
The Law and Practice of Advance Directives in the Islamic Republic of Iran

ZAIN ABBAS SYED, EHSAN SHAMSI-GOOSHKI &
ALIREZA PARSAPOOR

8.1 Introduction

Unlike other patient populations, end-of-life patients suffering a terminal illness often lose the capacity to make healthcare decisions. Advance directives (ADs) are one method for addressing such loss of capacity. They permit the decisions of competent patients about future treatments to be recorded for enactment if/when they lose mental capacity.

At present, physicians in the Islamic Republic of Iran tend to expend, often reluctantly, numerous resources caring for patients approaching the end of life. In fact, in a 2015 *JAMA* study comparing 16 Asian countries, Iranian physicians were among the least likely to withhold or withdraw treatment when presented with two scenarios of patients with no real chance of recovering a meaningful life.¹ Their response may have been influenced by the absence of ADs allowing the refusal of futile life-sustaining interventions in end-of-life patients, which are often demanded by relatives, as well as the lack of legislative and regulatory support for an alternative approach. A lack of hospice and in-patient/community palliative care services also provides Iranian physicians with few alternatives. The current situation imposes a significant financial burden on Iran's predominantly publicly funded national healthcare system, as well as on patients and their relatives, and results in suboptimal patient-centred outcomes during terminal illness.

There is therefore reason to believe that ADs could play a useful role in reducing futile healthcare expenditure on and interventions for end-of-life patients, alleviating guilt among relatives for taking decisions to withdraw/avoid futile treatments and promoting patient autonomy in a

¹ J. Phua et al., "Withholding and Withdrawal of Life-Sustaining Treatments in Intensive Care Units in Asia" (2015) 175(3) *JAMA Internal Medicine* 363.

healthcare culture that is largely family centric. AD implementation must, however, be sensitive to Iranian culture and social norms, including respect for the Islamic doctrine to which the nation and its infrastructure subscribe. Unfortunately, Islamic discourse on end-of-life healthcare ethics is rife with controversy, including on such issues as defining and determining death, the limits of personal autonomy and the freedom to refuse life-sustaining medical interventions even as a competent patient let alone once capacity has been lost. Therefore, the typical paradigm of honouring patient wishes, as expressed in an AD, to optimise patient-centred outcomes is not easily translatable in Iran.

Our discussion begins with a brief introduction to the history/culture of medical ethics and law in Iran. We then discuss the current legal status of ADs in Iran, including the criteria for their validity and their reliance on a surrogate decision-maker. We next reflect on the multitude of factors affecting the current (lack of) AD implementation in Iranian hospitals and community healthcare settings, including a critical-normative reflection on cultural, Islamic, legislative and infrastructural factors. We conclude by recommending a model for advance end-of-life decision-making in Iran. Although ADs can apply to a vast range of end-of-life treatment decisions such as artificial nutrition/hydration, resuscitation and hospital admission, our main example of AD application pertains to the withholding of life-sustaining treatment from terminally ill, mentally incapacitated patients. We also focus on ADs in the medical as opposed to psychiatric setting.

8.2 A History of Medical Ethics and Law in the Islamic Republic of Iran

Historically, the Iranian Zoroastrian medical tradition featured several commonalities with the Hippocratic tradition, although the latter's influence took hold during the Hellenistic period following Alexander III of Macedon's invasion of Iran and the subsequent migration of Nestorian Christians and Neo-Platonists to the interdisciplinary school of Gondhishapour in the then capital of the Iranian kingdom. Islam then entered the Iranian establishment in the seventh-century Sassanid period. The subsequent Golden Era of Iranian-Islamic medicine inspired the expansion of Hippocratic/Galenic medical ethical discourse, as seen in books such as *Ādāb al-Ṭabīb (Practical Ethics of the Physician)* by Al-Ruhawi, as well as Islamic medical theo-legal doctrine surrounding abortion, physician liability, patient consent and surrogate decision-making. However, owing

to the prevalence of *Ash'ariy* thinking, which opposed the use of philosophical reasoning in the derivation of ethics, most Islamic works on medical ethics followed a virtue ethics-based approach without reference to theoretical/religious reasoning. That approach continued until the establishment of modern medical schools in Iran in the twentieth century. However, the Islamic Revolution of 1979 gave rise to a novel bioethical movement in Iran, with the [Shia] *Mu'tazali* approach demonstrating that a reason-based juristic methodology was effective in responding to sensitive, modern bioethical issues, cementing the role of religious reasoning and derivation (through theology, law and ethics) as a tangible objective and standard of medical practice.²

In 1979, Ayatollah Ruhollah Khomeini, a jurisprudent-cleric from the Holy City of Qom, spearheaded a popular revolution to depose the Pahlavi monarchy in Iran. Widespread public discontent led the nation to reject the monarchy and vote in favour of an Islamic theocratic democracy, at the heart of which lay the doctrine of the Guardianship of the Jurist,³ granting divine authority to said Islamic Jurist to establish a government serving the interests of the Muslim nation, including the protection and propagation of its religious identity and infusion of Islamic doctrine into its state and public institutions. In the years since, Iran has experienced major academic and technological advances, including multidisciplinary engagement in the rapidly expanding field of Islamic bioethics/law, which has led to the ratification and implementation of several medical laws, including laws on the therapeutic termination of pregnancy, assisted reproductive technology, organ donation and brain death, as well as the integration of bioethics teaching into undergraduate medical syllabi and establishment of hospital ethics committees and national bioethics research centres. Thus, medical ethics is now among the most rapidly expanding, topical and translational academic fields in Iran.

8.3 The Regulation of Biomedical Ethics in Iran

To appreciate the legal position of ADs in Iran, one must first appreciate the basic structure of the Iranian Government and legislative apparatus.

² E. Shamsi-Gooshki, *Ethical, Legal and Jurisprudential Aspects of Do-Not-Resuscitate Orders in the Health System of Islamic Republic of Iran*, in *School of Traditional Medicine* (Tehran: Shahid Beheshti University of Medical Sciences, 2013).

³ M.T.M. Yazdi, *A Cursory Glance at the Theory of Wilayat alFaqih* (Qom: Ahlulbayt World Assembly, 2003).

