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The Proposed New Law on Advance Directives in Hong Kong: A Piecemeal Attempt at Codification?

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7.1 Introduction

The population of Hong Kong is ageing rapidly. Twenty per cent of the population was aged 65 or above in 2021, a percentage that is projected to reach 34% by 2066.[1] Hong Kong also has the highest average life expectancy in the world.[2] The increasing number of older people, coupled with rising life expectancy and the impact of chronic illness on physical, psychological and social well-being, suggests that the demand for high-quality end-of-life palliative care services will only continue to increase.

Despite the ever-escalating demand for long-term care, end-of-life care in Hong Kong remains underdeveloped. According to the Economist Intelligence Unit's Quality of Death Index, an instrument used to highlight advances in, the challenges of and gaps in end-of-life care policy and infrastructure in 80 countries worldwide, Hong Kong ranks relatively low at 22nd.[3] A good example of the policy and infrastructure gaps in end-of-life care in Hong Kong is the poor uptake of the advance directive (AD), or a statement in which a competent person makes an advance healthcare decision that is to be implemented in the event that the person loses capacity in the future. This is despite the generally accepted view internationally, which is that the use of an AD can encourage discussions about patients' care-related preferences and values, as well as provide

[1] Census and Statistics Department, Government of the HKSAR, Summary results of the 2021 Population Census, https://www.censtatd.gov.hk/en/web_table.html?id=1A. See also *Hong Kong Population Projections 2017–2066* (Kowloon: 2017), p. 7.

[2] At 83 and 88 years old for males and females respectively. See, further, M.Y. Ni et al., "Understanding Longevity in Hong Kong: A Comparative Study with Long-living, High Income Countries" (2021) 6 *The Lancet Public Health* e919.

[3] The Economist Intelligence Unit, *The 2015 Quality of Death Index: Ranking Palliative Care across the World* (London: The Economist Intelligence Unit, 2015), p. 15.

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clear documentation and facilitate regular review of such preferences and values.

This chapter first outlines the historical and current developments of ADs in Hong Kong. It then examines a number of legal and practical challenges in promoting the wider use of ADs in Hong Kong, including deficiencies in mental capacity law and inadequate promotion. The remainder of the chapter is divided into five parts. Section 7.2 traces the development of ADs in Hong Kong, leading up to the latest government proposal which is detailed in Section 7.3. Section 7.4 provides commentary on the legal obstacles that must be overcome for AD legislation to be successfully introduced in Hong Kong. Section 7.5 explores the local practice of ADs, as well as the sociocultural values and influences that shape this practice.

7.2 The Legal Framework: Historical Developments

Hong Kong currently lacks both a statute and local case law clarifying the legal status of ADs, although a legislative framework (discussed later in the chapter) has recently been proposed by the government. The common law principles in relation to informed consent with respect to medical treatment are generally applicable in making valid ADs to refuse life-sustaining treatment legally binding,[4] although, given the lack of relevant case law, it is unclear how such principles will be applied in individual cases. This is not to say that efforts to specify legal rules and/or guidance for ADs have not been made over the years. What follows is an outline of AD-related discussions and policy developments in the past two decades, which can be broadly divided into three stages.

7.2.1 Stage 1, 2002–2009: HKLRC Consultation

In 2002, the Hospital Authority, a statutory body that manages all government hospitals and institutions in Hong Kong, issued the first edition of the *Hospital Authority Guidelines on Life-Sustaining Treatment in the Terminally Ill*. This was primarily written as an elaboration of the section on "care for the terminally ill" in the Professional Code and

[4] See, for example, the case of *Re T (Adult: Refusal of Medical Treatment)* [1992] All ER 649.

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Conduct of the Medical Council of Hong Kong,[5] but as part of its guidance, there was a brief discussion of ADs. In particular, it was stated that reference was to be made to the practice in the United Kingdom,[6] as detailed in section 10 of the British Medical Association Guideline on Withholding and Withdrawing Life-prolonging Medical Treatment (1999).[7] Apart from stating that a valid AD refusing life-sustaining treatment must be respected, section 10 provided various principles as to how validity of ADs were to be determined, as well as their legal effect.

