

## Review Article

# Advance care planning in Asian culture

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Received 28 November 2019; Editorial Decision 2 July 2020; Accepted 20 July 2020

## Abstract

Ageing has been recognized as one of the most critically important health-care issues worldwide. It is relevant to Asia, where the increasing number of older populations has drawn attention to the paramount need for health-care investment, particularly in end-of-life care. The advocacy of advance care planning is a mean to honor patient autonomy. Since most East Asian countries are influenced by Confucianism and the concept of 'filial piety,' patient autonomy is consequently subordinate to family values and physician authority. The dominance from family members and physicians during a patient's end-of-life decision-making is recognized as a cultural feature in Asia. Physicians often disclose the patient's poor prognosis and corresponding treatment options to the male, family member rather to the patient him/herself. In order to address this ethical and practical dilemma, the concept of 'relational autonomy' and the collectivism paradigm might be ideally used to assist Asian people, especially older adults, to share their preferences on future care and decision-making on certain clinical situations with their families and important others. In this review article, we invited experts in end-of-life care from Hong Kong, Indonesia, Japan, South Korea, Singapore and Taiwan to briefly report the current status of advance care planning in each country from policy, legal and clinical perspectives. According to the Asian experiences, we have seen different models of advance care planning implementation. The Asian Delphi Taskforce for advance care planning is currently undertaken by six Asian countries and a more detailed, culturally sensitive whitepaper will be published in the near future.

**Key words:** palliative care, advance care planning, autonomy

## Introduction

Ageing has been recognized as one of the most critically important health-care issues worldwide. It is relevant to Asia, where the increasing number of older populations has drawn attention to the

paramount need for health-care investment, particularly in end-of-life (EOL) care. Despite the differences in the context of a 'good death,' patient autonomy has been regarded as one of the top priorities across cultures and religions. This is indicated as essential

for quality of dying. From a policy perspective, the advocacy of advance care planning (ACP) is a mean to honor patient autonomy (1). Recently, international Delphi consensus studies were conducted in the US and Europe to develop a definition of ACP and recommendations for its application (2). ACP was defined as the ability to enable individuals to define goals and preferences for future medical treatment and care, to discuss these goals and preferences with family and health-care providers, and to record and review these preferences if appropriate. Sudore et al. in the US has conducted a series of extensive studies on ACP. She has defined (3) and measured the outcome of ACP (4). She has defined (3) and measured the outcome of ACP, and studied strategies for engaging different populations such as the older adults, people with chronic illnesses, the homeless and prisoners (5–14). She has also investigated the obstacles of promoting ACP (15), designed a web-based tool—‘PREPARE’ to facilitate the implementation of ACP, conducted randomized controlled trial to demonstrate the efficacy of ACP for general public and cancer patients (16–22) and investigated the utilization of ACP on electronic record for emergency physicians and safety for patients (23–24).

However, the aforementioned studies were mainly conducted in the Western context. Since the majorities of Asians are Buddhists/Taoists, Muslims and Hindus rather than Christians/Catholics, the Asian view on life and death is quite different from that of the West especially under the influence of religions; for example, the Buddhism/Taoism are taking a rather naturalistic view toward death and family and physicians are the key person in EOL decision-making under Confucianism and Hinduism doctrines. Specifically, there are disparity in attitude toward advance directive (AD) by religions (25). Roman Catholics were more likely to object to withdrawal of life support, compared with Protestants, Jews and those with no religious affiliations. For Muslims, the responsibility of passing a final verdict regarding life-prolonging therapy rests with the physician; human life is dignified and should be sustained as long as it is sustainable, which should be decided based on the patient’s situation. Asian Indian Hindus were more likely to refuse life-sustaining interventions and more likely to engage in autonomous decision-making. For Buddhists, 75% did not want life-prolonging therapy, when considered futile. In summary, except Roman Catholics, Christians prefer a more aggressive way facing AD and EOL issues while the other religions taking a more naturalistic view. In addition, it is generally agreed that EOL communication in Asian countries such as Japan, Korea and Taiwan are usually rare and only a few patients’ EOL care preferences can be honored (26–28). Since most East Asian countries are influenced by the Confucianism and the concept of ‘filial piety (a virtue and primary duty to respect and care of parents and senior relatives),’ patient autonomy is consequently subordinate to family values (29–32) and physician authority (33). The dominance from family members and physicians during a patient’s EOL decision-making is recognized as a cultural feature in Asia. Physicians often disclose the patient’s poor prognosis and corresponding treatment options to the male, family member, rather to the patient him/herself. It is assumed that the patient might be unable to accept the truth of poor disease prognosis psychologically. In order to address this ethical and practical dilemma, the concept of ‘relational autonomy’ and the collectivism paradigm might be ideally used to assist Asian people, especially older adults, to share their preferences on future care and decision-making on certain clinical situations with their families and important others (28). The definition and recommendations of ACP need to be re-evaluated and redefined to be culturally specific for the Asian societies.

In this review article, we invited experts in EOL care from Hong Kong, Indonesia, Japan, South Korea, Singapore and Taiwan to briefly report the current status of ACP in each country from policy, legal and clinical perspectives.

### ACP in Hong Kong

The concept of planning ahead for EOL care has drawn increasing attention over the past two decades in Hong Kong due to an epidemiological transition of morbidity and mortality from acute health problems to chronic debilitating diseases. The average life expectancy at birth of people in Hong Kong was among the highest in the world, but its quality of death index lagged behind that of several other Asia-Pacific economies, including Taiwan, Singapore, Japan and South Korea (34). This raises the concern over how to improve the quality of EOL care rather than merely focusing on life preservation.

