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MANAGING END-OF-LIFE CARE IN MALAYSIA: THE ECONOMIC CONSIDERATIONS FROM THE ETHICAL AND ISLAMIC PERSPECTIVES

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Abstract

Since the turn of the 20th century, the increase in the degree of medical prevalence particularly at the end of life, has redefined the dimensions 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. This has impacted upon the delivery of end-of-life care, which focuses on providing a comfortable environment for patients who are suffering from incurable diseases and for whom death is imminent. The emergence of sophisticated medical devices and interventions has raised ethical issues relating to end-of-life decisions especially in withholding or withdrawing life sustaining treatments. In such a situation, economic considerations constitute an important factor in the provision of end-of-life care due to the costly and limited resources which are required for providing such life-sustaining treatment. Healthcare providers need to grapple with issues justifying resource allocation amongst patients, which are in turn contingent upon deliberations on medical futility. This paper seeks to discuss the economic considerations involved in the management of end-of-life care from the ethical and Islamic standpoints and ultimately, to provide recommendations for the promotion of a comprehensive national policy that is suitable and viable for the Malaysian healthcare environment.

Keywords: distributive justice, economic, end-of-life care, medical ethics, medical futility and Islamic law

Introduction

As medical development increasingly prolongs the life expectancy of those suffering from terminal illnesses, medical practitioners are confronted with difficult decisions on whether to forego or limit care at the end of life. Such decisions involve the need to precariously balance between the moral and ethical values of both physician and patient. Respecting a patient's autonomy may, in certain cases, run counter to what the physician believes would be in the best interests of the patient, and his duties of beneficence and non-maleficence. The situation becomes more complicated when the patient no longer possesses decision-making capacity, pursuant to which conflicts may arise between the physician and the patient's family with regard to end-of-life decisions, such as withholding and withdrawing life-sustaining therapy. Such therapeutic interventions for the most part, involve expensive equipment and resources which are limited in availability. Thus one of the prevalent issues in an end-of-life setting that doctors are confronted with, is resource allocation. Consequently, this warrants a deliberation on the ethicality of the justifications for resource allocation among terminally ill patients in Malaysia including a reference to the Islamic point of view on the matter, in view of Malaysia's demographic profile as a Muslim-majority country,

What Is End-Of-Life Care?

End-of-life care refers to the health and social care system required to address the physical, spiritual, emotional and social needs of patients who are suffering from serious illnesses, incurable diseases or are in the final stages of their lives.¹ From the health care perspective, end-of-life care is a specific component of palliative care,² which

¹ Colello KJ et al, "End-of-Life Care: Services, Costs, Ethics, and Quality of Care" in Adams SB (ed), *Comfort and Care at the End of Life* (Nova Science Publishers, New York, 2011) p 46; Tallon C, "Ethics and End of Life Care" (2012) 1(1) *JoOPM* 51, 52.

² Palliative care is defined by the World Health Organization as: "an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain

also entails the delivery of hospice care and focuses more on providing a comfortable environment to restore and improve patients' quality of life as far as it is practically possible, rather than to cure.³ ESMO defines "end-of-life care" as palliative care that is delivered when death is imminent.⁴ According to the United States National Quality Forum, end-of-life care applies when a patient's chronic illness is no longer curable and life-prolonging therapies are no longer appropriate, indicated or desired.⁵ It refers to "a specific phase of palliative care requiring specialised skills and services that may be served by the delivery of hospice care or other models of palliative care programmes."⁶ End-of-life care thus involves the mobilisation of an interdisciplinary team of professionals comprising doctors, nurses, social workers and psychologists with the assistance of chaplains, nutritionists, pharmacists and others.⁷ Due to the nature of its setting, doctors are often confronted by ethical dilemmas in making decisions that could hasten death by active⁸ or passive means.⁹

and other problems, physical, psychosocial and spiritual." See World Health Organization, *WHO Definition of Palliative Care*, <http://www.who.int/cancer/palliative/definition/en/>.

³ Colello et al, n 1; Chater K and Tsai CT, "Palliative Care in a Multicultural Society: A Challenge for Western Ethics" (2008) 26(2) *Australian Journal of Advanced Nursing* 95, 96; University of Minnesota Centre for Bioethics, *End of Life Care: An Ethical Overview* (2005), 16, <http://conservancy.umn.edu/handle/189>.

⁴ Cherny, "ESMO Takes a Stand on Supportive and Palliative Care", 1335.

⁵ National Quality Forum, *A National Framework and Preferred Practices for Palliative and Hospice Care Quality: A Consensus Report*, 3.

⁶ Ibid. at C-2. See also Robin B Rome et al., "The Role of Palliative Care at the End of Life.," *The Ochsner Journal* (2011) 11(4) (January 2011): 348-352.

⁷ Colello et al, 47; University of Minnesota Centre for Bioethics, 16; Kinzbrunner BM, "Palliative Care Perspectives" in Kuebler KK, Davis MP and Moore CD (eds), *Palliative Practices: An Interdisciplinary Approach* (Elsevier Mosby, St Louis, 2005), 10.

⁸ Active euthanasia occurs whenever positive and deliberate steps are taken which result in death such as injecting a lethal dose of medication into the patient or where the doctor assists the patient to bring about his or her death.

⁹ This refers to situations where available measures to prolong life are withheld or withdrawn, or in other words, no positive action is taken to extend the life of a terminally ill patient. This includes not commencing treatment if it is considered futile and will not help to improve the patient's condition, disconnecting life support

Ethical Issues in End-Of-Life Care

Decision-making in end-of-life care is often an intricate process, as the clinical evaluation of a terminally ill patient at this stage not only involves his or her physical prognosis, but considerations relating to the patient's emotional wellbeing such as their personal beliefs, values and customs which may be influenced by his or her religion and level of spirituality. This is augmented by technological advancements in medicine such as life-sustaining therapy, which have raised many ethical issues relating to the dying process where patients' values and quality of life are especially significant. One of the ethical dilemmas in end-of-life decisions lies at the core of bioethics itself: the sanctity of life. Both traditional and modern ethics subscribe to and uphold the concept that life is sacrosanct and must be treated with the utmost respect and dignity. An intentional act to end one's life threatens the core of this doctrine and is therefore considered to be a grievous wrong. According to Keown, the sanctity-of-life ethics derives from the notion that because all lives are intrinsically valuable, it is always wrong to intentionally kill an innocent human being.¹⁰ The same view is imbued in the religious approach to bioethics; the only difference is that while modern ethics views sanctity on the basis of the intrinsic value of human life, all major religions (in particular, Islam, Judaism and Christianity) attribute the sacredness of the principle to the fact that all life comes from and belongs to God, and only God has the right to take it away.¹¹ Human beings must therefore protect the gift of life to the best of their ability, and to intentionally commit any act that threatens

systems, discontinuing medical treatment necessary to sustain life or withholding supply of fluids and nutritional feeding. See Harris J, "Consent and End of Life Decisions" (2003) 29(1) *J Med Ethics* 10, 11.

