16

Advance Directives in Saudi Arabia: An Islamic Approach and Practical Implications

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16.1 Introduction

Saudi Arabia (SA) is an Islamic country in the southwestern part of Asia. It leads the Sunni Islamic world in many aspects, the most important of which is its responsibility for custody of the two holiest mosques in Islam. Making sense of advance directives (ADs) in SA, and the regulatory frameworks governing healthcare more generally, requires a careful understanding of the traditional Islamic religious legal framework of *Shariʾah*.

The main objective of this chapter is to offer clarity on how well-established principles, and Islamic statements of permissible and impermissible behaviour, should be reasoned through to provide an underpinning governance framework for healthcare practices at the end of life. We also review published evidence on the practical application of ADs in SA, and go on to examine the social and cultural factors that may explain the limited uptake of ADs. We then conclude with two arguments about how an appropriate role for ADs might be realised in the future – one concerning the need for legal clarity and the other concerning how to bring about improvements in professional knowledge and understanding.

16.2 Basic Legal Framework and the Role of Religion

The foundation of the Saudi legal system is *Shariʾah* law, or traditional Islamic law, which is supplemented by royal decrees, statutes, regulations and other legislative and policy documents in specific areas of law. As the Basic Law, or the Saudi equivalent of a constitution, states in Article 7: "Government in the Kingdom of Saudi Arabia derives its authority from the Book of God and the Sunnah of the Prophet

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(PBUH), which are the ultimate sources of reference for this Law and the other laws of the State".[1]

Because there are no specific laws or other legislative and policy documents derived from *Shari'ah* on ADs or end-of-life care and decision-making more generally, general *Shari'ah* principles apply. *Shari'ah* law is derived from two primary sources, the Quran and the Sunnah, or the practices and sayings of the Prophet Muhammad, as well as a number of secondary sources, including *Ijma*, or the consensus of Muslim scholars on particular issues, and *Qiyas*, or reasoning by analogy. To understand the permissibility of ADs under Islamic law, which is further discussed here, scholarly interpretations of the relevant parts of the Quran and Sunnah must be studied.

Actions in Islamic law are generally categorised within a scale of permissibility rather than the dichotomy of "do" and "do not". That scale includes the following categories:

1. Must do (*Wajib*)
2. Permitted (*Halal*/*Mubah*)
3. Favoured (*Mustahab*)
4. Detestable (*Makrouh*)
5. Forbidden (*Haram*)

Any given act is judged within one of these categories based on a ruling by a scholar, usually based on one of the Islamic jurisprudential (Fiqhi) schools of thought known as Madhahib. The four main schools in the Sunni Muslim tradition are Hanafi, Shafiite, Maliki and Hanbali, named after the main Imam who developed that madhab. The main Fiqhi school followed in SA is the Hanbali, named after Imam Ahmed ibn Hanbal (who died in AD 857).

The categorisation of an act under any of the five foregoing categories is based primarily on the presence of a text (in the Quran and/or Sunnah) that discourages or forbids that act. In the absence of such a text, the act is considered permissible (mubah) based on the Fiqhi principles of "the original status of things is permissibility" and "nothing is forbidden except with a proof". Such proof can be an *Ayah* (or verse) from the

[1] More on the legal system in SA and its religious basis can be found in A. Babgi, "Legal Issues in End-of-Life Care: Perspectives from Saudi Arabia and United States" (2009) 26 *American Journal of Hospice & Palliative Medicine* 119.

Quran[2] or a *hadith*, a record of the sayings or teachings of the Prophet Muhammad. Lower levels of proof include reasoning by analogy (*Qiyas*), whereby scholars reach a judgement that something is not permissible because it shares the same reasons as those of a known forbidden thing. For example, recreational drugs (e.g. heroin, cocaine, cannabis, etc.) are unanimously forbidden[3] using *Qiyas* despite the absence of any text that forbids them, given that they share the effect of "covering the mind" caused by alcohol.

One of the most common forms of Islamic legal guidance is the "*fatwa*" (plural: "*fatawa*/*fatwas*"), which is a religious/legal non-binding opinion issued by an authentic scholar or group of scholars usually through the so-called Fatwa Complexes. In SA, the highest – and only – authority is the Authority of the Grand Scholars (aka Council of Senior Scholars), led by the Mufti of the kingdom. Members of this authority are allowed to issue personal fatwas on individual affairs if asked to do so.

