賽馬會安寧頌
JCECC
Jockey Club End-of-Life Community Care Project

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

Initiated and Funded by

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Partner Institution

香港中文大學
The Chinese University of Hong Kong

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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.

THEMES

Advance Care Planning

Goals of care

Advance Directives

Truth-telling

Moral distress

Life-sustaining treatment

Futility

Informed consent

Cultural beliefs

Family conflict

Best interest

Case 1

Mr. Lau

CONFLICT BETWEEN TEAM MEMBERS

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.

Case 1

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.

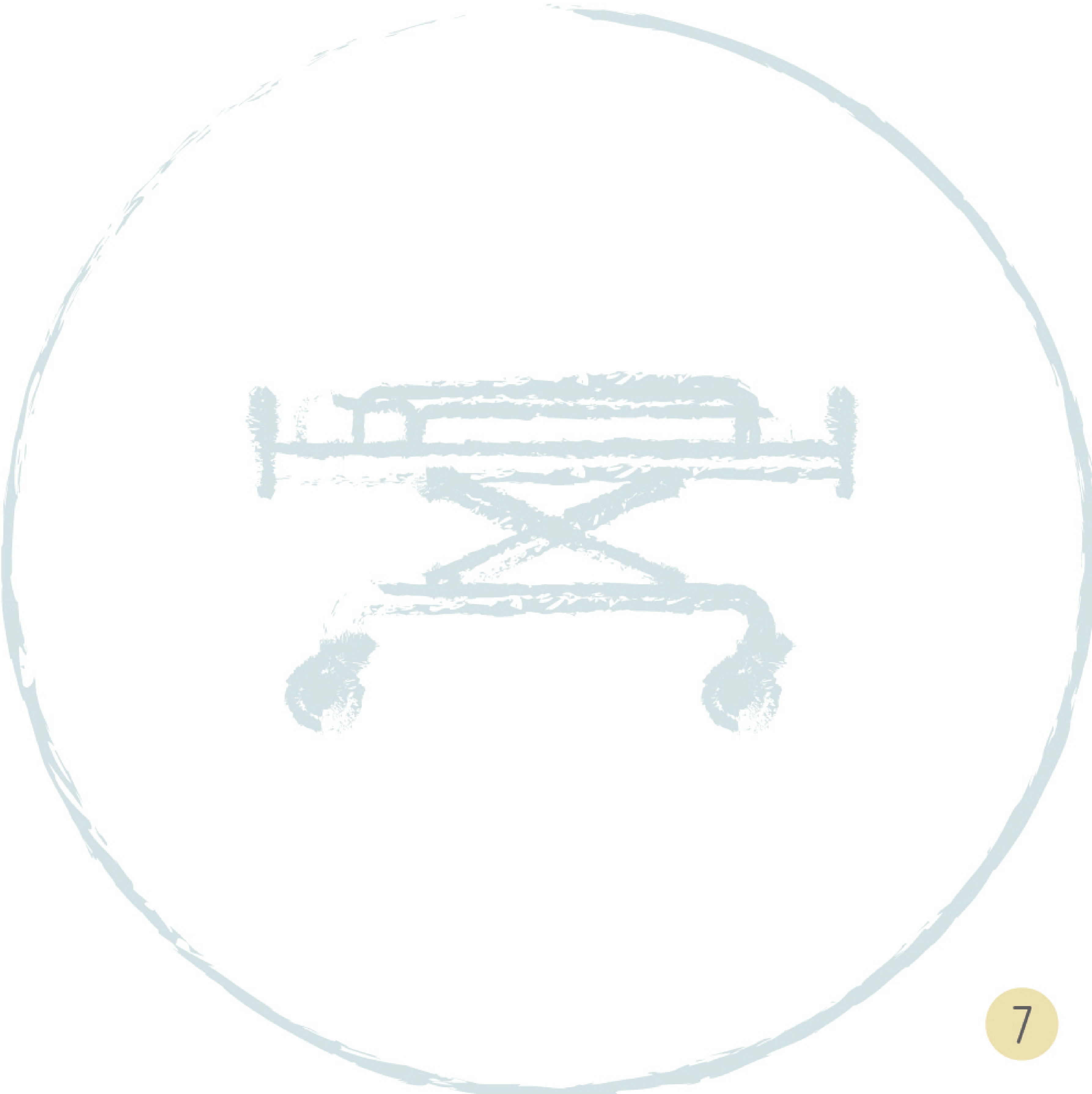
d. If the patient was already incompetent, did the patient previously express his values and preferences regarding life sustaining treatment?

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.



Case 2

Mr. Chan

FEEDING TUBE DECISION IN A DYING DEMENTED PATIENT

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.

Case 2

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.

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.

Case 3

Mrs. Wong

ICU TRIAGE FOR PATIENT WITH ADVANCED CANCER

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 mucous 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.

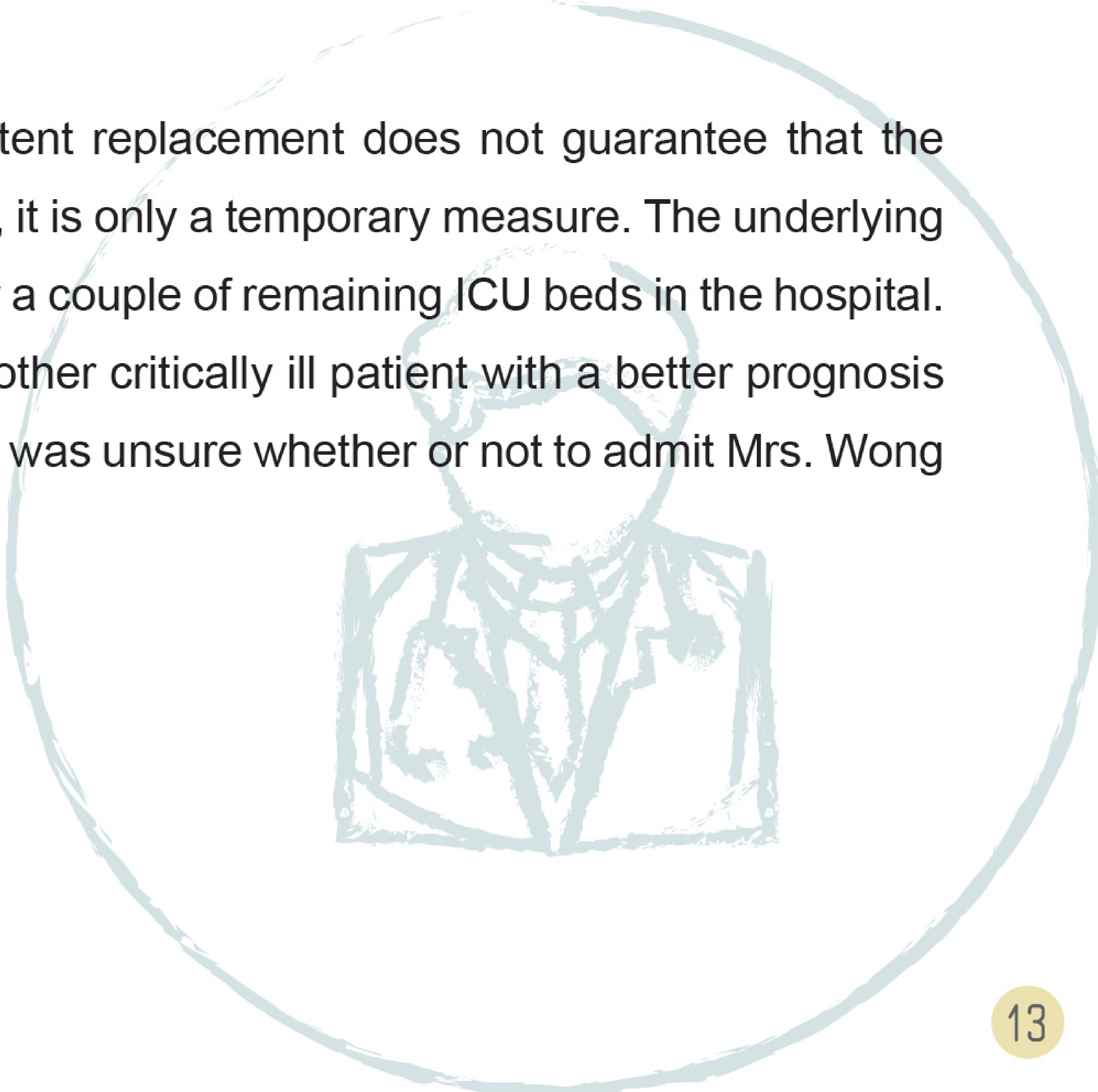
Furthermore, to plan for future medical decisions that may arise, Dr. Tong explained that if Mrs. Wong’s cancer causes blockage of her airway again leading to respiratory failure, she will likely require intubation but the chance that she will be able come off the ventilator would be very low. Given 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 knew 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?

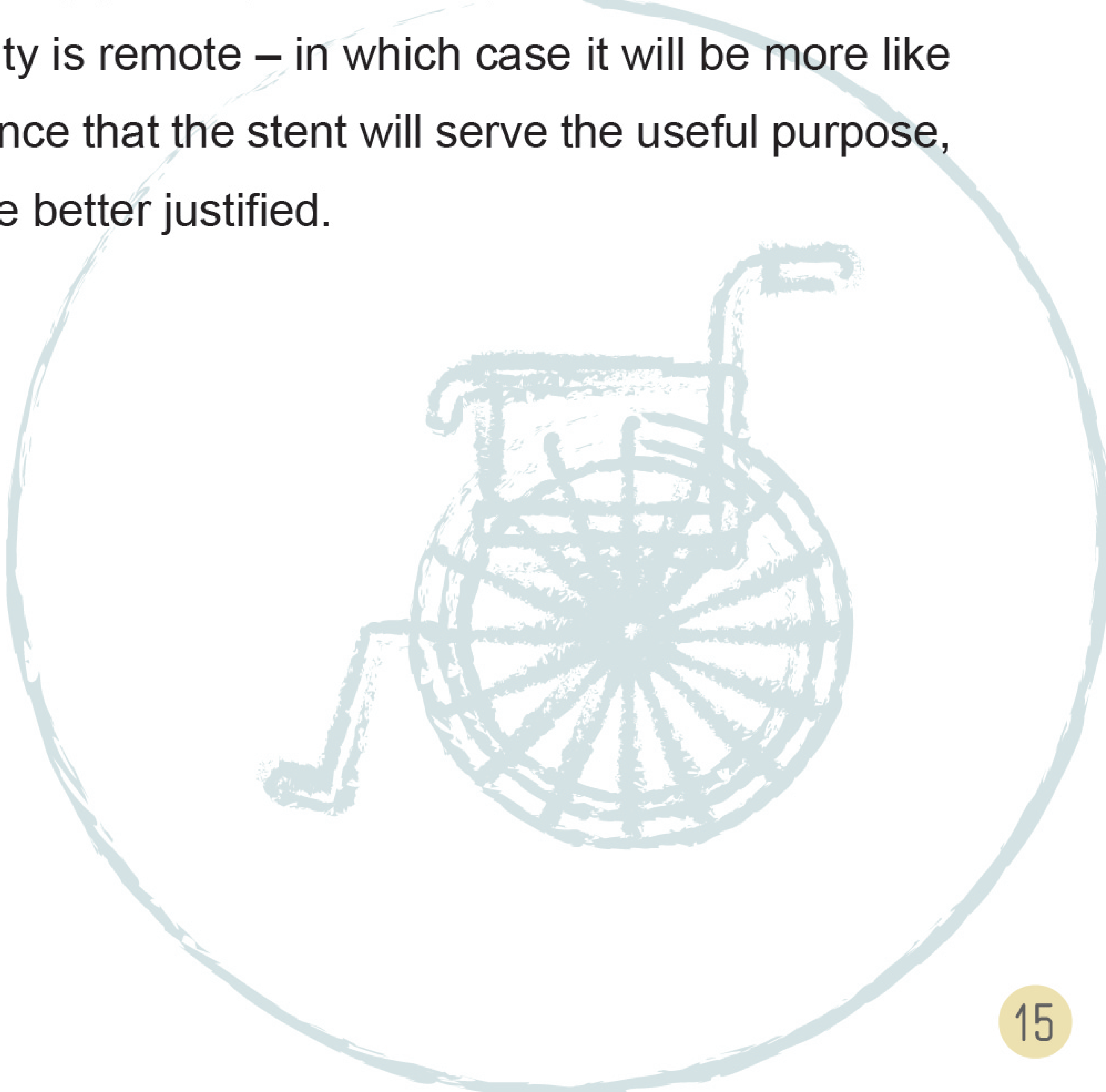
One may say that it is impossible to foresee and exhaust all possible scenarios to obtain the patient's advance instructions. That is why advance care planning should not be limited to treatment preferences for particular situations. When time and circumstances permit, it should also seek to clarify 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.



Case 4

Mrs. Kwok

FAMILY REQUESTS TO WITHHOLD THE TRUTH FROM PATIENT

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 oldest 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.