¹⁰ Keown J, "Courting Euthanasia? Tony Bland and the Law Lords" (1993) 9(3) *Ethics Med* 34.

¹¹ See, for example, Khan FA, "Religious Teaching and Reflections on Advance Directive-Religious Values and Legal Dilemmas in Bioethics: An Islamic Perspective" (2002) 30(1) *Fordham Urb LJ* 267; Zahedi F, Larijani B and Bazzaz JT, "End of Life Ethical Issues and Islamic Views" (2007) 6 *Iran J Allergy Asthma Immunol* 5; Markwell H, "End-of-Life: A Catholic View" (2005) 366(9491) *Lancet* 1132; Dorff EN, "End-of-Life: Jewish Perspectives" (2005) 366(9488) *Lancet* 862.

and violates its sanctity is to defy the will of God blatantly and place the wrongdoer in sin.

Nevertheless, advances in both technology and medicine in the past century as well as the shift in doctor-patient relationship have led to patient autonomy taking precedence over “sanctity of life”. This triggers an ethical dilemma, particularly when the patient’s autonomous choice is contradictory to what the doctor perceives to be in the patient’s best interests, and is antithetical to the doctor’s moral obligation and professional integrity. Many ethicists contend that doctors have a moral obligation that may outweigh their duty to respect a patient’s wishes particularly where end-of-life decisions are concerned.¹² A doctor’s obligation to his patient extends beyond the prevention of harm and includes restoration and improvement of the quality of life.¹³ Further, patients’ preferences are not decisive unless a beneficial medical perspective is present.¹⁴ Doctors are therefore not obliged to honour requests for interventions that confer no medical benefit to the patient or treatments that would expose the patient to more harm than good, as this would constitute a direct violation of the values of the medical profession and show disrespect towards the concept of patient autonomy.¹⁵ Medical interventions such as resuscitation, ventilation and the use of antibiotics in cases of infection may operate to save and prolong the life of a terminally ill patient. Such treatment may however run counter to the wishes of patients who may request that these be withdrawn or may refuse them altogether. For example, some patients may view cardiopulmonary resuscitation as a death-delaying act, which conflicts with their values and beliefs that one should not alter the course of nature. In cases where the condition of the patient

¹² See, for example, Baumgarten E, “The Concept of Patient Autonomy: Part 1” (1999) 2(3) *Medical Updates* 1; Brett AS and McCullough LB, “Addressing Requests by Patients for Nonbeneficial Interventions” (2012) 307(2) *JAMA* 149; Billings JA and Krakauer EL, “On Patient Autonomy and Physician Responsibility in End-of-Life Care” (2011) 171(9) *Arch Intern Med* 849; Pellegrino ED and Thomasma DC, “The Conflict between Autonomy and Beneficence in Medical Ethics: Proposal for a Resolution” (1987) 3 *J Contemp Health L & Pol’y* 23.

¹³ Pellegrino and Thomasma, 28.

¹⁴ Brett and McCullough, 149.

¹⁵ Brett and McCullough, 150. Also see Billings and Krakauer, 852.

necessitates respiratory therapy, some patients and family members may regard it as a non-beneficial treatment that impedes what they believe should be the natural process of dying.¹⁶ Consequently, such patients or their family members may seek a “do-not-resuscitate” order from their doctor. Doctors may, on the other hand, find that therapeutic interventions would be futile and no longer provide any curative benefit to a terminally ill patient but there is uncertainty or refusal on the part of the family members to allow life-sustaining treatment to be withdrawn. In these circumstances, doctors are confronted with the ethical dilemma whether to adhere to the patient’s and family members’ wishes or whether to decide on what is the best course of action for the patient. If death is hastened as a consequence of withdrawal of treatment, would such a decision violate the doctor’s moral obligation to prevent harm to the patient? It has been argued that it is permissible to withhold or withdraw treatment and allow the progression of the patient’s natural death.¹⁷ Nevertheless, it is pertinent that any decision to withhold or withdraw treatment should be based upon the expectation that the patient can no longer benefit from that treatment, it is medically futile¹⁸ and the doctor’s intention when doing so must be to relieve the patient of the burdens associated with that treatment.¹⁹

¹⁶ University of Minnesota Centre for Bioethics, 25-26.

¹⁷ Kinsella J and Booth MG, “Ethical Framework for End of Life Decisions in Intensive Care in the UK” (2007) 56(4) *J Natl Inst Public Health* 387, 388.

¹⁸ Medical futility is described as an intervention that will not be able to reach its intended goal. See Cavalieri TO, “Ethical Issues at the End of Life” (2001) 101(10) *J Am Osteopath Assoc* 616, 620. The determination of what may constitute medical futility itself raises several ethical concerns. The fact that such a decision rests solely in the hands of the health care providers may lead to possibilities of the discretion being exercised arbitrarily. For instance, medical treatment may be discontinued not only because it no longer benefits the patient, but such continuation may be considered futile in order to save cost: see University of Minnesota Centre for Bioethics, 31. In cases of a patient who has lost decision-making capacity without having issued any advance directive, conflicts may occur because of the proxy decision-maker’s misunderstanding of the prognosis, difference in values or attitude towards end-of-life care: see Cavalieri, 620.

¹⁹ Kinsella and Booth, 388. The justification for the permissibility of withdrawing medical treatment is based on the distinction between positive acts and omissions. According to the acts-omissions distinction: “in certain contexts, failure to perform

Ethical challenges are further compounded in cases of vulnerable and incompetent patients whose autonomy is compromised due to their restricted, or lack of, ability to form mature and rationale thoughts, and are thereby heavily dependent on outside influences or authorities to make decisions in their best interests. The absence of proxy consent by a patient adds complexity to end-of-life decisions. Doctors would have to rely on the patient's family members to decide what would have likely been the wishes of the patient, and when no proxy is identified family members may be hesitant to partake in the decision-making process.

