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JCECC
Jockey Club End-of-Life Community Care Project

CASEBOOK

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

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Contents

II. Cases and Commentaries

INTRODUCTION

This Casebook provides an open-access online 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.

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
Truth-telling
Advance Directives
Life-sustaining treatment
Informed consent
Moral distress
Family conflict
Futility
Best interest
Cultural beliefs

CASE 1

Mr. Lau

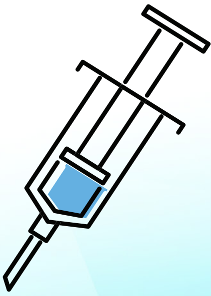
Conflict Between Team Members

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:

1. **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.

2. **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.

3. **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.

4. **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

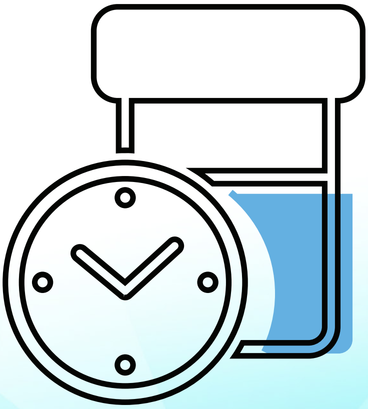
Feeding Tube Decision In A Dying Demented Patient

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.

Mr. Chan

Feeding Tube Decision In A Dying Demented Patient

Commentary

– Dr. Tse Chun Yan, Chairman, HA Clinical Ethics Committee (2005 to 2017)[i]

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.

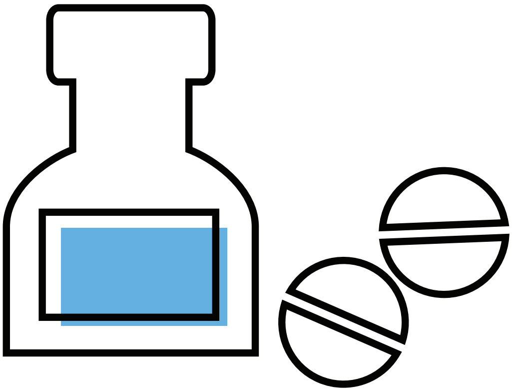
We can approach the problem step by step:

1. **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.

2. **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.

3. **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.



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[i] The case and commentary was adapted from an article by Dr. Tse Chun Yan, "Practical Approach to Clinical Ethics at the Bedside for General Physicians", published in Synapse, Newsletter of the Hong Kong College of Physicians, in August 2016. The case was originally presented by Dr. Wong Che Keung of Ruttonjee and Tang Shiu Kin Hospital on 23 April 2016 in the Clinical Ethics Day held in HA Head Office Lecture Theatre.

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, Ex-Director, CUHK Centre for Bioethics (2017-2022)

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?

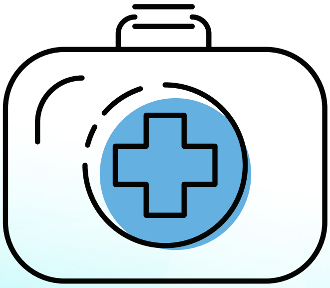
One may say that it is impossible to foresee and exhaust all possible scenarios to obtain the patient’s advance instructions. That is why advance care planning should not be limited to treatment preferences for particular situations. When time and circumstances permit, it should also seek to clarify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

CASE 4

Mrs. Kwok

Family Requests To Withhold The Truth From Patient

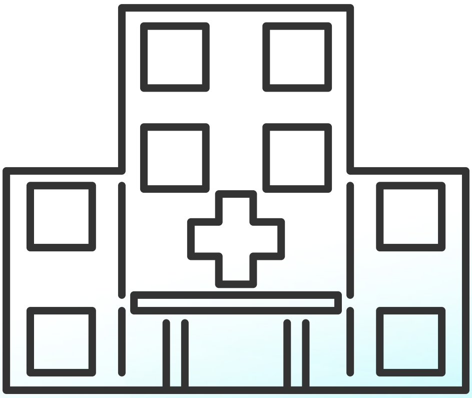
Commentary

– 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:

1. **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.

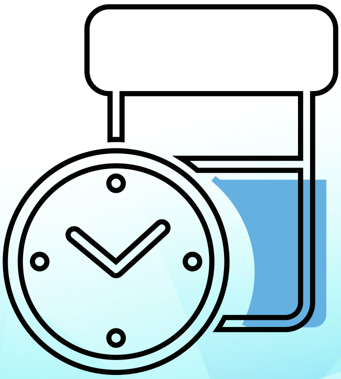
2. **Are there ways to reduce the harms of truth disclosure?**
   Experience especially in palliative care has shown that sensitive, skilled communication coupled with good psychological, social and spiritual support can reduce the harm from breaking bad news.

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.

1. **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.

2. **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.

3. **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.

4. **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.

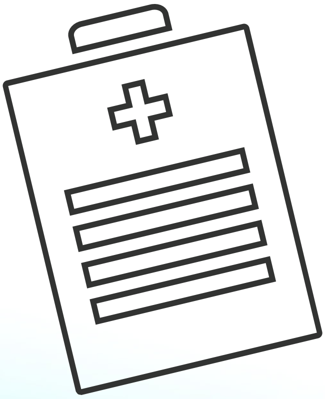
“Yeah. I don’t ever want to wear it again! Just let me go without making me suffer through all that! I’ve had enough!”

“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

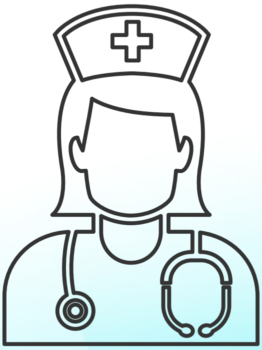
– Dr. Derrick Au Kit Sing, Ex-Director, CUHK Centre for Bioethics (2017-2022)

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

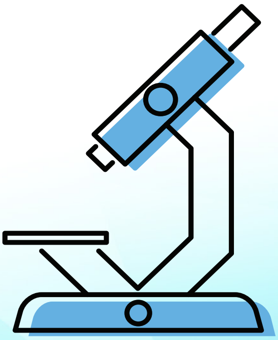
Disagreements Over Timing For Advance Care Planning

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.

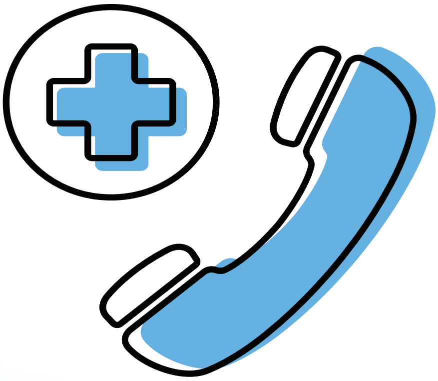
What can the nurse do?

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.