Mrs. Kwok

FAMILY REQUESTS TO WITHHOLD THE TRUTH FROM PATIENT

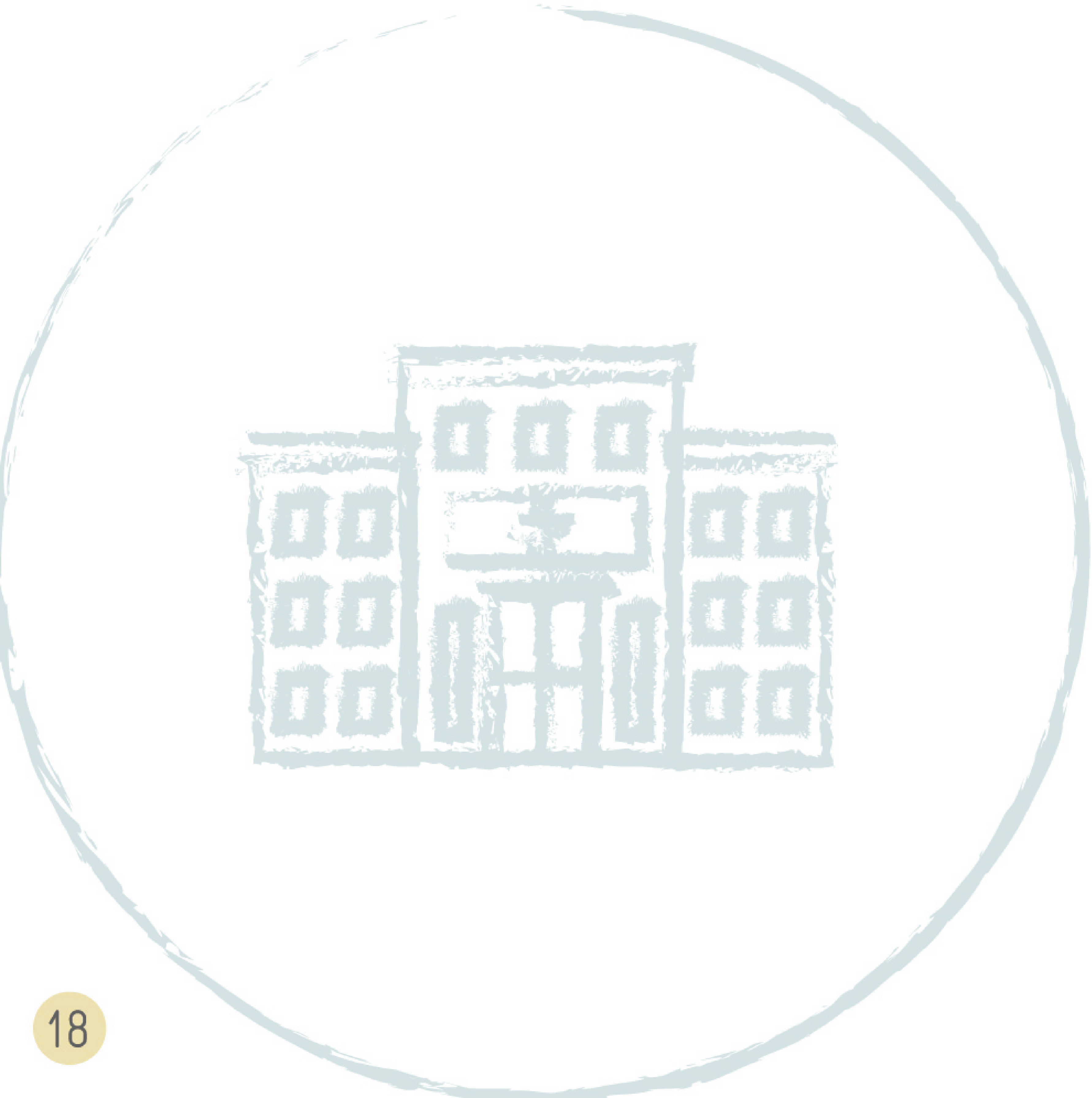
Commentary

- 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?

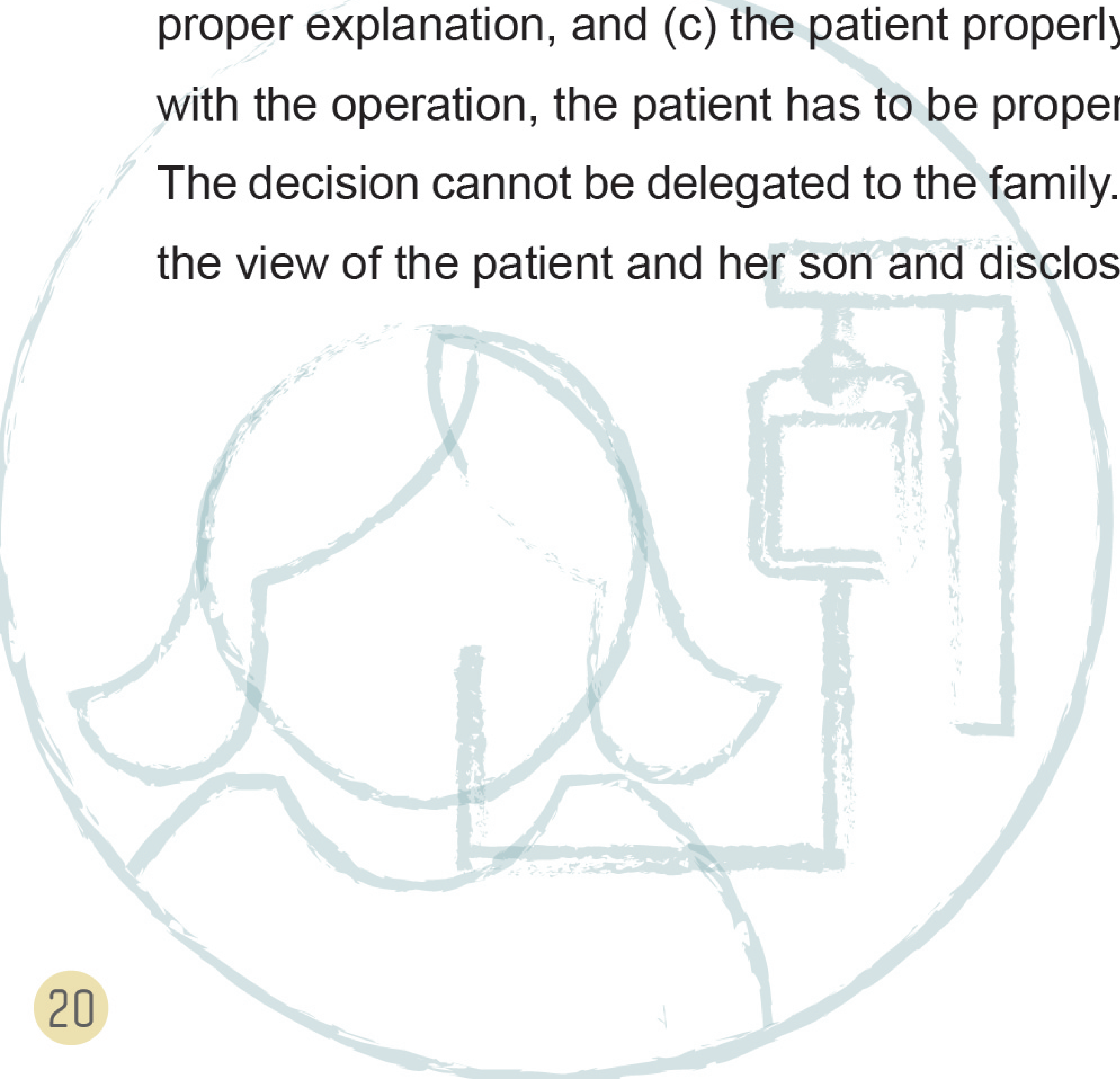
Experience especially in palliative care has shown that sensitive, skilled communication coupled with good psychological, social and spiritual support can reduce the harm from breaking bad news.

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 reassess 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.

Case 5

Mr. Chau

DISAGREEMENTS OVER TIMING FOR ADVANCE CARE PLANNING

Mr. Chau is a 75-year-old man who lives at home with his wife and his son's family. He was a former smoker and suffered from chronic obstructive pulmonary disease (COPD) for many years. Over the past year, he has become more easily short of breath with routine activities like walking around his home, dressing himself or taking a shower. He has also experienced more frequent exacerbations that led to several hospitalizations. In the last six months, he's already been admitted three times. Each time, he was put on a BiPAP machine for several days before his condition improved.

Last week, Mr. Chau was admitted again for another exacerbation of his COPD. After a week of treatment in the respiratory ward, he was finally able to come off the BiPAP mask. However, when the food tray was delivered to Mr. Chau, he pushed the food away. Ms. Leung, a registered nurse in the ward, saw this and recognized Mr. Chau from previous admissions. She approached Mr. Chau to ask why he didn't want the food.

Mr. Chau answered, "What's the point of eating? Just to keep coming back like this and be put on that mask? I'm as good as dead!"

Concerned, Ms. Leung asked Mr. Chau, "Is something wrong? I thought you'd be glad to come off the mask today."

Mr. Chau said, "Well, it's just temporary. I know how bad things are with my lungs. It's just a matter of time. I just don't want to go through the same ordeal over and over again, in and out of the hospital. Then one day, game over. If I'm going to die anyway, I don't want to be strapped to that mask up the final moment! You know how awful it is to be on the mask? You can't eat. You can't talk. It just blows air into your face!"

"It sounds like you're really concerned about being put on that mask again," Ms. Leung said.

"Yeah. I don't ever want to wear it again! Just let me go without making me suffer through all that! I've had enough!"

"Have you told your family how you feel?" asked Ms. Leung.

"I tried. But my wife and son...they won't listen. They don't want me to talk so negatively. They said that I should just listen to the doctor. The doctor barely even has time to talk to me!"

Feeling that Mr. Chau is probably correct about the advanced stage of his lung disease and that he's reasonable to prefer to be comfortable at this point, Ms. Leung decides to discuss Mr. Chau's concerns with Dr. Kam, the doctor-in-charge. She suggested that Dr. Kam should hold a family conference to explain his poor prognosis with his wife and son and to sign an advance directive for Mr. Chau.

However, Dr. Kam disagreed. "It's too premature to sign any advance directives and discuss end-of-life care issues. Mr. Chau's condition can still be relieved by the current treatments. He's ready for discharge soon!"
Ms. Leung felt powerless and does not know how she can help Mr. Chau.

Case 5

Mr. Chau

DISAGREEMENTS OVER TIMING FOR ADVANCE CARE PLANNING

Commentary

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

We may discuss this case as a scenario of moral distress in which the nurse Ms. Leung felt powerless for being unable to do what she considered the right thing for the patient, as the doctor-in-charge held a strong opposite view on what was right.

Ms. Leung's suggestion was to hold a family conference to explain the poor prognosis to the family, and to sign an advance directive for the patient.

Before considering her moral distress, it is useful to take a step back to ask a few questions:

How does Ms. Leung know that her suggestion is the right thing for the patient?
One point is in Ms. Leung's favour – Mr. Chau has tried but failed to get his family to talk about this issue. We can therefore be quite certain that a dialogue is what he wants. Note that the patient's readiness is an important consideration in deciding on the timing for advance care planning.

Was the doctor-in-charge Dr. Kam wrong?

Dr. Kam seemed to have bundled 'discussing end-of-life care issues' with 'signing advance directives'. In discussing end-of-life care issues and allowing the patient to express his/her wishes and values, the advance care planning process may or may not end up with signing an advance directive. In a fast-paced hospital operation, squeezing in the signing of advances directives into the short pre-discharge window may indeed be undesirable, but it is a reasonable time to initiate a dialogue with the patient and the family. Key decisions on withholding life-sustaining treatment such as BiPAP do not have to be forced into one session, but encouraging family members to listen to the patient may be achievable.

Note that in this case the nurse Ms. Leung apparently also fell into the same trap of bundling end-of-life care planning with the immediate decision to sign an advance directive. Had she put forth the suggestion to initiate a dialogue rather than immediately holding a family conference to sign an advance directive, she might have had a better chance of getting her suggestion supported.

Was it just about the BiPAP mask?

Mr. Chau was particularly vivid in articulating the burden of BiPAP, but he also questioned the point of eating, and expressed in general that he did not wish to go through the same ordeal over and over again, in and out of the hospital. It would be valuable to explore more about Mr. Chau's perspectives on medical care. Rather than narrowing focusing on his dislike of BiPAP, the clinical team can find out what medical care Mr. Chau considers too burdensome or intolerable and what he hopes the care to focus on, to develop a plan that honours his wishes appropriately.

Some assessment of his mood may also be called for. Depressive state is not uncommon in patients with advanced organ failure, if significant it may cloud the patient's judgement and perceptions on care plans. Without adequate background exploration and assessment, going directly into a family conference to make an advance directive may be undesirable.

Mr. Chau

DISAGREEMENTS OVER TIMING FOR ADVANCE CARE PLANNING

On moral distress

As separately reviewed by Prof. Helen Chan, "moral distress" was first defined by Jameton (1984) as the negative experience among health professionals when they know the right thing to do but cannot pursue that course of action due to institutional constraint. Much of the literature on this subject focus on moral distress in nursing. The definition of moral distress by Jameton may be disputed. A professional in moral distress is not always right. Moral intuition ('knowing the right thing to do') should go hand in hand with moral reflections and openness to ethical reasoning. Is the 'institutional constraint' real or perceived? If a nurse feels powerless, is it due to a culture of medical dominance (nurses expected to follow doctor's orders), or is it due to the individual nurse's lack of confidence to effectively articulate her case? Nonetheless, it should be fair to say that in some healthcare institutions, the ethical climate is clearly unfavourable for a 'speak-up' culture, and unsupportive of staff in moral distress.

What can the nurse do?

Ms. Leung may feel less distressed if she can explore the patient's wish further. The patient did not ask for a family conference to immediately sort out end-of-life issues and advance directives. What does he really want? As a first step, she may try to ascertain whether Mr. Chau does indeed wish healthcare professionals to mediate a dialogue with his family members concerning his future care. She may then relate such a wish to the wife and son, and at the same time provide them with initial information on the value of the advance care planning process. Mr. Chau is likely a long-term follow-up case. Once such initial exploration has taken place, further dialogue may be possible.

This may be a pragmatic approach to overcome a deadlock. One may argue that taking the pragmatic approach does not always work, and there may well be other scenarios where institutional constraint is undisputable and even unfair. In some circumstances, a healthcare professional may need to bring up the issue of concern to hospital management, or raise conscientious objection to unethical practice.

In this particular case, it would appear that there is room for further assessment of the patient, positive communication within the team, and dialogue with the patient's family.

Case 6

Mr. Ip

WITHHOLDING ANTIBIOTICS AT THE END OF LIFE

Mr. Ip is 96-years old. He lives at home with his wife and has several children in Hong Kong. He has a history of tuberculosis and chronic obstructive pulmonary disease. Over the past year, he started developing difficulty swallowing. A brain scan found evidence of multiple small subcortical strokes. He has been admitted multiple times for recurrent aspiration pneumonias. While each episode was accompanied by periods of confusion and increased debility, his mind would eventually clear and he would talk with his family and friends about Chinese history, one of his favorite subjects.

These multiple hospitalizations had been uncomfortable experiences for Mr. Ip. He sometimes experienced intractable nausea and vomiting and had to lie in bed for days on end. He would ask to go home soon after each time he was admitted. After one of these hospitalizations, he told his wife and his children, "I've lived a long life. When it's my time to go, please do not allow the suffering to be prolonged. I want to go peacefully."

The doctors at the hospital had discussed Mr. Ip's high risk of recurrent aspirations and the speech therapist had recommended placing a feeding tube. His family, heeding Mr. Ip's words and wanting to prioritize his comfort, opted instead for careful hand feeding.

One day, Mr. Ip started choking during a meal and had very labored breathing. He was immediately brought by ambulance to the A&E. He was admitted to the medical ward for aspiration pneumonia. Despite being placed on a facemask with the maximum amount of oxygen delivered, Mr. Ip remained hypoxic and in shock. One of his children at his bedside who is a physician knew that his father was imminently dying. He communicated this to his mother and siblings. Sobbing, Mrs. Ip nodded her head.

The doctor on the medical ward, Dr. Mok, approached the family to explain the plan of starting IV antibiotics and IV fluids. Mrs. Ip replied, "No doctor. We don't want you to start those treatments. It is my husband's wish that he would be able to go peacefully when his time has come. He would not want this to be prolonged."

Dr. Mok, while in agreement that Mr. Ip is critically ill and will unlikely survive, felt very uncomfortable with his wife's request. She felt she had an obligation to give a course of antibiotics because she cannot be absolutely sure that it would not work. In her mind she wonders, should she withhold what is considered standard treatment because of the family's request?

