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## The Law and Practice of Advance Directives in Taiwan

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### 4.1 Introduction

Achieving a good death (善終) is regarded as one of the Five Blessings (五福) of life in traditional Chinese culture. The introduction of modern Western medicine and the practice of cardiopulmonary resuscitation (CPR) and other forms of life-sustaining treatment (LST), however, made a good death difficult to achieve for many of those accepting end-of-life care in hospital settings. Through three decades of effort to promote hospice and palliative care, Taiwan has developed comprehensive and pioneering legislative frameworks to govern advance directives (ADs) and end-of-life decision-making more generally. In 2015, Taiwan was ranked number six in the world and number one in Asia in terms of “quality of death” by *The Economist*. Despite these advances, however, the uptake of ADs in Taiwan remains low, which may be the result of insufficient understanding and awareness, as well as sociocultural factors such as an emphasis on the role of the family in medical decision-making. This chapter begins with an introduction to the legal regulation of ADs in Taiwan, followed by a discussion of the available data on the practice of ADs and an exploration of the possible reasons for their low uptake. The chapter concludes with several suggestions for the way forward.

### 4.2 The Legal Regulation of Advance Directives in Taiwan

The regulation of ADs in Taiwan is governed primarily by two legislative frameworks, the 2000 Hospice Palliative Care Act (HPCA) and the 2019 Patient Right to Autonomy Act (PRAA). No court decisions to date have independently recognised the right of terminally ill patients to withhold or withdraw LST because the use of court decisions to resolve end-of-life care disputes is inefficient under the continental law system of Taiwan, nor is it an acceptable practice in medicine.

### 4.2.1 *Legislative Background*

Although the first hospice (安寧病房, or palliative care ward) in Taiwan was established in 1990 in a Christian hospital (MacKay Memorial Hospital),<sup>1</sup> and many academic medical centres have begun to establish palliative medicine wards, only a small portion of terminally ill patients are able to receive hospice care owing to the limited service volume and such care being an unfamiliar concept. Because the “doctor’s duty to rescue” was emphasised in the earlier version of the Medical Care Act<sup>2</sup>, many terminally ill patients received painful and burdensome CPR and other forms of LST in their final days in hospital. There was no definitive regulation or protocol concerning the withholding or withdrawal of LST from terminally ill patients prior to the HPCA’s enactment in 2000.

In response to the increasingly urgent need for Taiwan to establish clear legal procedures in relation to end-of-life care, a joint effort by healthcare professionals, social and religious leaders, legislators, and government officials was launched in 1993, with the HPCA finally being passed in 2000 after years of discussion and negotiation.<sup>3</sup>

### 4.2.2 *Hospice Palliative Care Act*<sup>4</sup>

The goal of the HPCA is to ensure that patients who are terminally ill have the freedom to choose hospice palliative care and refuse LST,<sup>5</sup> as demonstrated by Article 1, which states that the Act’s aim is to respect the wishes of terminally ill patients in relation to medical treatment and to protect their rights. A terminally ill patient is defined in Article 3 of the HPCA as an individual (i) who suffers from serious injury or illness, (ii) who has been diagnosed by a physician as incurable and (iii) for whom

<sup>1</sup> Hospice Foundation of Taiwan, “Hospice and Palliative Care Continues in Taiwan” (2020), [www.hospice.org.tw/content/3010](http://www.hospice.org.tw/content/3010).

<sup>2</sup> The 1986 version of the Medical Care Act, Article 42 of which states “Hospitals and clinics should immediately treat patients in critical condition with the equipment they have or take all necessary measures without undue delay.” The 2004 version has made the description of “duty to rescue” more flexible.

<sup>3</sup> S.Y. Tu [涂心怡], “The Companion of the Hospice Palliative Care Act and the Patient Right to Autonomy Act in the End of Life” [in Chinese], Hospice Foundation of Taiwan (2020), [www.hospice.org.tw/content/3154](http://www.hospice.org.tw/content/3154).

<sup>4</sup> Hospice Palliative Care Act (2021), <https://law.moj.gov.tw/ENG/LawClass/LawAll.aspx?pcode=L0020066>.

