The feeding paradox in advanced dementia: a local perspective

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ABSTRACT

Feeding problems are common in older people with advanced dementia. When eating difficulties arise tube feeding is often initiated, unless there is a valid advance directive that refuses enteral feeding. Tube feeding has many pitfalls and complications. To date, no benefits in terms of survival, nutrition, or prevention of aspiration pneumonia have been demonstrated. Careful hand feeding is an alternative to tube feeding with advanced dementia. In Hong Kong, the Hospital Authority has established clear ethical guidelines for careful hand feeding. Notwithstanding, there are many practical issues locally if tube feeding is not used in older patients with advanced dementia. Training of doctors, nurses, and other members of the health care team is vital to the promulgation of careful hand feeding. Support from the government and Hospital Authority policy, health care staff training, public education, and promotion of advance care planning and advance directive are essential to reduce the reliance on tube feeding in advanced dementia.

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Introduction

Hong Kong is facing an unparalleled challenge of rapid population ageing.[1] This demographic change results in an impending need for end-of-life care among older people with advanced dementia.[2] One of the natural stages of the dementia disease process is eating problems with poor appetite and swallowing difficulty, leading to malnutrition, weight loss, and aspiration pneumonia (AP).[3,4] Unless there is a valid advance directive (AD) refusing enteral feeding, family members and the health care team often feel compelled to initiate tube feeding. This leads to a very high prevalence of tube feeding in elderly with advanced dementia, especially those living in residential care homes for the elderly (RCHEs).[5,6]

Pitfalls of tube feeding

There are many reasons for placing a feeding tube in patients with advanced dementia. Medical, social, cultural, economic, ethical, psychological, and medicolegal factors all play a part in the decision.[7] Many older patients are commenced on tube feeding when they are dysphagic or are feeding inadequately. Probably due to inadequate information about the pitfalls of tube feeding, risk of AP and survival are the most frequently cited reasons by health care teams to insert a feeding tube.[8] To date, however, evidence has proven that tube feeding does not prevent AP.[9] On the contrary, AP might be increased by the use of enteral feeding.[10] Placement of a nasogastric tube weakens the lower oesophageal sphincter and reduces the efficiency of the valve that prevents gastric reflux into the upper digestive tract.[11] The use of tube feeding without oral feeding also leads to neglect of oral hygiene, resulting in bacterial colonisation and an increased risk of AP. Enteral feeding is unable to improve serum albumin, body weight, or lean muscle mass.[12] The use of a feeding tube causes patient discomfort, increased use of restraints, and consequent greater likelihood of pressure sore development.[13,14] Studies showed that RCHE residents with feeding tubes are frequently transferred to an emergency department for tube complications such as blockage and dislodgement.[15] To date, studies have not shown survival benefits in older people with tube feeding.[16] In a local study of 312 advanced cognitively impaired RCHE residents, 164 (53%) were being tube fed.[6] The 1-year mortality rate was 34% and enteral feeding was cited as an important risk factor for 1-year mortality (odds ratio=2.0; 95% confidence interval, 2.0-3.4; P=0.008).[6]

Careful hand feeding as an alternative

Careful hand feeding (CHF) has been advocated as an alternative for older people with advanced dementia and eating problems.[17] In CHF, the carer makes use of feeding techniques such as frequent reminders

to swallow, multiple swallows, encouraging gentle coughs after each swallow, limiting bolus size to less than one teaspoon, and judicious use of thickeners. The carer observes the patient for choking and pocketing of food in the mouth. The carer focuses on the older person during the entire feeding process and avoids distraction. The older person is placed in an upright position during the meal. Moistening foods with water or sauces, or alternating food with appropriate liquid consistency may help swallowing, for example, in patients with a dry mouth.

