

The role of the multidisciplinary team in decision making at the end of life

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Abstract

Background: When a parent is dying, there can be significant disagreement in the means and the motives of the primary surrogate decision-makers. How does one resolve the conflict between meeting one's filial obligation, the social responsibility to maintain hope and not give up on the care of a loved one, and protecting familial interests? This case report highlights the diverse concerns plaguing holistic palliative care and the importance of the multidisciplinary team in complicated care settings.

Methods: We discuss the case of a family in which the members were discordant in their preferred plans for the care of an unconscious, terminally ill loved-one. One family member advocated a palliative treatment approach, and another was keen to attempt 'cupping', an alternative treatment option with potentially dangerous consequences.

Results: The role of the family in the deliberative process varies significantly, influenced by several factors such as the patient's age, their dependency on the family unit, and their role in the family. Healthcare professionals tend to focus on elements of patient care specific to their area of practice, and may neglect others.

Conclusions: In view of the variation in family members' roles in the deliberative process, appraisal of individual cases is needed. A multidisciplinary team may be able to better reach a balanced outcome by considering family biases, and any potential competing goals of individual healthcare professionals.

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Introduction

The role of the multidisciplinary team (MDT) is critical to the provision of holistic care at the end of life, particularly within the culturally diverse, socially complex, clinically complicated setting of terminal care in South East Asia. Yet, because of shortages in personnel and trained specialists, its employ within the South East Asian setting has been limited. This case report takes the example of the dissonance between family-centric and atomistic concepts within the East Asian context – specifically within the Singaporean healthcare setting. It highlights the diverse concerns plaguing holistic palliative care

practices and the central role of the MDT in meeting palliative care goals (1). Familial determination, the primary product of Singaporean family-centric practice, is considered along with other sociocultural factors, to highlight the difficulties faced by healthcare professionals in addressing holistic end of life care in Singapore. Furthermore, we highlight the role of the MDT in better meeting the needs of local palliative care patients in complicated care settings.

The discord between the indigenous family-centric ethical model, which prizes a person's relational ties and responsibilities, and the more atomistic Western ethical model that forms the backdrop for this

discussion, has been well documented in Latin America, India, Saudi Arabia, Japan, Taiwan, Hong Kong, China, Korea and Singapore [2-7]. Here, the conflict of the family-centric model has been widely discussed [8-12]. In this model, the family actively participates in the decision-making process, yet this is often at the cost of direct patient involvement in the determination of their care. The propagation of family collusion may sit diametrically to the individualistic views of Beauchamp and Childress' 'Four Principles', specifically that of 'Respect for Autonomy' [13].

Within the end-of-life care decision-making process, family-centric decision-making is seen primarily to buffer and protect patients from 'bad news', which is envisaged to hasten death; champion the wishes of the patient in the physician-patient relationship, which is frequently seen as being unequal; and protect the interests of the patient and the family in the deliberative process [7-12]. Little, however, has been made of the discord present within the socioculturally variable concepts of family-centric determination, particularly in the face of evolving social, cultural and religious beliefs that have begun to affect the overarching goals behind this approach [14-17]. These changes are frequently case-specific and context-sensitive, leaving healthcare professionals with little means of understanding the evolving variations that exist between individuals in terms of their conceptions of familial responsibility.

In addition, rises in the incidence of collusion, circumnavigation of direct patient involvement in their own care, and conflict between the interests of the patient and the family have merely compounded worries about familial decision-making. This makes an unpredictable guide for patients, their families and healthcare professionals as they traverse the difficult waters of end-of-life determinations [19-22].

As a result, balancing the various competing interests and considerations, which may have been previously subject to a hierarchy of importance within any deliberation, has become an increasingly difficult task within the end-of-life setting [10-12]. How does one resolve the conflict between meeting one's filial obligation, the social responsibility to maintain hope and not give up on the care of a loved one, and protecting familial interests, when there is significant disagreement in the means and motives of the primary

surrogate decision-makers? To highlight these concerns, we discuss the case of a family with discordant plans for the care of its unconscious, terminally ill loved-one: one member advocated a palliative treatment approach, while another was keen to attempt alternative treatment options. Such a position is not unusual. However, in this case the alternative treatment, which was 'cupping', had potentially dangerous consequences.