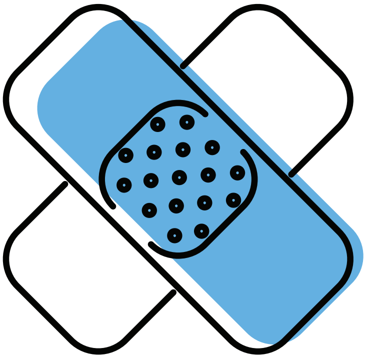
These multiple hospitalizations had been uncomfortable experiences for Mr. Ip. He sometimes experienced intractable nausea and vomiting and had to lie in bed for days on end. He would ask to go home soon after each time he was admitted. After one of these hospitalizations, he told his wife and his children, “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

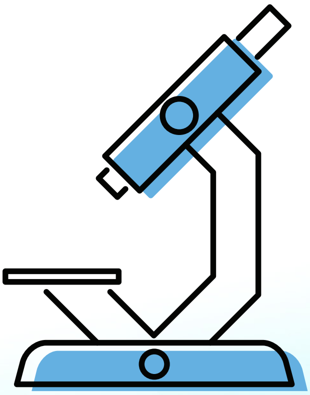
Mr. Ip

Withholding Antibiotics At The End Of Life

Commentary

– Dr. Christopher Lum, Consultant, CUHK Jockey Club Institute of Ageing

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:

1. What is the chance that Mr. Ip will survive if the antibiotic is given? Does it really cure him or prolong the dying process?
2. 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?
3. Is Mr. Ip's expressed wish and choice consistent when he was sick and when he was well?
4. Would there be any legal repercussions for Dr. Mok and the medical team if antibiotics were withheld?
5. 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?

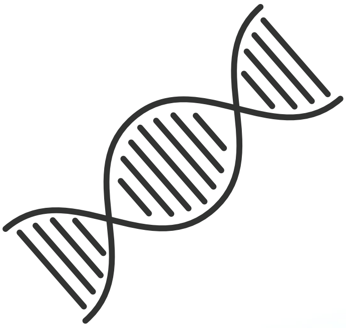
As in the case of Mr. Ip, his family had honored his wish to prioritize his comfort when they opted for careful hand feeding and accepted the associated risk of recurrent aspirations. This expected event has precisely occurred. At this time, his clinical state suggested that he was approaching his terminal 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

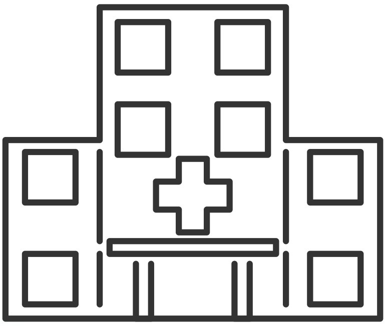
Mr. Ip

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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1. Tsevat J, Cook EF, Green ML, Matchat DB, Dawson NV, Broste SK et al. Health values of the seriously ill. Ann Intern Med 1995; 12(7): 514-520.

CASE 7

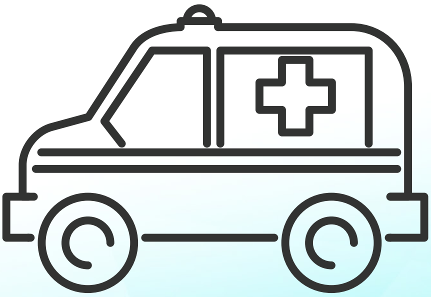
Ms. Ng

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.

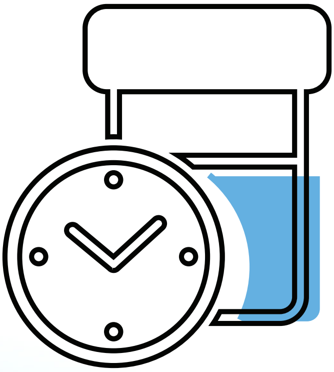
Unfortunately, the biopsy results revealed diffuse large B-cell lymphoma and oncology was consulted. The oncologist, Dr. Yim, explained the treatment options with Ms. Ng and Tom. The bad news is, she said, that this type of cancer is very aggressive. Without treatment, the cancer will progress quickly 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

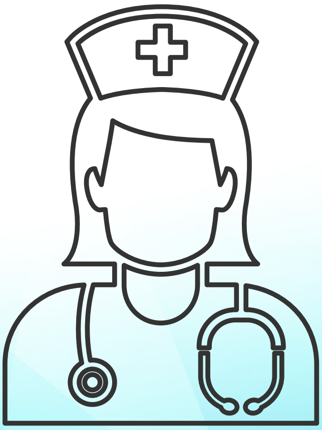
Opting For Chinese Over Western Medicine

Commentary

– Dr. Derrick Au Kit Sing, Ex-Director, CUHK Centre for Bioethics (2017-2022)

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.

Reference

1. Gillon, Ranaan. Ethics Needs Principles-Four Can Encompass the Rest-and Respect for Autonomy Should be "First Among Equals", Journal of Medical Ethics 29:307-312,2003.

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.

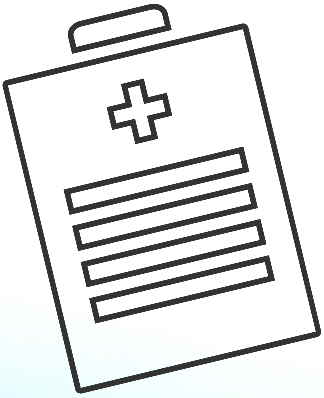
Karen replied, "Mom has already suffered enough. She doesn't recognize me anymore and she can't communicate. She just lies there. Putting in a feeding tube would be torturing her more." Karen opted for careful hand feeding. Her decision was documented in an advance care planning document which was sent 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, Honorary Consultant Geriatrician/ Clinical Associate Professor (Honorary)/ Clinical Lecturer (part-time), Department of Medicine & Therapeutics, Prince of Wales Hospital, The Chinese University of Hong Kong

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:

1. 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.

2. 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.

3. 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

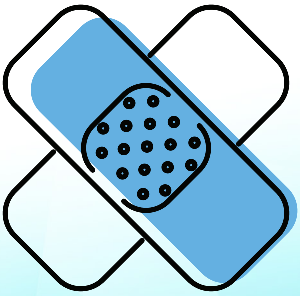
Filial Piety In End Of Life Care Decisions

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.

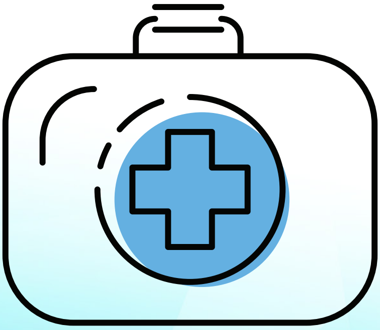
“We will assess you regularly for any symptoms and try to treat you in the aged home if possible. If a hospitalization is needed, we will try to arrange a direct admission to the geriatric ward in the hospital and avoid a trip to the A&E department. The only requirement for patients enrolled in this 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, Ex-Director, CUHK Centre for Bioethics (2017-2022)

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.

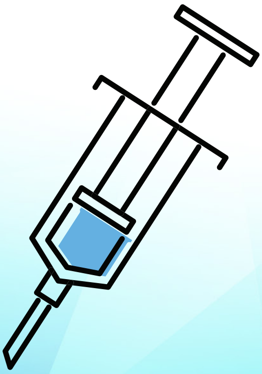
Commentary

-Dr. Tak Kwan Kong, Honorary Consultant Geriatrician/ Clinical Associate Professor (Honorary)/ Clinical Lecturer (part-time), Department of Medicine & Therapeutics, Prince of Wales Hospital, The Chinese University of Hong Kong

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.

