*

(guardian) in Islam, which is mentioned in the following verse of the *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.” (*An-Nisa'*: 6) 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 23<sup>rd</sup> 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.” (Council of Senior Scholars, n.d.) It is incumbent upon a *wali* to carry out his or her responsibilities in the best interests of his or her ward (*Sahih al-Bukhariyy*, Book 93, Hadith 14). 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 a evident need for medical experts to be consulted in each situation (Sachedina, 2005). 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 (Islamic Fiqh Academy, 2000) (in modern practice this would be a court of law).

There are some Muslim jurists who contend that the concept of advance directives is consistent with Islamic teachings and was practised even in the time of the Prophet Muhammad (peace be upon him) (Jahdali et al., 2012). When the Prophet (peace and blessings be upon him) 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 (peace and blessings be upon him) indicated his disapproval by waving his hand at them. When the Prophet (peace and blessings be upon him) came to his senses, he reproached the companions and voiced his displeasure at their actions (*Sahih al-Bukhariyy*, vol. 7, Book 71, Hadith 610). 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 (Jahdali et al., 2012). Accordingly, the issuance of advance directives is incorporated in the recommendations made by IMANA for the health care of Muslim patients (IMANA Ethics Committee, 2005). 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. Further, the purport and content of an advance directive cannot be antithetical to Islamic principles.

Another approach to advance directives is 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 (Abdul Rahman et al., 2017). Proponents of this view base this on the role of the *wali* expounded in the *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 directive. It is nevertheless submitted that this does not negate the importance of an advance 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 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*; 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.

Currently, the only *fatwa* specifically issued on advance medical directives is from the Islamic Religious Council of Singapore (MUIS). According to MUIS, Muslims are permitted to carry out advance care planning and draft their own advance medical directives, as it is considered to be a religious right which allows Muslims to make a dignified choice of their own care plans (Office of the Mufti, n.d.). The following is an excerpt of the statement released by the Office of the Mufti:

“This fatwa was issued based on the Islamic legal position that terminally ill Muslims can voluntarily refuse treatments. In this fatwa, a Muslim may choose not to seek or undergo active treatment, even if the medical condition is considered life threatening. It is also permissible for Muslims to accept or refuse pain and/or symptom relief, even if such treatments may hasten – although not directly cause – death. Both should not be misinterpreted as mercy killing or euthanasia which is prohibited in Islam...The basis for this ruling is a Prophetic tradition or *hadith* narrated by Imam Al-Bukhārī which speaks of a lady who has fallen ill and asked the Prophet Muhammad s.a.w. to pray for her recovery. To which the prophet said: “*If you are patient, the reward that awaits you is heaven. Or if you wish otherwise, I shall pray to Allah for your recovery.*” The woman then replied: “*In that case then I would want to be patient.*” This Prophetic tradition highlighted above also provides the principle that a Muslim possesses the right to decide the kind of therapy or otherwise that they would wish for themselves.”

The fatwa by MUIS also mentions that there are no preferences or hierarchy in Islam as to who should bear the responsibility to decide on behalf of incompetent patients. In such a situation, doctors should consult the patient's immediate family members such as the spouse and children during the decision-making process. Accordingly, engaging in advance care planning is consistent with Islamic teachings that encourage individuals to plan ahead and manage their affairs properly. In addition, MUIS views this process to be justified from the

Islamic standpoint, as it is a means of avoiding conflict that may arise in future pertaining to the patient's course of treatment.

