"To tube or not to tube (feed)"

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Case scenario:

A patient's daughter left a phone message:"My mother. Mrs F, has eaten nothing all weekend. What should we do?" A 70-year-old woman with dementia, Mrs F rarely speaks, is confined to a wheelchair, and requires diapers for incontinence. The family had been increasingly worried as she had stopped feeding herself. Even with hand feeding by relatives, her intake continues to decline significantly. The family thus ask you if she should be fed through a feeding tube? The situation evokes strong and conflicting reactions. The patient's sister says, "We can't let her starve to death to death!" The daughter, however; says, "She's telling us to stop. We're just torturing her."

(Adapted from: B Lo. Resolving ethical dilemmas. A guide for clinicians. 5th ed.)

Singapore's ageing population will result in greater increase in cases of end of life (EOL) care and its ethical dilemmas.

Artificial nutrition and hydration (ANH) is a medical intervention and not just a provision of food and water. It is a medical treatment, with its benefits and harms, thus requiring careful consideration if there is greater harm than benefit (principle of proportionality versus the absolute duty to preserve life). We may inadvertently extend life but worsen the suffering.

The family should be informed of both the benefits and harm of ANH before they decide on any intervention. All medical treatment should have a goal and family should ask what the goal of inserting a feeding tube is. We may ask what the feeding tube will accomplish in a particular case. Is it to improve the quality of life or merely to prolong life for as long as possible? If so, is that a reasonable goal? Is that the family's goal or is that the patient's goal?

Will it make the patient more comfortable? Most patients seem to find feeding tubes very uncomfortable – all you have to do is watch how many try to pull them out.

The right to choose not to undergo treatment comes under the principle of informed consent and the right to self-determination. Difficulty arises when the patient is not able (has no mental or decisional capacity) to express his wishes and no documentation is available to indicate their preferences. Often, family or friends (surrogates) become decision makers with the burden falling on them and not the dying person.

Physicians may not be clear about whether there is a difference between withholding (not starting) and withdrawing (stopping) a treatment when both are nowadays considered as the same. A decision not to act is still an act, thus not providing ANH is no different from removing ANH.

Many physicians may wish to avoid conflicts with the family or are misinformed about the benefits of tube feeding in advanced dementia and may be unaware of the harms. ANH carries many false promises as it does not provide benefits of prolonged life, less aspiration, ease of symptoms, ease of medication provision or nutritional status.

Dying persons often do not experience thirst and hunger - giving ice chips and oral hygiene can alleviate dry mouth symptoms. Oral food and fluids should be encouraged as it gives comfort, pleasure as well as autonomy and dignity.

Most persons will say no when asked if they wish to be kept alive via ANH if they become demented at the end of their lives. However, in times of crisis, many will have tube placed. The weight loss, malnutrition and dysphagia are terminal signs of the end stages of dementia as a disease. More than 20% of demented patients in hospitals or nursing homes in the US have had tubes placed but nearly half died within a year. Moreover, provision of ANH often requires restraints to prevent self-extubation.

In an acute emergency situation, both family and physician can come under distress as the atmosphere is filled with emotion. Confusion sets in to cloud the thinking further.

We can play our role as the patient's advocate (respecting his choices). However, when that has not been stated and documented, we can act as a guide in helping the family and surrogates in making a decision with the patient's best interest. During a consultation, communications between the FP and family members can be aided by the table on the next page:

Table 1:
Questions to Ask Regarding the Ethics of Providing ANH at the End of Life — Processes and relevant Questions

Framing process	1. Is the patient able to make autonomous decisions? 2. Are the patient's choices in line with professional assessment of beneficence? 3. Are there conflicts in an ethical or moral sense? 4. What is the nature of the decision that needs to be made?
Data collection process	1. What are the facts regarding diagnosis, prognosis, and treatment outcome for this patient at this point in time? 2. What are the religious, cultural, social, spiritual, and personal issues for this particular patient? 3. What is the degree of physical, psychological, and spiritual suffering that the patient is experiencing? 4. Is the patient clinically depressed, and if so, is it influencing his or her decision-making abilities? Will treatment of the underlying depression result in a different outcome? 5. Is the patient demented? If so, does the harm of providing ANH outweigh the benefit?
Decision-making process	1. Is the patient or a surrogate making the decision? 2. Is there adequate information on the values, preferences, and wishes of this patient? 3. What clinical options have been outlined? 4. Have the ethics of each course of action been weighed and their true intent delineated (e.g., fiscal consequences to the family determines removal of ANH)?
Individuality process	1. Has every patient been treated as a unique case? 2. Has a blanket approach to provision, withholding, and withdrawing ANH been taken? Have institutional policies, procedures, and culture been adequately evaluated to prevent a blanket approach to care? 3. Is the decision right for this particular patient at this particular time and in this particular place? 4. Has the decision been re-evaluated on a daily or even hourly basis? 5. Has patient autonomy been sacrificed for sparing professional and/or family distress? 6. Have steps been taken to ensure that stopping ANH has not resulted in stopping care? 7. Has open ongoing communication been central to the process? 8. Has adequate support been provided to the patient, the family, and the staff to ensure successful outcome, regardless of what course of action is taken?
Reference: Huerberger	