CASE 11

Mr. Tse

Mentally Incapable Of Making End Of Life Care Decisions

Mr. Tse, a 70-year-old man, was brought to hospital and admitted to the medical ward by his son. Mr. Tse complained of not being able to swallow. He lived alone, had a history of drinking many cans of beer, and his son visited him occasionally. The history of the swallowing problem was uncertain. He appeared emaciated. An OGD was carried out and a tumour obstructing the oesophagus was found. The surgical team concluded that Mr. Tse was too frail to undergo any palliative stenting procedure. The Medical Oncology team recommended that a course of chemotherapy might be tried, but that his nutritional status should be optimized first. His body mass index was 12 kg/m^2 and he was unable to ambulate, being dependent for the basic activities of daily living.

In the meantime a nasogastric tube was inserted since Mr. Tse was unable to tolerate any food. However, he kept pulling the tube out and had to be restrained. Several conversations with Mr. Tse were attempted to elicit his preferences. Conflicting stories were obtained: sometimes he wished to do whatever the doctors recommended; sometimes he wanted to eat chicken and demanded this; sometimes he refused all treatment and wanted to be left alone. His son was consulted for an opinion on his feeding method, but was unsure what to do. After a few weeks a Mini Mental State Examination was carried out, revealing a score of 10.

How would ethical considerations guide the management of this patient?

Commentary

– Dr. Christopher Lum, Consultant, CUHK Jockey Club Institute of Ageing

The case of Mr. Tse posed an ethical dilemma for clinical care and management. Most specialty textbooks focus on disease treatment and doctors are trained to treat a disease or a single problem. Thus the Oncology team recommended that "a course of chemotherapy may be tried, but that his nutritional status should be optimized first". As per the recommendation, the primary care team inserted a nasogastric tube but this was repeatedly pulled out by Mr. Tse. Although attempts were made to explore the wishes of the patient (it was uncertain what wishes were explored, re: on feeding mode, whether to receive chemotherapy or not, etc.), replies were inconsistent. The team attempted to consult Mr. Tse's son, but he was unable to give an answer on what to do. Should the team continue to enforce the method of nasogastric tube feeding in attempt for later chemotherapy despite Mr. Tse struggling with this? Or should the team "abandon" Mr. Tse in view of his reluctance to receive treatment?

The four principles of Beauchamp and Childress (2001) on medical ethics, namely autonomy, beneficence, non-maleficence, and justice, have been pillars in this area for decades. These four pillars are inter-related and not standalone principles. For example, while we are to respect an individual's autonomy on decision-making, he/she should be given adequate and truthful information on beneficence and non-maleficence before making the decision. As a prerequisite, Mr. Tse needed to have the mental capacity to make judgements and decisions. As for the situation of Mr. Tse, his decision was inconsistent and there was doubt on his mental capacity to make judgement. His cognitive function was assessed with Mini Mental State Examination (MMSE), in which he scored 10/30, showing that he was at a level of severe cognitive impairment by convention. However, one has to rule out the possibility that he was suffering from pseudo-dementia (e.g. depression related to the diagnosis or current treatment received) that was reversible. Even if his cognitive impairment was irreversible, a low score does not exclude him from having the ability to make decisions on his own. Proper assessment of his ability to retain, comprehend and balance information was required before being able to judge whether Mr. Tse was capable of making decisions on his medical treatment. Assuming Mr. Tse was genuinely not able to make judgement, it was reasonable to seek opinion from his son who should act as the surrogate for Mr. Tse, i.e. to make decisions as if he were Mr. Tse.

However, in recent years, there are concerns that the four principles alone are not sufficient in themselves. There are also debates about what constitutes “beneficence” or “non-maleficence”. Should an extension of life be the only outcome of such interests? A study has shown that for some, being handicapped or not being able to live independently are more intolerable than death (Tsevat J, 2004). Furthermore, more than 95% of the local population is Chinese, which follows the philosophy of filial piety in Confucianism. It is difficult to adopt an individualistic approach and neglect the views of family members. A practical “four quadrants” approach that takes into account the medical indications, patient preference, quality of life, and contextual features is advocated (Sokol DK, 2008; Jonsen AR, 2010; Tse CY 2016).

On medical indications for treatment, the medical team should be the best party to make recommendations based on the principles of beneficence and non-maleficence. Recommendations should not be based on an “average” patient but should be based specifically on Mr. Tse. As illustrated in this case, chemotherapy for oesophageal cancer may extend the median survival for a certain duration. The trade-off comes with the side effects of the chemotherapy. Yet, in the case of Mr. Tse who at that point was so emaciated, debilitated and generally frail, it was highly unlikely that he could tolerate chemotherapy or that chemotherapy would extend his overall survival. Medical indications for chemotherapy are debatable, so was the indication for a nasogastric tube for nutrition build-up, which serves as a primer to chemotherapy.

As to the patient’s preference, it was clear that Mr. Tse had repeatedly pulled out the nasogastric tube. That was obviously not his preference. As indicated, he wanted to eat chicken and demanded it. Was there a reason why he was not allowed to have chicken as he preferred? Had there been discussion with Mr. Tse on his preference to receive chemotherapy? Had he been given adequate information on not only the “success rate” and side effects of chemotherapy, but also the “success rate” and side effects of priming with nasogastric tube, as well as the expected life conditions after a “successful” chemotherapy? In other words, Mr. Tse needed to be discussed on the whole “management package” instead of on each of the individual procedures by isolation. If Mr. Tse was incapable to understand and judge, his previously expressed goals, values and preferences in life might be sought from his son. The information should then be used to evaluate whether the procedures (use of nasogastric tube, giving chemotherapy) violated the previously expressed goals, values and preferences of Mr. Tse, and to help his son arrive at a decision for Mr. Tse.

Quality of life (QOL) may pose a difficult issue as individuals may vary on what constitutes a good QOL, or on what life conditions are considered unacceptable. If a patient is cognitively sound, then one may discuss with him/her wishes or values, and what is considered an intolerable lifestyle over an estimated life span. In the case of Mr. Tse who could not give a sound decision, previously expressed opinions on the above matters could be sought from the son.

As alluded to above, the Chinese have a strong culture of filial piety which is largely influenced by Confucianism. This contextual feature has to be considered, especially given that the family's view is sought when a patient has not expressed prior wishes. This presents the family members with the most difficult decision or unbearable responsibility when it comes to "refusing" a course of treatment which is "medically indicated". However, the focus should NOT be on "accepting" or "refusing" a conventional treatment. Rather, the family should be discussed on different options of management directions, and arrive at a joint decision that is in the best interests of Mr. Tse based on the above three areas.

