Advance Directives across Asia

A Comparative Socio-legal Analysis

Edited by Daisy Cheung
and Michael Dunn



ADVANCE DIRECTIVES ACROSS ASIA

This book is the first to consider comprehensively and systematically the law and practice of advance directives across Asia. It will thus be important not only as a reference volume that documents how advance directives are regulated and used throughout Asia, but also as an exploration of the concept of the advance directive itself, in context. By examining how advance directives operate in Asian countries, we will also shed light on the principle of personal autonomy in this context, alongside other values and religious and socio-cultural factors that shape health and care decision-making. As such, this book will have broad appeal not only to Asian scholars, students, policymakers and practitioners in the fields of health law and ethics and end-of-life care more generally, but will also be of wider interest to an international academic audience in the fields of law, ethics and health and social care research. This title is also available as open access on Cambridge Core.

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Published online by Cambridge University Press

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CAMBRIDGE
UNIVERSITY PRESS

Published online by Cambridge University Press

CAMBRIDGE
UNIVERSITY PRESS

Shaftesbury Road, Cambridge CB2 8EA, United Kingdom

One Liberty Plaza, 20th Floor, New York, NY 10006, USA

477 Williamstown Road, Port Melbourne, VIC 3207, Australia

314–321, 3rd Floor, Plot 3, Splendor Forum, Jasola District Centre, New Delhi – 110025, India

103 Penang Road, #05–06/07, Visioncrest Commercial, Singapore 238467

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www.cambridge.org
Information on this title: www.cambridge.org/9781009152624

DOI: 10.1017/9781009152631

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When citing this work, please include a reference to the DOI 10.1017/9781009152631

First published 2023

A catalogue record for this publication is available from the British Library

ISBN 978-1-009-15262-4 Hardback

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Published online by Cambridge University Press

11

Advance Directives and the Turkey Context

YESIM ISIL ULMAN*

11.1 Introduction

Caring for a patient who is at the end of life should ethically be in accordance with human rights and dignity based on the value of life, in the concept's secular sense, meaning that life is a basic good that possesses intrinsic value ranging from the right to life to the avoidance of overly burdensome and futile medical interventions to achieve a death with dignity. It encompasses caring for others with due respect paid to their own choices and preferences on the basis of human rights and dignity.

One way of respecting patient preferences is via an advance directive (AD), the main underlying ethical principle of which is respect for patient autonomy. Such respect is honoured by executing the AD when the person concerned has the capacity to make informed decisions and give consent. Respect for patient autonomy requires that patients have an opportunity to make their own moral choices and achieve their own wishes and preferences. Doing so is a universal and even existential component of being human in compliance with the concept of human dignity, regardless of geographical borders, cultural factors and sociological differences. Such an approach supports the process of advance care planning as a way to improve end-of-life care when decisions are taken openly and straightforwardly in a pluralistic manner with the support of family and relatives, and the role of ADs is to ethically implement and legally document the process.

In the end-of-life context, respect for human dignity, whereby all human beings possess equal and inherent worth, and therefore ought to be accorded the highest level of respect and care,[1] entails paying

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Acknowledgments: I am grateful to the editors of this book Assistant Professor Daisy Cheung and Associate Professor Dr Michael Charles Dunn for their scholarly efforts and comments on the piece.

[1] R. Andorno, "Human dignity and human rights as a common ground for a global bioethics" (2009) 34(3) *Journal of Medicine and Philosophy* 223.

https://doi.org/10.1017/9781009152631.014 Published online by Cambridge University Press

particular attention to the decision-making process regarding medical treatment at the end of life as a high-quality procedure, especially for particularly vulnerable patients. Respecting people's views on how they would like to be treated should be considered in terms of the value of life and dying in dignity, both of which extend beyond national borders and cultural features. Palliative care and high-quality end-of-life care are also important components when considering an ethical and legal framework for legislating ADs.