In 2004, the Hong Kong Law Reform Commission (HKLRC) issued a public consultation paper entitled *Substitute Decision-Making and Advance Directives in Relation to Medical Treatment*,[8] the results of which were published in a report in 2006.[9] In this report, the HKLRC recommended that the government promote the concept of ADs under the existing common law framework instead of by legislation, as it was considered premature to legislate while the concept of ADs was still new to the community.[10] The government was recommended to review its position and reconsider the appropriateness of legislation once the community had become more familiar with the concept.[11] While noting that the lack of an agreed form of AD would likely lead to difficulties and uncertainty for both patients and doctors,[12] the HKLRC rejected the option of legislating a statutory form due to the prematurity of legislation at that stage.

In response to the HKLRC's report, the Hong Kong Food and Health Bureau (FHB) issued a consultation paper in 2009 entitled *Introduction of the Concept of Advance Directives in Hong Kong*,[13] with stakeholders consulted on (i) the procedures for making, altering and revoking ADs, (ii) the content of the information package on ADs for the public, and

[5] Hong Kong Hospital Authority, *Hospital Authority Guidelines on Life-Sustaining Treatment in the Terminally Ill* (April 2002), p. 3 (hereafter 'HA 2002 Guidelines').

[6] See HA 2002 Guidelines (note 5), p. 13.

[7] Included as Appendix 3 of the HA 2002 Guidelines (note 5).

[8] Hong Kong Law Reform Commission, *Substitute Decision-Making and Advance Directives in Relation to Medical Treatment: Consultation Paper* (July 2004).

[9] Hong Kong Law Reform Commission, *Substitute Decision-Making and Advance Directives in Relation to Medical Treatment: Report* (August 2006).

[10] Ibid., paras. 8.35 and 8.36.

[11] Ibid., para. 8.40.

[12] Ibid., para. 8.38.

[13] Food and Health Bureau, Government of the HKSAR, *Introduction of the Concept of Advance Directives in Hong Kong* (December 2009).

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(iii) the need to promulgate guidelines for handling ADs. The majority of views it received agreed that a non-legislative approach to AD promotion should be adopted in Hong Kong.

7.2.2 *Stage 2, 2010–2019: Hospital Authority Initiatives*

In 2010, the Hospital Authority issued *Guidance for Hospital Authority Clinicians on Advance Directives in Adults*[14] for the reference of clinicians working in Hospital Authority hospitals.[15] This contained a model AD form that was based on that of the HKLRC. The guidance was then updated in 2014. The changes introduced included (i) the provision of a shorter version of the AD form for terminally ill patients refusing CPR only and (ii) the extension of the scope of application of ADs such that, in addition to (a) terminally ill and (b) in a persistent vegetative state or a state of irreversible coma, a new category of 'other end-stage irreversible life-limiting condition[s]' was added.

In 2014, the Hospital Authority also issued *Guidelines on Do-Not-Attempt Cardiopulmonary Resuscitation* (DNACPR). Under these guidelines, the doctors in charge of non-hospitalised patients could sign a DNACPR form on their patients' behalf if there was a valid and applicable AD refusing cardiopulmonary resuscitation (CPR). The doctors signing this form would certify that the AD was valid, and that the patient was already in a condition in which the AD would apply.[16] This was designed to assist 'emergency rescue personnel' to respect the patient's advance decision,[17] but this approach was not accepted by the ambulance services in Hong Kong[18] due to concern over the 'duty to resuscitate' in the Fire Services Ordinance (FSO). This will be discussed further later in the chapter.

[14] Hong Kong Hospital Authority, *Guidance for HA Clinicians on Advance Directives in Adults* (July 2010).

[15] All public hospitals in Hong Kong fall under the jurisdiction of the Hospital Authority. Private hospitals are not regulated by the Hospital Authority, and therefore these guidance documents would not apply directly.

[16] Hong Kong Hospital Authority, *Guidelines on Do-Not-Attempt Cardiopulmonary Resuscitation* (October 2014).

[17] Food and Health Bureau, Government of the HKSAR, *End-of-Life Care: Legislative Proposals on Advance Directives and Dying in Place* (September 2019), para. 4.32. (hereafter 'End-of-Life Care Consultation Paper 2019').

[18] C.Y. Tse, "Advance Directives in Hong Kong" (November 2018) *Hong Kong Society of Palliative Medicine Newsletter* 6, 8.

