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The Law and Practice of Advance Directives and End-of-Life Care in Malaysia

SHARON KAUR, THOMAS TAN HOOI WANG, JENNY KA YAN YAU & RICHARD BOON LEONG LIM

9.1 Introduction

Malaysia is a multicultural and multifaith society. Although Islam is recognised[1] as the religion of the Federation of Malaysia, the country's legal system is most accurately described as a hybrid system comprising both secular and Islamic laws. Islamic law is primarily limited to family law matters,[2] whereas most areas relating to the provision and regulation of healthcare are governed by secular laws. In general, there is little tension or overlap between the two legal systems. However, in a number of situations,[3] the courts have had to navigate a difficult path between the two, a task made all the more difficult by social, political and religious forces. Whilst there have to date been no legally contested cases involving advance directives (ADs) or end-of-life decisions in Malaysia, it is probably only a matter of time before cases involving these issues are raised.

At present, there is no specific legal regulation that addresses ADs or care at the end of life in Malaysia. However, in 2019, the Ministry of Health (MOH) published the National Palliative Care and Care Policy and Strategy Plan 2019–30,[4] which is meant to serve as a road map towards the achievement of good palliative care nationwide and the integration of palliative care into the national healthcare system. It has been estimated that 100,034 of the Malaysians who died in 2014 required

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[1] Federal Constitution of Malaya 1957, Art. 5.

[2] S.S. Faruqi, *Our Constitution* (Subang Jaya: Sweet & Maxwell, 2019), p. 44.

[3] For instance, the unilateral conversion of children to a different faith after a divorce or the right of transgender Muslims to cross-dress.

[4] Ministry of Health Malaysia, *National Palliative Care Policy and Strategic Plan 2019–2030* (October 2019), www.moh.gov.my/moh/resources/Polisi/BUKU_NATIONAL_PALLIATIVE_CARE_POLICY_AND_STRATEGY_PLAN_2019-2030.pdf.

palliative care, with that number slated to rise to approximately 230,000 by 2030.[5] Although the policy does not address the issue of ADs specifically, strategy 2 focuses on ensuring that all people should have "their needs recognised within the healthcare system and community they live in",[6] forming the basis for incorporating individual interests and values into palliative care. The implementation of training in advance care planning (ACP) as part of Malaysia's national palliative care strategy also constitutes a positive development, as advance care plans (ACPs) are commonly viewed as an important element of end-of-life care as a means of respecting the wishes of patients even once they have become incapacitated. Of course, the effective and meaningful implementation of ACPs depends on how well such plans are drawn up and the extent to which they are honoured. An important aspect of both is the development of good governance mechanisms. With respect to ADs in particular, both the Malaysian Medical Council (MMC) and MOH have published guidance documents in recent years.

Given the lack of formal legal recognition of ADs and ACPs and moves to embed the latter into palliative care practice in Malaysia, it is worth considering how the law potentially applies in situations in which particular decisions need to be made at the end of life and when the individual in question no longer has the capacity to decide.

This chapter considers the role of ADs in Malaysia, beginning with a discussion of the legal principles that are likely to apply in the end-of-life decision-making context. Section 9.2 then examines the professional guidance that has thus far been issued on ADs and highlights points of concern that such guidance has failed to address. Section 9.3 turns to consideration of the limited empirical data on AD awareness in Malaysia, followed by a discussion in Section 9.4 of the various sociocultural factors that may influence the acceptance of ADs, with a particular focus on the significant roles played by the family and physicians. Religion as a key influence is also explored in relation to Malaysian attitudes towards ADs.

9.1.1 Relevant Legal Principles in End-of-Life Decision-Making

Malaysia's legal system is made up of the Federal Constitution, or the "supreme law" of Malaysia,[7] acts enacted by Parliament and case law.

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[5] Ibid., p. 24.
[6] Ibid., p. 26.
[7] Federal Constitution of Malaysia 1957, Art. 4(1).

