Advance Directives in China's Mainland: An Emerging Framework?

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12.1 Introduction

China's mainland is rapidly becoming an ageing society. In 2010 there were 168 million Chinese people aged 60 years of age or above – and the elderly population is projected to increase to 402 million by 2040, representing about 28% of the projected total population of China. Accordingly, it is expected that there will be increased demands for high-quality healthcare in general, and for greater autonomy in end-of-life care. While they have attracted controversy, Advance directives (ADs) are considered as potentially useful legal instruments to promote patient autonomy at the end of life.²

This book defines an AD as a statement in which a competent person makes an advance decision in any number of areas (including healthcare, social welfare and any other personal matters), to be implemented in the event that the person becomes incompetent (loses mental capacity) in the future.³ Even by this arguably narrow definition, it should be stated that China's legal system does not provide a normative framework governing the use of ADs. In recent decades, however, new developments in both law and a professional code of ethics have emerged, and one might reasonably expect these new rules and guidelines will centre patient autonomy, echoing the spirit of ADs.

This chapter explores the emerging normative framework governing the use of ADs in China, which primarily consists of relevant provisions

¹ World Health Organization, China Country Assessment Report on Ageing and Health (Geneva: WHO, 2015), apps.who.int/iris/bitstream/handle/10665/194271/9789241509312_eng.pdf?sequence=1, p. 15. "China's mainland" or "Mainland China" is referred to as "China" in the chapter for better clarity.

 $^{^{\}rm 2}\,$ D. Cheung, M. Dunn and R. Huxtable, Introduction, in this volume.

³ Ibid.

from the Civil Code⁴ and the Chinese Medical Doctors' Code of Ethics (CoE).⁵ The chapter argues that where the stakeholders (primarily doctors, and patients' family members who play a part in medical decision-making) choose to respect a patient's will (made before they lost mental capacity), this framework provides such a legal and ethical basis. However, the chapter also observes that such a normative framework is rarely applied in legal proceedings, as revealed by a thorough search of the judicial database for courts' judgments, or in healthcare practice. The chapter will also survey a number of civil society organisations that advocate for the use of ADs in China, before forming a conclusion.

12.2 Making Sense of the Emerging Normative Framework

For the purposes of this chapter, I draw upon a broad definition of ADs to examine the law and professional guidelines in China. The term "advance directive" refers to two types of statements in which the patient may (a) appoint a substitute decision-maker for and by the patient concerned (power of attorney); and/or (b) make specific decisions for future healthcare planning (generally known as a living will). It is the latter meaning of AD that this book adopts, even though recognising its limitations. In this chapter however, given the significance of the adult guardianship system in China, and the general absence of specific laws or regulations on ADs, the norms that apply to both forms of ADs will be considered. This section first explores the relevant provisions of the adult guardianship system as provided in the *Civil Code*, and which I suggest could potentially provide a legal basis for a Chinese version of power of attorney. It then examines the provisions of the *CoE* that direct Chinese doctors to respect the living wills made by mentally competent patients.

12.2.1 Adult Voluntary Guardianship: Chinese Version of Power of Attorney

The enforcement of China's *Civil Code* which adopted provisions on adult guardianship law began on 1 January 2021. The code is not entirely

⁴ Civil Code of the People's Republic of China (adopted at the Third Session of the Thirteenth National People's Congress on 28 May 2020; entered into force on 1 January 2021).

⁵ Chinese Medical Doctor Association, Chinese Medical Doctors' Code of Ethics (25 June 2014).

new, however, as it was initially introduced in 2017 by another piece of legislation, the *General Provisions of Civil Law*,⁶ as part of a project preparing for the final *Civil Code*.

Adult guardianship authorises a third party (i.e. the guardian) to make legally binding decisions on behalf of another person under their guardianship. The legitimacy of adult guardianship and other forms of substitute decision-making arrangements have been the subject of considerable debates and controversies since the adoption of the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)⁷ and the first General Comment No.1 on article 12 – Equal recognition before the law. 8 China has been a State Party to the UNCRPD since 2008, and the reform of the law regarding adult guardianship is arguably a step towards maximising the autonomy of persons with disabilities, who are often made subjects of adult guardianship. 9 Although the chapter focuses on the current applicable law, it acknowledges the visible gap between domestic law and the relevant requirements made by the UNCRPD.