Essentially, the public elects the President, Members of Parliament and the Assembly of Experts. The latter consists of a chamber of religious jurists tasked with appointing the country's Supreme Leader (*Waliy-i-Faqih*), who must be a religious jurist. The Supreme Leader and Parliament together appoint the Guardian Council consisting of six lawyers and six Islamic jurists, whose tasks include the ratification (or rejection) of laws passed by Parliament based on whether they are in keeping with *Shariah* (Islamic law) and the Constitution. In the event of disagreement between the Guardian Council and Parliament, an Expediency Council appointed by the Supreme Leader mediates a resolution. Importantly, Iran has a Romano-civil legal system, although, unlike in other civil law countries such as France, Iran recognises the legally binding nature of a *fatwa* (edict/judgment) issued by an Islamic jurist in areas for which there is no statute or by-law (Article 167, the Constitution).⁴

Today, medical practice in Iran is governed at three levels: by statute laws, executive by-laws and official regulations/guidelines. The latter two gain legal standing through acts of legislation that empower state ministries/councils to implement by-laws or official regulations, as per Article 138 of the Constitution,⁵ which grants individual ministers the right to "frame regulations and issue circulars in matters within their jurisdiction". This three-level hierarchy is demonstrated in the legal regulation of organ donation in Iran:

- Statute law: The Law on Organ Transplantation of Dead Patients or Patients in Whom Brain Death Has Been Confirmed (2000) - Parliament of the Islamic Republic of Iran.⁶
- Executive by-law: Ratified by the Council of Ministers as per the recommendation of the Ministry of Health and Medical Education (MOHME), including particulars of the Statute's implementation and standards.⁷
- Official regulation: Published by the National Clinical Ethics Committee (and ratified by MOHME) on the necessity to confirm

⁴ The Constitution of the Islamic Republic of Iran. Last reviewed in 1989.

⁵ Ibid.

⁶ Parliament of the Islamic Republic of Iran, "قانون پیوند اعضای بیماران فوت شده یا،" [The Law on Organ Transplantation of Dead Patients or Patients in Whom Brain Death Has Been Confirmed] (1379 [AD 2000]).

⁷ Council of Ministers, "Executive By-law of the Law on Organ Transplantation of Dead Patients or Patient in Whom Brain Death Has Been Confirmed" (1381 [AD 2002]).

brain death and implement do-not-resuscitate (DNR) orders for such patients regardless of organ donor status.⁸

Iran has several national ethics policymaking bodies responsible for composing guidelines and regulations at the tertiary level. The Supreme Council on Medical Ethics (SCME) is the highest such body and participates in approving MOHME frameworks. It is chaired by the Minister for Health and Medical Education and includes representatives of the Iranian Legal Medical Organisation (medical forensics, including regulation of pregnancy termination), the Islamic Republic of Iran Medical Council (IRIMC) (a physician licensing body) and other important health institutions/stakeholders. The SCME reviews and provides final approval for ethical guidelines produced by second-tier policymaking bodies, including the National Clinical Ethics Committee (NCEC), National Committee for Ethics in Biomedical Research (NCEBR) and National Committee for Ethics and Medical Education (NCEME). The NCEC was established for policymaking, supervisory and decision-making activity in the field of clinical ethics, whilst the NCEBR and NCEME are responsible for research ethics and medical education ethics, respectively.

8.4 Advance Directives in the Legal System of Iran

Although ADs are essentially unutilised in the Iranian healthcare system (see next section), the law provides for their *potential* use, albeit only as a guide to decision-making (an advance *recommendation*) rather than a binding advance *directive*. As there is no statute law regulating ADs, AD implementation is primarily governed at the tertiary level of official regulations under the SCME Iran Charter of Patient Rights (2009) and IRIMC General Guidelines of Professional Ethics (2020).

The Iran Charter of Patient Rights (2003, revised 2009) was composed to elaborate on Article 29 of the Constitution, which recognises health/treatment services and medical care as a “universal right”. The first version (2003) of the charter commented on classical issues such as the right to the best possible treatment, confidentiality and the consent/refusal of treatment except in emergencies. However, owing to its

⁸ Q. Janbaba'iy, “افراد دچار مرگ مغزی با شرایط غیر کاندید اهداء عضو” [Brain Death Patients Who Do Not Possess the Criteria for Organ Donation], Ministry of Health & Medical Education of the Islamic Republic of Iran (1397 [AD 2019]).

wording and lack of auditing and stakeholder consultation, it lacked effective implementation.⁹ Therefore, a revised version was spearheaded by Parsapoor et al. at the Medical Ethics & History of Medicine Research Centre at Tehran University of Medical Sciences.¹⁰ The 2009 version followed extensive stakeholder consultation, was developed with special attention to the cultural issues of Iran and avoided contradiction with Islamic law. It is also patient centric, and, in chapter 3, elaborates on the issues surrounding autonomy, decision-making, ADs and surrogate decision-making.

In addition, in 2020 Shamsi-Gooshki et al., under the auspices of the IRIMC, composed the General Guidelines of Professional Ethics to act as a subsidiary to the disciplinary by-law.¹¹ Currently, the IRIMC Disciplinary By-Law is a general document, which, in Article 6, instructs the IRIMC to develop professional ethics guidance, thereby explicitly stating the ethical obligations and standards of medical professionals, including extensive elaboration in areas such as respect for patient autonomy.

Importantly, both documents are legally enforceable, not just “best practice guidelines” unless retracted by the Court of Administrative Justice. The charter gains its status by merit of its endorsement by MOHME and Article 138 of the Constitution. In the case of the Professional Ethics Guidelines, the statute establishing the IRIMC grants it the authority to take disciplinary action against its members (licensed physicians) for noncompliance with its professional guidelines. Thus, noncompliance with these codes of practice is a matter of both professional and legal compliance. In fact, they have recently been referred to in official court rulings on physician liability/negligence.¹²

⁹ F. Rangraz Jeddi and R. Rabii, “Level of Observance of Patients’ Rights Charter in Kashan Public Hospitals” (2007) 10(1) *Behbood* 62 [in Farsi]; S.H.E. Razavi et al., “An Evaluation of Adherence to the Patient’s Rights Charter among Patients and Physicians at the Emergency Department of Imam Khomeini Hospital, Tehran” (2006) *DARU Journal of Pharmaceutical Sciences* 17 [in Farsi]; S. Joolae, “The Introduction of Patients’ Rights Charter and the Approaches to Promote Observing Them in Iran” (2008) *Abstracts of Nursing Section of the Second International Conference of Iranian Medical Ethics, Tehran University of Medical Sciences*, pp. 8–9, <http://fnm.tums.ac.ir/userfiles/NursingEthics/AbstractsOfThe2thInternationalConferenceOfIranianMedicalEthics-NursingSection.pdf>.