In some circumstances, English common law and equity principles may also apply. More specifically, the Civil Law Act of 1956 provides that common law principles may apply in cases "as the Circumstances of the States permit", with attention paid to the necessity of applying such principles in "local circumstances".[8] It is important to note, however, that the Civil Law Act stipulates that common law developments after 7 April 1956 cannot be considered by the Malaysian courts.[9] The language used in the Civil Law Act also indicates that "common law" refers to principles developed and followed in common law cases, not to common law statutes.[10] Thus, the only way in which such principles can be directly incorporated into Malaysian law and applied by the courts is for Parliament to enact laws that take into account common law developments subsequent to the aforementioned cut-off date.[11] However, the courts have allowed for the consideration of current common law principles in certain cases as being of persuasive authority, which suggests that Malaysian judges have the discretion to apply the common law principles of other Commonwealth jurisdictions to local cases if deemed necessary, even if said principles were developed after 1956.

Given that there are currently no statutes or regulations in Malaysia that specifically address the issue of ADs, it is possible that common law principles, particularly those on advance refusals and the right to refuse treatment more generally,[12] may be applied in cases concerning ADs.

In cases in which there is no evidence of advance decision-making, there is also no specific law in Malaysia that deals with the issues of incapacity and surrogate health decision-making. The only statute that makes some provision for surrogate decision-making is the Mental Health Act 2001 (MHA). The main purpose of the MHA is to provide for the compulsory detention and treatment of mentally ill persons who are deemed to pose a risk to others or to themselves.[13] Accordingly, in situations involving surrogate healthcare decisions, the Act is limited in

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[8] S.S.S. Ahmad, "Update: Introduction to the Malaysian Legal System and Sources of Law", GlobaLex (2014) , www.nyulawglobal.org/globalex/Sources_Law_Malaysia1.html.

[9] Ibid.

[10] Ibid.

[11] Ibid.

[12] *Re T (Adult: Refusal of Medical Treatment)* [1992] 3 WLR 782, [1992] 3 Med LR 306, [1992] 4 All ER 649 as an example.

[13] Mental Health Act 2001.

its application[14] and is usually considered a blunt instrument that does not engage with the challenges of trying to meet the needs of incapacitated individuals in a meaningful way.

Two additional points are worthy of note. The first is that individuals are not permitted to choose their own health proxies under the MHA because surrogate decision-makers are prescribed under section 77 of the Act and the courts are responsible for appointing a committee of the person under section 58.[15] Whilst the mental health context admittedly differs from the end-of-life decision-making context, the inability to choose one's own health proxy is in direct opposition to the philosophy of the AD, wherein individuals are afforded the freedom to choose healthcare proxies who are likely to share their values and interests.

The second point is that there is no oversight of surrogate decision-making under the MHA, and it appears that surrogates have unfettered discretion in making decisions on behalf of incapacitated individuals. There is nothing in the MHA that requires either the relatives or physicians of persons declared incompetent to make any sort of inquiry regarding those persons' interests. The only protection afforded a mentally disordered person is found in section 86,[16] which renders it an offence to ill-treat or wilfully neglect a patient. The section fails to recognise that it is possible to make a decision against the interests of a person, that is, to fail to respect his or her wishes and interests without being considered to have ill-treated or wilfully neglected him or her. The ethos of the MHA thus again appears to run contrary to the underlying tenets of ADs and ACP more generally, that is, to allow individuals to take control of decisions that affect their care and to promote patient autonomy.

9.2 Advance Directives: Professional Guidance

Although ADs are not subject to legal regulation in Malaysia, and whether common law principles apply remains unclear, there are professional guidelines in the country that touch upon ADs. This section discusses the professional guidance issued by the MMC and MOH.

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[14] For example, situations in which proxies are appointed are limited to specific interventions under section 77 and to instances in which a person is a danger to him or herself, wherein a committee is appointed under section 58.

[15] Mental Health Act 2001, ss. 77, 85.

[16] Mental Health Act 2001, s. 86.