Cupping

While there are a number of variations of this 2000 year-old traditional Chinese medicine (TCM) therapy, including 'moving cupping', 'flash cupping', 'retained cupping', 'needle cupping' and 'medicinal cupping', the most frequently employed forms within local practice are wet or dry cupping [23-25]. In dry cupping, an earthenware, bamboo or glass cup is applied to selected accupoints on the skin, and the skin is gently drawn upwards into the cup by way of creating a vacuum. Wet cupping involves the additional step of making small incisions in the skin, such that blood is drawn out when the suction cup is applied [23-25]. Cupping is used in diverse clinical considerations such as the treatment of acne, lumbar disc herniation, cervical spondylosis, dyspnoea, herpes zoster, Bell's palsy, and cough [23-25].

A recent systematic review revealed that determining the efficacy and safety of this procedure, in the face of a heterogeneity in the methodology and settings, is difficult [23-25]. Saliently, within the context of the case presented here, specifically a patient with Stage 4 diffuse large B-cell lymphoma, Tazi et al. [25] commented that the application of cupping within the realms of haematological malignancies raises concerns with regards to both the efficacy of the procedure, and its risks, which include infections and bleeding.

Here it is the concerns about the modality of cupping and the decision-making process with regards to the care of an incompetent patient – in a society that has, at least in part, embraced the Best Interest Principle (BIP), which frame the case for the wider use of an MDT approach in family-centric societies [26,27]. Drawn from the Mental Capacity Act, the BIP seeks to provide a holistic assessment of the particular

patient's situation and set out the overall goals of care for the patient [26,27].

Case report

Consider the case of a 74-year-old Malay man who had suffered a relapse of Stage 4 diffuse large B-cell lymphoma six months after being declared to be in remission following aggressive chemotherapy. Presenting with bone marrow and cerebral involvement, he deteriorated rapidly and further chemotherapy was deemed unsuitable.

The patient was married with four adult children. The eldest son held TCM in high regard and was keen to pursue alternative treatments including cupping and the consumption of Chinese medicines. His wife, on the other hand, was keen to employ conventional palliative care treatment methods. These contrasting positions created a number of concerns.

Firstly, the dispute between mother and son was complicated by differences in opinion as to who was the main decision-maker. The patient's considered the main decision-maker from a legal perspective, while from a religious perspective, the local Imam maintained that the oldest son should have that responsibility. The patient's other children were divided in opinion.

As a result of these differences, there were three key considerations in this patient's case. The first regarded the matter of deciding who should be the primary decision-maker in a society that still tends to defer to the family on end-of-life matters, particularly when the patient himself is unable to make his decision known, and has not previously designated a proxy. The second consideration, from a medical point of view, regards whether cupping, replete with its risk of haemorrhage – particularly in a patient with thrombocytopenia from marrow failure – ought to be proscribed. Thirdly, if, as would be expected, the medical team strongly recommended against the use of cupping, should the family be allowed to take the patient home? In this situation, the patient's safety likely to be compromised since cupping may be administered once discharged from hospital.

The lack of evidence on the efficacy and safety of cupping and the potential risks of bleeding led to a

request of the TCM practitioner to discuss their treatment plans with the medical team. The TCM practitioner declined this offer and was resistant to discussing the matter by telephone. As a result, further discussions were held with the patient's family, bringing into focus the issues of the decision-making process. Indeed, while it might be argued that, in the case of an incompetent patient, care decisions ought to be determined using the BIP, as stated by the Mental Capacity Act, in truth local physicians still defer to the family for such determinations [26,27]. Aside from being a part of local lore, reliance upon the family for end-of-life determinations also seems to be led by practical considerations [10,11].

This is particularly evident in Singapore, which employs Confucian ideals in its national ideology of 'shared values'; this has further imprinted the role of the family "as the basic unit of society" across all races within this cultural melting pot [29-31]. Furthermore, the statutory obligation on children to pay maintenance for their parents and the use of means testing of the family, rather than the individual, in the disbursement of funds by the Medical Endowment Fund, act to reinforce a transcultural view of the primacy of the family unit within this multi-religious, multicultural nation [32-35].