Hong Kong, which has been a British colony for over a century but with the majority of the population being Chinese, is a place mixed with the cultures of East and West. While the western belief of self-determination and person-centered care is being highly upheld, the traditional Chinese belief of collectivism in major decision-making and medical paternalism is still preserved (35). These conflicting beliefs add challenges to the implementation of ACP. Following two rounds of public consultation on legislation on ADs launched by the local government in 2004 and 2009, there has been considerable awareness that planning for EOL care involved many aspects beyond the legal concerns and legislation alone and is unlikely to prevent tensions and conflicts between families and health-care teams over patient care (36).

The hospital authority that governs the local public hospitals has recently issued a set of ACP guidelines to provide practical guidance for clinicians on conducting ACP discussions (37). In this document, ACP is defined as a proactive communication process regarding EOL care. While the primary target group is patients with advanced progressive disease, the guidelines extend the scope to include family members of the mentally incompetent and minor patients. However, before this, a number of initiatives had been developed to promote ACP across care settings to empower patients to share their EOL care preferences and to engage family members in the ACP process. One of the first published ACP studies in Hong Kong found that frail older adults living in residential care homes were open to discussing their EOL care and the ACP discussion enabled them to reflect upon their underpinning values, increased their understanding about EOL care and thereby the stability over EOL care preferences, as well as alleviated their existential distress (38). With increased confidence on its public acceptance, attempts were made to conduct ACP through home visits so as to reach the home-living patients and engage their family members in this important dialog (39). These studies provided further evidence on the importance of ACP in increasing family members’ understanding about patients’ care wishes and increasing preparedness of health-care team for the difficult conversation. In addition, there have been growing interest in developing strategies and tools for promoting the concept in a more systematic manner and building capacity to enhance the sustainability of the practice in various care settings (40–41). Hence, the Jockey Club Charities Trust provided a huge amount of funding support for a community-wide campaign on EOL care. Along with this movement, the Food and Health Bureau of Hong Kong also launched a public consultation again in 2019

on formulating a statutory framework for ADs and removing legal barriers to dying in place, one of the aspects covered by ACP (42). All these recent changes revealed that the implementation of ACP involved a wide range of issues at individual, familial, organizational and socio-cultural levels.

### ACP in Indonesia

Indonesia is currently facing an epidemiological transition towards an increasingly aging society and advanced cancer population. As the fourth most populous country in the world, Indonesia is a home for over 265 million inhabitants with the average life expectancy at birth of 71.7 years, dramatically rising from 45 years in 1970 and 63.6 years in 1990 (43–44). This condition had led to the shift towards an aging population, with the share of the elderly population of 22 million in 2017 to an estimated 61 million in 2050, attributing to 19% of the total population (45). More than one-fourth of this age group population had reported at least one form of disability (46). At the same time, cancer prevalence in this country is rising to 29% over the last 5 years, with more than 70% of cases being admitted in the advanced stage (47). These transitions underlined the urgent needs of quality palliative and EOL care. To ensure that palliative and EOL patients receive care consistent with their values, ACP is required to help health-care professionals understand the patient's wishes and preferences for future care and treatment.

Advance care planning in Indonesia remains in its infancy. In terms of regulation, the do-not-resuscitate (DNR) form is the only recognized and widely used format of written documentation of ACP in Indonesia. It has taken 15 years since palliative care initiation in Indonesia to have palliative care regulation integrated into its national policy in 2007 (48–49). In one of its decree, an AD is recognized as a written form documenting patient's surrogate decision maker and wishes and preferences on future medical care and treatment, particularly in relation to life-sustaining treatment (LST) withdrawal when it is considered not beneficial. It is recommended that a competent patient is provided sufficient information prior to complete and sign an AD. A palliative care team is suggested to play the role of initiating the discussion with the patient. In a case an incompetent patient has no AD, the family may provide a consensus based on patient's best interest as guidance for health-care professionals. Health-care professionals are allowed to make decisions of DNR if patient considered terminal and resuscitation could not cure the patient nor improve his or her quality of life based on the most recent scientific evidence (50).

In terms of practice, various conditions may serve as potential challenges for ACP in Indonesia. The lack of integration of palliative care service in most part of the country, coupled with the sociocultural influence on health-care decision making had rendered care in the EOL very complex in Indonesia (51). Illness is a shared family affair, where communicating EOL to the patient is considered as a taboo (52). Family plays a central role in health-care decision making in Indonesia, particularly for the elderly population (53). Although mutual understanding had become a general preference of both patients and physicians, a one-way communication style is still a common doctor-patient type of communication. Health-care professionals' time constraint, lack of knowledge on ACP, lack of communication skills, discomfort in breaching death-and-dying-related communication, together with lack of guidelines, legal and institutional support were among the possible barriers (54).

Meanwhile, a lack of awareness of the concept of ACP may contribute to one of the major obstacles for ACP implementation

in Indonesia. To provide basic palliative care knowledge, the government, through the National Cancer Control Committee, is conducting training of trainers to internists and pediatricians of provincial hospitals and general practitioners and nurses in primary care clinics in 34 provinces of Indonesia (55). Since 2015 an education session of ACP has been integrated into palliative care training programs to several health-care professionals in referral and regional hospitals in Jakarta and West Java, as a collaboration of local non-governmental organizations (Indonesian Cancer Foundation and Rachel House Foundation) with Singapore International Foundation. However, currently, no formal training or education available for ACP, nor public education to promote ACP, either on a smaller or on a larger national scale. Not surprisingly, the complex concept of ACP as an ongoing process of value identification is mostly foreign for Indonesian health-care professionals, even though it might have been practiced at a certain level without formal recognition as ACP. Unfortunately, no studies are available to provide information on the perspective and practices of ACP in Indonesia.

