CASEBOOK ON ETHICAL DECISION-MAKING IN END-OF-LIFE CARE OF OLDER ADULTS
INTRODUCTION

This Casebook provides a resource for doctors, nurses, social workers and allied health professionals who face ethical issues when caring for older adults at the end of life. The cases are selected in consultation with healthcare and social care professionals serving older adults in hospitals, clinics, and the community that present common, yet challenging ethical situations that arise in Hong Kong. An expert commentary for each case provides a perspective on the ethical challenges and a practical clinical approach. Background readings on key topics in end-of-life care of older adults and additional resources are also provided. The Casebook will continue to be updated with additional cases and background readings over time.

The Casebook is developed under the Jockey Club End-of-Life Community Care Project (JCECC) in collaboration with the CUHK Centre for Bioethics. The idea for this Casebook stems from the Singapore Bioethics Casebook Project at the NUS Yong Loo Lin School of Medicine, which provides an online resource for healthcare professionals in tackling ethical issues that arise in care settings in Singapore. We developed this Casebook with the same intention to support healthcare providers practicing in Hong Kong with locally contextualized perspectives and insights. Please visit: http://www.ioa.cuhk.edu.hk/en-gb/casebook for the online version.

While the cases that appear in the Casebook are based on real-life scenarios, all characters’ names and other descriptions and events are modified and no identifying information of any individuals is provided.
Mr. Lau is an 89-year-old long-term resident at a home for the aged. He started living at the home about 8 years ago after he was hospitalized for a stroke resulting in right-sided weakness and became wheelchair bound. He was never married and has two sisters who visit him every now and then.

Two weeks ago, Mr. Lau was admitted to the hospital after falling from his wheelchair and broke his hip. He was admitted to the orthopaedics ward. Dr. Shan, the orthopaedic consultant felt he was not a surgical candidate for hip replacement due to his poor underlying health status and he was already wheelchair-bound. Over the next few days, Mr. Lau developed a fever and cough, and was diagnosed with pneumonia. Despite being treated with antibiotics, his respiratory status worsened. He struggled to maintain oxygenation despite being on the maximum amount of oxygen that can be delivered to his face mask.

Given his deteriorating condition, the orthopaedics medical officer, Dr. Lo, phoned Mr. Lau’s sisters and explained: “Your brother has a serious pneumonia. If we don’t connect him to a breathing machine soon, he will soon die.” His sisters agreed with inserting a breathing tube, and Mr. Lau was connected to a ventilator. A feeding tube was inserted and tube feeds were initiated.

Dr. Hong is the intern who has been caring for Mr. Lau over these past few weeks in the hospital. Now that Mr. Lau is on the breathing machine, Dr. Hong was distressed at doing repeated arterial blood draws on the patient to monitor Mr. Lau’s blood gases because of the pain the procedure caused. Both his arms were badly bruised from the frequent blood draws. He felt that keeping Mr. Lau alive on the ventilator was torturing the patient. He did not think that his senior Dr. Lo had a proper informed discussion about the risks and benefits of the treatments with his family.

Fortunately, after a week on the ventilator, Mr. Lau’s respiratory status improved, and he was successfully extubated.

A day later, however, Mr. Lau was having more difficulty breathing again. Dr. Lo spoke with the consultant Dr. Shan who agreed with re-intubating the patient. He then told Dr. Hong to call the anesthesiologist to come to perform the intubation. Dr. Hong became concerned that putting Mr. Lau back on the ventilator would be futile treatment since he is unlikely to leave the hospital alive and it would only serve to prolong his dying and increase his suffering. He is uncertain whether or not to follow his senior’s orders to call the anesthesiologist.
Mr Lau  
CONFLICT BETWEEN TEAM MEMBERS

Commentary  
- Dr. Tse Chun Yan, Chairman, HA Clinical Ethics Committee (2005 to 2017)

Dr. Hong was concerned that further intubation and mechanical ventilation would be futile and not in the best interests of the patient. Whether this view is appropriate would depend on the following factors:

a. Was the patient still competent?
Being 89 years old and having a stroke does not necessarily mean that the patient was not competent. If the patient was still competent, the view of the patient should be sought.

b. How was the quality of life of the patient before the accident?
Being 89 years old and wheelchair bound from a stroke does not necessarily mean that the patient had a poor quality of life. Quality of life is one important consideration in balancing the harms and benefits of an invasive treatment.

c. Was there input from a relevant specialist about the prognosis on further intubation?
Dr. Hong’s consultant, by deciding to re-intubate the patient, indicated that there was still a chance of recovery from the pneumonia. However, Dr. Hong considered further treatment futile. Dr. Hong himself was a house officer, while his consultant was an orthopaedic specialist. In view of the difference in view, it would be useful to seek a second opinion from a relevant specialist, e.g. in geriatrics or respiratory medicine.

d. If the patient was already incompetent, did the patient previously express his values and preferences regarding life sustaining treatment?
If there was a chance of meaningful recovery from the pneumonia, knowing the patient’s prior values and preferences would be important in deciding whether to re-intubate or not.

If, after considering the above factors, Dr. Hong considers that re-intubation would be futile and not in the best interests of the patient, it would be proper that he does not simply follow the instruction of his senior without question. Dr. Hong has an ethical duty to exercise his own independent professional judgment and to act in the patient’s best interests.