In the 2014 position statement on feeding tubes in advanced dementia published by the American Geriatrics Society, feeding tubes are not recommended.[18] It emphasises that CHF should be offered as it is at least as good as tube feeding for the outcomes of death, AP, functional status, and comfort.[19,20] Older patients with dementia can still form a relationship with their carer. Actions by the carer can influence food intake of an older person with dementia and include touching, kissing, hugging, and responding to non-verbal cues.[21] Caregivers can provide patients frequent reminders to swallow, perform multiple swallows, make gentle small coughs between feeds, and assume an appropriate posture to reduce the risk of AP. A pleasant quiet environment with less distraction is desirable during the whole feeding process.

Reasons for a high prevalence of tube feeding in advanced dementia in Hong Kong

Family factors

Tube feeding is prevalent in Hong Kong among older patients with advanced dementia for multiple reasons. Family members may think that they cannot allow the demented relative to starve. This may be affected by the Chinese culture that emphasises eating and avoidance of hunger at all costs. To achieve this, there seems to be little other choice. Physicians may be too optimistic and inform family members that the tube can be removed if the patient regains the ability to eat normally.[22] The chance of stopping tube feeding, however, is lower than 20% in all indications for tube feeding.[23] Family members may insist on aggressive measures at all costs, despite the futility.

Health care team factors

The current medical culture in Hong Kong is predominantly biomedical, with life preservation the overwhelming principle.[24] Physicians may recommend tube feeding in older patients with advanced dementia because they believe clinical outcomes can be thereby improved.[25] Many physicians are under pressure from family members when discussing tube feeding.[26] The health care team may be unfamiliar with the current literature about the pitfalls of tube feeding and may not realise that there is also an option of CHF. The health care team may also fear legal consequences if patients with advanced dementia are not fed with a feeding tube.

對於晚期認知障礙症的老年患者進行餵飼的矛盾：本地的現象

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晚期認知障礙症的老年患者經常出現餵飼問題。除非患者預設醫療指示聲明拒絕接受經腸道餵飼，否則當失去吞嚥能力時，大多須接受管飼。管飼餵食存在許多問題甚至會引起併發症。迄今已證明管飼餵食對於提高生存率、給予營養或防止吸入性肺炎均沒有好處。對於晚期認知障礙症的老年患者來說，「人手小心餵食」是替代管飼的另一方法。香港醫院管理局為人手小心餵食制定了明確的道德準則。儘管如此，如果未能為患者進行管飼，便會引發許多實際的問題。醫生、護士和其他醫護人員的培訓對於人手小心餵食至為關鍵。政府和醫院管理局政策上的支持、醫護人員培訓、公眾教育、推廣預設臨終照顧計劃和預設醫療指示，對於減少晚期認知障礙症的老年患者對管飼的依賴相當重要。

Lack of an advance directive and advance care planning

Advance care planning (ACP) is a process of communication among patients, their family, and important others about the care they wish to receive if they are unable to make decisions.[27] Often one of the discussions relates to the decision to start tube feeding in the presence of severe eating problems. One outcome of ACP is an expressed wish that is not legally binding. Another option is for the patient to sign an AD, a formal tool that respects the autonomy of patients and in which any decision must be adhered to by the health care team.[28] In Hong Kong, life-sustaining treatment, including tube feeding, can be withheld if there is a valid AD when the patient is in an irreversible coma, persistent vegetative state, terminal illnesses, or other end-stage irreversible life-limiting condition.[29] Nonetheless until recently ACP and AD have been seldomly discussed in Hong Kong.[30] When a patient without an AD is unconscious due to an advanced irreversible illness, the decision to withhold or withdraw tube feeding is made by consensus of the health care team and family members according to the best interests of the patient, taking into account any prior wish or treatment preference. Without knowing the exact wishes of the patient, many health care teams and family members are compelled to start tube feeding.

