

PRESERVING PATIENT AUTONOMY AT THE END OF LIFE: A LEGAL APPRAISAL OF THE POSITION OF ADVANCED MEDICAL DIRECTIVES IN MALAYSIA AND INDONESIA

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ABSTRACT

Respect for patient autonomy is a bioethical principle that has become increasingly imperative, particularly in the 21st century. However, in many Asian countries, medical paternalism to a larger degree remains prevalent in the healthcare setting. While a doctor is ethically and legally bound to respect a patient's values and wishes in administering treatment, the duty to do so is more complex in end-of-life care, where the patient is unable to partake in the decision-making process. Accordingly, it has been argued that advanced medical directives (AMDs) could ensure that the patient's right to make autonomous decisions is preserved and will not be defeated by any future incapacity. It also serves to extenuate the ethical dilemma faced by doctors in determining the course of treatment according to the incompetent patient's wishes. In turn, this facilitates healthcare providers to manage the distribution of scarce medical resources effectively. The need for AMDs is seen to be increasingly pressing in ageing countries such as Malaysia and Indonesia, where end-of-life care has yet to be integrated into mainstream healthcare services. This paper seeks to discuss the viability of integrating AMDs into the Malaysian and Indonesian regulatory frameworks on health care, by employing the qualitative method of content analysis of both primary and secondary sources of the two countries. Findings show that statutory reform is both recommended and necessary to ensure better management of medical resources, as well as to promote the delivery of a more inclusive and compassionate healthcare system.

Introduction

Since the turn of the 20th century, advancements in medical prevalence particularly at the end of life, have shifted the dimension and blurred the line between life and death. Medical treatment and equipment are now able to prolong the life expectancy of patients suffering from life-limiting illnesses even in the absence of any brain activity. Consequently, patient autonomy has taken precedence over medical paternalism in medical decision-making, amidst the fears that one's dying phase would be suspended indefinitely by medical intervention.

Advance medical directives (AMDs) were developed as a response to address this concern, providing a means for patients to preserve their right to self-determination in situations where they might lose the ability to decide on the course of their medical treatment. As an embodiment of a patient's anticipatory medical decisions, as well as his or her values in relation thereto, AMDs not only enhance patient autonomy but also serve to facilitate doctors in performing their ethical obligations towards the patient at a time when the latter might not be able to participate in the decision-making process. The development of AMDs is seen to be more prominent in its place of origin, that is, the United States compared to other parts of the world. In Malaysia and Indonesia, particularly, the use of AMDs is still in its infancy, and to date, the matter has yet to be properly legislated in both countries.

The Malaysian literature on issues pertaining to end-of-life care, advance care planning (ACP) and AMDs do not appear to be as broad and comprehensive compared to the extent of international studies written on the subject matter. An examination of the local work thus far, reveals that there has been, for the most part, quantitative research conducted on the palliative care setting in Malaysia to identify the challenges faced by nurses and caretakers in dealing with the terminally ill (Namasivayam et al., 2014; Beng et al., 2013); the need for effective engagement between nurses and patients' families (Namasivayam et al., 2011); the knowledge and attitude of nurses in dealing with concepts of death and dying in end-of-life care (Subramanian & Chinna, 2013), the adequacy of holistic palliative care (Loh, 2006) and the awareness of advance medical directives among Malaysians (Lim et al., 2020; Koh et al., 2017; Siew et al., 2016; Htut et al., 2007). Accordingly, for the past decade, there have been a growing number of qualitative studies discussing the need and viability for AMDs to be implemented and regulated in Malaysia (Alias et al., 2020; Tan, 2018; Chan, 2019; Kassim & Alias, 2015).

Similarly, studies on such issues in Indonesia are also limited; mostly address the difficulties in implementing palliative care (Putranto et al., 2017; Arisanti et al., 2019; Tampubolon et al., 2021). Other research publications discuss, among others, the issue of ACP as an educational intervention (Fauziningtyas, 2018) and its implementation with regard to cancer patients and family caregivers (Martina et al., 2022). Most recently, a 2023 study conducted by Martina et al. provided valuable insight into the current position of ACP in Indonesia and the challenges in its implementation.

The Nature of End-of-Life Care

The term "*end-of-life care*" is generally used to refer to the health and social care system required to address the physical, spiritual, emotional, and social needs of patients who are suffering from serious illnesses, or incurable diseases or are in the final stages of their lives, and includes acute care and long-term care (Tallon, 2012; Colello et al., 2011). End-of-life care falls within the spectrum of palliative care. The European Society of Medical Oncology (ESMO) defines "*end-of-life care*" as palliative care that is delivered when death is imminent (Cherny, 2003). According to the United States National Quality Forum, end-of-life care applies when a patient's chronic illness is no longer curable and life-prolonging therapies are no longer appropriately indicated or desired (National Quality Forum, 2006). It refers to "*a specific phase of palliative care requiring specialised skills and services that may be served by the delivery of hospice care or other models of palliative care programmes*" (National Quality Forum, 2006).