Currently, there is no consensus definition of ACP available in Indonesia, yet it is translated into living will or last will in the national guidelines for cancer palliative program. In the new draft of the Ministry of Health Regulation on Palliative Care, the term ACP will be introduced as one of the palliative care services implementations, together with other services such as symptoms management, psychosocio-spiritual support, bereavement support and final care of life. However, more detailed guidelines or recommendations on how ACP can be implemented in Indonesia have not existed.

It is evident that much remains to be done in Indonesia in relation to ACP. More research is urgently required to provide evidence on influencing factors for ACP practice in Indonesia, whether and how ACP can be helpful in the management of palliative cases in Indonesia, and how ACP can be best integrated into medical care delivery in Indonesia. The future directions for the implementation of ACP in this country include the integration of ACP in the formal education of medical doctors and nurses, a national public campaign to promote ACP, institutional support for ACP and the development of a guideline for ACP implementation in the local context.

### ACP in Japan

Japan has experienced a super-aging society since 2007. The number of patients who died of cancer has continued to increase over the past decades (56). More than 995 000 patients were diagnosed with cancer in 2016, and more than 373 000 patients died of cancer in 2017. To help cancer patients receive quality EOL care consistent with their goals and preferences, it is essential to promote ACP through timely and compassionate EOL discussions with patients and their families. Traditionally, nondisclosure of EOL issues to cancer patients has been a typical practice in Japan. Patients often value 'heart-to-heart communication' (ishin-denshin), which involves understanding others without words, entrust EOL medical decision-making to others (omakase) such as families and physicians, and expect family-centered decision making (57–59). Families used to be the ones who consented to DNR orders in almost all cases (60–61). However, findings of recent domestic surveys suggest positive changes in cancer patients' and physicians' attitudes toward ACP. For example, one survey involving Japanese patients who had been informed about the cessation of anticancer treatment revealed that the majority preferred their physicians to respect their sense of values and explain the status of their illness as well as how their life expectancy would influence their future plans (62). Most Japanese

oncologists reported that they would discuss EOL issues such as the option of forgoing anticancer treatment, prognosis, DNR status, hospice referral and place of death when the need arise, although the timing of initiating such discussions might vary widely (63–64). Another nationwide survey demonstrated that nearly a half of terminally ill cancer patients in palliative care units had ADs for various LST, and over two-thirds of patients with decisional capacity were involved in the DNR decision (65).

In 2017, the Ministry of Health, Labour and Welfare (MHLW) conducted a nationwide survey to clarify Japanese people's perceptions regarding EOL care (66). Among the general public ( $n = 973$ ), care staff ( $n = 537$ ), nurses ( $n = 1620$ ) and doctors ( $n = 1088$ ) who responded, only 3.3%, 7.6%, 20% and 22%, respectively, reported that they knew ACP well; however, up to 65–80% of them agreed with its concept when its meaning was explained. It also showed that 66–78% of the respondents agreed with the concept of AD, although only less than 10% reported that they had actually completed ADs, and less than a fourth agreed that ADs should be enacted.

In 2018, the MHLW revised the guidelines on decision-making process on EOL care (67). The concept of ACP was then officially introduced in the guidelines as a process in which the individual repeatedly discusses EOL care with his or her families and/or other closely related people and health-care professional team in advance. To promote ACP based on the guidelines, a government-commissioned educational project called 'Education For Implementing End-of-Life Discussion (E-FIELD)' was launched. The E-FIELD provides interdisciplinary HCPs with one-day workshops on ACP that includes lectures, role-plays and group works throughout the country. Furthermore, the Ministry publicized a nickname of ACP ('jinsei kaigi' or life meeting) and logo mark to raise public awareness. After the introduction of ACP by the government, several professional societies such as Japan Medical Association, Japan Geriatric Society and Japan Pancreas Society published position statements, clinical guidelines and/or brochures for the public regarding ACP. Various communication skills training programs are also available. In addition to the 'SHARE' program that was established and implemented in Japan (68), those developed in the US (e.g. 'Serious Illness Care Program' and 'VitalTalk') have recently been introduced to Japanese health-care professionals (69–70). Yet, a standardized model of ACP for cancer patients and their families has yet to be established, and there is no reimbursement system solely for ACP.

A number of recent research investigations have explored cancer patients' perceptions of and preferences for ACP discussions (62, 71–74). Nationwide surveys among bereaved families of cancer patients also provided useful findings about the optimal timing of EOL discussions, and recommended care strategy to help families maintain hope and prepare for death (75–76). A retrospective study indicated that the provision of prognosis information to advanced cancer patients was significantly associated with longer duration between the last day of chemotherapy or the day of confirmed DNR order and death (77). Currently, several prospective studies are under way to examine the effects of various ACP interventions for patients with serious illnesses including cancer.

It is evident that the development of ACP in Japan is still in its infancy. Future policies and education programs should continue to address how to respect patient preferences through shared decision-making while ensuring that family harmony is maintained. More clinical experiences, discussions and empirical research regarding ACP at all levels are clearly needed to develop a culturally appropriate ACP in Japan.

## ACP in South Korea

South Korea is the country with the population of 50 million and is ranked the 27th most populous country in the world. The life expectancy of Korean is 83-years old and South Korea is a rapidly aging society with 14.3% (768 million) of the population who are 65 years of age or older (78). The number of deaths in the year of 2018 was near 300 000, and more than 45% of them were over 80-years old. The most common cause of death was cancer. Among cancer deaths, the rate of hospice service usage has increased from 7% in 2008 to 22% in 2017 since the insurance reimbursement for hospice was launched in 2015 (79).