Case 6

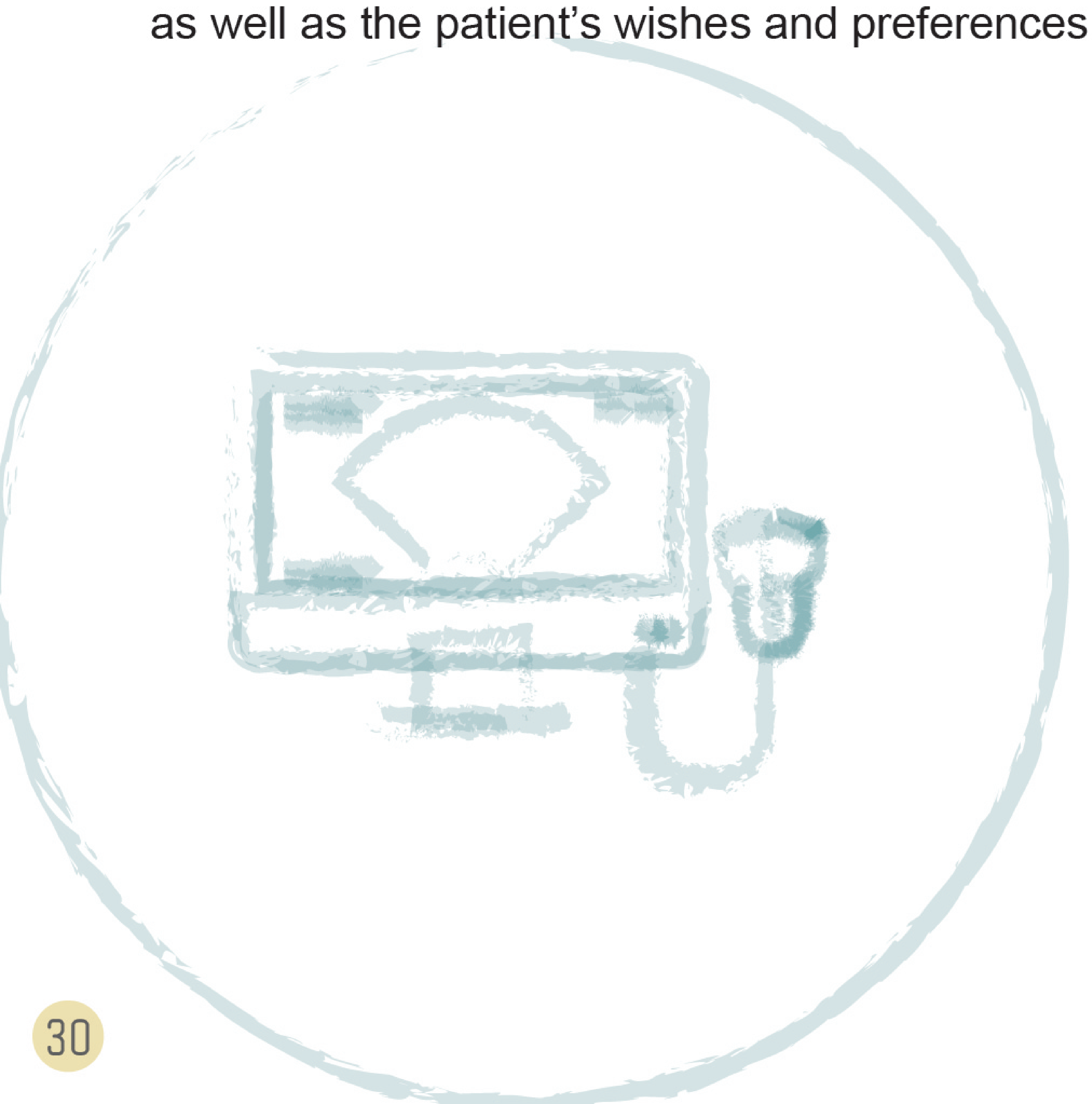
Mr. Ip

WITHHOLDING ANTIBIOTICS AT THE END OF LIFE

Commentary

- Dr. Christopher Lum, Consultant Geriatrician, Shatin Hospital

The practice of medicine is as humanistic as it is scientific. Its scientific basis rests upon empirical research that controls all but one single factor. The humanistic aspects anchor on having a caring attitude, respecting individual judgment and choice, and acknowledging our limitations and uncertainties in medicine. Treating patients as a sum of individual diseases where each disease is treated linearly may not benefit patients. In reality, patients commonly have interacting comorbidities and deciding the best management requires looking at each patient holistically. In this case, Dr. Mok might have considered aspiration pneumonia in isolation as a “single disease” in deriving the use of antibiotics as the “standard” treatment. Saving Mr. Ip’s life by treating his pneumonia might have been considered the single most important surrogate marker of success that would benefit the patient. Background interacting conditions that should also be factored into his care including his COPD, multiple subcortical infarcts, swallowing difficulty, recurrent pneumonia and increasing debility were under-weighed if not overlooked. In the case of Mr. Ip, his subcortical infarcts and breathing-swallowing incoordination from his COPD, both irreversible, had led to recurrent aspiration pneumonia which would likely be his expected terminal event. Patient management should be considered in the context of interacting co-morbidities and their reversibility as well as the patient’s wishes and preferences.



Upon hearing the request from Mrs. Ip to withhold antibiotics, it is worthwhile for Dr. Mok to consider the following points:

a. What is the chance that Mr. Ip will survive if the antibiotic is given? Does it really cure him or prolong the dying process?
b. What will Mr. Ip experience during the process if the antibiotic is given? Will this experience be compatible with his expressed wish, or the contrary?
c. Is Mr. Ip's expressed wish and choice consistent when he was sick and when he was well?
d. Would there be any legal repercussions for Dr. Mok and the medical team if antibiotics were withheld?
e. Mr. Ip did not complete an advance directive but expressed his wishes verbally to his family. Are his family's words enough to be relied upon as evidence of Mr. Ip's wishes?

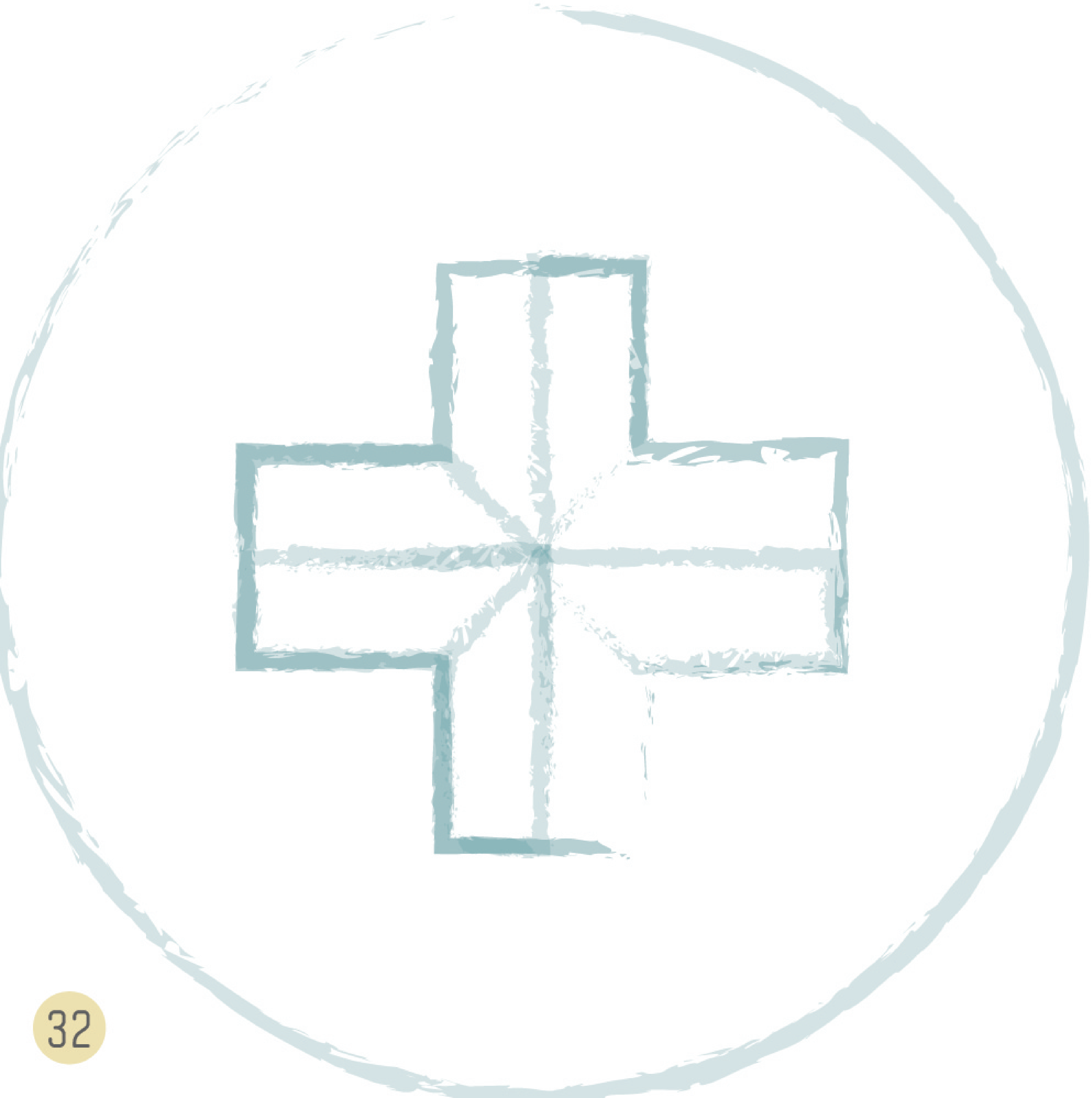
As in the case of Mr. Ip, his family had honored his wish to prioritize his comfort when they opted for careful hand feeding and accepted the associated risk of recurrent aspirations. This expected event has precisely occurred. At this time, his clinical state suggested that he was approaching his terminal state. Though episodic antibiotic treatment may be useful in controlling sepsis initially, its frequent and intermittent use will likely to induce antibiotic resistant infections and fails at the end. Even if Mr. Ip survived this time, this "successful" antibiotic treatment would be at the expense of culminating intolerable, uncomfortable experiences in Mr. Ip's worldview, and he had clearly expressed his wish not to prolong this suffering. This wish was consistently expressed even on good days when he was not under stress or acutely ill, thus likely a thoughtful decision. Repeated use of antibiotics against his wish will add unfavorable psychological on top of physical suffering to Mr. Ip.

Case 6

Mr. Ip

WITHHOLDING ANTIBIOTICS AT THE END OF LIFE

Survival is often considered the ultimate benefit and death the most dreaded ending by many medical providers. While death is, and should be, an adverse patient outcome; it is not, and should not be, the only one outcome to be considered. Other outcomes such as disability and/or the loss of ability to participate in social activities may be viewed as more detrimental than death by patients.[1] It is thus acceptable and legal to withhold any life-sustaining treatment (including antibiotics) if it is judged to do more harm than good to a patient, or if the treatment is futile. As a matter of fact, the International Code of Medical Ethics published by the World Medical Association (2017) has recently revised the statement that "the health" in general of a patient is now the doctor's first consideration from “the health and life" in the original declaration. This change highlights that survival is not the sole factor to be considered in assessing beneficence and maleficence in medical practice. This principle is also reflected in the Hospital Authority Guidelines on Life-sustaining Treatment in the Terminally ill (2015) that states, “It is not an appropriate goal of medicine to sustain life at all costs with no regard to its quality or the burdens of the treatment on the patient.”



In this era of defensive medicine, Dr. Mok may have concerns about liability if she withholds antibiotic treatment in the absence of a written advance directive (AD). It should be noted that while an AD document is preferred, it is not considered a necessity in the decision to withdraw or withhold life-sustaining treatment(s). The decision to treat / not to treat should take into account the patient's wishes if he is conscious and cognitively sound. For a patient who is mentally incompetent, the decision should be made through consensus building between the medical team and the patient's close relatives based on the best interests of the patient. The patient's prior wishes and values would be important in deciding what is in his best interests. In the case of Mr. Ip, one of his children was a medical doctor and knew his father was imminently dying. He had communicated this to close family members including the patient's wife and other siblings. It appeared that consensus had been reached among his family to respect Mr. Ip's wish, and the decision was articulated by Mrs. Ip. To alleviate anxiety about carrying out this decision, Dr. Mok may ascertain from Mrs. Ip and other family members on their understanding of potential consequences of withholding antibiotic treatment, the patient's personal values and beliefs, any previously expressed wishes, and whether all important family members share the same goal and management direction. When in doubt, opinion from the Clinical Ethics Committee can be sought.