11.1.1 The End-of-Life Context in Turkey

Turkey's life expectancy at birth is comparable to global figures. Whilst the country's birth rate and newborn mortality rate have declined, the elderly proportion of the total population rose by 21.9 per cent over the 2014–19 period.[2] As life expectancy for the elderly has lengthened in Turkey, health problems have changed, and there is greater demand for long-term care and control. According to public health specialist Reyhan Uçku, mortality and morbidity rates have increased in line with global statistics on such non-communicable diseases as cardiovascular diseases, cancer, respiratory diseases and Alzheimer's disease, which has resulted in a rising need for end-of-life care. She has, as a result, called attention to the deficiencies in healthcare delivery for the elderly and end-of-life care in Turkey.[3]

Turkey's low ranking in the Quality of Death Index, 47th amongst 80 countries worldwide according to an Economic Intelligence Unit report, is quite alarming, raising questions about the quality of end-of-life care in the country.[4] Whilst a government-led strategy is in place for the development and promotion of national palliative care, the strategy's milestones are loosely defined, with no targets specified, and the mechanisms for achieving them are also limited. Furthermore, the degree of correlation between Turkey's overall Quality of Death score and per capita healthcare expenditure is also rather low. It is stated in the aforementioned

[2] Turkish Statistical Institute (TUIK), "Elderly statistics" (2020) https://data.tuik.gov.tr/Bulten/Index?p=Istatistiklerle-Yaslilar-2020-37227.

[3] R. Uçku, "Healthcare provision at the end-of-life: what are the needs and delivery?" [in Turkish] (2016) 31(1) *Toplum ve Hekim* 5.

[4] The Economist Intelligence Unit, *The 2015 Quality of Death Index: Ranking Palliative Care across the World* (London: 2015), https://eiuperspectives.economist.com/sites/default/files/2015%20EIU%20Quality%20of%20Death%20Index%20Oct%2029%20FINAL.pdf, pp. 15, 16, 23–25, 32, 37.

https://doi.org/10.1017/9781009152631.014 Published online by Cambridge University Press

report that Turkey falls into the category of government subsidies or programmes being available for individuals requiring access to palliative care services, but the qualification criteria are unclear, and subsidy funds and programmes are limited and/or difficult to access. Moreover, Turkey has a shortage of specialised palliative care professionals, and accreditation for specialist palliative care training is not the norm.[5]

Although end-of-life care is available in Turkey in both the private and public sectors, in accordance with a 2014 regulation, Uçku comments that such care services are far from prevalent, are often poorly organised and are not coordinated or integrated with other components of the healthcare system. There are also shortcomings in capacity. The number of trained, competent healthcare staff is far from sufficient, and health coverage in the field is also insufficient. There is a need for efficient policies that are responsive to needs on the ground.[6] The Ministry of Health has initiated a 2013–23 target plan to increase palliative care capacity by establishing new centres and hospices in Turkey. Medical experts, however, are of the view that palliative care coverage should be expanded. They also recommend that a system whereby certain types of healthcare expenses can be refunded should be realistically implemented and that multidisciplinary healthcare staff, including psychologists, social workers, physiotherapists, spiritual support personnel and volunteers, should be put in place to meet the needs of patients and improve their access to end-of-life care.[7]

In addition to the need for improved end-of-life care, there have also been calls for the development of AD legislation amongst academics and professionals as part of a growing emphasis on patient preferences.[8] Such legislation is a particularly important issue for Turkey, given its ratification of the Council of Europe's Convention on Human Rights and Biomedicine ("Oviedo Convention"), as discussed later. This chapter considers ADs in the Turkish context, beginning with a consideration of the possible legal bases for such directives in Turkey. It then explores the relevant professional guidance from medical associations, as well as empirical data relating to the level of awareness of ADs amongst patients and healthcare professionals. The sociocultural factors that pose potential obstacles to the introduction and implementation of

[5] Ibid, pp. 5–8.
[6] See note 2, pp. 7–8.
[7] A. Bilen, "Palliative care" [in Turkish] (2016) 31(1) *Toplum ve Hekim* 25, 28.
[8] See Section 11.5, The Way Forward for further details.

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ADs in Turkey are also discussed, and the chapter concludes with some thoughts about the way forward.

11.2 The Legal Framework

Although Turkey does not have any specific laws dealing with ADs, there are several sources of law that are relevant in considering this issue, as well as end-of-life decision-making more generally.

