

ORIGINAL ARTICLE

Cultural considerations in forgoing enteral feeding: A comparison between the Hong Kong Chinese, North American, and Malaysian Islamic patients with advanced dementia at the end-of-life

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Abstract

Cultural competence, a clinical skill to recognise patients' cultural and religious beliefs, is an integral element in patient-centred medical practice. In the area of death and dying, physicians' understanding of patients' and families' values is essential for the delivery of culturally appropriate care. Dementia is a neurodegenerative condition marked by the decline of cognitive functions. When the condition progresses and deteriorates, patients with advanced dementia often have eating and swallowing problems and are at high risk of developing malnutrition. Enteral tube feeding is a conventional means of providing artificial nutrition and hydration to meet nutritional needs, but its benefits to the frail population are limitedly shown in the clinical evidence. Forgoing tube feeding is ethically challenging when patients are mentally incompetent and in the absence of an advance directive. Unlike some developed countries, like the United States of America, death and dying is a sensitive issue or even a taboo in some cultures in developing countries that forgoing enteral tube feeding is clinically and ethically challenging, such as China and Malaysia. This article in three parts 1) discusses the clinical and ethical issues related to forgoing tube feeding among patients with advanced dementia, 2) describes how Hong Kong Chinese, North American, and Malaysian Islamic cultures respond differently in the decision-making patterns of forgoing tube feeding for patients with advanced dementia, and 3) reiterates the clinical implications of cultural competence in end-of-life care.

KEYWORDS

bioethics, cultural competence, dementia, end-of-life, enteral nutrition

1 | INTRODUCTION

Culture encompasses multiple components, including language, behaviour, and customs that are specifically unique to ethnic, racial or religious groups.¹ In clinical settings, cultural competence refers to a

skill to provide care accommodating patients' cultural practice and religious beliefs.² A culturally competent health care system improves health outcomes and patient satisfaction, enhances quality of care, and eliminates racial and ethnic health disparities. Studies, however, show that many physicians are insufficiently prepared to

¹Expert Panel on Cultural Competence Education for Students in Medicine and Public Health (2012). Cultural Competence Education for Students in Medicine and Public Health: Report of an Expert Panel. Washington, D.C.: Association of American Medical Colleges and Association of Schools of Public Health.

²Betancourt, J.R., Green, A.R., Carrillo, J.E., Ananeh-Firemong, O. (2003). Defining Cultural Competence: A Practical Framework for Addressing Racial/Ethnic Disparities in Health and Health Care. *Public Health Reports*. 118(4), 293-302.

be sensitive to the needs of increasingly diverse populations in age, religion, migrant status, and ethnicity.^{3,4} Failing to recognise and provide care according to patients' health-related beliefs and cultural values can lead to distrust in the patient-healthcare relationship, patients' dissatisfaction in obtaining quality care services, and adherence to treatment.^{5,6} In the clinical setting, particularly in the area of death and dying, physicians' understanding of patients and families values is essential for the delivery of culturally appropriate care.

2 | EPIDEMIOLOGY OF ADVANCED DEMENTIA

Dementia, a progressive neurological condition marked by the deterioration of cognitive functions, is one of the top ten causes of death worldwide.⁷ The global prevalence of dementia is between 5-8% and varies greatly by country,^{8,9} ranging from 8.8% in the United States of America (USA),¹⁰ 7.2% in Hong Kong,¹¹ 6% in Malaysia.¹² The variable estimates reflect real geographical differences, genetic predisposition, and regional medical practitioners' expertise in recognising dementia. Age and gender are major risk factors for dementia.¹³ A longitudinal population-based study included 42,996 people with 835 dementia cases for people years of follow-up. Incidence rates of dementia increased exponentially with age from 2.4 to 70.2 per 1000 person-years, respectively in the aged 65-69 and 90 or above group. Females were also at increased risk than males for developing dementia, especially above the age of 80.¹⁴ The global estimate pop-

ulation living with dementia is 24.3 million with an anticipated annual increase of 4.6 million newly diagnosed cases of dementia globally.¹⁵ This phenomenon is known as the "Silver Tsunami".¹⁶

Dementia progresses differently in each individual, and the three-stage model characterised by mild (early stage), moderate (middle stage), and severe (late stage), provides a useful description of symptom trajectory.¹⁷ At the early stage, patients with mild dementia may be able to function independently, with an occasional report of short-term memory lapses and difficulty expressing ideas. At the middle stage, earlier symptoms become increasingly evident. Patients with moderate dementia might feel moody and have a progressive decline in cognitive functioning. At the late stage, patients with advanced dementia are unable to communicate and maintain bodily functions. They also progressively decrease oral intake when they are no longer able to recognise food, feed themselves independently, or experience eating problems. A prominent consequence as a result of eating and swallowing difficulties is the risk of developing malnutrition.¹⁸

Enteral tube feeding, through a nasogastric (NG) route or percutaneous endoscopic gastrostomy (PEG) tube, is a highly prevalent measure for providing artificial nutrition and hydration to patients who cannot eat or drink enough orally. For NG intubation, a thin plastic tube is inserted through the nostril, down the oesophagus, and into the stomach. For PEG, an invasive operation is required to insert the tube into the stomach through the abdominal wall. Benefits of tube feeding include providing nutrition on a daily basis and improving strength. The intubation procedure of tube feeding also has its complications. The tube placement can cause discomfort and can be painful, and adversely affect the quality of life through increased use of physical or chemical restraints that prevent the patient from pulling out the tubes, outside the usual indications for preventing falls and wandering. Physical and chemical restraints are sometimes overused to compensate understaffing.¹⁹ This raises concerns as restraints not only limit the patients physical activity that leads to bedsores, frozen joints, and muscle atrophy, but also there is no study supporting its effectiveness in preventing feeding tube dislodgement.²⁰

For patients with temporary swallowing difficulties, tube feeding is commonly initiated to deliver sufficient nutrition and hydration to support life and then remove the tube when the patient regains food

³Mygind, A., Norredam, M., Nielsen, A.S., Bagger, J., Krasnik, A. (2008). The Effect of Patient Origin and Relevance of Contact on Patient and Caregiver Satisfaction in the Emergency Room. *Scandinavian Journal of Public Health*. 36(1), 76-83.

⁴Ohana, S., & Mash, R. (2015). Physician and Patient Perceptions of Cultural Competency and Medical Compliance. *Health Education Research*. 30(6), 923-934.