Practical issues in not using tube feeding

In Hong Kong, there are practical issues associated

with not using a feeding tube. Hand feeding is time-consuming. In the hospital environment, because of staff shortages, it is difficult to provide quality CHF to all patients with advanced dementia having eating problems. If an older patient is feeding poorly, it is difficult to discharge them from hospital, especially if they are returning to a RCHE. The environment can also affect feeding.[31] Medical wards in Hong Kong public hospitals are often elderly unfriendly, crowded, noisy, and without privacy. In addition, nurses may be reluctant to hand feed the advanced dementia patient with dysphagia after assessment by a speech therapist. Without strong hospital policy support, nurses understandably are concerned about medicolegal consequences should the dysphagic elderly patient aspirate following CHF. Hence, not uncommonly, they will ask relatives who have 'refused' tube feeding of an elderly dysphagic older to feed them. Family members who are unable to come to the hospital 2 or 3 times a day will have little choice but to alter their decision and agree to tube feeding. In RCHEs, manpower issues and the crowded environment are barriers to quality feeding of those with dementia. Older RCHE residents who are offered CHF but are feeding poorly will soon become dehydrated, especially in summer. Staff in RCHEs will soon bring their older residents back to the emergency ward/department if they cannot eat or are eating poorly, leading to a 'revolving door' phenomenon. Alternative ways of hydration, including hypodermoclysis (subcutaneous fluid infusion), are not practised in RCHEs in Hong Kong.[32] Not many family doctors are equipped with the knowledge or have the time to take care of advanced dementia cases with feeding problems in RCHEs. Many medications need to be taken orally and administration via an enteral tube may appear to be the only alternative in dysphagic patients.

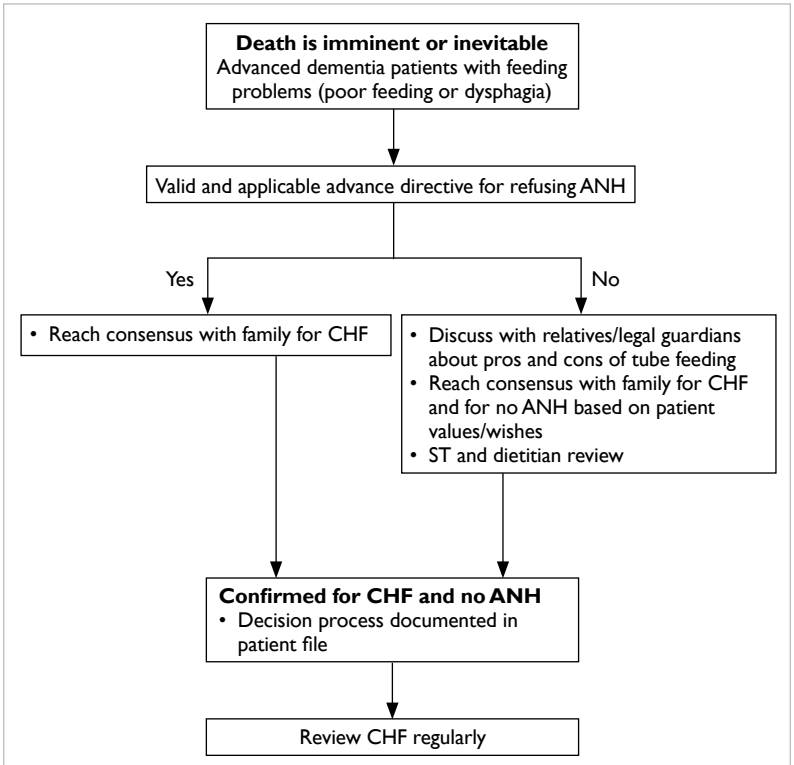

FIG 1. Careful hand feeding workflow for patients facing imminent death
Abbreviations: ANH = artificial nutrition and hydration; CHF = careful hand feeding; ST = speech therapist

