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The Meaning of Food amongst Terminally Ill Chinese Patients and Families in Singapore

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Abstract

The concept of feeding at the end of life is frequently an emotive issue. Here, we present a series of cases set within Confucian inspired Singapore that highlight the various views held by local Chinese patients and their families as they confront a number of difficult issues pertaining to withdrawing and withholding feeding at the end of life. These findings are readily applicable to patients of East Asian backgrounds and help to shed light upon the competing considerations faced by patients and their families when considering the issue of feeding at the end of life.

Keywords: Food, Singapore, filial piety, end of life, palliative care.

Introduction

Food satiates more than simple biological functions for the terminally ill but brings to fore the many roles family and carers play in seeing to the needs of these patients. Within the setting of advanced cancer, patients frequently develop a complex syndrome that combines weight loss, muscle wasting, anorexia, chronic nausea and weakness that distress both patients and their families (Bruera 1997). When faced with such a predicament, patients and families look to means of reversing this decline, frequently turning their attentions to the almost ubiquitous presence of anorexia (Krishna 2011a, Ho et al 2010). This concern tends to increase as patients become less able to take food orally and high levels of emotional distress amongst family members have been reported with such occurrences (Krishna 2011a, Ho et al 2010, Yamagishi et al 2010).

Despite evidence to the contrary, the provision of food either orally, through a feeding tube or via other means of artificial nutrition and hydration continues to be perceived as a key means of overcoming this deterioration, increase strength and alertness and sometimes in the vain hope that it may prolong life (Krishna 2011a, 2011b, Ho et al 2010, Oh et al 2007). Underpinning this is the belief that such provision of sustenance is a sign of non-abandonment (Krishna 2011a, 2011b, 2011c, Ho et al 2010, Ke et al 2008, Bowman and Singer 2001). An appreciation of these regnant cultural and therapeutic considerations are critical to the promotion of appropriate end of life cancer care (Krishna 2011a, 2011b, 2011c, Ho et al 2010). Here we present a number of cases that highlight the main themes of the role of food gleaned from our study into the meaning of food and feeding amongst the majority Chinese populous of Singapore and the specific role family plays within such beliefs (Chai et al 2013).

Reassurance

Mr. Z, a retired 60 year old lorry driver with a diagnosis of locally advanced nasopharyngeal cancer (NPC) developed severe mucositis whilst undergoing chemo-radiotherapy. As a result of painful swallowing that appeared resistant to the limited western medicines that the family would allow, his wife sought alternatives treatment in the form of Traditional Chinese Medicine (TCM). Convinced by the advice given, she returned with health supplements that amounted to a daily tablet burden of about 200 capsules and pills. Despite the difficulty in swallowing, he continued to take the 200 tablets daily for fear of disappointing his wife and to reassure her and the family that he was still fighting on.

Chinese culture places an emphasis on the family collective (Ho et al 2010, Ke 2008, Krishna 2011a, 2011b, 2011c). Here the interests of the family outweigh those of a singular member (Ho et al 2010, Ke 2008, Krishna 2011a, 2011b, 2011c). Personal sacrifice for the benefit of the family as a whole is expected and is seen as part of one's familial duties (Krishna 2012). In this case there were 2 roles that were being met. Mrs. Z undertook the 'protective role' to obtain appropriate food, though the provision of these supplements was at no small financial cost and personal sacrifice (Krishna 2012). Here she meets her familial duty to provide for her loved one and to set about circumnavigating any obstacles that lie between her loved one's present state and their desired recovery. Family members were shown to report guilt and sadness as a result of failing to meet these 'provider' and 'protective' roles (Ho et al 2010, Chai et al 2013).

Mr. Z on the other hand, explained that he dutifully consumed the health supplements in an attempt to reassure his wife and the family as a whole that he was continuing to fight his illness. He added that persevering with this daily ritual despite significant physical pain registered his appreciation for her efforts and acknowledged the continued financial and emotional support provided by his family. It was a sacrifice he felt obliged to make and one in keeping with his duty to the family to allow them to care for him and show their fealty toward him (Ho et al 2010, Ke 2008, Krishna 2011a, 2011b, 2011c).

The ‘appropriate food’ obtained was in this case, in the form of tablets and capsules which were seen as a means to nourishing the healthy 'qi', restoring the normal pattern of health, overcoming the significant side effects of Western medicine[8] and crucially in defeating the disease (Shih 1996, Bowman 2001, Lam 2001, Chen 2001, Payne et al 2008, Lai and Surood 2009). For Mrs. Z and the family, TCM was held to be free of adverse effects and was better for 'clearing the roots' of the disease (Lam 2001). It is also believed to help balance the Yin and Yang elements of one’s body and exemplifies the coming together of strands of Taoist beliefs and Confucian tenets within local deliberations

(Shih 1996, Bowman 2001, Lam 2001, Chen 2001, Payne et al 2008, Lai and Surood 2009).