The change in the place of death has also changed a lot recently. In the past, even in the early 1990s in South Korea, most people hoped to die at their homes (80–82), because dying away from home was considered as a tragedy and bad luck, especially in rural areas, but according to a survey, many people in Korea still wish to pass away at their homes, surrounded by their loved ones, but the rate of dying at home was 14.4% and especially in cancer patients, it was 6.2% in 2017 (79). Also, traditionally, children of elderly patients with terminal illnesses made EOL decisions for their parents, keeping the diagnosis of a life-limiting-illness secret from the patients (83). In addition, in many cases, the resuscitation order was created almost immediately before the death (84). Back then, the concepts of ACP, good death and patient autonomy were not widespread. However, there were two significant events in our society that resulted in changes. One is the Boramae hospital case, which a drunken man fell and had an emergency operation for subdural hematoma. The patient's wife strongly asked her husband to be discharged from the hospital against the doctor's advice. Eventually the patient died. After his death, the patient's brother filed a lawsuit against the doctor for being an accessory to murder. After this case, doctors were repulsed against hopeless discharge or discharge against medical advice. The second case is that of Grandma Kim, she had lung cancer and became vegetative state after bleeding excessively from a lung biopsy in 2008. Her children asked to stop LST. Her family sued the hospital for refusing the request and won the trial. She demised in 2010.

After these series of events, Koreans felt the need for legislation related to LST and have discussed this issue since 2010. Finally, 'the Act on decisions on Life-Sustaining Treatment (LST) for patients in hospice and palliative care or at the end of life' (Act No. 14013) was announced in March of 2016 and this Act was enforced in February in 2018 (85). The purpose of this new Act is to prescribe matters necessary for hospice and palliative care and LST for patients at the EOL, determination to terminate such LST, to protect the dignity and value of human beings by assuring the best interest of the patients and by respecting their self-determination. Later, the revision was made in March 2018, expanding the types of life-prolonging interventions, the definition of life-limiting illness, and reducing the influence of families that must be agreed when patients are unconscious.

The AD and physician orders for LST (POLST) are formulated as legal forms related to this act, people can write fill up these documents in registration offices and hospitals that also have ethics committees. Each document needs to be uploaded in the National Agency for Management of LST registry. After registration, the institution can get reimbursement for the documents or performance related LST from the government. The legal Act was enforced only for a year, but it brought positive influence toward ACP, protecting patients' dignity and respecting self-determination. However, enhancements to the Act and its promulgation are needed. Many people are still unfamiliar with terms like AD, POLST or ACP (86). Some doctors may feel forced to register without having enough information or

time to think through in advance. Also, it is not applied to all hospitals and people yet. Therefore, advertisement and education in detail should be tailored for patients, health-care providers and for the general public because their attitudes and level of awareness are quite different (87–90).

There was a report that increased participation of patients in EOL discussions after conducting structural consultations related to AD even before the Act was implemented and the knowledge for advance care plan had a positive impact on quality of life (91). But, there are few studies that have been published after the Act enforcement. According to a recent university hospital press release, patients have made more decisions (29%) on their own than in the past (1% (92–93)).

Although ACP legally has already begun in South Korea, there is still a great need for conceptual propagation of ACP with continual improvement in education and policy (94), and a culture that respects the best interests and preferences of patients through discussions with individuals, families and closely related people (94). Also, more research is needed on our clinical experience and the influence of culture.

### ACP in Singapore

Advance care planning forms the foundation of precedent autonomy and is a key tenet of good EOL care. As a complex intervention, it has been shown to promote person-centered care through respecting EOL care preferences, decreasing the use of aggressive and burdensome interventions and reducing post bereavement distress amongst family members (95). The earliest statute relevant to ACP in Singapore would be the Advance Medical Directive or AMD. The AMD was enacted in 1996 with the intention of allowing an individual to sign in advance a legal document to inform one's doctor that one does not want the use of any extraordinary LST to prolong life, in the event that one is terminally ill and mentally incapacitated from making decisions (96). However, the AMD applies only to a very narrow scenario and as a document, does not adequately address the broad spectrum of advance decisions (AD) that can be explored as well as the values and personhood underlying such decisions for any individual. There has also been poor uptake of the AMD by the general public and up till 2015, less than 25 000 people had signed an AMD (97).

Like many Asian cultures, death remains a taboo subject and non-disclosure of diagnosis and prognosis of a life-limiting illness is a common practice in Singapore, particularly towards the elderly. There are likely to be inter-generational differences in the perceptions of receptivity towards talking about death and dying. In a local study done in year 2000 on the preferences and choices of a group of elderly Chinese subjects attending a day care center in Singapore, 43 subjects median age 71-years old were interviewed. Only 16.3% have heard of the AMD. Contrary to the popular approach of collusion, 83.7% and 76.7% of the subjects preferred to be told of the diagnosis and prognosis of a terminal illness, respectively (98).

A decade later, in a study on the knowledge, attitudes and practices of the advance medical directive in a residential estate in Singapore in 2010, 414 residents were surveyed and only 37.9% of the participants knew about the AMD prior to this study (99). Respondents who did not wish 'to be kept alive indefinitely on a life-support machine' and accepted the 'imminence of death' were more willing to sign an AMD. The article concluded that there is a need to increase awareness of the AMD. A retrospective medical chart review of all 683 adult patients who died without intensive care unit (ICU)

admission in a Singaporean hospital in 2007 showed that there were DNR orders for 66.2% of patients. Orders to limit life-sustaining therapies, including ICU admission, intubation and vasopressors were infrequent. Discussions with alert and conversant patients on DNR orders occurred ~5% of the time, while discussions with family members occurred 80% of the time. The article concluded that there was a lack of commitment by doctors on orders for DNR/CPR and to limit life-sustaining therapies, infrequent discussions with patients on EOL decisions, and excessive burdensome interventions for the dying (100). A survey on death attitudes of doctors and nurses carried out by Lien Foundation in 2014 revealed that 53% of all doctors are comfortable discussing death and dying with their patients but only 31% of nurses are comfortable discussing death (101).