Hospital Authority guidelines on life-sustaining treatment in the terminally ill

Artificial nutrition and hydration (ANH) refers specifically to those techniques for providing nutrition or hydration which are used to bypass the swallowing process. They include the use of nasogastric tubes, percutaneous endoscopic gastrostomy, intravenous or subcutaneous fluid, and parenteral nutrition. In September 2015, the Hospital Authority guidelines on life-sustaining treatment in the terminally ill was updated. Among other key end-of-life care issues, the guidelines provide a clear picture of CHF and ANH from the ethical perspective.[33] It states that when death is imminent (death is expected within a few hours or days) and inevitable in a mentally incompetent patient without a valid AD, it is acceptable to withhold or withdraw ANH. This follows the same principles that apply to other life-sustaining treatments. Notwithstanding, if a patient is in or near the end stage of a disease or condition and is mentally incompetent, and death is not imminent, the balance of benefits and burdens of ANH may become unclear. The guideline states that if the patient does not have a valid AD refusing ANH, the consideration of withholding or withdrawing ANH requires additional safeguards. There must be consensus within the health care team and with the family (if any) that a decision to withhold or withdraw ANH is in the best interests of the patient, taking into account their prior wishes and values. The health care team must include at least two doctors, one of whom must be a specialist in a relevant field, eg geriatrician or palliative care specialist. In addition, if the patient is unable to swallow, the health care team should seek advice from the 'cluster clinical ethics committee', before making a decision to withhold or withdraw ANH, unless before losing capacity, the patient has clearly expressed a wish to refuse ANH (as reported clearly by family members or documented in medical notes when the patient was still competent) or the patient actively and repeatedly resists ANH such as repeatedly pulling out a nasogastric tube. Based on the principles stipulated in the Hospital Authority guidelines,[33] Figures 1 and 2 were drawn showing the flowcharts when death is imminent/inevitable and when death is not imminent, respectively.