The World Health Organisation (WHO) defines "*palliative care*" as "*an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering through early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual*" (World Health Organisation, 2002). A corresponding description is provided by the National Institute of Clinical Excellence (NICE) in the UK: Palliative care is "*the active holistic care of patients with advanced, progressive illness.*"

Management of pain and other symptoms and provision of psychological, social, and spiritual support is paramount. The goal of palliative care is the achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments” (National Institute of Clinical Excellence, 2004). Similarly, the view of the WHO is also endorsed by ESMO, which refers to palliative care as “*care that aims to optimise the comfort, function and social support of the patients and their family when cure is not possible. This dimension of care emphasises the special needs of patients whose illness is either unlikely to be cured or that is incurable. These needs include physical and psychological symptom control, education, and optimization of community supports”* (Cherny, 2003). Palliative care aims to relieve suffering throughout the disease trajectory and applies to all forms of life-threatening illnesses (Rome et al., 2011). Consequently, it constitutes an extension of care that covers all stages of the disease, including but not limited to the end-of-life phase (Davis & Kuebler, 2007).

According to Kinzbrunner (2005), the term “*end-of-life care*” is a valid descriptor to characterise care delivered in the final phase of life. To this end, it serves to distinguish between two categories of patients receiving palliative care: those who are terminally ill and those who are not.

The Importance of Patient Autonomy at the End of Life

Autonomy is considered by many bioethicists as the most important bioethical principle in medical practice (Steinberg, 2003). It is the fundamental right of the patient to conduct and manage his own affairs, including deciding what should be done with his body. Particularly in medical decisions, patients’ preferences are to be given pre-eminence since medical decisions reflect value judgments, and patients are therefore the best authority to decide their own values and goals rather than doctors (Brett & McCullough, 2012). The doctor-patient covenant is seriously breached if the doctor offers medical procedures that conflict with the patient’s values (Billings & Krakauer, 2011).

The strong deference to patient autonomy is attributable to several factors such as the emphasis on individualism and self-responsibility, and rapid technological advancements (da Rocha, 2009). The emergence of sophisticated devices and treatments in medicine such as life-sustaining interventions, for example, have elicited a lot of ethical issues in the dying process, where patients’ values mattered the most. There exist many occasions in which the medical profession may face ethical dilemmas, particularly in handling terminally ill patients who are incompetent. Patients’ values and spiritual beliefs are particularly significant at the end of life as it provides a sense of security and belonging to the patient by offering him a way to find meaning in dying as in life (Chater & Tsai, 2008; Mazanec & Tyler, 2003; Daaleman, 2000). It has been constantly promoted in modern medical practice that clinical assessments on the quality of life at this stage are not solely contingent on medical findings, but “*should be based primarily on the patient’s values, goals and beliefs”* (Billings & Krakauer, 2011), which makes respect for autonomy more pertinent in end-of-life care. Understanding patients’ preferences, which are usually shaped by their values and beliefs, is the first step towards respecting patient autonomy at the end of life.

The Significance of Advance Care Planning (ACP) and Advance Medical Directives (AMDs)

One of the main attributes of the end-of-life decision-making process is the significant and compelling deference to patient autonomy. While a doctor is lawfully bound to respect a patient’s preference and personal values in administering the requisite treatment, it has been shown that this proves to be more complex when the patient is incompetent. The conception of AMDs served as a means of responding to this dilemma, and to address the fear that many people have over the fact that it had become clinically possible to continuously be kept “*alive*” in a state where they have lost all cognitive functions and are incapable of exercising any control over how they wish to be treated. An AMD operates as an assurance that the right of an individual to make autonomous decisions will not be defeated by any future incapacity, and thus, in this respect, functions as an enhancement of patient autonomy.

ACP is the discussion process between doctor and patient, which may also include family members, to develop and document a valid projection of the patient’s wishes concerning the type of medical care in situations where he becomes unable to communicate (Htut et al., 2007). The model for ACP involves a structured process where doctors engage with patients to understand the latter’s needs, values, goals, and thought processes, as well as establish a trustworthy relationship for shared decision-making (Emanuel et

al., 2000). It is a continuous discussion that needs to be reviewed and reaffirmed periodically throughout the patient's clinical course and while the patient possesses the requisite mental capacity, to ensure that the decision documented reflects the patient's current and true wishes upon having been properly informed of the treatment options (Mullick et al., 2013).

Proper ACP, which includes the formulation of AMDs, functions to enhance patient autonomy as it entails the consequential involvement of the patient in expressing and validating his values and wishes in anticipation of a situation where he might lose his decision-making capacity. It stems from the theoretical rationale that if patients have the right to refuse treatment even when such refusal might endanger their lives, then they should be entitled to exercise the same right when they become incompetent, which is facilitated by the use of AMDs (Andorno et al., 2009). An AMD is a written statement made by a person while he is competent pertaining to future medical treatment, in the event he becomes incapable of decision-making when the need arises. It consists of anticipatory instructions and decisions as to the extent of treatment that a person agrees or refuses to receive, the circumstances in which treatment may or may not be provided, and may also include the appointment of a proxy who is authorised to make health care decisions on the person's behalf (Capron, 2009). The existence of a valid AMD acts as a guide for doctors to determine the course of treatment that represents the patient's values and wishes when he is unable to partake in the decision-making process. It not only fulfills the ethical obligation of doctors in respecting the autonomy of their patients but also promotes the biomedical principle of justice, where the management of health care resources is concerned. In this respect, the implementation of AMDs enables a more functional allocation of expensive life-sustaining medical equipment, especially in institutions that have limited healthcare budgets (Astroff, 1997). From the personal viewpoint of the patient and family members, an AMD provides a formal assurance that health care decisions will conform to the patient's individual wishes and interests at a time when the patient's active participation may not be possible and help to alleviate the psychological burden experienced by not only the family members but also health care providers (Pellegrino & Thomasma, 1998).