Economic Considerations in End-Of-Life Care

When certain interventions are considered to be clinically futile and confer no benefit on the patient, there is no ethical obligation to administer or continue such treatment.²⁰ Considerations of medical futility in turn are manifestly linked to the issue of distributive justice. For instance, the fear that because findings of futility rest solely in the hands of the health care providers may lead to possibilities of the discretion being exercised arbitrarily.²¹ Medical treatment may be discontinued and deemed futile not only because it no longer benefits the patient, but because it would be more cost-effective to do so, particularly in the case of the elderly, the uninsured and segments of the community who are at a financial disadvantage.²²

Further, medical treatment at the end of life involves the utilisation of equipment and assets which are costly and limited and

an act, with foreseen bad consequences of that failure, is morally less bad than to perform a different act which has the identical foreseen consequences. It is worse to kill someone than to let them die." See Glover J, *Causing Death and Saving Lives* (Penguin, Harmondsworth, 1977), 92-93; McLachlan HV, "The Ethics of Killing and Letting Die: Active and Passive Euthanasia" (2008) 34(8) *J Med Ethics* 636, 637-638. Thus, acting to kill a patient even for good reasons may seem wrong, whereas omitting to act by withholding life-saving treatment may seem right in certain compelling circumstances.

²⁰ Cavalieri, 619.

²¹ University of Minnesota: Centre for Bioethics, 31.

²² Marshall B Kapp, "Economic Influences on End-of-Life Care: Empirical Evidence and Ethical Speculation," *Death Studies* (2001) 25(March) 251.

which has a significant impact on an institution's financial and human resources. Resource allocation is therefore one of the discernible ethical issues that places doctors in a quandry, particularly in an end-of-life care setting where they have to decide whether to withdraw futile life support from a patient whose death is imminent, and allot it to other patients who require such therapy and have a better chance at survival. This point relates to the concern that limitation in health care resources, in terms of medical professionals and personnel, medicine, equipment and infrastructure, may be used as a reason to ration the application of valued resources and discriminate its distribution to certain groups of patients.²³

The principle of justice in the context of bioethics requires equity to be exercised in the allocation of health care resources and services. It necessitates fair adjudication in the delivery of health care at the individual level in ensuring that the patient receives fair treatment, and at the societal level in terms of just distribution of health care resources.²⁴ In practice, different health care policies may adopt distinct strategic measures to implement the social justice. Some employ the cost-benefit analysis which measures both the benefits and economic costs, while others implement cost-effectiveness analysis in which the assessment of benefits are based on life expectancy, quality-adjusted life years or type of illness.²⁵ Although there may be no concordance on a particular single scheme, the common goal of health care policies is to promote a fair access to basic health care for each individual. Medical decisions in end-of-life care however, are relatively more difficult since they involve the allocation of scarce life-sustaining treatments that cannot be provided to every patient.

The above form of rationing for patients at the end of life which is referred to as "micro allocation" involves creating a just balance between several criteria: (1) the treatment's likelihood of success, so that scarce resources are distributed to patients who can

²³ S Coppa, "Futile Care: Confronting the High Costs of Dying.," (1996) 26(12) *The Journal of Nursing Administration* 18.

²⁴ Cavalieri, 618.

²⁵ See Beauchamp and Childress, 195-199; Kinsella and Booth, 387; McMurray et al, 4.

reasonably benefit from it; (2) medical utility, which focus on maximising a patient's welfare and needs; and (3) the avoidance of wastage and inappropriate utilisation of resources that can be applied towards treating and saving more people.²⁶ Some ethicists aver that the rule of justice must also be applied in cases where a terminally ill and/or dying patient requests for certain medical therapies to be continued, by evaluating such a decision against the consequential benefits and costs.²⁷ Thus, it is ethically acceptable for health care providers to deny the patient's demands if there is cogent evidence that the treatment requested carries little or no benefit, or when inordinate public funds would be needed to provide such treatment which would result in an inefficient use of resources. It is important to note however that doctors should not withhold or withdraw treatment solely on the basis of resource constraints, but instead to prudently balance their professional obligations in delivering a good standard of care towards patients with their duties towards funding bodies and society at large.²⁸

The Islamic Perspective on Economic Considerations in End-of-Life Care

The most pronounced and distinctive precept in Islam is the belief in One God i.e. monotheism. The very purpose of all creation is to submit to and worship God, by obeying His divine law. The *shari'ah* or Islamic law is based on two primary sources: (a) the Qur'an, which is the Glorious Book which Muslims believe to be the word of God. This is affirmed at the start of the second chapter, where God declares, "This is the Book about which there is no doubt, a guidance for those conscious of Allah." (*Surah al-Baqarah* 2:2); and (b) the *Sunnah* of Prophet Muhammad (pbuh)²⁹. The important and sacred

²⁶ See Beauchamp and Childress, 264-272.

²⁷ See Meisel A, "End-of-Life Care" in Crowley M (ed), *From Birth to Death and Bench to Clinic: The Hastings Center Bioethics Briefing Book* (The Hastings Center, Garrison, New York, 2008), 53.

²⁸ General Medical Council, "Treatment and Care towards the End of Life: Good Practice in Decision Making," 2010, <http://www.gmc-uk.org/guidance>.

²⁹ This refers to the words, conduct and tacit approval of the Prophet (peace and blessings be upon him).

position of the *Sunnah* of the Prophet (pbuh) as the second primary source of the *shari'ah* is confirmed by many verses in the Qur'an, for example in *Surah al-Nisa'*, 4:59: "O you who have believed, obey Allah and obey the Messenger and those in authority among you. And if you disagree over anything, refer it to Allah and the Messenger, if you should believe in Allah and the Last Day. That is the best [way] and best in result." Muslims are therefore commanded by God to study the life of the Prophet (pbuh), obey him and emulate his attributes and mannerisms in order to attain success in this world and the afterlife. For Muslims the Prophet (pbuh) is the embodiment of perfect human conduct: "There has certainly been for you in the Messenger of Allah an excellent pattern for anyone whose hope is in Allah and the Last Day and [who] remembers Allah often." (*Surah al-Ahzab*, 33:21). The *Sunnah* serves a key role in reiterating and explaining *Qur'anic* injunctions; God confirms this in *Surah al-Nahl*, 16:44: "[We sent them] with clear proofs and written ordinances. And We revealed to you the message that you may make clear to the people what was sent down to them and that they might give thought." The *Sunnah* of the Prophet (peace and blessings be upon him) is recorded in the form of narrations made by the companions of the Prophet (peace and blessings be upon him) which are known as *hadith*.