Before embarking on a closer examination of the adult voluntary guardianship system, it should be noted that the role played by guardians on behalf of those they are responsible for goes beyond mere decision-making. Guardianship in the Chinese context includes the extension of a combination of both rights (or powers) over the person under guardianship, in addition to having a duty of care to ensure the protection of personal rights, property rights and other rightful interests of the person. ¹⁰ In practice, guardians also have a duty of responsibility for many aspects of the life of the person under guardianship, such as caring for the person on a daily basis. A guardian may also be liable for the actions of the person under guardianship, for instance, if the person under guardianship causes injury to a third party or their property, and the guardian is deemed not to have fulfilled their oversight duty. ¹¹

⁶ The General Provisions of Civil Law of the People's Republic of China (adopted at the Fifth Session of the Twelfth National People's Congress 15 March 2017; entered into force on 1 October 2017; repealed on 1 January 2021).

United Nations Convention on the Rights of Persons with Disabilities (adopted on 13 December 2006; entered into force on 3 May 2008) 2515 UNTS 3.

⁸ CRPD Committee, "General Comment No 1: Article 12: Equal Recognition before the Law" (11 April 2014) UN Doc CRPD/C/GC/1.

⁹ B. Chen, "Controversy and consensus: does the UN Convention on the Rights of Persons with Disabilities prohibit mental health detention and involuntary treatment?" (2020) 1 Foundation for Law and International Affairs Review 39.

¹⁰ Civil Code, art. 34.

¹¹ Ibid., art. 1189.

In such a context where guardians have a significant responsibility and power over the life of the person under guardianship, the *Civil Code* allows the person under guardianship to be involved in the process of choosing the individual who will be appointed as guardian, while the person retains the mental capacity to make rational decisions. ¹² Before moving to the specific arrangements of voluntary guardianship, it is equally important to briefly examine the provisions on mental capacity and adult guardianship in general.

The Civil Code adopts the term of "capacity for performing civil juristic acts" that is based on the assessment of whether an adult can "comprehend his own conduct". 13 For adults who are considered as going to lose or having already lost full or partial capacity for performing civil juristic acts, guardians could be appointed in three major methods. The first one is appointing guardians by a legal order of close relatives, 14 where the spouse of the person is the most prioritised candidate of guardian, followed by one's parents and adult children; if all the candidates are inapplicable or unable to take the responsibility, other close relatives or other willing and approved individuals or organisations would also become eligible. 15 Guardians may also be appointed by agreement among eligible candidates of guardianship, ¹⁶ and by voluntary or prearranged guardianship.¹⁷ In circumstances where conflict arises over the choice of guardian, the law states that the local village, neighbourhood committee or local government's civil affairs department should intervene, or the issue be resolved in a court of law. 18 As a last resort, in instances where there are no eligible family or others who can take on the responsibility, the local village or neighbourhood committee or local government's civil affairs department would take on the responsibility of guardianship. 19 Since guardianship in the Chinese context consists of both decision-making rights as agent and a duty of care, the legal order prescribed in article 28 of the Civil Code serves the purpose of ensuring that the person believed to be in need of such will ultimately be assigned a guardian.

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12 Ibid., art. 21.
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¹³ Ibid.

¹⁴ Civil Code, art. 28.

¹⁵ Ibid.

¹⁶ Civil Code, art. 30.

¹⁷ Ibid., art. 33.

¹⁸ Ibid., art. 31.

¹⁹ Ibid., art. 32.

Given that the state does not generally provide guardians with sufficient financial remuneration or other resources to enable them to carry out their guardianship responsibilities efficiently and effectively, to be appointed as a guardian requires a significant psychological and financial commitment.

Voluntary guardianship, or prearranged guardianship, since guardianship can hardly be genuinely voluntary, was introduced in 2017 by the *General Provisions of Civil Law*, and it reflected the principle of maximum respect for the autonomy and wills of persons under guardianship.²⁰ An official English translation of article 32 of the *Civil Code* reads:

An adult with full capacity for performing civil juristic acts may, in anticipation of incapacity in the future, consult his close relatives, or other individuals or organisations willing to be his guardian, and appoint in writing a guardian for himself, who shall perform the duties of guardian when the adult loses all or part of the capacity for performing civil juristic acts.²¹

The provision suggests that the appointed guardian will serve the function of a power of attorney, as happens when a competent person appoints a representative to make future healthcare decisions on their behalf, in the event they lose the capacity to do so themselves at some future time. In the context of Chinese civil law, entering a contract of healthcare services with a healthcare service provider, such as a hospital or clinic, deciding on a treatment plan, and, perhaps more controversially, signing on the informed consent documentation are often considered as the so-called civil juristic acts mentioned previously.