11.2.1 Oviedo Convention

The first source is the Oviedo Convention. International treaties are one of the sources of written law in Turkey; once such treaties have been adopted by the Grand National Assembly of Turkey, they have the force of law and are hierarchically above national laws.[9] The Oviedo Convention was ratified by Turkey on 4 April 1997, adopted in 2003 and entered into force in 2004 with the name *Insan Haklari ve Biyotıp Sozlesmesi* (Convention on Human Rights and Biomedicine).

The Oviedo Convention provides an ideal framework for the ethical and legal aspects of treating patients with dignity and preserving human rights. With regard to persons lacking capacity, the convention clearly states in Article 9 that "previously expressed wishes relating to a medical intervention by a patient who is not, at the time of the intervention, in a state to express his or her wishes shall be taken into account".[10]

The Guide on the Decision-making Process Regarding Medical Treatment in End-of-life Situations issued in 2014[11] by the Council of

[9] Ö.C. Eren and E.E.V. Lutz, "Turkey and the Council of Europe's Oviedo Convention on its 20th anniversary" (2017) 22(2) *Anatolian Clinic Journal of Medical Sciences* 73.

[10] In addition, the principle of equitable access to health care (Article 3), the requirement of informed consent for any medical treatment (Article 5) and special safeguards to protect persons unable to provide consent (Article 6) present a framework for the inclusion of ADs in the jurisdiction of Turkey based on human rights and human dignity. See I.S. Sogut, "The effect of the Convention on Human Rights and Biomedicine (Oviedo Convention) on domestic law regulations" (2018) 14 *TipHD* 181.

[11] The guide was translated into Turkish in 2014: see further Council of Europe, *Yaşamin Son Döneminde Tibbi Tedavide Karar Verme Sürecine İlişkin Kilavuz [Guide on the Decision-making Process Regarding Medical Treatment in End-of-Life Situations]* (Yesim Isil Ulman, PhD, Trans.) (2014), https://rm.coe.int/CoERMPublicCommonSearchServices/DisplayDCTMContent?documentId=09000016806ad65a. The translated guide is distributed with the support of Acibadem University. The Turkish version of the guide was introduced at a Joint Symposium on the End of Life in collaboration with the Council of Europe and Acibadem University on 25 October 2016. The symposium booklet contained

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Europe elaborates on the formal legal arrangements for previously expressed wishes, including as one of the options ADs, or "written documents drawn up by a person having legal capacity (who has attained majority and is able to express a free and informed wish) containing provisions relating to medical treatment in the event that he or she is no longer capable of taking part in the decision-making process".[12] It further states that written ADs are the most direct means of reflecting patients' wishes and, as long as requirements to ensure validity and accessibility are fulfilled, they should take precedence over all other non-medical opinions expressed in the decision-making process.[13] The guide, however, leaves it up to ratifying states to decide whether to give legal binding force to previously expressed wishes.[14]

Although the Oviedo Convention is considered a part of Turkey's internal law, and although its first provision requires signatories to make their domestic law compatible with the convention by making any necessary amendments, Turkey has not yet fulfilled this requirement in full.[15] This is particularly true in relation to Article 9. There remains a lack of legislation on or formal legal regulation of ADs in Turkey, which means that the legal efficacy, content and limits of such documents remain uncertain.[16] Moreover, the Council of Europe's aforementioned guide, which has been translated into Turkish and widely adopted within Turkey, has not been formalised into legal governance requirements concerning how end-of-life care ought to be provided or what role ADs have.

11.2.2 *Additional Legal Frameworks*

Whilst there is no local legislation that deals directly with the subject matter of ADs, there are a number of local laws that sit alongside the

an AD written by Professor Steven Miles to set an example of what an AD is and what the scope and content of an AD can be. I translated this AD into Turkish for the accessibility of academic and public circles in Turkey. See further Council of Europe and Acibadem University, "End of Life Care Symposium" (2016), www.acibadem.edu.tr/doc/EndofLifeCare-kitapcik.pdf.

[12] *Guide on the Decision-making Process*, note 11, p. 17.

[13] Ibid., p. 18.

[14] Ibid., p. 20.

[15] I.S. Sogut and E. Tuna, "Legal instruments on patient's living medical wills" (2017) 12 *TipHD* 255.

[16] See note 1, p. 223.

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Oviedo Convention in Turkish domestic law and that could potentially be interpreted to provide an additional legal basis for ADs.