⁵ibid.

⁶Paez, K.A., Allen, J.K., Beach, M.C., Carson, K.A., Cooper, L.A. (2009). Physician Cultural Competence and Patient Ratings of the Patient-Physician Relationship. *Journal of General Internal Medicine*. 24(4), 495-498.

⁷World Health Organization. (2018). The top 10 causes of death. Retrieved October 14, 2018, from <https://www.who.int/news-room/fact-sheets/detail/the-top-10-causes-of-death>.

⁸Prince, M., Bryce, R., Albanese, E., Wimo, A., Ribeiro, W., Ferri, C.P. (2013). The Global Prevalence of Dementia: A Systematic Review and Meta-analysis. *Alzheimer's & Dementia*. 9(1), 63-75.

⁹van der Flier, W.M., & Scheltens, P. (2005). Epidemiology and Risk Factors of Dementia. *Journal of Neurology, Neurosurgery & Psychiatry*. 76(Suppl V), v2-v7.

¹⁰Langa, K.M., Larson, E.B., Crimmins, E.M., Faul, J.D., Levine, D.A., Kabeto, M.U., Weir, D.R. (2017). A Comparison of the Prevalence of Dementia in the United States in 2000 and 2012. *JAMA Internal Medicine*. 177(1), 51-58.

¹¹Wu, Y.T., Lee, H.Y., Norton, S., Chen, C., Chen, H., He, C., Fleming, J., Matthews, F.E., Brayne, C. (2013). Prevalence Studies of Dementia in Mainland China, Hong Kong and Taiwan: A Systematic Review and Meta-analysis. *PLoS One*. 8(6), e66252.

¹²Kadir, K., Azman, R., Krishnaswamy, S. (1997). Prevalence of Dementia among Elderly Malays in an Urban Settlement in Malaysia. *Neural Journal Southeast Asia*. 2, 159-162.

¹³Seshadri, S., Wolf, P.A., Beiser, A., Au, R., McNulty, K., White, R., D'Agostino, R.B. (1997). Lifetime risk of Dementia and Alzheimer's Disease. The Impact of Mortality on Risk Estimates in the Framingham Study. *Neurology*. 49(6), 1498-1504.

¹⁴Fratiglioni, L., Launer, L.J., Andersen, K., Breteler, M.M., Copeland, J.R., Dartigues, J.F., Lobo, A., Martinez-Lage, J., Soininen, H., Hofman, A. (2000). Incidence of Dementia and Major Subtypes in Europe: A Collaborative Study of Population-based Cohorts. *Neurologic Diseases in the Elderly Research Group*. *Neurology*. 54(11), 10-15.

¹⁵Ferri, C.P., Prince, M., Brayne, C., Brodaty, H., Fratiglioni, L., Ganguli, M., Hall, K., Hasegawa, K., Hendrie, H., Huang, Y., Jorm, A., Mathers, C., Menezes, P.R., Rimmer, E., Scazufca, M. (2005). Alzheimer's Disease International. Global Prevalence of Dementia: a Delphi Consensus Study. *Lancet*. 366(9503), 2112-2117.

¹⁶Barusch, A.S. (2013). The Ageing Tsunami: Time for a New Metaphor? *Journal of Gerontological Social Work*. 56(3), 181-184.

¹⁷Morris, J.C. (1993). The Clinical Dementia Rating (CDR): Current Version and Scoring Rules. *Neurology*. 43(11), 2412-2414.

¹⁸Mitchell, S.L., Teno, J.M., Kiely, D.K., Shaffer, M.L., Jones, R.N., Prigerson, H.G., Volicker, L., Givens, J.L., Hamel, M.B. (2009). The Clinical Course of Advanced Dementia. *New England Journal of Medicine*. 361(16), 1529-1538.

¹⁹Evans, D., & Fitzgerald, M. (2002). Reasons for Physically Restraining Patients and Residents: A Systematic Review and Content Analysis. *International Journal of Nursing Studies*. 39(7), 735-743.

²⁰Brooke, J., & Ojo, O. (2015). Enteral Nutrition in Dementia: A Systematic Review. *Nutrients*. 7(4), 2456-2468.

intake ability. In this case, a tube feeding bears a symbolic role as caregiving and is regarded as sustenance that facilitates recovery in an otherwise healthy individual that temporarily prevents oral feeding. Most clinicians would recommend tube feeding when malnutrition is predominantly the cause of a reversible condition for a limited time, for example, patients suffering from a stroke. Tube feeding is also used in long term care patients if there is consent. In the contrary, the use of a feeding tube on patients with advanced dementia poses a special challenge since swallowing difficulties is irreversible (permanent dysphagia). Placement of tube feeding to solve malnutrition at the end-of-life among frail elderly, however, is debatable. Research suggests that there is no medical benefit and it has detrimental effects on patients care.²¹ The ethical challenge is how to uphold the dignity at the end-of-life in the face of the technological imperative that is capable of conserving life. Discussion with the patient and family regarding the provision or withholding of artificial nutrition and hydration is an integral part of the care plan, and it becomes more ethically challenging when the patients deteriorate and become mentally incompetent. Without an advance directive indicating a prior wish, numerous concerns have arisen regarding the care of the older adult at the end-of-life, where surrogate, for example, family or close friends inevitably are required to assume the crucial decision-making role.

The role of religion, culture, and beliefs play a significant part in healthcare decision-making and greatly influence how an individual might view illness or treatment. Hong Kong, North America and Malaysia each have unique cultural customs and religious beliefs that provide distinctive avenues for exploring these influences in the discussion related to health. The population of Hong Kong comprises of more than 90% Chinese,²² who traditionally embrace relational autonomy with the family and who consider death as a taboo.²³ These cultural values influence the local family making a decision related to the end-of-life care for patients with advanced dementia. North America has a very diverse society due to migration from across the world, but it retains a majority Christian faith tradition population such that attitudes towards end-of-life care are formed in relation to the widespread influence of Christianity. Malaysia is known its ethnic-diversity. More than 90% population is comprised of three major ethnic groups, which are Malay (69.1%), Chinese (23.0%), Indian (6.9%) and others indigenous population (1.0%).²⁴ Islam is the dominant religion in Malaysia and three-fifths of Malaysians practice this faith (61.3%), followed by one-fifth who are Buddhist (19.8%), and

one-tenth who are Christian and others, such as Hinduism and Sikhism.²⁵ Islamic religious values play a central role in Malaysian culture and this fact has a significant implication in healthcare.²⁶