¹⁰ A. Parsapoor et al., “Patient’s Rights Charter in Iran” (2014) 52(1) *Acta Medica Iranica* 24.

¹¹ E. Shamsi-Gooshki et al., “Developing ‘Code of Ethics for Medical Professionals, Medical Council of Islamic Republic of Iran’” (2020) 23(10) *Archives of Iranian Medicine* 658.

¹² See Rangraz Jeddi and Rabii, note 9.

Chapter 3 of the charter specifies that “every individual has the right to a free choice and decision about receiving healthcare services”, including the right to “reject proposed treatments after being informed of the medical consequences of their decision except in cases of suicide or harm to others”. The charter also emphasises optimising capacity to make autonomous decisions: “[I]f the patient lacks sufficient capacity to make decisions, but can participate in some parts of decision making reasonably, their decision must be respected”.

Section 3-1-5 of the (original Persian language)¹³ charter stipulates that the scope of individual choice in healthcare decision-making includes “[a] patient’s **registered** advance directive made at a time when the patient retained capacity for decision making to be used to **guide** medical treatment when the patient lacks capacity for decision making, provided it is **in keeping with the legal requirements of the healthcare team** and the **surrogate decision-maker [SDM]**” (emphasis added). The first point to note is the essential loss of (legal) autonomy that is incurred upon a patient’s loss of mental capacity in Iran. In fact, the (legal) decision-making rights of an incompetent patient are passed in full to their SDM when they lose capacity (elaborated upon later). Therefore, the SDM is obliged to use a registered AD, if it exists, only to *guide* their decision on the patient’s behalf. The second point is that, in addition to the basic criteria for informed consent/refusal, the criteria for a valid AD include the following:

8.4.1 Registered

There is currently no national/regional registry for ADs in Iran, and therefore no clear mechanism for healthy patients to register their wishes in advance. Thus, the mechanism for potential AD registration envisaged by the charter is currently limited to an inpatient environment in which an unwell patient is consulted regarding their prognosis and future treatment decisions, and their wishes are documented in the patient’s notes. This constitutes “registration”, that is, documentation. The charter does not elaborate on any procedural requirements for such documentation, such as the necessity for witnesses or multidisciplinary team involvement.

¹³ A. Parsapoor, A. Bagheri and B. Larijani, *منشور حقوق بیمار در ایران [Iran Patient Rights Charter]* (1388 [AD 2009] زمستان، *تاریخ و اخلاق پزشکی، [Medical History & Ethics]* Winter issue.

8.4.2 *In Keeping with the Legal Requirements of the Healthcare Team*

In broad terms, an AD is invalid if it requests a physician to carry out a treatment that contradicts their professional obligations or expected standards of practice, as outlined in the Professional Ethics Guidelines. Thus, ADs are void if they request illegal procedures or those deemed negligent/liable, including euthanasia. By extension, ADs must also respect the usual standards of consent in competent patients, including not requesting treatments/procedures outside “options deemed scientifically/technically reasonable/authentic” (Chapter VII Article 67, the Professional Ethics Guidelines). Importantly, the charter obliges physicians to deliver “appropriate healthcare”, which includes consideration of the justice of healthcare resource allocation, respect for patient dignity, the avoidance of unnecessary pain and palliation approaches.

Currently, there are no clear guidelines on how to address situations in which patients express their wish, via an AD, to refuse an intervention but are likely to die or suffer serious harm due to the refusal. Interestingly, however, the Professional Ethics Guidelines, in the case of patients possessing capacity, oblige doctors to make their “best effort to convince the patient” and, if unsuccessful, to “refer the case to the hospital ethics committee”. As ADs are not currently practised in Iran, it is unclear whether the same approach, attempting to convince the patient and referring him/her directly to the hospital ethics committee, applies to the patient’s SDM. What is clear, however, is that patient autonomy does not by default trump the preservation of life in the current Iranian-Islamic legal system, and the issue remains controversial in Islamic legal discourse.

8.4.3 *In Keeping with the Legal Requirements of the Surrogate Decision-Maker*

According to the charter, “[i]f the patient is not able to make decisions for any reason, all patient rights mentioned in this charter apply to the [SDM]”, irrespective of whether an AD exists. The SDM (the *valiy* or “guardian”) is a phenomenon rooted in the Islamic Guardianship Law.¹⁴

¹⁴ The Civil Code of the Islamic Republic of Iran, Book 8 On Children, Chapter 3 On the Natural Guardianship of the Father and Paternal Grandfather over the Child. (1307 [AD 1982]).

Essentially, the legal guardian (and SDM) of a child (defined in Islamic law as a person below the age of puberty) is the child's father or paternal grandfather. After puberty (and "mental maturity"), a person becomes their own legal guardian. If during adulthood, a patient loses decision-making capacity, Iranian law recognises the patient's father or paternal grandfather as their guardian. In the absence of a father/paternal grandfather (which is the case with the majority of elderly patients admitted to hospital), the Islamic Jurist becomes the default guardian (and SDM) tasked with making best-interest decisions on the patient's behalf in all walks of life, including health. In theory, the Islamic Jurist in question is the Supreme Leader, although in practice such authority is indirectly transferred to a regional/local judge in a Court of Islamic Governance. The judge should then vet and appoint an individual (usually a family member) to act as an SDM/guardian on his behalf. However, if an adult has never possessed "mental maturity", owing, for example, to a syndrome/disability since childhood, then the guardianship of their father/paternal grandfather continues by default into the person's adulthood without intervention from the Islamic Jurist. If the father/paternal grandfather passes away, then guardianship (and SDM) rights pass to the Islamic Jurist (i.e. the courts) and follow the process outlined previously for appointing a relative as SDM.

SDMs are a necessary part of the healthcare system in Iran, as a legal decision-maker is required for an incapacitated patient. The Islamic Jurist is obliged to appoint the party who is best placed to protect the patient's best interests and make decisions on their behalf (usually a close relative). An AD is not a legally binding decision in this context because there is no recognition of precedent autonomy in Iranian-Islamic law. Thus, it can at most serve as a **guide** for the SDM's decisions.