Filial Piety

Madam W was a 75 year old Chinese lady with a diagnosis of metastatic breast cancer which had progressed to involve her bones and brain. This left her with a fluctuating level of consciousness that made it difficult for her family to feed her. This duly raised their concern about her nutritional status. As a result the family opted for NG (Naso-Gastric) feeding despite being cognizant of the fact that it was unlikely to provide any meaningful comfort to her, nor improve her quality of life or her overall prognosis (Krishna 2011a, Ho et al 2010). They were also aware that quite to the converse, this intervention could cause her harm and discomfort however for the family, the overarching concern remained focused upon meeting their filial duties which they believed took the form of feeding their mother (Garanis-Papadatos and Katsas 1999, Bowman 2001, McClement et al 2003, Chiu 2004, Kwok et al 2007, Ke 2008, Ho et al 2010, Krishna 2011a, 2011b, 2011c). They felt that without nutrition, their mother would effectively starve to death and this would reflect a failing in their filial duties (Garanis-Papadatos and Katsas 1999, Bowman 2001, McClement et al 2003, Chiu 2004, Kwok et al 2007).

Filial piety plays an important role in the Chinese culture. One can trace its roots to the study of Confucianism, which remains widely practiced despite the diversity in cultural and religious beliefs in Singapore (Ho et al 2010). Indeed Hsiao (孝Filial piety) is amongst the five integral concepts of Confucianism. The rest are Ren (仁 Humanity), Yi (義 Righteousness), Zong (忠 Loyalty), and De (德 virtue) (Shih 1996, Lam 2001, Chen 2001, Xu et al 2006, Payne et al 2008, Lai and Surood 2009).

According to Confucian belief, filial piety is essential for one's own well-being and happiness and arises from meeting one's obligations to provide for the material and mental well-being of one's aged parents (Lai and Surood 2009). Such beliefs underlie some of the conundrums faced by families in setting out end of life plans and particularly when contemplating decisions to forgo life sustaining therapies (Kwok et al 2007).

Driven by the need to meet this perceived obligation, children may feel obliged to advocate for aggressive treatment despite being aware that they do so against medical advice and for treatments that are more likely to have negative connotations upon the patient’s well being (Bowman and Singer 2001, Chiu et al 2004, Ho et al 2010, Krishna 2011a, Chai et al 2013). Many feel that it is their duty to protect the health, safety and general well-being of their parents and family members (Ho et al 2010, Krishna 2011a, Chai et al 2013). After all according to a traditional Confucian interpretation, a child who agrees to a parent’s refusal of treatment would be violating the principle of filial piety (Bowman and Singer 2001). To some within the local setting, failing to provide loved ones with this essential ingredient to health, life and well being is simply remonstratable (Ho et al 2010, Krishna 2011a, Chai et al 2013).

In part, this stance ties into the view that the act of providing food is seen as an expression of love and caring (Garanis-Papadatos and Katsas 1999, Bowman 2001, McClement et al 2003, Chiu 2004, Kwok et al 2007, Ke 2008, Ho et al 2010, Krishna 2011a, 2011b, 2011c, Chai et al 2013). Therefore discontinuing with the provision of food is seen to be callous and likened to severing all links and relationships with one's family particularly within a society that sees a patient's declining status in the terminal stages of cancer not as a function of disease progression but of decreased food intake (Slomka 2003, Ho et al 2010, Krishna 2011a, Chai et al 2013). Family members tend to feel that the provision of more calories would halt, or reverse this decline (Bowman and Singer 2001, McClement et al 2003, Chiu 2004, Kwok et al 2007, Ho et al 2010, Krishna 2011a, Chai et al 2013). Additionally, many are under the impression that any withholding or withdrawing of food would result in suffering, pain and a hastening of death (Bowman and Singer 2001, McClement et al 2003, Chiu 2004, Kwok et al 2007, Ho et al 2010, Krishna 2011a, Chai et al 2013). Death by starvation is particularly concerning given the Chinese believe that death in such circumstances, will result in a ‘starving soul’ or ‘hungry ghost’ after death (Goh 2007, Goh 2008).