This article has three parts: 1) discuss the clinical and ethical issues related to forgoing tube feeding among patients with advanced dementia, 2) describe how Hong Kong Chinese, North American, and Malaysian Islamic cultures respond differently in the decision-making patterns of forgoing tube feeding for patients with advanced dementia, and 3) reiterate the clinical implications of cultural competence in end-of-life care. In this article, patients with advanced dementia refers to those who have a profound cognitive impairment, total functional dependence, and inability to ambulate.²⁷

3 | CLINICAL AND ETHICAL CONSIDERATION OF FORGING TUBE FEEDING FOR PATIENTS WITH ADVANCED DEMENTIA

An ethical practice, using the four ethical principles as the framework for the decision-making process, advocate patient-centred care in the clinical context.²⁸ "Patient autonomy" advocates respecting patients' self-determination of care. "Beneficence" promotes the duty to care in accordance with patients' welfare and interests. "Non-maleficence" commends any medical decisions that should prevent harms. "Justice" suggests a fair treatment of patients irrespective of individual background. The following discussion assumes a patient with advanced dementia has come to the end-stage of life who has lost their swallowing ability.

Patient autonomy is a core consideration in clinical practice. Autonomy is optimally respected when competent patients adequately understand the risks, benefits, and consequences of each available treatments, and when they can make an informed decision according to personal values. Respect for patients' autonomy also extends to respect for patients' bodily integrity.²⁹ One of the effects of dementia is the growing loss of mental capacity due to declining cognitive function. If a patient with dementia is at an early stage and has made a valid advance directive stating a preference deferring tube feeding, the healthcare team should respect the advance decision and withhold treatment according to the indicated wish when the patient becomes too ill to decide at a later moment of life. For those who are at an advanced stage and have not indicated prior wishes before the disease had progressed, they are no longer

²¹Mitchell, S.L. (2015). Advanced Dementia. *The New England Journal of Medicine*. 372, 2533-2540.

²²Census and Statistics Department, Hong Kong Special Administrative Region. (2016) Hong Kong 2016 Population By-census - Thematic Report: Ethnic Minorities. Retrieved April 24, 2019, from <https://www.statistics.gov.hk/pub/B11201002016XXXXB0100.pdf>.

²³Bowman, K.W., & Singer, P.A. (2001). Chinese Seniors' Perspectives on End-of-life Decisions. *Social Science & Medicine*. 53(4), 455-464.

²⁴Department of Statistics, Malaysia Office Portal. (2019). Population & Demography. Retrieved April 20, 2019, from https://www.dosm.gov.my/v1/index.php?r=column/ctwoByCat&parent_xml:id=115&menu_xml:id=L0pheU43NWJwRWV5ZklWdzQ4TlhUUT09.

²⁵Ewelina U. Ochab. (2019). Religious Freedom In Malaysia Under Microscope. Retrieved April 4, 2019, from <https://www.forbes.com/sites/ewelinaochab/2019/04/01/religious-freedom-in-malaysia-under-microscope/#723bc39dd30>.

²⁶Sheikh, A., & Gatrad, A.R. (2008). *Caring for Muslim Patients*. London: Radcliffe Publishing.

²⁷Mitchell, S.L., Black, B.S., Ersek, M., Hanson, L.C., Miller, S.C., Sachs, G.A., Teno, J.M., Morrison, R.S. (2012). Advanced Dementia: State of The Art and Priorities for the Next Decade. *Annals of Internal Medicine*. 156, 45-51.

²⁸Beauchamp, T.L., & Childress, J.F. (2001). *Principles of Biomedical Ethics*, 5th edition. Oxford: Oxford University Press.

²⁹Herring, J., & Wall, J. (2017). The Nature and Significance of the Right to Bodily Integrity. *The Cambridge Law Journal*. 76(3), 566-588.

competent to voice wishes and thus are regarded as mentally incapacitated. In this case, family members usually become the surrogate decision-makers.

Very often, surrogate decision-makers are inclined to initiate tube feeding, fearing that the tube feeding withdrawal would result in starvation.³⁰ A study shows that patients at the terminal stage, indeed, are unlikely to feel hunger or experience sensations of starvation,³¹ and decrease food and fluid intake slowly over time because the brain begins to stop functioning. Giving a large amount of food and fluids artificially via tube feeding to an elderly patient who has been on a reduced intake of food can be harmful. Reported mechanical and infectious complications of tube feeding include nasopharyngeal lesions, pressure sores, aspiration, and sinusitis.^{32,33} A study evaluated the complications of tube feeding in patients with advanced dementia and found that the use of tube feeding may lead to a 46.7% increase in the frequency of aspiration pneumonia complications.³⁴ Systematic reviews studied the efficacy of tube feeding in patients with advanced dementia have failed to show demonstrable benefits in prolonging lifespan or functional or cognitive status.³⁵

Beneficence requires healthcare professionals to act in the best interest of patients. Based on the clinical evidence, enteral tube feeding results in more harm than benefits for patients with advanced dementia such that non-maleficence prevails and suggests tube feeding should not be initiated. Contrary to clinical evidence, most physicians were falsely optimistic about tube feeding outcomes and resulted in the prevalent use of enteral tube feeding.^{36,37,38} It could be reasoned that physicians may have a misconception and inadequate information about the benefits and pitfalls of tube feeding. Other factors that contribute to the widespread

use of enteral feeding in patients with advanced dementia include a lack of religious knowledge,³⁹ and the fear of legal allegation.⁴⁰

Careful hand-feeding, an alternative approach to tube feeding, is increasingly adopted allowing patients with swallowing problems to enjoy the gratification of eating.⁴¹ Hand-feeding involves techniques of feeding bolus portions, reminding the patients to swallow, and encouraging gentle coughs after each swallow. During the entire feeding process, the caregiver focuses on the older person and avoids distraction. Oral hand-feeding provides a possibility of experiencing food pleasures and enjoyment that tube feeding cannot offer, though it requires a substantial workforce and time investment. One study showed that the clinical outcome of maintaining nutrition by careful hand-feeding might be comparable to tube feeding,⁴² although it cannot prevent aspiration events. After balancing the benefits and burdens of the various options, several professional societies do not recommend the use of enteral nutrition in the terminal phase of dementia and encourage careful hand-feeding as an alternative way for patients with advanced dementia.^{43,44,45}

4 | CASE DISCUSSION: TUBE FEEDING DECISION-MAKING IN CULTURAL CONTEXT

The above section discusses clinical and ethical considerations in the debate about forgoing tube feeding when medicine fails to adequately provide comfort and proper emotional care to the dying and frail population. Other non-clinical factors, such as ethics differences and socio-cultural practices are also important considerations for understanding attitudes toward therapeutic feeding.