It is clear that voluntary guardianship and its terms and conditions must be agreed in writing,²² but less transparent are the mechanisms to ensure its enforcement. The *Civil Code* does not elaborate on which aspects of decision-making capacity should be assessed and how the capacity for performing civil juristic acts should be assessed and declared. In the context of healthcare services, it seems reasonable to assume that relevant medical professionals are best suited to make such an assessment. However, the Civil Procedure Law contains a section detailing the special procedure for declaring full or partial loss of capacity, a decision which

²⁰ Ibid., art. 35.

²¹ Ibid., art. 32.

²² Ibid.

must be made by a court.²³ A careful reading leads one to infer that this procedure applies in assessing capacity, since the *Civil Code* is silent on this issue. On the other hand, it has been common practice that public notarisation is sufficient to activate voluntary guardianship, in which case, the aforementioned court proceeding is bypassed or simply ignored.²⁴ This uncertainty in activating voluntary guardianship might be a factor influencing its utilisation in practice, an issue which will be explored later in the chapter.

Once the guardianship is established, the guardian's action must be based on the Best Interest Principle of the person under guardianship.²⁵ The *Civil Code* does not elaborate on what actions the guardian is required to fulfil under the Best Interest Principle. One interpretation of this provision given by the Leadership Unit for implementing the *Civil Code* of the Supreme People's Court provides an example of this principle:²⁶ the guardian may dispose of the property of the person under guardianship only for the express purpose of defending his or her interests, an eventuality that is also provided for in the *Civil Code*. Interestingly, however, such an interpretation also provides that the essence of the Best Interest Principle is to fully respect the wishes of the adult under guardianship, another principle that governs the guardians' actions.

Article 35 of the *Civil Code* obliges guardians to give maximum respect to the true wishes of the person, by supporting the person to undertake matters that are appropriate to their capacity, while refraining from intervention.²⁷ The principles of "Best Interest" and "maximum respect for true wishes" have the potential to come into conflict with each other; however, the practice as reflected in judicial proceedings and published medical studies seems inadequate to form a basis on which to examine the actual tension, as will be discussed later. These principles might be admittedly more relevant to the daily decision-making for

²³ The Civil Procedure Law of the People's Republic of China (adopted at the Fourth Session of the Seventh National People's Congress on 9 April 1991; amended on 8 October 2007, 31 August 2012, and 27 June 2017), chapter 14, section 4.

Shanghai Notary, "Enforcing my voluntary guardianship when I become confused" (China, 27 August 2018) www.shnotary.org.cn/info/db53f9b27389432fa77177e8242535c7.

²⁵ Civil Code, art. 35.

²⁶ The Leadership Unit for Implementing the Civil Code of the Supreme People's Court, Understanding and Applying the General Provisions of the Civil Code of People's Republic of China (Beijing: People's Court Press, 2020), p. 213.

²⁷ Civil Code, art. 35.

persons with intellectual disabilities or mental health problems than ADs in end-of-life care or healthcare generally. At the very least, however, the principle of maximum respect for autonomy, as well as other provisions examined previously, demonstrates a clear direction in law that the autonomy of the persons whose mental capacity might be in question should be given serious consideration and respected as far as possible.

12.2.2 Code of Ethics: Respecting for Living Wills at End-of-Life Care

The Chinese Medical Doctor Association, representing 2.3 million members, issued the *CoE* on 25 June 2014. The association claims that the binding force of the *CoE* lies between non-binding declaration and formally binding regulation,²⁸ the exact implication of which warrants further clarification.

The *CoE* is comprehensive in content, consisting of 40 articles that are divided into the following sections: basic principles, doctor–patient relationship, the relationship with fellow doctors, doctor–society relationship and doctor–enterprise relationship. Patient autonomy is one of the key themes. Article 1 requires doctors to give adequate respect to their patients, ²⁹ and article 9 asks medical professionals to listen to the patients and to strive to build relationships of mutual trust. ³⁰ In doing so, doctors are required to communicate with their patients in a manner that is understandable to the patient. ³¹ An example here would be the procedure of obtaining informed consent before a surgical operation; it is expected that a special examination or treatment would not be conducted as a mere box-ticking exercise or an excuse for avoiding possible liability. ³²

It is also evident that the framework is grounded in paternalism. The *CoE* allows doctors to conceal information considered to be potentially harmful should it become known to the patient.³³ Guided by arguably competing approaches, some provisions read less clear. For example, article 23 of the *CoE* requires doctors to respect patients' "reasonable"

²⁸ Chinese Medical Doctor Association, "Promote noble medical ethics and build a harmonious doctor-patient relationship: the Chinese Medical Doctors' Code of Ethics officially released" (China, 25 June 2014) www.cmda.net/bmdt8/9666.jhtml [in Chinese].