Mr. Tse

Mentally Incapable Of Making End Of Life Care Decisions

It would be worthwhile reviewing the following aspects with the son:

1. Current diagnosis;
2. Usual treatment of the condition and the particular circumstances of Mr. Tse resulting in the need of special consideration;
3. Explore whether Mr. Tse had expressed any prior wishes, preferences and views in life;
4. Discuss and suggest management options in the light of any known wishes, preferences and valued aspects in life, as well as any limitations that may not be acceptable to Mr. Tse;
5. Family should be supported in reaching a difficult decision that is in the best interests of Mr. Tse and is based on the best guess of his wishes. It should also be made clear how the team and family are to work together towards fulfilling the final wishes for Mr. Tse in his final journey.

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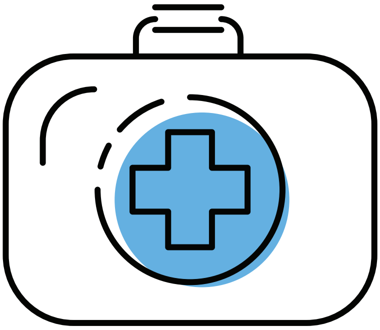
CASE 12

Mrs. Cheung

Continuation Of Dialysis Therapy

Mrs Cheung was a 75-year-old woman previously living alone and undertaking CAPD. She suffered a stroke with hemiplegia and became cognitively impaired. She could not take care of her CAPD anymore. There are no family members to help with the CAPD. She has assets and thus is not qualified for CSSA. Her children cannot afford private OAH with CAPD facilities. She is confused and cognitively impaired to an extent that she constantly pulled at her Tenckhoff catheter and required 24-hr restraints to prevent that. Now she has been staying for several months in the rehab hospital. What are the ethical concerns and what should be the approaches of the clinical team?



Commentary

– Dr. Christopher Lum, Consultant, CUHK Jockey Club Institute of Ageing

Older patients differ from younger patients in that they have multiple medical conditions rather than a single disease. Decision-making on the clinical management of a single medical disease is usually much more straightforward. Yet when multiple conditions set in, one has to set out a care plan using an integrative, whole-person approach.

This is illustrated in the case of Mrs Cheung, who was supposed to have only one single condition (chronic renal failure [CRF], was on renal replacement therapy [RRT]) and had been in a good physical state (lived alone and managed her own CAPD) following prior RRT. However, she suffered a stroke with cognitive impairment. She was left disabled and could not live alone or manage the RRT by herself. On numerous occasions she had also attempted to pull out her Tenckhoff catheter and needed to be restrained. The Clinical Team was likely to face a dilemma as to whether the RRT should be continued (beneficence). Since Mrs Cheung was reliant on the RRT, if it was withdrawn would it be equivalent to active euthanasia (maleficence) which is illegal in Hong Kong? She had also been in hospital for a long time, so was this fair to others who were waiting for rehabilitation (justice)? What overall care plan should be suggested to family members?

Of these questions, the one relating to justice is probably the easiest to answer. A doctor has a duty of care once a doctor-patient relationship is established, as in the case of Mrs Cheung. Though resources are scarce, it is unethical to “dispose” of Mrs Cheung without coordinating appropriate care. Under the Mental Ordinance of Hong Kong, one can apply through the Guardianship Board to appoint an official guardian to oversee a person’s finances (within limits), as well as his or her placement in and receipt of medical care. Although Mrs Cheung’s assets were likely to exceed the limits applicable to decisions made by the appointed guardian, family members could trigger Part II of the Ordinance to sell the assets through the High Court to finance her future care plan. This may take months to realize, and a discussion between the high-level hospital management and social welfare department is required with regard to interim discharge placement before a permanent decision is made.

CASE 12

Mrs. Cheung

Continuation Of Dialysis Therapy

Beneficence, non-maleficence, autonomy and justice have been the pillars of medical ethics for decades. Yet there is no hierarchical level applied to the pillars, what happens if one pillar contradicts the other (as in Mrs Cheung's case in which elements of both beneficence and non-maleficence could apply)? A new approach, taking into consideration the medical indications, the patient's preferences, quality of life and contextual factors, is recommended.

When it comes to assessing medical indications (medical beneficence and non-maleficence), one has to adopt an integrative, whole-person approach. As in Mrs Cheung's situation and before her stroke, the RRT had benefited her, offering increased survival potential and reduced symptoms of CRF. However, the benefit of RRT is likely to be greatly attenuated due to significant functional limitations following the stroke. Although there was little information on her detailed functional state, she was likely to be in the frail category which is an independent predictor of falls, hospitalization and even death. On top of this, she had to be restrained and was predisposed to all of the hospital-acquired complications including autonomic dysfunction, sphincter problems, infections and pressure-related skin injuries. In addition, her attempts to pull out the Tenckhoff catheter reduced the efficacy of the RRT and introduced the risk of visceral tears and peritonitis, which was the most significant element of maleficence. Overall, it was likely that the survival benefits of RRT would occur over days or weeks and this would be at the expense of repeated trauma and discomfort (both psychological and physical). On balance and given the current information, the overall benefits of the current medical intervention (continuation of RRT and restraining of the patient) were marginal. The balance might be tilted more towards intensive medical intervention (for RRT) if Mrs Cheung showed significant functional and cognitive improvement, resulting in her not needing to be restrained and not pulling out the Tenckhoff catheter.

On the aspect of the patient's preferences, Mrs Cheung was cognitively impaired and could not make a logical judgement or decisions. One has to ask if she had previously made a decision regarding an Advance Directive (AD) or Advance Care Plan (ACP). Having said this, current AD / ACP forms do not have a category for "condition-specific items" (e.g. preference whether to use / not use CAPD). However, provided that the ACP (if one is available) is conducted properly, documented information on the patient's values / preferences / least tolerable bodily state in life would give a guide to her personal preferences and choices. In Mrs Cheung's case, I presumed she did not have an AD / ACP. One had to discuss with her family members whether she had ever expressed views on her goals and preferences for clinical management, and what physical state she would consider to be beyond acceptable.

Every individual may have different life values and it is difficult to generalize. Having said that, some domains are likely to be common – for example, respect, dignity, freedom and being free from pain / discomfort. Although we could not hold a meaningful conversation with Mrs Cheung, her act of repeatedly pulling out the Tenckhoff catheter would suggest she experienced the discomfort with it. She was “confused” and needed to be restrained. One wonders if the “confusion” was a natural act to remove the thing (Tenckhoff catheter) that was causing the discomfort. Yet being restrained resulted in more discomfort and distress (and possibly even more and extended discomfort beyond immediate harm, as discussed in the earlier paragraph on medical indications). If one factors this Quality of Life into the decision on medical indications, the results might tilt towards non-maleficence with the continuation of the RRT.