9.2.1 Guidance from the Malaysian Medical Council

The MMC is constituted under the Medical Act 1971 as the regulator of physicians in Malaysia, and therefore has disciplinary jurisdiction over all registered physicians in the country.[17] Whilst guidelines issued by the MMC are not legally binding, a physician who fails to comply with them may be subject to the council's disciplinary jurisdiction.[18] The Medical Act provides the MMC with wide disciplinary powers that range from reprimanding practitioners to striking their names off the Malaysian Medical Register.[19] The MMC may also refuse to renew physicians' annual practising certificates.[20] Two of the guidance documents issued by the MMC touch upon ADs: (i) the Guidelines on Consent for Treatment of Patients by Registered Medical Practitioners 2017[21] and (ii) the Code of Professional Conduct 2019.[22]

9.2.1.1 Guidelines on Consent for Treatment of Patients by Registered Medical Practitioners (2017)

Clause 18 of the 2017 Guidelines states that doctors "should refrain from providing treatment or performing any procedure where there is an unequivocal written directive by the patient that such treatment or procedure is not to be provided in the circumstances which now apply to the patient (Advance Care Directive)".[23] However, the clause does not apply when the directive contains instructions for such illegal activities as euthanasia or the termination of a pregnancy. In addition, medical practitioners are advised to consider the following:

(i) Whether the directive is sufficiently clear and specific to the circumstances that have arisen;
(ii) Whether the directive was made in contemplation of the current situation; and
(iii) Whether there is any reason to doubt the patient's competence or voluntariness at the time of making the directive (in terms of being subject to undue pressure).[24]

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[17] Medical Act 1971, s. 4.

[18] Medical Act 1971, s. 29(2)(b).

[19] Medical Act 1971, s. 30, 19.

[20] M.K.M. Tan, "Considerations for Introducing Legislation on Advance Decisions in Malaysia" (2018) 10 *Asian Bioethics Review* 87, 87.

[21] Malaysia Medical Council, *Guidelines on Consent for Treatment of Patients by Registered Medical Practitioners* (2017).

[22] Malaysia Medical Council, *Code of Professional Conduct* (2019).

[23] See note 21, para. 18.

[24] Ibid.

Clause 18 also goes on to provide the following:

> In an emergency, the medical practitioner can treat the patient in accordance with his or her professional judgment of the patient's best interests, until legal advice can be obtained on the validity or ambit of any Advance Care Directive that may have been given by the patient. Where there are concerns about the validity or ambit of an Advance Care Directive in a non-emergency situation, the medical practitioner should consult the patient's spouse or next of kin or legal guardian and the medical practitioner should also consider the need to seek legal advice and to discuss the issue with his or her Colleagues, or other clinicians involved in the patient's care. Such discussions should be documented in the patient's medical case notes.[25]

9.2.1.2 Code of Professional Conduct 2019

Clause 1.14 of the 2019 Code of Professional Conduct states that a practitioner may be confronted with a living will (or advance medical directive (AMD)[26]), which is a written statement detailing a person's desires regarding future medical treatment in circumstances in which he or she is no longer able to express informed consent.[27] Such circumstances may be imminent death, terminal illness or severe and irreversible conditions.[28] Any decision made by the practitioner to comply or not comply with the AMD must be made in consultation with the patient's relatives and next-of-kin.[29]

9.2.2 Guidance from the Ministry of Health

9.2.2.1 Guidelines for Resuscitation Training for Ministry of Health, National Committee on Resuscitation Training 2016 (NCORT Guidelines)

Part 6.4 of the NCORT Guidelines[30] contains a discussion on the ethics of resuscitation and end-of-life issues. Notably, in relation to resuscitation, the NCORT Guidelines recognise that there has been a shift in

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[25] Ibid.

[26] It is interesting to note that despite these documents being issued by the same entity, the words used to describe ADs are slightly different.

[27] See note 22, cl. 1.14.

[28] Ibid.

[29] Ibid.