In the absence of any direct ruling on a specific matter in the primary sources, Islamic jurisprudence allows for the application of *ijtihad*, generally translated as deductive reasoning. The position of *ijtihad*, as the secondary source of the *shari'ah* is affirmed in the following *hadith*: "When the Messenger of Allah (peace and blessings be upon him) intended to send Mu'adh ibn Jabal to the Yemen, he asked: How will you judge when the occasion of deciding a case arises? He replied: I shall judge in accordance with Allah's Book. He asked: (What will you do) if you do not find any guidance in Allah's Book? He replied: (I shall act) in accordance with the *Sunnah* of the Messenger of Allah (peace and blessings be upon him). He asked: (What will you do) if you do not find any guidance in the *Sunnah* of the Messenger of Allah (peace and blessings be upon him) and in Allah's Book? He replied: I shall do my best to form an opinion and I shall spare no effort. The Messenger of Allah

(peace and blessings be upon him) then patted him on the breast and said: Praise be to Allah Who has helped the messenger of the Messenger of Allah to find something which pleases the Messenger of Allah.”³⁰ The deduction of rulings from the sources of the *shari‘ah* is regulated by the methodological principles of Islamic jurisprudence (*usul al-fiqh*). These principles aim to guide the Muslim jurist to gain proper knowledge of the sources of the *shari‘ah* and the methodology of juridical deduction and inference, and to distinguish and select between the methods to best address a particular issue which is closest to the relevant unequivocal text in the sources of the *shari‘ah*.³¹ *Ijtihad* is thus the dynamic arm of the *shari‘ah*, which enables the latter to respond to novel and contemporary problems that may arise from time to time, and for which no clear definitive ruling can be found in the sources of the *shari‘ah*.³² The guiding principles, rules and regulations in the main sources govern the Islamic way of life, and together with *ijtihad* provide a comprehensive moral and juridical framework to address and accommodate issues relating to human conditions.³³

One of the main characteristics of Islamic jurisprudence is that each deliberation in resolving any given issue must observe the fundamental objectives of the *shari‘ah*, which are properly known as *maqasid al-shari‘ah*. These comprise the protection of one’s faith and belief, preservation of life, protection of progeny, maintenance of intellect, and preservation of property or wealth. Al-Raisuniyy defined *maqasid al-shari‘ah* as the objectives or aims of the *shari‘ah* for the sake of the human being’s best interests.³⁴ Wahbah al-Zuhailiyy stated that the term basically means meanings and purposes that are of concern in law (in all parts or some of it) or the goal of the laws and the wisdom underlying the promulgation of each

³⁰ *Sunan Abi Dawud*, Book 24, Number 3585 < http://sunnah.com/abudawud/25 [accessed 14 November 2014]

³¹ Kamali MH, *Principles of Islamic Jurisprudence* (Pelanduk Publications, Petaling Jaya, 1989), 3-4.

³² Gatrad AR and Sheikh A, “Medical Ethics and Islam: Principles and Practice.” (2001) 84 *Arch. Dis. Child.* 72, 73.

³³ *Ibid.*

³⁴ Ahmad al-Raisuniyy, *Nazariyyat al-Maqasid^cInda al-Imam al-Shatibi*, 19.

law.³⁵ According to Ibn ʿAshur, the general rules of *maqasid al-shariʿah* are aimed at preserving the social order of the community and to ensure its healthy process by promoting the well-being and righteousness of that which prevails in it, namely mankind. The well-being and virtue of human beings consist of the soundness of their intellect, the righteousness of their deeds as well as the goodness of the things of the world where they live that are put at their disposal.³⁶

To summarise the above, the term *maqasid al-shariʿah* thus refers to the objectives that Islam seeks to achieve by implementing its legal rulings. It forms the basis or starting point for Muslim jurists in deriving legal rulings for general or specific situations or incidents, and acts as a benchmark for Muslim jurists to arrive at correct and proper decisions, ensuring that they do not contradict the spirit of the *shariʿah*. In short, the understanding of *maqasid al-shariʿah* assists the process of *ijtihad* by leading jurists in the right direction.³⁷

Medical decision making in Islam must therefore operate within the ethical framework imbued in *maqasid al-shariʿah*, in that any medical action must observe and fulfil one of the purposes of the *shariʿah* in order for it to be ethical; conversely, infringement of any of the fundamental objectives would render such action impermissible.³⁸ The application of *maqasid al-shariʿah* in the context of medical practice can be examined and construed as follows.³⁹

(1) ***Protection of one’s faith and belief.*** This can be viewed from

³⁵ Wahbah al-Zuhailiyy, *Usul al-Fiqh al-Islami*, vol. 2, (Damsyik: Dar al-Fikr, 1996), 1017.

³⁶ Ibn ʿAshur, *Ibn ʿAshur: Treatise on Maqasid al-Shariʿah*, trans. Muhammad el Tahir el Mesawi, (Petaling Jaya, Islamic Book Trust, 2006), 87.

³⁷ See Yusuf al-Qaradawiyy, *Dirasah fi Fiqh Maqasid al-Shariʿah: Bayna al Maqasid al Kuliyyah wa al Nusus al Juz’iyyah*, (Cairo: Dar Al Shuruq, 2006).

³⁸ Rathor MY, Abdul Rani MF, Mohamad Shah AS, Leman WI, Sheikh Farid UA and Omar AM, “The Principle of Autonomy as Related to Personal Decision-Making Concerning Health and Research from an ‘Islamic Viewpoint’” (2011) 43 *JIMA* 27, 28; Kasule O, “Medical Ethics From Maqasid Al Shari’at” (2004) *Arab J. Psychiatry*; Saifuddeen SM, Rahman NNA, Isa NM and Baharuddin A, “Maqasid Al-Shariah as a Complementary Framework to Conventional Bioethics” (2013) *Sci. Eng. Ethics* 1, 7.