It would be appropriate to discuss further with his seniors, to raise his views and to suggest seeking a second opinion from a relevant specialist. Because what is in a patient’s best interests is often a value-laden decision, in making the decision, it is useful to build consensus with the patient and his family members and among members of healthcare team, taking into account views from different perspectives.

If consensus cannot be reached within the healthcare team, if time allows, the clinical ethics committee of the hospital can be consulted. Another alternative is to consider a time-limited trial of treatment. The healthcare team should work out with the patient and family a well-defined set of therapeutic goals and end points and a well-defined period of trial time. If no progress is made towards the agreed therapeutic goals at the end of the trial period, decision can be jointly made to withdraw the life sustaining treatment.
Mr. Chan was an 84-year-old male, with a history of hypertension, diabetes and recurrent ischaemic stroke. His wife died a few years ago. He had two sons and one daughter living in Hong Kong. He was diagnosed to have vascular dementia five years ago and became chair-bound. For two years, he lived with his second son’s family, cared for primarily by his daughter-in-law Mary. However, Mr. Chan had gotten progressively weaker in the last few months and Mary no longer could transfer him out of bed alone. Mr. Chan was then brought to live at a private old aged home.

In the last year, he became bed bound and double incontinent and required assisted feeding. He also had recurrent hospital admissions due to chest infections and the speech therapist recommended puree diet and thickener in fluid. After an episode of aspiration pneumonia, the speech therapist suggested non-oral feeding due severe oropharyngeal dysphagia.

The doctor asked to meet with the family and the second son and the daughter came. His son said, “Father would not want to have a feeding tube placed. He had seen many tube-fed elderly people at the old age home. They just lied in bed all day and it was not a life that he wanted. He told us that he would rather die than have one put into him.”

The daughter had also heard her father express that and they both made the decision for careful hand feeding rather than tube feeding. They understood the risk of aspiration, pneumonia and death.

The patient tolerated careful hand feeding for several months. However, he then developed fever and became unarousable. He was transferred to the hospital and was found to have a severe pneumonia. He was kept nil by mouth and given parenteral antibiotics. His second son and daughter were informed of deteriorating clinical condition and imminent death. They understood and agreed to continue conservative management.

The next day, however, the oldest son turned up and insisted on starting tube feeding. He accepted that his father was dying and agreed to continue comfort care and continue DNACPR order. However, he said “It’s important that my father would die with a full stomach. I do not want him to become a hungry ghost.” The clinician was not sure whether he should simply reject the son’s request or not.
Mr Chan
FEEDING TUBE DECISION IN A DYING DEMENTED PATIENT

Commentary
- Dr. Tse Chun Yan, Chairman, HA Clinical Ethics Committee (2005 to 2017)

Cultural factors are among various important contextual features that should be considered in clinical ethics case analysis. The Chinese may have some deep-rooted views about death and dying that the patient may value. Such views may have to be respected in suitable situations. However, this does not mean that traditional cultural views should be accepted without question. Cultural considerations have to be individualized and carefully weighed against other important considerations.

We can approach the problem step by step:

a. Was tube feeding going to prolong the patient’s life at this stage?
The patient was dying from the severe pneumonia. Starting tube feeding would not prolong the patient’s life. Inserting a feeding tube was not comfortable, and there could even be risk of further aspiration if tube feeding were started.

b. Was the wish to die with a full stomach the wish of the patient?
Though “dying with a full stomach” is a traditional preference among some elderly Chinese, the request was raised by the patient’s son and not the patient. There was no evidence that the patient previously requested, while competent, to have a full stomach in the dying phase. On the contrary, the patient previously voiced out his dislike against tube feeding.

c. Balancing the benefits and harms, should tube feeding be provided?
Decision to tube feed or not should depend on whether the treatment was in the patient’s best interests, rather than what the family members preferred. Here, balancing the benefits and harms, and taking into account the wish of the patient, it should be quite clear that tube feeding was not in the patient’s best interests and thus should not be provided.

After reaching the conclusion that tube feeding should not be provided, the doctor had to handle the son’s request in an appropriate manner. Rather than just telling the patient’s son that he had no right to request the treatment, it would be better for the patient’s son to understand the rationale of the final decision. This would help to reduce conflicts and reduce guilt feelings in the son after the patient’s death. The doctor should explain to the son that treatment given had to be in the patient’s best interests, and that tube feeding would do more harm than good to the patient and was not in line with the wish of the patient. It would be useful to involve the other family members in the discussion, who might understand better the view of the healthcare team. If differences in opinion persisted despite thorough communication, the healthcare team was not obliged to provide clearly futile treatment not in the best interests of the patient. Adequate documentation of the rationale for the final decision should be made in the medical notes.

i The case and commentary was adapted from an article by Dr. Tse Chun Yan, “Practical Approach to Clinical Ethics at the Bedside for General Physicians”, published in Synapse, Newsletter of the Hong Kong College of Physicians, in August 2016. The case was originally presented by Dr. Wong Che Keung of Ruttonjee and Tang Shiu Kin Hospital on 23 April 2016 in the Clinical Ethics Day held in HA Head Office Lecture Theatre.
Mrs. Wong is a 65-year-old retired teacher. She lives with her husband and they have no children. She is an active person who enjoys going on hikes with her husband. About two months ago, Mrs. Wong presented to the hospital with respiratory failure and was emergently intubated and admitted to the ICU. She was found to have tracheal and right bronchial obstruction by a mediastinal mass. The cardiothoracic surgical (CTS) team placed a tracheal stent and performed a mediastinoscopy with mediastinal lymph node biopsy. Although her respiratory status initially improved after stenting, her course was complicated by stent migration causing lung collapse. The CTS team brought her back to the OT and the stent was successfully replaced. Still, for a couple of weeks, her condition remained difficult to manage as she developed ventilator-associated pneumonia and had frequent episodes of desaturation due to mucus plugging.