²⁹ *CoE*, art. 1.

³⁰ Ibid., art. 9.

³¹ Ibid., art. 10.

³² Ibid., art. 12.

³³ Ibid., art. 22.

requests and choices, including their right to accept or decline any medical recommendation.³⁴ Yet there remain the problematic questions of how to assess "reasonableness" in this context as there is no standard measure, or what consequences should follow when patients decline medical recommendations, both of which requires further research.

The most relevant provision relating to ADs is article 20, the first sentence of which requires doctors to take seriously patients' life-sustaining decisions.³⁵ It is followed by the second sentence which states that doctors should also respect any wishes expressed by patients through living wills and substitute decision-making arrangements made while patients lost their mental capacity.³⁶ The text is unclear on whether the endorsement of living wills is limited within the scope of maintaining or withdrawing life-sustaining arrangements. Nonetheless, even for patients whose capacity for performing civil juristic acts is in question, their doctors should facilitate their maximum participation in all aspects of medical decision-making.³⁷ There does not appear to be any empirical research on how these articles operate in practice, or how doctors have implemented any such living wills (if at all), so it remains unclear whether article 20 has been put into practice and, if so, how this was done, the circumstances, and with what consequences.

12.2.3 Summary

The normative framework governing mental capacity and professional ethics in China represents a mixed package which endorses both paternalistic benevolence and personal autonomy. Maximum respect for autonomy and involvement in healthcare decision-making goes hand in hand with the Best Interest Principle in the *Civil Code* and the "reasonableness" assessment in the *CoE*.

That said, it is equally evident from this discussion that both the voluntary guardianship in the *Civil Code* and the living wills provision in the *CoE* offer at least a possibility that ADs could become functional in China. From a historical perspective, the current normative framework demonstrates a step towards respecting patients' autonomy in healthcare

³⁴ Ibid., art. 23.

³⁵ Ibid., art. 20.

³⁶ Ibid. The chapter notes that substitute decision-making arrangements are not generally regarded as a process authorised to respect prior wishes alongside living wills.

³⁷ *CoE*, art. 25.

decision-making. For all stakeholders who have concerns about ADs, they at least have something to start with, albeit there remains considerable uncertainty. On the other hand, however, the fact that adult guardianship has undergone recent reform may imply that legally binding ADs are not likely to be introduced in the foreseeable future. The adult guardianship system may reinforce the pre-existing practice and culture which prioritises substitute decision-making arrangements over giving consideration to patients' wishes expressed through living wills. Given these possibilities, the form in which these will ultimately be adopted depends on how this will be practiced on the ground.

12.3 Explanations for Under-implementation

The previous section argued that the current normative framework at least creates the possibility that ADs could be made and respected, both legally and ethically. This section explores the extent to which this theoretical possibility has been realised. It does so firstly by examining the databases of courts' rulings and medical research, specifically seeking evidence that would suggest real-world use and application of the aforementioned legal and ethical provisions.

Before its introduction in 2017 by the *General Provisions of Civil Law*, the actual application of voluntary guardianship was long-awaited. However, based on the search results from *China Judgments Online*, the official publicly accessible database of courts' rulings, there has yet to be a case where the court has been called upon to decide on the legality of voluntary guardianship.³⁸ Moreover, the *CoE* was mentioned by a plaintiff in only one case, and the court did not address the question of

In January 2021, the author conducted keyword searches in Chinese that referred to voluntary guardianship (意定监护), article 33 of the General Provisions of Civil Law (民法总则第三十三条) and article 32 of the Civil Code (民法典第三十二条). There are dozens of cases that mention these keywords but none of them are about medical decision-making. In one case, however, the court recognised the legality of a power-of-attorney form provided by the hospital and signed by the patient in which the patient appointed one of her children to decide on whether to withdraw or refuse life-sustaining treatment. The court ruled that this form served a similar function of voluntary guardianship but on different legal basis. At the very least, the case suggests the power-of-attorney practice exists and its legality could be accepted in court, though on an individual basis. See the case of Beijing Second Intermediate People's Court No. 7645 Civil Case of 2020-Final Judgment (Case reference code is translated by author from 北京市第二中级人民法院 (2020)京02民终7645号民事判决书). Further research is required to explore the extent to which this practice is widely adopted nationwide.