In Madam W’s case allowing the insertion of NG tube enabled the family time to accept her poor prognosis and time to come to terms with their impending loss. Importantly for them, it allowed them a chance participate in their mother’s patient’s physical care, continue show their affection towards her and redress their own beliefs about the disease process and shift primary focus away from food (Slomka 2003, Goh 2007, Goh 2008, Chiu et al 2009).

Comfort, Hope and Balancing Competing Goals of Care

Mr. T was a 75 year old retired sailor who was diagnosed with metastatic colon cancer with multiple peritoneal metastases. He had recurrent admissions to hospital for the management of intestinal obstruction previously and presented this time with a bowel perforation. He became acutely unwell, lethargic and drowsy for most part of the day. However despite his fluid overloaded state and against medical advice, his daughter insisted that gentle hydration be provided. Underpinning this was what she saw as a source of comfort and one that would circumnavigate death by ‘starvation’ (Ho et al 2010, Krishna 2011a, Chai et al 2013).

In her opinion, the failure of medical professionals to accede to her request was tantamount to reckless abandonment and medical failure (Oh et al 2004, Oh et al 2007, Van der Riet et al 2008, Chiu et al 2009, del Rio et al 2011). She argued that food and drink was part of basic care and demonstrates her continued support of him even at the bleakest of times. She also felt that it maintained his hope especially when he saw that even at this stage of life his family remained hopeful, positive and supportive of him. Her position tugged on the sentiments of many of the health care professionals that were involved in her families’ care and some argued that the emotional needs, familial values and cultural views of patient’s family and caregivers must also be addressed and within any risk benefit analysis that ensued, adequate consideration ought to be apportioned to these factors above and beyond simple clinical considerations (Van der Riet et al 2008, Chiu et al 2009, del Rio et al 2011).

From our yet unpublished data on the attitudes of Singaporean Chinese patients and their families, 76% of patients and 85% of family members believed patients could not get appropriate nutrition without artificial hydration (Chai et al 2013). Additionally 56% of patients and 84% of family members said that withholding rehydration would cause premature death (Chai et al 2013). The provision of subcutaneous fluids for Mr. T is a simple and yet minimally invasive procedure, some of the health care practitioners argued, and even though it is not clinically advisable, it continued to provide emotional comfort for both patient and caregiver.

For health care practitioners too, the issue of withdrawing and withholding hydration can be distressing (Slomka 2003). In Korea, 78.1% of physicians caring for patients with advanced or terminal stage cancer opined that intravenous (IV) nutrition should be administered if patients were unable to consume orally (Oh et al 2007). The authors reported that respondents saw the provision of IV nutrition and hydration as part of a minimum standard of care and withholding or withdrawing it was ethically unacceptable and detrimental to good symptom management (Oh et al 2007).

Here balancing the wishes of the family with respect to the provision of food and fluids runs parallel to caregivers' own cultural, societal and religious beliefs and views of their professional duties. Failure to appropriately appraise and address these concerns will only propagate mistrust and dissent within the multidisciplinary team (MDT).

Maintaining a Sense of Normality and Family Bonds

Madam T, a 56 year old housewife with 2 children, was diagnosed with metastatic colon cancer with peritoneal involvement that continued to progress despite multiple lines of chemotherapy. As a result Madam T required recurrent admissions to the hospital for management of intestinal obstruction. Episodes of recovery with the aid of 'gut rest' and steroids became increasingly shorter and once again she was confronted with a choice between a venting nasogastric (NG) tube or a gastrostomy but turned both down. In her reckoning, even though the venting gastrostomy will allow some normality into her life and enable her to participate in family meals, enjoy the company of her family and the taste of her food, the stigma of obtaining nutrition and excreting it via a tube was ‘unpalatable’ to her.

In the Chinese culture, eating together as a family is important (Chai et al 2013). Having a meal together brings into context food as an expression of social support, group cohesion and identity. The act of eating itself is associated with social interchange and reinforces one’s sense of community. Providing food for another was seen as creating and maintaining these bonds of sharing and concern. Madam T acknowledged as much and admitted to it being a motivation to 'fight on' however she also subscribed to the belief that any deviation from the ‘norm’ devalued the individual.

This was more than a body image concern but delved deeper into the manner that consuming food is conceived. Such stigma is a very strong social force that has profound consequences for patients and their status within their respective social environments. Combined with her interpretations of the teachings of Confucian and her familial beliefs, Madam T felt that both these interventions would leave her virtually house bound and isolated, unable to interact with others without the constant reminder that these tubes brought of her ‘abnormality’ and denied her the social benefits of actually eating (Chiu et al 2004, Oh et al 2004, Oh et al 2007, Kwok et al 2007, Payne et al 2008, Lai et al 2009, Chai et 2013).