The Mental Capacity Act was enacted in 2008 allowing an individual to nominate another person or donee to act on his or her behalf in event he or she loses mental capacity, for financial and health-care matters. However, this precludes the donee from making decisions regarding potentially LST on behalf of the individual (102). Whilst the limited research showed gaps and barriers, clearly there is a need for a systematic approach to training health-care professionals in carrying out this difficult conversation as well as in implementing a system to capture and honor patients' preferences.

In 2009, the ACP faculty Respecting Choices (RC) of Wisconsin, US was invited by the National Healthcare Group, Singapore to train health-care professionals from various health-care systems in their paradigm of ACP. RC espoused a staged approach to ACP, the constructs of the conversation being dependent on the health status of the individual. Though suitable for healthy individuals as well, RC recommended that Singapore start ACP conversations with people with advanced illness, when ACP is most relevant and more likely to be carried out by health-care professionals. Small pilot projects were started in various groups such as people with advanced heart failure and respiratory disease but these early efforts were stumbled by multiple barriers such as lack of clinician time as well as the perspective that ACP conversations are secondary to clinical treatment.

In 2010, the Ministry of Health of Singapore commissioned the Lien Centre for Palliative Care to formulate a National Strategy for Palliative Care that delineated 10 key goals for palliative care in Singapore, one of which is that all patients at the EOL have access to ACP (103).

In 2011, the Ministry of Health injected seed funding and appointed the Agency for Integrated Care (AIC) as the programme manager for the national ACP programme, which subsequently was aptly renamed as Living Matters (104). A national ACP Steering Committee was formed to oversee ACP efforts, aided by sub committees, e.g. training and curriculum, forms and documentation and information technology sub committees.

Respecting Choices taught that the elements of successful ACP implementation were 4-fold, namely (1) engagement of the community, (2) training in ACP facilitation, (3) building a system to capture and honor preferences and (4) implementing quality improvement and audit checks. At the beginning of the programme, it was realized that the lack of buy in from clinicians is a major impediment and grassroots efforts were implemented at engaging senior hospital leaders as well as the broad swathe of health-care professionals in major hospitals. Outreach efforts took the form of hospital conferences, talks at multidisciplinary forums and patient support groups. Collaborations with media, arts-related groups and national bodies promoted community engagement. In 2018, the Singapore Hospice Council launched the 'Live Well. Leave Well.' campaign to encourage

Singaporeans to start early EOL conversations with their loved ones (105).

Systematic training in ACP facilitation took place in various re-structured hospitals to build capabilities in ACP facilitation and advocacy. The health-care professionals who attend training come from diverse backgrounds and vocations including staff from nursing homes and community home care services as well as doctors, nurses and allied health providers. Different health providers had different systems of capturing the ACP forms, but this was aligned in year 2017 with the advent of the national ACP system, implemented by AIC.

Over the last decade, there was a steady rise in number of ACP documents completed and tracked on a national level, from 3 in year 2011 to a cumulative number of ~14 000 in 2018. This does not include the conversations that take place between health-care professionals, patients and their loved ones and documented in the electronic medical records apart from completed ACP forms. ACP conversations probably have been taking place in clinical practice though the Living Matters framework was an added impetus to the ACP movement to match the sophistication of medical advancement with conversations about what people really want and value when seriously ill. Though similar in some shared practices, different hospitals drove ACP according to different models of implementation in a real-life experiment. In some hospitals, the programme was clinician led while in others it was driven by social workers. At the beginning of the Living Matters programme, various re-structured hospitals were loosely guided by key performance indicators. Quality improvement and audit checks were not well aligned across institutions. In the international literature up till 2018, outcomes of successful ACP were not clearly defined (106).

Advance care planning in Singapore started out as a hospital centric practice and amongst patients with life-limiting illness (107). Whilst this has the advantage of diffusing the practice of ACP within well-resourced stakeholders in the health-care continuum, it has reinforced the misconception that ACP is only for the very sick within large hospital settings. Anecdotally, within a hospital system in Singapore, only ~40% of patients were able to participate in the conversation and the large majority of the conversations were carried out with the loved ones of the patients. In the absence of decision-making capacity of the patient at the point of ACP facilitation, the question posed to the patient's loved ones is what they think the patient would have wanted. It has been shown in international and local studies that surrogates' understanding of patient's wishes, that is substituted judgment, is often inaccurate. (108–109) This also goes against the grain of the true tenet of ACP as an iterative conversation that should start when people are relatively well and evolves over time as the individual's health status and values change. This is especially so as anyone can suddenly become seriously ill and mentally incapacitated.

A survey amongst 406 community-dwelling residents living in Housing and Development Board (HDB) apartments across Singapore was carried out in 2017, this time evaluating awareness of and attitudes towards ACP (110). 14.4% of participants had heard of ACP, mainly through the media (67.9%), from family and friends (21.4%) and health-care providers (21.4%). 26.8% of those who had heard of ACP knew how to begin an ACP discussion and 12.5% of them had a prior ACP discussion. After explanation of what ACP entails, 60.1% of participants were willing to begin an ACP discussion. Being of an older age, having a life-threatening illness, and having more knowledge about ACP were significant factors associated with willingness to have an ACP discussion. Barriers included perceiving oneself as still healthy and preferring the

family to make decisions instead. The study concluded that there is low awareness but high-expressed willingness to engage in an ACP discussion amongst those surveyed. More is needed in community engagement and raising awareness on ACP.