The first is the 1982 Constitution. Section 2, Article 17 on Personal Inviolability and Material and Moral Existence of the Person states the following.

> Everyone is entitled to right to life, to protect and develop her/his material and moral existence. Personal integrity is inviolable unless there exists any medical necessity and legally binding situation stated by law; no one can be subject to scientific or medical trials without her/his consent. No one can be subject to torture or degrading treatment that is incommensurable with human dignity.

Although not specifically addressing the topic of end-of-life care, the constitutional principles of human rights and dignity contained within this section of the Constitution could provide a foundation for the introduction of ADs.

The second local law is the Civil Code, which some jurists have suggested could potentially be amended to cover ADs in accordance with the Oviedo Convention and Turkish Constitution. For example, Cetinel proposes that Article 23 of the Civil Code, which "protects the personal rights of the individual and states that such rights are indefeasible",[17] could be amended to cover ADs.[18] It has also been suggested, however, that Article 23 might pose difficulties for the refusal of life-saving treatment, which could be seen as a waiver of the rights to life and bodily integrity.[19]

The third local law possibility can be found in the Patient Rights Regulation, which came into effect in 1998. This regulation was issued by the Ministry of Health in light of international covenants, the Turkish Constitution, and other legal documents and legislation with the purpose of allowing patients to exercise rights in healthcare settings in accordance with human dignity and of protecting patients from violations of their

[17] G. Sert and T. Guven, "Examining the ethico-legal aspects of the right to refuse treatment in Turkey" (2013) 39 *Journal of Medical Ethics* 632.

[18] M.U. Cetinel, "Living wills and powers of attorney in view of patient preferences in comparison with Turkish-German Civil Codes, some suggestions" (2019) 3 *3rd International Medical Law Congress, Book of Proceedings* 567, 567 [in Turkish]. Specifically, Cetinel argues that a person's wishes about bodily integrity are not only about physical bodily integrity, but also about his or her own values about their existence as a living being with moral values. Cetinel thus considers Article 23 to be a gateway to ADs and extends her argument through comparisons with the German Constitution.

[19] See note 17.

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fundamental rights.[20,21] The Patient Rights Regulation states that a patient's previously expressed wishes should be taken into consideration during any medical intervention and, if the patient's capacity is lost intermittently, that his or her informed consent should be obtained prior to the intervention at a time when he or she is conscious and sane (Article 24). A patient also has the right to reject or withdraw a treatment that is planned or being carried out for him or her except in legally binding situations or when negative consequences may arise from such rejection/withdrawal (Article 25).

Although the aforementioned articles currently provide only for the requirement to obtain informed consent prior to medical interventions, not to prepare ADs with patients,[22] the Patient Rights Regulation is the only document that explicitly refers to the right to refuse treatment.[23] Accordingly, it has been argued that Article 24 provides an appropriate basis for AD legislation in Turkish law.[24] It should be noted, however, that the language of Article 24 contains significant limitations on the exercise of the right to refuse treatment:[25] (i) in cases where treatment has already begun, consent can be withdrawn only if there are no "medical drawbacks" of doing so and (ii) consent cannot be withdrawn in "emergency situations threatening the life or one of the vital organs [of the patient]".[26] It thus appears doubtful that these articles could serve as the basis for ADs without significant amendments. Unfortunately, owing to the low normative status of the Patient Rights Regulation in Turkish law, as a document issued by the Ministry of Health rather than Parliament, provisions contained in higher status laws, including the Constitution and Civil Code, would need to be clarified before the regulation could be amended in any meaningful way.[27] In a similar vein, Irmak elaborates on the refusal of treatment in light of medical

[20] Patient Rights Regulation, Article 1.
[21] There are studies showing, however, that there is a "marked discrepancy" between patients' rights in principle and how they are applied in practice, with patients stating that these rights are not respected in practice. See further E. Aydin, "Rights of patients in developing countries: the case of Turkey" (2003) 3(1) *Yogun Bakim Dergisi* 37.
[22] I. Koşar et al., "Assessment of knowledge and preferences regarding advance directives among patients in university family medicine outpatient clinics" (2020) 6 *Gerontology & Geriatric Medicine* 1.
[23] See note 17.
[24] See Sogut, note 10, pp. 191–2.
[25] See note 17.
[26] Ibid.
[27] Ibid.