<sup>5</sup> Hospice palliative care is defined in Article 3 of the HPCA as “mitigatory and supportive medical care given to relieve terminal illness patients from and rid of physical, mental and spiritual pain, to improve their quality of life”.

there is medical evidence showing that the inevitable prognosis is death within the near future.

Whilst the term “advance directive” is not used in the HPCA, Article 4 establishes a mechanism called the “letter of intent” by which a terminally ill patient can make a decision about whether he or she wishes to receive hospice palliative care or LST. To make a letter of intent, an individual needs to be a capacitous adult (Article 5).<sup>6</sup> The letter, which should state the individual’s wishes regarding the receipt of hospice palliative care or LST, should also contain his or her personal information and the date on which the letter was written (Article 4). The signing of the letter of intent should be witnessed by two individuals with full capacity. However, neither healthcare workers who are affiliated with medical institutions that provide hospice palliative care nor the individuals who will carry out the individual’s wishes with respect to LST are permitted to act as witnesses to avoid conflicts of obligations or roles (Article 4). Individuals can withdraw their wishes in writing at any time, either on their own or via their medical surrogate agent (Article 6), who can be appointed as part of the letter of intent (Article 5).

Once the letter of intent has been signed, the relevant competent authority (as defined in the HPCA) will note the letter’s existence in the individual’s national health insurance certificate, and the letter will be stored as an electronic file in the central competent authority’s database. If the contents of the letter of intent are inconsistent with the written wishes specified by the individual during the consent process prior to clinical treatment, the contemporaneous written consent, or refusal of consent, will prevail. In terms of application, where there is a signed letter of intent refusing consent to CPR or other forms of LST, these interventions cannot be administered as long as two physicians have confirmed that the patient is terminally ill (Article 7). If CPR or other LST has already begun, and the foregoing conditions have been satisfied, Article 7 (5) allows such treatment to be terminated or withdrawn.

Where there is no letter of intent, and the patient is unable to express his or her wishes clearly, Article 7(3) of the HPCA provides that consent can be given instead by his or her closest relative, or by the physician in the patient’s medical best interests, although it is explicitly stated that neither of these decisions can contradict the patient’s previously

<sup>6</sup> A minor can sign a letter of intent with the consent of his or her legal representative, and where a minor cannot express his or her will, the legal representative is to sign the letter of intent (see further Article 7 of the HPCA).

expressed wishes. Article 7(4) provides a list of “closest relatives”, which are defined broadly to include third-degree relatives and first-degree relatives by marriage. In the event of disagreement between a patient’s closest relatives, the order in which the relatives are listed in Article 7(4) determines their priority. Article 7 defines the essential elements and practice of ADs for the withdrawal/withholding of CPR/LST from terminally ill patients. It also indicates the priority ranking of decision types: first, the patient’s personally signed AD/letter of intent; second, an AD/letter of intent signed by the patient’s surrogate or closest relative; and, third, a doctor’s medical order when the patient has no close relatives. In the third condition, the doctor’s decision must be made in the best interests of the patient after consultation with a palliative care specialist. None of these surrogate decisions should be contrary to a patient’s formerly expressed wishes.

The HPCA stipulates strict penalties for the violation of Article 7, which provides for the circumstances in which CPR or LST should be withheld. Article 10 states that physicians who violate Article 7 will be fined a sum between NT60,000 and NT300,000, and will either be suspended from practice for a period of between one month and one year or have their licence revoked completely. In terms of individuals who choose to end the lives of their family members without following the procedures laid down by the HPCA, court decisions suggest that such actions will be considered homicide.

#### 4.2.3 *Concerns with the HPCA*

After the HPCA’s passage in 2000, clinical practice relating to end-of-life care in Taiwan changed gradually but remarkably. Both patients and doctors began to embrace the concept of respecting patients’ autonomous decisions at the end of life and to recognise that refusing CPR and LST was acceptable as long as the relevant procedures and documentation required by the HPCA were followed.

