Chapter XXI

Ethical Challenges of Engaging Chinese in End-of-Life Talk

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ABSTRACT

In Hong Kong, end-of-life practice ideally adheres to values that include respect for the patient's self-determination and an understanding shared by and consented to by the patient, the family and the healthcare team. However, consensus about end-of-life care is seldom reached within this trio before the patient become critically ill or mentally incompetent. This chapter examines the customary belief, protectiveness in medical care, which hinders Chinese patients and families in their discussion of life-sustaining treatment; challenges the practice in question; and discusses the possibility of engaging frail nursing home residents in dialogue by using the "Let Me Talk" advance care planning program.

MAKING TREATMENT DECISIONS AT THE END OF LIFE

Medical technology has a powerful allure, yet there is distorted clinical evidence concerning its relevance for end-of-life care. As imminent death approaches, the clinical attractions of advanced technology lose their charm. Examples include the once routine practice of resuscitation of patients regardless of disease severity and prognosis, the institution of mechanical ventilation for patients with advanced and progressive chronic respiratory disease, and the provision of artificial feeding for patients in persistent vegetative state or with advanced dementia. Arguably these treatments have questionable utility because of predicted improbable outcomes, improbable success, and unacceptable benefit-burden ratios (Beauchamp & Childress, 2001).

Post-resuscitation studies have shown that the survival to discharge rate of adult resuscitation was 14.6%, the rate decreased if associated with sepsis, malignancy, dementia, coronary artery disease and physical dependence (Ebell, Becker, Barry & Hagen, 1998). In addition, neurological and other sequelae are often found among survivors after prolonged resuscitation. Finucane and associates (1999) conducted a systematic review of tube feeding in the care of patients with advanced dementia and found little evidentiary basis for the practice. Instead of preventing suffering, instituting tube feeding can cause more suffering, such as problems with diarrhoea, clogging of tubes, and the tendency of patients with dementia to pull out tubes with consequential physical restraint.

The complexity of making life-sustaining treatment (LST) decisions can be characterized by competing views regarding prognostication and clinical outcomes in the context of the varying personal, professional, legal and ethical responsibilities of decision makers. Over the past few decades, several broad areas of legal consensus surrounding the withholding and withdrawal of LST at the end of life have emerged in European and North American countries, as well as Hong Kong. First, LST refers to all treatments which have the potential to postpone the patient's death, and includes, for example, cardiopulmonary resuscitation, artificial ventilation, specialized treatment for particular conditions such as chemotherapy and dialysis, antibiotics when given for a potentially life-threatening infection, and artificial nutrition and hydration. Second, there is no ethically important distinction between withholding and withdrawing LST. Third, the patient's preference should be taken into account when such decisions are made. Fourth, a surrogate can make end-of-life decisions for mentally incapacitated patients. Such decisions are based on the surrogate's perceptions of the patient's previous wishes or the patient's best interests (Hospital Authority Hong Kong, 2002).

Overarching the broad areas of consensus is the patient's right to decide. Often such decisions are made when the patient becomes imminently terminal, but are implemented, regardless of mental capacity, at a later moment of life. The verbal or written advance directive of the patient, stating a preference for treatment limitation, should be respected (Law Reform Commission Hong Kong, 2006). In situations where the patient's preference is not known, a surrogate can make decisions based on the perceived best interests for the patient. The surrogate can be a family member of the patient or a legal guardian (Hospital Authority Hong Kong, 2002).

To facilitate better decision making, professional guidelines for informing local practice have been formulated. It is noteworthy that different places vary in their interpretations. Examples are the legal rights of next of kin when consenting to or refusing treatment. In the U.S., the consent of the next of kin is required (Pang, Volicer & Leung, 2005c), while the next of kin's consent is regarded as important but not determinative in Hong Kong, where physicians and legal guardians bear responsibility for the decision. In accordance with Hong Kong Hospital Authority guidelines on life-sustaining treatment for the terminally ill (2002), it is ethically and legally acceptable to withhold or withdraw LST when (a) a mentally competent and properly informed patient refuses LST, and/or (b) the treatment is futile. The decision-making process, except when the treatment is physiologically futile and thus not an option, should basically be a consensus-building process among the healthcare team, the patient and the family.

However, it is doubtful to what extent these good practice guidelines, which uphold the patient's right to self-determination and shared decision-making between the patient and clinician with family involvement, are articulated in actual practice. Most patients often become too ill to take part in the decision making, or that doctors solicit family members' support without involving patients in conversations about end-of-life treatment options. In both situations, the patients' right to self-determination is undermined and their wishes are not well presented in the deci-

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