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paternalism and proposes reforms in the legal documents defining and regulating patient rights in Turkey to strengthen such rights in relation to patient autonomy.[28]

11.3 Professional Guidance

Given the lack of a specific legislative framework regulating ADs, the professional guidance issued by various professional organisations should also be considered. In addition to the Council of Europe's guidance discussed previously, several Turkish professional organisations have also issued guidance in relation to the end of life.

In 2016, the Turkish Society of Medical and Surgical Intensive Care issued a guidance document entitled "Problems and Possible Solutions Faced by Terminally Ill Intensive Care Patients: Views from the Turkish Society of Medical and Surgical Intensive Care",[29] which affirms the importance of a patient's right to make medically informed, autonomous decisions, as well as the importance of a patient's right to refuse futile treatment. In the document, the society specifically calls attention to the role of ADs in actualising patients' wishes and in respecting patients' self-determination, as expressed in advance with decision-making capacity concerning the withholding or withdrawal of treatment in the circumstances of worsened quality of life at the end of life with a prolonged dying process. Interestingly, the society expresses cultural reservations about euthanasia and physician-assisted suicide, but advises that improved palliative care services and pain control be provided and fostered by psychological and social support via a multidisciplinary approach. Dying with dignity in a peaceful and compassionate way surrounded by loved ones is stated in the document to be the right of everyone at a terminal stage.[30]

The Turkish Society of Intensive Care has taken a similar stance. In its "Opinions and Suggestions of the Turkish Society of Intensive Care on Healthcare during the End-of-Life Period",[31] also issued in 2016, it calls

[28] N. Irmak, "Right to refuse treatment in Turkey: a diagnosis and a slightly less than modest proposal for reform" (2016) 42(7) *Journal of Medical Ethics* 435.

[29] Turkish Society of Medical and Surgical Intensive Care, "Problems and possible solutions faced by terminally ill intensive care patients: views from the Turkish Society of Medical and Surgical Intensive Care" (2016) 31(1) *Toplum ve Hekim* 42 [in Turkish].

[30] Ibid., pp. 44–6.

[31] Turkish Society of Intensive Care, "Opinions and suggestions of the Turkish Society of Intensive Care on healthcare during the end-of-life period" (2016) 31(1) *Toplum ve Hekim* 58 [in Turkish].

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for public engagement to be conducted through multilateral dialogue amongst social actors, professional expertise bodies, the Turkish Medical Association, university law faculties and policymakers to enlighten the Turkish people on medical, legal and ethical issues in order to remove the cultural factors that may hinder the acceptance of refusals of futile treatment.[32]

Most recently, and perhaps most importantly, the "Declaration on End-of-Life Decisions" issued by the Turkish Medical Association in 2020 contains two sections that appear relevant to ADs.[33] The first states that, where life support is envisaged, the patient's primary physician should seek the patient's opinion on life support and suggest that the patient express his or her will in advance in situations wherein he or she may lose decision-making ability.[34] Whilst this provision refers to the prior expression of wishes, it is similar to Article 24 of the Patient Rights Regulation and may thus be seen as focusing primarily on the obtaining of informed consent ahead of time in cases in which the patient may lose capacity. It does, however, encapsulate to some extent the normative ethical value of prioritising patient choices in such cases. More importantly, in the second relevant section, which appears under the heading "Living Will", the association provides a clear definition for what appears to be the equivalent of an AD:

> A living will is the patient's verbal, written, and sometimes even witnessing statement about what he wants or does not want to be done, at any stage of the treatment of his chronic disease, after he loses his decision-making ability. These decisions are mostly about terminating treatment that will not provide any benefit to the patient, asking for "Do-Not-Resuscitate" [DNR] when he is unable to regain lost functions, or not continuing life support treatments or artificial nutrition.[35]

This definition demonstrates that the association is supportive of the promotion of an individual's decision-making and self-determination capacity to determine his or her preferences as to whether treatment should be withheld or withdrawn, particularly in the form of an AD. The declaration concludes with an affirmation of the right of every person to

[32] Ibid.
[33] Ethics Committee, Turkish Medical Association, "Turkish Medical Association Ethics Declarations: Statement on End-of-Life Issues, Ankara" (2020), www.ttb.org.tr/kutuphane/etikbildirgeler2020.pdf, pp. 36–40.
[34] Ibid., p. 37.
[35] Ibid., pp. 38–9.