[30] Ministry of Health Malaysia, *Guidelines for Resuscitation Training for Ministry of Health* (2016).

emphasis from a doctor-centred (beneficence) approach to a patient-centred (autonomy) approach.[31] Furthermore, they place the onus on healthcare providers to "equip themselves with sound knowledge in resuscitation and ethical issues pertaining to it in making end of life decisions".[32]

Paragraph 6.4.2, entitled "Advanced directives", specifically addresses the issue of ADs, stating that "Advanced medical plan and directives when made, should be clearly documented and visible in [the] patient's notes for other healthcare personnel to recognize on the spot. However, over time the situation or perspectives of [the] patient might change and do not attempt resuscitation (DNAR) orders should be revised accordingly. Exemption from DNAR should also be clearly specified".[33]

9.2.3 Discussion

The fact that the foregoing professional guidance exists despite the lack of a clear legal framework for ADs in Malaysia suggests that there is acknowledgment that ADs are being practised on the ground and that practice guidelines need to reflect that reality, as well as offer guidance on how healthcare professionals should deal with ADs even if the law does not do so. Thus, whilst the guidance documents discussed here are not legally binding, they can arguably play an important role in establishing the professional requirements of health professionals in practical settings even if those requirements are not underpinned by a formal regulatory framework. It is worthy of note, however, that none of the guidelines require healthcare professionals to take a proactive approach in encouraging patients to make an AD, or supporting them in doing so, as part of their responsibility to fulfil quality end-of-life

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[31] Ibid., para. 6.4.1.

[32] Ibid.

[33] Ibid., para. 6.4.2. Whilst the term "DNAR order" is used, it is unlikely that this paragraph refers to the type of order that is based on a doctor's clinical judgement of futility; rather, it likely refers to the type of AD that is patient led and that lays out the person's personal wishes concerning how he or she does not want to be treated. This is the case because in the following paragraph, which covers the withdrawal and withholding of therapy, the existence of an "advanced medical directive" is listed separately from other clinical considerations that might point to medical futility, and the existence of the "advanced medical directive" is in itself one of the situations in which a healthcare provider is expected to consider withholding or withdrawing cardiopulmonary resuscitation.

care requirements. Instead, the guidelines appear to be entirely reactive, focusing only on what healthcare professionals should do if they encounter an AD in their practice.[34]

Of the three guidance documents, the 2017 Guidelines provide the most detail on what medical practitioners should do when provided with an AD. They highlight several important factors that medical practitioners should consider, namely, clarity, applicability and whether there was voluntary consent, although there are no definitions of the terms "competence", "voluntariness" or "undue pressure".[35] The absence of such definitions is likely to render the operationalisation of the guidelines more difficult given the lack of guidance on how the aforementioned factors should be properly assessed. The need for clarity is emphasised by the requirement that any AD be "unequivocal",[36] although no such requirement is explicitly stated in the 2019 Code of Conduct. Both that document and the 2017 Guidelines indicate that doctors should implement an AD only when it is in a written format,[37] and the NCORT Guidelines suggest that ADs should be clearly documented in patients' medical records.

Both the 2017 Guidelines and the 2019 Code of Conduct also emphasise the importance of family involvement when it comes to the acceptance and implementation of a patient's AD. The former requires that a medical practitioner "consult the patient's spouse or next of kin" in a non-emergency situation, and the latter requires that the decision to implement an AD be made in consultation with the patient's family.[38,39] Whilst these requirements reflect the family-oriented approach in medical decision-making that is still very much followed in Malaysia, as further discussed in Section 9.4 of this chapter, none of the guidelines make reference to persons who may be nominated by patients as their

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[34] This claim is also supported by the fact that Hospis Malaysia, the largest hospice facility in Malaysia, notes in its brochure on "decision making for the end of life" that those who want to write an advance care plan should consult doctors about their wishes, suggesting that the initiative to draw up an AD is expected to be taken by patients themselves. See Hospis Malaysia, "Patient and Caregiver Resources" (2018), www.hospismalaysia.org/resources/.

[35] See note 21, para. 18.

[36] Ibid.

[37] In this vein, Tan notes that verbal requests are more common in the Malaysian setting, and it is therefore a concern that no mention is made of them in the 2017 Guidelines (see note 20).

[38] See note 21, para. 18.

[39] See note 22, cl. 1.14.

healthcare proxies. Individuals who are estranged from their families or who are in same-sex partnerships (which are not legally permitted in Malaysia) may prefer not to have their relatives involved in decisions about their care, which renders the requirement to consult family members problematic.