However, the HPCA has a number of limitations. First, it has been argued that the Act’s protection of patient autonomy is insufficient. For example, Article 8 requires that physicians inform terminally ill patients *or* their family members of the patient’s condition, hospice palliative care treatment and LST choices. Article 8 further stresses that patients are to be informed if they explicitly express the desire to be informed of their condition. Although this stipulation, on the one hand, protects a patient’s legal right to know about his or her own diagnosis, on the other hand, it

also seemingly permits the traditional practice of information (bad news) being shared only with a patient's family members but not the patient. Owing to such a vague zone of who can or should be informed of a diagnosis, some have argued that the individual's right to informed consent is not fully protected under the HPCA.<sup>7</sup> However, such criticism lacks understanding of the fact that medical practices must progress over time with the evolution of social conceptions of patient autonomy. In a family-oriented model of end-of-life care practice such as that which prevails traditionally in Taiwan, the patient's right to informed choices is made clear and affirmed through efforts to advance legal frameworks.

Second, the HPCA applies only to terminally ill patients. It does not cover individuals who cannot be described as having a terminal illness, such as those in a permanent vegetative state, those with severe dementia, those in an irreversible coma or those with motor neuron impairment arising from such rare diseases as amyotrophic lateral sclerosis. In response to this concern, representatives of rare disease patient groups and Legislator Yu-Shin Yang of the Legislative Yuan (the unicameral legislature of Taiwan) have launched efforts to meet the needs of these groups by advocating for a more fundamental solution through a legislative framework aimed at protecting a patient's right of self-determination.

#### 4.2.4 *Patient Right to Autonomy Act*

The PRAA was passed in December 2015, announced in January 2016 and became effective in January 2019. Its aims, as stated in Article 1, are to respect patient autonomy in the healthcare context, to safeguard patients' right to a good death and to promote a harmonious physician-patient relationship.

The scope of the PRAA is wider than that of the HPCA. It no longer limits the withdrawal or withholding of CPR and LST to cases of terminal illness assessed by two specialist physicians. The LST category has also been broadened to include such interventions as artificial nutrition and hydration and antibiotics where they are being used to sustain life. Moreover, the PRAA expands the clinical conditions in which CPR and other forms of LST can be withdrawn or withheld beyond terminal

<sup>7</sup> C. Chen, "Legislating the Right-to-Die with Dignity in a Confucian Society – Taiwan's Patient Right to Autonomy Act" (2019) 42(2) *Hastings International and Comparative Law Review* 485.

illness: (1) irreversible coma; (2) a permanent vegetative state; (3) severe dementia; or (4) other disease conditions announced by the central competent authority (as defined in the PRAA) that meet the requirements that the condition or suffering is unbearable, the disease is incurable and no other appropriate treatment options are available given the medical standards at the time of the disease's occurrence. The patient's condition must also be diagnosed by two physicians in relevant specialties and confirmed through at least two consultations convened by the palliative care team (Article 14).

In terms of decision-making, the PRAA provides for an "advance medical decision" (預立醫療決定), defined as "a prior written and signed statement expressing the willingness of a person to accept or refuse life-sustaining treatment, artificial nutrition and hydration or other types of medical care, and their wishes relating to a good death, when they have been diagnosed with specific clinical conditions" (Article 3). As noted previously, the scope of this AD is wider than that of the letter of intent under the HPCA, which covers only decision-making with respect to hospice palliative care and LST.

The PRAA also provides more comprehensive protection for a patient's right to informed consent. Article 4 states that patients have a right to be informed of their diagnosis and treatment options, as well as the potential effectiveness and risks of those options, and the right to choose and make decisions regarding treatment options. Moreover, a patient's legal representative, spouse, relatives, healthcare agents and other closely related people (defined in the PRAA as "parties concerned") are not to prevent a medical institution or physician from acting on the patient's treatment decisions. This measure arguably provides patients with a rights-based form of resistance against the common phenomenon of family-based decision-making in Chinese culture, discussed further subsequently, and physicians with a way to preserve their authority to carry out a patient's decision free of family influence. Accordingly, there is much greater emphasis in the PRAA on both enhancing and protecting patients' autonomous decision-making, as expressed through an AD and other legislative requirements.