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die with dignity. These guidelines have been drafted on the basis of systematic, well-planned, multilateral discussions amongst experts in human sciences, medicine, biosciences, law and social sciences.[36] What is needed at this stage to take steps to implement these principles in practice is the engagement of policymakers.

11.4 The Sociocultural Context of Advance Directives in Practice

Despite the clear endorsement of ADs in professional guidance, available empirical data suggest that there is a relatively low level of awareness of ADs amongst both patients and healthcare professionals. In Koşar et al.'s study of 300 patients in outpatient clinics, 70 per cent of patients were found to be unaware of ADs prior to the survey.[37] Tekpınar and Uludağ's study of 372 healthcare professionals found that more than half (53.8 per cent) had inadequate knowledge of ADs.[38]

Interestingly, however, these studies also found that, upon understanding what ADs are, the majority of participants were in favour of the concept, reflecting the outcomes of similar empirical studies conducted in the United States and China.[39] Of the 300 patients in Koşar et al.'s study, 78 per cent agreed that ADs were useful and necessary.[40] Of the healthcare professionals in Baykara et al.'s study, 77.9 per cent stated that ADs should be clearly legislated, whilst 70.3 per cent supported consideration of the previously expressed wishes of incapacitated patients during a medical intervention, and 52.9 per cent agreed that patients who had signed DNRs should not have their decisions interfered with.[41] These findings suggest that raising the awareness of the population in relation

[36] See, for example, the list of contributors in the Turkish Medical Association Ethics Declarations (see note 33).

[37] See note 22.

[38] By profession, this was 55.9 per cent of the doctors, 71.4 per cent of the assistant doctors and 42.7 per cent of the nurses. See further L. Tekpınar and A. Uludağ, "Perspective of doctors and nurses on the principle of extended autonomy in Konya, Turkey" (2021) 83(4) *OMEGA – Journal of Death and Dying* 884.

[39] L.L. Emanuel et al., "Advance directives for medical care – a case for greater use" (1991) 324(13) *The New England Journal of Medicine* 889; P. Ni et al., "Advance directives and end-of-life care preferences among adults in Wuhan, China: a cross-sectional study" (2021) 21 *BMC Public Health* 2042.

[40] See note 22.

[41] N. Baykara et al., "Factors affecting the attitudes and opinions of ICU physicians regarding end-of-life decisions for their patients and themselves: a survey study from Turkey" (2020) 15(5) *PLoS ONE* e0232743.

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to ADs is likely to have a positive impact on the use of ADs in practice if they are legislated or otherwise formally introduced and, prior to that being accomplished, on the likelihood that end-of-life wishes will be clearly expressed by patients.

There are, however, certain sociocultural factors that may affect the implementation of ADs in practice. Most prominently, paternalism appears to be a core feature of the Turkish healthcare context. In their comparative analysis of differing approaches to ADs in Europe, Andorno et al. noted that despite Turkey's ratification of the Oviedo Convention, the use of ADs in the country was practically non-existent in medical practice owing to the strong paternalism that dominates the doctor–patient relationship[42] and that this "culture of paternalism" is in direct contradiction of the Oviedo Convention.[43] Sert and Guven provide further support for this claim, arguing in particular that paternalistic interventions, as well as paternalistic interpretations of provisions that deal with emergency situations, which do not require informed consent, in cases where there is a wish to refuse treatment are often the norm owing to the lack of clear definitions and guidelines on whether patients have a right to refuse treatment.[44]

There are also empirical data that support the claim. In their study of 207 physicians presented with case studies involving the fundamental principles of bioethics, Ersoy and Gündoğmuş found that 83.6 per cent of the participating physicians would try to save the life of a patient who had indicated prior to losing consciousness that he or she did not want to live with the aid of artificial respiration; only 13 per cent said they would respect the wishes, living will or previous consent of the patient.[45] On the basis of these results, the authors concluded that the participants in their study had a low degree of sensitivity to ADs.