It is also notable that although the 2017 Guidelines ask medical practitioners to respect unequivocal written directives provided by patients, practitioners are also given a wide scope of discretion in the case of an emergency to treat the patient as they see fit until they can obtain legal advice on any directive in place.[40] Given the lack of clear legal rules on ADs, it is unclear how the validity of an AD could be demonstrated, although it is conceivable that common law principles on advance refusals would be relied upon in legal advice. More importantly, whilst obtaining legal advice may be feasible in non-emergency cases, permitting medical practitioners to treat patients as they see fit until such advice can be obtained in emergency cases in effect allows them to override what may be the unequivocal, written wishes of the patient. Tan further argues that a patient's wishes may be disregarded not only in emergency cases but also in non-emergency cases given that the wording of clause 18 states that medical practitioners "should" refrain from providing treatment contrary to an AD,[41] which suggests some flexibility in the requirement. The same can also be said of the 2019 Code of Conduct. The last line of clause 1.14, which states that "any decision by the practitioner, to comply with or not to comply with the AMD, must be made in consultation with relatives and next-of-kin of the patient",[42] suggests that medical practitioners have the flexibility not to comply with the explicit wishes of a patient, as written in his or her AD, as long as that decision is made in consultation with family members.

Tan additionally points out that, contrary to usual practice, the 2017 Guidelines unrealistically assume that the physician treating the patient will be aware of the existence of his or her AD and that the content thereof will be available to the physician at the relevant time, including during an emergency.[43] Furthermore, the 2017 Guidelines do not consider care in non-hospital settings, such as care homes or hospice

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[40] See note 21, para. 18.
[41] Tan, note 20, 91.
[42] See note 22, cl. 1.14.
[43] Tan, note 20, 91.

facilities, which is problematic given that both the number of elderly people and the number of care homes are increasing in Malaysia.[44]

Thus, whilst the professional guidelines discussed previously provide some level of guidance for medical practitioners who may encounter ADs in their practice, there remain a number of concerns that need to be addressed. In particular, the phrasing of the guidelines suggests that the explicit wishes of the patient, even if clearly documented in a written format, are not necessarily given priority. Hence, the views of the physician, in consultation with family members, are still likely to take precedence, which is contrary to the principle of respect for patient autonomy.

9.3 The Practice of Advance Directives in Malaysia

There are no official statistics on the number of ADs in Malaysia, and there is a lack of empirical data on AD implementation in the country. However, a number of studies have demonstrated a very low level of awareness of ADs amongst the elderly. For example, a study conducted in 2007 by Htut et al. involving 15 elderly patients representing different ethnic and religious groups in Malaysia discovered that none of the respondents had heard of ADs or ACPs, although most agreed after discussion that plans for future medical management were something they should consider, with 5 expressing eagerness to make an AD for themselves.[45] Ten years later, a similar study carried out with a larger pool of respondents reported that only 8 out of 70 had heard of ADs, with none having drawn one up.[46] In this 2017 study, 70 per cent of the respondents (49 out of 70) said that they were open to the concept of using ADs.[47]

A recent study on end-of-life care in nursing homes found that none of the respondents had any ideas about or had discussed their end-of-life preferences with anyone.[48] After being afforded an opportunity to discuss their end-of-life plans and the AD concept for the first time with the researcher, nine respondents expressed positive feelings about the

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[44] Ibid.

[45] Y. Htut et al., "The Views of Older Malaysians on Advanced Directive and Advanced Care Planning: A Qualitative Study" (2007) 19(3) *Asia-Pacific Journal of Public Health* 58.

[46] T.L. Koh et al., "Advance Directives among Elderly Population: A Malaysian Experience" (2017) 13 *Journal of the Indian Academy of Geriatrics* 62.

[47] Ibid., p. 65.

[48] N.X. Jiao and N.A.M. Hussin, "End-of-Life Communication among Chinese Elderly in a Malaysian Nursing Home" (2020) 7(1) *Journal of Patient Experience* 62, 65.

experience and reported being motivated to initiate such a discussion with family members.[49]

Although empirical data remain limited, the data from these studies suggest that Malaysians previously unfamiliar with the concept of ADs may still be open to their use once informed of them. Additionally, although the studies sampled only a small pool of elderly individuals, they suggest a continuing lack of awareness in Malaysia about the existence of ADs and how they might be implemented. Knowledge deficiency concerning the purpose and use of ADs in Malaysia appears to constitute a very strong barrier, one that needs to be overcome if they are to be encouraged. This lack of knowledge and awareness is further discussed in Section 9.4 in the context of the physician's advisory role in ADs.