It is important to emphasise here that *fatawa* are the intellectual outcome of a meticulous process known as *Ijtihad*, which ensures that these rulings are aligned to Islamic scripture and the purposes of *Shari'ah* Law (*Maqasid*), as we have discussed elsewhere.[4] The five higher goals of *Shari'ah* can be summarised as preserving the faith, body/soul, mind/intellect, lineage/progeny and wealth/property. The morality and legality of any act is measured against these goals; the more the goals are achieved by the act, the more legal and moral it becomes and vice versa (see previous discussion of the scale of permissibility). In the event that two or more of the goals contradict one another, for example, if someone were dying of thirst and the only drink he or she could find was alcohol, then the priority would be placed on saving the person's life within the limitations detailed in the sub-principles of the major Fiqhi maxims, as described in the next section. The preservation of any one of the goals is attained both by the provision of its maintaining factors, such as the importance of staying healthy and abstaining from

[2] For example, "And do not kill your children for fear of poverty. We provide for them and you. Indeed, their killing is ever a great sin" (Quran, 17:31), which is used as proof that abortion is forbidden (unless there is a genuine cause).

[3] Y.H.M. Safian, "An Analysis on Islamic Rules on Drugs" (2013) 1 *International Journal of Education and Research* 1.

[4] N. Alsomali and G. Hussein, "CRISPR-Cas9 and He Jiankui's Case: An Islamic Bioethics Review using *Maqasid al-Shari'a* and *Qawaid Fighiyyah*" (2021) 13 *Asian Bioethics Review* 149.

anything that could endanger one's life. Saving a life, according to the Quran, is rewarded as if all human lives were saved: "and whoever saves a life, it will be as if they saved all of humanity" (Quran, 5:32).

16.2.1 Healthcare Context: Lessons for the End of Life

Emphasis on the sanctity of life, as demonstrated by the importance the Quran places on the saving of a life, is particularly significant in the healthcare context. As with all other religions, life is sacred in Islam and Muslims are obliged to safeguard it, and the preservation of life is amongst the highest purposes of *Shari'ah*. Moreover, life is believed to be given and owned by Allah, and hence only He can take it. In other words, no Muslim is allowed to take his or her own life, or to help anyone else, Muslim or not, to take his or her life, although, as we shall see, there are instances in which the withdrawal or withholding of futile treatment is permitted or even required.

Illness is generally believed to be a test from Allah, a test of His servants' patience and a means of helping them to erase some of their sins. Whilst all suffering and death is determined by the will of Allah,[5] however, that does not mean that suffering and death should be sought or tolerated unnecessarily, with many *hadith* encouraging Muslims to seek remedies for their illnesses. Examples include the following:

> Narrated by Abu Huraira: The Prophet (□) said, "There is no disease that Allah has created, except that He also has created its treatment" (Sahih al-Bukhari: 5678).
>
> Narrated by Usamah ibn Sharik: The Prophet (□) said, "Make use of medical treatment, for Allah has not made a disease without appointing a remedy for it, except for one disease, namely old age (aging)" (Sunan Abi Dawud: 3855).

Scholars have proposed differing views in relation to the treatment that should be sought. For example, a very prominent scholar, Imam Ahmed ibn Taimiya (who died in AD 1328), stated that seeking treatment can itself fall anywhere on the aforementioned scale of permissibility based on the weighing of its benefits and harms, as follows:[6]

[5] See, for example, Quran, 57:22.

[6] M.M. Malik, "Islamic Perceptions of Medication with Special Reference to Ordinary and Extraordinary Means of Medical Treatment" (2013) 4(2) *Bangladesh Journal of Bioethics* 22.

1. If the treatment is more harmful than the disease or the person believes that he will be cured by the medicine (not by the will of Allah), then it is forbidden (*haram*);
2. If the treatment has equal value to no-treatment, then it is permissible (*mubah*);
3. If the treatment is likely to be beneficial, then it is favoured (*mustahab*); and
4. If the treatment is necessary to stop the harm to oneself or others, then it should be done (*wajib*).

Other scholars have divided the seeking of treatment into three categories: obligatory (where the disease is treatable or is a communicable disease that could be harmful to others), optional (where the treatment is experimental or the overall benefit is unclear) and abstinence (where the treatment would be futile or even harmful).[7] It thus appears that in situations in which a treatment could be futile or harmful, Islamic law principles would generally dictate that the individual not seek treatment, which is consistent with the withholding or withdrawal of futile or burdensome life-sustaining treatment at the end of life. This view is also in line with the concept of death in Islam. Muslims believe that death is like crossing a bridge between this temporary life (of action) and the eternal hereafter life (of judgement and rewards).[8] In other words, Muslim patients should not expect to be immortal or believe that they can delay death, which further supports the idea that the artificial and futile prolonging of life is not consistent with Islamic principles.