This section begins with a case vignette highlighting the assent of the culture of biomedicine in the approach to clinical ethics problems at the bedside. We analyse the case by comparing and contrasting how Hong Kong Chinese, North American, and Malaysian Islamic,

³⁰Brody, H., Hermer, L.D., Scott, L.D., Grumbles, L.L., Kutac, J.E., McCammon, S.D. (2011). Artificial Nutrition and Hydration: The Evolution of Ethics, Evidence, and Policy. *Journal of General Internal Medicine*. 26(9), 1053-1058.

³¹Gillick, M.R. (2000). Rethinking the Role of Tube Feeding in Patients with Advanced Dementia. *New England Journal of Medicine*. 342(3), 206-210.

³²Blumenstein, I., Shastri, Y.M., Stein, J. (2014). Gastroenteric Tube Feeding: Techniques, Problems and Solutions. *World Journal of Gastroenterology*. 20(26), 8505-8524.

³³Higaki, F., Yokota, O., Ohishi, M. (2008). Factors Predictive of Survival After Percutaneous Endoscopic Gastrostomy in the Elderly: Is Dementia Really a Risk Factor? *American Journal of Gastroenterology*. 103(4), 1011-1016.

³⁴Mitchell, S.L. et al., op. cit. note 18.

³⁵Goldberg, L.S., Altman, K.W. (2014) The Role of Gastrostomy Tube Placement in Advanced Dementia with Dysphagia: A Critical Review. *Clinical Interventions in Aging*. 9, 1733-1739.

³⁶Hanson, L.C., Garrett, J.M., Lewis, C., Phifer, N., Jackman, A., Carey, T.S. (2008). Physicians' Expectations of Benefit from Tube Feeding. *Journal of Palliative Medicine*. 11(8), 1130-1134.

³⁷Vitale, C.A., Hiner, T., Ury, W.A., Berkman, C.S., Ahronheim, J.C. (2006). Tube Feeding in Advanced Dementia: An Exploratory Survey of Physician Knowledge. *Care Management Journals*. 7(2), 79-85.

³⁸Luk, J.K., Chan, F.H., Hui, E., Tse, C.Y. (2017). The Feeding Paradox in Advanced Dementia: A Local Perspective. *Hong Kong Medical Journal*. 23(3), 306-310.

³⁹Clarfield, A.M., Gordon, M., Markwell, H., Alibhai, S.M. (2003). Ethical Issues in End-of-life Geriatric Care: The Approach of Three Monotheistic Religions-Judaism, Catholicism, and Islam. *Journal of the American Geriatrics Society*. 51(8), 1149-1154.

⁴⁰Luk, J.K. et al, op. cit. note 38.

⁴¹DiBartolo, M.C. (2006). Careful Hand-Feeding: A Reasonable Alternative to PEG Tube Placement in Individuals with Dementia. *Journal of Gerontological Nursing*. 32(5), 25-33.

⁴²Hanson, L.C. (2013). Tube Feeding Versus Assisted Oral Feeding for Persons with Dementia: Using Evidence to Support Decision-Making. *Annals Of Long-Term Care*. 21(1), 36-39.

⁴³American Geriatrics Society Ethics Committee and Clinical Practice and Models of Care Committee. (2014). American Geriatrics Society Feeding Tubes in Advanced Dementia Position Statement. *Journal of the American Geriatrics Society*. 62(8), 1590-1593.

⁴⁴Sobotka, L., Schneider, S.M., Berner, Y.N., Cederholm, T., Krznaric, Z., Shenkin, A., Stanga, Z., Toigo, G., Vandewoude, M., Volkert, D. (2009). ESPEN Guidelines on Parenteral Nutrition: Geriatrics. *Clinical Nutrition*. 28(4), 461-466.

⁴⁵Schwartz, D.B., Barrocas, A., Wesley, J.R., Klinger, G., Pontes-Arruda, A., Arenas Márquez, H., James, R.L., Monturo, C., Lysen, L.K., DiTucci, A. (2014). Gastrostomy Tube Placement in Patients with Advanced Dementia or Near End Of Life. *Nutrition in Clinical Practice*. 29(6), 829-840.

and cultures interplay in the decision-making for end-of-life care among patients with advanced dementia in the case study.⁴⁶

The Case Description

Mr John is an 84-year-old male, with a history of hypertension, diabetes and recurrent ischaemic stroke. His wife died a few years ago. He has two sons and one daughter. He was diagnosed with 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. Mr John became progressively weaker in the last few months, and Mary no longer could transfer him out of bed on her own. Mr John was then brought to live in a private nursing 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 a puree diet and thickener in the fluid. After an episode of aspiration pneumonia, the speech therapist suggested non-oral feeding due to severe oropharyngeal dysphagia.[^]

The doctor asked to meet with the family and the second son, and the daughter also came. The son said, "Father would not want to have a feeding tube placed. He had seen many tube-fed older adults at the nursing home. They just lay 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 a fever and became unarousable. He was transferred to the hospital and was found to have severe pneumonia. He cannot take any substances orally and thus has to be given parenteral antibiotics. His second son and daughter were informed of his 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. The clinician was not sure whether he should merely reject the son's request or not.

[^] Oropharyngeal dysphagia is medical for swallowing difficulties for certain foods or liquids, or cannot swallow at all.

⁴⁶Tse, C. Y. (2016). Practical Approach to Clinical Ethics at the Bedside for General Physicians. Synapse, Hong Kong College of Physicians. Retrieved January 10, 2019, from <http://www.hkcp.org/docs/Synapse/synapse201608.pdf>.