This is not to say that the PRAA does not envisage a role for the family in the end-of-life process, and indeed there are implicit tensions between the value of maximising respect for patient autonomy and the value of involving the family in identifying patients' best interests within some of the PRAA's articles. For instance, after specifying the list of items about which a medical institution or physician must inform the patient

(in other words, the scope of the physician's "duty to inform"), Article 5 states that "in the absence of clear objections from the patient, the parties concerned may also be informed". Thus, unless the patient explicitly objects, his or her physician is permitted to share this information with his or her family. It is noteworthy that instead of requiring consent from the patient before such information is shared, the presumption is that the family is to be informed. Therefore, it is important to recognise that this requirement could be interpreted such that it does not mandate the physician to initiate a discussion with the patient about sharing information with his or her family during which the patient may or may not express an objection.

Another notable feature of the PRAA is the way in which it embeds the process of making an AD in a wider legal requirement to instigate advance care planning (ACP; 預立醫療照護諮商). The procedures for establishing an "advance decision" through ACP consultation must fulfil the following requirements: (i) a medical institution has provided consultation on ACP to the declarant and affixed its seal on his or her advance decision; (ii) the advance decision must be notarised by a notary public or witnessed by two or more persons with full disposing capacity; and (iii) the advance decision must be registered in the declarant's national health insurance IC card. Furthermore, ACP must take place with the participation of at least one relative of a first or second degree of affinity (Article 9).

The Taiwanese Government has not yet taken any steps to cover ACP through the national health insurance system, which means that ACP participants currently need to pay a small out-of-pocket fee, generally in the region of US\$80–150, depending on the standard set by the individual hospital. Some have thus argued that financial incentives may be necessary to increase the public's willingness to embark on ACP consultation.<sup>8</sup> This author argues, however, that because ACP is resource-demanding and time consuming (as with any counsel of a psychologist or social worker), if the patient in question lacks motivation and understanding of the value and importance of ACP, then a fee-waiver policy would simply place an unnecessary burden on ACP consultants and waste scarce resources.

<sup>8</sup> Y.J. He et al., "Overview of the Motivation of Advance Care Planning: A Study from a Medical Center in Taiwan" (2021) 18 *International Journal of Environmental Research and Public Health* 417.

Other components of Article 9 are also worth noting. For example, it is expressly stated in Article 9(3) that at least one relative of a first or second degree of affinity must participate in the ACP process, which is in line with the emphasis on family-oriented decision-making in the Taiwanese context.<sup>9</sup> The rationale for such a legal design is that when tough end-of-life choices need to be made, family members must often act as patients' surrogate decision-makers. The purpose of requiring close relatives to participate in the procedures of ACP consultation and AD signing is to build understanding of and consensus on a patient's informed choices among family members to ensure that when the time comes to execute the AD there will be less disagreement and conflict.

#### 4.2.5 *Differences between the HPCA and PRAA*

Whilst the HPCA and PRAA both concern a patient's advance expression of his or her wishes in relation to end-of-life care, there is a significant difference between them in terms of physician liability. As discussed previously, the HPCA includes strict penalties for physicians who violate end-of-life procedures. The PRAA, in contrast, contains no such punitive measures, which were removed during the legislative process. The Ministry of Health and Welfare has explained that "since patient autonomy involves ethics, professional judgement, personal belief and other variables, using penalty or compulsory means to force physicians, patients or families to comply with the law would be non-beneficial to the promotion of such legislation".<sup>10</sup>

One of the difficulties that arose during the legislative process concerned physicians' unwillingness or refusal to withhold or withdraw LST and/or artificial hydration or nutrition from non-terminally ill patients due to conscientious objection.<sup>11</sup> Indeed, Article 14 allows very wide space for professional autonomy in that it permits a physician to refuse to implement a patient's AD on the basis of his or her "professional expertise or wishes", a wider scope of opt-out for a professional than

<sup>9</sup> This is the case unless all of the patient's first- and second-degree relatives are deceased, missing or have specific reasons for exemption (Article 9(3) of the PRAA).