## **6. Proposed Recommendations for the Implementation of Advance Medical Directives in Malaysia**

For advance medical directives to be effectively implemented, the issues and limitations in the use of advance medical directives must be addressed and given due consideration. One of the basic difficulties in advance medical directives is in stipulating its contents. Some people might find it an arduous task to express or formulate their wishes regarding a future medical situation with certainty. Envisaging with precision the type of treatment they would or would not want in circumstances that have not materialised may prove to be complicated to a person to whom such circumstances, at present, may still appear to be a foreign notion (Shaw, 2012; Andorno et al., 2009, Nanovic, 1990). The terms used in an advance directive may also complicate the process of preparing the instructions, for example generic phrases such as "heroic measures", "life-prolonging measures" and "terminal condition" are too subjective and may cause confusion to doctors in ascertaining the actual intent of the directive (Capron, 2009; Astroff, 1997). On the other hand, a detailed checklist would be too restrictive and may not be applicable to a change in a person's medical situation. Accordingly, a balance has to be drawn to ensure that the advance directive is not too narrowly or generally drafted, but specific enough to be able to convey the patient's true wishes and result in a clear understanding on the part of the attending doctor. Capron suggests that an advance directive should represent the patient's "values history", enabling health care decisions to be aligned with how the patient has lived his life (Capron, 2009). Hence although it may not be possible to have an advance directive which comprehensively covers every possible medical condition, a person would still be able to enunciate his personal values which can be applied across a varied range of circumstances (Astroff, 1997).

Secondly, the drafting of a proper advance directive may be encumbered by the lack of relevant information due to the fact that doctors may be unskilled in facilitating discussions for the purpose of advance care planning (Pérez et al., 2013). Inadequate information hinders the patient from making an autonomous decision and would therefore cast serious doubts over the validity of his advance directive (Shaw, 2012; Maclean, 2006). Further, doctors may require a considerable amount of time to ensure that the patient fully understands the different medical conditions that may arise and the choices that would be available, which may in turn incur additional financial cost with regard to the consultation process. There is also fear that advance medical directives may be abused by doctors or family members due to financial considerations (Andorno et al., 2009). Certain family members may have ulterior motives in insisting that the advance medical directive be complied with despite reservations of other relatives as to its authenticity. Where palliative care is concerned, doctors have to contend with limited and costly medical resources particularly in respect of life-sustaining treatment. Advance refusals facilitate the management of medical funds as they decrease dependency on



such treatment and allow doctors to apportion relevant resources according to society's health care needs (Stern, 1994). In this regard, a doctor's decision to implement an advance directive which the patient's family is unwilling to acknowledge, may be seen to be a dubious act driven by economic interests, leading to undesirable conflict between the two parties. Further complications may surface when there is doubt as to the patient's advance refusal which is made in connection with life-sustaining treatment. In an emotionally tense situation, family members may hesitate and find it distressing to decide whether or not to withdraw treatment that may hasten the death of their loved one (Stern, 1994).

Evidently, the most challenging aspect for the effective implementation of advance care planning and advance medical directives is the lack of knowledge and understanding of the subject matter not only on the part of those on the receiving end of health care, but also those involved in the provision of medical services. This makes it difficult for advance medical directives to be made part of a patient's medical routine. Although advance care planning is a process that should be initiated earlier when the patient is healthy, many medical practitioners affiliate advance medical directives with medical crises and thus, discussions take place when the patient may not be in the right frame of mind to make important decisions concerning his treatment preferences should he lose the capacity to consent (Capron, 2009; Pérez et al., 2013). Another difficulty is that even though the patient may have executed a valid advance medical directive, the doctor or family members may not be able to trace where it is located in order to identify the patient's actual wishes when the need arises (Maron, 2011; Nys, 1997).

There is accordingly an apparent need to establish legal standards and proper rules of conduct in order to address the various issues pertaining to advance medical 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 medical directives and guide doctors in its proper implementation. Legislating the use of advance directives will therefore provide assurance to doctors that their actions in relation thereto are ethically and legally valid, and operate as a safeguard in the preservation of a patient's autonomous rights and best interests during both periods of competency and incapacity, therefore preventing potential abuse.