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Case 7

Ms. Ng

OPTING FOR CHINESE OVER WESTERN MEDICINE

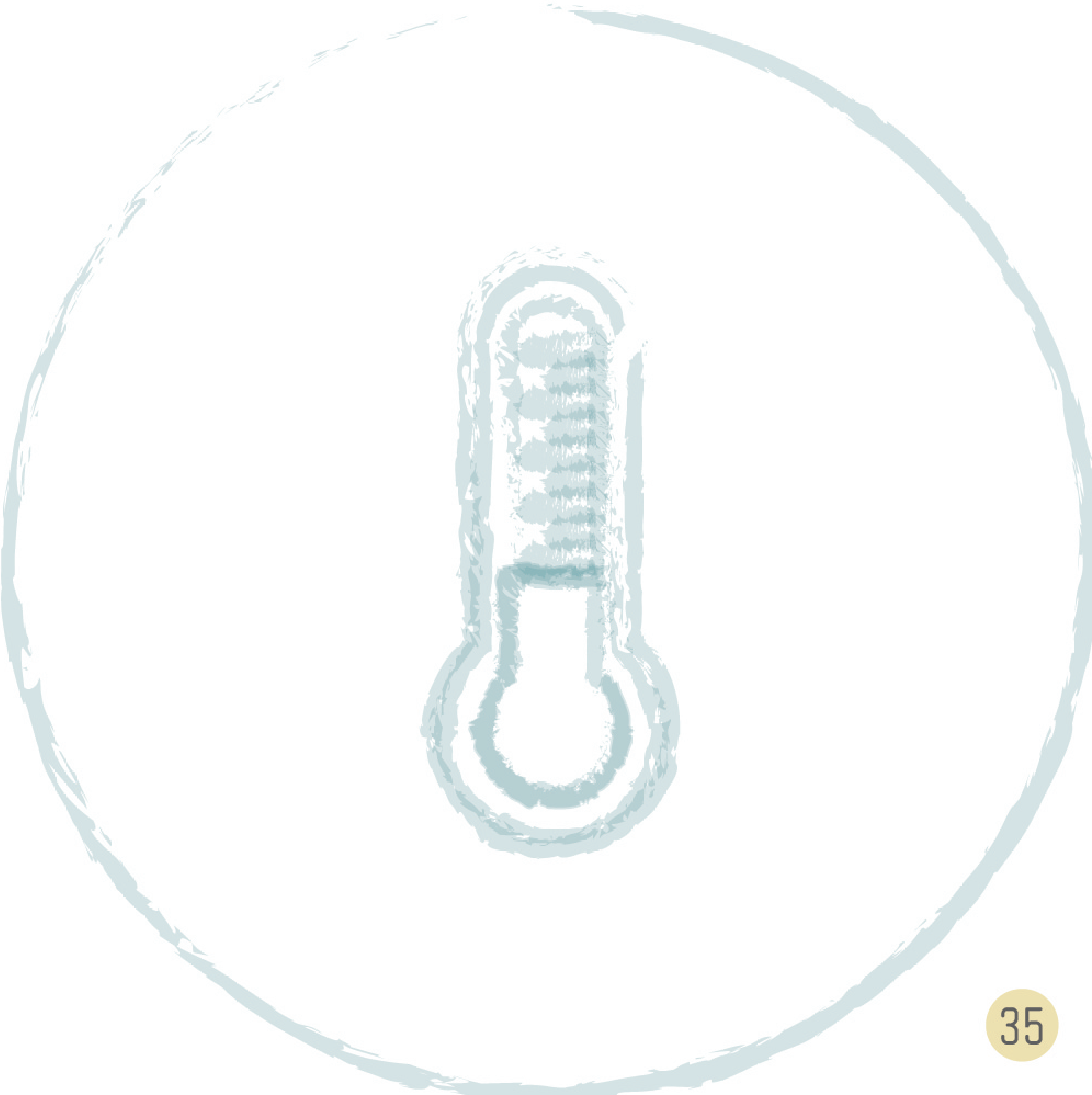
Ms. Ng is a 66-year-old woman who is an herbalist and rarely gets sick. She attributes her good health to her careful attention to her diet and use of traditional Chinese medicine. She is a single mother who raised her son, Tom, now in his 40s, while keeping up her small herbal medicine shop. However, over the last two months, she experienced worsening cough, shortness of breath, and swelling in her face. At Tom's insistence, she reluctantly went to the hospital A&E. On a chest x-ray, a large mediastinal mass was found. Her doctor explained that the mass was compressing a large vein in her neck called the superior vena cava which was the reason for her shortness of breath and facial swelling. She was admitted to the medical ward, steroids were started, and a core biopsy of the mass was obtained.

Unfortunately, the biopsy results revealed diffuse large B-cell lymphoma and oncology was consulted. The oncologist, Dr. Yim, explained the treatment options with Ms. Ng and Tom. The bad news is, she said, that this type of cancer is very aggressive. Without treatment, the cancer will progress quickly and will be fatal in a matter of weeks. The good news is, if cancer treatments involving chemotherapy and immunotherapy are initiated, there is a 50% chance of long term cure. Even if the treatments fail to cure her, there is still a 60% chance of controlling her cancer for quite some time. "If I were you, I would start these treatments in the hospital right away," she recommended.

Ms. Ng shook her head. "I don't believe in your medicines, doctor. I will go to a traditional Chinese medicine practitioner who I know will help me." Tom, however, was very alarmed. "Mother, if you don't start these treatments in the hospital now, it may be too late!" Still, she refused and asked to be discharged.

Meanwhile, the ward physicians and nurses tried to convince Ms. Ng to start the cancer treatments. Dr. Yim arranged for cancer survivor volunteers to meet with Ms. Ng to share their experience. Still, nothing changed Ms. Ng's mind. Dr. Yim had further meetings with Ms. Ng and her family including her son and her sister. While Tom continued to beg his mother to reconsider, his sister supported her decision. Knowing that Ms. Ng is a strong believer in Chinese medicine her whole life, her sister said, "Her mind is made up. I can only support what my sister thinks is best for her."

After the meeting, Tom pulled Dr. Yim aside to speak with her alone. "I know my mother said she doesn't want the cancer treatments, but I think she's a making a mistake!" he exclaimed. "Please save her, Dr. Yim!" Dr. Yim knows that Ms. Ng is of sound mind and is capable of making her treatment decisions. However, she's very uncomfortable herself with the patient's decision and wonders if there's anything else she can do.



Case 7

Ms. Ng

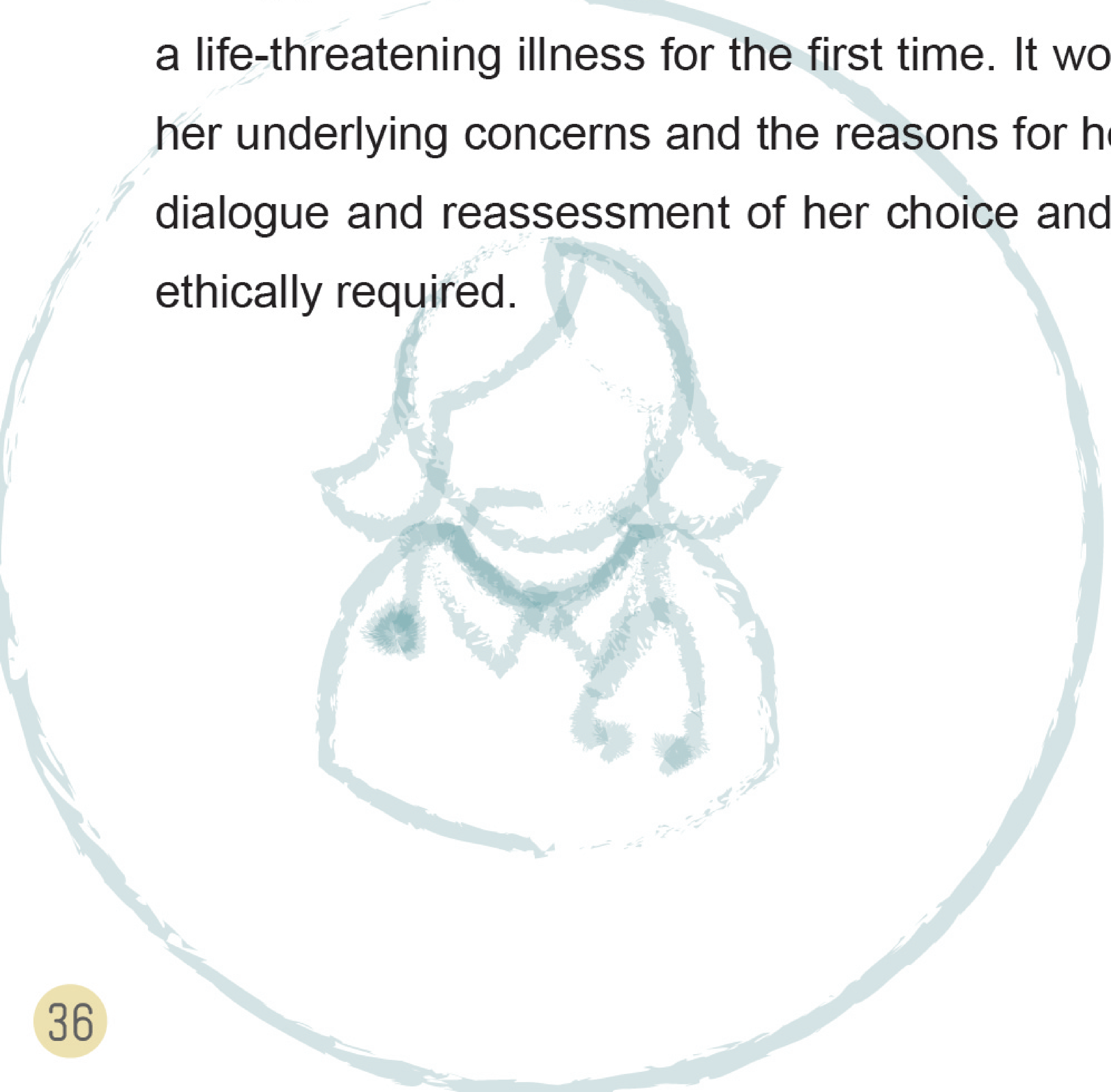
OPTING FOR CHINESE OVER WESTERN MEDICINE

Commentary

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

Mentally competent adult patients have the right to refuse to consent to medical treatment for any reason, or even no expressed reason at all, even where that decision may lead to death. The underlying ethical principle is to respect a person as an autonomous agent. Raanan Gillon, Emeritus Professor of Medical Ethics at Imperial College London, advocates this emphasis on autonomy, describing it as "primus inter pares" ("the first among equals") among the four ethical principles put forth by Beauchamp and Childress.[1] In philosophical ethics this has been disputed but medical practice do in fact abide by the absolute requirement of obtaining informed consent.

However, it is important to remember that refusal of medical treatment by the patient is not a permanent, irreversible refusal. In this case, Ms. Ng did in fact change her mind about immediate discharge from the hospital, and stayed on to complete the course of steroid treatment. This is a good indication that: Firstly, she is not giving up on herself and, secondly, when symptoms are significant, she may concede to receiving Western medicine treatment to an extent. Note also that in any patient first receiving the diagnosis of cancer (or other life-threatening illness) it may take time to 'swallow' the news and to accept the full implications of a treatment decision. Ms. Ng has a strong personal belief in traditional Chinese medicine, but she is also another human being facing a life-threatening illness for the first time. It would be important to attend to her emotions, explore her underlying concerns and the reasons for her reluctance to use Western medicine. Continuous dialogue and reassessment of her choice and preferences over time may be useful, and indeed ethically required.



In this case, there are at two other aspects worth discussing:

1. Traditional Chinese medicine as a treatment option: The case doctor and the son are particularly uncomfortable, even distressed, that Ms. Ng should refuse a rather evidenced-based efficacious treatment. What is unknown in this case is whether well-practiced Chinese medicine may also have efficacy. Certainly traditional Chinese medicine has generally much fewer controlled studies as evidence, but it would be a valid question to ask an informed Chinese medicine practitioner, or to search medical literature on the subject. A physician who pays respect to the knowledge base of traditional Chinese medicine is also indirectly respecting the patient's such preference. By doing so, he/she may also be more effective in arguing that the recommended treatment is better than Chinese medicine for this malignant lymphoma condition.

2. The son and the sister holding different views: On whether to respect the refusal of treatment by Ms. Ng, the son focused on the missed benefit ('beneficence principle') while the sister was inclined to respect the autonomy of Ms. Ng. If one does agree that, philosophically, respect for autonomy is indeed "the first among equals", should one then take side with the sister against the son? This however is not a good approach in handling disagreement among family members, as it may escalate the conflict rather than help its resolution. Rather, it may be more helpful to acknowledge that both are acting from what they think is best for the patient. Alternative options may be explored with the Ms. Ng and her family such as a time-limited trial of treatment with Chinese medicine and if disease progression continues, then switch over to Western medicine if her health condition allows.

References

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Case 8

Mrs. Yeung

CHALLENGES IN CAREFUL HAND FEEDING

Mrs. Yeung is an 87-year-old woman with advanced dementia. She is widowed and has been living at an old age home for the past five years. Over the last couple of years, she has become bedbound and nonverbal. She no longer recognizes her daughter Karen who visits regularly. She requires assistance with feeding and had lost over ten pounds in the last year due to poor oral intake.

Over the last week, Mrs. Yeung was admitted to the hospital for increased lethargy. She was found to have a urinary tract infection and was treated with antibiotics and intravenous fluids. While she became more alert after a couple of days of treatment, she had failed her swallowing evaluation. The speech therapist documented that she was at high risk for aspiration and recommended non-oral feeding.

The doctor on the geriatrics ward discussed the question of nasogastric feeding tube insertion with Karen. He explained that Mrs. Yeung's reduced food intake and swallowing difficulties are part of her advanced illness and suggested careful hand feeding as an alternative.

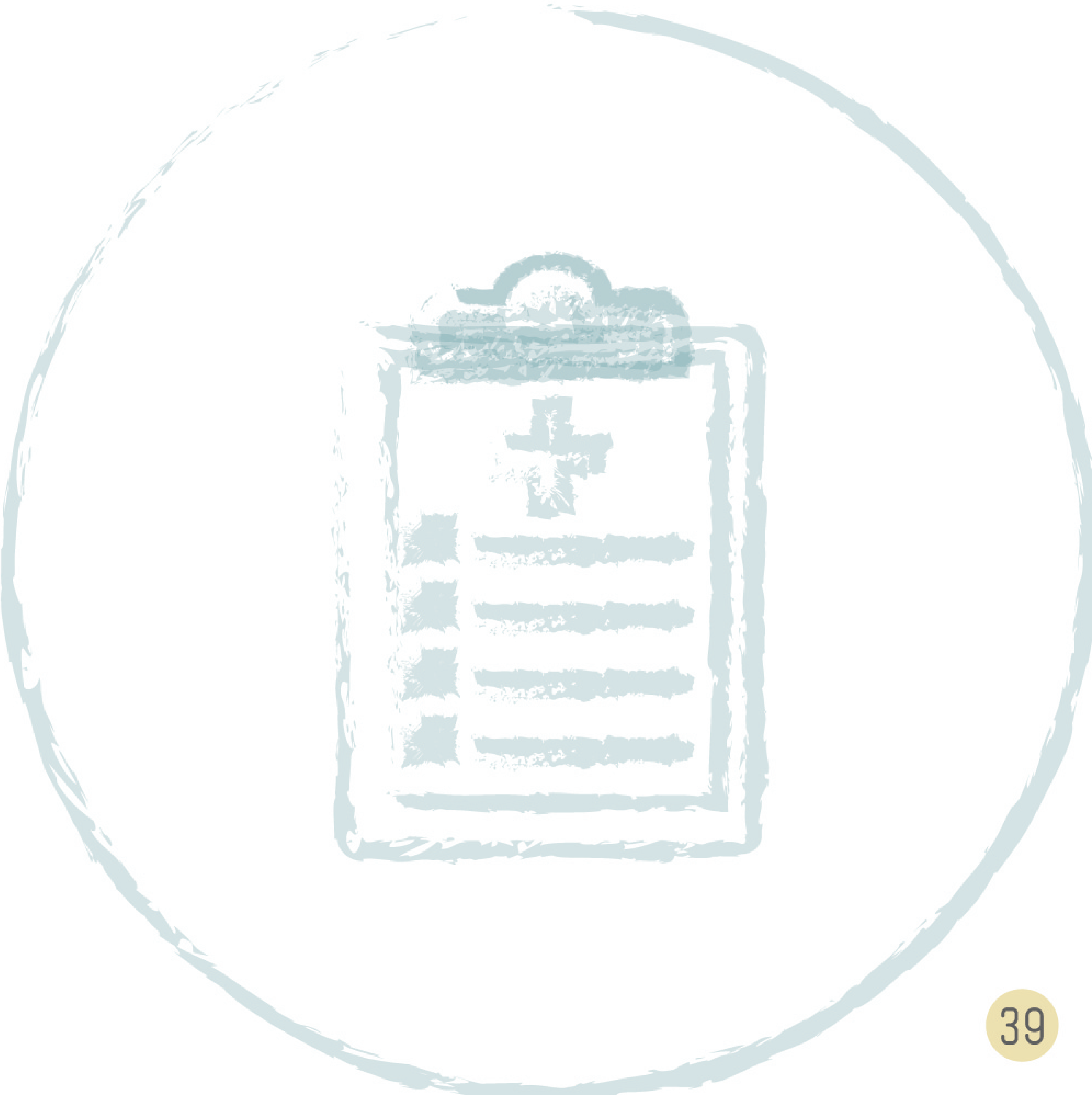
Karen replied, "Mom has already suffered enough. She doesn't recognize me anymore and she can't communicate. She just lies there. Putting in a feeding tube would be torturing her more." Karen opted for careful hand feeding. Her decision was documented in an advance care planning document which was sent back to the old age home when Mrs. Yeung was discharged.