In 2018, a national evaluation of the Living Matters framework commissioned by the Ministry of Health was carried out. Concordance with ACP preferences was studied in a sample of 1731 decedents aged 21 years and above who completed the ACP documentation (111). More than 90% opted for no cardiopulmonary resuscitation. Approximately 40% expressed a wish to pass away at home, and ~30% expressed a preference for death in an institutional setting (hospital, nursing home, hospice). Whilst the level of agreement in terms of preferences for CPR and comfort measures was very high among the deceased population who completed their ACP, ~50% of the sample died at their preferred place of death. A local study of individual, clinical and system factors associated with the place of death concluded that besides cultural and clinical factors, system-based factors including access to home palliative care and ACP discussions were found to influence the likelihood of home deaths (112). Increasing the reach of home palliative care services and encouraging ACP may facilitate honoring patients' preferences for home deaths.

A qualitative study of the implementation of ACP in re-structured hospitals in Singapore described the importance of a cultural and behavioral transformation driven by committed leadership and shared organizational purpose (113).

Current efforts at promoting ACP are aimed at shifting the conversation upstream to the polyclinics and specialist outpatient clinics to patients with chronic disease and more well but middle aged to elderly people. Efforts have also been made to engage private family physicians in understanding their role in ACP. An ACP awareness week was organized across the heartlands of Singapore to reach out to the masses about having dinner table conversations and what 'Living Well, Leaving Well' meant. New task forces under the purview of the national ACP Steering Committee were set up, namely the outpatient ACP taskforce, the community outreach taskforce and the ACP research and development sub-committee. The Ministry of Health of Singapore has been supportive of these broad efforts at ramping up ACP across the health-care continuum as well as in the community. With the surge in use of information technology, there are concurrent efforts at looking at how to educate the public on various forward planning instruments including LPA and ACP and to unite these in a one stop portal as touchpoints of care in a person's health-care journey.

Much remains to be done, including improving quality of ACP training, facilitation and documentation as well as aligning quality measures and audits of the process of ACP. There are research gaps in how ACP can be best implemented in Singapore's melting pot of cultures, how to improve shared decision making between patients, their loved ones and health-care providers as well as how to enhance tracking of quality of ACP process beyond tracking number of ACP documents and measuring concordance between clinical outcomes and preferences.

With the passing of laws in neighboring countries such as the 'Patient Right to Autonomy Act' in Taiwan and the 'Medical Treatment Planning and Decisions Act' in the state of Victoria, Australia, it remains to be seen how the laws and policies implemented within Singapore will evolve to meet the ethicolegal challenges that inevitably arise from the practice of ACP.

In April 2021, when Singapore will host the eighth ACP International conference, it is hoped that this sentinel event will further spur

**Table 1.** Definition of advance care planning (ACP) in each country

	Definition of ACP
Hong Kong	A proactive communication process regarding end-of-life (EOL) care. While the primary target group is patients with advanced progressive disease, the guidelines extend the scope to include family members of the mentally incompetent and minor patients (37).
Indonesia	No consensus definition on ACP yet.
Japan	A process in which the individual repeatedly discusses EOL care with his or her families and/or other closely related people and health-care professional team in advance (67).
Korea	The process by which patients with medical staff voluntarily discuss the goals and specific methods of care to be performed in the future so that the patient's autonomy and best interests can be realized. ACP can occur at any stage of the illness and is often initiated at the request of the patient or on the recommendation of the medical professionals in the condition of aggravating the disease. The attending physician will provide the patient with information about the pros and cons of the treatment options that can be selected according to the progress of the disease to assist in the judgment and to record the medical records. Records may also include discussion about physician orders for life-sustaining treatment (POLST) or advance directive (AD) and hospices as required by law (122).
Singapore	The process of discussion with patients with regards to their values, preferences and wishes for care in event they become seriously ill and unable to make decisions for themselves (123).
Taiwan	The process of communication between the patient and medical service providers, relatives and other related parties regarding the proper care that shall be offered to the patient and the options he or she has to receive or refuse life-preserving treatments and artificial nutrition and hydration when the patient is in specific clinical conditions, unconscious or unable to clearly express his or her wishes (124).

impetus in efforts at ACP in the country and the region and bring person-centered care to the heart of medicine.

### ACP in Taiwan

Under the influence of Confucianism, traditional Taiwanese people take a conservative attitude toward the issue of dying and death. Society treats the topic of dying and death as a taboo; therefore, family rarely discuss it explicitly with their loved one even who is diagnosed with a terminal disease. Collusion is a longstanding tradition, and patients are denied the opportunity of participating in medical decision-making, including decisions with regards to LST. The family usually takes over the responsibility of medical decision-making for the patients. Unsurprisingly, the AD completion rate is low at ~7–8% as a result of poor communication (114). Studies showed that age, cognitive state, previous discussions of DNR orders with family members or physicians and the nursing home policy were factors related with completion of AD (115). From the family caregivers' perspective, if the family caregiver is primary, willing to disclose illness with the patient, familiar with the Natural Death Act and takes a less negative perception toward the Natural Death Act, he or she is more willing to help the patient to complete the AD (116). From the physicians' perspective, prior experience of working in a hospice, attitudes towards the Natural Death Act and knowledge about the Natural Death Act were three important factors that positively influenced the participation in ACP (117).

Taiwan is the first Asian country to legalize the Patient Right to Autonomy Act (118) following the Natural Death Act in 2000. The Natural Death Act guarantees dying patients the right to withhold and withdraw LST; however, the family can decide for the patient and the context is limited to LST and the Act comes into play only when the patient is imminently dying.

The Patient Right to Autonomy Act goes one step further compared with the Natural Death Act; it is applicable to healthy people, the content includes issues related to artificial hydration and nutrition as well as LSTs; and it could only be amended by the patient himself or herself.