whether the *CoE* had been breached. The search results suggest rare, if not non-existent, application of the current normative framework of ADs in Chinese courts. Healthcare services appear not to utilise the normative framework either. Extensive and close searching of *CNKI.NET*, the largest electronic database for academic papers, failed to identify any research studies on the actual application of ADs or the *CoE* provision. Most of the several dozen relevant papers are either theoretical or seek to promote its regulation by introducing foreign law on ADs. The following sections will explore why implementation has been weak, firstly by presenting the factors in the normative framework, followed by a discussion on attitudinal and cultural underpinnings.

12.3.1 Legal Uncertainty and Practical Unnecessity

In the previous discussion of the normative framework, I briefly touched on the matter of legal uncertainty. The *Civil Code* does not specify who should be appointed to assess the extent of incapacitation, or the procedure for activating voluntary guardianship. Moreover, the *CoE* fails to clarify the determination of the concept of reasonableness in patients' wills, or whether the respect for living wills applies only in end-of-life decisions. Even though awareness of ADs has been growing, it would be reasonable to assume these uncertainties do not encourage patients or doctors to invest their time and energy in these matters. This would be particularly the case when they are unsure of the legal or practical consequences that will follow.

Risks exist in the application of ADs in light of other relevant rules. For example, faced with a living will that outlines a refusal of life-sustaining treatment, the doctor will be placed in a dilemma: on one hand, the *CoE* imposes an ethical duty on the doctor to respect the living will, if they are convinced that the patient's refusal of treatment is "reasonable" and all other conditions are met.³⁹ On the other hand, the doctor has a legal obligation to save lives, and, moreover, the law does not appear to allow exceptions, even where living wills specify the patients' refusal of life-saving treatment. For example, the Law on Practicing Doctors (LPD) explicitly requires doctors in China to adopt emergency treatment measures, and stipulates that doctors cannot refuse to give

³⁹ CoE, art. 20.

emergency treatment.⁴⁰ The penalties for non-compliance range from suspension for 6–12 months, to having their medical license revoked, to facing even criminal prosecution if their (in)actions result in delays in the rescue and treatment of patients in emergency and critical condition, and serious consequences due to negligence.⁴¹ Similar provisions are also to be found in lower-ranking regulations, such as the *Administrative Regulations on Medical Institution* in 1994⁴² and *The Guiding Opinions on the Establishment of an Emergency Relief System for Diseases* in 2013.⁴³

It could be argued that respecting the refusal of life-sustaining treatment through a living will does not violate these general rules. Front-line practitioners, however, appear to feel assured when they are explicitly guided by clear rules that support their legal and ethical obligations to comply with the living will.⁴⁴

In addition to these legal uncertainties in the rules and their legal consequences, substitute decision-making by formal voluntary guardianship may be seen to be unnecessary in practice. It has been widely acknowledged that the procedural requirement established by the *Civil Procedure Law* for declaring the capacity for performing civil juristic acts, the precondition for validating adult guardianship in theory, is facing significant practical difficulties. More importantly, family members are granted considerable rights to information and decision-making in healthcare services. Since in most cases, it is family members

⁴⁰ The Law on Practicing Doctors of the People's Republic of China (adopted by the third session of the Standing Committee of the National People's Congress on 26 June 1998; entered into force on 1 May 1998), art. 24.

⁴¹ LPD, art. 37.

⁴² The State Council of China, Administrative Regulations on Medical Institution (adopted on 26 February 1994; amended on 6 February 2016), art. 31, www.nhc.gov.cn/fzs/s3576/201808/f674e82257a2471a9a68f5c369403042.shtml.

⁴³ The State Council of China, The Guiding Opinions on the Establishment of an Emergency Relief System for Diseases (1 March 2013) section 4(2), www.gov.cn/zwgk/2013-03/01/ content_2342656.htm.

⁴⁴ Y. Sun, Research on Advance Health Care Directives (Beijing: Legal Publishing House in China, 2019) pp. 8–9.

⁴⁵ S. Zhang, "Predicament and solution in the implementation of intended guardianship system" (2020) 2 *Oriental Law* 121.