³⁹ See Kasule, “Medical Ethics From Maqasid Al Shari’at.”

two perspectives: (a) the role that medicine plays in order to enable a Muslim patient to perform acts of worship i.e. his duties and obligations to God, his family members and society at large, by promoting and maintaining the patient's mental and physical well-being; and (b) the Islamic philosophy on obedience and accountability to God denotes that any medical action must not be inconsistent with the rulings laid down in the sources of the *shari'ah*.

- (2) **Preservation of life.** The purpose of medicine is to help cure illness and alleviate pain and suffering, which in essence ensures that the quality of life is preserved as far as possible. Muslims believe death is definite and is the sole prerogative of God, and thus any act to hasten or delay the dying process goes against the spirit of the *shari'ah* and is strictly forbidden. Medical treatment protects the sanctity of life by contributing towards the maintenance and continuance of one's physiological functions until the moment of death arrives.
- (3) **Protection of progeny.** Medical care and research in relevant fields such as obstetrics, gynaecology, paediatrics and reproductive medicine are instrumental in advancing the well-being of both parents and child during the various stages of fetal development, from conception to birth and the post-natal phase. The promotion of good health also serves to contribute to a good lineage of descendants.
- (4) **Maintenance of intellect.** Mental awareness and clarity of mind are important in the life of a Muslim not only due to the imperative significance Islam places on one's accountability for his every conduct, but also because the impairment of cognitive faculties may lead to immoral and harmful acts. Medicine helps to preserve and improve one's psychological state and intellectual function not only by curing the body from physical infirmity but also mental illnesses.
- (5) **Preservation of property and wealth.** A community's state of health has a significant bearing on its level of fiscal productivity and accrual of revenue. Healthy members of society are able to effectively contribute to economic growth on both micro and macro levels, thus leading to an increase in

a state's wealth and improved standards of living. Medicine thus plays an important role in ensuring that a community as a whole is able to benefit from the optimal utilisation of human resource.

Life-sustaining therapy involves the utilisation of resources which are costly and are often limited in availability. Consequently, Islam recognises resource allocation in end-of-life care as a legitimate concern where doctors may face the challenging decision whether one patient is better entitled to the limited equipment and treatment than the other. Competition for the same scarce resources in the delivery of end-of-life care is to be examined in the light of two objectives of the *shari'ah* namely, the preservation of life and the protection of property. The underlying considerations in balancing between both interests lie in a patient's quality of life, which is intrinsically linked to considerations of futility and the need to avoid putting such resources to waste.

Islam discourages wasting in any form, as enunciated in the Qur'an, "...and do not spend wastefully. Indeed, the wasteful are brothers of the devils, and ever has Satan been to his Lord ungrateful."⁴⁰ Applying limited resources which are subject to competing demands in cases where the patient's condition is unlikely to improve from it and recovery is dismal, would be regarded as a waste when it can be used to benefit patients who have a better prognosis of being cured.⁴¹ There is accordingly no obligation for doctors to administer or continue treatment that would not provide a better quality of life to the patient.⁴² Thus, in futile cases where death is inevitable, the preservation of life concedes to the protection of property i.e. medical resources. According to a well-known

⁴⁰ *Surah al-Isra'*, 7:26-27.

⁴¹ Omar Hasan Kasule, "Artificial Life Support," *Islamic Medical Education Resources*, 2006, <http://omarkasule-tib.blogspot.my/2011/05/0608231-artificial-life-support.html>. Abu-El-Noor and Abu-El-Noor, 12.

⁴² Abu Fadl Mohsin Ebrahim, "End of Life Issues: Making Use of Extraordinary Means to Sustain Life" in Federation of Islamic Medical Associations, *FIMA Year Book 2005-2006: Geriatrics and End of Life Issues: Biomedical, Ethical & Islamic Horizons* (Jordan Society for Islamic Medical Sciences, 2006), 74.

contemporary Islamic jurist, Yusuf al-Qaradawiyy, it is lawful to withdraw life support systems from patients suffering from brain death.⁴³ Without these machines, death would be inevitable for such patients and thus the function of the machines would be to merely prolong the process of death. Furthermore, since such machines are expensive and scarce it would not be possible to provide them to all patients. Thus, such treatment should be given to those who have a better prospect of recovery rather than to those whose deaths are unavoidable.⁴⁴

Allowing the distribution of resources to patients who may better benefit from them complies with the juridical principle that allows for one to choose the lesser of two evils in order to achieve the greater good: *dafu a'dham al-mafsadaini bihtimal aisarihima*⁴⁵ as well as *al-maslahatu al-ammatu muqaddamatun ala al-maslahatu al-khassah* where public interest is to be given priority over the consideration of individual interests. The principle of repelling the greater harm by bearing the lesser of the two is discernible from a *hadith* narrated by Anas bin Malik: "A Bedouin came and passed urine in one corner of the mosque. The people shouted at him but the Prophet stopped them till he finished urinating. The Prophet (pbuh) ordered them to spill a bucket of water over that place and they did so."⁴⁶ In his commentary, Ibn Hajar al-Asqalaniyy explained that the Prophet (pbuh) ordered his Companions to do so in order to avoid a greater harm (which among others, would have been the untoward soiling of a wider area of the mosque) by suffering a lesser harm.⁴⁷ Thus, an individual may have to sustain a harm in order to protect and prevent harm to a larger group of people: *yatahammalu al-darar al-khas li dafi al-darar al-am*.⁴⁸ In Islam it may be necessary in

⁴³ Yusuf al-Qaradawiyy, *Fatawa Mu'asirah*, vol. 2, (Egypt: Dar al-Wafa il al-Tiba'ah wa al-Nashr wa al-Tawzi', 1993), 527-529.

⁴⁴ Ibid.

⁴⁵ This can be translated as "warding off the greater of two evils by committing the lesser."

⁴⁶ *Sahih al-Bukhariyy*, Book 4 (Book of Ablutions (Wudu')), Hadith no. 88, <http://sunnah.com/bukhari/4>.

⁴⁷ Ibn Hajar al-Asqalani, *Fathul Baari: Penjelasan Kitab Shahih al-Bukhari*, vol. 2 (Jakarta, Pustaka Azaam, 2006), 283-284.

⁴⁸ Kasule, "Medical Ethics From Maqasid Al Shari'at."

such a situation to: (1) examine and contemplate the needs of two individuals competing for the same resources, and (2) to balance between individual interests and societal needs.⁴⁹ Applying this to an end-of-life care setting, the greater good would thus be in the form of preserving limited resources and benefitting other lives, which is to be weighed against the lesser harm of withholding or withdrawing the utilisation of such resources from patients with no hope of eventual recovery.