Since the patient was receiving ongoing RRT, there might have been concerns as to whether not continuing RRT was equivalent to active euthanasia. While taking action to end a life prematurely is considered active euthanasia and a criminal act in Hong Kong, withholding a futile treatment and allowing death to take its natural course is acceptable locally. In Hong Kong, a Chinese society where strong family ties prevail, it is advisable to listen to and to reach a consensus with (and among) family members

Overall, the essential question was whether Mrs Cheung would experience significant functional and cognitive improvement which would enable her to receive CAPD safely. One should discuss the medical conditions candidly with the family members (including their views on quality of life) using an integrated, whole-person assessment approach (instead of just from a medical or individual disease viewpoint), explore whether the patient had previously expressed any preferences regarding the goals of clinical management, give your recommendations based on the above and reach a consensus with the surrogates. During times of uncertainty, one may attempt a trial while hoping for the best, despite preparing for the worst. In Mrs Cheung’s case and assuming that the physical improvement had already plateaued off, one might suggest limited restraint (e.g. mitts only) to avoid her pulling out the Tenckhoff catheter. If this proved successful, all would be happy to see the extension of life within acceptable limitations. Previous discussions on the Guardianship Board application / High Court application to manage assets would also apply here. On the other hand, if Mrs Chung pulled out the Tenckhoff catheter again, not reinserting it and providing medical treatment alone to reduce distressful symptoms could be acceptable and might be in the best interests of Mrs Chung. Again this should be thoroughly discussed with family members. Consensus can commonly be reached when the healthcare team and family members both work together in partnership towards the common goal of the “best interests” of the patient.

CASE 13

Mrs. Wong & Mrs. Tam

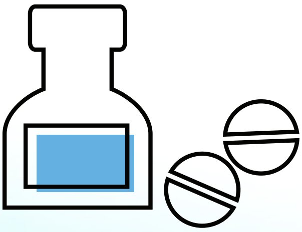
Treatment Priority During The Covid-19 Pandemic

Suppose now you have two patients:

A) Mrs. Wong/63. She has metastatic cancer disease. She has previously tried two different anti-cancer treatments yet the cancer still progresses, and now she is on a trial of the third treatment. She has received two doses of COVID vaccine, but unfortunately she still contracted COVID and is now down with it.

B) Mrs. Tam/83. She lives alone, with a few common chronic diseases on medical treatment. Her basic ADL is ok but requires home helper services for household chores. She is most worried about the side effects of COVID vaccine and has not received one. Now she is down with COVID.

Both patients are now hospitalized with equally high viral load and require the same level of high flow oxygen. You have only one course of the new anti-viral therapy. Whom will you give the treatment to? A or B?

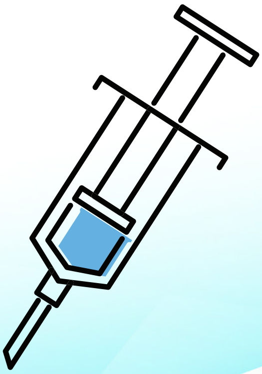


Commentary

– Dr. Mok Chun Keung, Consultant, M&G, Tuen Mun Hospital

Prioritization of patient management is not uncommon in clinical practice because of the mismatch between supply and demand in health care. However, only in extreme crisis situation of resource scarcity (e.g. during wartime or the current COVID epidemic) can resource "rationing" be implemented. Rationing means that indicated patients are denied of such critical treatment because of resource scarcity. The underlying ethical principle of rationing is "Justice" (mainly "Distributive Justice"). It requires every patient to be treated with equal respect, avoiding value judgements based on one's functioning level and quality of life, etc. Patients with an equal chance of benefiting from a treatment should have an equal chance of receiving it (1).

Facing the COVID crisis, Hospital Authority (HA) has issued "An Overarching Framework for Ethical Considerations in Resource Allocation of Intensive Care and Ventilator Support During COVID-19 Pandemic" in 2020 (2). It aimed to help frontline clinicians to face the difficult challenge of critical resources allocation to an overwhelming number of COVID patients. Although this is meant to be an internal guideline only, the principles behind should be applicable to not only HA, but also the entirety of medical professions. In the guideline, besides considering Justice together with Beneficence, Non-maleficence and Respect for Autonomy (i.e. the four bioethical principles), the following three factors were also taken into account (3).



1. Maximization of the incremental health benefit to the patient population: treatment priority should be given to those whose conditions are “the most urgent, the least complex, and who are likely to live the longest, hereby maximizing overall benefit in terms of reduced mortality and morbidity”. Short-term benefits (hospital survival or similar short-term patient-centered outcomes, such as 3 to 6 month survival) should be the first consideration. Treatment priority should be given to patients of whom the treatment will likely make a significant difference in the survival. Longer-term benefits such as life-years saved are much more complex and should be of secondary priority.

2. Efficiency: scarce resources should be used efficiently but a simple “cut-off” policy (e.g. based on age or disability) would be, albeit efficient, ethically unacceptable.

3. Proportionality: stringency of rationing policy needs to be proportionate to the gravity of the crisis and be constantly reviewed. Rationing should only be taken as the last resort when other alternatives are not feasible.

It should be noted that the four bioethical principles are still applicable to individual doctor-patient relationship during the crisis. The use of “time-limited” trial in ICU care can be used to assess Beneficence vs. Non-maleficence for suitable patients, which is also in line with the principle of Justice. Proper communication with patients and relatives should be conducted before the trial. High treatment burden and mere prolongation of the dying phase are not appropriate at ordinary times, and even unethical during the crisis. As discussed, Justice is the core principle of rationing, and Respect for Autonomy is always a must. Additional principles as mentioned above (maximization of health benefit, efficiency, and proportionality) are put forth for broader considerations at the population and societal levels.

All these principles are prima facie principles and should be followed unless they conflict with each other, or with other equally strong or even stronger obligations. They are applicable to both COVID and non-COVID patients. A process of ethical analysis would be needed for individual case consideration, which would involve the judgment and weighting on all of the relevant principles. A fair, open, and transparent allocation process for the patients (involving the relevant stakeholders) should not only be done, but also be seen to be done.

Coming back to the two patients in the case, one should try to avoid discrimination on the basis of age, vaccination history, and social status, etc., which are common areas leading to discrimination. Physiological age, rather than the chronological one, is a better measurement of fitness for medical interventions. The older fit could have better prognosis than the younger sick. The clinical experience of COVID treatment in the local setting should be reviewed to compare the short-term prognoses of the two patients mentioned. The treatment decision should be in line with the overarching framework as mentioned above. The patient's autonomy should be respected even if she is the one chosen to have the treatment. She may prefer not to receive the treatment if she perceives that the burden caused by the treatment or side-effects are too high. The assessment and treatment decision are better made by a separate and neutral panel, preferably including clinicians, infective disease experts, ethicists and community stakeholders. The hospital ethical committee is an appropriate body to serve this function. The clinical frontline team could then be spared from the stress of making the hard decision and the tension with the disappointed patients and relatives. No matter what the final decision is, the principle of "No Abandonment" of clinical care should be followed. Both patients should receive continuous medical support, including proper palliative care, throughout the trajectory of their illnesses.

Resource allocation with Justice involves several philosophical theories and approaches, including egalitarian, communitarian, libertarian, and utilitarian (4). However, no single theory could cover all the situations in all societies. The society needs to choose and study in depth the scenarios facing them. The approach should be communicated to the public at the outset to allow time for public discussion and buy-in. Interested readers can refer to the two related articles (5) (6).