4.1 | Hong Kong Chinese Perspective

Hong Kong, now a territory of China, was a former British colony from 1841 to 1997 and the British Common Law system remained in place after 1997.⁴⁷ British influence on the local medical practice also endures after the sovereignty handover to China. Like the United Kingdom, artificial nutrition and hydration are classified as medical treatment in common law and could be withdrawn or withheld after considering the balance of benefits and burdens of the treatment, and the patient's value and preference into account.⁴⁸

Hong Kong Chinese culture honours longevity and life preservation is a prevailing value held by the family.⁴⁹ As advanced dementia is seen as a degenerative life process, family members of the patients living with dementia accept that they need to address the swallowing difficulty issue during the course of care, and generally attempt to solve the problem using medical interventions. A local study surveyed Chinese family caregivers of older people with dementia with the use of life-sustaining treatments, including tube feeding and findings showed that Chinese caregivers had a poor understanding of the benefits and risks related to life-sustaining treatments but were reluctant to forgo these treatments.⁵⁰ This could relate to the local culture understanding of food as a high priority, where eating not only meets physiological needs but is also viewed as a blessing.⁵¹

In Chinese culture, food is symbolic of family love and caring that eating and drinking are recognised as the essence of life. When patients with advanced dementia fail to consume food orally and rely on mechanical assistance, families tend to prefer the use of tube feedings. Many hold the view that continuing feeding is the humane option, assuming that feeding is a fundamental component of care to maintain a quality of life for the patient, even at the end-stage of life. An underlying positive culture connotation of "dying with a full stomach" may be unique to Chinese society, and "starvation and dehydration" are viewed as cruel ways to die. Caregivers felt emotionally uncomfortable about the absence of food and fluid intake, and they were distressed if forgoing tube feeding would lead to starvation or cause suffering of the patients. Choosing not to initiate tube feeding can be a morally agonising time as family members might be judged by how adequately their parents are fed.

As in the case example, the central phenomenon underlying the behaviour of Mr John's elder son reflect how filial piety, a virtue of respect

⁴⁷Carroll, J.M. (2007). A Concise History of Hong Kong. Lanham, MD: Rowman & Littlefield Publishers.

⁴⁸Quality & Safety Division, Patient Safety & Risk Management Department. (2018). Hospital Authority Guidelines on Life-sustaining Treatment in the Terminally Ill. Retrieved December 12, 2018, from http://www.ha.org.hk/haho/ho/psrm/HA_Guidelines_on_Life_sustaining_treatment_en_2015.pdf.

⁴⁹Pang, S.M.C., Volicer, L., Chung, B., Chung, Y.M., Leung, W.K.A., White, P. (2007). Comparing the Ethical Challenges of Forgoing Tube Feeding in American and Hong Kong Patients with Advanced Dementia. *Journal of Nutrition, Health and Aging*. 11(6), 495-501.

⁵⁰Kwok, T., Twinn, S., Yan, E. (2007). The attitudes of Chinese Family Caregivers of Older People with Dementia Towards Life-sustaining Treatments. *Journal of Advanced Nursing*. 58(3), 256-262.

⁵¹Chan, H.Y.L., & Pang, S.M.C. (2011). Cultural Aspects of Forgoing Tube Feeding in American and Hong Kong Chinese Patients at the End-of-life. In V.R. Preedy (Ed.), *Diet and Nutrition in Palliative Care* (pp. 145-154). Boca Raton, FL: CRC Press.

for older adults' in Confucian moral philosophy, is deeply rooted among the Chinese family. Filial piety alludes to the duty of the younger generation to care for the older adult within the family unit that should not be trifled with. To exercise filial piety, young family members are encouraged to translate the act of caring into 'doing everything possible' to rescue patients with the best effort to save a life and maintain the life of the elders even in the face of what physicians might consider "futile". If the son or daughter denies any life-saving intervention for a terminally ill older patient, s/he might be criticised, and confronted by other relatives for violating the principle of filial piety and the principle of saving the dying. The discussion of death is still a cultural taboo in many families, so avoiding the mention of the prospect of dying is also considered filial piety. The young generation refrains from exploring the older adults' perspective as they are ageing, making advance end-of-life care planning difficult. Poor understanding about the disease trajectory, cultural meaning of feeding, and benefits of enteral tube feeding are common obstacles in making feeding-related decisions.

A qualitative study at a long-term healthcare unit in Hong Kong notes a paradigm shift in the attitudes towards forgoing tube feeding among family members of patients with advanced dementia that they are keen to forgo treatments that might cause discomfort.⁵² Despite the shifting attitude, healthcare providers in Hong Kong felt challenged discussing when the decision to forgo tube feeding should be made. Many still consider tube feeding patients to be safer than oral feeding, and careful hand-feeding is rarely attempted. Some also worried that forgoing tube feeding may be perceived to be giving up on the patient thereby compromising their professional identity. Some may be concerned that forgoing tube feeding could be viewed as neglect that might be a cause of complaint or even regarded as a form of negligence. These clinical and moral tensions are intensified when the health care team are unfamiliar with the clinical evidence of the shortcomings of tube feeding. With these combinations of multiple factors, the prevalence of tube feeding among cognitively impaired elderly residents in healthcare homes is high.

In addition to healthcare providers behaviour and cultural factors, another reason that contributes to the high prevalence of tube feeding use among patients with advanced dementia in Hong Kong is the lack of advance care planning.⁵³ When the patients have not expressed their preferences for tube feeding, family members are uncertain about the proper choice and the default decision is almost always to give and continue tube feeding. Sometimes the family members are determined to override a patient's expressed preference. In Hong Kong, family members do not by law have the right to make a proxy decision for patients (except where a legal guardian is appointed), but culturally family involvement is valued and relational autonomy plays a large and important role in medical decision-making.⁵⁴

In the case study presented, disagreement between family members regarding a patient's treatment is common in actual clinical

settings. Such conflict becomes more complicated as the patient approaches their end of life. If this case scenario occurs in Hong Kong, physicians have the responsibility to provide the legal guardian and family members involved in the decision-making process with adequate information about therapeutic options for consensus building.

4.2 | North American Perspective: The United States of America

Due to its history of migration from across the world, the United States of America (USA) could be said to neither have a unitary cultural nor unitary bioethical view. Nevertheless, some significant cultural trends and commonalities can give guidance as to the types of discussions and decisions likely to occur surrounding artificial nutrition and hydration. In this section, three major themes are addressed: religious views, with a focus on Roman Catholic tradition, the influence of the "culture of biomedicine," and the importance of respecting diverse and minority opinions in the US. The case is then evaluated based on these three contexts.