The Patient Right to Autonomy Act was passed by the Legislative Yuan in Taiwan in the end of 2016 and enacted on 6 January 2019. This Act is established to ensure respect for patient autonomy, protect the right of patients to a good and natural death and promote harmonious physician–patient relationship. It advocates AD through the process of ACP consultation. It is aimed for person under any of the five clinical conditions: person diagnosed with terminally-ill diseases; with irreversible coma; in vegetative state; with terminal dementia or incurable diseases. It defines ACP as The process of communication between the patient and medical service providers, relatives, and other related parties regarding the proper care that shall be offered to the patient and the options he or she has to receive or refuse life-preserving treatments and artificial nutrition and hydration when the patient is in specific clinical conditions, unconscious or unable to clearly express his or her wishes.

Since ACP consultation is mandatory in order to sign AD, people eligible for the consultation must be 20-years old or above. During the ACP consultation clinics, patients meet the medical team in the company of at least one relative with or without the medical surrogate. The medical surrogate is defined as someone who has no conflict of interest with the patient such as an organ transplant donor except successor to the patient. The medical team will discuss in detail on the possible LSTs and artificial hydration and nutrition under any one of the aforementioned five clinical conditions to the patients for at least an hour. The medical team usually comprises of a medical doctor, a nurse and a social worker/psychologist. In Taiwan, although the majority of health-care services are covered by the National Healthcare Insurance (NHI), the ACP services are not supported by the NHI system yet. The ACP participants need to pay an out-of-pocket fee of (~120 USD) for the person for the ACP consultation. If there is a second person who wishes to consult the medical team, such as the family member, there would a concession charge of 83 USD for the second person and so on. An unified AD form would be completed to record the patient's EOL care preferences if appropriate. After the patient signing AD with two witnesses, the AD form will be uploaded and stored in an online electronic platform and reported

**Table 2.** Comparison of ACP in six Asian countries

	Legislation	ACP clinic	Proxy surrogate	Reimbursement
<b>Hong Kong</b>	<p>No specific legislation on AD and ACP.</p> <p>- The legal status of AD is currently recognized under the common law framework, but the content documented in an ACP form is only used for reference and not legally binding.</p> <p>- The Food and Health Bureau conducted a public consultation to seek views on legislation for AD in 2019 to clarify legal uncertainties and provide protection to both health-care providers and care recipients. The government position yet to be concluded.</p>	<p>Yes, but not widely available. Some palliative care specialists or geriatricians working in public hospitals operate ACP clinics at their own initiative. Some private general practitioners also provide consultation services on ACP.</p>	<p>No</p> <p>- Family members do not have a legal right to make treatment decisions for patients, but the hospital authority encourage the health-care providers to involve the family in the decision-making process and work towards a consensus if the patient has not made advance refusal to treatment. The final decision is made by the health-care team based on the best interest's principle.</p> <p>- The Department of Justice conducted a public consultation on the scope of Continuing Powers of Attorney for medical and health-care treatments in 2018. The government position yet to be concluded.</p>	<p>No specific reimbursement, but there is no additional charge if ACP provided as part of the care during follow up medical appointment in outpatient clinics or the stay in hospitals or care home.</p>
<b>Indonesia</b>	<p>Yes, but limited.</p> <p>1. Decision of Ministry of Health, No 812, 2007 on 'Regulations for Palliative Care': addressed AD, DNR directive, appointment of proxy or surrogate and palliative care team role in the conversation</p> <p>2. Regulation of Ministry of Health, No 37, 2014 on 'Determination of Death and Utilization of Donor Organs,' article 14–15: addressed AD, criteria for withholding/withdrawal of LST, and the role of proxy or surrogate</p> <p>The term ACP has not been introduced nor the guidance on how ACP can be approached or initiated.</p>	<p>No officially recognized setting dedicated for ACP.</p> <p>Clinicians may have practiced the elements of ACP without necessarily being familiar with the term.</p>	<p>Yes, formal regulation mentioned about proxy or surrogate appointment and their role in the do-not-resuscitation (DNR) directive or the withdrawal/withholding of life-sustaining treatment (LST) in incompetent patient.</p> <p>1. Decision of Ministry of Health, No 812, 2007 on 'Regulations for Palliative Care'</p> <p>2. Regulation of Ministry of Health, No 37, 2014 on Determination of Death and Utilization of Donor Organs, article 14–15</p>	<p>No reimbursement for ACP alone.</p>