In seeking meaning at the end of life, what comes to the fore are quality of life (or quality of dying), independence, dignity and comfort. Life at all costs, quantity of life and control recedes into the background.

Albert Jonsen has stated:
"In our opinion, a decision to forgo ANH is ethically permissible when:

1. No significant medical goal other than maintenance of organic life is possible;
2. The patient is so mentally incapacitated that no preferences can be expressed now or in the future;
3. No prior preferences for continued sustenance in such a situation has been expressed;

(continued on Page 27)

(continued from Page 24: "To tube or not to tube (feed)")

4. The patient's situation is such that no discomfort or pain will be experienced by discontinuing the intervention.

He went on to say "… ANH should be evaluated in light of the principle of proportionality, i.e. the assessment of the ratio of burdens to benefits for the patient. We support the view that if a patient has formulated an advanced directive which specifically mentions omission of ANH in a condition of advanced dementia, such a directive should be honoured."

Coming back to the question of whether to nasogastric tube or not to tube Mrs F, we must weight all factors. Whether Mrs F had her advanced care plans made, and whether she had pre-specified that she wanted or objected to such a tube being placed. We next have to consider medical indications for this, and then address family's concerns, before coming to a decision together. This article is not meant to be prescriptive as the case scenarios will vary not just from patient to patient, but also in the various settings of Family Medicine. So in the end, the answer is, "it depends".

References

1. Heuberger R. Artificial nutrition and hydration at the end of life. J Nutrition for the elderly 2010.
2. Bernard Lo. Resolving ethical dilemmas. A guide for clinicians. 5th Ed.
3. Jonsen A et al. Clinical ethics. 8th Ed.

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Let us refer back to the beginning of the article where I had listed the characteristics of the traditional model of medicine. From here we can then derive some of the challenges facing telemedicine that needs to be addressed. I think some of these will eventually be overcome with the help of technology if we give it enough time.

1. Since there is no face to face consultation with the doctor, the **identity** of the patient is not obvious and has to be verified, how can the doctor be reassured that the patient on his screen is the patient being treated?

2. Telemedicine is a trade-off between **convenience** and good clinical care.
   a. The doctor will not be able to perform a **physical examination**,
   b. Certain aspects of **communication** with the patient such as non verbal cues will be left out.
   c. Telemedicine allows distances to be bridged and patients in remote locations to have access. For example in a mountain camp, on an aircraft, or on the international space station. However, in the context of Singapore where there is easy access to medical care both in distance and in time, how much advantage does telemedicine really provide?

3. A **duty of care** is harder to establish - Does the physician and the patient need to establish a doctor patient relationship? How can this be done in telemedicine?

4. The medical records are generated electronically and stored in the cloud. Issues of **confidentiality**, data sharing and **privacy** will have to be strictly observed. In light of recent cases of security breach and data hacking, how safe is such information from falling into the wrong hands?

5. **Regulating** telemedicine in the absence of brick and mortar premises may not be straightforward. Do local laws cover non-healthcare companies? How can one assure quality and safety for services provided in another jurisdiction?

6. And finally how does the healthcare professional charge for the services? Someone will need to pay for the development costs for the technology and use of third party apps. Current practices of paying for consultations may have to be changed to give credit to the work and advice that is transmitted electronically.

It is with these factors in mind that the College of Family Physicians Singapore (CFPS) and the Singapore Medical Association (SMA) issued a joint advisory on "Participation in Telemedicine" on 26 January 2018. It echoed the challenges facing Telemedicine at this current moment and stated that:

"… we are of the opinion that the current telemedicine technology is unable to replace a face-to-face consultation, which typically includes a physical examination, except for the most minor of conditions. For example, it is not possible for a doctor practising telemedicine to assess a patient with asthma or exclude red flags in a patient with gastroenteritis. Therefore, doctors who sign on to businesses offering telemedicine need to be aware that their clinical decisions must always be justifiable and defensible."

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