Man Yi, a personal care worker at the home, found it very difficult to continue to feed Mrs. Yeung. She is very weak and could only take in a few spoonfuls of food at a time. Mealtimes would take over an hour and Man Yi cannot afford to take that time when she has many other residents to care for. Besides, noting the speech therapist's assessment, she is concerned that she would cause Mrs. Yeung to have an aspiration episode while feeding her. She raised her concerns with the nursing supervisor.

The nursing supervisor replied, “Let’s have a talk with her daughter then. If she doesn’t want to insert a feeding tube like everyone else, then she needs to either come herself to assist with her meals or arrange for someone who can. What if she chokes? Then the responsibility would fall on us. Besides, this ACP document belongs to the hospital. I’m not sure if we’re obligated to follow this anyway.”

During the meeting, Karen was surprised and upset upon hearing the old age home’s refusal to continue careful hand feeding. She exclaimed, “At the hospital, they said that she can continue to be fed by the staff here! I work full time at the post office and can’t come to feed her myself. I cannot afford to hire a maid!”

Man Yi felt at a loss for what to do. She recognizes the daughter’s wish to keep Mrs. Yeung comfortable but she cannot manage her workload if it takes so long to feed Mrs. Yeung. Her nursing supervisor suggested that they should send Mrs. Yeung back to the hospital. It seems that they don’t have another option.



Case 8

Mrs. Yeung

CHALLENGES IN CAREFUL HAND FEEDING

Commentary

- Dr. Tak Kwan Kong, Clinical Associate Professor (Honorary), Department of Medicine and Therapeutics, Prince of Wales Hospital, CUHK

1. What are the pros and cons of careful hand feeding vs tube feeding in advanced dementia patients with swallowing problems?

	Careful hand feeding	**Nasogastric tube feeding**
Pros	• Pleasure of eating/ drinking • Comfort, companionship, intimacy	• Fast technique of by passing the swallowing process in the provision of nutrition or hydration, and administration of oral medication
Cons	• Staff concern on aspiration risk with medicolegal consequence • Difficult to implement quality feeding without adequate resources (human presence, time, patience), ending up in poor feeding and dehydration, and consequent repeated hospitalizations • Distress related to eating/ drinking, e.g. choking	• Aspiration pneumonia is not prevented (as reflux of gastric contents and aspiration of saliva continue with tube feeding), but may even be increased • Distress from tube insertion or its complications (irritation, blockage, dislodgement) • Immobilization and agitation from increased use of hand restraints

2. How should advance care planning be done for advanced dementia patients with unsafe swallowing?

For a patient who has a serious illness, planning on future medical and personal care at the end of life can be done via an advance care planning (ACP) process involving the patient, family and healthcare workers and takes into consideration factors such as disease prognosis, benefits and burdens of treatment, values and preferences of the patient. Usually ACP is a process of communication intended for mentally competent patients. In the Hospital Authority of Hong Kong, the term ACP extends beyond communication with mentally competent patients to include that with family members of mentally incompetent patients. Decision-making regarding the patient's future medical or personal care should be done by consensus building among members of the healthcare team and with the patient's family, based on the best interests of the patient.

Mrs. Yeung suffered from advanced dementia, could not communicate, and was judged by the geriatrician as lacking mental capacity to consent, but her wish may still be implied and understood from her body language (e.g. repeatedly pulling out the nasogastric tube). While her daughter, Karen, cannot insist on, or consent to, a treatment on behalf of the patient, her views help to understand Mrs. Yeung's previously expressed views on end-of-life decisions. The decision-making process on dysphagia assessment and management in advanced dementia patients is complex and is ideally a combined effort of the multidisciplinary team. The speech therapist documented that Mrs. Yeung was at high risk for aspiration and recommended non-oral feeding. However, dementia patients may under-perform on formal swallowing tests because of distress, unfamiliar test environment (e.g. tilt-table), and distasteful artificial barium-modified food. The observations of the usual swallowing ability of Mrs. Yeung during meal time by nurses and family members should also be considered when assessing the safety of oral feeding. Geriatricians have a role to diagnose and treat conditions impairing swallowing, e.g. delirium, depression, oral candidiasis, and discontinue medications causing dry mouth and impairing swallowing (e.g. antipsychotics). In the ACP process, it is important to consider the context, including the available support systems and resource availability. While the geriatric ward where Mrs. Yeung stayed had the appropriate support and resources to practise careful hand feeding, the aged home where Mrs. Yeung was subsequently discharged to did not and this may result in rebound hospitalizations. Careful transitional care planning and collaboration between hospital and aged home staff are important for success of smooth transfer of care from hospital to the community. The pros and cons of careful hand feeding vs tube feeding (see above) should therefore be carefully reviewed and discussed before drawing up an individualized advance care plan that is practicable.

3. How to optimize clinical ethical decisions when faced with ethical and legal dilemmas in the care of advanced dementia patients?

The ethico-legal dilemmas in this case are that while the hospital multi-disciplinary team (experts) recommended careful hand feeding in their ACP (not legally binding) for an advanced dementia patient whose swallowing was judged unsafe by the speech therapist, the aged home staff (frontline) did not have the supporting practice (education, operational policy and human resources) and expressed litigation concern. A common argument for not starting tube feeding in this situation is that the burden of tube feeding is high and the intervention adversely impacts on the quality of life of terminally ill patients. Despite Mrs. Yeung is in an advanced stage of dementia, she has just been recovering from an acute illness (urinary tract infection), it is thus arguable to label her as terminally ill. Moreover, Mrs. Yeung had lost over ten pounds in the last year due to poor oral intake, and was likely having malnutrition, which reduced her immunity and made her susceptible to infections. Tube feeding, on a short-term basis, may be a quick treatment to restore her nutrition and body weight and optimize her condition. However, quality studies are lacking to address whether or not tube feeding can improve nutritional status for advanced dementia patients. The British Geriatrics Society and the Royal College of Physicians recommended that if in doubt, a trial of nasogastric feeding with clear agreed objectives may be appropriate in managing dysphagia in older people towards the end of life. Tube feeding should then be withdrawn if failing to achieve the objectives.

There are many ways of thinking about ethical issues in geriatrics that help to reduce our shortsightedness in order to benefit patients and ourselves. In addition to the usual "mainstream" ethical approach (based on the ethical principles of autonomy, beneficence, justice, non-maleficence), there are also narrative approaches which take into consideration values and expectations, limitations/uncertainties and concerns, and the context (patient-doctor-family-care worker, hospital-community). This requires active listening and dialogue; commitment, compassion, and courage to approach the ethical dilemmas in caring for elderly people. How certain is Mrs. Yeung terminal and without any remediable cause(s) for her impaired swallowing? Do we know what is valued by Mrs. Yeung? What is the expectation of her daughter Karen and can she be involved as an informal carer? Does Karen have similar fear of unsafe swallowing as the aged home care worker Man Yi so much so that Karen is reluctant to hand feed her mother to avoid the guilt of causing her mother to choke to death? How can the aged home nursing supervisor and the hospital team give support to Man Yi and Karen?

4. Guidance for hospital and aged home staff presented with a similar situation

Ideally, this situation may have been prevented by collaborative discharge planning between providers/carers in the hospital and community setting. Short of this, the following tactics may be of help:

- Close liaison between the hospital out-reach community geriatric assessment team (CGAT) and the aged home staff for post-discharge patients; e.g. review of oral intake of Mrs. Yeung soon after discharge by CGAT, education of aged home staff on safe swallowing techniques and postures, a hotline accessible to aged home staff to call for help and advice by CGAT.

- Attitude of moving away from risk-centred medicine to person-centred care: Since the focus on risk-centred medicine (unsafe swallowing, aspiration risk) has created anxiety, fears and defensiveness in aged home staff and probably also the hospital team and the patient's daughter, it may be reassuring if the speech therapist acknowledges "relative" rather than "absolute" swallowing risk, and avoids recommendation of "non-oral feeding" in documentation, which may be seen as expert opinion with litigation consequences. The speech therapist and CGAT team can teach Karen on safe hand feeding techniques, diverting the focus from aspiration to human touch, and encourage Karen to try to come to the aged home after work and hand feed her mother carefully. Karen can also consider recruiting volunteering friends and neighbours to provide careful hand feeding for her mother at the aged home.

- ACP is not a one-off but rather an ongoing process of discussion and review as the patient's condition or preference changes. If Mrs. Yeung is distressed (e.g. due to choking) despite careful hand feeding and continues to lose weight, CGAT can discuss with her daughter on the option of short-term tube feeding and assess for any improvement and tolerability. If Mrs. Yeung's condition improves after short-term tube feeding, careful hand feeding can be reintroduced.

Case 9

Mrs. Tsang

FILIAL PIETY IN END OF LIFE CARE DECISIONS

Mrs. Tsang is a 90-year-old woman with a history of myocardial infarction, atrial fibrillation, and congestive heart failure. Since her husband passed away eight years ago, she has been living in a residential care home for the elderly. She looks forward to regular visits from her daughter, Ga Yan, who always brings her favorite paper-wrapped cakes from her old neighborhood bakery. However, she misses most her elder son, Ga Kit, who lives in Canada with his family and returns to Hong Kong about once a year.

In the past year, Mrs. Tsang has required repeated hospitalizations every few months for exacerbations of her heart failure. Each time when the symptoms come on, she experiences swelling in her legs and could barely catch her breath when she takes a few steps or lies in bed. In the hospital, she is treated with IV diuretics that remove fluid from her body and her breathing improves. After each hospitalization, however, she returns to the aged home more debilitated. After her last discharge, she can barely stand on her feet before she feels that her legs give out beneath her.

Ivy, the nurse from the community geriatric assessment team, makes a visit with Mrs. Tsang at the aged home two weeks after her last hospitalization. Noting Mrs. Tsang's progressive decline and weight loss over the past several months, she decides to arrange a meeting with the Mrs. Tsang, who is of sound mind, and Ga Yan to discuss advance care planning.

At the meeting, Ivy expressed her concern about Mrs. Tsang's declining health and asked what Mrs. Tsang hopes for in her care going forward. Mrs. Tsang replied, “I know that my health is not good. I just wish that I don't need to keep going back to the hospital. The staff is always too busy to be able to pay you much attention.” Ga Yan nods her head in agreement. “Mother's been through a lot lately with so many hospitalizations. She really dislikes being in the hospital.”

Ivy then explains the end-of-life care (EOL) service that is provided by her hospital, which can help support Mrs. Tsang by avoiding hospitalizations if possible and focusing on her comfort.

“We will assess you regularly for any symptoms and try to treat you in the aged home if possible. If a hospitalization is needed, we will try to arrange a direct admission to the geriatric ward in the hospital and avoid a trip to the A&E department. The only requirement for patients enrolled in this programme is that they would need to agree to not for resuscitation. In other words, in the event the heart stops, the patients would forgo any attempts by the medical team at restarting the heart.”

Mrs. Tsang was alarmed. “I would still want the doctors to try to restart my heart if it stops!”

Hearing her mother’s words, Ga Yan sighs. “This programme sounds great in many respects, except that my mother’s not ready to give up yet. I’m afraid my mother will not be a good fit for your programme.”

Ivy made some notes in her records, and did not bring up the EOL service again.

Some months later, Mrs. Tsang was found to be unarousable by the carer in the home and was immediately brought by ambulance to the hospital. In the A&E, the doctors found her oxygen level and blood pressure to be low. Concerned that she is in respiratory failure and in shock, they immediately placed Mrs. Tsang on a noninvasive ventilation mask. Her oxygen level came back up after this treatment and when her condition appears more stabilized, she was admitted to the medical ward. Then the nurse on the ward calls Ga Yan and told her to come to the hospital immediately.

Case 9

Mrs. Tsang

FILIAL PIETY IN END OF LIFE CARE DECISIONS

When Ga Yan arrived on the ward, she was greeted by Dr. Leung, the medical officer in charge of Mrs. Tsang's care. He explains, "I'm worried that your mother's condition may become unstable at any time. Given her serious heart condition and overall poor health, I think that in the event that her heart were to stop, I do not think that doing CPR would be in her best interest."

Ga Yan replied, "A nurse had discussed this with my mother a few months ago at the home and my mother still wanted the doctors to try to restart her heart if it stops! Those were her exact words. I'm not sure what to do, doctor! Let me first speak with my brother!"

Dr. Leung nods. "Sure, please go ahead. You can inform the nurse after you've made your decision and you can ask to speak with me at any time. It's best that a decision can be made today, as things can change quickly."

Ga Yan immediately phones Ga Kit in Canada, which is now close to 3am. Fortunately, the phone was answered. Ga Yan explained the situation and asked her brother what he thought.

"It's no question," said Ga Kit. "Even though I wasn't part of the conversation that you and mother had with the nurse, still it was mother herself who said she wanted to be resuscitated. How can we as her children go against her wish! Besides, if there is a way to allow mother to live a longer life, it would go against filial piety (不孝) to not support that. In the morning, I'm going to take the first flight out to Hong Kong. Watch over mother until I get there!"

Hearing her brother's words, Ga Yan feels more conflicted. Her brother had not seen their mother in months. He doesn't know how much their mother has suffered. She also doesn't know whether her mother really understands what CPR would mean for someone in her condition at the time the nurse at the aged home brought it up. She certainly could not have imagined how sick she would be when this decision would need to be acted upon.

On the other hand, she wishes that her mother would be comfortable and have dignity when she is at the end of her life and is inclined to go along with Dr. Leung's recommendation for not attempting CPR. However, she does not want to go against her brother's viewpoint, and what her mother had stated in the past.

Case 9

Mrs. Tsang

FILIAL PIETY IN END OF LIFE CARE DECISIONS

Commentary

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

The daughter of Mrs. Tsang, Ga Yan, is in a difficult situation. Mrs. Tsang is unconscious, the case doctor advises that, given her serious heart condition and overall poor health, doing CPR would not be in her best interest. She is asked to inform the doctor of a decision within the day, as her mother's condition is not stable. In previous encounter with the nurse from community geriatric assessment team, her mother apparently expressed a wish to live on even if resuscitation was required, but Ga Yan is not sure if in that brief dialogue her mother really understood what CPR would mean. She herself wishes that her mother could go through the end of life phase in comfort and with dignity. Her brother in Canada considers that it would go against filial piety (不孝) to not support their mother's apparent wish to live on.