Justifying the allocation of limited resources on the necessity of preserving property can also be viewed from a different perspective. Medical interventions in end-of-life care incur heavy expenses which may be inordinately burdensome on family members or state resources. Such expenditure could be better applied to sustain the patient's family who may have limited means of financial support and, in the case of state funding, such costs could be utilised for the care of members of the community who are in dire need such as orphans as well as the poor and underprivileged.⁵⁰ Accordingly, Islam does not impose any obligation upon Muslims to persist in seeking life-sustaining treatment for their family members if it places them in a lot of difficulty.⁵¹

The concept of justice is an integral essence of Islamic philosophy and is commanded to be applied in all aspects of life. The importance of upholding justice is mentioned numerous times in the Qur'an, among others in *Surah Al-Nahl*, 16:90: "Indeed, Allah orders justice and good conduct and giving to relatives and forbids immorality and bad conduct and oppression. He admonishes you that perhaps you will be reminded." The duty to establish and implement justice is a trust from God to all mankind and served as the main purpose for which the prophets were sent: "Indeed, Allah

⁴⁹ Choong K and Chandia M, "Technology at the End of Life: 'Medical Futility' and the Muslim PVS Patient" (2014) 2013 *Int. Rev. Law* 9, 13.

⁵⁰ Kasule, OH, "Rulings on Euthanasia from the Perspective of Purposes (*Maqasid*) and Principles (Qawa'id) of the Islamic Law (Al-Shari'ah)" in Federation of Islamic Medical Associations, *FIMA Year Book 2005-2006: Geriatrics and End of Life Issues: Biomedical, Ethical & Islamic Horizons* (Jordan Society for Islamic Medical Sciences, 2006), 92.

⁵¹ *Ibid*; Abu Fadl, "End of Life Issues: Making Use of Extraordinary Means to Sustain Life", 74.

commands you to render trusts to whom they are due and when you judge between people to judge with justice. Excellent is that which Allah instructs you. Indeed, Allah is ever Hearing and Seeing;”⁵² and in another Qur’anic verse: “We have already sent Our messengers with clear evidences and sent down with them the Scripture and the balance that the people may maintain [their affairs] in justice.”⁵³

Islam considers justice in resource allocation to be one of the most fundamental components in state governance for the creation of a just and equitable society. Reciprocal responsibility in ensuring that the welfare of others is taken care of is integral in maintaining social balance. Wealth must therefore not circulate only among the affluent.⁵⁴ “And what Allah restored to His Messenger from the people of the towns - it is for Allah and for the Messenger and for [his] near relatives and orphans and the [stranded] traveller - so that it will not be a perpetual distribution among the rich from among you. And whatever the Messenger has given you - take; and what he has forbidden you - refrain from. And fear Allah; indeed, Allah is severe in penalty.”⁵⁵

Distributive justice in Islam thus consists of the following three elements:⁵⁶ (a) guarantee of fulfilment of each person’s basic needs; (b) equity but not equality in personal incomes; and (c) elimination of extreme inequalities in personal income and wealth. The Islamic socio-economic philosophy recognises that when the minimum needs of every member of society have been satisfied, the reality of relational differences in personal incomes is justifiable based on merit.⁵⁷ Inequality in the quantum of earnings is therefore valid if it is predicated on differential abilities and contributions of

⁵² Al-Qur’an, *Surah al-Nisa’*, 4:58.

⁵³ Al-Qur’an, *Surah al-Hadid*, 57:25.

⁵⁴ Mohammad Reza Heidari, “A Comparative Analysis of Distributive Justice in Islamic and Non-Islamic Frameworks,” in *2nd Islamic Conference (IECONS2007)* (Faculty of Economics and Muamalat, Universiti Sains Islam Malaysia, 2007).

⁵⁵ Al-Qur’an, *Surah al-Hashr*, 59:7.

⁵⁶ Ahmad K and Hassan A, “Distributive Justice: The Islamic Perspective” (2000) 8 *Intellect. Discourse* 159, 164.

⁵⁷ See Zubair Hasan, “Distributional Equity in Islam,” in *Distributive Justice and Need Fulfilment in an Islamic Economy*, 1988, 35–62; Ahmad and Hassan, “Distributive Justice: The Islamic Perspective.”

each individual. This is based on the Qur'anic wisdom found in *Surah al-Nisa'*, 4:32, which also contains a reminder for mankind to not envy or resent the provision that others have been given: "And do not wish for that by which Allah has made some of you exceed others. For men it is a share of what they have earned, and for women it is a share of what they have earned. And ask Allah of his bounty. Indeed Allah is ever, of all things, Knowing."

There is a paucity of literature which focuses on addressing the concept of justice in the context of Islamic bioethics, although in practice many Muslim doctors consider the principle to be paramount.⁵⁸ Jurisprudentially, the same precepts of distributive justice in Islam can be made applicable to the issue of resource allocation in end-of-life care. Thus, every patient must not be denied his/her basic right to receive proper medical treatment. At the same time however Islam recognises that in terms of therapeutic interventions, it is justified to withdraw or withhold them from patients who will obtain no benefit from such therapy. Such relational difference in treatment is considered valid based on the varying needs and conditions of each patient.

Addressing Economic Considerations in Managing End-of-Life Care in Malaysia

The evidence of a clear nexus between medical futility and economic considerations necessitates deliberation on how futility itself should be ascertained, to ensure the effective delivery of end-of-life care. Those who advocate medical futility as a legitimate and viable justification for withholding or withdrawing life-sustaining therapy argue that it should not be perceived as sounding the death knell for terminally ill patients and denying them medical care. First and foremost, futility can be determined by balancing between both objective and subjective elements:⁵⁹ (a) effectiveness of the therapy

⁵⁸ See Kiarash Aramesh, "Justice as a Principle of Islamic Bioethics.," (2008) 8(10) *The American Journal of Bioethics : AJOB* 26, doi:10.1080/15265160802485052.