The Current Position of ACP and AMDs in End-of-Life Care in Malaysia and Indonesia

It is important to reiterate at this juncture, that the delivery of care at the end of life is a component under the wider scope of palliative services. Thus, the development of the latter inevitably impacts how end-of-life care is carried out in Malaysia and Indonesia.

Malaysia

The first palliative care service in Malaysia found its roots in the establishment of a hospice home care initiative by the Penang Cancer Society in 1991. In August of the same year, Hospis Malaysia was founded, a non-profit charitable organisation dedicated to providing professional palliative care services to those suffering from life-limiting illnesses. A few years later, other states such as Sabah, Malacca, and Sarawak began to follow suit and offer hospice services. In 1995, the first hospital-based palliative care unit was set up in Queen Elizabeth Hospital, Kota Kinabalu. This development accordingly formed the catalyst that precipitated the expansion of palliative care services in the country (Lim, 2004).

Malaysia appears to have covered a lot of ground in two decades in terms of developing and integrating palliative care in the provision of health care services. In 2005, MOH recognised palliative medicine as a sub-specialty in 2005 (Wright et al., 2010). Subsequently in 2010, an operational policy on palliative care services was issued by MOH's Medical Development Division, which aims to guide healthcare providers on the scope, components, training requirements, as well as the types of palliative care services and organisational structures based on an integrated palliative care model which was to be carried out in collaboration with community-based centres. This has since been replaced by the National Palliative Care: Policy and Strategic Plan 2019-2030 (Medical Development Division, 2019).

Currently, most hospitals in Malaysia now have palliative care units or palliative care teams. In the past decade, records have shown a total of over 20 palliative care units and 49 palliative care teams established in government hospitals, with seven hospitals offering consultancy services and four hospitals with dedicated palliative care clinics/centres (Medical Development Division, 2019). Yet despite such progress, palliative care in Malaysia is still relatively in its infancy and faces many challenges in terms of its implementation. In terms of global standing, a 2015 Economist Intelligence Unit (EIU) report ranking

end-of-life care placed Malaysia 38th out of 80 countries (The Economist Intelligence Unit 2015). In a 2017 global survey issued by the End of Life Studies Group, the University of Glasgow, Malaysia was included in the cluster of countries (Category 3a) where the number of palliative services is limited concerning the size of the population (Clark et al., 2020).

The use of AMDs in medical care is a relatively novel concept in Malaysia. This could be primarily attributable to the cultural conditions and lack of exposure to the subject matter in Malaysia. The level of awareness, both on the concept of palliative care in general and specifically on AMDs, has been documented by local studies. In a 2020 survey conducted by Htut et al., (2020) it was found that only 3.1% of the respondents had heard of ACP or AMDs. The majority, however, were reported to be receptive to the idea of ACP, and the desire to be able to maintain their autonomy when seriously ill as well as to reduce the burden of their families, were cited as the two top motivating factors for ACP. A report issued by Hospis Malaysia in 2016 revealed that out of the 600 respondents interviewed, 24.7% answered that they were aware that there existed a provision of services *“to relieve the suffering and improve the quality of life for patients and their families living with or dying from a chronic illness”*, and only 17.2% correctly identified it as hospice or palliative care (Sekhar et al., 2016). Further, a study carried out on Malaysian palliative nurses indicated that there was still a lack of knowledge concerning end-of-life care and poor perception of end-of-life issues among them (Subramanian & Chinna, 2013).

Statistics in a study conducted to evaluate the attitudes of older Malaysians towards ACP (Siew et al. 2016) indicated that the majority were receptive to the concept. Those who were opposed to it primarily justified their response on the basis that they did not have sufficient information on ACP and would prefer their family members to make end-of-life decisions on their behalf when it became necessary. Religious beliefs were also cited as a significant reason for their refusal to participate in ACP, as they felt that it was a matter best left to God to decide, a factor which is found to be consistent with the findings of the 2007 survey conducted among elderly Malaysians around the same age group, although the latter was conducted in a smaller cohort (Htut et al., 2007). Another local study carried out by Koh et al., (2017) among a different group of senior citizens also generated similar results, which reported that a minority of the respondents chose not to have AMDs and preferred to leave it to their doctors to decide. Despite not being exhaustive findings, it is submitted that the aforementioned analyses on ACP and AMDs help to provide insight into the perceptions of Malaysians on the subject.

