

Introducing the Use of Advance Care Planning and Advance Directives in Hong Kong?

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In December 23, 2009, the Food and Health Bureau (FHB) issued a Consultation Paper entitled "Introduction of the Concept of Advance Directives in Hong Kong". This consultation paper was issued in response to a report published by the Law Reform Commission (LRC) in August 2006 entitled "Substitute Decision-making and Advance Directives in Relation to Medical Treatment". In the Consultation Paper, the Government agreed with the LRC's view that "it would be premature to attempt to formulate a statutory framework and to embark on any legislative process for advance directives, without greater public awareness of the issues involved."¹ Secondly, the Government made it clear that "it has no intention at this stage to actively advocate or encourage the public to make advance directives."² What the Government was prepared to do was (1) To produce and make available to the general public an information package on advance directives (AD); (2) To develop any necessary guidelines and procedures for making and executing AD after consultation with the public and the medical and legal professions; (3) To consult the public about the acceptance of advance care planning (ACP) and the best way to promote this concept in Hong Kong.

In this paper I wish to discuss two points in the Consultation Paper, one related to ACP and the other to AD. I like to argue that conceptually ACP is primary and AD is secondary. This is so because ACP is a process of communication among patients, family members, health care professionals (HCP), spiritual advisers, lawyers and any significant others about the patient's preferred medical care in the future when the patient can no longer make healthcare decisions. ACP takes place in the context not only of a patient-HCP relationship, but also in the context of patient-family-HCP relationship. In the ACP process, patients may speak with any one or all of the participants mentioned above to discuss their own values, beliefs, preferences and attitudes regarding appropriate medical interventions when they become seriously ill and/or lose their decision-making capacity. It is an integral part of medical care for elderly patients that are documented and reviewed regularly. In the case of patients with an illness that may deteriorate into a life-threatening illness, it can be expected that the ACP process will lead to the discussion and drawing up of an AD, but the latter is not a necessary product of the ACP process. The real benefit of the ACP process is two-fold: for patients and their families, it becomes a way to prepare for death, strengthen interpersonal and interfamily relationships, relieve family members and love ones of making decisions on behalf of patients and allow

patients to maintain control over healthcare decisions related to their dying and death. On the other hand, the ACP process assists the HCPs and family members to interpret the AD with greater certainty since the AD is the product of a process in which they are participants.

The consultation paper attributes the Chinese taboo that forbids the discussion of the patient's death as the reason for the infrequent use of ACP process in Hong Kong, and speculates that perhaps when the public has become more familiar with the concept of AD, it may find ACP more acceptable. This is unlikely to be the case, for if the taboo affects the ACP process, it is difficult to see how the making of an AD is immune from it. The real cause(s) of the infrequent practice of ACP in Hong Kong must be sought elsewhere. Firstly, HCPs in Hong Kong are not sufficiently trained to engage patients and families in the ACP process and they feel uncomfortable to raise death and dying issues with them. Secondly, the ACP process is time-consuming and it requires the HCPs to set aside time from their busy schedule to participate in the discussion of their patients' physical, mental, emotional, relational and spiritual concerns about their ageing, dying and death. It is a process that requires sensitivity and patience and HCPs can not participate or perceived by patients to participate in a hurry. Furthermore, since patients' preferences towards end-of-life treatments may be unstable and change with time,³ the ACP process is an ongoing one that may take several sessions to complete and requires patients being able to see the same HCPs each time they visit the clinic. It is therefore reasonable to speculate that the real causes of the infrequent practice of ACP in Hong Kong are due to the deficient training of HCPs in the ACP process, the extreme time constraints under which Hong Kong HCPs operate, and the uncertainty of patients' ability to see the same HCPs over a period of time required by the ACP process. Nonetheless, the ACP concept should be promoted in Hong Kong, with emphasis on the need of ACP training programmes for practitioners and the need to allocate extra resources devoted to ACP. But if AD is the "natural product" of the ACP process, then arguably ACP should be promoted prior to or at the same time when AD is being promoted. There are reasons to be skeptical that "ACP would be[come] a concept acceptable to the public...when the public has become more familiar with the concept of advance directive."⁴

A second point in the Consultation Paper that merits further clarification is the definition of "terminally ill", particularly in relation to the activating and revoking an AD. Both the LRC Report and the Consultation Paper state that the AD will become operative (activated)



when the patient is in any one of the three conditions, namely, terminally ill, a state of irreversible coma or a persistent vegetative state. While patients in irreversible coma or persistent vegetative state can be safely assumed not to possess the decision-making capacity, it is not clear if the same can be assumed for patients who are "terminally ill", defined as "patients who suffer from advanced, progressive, and irreversible disease, and who fail to respond to curative therapy, having a short life expectancy in terms of days, weeks or a few months."⁵ Conceivably, a terminally ill patient may retain a low but sufficient level of mental competence to participate in decision-making up to the time of death. In this case, the patient's AD would never be activated. It seems that this point is less than explicit in the Consultation Paper. However, in Section II-4 of the proposed model form of AD, there is a sentence that may function to qualify the state of "terminally ill" in relation to activating the patient's AD: "If I become terminally ill or if I am in a state of irreversible coma or in a persistent vegetative state..., so that I am unable to take part in decisions about my medical care and treatment, my wishes..." (Paper, p.20) This means that only if the patient is terminally ill and simultaneously mentally incompetent will the patient's AD be activated. Before this condition is fulfilled, the patient remains an autonomous agent.

Imagine a 68-year-old patient with widespread metastatic breast cancer that was refractory to chemotherapy and radiotherapy and considered by the treatment team as terminal. Despite the fact that she was also known to have early dementia, she was able to participate fully in the ACP process initiated by her HCPs, leading to the making of an AD. But her health condition steadily deteriorated and about six weeks after she made the AD, she was taken to the Accident and Emergency (AE) Department by her friends due to her respiratory distress. She was diagnosed to be in

respiratory failure, but the AE doctor did not initiate cardiopulmonary resuscitation (CPR) because her AD was found on the chart. At that point, one of her friends who shared the same apartment with the patient requested the doctor to resuscitate the patient because the patient had revoked her AD several days ago. The friend produced an AD revocation with a barely legible signature of the patient. The friend claimed that even though the patient was at times disoriented, she, as a witness to the revocation, was convinced that the patient was lucid when she signed the revocation. Was the patient competent when she revoked her AD? Was the witness certain of her competence? It is prudent for the Consultation Paper to provide mechanisms to revoke an AD either orally or in writing, as potential tragedies can be avoided in the event that patients want to change their mind from declining to accepting life sustaining treatments. However, FHB considers both oral and written revocations to be valid so long as they are witnessed, minimally, by any independent witness as long as the witness is at least 18 years of age and does not have an interest in the patient's estate. While a low threshold for revoking an AD is important, it should not be so low as to render revoking an AD vulnerable to misunderstanding or abuse. It is more reasonable to require a doctor to assess the patient's decision-making capacity and to witness the patient's revocation of her AD.

References

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2. Ibid., paragraph 15, p. 5.
3. Danis M., Garrett J., Harris R., Patrick D. Stability of choices about life-sustaining treatments. *Ann Intern Med.* 1994 Apr 1; 120(7):567-73.
4. Food and Health Bureau, Hong Kong SAR Government. Introduction of the Concept of Advance Directives in Hong Kong [Internet]. 2009. para. 20, p. 6-7. pdf
5. Ibid., Annex B, p. 17.
6. Ibid., p. 20.