Eventually, her condition improved and she was successfully weaned from the ventilator. That day, the biopsy results came back. Unfortunately, it confirmed advanced stage of an undifferentiated carcinoma with evidence of left adrenal metastasis on CT scan. An oncologist was consulted about treatment options and indicated that the patient is not a candidate for chemotherapy or radiation due to her tenuous respiratory status.

Dr. Tong, the ICU physician taking care of Mrs. Wong, broke the news with the patient and her husband. He explained the overall poor prognosis and the high likelihood that the respiratory failure could recur as this cancer is unresectable. This was shocking news to Mrs. Wong and her husband. Nevertheless, they were able to accept this news.

Furthermore, to plan for future medical decisions that may arise, Dr. Tong explained that if Mrs. Wong’s cancer causes blockage of her airway again leading to respiratory failure, she will likely require intubation but the chance that she will be able come off the ventilator would be very low. Given that the harm would likely outweigh the benefits of this treatment, Dr. Tong made the recommendation that the patient not be re-intubated again in the future.

Hearing this, Mrs. Wong nods in agreement. “I would not want to be hooked up to a breathing machine again if I cannot come off. This is not the state that I want to be at the end of my life,” she said with her husband sitting beside her and holding her hand.

A couple days after this conversation, Mrs. Wong was transferred to the medical ward to continue her antibiotics course. A week later, she suddenly developed respiratory distress and then had a cardiac arrest. She was resuscitated in less than one minute with return of spontaneous circulation and breathing but remained unconscious. The CTS team performed a bronchoscopy and found that her respiratory failure was due to stent migration of a poorly-fitted stent. They had purchased a tailor-made stent for her and planned to take her to the OT for stent replacement. Meanwhile, the CTS team requested that the patient be admitted to the ICU since the patient needed to be intubated for the procedure and will likely need ventilator care afterwards.

The case medical officer consulted Dr. Tong on the question of ICU admission. He conveyed that the husband is sobbing at the patient’s bedside and is pleading with the doctors to “do everything to save my wife.” When considering this question, Dr. Tong thought of the following. Although he and the patient had previously agreed on the plan for no re-intubation, Dr. Tong felt that plan was made without knowledge of the availability of a new stent. According to the CTS team, the stent replacement, if successful, may possibly allow the patient to come off the ventilator again and live for several weeks or perhaps a couple of months.

On the other hand, Dr. Tong also know that the stent replacement does not guarantee that the patient can come off the ventilator. Even if she does, it is only a temporary measure. The underlying cancer is not reversible. Furthermore, there are only a couple of remaining ICU beds in the hospital. If he admitted Mrs. Wong to a bed, it may leave another critically ill patient with a better prognosis after ICU care without a bed when needed. Dr. Tong was unsure whether or not to admit Mrs. Wong to the ICU.
Mrs Wong
ICU TRIAGE FOR PATIENT WITH ADVANCED CANCER

Commentary

- Dr. Derrick Au Kit Sing, Director, CUHK Centre for Bioethics

We often think of ethical decision-making as making the ‘right’ decision but in real bedside scenarios there will be dilemmas where it is unclear if a single ‘right’ decision exists. The decision would have been straightforward in this case if the intervention were clearly medically futile. In this case, even though the underlying malignant condition is beyond active interventions, the CTS team considered that the tailor-made stent replacement “may possibly allow the patient to come off the ventilator” and the patient may live for several weeks or a couple of months if successfully weaned. Note that the patient had been through this once – with a stent (not tailor-made) successfully placed before, she was successfully weaned from the ventilator after a couple of weeks.

The decision would also have been straightforward had the patient expressed that she would never wish to be intubated again after that experience. But in this case, what she said was that she would not want to be hooked up to the machine at the end of her life. This left us with significant uncertainty: Did she mean “refusing intubation till the very end”, or did she mean that at this end stage of her life, with a few weeks or a couple of months to go, she already wished no more intubation – even if there was hope of extubation?

One may say that it is impossible to foresee and exhaust all possible scenarios to obtain the patient’s advance instructions. That is why advance care planning should not be limited to treatment preferences for particular situations. When time and circumstances permit, it should also seek to clarify the rationale behind the patient’s decisions. If the patient’s values and views (particularly on burdensome treatments) can be understood, it will be helpful in handling unforeseen scenarios.

The husband sobbingly pleaded to ‘do everything to save my wife’. He was unlikely to literally mean ‘doing everything’ – for instance, would he wish her to undergo aggressive chemotherapy beyond this critical stage? It may be appropriate at this juncture to emotionally support him and then invite him to consider: “What do you think she would have wanted if she were able to express her wish at this juncture?”

The underlying concept here is “substituted judgement”. A loved one, often a family member, is asked to make a difficult decision regarding withholding a life-sustaining treatment. A distinction needs to be made – though sometimes difficult – between what the patient would have wanted and what the loved one wishes. The patient’s voice should take priority over the loved one’s own view. In this case it is not clear if such distinction has been made.