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CASE 14

Mr. Cheung

Ethical Dilemma Related To “Dying At Home”

Mr. Cheung, a 68-year-old gentleman, was diagnosed of advanced pancreatic cancer. He preferred palliative care and symptom control. He used to be a successful small shop owner and enjoyed the life with his beloved family. He was a non-smoker, social drinker with good health before the diagnosis. He lived with his wife. His adult children and grandchildren visited him frequently. Mr. and Mrs. Cheung had good relationship all along. Mrs. Cheung was taking good care of her husband in all aspects and followed his decisions in most of the major family issues.

Few months later, Mr. Cheung’s conditions further deteriorated and became home bound. His medical follow-up was shifted from the out-patient clinic to a home-visit approach. The palliative home care nurse offered a home visit to Mr. Cheung. On arrival, Mr. Cheung was sitting on the sofa with both lower limbs elevated by a comfortable stool. Both his wife and daughter were performing gentle massage to him. He had cachectic appearance and decreased duration of concentration during the conversation.

During the home visit, the home care nurse had an updated assessment of his physical and psycho-spiritual conditions. Mr. Cheung and his family members were coping well at home with the support of the palliative care team. Mr. Cheung had a clear mind and was mentally alert. Pain and other symptoms were well under control except for insomnia and an occasional sense of nausea.

- Mr. Cheung asked “When should I go to the hospital? Can I have a try of my favorite dish, braised pork with preserved vegetable (梅菜扣肉), before the admission?”
- Mrs. Cheung replied “You do not need to go back to the hospital for follow-up. That’s why the home care nurse comes to visit you. Braised pork is unhealthy, so don’t try it anymore.”
- The daughter further explained “Most of the major examinations have already been done. Are you thinking of any specific treatments, or do you wish to see the doctor?”
- Mr. Cheung replied “Nothing special. Just want to know when I need to return to the hospital.”
- The home care nurse further clarified with Mr. Cheung “Can you tell me the reasons why you are repeated asking about hospital admission?”
- Mr. Cheung said “I am no longer able to walk and wet my trousers more frequently. I think it’s time for me to be admitted.”
- The home care nurse answered “Hospital admission cannot change these conditions. Is there anything more important in your mind?” and paused a while, allowing Mr. Cheung to react.
- Mr. Cheung expressed “Am I going to die? People should be admitted to the hospital in their last days of life.”
- The home care nurse acknowledged Mr. Cheung “Your perception is very reasonable. What about your own thoughts? Would you prefer to stay at home or go to the hospital when you are very weak physically?”
- Mr. Cheung said “Indeed I would like to stay at home with my beloved family members. On the other hand, I don’t want to burden them anymore. I believe that everybody must go to the hospital when they are no longer able to take care of themselves.”
- The home care nurse replied “There are no fixed rules regarding whether you should or should not go to the hospital. It depends on your preferences and the practical situations. We will try to work it out with the whole team, including your doctor-in-charge and family members, to see how to keep you stay at home with high quality of life, if this is what you want. Of course, we will also discuss other possible ways of handling your situations with your wife and daughter as a contingency plan.”
- Mr. Cheung became tearful and expressed “Is it possible? I don’t mean I truly wish to be admitted. Just my worries. If I can stay at home until my last breath, it will be much better.”

- The daughter echoed with Mr. Cheung's wish "You will never be our burden. Instead, you are our spiritual pillar. We will try our best to look after and stay with you for as much as we can. Just like how you took care of us when we were toddlers."
- Mrs. Cheung said "Yes, you should know that all of us care so much about you. You took care of us in the past and are still our emotional support now. I can cook healthy and delicious dishes for you anytime."
- Mr. Cheung asked again "Can I have braised pork with preserved vegetable and beer, please?"
- The wife said "Definitely not. You are a patient."

The home care nurse interviewed Mrs. Cheung in the kitchen separately, checking her concerns and clarifying some of her myths.

- Mrs. Cheung said "It is impossible for me to cook such an unhealthy dish for a seriously ill patient."
- The home care nurse guided Mrs. Cheung's thinking and asked "Do you know why your husband has such a strong desire to eat braised pork with preserved vegetable, even though he knows it is unhealthy?"
- Mrs. Cheung replied "Many years ago, we used to enjoy this home-made dish with soft drinks and beer in the evening after long working hours. At that time, our children were very young and we did not have many enjoyable activities. This was one of the common activities that he could enjoy and felt relaxed at home. He seldom went out by himself and preferred watching our children play among themselves at home."
- The home care nurse asked "What are the pros and cons for him to take this 'unhealthy food'?"
- Mrs. Cheung said "He is ill and should take as much healthy food as possible. I understand that he wishes to bring back the memory of a previous enjoyable moment. But actually, he cannot tolerate the food and may even vomit it out."

The daughter came into the kitchen and joined the conversation.

- The home care nurse asked “Do you know the reasons why he is asking for it, even though he fully understands that he cannot take too much of it and may even not be able to tolerate?”
- Mrs. Cheung said “Maybe he wishes to take it with us and recall the happiness of food sharing in the past. I am not sure. It seems to be the most likely reason. He is a disciplined person and seldom has any inappropriate requests.”
- The home care nurse further asked “If this is the reason, what would be your decision?”
- The daughter said “He likes it. Let him try. As long as there is no harm done to him and it is not contradicting with the medical and nursing advices.”
- The home care nurse answered “We have no objection in letting him try. As you know, the texture of this dish is very soft and can be easily dissolved in mouth. You can create a relaxing environment at home and share the food with him. Not aiming to make him swallow it, but just let him taste it and spit it out. The most important point is to create an enjoyable moment for him through sharing.”

After the discussion, Mrs. Cheung returned to the sitting room.

- Mrs. Cheung told Mr. Cheung “I am going to prepare your favorite dish tonight. Do you want a mouthful of beer too?”
- Mr. Cheung was excited and asked “Is it for real? I can have some beer too?”
- Mrs. Cheung said “Yes. I have never lied to you. But just a small amount. Not all is for you, we need to share together.”
- Mr. Cheung told his daughter “I always tell people that your mum is the most understanding and caring wife in the world.”

The patient’s daughter followed up the preparation of dying at home for handling the different situations that might possibly happen in the dying process, including the modification of basic care as the patient’s conditions further deteriorated, special arrangement with the funeral home, liaison with the relevant religious parties, arrangement of doctor home visits, handling of uncontrolled symptoms, and steps to take under special circumstances.

CASE 14

Mr. Cheung

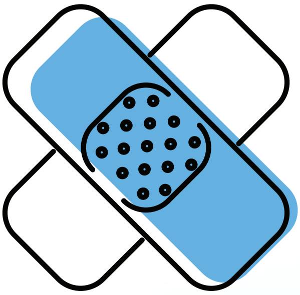
Ethical Dilemma Related To “Dying At Home”

Commentary

– Dr. Lai Tze Kwan Theresa, Associate Professor of Practice cum Programme Leader of Bachelor of Nursing (Honours), Cartias Institute of Higher Education

The above scenario is a common situation that many dying patients and their family members encounter. They are supportive and want to do everything they can to fulfill the patients’ wishes and needs. At the same time, they are confused as to what is good for the patients.