Continued



**Table 2. Continued**

	Legislation	ACP clinic	Proxy surrogate	Reimbursement
Japan	No, but the Ministry of Health, Labour and Welfare (MHLW) issued guidelines addressing the importance and definition of ACP in 2018. (Those guidelines issued by the MHLW and by the Medical Societies could be considered when judging the existence of negligence as a part of standard of care in tort litigation.)	No officially recognized one. But given the broad definition of ACP in Japan, many clinicians intentionally or unintentionally practice ACP in clinics.	No legally bound proxy or surrogate designation system. However, many different forms of 'ACP brochures' or private 'ADs' across Japan include space where an individual can write about his or her personal representative who could make decision on his or her behalf should the individual lose decisional capacity. (Those guidelines issued by the MHLW and by the Medical Societies could be considered when judging the existence of negligence as a part of standard of care in tort litigation.)	No reimbursement by ACP alone. However, the provision of EOL care per the guidelines published by the MHLW is among the criteria required for medical fee for hospitals for community-based care and terminal care at home as well as for nursing care fee for terminal care at home.
Korea	Yes Act No. 14013, 3 February 2016	No The concept of ACP Clinic is not clear in Korea. But there are many AD registry sites (e.g. public health-care center in each village and nonprofit foundations) where people can counsel and make an AD. And in many designated hospitals (usually big general or university hospital), the terminal patients can counsel and write documents like POLST.	No if the patient is not able to express his or her intention, two or more family members of the patient shall identically state the patient's intention for the LST, and the doctor in charge and the medical specialist in the relevant field verify the contents of the statements together.→ this is not an exact surrogate.	Yes But, the government give only small reimburse when we see patients, upload the related documents online system and put the designated order code in EMR only in a designated hospital that have the ethics committee for LST.
Singapore	Enforcement Date: 4 February 2018 'Act on hospice and palliative care and decisions on life-sustaining treatment for patients at the EOL' Yes In Singapore, the only statute that governs forward planning for care when one is seriously ill is the Advance Medical Directive: <a href="https://www.moh.gov.sg/cost-financing/policies-and-legislation/advance-medical-directive">https://www.moh.gov.sg/cost-financing/policies-and-legislation/advance-medical-directive</a>	Yes ACP may be facilitated in the outpatient setting in dedicated ACP clinics in some restructured hospitals, together with the medical consultation in some specialist outpatient clinics or in the community such as by voluntary welfare organizations.	Yes The ACP framework in Singapore is promulgated nationally by the Agency for Integrated Care and named 'Living Matters.' It encourages the nomination of a health-care spokesperson whom doctors can consult in event an individual becomes seriously ill. Singapore is in the process of crafting public education to align the health-care spokesperson nominated in the ACP process and the donee nominated under the Lasting Power of Attorney (LPA).	There is no reimbursement for ACP alone. ACP in Singapore started with seed funding from the government to encourage pilot projects and engagement efforts. This seed funding is reviewed every few years. There is no systematic reimbursement of ACP completed by health-care providers and community workers and practice may vary from setting to setting with some clinics charging patients for ACP whilst others offering it for free or as part of medical consultation.

Continued

Table 2. Continued

Legislation	ACP clinic	Proxy surrogate	Reimbursement
<p>The advance medical directive is a legal document that one signs stating one's wish not for any extraordinary LST in the event one becomes terminally ill and unconscious. Another pertinent statute is the Mental Capacity Act <a href="https://sso.agc.gov.sg/Act/MCA2008">https://sso.agc.gov.sg/Act/MCA2008</a>, which allows an individual to make a LPA and nominate a proxy or donee to make decisions for oneself in event of loss of mental capacity. <a href="https://www.msf.gov.sg/opg/Pages/The-LPA-The-Lasting-Power-of-Attorney.aspx">https://www.msf.gov.sg/opg/Pages/The-LPA-The-Lasting-Power-of-Attorney.aspx</a>. However, the ambit of this Act excludes decisions regarding LST or any other treatment that is necessary to prevent a serious deterioration in one's condition. There is no overarching statute governing the broader practice of ACP in Singapore but as a process of clinical care and documentation, it is not exempt from medicolegal scrutiny.</p>	<p>Yes</p> <p>There are more than 100 ACP clinics in various hospitals in Taiwan and the number is rapidly growing.<sup>v</sup></p>	<p>Yes</p> <p>The medical surrogate is defined as someone who has no conflict of interest with the patient such as an organ transplant donor except successor to the patient.</p>	<p>No</p> <p>The ACP participants need to pay an out-of-pocket fee of (approximately 120 USD) for the person for the ACP consultation. If there is a second person who wishes to consult the medical team, such as the family member, there would a concession charge of 83 USD for the second person</p>
<p>The Patient Right to Autonomy Act was passed by the Legislative Yuan in Taiwan in the end of 2016 and enacted on 6 January 2019.</p>	<p>Yes</p>	<p>Yes</p>	<p>No</p>
Taiwan			

on the personal health-care intelligent card. Thereafter, all hospitals in Taiwan would acknowledge that the patient has completed the AD and will act accordingly. Today, nearly 100 hospitals all over Taiwan have provided ACP consultation clinics.

Before the enactment of the Patient Right to Autonomy Act, several indigenous studies investigate the effect of ACP to terminally ill cancer patients. A randomized controlled study concluded that ACP improved psychological distress, but not quality of life or preferred EOL care of the patient (119). In addition, a large-scale ACP communication program in Taipei showed there is an increased AD completion rate (82.6%) to the eligible population as a result of the program (120) and utilization of LST decreased following AD completion (121). Since the concept of ACP is relatively new in Taiwanese society and the development of ACP is still at a preliminary stage, more evaluation is needed to audit the effectiveness and consolidation of ACP consultation clinic in the future.

## Conclusion

As the concept of patient autonomy continues to evolve in Asia, more countries begin to reflect on the issues of AD through the process of ACP to attain a better quality of dying among patients (Table 1). According to the Asian experiences, we have seen different models of ACP implementation (Table 2). The Asian Delphi Taskforce for ACP, under the supervision of Asian Pacific Hospice Network, has been working vigorously on the definition, roles, tasks and recommendations for ACP tailored for the Asian culture (125). The Asian Delphi Taskforce for ACP is currently undertaken by six Asian countries and a more detailed, culturally sensitive whitepaper for the Asian population will be published in the near future.

## Conflict of interest statement

None declared.

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### Mini-abstract

The advocacy of Advance Care Planning (ACP) is a means to honor patient autonomy. Since most East Asian countries are influenced by the Confucianism and the concept of “filial piety”, patient autonomy is consequently subordinate to family values and physician authority. The dominance from family members and physicians during a patient’s end-of-life decision-making is recognized as a cultural feature in Asia. In order to address this ethical and practical dilemma, the concept of ‘relational autonomy’ and the collectivism paradigm might be ideally used to assist Asian people, especially older adults, to share their preferences on future care and decision-making on certain clinical situations with their families and important others. In this review article, we invited experts in end-of-life care from Hong Kong, Indonesia, Japan, South Korea, Singapore and Taiwan to briefly report the current status of ACP in each country from policy, legal and clinical perspectives.