The influence of Roman Catholic doctrine has had a tremendous impact on US policymaking. Though Protestant Christianity is the most common religious tradition in the USA, Protestantism has no central authority, which has left Roman Catholicism in a position to influence policy as the primary arbiter of a Christian view. In this view, the advances in medicine lead to the question of the moral limits of preserving life and health. The Roman Catholic doctrine of ordinary-extraordinary treatment distinction has long been used as a guide concerning the appropriate medical treatment relative to specific life issues. The distinction originates from Roman Catholic church teaching.^{55,56} Ordinary care refers to treatment to directly improve the patient's health trajectory without incurring severe pain or extraordinary costs. US Catholic Bishops also emphasize the need for a health care system that prioritises universal access and care for the poor, so that financial costs need not be a primary consideration in an appropriate health care system.⁵⁷ It is often regarded as morally obligatory to offer care for patients since the treatment is likely to help the patient without imposing excessive burdens to the overall quality of the patient's life. Extraordinary care refers to treatment that would cause sorrowful pain and would be burdensome, beyond the patient's economic means, despite failing to commensurate improvement in health and only prolong the suffering of a dying person. This distinction facilitates an informed consideration in assessing whether to provide particular medical treatments or procedures about what would be in patient's best interest. It also has been used

⁵⁵May, W.E. (1990). Criteria for Withholding or Withdrawing Treatment. *The Linacre Quarterly*. 57(3), 81-90.

⁵⁶Pope Pius XII. (2009). *The Prolongation of Life: Address to an International Congress of Anaesthesiologists on November 24, 1957*. The National Catholic Bioethics Quarterly. 9(2):327-332. Pius XII's address to the International Congress of Anaesthesiologists in 1957 included the words: "...normally one is held to use only ordinary means—according to circumstances of persons, places, times, and culture—that is to say, means that do not involve any grave burden for oneself or another. A stricter obligation would be too burdensome for most men and would render the attainment of the higher, more important good too difficult.

⁵⁷US Conference of Catholic Bishops, op. cit. note 54.

⁵²Pang, S.M.C. et al, op. cit. note 49.

⁵³Luk, J.K. et al, op. cit. note 38.

⁵⁴US Conference of Catholic Bishops. (2009). *Ethical and Religious Directives for Catholic Health Care Services*, 5th ed. Washington DC: USCCB. Retrieved May 2, 2019, from <http://www.usccb.org/issues-and-action/human-life-and-dignity/health-care/upload/Ethical-Religious-Directives-Catholic-Health-Care-Services-fifth-edition-2009.pdf>.

to mark the difference between obligatory and non-obligatory care for the patients to accept and others to provide.

In a 1983 report of the US President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research, it was suggested that the distinction between obligatory and non-obligatory care had become confused and not useful for public policy, and that even the Vatican had questioned the usefulness of the terminology.^{58,59} A new terminological distinction between "proportionate" and "disproportionate" has been suggested as a better way to express the process of making a correct judgement "by studying the type of treatment to be used, its degree of complexity or risk, its cost and the possibilities of using it, and comparing these elements with the result that can be expected, taking into account the state of the sick person and his or her physical and moral resources".⁶⁰ Regardless of the terms used, in practice, the underlying distinction continues to hold sway among the general population, particularly those who follow the Roman Catholic faith. In addition, a number of Protestant denominations have similar guidelines.⁶¹

A second topic concerns the extremely strong influence of biomedicine as a cultural force of its own.⁶² In the USA, technological medicine has become the norm, and it is often taken for granted as a baseline state of affairs for much of the population. This means that the logic of medical care often eclipses other cultural or religious systems that would otherwise take prominence in other countries. There is also an increasing emphasis in society on quality of life, comfort, and dignity as primary goals of end-of-life care decision-making.⁶³ In many cases, regardless of religious background, families in the US prioritise making end-life care as comfortable as possible, which coincides with the rapid growth of palliative care specialisation within the country.^{64,65} Furthermore,

there is an emphasis on clinical evidence, which has shown that tube feeding not only does not improve nutrition or prolong life in patients with advanced dementia, but it may also cause considerable discomfort. With the combined trajectory of medical practice and the specific reasoning behind legal cases within the country,⁶⁶ the possibility of forgoing medically futile care has become more broadly accepted as the baseline among a large part of the general population, particularly those with higher levels of education and in urban areas.

Finally, it is crucial to address the presence of cultural diversity within the US itself, due to a wide variety of minority cultural and religious views within the country. Though Christianity is the most common religious tradition, the US has substantial regional populations of individuals who follow world religions including Islam, Judaism, Hinduism, and Buddhism, and it is also important to acknowledge the importance of minority religions with origins in North America (such as the Church of Jesus Christ of Latter-day Saints), as well as other minority cultures and faiths including Caribbean, South Asian, African, Hispanic, and Indigenous traditions. There is also a sizable Chinese-American population, and so the end-of-life health-care dilemmas faced in Hong Kong are also at times relevant to these groups in the US.

In the case of Mr John, multiple questions may be asked depending on the background of the patient and his family. If they are from the Roman Catholic faith tradition, it may be relevant to determine whether a feeding tube constitutes an ordinary or extraordinary means of keeping a patient alive at end-stage of life. Scholars draw different conclusions on the necessity of providing artificial nutrition and hydration (ANH) in cases of dementia. Punzo, for example, suggests that it is extraordinary and not obligatory "due to a lack of evidence supporting the nutritional or symptom palliation benefits of such procedures".⁶⁷ Others find the descriptions of ANH as obligatory and ordinary care for patients with Persistent Vegetative State (PVS) to be the best guidance for dementia, regardless of the differences between the conditions.^{68,69,70} Often, rather than reading official doctrine materials, families will ask to consult local clergy in person to discuss the case before making a decision. If the intervention is determined to constitute morally extraordinary care means that it is similar to other medical interventions, such as ventilators or dialysis machines, then it may be acceptable to withdraw care. The

⁵⁸President's Commission for the Study of ethical Problems in Medicine and Biomedical and Behavioral Research. (1983). *Deciding to Forego Life-sustaining Treatment: A Report on the Ethical, Medical, and Legal Issues in the Treatment Decision*. Washington, DC: Government Printing Office.

⁵⁹Bergstresser, S.M., & Castellanos, E. (2015). Feeding Versus Artificial Nutrition and Hydration: At the Boundaries of Medical Intervention and Social Interaction. *International Journal of Feminist Approaches to Bioethics*, 8(2), 204-225.