There is currently no official guidance on the procedure for an SDM who wishes to act in opposition to a registered AD. However, according to the charter, where "the surrogate decision-maker is opposed to treatment, against the physician's advice, the physician can refer to related authorities [e.g. the hospital ethics committee] for reconsideration". This clause essentially exists to safeguard patients when there is suspicion that an SDM is making decisions that are not in the patient's best interests or when there is a conflict of interest (e.g. avoiding treatment costs to maximise personal inheritance). However, the more likely situation is that of an SDM requesting a futile intervention, such as continuing antibiotics for a dying patient, in opposition to that deemed appropriate by the treating physician. In this situation, the physician would be

advised to consult the hospital ethics committee if efforts to negotiate the issue on the ward were unsuccessful.

8.5 Advance Directives in Practice

Whilst Iranian law provides for the potential use of ADs, in our experience they are essentially non-existent in Iranian hospitals and community healthcare settings. That said, there is some evidence that Iranian doctors and nurses support the use of ADs for decisions about resuscitation,¹⁵ with one study demonstrating nurses' explicit support for honouring the previously declared wishes of patients, including the wish not to receive life-prolonging treatment.¹⁶ However, the authors are unaware of any other studies in either English or Persian on AD usage rates or the implementation of or barriers to ADs in Iran. We are also unaware of any best-practice/clinical guidelines specifically on AD implementation from Iranian medical associations or hospital ethics committees.

Nonetheless, efforts are being made to develop the practice of appropriate end-of-life decision-making in Iran. For example, many cancer patients with progressive/terminal prognoses benefit from advance care plans (ACPs) to limit futile interventions such as cardiopulmonary resuscitation (CPR).¹⁷ The Shahid Beheshti University of Medical Sciences, Tehran, also recently published detailed clinical practice guidelines on palliative care for end-stage cancer patients, including recommendations for ACPs and the avoidance of futile interventions such as CPR.¹⁸ It would be fair to say, however, that the practice of avoiding CPR is not in widespread use nationally. Also, although ACPs constitute a beneficial approach for cancer patients, ADs aim to capture a much wider population, including those admitted to hospital without a known terminal diagnosis. In this context, the authors believe there is value in

¹⁵ M. Fallahi et al., "Nurses and Physicians' Viewpoints about Decision Making of Do Not Attempt Resuscitation (DNAR)" (2018) 13 *Multidisciplinary Respiratory Medicine* 20.

¹⁶ F. Razban et al., "Critical Care Nurses' Attitude towards Life-Sustaining Treatments in South East Iran" (2016) 7(1) *World Journal of Emergency Medicine* 59.

¹⁷ M. Ghajarzadeh et al., "Perspectives of Iranian Medical Students about Do-Not-Resuscitate Orders" (2013) 8(3) *Maedica* 261.

¹⁸ Department of Health, Shahid Beheshti University of Medical Sciences, ارائه ی مراقبت های تسکینی به بیماران مبتلا به سرطان در مراحل انتهایی در بخش طب تسکینی: راهنمای طباطبائی بالینی. [Clinical Practice Guideline: Delivering Palliative Care to End-stage Cancer Patients on Palliative Care Wards] (1399 [AD 2020]).

reflecting on current literature on the landscape of end-of-life decision-making in Iranian healthcare to better understand the context in which ADs could be practised. We draw in particular on the literature on DNR orders, of which there is a good amount, as a type of life-sustaining intervention withheld from end-of-life patients on the basis of practitioner-determined medical futility.

It is evident from the literature that there is support from both society and healthcare professionals in Iran for an approach that limits the use of futile, life-sustaining interventions in patients approaching the end of life. For example, studies show the practice of DNR orders to be present to some degree in Iranian hospitals,¹⁹ with the majority of doctors,²⁰ nurses,²¹ relatives²² and even patients supporting the practice.²³ The common reasons offered for such support include protecting the dignity of the patient,²⁴ reducing futile interventions,²⁵ economic costs and pain/suffering,²⁶ and relatives sacrificing their own use of health resources for others.²⁷ Most of the participants in these studies agreed that DNR decisions should be led by physicians²⁸ with the consent of the patient/relatives²⁹ and in conjunction with the wider healthcare team. Interestingly, physicians were found not to support DNR orders for those not at risk of imminent death (i.e. those with a 6–12 month prognosis),³⁰ a stance mirrored in one hospital's palliative care guidelines.³¹

¹⁹ See note 17.

²⁰ See note 17; M. Fallahi et al., "The Iranian Physicians Attitude toward the Do-Not-Resuscitate Order" (2016) 9 *Journal of Multidisciplinary Healthcare* 279.

²¹ S. Mogadasian et al., "The Attitude of Iranian Nurses about Do-Not-Resuscitate Orders" (2014) 20 *Indian Journal of Palliative Care* 21.

²² M. Tajari et al., "Attitudes of Patients' Relatives in the End Stage of Life about Do-Not-Resuscitate Order" (2018) 7(5) *Journal of Family Medicine & Primary Care* 916.

²³ M.R.F. Bordbar et al., "Investigating the Attitude of Healthcare Providers, Patients, and Their Families toward 'Do-Not-Resuscitate' Orders in an Iranian Oncology Hospital" (2019) 25(3) *Indian Journal of Palliative Care* 440.

²⁴ F. Bahramnezhad et al., "Iranian Nurses' Perspective on Non-Resuscitation: Content Analysis" (2016) 5(6) *International Journal of Medical Research & Health Sciences* 136.

²⁵ M. Cheraghi et al., "Experiences of Iranian Physicians regarding Do-Not-Resuscitate: A Directed-Content Analysis" (2016) 9 *Journal of Medical Ethics and History of Medicine*.

²⁶ See note 22; A. Assarroudi et al., "Do-Not-Resuscitate Order: The Experiences of Iranian Cardiopulmonary Resuscitation Team Members" (2017) 23(1) *Indian Journal of Palliative Care* 88.

²⁷ See note 24.

²⁸ See note 21.

²⁹ See note 17.

³⁰ See Fallahi et al., note 20.

³¹ See note 18.