This paternalism is manifested not only in approaches towards medical intervention, but also in the choice of whom to communicate with in relation to end-of-life measures. Sert and Guven argue that discussing death with patients at the end of life still appears to be taboo amongst healthcare professionals in Turkey, who often choose to discuss such

[42] R. Andorno et al., "Advance health care directives: towards a coordinated European policy?" (2009) 16 *European Journal of Health Law* 207, 223.
[43] Ibid., p. 227.
[44] See note 17.
[45] N. Ersoy and Ü.N. Gündoğmuş, "A study of the ethical sensitivity of physicians in Turkey" (2003) 10(5) *Nursing Ethics* 472.

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issues with the family instead of the patient.[46] Sert and Guven's claim here is that professionals aim to shield patients who are close to death from the difficulties associated with making decisions about their care for their own good, turning to the family as a protective mechanism to relieve patients of any distress resulting from conversations about their care at the end of life. Whilst this behaviour can be seen as in line with the importance of family in Turkey, where familism and collectivism continue to be the leading values, as demonstrated by cross-national value surveys,[47] and where the family is frequently involved in medical decision-making,[48] Guven and Sert argue that simply attributing it to the role of the family in the Turkish social structure "fail[s] to acknowledge the effect of the authority and influence of the paternalist healthcare professional".[49] Thus, professionals' motivation to rely on the family for decision-making in this context is paternalistic rather than grounded in a commitment to patients' meaningful relationships with family members or in the family's status as a decision-making authority independently of a specific patient. Setting the reasons for this behaviour aside, removing the patient from discussions about end-of-life care can result in a patient's desire to refuse life-sustaining treatment being overlooked or disregarded, particularly as anecdotal evidence suggests that families are likely to demand heroic measures in such situations.[50]

11.5 The Way Forward

Whilst paternalism remains a key feature of healthcare professionals in Turkey, it has been argued within Turkey that there should be a move towards a more patient autonomy-centred approach, an argument that reflects the broad consensus in Anglo-American bioethical discourse. Accordingly, the concept of patient rights has become more popular following the issuance of the Patient Rights Regulation by the Ministry of Health.[51]

[46] See note 17.
[47] M.A. Kara, "Applicability of the principle of respect for autonomy: the perspective of Turkey" (2007) 33 *Journal of Medical Ethics* 627.
[48] T. Guven and G. Sert, "Advance directives in Turkey's cultural context: examining the potential benefits for the implementation of patient rights" (2010) 24(3) *Bioethics* 127, 129.
[49] Ibid., p. 130.
[50] See note 17, p. 634.
[51] See Guven and Sert, note 48.

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As the evolution of professional guidance over the past few years demonstrates, there is also considerable support for ADs and the valuing of patients' wishes at the end of life from the disciplines of medicine, law and ethics, as well as from medical specialty societies and medical associations. From the viewpoint of family physicians, for example, Kahveci argues that considering patient involvement in the decision-making process and respecting patients' wishes would render healthcare delivery more democratic.[52] Guven and Sert, as discussed previously, have criticised paternalistic practices in the healthcare setting and emphasised the need for coordinated efforts to achieve legislation on ADs and living wills.[53]

In their paper on the ethical approach to end-of-life preferences and decisions, Akpinar and Ersoy argue that fulfilling a patient's previously expressed wishes is an ethical responsibility for healthcare professionals and that it is thus ethically permissible and appropriate for a physician to withdraw or withhold life-sustaining interventions owing to such wishes if they are formulated in a living will.[54] İmamoğlu draws particular attention to the function and effectiveness of living wills and ADs and proposes that they should be expressly regulated by law in order to guide patients, relatives and healthcare professionals in the provision of high-quality end-of-life care to terminally ill patients.[55] Finally, Kalkan and Mirici, two intensive care clinicians, remark in their survey of DNR decisions that the principle of patient autonomy should encompass respect for a patient's previously expressed wishes, namely, in the form of living wills, and that such respect should be promoted to a greater extent to both doctors and patients. They call for consensus to be reached amongst medical, ethical and legal disciplines on the evaluation of living wills in terms of patient autonomy.[56] Importantly, this approach to justifying and developing a more robust AD regime in Turkey, one built

[52] R. Kahveci, "A step towards democratization of health care services: patient involvement in terminal life support decisions" (2007) 15 *Turkiye Klinikleri Journal of Medical Ethics* 90, 93 [in Turkish].

[53] See Guven and Sert, note 48, p. 127.