There is an underlying issue of scarcity of ICU beds. Any patient admitted to ICU and occupying an ICU bed for a prolonged period may potentially affect the chance of admission for a subsequent patient. Admission criteria to ICU are often based on severity, prognosis, and reversibility of the critical condition. When two patients present at the same moment competing for the only remaining bed, it may be reasonable to consider their relative likelihood to benefit. In this case there are still a few beds vacant and it can be problematic to exclude a patient solely based on the worry that a future patient may lose out.

From the point-of-view of the ICU team, a pragmatic approach is tempting – based on experience of how soon the few remaining vacant beds will last, and whether this patient is likely to occupy a bed for a prolonged period, the team may consider this patient to have “low net benefit” compared to another prospective patient. But the point in this case is that it is not clear if the tailor-made stent procedure has “low net benefit”. It would be helpful for the ICU team to seek more clarification from the CTS team on the specific point that the stent “may possibly allow the patient to come off the ventilator”. It makes some difference if that possibility is remote – in which case it will be more like a medically futile intervention. If there is a good chance that the stent will serve the useful purpose, the decision of this last round of intervention may be better justified.
Mrs Kwok has been healthy her whole life. At the age of 88, she takes regular walks in her neighborhood and does some cooking and light housework in the home. She lives with her husband and her eldest son’s family. She also has a younger son and a daughter and enjoys visits from her many grandchildren. About a week ago, she developed abdominal pain, nausea and vomited a few times. Her eldest son, Chung Man, brought her to the hospital and she was admitted to the medical ward.

A CT scan of her abdomen showed evidence of bowel obstruction from a mass in her colon. A nasogastric tube was placed for decompression and dark green bilious fluid immediately drained into the collecting container. A colonoscopy with biopsy was subsequently performed which confirmed the diagnosis of colorectal cancer. Upon seeing the biopsy report, the medical officer, Dr. Leung, went to speak with the patient. He found the patient asleep in her bed while Chung Man sat beside her.

The doctor informed Chung Man of the diagnosis. Looking concerned, he asked, “What can be done, doctor? How can we let her eat? She can’t keep anything down now.” Dr. Leung replied, “We’ll need to ask our surgery consultant to see your mother first before we know what treatment options would be best for her.”

Chung Man replied, “Ok. Doctor, please don’t tell my mother about the diagnosis. I don’t want to upset her and cause her to be overly anxious.”

Dr. Leung nodded. He had wondered whether the patient has any cognitive impairment as she seemed to have some trouble with her memory and wasn’t sure about her decision-making capacity anyway. He asked a geriatrics consultant to assess her cognitive status.

After a thorough evaluation, the geriatrics consultant thought Mrs. Kwok has mild cognitive impairment but felt that she has capacity to make medical decisions about treatments for the cancer. The geriatrician then asked the patient whether she would like to find out from the doctors about her condition. Mrs. Kwok shook her head. “No, I don’t need to know. You should just tell everything to my son.”

Then the geriatrician pressed on, “If you don’t know about your condition, then you wouldn’t be able to make good decisions about your care.” To that, Mrs. Kwok replied, “I want Chung Man to make all decisions for me. I’m too old. I don’t know very much and these medical things are too complicated for me. I trust my son would know what to do.”

The next day, the surgeon saw Mrs. Kwok and recommended surgical resection of the mass to the team. However, when Dr. Leung informed the surgeon that the patient does not know about her condition and prefers not to find out and defers all decision-making to her son, the surgeon was unwilling to comply. He responded, “How can we keep the truth from a competent individual, especially one who we may be doing surgery on? I do not feel comfortable cutting into the body of someone who did not agree to the surgery herself. What will happen when the patient wakes up and finds a big incision in the middle of her abdomen? We cannot lie to her!”

Dr. Leung is unsure whether or not to tell the patient the truth.
Commentary

- Dr. Tse Chun Yan, Chairman, HA Clinical Ethics Committee (2005 to 2017)

The role of the family in decision-making in Chinese society

The case illustrated the importance of cultural factors in ethical dilemmas related to breaking bad news. Here, there was discordance between the view of the patient’s son and the surgeon. Mrs. Kwok’s son did not want the patient to know, in order to protect the patient from psychological harm. Such an attitude has been common in Chinese families, and ethicists have raised the concepts of protective truthfulness and family determination to justify deceiving a patient who wants to know the truth.

It is true that, in traditional Chinese culture, major decisions are often made by the whole family together. But this does not necessarily mean excluding the patient, and some have questioned whether the principle of non-maleficence can really override the principle of autonomy in such a situation. However, in this particular case, the view of Mrs. Kwok herself was in line with her son. She did not want to know, and wanted her son to make treatment decisions for her. In this case, can we simply follow the wish of the patient and her son?