Taken together, the preliminary data presented in this section suggest that if more Malaysians were made aware of the AD concept and the use of ADs was encouraged to a greater extent, by the medical community for example, then a greater number of Malaysians would be likely to make ADs. Nevertheless, there are a number of factors related to Malaysia's sociocultural context that may exert an adverse impact on AD acceptance in the country. These factors are explored in Section 9.4.

9.4 Sociocultural Factors Influencing the Acceptance of Advance Directives in Malaysia

9.4.1 Influence of Family Members in Decision-Making

Much that has been written on the regulation and use of ADs in Malaysia highlights the key role that the family plays in medical decision-making. Malek et al. describe the family as an important aspect of a patient's attitudes towards making an AD, similarly to other Asian countries with a family-centred culture.[50] The concept of ADs is based on the principle of patient autonomy, a type of autonomy that is considered to still be in a "nascent stage" in Malaysia given the prioritisation of family-based, collective decision-making and deference to physician expertise.[51]

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[49] Ibid., 67.

[50] M.M. Malek et al., "Honouring Wishes of Patients: An Islamic View on the Implementation of the Advance Medical Directive in Malaysia" (2021) 28(2) *Malaysian Journal of Medical Sciences* 28, 32.

[51] H.Y. Chan, "Regulating Advance Decision-Making: Potential and Challenges for Malaysia" (2019) 11 *Asian Bioethics Review* 111, 115.

According to Malek et al., the idea of patient autonomy "seems to clash with local practice" because most patients are heavily influenced by their families and doctors,[52] especially in situations involving end-of-life care. Patient autonomy is usually considered in conjunction with family-centred decision-making and professional medical expertise in this context.

The aforementioned studies conducted on ADs in Malaysia also support the claim that the family plays a significant role in the context of medical decision-making. For example, the majority of participants in the 2007 study by Htut et al. had nominated family members as their surrogate decision-makers, and even those participants who expressed an interest in ADs indicated that they would discuss the matter with their families.[53] A 2016 study on ACP conducted by Lai et al. found 87 per cent of participants preferred a "family-based decision-making process" pertaining to end-of-life care.[54] The authors argued that such a preference was likely the result of Malaysia's collectivist society, which "reverses the role of the individual" and "places more importance [on] family" for decisions, indicating that the opinions of family are far more influential for most patients than their own wishes.[55]

The aforementioned 2020 study on end-of-life care in nursing homes echoes this argument, with its authors stating: "Malaysia is very much a collectivist society. As such, most decisions related to elderly nursing home residents are influenced by the residents' family and friends".[56]

Whilst this emphasis on a family-oriented decision-making model may seem problematic for the acceptance and implementation of ADs, which tend to be conceived of as an individual expression of preference, that does not appear to be straightforwardly the case for at least two reasons. The first is that there are cases in which individuals wish to make an AD precisely *because* of their strong family ties, as demonstrated in

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[52] M.M. Malek et al., "Islamic Considerations on the Application of Patient's Autonomy in End-of-Life Decision" (2018) 57 *Journal of Religion and Health* 1524, 1528.

[53] See note 45, 62.

[54] P.S.M. Lai et al., "The Development and Validation of the Advance Care Planning Questionnaire in Malaysia" (2016) 17 *BMC Medical Ethics* 61, 69.

[55] Ibid.