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7.2.3 Stage 3, 2019–Present: Reforms

In 2019, the FHB issued a public consultation paper entitled *End-of-Life Care: Legislative Proposals on Advance Directives and Dying in Place*[19] to consult the public on several proposals, including (i) whether to codify the current common law position in respect of ADs and strengthen the safeguards attached to them and (ii) whether to remove the legislative impediments to AD implementation by emergency rescue personnel. In the consultation paper, the FHB acknowledged that the lack of AD legislation in Hong Kong had created practical difficulties in AD implementation and, in particular, posed two concerns.[20] First, as a result of the lack of legal guidance on ADs, healthcare professionals may be unwilling to initiate discussions with patients about ADs or implement their ADs owing to concerns that they may not have legal protection in doing so. Second, it is unclear whether an AD would supersede another statutory provision if the two were in conflict.[21] In July 2020, the FHB released a consultation report[22] mapping out the way forward. Significantly, according to the report, the government considered that it was now an appropriate time to consider AD legislation. Introducing a consistent legal framework for ADs could remove conflicts with other laws and policies and afford protection to treatment providers (including health care professionals and emergency rescue personnel) acting in good faith and with reasonable care.

7.3 The Legal Framework: Legislative Proposal

The legislative framework proposed by the government in its 2019 consultation paper is built on four fundamental principles:

(i) The patient's right to self-determination must prevail in the case of conflict between the wishes of the patient and those of his family members.

[19] See End-of-Life Care Consultation Paper 2019 (note 17).
[20] Ibid., para. 3.2.
[21] The consultation paper gives two examples, namely conflicting provisions in the Fire Services Ordinance and the Mental Health Ordinance. See further, End-of-Life Care Consultation Paper 2019 (note 17), para. 3.2(b).
[22] Food and Health Bureau, Government of the HKSAR, *End-of-Life Care: Legislative Proposals on Advance Directives and Dying in Place* (July 2020) (hereafter 'End-of-Life Care Consultation Report 2020').

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(ii) A valid and applicable AD overrides treatment decisions based on a treatment provider's interpretation of the patient's best interests.
(iii) Individuals have primary responsibility for ensuring that the original copy of their AD is presented to treatment providers as proof of a valid AD.
(iv) Sufficient safeguards need to be provided to preserve lives – if any grounds for doubt about the validity or applicability of an AD, treatment providers must continue to provide clinically indicated emergency life-sustaining treatments.

The key features of the legislative proposal,[23] which for the most part track the guidance issued by the Hospital Authority, are as follows:

7.3.1 Definition and Scope

An AD must be made by a mentally competent person who is aged 18 or above.[24] Life-sustaining treatments (including artificial nutrition and hydration) are considered a type of medical treatment that can be withheld or withdrawn from a patient in accordance with his AD. The pre-specified conditions of an AD include (i) terminal illness; (ii) a persistent vegetative state or state of irreversible coma; and (iii) other end-stage irreversible life-limiting conditions. An AD cannot include (i) a refusal of basic and/or palliative care that is essential to keep a person comfortable, such as nursing care and pain relief; (ii) a refusal of the offer of food and drink by mouth; or (iii) anything that is against the law, such as euthanasia.

In terms of the form of the AD, the government is proposing to use a non-statutory model rather than a statutory prescribed form.[25] However, ADs not made in that form would still be accepted if they contained statements that are clearly written and unambiguous. A person may choose to adopt other AD forms to set out other (additional) pre-specified conditions.

[23] As laid out in the End-of-Life Care Consultation Paper 2019 (note 17) and the End-of-Life Care Consultation Report 2020 (note 22).

[24] Currently, the only patients permitted to sign ADs within the Hospital Authority are those with advanced illnesses. The government proposes making it permissible at any time as long as the person concerned is mentally capable and not subject to any undue influence. This is consistent with the practice in many jurisdictions overseas, which encourage individuals to make an AD when they are well and healthy.

[25] This is in contrast to the DNACPR form, which the government proposes to be in a statutory-prescribed form.

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An AD will take effect when the person concerned no longer has the capacity to make healthcare decisions. An AD will not be applicable (i) if the patient has the capacity to make a decision at the time the treatment concerned is proposed; (ii) if the decision to be made concerns treatments or conditions not specified in the AD; or (iii) if there are reasonable grounds for believing that the patient did not anticipate the current circumstances and, if he had, he might have made a different decision.