Whilst the relatives involved in the studies discussed here generally supported DNR orders, relatives can still play a key part in preventing their implementation. In contrast to the perception of healthcare professionals, patients' relatives disagree that resuscitation is "undignified".³² It is also a matter of conscience for Iranian families to feel that they have done their utmost for the patient to avoid guilt.³³ It may also be the case that families disagree with physicians' suggestions for palliation and apply pressure for maximal intervention owing to poor communication on the latter's part regarding patients' poor prognosis.³⁴ Such poor communication may be related to the difficulties perceived by healthcare professionals of discussing dying/DNRs with patients/relatives,³⁵ as well as their expected role in prolonging life³⁶ and even providing hope to patients despite their imminent death.³⁷ It may also reflect a general weakness in communication skills and in the physician–patient relationship in Iranian healthcare culture. We will explore these issues further in the next section.

In sum, we can see that there is societal and professional support in Iran for restricting the use of futile interventions in terminally ill/end-of-life patients, as well as for the necessity of patients' advance participation in such decisions. It is unlikely, however, that ADs could function outside the terminal illness/end-of-life context. AD implementation clearly requires management of the emotional and cultural dynamic of relatives' perceived role in patient care, as well as of their expectation to receive comfort/hope from physicians in addition to physicians' duty to deliver candid and honest information on prognoses.

8.6 Critical Analysis of the Reasons for the Lack of AD Use in Iran

In this section, we distil the literature to answer a simple question: What are the factors currently preventing the utilisation of ADs in the Islamic Republic of Iran?

³² See note 22.

³³ See note 25.

³⁴ Ibid.

³⁵ See note 21.

³⁶ See note 17; note 21; K. Mirzaei et al., "Patients' Perspectives of the Substitute Decision-Maker: Who Makes Better Decisions?" (2011) 37(9) *Journal of Medical Ethics* 523.

³⁷ See note 21.

8.6.1 *Legal*

Clause 295 of the Islamic Penal Code specifies that when a duty (e.g. of care) is neglected, a penalty is applicable to the person entrusted with that duty. This means that, by default, medical practice in Iran is often defensive, with the objective of avoiding liability by favouring life-prolonging interventions. Despite evidence of support for DNR orders among healthcare professionals, there is also evidence of ignorance and fear of legal retribution among physicians/nurses regarding commencing, signing or implementing DNR orders.³⁸ As mentioned previously, the fact that Iran has a civil legal system means that physicians look to and expect written guidelines at the least and executive by-laws or parliamentary statutes at best to govern the practice of ADs and DNRs. In the absence of clear statute law governing this area, it is difficult for Iranian healthcare professionals to abandon their defensive stance, particularly when faced with pressure from relatives to engage in maximal intervention. At the same time, the Professional Ethics Guidelines (Article 27, Chapter IV) forbid futile intervention for fear of litigation, although they fail to clarify the exemption from litigation in the case of ADs to refuse life-sustaining interventions. This creates a dilemma for Iranian physicians. For the sake of brevity, the authors refer readers to the PhD thesis of Shamsi-Gooshki,³⁹ who concluded that according to Islamic, civil, criminal, and professional liability standards and laws, DNR orders can be considered legal and judges may not hold a physician liable for implementing such an order.

Furthermore, the practice of surrogate decision-making in Iran has not taken place in the way envisaged by the charter, largely because it requires a lengthy legal process that conflicts with the obligation to provide timely care. Therefore, physicians usually consult the relatives/next of kin present at the bedside, which constitutes accepted practice in Iranian culture. This, despite being unlawful, has received little known opposition from the legal authorities. Nevertheless, Mirzaei et al. reported that “the people we usually consult for decisions concerning patient treatment are significantly different from the patients’ preferred substitute decision-maker”.⁴⁰ They also showed that there is no clear demographic predictor in Iranian society

³⁸ See note 21; note 24; note 25.

³⁹ E. Shamsi-Gooshki, *Ethical, Legal and Jurisprudential Aspects of Do-Not-Resuscitate Orders in the Health System of Islamic Republic of Iran*, PhD thesis, Shahid Beheshti University of Medical Sciences (2013).

⁴⁰ See Mirzaei et al., note 36.

regarding preferred SDMs, for example, a wife choosing her husband, parents choosing their eldest son, and that the preference is highly subjective and based on the individual patient's circumstances. That said, the lack of an official, legally appointed SDM would not be a reason to invalidate or devalue a registered AD, which would retain its place as a useful guide to patient preferences for whoever assumes the decision-making role, even if such decision-makers do not currently have authority according to the letter of the law.

8.6.2 *Islamic*

The three levels of the legal regulation of bioethics in Iran are all subject to the "sieve" of Islamic law, meaning that any laws, by-laws or official regulations/guidelines must be consistent with Shariah or face rejection by the Guardian Council (in the case of statutes) or the Court of Administrative Justice (in the case of by-laws and official regulations/guidelines). Thus, the Islamic legal stance on the issue of ADs is extremely important.

(Shia) Islamic law is derived from four canonical sources: the Koran, *Hadith* (verbal narrations from the Holy Prophet and his family, peace be upon them), 'Aql (logic) and *Ijmā'* (consensus of jurists). Shia Islamic jurists, referred to as Mujtahids or colloquially as Ayatollahs, receive several decades of vigorous training in religious seminaries in the traditional Islamic sciences, including Arabic grammar, logic, theology, philosophy, jurisprudence, history, *Hadith*, exegesis and many more in order to be able to independently derive law from primary canonical sources. Normative Islamic laws are divided into five types: *Wajib* (obligatory), *Mustahab* (recommended), *Mubah* (permissible), *Makruh* (not recommended) and *Haram* (impermissible). The avoidance of a *wajib* action or committing of a *haram* action warrants divine punishment; hence, much of an Islamic jurist's work involves trying to understand these "red lines" of the Shariah and feeding such understanding into a practical legal system such as that functioning in Iran. The final edict of a Mujtahid is known as his *fatwa*, or ruling, on a specific topic; for example, the *fatwa* for abortion is impermissibility unless certain conditions are met. Importantly, within the Shia clerical institution, Mujtahids are arranged in a hierarchy. A Faqih is a higher level Mujtahid who has broad understanding of various Islamic legal disciplines and teaches others to become Mujtahids. Higher on the hierarchy is a Marja' (colloquially known as a "Grand Ayatollah") who is recognised as the most

knowledgeable among the Fuqaha (pl. Faqih) and publishes a book of Islamic Edicts (*Risalah 'Amaliyyah*) on day-to-day issues faced by Muslims in, for example, the areas of cleanliness, prayer, fasting, transactions/economics, marriage, divorce and medical issues. It is these Maraji' (pl. Marja') whom lay Shia Muslims are obliged to follow on day-to-day issues, including normative healthcare decision-making. There are currently several recognised Maraji' in the Holy City of Qom (Iran) and the Holy City of Najaf (Iraq), which are the two main religious seminaries of the Shia world. Naturally, having numerous Maraji' creates a diversity of opinion, which can create challenges for the Iranian legal system when deciding whether to accept or reject a parliamentary statute. However, the current practice of the Guardian Council and Court of Administrative Justice is to respect the viewpoint of the Supreme Leader (who is also a Grand Ayatollah) or, in areas where he has not issued a *fatwa*, to choose among the viewpoints of other Grand Ayatollahs.