[56] Jiao and Hussin, note 48, 67: citing the work of T. Oka et al., "The Diversity of Indigenous Wisdom on Grief: Exploring Social Work Approaches to Bereavement", in *The IAFOR International Conference on the Social Sciences: Hawaii 2017 Official Conference Proceedings* (Honolulu: IAFOR, 2017) on the determination that Malaysia is a collectivist society.

the 2007 study conducted by Htut et al.,[57] wherein some respondents indicated that their interest in pursuing an AD stemmed from a desire not to be a burden on their families. The second reason is that even when a family-based decision-making approach is adopted, that approach does not automatically exclude ADs. For example, in the 2017 Koh et al. study,[58] only 6 of the 70 participants stated that they opposed ADs because they preferred to leave medical decision-making to their families. Furthermore, 26.5 per cent of the participants stated that they preferred to have a family member act as a power of attorney to execute their ADs,[59] suggesting that the family may still have a role to play even if an individual wishes to make an AD and, further, that in a sociocultural context that emphasises the role of the family, the two can in fact be complementary.

Thus, whilst it is clear that the family plays a significant role in the context of end-of-life decision-making, the ways in which that role affects an individual's desire to make an AD may differ. On the one hand, those who wish their family members to make decisions on their behalf may be less likely to consider it necessary to make an AD. On the other, data suggest that others may not perceive a family role in decision-making to exclude the making of an AD, with some even likely to view family members as having a role in the making thereof.

9.4.2 The Role of Physicians

9.4.2.1 Important Advisory Role

Medical professionals play an important advisory role in the process of end-of-care decision-making in Malaysia because discussions about end-of-life decisions often involve complex medical issues on which medical professionals are considered best placed to provide advice. Additionally, some evidence suggests that patients prefer to have such discussions with their treating physicians. In their 2007 study, Htut et al. found that when respondents were asked who they should discuss ACP with, the majority cited their attending doctors. Interestingly, they

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[57] See note 45, 62.

[58] See note 46, 65.

[59] It is not made clear in the study what the authors mean by a "power of attorney to execute an AD". Presumably, given the lack of clear legal guidelines on the format and requirements of an AD, it refers to the possibility of a family member executing an AD on a patient's behalf.

preferred hospital-based specialists to regular general practitioners. They expressed confidence in hospital specialists because "they know me better", "they have more experience" and "they are more appropriate to discuss this [issue] with".[60]

The key advisory role played by physicians can have an adverse effect on the acceptance and implementation of ADs in two ways. The first relates to whether physicians provide information on and encourage their patients to make ADs as part of their advisory role. Limited data from the 2016 Lai et al. study suggest that they do not. Lai et al. found that 89 per cent of their respondents who were against ACP stated that they had not been given enough information to make an informed choice and that that lack of information had influenced their objections.[61] The respondents also stated that if doctors were to provide sufficient information to patients regarding ACP, that would facilitate their acceptance of both ACP and ADs.[62] This finding is supported by the aforementioned fact that the professional guidelines issued by the MMC and MOH do not in fact require or even encourage physicians to initiate conversations about ADs or ACP more generally.

The second way in which physicians' key advisory role could potentially have an adverse effect is that individuals may prefer to rely on their treating physicians for medical decision-making rather than make their own ADs. There are limited empirical data supporting this possibility: in the 2020 study on end-of-life care in nursing homes, over half of the 13 respondents indicated that they would prefer to let their doctors handle decision-making for them and communicate with their families regarding end-of-life care.[63]

9.4.2.2 Public Interest versus Private Interests and the Important Role of Experts in the Islamic Context

It would appear that the key role of the physician is even more significant in the context of Islam, which can be attributed to the Islamic emphasis on the public interest rather than the interests of individuals. Salleh argues that physicians who possess the requisite training and are charged with saving lives may be deemed to be in a better position than the patient to ascertain the right choice, which he explains as follows:

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[60] See note 45, 63.

[61] Lai et al., note 54, 69.

[62] Lai et al., note 54, 69.

[63] Jiao and Hussin, note 48, 68.