<sup>10</sup> Ministry of Health and Welfare, "Protecting the Autonomy of Patients, Passing the Third Reading of the Patient Right to Autonomy Act" [in Chinese] (18 December 2015), [www.mohw.gov.tw/cp-2651-19687-1.html](http://www.mohw.gov.tw/cp-2651-19687-1.html).

<sup>11</sup> D.F.C. Tsai and H.H. Kuo, "The Ethical Perspectives and Practical Challenge of the Patient Right to Autonomy Act" [in Chinese] (2017) 21(1) *Formosan Journal of Medicine* 62.

reliance on his or her personal values or beliefs. In such a case, the physician is required only to inform the patient or parties concerned (Article 14), and the patient may then turn to other healthcare professionals who are able to assist.

Article 14 further protects physicians from liability by stating that they will not be subject to criminal or administrative liability if they terminate, withdraw or withhold LST and/or artificial nutrition and hydration in accordance with the article and that they will bear no responsibility to compensate for any damage incurred unless intentional or grossly negligent conduct is involved and the action is in violation of the patient's AD. These detailed, comprehensive guarantees of protection from liability for physicians, which resulted from negotiation during the legislative process, are arguably a way to reduce the pressure and burden involved in forgoing LST and/or artificial nutrition and hydration and to provide reassurances to mitigate the tensions that may arise.

### 4.3 Professional Guidelines Relating to Advance Directives in Taiwan

Whilst the HPCA and PRAA have been promoted and endorsed by many professional associations in Taiwan,<sup>12</sup> unlike their Western counterparts few of these associations have issued professional guidelines concerning end-of-life care, although the Taiwan Academy of Hospice Palliative Medicine, whose members are primarily physicians practising in the field of palliative medicine, issued a position statement expressing a firm objection to euthanasia and physician-assisted suicide in 2017.<sup>13</sup> The National Health Research Institute also published a "White Paper for Palliative Care in Taiwan" in 2019<sup>14</sup> and a "Policy Statement and Action Plan for Palliative Care in Taiwan"<sup>15</sup> in 2020. However, although both

<sup>12</sup> For example, since the announcement of the PRAA in January 2016, professional societies, associations, medical centres and hospitals have devoted considerable time and effort to introductory programmes, training courses, seed teacher licensing workshops, conferences and continuing medical education classes about the PRAA.

<sup>13</sup> Taiwan Academy of Hospice Palliative Medicine, "Position Statement on Euthanasia and Physician-Assisted Suicide" (25 May 2017) [www.hospicemed.org.tw/ehc-tahpm/s/w/Statement/article/096b75c16d004db0b950248398e7a30b](http://www.hospicemed.org.tw/ehc-tahpm/s/w/Statement/article/096b75c16d004db0b950248398e7a30b).

<sup>14</sup> National Health Research Institutes, "White Paper for Palliative Care in Taiwan" (September 2019), [tinyurl.com/2zaadk9](http://tinyurl.com/2zaadk9).

<sup>15</sup> National Health Research Institutes, "Policy Statement and Action Plan for Palliative Care in Taiwan" (March 2020), [tinyurl.com/2p8p3npc](http://tinyurl.com/2p8p3npc).

relate to the future development and promulgation of a comprehensive national plan for advancing citizens' rights and dignity with high-quality end-of-life care, as well as the expansion of ACP within hospitals, neither make any mention of ADs. Thus, there is likely to remain much uncertainty in practice about how the basic legal provisions should be implemented and managed in professional healthcare settings.

#### 4.4 The Practice and Sociocultural Context of Advance Directives in Taiwan

This section now considers the practice of ADs in Taiwan in light of the implementation of the aforementioned frameworks, as well as the socio-cultural factors affecting such practice.

As of March 2022, of Taiwan's population of 23 million, approximately 800,000 people (3.4 per cent) had completed a letter of intent under the HPCA, and only 33,000 (0.14 per cent) had completed an AD under the PRAA.<sup>16</sup> It is understandable that the completion rate of ADs would be low, as the PRAA has been in force only since 2018. However, the reasons for the low uptake are still worth exploring, given the pioneering nature of this legislation. Two possible such reasons, namely, insufficient awareness and/or understanding of ADs and the sociocultural emphasis on family-based decision-making, are explored next.