Psychological harm to the patient

Firstly, let us look at psychological harm to a patient from truth disclosure in general. To balance the principles of non-maleficence and autonomy, we have to answer two questions:

a. Can non-disclosure actually avoid psychological harm?
   There is little evidence that terminally ill patients who are not told the truth die happily in blissful ignorance. When the patients guess the diagnosis and prognosis themselves, psychological harm will still occur. There could be extra harm to patients who guessed the diagnosis themselves. A conspiracy of silence usually results in a heightened state of fear, anxiety and confusion. It undermines trust towards the clinical team, and breaks down communication with family members. Patients are unable to obtain information they want to know, express emotions after guessing the diagnosis, obtain appropriate psychological and spiritual support, nor make suitable plans for their limited future with the family. Worse still, patients may pretend that they do not know in order to please family members.

b. Are there ways to reduce the harms of truth disclosure?
   Experience especially in palliative care has shown that sensitive, skilled communication coupled with good psychological, social and spiritual support can reduce the harm from breaking bad news.
This would mean that if the patient wants to know, the doctor should disclose the truth in the aforementioned manner rather than deceive the patient and let the patient guess the diagnosis himself/herself.

Nonetheless, we still need to address the culture issue. We should respect the desire for family involvement in the communication and decision-making process. The approach must also be individualized. Although recent studies have shown that most Chinese patients want to know the diagnosis, there could be a small number of patients who do not want to know. We need to sensitively explore what the patient already knows and how much he/she wants to know. Those who do not want to know may have denial or avoidance as a defense mechanism, and we should not break the defense mechanism without appropriate support. To respect the patient, we may withhold information, but we should not lie. We also need to re-assess the situation as the disease progresses.

Legal reasons for disclosure

Secondly, we need to know whether there are legal reasons why disclosure has to be made. For a mentally competent patient, it is a legal requirement that a doctor must obtain consent from the patient before providing medical treatment. According to the Hong Kong Medical Council Code of Professional Conduct, consent is valid only if (a) it is given voluntarily, (b) the doctor has provided proper explanation, and (c) the patient properly understands. This implies that, in order to proceed with the operation, the patient has to be properly informed and to consent to the treatment herself. The decision cannot be delegated to the family. Then, does it mean that we should simply disregard the view of the patient and her son and disclose the bad news?

A pragmatic approach

In this particular situation, we can overcome the apparent dilemma by taking a step-by-step pragmatic approach.

a. Step 1:
We start off by discussing with the son about whether surgery should be done for the patient. There should not be a confidentiality problem because this was the request from the competent patient herself. If the son agrees to surgery, we then move onto step 2.

b. Step 2:
We then explain to the son sensitively that, legally, the patient has to be properly informed and consent to surgery before surgery can be done. We also explain that it is actually better to disclose the diagnosis and explain the operation to the patient sensitively, than to have the patient find out herself what is wrong and what has been done. If the son agrees, we then move onto step 3.

c. Step 3:
We then explain to the patient sensitively that the doctor has followed her request to discuss with her son and her son has decided that surgery should be done for her condition. However, she needs to consent to the operation herself, and thus the doctor has to discuss with her directly. If the patient agrees, we then move onto step 4.

d. Step 4:
We then break the bad news to the patient sensitively and discuss the treatment plan to obtain a proper consent. Appropriate support to the patient should be given along the way.

Going through these steps and with agreement from the son and the patient, the disclosure does not violate any ethical principles. If the son does not agree, or if the patient still does not want to discuss the illness, further discussions should involve a senior clinician with good knowledge and skills in breaking bad news. One should try to explore the concerns of the son and the patient, to assess any misconceptions, denial and anxiety, and to provide clarification and support. At the end, one should be able to succeed.
Introduction

In Hong Kong, tube feeding in advanced dementia patients is highly prevalent, particularly amongst those living in residential care homes for the elderly (RCHEs). However, feeding tubes are most frequently placed during an acute hospitalization where decisions are made with healthcare providers who are unfamiliar with the patients. Clinicians commonly rely on the swallowing assessment that a patient is high aspiration risk to justify feeding tube placement. This can be problematic if the decision neglects to consider other factors that are important to the best interests of the patient. Compounding the problem is the fact that many clinicians have inaccurate expectation of benefits from tube feeding that is not supported by evidence. Given that tube feeding carries significant risks and can negatively impact a patient’s quality of life, healthcare providers have an important responsibility to help families make informed decisions that support their loved one’s values and best interests. This article provides a step-by-step approach to guide clinicians on the decision-making process about feeding tube placement in advanced dementia patients [Figure 1].

Step 1: Investigate the etiology of the feeding problem

Eating difficulties in dementia patients can be due to many causes. The first step is to thoroughly evaluate whether the underlying cause is reversible. For example, poor appetite can be due to depression, dental problems, untreated pain, dry mouth, constipation, and medication side effects. All of these can be reversed with proper treatment. For problems that are manifestations of dementia such as apraxia resulting in inability to use utensils or refusal to open the mouth, conservative strategies such as providing finger food, cueing, altering the environment, and stimulation with different food temperatures, textures, and flavors can be tried. In Hong Kong, specialized dementia feeding programs in certain public hospitals have been successful in overcoming eating difficulties in some dementia patients through conservative feeding strategies.

Step 2: Determine the patient’s overall prognosis

Healthcare providers and family often don’t recognize that dementia is a terminal illness. Average life expectancy after initial diagnosis is 4 to 9 years. Difficulty swallowing leading to recurrent aspiration pneumonia is common in patients in the advanced stage and may be a sign that the patient is near the end of life. Recognizing the patient’s stage in the disease trajectory is important to determine the prognosis and the likelihood of benefit from tube feeding. Prognostication tools such as the Functional Assessment Staging Tool (FAST) can help clinicians make this determination. Consultation with a geriatrics specialist may be helpful in some cases.