⁴⁶ C. Ding, "Family members' informed consent to medical treatment for competent patients in China" (2010) 8(1) China: An International Journal 139; V.L. Raposo, "Lost in 'culturation': medical informed consent in China (from a Western perspective)" (2019) 22(1) Medicine, Health Care and Philosophy 17.

who serve as the substitute decision-makers, proceedings before the court would not be regarded as necessary. 47

12.3.2 Attitudinal and Cultural Factors

In addition to the previous analysis, there also exists a body of literature that explores attitudinal and cultural factors that drive the slow translation of ADs into practice. For example, the low awareness-rate of ADs among all stakeholders (including the persons themselves, their family members, and doctors and nurses), the tradition of avoiding discussions about death, and the parent–child relationship under Confucianism are widely believed to be the main social and cultural factors relevant to the promotion of ADs. This proposition appears to be supported by empirical studies conducted in China in recent years.

Although there are no available national studies, some medical research papers have explored stakeholders' attitudes towards ADs with relatively small samples or at the local level. For example, a study on the acceptance of ADs consisting of 280 senior patient-participants with chronic disease living in the community suggests that educational level and attitudes to death have the most significant influence on acceptance level. Those patients with higher educational levels indicated a higher acceptance level towards ADs in their responses. Participants who indicated that they had a higher level of acceptance of death as a natural consequence of life also had a higher level of acceptance of the use of ADs (mainly being more open to the idea of and use of ADs). ⁵⁰

⁴⁷ B.Y. Huang et al., "The do-not-resuscitate order for terminal cancer patients in mainland China: A retrospective study" (2018) 97(18) *Medicine* e0588.

Y. An and M. Zou, "An assessment of advance directives in China: the 'coming of age' for legal regulation?" (2018) 20(1) Marquette Benefits & Social Welfare Law Review; Y. Zhou, "Care issues at the end-of-life in China" (2016) 45(2) Development and Society 231; M.C. Stuifbergen and J.J.M. Van Delden, "Filial obligations to elderly parents: a duty to care" (2011) 14(1) Medicine, Health Care and Philosophy 63; Y. Yang, "A family-oriented Confucian approach to advance directives in end-of-life decision making for incompetent elderly patients", in R. Fan (ed.), Family-Oriented Informed Consent (Springer, 2015), pp. 257–70.

⁴⁹ Z. Yang and H. Zhang, "Acceptance of advance directives and influencing factors among elderly patients with chronic diseases in the community" (2020) 23(31) *Chinese General Practice* 3949.

The authors suggest that patients who perceive death as an escape may be less willing to discuss ADs with their family because this may lead to conflicts in the process of decision-making, namely because the Chinese concept of filial piety is likely to cause family members to want to keep them alive at all costs. This does not appear to be a convincing

Another study of 249 family members of stroke patients investigated their attitudes towards setting up ADs.⁵¹ Only 40% of participating family members agreed with the idea of setting up ADs; a quarter of participants explicitly disagreed and the remaining 35% preferred not to answer for a variety of reasons. The reasons for family members' disapproval of ADs included the following: "the patients' choice is not necessarily reasonable" (33.3%), "family members cannot accept that their relatives would be left to die" (25.2%), "our family cannot afford a free choice among different types of cares" (14.3%), "the medical decision should be made by me (or other family members)" (12.9%) and "family members concern that doctors would not actively rescue the patients with ADs" (13.6%). Interestingly, the study also asked whether participating family members would themselves have ADs. Of 128 family members who answered "no", 67 respondents believed doctors and family members were capable of making wise decisions on their behalf, while 60 respondents stated that they did not have adequate information to make ADs. In addition to the low awareness, it also reflects an evident attitudinal and cultural preference that favours substitute decisionmaking arrangements over respect for patients' autonomy by ADs. Such a cultural preference likely also stems from what has been described as the family-based decision-making model prevalent in Confucian Chinese societies, where the family, rather than the individual patient, is seen as the primary unit of medical decision-making.⁵²

A study in 2020 explored attitudes of 530 healthcare professionals towards ADs.⁵³ Its findings revealed that awareness of ADs among healthcare professionals is still low; only 44.5% of the participants knew about ADs. That study adopted a broader definition of ADs, including both types of living wills and powers-of-attorney. Of the participating

explanation, however, given that this kind of conflict with family members is likely to be present regardless of the patient's attitude towards death.

⁵¹ X. Wu et al., "Study on family members' attitudes towards setting up advanced directives for stroke patients" (2020) 637 *Medicine and Philosophy* 18.