⁶⁰Haas, J.M. (2009). Therapeutic Proportionality and Therapeutic Obstinacy in the Documents of the Magisterium (pp 143-157). In E. Sgreccia, & J. LaFitte (Ed.) *Alongside the Incurably Sick and Dying Person: Ethical and Practical Aspects—Proceedings of Fourteenth Assembly of the Pontifical Academy for Life*, Vatican City, 25-27 February 2008. Vatican City: Libreria Editrice Vaticana.

⁶¹Cooperman, A., Masci, D., O'Connell, E. (2013). Religious Groups' Views on End-of-Life Issues. Retrieved April 20, 2019, from <https://www.pewresearch.org/wp-content/uploads/sites/7/2013/11/end-of-life-religious-groups-views.pdf>. This is more likely the case with "Evangelical" or other non-mainline Protestant denominations. For example: Church of Jesus Christ of Latter-day Saints (Mormon Church), Seventh-day Adventist Church, and Southern Baptist Convention.

⁶²Kleinman, A., & Benson, P. (2006). Anthropology in the Clinic: The Problem of Cultural Competency and How to Fix It. *PLoS Medicine*, 3(10), e294.

⁶³Cohen, M.Z., Torres-Vigil, I., Burbach, B.E., de la Rosa, A, Bruera E. (2012). The Meaning of Parenteral Hydration to Family Caregivers and Patients with Advanced Cancer Receiving Hospice Care. *Journal of Pain and Symptom Management*, 43(5), 855-865.

⁶⁴Dumanovsky, T., Augustin, R., Rogers, M., Lettang, K., Meier, D.E., Morrison, R.S. (2016) The Growth of Palliative Care in US Hospitals: A Status Report. *Journal of Palliative Medicine*, 9(1), 8-15.

⁶⁵Wildes, K.W. (1996). Ordinary and Extraordinary Means and the Quality of Life. *Theological Studies* 57(3), 500-512.

⁶⁶Bosslet, G.T., Baker, M., Pope, T.M. (2016). Reason-giving and Medical Futility: Contrasting Legal and Social Discourse in the United States with the United Kingdom and Ontario, Canada. *Chest*, 150(3), 714-721.

⁶⁷Punzo, V.A., (2013). Alzheimer's Disease, Tube Feeding, and Prudential Judgment. *The National Catholic Bioethics Quarterly*, 13(3), 471.

⁶⁸US Conference of Catholic Bishops, op. cit. note 54.

⁶⁹Degnan, M., (2008). Are We Morally Obligated to Feed PVS Patients Till Natural Death?. In C. Tollefsen (Ed.), *Artificial Nutrition and Hydration: The New Catholic Debate*. (pp. 39-60). Springer, Dordrecht.

⁷⁰May, W.E. (2008). Caring for Persons in the "Persistent Vegetative State" and Pope John Paul II's March 20 2004 Address "On Life-sustaining Treatments and the Vegetative State". In C. Tollefsen (Ed.), *Artificial Nutrition and Hydration: The New Catholic Debate*. (pp. 61-76). Springer, Dordrecht.

withdrawal of a feeding tube, in this case, would not be seen as directly taking the life of a person, although it may contribute to the person dying earlier than if aggressive treatment had been adopted.

If the family is invested in a mainly biomedical view, then the declining swallowing ability of the patient over time is likely to be viewed as a natural progression of a terminal disease, and accepting the patient's progressive deterioration is likely to be seen as allowing death to take its natural course. In this context, tube feeding is considered to be a form of medical treatment that is similar to cardiopulmonary resuscitation and medical ventilation. Furthermore, forgoing tube feeding among patients with advanced dementia could be viewed as morally desirable as a way to alleviate suffering.

If Mr John's family is from a minority population within the US, specific elements of that cultural background are relevant to the decision-making process. For example, if the family has recently migrated to the US from Hong Kong or other areas with a Chinese cultural background, the "hungry ghost" dilemma may also be relevant in the US. There is an increasing emphasis on the concept of cultural competence, though others have extended the concept towards the concept of "cultural humility", which "takes into account the fluidity of culture and challenges both individuals and institutions to address inequalities".⁷¹ The impact of culture remains and will remain important not only between the US and other countries but also within the country itself.

4.3 | Malaysian Perspective in Southeast Asia

The Malaysian culture also shares a similar practice with Hong Kong Chinese that continuation of feeding patients with advanced dementia with poor oral intake is usually considered vital. Islamic medical ethics guided by Islamic law (Maqasid al-Sharia) provides fundamental guide references to life, disease, and death governing the behaviour of individuals towards oneself, family, and the broader Muslim society. Under Islamic law, the sanctity of life is paramount, noting that life is precious and sacred. In the Qur'an, God described the creation of human life as "khalqan aakhar", which means "Blessed be the Best of creators!" (Qur'an: 23:14). In this regard, human bodies are viewed as a blessing from God. Every moment of life has great value, and therefore, it must be respected and preserved even if it has poor quality.

Muslims also believe that all healing comes ultimately from God. Islamic bioethics states: "whoever slays a soul, unless it is for assassination or mischief in the land, it is as though he slew all men; and whoever keeps it alive, it is as though he kept alive all men" (Qur'an: 5: 32). According to this verse, saving a life is an obligation, and the unwarranted taking of life is a significant crime.⁷² In other words,

saving a life is a duty and taking a life is a sin. When getting sick, patients have a responsibility to seek out and receive appropriate medical care, while healthcare providers have clear obligations concerning the duty to treat.

The oath of a Muslim physician also includes the protection of human life in all circumstances, and that it is the ethical duty of the doctors to do their best for the patient until he naturally dies. Accelerating the dying process by withdrawing food and drink is forbidden, but Islamic law permits withdrawing futile, death-delaying treatment, including life support. The virtue of treatment varies by the health trajectory of a specific illness that necessitates particular rulings.⁷³ Treatment should be provided if it means the patient will recover one's health and should not be used as a means to merely prolong the final stages of a terminal illness or if it causes more harm to the patient. This fundamental Islamic ruling is consistent with other religion's rulings, for example, the Roman Catholic ordinary/extraordinary distinction.

