Clinicians are often facing clinical dilemma when making decisions on withholding or withdrawing life sustaining treatment. Ethical perspective in health care decision is becoming important in our contemporary pluralistic society.

A 74 year-old gentleman with history of COPD and dementia is admitted with acute exacerbation of COPD. He deteriorates rapidly into severe type II respiratory failure. What will you do? A 25 year-old man with Duchenne Muscular Dystrophy is put on nasal non-invasive ventilation (NIV) for 4 years. If he deteriorates, what will you do?

Chronic chest conditions such as COPD, occupied around 10% of the medical bed days in Hong Kong public hospitals. Treatment decisions for patients who suffer from advanced lung diseases then become important, especially towards end-of-life. Local data on treatment outcomes are available to guide treatment efficacy. A local study showed that COPD patients who survived after NIV treatment for acute exacerbation had a high risk of readmissions and life threatening events; with one year mortality as high as 49.1%. In another study performed in a cohort of COPD patients with DNI (do not intubate) orders and who were put on NIV, the one year actuarial survival was 29.7%.

While evidence-based medicine provides data on treatment efficacy or adverse effects; the interpretation of benefits, burdens and best interest are often affected by patient’s specific condition, preferences and values. Family’s view also plays an important role. Principle-based ethics are widely used to guide ethical decision: beneficence, non-maleficence, autonomy and justice (Beauchamp and Childress). Within a Chinese society, the application of such may be different because of culture factors. The goal of medical ethics is to improve patient care by identifying, analyzing and attempting to resolve ethical problems that arise in clinical practice.

In following the guidance of ethical principles, the flow of ethical decision making is illustrated by Figure 1.

In Figure 2, a number of related factors in ethical decision making are included; these include: (1) Process of communication, (2) Role of family in decision making, (3) Personal values affecting decision making, (4) Social factors, (5) Role of surrogate decision maker and (6) Role of advance directive. Some of the issues will be discussed in the following.

Figure 1: Ethical approach to decision making process
DNR / DNI preference of patients with advanced COPD

Studies showed that patient-physician barriers did exist and affected communication on end-of-life issues. Physicians often express psychological difficulty in discussing sensitive issues like DNI. A local survey was conducted on 99 advanced COPD for their DNI preference after acute exacerbation. Results showed that 5% of patients had already decided for DNI order, 13% did not show their preference, 41% preferred DNI, and 40% would choose intubation. This study showed that the majority of COPD patients was willing to discuss DNR issues.

How were DNR/ DNI orders given?

Should DNI decision be made by doctor, patient or family? A European survey on end-of life decision in Respiratory Intermediate care units showed that majority of decisions involved family members (57.2 %), followed by nurses (55.9%), all patients who were mentally competent (36.6%), then religious personnel (28.9 %). In a local retrospective review of 49 COPD patients who died with DNR order, 69.4% patients were put on oxygen, 20.4% had history of intubation, 12.8% had resuscitation history. Among these patients, the number of hospital admissions (over 2 years) were 9.73 ± 6.07, the days in hospital (over 2 years) were 181.2±146.23. Three patterns of decision making mode were found: “Patient-initiated, and shared decision making with physician” in 28%; “Physician-initiated, and shared decision-making with patent/ family” in 48%, and “Physician-initiated, and shared decision-making with family only, no patient participation” in 24%. The mean duration of survival after DNI decision in these three groups was 369.8±389.42 days, 184.1± 376.33 days and 43.8± 59.09 days respectively (p=0.072). These figures showed that a quarter of our patients had made their decision more than a year before death. In another quarter, the decision was initiated by physician, with shared decision making with family quite closed to death, this group of patient was too ill and mentally incompetent to make their own decision, hence family was involved.
What are the concerns affecting decision making?

Understanding factors affecting patient’s decision is important for communication. In the local qualitative study of 19 advanced patients, three groups of factors were found to affect patient’s decision making: (1) Prognostic awareness, (2) Burden of illness (treatment burdens, symptom burdens, care burdens), (3) Existential concerns (the will to live, life values, death & dying concerns). These factors interact and influence patient’s decision making as illustrated in Figure 3.

In assessing quality of life concerns in advanced COPD, a locally generated end-of-life questionnaire may be promising.

How do COPD patients die in Hong Kong?

Unlike malignant diseases, it is often more difficult to define end-of-life phase for organ failure patients who run downhill courses punctuated by exacerbations. An audit performed in an acute regional hospital for 2000-2001 showed that 29% of COPD who died had received intensive care in the last admission [unpublished data]; whereas only 4% of COPD who died in an extended chest hospital (Haven of Hope Hospital) received active CPR. The different care types provided may imply the unpredictable disease trajectory of COPD. For those advanced COPD patients under the care of chronic institution, majority of them would have DNR issue discussed before death.

Future direction

In Hong Kong, the Law Reform Commission has made recommendations to the government regarding the future direction of advance directives. Advance care planning, as defined as a process of communication among patients, health care providers, families, and important others regarding the kind of care that will be considered appropriate when the patient cannot make decisions, would be very helpful to guide treatment goal and improve quality of care in patients with advanced respiratory diseases.

Figure 3. Patient’s concerns that affect DNI decision

References