In the past decade, however, issues regarding its importance and calls by the medical community for increased awareness as well as the wider implementation of ACP made local newspaper headlines. Malaysian doctors have voiced the need for AMDs to assist them in managing their patients more effectively, especially in dealing with disputes among family members as to what would be the best course of action for the patient (Mageswari, 2014). There is also concern among the religious groups in Malaysia that proper guidelines be issued concerning AMDs and the right of family members to decide on a patient's behalf (The Star Online, 2014). To this end, some effort has been initiated to discuss the issue among the relevant sectors, which have recognised the evident need for a comprehensive regulatory framework to be developed, taking into account the different religious and cultural views (Yusof, 2015).

At present there is no regulatory instrument that specifically addresses the issue of ACP or AMDs in Malaysia. General mention is made under Clause 5 of Section II of the Code of Medical Ethics of the Malaysian Medical Association (“CME”), which states that in the case of a dying patient, *“[o]ne should always take into consideration any advance directives and the wishes of the family in this regard”*. The WMA Declaration of Venice on Terminal Illness, which is referred to in Appendix IV of the CME for example, recognizes the right of patients to develop AMDs that describe their preferences regarding medical care if they are unable to communicate and the designation of a substitute decision-maker to make decisions that are not expressed in the AMD (World Medical Association n.d.). It also highlights the importance of ACP, particularly concerning life-sustaining treatment and palliative measures that might hasten death.

It is clear from the CME that doctors must give precedence to AMDs, which are an embodiment of the patient's right to self-determination, in deciding whether a particular medical treatment is to be administered during the patient's incapacitated state. The obligation to abide by a patient's wishes and preferences is accordingly subject to the condition that the AMD in question must be valid, which necessitates the determination of the patient's competency. This is reflected in several parts of the Consent for Treatment of Patients by Registered Medical Practitioners issued by the Malaysian Medical Council ("*Consent Guideline*").

Certain provisions in the Consent Guideline are particularly relevant in the context of end-of-life decisions. Clause 17 covers the autonomous right of competent patients to refuse medical treatment and restates that such right exists "*regardless of the reasons for making the choice whether they are rational, irrational, unknown or even non-existent.*" Administering treatment against the wishes of the patient could incur liability for assault or battery. The procedure for documenting a patient's refusal is similar to consent-taking, including the need to review a patient's prior refusal if there is a significant change in the patient's condition. The provision further cautions that where a patient refuses to consent to a life-saving procedure due to religious or cultural beliefs, and there may be a pressing need for such procedure to be carried out in the course of treatment, it would be advisable for the doctor to seek a judicial declaration to protect himself from future legal action.

Another significant provision is clause 18, which highlights the duty of doctors to give precedence to AMDs, in deciding whether a particular medical treatment is to be administered during the patient's incapacitated state. The relevant details can be summarised as follows:

- (a) A doctor must comply with an unequivocal refusal to treatment in a patient's written directive in the circumstances specified therein;
- (b) A doctor must not comply with an AMD that contains unlawful instructions such as euthanasia or the termination of pregnancy;
- (c) A doctor should determine the validity of an advance directive by considering the following factors;
- (d) Whether it is sufficiently clear and specific to apply to the clinical circumstances which have arisen;
- (e) Whether it can be said to have been made in contemplation of the current circumstances (for example, whether the AMD was made before or after the diagnosis of the current illness); and
- (f) Whether there is any reason to doubt the patient's competence at the time that the directive was made, or whether there was any undue pressure on the patient to make the AMD;
- (g) If the doctor is in doubt about the validity of an AMD, he should consult the patient's spouse or next of kin, and the doctor should also consider the need to seek legal advice and discuss the issue with his or other clinicians involved in the patient's care;
- (h) In emergency cases, the doctor can treat the patient following his professional judgement of the patient's best interests until legal advice can be obtained on the validity or scope of the patient's AMD.

Indonesia

The history of palliative care in Indonesia can be originally traced to 1992, with the establishment of *Pusat Pengembangan Paliatif dan Bebas Nyeri* in the East Java Province of Surabaya (Witjaksono et al., 2014). However, progress in the delivery of such care in the country remains underdeveloped and sporadic, which is primarily attributed to insufficient funds and inadequate resources (Martina et al., 2023a). Currently, palliative care services are mainly concentrated in two major cities, Jakarta and Surabaya where most of the facilities for cancer treatment are located (Rochmawati et al., 2016). Since

2015, 12 hospitals in Jakarta have undergone basic training on palliative care, a collaborative effort by the Singapore International Foundation at the Cancer Foundation Jakarta (Putranto et al., 2017). The Indonesian Ministry of Health has recently conducted systematic palliative care training for practitioners in primary health care facilities across the country. Further, formal education in palliative care is currently included under the internal medicine specialization of psychosomatic and palliative medicine. However, the shortage of palliative specialists has inhibited further development in the delivery of such care.

As far as global ranking is concerned, Indonesia is positioned 53rd out of 80 countries that were included in the 2015 study conducted by the EIU (Economist Intelligence Unit, 2015). Similar to its neighbouring country, Malaysia, the number of palliative services in Indonesia is found to be limited vis-à-vis its demographic statistics, according to a 2017 survey by the University of Glasgow (Clark et al., 2020). Despite impediments in providing palliative care on a wider scale, numerous local research on palliative care and AMDs have been conducted by the medical community, particularly in the past decade, highlighting the various factors that need to be addressed, the responses of Indonesian patients and the nurses, as well as the compelling need for a structured regulatory framework to be in place, while at the same time providing the relevant education and training in palliative care and ACP to doctors and nurses.