Despite our best efforts and significant religious, familial and psychological support, Madam T remained unmoved highlighting that for some the cultural and social expressions of how food is consumed takes priority over other considerations.

Discussion

Regnant practice in many palliative care settings in Singapore remains one that would see the routine continuation of clinically assisted hydration and nutrition (CANH) unless medically contraindicated echoing the position taken by Singapore's Advanced Medical Directive Act (AMD) 2007. On the surface such a position acts to distance this legislature from the practice of euthanasia but in truth it also acknowledges the influence of prevailing sociocultural beliefs on the position of food and hydration at the end of life within the local setting (sec 17 of AMD Act 2010) (McCann et al 1994). Our case studies highlight this oft-neglected impetus for such a provision and reiterate the need to move considerations of withholding and withdrawing CANH beyond simple clinical considerations. No longer is it sufficient to balance considerations solely upon (1) access to CANH (2) the risks or grave inconvenience as a result of its application (3) the probability of intense pain or (4) costs considerations and or (5) deliberation of the intense fear or strong psychological repugnance on the part of the patient (Lynn and Childress 1983, McCann et al 1994). Wider sociocultural considerations too must be given fair weighting in these deliberations, beyond simply the explorations of possibility of extending life under humane and comfortable conditions, ensuring that any decision is in keeping with a patient's values about life and the way it should be lived and their likely reaction to sickness, suffering and medical intervention.[34] Ours case studies highlight the importance of familial, cultural and indeed the patient's own beliefs of food within such deliberations (Lynn and Childress 1983).

On a wider scale, these case studies highlight the need for continued attempts at situationalized care provision especially within an increasing acculturate society such as it is in Singapore (Ho et al 2010, Chai et al 2013). Here the continued intermingling of cultures and religious beliefs with personal values and goals make for very individualized patient centered care provision and reiterate the need not only for holistic appraisals of care but particularized balancing of care requirements.

Limitations

Whilst these cases do mirror a spectrum of clinical presentations and local attitudes towards food at the end of life care and do help explicate the rationale for Singapore's AMD Act, the lessons and conclusions drawn require further elucidation and wider study. This is particularly apparent given the diversity of cultural, societal, familial and religious differences present within this and many other South East Asian nations such as Malaysia, Brunei, Indonesia and Thailand.

Further whilst the conclusions drawn do appear to represent the majority view of the Chinese population in Singapore, a significant consideration that requires closer scrutiny is the influence of Confucian beliefs that do underpin this position. Whilst the cases of Mr T and Madam W highlight the continued dominance of familial led determinations that are drawn from Confucian beliefs and Madam T and Mr Z who continue to practice strong Confucian led beliefs evidence does suggest that rather than the homogenous view that is portrayed here, the strength and manner that Confucian beliefs are held differ significantly particularly in light of the growing influence of Western and Christian religious and ethical concepts. Similarly the infusion of other local beliefs and cultural values may also alter the positions taken by local patients and families on this matter.

Additionally the manner that care determinations were made in light of a lack of AMDs on the part of Mr T and Madam W and the subsequent employ of family led care determinations do not fully reflect a growing movement amongst patients and families to stipulate the manner that they wished to be cared for in the event of incompetence or severe frailty. Similarly Madam T's and Mr Z's respective choices to interpret their filial obligations thus, does not necessarily represent the dominant view of elderly Chinese patients reiterating the need for wider study.

Finally whilst all four cases did not suffer significant ill effects from the employ of these interventions, in reality side effects of prolonged hydration and NG feeding cannot be understated. As a result the conclusions arrived at by the physicians in the care of these four patients need not be reflective of the current views and general practices of palliative care teams as a whole in Singapore but ought to be seen as simply reflecting the treatment approaches employed for these specific cases based upon their particular conditions and psychosocial circumstances.

Conclusion

This case series has sought to explore the width of opinion regarding the employ of food at the end of life amongst palliative care patients and the influence of prevailing sociocultural sensitivities upon these deliberations to emphasize three key issues. The first is the importance of sociocultural awareness in care determinations and provisions. The second is that each decision made must reflect the particular considerations of the specific patient and their clinical context rather than be entirely led by prevailing sociocultural norms and values. Finally there must be balance between adherence to and respect for sociocultural beliefs in care provisions and ensuring that care provision remains within institutionally accepted, legally defined, professionally delineated and ethically acceptable standards of care so that the best interests of the patient are not compromised.

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