Figure 1. Steps to considering feeding tube decisions in advanced dementia patients

| Step 1 | Investigate the etiology of the feeding problem |
| Step 2 | Determine the patient’s overall prognosis |
| Step 3 | Weigh risks and benefits of tube feeding and alternatives based on evidence |
| Step 4 | Individualize decision through a shared decision-making process with family |
| Step 5 | Comply with institutional policies on artificial nutrition and hydration (ANH) in terminally ill patients |
BACKGROUNDER

DECISIONS ABOUT FEEDING TUBES IN ADVANCED DEMENTIA

Step 3: Weigh risks and benefits of tube feeding and alternatives based on evidence

If a reversible cause cannot be identified and conservative strategies have been exhausted, clinicians should then determine how the evidence for tube feeding applies to the patient at hand. Contrary to a common misconception amongst healthcare providers that tube feeding can improve survival, this has not been shown in studies for patients with advanced dementia.14,19 This is consistent with the findings of a local study of elderly RCHE residents with advanced dementia where 1-year mortality was high at 34% and enteral feeding was a risk factor for mortality.2

In advanced dementia patients, tube feeding has not been shown to prevent aspiration pneumonia. Aspiration of oropharyngeal contents and regurgitated stomach contents can still occur.16,20 Tube feeding may even increase aspiration events since it decreases the lower esophageal sphincter pressure, making gastroesophageal reflux more common.21 Furthermore, tube feeding has not been shown to improve functional and nutritional status in advanced dementia patients.6,14,20 Tube feeding carries other significant risks including bleeding, mucosal erosion, vomiting, diarrhea, and tube blockage and dislodgement requiring repeated re-insertions.6 In Hong Kong, nasogastric tubes are more commonly used than percutaneous endoscopic gastrostomy tubes but are more uncomfortable.5 Physical restraints may be used to prevent patients from pulling out the tube. This not only worsens agitation in a demented patient, but also limits mobility leading to increased rates of pressure sores.19,23

An alternative strategy for feeding problems in advanced dementia is careful hand feeding (CHF).24 In CHF, a trained carer feeds the patient orally using feeding techniques and closely observes the patient for choking and pocketing of food. Although CHF cannot prevent aspiration events, it is no worse than tube feeding for the outcomes of aspiration pneumonia, functional status and death.22,25 CHF may be preferable when considering the patient’s quality of life. Unlike tube feeding, CHF allows patients to enjoy the pleasure of eating and socialization during meal times. Given these risks and benefits, the American Geriatrics Society recommends CHF over feeding tubes for eating difficulties in older adults with advanced dementia.26

Step 4: Individualize decision through a shared decision-making process with family

Clinicians should involve the family in the decision-making when considering the option of tube feeding and its alternatives. The decision should prioritize any preferences of the patient if known, such as documented in an advance directive. If the patient’s preferences are not known, then the decision should be based on the patient’s best interests. Besides having a firm grasp of the clinical facts and evidence, clinicians should consider other factors including psychological, cultural, economic and institutional factors that may come into play.27

Families often experience distress when seeing a loved one without adequate nutrition, as providing nourishment is commonly seen as a way to nurture and comfort one who is ill.28 It may take time for families to accept the fact that their loved one is near the end of life and that placing a feeding tube is not going to “fix” the problem. Furthermore, families may hold certain cultural or religious beliefs that influence their perspectives. Clinicians should take on a respectful attitude when listening to their concerns, provide support, and try to find common ground when disagreements arise. A common concern raised by families in the local culture is the fear that their loved one will “starve to death.”27 Clinicians should respond empathically by acknowledging the families’ distress in seeing their loved one’s deterioration and reassure them that their loved one is not experiencing hunger at this advanced stage of illness. The patient is dying because the disease process is causing the body to shut down and not because inadequate nutrition is provided. It should be emphasized that CHF can promote comfort for their loved ones when they are near the end of life.1

It is also important to understand other team members’ and carers’ concerns in the decision process. Practical issues such as the availability of trained staff or caregivers to dedicate time for CHF in the hospital and when patients return to their place of residence are important to consider. As are potential concerns from healthcare staff about legal liability if a patient subsequently aspirates after being hand fed. Institutions need to have strong policy support for CHF and a culture that promotes end-of-life care in order for this practice to be successfully implemented.27
Step 5: Comply with institutional policies on artificial nutrition and hydration (ANH) in terminally ill patients

When the healthcare team and family jointly decide that tube feeding is not in the best interest of a patient, clinicians should follow their institutional policies on withholding tube feeding. In Hong Kong public hospitals, clinicians should refer to the Hospital Authority’s Guidelines on Life-Sustaining Treatment in the Terminally Ill. For patients whose death is imminent (death is expected within a few hours or days), it is acceptable to withdraw or withhold ANH without a valid advanced directive. For patients whose death is not imminent, the decision requires consensus with the family and within the healthcare team. The team must include two doctors, one of whom is a specialist in a relevant field (e.g., geriatrics or palliative care). In the case where the patient is unable to swallow and thus CHF cannot be offered as an alternative, the team must also seek advice from the cluster clinical ethics committee. Two exceptions to this requirement are 1) patients who have previously expressed a clear wish to refuse tube feeding verbally to family members or in an advanced directive and 2) patients who are actively and persistently resisting tube feeding, such as repeatedly pulling out their nasogastric tube (HA Guidelines 2015).

