Advance Directive: More than an advance refusal in need

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With the release of the consultative paper on advance directives (AD) by the Food and Health Bureau HKSAR in Dec 2009, it is timely to have more open discussions on AD and its related process – advance care planning (ACP).

A public forum on advance directives was held on 6th March 2010 in the City University of Hong Kong. This forum is co-organized by Society for the Promotion of Hospice Care; Governance in Asia Research Centre, City University of Hong Kong; Hong Kong Hospice Nurses’ Association; Hong Kong Society of Palliative Medicine.

The forum included a comprehensive program with talks delivered by Dr. Chan Ho-man on “Ethical consideration of advance directives”; Dr. Doris Tse on “Advance care planning”; Dr. Tse Chun-yan on “Practical difficulties in executing advance directives”; Ms Faye Chan on “Promotion of advance care planning and advance directives in the community”. The organizers see this as a good opportunity to clarify the issues related AD, and to facilitate open discussion on a topic that is relevant to all citizens of Hong Kong.

Albeit a new concept to the public in Hong Kong, advance care planning in the form of discussion on preferences of life sustaining treatments is not totally new in health care. Years ago, the Hospital Authority had promoted the use of DNR form. The DNR form, in analogy to the AD form, is just a tool. Recent local studies have shown that patients with advanced cancer had DNR order established in near 99% if they ever received palliative care and in 86.3% of those who did not receive any palliative care. Another study on local patients who died from cancer and chronic non-cancer diseases showed that 95.6% of cancer patients and 80.0% to 89.5% of patients with chronic diseases had DNR order in place. The discussion of CPR and DNR was conducted directly with patients in 40.1% and 11.5% with cancer and non-cancer respectively. Multiple factors could account for the quoted differences. Nonetheless, patients who have chronic non-cancer diseases also have significant palliative care needs and ACP is relevant and applicable in their model of care.

The development of palliative care in Hong Kong, the effort of Hospital Authority in setting guidelines on withholding and withdrawing life sustaining treatment and the promotion of the DNR form are factors that might have shaped these findings in various local studies. It also seems that the DNR form, a tool itself, has served beyond that. The concept has been incorporated into local clinical practice as many of these DNR orders and their discussions are conducted and documented without confining to the original form.

Photos of the Forum on AD
The audiences
The speakers & chairs
Editors’ Column

Could one be just as optimistic in promotion of AD, which is a tool for advance care planning? Perhaps experience elsewhere could shed light on this.

AD has been promoted in other places with the main theme of promotion of patients’ autonomy. The Patient Self Determination Act (PSDA) enacted in US in 1990 was historic in this movement, and efforts have been given to improve end-of-life care. The SUPPORT study (Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments) included a 2-year prospective observational study (phase I) with 4301 patients followed by a 2-year controlled clinical trial (phase II) with 4804 patients and their physicians randomized by specialty group to the intervention group (n=2652) or control group (n=2152). The phase I observation of SUPPORT confirmed substantial shortcomings in care for seriously ill hospitalized adults - only 47% of physicians knew their patients prefer no CPR, 6% of DNR orders were written only 2 days before death, and 38% of deaths spent at least 10 days in ICU.

Despite an increase in recording of completed AD by the physician from 6%-35% to 78% at phase II post interventional study, there were no improvement in patient-physician communication, incidence or timing of written DNR orders, physicians’ knowledge of their patients’ preferences not to be resuscitated, number of days spent in an ICU, and the level of reported pain. The SUPPORT investigators concluded that in order to improve the experience of seriously ill and dying patients, greater individual and societal commitment and more proactive and forceful measures may be needed. Although the SUPPORT study yielded negative results in terms of the targeted outcomes after intervention, it does bring insights into planning for better end-of-life care.

The objectives of advance care planning are not limited to making an AD. The communication process of ACP can bring along better understanding and stronger relationships among the family members, and solace to all at the end-of-life when making decisions are often difficult and stressful. In traditional Chinese culture where family decisions are honoured, it is important that these goals are brought to light and not being overpowered by that of enhancing patients’ autonomy.

Finally, an AD will fail short of enhancing patients’ autonomy if planning for better end-of-life care depends solely on advance refusal - the true nature of an AD form. Indeed, why should one find the AD form compelling in driving for better end-of-life care and not merely a statement of giving up opportunities? The answer to this question resides in what is fundamental in enhancing patients’ autonomy, that is to empower patients to make informed choices and quality palliative care should be among the options. Unless we have quality palliative care equitable to all, an AD could remain as a tool for achieving a narrow range of autonomy, and with withholding or withdrawal of life sustaining treatment portrayed as omission of care.

Palliative care in Hong Kong has moved beyond from the scope of cancer in public health care. We welcome the commitment of our Government to support the pilot of renal palliative program in Hong Kong. We hope this marks the first step in the strategic development of palliative care for non-cancer in Hong Kong.

References
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