Importantly, the accurate derivation of Islamic law requires not only mastery of traditional Islamic sciences but also an accurate conception of the subject matter for which the divine law needs to be derived. On this, there sometimes exist fundamental infrastructural limitations on obtaining reliable and accurate *fatawa* (pl. of *fatwa*) on medical issues from Grand Ayatollahs. For example, the *fatawa* on some medical issues lack reliability owing to the incorrect/lack of communication of facts by those who submit questions on the websites of the Maraji'. There is also often a lack of application of secondary laws/principles (*al-ahkam al-thanawiyyah*), which function to abrogate primary impermissibility. An example of a secondary law would be the permissibility of examining the private parts of a patient owing to the secondary principle of *avoiding hardship*, thereby abrogating the primary impermissibility of looking at this part of the body owing to the necessity of treatment for a physical ailment that is causing/could cause *hardship*. Many other opportunities exist in the medical arena for the application of secondary principles. Furthermore, there is often an inherent neglect of the role of a given medical issue in Muslim society (involving considerations of justice, economic factors and the public good), which could in turn affect a *fatwa* on it were these considerations taken into account.⁴¹ Much of this

⁴¹ Z.A. Syed, "On the Need for a Pragmatic, Multi-disciplinary, Evidence-Based Approach to Seeking a Fatwa on the Issue of Organ Donation after Death", in M. Abdul-Hussain et al. (eds.), *Organ Donation in Islam: The Interplay of Jurisprudence, Ethics and Society*, (Lanham, MD: Lexington Books, in press).

unreliability may result from the *unilateral* process by which *fatawa* are sought, as well as from a lack of stakeholder consultation or multi-disciplinary input. The derivative reasoning for medical *fatawa* is also seldom published, resulting in the inability of ethicists, lawyers or clinical academics to analyse them. Admittedly, there are also tensions within some Islamic academic circles about the influence of “bioethics” (perceived as a Western secular movement) on the traditional Islamic legal approach to contemporary medicine, perhaps hampering engagement. The issue of ADs is also not immune from the consequences of this infrastructural limitation, as demonstrated later.

Furthermore, it is important to note that, in our view, “Islamic medical ethics” is not an accurate phrase, as in reality the only normative source in Islam is Islamic law (*fiqh*). However, within the field of Islamic medical law, traditional legal precepts have in recent times been organised into a system resembling something like the four-principle approach of Western clinical ethics.⁴² We therefore apply and critically analyse the application of these principles to the issue of ADs in the following:

8.6.2.1 Principles that May Negate Respecting an AD to Limit Life-Sustaining interventions

- The Rule of the Preservation of Life:⁴³ Islamic law grants fundamental importance to the preservation of life, as per the Koran 5:32, numerous *hadith* and ‘*Aql* (logic), which is why decisions about forgoing life-sustaining interventions are treated with caution. However, it could be argued that the current conceptualisation of life and death as a two-paradigm phenomenon results in the misapplication of this rule to dying patients. Reality is in fact closer to a three-paradigm concept involving (i) life, (ii) *al-ihtiḍār* (dying) and (iii) death. *Al-ihtiḍār* is a noun that refers to a person who is approaching death, that is, for whom the dying process has begun. Implicit within it is the recognition that death (i.e. separation of the soul from the body) is a gradual process rather than a single event. It can be appreciated from the Islamic acts of worship associated with *al-ihtiḍār* (such as turning the patient’s feet towards Mecca, the recommendation to recite certain verses of the Koran, the recommendation to moisten the patient’s lips and avoiding placing heavy objects on the patient’s chest) that there is

⁴² M. Muhaqiq-Damad, *فقه پزشکی [Medical Fiqh]*. Tehran: انتشارات حقوقی [Intishārāt-i-ḥuqūqī (publisher)], 1391 [AD 2012].

⁴³ See note 39.

an acceptance that the time of death is approaching. From such appreciation, many legal precepts such as the obligation to “save life” can be dissolved, as it can be argued that the patient is approaching (destined) death and therefore is not the intended subject of the obligation to preserve life. Of course, not all patients to whom ADs can be applied are in a state of dying, thus limiting the utility of this solution.

- The Rule of No Harm (*La Darar wa La Dirar fi al-Islam*):⁴⁴ Based on a widely narrated *hadith*, this rule can be translated broadly as “non-maleficence” to the self/others. It could be argued that accepting a patient’s AD to withhold life-sustaining interventions would (whilst having established a duty of care) makes one complicit in harming the patient by not providing treatment. It also calls into question the original validity of such an AD, as the rule could be used to limit the scope of personal autonomy to instances of self-harm. However, one could also argue the opposite, as many life-sustaining interventions such as CPR are in fact futile for terminally ill patients and constitute harm without benefit.
- The Rule of Destruction and Causation (*Itlaf wa Tasbib*):⁴⁵ Derived from numerous *hadith*, this rule creates liability for a physician who either directly harms a patient or plays a role in the causality of that harm, for example, by ordering a DNR or even respecting an AD to refuse life-sustaining intervention where a duty of care exists. However, in our view, the rule is unlikely to cause liability, as the major potential application of ADs in Iran is to *futile* life-sustaining interventions, where a role in causing harm is difficult to prove.

8.6.2.2 Principles that May Favour Respecting an AD to Limit Life-Sustaining Interventions⁴⁶

- The Rule of Consent (*Idn*): It is generally accepted among Shia jurists that consent is required for medical intervention, and that not obtaining it can incur liability. Thus, if a patient has refused certain interventions via an AD, it would be unlawful to deliver them in opposition to said directive. That said, whether such a right extends to refusing life-sustaining treatment without contradicting the Rule of No Harm remains a matter of controversy among Islamic jurists. Some

⁴⁴ See note 42.