This case illustrates that difficult end of life decisions such as CPR is often not merely about a 'right' decision based on one or two 'correct' ethical principles. When a patient becomes mentally incapacitated near end of life, what is in the patient's best interest (more accurately 'best interests' – it is not a single dimensional concept of benefit) is a mix of medical prognosis, judgement of benefit and burden of further active – possibly aggressive – interventions, and patient's prior expressed wish and known values.

A DNACPR decision may be made easier if there is a clearly written valid and applicable advance directive. In this case, Mrs. Tsang's prior expressed preference (to live on) reflects her values at the time of the conversation, but it does not amount to a clear advance directive. In any case, an advance directive states what medical interventions a patient would not wish to receive when his/her condition has come to a certain future state (e.g. irreversible coma, terminally ill). Even if a patient had expressed a prior wish not to withhold CPR under any circumstances, the medical team is not obliged to always follow the patient's instruction. The judgment of the medical team would also factor in the decision.

When the case doctor advised Ga Yan that, in his judgment, CPR would not be in Mrs. Tsang's best interest, it is unclear whether he has taken into account Mrs. Tsang's prior expressed wish. He can try to explore with the daughter about the context for her mother's wish - e.g. did her mother have a good understanding about CPR and the expected outcomes for someone in her condition? Perhaps her mother's statement is an expression of her worry that the doctors would "give up" on her rather than to be interpreted as an advance instruction on her CPR decision.

If this is the case, then it may problematic to request Ga Yan to come back with a 'decision' on CPR or DNACPR. This creates a substantial psychological burden for her, implying that it would be her sole responsibility to come up with this 'decision' in the fact of conflicting considerations. If CPR is considered to be not indicated, it is preferable for the medical team to state that more explicitly, to clarify from the outset and such decision is a shared decision between the medical team and the family, making reference to patient's prior wish and values.

The Law in Hong Kong does not adopt the U.S. legal framework for surrogate decision-making by family members. As such, what the family members are asked to do, in most circumstances, is a substituted judgment – imagining what the patient would have wanted if she were still able to express her views in this particular scenario. Substituted judgment is a meaningful concept that many lay persons (possibly also healthcare professionals) would find difficult in practice.

Noting that the son of Mrs. Tsang is flying back immediately from Canada, if the patient's condition allows, it is desirable to hold a family conference after he is back, to better inform him of the Mrs. Tsang's present medical condition and prognosis.

What if Mrs. Tsang deteriorates quickly with cardiac arrest and there is no time for shared decision making? We do not have sufficient information on the medical prognosis, including whether Mrs. Tsang is likely able to come off the ventilator once resuscitated. From the given information, it is not clear that Mrs. Tsang's condition is medically futile (in the strict sense of physiological futility), CPR may still be justified. In such case, suitable counselling and support should be provided to Ga Yan, to relieve her of the sense of guilt from filial piety.

Finally, it may be noted that the original message given to Mrs. Tsang and Ga Yan concerning the 'requirement' for enrolling in the direct admission programme to the geriatric ward is somewhat problematic. Whereas it may be a fact that the programme is designed to serve patients who indicated a wish not to receive CPR in the advance care planning process, it is quite another matter to 'require' a patient to agree to DNACPR just because he/she prefers direct admission to the geriatric ward as part of her goal of maximizing comfort. Good end of life care programmes should not use their services as 'incentives' to influence the patient's DNACPR decision. I am sure this was not the intention of the clinical team, but careful communication is needed here.

Case 10

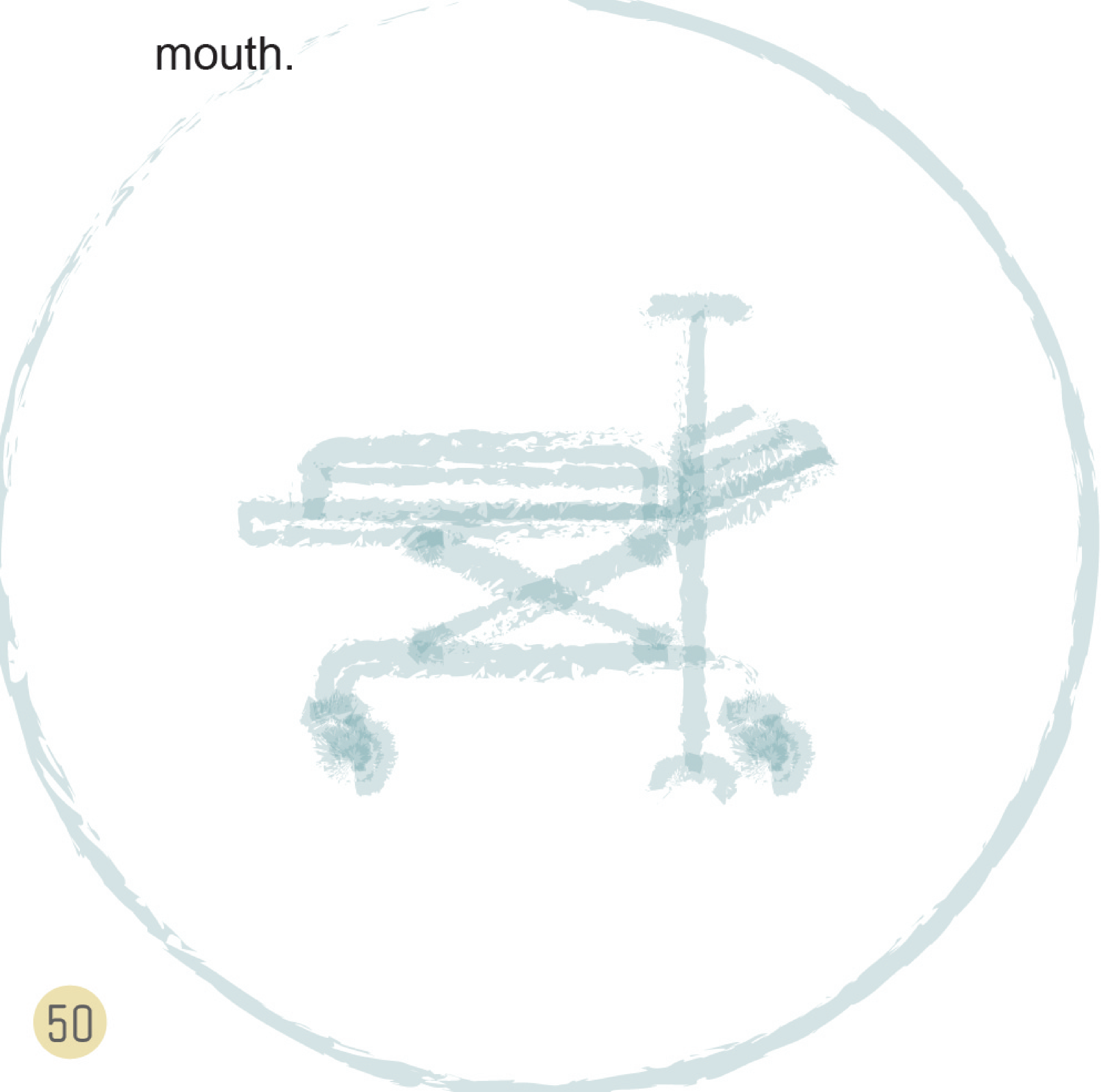
Mrs. Leung

MISCOMMUNICATION WITH FAMILY IN ADVANCE CARE PLANNING

Mrs. Leung, an 80 year old lady, was admitted to the medical ward of an acute hospital, with orthopnea. She has a 10 year history of congestive heart failure and recent echocardiogram shows that the ejection fraction is 15%, on optimal medical therapy. She has increasing bradycardia, and rapidly deteriorating renal function. She lives with her husband, and have had advance care planning conversations with the medical team in charge, and after discussion with cardiologist for suitability of pacing, and renal physicians for dialysis, who considered that there will be no benefit for these procedures and the patient also preferred medical therapy alone, the management plan was to just continue medical therapy.

She was given iv. Dobutamine drip and oxygen. She was unable to lie down and had to be upright all the time, being very dyspneic. Her mouth became very dry and cracked, with some bleeding. The ward was full of extra beds and her bed was situated half way into the main passage way to the toilet and shower room.

In view of the undesirable surroundings and lack of personal comfort care, it was planned to transfer her to a non-acute hospital for palliative care. Just as this decision was made, her daughter appeared and threatened to complain to the Patient Relations Office, demanding pacing and dialysis and refusing to let her mother be transferred. She is a nurse and had seldom visited in the past. Because of this occurrence, the transfer was delayed pending explanations and interviews with the daughter. The patient died the next day, in great distress and with cracked and bleeding mouth.



Commentary

- Dr. Tak Kwan Kong, Clinical Associate Professor (Honorary), Department of Medicine and Therapeutics, Prince of Wales Hospital, CUHK

The ethical dilemmas in this case are that while the acute medical team recommended palliative care in their advance care planning (ACP) for an advanced heart failure patient whose bradycardia and rapidly deteriorating renal function were considered not benefiting from pacemaker implantation and dialysis by the cardiologist and renal physician, the daughter of the patient demanded for such interventional procedures. There is disagreement between a family member and the acute medical team, and probably disagreement among family members about End of Life (EOL) decisions.

There are several points in the case that require further clarification:
While it was mentioned that the patient had advance care planning conversations with the acute medical team in-charge and expressed preference for medical therapy alone, it is unclear if her family (husband, daughter, and other children if any) was involved in the ACP. Are these just conversations without a structured process with clear documentation of details of the ACP discussion for continuity of care? What were the expressed value and preferences of the patient, and did her family members (husband, daughter, and other children if any) share similar views? The case was so presented that the daughter insisted on treatment procedures not wanted by the patient, but had the caring team evaluated how well can her daughter can convey the views and values of the patient on EOL decisions. Did the patient appoint any substitute decision maker (SDM) to represent her should she become mentally incompetent?

Case 10

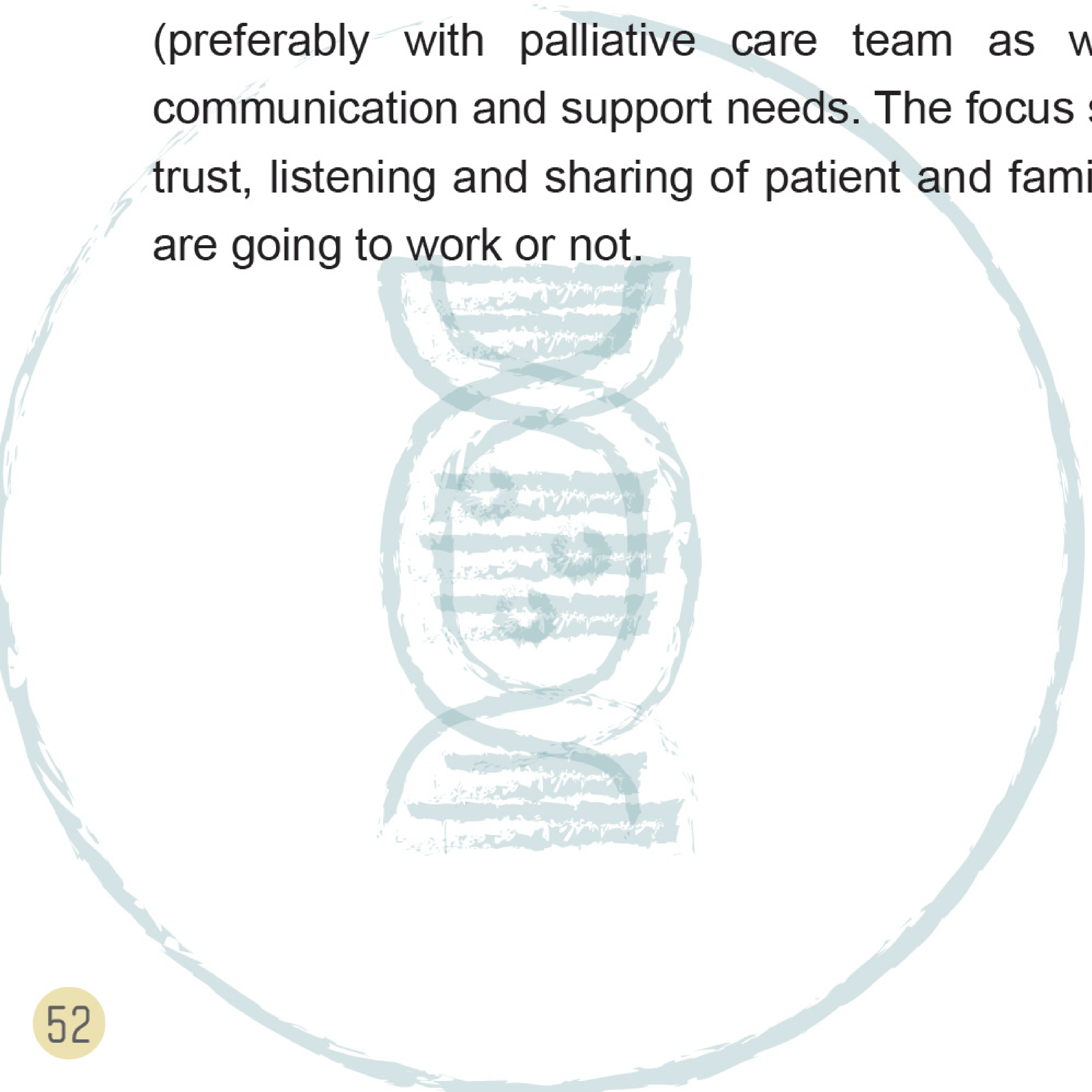
Mrs. Leung

MISCOMMUNICATION WITH FAMILY IN ADVANCE CARE PLANNING

Advance care planning process to recognize autonomy:
For a patient who has a serious illness, planning on future medical and personal care at the EOL can be done via an advance care planning (ACP) process involving the patient, family and healthcare workers and takes into consideration factors such as disease prognosis, benefits and burdens of treatment, values and preferences of the patient. Decision-making regarding the patient's future medical or personal care should be done by consensus building among members of the healthcare team and with the patient's family, based on the best interests of the patient.

The decision-making process on EOL care in advanced heart failure is complex and is ideally a combined effort of palliative care and heart failure caring teams. The traditional model of ACP that focus on determining the medical interventions and life-sustaining treatments that are preferred at EOL has been challenged as ineffective as it is impossible to know the future context in which these decisions will be made. In the new value-based model of ACP in heart failure EOL care, the patient and their SDM acquire the information and develop the skills needed to participate in the complex medical decisions that may be needed as their medical condition worsens. It has been proposed that this approach is more likely to ensure that the care an individual receives is concordant with their values, goals and wishes, though its effectiveness has yet to be determined.