Conclusion

The decision about tube feeding for advanced dementia patients should be made in accordance with the ethical principles of patient autonomy and benevolence. Still, it should be a shared decision that ensures accurate communication about the patient’s prognosis, risks and benefits of tube feeding versus alternatives, and respects the family’s and healthcare team’s perspectives. Ideally, patients diagnosed in the early stages of dementia would have a chance to express their preferences about tube feeding and other preferences for future medical care while mentally sound. The advance care planning process can continue with the family after the patient loses capacity whenever signs of disease progression appear. In this manner, families will have more time to come to terms with the expected trajectory of their loved ones’ illness and avoid the need to make decisions during a “crisis” when the patient is hospitalized. Through earlier conversations, families can also make better decisions that honor their loved ones’ wishes and provide them with dignified care at the end of life.

References

BACKGROUND
ADVANCE CARE PLANNING AND ADVANCE DIRECTIVES IN HONG KONG: CONCEPTS AND DEVELOPMENTS

- Dr. Tse Chun Yan, Chairman, HA Clinical Ethics Committee (2005 to 2017)

Background

With contemporary development in medical technologies, many life-sustaining treatments can still be offered near the end of life. However, some of these only prolong the dying process, doing more harm than good, and are against the patient’s wishes. It is generally agreed that such futile treatments may be withheld or withdrawn in suitable situations.1 Firstly, when a competent patient decides not to receive a life-sustaining treatment (LST), the refusal must be respected. Secondly, for an incompetent patient, when the healthcare team and the family members consider that the treatment is not in the patient’s best interests, the treatment can be withheld or withdrawn. However, deciding what is in the patient’s best interests often involves not only medical considerations, but also quality of life considerations which can be value laden. If the prior preferences or values of the incompetent patient are not known, there could be difficulties for the healthcare team and family members to reach consensus.

Such difficulties could be alleviated if the patient, while competent, has made an advance decision refusing certain LSTs. The person may specify what LST one does not want under what situations (e.g. terminally ill or irreversible coma). In Hong Kong, the term Advance Directive (AD) usually refers to this. In some other countries, such advance refusal is called ‘living will’, and the term AD may also include appointment of a proxy decision maker on healthcare issues. Under the common law framework in Hong Kong, according to the Law Reform Commission of Hong Kong (LRC) Report on AD in 2006,2 a valid and applicable AD refusing medical treatment has the same effect as a contemporaneous oral instruction, and must be respected. However, a proxy directive on healthcare issues currently does not have legal status in Hong Kong.

Development of guidelines on AD

ADs were seldom discussed among healthcare professionals or among the public in Hong Kong until 2004, when LRC issued a public consultation paper on ADs. In 2006, LRC released her report on the issue, recommending ADs to be promoted under the existing common law framework instead of by legislation. LRC further proposed a model AD form, the scope of which is limited to the terminally ill, irreversible coma, and persistent vegetative state. But it is not the only format of ADs that can be used under common law. In 2009, Health and Food Bureau of the Government of HKSAR issued the Introduction of the Concept of Advance Directives in Hong Kong Consultation Paper.3 In the Paper, the Government expressed no intention to advocate the public to make ADs, but suggested to provide more information to the public about the concept of an AD, and to have guidelines for professionals. Furthermore, the Paper considered whether to promote the concept of advance care planning (ACP) in Hong Kong.

In 2010, the Hospital Authority of Hong Kong (HA) issued the Guidance for HA Clinicians on Advance Directives in Adults, and revised the Guidance in 2014 and 2016.4 The HA AD form was modified from the LRC model form. In its 2010 version, the scope of the HA AD form was limited to the terminally ill, irreversible coma, and persistent vegetative state. Upon revision in 2014, a new category “other end-stage irreversible life-limiting condition” (such as end-stage renal failure, end-stage chronic obstructive pulmonary disease, and end-stage dementia, etc.) was added. According to the Guidance, the validity of an AD may be doubted if:

- the AD is ambiguously drafted,
- the AD was not properly signed,
- there are claims or suggestions that the patient had been under undue influence at the time of making the AD,
- there is reason to suspect that the patient was not competent or was not properly informed when the AD was made, or
- the patient has done something that clearly goes against the advance decision which suggests that he/she has changed his/her mind.

An AD becomes applicable when the patient suffers from the pre-specified condition, and is no longer competent. A valid and applicable AD has legal status, and family members cannot override it. If there is doubt about the validity or applicability of an AD, the healthcare team should continue to provide all clinically indicated emergency LSTs, while waiting for clarification. Such treatments may be withdrawn after the validity and applicability of the AD becomes clear.
Making AD via advance care planning

The approach to the making of an AD varies among different countries. Currently in HA, ADs are usually made by patients with advanced irreversible illnesses via advance care planning (ACP). ACP is often defined as a process of communication among patients, their health care providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient cannot make decisions. Some places adopt a broader definition and include discussions with family members of incompetent or minor patients within the scope of ACP.