In Mr. Cheung’s case, the background information reveals that he was a family man and wished to stay with his family most of the time. We feel a strong sense of separation grief from his dialogue with the home care nurse. His wife and daughter were caring, but unable to understand his true emotions and underlying intentions. They just focused on the practical issues and based their solutions on what they believed is good for people with advanced illness. We learn that they were all supportive, but no one could hear the inner voice of the patient except for the home care nurse.



What kinds of ethical principles are being considered?

We will try to explain the above scenario from the perspective of an ethical dilemma. More specifically, we are going to explain the application of the following ethical principles in his case one-by-one. They are autonomy, beneficence, non-maleficence and respect.

Autonomy: Mr. Cheung expressed that he wished to stay at home with his family members for as long as possible. His family members also supported his thought and managed his daily care routines well with the instructions and advices from the home care team. After the nurse's assessment, it was highly possible that dying at home could be achieved if the symptoms of Mr. Cheung continued to be well under control in the near future. We respect the patient's choice regarding the most suitable place of death.

Beneficence: It is clear that the choice of dying at home did not only benefit the patient, but also his family members. He knew what was going on and his wishes were acknowledged, thereby having a reduced sense of uncertainty. From the perspectives of the family members, they could spend more time with the patient and did not need to travel frequently between the hospital and their home. They could see each other more frequently without being confined by the visiting hours of the hospital.

Non-maleficence: When Mr. Cheung asked for the so-called unhealthy food, the home care nurse tried to guide his wife to think more about the underlying reasons why Mr. Cheung had such a request. Even though the food might not have much nutritional value for him, the emotional value could not be neglected. If the action does not do significant harm, but may bring subtle benefit to the patient, then it may be worthwhile to do so. Throughout the process, it is clear that the respect of his decision was fully demonstrated.

Respect: Mr. Cheung was a successful small business owner. He used to make major decisions for his business and family. He became a more dependent and vulnerable person due to his medical conditions. As his formal or informal caregivers, it is important to be sensitive and respectful of his wishes. On the other hand, we also need to respect the family's decisions. If there are conflicts between the patient and his family, we need to facilitate their communication from different points of view and head in the same direction for the future care plan.

CASE 14

Mr. Cheung

Ethical Dilemma Related To "Dying At Home"

How does it work from a nursing perspective?

The Satir Transformational Systemic Therapy helps to explain the transformational changes of Mr. Cheung and his wife during the therapeutic process. The core elements include experiential, systemic, positively directional, change-oriented and congruence.

Experiential: Through the behaviors and conversations between Mr. Cheung and his family, we only know that he made a humble request to his wife that he wanted to have his favorite dish before admission. It seemed to be a simple request from a patient with advanced illness. His coping stance was likely to be "Placating" or "Congruent", depending on the couple's usual communication patterns. When we go deeper into the feelings of the patient, he might have experienced a sense of powerlessness and loss of control. His feelings could be sadness, fear and anxiety. His perception might be to simply have a good last supper with his family before being admitted to the hospital, from which he believed he won't have a chance to be discharged again. His expectation might be to share a piece of memory with his beloved family. The yearnings from the bottom of his heart might be to be loved by someone and maintain the connections with them. The deepest level of his "self" could be "I am a loveable husband and father with harmonious family relationships."

Systemic: By facilitating Mr. and Mrs. Cheung to experience their feelings and discover their needs, the home care nurse guided Mrs. Cheung to think about the pros and cons of addressing Mr. Cheung's request. When she knew more about the patient's needs and the underlying reasons of his request from a new perspective, her decision making was affected in a positive way within the interactive system.

Respect: Mr. Cheung was a successful small business owner. He used to make major decisions for his business and family. He became a more dependent and vulnerable person due to his medical conditions. As his formal or informal caregivers, it is important to be sensitive and respectful of his wishes. On the other hand, we also need to respect the family's decisions. If there are conflicts between the patient and his family, we need to facilitate their communication from different points of view and head in the same direction for the future care plan.

Positively directional: By improving the mutual understanding within Mr. Cheung's family, they were able to express their wishes and needs directly without hiding their emotions. Individual personal growth and the hopeful atmosphere created a more favorable environment for them to work out a realistic plan for Mr. Cheung, such as having a nice and simple meal with his core family members at home.

Change-oriented: Since a realistic hope was formulated, Mr. Cheung could express his worries and wishes directly. Mrs. Cheung could support her husband's wishes and showed her love by performing the desired behavior, such as preparing the requested dish. The home care nurse helped them achieve transformational changes by empowering them using a down-to-earth approach.

Congruence: After establishing an open communication and therapeutic relationship, the home care nurse did not only take up the role of providing physical care to the patient, but also that of providing holistic nursing advices. She also helped Mr. Cheung keep a sense of living, instead of simply waiting to die. Since we believe that dying is only a part of our lives, the patient could still have something worthwhile to do even in his very late stage of life.

All of the above nursing perspectives focus on high-quality, compassionate and culturally sensitive patient care, and tailored to Mr. Cheung's needs.

CASE 15

Mr. Woo

Toileting Issues In End Of Life Care

Mr Woo (85 years old) is a patient with late-stage liver cancer, who has only about half a year of remaining life expectancy. Before being diagnosed, Mr Woo had decent physical and psychological conditions. He could take care of himself and had never needed to be hospitalized for treatment. For this reason, Mr Woo was very proud of himself. However, his conditions have recently been deteriorating at a rapid pace, forcing him to be hospitalized immediately. Since Mr Woo does not genuinely believe that he is about to die, he wants to create a sense of “feeling alive” for himself, and he does not want the healthcare staff to treat him like a dying patient. However, it is an undeniable fact that Mr Woo’s conditions are getting worse, as he begins to experience symptoms such as dizziness and drowsiness, thereby needing to stay in bed for most of the time. Given Mr Woo’s frail conditions, the healthcare staff believes that if he is allowed to go to the toilet by himself, then the risks of falling and fainting may arise. In view of this, the nurse told Mr Woo, “Since you are currently on an IV drip, it may not be that convenient for you to go to the toilet on your own. We will help you put the diapers on.” Mr Woo nervously asked, “Diapers? Do you mean that I need to stay in bed while toileting? Don’t tell me you can’t send a staff to assist me with the toileting routines!” The nurse answered, “I am very sorry about that. Our manpower is limited. In addition, we are worried about your safety.” Mr Woo became angry and did not accept the nurse’s explanation, as he perceived the use of diapers to be a severe violation of his dignity. After a while, Mr Woo even ranted, “As the doctor said that I cannot live for much longer, why can’t you satisfy my humble wish of being able to go to the toilet on my own, even when I am approaching the end of my life? Why are you forcing me to use the diapers, even when I can walk independently and still have a call of nature, and I am not like those incontinent patients who can’t control themselves? As I am already about to die, why do you think it matters to me if I am safe or not when going to the toilet?”

In the above case, given the shortage in resources and manpower, the actions taken by the healthcare staff seemed to be reasonable, yet they indeed contradicted with Mr Woo’s preferences. So, given that Mr Woo is dying soon, how should the healthcare staff balance his interests in different aspects and thereby provide the optimal end-of-life care? What would be the considerations with respect to clinical ethics?