7.3.2 Formalities

Turning to the formalities, the government proposes mandating that the making and modification of an AD must be in writing to be legally valid, which would also serve to reduce uncertainty and potential disputes concerning validity. In contrast, no unnecessary hurdles should be imposed upon those wishing to revoke an AD, and so it is proposed that both verbal and written revocations be considered valid.

As to witnessing, the government has proposed adopting the same arrangements as those currently practised by the Hospital Authority, of which there are two notable features. The first is that the making and modification of an AD requires two witnesses, one of whom must be a medical practitioner. As part of the witnessing requirement, a capacity test for the making of the AD is included, namely that the medical practitioner should be satisfied that the person has capability to make an AD, and has been informed of the nature and effect of the AD and the consequences of refusing the treatments specified in the AD.[26] The second is that revocation can be made verbally or in writing. No witness is required for written revocation, but at least one witness who has no interest in the estate of the person making the AD is required for verbal revocation, and a second witness is required for the report of verbal revocation made by a single family member or carer. A person can also revoke his own AD by tearing it up or otherwise destroying it or asking some other person to do so in his presence and by his direction.

There will not be any central registry for AD, but a flagging alert is currently set up within the Hospital Authority Clinical Management System (CMS) to facilitate communication, even though the information contained therein is used only as a reference. The government is currently considering the feasibility of leveraging the existing Electronic

[26] See End-of-Life Care Consultation Report 2020 (note 22), para. 4.7.

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Health Record Sharing System (eHRSS) to store and allow access to AD records by designated healthcare professionals and of accepting certified true copies of ADs to ensure that a patient's trusted family members or carers can produce the AD in timely fashion. Original AD documents would still be required as proof because storing records in the eHRSS is voluntary and there might be the possibility of a time lag between the latest status of the AD and its record in the eHRSS. Further, given that it may not be practicable to require emergency rescue personnel to first find out the eHRSS record of an AD while carrying out resuscitation at the same time, the government is also proposing that emergency rescue personnel may rely on the production of an original AD document attached to a signed DNACPR form, and it would be the responsibility of the individual/family to draw the attention of emergency rescue personnel to the existence of the AD.

7.3.3 Safeguards

The following safeguards are required to be implemented to ensure the validity of an AD. First, in normal circumstances, the original copy of the AD should be presented. If a valid AD is said to exist, but the original copy is not immediately available, the treatment provider should continue to provide emergency life-sustaining treatment while waiting for clarification. However, if the treatment provider (e.g. a clinical team) knows that a valid and applicable AD exists and the patient's family members agree, then the patient's advance refusal of such treatment should be respected.[27]

Second, the AD should be sufficiently clear and not under challenge, for example on the grounds of undue influence or lack of capacity. If an AD is challenged at the scene, its validity must be regarded as in doubt, and the treatment provider should continue to provide emergency life-sustaining treatment while waiting for clarification. Third, the AD must not have been withdrawn. Finally, the person must not have done something that clearly goes against the AD, thereby suggesting that he has changed his mind.

Safeguards should also be afforded to treatment providers. They should not incur any civil or criminal liability (i) for carrying out or continuing a treatment if, at the time, they reasonably believe that a valid

[27] This arrangement, while retaining flexibility, is likely to cause confusion and variation in implementation.

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and applicable AD does not exist or (ii) for the consequences of withholding or withdrawing a treatment from an individual if, at the time, they reasonably believe that a valid and applicable AD exists. The same applies to CPR emergency rescue with/without a DNACPR form.

7.3.4 Non-hospital Settings

In an emergency situation, when an unconscious patient with impending cardiac arrest is seen by emergency rescue personnel, it can be difficult for them to tell whether the patient is in a condition specified in his AD. Accordingly, the Hospital Authority developed guidelines and a DNACPR form (specifying that CPR not be performed on a person when cardiac arrest is anticipated) for non-hospitalised patients in 2014. Doctors who sign the DNACPR form certify that the AD is valid and applicable. The government is now proposing the following: (i) that after ADs are legislated, emergency rescue personnel should respect a valid and applicable AD presented to them; (ii) to amend the FSO accordingly to enable such personnel to accept DNACPR forms (with or without an AD);[28] and (iii) to use a statutory prescribed DNACPR form for the sake of simplicity, instead of a non-statutory prescribed form.