⁴⁵ *Ibid.*

⁴⁶ *Ibid.*

scholars are of the opinion that the duty of stewardship (and of not doing harm) to oneself is an *act of worship* as opposed to a *transaction* or *law*, and thus does not fall under the authority of state enforcement, just as the state has no right to enforce prayer or fasting upon Muslims, as these are acts of worship between each person and God. Thus, whilst it might be considered a “sin” to refuse consent via an AD for life-sustaining treatment (due to neglecting a *wajib* act of worship), a physician cannot act in opposition to such refusal owing to insufficient argument to abrogate the right of consent. However, this approach is not accepted by all scholars.

- The Rule of Acquittal (*al-bara'at*): Derived from numerous *hadith*, a physician can avoid liability when a patient has agreed to the risks of intervention, provided that the physician has not been negligent in their duty. Thus, if a patient provides both consent and acquittal, they are removing liability from the physician even if harm occurs (e.g. by not conducting CPR, where that is considered the standard). However, some jurists disagree with the exculpation of a murderer by their victim before the victim's death, which could be applied to oppose the application of the Rule of Acquittal to life-sustaining interventions via an AD.
- The Rule of Beneficence (*Ihsan*): Based on the Koran 9:91, this rule broadly compares to “beneficence” and could be used to remove a physician's liability for respecting an AD to avoid life-sustaining treatment such as CPR, provided that the *intention* behind such avoidance is to do good to the patient and that no financial reward is involved.
- The Rule of Respecting Persons (*hurmat al-nufus*): This rule, based on *hadith*, instructs respect for persons and could be applied to remove a physician's liability for respecting an AD to refuse undignified interventions, such as intensive care unit admission or CPR. The rule would gain particular traction if it were also proven that such interventions would be futile for the patient in question.
- The Rule of No Hardship (*La Haraj*): Based on the Koran 22:78, the essence of this rule is to remove/avoid intolerable hardship when a Muslim is trying to follow the Shariah, as per the standard of acceptable hardship for the common layperson. If accepting life-sustaining interventions (as per one's perceived religious obligation to preserve their life) in a terminal illness setting would create physical hardship (e.g. owing to the side effects of chemotherapy), then one is not obliged to do so, and an AD to refuse such treatment might be considered valid, although this remains a controversial viewpoint.

- The Rule of *Iztirar* (Difficulty/Desperation): Similar to the previous rule, this rule, based on the Koran 2:173, negates an obligation when fulfilling it would cause severe difficulty. It could be used, for example, to validate an AD to refuse a life-sustaining intervention if the case were made that accepting the intervention would, by prolonging life, subject the patient to intolerable difficulty.
- The Rule of Public Good (*Maslaha*):⁴⁷ When there is sufficient ambiguity among canonical sources on an issue, an Islamic jurist can resort to the Rule of Public Good, reasoning, for example, on the basis of considerations surrounding the just allocation of limited public health resources and/or the need to avoid wastage or futile expenditure on patients with a poor prognosis. The rule could aid the acceptability of ADs to refuse futile, life-sustaining interventions from an Islamic jurisprudential perspective.

In summary, there is currently no clear or authoritative *fatwa* on the validity of an AD to refuse life-sustaining interventions.⁴⁸ It remains the duty of Islamic jurists to weigh up the foregoing principles against one another, while also considering other evidence from the canonical sources, to come to an accurate conclusion.

8.6.3 Social

For many, the non-binding nature of an AD on a patient's SDM could be viewed as undermining autonomy. However, it is worth considering how this approach, in our opinion, functions relatively comfortably within the family-centric patient autonomous healthcare culture of Iran. Here, "family-centric patient autonomous" is used in opposition to "patient-centric patient autonomous", the latter being a more representative construct for Western cultures. In our experience in Iran, the family is an integral part of a patient's healthcare decisions, and is what most patients autonomously want/prefer, as their decisions affect not only themselves but also their family, emotionally, spiritually, financially and practically. This is not to say that healthcare professionals should put the interests of family members on par with the interests of patients when making decisions (which would contradict the Professional Ethics Guidelines); rather, it is acceptance of the fact that Iranian patients

⁴⁷ See note 39.

⁴⁸ See note 25.

intentionally wish to consider their family's interests and seek their active involvement in healthcare decision-making, particularly at the end of life. Therefore, respect for patient autonomy requires the inclusion of family members in the discussion. The complete exclusion of the patient at the expense of their SDM in healthcare decision-making, however, is obviously problematic. Hence, ADs can arguably play an essential role in Iran for the purpose of optimising the delivery of appropriate medical interventions at the end of life. It would be fair to say then that ADs in Iran would not function as an opportunity to defend an extreme liberal individualistic right of autonomy,⁴⁹ but rather as a way to provide appropriate, patient-centric healthcare in a culture that currently functions using a family-centric patient autonomous model. Furthermore, the current system almost always "works" by merit of the fact that the family members who could take legal action against a physician are involved in the decisions being made for the incapacitated patient. Obviously, this does not necessarily translate into the best outcomes for the patient, and it also cannot be assumed that all patients want to include their family members, as will be mirrored in our recommendations at the end of the chapter.

On a separate issue, much of the motivation for end-of-life care planning is a direct product of each individual patient's health reflexivity and of society's need to plan for death. The broader inclusion of the public within healthcare discourse is also required to normalise such planning and address the anxieties associated with it.

8.6.4 Cultural

It is not uncommon in Iran for cultural beliefs to be expressed using the language of religion even when not necessarily endorsed by Islam. For example, whilst it is the case that Islamic doctrine exerts a significant influence on the beliefs of healthcare professionals,⁵⁰ relatives⁵¹ and patients⁵² about DNR orders, such beliefs are in fact cultural (non-religiously substantiated) beliefs about not intervening in divine fate⁵³

⁴⁹ N. Yavari and A. Parsapoor, "The Domain of Autonomy, Limitations and Solutions" (2017) 10(1) *Iranian Journal of Medical Ethics and History of Medicine* 182.

⁵⁰ See note 21.

⁵¹ See note 22.

⁵² See note 23.