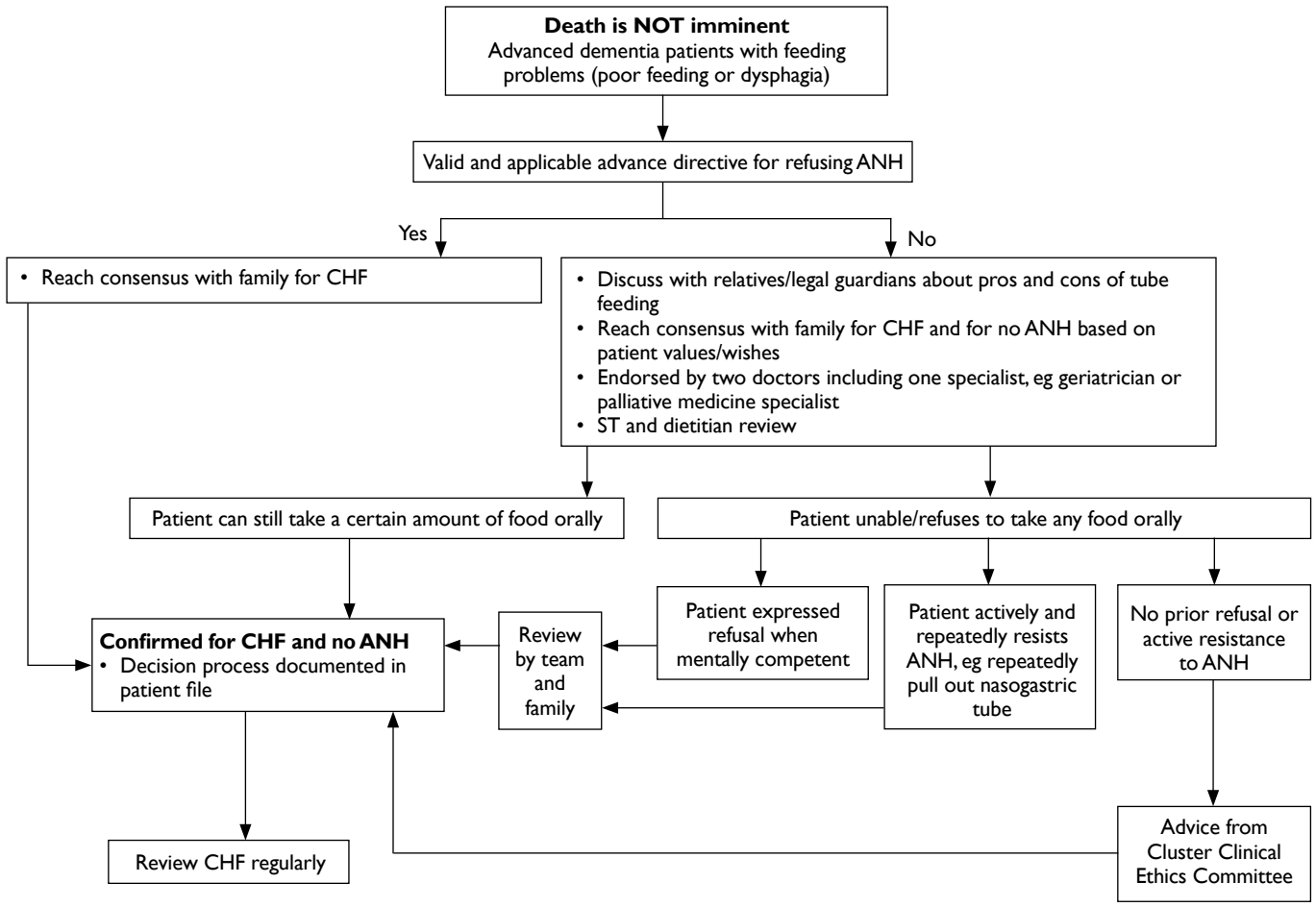

FIG 2. Careful hand feeding workflow for patients not facing imminent death
Abbreviations: ANH = artificial nutrition and hydration; CHF = careful hand feeding; ST = speech therapist

The way forward for feeding patients with advanced dementia in Hong Kong

There is no definitive solution for feeding problems in older patients with advanced dementia. In the absence of a valid AD, patient management should be individualised, and the decision for tube feeding or CHF should be shared between the health care team and family members, based on the patient's previously expressed wishes and best interests. The health care team should accept and respect the family's choice of CHF instead of tube feeding. Experienced nurses and doctors should be responsible for discussing the pros and cons of tube feeding with the family to achieve a consensus. Clear hospital guidelines and protocols should facilitate CHF and effect a cultural change.[34] Staff sentiments and medicolegal concerns should be addressed. Clear Hospital Authority or hospital policy to support CHF will help alleviate the concerns of nursing staff. Training of doctors, nurses, and other members of the health care team is vital to the promulgation of CHF. There is an urgent need to enhance the environment of public hospital wards so that they are more elderly friendly. Training of RCHE staff and the staff ratio are important factors that will determine the success of CHF in the community of Hong Kong. Without a well-prepared staff, patients on CHF will soon be put on enteral feeding. The Social Welfare Department can ensure it is part of the licensing requirement to have end-of-life care that includes CHF in most, if not all, RCHEs. More palliative care training should be given to primary doctors who look after older people with advanced dementia.[35] Recently, all medical students at the University of Hong Kong have been seconded to RCHEs to learn about community geriatrics as part of their undergraduate training. They have first-hand experience, under the guidance of geriatricians, of how the elderly with advanced dementia are cared for in RCHEs. More education about feeding issues in dementia should be offered to the public.

Furthermore, ACP and AD should be promoted in Hong Kong so that patients can elect a particular mode of feeding while they are mentally capable.[36] At the time of writing this article, the Hong Kong SAR Government is exploring the realisation of enduring power of attorney for health care decision, allowing mentally incapacitated older people to express their wishes through a chosen advocate.[37] It is hoped that the decision to accept enteral feeding or not can be included in the scope of the power of attorney.

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