7.4 Discussion

While the move to legislate on ADs is a welcome one, there remain legal obstacles to overcome. The government has stated that it is not prepared to enact all-encompassing legislation on mental incapacity, which would impact upon such areas as ADs, healthcare decision-making by attorneys and guardianship.[29] It is also unlikely for the government to overhaul the outdated mental health legal regime in Hong Kong. Consequently, the piecemeal attempt of the government at codifying the law on ADs is inadequate for two reasons. The first relates to inconsistencies or ambiguities in existing law. In addition to proposing separate legislation on ADs, the HK government is also currently proposing new legislation on

[28] It is not proposing, however, that ambulance or fire personnel accept ADs per se, as it may not be within their expertise to determine the applicability of an AD (which requires confirmation that a pre-specified medical condition has arisen).

[29] See End-of-Life Care Consultation Report 2020 (note 22), para. 5.8.

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continuing powers of attorney, which will cover health, welfare and other personal matters. These new laws will add to existing decision-making tools, such as enduring powers of attorney. Such a piecemeal approach to legal regulation fails to take into account the fact that these are all components in the overall promotion of autonomy of the individual concerned, and need to be viewed in this larger context. Without an overhaul of mental health law in Hong Kong that considers all of these tools in a holistic manner, there may be ambiguities in the definitions of legal terminology and unclear overlapping boundaries or even inconsistencies between different legal tools.[30]

The second reason is that the lack of an overarching mental capacity test results in ambiguity as to what the test for mental capacity in relation to the making of ADs in Hong Kong should be. As discussed previously, the proposed formulation is that the medical practitioner must be satisfied that the person has the capability to make an AD, but what this capability entails is not further elaborated upon. There are several formulations of the capacity test that may apply, as detailed next.

Common law. The common law test for capacity that applies in Hong Kong is the test as developed by case law in the United Kingdom prior to the enactment of the Mental Capacity Act 2005. The steps of this test are generally taken to be the three steps as described in the foundational case of *Re C*[31], namely: (i) whether the patient is capable of understanding and retaining the treatment information; (ii) whether the patient believes it; and (iii) whether the patient is capable of weighing that information, balancing risks and needs. In the context of ADs, further principles as to the scope of anticipatory refusals can be found from the cases of *Re T* and *Bland*[32]. Taken together, these cases and principles demonstrate how one's capacity to make an AD should be assessed, looking at both (i) the individual's ability to refuse a particular medical treatment and (ii) whether or not the individual intended for the anticipatory refusal to apply to the future circumstances in question.

[30] These piecemeal attempts are also unlikely to satisfy the requirements of article 12 of United Nations Convention on the Rights of Persons with Disabilities, which require states parties to take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity (article 12.3).

[31] *Re C (Adult: Refusal of Medical Treatment)* [1994] 1 All ER 819.

[32] *Airedale NHS Trust* v. *Bland* [1993] AC 789.

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Mental Health Ordinance. The MHO contains a different capacity test for the consent to treatment of mentally incapacitated persons, which, for this part of the MHO, is defined as either (i) a 'patient', or a person suffering or appearing to be suffering from mental disorder or (ii) a 'mentally handicapped person', or a person with sub-average general intellectual functioning with deficiencies in adaptive behaviour.[33,34] The test, as contained in section 59ZB(2) of the MHO, is whether the person is capable of understanding the general nature and effect of the treatment or special treatment. Putting the flaws of this test to one side,[35] this is a *different* test for capacity to the consent of treatment that only applies to individuals defined as mentally incapacitated in the MHO, suggesting that, for such individuals, the section 59ZB(2) test should be used instead of the common law *Re C* test to assess the individual's ability to refuse that treatment. If this is to be the correct approach, how do we justify and reconcile the fact that two different tests are being used in the same context?

Hospital Authority guidelines. In addition to the two legal tests described previously, other relevant capacity tests have been laid out in various guidelines issued by the Hospital Authority. While these tests are not legally binding, they constitute the practice guidance that doctors in the public sector follow when implementing the law, and thus are worthy of consideration. Two formulations of the test for capacity are laid out here:

(i) 'A competent adult is defined as one with decision-making capacity, which consists of the elements of (i) the ability to understand the medical information presented; (ii) the ability to reason and consider this information in relation to his own personal values and goals; and (iii) the ability to communicate meaningfully.' (from the *Hospital Authority's Guidelines on In-Hospital Resuscitation Decisions*, issued in 1998).