Drawing from the experience of the UK which has specific legislation on the subject matter, it is submitted that any move to regulate advance care planning and advance medical directives should take into account the following basic requirements:

- (a) The conditions as to the validity and applicability of advance medical directives. This includes the need for prior consultation with a doctor and a prerequisite for advance medical directives to specify in clear terms as to when the instructions would be operative (Stern, 1994; Capron, 2009);
- (b) The factors to determine whether the person is competent. This would be relevant during

the process of drawing up the advance medical directive and at the time when doctors need to decide whether to put the advance directive into effect;

- (c) Any restriction as to what an advance directive may contain. For example, the MCA Code of Practice in the UK states that an advance directive cannot include a refusal to be provided basic care such as warmth, shelter, actions to keep a person clean and the offer of food and water by mouth, although artificial nutrition and hydration may be refused (Department of Constitutional Affairs, 2007);
- (d) A scheme to verify that the person has been provided with adequate information during advance care planning and to record the values which are held by the patient to be significant in forming decisions (Stern, 1994);
- (e) A system to facilitate the safekeeping and retrieval of advance medical directives;
- (f) The means by which an advance directive may be revoked and whether it may be done partially without affecting the applicability of the advance medical directive to other circumstances in the future (Stern, 1994);
- (g) The measures to be taken in the event that an advance directive is found to be ineffective or its validity and/or applicability is disputed. This also requires the need for a guideline indicating how the best interests of the patient should be determined, and reference to a judicial forum in order to obtain a declaration affirming that the doctor's choice of action is legally justified;
- (h) The appointment of a health care proxy, including the instrument by which he is to be appointed, the scope of appointment and circumstances in which his authority may be overridden.
- (i) The legal effect of an advance directive and its limitations. It is important that the legislative and/or regulatory instrument contain provision(s) expressly stating that compliance with a valid advance directive will absolve the doctor from liability. It may also include limitation of liability in other circumstances, for example those set out under section 25 of the MCA. Further, an advance directive cannot authorise any act which would be contrary to existing law. For example, in the Malaysian context, an advance directive instructing the doctor to commit an act of euthanasia would be unlawful as it would be equivalent to culpable homicide not amounting to murder under section 299 of the Penal Code.

In addition to the above, a regulatory framework on advance medical directives in Malaysia must necessarily incorporate the requirement for the patient's religious principles to be considered in its implementation. Therefore, the steps to be taken with regard to this aspect, which include reference to a proper religious authority should also be stipulated. The obvious

concern in referring an urgent matter either to a judicial or religious body is that related to timing. In this respect, section 26(5) of the MCA could be referred to in order to obtain some guidance on this issue; it accordingly states that pending a relevant decision by the court, doctors can continue to provide life-sustaining treatment or do any act which he reasonably believes to be necessary to ensure that the patient's condition does not deteriorate. As far as the discussion on the Islamic perspective is concerned, there have been positive developments in Malaysia to discuss the validity and implementation of advance medical directives. In April 2015, Institut Kefahaman Islam Malaysia (IKIM) initiated an expert discourse to discuss the concept and identify issues relating to advance medical directives from the local context. This was followed by a second expert discourse in August 2017, where the position of advance medical directives from the Islamic perspective was deliberated at length among members of the academic and medical fraternities, with the aim of proposing a set of guidelines for the implementation of advance medical directives in Malaysia.

## **7. Conclusion**

The importance of implementing advance medical directives has been mooted by Malaysian doctors as the constructive mechanism to resolve the ethical dilemmas in end-of-life decisions, following the practice by countries who have advanced palliative care systems. Legislating the use of advance directives will provide assurance to doctors that their actions in relation thereto are ethically and legally valid. It will also operate as a safeguard in the preservation of a patient's autonomous rights and best interests during both periods of competency and incapacity, therefore preventing potential abuse.

The construction of advance medical directives in Malaysia into a proper recognised mechanism in order to facilitate doctors to make decisions on a patient's treatment when the latter loses his capacity to consent, requires further analysis. Accordingly, this necessitates a detailed insight into the approach that doctors should exercise in advising patients on the significance, purpose and content of advance medical directives, the manner in which advance directives should be drafted, the prerequisites in order for such document to be valid, and the delimitations in its implementation. Concomitantly, the legality of advance medical directives needs to be examined against the existing statutory instruments, as well as the means by which they may be subsumed into the local regulatory framework. Further, a regulatory framework on advance medical directives in Malaysia must necessarily incorporate the considerations of local circumstances in its implementation, particularly the precepts under the Islamic perspective, in view of the country's religious demography and its sanctified position in the Malaysian Federal Constitution.

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