##### 4.4.1 *Insufficient Awareness and/or Understanding*

There are data suggesting that there is insufficient awareness and understanding of the concepts of ADs and palliative care among the general public. In 2016, Lin et al. reported that the majority of the elderly individuals and their family members whom they had surveyed in the intensive care unit of a medical centre in central Taiwan had an insufficient understanding of ADs.<sup>17</sup> In a more recent study conducted in 2021 that compared the differences in AD acceptance between millennials and baby boomers, Liang et al. found that, despite the Ministry of

<sup>16</sup> 安寧緩和醫療、器官捐贈及預立醫療決定整合資訊系統平台 [Integrated Information System Platform for Palliative Care, Organ Donation and Advance Medical Decisions] [in Chinese], <https://hpcod.mohw.gov.tw/HospWeb/>.

<sup>17</sup> H.C. Lin et al., "Exploring Understanding of Advance Directives among the Elderly ICU Residents and Their Families at a Medical Centre in Central Taiwan" [in Chinese] (2016) 11(1) *Taiwan Geriatrics & Gerontology* 50.

Health and Welfare of Taiwan announcing measures associated with the PRAA to assist the general public in understanding ADs, participants from both generations were still unfamiliar with ADs and who was able to accept palliative care.<sup>18</sup>

The data from these studies align with commentary suggesting that the general public has misconceptions concerning the nature of advance decisions to refuse LST such as CPR and of hospice care. Among the misconceptions are that signing up for either effectively means that they have “given up” or that they are giving up all treatment.<sup>19</sup> Liang et al. similarly found the low willingness among their participants to sign a letter of intent under the HPCA to be “associated with their erroneous perception that signing the intent [letter] means giving up all medical treatment”.<sup>20</sup>

In relation to medical professionals, the data are slightly less clear. Preliminary data from Chen et al. suggest that the PRAA has had a significantly positive impact on the knowledge of healthcare practitioners, with concepts such as “informed consent” and “decision-making directives” becoming more widely accepted in 2018 (as compared with 2013).<sup>21</sup> In a study conducted among healthcare professionals in the field of nephrology, Chiu et al. found that when asked about their knowledge of laws related to ADs, there were three particular areas in which the respondents achieved relatively low scores: (i) understanding of the scope of the HPCA following its revision; (ii) understanding of the matters that one should be aware of when intervening with an AD; and (iii) the difference between an AD and a do-not-resuscitate order.<sup>22</sup> Whilst the latter study does not provide us with sufficient information to properly interpret its results,<sup>23</sup> taken together the findings of the two studies seem

<sup>18</sup> Y.W. Liang et al., “Differential Acceptance of Advance Directives between Millennials and Baby Boomer Generations: A Cross-Sectional Survey Study Among College Students and Their Relatives” (2021) *Journal of Palliative Care* 1.

<sup>19</sup> C.Y. Wu, “Hospice and Palliative Care and Do-Not-Resuscitate” [in Chinese] (2014) 34 (7) *Health News KMHU* 7.

<sup>20</sup> See note 18, p. 2.

<sup>21</sup> I.H. Chen et al., “Knowledge of and Barriers to Palliative Care Perceived by Healthcare Providers before and after Promotion of the Patient Autonomy Act: A Cross-Sectional Study” (30 March 2020), [www.researchsquare.com/article/rs-19867/v1](https://www.researchsquare.com/article/rs-19867/v1).

<sup>22</sup> T.C. Chiu et al., “An Investigation on the Cognition of Advance Directive and Willingness to Promote Advance Directive in Nephrology Staff” [in Chinese] (2019) 18 (2) *Journal of Taiwan Nephrology Nurses Association* 1.

<sup>23</sup> We do not know, for example, what is covered by each of these areas (in particular what the authors mean by matters that one needs to be aware of when intervening with an AD), how these questions were scored and how many of the sample population of 65 performed poorly on the questions.

to suggest that although efforts to promote the PRAA appear to have had a positive effect on healthcare professionals in Taiwan, there are still specific areas in which their knowledge and understanding remain weak and require further training.