⁵⁹ Edmund D Pellegrino, "Decision at the End of Life : The Use and Abuse of the Concept of Futility," in *The Dignity of the Dying Person*, ed. Juan De Dios Vial Correa and Elio Sgreccia (Vatican City: Libreria Editrice Vaticano, 2000), 85–110, 93.

in treating the underlying pathology which is measured based on the patient's medical prognosis, likelihood of recovery and physiological status; (b) the patient's assessment as to whether such therapy is beneficial and worthwhile, depending on his or her personal values and goals; and (c) the burden that such therapy would impose on the patient in terms of physical, psychological, economic and social implications. Whether a medical intervention is morally justified is thus contingent upon a finding that all three components are favourable to the patient's best interests. Secondly, a doctor who is bound to abide by the ethical obligations of beneficence and non-maleficence would never rule out or refuse to provide any treatment that would benefit his or her patient.⁶⁰ A determination of futility does not in any way vitiate the doctor's continuous duty to palliate and provide symptomatic relief to the patient, and ensure the patient's comfort as he or she nears the end of life.

With respect to the economic considerations that may be involved, it has been suggested that these may be addressed by properly instituting policies and guidelines on futility and implementing advance care planning⁶¹ Advance care planning which entails the issuance of advance directives, helps to instruct patients as to their autonomous rights and provides them the option of choosing alternative care programmes such as hospice care over aggressive life-sustaining treatments. This will serve to facilitate the decision-making process, allowing doctors to assess their patients' needs and wishes while respecting the latter's preferences on how they wish to be cared for at the end of life, and consequently allow for more efficient apportionment of health care resources.

The existence of a valid advance directive acts as a guide for

⁶⁰ University of Minnesota: Centre for Bioethics, 3.

⁶¹ Susan E Sheehan, 'On Roses and Rationing: The Economics of Health Care Access' (2004) 4 *Praxis* 22, 24-25; Coppa. Writers such as Truog and Kapp disagree that such measure would be effective in the proper allocation of resources. They contend that it is very unlikely that futility can be determined objectively and does not constitute a just method of balancing between the needs of an individual with societal interests. See Robert D Truog, Allan S Brett, and Joel Frader, "The Problem with Futility," in *Health Care Ethics in Canada*, ed. Françoise Baylis et al., 3rd ed. (Toronto: Nelson Education Ltd, 2011), 408-14; Kapp, "Economic Influences on End-of-Life Care: Empirical Evidence and Ethical Speculation."

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. 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.⁶² The implementation of advance directives thus enables a more functional allocation of expensive life-sustaining medical equipment, especially in institutions that have limited health care budgets.⁶³ From the personal viewpoint of the patient and family members, an advance directive provides a formal assurance that health care decisions will conform to the patient's 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.⁶⁴

Currently however, there is no regulatory instrument that specifically addresses the issue of advance care planning or advance 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 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

⁶² Kristina Stern, "Advance Directives," (1994) 2 *Medical Law Review* 57, 69 doi:10.1093/medlaw/2.1.57.69.

⁶³ RE Astroff, "Who Lives, Who Dies, Who Decides: Legal and Ethical Implications of Advance Directives," (1997) 7(1) *Windsor Rev. Legal & Soc. Issues* 1, 13.

⁶⁴ *Ibid.*, 12-13; Edmund D. Pellegrino and David C. Thomasma, *For the Patient's Good: The Restoration of Beneficence in Health Care* (New York: Oxford University Press, 1988), 136-147; Alexander Morgan Capron, "Advance Directives," in *A Companion to Bioethics*, ed. Helga Kuhse and Peter Singer, 2nd ed. (West Sussex: John Wiley & Sons, 2009), 299-311., 301.

Appendix IV. Principle 5 of 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 directive.⁶⁵ It also highlights the importance of advance care planning particularly with respect to life-sustaining treatment and palliative measures that might hasten death. In addition, the importance of advance directives is recognised under Clause 18 of the guideline issued by the Malaysian Medical Council on consent for treatment (Consent Guideline).⁶⁶ The relevant details under Clause 18 (Advance Care Directives or Living Wills) 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)
 - (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

⁶⁵ World Medical Association, "WMA Declaration of Venice on Terminal Illness," October 2006, <http://www.wma.net/en/30publications/10policies/i2/index.html>.

⁶⁶ Malaysian Medical Council, "Consent for Treatment of Patients by Registered Medical Practitioners," 2013, [http://medicalprac.moh.gov.my/v2/uploads/Consent Guidelines - Adopted 20131126 \(2\)-A.pdf](http://medicalprac.moh.gov.my/v2/uploads/Consent%20Guidelines%20-%20Adopted%2020131126%20(2)-A.pdf).

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 colleagues 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.

The Consent Guideline however does not address all relevant aspects pertaining to advance directives such as the considerations in ascertaining the patient's competency and best interests, and provides no clear guidance as to how doctors should initiate and carry out advance care planning and draw up advance directives.

One of the basic difficulties in advance directives is in stipulating its contents. Some people might find it an arduous task to express or formulate with certainty their wishes regarding a future medical situation. 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.⁶⁷ The terms used in an advance directive may also complicate the process of preparing the instructions. For instance 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.⁶⁸ 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. A balance has to be

⁶⁷ David Shaw, "A Direct Advance on Advance Directives," (2012) 26(5) *Bioethics* 267, 273 doi:10.1111/j.1467-8519.2010.01853.x.; Capron, "Advance Directives", 302; Andorno, Biller-Andorno, and Brauer, "Advance Health Care Directives: Towards a Coordinated European Policy?" (2009) 16 *European Journal of Health Law* 207, 209 doi:10.1163/157180909X453053.; Nanovic, Susan J. "Living Will: Preservation of the Right-to-Die Demands Clarity and Consistency." (1990) 95 *Dick. L. Rev.* 209, 215.

⁶⁸ Capron, "Advance Directives", 302; Nanovic, "Living Will: Preservation of the Right-to-Die Demands Clarity and Consistency.", 215; Astroff, "Who Lives, Who Dies, Who Decides: Legal and Ethical Implications of Advance Directives.", 9.

accordingly 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.⁶⁹ 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.⁷⁰

Evidently, the most challenging aspect of the effective implementation of advance care planning and advance 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 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 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.⁷¹ Further, 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.⁷² Inadequate information hinders the patient from making an autonomous decision and would thus cast serious doubts on the validity of his advance directive.⁷³ Effective communication is thus

⁶⁹ Capron, "Advance Directives.", 303.

⁷⁰ Astroff, "Who Lives, Who Dies, Who Decides: Legal and Ethical Implications of Advance Directives." 10.