It is unsurprising then, that Foo et al. [36] found 59.9% of Singaporean healthcare professionals would overturn the previously stated wishes of a now unconscious patient in favour of the wishes of the family. Ching et al [37] also found that only 9% of alert, terminally ill patients within a Singaporean health facility were involved in their own end-of-life care plans. Krishna [10-12] explains that dependence upon the family unit and the circumnavigation of direct patient participation in their own care, may be explained by the presence of a wide application of collusion within the local health setting. This collusion is largely driven by the wish to maintain hope and protect loved ones from 'bad news' that may be detrimental to their health.

In many cases where the patient is no longer competent, healthcare professionals maintain this approach to care determination despite the institution of the BIP for such circumstances. In some cases this creates a situation where the family members are unable to agree upon the next course of action. In the

present case, the situation is further complicated by the potential danger to his health from the cupping treatment advocated by the patient's son. Being cognizant that the hospice would not allow cupping within its premises, and that hospital discharge would not be viable given the lack of daytime care for the patient, the son was keen for his father to be permitted day leave. It was clear, in this case, that cupping appointments would be made during these periods of day leave.

Applying an MDT approach to the appraisal of this patient's situation, the palliative care team considered the lack of evidence for the efficacy of the treatment, the risks of cupping to a patient prone both to bleeding and infections, the resistance of the rest of the family towards TCM, and the lack of evidence that the patient himself would have wished to undergo cupping. The decision was made, in the patient's best interests, to deny day leave and cupping on the hospice premises. The reasons for this decision were explained to the family, and more innocuous TCM options were offered, as well as a number of alternative practitioners from whom the son could seek second opinions as to the viability of cupping as a treatment for his father.

Initially, despite the MDT's explanations and now opposition of all other family members, the son remained adamant to pursue the cupping treatment. However, after realising that other TCM practitioners would not advocate this procedure for his father, in the face of resistance faced both from his family and the MDT, and the lack of cooperation from his own TCM practitioner, the son's request was rescinded. In later discussions the son accepted that the treatment he proposed was not in his father's best interests but had represented his own needs to meet his filial obligations.

Discussion

Much has been said of the inadequacies and limitations of Western-inspired atomistic principles when applied to the local context where family-centric views dominate. Conversely, little has been made known of the issues surrounding the family-centric model. Rather than being a homogenous concept, family-centric views – within a local setting that itself

is evolving in light of changes in social, cultural, religious and practical considerations – have been shown to be composed of diverse stands. Consequently, the role of the family in the deliberative process varies significantly, influenced in part by the patient's age, their dependency on the family unit, role in the family, illness, cognitive function, psychological makeup and beliefs, as well as those of the family members to their filial obligations. Variance in the strength of the family determination is also subject to the psychological make-up, beliefs, values and goals of the various family members involved, as well as the quality of the relationship shared between individual family members and the patient.

Such variances require a case-specific appraisal of each individual case. In the case presented here, the possibility of a breach in the basic standard of care, risks to the patient, the prevailing indecision amongst the family members and concerns about the psychological and spiritual state of the family members, require wider oversight and tampering of the deliberative process, and marshalling of standards by the MDT. This is likely to occur more often, given growing concerns that 'familial obligations' are directed more to the interests of the wider family in meeting their filial obligations by 'battling' the disease and not giving up hope, rather the interests of the patient who may have wished for goals of comfort and dignity in the final stage of care. Additionally, there is a suspicion that individual family members may have particular interests with regards to the fate of the patient in a society, which leaves the major portion of the patient's financial, psychological, spiritual and social care to the family. In such circumstances the role of the MDT becomes clear.