See, for example, X. Chen and R. Fan, "The family and harmonious medical decision-making: cherishing an appropriate Confucian moral balance" (2010) 35 Journal of Medicine and Philosophy 573; R. Fan and B. Li, "Truth-telling in medicine: the Confucian view" (2004) 29 Journal of Medicine and Philosophy 179; R. Fan, "Self-determination vs. family-determination: two incommensurable principles of autonomy" (1997) 11 Bioethics 309.

⁵³ W. Ma and Q. Xue, "Factors associated with attitudes and behavioural intention concerning advance directives among physicians and nurses" (2020) 23(31) Chinese General Practice 3935.

professionals, 84% and 70.4% approved of living wills and powers-of-attorney respectively. Regarding living wills, the reasons for approval include respect for patients' right to choose (98.2%), reducing unnecessary suffering (91.7%) and over-treatment (77.3%), avoiding conflict of opinions among family members in resuscitation (74.4%), reducing family members' financial (74.4%), psychological/ethical (73.7%), and caring (72.6%) burden and improving patients' quality of life (73%).

Similar considerations shaped reasons for approving of powers of attorney, but, interestingly, some other reasons were also mentioned, for example, "avoiding the difficulties among different choices faced by doctors" and "saving time for treatment". Among those who disapprove of ADs (16% for living wills and 29.6% for powers of attorney), legal uncertainty represented the shared reason, 68.2% and 66.2% respectively. Regarding living wills, other major reasons for disapproval include losing opportunities for resuscitation, depriving the patient's right to life, conflicts of opinions between patients and family members, violating professional ethics, being uncomfortable discussing the topic with patients, hindering technological progress and lack of time for doctor-patient communication. Among those who disapproved of powers of attorney, there were concerns that "the patients' decision to refuse treatment could be changed by their agents" and "the patient might lose autonomy if the power-of-attorney is signed under pressure". A particularly potent reason was that "family members would become the agent in decision-making automatically", meaning powers of attorney are unnecessary.

While further empirical research is needed, particularly at the national level, existing studies provide a glimpse into the role that ADs may be able to play in China. Although resistance from family members to the idea of ADs is likely to pose a challenge to the uptake of ADs, healthcare practitioners appear surprisingly supportive of living wills in particular, which may be a positive factor in facilitating further awareness and support of ADs in China over time.

12.4 Ongoing Projects Promoting Advance Directives in China

Nonetheless, the attitudinal and cultural factors discussed here are subject to change. As well as a critical review of the literature explaining the status quo, the chapter also considers some pilot projects that promote ADs and were initiated by civil society organisations. These projects are still in their early stages, and their scope is largely limited to urban areas

and particular social groups. But they are potential change-makers through their active engagement with social discussions and practice.

12.4.1 Promotion by Beijing Living Will Promotion Association

Beijing Living Will Promotion Association (BLWPA) was established in 2013 as a non-governmental organisation with the ultimate goal being to promote the idea of "die with dignity" and living wills.⁵⁴ In addition to distributing information booklets and public advocacy through mass media, one of its key works is supporting more people in thinking about their end-of-life decisions and making their living wills.

BLWPA's official website (www.lwpa.org.cn) provides a tool by which people can complete a form indicating their wills and preferences regarding their end-of-life decisions. Informed by "My Five Wishes" in the United States, BLWPA guides its users to consider their wishes for wanting (a) certain elements involved in medical treatments (such as "I do not want any treatment or examination that would increase pain even when doctors and nurses believe it to be beneficial" and "I do want to keep my body clear all the time"); (b) life-sustaining treatment (including applying Cardiopulmonary Resuscitation, feeding tube, or expensive antibiotics); (c) how other people will treat me (such as "I want to die at home if possible" and "I do not want to be disturbed by volunteers"); (d) what I want my family members and friends to know (such as "I want my family to know I love them" and "I do not want any memorial service"); and (e) who will help me (appointing a substitute decision-maker to ensure these wishes would be respected as much as possible). Users need to register with BLWPA's website to access the form, which requires that the contact information of relevant family members or friends be provided. The default setting is that the wills are activated only when two medical professionals believe the person concerned has become incompetent. BLWPA also recommends its users to notarise their wills, the purpose of which is most likely to enhance the wills' legal status, so that doctors are more likely to follow the directives set out within the wills. That said, BLWPA acknowledges that the wills are not legally binding, as China has not enacted any law that clarifies the doctors' roles and responsibilities in acceding to the directions stipulated within the wills.

⁵⁴ Zhou, note 48.