(ii) 'To demonstrate capacity to refuse treatment, individuals should be able to:

[33] There is another definition that applies for the purposes of Part II of the MHO, which deals with the management of the property and affairs of mentally incapacitated persons (as defined in the MHO).

[34] While a very problematic definition of incapacity, a discussion of why this is the case is beyond the scope of this chapter. See further D. Cheung, "Mental Health Law in Hong Kong: The Civil Context" (2018) 48 *Hong Kong Law Journal* 461.

[35] See further Cheung, ibid.

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a. Understand in simple language what the medical treatment is, its purpose and nature and why it is being proposed;
b. Understand its principal benefits, risks and alternatives;
c. Understand in broad terms what will be the consequences of not receiving the proposed treatment;
d. Retain the information for long enough to make an effective decision;
e. Use the information and weigh it in the balance as part of the decision-making process;
f. Make a free choice (i.e. free from pressure).' (Adopted from the British Medical Association in the Hospital Authority's most recent *Guidelines on Life-sustaining Treatment in the Terminally Ill* (2020)).

Both of these formulations are notably different from the two legal tests described previously, with the 1998 and 2020 formulations additionally requiring a higher level of reflection and a voluntariness requirement, respectively, which are not generally required for decisional capacity as defined by the law. In addition to contributing to the chaos that is the definition of mental capacity in this context in Hong Kong, the fact that the Hospital Authority saw it necessary to lay out its own tests for capacity suggests that they felt that the current position was inadequate, or at least not clear enough.

Thus, while the legislative initiative for ADs is no doubt welcome, the importance of legislating a unified, statutory capacity test cannot be understated. The unwillingness of the government to deal with this issue may cause ambiguity and difficulty in the implementation of ADs by medical practitioners in the long run.

7.5 Local Practice, Value Commitments and Sociocultural Influences

Turning to the practice of ADs in Hong Kong, the number of ADs signed in recent years has been on the rise. The number of ADs signed by Hospital Authority patients between the years of 2012–18 is as follows:[36]

[36] Government of the HKSAR, "LCQ15: Advance Directives in relation to Medical Treatment", 22 May 2019. These figures do not include, however, (i) the number of valid ADs received, (ii) the number of ADs that were implemented, and (iii) the number of ADs produced that were not made in accordance with the Hospital Authority's model form.

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Year	Month	Number of ADs signed
2012	From August 21 to December 31	150
2013	From January 1 to December 31	325
2014	From January 1 to December 31	491
2015	From January 1 to December 31	706
2016	From January 1 to December 31	937
2017	From January 1 to December 31	1395
2018	From January 1 to December 31	1557
Total number of ADs signed		5561

There has been some suggestion that this tenfold increase in the number of signed ADs is not indicative of an increase in awareness or acceptance of ADs generally, but rather a result of the changing demographic of service users of the Hospital Authority, who take care of a disproportionately high percentage of persons with life-limiting illnesses.[37] This is consistent with empirical research that has demonstrated both a low level of awareness and a low uptake of ADs in Hong Kong.[38]

While the general lack of awareness about ADs may be readily explainable by inadequate promotion and education,[39] an interesting phenomenon that warrants further investigation is what appears to be a discrepancy between positive attitudes towards ADs and the actual making of ADs. For example, Chan et al.'s study (2019) found that, while only 368 of their participants (18.4%) had heard of ADs, the vast majority of those (80.2%, or 295 people) said they had made or intended

[37] Service utilisation of Hospital Authority hospitals is increasingly being taken up by these patients, particularly in their last year of life. This is further demonstrated by the fact that 90% of deaths occur in Hospital Authority hospitals. See further J. Yuen, "Advance Directives and End-of-Life Decision-Making in Hong Kong: A Medical Perspective", presentation given at the "Living Will, Living Well: Advance Directives across Asia" webinar on 2 October 2020.

[38] In relation to lack of awareness, see, for example, C.W.H. Chan et al., "Prevalence, Perception, and Predictors of Advance Directives among Hong Kong Chinese: A Population-Based Survey" (2019) 16 *International Journal of Environmental Research and Public Health* 365; F.H. Ting and E. Mok, "Advance Directives and Life-sustaining Treatment: Attitudes of Hong Kong Chinese Elders with Chronic Disease" (2011) 17 *Hong Kong Medical Journal* 105; and E.C. Hui et al., "Medical Information, Decision-Making and Use of Advance Directives by Chinese Cancer Patients in Hong Kong" (2016) 8 *Asian Bioethics Review* 109. In relation to low uptake, see Chan et al., Prevalence, Perception and Predictors (see earlier citation in this footnote).