A recent study by Martina et al., (2023b) suggests that cancer patients are more willing to hear from their doctors themselves about their illness, rather than have the information mediated by a family caregiver, as is the normative practice in Asian societies. Out of the 1,030 respondents who participated in the online survey, approximately 66% were prepared to discuss end-of-life decisions, and half of the participants were predisposed to documenting their choice of a health proxy and their treatment preferences at the end of life. The study also showed that almost 70% of the cancer survivors who had considered ACP but had never discussed it with others, were willing to engage in the process, indicating that such needs were not appropriately addressed by healthcare professionals, which may be principally attributed to a lack of requisite training on ACP rather than awareness. This corresponds with the findings of the research by Sari and Hidayati (2021) in which the preparedness of palliative nurses to promote ACP was measured, where it was shown that there was a high willingness on their part to engage in discussions and promote ACP. However, out of the 150 nurses who were selected for the survey, the majority had never undergone training on ACP and lacked the necessary skills to effectively implement ACP throughout the disease trajectory, especially in end-of-life care.

As in the case of Malaysia, there appears to be no legislation or a proper regulatory framework governing ACP or AMDs in Indonesia. It is to be noted that there have been a few initiatives that have been undertaken by the Indonesian government in recognising the need for palliative care to be made available to patients on a more pervasive scale. In 2007, The Indonesian Minister of Health issued the National Policy on Palliative Care (NPPC), which aimed to achieve the following objectives (Kementerian Kesehatan Indonesia, 2007):

- (a) To ensure quality palliative care is delivered according to the necessary standards throughout the republic;
- (b) To provide structured guidelines and directives on the implementation of palliative care;
- (c) To produce trained medical and non-medical personnel; and
- (d) To provide the requisite resources and facilities.

The NPPC contains several provisions that highlight elements of ACP and AMDs. For instance, paragraph 1(e) in Part IV (Medico-legal Aspects in Palliative Care) states that the palliative care team should endeavour to obtain the patient's wishes and statement while he/she is competent on the type of treatment that he/she would consent to or refused when she is unable to partake in the decision-making process. This includes the appointment of a healthcare proxy who will make decisions on the patient's behalf when he/she is no longer competent. The statement must be in written form and will be the main guide for the palliative care team to decide on the incompetent patient's course of treatment. The NPPC also recognises the function of an AMD in cases where the patient does not wish to be resuscitated (DNR) (paragraph 2(c) of Part IV); in such a situation, the next of kin cannot make a DNR decision, unless it has been specifically stated in the patient's AMD. However, in certain justified circumstances, the patient's close

family members may seek a judicial declaration for the DNR request to be granted. The succeeding provision further grants the right to the palliative care team to decide to not resuscitate the patient when the latter is terminal, and it is clinically indicated that such intervention will not cure or improve the patient's quality of life.

Directive no. 3 of 2014 issued by the Indonesian Minister of Health on Determination of Death and Utilisation of Donor Organs (Kementerian Kesehatan Indonesia 2014) ("*2014 Directive*") also refers to an AMD in clauses 14 and 15 of Chapter III (Withholding or Withdrawal of Life-Sustaining Treatment). In cases where the patient is in a terminal state and treatment is futile, the medical team attending to the patient must consult a team of doctors appointed by the hospital's medical committee/ethics committee on the decision of whether to withhold or withdraw such therapy. The consent of the family members must also be obtained. Clauses 14(d) and (e) list down the types of life-sustaining treatment that may be withheld and withdrawn, except for oxygen and artificial nutrition and hydration. Under clause 15, the patient's family members may request the doctor to withhold or withdraw life-sustaining treatment or ask for a reassessment of the patient's medical condition. Such a request by the family members can only be made:

- (a) If the patient is incompetent and has articulated his wishes in an AMD:
 - (i) Specifying that life-sustaining treatment should be withheld or withdrawn when such treatment is futile; or
 - (ii) where the patient has appointed a surrogate decision-maker; or
- (b) If the patient is incompetent and has not indicated his wishes, but the family members believe that such withholding or withdrawal would be what the patient would have wanted, based on his personal values and religious beliefs.

Subsequently, paragraph 6 of clause 15 stipulates that in the event of a dispute between the family's request and the recommendation by the medical committee or ethics committee, where the former insists that life-sustaining treatment be withheld or withdrawn, the patient's family will be held legally liable.

To date, palliative care has not been formally integrated into the national health care system in Indonesia or mentioned in other central policies, apart from the NPPC and the 2014 Directive (Martina et al., 2023a). In recent years however, studies have shown that there are calls from the medical fraternity for laws to be enacted to accord them protection from legal liability in implementing ACP, as well as clear and comprehensive guidelines that cover the different aspects of ACP and how to deliver culturally sensitive care (Martina et al., 2021).