⁷¹ Capron, "Advance Directives.", 304, 309; Pérez MD V, Macchi MJ and Agranatti AF, "Advance Directives in the Context of End-of-Life Palliative Care." (2013) 7 *Curr. Opin. Support. Palliat. Care* 406, 408.

⁷² Capron, "Advance Directives.", 304; Pérez, Macchi, and Agranatti, "Advance Directives in the Context of End-of-Life Palliative Care.", 407.

⁷³ Pérez, Macchi, and Agranatti, "Advance Directives in the Context of End-of-Life Palliative Care.", 407.; Shaw, "A Direct Advance on Advance Directives", 273; A.

the key and to address this, it is suggested that modules and training programmes on advance care planning should be drawn up to include this skill and impart the requisite knowledge to health care practitioners.

From the Islamic standpoint, some Muslim jurists contend that the concept of advance directives is consistent with Islamic teachings and was practised even in the time of the Prophet Muhammad (pbuh).⁷⁴ When the Prophet (pbuh) became terminally ill there were times when he would lose consciousness. On 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.⁷⁵ This situation was enunciated in the following *hadith*: “It was narrated by Ibn ‘Abbas and ‘Aisha r.a. that: “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, “None of those who are in the house but will be forced to take medicine in the side of his mouth while I am watching, except Al-'Abbas, for he had not witnessed your deed.”

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

R. Maclean, “Advance Directives, Future Selves and Decision-Making,” (2006) 14(3) *Medical Law Review* 291, 292, doi:10.1093/medlaw/fw1009.

⁷⁴ See for instance, Hamdan Al-Jahdali et al., “Advance Medical Directives: A Proposed New Approach and Terminology from an Islamic Perspective,” (2012) 16(2) *Medicine, Health Care and Philosophy* 163, doi:10.1007/s11019-012-9382-z; FA Khan, “Religious Teaching and Reflections on Advance Directive-Religious Values and Legal Dilemmas in Bioethics: An Islamic Perspective,” (2002) 30(1) *Fordham Urb. LJ* 267.

⁷⁵ *Sahih al-Bukhari*, Vol. 7, Book 71, *Hadith* 610.

wishes.⁷⁶ In recognition of this principle, the issuance of advance directives is incorporated in the recommendations made by IMANA for the health care of Muslim patients.⁷⁷ 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.

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* (legal guardian) upon obtaining the opinion and advice of doctors.⁷⁸ Proponents of this view base this on the role of the *wali* expounded in the Qur'an in *Surah al-Nisa'*, 4:6: "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 responsibility of a *wali* to manage the proprietary affairs of the vulnerable is thus, by deduction, made applicable to that of medical decisions made on behalf of incompetent patients. This is articulated in a religious edict issued by the Saudi Council of Senior Scholars, in which it was unanimously agreed that, "it is not permissible to operate on a patient without their 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."⁷⁹ Therefore

⁷⁶ Al-Jahdali H, Baharoon S, Al Sayyari A and Al-Ahmad G, "Advance Medical Directives: A Proposed New Approach and Terminology from an Islamic Perspective" (2012) 16 *Med. Heal. Care Philos.* 163, 167.

⁷⁷ IMANA Ethics Committee, "Islamic Medical Ethics : The IMANA Perspective," (2005) 37 *JIMA* 33.

⁷⁸ Noor Naemah Abdul Rahman, Ridzwan Ahmad, and Luqman Abdullah, "AMD Dan Beberapa Persoalan Hukum," in *Arahan Perubatan Awal: Perspektif Bioetika Islami*, ed. Shaikh Mohd Saifuddeen Shaikh Mohd Salleh and Mohammad Mustaqim Malek (Kuala Lumpur: IKIM Press, 2017).

⁷⁹ Decree of the Council of Senior Scholars no. 119, "Performing Surgery without

during the period of incapacity, the *wali* is conferred the right to decide for the patient. 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 as laid down in the Qur'an in *Surah al-Isra*, 17:34: "And do not approach the property of an orphan, except in the way that is best, until he reaches maturity. And fulfill [every] commitment. Indeed, the commitment is ever [that about which one will be] questioned." Accordingly, this is to be achieved through consultation and a mutual decision-making process with medical experts.

Conclusion

Economic considerations constitute an intrinsic component of end-of-life care, in which doctors have to balance the interests of the individual patient with that of other patients against the limited availability of resources. Ensuring the just apportionment of such resources is an ethical dilemma that weighs heavily on the part of the decision makers. Accordingly, such decisions cannot be solely based on resource constraints, but must solicitously take into account considerations of medical futility and a doctor's professional obligation to deliver good quality care to the patient and society at large. If a decision to withhold or withdraw life-sustaining interventions is made, it is important for doctors to reassure the patient's family that the welfare of the terminally ill patient will not

the Consent of the Patient or Their Guardian," *General Presidency of Scholarly Research and Ifta'*, accessed December 18, 2018, <http://www.alifta.com/Search/ResultDetails.aspx?language=en&lang=en&view=result&fatwaNum=&FatwaNumID=&ID=175&searchScope=17&SearchScopeLevels1=&SearchScopeLevels2=&highLight=1&SearchType=exact&SearchMoesar=false&bookID=&LeftVal=0&RightVal=0&simple=&Se>.

be prejudiced or neglected, and that doctors will continue to provide compassionate care and comfort to such patient.

To this end, there is a need for the issuance of proper directives on the ascertainment of futility as well as advance care planning, to facilitate doctors in dealing with economic considerations in the provision of end-of-life care. As illustrated in the preceding paragraphs, the significance and implementation of advance medical directives also constitutes a valid instrument from the Islamic perspective to address the issue, with the involvement of the patient's *wali*. It is suggested that such protocols or guidelines should come from the Malaysian Medical Council as the authoritative body governing all divisions of medical practice, in order to provide uniformity and lay down a degree of compliance on the part of health care practitioners. In addition, regulating the use of advance directives will 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, thus preventing potential abuse.

Ultimately, medical decision-making should not be purely clinical judgments but a concerted effort between doctor and patient. Knowledge, understanding and effective communication are therefore fundamental, and this necessitates a structured approach to guide health care personnel in discerning ethical justifications in end-of-life decisions. This allows for better conciliation and leads to a smoother and efficacious process of shared decision-making that is intrinsically valuable in modern medical practice.

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