While considering death as an inevitable part of human existence, Islamic medical ethics forbids passively or actively causing death even if the disease is incurable and treatment is futile. In such a situation, the ill person is allowed to either continue accepting or refusing medical treatment. Muslim jurists opined that seeking treatment for a Muslim patient suffering from diseases with no hope of recovery is not mandatory.⁷⁴ The opinion is supported by a *hadith* which tells the story of a woman who suffers from an incurable illness and asked Prophet Muhammad (ﷺ) to pray for her. The Prophet then told her:

"If you are patient, the reward that awaits you is heaven. Or if you would rather I pray to Allah for your recovery." The women then replied: "In that case then I would want to be patient."

From the Islamic perspective, the principle rule that governs the care of terminally ill patients is the prevention of harm. This Islamic principle is equivalent to the biomedical principle of non-maleficence. When a decision is needed in choosing between two harmful treatments, the less harmful treatment should be selected. The choice of withdrawing life support, when necessary, is made when the following criteria are met: the death (brain or cardiovascular death) is certified by three clinical experts in the field, and the withdrawal of life support decision is made by two clinical specialists (who are not involved with organ donation) and with consent from family members.⁷⁵

In the medical context as it applies to the case of Mr John, Islamic law recognises nutritional support as primary care and not medical

⁷¹Fisher-Borne, M., Cain, J.M., Martin, S.L. (2015). From Mastery to Accountability: Cultural Humility as an Alternative to Cultural Competence. *Social Work Education*, 34(2),165-181.

⁷²Shomali, M.A. (2008). Islamic Bioethics: A General Scheme. *Journal of Medical Ethics and History of Medicine*. 1,1.

⁷³Sultan, M. (2017). Pulling the Plug: The Islamic Perspectives on End-of-Life Care. Retrieved November 13, 2018, from <https://yaqeeninstitute.org/en/maryam-sultan/pulling-the-plug-the-islamic-perspectives-on-end-of-life-care/#ftnt11>.

⁷⁴Nasir, N.M. (2017). Fatwas Of Singapore: Science, Medicine and Health. Office of the Mufti, Islamic Religious Council of Singapore. Retrieved December 20, 2018, from <https://muisfatwa.pressbooks.com/chapter/medicine-health-and-treatment/>.

⁷⁵Malaysian Fatwa (Islamic Guide). Retrieved December 20, 2018, from <http://e-smaf.islam.gov.my/e-smaf/fatwa/fatwa/find/3>.

treatment. There is a duty to feed people who are no longer capable of feeding themselves unless it poses more harms than benefits or it goes against the patient's advance directive,⁷⁶ permissible by the Islamic law. Therefore, forgoing nutrition to induce death by starvation is a crime according to Islamic law and contrary to both the fundamental importance of the sanctity of life and the duty to provide nutrition to an Islamic person. Refusing tube feeding and waiting for death for illnesses that can be treated is seen as suicide, which is also forbidden under Islamic law.

Although the ruling on medical treatment at the end of life between Sunni and Shiite (Shia) Muslims is similar,⁷⁷ subtle differences in their other practices are widely known and commonly seen.⁷⁸ For example, although the Sunni Muslims in Saudi Arabia believe that end of life artificial hydration and total parenteral nutrition should be continued, the Shiite (Shia) Muslims in Iran believe that artificial hydration and total parenteral nutrition should be avoided.⁷⁹ An explanation of these different practices, however, cannot be found in the literature. Therefore, it is best to make a decision with regards to artificial nutrition and hydration among Muslims on a case-to-case basis.

5 | CLINICAL IMPLICATIONS

Divergent socio-cultural practices and religious beliefs contribute to varying views towards disease progression and medicalised attitudes of treatment, in particular to end-of-life care. Hong Kong Chinese and Malaysians of Islamic faith hold a perspective in sharp contrast to the prevailing North American belief system that views a patient's comfort as the priority and tube feeding as a medical intervention.

Cultural considerations have to be individualised and carefully weighed against other relevant factors. At the practical level, first and foremost, healthcare providers should be respectful of and responsive to the needs of diverse patients. This means that the healthcare provider should be attentive to a patient's cultural beliefs and health practices, and apply that knowledge in the physician/ patient consultation. Second, the healthcare provider should clarify the clinical course the patient will be undertaking, provide health information, and explain any and all possible foreseen complications. Third, the healthcare provider should explore with a patient any prior indicated preferences about medical intervention and establish a treatment plan that aligns with the goals of care (i.e., quality of life and values of dignity). If a patient with advanced dementia is incapacitated, healthcare providers ought to engage in the

shared decision-making process with surrogate decision-makers. Healthcare providers should take a patient's implicit beliefs and values into medical consideration, providing adequate supportive yet not aggressive care for their patients near the end of life.

End-of-life communication has been introduced as an essential component of medical schools' curricula, though cultural competence is not fully incorporated into a student's learning until it is exercised in clinical practice. Ethics and clinical curricula should incorporate the topic to equip future medical professionals with knowledge about the need for cultural sensitivity, mainly when teaching about end-of-life care. A more standardised content on understanding cultural practices of different ethnic, religious, or migrant groups should be made available to medical students and practitioners alike.

ACKNOWLEDGEMENTS

The work on this paper was inspired by the conversation at the meeting of Asia Pacific Bioethics Education Network (APBEN) hosted at the Chinese University of Hong Kong in 2018 and 2019. The authors would like to extend their thanks to APBEN members for their invaluable input and support.

CONFLICT OF INTEREST

The authors declare no conflict of interest.

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⁷⁶Nasir NM, op. cit. note 74.

⁷⁷Mobasher, M., Aramesh, K., Zahedi, F., Nakhaee, N., Tahmasebi, M., & Larjani, B. (2014). End-of-life Care Ethical Decision-Making: Shiite Scholars' Views. *Journal of Medical Ethics and History of Medicine*, 7, 2–11.

⁷⁸Alibhai, S.M.H. (2008). Duty to Feed in Cases of Advanced Dementia. *Journal of Religious Ethics*, 36(1), 37–52.

⁷⁹Alsolamy, S. (2012). Islamic Views On Artificial Nutrition And Hydration In Terminally Ill Patients. *Bioethics*, 28(2), 96–99.

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How to cite this article: Ngan OMY, Bergstresser SM, Sanip S, Emdadul Haque ATM, Chan HYL, Au DKS. Cultural considerations in forgoing enteral feeding: A comparison between the Hong Kong Chinese, North American, and Malaysian Islamic patients with advanced dementia at the end-of-life. *Developing World Bioeth.* 2019;00:1-10. <https://doi.org/10.1111/dewb.12239>