> Generally, Muslim scholars view that there is a limit to [a] patient's autonomy in choosing the forms of medical treatment and care, as [a] doctor's professional advice should also be considered. This is because choices made to satisfy personal interests and satisfaction are contrary to Islamic values. The emphasis in Islam is more on public interest compared to personal interest. Furthermore, Islam puts the emphasis on doctor[s'] efforts in saving lives. However, Islam also recognises the limitation of human endeavour, and as such all efforts must be followed by tawakkal. Having said that, doctors should exhaust all possible avenues in order to save a patient's life.[64]

In the specific context of ADs, Malek argues in a similar vein:

> In general terms, Islam does not disapprove [of] the application of AMD [s] [advance medical directives] in end-of-life decision-making. However, the application of [an] AMD may have certain limitations that must be addressed… Besides that, respecting autonomy via AMD[s] should not diminish the physician's role in decision-making as an expert in the medical field. Many Islamic views stress the necessity of taking the judgment of experts into account. Before any medical procedure is executed, it must undergo thorough medical evaluation and [the] judgment of experts. Therefore, patients must consult doctors before they can carry out their right to self-determination.[65]

Thus, whilst Malek is supportive of the right to autonomy and self-determination, he argues that patient autonomy should be "contextualised" according to Islamic values.[66] This contextualisation includes the prioritisation of the physician's views, as physicians are generally regarded as the "decision-making authority for patient care" in Malaysian society.[67] Malek further suggests that such deference to physicians confirms the influence of medical paternalism in healthcare decisions within the context of Islam.[68] Physicians must use their experience to judge whether a patient's choice "would bring more harm than good",[69] demonstrating that they have the authority to override any decisions made by their patients in order to follow Islamic principles. According to this reasoning,

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[64] S.M.S.S.M. Salleh, "Advance Medical Directive: How Prepared Are We?" *The Star* (2015), www.ikim.gov.my/index.php/2015/09/08/advance-medical-directive-how-prepared-are-we/.

[65] M.M. Malek, "Applying Advance Medical Directive" (2017) *The Star*, www.thestar.com.my/opinion/columnists/ikim-views/2017/08/01/applying-advanced-medical-directive-islam-allows-its-application-in-endoflife-decisionmaking-but-the.

[66] Malek et al., note 52, 1529.

[67] Ibid.

[68] Malek et al., note 52, 1533.

[69] Ibid.

physicians should have the final say as to whether a patient's choice is implemented even when the patient has made an AD.

9.4.3 The Role of Religion

In addition to the significance of Islam in providing a context for the prioritisation of medical expertise, studies also indicate that religion is an important factor that comes into play when individuals are deciding whether or not to make an AD. The 2007 study of Htut et al., for example, reported that "the majority of respondents believed that their views on ADs were influenced by their religion", especially those of Islamic faith.[70] Most of them thought that it was best to leave matters pertaining to end-of-life care to either God or fate. Similarly, in their 2016 study, Lai et al. also identified fate and religion as two of the main justifications against ACP for participants who disapproved of it, with the majority of participants choosing fate and religion as reasons for not making an AD.[71]

Not all of the reported data are consistent. For example, in the 2017 study conducted by Koh et al., only 7.4 per cent of respondents (5 out of 70) said they would leave the decision-making process up to God or fate,[72] whereas 3 of the 13 respondents in the 2020 study on end-of-life care in nursing homes cited religion as playing the most important role in end-of-life care.[73] This evidence does not necessarily contradict the significance of religion, although it does suggest that even when religion is a factor that is taken into account, or a perspective through which many view the end-of-life process, it may not necessarily have an adverse effect on the use and acceptance of ADs.

9.5 Conclusion

ADs and end-of-life planning are not specifically regulated in Malaysia. This lack of regulation and what appears to be a low prevalence of ADs are influenced by many factors, including low levels of public awareness of ADs, dependence on family and physicians to make end-of-life decisions collectively (or in some cases on patients' behalf) and religious

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[70] See note 45, 63.

[71] Lai et al., note 54, 68.

[72] See note 46, 65.

[73] Jiao and Hussin, note 48.

factors. Studies show, however, that patients are willing to consider ADs once they have been informed of them, suggesting that higher levels of awareness may lead to more people using ADs. The National Palliative Care and Care Policy and Strategy Plan 2019–30 has established a well-designed road map for embedding ACP services in hospitals and the community by training palliative care professionals and creating greater awareness within the profession and society, which is the first step towards recognising the value of ADs and ACP more generally in Malaysia. Well thought out governance mechanisms and legal regulations should also be put in place to ensure that the rights of patients are preserved, and patient autonomy is promoted.