In addition to such principles and interpretations, *fatwas* are also a source of guidance in the healthcare context. Most of the leading *fatwas* related to organ donation, blood transfusion, cardiopulmonary resuscitation (CPR)[9] and many others were the result of doctors or patients submitting questions in pursuit of religious fatwas from the Council of

[7] M.A. Albar, "Seeking Remedy, Abstaining from Therapy and Resuscitation: An Islamic Perspective" (2007) 18 *Saudi Journal of Kidney Diseases and Transplantation* 629 (as cited in H. Al-Jahdali et al., "Advance Medical Directives: A Proposed New Approach and Terminology from an Islamic Perspective" (2013) 16 *Medicine, Health Care and Philosophy* 163).

[8] Death is described in the Quran as the "true life" or the "life indeed" (Quran, 26:64).

[9] The Permanent Committee for Scholarly Research and Ifta', "Fatwa no. 8926: Ruling on Cardiopulmonary Resuscitation", in *Fatwa Collections* (Riyadh: General Presidency of Scholarly Research and Ifta', 1988), Group 1, Vol. 25: Miscellaneous Fatwas 2, pp. 71–5, www.alifta.gov.sa/En/IftaContents/PermanentCommitee/Pages/FatawaChapters.aspx?cultStr=en&View=Page&PageID=9745&PageNo=1&BookID=7.

Senior Scholars.[10] Arguably, this is a unique feature of the Saudi context in that clinical/medical decisions are not made solely within the confines of the doctor–patient relationship, as the scholars who are expected to rule by way of *fatwas* are mainly non-medical by profession. It is important to acknowledge the challenges associated with this feature of the Saudi context: because it is essential in Islamic jurisprudence for Islamic scholars to fully comprehend an issue in order to judge its suitability, they require a healthcare expert to explain the issue to them in lay terms and to answer their questions. That expert is usually a medical doctor. Whilst this is entirely understandable, the problem is that those providing the requested explanations are usually physicians, who may have their own preferences in the matter, which could result in experts advocating for what they think is right. The end result could be an indirect form of medical paternalism, aggravated by the religious cover it may have if the decision-making authority seems to have moved from a physician to a religious scholar.

The most relevant *fatwa* in the end-of-life context is likely the famous Fatwa No. 12086 issued on 28/3/1409 (H) (i.e. AD 1989) by the Presidency of the Administration of Islamic Research and Ifta', Riyadh, KSA. This *fatwa* relates to do-not-resuscitate (DNR) orders and states that "if three knowledgeable and trustworthy physicians agreed that the patient condition is hopeless; the life-supporting machines can be withheld or withdrawn. The family members' opinion is not included in decision-making as they are unqualified to make such decisions".[11] This *fatwa* is a good example of the unique role that *fatawa* play in the Saudi legal system: although they are not laws per se, they can be used as legal evidence in the absence of law. This is demonstrated by the fact that, despite there being no mention of DNR orders in any Saudi law, the practice of DNR in Saudi hospitals has been reported for more than

[10] The Permanent Committee for Scholarly Research and Ifta', "Fatwa no. 19165: Ruling on Using Euthanasia to End Suffering", in *Fatwa Collections* (Riyadh: General Presidency of Scholarly Research and Ifta', 1988), Group 1, Vol. 25: Miscellaneous Fatwas 2, pp. 84–91, www.alifta.gov.sa/En/IftaContents/PermanentCommitee/Pages/FatawaChapters.aspx?cultStr=en&View=Page&PageID=9748&PageNo=1&BookID=7.

[11] The Permanent Committee for Scholarly Research and Ifta', "Fatwa no. 12086: Ruling on Cardiopulmonary Resuscitation", in *Fatwa Collections* (Riyadh: 1988), Group 1, Vol. 25: Miscellaneous Fatwas 2, pp. 79–82, www.alifta.gov.sa/En/IftaContents/PermanentCommitee/Pages/FatawaChapters.aspx?View=Page&PageID=9746&CultStr=&PageNo=1&NodeID=1&BookID=7.