It remains unknown how many people have used BLWPA's service. However, arguably due to BLWPA's advocacy, directly or indirectly, the Chinese Government initiated a pilot project on palliative care in 76 cities or districts nationwide in 2019. Legal recognition of living wills is not mentioned in the policy document of the pilot project. Nonetheless, the development of such services would be expected to have an impact on the social attitudes towards end-of-life care and surrounding legal arrangements.

12.4.2 Active Use of Voluntary Guardianship by the LGBT Community in China

The process of civil law reform in China has provoked deep concerns from among interest groups and stakeholders, among these groups being China's lesbian, gay, bisexual, and transgender (LGBT) community. In the final text of the *Civil Code*, neither same-sex marriage nor civil partnership is legalised. Thus, there exists the need for other legal tools or formal arrangements that would help to ensure a legal bond between homosexual couples in China. Voluntary guardianship, therefore, has become a heated topic within the community and has raised some scholarly concerns. ⁵⁶

Yanhui Peng, a community leader from the group LGBT Rights Advocacy China, shared in an online panel in 2020 that they are exploring whether voluntary guardianship could be helpful in gaining control in a variety of issues faced by the LGBT community in China. By setting up voluntary guardianship, community members seek to make their partners legitimate agents or decision-makers on medical treatment, living arrangements as they become older, property and litigation.⁵⁷

Facing the legal uncertainty discussed here, Peng also recommends notarising the voluntary guardianship documents. To promote voluntary guardianship among the community members and to advocate for

S. Zhang and G. Wu, "Exploring the legal application of voluntary guardianship to homosexual community" (2019) 2 Cross-strait Legal Science 70.

National Health Commission of the People's Republic of China, "The Notice of Second Pilot Projects of Palliative Care" (China: 2019) www.nhc.gov.cn/cms-search/xxgk/getManuscriptXxgk.htm?id=efe3ed3d9dce4f519bc7bba7997b59d8 [in Chinese].
S. Zhang and G. Wu, "Exploring the legal application of voluntary guardianship to

⁵⁷ EqualRights.hku.hk, "Adult guardianship and autonomous decision-making" (Hong Kong: 2020), www.equalityrights.hku.hk/post/成人監護與自主決策-代表與被代表的那些事(上).

equal rights of the LGBT community, LGBT Rights Advocacy China actively works with notary agencies in different areas. Through their active engagement, Nanjing Public Notary Office has publicly promoted their services in setting up voluntary guardianships for medical decision-making to the LBGT community in their social media accounts. ⁵⁸

How these voluntary guardianship arrangements function in practice, especially in the healthcare setting, requires further observation. The efforts from the community, nevertheless, are creating or expanding the possibility that the normative framework of ADs could be activated, thereby changing social attitudes and awareness of ADs.

12.5 Conclusion

This chapter has drawn on related practice and scholarly literature to examine the current semi-normative framework for ADs in China, including related practice and scholarly discussion. Without specific legislation that acknowledges and gives binding force to ADs, China's new *Civil Code* nevertheless sets out legal criteria by which a person may be assessed as lacking in decision-making capacity, and guidance on the appointment of substitute decision-makers for such people. The *CoE* requires Chinese medical practitioners to respect patients' expressed wills made at a time when the patient was of mental capacity and able to make rational decisions, and to ensure patients' maximum participation in the decision-making process, even when the patients are considered to be beyond capacity. The chapter presents a discussion of such a framework of norms that may potentially have a positive impact on practices related to advance healthcare directives.

Existing evidence derived from judicial proceedings and medical research literature suggests it is rare, if not non-existent, that the framework has actually been translated into medical practice. The chapter considers the legal, attitudinal and cultural factors that hinder the implementation of ADs. In addition, it has also surveyed two leading examples

But the article was later deleted without explanation, see D. Wang, "I notarise voluntary guardianship for same-sex couples" (China: 2019), www.sohu.com/a/330829888_ 120146415 [in Chinese]. The deleted post could be found at Nanjing Public Notary Office, "Notarising voluntary guardianship (for LGBT community)" (China: 2019), mp.weixin.qq.com/s/nT9jmcf5jYe1PBIRSOsxsw?fbclid=IwAR2de0PFyxuWJ4vrihYZQxX qcCTgkXnWrRv8Jq7xMxvPR7sdZyXJRHHVKms.

of civil society-led pilot projects that promote ADs in China, presenting a wider landscape of the relevant practice. With only a vaguely promising prospect that the social attitudes of stakeholders will become more friendly to broader implementation of the power of attorney and living wills in their current form, it is argued that the current legal, policy and economic-social context in China appears unready for the legislation of legally binding ADs.