The dissatisfactions and complaints in this case may be prevented by a timely and structured ACP process involving the patient, her family and senior clinicians involved in the acute medical care (preferably with palliative care team as well), addressing their specific needs, including communication and support needs. The focus should be on good communication and establishing trust, listening and sharing of patient and family's values, rather than whether such interventions are going to work or not.



1. Reveal disease prognosis: breaking the bad news to make patient and her family (including her daughter) aware that the patient is approaching her last days of life, and that palliative care is an integral part of heart failure EOL care.

2. Symptom management: a frank discussion with the patient and family on the potential benefits, harms and burdens of various treatment options and its impact on her symptoms and quality of life. Though the daughter insists on pacing and dialysis as the treatments of her mother's slow heart rate and deteriorating kidney function, both conditions can arise from drugs used to treat heart failure, e.g. excess doses of digoxin, beta-blockers and diuretics. Her dry, cracked mouth may reflect excess diuretics pushing her to a dehydrated state. The caring team needs to review and optimize her anti-failure drug treatment regime to achieve the best symptomatic control.

3. Listen to values and preferences of the patient and to align expectations and goal of care among patient, family, and healthcare workers.

4. The care environment: It is a challenge to achieve personalised care, treatment and support for a frail old patient approaching EOL within a fast-paced busy acute hospital. But EOL care start in acute hospital.

Thus, acute medical team needs to be supported and closely linked with geriatric and palliative care teams. The transferal from acute hospital (where pacing and dialysis are available) to non-acute hospital (where palliative care is available) may be perceived as withholding of treatment or abandonment of care by her daughter. Thus, the question is best formulated not as the withholding of treatment but instead on the patient's best interest.

Studies have shown that an integrated heart failure palliative care program can significantly improve quality of life for heart failure patients at EOL. Integrating the palliative care provider into the heart failure team has the advantage of reducing care fragmentation. This also decreases the emotional distress for the patient and family arising from the perception that their EOL care is no longer provided by a team they trust.

BACKGROUNDER

(1) DECISIONS ABOUT FEEDING TUBES IN ADVANCED DEMENTIA

- Dr. Jacqueline Yuen, Clinical Lecturer, Department of Medicine and Therapeutics, CUHK

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).[1,2] However, feeding tubes are most frequently placed during an acute hospitalization where decisions are made with healthcare providers who are unfamiliar with the patients.[3] 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.[4-7] Given that tube feeding carries significant risks and can negatively impact a patient's quality of life,[8] 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.

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.[9] 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.[8] 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.

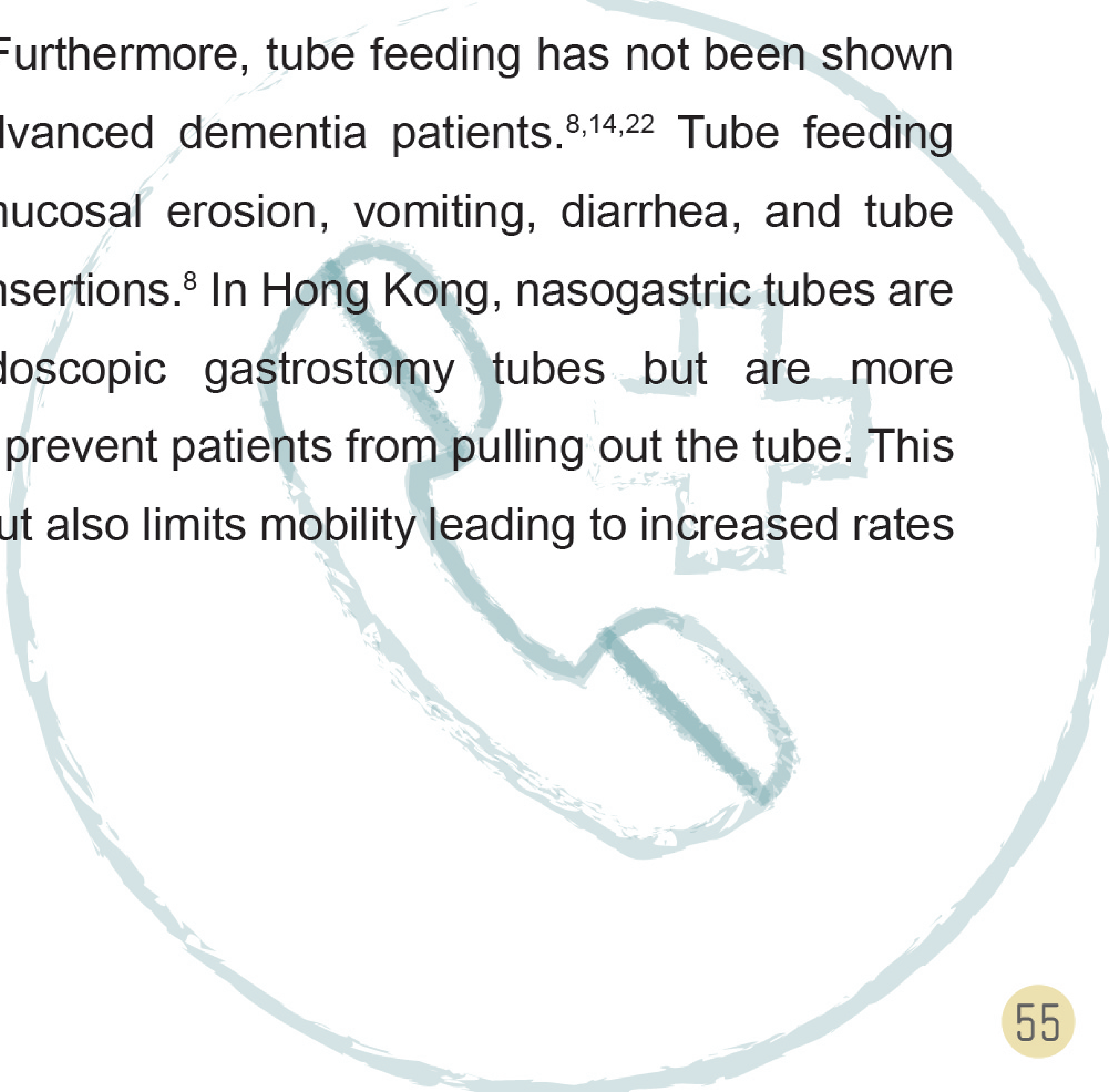
Step 2: Determine the patient's overall prognosis

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.[10,11] 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.[12] 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.[13] Consultation with a geriatrics specialist may be helpful in some cases.

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.[14-18] 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 oral secretions and regurgitated stomach contents can still occur.[19,20] 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.[8,14,22] Tube feeding carries other significant risks include bleeding, mucosal erosion, vomiting, diarrhea, and tube blockage and dislodgement requiring repeated re-insertions.[8] In Hong Kong, nasogastric tubes are more commonly used than percutaneous endoscopic gastrostomy tubes but are more uncomfortable.[3] 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.[15,23]



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]

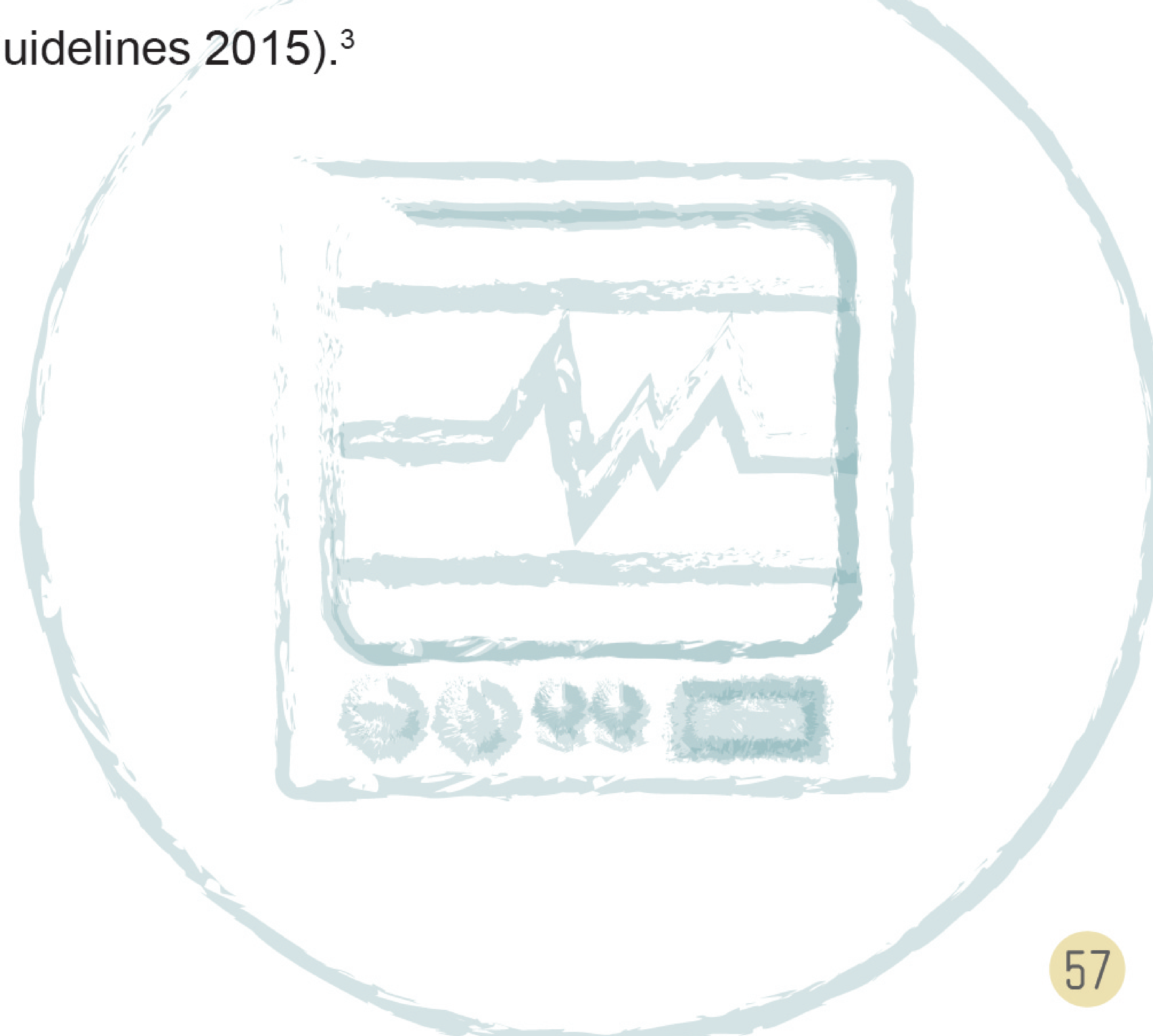
Step 4: Individualize decision through a shared decision-making process with family
Clinicians should involve the family in shared decision-making when considering the option of tube feeding and its alternatives. The decision should prioritize any preferences of the patient if known, such as documented 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.[3]

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]

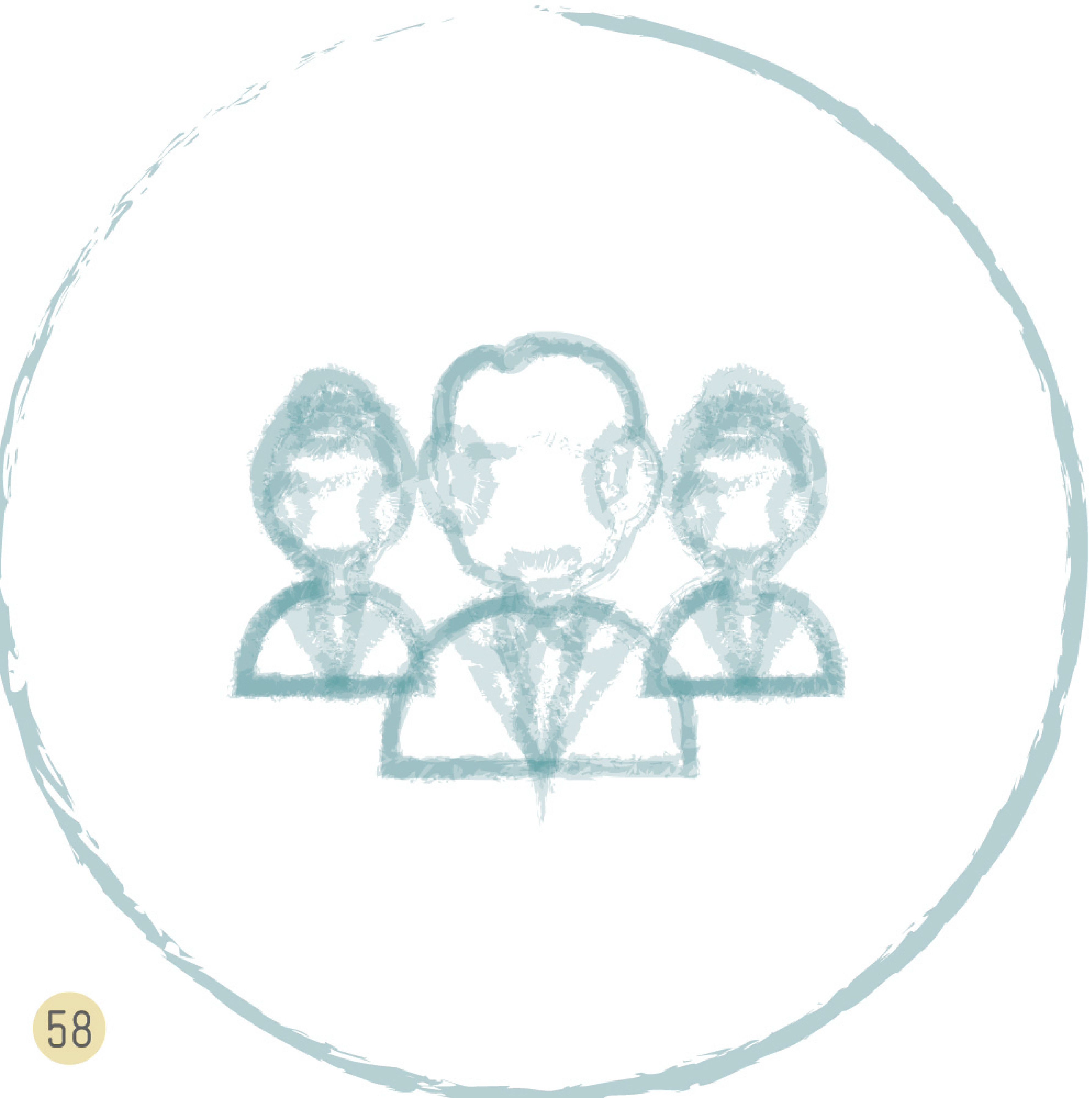
Step 5: Comply with institutional policies on artificial nutrition and hydration (ANH) in terminally ill patients

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.[3] 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).[3]



Conclusion

The decision about tube feeding for advanced dementia patients should be made in accordance to 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.