20 years[12] and the only reference "legalising" this practice over the years is the aforementioned fatwa. *Fortunately*, there has not been a single case of the family of a patient who died while under a DNR order suing the patient's doctor and/or the hospital at which he or she was admitted. It would be interesting to see how the Saudi courts would handle such a case and whether the *fatwa* alone would be sufficient to clear the doctor/hospital of liability.

16.2.2 Advance Directives

The foregoing discussion of the end-of-life care context in SA demonstrates the general permissibility of withholding or withdrawing futile or harmful life-sustaining treatment, as well as the very specific *fatwa* guidance in relation to DNR orders. Given that there are no laws or *fatwas* directly addressing the issue of ADs, however, how should we understand the permissibility of preparing and implementing ADs under Islamic law?

At least two sources of religious guidance can be drawn upon in understanding ADs under Islamic law. The first, which aids understanding of the individual's own role in end-of-life decision-making, is a well-known *hadith* about the Prophet Muhammad's illness and death:

> This Hadith Narrated by Ibn ʿAbbas and ʿAisha (R.A): Abu Bakr kissed (the forehead of) the Prophet when he was dead. ʿAisha added: We put medicine in one side of his mouth but he started waving us not to insert the medicine into his mouth. We said, "He dislikes the medicine as a patient usually does". But when he came to his senses he said, "Did I not forbid you to put medicine (by force) in the side of my mouth?" We said, "We thought it was just because a patient usually dislikes medicine". He said, "All of those who are in the house will be forced to take medicine in the side of their mouth while I am watching, except for Al-ʾAb-bas, for he had not witnessed your deed". (Translation of Sahih Bukhari. Book of Medicine, *Hadith* number 2012)[13]

This *hadith* demonstrates both a patient's right to refuse treatment and the fact that this right cannot be overridden by the wishes of others, even his or her closest relatives. Al-Jahdali et al. further interpret the *hadith* as conveying three principles: (i) Muslims are permitted not to receive

[12] A. Mobeireek, "The Do-Not-Resuscitate Order: Indications on the Current Practice in Riyadh" (1995) 15 *Annals of Saudi Medicine* 6.
[13] Al-Jahdali et al., note 7.

treatment, especially if they have an incurable disease; (ii) those taking care of patients are not permitted to force a patient to accept a certain treatment, especially when they know that the patient does not want it; and (iii) those persons will be held accountable for their actions if they do force the patient to do so,[14] or, in other words, a patient whose right has been unlawfully overridden has the right to seek retaliation for the (ab) use of his or her state of unconsciousness.

In the context of ADs, these principles can be understood as providing patients with the right to specify beforehand what they do not want to be done to them at the end of life, including choosing whether or not medication or other treatment options will be administered to them. In addition, they demonstrate that ADs should not be overridden and that those who attempt to do so can be held accountable for that attempt, even if made in good faith.

The second source of religious guidance comes from Fiqhi principles, which represent a practical framework for legal and moral decision-making through the categorisation of general rules under which there are sub-principles that are derived primarily from the text of the Quran and Sunnah.[15] Next, we discuss the five main Fiqhi principles agreed upon by most Sunni scholars, as well as some of their main sub-principles, and our interpretation of how they might be applied in the AD context.

I. The Principle of Intention (*Qaidat Al Niyyah*)

This principle states that actions are judged by (or based upon) their intentions. Any act of a human being must come from and is based on his or her will and intention. Under this principle, there is a sub-principle which states that "the means are judged as the ends", or, in other words, the means are judged using the same criteria as those used to judge the intention. Thus, if the intention is wrong, the means will also be considered wrong. In the AD context, this sub-principle can be understood to mean that when a person writes an AD, he or she cannot request illegitimate interventions to achieve a legitimate purpose or legitimate interventions to achieve an illegitimate purpose. For example, even if further treatment would be futile, burdensome or harmful, and the patient would die from the legitimate withdrawal of life-sustaining

[14] Ibid.
[15] See note 4.

treatment, he or she cannot in his or her AD request extensive doses of analgesics that could lead to death.

II. The Principle of Certainty (*Qaidat Al Yaqeen*)

This principle states that certainty cannot be removed by doubt; that is, what is known to be a fact cannot be overridden by what is doubtful. Under this principle, there is a sub-principle which states that what is proven by evidence is valid unless denied by contrary evidence of equal or better strength. In the AD context, this can be understood to mean that where an AD is considered to have been validly made (e.g. the patient was considered competent to make the AD at the time of its drafting) or is considered to apply (e.g. the patient has lost capacity), doctors should implement the AD unless they have contrary evidence of equal or better strength, such as strong evidence that the patient was not competent at the time he or she made the AD.