Legislating AMD: An Insight into the UK Experience

The importance of a regulatory framework on end-of-life care, including that of ACP and AMDs can be seen from the experiences of the UK, in which the provision of end-of-life care has been fully integrated into its respective mainstream health care services (Clark et al., 2020). The Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021 reports that the UK occupies the topmost ranking above 81 countries across the world (Finkelstein et al., 2021). One of the key findings of the report is that the leading countries share a common feature: the substantial impact of palliative care on policy and the existence of palliative care guidelines, where aspects such as advanced medical directives have been legislated (Clark et al., 2020).

Under English common law, whether the patient has given valid consent or refused medical treatment essentially rests on whether he did so upon being properly informed, that it was done voluntarily, and whether he possessed the capacity to decide at the time when it was made. In *Re T (adult: refusal of treatment)*(1992) 4 All ER 649, the test of competency as laid down by the House of Lords necessitated the following conditions to be fulfilled: at the time when the decision was made, (1) the patient must have had the legal capacity and possessed the requisite competence to consent or refuse treatment. In other words, the patient must be an adult and must not suffer from any impairment that may undermine his ability to make up his own mind. It is important to note that a person with reduced capacity does not however *ipso facto* render him incapable of deciding as to the treatment in question. Doctors must consider

whether the patient had a capacity that was commensurable to the gravity of the decision that he purported to make, and (2) the patient must have been aware and intended for the scope and basis of his consent to be applicable in that particular situation. In *Airedale NHS Trust v Bland* (1993) 1 All ER 821, the court drew attention to the need for special care in ensuring that a prior anticipatory refusal could still be regarded as relevant to the situation at hand; and (3) the patient must have known the nature, purpose, and effect of the treatment to which he is consenting. This third element was further clarified in *Re C (adult: refusal of medical treatment)* (1994) 1 All ER 819; to determine whether the patient has sufficient understanding, it must first be proven that he understood and is able to retain the information given pertaining to the treatment, secondly, that the patient believes it, and thirdly, that the patient is able to internalise and weigh such information by balancing the need for such treatment with the risks that may be involved, before making a choice.

The conditions of a valid consent as set out above are therefore applicable in determining the legitimacy of an AMD i.e. whether the person making the advance medical directive was provided the necessary information and was indeed competent at the time when he expressed his preferences. In the event that the person does not satisfy the aforementioned criteria for competency as set out in *Re T (adult: refusal of treatment)* (1992) 4 All ER 649, his advance medical directive will not be valid and therefore any act or decision pertaining to the person's medical treatment during his period of incapacity must be made in his best interests.

The aforementioned common law principles were adopted and incorporated in the first formal move to recommend the use of AMDs in the form of the 1993 report produced by the UK Law Commission (The Law Commission, 1993), and the House of Lords Select Committee on Medical Ethics in 1994, which proposed a code of practice as a guide for health care professionals in the use of AMDs (Select Committee on Medical Ethics, 1994). These developments eventually led to the passing of the Mental Capacity Act 2005 ("MCA"), which came into effect on 1 October 2007.

The MCA currently regulates the validity and implementation of advance directives in the UK. This piece of legislation is to be read together with the MCA Code of Practice, which supports the legal framework provided by the MCA and acts as a guide as to how the provisions of the latter are to be implemented. In doing so, reference must also be made to the Explanatory Notes to the MCA prepared by the Department for Constitutional Affairs and the Department of Health, which are intended to assist the understanding of certain provisions of the statute.

Under section 24(1), an "advance decision" is defined as a decision made by a person of 18 years of age who has the capacity to decide, that if —

- (a) at a later time and in such circumstances as he may specify, a specified treatment is proposed to be carried out or continued by a person providing health care for him, and
- (b) at that time he lacks the capacity to consent to the carrying out or continuation of the treatment, the specified treatment is not to be carried out or continued.

An advance decision under the MCA thus relates to a valid anticipatory refusal of treatment; contrarily doctors are not bound to honour requests for treatment if they do not appear to be in the best interests of the patient (Andorno et al., 2009). Such a person may also either verbally or in writing, withdraw or make changes to his advance directive at any time provided that he has the capacity to do so. It is important to note that by section 62 of the MCA, a person is prohibited from making an advance directive in contravention of the law relating to murder or manslaughter, or assisted suicide. Thus, an advance directive that contains instructions to terminate the person's life when he becomes incapacitated, for example, will not be valid.

The conditions for a valid consent and test of competency under common law are manifested in the provisions about the validity and applicability of an advance directive under section 26 of the MCA. Doctors must first ascertain whether the patient has, at the material time, the capacity to consent to or refuse the treatment in question. If the patient possesses the required capacity, then the advance directive in relation to such treatment will not be applicable, since such a decision would only be operative upon the patient's loss of capacity. Section 1 of the MCA states the general rule that a person shall be assumed

to have capacity unless it is established that he lacks capacity. In order to ascertain what amounts to incapacity, the provision must be read together with sections 2 and 3. Section 2 defines incapacity as the inability of a person to make decisions for himself in relation to a matter due to a mental impairment or disturbance. Section 3 further clarifies that "*inability*" under section 2 means that the patient cannot understand or retain the information relevant to the decision that he purports to make, nor is he able to weigh such information during the decision-making process. Section 3 thus reiterates the common law test of competency as laid down in the case of *Re C (Adult: Refusal of Medical Treatment)* (1994) 1 All ER 819. In addition, a patient who cannot communicate his decision in any way at all is also considered to be incapable of deciding for himself.