[39] See also Chan et al., Prevalence, Perception and Predictors, ibid., where 72.7% of their 2002 participants expressed the view that ADs were inadequately promoted in the community.

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to make an AD.[40] Out of these 295 people, however, only 11 of them had actually made an AD (i.e. only 3.7%). While not all studies have been able to demonstrate such a high level of positivity in attitude towards ADs,[41] there remains a significant discrepancy between reported attitudes towards ADs and actual uptake of ADs.

Although the reason for this discrepancy requires further study, some preliminary comments may be offered. There is of course the question of whether such positive attitudes towards ADs as reported by patients are reflective of their true preferences, but, assuming that they are, there appears to be some difficulty in the translation of that preference into action. This could be due to several reasons, two of which are briefly explored here. The first is resistance from family members and/or caregivers. Studies have shown that family members often feel compelled to maintain the patient's life, and are unwilling to forgo life-sustaining treatment. This stems from a strong belief in Confucian filial piety, according to which 'everything must be done' to save the patient, even if this may not be in line with the patient's own preferences.[42] This resistance from close family members can be a crucial factor contributing to the failure of the person to make an AD, because the unit of decision-making in Chinese culture, and in particular medical decision-making, is generally seen as the family.[43] As Fan and Li

[40] See Chan et al, Prevalence, Perception and Predictors (note 38). This level of positivity towards ADs is consistent with L.W. Chu et al., "Advance Directive and End-of-Life Care Preferences among Chinese Nursing Home Residents in Hong Kong" (2011) 12 *Journal of the American Medical Directors Association* 143, where it was found that 88% of a sample of 1600 older Chinese adults residing in nursing homes in Hong Kong expressed a preference for having an AD concerning their medical treatment in the future.

[41] See, for example, Ting and Mok, Advance Directives and Life-sustaining Treatment (note 38), which found that 49% of their 219 participants would sign an AD after they had been informed about the concept and Hui et al., Medical Information (note 38), which found that 33% of their 288 participants would sign an AD after they were informed about the concept.

[42] R.Y.N. Chung et al., "Examining the Gaps and Issues of End-of-Life Care among Older Population through the Lens of Socioecological Model – A Multi-Method Qualitative Study of Hong Kong" (2020) 17 *International Journal of Environmental Research and Public Health* 5072, 5077. See also T. Kwok, S. Twinn and E. Yan, "The Attitudes of Chinese Family Caregivers of Older People with Dementia towards Life Sustaining Treatments" (2007) 58 *Journal of Advanced Nursing* 256, where it is argued that filial piety contributes to the difficulties in making decisions related to life-sustaining treatment, particularly if the decision to forgo such treatment is seen as incompatible with one's filial duties.

[43] See, for example, Y. Cong, "Doctor–Family–Patient Relationship: The Chinese Paradigm of Informed Consent" (2004) 29 *Journal of Medicine and Philosophy* 149 and H.M. Chan, "Informed Consent Hong Kong Style: An Instance of Moderate Familism" (2004) 29

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have argued, families are autonomous entities that are themselves the source of legitimating authority.[44] Because the family is the autonomous unit, medical decisions need to be made by the family as a whole, and not by the person herself.[45] This means that where there is strong objection from the family, the person will not likely proceed with an AD even if that is her preference. There is thus a need to encourage not only education and promotion targeted towards individuals who might wish to make ADs, but also their family members, such that open discussions between family members about one's end-of-life preferences can be encouraged. This, in turn, will make it more likely that family support for a decision to make an AD can be obtained, making the individual more likely to proceed with the AD.