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BACKGROUNDER

(2) 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 a "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.[5] Some places adopt a broader definition and include discussions with family members of incompetent or minor patients within the scope of ACP. [6,7]

In September 2015, HA updated her Guidelines on LST in the Terminally Ill, and added a new section on ACP.[8] 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.[9] 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.[10] In Hong Kong, the HA DNACPR form for non-hospitalized patients promulgated in 2014 is along this direction.[11] 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 59ZF 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,[12] 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.[13] 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.[14] 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,[15,16] and the acceptability of treatments resulting in certain diminished states of health may increase with time.[17] 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.[18,19] 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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BACKGROUNDER

(3) MORAL DISTRESS AMONG HEALTH PROFESSIONALS: WHAT AND WHY

- Dr. Helen Chan, Associate Professor (by courtesy), CUHK Jockey Club Institute of Ageing, CUHK

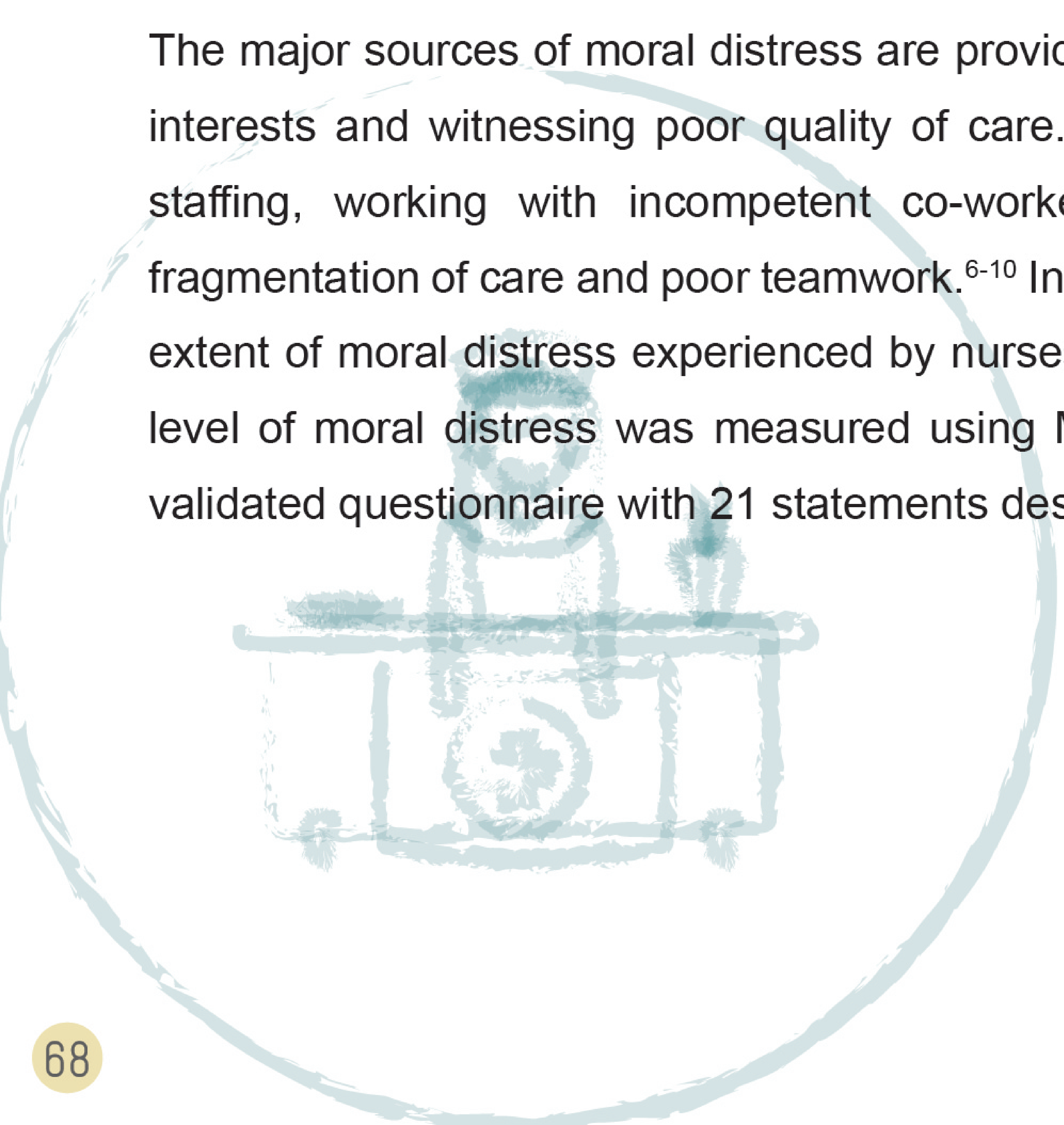
What is moral distress?

Moral distress is defined as the negative experience among health professionals when they know the right thing to do but cannot pursue that course of action due to institutional constraint.[1-2] It is different from work stress and compassion fatigue although these may be experienced simultaneously.[3-4] The negative emotions that resulted from the initial moral distress would persist as a lingering feeling of unease and accumulate over time.[2] The unresolved moral distress can result in health professionals being desensitized to ethical challenges.[4]

Prevalence and sources of moral distress

The concept of moral distress originated from nursing research, but empirical evidence consistently showed that moral distress is experienced by various types of health professionals, including physicians, pharmacists, social workers, and other allied health professionals.[6-7] Studies also found that moral distress is reported across different specialties, such as critical care, surgical care, oncology care and paediatric care, and healthcare settings, including acute care, critical care and long-term care.[3-7] There is growing awareness that moral distress is also common in medical students, residents and junior staff.[8-9]

The major sources of moral distress are providing futile care or care which is not in patients' best interests and witnessing poor quality of care. Other reasons for moral distress are inadequate staffing, working with incompetent co-workers, inappropriate use of healthcare resources, fragmentation of care and poor teamwork.[6-10] In 2016, a local survey was conducted to examine the extent of moral distress experienced by nurses in the acute hospital setting in Hong Kong.[11] The level of moral distress was measured using Moral Distress Scale-Revised (MDS-R) which is a validated questionnaire with 21 statements describing different ethically challenging situations.[5]



As shown in Table 1, most of the items with the highest scores were related to end-of-life care. It seems that moral distress arises when nurses perceived a gap between the provision of quality end-of-life care and the care that patients received in practice. Moreover, the findings showed that the level of moral distress of nurses working in various specialties or department, including oncology, surgical and emergency care, were comparable to those in critical care units. Perhaps the increased prevalence of chronic progressive diseases and the ageing population prompt the need to place a greater emphasis on end-of-life care across different units.

Table 1. Top five Moral Distress Scale-Revised (MDS-R) items* (N=447).

Five MDS-R items with the highest frequency score	Mean ± SD
Follow the family's wishes to continue life support even though I believe it is not in the best interest of the patient.	5.61 ± 4.00
Carry out the physician's orders for what I consider to be unnecessary tests and treatments.	5.19 ± 4.05
Initiate extensive life-saving actions when I think they only prolong death.	5.14 ± 3.88
Continue to participate in care for a hopelessly ill person who is being sustained on a ventilator, when no one will make a decision to withdraw support.	4.39 ± 3.87
Work with nurses or other healthcare providers who are not as competent as the patient care requires.	4.20 ± 3.65

*Respondents were asked how often they encountered these situations in their care practice (frequency) and the level of disturbance they experienced in these situations (intensity) using a 5-point Likert scale respectively. The frequency scale ranged from 0 (never) to 4 (very frequently), whereas the intensity scale from 0 (none) to 4 (great extent). The frequency score and the intensity score are multiplied for each item.

BACKGROUNDER

(3) MORAL DISTRESS AMONG HEALTH PROFESSIONALS: WHAT AND WHY

Impacts of moral distress

Clearly, moral distress is an issue highly pertinent to the cost, quality and sustainability of healthcare services. Moral distress may manifest itself as anger, impatience and depression due to emotional exhaustion, frustration, guilt, shame, powerlessness, or distancing from clients and being silent and indifferent towards patients' care.[6-7]

On the other hand, moral distress can also affect the wellbeing of health professionals, causing somatic symptoms such as palpitations, insomnia, nausea, fatigue, headaches, tearfulness and gastrointestinal upset.[7] Evidence suggests that moral distress is significantly associated with burnout in critical care providers. The physical and psychological sequelae intertwine, resulting in poor job satisfaction, low workplace morale, and absenteeism.[6] Some studies found that moral distress is associated with poor staff retention, since health professionals may perceive themselves as moral agents who fail to fulfil their moral obligations, resulting in compromised professional integrity.[8]

Could we address moral distress?

Moral distress may be a communal experience to be interpreted in a broader context, rather than just as an individual experience. Institutional constraint is widely recognized as a contributing factor to moral distress. The implicit and explicit values of the organization affect the attitudes and behaviours of the health care providers in the clinical environment.[6, 12-14] Recent literature noted that the socio-political healthcare context driven by government fiscal plan and policies that affect its structure and resources also play a role in shaping the ethical climate of healthcare organizations.[3, 15]

To mitigate moral distress, relevant interventions should be built into the systems and organizations with the goal of cultivating moral resilience among health professionals so that they could recognize the experience of moral distress and have the internal capacities to uphold their moral obligations.[11-16] Following are some suggested ways for addressing moral distress:

Ethics education

The concept of moral distress should be introduced in both the pre-registration training curriculum for health professionals and continuing professional education in order to foster self-awareness towards moral distress. Monrouxe et al. (2017) underscore the importance of developing students' moral decision-making skills when confronting with ethical dilemmas. Small clinician-led interactive sessions would enable them to understand the ethical complexities and develop confidence and skills in managing the situations.[9] However, moral distress cannot be reduced simply through developing ethical competence. Health professionals with a heightened awareness of good healthcare are more susceptible to moral distress when they fail to act on the right course of action. Berger (2014) suggested that training on mediation and communication is also important for health professionals to improve their conflict management skills as well as patient-clinicians relationships.[8]

Organizational support

A wide range of interventions can be offered by the organization as structural empowerment so as to support health professionals in addressing moral distress. For example, multidisciplinary forums to encourage open discussion about ethical issues and operational constraints that have arisen in clinical care, mentoring for junior staff who may experience dissonance between what they have learnt and what they actually encounter in the clinical setting, regular structured debriefing sessions for ethically challenging situations in individual departments or units, and counselling services.[3, 8, 15-17] Through open dialogue in these avenues, health professionals are encouraged to speak up, identify the contributing factors to moral distress and develop appropriate strategies in a collaborative approach. All these interventions indeed are supporting health professionals to co-create a culture of ethical practice. In addition to the aforementioned organizational measures, clinical ethics committees serve as a main resource for clinicians to seek for advice. The role of clinical ethics committees have emerged from formulating ethical guidelines to providing ethics consultation in various formats to support clinicians in clarifying their ethical concerns and moral obligations.[18-19]

Conclusion

Moral distress is a common phenomenon in day-to-day clinical practice across health care settings. It jeopardizes not only the wellbeing of health professionals, but also the quality and sustainability of health care services. Ethics education is imperative to deepen the moral sensitivity of health professionals. More importantly, the reciprocal influence between the ethical climate of the health care environment and health professionals underscores that there should be proactive interventions or changes in parallel at the organization level to construct a supportive culture for ethical practice.

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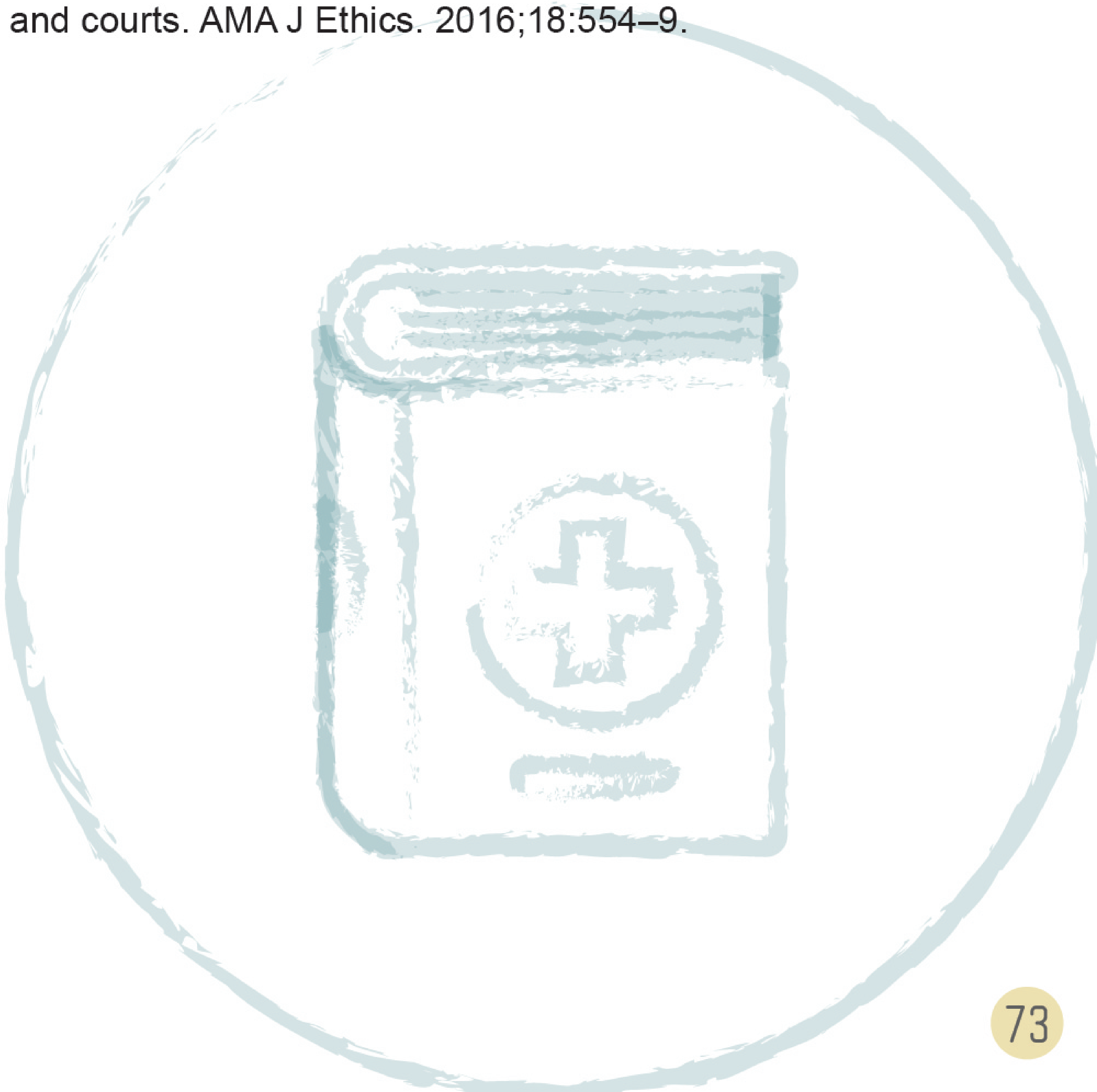

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