III. The Principle of Injury (*Qaidat Al Dharar)*

This principle states that harm may be neither inflicted nor reciprocated in Islam. Harm must be eliminated but not by means of another harm. Under this principle, there is a sub-principle stating that harm is to be prevented to the greatest extent possible. In the end-of-life context, where continuing treatment would be futile in terms of recovery and would be burdensome or even harmful in terms of pain and suffering, an AD can be seen as a way to prevent and limit the harm caused to the patient. That view would, of course, be based on the view that the infliction of such prolonged pain and suffering would bring greater harm than bringing about death more quickly by following a patient request in an AD to withhold or withdraw life-sustaining treatment. This is the case because another sub-principle states that an injury cannot be relieved by inflicting or causing a harm of the same degree, which suggests that any option that could inflict some kind of harm, such as the withdrawal or withholding of life-sustaining treatment that would ultimately result in death, would need to be assessed as to whether it might cause equal or greater harm to the patient than what he or she is currently suffering, as well as what the projected outcomes might be.

IV. Principle of Hardship (*Qaidat Al Mashaqaat*)

The basic principle here is that difficulty calls forth ease, and is the basis for allowing an exception to the rules where adherence to the rules would

result in great hardship.[16] Whilst this principle deals primarily with what exceptions are permissible in situations of necessity, a sub-principle which states that "what is allowed for a cause (justification) goes with the cause" may be relevant in the AD context: if the AD's validity and applicability are justified by the patient's loss of capacity, they should become void as soon as he or she regains capacity.

V. The Principle of Custom or Precedent (*Qaidat Al Urf*)

This principle states that custom or precedent has legal force. What is considered customary is what is uniform, widespread, predominant and not rare. Customary practices are those that are acceptable to people of a sound nature and enjoy universal or general acceptance by a given country or generation. Custom in a given society can take the form of words, actions, abstinence or a mixture thereof. Under this principle, there is a sub-principle stating that only known customs, not rare ones, are recognised; in other words, transient customs are not recognised. In the wider healthcare context, this sub-principle could be understood as a form of norm-setting by clinical professionals, which in turn renders the customary practice legitimate. Thus, in so far as a practice is customary, it sets a precedent that should be followed. In the more specific AD context, it would mean that if healthcare professionals used ADs customarily, that usage would constitute a bottom-up approach to the legitimisation of the use and implementation of ADs as professionally acceptable, or even required, behaviour.

Another sub-principle states that things are defined by customs, not only by language, and that the way in which people use words can be used as evidence. In the context of ADs, this sub-principle can be understood as follows: where patients use terms in their ADs that are ambiguous or capable of being interpreted in more than one way, the most common, or public, interpretation should be used. For example, if a patient expresses a desire to have all care withdrawn in the face of a life-limiting diagnosis, it would be appropriate for the phrase "all care" to be interpreted in terms of medical treatment interventions rather than basic

[16] J. Auda, *Maqasid Al-Shariah: A Beginner's Guide* (Richmond, UK: International Institute of Islamic Thought, 2008), https://iiit.org/en/book/maqasid-al-shariah-a-beginners-guide/; A.H. Thahir, *Ijtihād Maqāṣidi: The Interconnected Maṣlaḥah-Based of Islamic Laws*, I. Haaz (ed.), (Geneva: Globethics.net, 2019), www.globethics.net/documents/10131/26882166/GE_Theses_30_isbn9782889312207.pdf/5b3a4fd5-b30f-b5d6-8c07-19251ccaacc4?t=1587732852812.

palliative care support that mitigates pain or suffering in the last moments of life. This is the case because despite the fact that "all care" could reasonably incorporate all healthcare interventions, laypersons would be unlikely to interpret the phrase in those terms.

With respect to the specific content of an AD under Islamic principles, Albar and Chamsi-Pasha have identified four elements that can be included: (i) a request to discontinue treatment; (ii) an instruction to switch off life-support equipment; (iii) the inclusion of organ donation; and (iv) power of attorney (*wakalah*).[17] In relation to the discontinuation of treatment, these authors argue that treatment can be discontinued if continuing it would not improve the patient's condition or quality of life and the intention is not to hasten death but rather to refuse "overzealous treatment". This argument is in line with the principles and interpretations discussed previously, which consider the withdrawal or withholding of treatment to be permissible where treatment is futile. Albar and Chamsi-Pasha also argue that palliative care aimed at maintaining personal hygiene and basic nutrition should not be discontinued, which is in line with the idea that only futile or harmful interventions can and should be stopped. Care that is beneficial, at least in terms of quality of life, should remain as a treatment or "remedy" that should be sought when ill.