[54] A. Akpinar and N. Ersoy, "Life-sustaining treatment: when should it be withheld or withdrawn?" (2012) 27(1) *Turkish Journal of Oncology* 37, 38–40 [in Turkish].

[55] S.H. İmamoğlu, "Certain issues concerning patient's will" (2016) 65(1) *Ankara Üniversitesi Hukuk Fakültesi Dergisi* 199, 200–6 [in Turkish].

[56] E.A. Kalkan and A. Mirici, "Opinions of chest physicians about the do-not-resuscitate orders: respect for patient's autonomy or medical futility?" (2018) 9(2) *Yoğun Bakım Derg* 34, 37.

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on respect for human dignity and personal autonomy, would also bring Turkey more closely into alignment with other countries.

In practical terms, internationally ratified and legally binding conventions offer an appropriate infrastructure for Turkey in terms of reforming end-of-life decision-making, as well as the inclusion of ADs in legislation on the basis of human rights and dignity. They are an important and necessary starting point for further legislative developments and the formalisation of a legally ratified regime for ADs in end-of-life care. What is also urgently needed is for policymakers to take responsible steps forward to represent the public's views on how the international consensus surrounding end-of-life care and decision-making processes should be tailored to the contemporary norms of Turkish society. However, it is also important to gather the collaborative efforts of medicine, ethics, philosophy, sociology and law in evaluating ADs and designing legislation specific to them. Promoting ethical consultation would be highly valuable to enhancing the end-of-life decision-making process in clinical practice and to addressing some of the paternalistic practices documented previously. Training healthcare professionals in both the concept of ADs and the discussion of end-of-life preferences with patients is also crucial.[57]

In order to develop a legally robust and practically applicable approach to ADs, legislators and professionals in Turkey need to address concerns about how ADs have been put into practice elsewhere. Such concerns include worries about the stability of patient preferences over time, necessitating an ongoing review of any directive made and ensuring an ongoing conversation between the patient and doctor to ascertain any changes that may need to be captured in a revised statement timed in an appropriate manner.[58] As Lo and Steinbrook have argued, it will also be important going forward to not see ADs simply as the fulfilment of a legal process, where the emphasis is on documentation and process. Instead, ADs should be embedded in good clinical practice, where communication between doctor and patient creates a space for a meaningful exchange about the patient's values, perhaps as part of a broader care-

[57] Avcu et al.'s 2018 study found that, in a sample of 443 physicians, a significant majority (84 per cent) had never received any training in relation to discussions with "patients in the last days of life about their last wishes for life". See further R. Avcu et al., "How would doctors want to die if they had a terminal stage illness? A survey study" (2018) 18 *Ankara Medical Journal* 575.

[58] S.E. Hickman et al., "Hope for the future: achieving the original intent of advance directives" (2005) *The Hastings Center Report* S26.

https://doi.org/10.1017/9781009152631.014 Published online by Cambridge University Press

planning process, and within which a discussion about the appropriateness of an AD takes place.[59] Finally, as Brock argues, it is vital that concerns relating to the proper assessment of a patient's competence and his or her full understanding of relevant treatments, consequences and alternatives prior to the AD being made are properly addressed.[60]

There is also a need for in-depth studies exploring social and cultural factors to promote public engagement and public participation led by academe, civil society actors, specialty societies and professional associations. Such studies are likely to aid the development of more patient-centred healthcare provision while simultaneously clarifying the role of family members in the enactment of an AD and in shaping their loved one's end-of-life care more broadly. They might also function to challenge, and subsequently diminish, paternalism and to trigger a public conversation leading to improvements in patient-physician interactions on the basis of trust in balance with patient autonomy and beneficence. This pluralistic way forward, focusing on open dialogue, can ensure that new laws and practices are supported in ways that are feasible, pragmatic and underpinned by a fundamental respect for the values of human dignity and personal autonomy.

[59] B. Lo and R. Steinbrook, "Resuscitating advance directives" (2004) 164 *Archives of Internal Medicine* 1501.

[60] D.W. Brock, "Death and dying: the incompetent patient", in R.M. Veatch (ed.), *Medical Ethics*, 2nd ed. (Sudbury, MA: Jones and Bartlett Learning, 1997), pp. 370–2.

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