In September 2015, HA updated their Guidelines on LST in the Terminally Ill, and added a new section on ACP. The updated Guidelines recommend that the ACP process may be initiated in any of the following situations: following the diagnosis of a life-limiting condition with a rapid downhill course, early cognitive decline in dementia, significant disease progression, discontinuation of disease-targeted treatments, transition to palliative care, recovery from an acute severe episode of a chronic disease, following multiple hospital admissions, or when the patient becomes institutionalized. However, the approach must be individualized, and it is important to assess whether the patient is ready for such a discussion before embarking on it. The discussion should be made sensitively with good communication skills. A rigid, routinized or checklist approach is not recommended. The scope of the discussion may include anticipated progression and prognosis of the illness, treatment options available and the benefits and risks, the patient’s preferences and values regarding medical and personal care, and views and concerns of family members. Outcomes of ACP may include decisions on preferences for future medical or personal care, making an AD, and assigning a family member for future consultation when the patient becomes incapacitated.

Respecting an AD in an emergency situation

Before deciding to respect an AD, a doctor has to judge whether the AD is valid and applicable. This is not easy in an emergency situation, especially if there is an out-of-hospital cardiac arrest, which requires an immediate decision. To overcome this difficulty, many states in the USA developed the “Physician Orders for LST” (POLST) system. In the UK, guidelines and procedures have been developed to enable compliance to a Do-Not-Attempt Cardiopulmonary Resuscitation (DNACPR) form by other health care providers, including ambulance staff. In Hong Kong, the HA DNACPR form for non-hospitalized patients promulgated in 2014 is along this direction. Unfortunately, the approach is not yet accepted by the ambulance crew, because of the concern over the “duty to resuscitate” in the Fire Services Ordinance.

Legislation for AD

While the HA guidelines may facilitate the use of ADs and ACP in the Hospital Authority, there have been questions raised by professionals and members of the public regarding ADs and ACP. One of the concerns is the lack of legislation on ADs in Hong Kong. Although the Law Reform Commission report of 2006 expressed that, under the common law framework, a valid and applicable AD refusing medical treatment must be respected, there could be grey areas. Under Section 592F of the Hong Kong Mental Health Ordinance Cap 136, a doctor may provide life-sustaining treatments to an incompetent patient without consent if this is in the best interests of the patient. The relationship with an advance refusal of treatment is not mentioned in the legislation. Some may argue that, based on the patient’s best interests, a doctor can override his/her AD. Although, in the great majority of cases, the patient’s advance refusal and the patient’s best interests are in line, it will be useful to have legislation to clarify the relationship between this section of the Ordinance and an AD, to avoid controversies in difficult cases.

Healthy members of the public making an AD

The approach towards promotion of ADs among healthy members of the public differs among different countries, ranging from wide promotion in the USA to a more judicious approach in the UK. Some consider that there could be problems in indiscriminate signing of ADs among healthy members of the public. There is not much controversy in making an advance directive for the condition of permanent severe neurological injury. Such injury may result from unexpected catastrophic events, for example, massive stroke or trauma. Because the poor quality of life of permanent severe neurological injury per se is the same regardless of the underlying cause of the condition, the decision is more straightforward. However, an advance decision regarding future terminal illness can be problematic in several ways. Firstly, to properly cover a range of possible scenarios that can lead to a terminal illness in the future, the information needed may be overwhelming and distressing. Secondly, the quality of life of
different illnesses in the terminal phase can be quite different, and it may not be appropriate to make a broad brush decision without knowing what will be faced. Thirdly, a healthy person’s perception of hypothetical illness states may be worse than the perception of a chronically ill patient, and the acceptability of treatments resulting in certain diminished states of health may increase with time. This implies that a person’s preference for treatment may change when the person becomes ill.

Actually, when a serious illness is diagnosed, most patients still have the capacity to make appropriate decisions. It may be more useful for healthy members of the public to prepare themselves and their families for contemporaneous decisions that arise during future illness, rather than make premature advance decisions about LSTs. To get better prepared for such decisions, it is important for healthy members of the public to learn more about the dying process, and to understand the meaning of LSTs and ADs. While they may not necessarily sign an AD before the onset of a serious illness, elderly members of the public should be encouraged to discuss with their family about preparation for death, and to express personal values and preferences about end of life care. This requires concerted efforts in public education by healthcare providers, social agencies and the Government of Hong Kong. If an elderly but relatively healthy member of the public prefers to sign an AD, the AD can be limited to the goals of care in the event of permanent severe neurological injury. When the person develops a serious illness, the AD can then be extended to other relevant scenarios.

What should be done to reduce difficulties in end-of-life decisions in Hong Kong?

While the Hospital Authority should continue to promote ADs in patients with advanced incurable illnesses as part of ACP, more work needs to be done in other aspects. There should be more education among healthcare professionals about ACP/ADs to improve their knowledge and communication skills required to handle such issues. For the general public, more death education should be promoted, so that people can have appropriate knowledge and emotional preparedness to face their own illnesses, as well as illnesses of family members and friends that may be expected or unexpected.

To improve the quality of dying, we should look beyond ACP/ADs. The overall medical care and social support for end-of-life patients should be improved, without which there could be difficulties to achieve some of the expressed preferences and wishes of the patient, e.g. good symptom control, preferred place of death etc. The improvement should not be limited to specialist palliative care, but should also include all services that have a role in looking after dying patients. To make this happen, there is a need for a government policy on end-of-life care, revising/enacting relevant legislations as necessary. After all, death is the common destiny of all human beings. It will be good if we can have some say about how to travel through this last journey of our life peacefully, and leave a fond memory among those we treasure in our lives.

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