#### 4.4.2 *Emphasis on the Role of the Family*

In addition to insufficient awareness and understanding of ADs, particularly among the general public, the low uptake of ADs may also be explained by certain sociocultural characteristics of Taiwan. In addition to the taboo associated with death, which results in the avoidance of conversations about end-of-life care,<sup>24</sup> there is a significant emphasis on the role of the family in the medical decision-making context. Medical decisions in Taiwan are commonly seen as family decisions that should be made collectively between the family and the patient rather than decisions that patients should make on their own.<sup>25</sup> In extreme cases (which were not uncommon as recently as one or two decades ago), the family takes complete responsibility for medical decision-making, with patients denied any opportunity to participate. Presumably, however, this type of collusion between physician and family will be made much more difficult by the regulatory requirement to inform patients of their diagnosis, treatment options and right to make autonomous decisions, as enshrined in the PRAA.

In addition, because of the strong influence of the Confucian doctrine of filial piety, which results in adult children remaining subordinate to their parents and being expected to provide care without question, in some instances adult children in Taiwanese society do not proactively engage in discussions about ADs with their parents or other elders.<sup>26</sup>

<sup>24</sup> See note 11; S.Y. Cheng et al., "Advance Care Planning in Asian Culture" (2020) 50(9) *Japanese Journal of Clinical Oncology* 976, 982; H.T.S. Lee et al., "Cultural Perspectives of Older Nursing Home Residents Regarding Signing Their Own DNR Directives in Eastern Taiwan: A Qualitative Pilot Study" (2016) 15 *BMC Palliative Care* 45.

<sup>25</sup> H.H. Chou, "Exploring the Issues of Advance Directives in Patients with Mild Dementia in Taiwan" (2020) 74(3) *Acta Medica Okayama* 215; S.C. Lee, "Family Consent in Medical Decision-Making in Taiwan: The Implications of the New Revisions of the Hospice Palliative Care Act", in R. Fan (ed.), *Family-oriented Informed Consent* (Cham, Switzerland: Springer International Publishing, 2015), pp. 125–36; Lee et al., *ibid.*; 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; Cheng et al., *ibid.*

<sup>26</sup> Chou, *ibid.*

#### 4.4.3 *The Way Forward*

What might be the way forward for Taiwan in light of these possible challenges to the acceptance and uptake of ADs? In terms of improving awareness and understanding, there are data suggesting that implementing ACP programmes containing education on palliative care and ADs has the potential to improve knowledge of and attitudes towards ADs in Taiwan.<sup>27</sup> The lack of focused good practice guidelines emanating from within the healthcare profession on how to translate basic legal requirements into a complex, skilled and multidisciplinary process of making advance care plans and advance decisions across different health and community care settings should also be addressed.

Additionally, the 2018 study of Chu et al. on the factors associated with the completion of ADs found that patients were more likely to complete them if social workers participated in the ACP meeting required by the PRAA.<sup>28</sup> The authors observed that social workers provide support in multiple ways, including offering patients more information about their rights, identifying the major decision-makers among family members and offering emotional support. Because of such support, they suggested that social workers have an important role to play in the ACP process. In light of these findings, the development and implementation of ACP programmes that provide education on ADs, as well as further research on the proper role of social workers in the ACP process, may be steps that can be taken to improve the uptake of ADs in Taiwan.

A thornier issue may be the cultural influences on the acceptance of ADs. For example, both the traditional emphasis on family-based decision-making in the medical context and the expectation that children will take care of their parents in their old age without question may make it difficult for families to support an individual-oriented form of decision-making through the practice of ADs. However, from the author's experience and observations in clinical practice and ethics consultation, such traditional

<sup>27</sup> C. Sung et al., "The Effects of the ACP Program on Knowledge and Attitude of Palliative Care and Advanced Directives among Elders in Long-Term Care Facilities" (2013) 11(3) *International Journal of Evidence-based Healthcare* 250. See D. Chu et al., "Factors Associated with Advance Directives Completion among Patients with Advance Care Planning Communication in Taipei, Taiwan" (2018) 13(7) *PLOS ONE* e0197552 for data suggesting that comprehensive palliative care training programmes targeted at healthcare providers may also help to facilitate the completion of ADs.