Questions to think about:

- How should the healthcare staff apply the ethical principle of “respect for autonomy” in this case?
- What is the role played by the patient’s dignity in end-of-life care?
- Can the efficiency and safety of care provision override the patient’s subjective preferences? Why?
- How should the person-in-charge of a ward or department strike a balance between resources allocation and satisfaction of the needs of individual patients?

Commentary

– Prof Roger Y. Chung
Co-Director, Centre for Bioethics
Associate Director, Institute for Health Equity
Associate Professor, School of Public Health and Primary Care
The Chinese University of Hong Kong

Here are some of the morally relevant features of the case:

- Conditions:
  - Terminal cancer patient
  - Irreversible condition
  - Continually deteriorating with debilitating symptoms
  - Risk of fall if not escorted
  - With certain degree of mobility (i.e., can walk)
  - Not incontinent

- Patient's perspective:
  - Patient does not accept his disease's terminal status and/or being regarded as a terminal patient
  - Using adult diapers is a matter of dignity to the patient
  - Clearly rejects the use of adult diapers
  - Seems to understand the risk of fall, and does not think that it outweighs the concern for dignity and autonomy

- Environmental/external factors:
  - Limited human resources for caring of essential activities of daily living

CASE 15

Mr. Woo

Toileting Issues In End Of Life Care

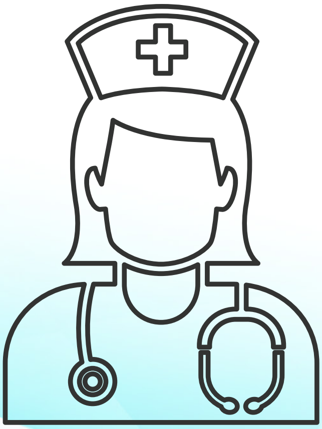
In Beauchamp and Childress's Principlism, "respect for autonomy" is a prima facie bioethical principle that is decision-specific. In other words, it is specific to a single medical decision with regards to whether a patient accepts or rejects a treatment. In this case, the decision is specific towards whether or not Mr Woo accepts using adult diapers to avoid the risk of fall as well as circumvent the external/environmental issue of lack of human resources. Even though wearing adult diapers or not is not a medical decision as high-staked as approving a surgical procedure, it is nevertheless a decision that the patient has mental capacity to make. Moreover, this intervention is a matter of dignity towards the patient. Dignity refers to the inherent worth and value of each individual, and it certainly encompasses respect for a person's autonomy, privacy, and avoidance of treating individuals as mere objects or means to an end. In other words, violations of dignity can occur through actions that undermine a person's autonomy, privacy, or treating them disrespectfully or in a dehumanizing manner. If we put the morally salient features of the scenario on a principlist balance scale, "respect for autonomy" definitely carries weight towards not wearing the diapers.

However, on the other side of the scale, the prima facie principles of "beneficence," "justice," and "non-maleficence" are also at play. Specifically, the avoidance of harm due to fall can be interpreted as an adherence to the principle of "beneficence" in the form of positive prevention of harm. On the other hand, the concern for inadequate human resources is a matter of "distributive justice," which specifically concerns the inequitable distribution of resources to other patients if more resources need to be allocated to aid Mr Woo to the restroom on a regular basis. Moreover, the administration of adult diaper would likely not inflict harm on Mr Woo, thereby adhering to the principle of "non-maleficence," which requires healthcare provider to at least do no harm to the quality of life of the patient with any treatment/intervention. (Note that to Beauchamp and Childress, quality of life is the criteria that matters in the principle of non-maleficence.) Nevertheless, one could still argue that while the diaper intervention may not inflict severe physical harm to the patient, it could still inflict minor physical harm (e.g. skin irritation, allergic reaction, fungal infection, etc.) if diapers are not changed on a regular basis. Also, it could inflict psychological harm towards the patient, which is also encompassed in the common understanding of quality of life. This psychological harm is very obvious in the case of Mr Woo, who expressed his disapproval of such intervention with anger and complaint.

Remember that all these principles operate in prima facie manner, meaning they should be taken as equally basic principles that should be followed at their face value, but are not absolute. In other words, in case of conflict among these principles, justifications are needed to side with one "actual obligation" (i.e., all-things-considered obligation) as your final verdict that would override the rest of the other moral considerations. However, even having a final verdict of actual obligation does not mean that other moral considerations have to be completely silenced or canceled out; rather, going for one actual obligation would leave behind moral residues of other moral considerations, which would in turn give rise to new moral obligations.

In this case, Mr Woo clearly rejects the use of adult diapers. Therefore, to administer adult diapers against his will, hard paternalism will need to be imposed. According to Beauchamp and Childress, to justify hard paternalism in healthcare, the following conditions must be satisfied:

1. A patient is at risk of a significant, preventable harm (i.e., fall can be significant but preventable harm)
2. The paternalistic action will probably prevent the harm (i.e., avoidance of fall is likely)
3. The prevention of harm to the patient outweighs risks to the patient of the action taken (i.e., the prevention of fall may likely outweigh the risk of other more minor physical harm to the patient, but questionable whether it could outweigh the risk to the patient's psychological well-being in this case, especially when the patient seems to be fine with bearing that risk of fall)
4. There is no morally better alternative to the limitation of autonomy that occurs (i.e., in the case of limited resources, there does not seem to be alternative; however, we can always think outside the constraints of one hospital – e.g. can the patient be transferred to another hospital with more resources? Are the non-hospital caregivers allowed to aid the patient according to the hospital policy? Does Mr Woo have someone (rather than hospital staff) who can help him with toileting?)

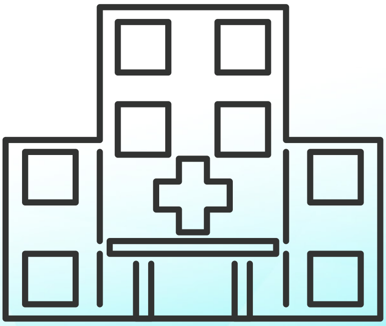


Consequently, the least autonomy-restrictive alternative that can secure the benefit should be adopted. Given that the satisfaction of Conditions 3 and 4 are rather dubious, it seems difficult to justify the practice of hard paternalism in this case – i.e., no adult diapers for Mr Woo seems to be the final verdict.

Finally, even if the adult diapers are not administered to Mr Woo (i.e., actual obligation), it does not silence the moral concerns of avoidance of fall and distributive justice (i.e., moral residues). They are still important moral concerns that need to be observed and addressed with other means and approaches. I will leave this to the students for their deliberation of what can be done to address the moral residues if diapers are not going to be administered.

Some important notes:

- Dignity conventionally falls under the principle of respect for autonomy in Beauchamp and Childress's bioethical framework
- Quality of life is the criteria that matters when one talks about harm and thus the principle of non-maleficence in Beauchamp and Childress's bioethical framework
- Violations of dignity can certainly impact a person's quality of life, but these two concepts are not interchangeable. Violations of dignity can occur even if there is no direct impact on an individual's quality of life, and vice versa.
- Principlism offers only one, but an influential, method in balancing the different moral obligations in bioethical scenarios. Other tools can also be useful in helping us deal with ethical dilemma that we may encounter in healthcare settings (e.g. narrative ethics, care ethics).



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