Secondly, the advance directive must be valid in that it must not have been withdrawn when the patient had the capacity to do so, or overruled by a lasting power of attorney executed after the advance directive was made, which conferred authority on a health care proxy to decide on the treatment to which the advance directive relates. The validity of an advance directive may also be negated if the patient does something contrary to the advance directive made and that clearly indicates his intention to not be bound to it.

Thirdly, the advance directive must be applicable to the treatment in question meaning that it is a treatment that is specifically addressed in the advance directive and the circumstance in which the patient's advance directive is referred to is that which is mentioned in the advance directive. An advance directive may not be relevant if there is a reason to believe that the present situation had not been accounted for by the patient at the time when he made the decision and that it would have influenced his preferences had he anticipated it.

A person who wishes to make an advance refusal of life-sustaining treatments must fulfil additional requirements under section 5 for such a decision to be valid. The decision or statement must:

- (a) Be verified by a statement by the person to the effect that it is to apply to that treatment even if life is at risk;
- (b) Be in writing;
- (c) Be signed by the person or by another individual in the former's presence and by the person's direction, and the signature is made or acknowledged by the person in the presence of a witness. The witness must also sign it, or acknowledge his signature, in the person's presence.

There is no specific definition as to what amounts to "*life-sustaining treatment*" under the MCA. Section 4(10) defines it as "*treatment which in the view of a person providing health care for the person concerned is necessary to sustain life*". Accordingly, this would be a matter for doctors to assess and decide in each particular situation. The MCA Code of Practice states that an advance directive cannot include a refusal to be provided basic care such as warmth, shelter, actions to keep a person clean, and the offer of food and water by mouth, although artificial nutrition and hydration may be refused.

Sections 9-14 of the MCA deal with lasting powers of attorney. Under the MCA, the scope of authority in a lasting power of attorney does not only cover property and financial affairs but also encompasses personal welfare, which includes health care matters and consent to medical treatment. In the latter case, section 11(7)(a) states that the lasting power of attorney would have no effect if the donor is able to make his own decisions. The lasting power of attorney is also invalid if the donor had made an advance directive with regard to a particular treatment under sections 24-26. However, if the lasting power of attorney was executed after the advance directive was made conferring authority to the health care proxy to decide whether to consent or refuse the treatment, then the attorney has the option whether or not to follow the donor's directives. An exception is made to life-sustaining treatment, in which case a healthcare proxy can only have the right to decide if the lasting power of attorney specifically authorises it.

Issues and Challenges for the Implementation of AMD in Malaysia and Indonesia

One of the primary challenges in dealing with an AMD lies in defining its substance. The drafting of a proper and suitable advance directive may be encumbered due to insufficient information, as doctors may lack the expertise to facilitate discussions for advanced care planning effectively (Capron, 2009; Pérez et al., 2013). Inadequate information impedes the patient's ability to make an autonomous decision, raising doubts about the validity of his or her AMD (Shaw, 2012; Maclean, 2006).

Additionally, doctors may need to spend a considerable amount of time to ensure the patient fully comprehends potential medical conditions and available treatment choices, which in turn may incur additional financial costs for the consultation process. Concerns may also arise about potential abuse of advance directives by doctors or family members for financial reasons (Andorno et al., 2009).

In the context of palliative care, doctors are confronted with limited and expensive medical resources, especially in terms of life-sustaining treatment. AMDs help manage medical funds by reducing dependency on such treatment, allowing doctors to allocate resources based on society's healthcare needs. However, implementing an AMD against the wishes of the patient's family may be viewed as a questionable act driven by economic interests, leading to conflicts between the parties. Complications may arise when there is uncertainty about the patient's AMD relating to life-sustaining treatment, creating emotional tension for family members in deciding whether to withdraw treatment (Stern, 1994). In non-Western cultures, particularly in Asian communities such as Malaysia and Indonesia, patient autonomy is viewed differently than that in the West, with family members playing a more dominant role than the patient in the decision-making process, where they prefer to be the first point of contact to be fully informed of the patient's condition and then conclude as to how much disclosure is to be relayed to the latter. Consequently, this may contribute to missed opportunities for patients to timely engage in ACP (Martina et al. 2023a). Unlike the position in the West, medical paternalism is still very prevalent in the doctor-patient relationship in Malaysia and Indonesia (Alias et al., 2021; Martina et al., 2022). Religiosity and cultural values in both countries are also significant factors that influence medical decision-making, including patients' mental preparedness for ACP (Alias et al., 2021; Rochmawati et al., 2018). Concomitantly, being the largest archipelago in the world and home to over 1300 ethnic groups, Indonesia's geographical landscape, and heterogeneity in terms of population pose a considerable challenge in the delivery of equitable health care services (Mahendradhata, 2017; Martina et al., 2023a).