<sup>28</sup> Chu et al., *ibid.*

concepts and practices have changed gradually but remarkably in the past two decades, during which Taiwan has also undergone tremendous transformation in terms of political freedom and a democratic system.<sup>29</sup> The young and even middle-aged adults who have grown up in a rapidly developing democratic society that emphasises personal freedoms and individual rights are likely to have little difficulty embracing patients' right to autonomy in medical decision-making. The aforementioned cultural influences and traditional practices are increasingly being transformed into an endorsement of patient autonomy and self-determination, or at least "shared decision-making", as more desirable standards. Portrayals of Chinese culture as characterised by "family-determinism" rather than "individual-determinism" are imprecise, dichotomised, unfeasible and inapplicable to the current Taiwanese context.<sup>30</sup>

The AD approach in the PRAA is family oriented to some extent. As discussed previously, whilst the Act protects individuals' right to informed consent and to treatment in accordance with their wishes without familial interference, it also contains provisions that presume that information about a patient's condition should be shared with family members unless otherwise explicitly indicated and, more importantly, that *require* a family member to attend the ACP meeting in order for the individual to be able to make an AD.

Hence, the PRAA preserves key features of family-based decision-making while advocating for respect for individual autonomy, and should arguably be promoted as such to emphasise its alignment with certain traditional cultural elements. In this sense, describing the Act in terms of a basic requirement to protect a person's autonomy rights fails to do justice to the complex and multiple values that intersect within its regulatory requirements and that need to be negotiated by practitioners, patients and family members in practice. The Asian Delphi Taskforce for Advance Care Planning has done initial work on developing good practice in light of these tensions, in particular through its publication of the 2019 Taipei Declaration on Advance Care Planning, which recommends tasks for each role in ACP, taking into account Asian cultural

<sup>29</sup> According to the newly released "democratic index", Taiwan is categorised as a fully democratic regime. It ranks number 8 in the world and number 1 in Asia. Economist Intelligence Unit, "Democratic Index 2021" [www.eiu.com/n/campaigns/democracy-index-2021/](https://www.eiu.com/n/campaigns/democracy-index-2021/).

<sup>30</sup> R. Fan, "Self-Determination vs. Family-Determination: Two Incommensurable Principles of Autonomy" (1997) 11 *Bioethics* 309.

influences.<sup>31</sup> Of particular note here is (i) recognising that family members and other caregivers have needs that should be attended to as part of the patient's care; (ii) expecting family members to participate actively in ACP discussions; and (iii) co-opting family members in the ACP process to remind, help or accompany the patient in the process of sharing goals and preferences.

#### 4.5 Conclusion

Over the past two decades, Taiwan has developed comprehensive legislative frameworks for ADs and end-of-life decision-making that have expanded over time. It is particularly notable that Taiwan's recent approach has been to embed ADs within a wider regulatory push towards introducing and improving ACP more broadly. The legislation now in place emphasises the importance of the fundamental ethical principle of respect for patient autonomy while simultaneously aiming to enable patients' family members to retain a central role in medical decision-making in ways that are likely to give rise to tensions in practice.

Despite the enactment of the two pieces of legislation discussed herein, however, AD uptake remains low in Taiwan. Further research needs to be conducted to learn more about the practice of ADs in Taiwan, but the existing data suggest that greater effort needs to be devoted to increasing the awareness and understanding of the general public (and healthcare professionals to a lesser extent) about ADs and end-of-life care. Whilst certain cultural factors may hinder the acceptance of ACP and ADs, efforts to implement them in a culturally sensitive manner, such as the PRAA provisions discussed here do, as well as the recommendations of the Asian Delphi Taskforce for Advance Care Planning in the 2019 Taipei Declaration on Advance Care Planning, are important steps towards aligning high-quality end-of-life care and decision-making in ways that endorse the conflicting ethical values that play out within the healthcare context in Taiwan.

<sup>31</sup> C.P. Lin et al., "2019 Taipei Declaration on Advance Care Planning: A Cultural Adaptation of End-of-Life Care Discussion" (2019) 22(10) *Journal of Palliative Medicine* 1175.