The instruction to switch off life-support equipment pertains primarily to the case of brain death, for which several *fatwas* provide guidance,[18] and organ donation, which is beyond the scope of this chapter. In terms of power of attorney, or *wakalah*, Albar and Chamsi-Pasha contend that it would be prudent for Muslims to entrust someone (their *wakil*, or authorised representative) with the power of attorney in their living will. Should the person in question subsequently become incompetent, the *wakil* would be responsible for conveying the wishes stated in his or her living will. Accordingly, it can be seen that the term "power of attorney" as used here goes beyond the conventional sense of an individual being granted the power to make decisions on behalf of another, extending it to the role of the *wakil* as a conveyor or even interpreter of the content of an AD. It should be noted that the content of a living will should not include any clauses that contrast with or contradict the rulings of *Shari'ah*; as long as that is the case, there

[17] M.A. Al-Bar and H. Chamsi-Pasha, *Contemporary Bioethics: Islamic Perspective* (Springer, 2015).

[18] See further chapter 14 of Al-Bar and Chamsi-Pasha, note 17.

would arguably be no justification for ignoring the directive.[19] Moreover, the *wakil* is committed to following the instructions in an AD without any alteration or hiding.[20] The *wakil* is considered a witness to the wishes of the person making the AD and is legally and morally bound to express and convey those wishes to others, including healthcare providers.[21]

16.3 Practice and Sociocultural Context of Advance Directives in Saudi Arabia

In the previous section, we have considered how ADs would likely be regulated under Islamic law, although we should again emphasise that there are no specific laws, regulations or *fatwas* on this issue as yet. Moreover, there are no guidelines produced by healthcare professional bodies that mention an explicit role for ADs. We now turn to consideration of the situation relating to ADs on the ground. In particular, this section considers (i) knowledge of and attitudes towards ADs and (ii) the sociocultural factors that affect their acceptance in SA.

In terms of knowledge of ADs, whilst there appear to be no clear data on patient awareness, Baharoon et al. found in 2019 that there was a general lack of understanding on the part of patients about their illness and their options. Of their sample of 300 patients, only 25.3 per cent understood that their disease was incurable, and 54.7 per cent inaccurately thought that their disease was curable. Twenty per cent of the sample reported that their doctors had not discussed their prognosis with them directly. Less than 8 per cent understood the meaning or potential outcome of CPR, intubation or mechanical ventilation or how these interventions were relevant to their condition.[22] This general lack of understanding on patients' part about their illnesses and options is likely to affect their ability and desire to engage in advance care planning.

With respect to healthcare practitioners, a 2019 study on the knowledge and attitudes of physicians and nurses towards ADs for cancer patients found that 64.9 per cent of the participating physicians provided

[19] See note 17, p. 256.

[20] See "Then whoever alters the bequest after he has heard it – the sin is only upon those who have altered it. Indeed, Allah is Hearing and Knowing" (Quran, 2:181).

[21] See note 17, p. 256.

[22] S. Baharoon et al., "Advance Directive Preferences of Patients with Chronic and Terminal Illness towards End of Life Decisions: A Sample from Saudi Arabia" (2019) 25 *Eastern Mediterranean Health Journal* 791.

correct definitions of ADs, whereas the figure for the nurses was significantly higher, at 82.4 per cent.[23] The nurses in the study thus had a much better understanding of ADs, interestingly, with the independent predictors of AD knowledge being female sex and level of education. In terms of attitudes, a 2018 study on the knowledge and attitudes of emergency department and intensive care physicians towards DNR orders found that even though only 13.4 per cent of the sample of 112 mostly Muslim physicians had made ADs themselves, 86 per cent believed that every patient should have an AD. In an earlier study in 2010,[24] Tayeb et al. found that although some medical staff, including physicians, were unaware of what an AD is, most of their participants (who included a range of persons involved in end-of-life care) agreed with the concept of ADs after it had been explained to them. In discussing these findings, the authors argued that ADs were underused in their hospital and that their adoption should be encouraged given that the practice was widely accepted by their sample of 284 Muslim participants.

The data thus far seem to suggest that the concept of ADs is not unknown or unwelcome to physicians. Nevertheless, the few data we have regarding the use of ADs in SA suggest that they are not commonly used in practice. Beyond the likely lower levels of awareness amongst patients, which can be deduced from the aforementioned study conducted by Baharoon et al., do sociocultural and religious factors also play a role?