⁵³ See note 24 and note 25; F. Bahramnezhad et al., "Do-Not-Resuscitate in Iranian Muslim Families: A Conventional Content Analysis" (2018) 32(5) *Holistic Nursing Practice* 240.

by trying to plan for/give in to what might be an end-of-life event or expectations that God will perform a miracle for end-of-life patients (*shafa*). Families often interpret this to mean “doing everything possible” until the patient’s heart stops, an approach that makes it difficult for both Iranian healthcare professionals and families to engage proactively in future end-of-life planning. In addition, theological beliefs about illness being a source of forgiveness for sins are sometimes misapplied, resulting in a contradiction in the case of interventions that reduce suffering (which God had destined) at the end of life for the person’s salvation. In Iranian culture, when someone suffers from illness at the end of life, it sometimes provides their families with solace, knowing that their loved one’s sins may have been forgiven and that they may enjoy a peaceful life in the grave, on the Day of Judgement and thereafter. Despite the relatively institutionalised nature of the Shia Islamic clergy in Iran, the aforementioned beliefs remain prominent in society, implying a lack of adequate intervention by the clerical establishment, despite relatives often expressing a need for help from clergymen in healthcare decisions.⁵⁴

8.6.5 *Infrastructural*

The current literature reveals evidence of concern regarding the association between DNR orders and reduced quality of care.⁵⁵ Given the underdevelopment of palliative care services outside the cancer arena in Iran, it may feel uncompassionate for doctors to implement DNR orders without a viable alternative treatment approach using palliative services. If one is not to resuscitate a dying patient without a clear plan for symptom control, for example, sedation, antipsychotics, anti-emetics and pain relief, then it may seem more uncompassionate to abandon the patient (at home or in hospital) without some intervention, even if futile, which reflects broader cultural issues. Furthermore, relatives may not expect maximal intervention for a patient being cared for in a hospice but may expect it while the patient is still in a hospital, where the predominant approach is to provide active treatment.

In addition, the current system of documentation in Iran is inadequate for advance end-of-life decision-making. For example, although nurses and doctors prefer a written DNR or DNR sheet/card, DNR orders often

⁵⁴ See Bahramnezhad et al., *ibid*.

⁵⁵ See note 22.

take the form of informal or verbal orders, creating operational challenges,⁵⁶ and are often not considered. The end result is often futile or “slow-code”/tokenistic resuscitation for the benefit of relatives. However, Iranian doctors and nurses generally agree that DNR orders should ideally be signed before admission.⁵⁷

8.6.6 *Medical Education*

It has been suggested that the culture of healthcare delivery in Iran is in some areas “stereotyped”, with physicians not encouraged to think critically and analytically about their treatment decisions, leading them to adopt a one-size-fits-all approach for their patients.⁵⁸ This situation results in a lack of thought regarding the appropriateness of resuscitation for patients with extreme frailty suffering from multiple comorbidities compared to healthier, functionally independent patients. In fact, there are currently no clinical practice guidelines that explicitly pertain to the practice of DNR orders in Iran, which prevents healthcare professionals from proactively inculcating them into their specialist training and practice.

8.6.7 *Professional Considerations*

The issue of defensive medical practice in Iran remains a prominent barrier to ADs, as in many countries debating appropriate end-of-life care. Therefore, considering a shift towards the avoidance of harm to patients through futile interventions may optimise the provision of more appropriate healthcare. Much of the aforementioned paradigm of defensive practice is a result of the inappropriate application of the beneficence used in living patients to the context of dying patients, whereas a greater focus on autonomy, the avoidance of harm and justice would be more appropriate for the latter patient group.

Ways of developing and strengthening the physician–patient relationship in contemporary Iranian healthcare are also needed. Patients need to feel empowered to request information on their prognoses and be able to understand that information to play their essential role in the process of shared decision-making. Similarly, Iranian physicians need to recognise

⁵⁶ See Assarroudi et al., note 26.

⁵⁷ See note 15.

⁵⁸ See note 25.

that seeking greater patient involvement is in no way a demotion of their experience or insight into optimal treatment, but in fact represents an approach towards optimising the delivery of patient-centric care.

8.7 Future Directions

In summary, it can be said that according to contemporary interpretation, the law in Iran recognises “advance recommendations” as opposed to “advance directives”. The limits on personal autonomy also remain hotly debated in Islamic and legal circles. Whilst ADs have the potential to play an important role in improving end-of-life healthcare decision-making in Iran, several factors must be addressed to improve their implementation, including the following.

- A clear *fatwa* on the issue of ADs, including clarification of the scope of personal autonomy to refuse life-sustaining medical interventions that may be futile or otherwise: as with the majority of contemporary biomedical ethical issues in Iran, legislative/regulatory change often starts with an authoritative *fatwa* from a Grand Jurist, particularly the Supreme Leader, creating momentum within the governmental apparatus to address the issue as a priority. As the phenomena of precedent autonomy and ADs are new to Islamic law, an innovative approach may be required to provide an appropriate solution. Such a *fatwa* must also seek multidisciplinary input, be based on the best available evidence and appreciate the role of ADs in the broader healthcare system, including considerations of optimising patient outcomes and the just distribution of limited healthcare resources.
- Legal documents or official guidelines on ADs: although the charter mentions the role of ADs, more elaboration is required in the form of a focused, comprehensive law or official guidelines with legal standing ratified by the Iranian parliament or MOHME/SCME of IRIMC to provide clarity for physicians who wish to incorporate ADs into their practice and to help service providers to create the necessary infrastructure to support their implementation. Such guidelines should also include recommendations on best practice, as well as multidisciplinary team and family involvement.
- Reform of the SDM system in Iran: current practice does not reflect the law (and vice versa), including the lack of an officially appointed SDM, the impracticality of seeking a court-appointed SDM, the lack of patient participation in the appointment of SDMs and the limitation

of SDM status to fathers/paternal grandfathers, where they are still alive.

- Statute legislation to clarify a physician's liability when limiting futile life-sustaining interventions, including DNR orders, which could also incorporate articles on ADs.
- Development/empowerment of local hospital ethics committees to oversee the implementation and regulation of ADs in Iranian hospitals and community healthcare settings via clear official guidance and protocols for dispute resolution between relatives and healthcare professionals.

These recommendations constitute a set of first steps that the authors believe have the potential to stimulate legal, cultural, educational and social change in end-of-life decision-making in Iran, which, as per the foregoing discussions, is essential to improve patient outcomes while respecting the nation's Islamic doctrine and family-centric healthcare. Without such change, ADs will remain an underutilised tool with neglected potential.