The second reason is the lack of effective communication and coordination on the part of healthcare and other professionals regarding the making of ADs. While a person may be inclined to make an AD, a number of institutional factors may have a large effect on whether this is put into action. Cheung et al., for example, present a compelling case of "unprepared healthcare professionals and healthcare system" as one of the barriers to advance care planning more generally.[46] One of the various examples of this was a patient's experience with an oncologist, who kept persuading him to receive treatment despite an expressed reluctance to receive futile life-sustaining treatment. Chan et al.'s study also sheds some light on the importance of the role of healthcare professionals. When asked, the majority of their participants expressed that they would agree to making ADs (to varying degrees) in the following scenarios: (i) if healthcare professionals can provide a clear explanation and recommendation on ADs, (ii) if there is effective communication and coordination among healthcare professionals at different institutes to execute their decisions, and (iii) if they could have a thorough discussion

Journal of Medicine and Philosophy 195. More recently, see J.T.K. Cheung et al., "Barriers to Advance Care Planning: a Qualitative Study of Seriously Ill Chinese Patients and Their Families" (2020) 19 *BMC Palliative Care* 80. There is, however, evidence suggesting that this is not such a straightforward picture. See, for example, Hui et al., Medical Information (note 38), where the number of patients who preferred to make decisions alone exceeded those who invited family members to be decision-making partners.

[44] R. Fan and B. Li, "Truth-Telling in Medicine: The Confucian View" (2004) 29 *Journal of Medicine and Philosophy* 179, 188.

[45] C.Y. Tse and J. Tao, "Strategic Ambiguities in the Process of Consent: Role of the Family in Decisions to Forgo Life-Sustaining Treatment for Incompetent Elderly Patients" (2004) 29 *Journal of Medicine and Philosophy* 207, 212.

[46] Cheung et al., Barriers to Advance Care Planning (note 43).

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and follow-up with health professionals about ADs. This demonstrates the importance of healthcare professionals in facilitating the process of making an AD, and is consistent with the significant trust that is placed in medical practitioners by patients in Chinese culture.[47]

7.6 Conclusion

In light of Hong Kong's rapidly ageing population, and the resulting, inevitable increase in the demand for high-quality end-of-life palliative care services, there is a crucial need to identify and examine policy and infrastructure gaps in end-of-life care in Hong Kong. One key area that needs to be addressed is the regulation and implementation of the AD, an important tool that encourages discussions about end-of-life care and allows for an individual's wishes to be clearly documented and carried out. This chapter has first examined the legal and institutional framework of ADs in Hong Kong, in particular the government's latest proposal in legislating ADs which is a positive step in the right direction despite some remaining legal obstacles to overcome. The chapter then highlighted the socio-familial influences that may hinder the government's attempt to expand the take up of ADs. In a society where the family is often seen as the unit for healthcare decision-making, and Confucian doctrines like filial piety are a driving force behind the behaviour of family members at the end of life, the AD is perhaps even more important as a way to initiate end-of-life care discussions with one's family, so as to make clear one's wishes to the family and engender support from the family for one's end-of-life care preferences.

Hong Kong has come a long way since the Hospital Authority first included a discussion of ADs in its 2002 *Guidelines for Life-sustaining Treatment in the Terminally Ill*. While the government's proposal for AD legislation is a significant step towards facilitating large-scale uptake of ADs across Hong Kong, there remain both legal and practical obstacles that need to be confronted. In relation to the former, the validity and application of an AD rely heavily on a workable and consistent definition of mental capacity, which is something that Hong Kong does not currently have and will not likely have in the near future. In relation to the latter, the inadequacy of promotion and education about ADs needs to be tackled on a systematic basis, to address the clear gaps in awareness

[47] See, for example, K.W. Bowman and P.A. Singer, "Chinese Seniors' Perspectives on End-of-Life Decisions" (2001) 53 *Social Science & Medicine* 455.

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across Hong Kong society. This promotion and education needs to target not only individuals who may make ADs, but also family members and caregivers, whose insufficient understanding of ADs may currently prevent them from supporting the making of ADs by their family members.[48] Improvement of support from healthcare professionals at the institutional level is another key area that needs to be urgently addressed. Finally, because empirical research in this area in Hong Kong has mostly focused on the making of ADs, there is little to no information about the interpretation and implementation of ADs by healthcare professionals. This is a gap that needs to be addressed – a better grasp of how ADs are implemented after they are signed is crucial to our understanding of ADs in the Hong Kong context.

[48] See also Kwok, Twinn and Yan, Attitudes of Chinese Family Caregivers (note 42), for a discussion regarding how the lack of knowledge about life-sustaining treatment may compound the cultural bias of family members and caregivers in refusing to forgo life-sustaining treatment even in critical illness.

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