The case presented here reaffirms the importance of these considerations, and affirms that in the light of the patient's incapacitated state, the duty of the medical team ought to be focused on maintaining the best interests of the patient. This seems particularly important within a palliative care backdrop that prides itself on its holistic and family-inclusive approach. Here, this inclusive approach cannot be seen to be compromised by the team's sensitivity to the social and psychological needs of the family member, nor can it be hijacked by a wish to maintain a good working relationship between the team and the family;

in this case by agreeing to the use of cupping in the hospice, or the sanctioning of day leave.

This case highlights the importance of the MDT approach in monitoring the nature of care provision and the manner that it is delineated in discussions. The MDT is seen as the point of ‘balance’ to various ideas, opinions and the varied perspectives of all involved in a patient’s care. It also serves to determine the multitude of care and support issues within the locus of concern of a particular patient, in order to provide a holistic view of the situation. Much of this aspect is to ensure that all decisions made by the palliative care team are well-considered, equitable, effective, accountable and focused upon providing the patient and their families with the best and most appropriate care, as determined by their individual circumstances.

Through the appropriate consideration of both clinical and psychosocial issues, as well as the values, cultural and spiritual matters relevant to the patient, decision-making and care provision will move beyond a purely clinically orientated approach to one that is in keeping with the central tenets espoused by palliative care. Through open discussion underlined by professional respect and courtesy, a platform for considering the myriad matters pertaining to the case is allowed a voice and duly considered in among the other determinants of care provision. By seeking a consensus decision and engaging all members of the team, it is believed that single considerations, individuals or perspectives will not influence the MDT. Each aspect is weighed up against the particularities of individual cases, given a certain ‘weight’, balanced, and then a decision is taken. Within such a model, ‘weight’ refers to the importance and pertinence a specific matter holds within a deliberation. It should be noted that the importance of any element within the discussion is determined by the clinical, psychosocial and spiritual context of patient and their family’s situation, rather than by the seniority or ‘vocal tenacity’ of a member of the MDT. Thus there are times at which the input of the physician is not the most important. For example, in cases with significant psychosocial considerations, the pivotal input might be that of the medical social worker.

Given the width of consideration and the variability of individual factors to each specific aspect, it is logical

to envisage that an MDT, rather than an individual member of the health profession, is better equipped to elucidate the priorities in each case.

The various specialists that make up an MDT are able to focus on different elements of care, allowing the MDT as a whole to better understand the individualized beliefs of respective parties connected with the patient’s care. This is particularly important within the end-of-life setting. For example, in the studies of Ching et al. and Foo et al., which explored the practices of palliative care and oncology specialists, a relative intransigency is revealed among medical practitioners to move towards a patient-determined care approach. This may reveal personal views on family-centric values, or simply pressure from the family to comply with their decisions [36,37]. Furthermore, Yang et al. revealed that many healthcare professionals tend to focus on specific elements of patient care [38]. For example, physicians tended to focus on clinical considerations, while nurses focused upon the psychosocial aspects of care [38]. An MDT is best able to deal with this bias, particularly in the face of so many goals and competing intentions, securing unanimity in the decision-making process and assuring as far as possible that all matters are well considered and a balanced outcome is reached.

To aid this process, the narrative of patients and their families becomes pivotal in meeting the goals of individualized care. Given that narratives appear to be situational and listener-dependent, the members of the MDT may best capture these differences in understanding and interpretation, since they care for patients in different stages of illness and in various settings. The appreciation of these facets is crucial, as is the assimilation of narratives and nonverbal aspects of such communications, which are best understood by appreciating the various elements of social, cultural, religious and personal values upon which these statements are made.

Conclusions

Family-centric ethical frameworks are evolving on an individual basis and thus require a particularized view of each family’s deliberative process. In the face of competing interests, the family may be pulled in

opposite directions and it is the duty of the medical team to help maintain calm and stability. The deliberative process involving an unconscious patient must revert to the best interests principle as determined by a MDT, which allows for better balanced deliberation and decision-making, particularly within the emotionally charged setting of the determination of end-of-life care.

Early involvement of the MDT will better aid the deliberative process and better facilitate transparent and accountable decisions that do not compromise the patient's interests or care. While the MDT must be sensitive to the cultural and familial beliefs, values and interests, it is integral that the patient's needs and interests are not compromised.

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