16.3.1 Role of the Family

Available empirical data suggest that the family plays a significant role in medical decision-making in SA. In a 2012 study on end-of-life practices in a tertiary intensive care unit in Saudi Arabia, it was found that in 88 per cent of their sample of 135 patients who had died after an end-of-life decision, the family or surrogates had been informed and were involved in these decisions.[25] This finding is consistent with the description in Tayeb et al. of the distinct nature of the Saudi family and

[23] I.N. AlFayyad et al., "Physicians and Nurses' Knowledge and Attitudes towards Advance Directives for Cancer Patients in Saudi Arabia" (2019) 14 *PLoS ONE* e0213938.

[24] M.A. Tayeb et al., "A 'Good Death': Perspectives of Muslim Patients and Health Care Providers" (2010) 30 *Annals of Saudi Medicine* 215.

[25] A.S. Aldawood et al., "End-of-Life Practices in a Tertiary Intensive Care Unit in Saudi Arabia" (2012) 40 *Anaesthesia and Intensive Care* 137.

its composite interrelations and strong ties, whereby the patient and family are seen as one unit,[26] as well as the view of Al-Jahdali et al. that illness is considered a "whole-family affair" in Muslim culture.[27] Al-Jahdali et al. further argue that family members may even prefer that a patient not be directly informed of a life-threatening diagnosis or prognosis,[28] and may demand to make end-of-life medical decisions for the patient, decisions that often involve heroic interventions that the patient may not have wanted.[29]

This is perhaps the reason why, despite the cultural significance of the family, studies have shown that a considerable percentage of patients prefer not to consult their family members on end-of-life decision-making. For example, in the previously described study by Baharoon et al., 25 per cent of the sample wanted to be the sole decision-maker, with 55 per cent wanting their family to participate in decision-making.[30] In a 2009 study by Al-Jahdali et al. of advance care planning preferences amongst dialysis patients,[31] one survey question asked participants what they would wish to do if they were transferred to hospital and told by a doctor that their chances of survival were hopeless/dismal. One of the response options queried whether the participant would, in such a scenario, wish to consult their family members before making a decision, and 28 per cent of the sample stated that they would not.

Whilst it is interesting that a significant percentage of patients appear *not* to want to involve their families in end-of-life decision-making, the importance of the family in Muslim cultures such as that of SA and family participation in (or in some cases, takeover of) decision-making in the majority of cases may create difficulties for the use of ADs in SA, at least in a format that emphasises the role of the individual as the sole or primary decision-maker.

[26] See note 24.

[27] Al-Jahdali et al., note 7.

[28] This argument is also consistent with the view of Baharoon et al. that there is a strong belief amongst Saudi citizens that discussing serious illness openly with the patient will cause unnecessary depression or anxiety. As a result, relatives may require physicians to offer hope to the patient or at least request that the patient not be informed of the seriousness of his or her condition, corresponding with their data indicating that many patients are not aware of or informed about their terminal prognosis (see further note 22).

[29] Al-Jahdali et al., note 7, p. 165.

[30] See note 22, p. 794.

[31] H.H. Al-Jahdali et al., "Advance Care Planning Preferences among Dialysis Patients and Factors Influencing their Decisions" (2009) 20 *Saudi Journal of Kidney Diseases and Transplantation* 232.

16.3.2 *Difficulties Concerning Discussions about Death and Dying*

Another relevant factor emerging from the limited empirical research available is the perception that death is not a favoured topic, with discussion of it sometimes avoided, which affects the willingness of doctors and patients to engage in advance care planning more broadly. For example, in the aforementioned study by Tayeb et al., the following was reported: "Some focus group members were concerned about our society's tendency to consider death as taboo, something that human beings cannot interfere with. Participants informed us of cases in which healthcare providers avoided end-of-life discussions because they believed that it is beyond our control as humans".[32]

This view aligns with the perception, mentioned by Baharoon et al., that Arab patients prefer not to discuss ADs owing to a fear of discussion of death and all news related to it,[33] as well as with the problems of palliative care in SA discussed by Alshammaray et al., which include a general unwillingness to discuss issues of death and dying.[34]

There is, however, preliminary evidence from Baharoon et al. suggesting that Arab patients may be more willing to discuss end-of-life decisions, as well as ADs, than previously thought.[35] Although the authors found the majority of their sample to lack knowledge and understanding of their illness and options, as discussed previously, they also found that their patients were generally willing to engage in end-of-life care planning with their doctors and to make decisions about end-of-life care.[36] Despite their participants' limited knowledge of CPR or mechanical ventilation, the majority were capable of making sensible judgements about end-of-life matters, and, when asked directly about their end-of-life preferences, 90 per cent of the sample had formulated opinions on whether resuscitative care would be desirable.[37] Given the limited scope of the study, however, more research is required to substantiate the authors' observation. Nevertheless, avoidance of discussions of death and dying may well contribute to the general lack of discussion surrounding end-of-life care and decision-making, which in turn renders the use of ADs in SA more difficult.