The most challenging aspect of effectively implementing ACP and AMDs stems from a lack of knowledge and understanding among both healthcare providers and recipients. This makes it difficult to integrate an AMD into a patient's medical routine. Although the initiation of ACP ideally should be carried out during a patient's health phase, medical practitioners however, often associate it with crises, leading to discussions at times when patients may not be in the right mindset to decide on their treatment preferences should they lose the capacity to consent (Pérez et al., 2013). Rather than focusing on writing treatment plans in advance, ACP should essentially revolve around exploring patients' values, wishes, and preferences continuously through their trajectory of illness (Martina et al., 2023a).

Proposed Recommendations

There is accordingly an apparent need to establish legal standards and proper rules of conduct to address the various issues pertaining to AMDs. It is submitted that this is best addressed by means of statutory reform, supported by other regulatory instruments such as practice guidelines. This will accord proper direction to both doctors and patients in formulating AMDs and guide doctors in their proper implementation. Legislating the use of AMDs will thus assure doctors that their actions in relation thereto are ethically and legally valid, and operate as a safeguard in the preservation of a patient's autonomous rights and best interests during both periods of competency and incapacity, thus preventing potential abuse.

Drawing from the experiences of countries such as the UK which have specific legislation on the subject matter, it is proposed that any effort to regulate ACP and AMDs should consider the following fundamental requirements:

- (a) Specifications regarding the validity and applicability of AMDs, emphasising the necessity for prior consultation with a doctor and a clear indication of when the instructions become effective.
- (b) Criteria for determining a person's competence. This is crucial during the drafting of the advance directive and when doctors assess whether to implement it.
- (c) Restrictions on the content of an AMD, as exemplified by the MCA Code of Practice under paragraph 9.28, which states that an AMD cannot include a refusal of basic care such as warmth, shelter, cleanliness, and oral food and water, although the refusal of artificial nutrition and hydration may be permissible.
- (d) Establishment of a framework to confirm that the person has received sufficient information during ACP, recording the patient's significant values for decision-making.
- (e) Implementation of a system for secure storage and retrieval of AMDs.
- (f) Procedures for the revocation of an AMD, including partial revocation without affecting the applicability of the AMD to other circumstances in the future.
- (g) Measures to address situations where an AMD is deemed ineffective or there is a dispute over its validity and/or applicability. This includes guidelines for determining the patient's best interests and the option to seek a declaration through a judicial forum to affirm the legal justification of the doctor's chosen course of action.
- (h) Appointment of a health care proxy, detailing the instrument for appointment, the scope of authority, and conditions under which the proxy's authority may be overridden.
- (i) Clarification of the legal effects and limitations of an AMD. It is crucial for the legislative or regulatory instrument to explicitly state that compliance with a valid AMD absolves the doctor from liability. Additionally, it may include limitations of liability in other circumstances, such as those outlined in section 25 of the MCA. An advance directive cannot authorise actions contrary to existing law, for instance, instructing a doctor to commit euthanasia, which is unlawful in Malaysia and Indonesia. In Malaysia, euthanasia is equivalent to culpable homicide not amounting to murder under section 299 of the Penal Code. Under the Indonesian Code of Medical Ethics, it is stipulated that according to religion, the laws of the country, and medical ethics, a doctor is prohibited from ending the life of a terminally ill patient (Kode Etik Kedokteran Indonesia, 2004).

It is however pertinent to note that the adoption of such legal standards on advance directives in Malaysia and Indonesia must take into account the demography and socio-cultural fabric of both countries. Accordingly, this not only constitutes a requirement of legality but corresponds with the importance of value and social considerations that significantly influence a patient's wishes in forming medical decisions (Padela, 2006; Htut et al., 2007; Betancourt, 2004). Alternatively, in the absence of current legislation to govern the implementation of ACP and AMDs in Malaysia, some authors have suggested that the determination of a healthcare proxy in the form of a surrogacy ladder guideline be formulated in line with cultural precepts (Katiman et al., 2022).

Conclusion

It is estimated that approximately 1.45 million persons in Indonesia require palliative care every year, although the actual figure may be higher. In Malaysia, it is reported that four out of 10 Malaysians will require end-of-life care, which is equivalent to an estimated 56,000 patients per year, indicating a growing burden for local palliative care. The preceding discussion lends credence to the fact that both countries face similar challenges in advancing ACP and AMDs in the delivery of competent and sensitive care in a culturally diverse society. To this end, a structured regulatory framework must be in place, backed by

adequate resources and facilities to not only provide quality palliative care to the masses but also to educate and train health care professionals. It is submitted that statutory reform will not only serve to solidify the autonomous rights of a patient but also provide an authoritative source upon which doctors may base their actions to ensure that they are legally protected from any liability in attending to incompetent patients. Both Malaysian and Indonesian legislators would need to ensure that the codification of legal standards is suited to local circumstances. Among the major factors that would need to be considered are ethnicity and religious values, which bear a significant influence on healthcare decision-making in both societies. Accordingly, in order to effectively regulate and address the issues in advance care planning, there needs to be a concerted effort involving doctors, academicians, lawyers, religious authorities, and relevant government agencies to contribute their knowledge and expertise toward the development of a pragmatic and viable ACP model in Malaysia and Indonesia, as well as to educate legislators and the general public on the importance and use of AMD to facilitate statutory reform.

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