[32] See note 24, p. 217.
[33] See note 22, p. 794.
[34] S. Alshammaray et al., "Development of Palliative and End of Life Care: The Current Situation in Saudi Arabia" (2019) 11 *Cureus* e4319.
[35] See note 22, p. 794.
[36] Ibid.
[37] Ibid., p. 795.

16.4 The Way Forward

In considering the way forward, there are two key points to highlight. The first is that the lack of specific legislation or guidance on ADs is problematic and that, in this area, reliance on "on-call" *fatwas* may not be the best way forward. We argue that what is needed is the empirically guided development of clear policies related to ADs that are supported by a clear legal framework clarifying the roles and responsibilities of the patient, the family and caregivers through enacted laws. To achieve such development, we believe that relevant issues pertaining to ADs (amongst other end-of-life care issues) need to be identified, analysed and explained to the scholarly authorities to allow them to provide caregivers with an outline of how to approach the concept of ADs within the limits of Islamic guidance. Further, previous works within and beyond the *fatwas* need to be gathered, studied and summarised to develop guidelines for this practice. As stated earlier, not all *fatwas* are articulated as laws, although they can be used as supporting defence, if needed, as in the aforementioned example of DNR orders. We do not think that this is an ideal situation. The role of *fatwas*, and more broadly of the *fatwa*-issuing bodies, should be clarified, and these should be incorporated into mainstream guidance, as with the example of the National Guidelines for Informed Consent.[38]

The second point to highlight relates to the training of healthcare professionals on the concept and application of ADs, as well as on end-of-life issues more generally. The studies discussed here suggest that healthcare professionals in SA do not often initiate or engage in discussions of poor prognoses or end-of-life issues with their patients, possibly owing to misconceptions about patients' willingness to discuss such issues. This leads to a lack of understanding on the part of patients about their illnesses and their options, which includes the possibility of indicating a preference beforehand via an AD. Comprehensive and uniform training on ADs and end-of-life issues, including training on how discussions of such issues should be conducted, would be helpful in increasing both patient awareness and the use and implementation of ADs in SA.[39]

[38] Saudi Ministry of Health, *Saudi Guidelines for Medical Informed Consent* (Riyadh, 2019), www.moh.gov.sa/en/Ministry/MediaCenter/Publications/Pages/Saudi-Guidelines-for-Informed-Consent.pdfwww.shc.gov.sa/en/CouncilDecisions/Pages/Decisions260.aspx#.

[39] See also AlFayyad et al., note 23, p. 9, which also recommends more uniform training on ADs for doctors and nurses, as well as access to AD registers.

16.5 Conclusion

Owing to the absence of a specific legislative framework, policy or religious guidance on the topic of ADs (despite the presence of guidance on other end-of-life care-related issues), uncertainty remains over the acceptability and role of ADs in SA. In this chapter, we have considered how Islamic Fiqhi principles might apply. Although there is a general emphasis on the sanctity of life in Islam, Islamic principles concerning the seeking of treatment and the Muslim concept of death provide the basis for an interpretation that could permit ADs in situations where treatment would be futile or even harmful. Fatwa No. 12086, although specifically addressing the issue of DNR orders, supports this interpretation.

However, although there appears to be a general acceptance of ADs in Islamic law, and although empirical data suggest that the concept of ADs is not unknown or unwelcome to healthcare practitioners in SA, clear evidence of AD practice on the ground is lacking. Whilst the absence of specific laws or policies pertaining to ADs is likely a contributing factor, the paucity of ADs in practice may also be the result of such sociocultural factors as the significant role of the family in decision-making or the observed difficulties of engaging in discussions of death and dying. We concluded the chapter with some specific recommendations for how SA might approach ADs moving forward, including the formulation of clearer laws, policy and/or guidance, as well as comprehensive and uniform AD training for healthcare professionals.