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Lalit RK Krishna

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Lalit RK Krishna

National Cancer Centre, Singapore

Abstract

Familialism is a significant mindset within Singaporean culture. Its effects through the practice of familial determination and filial piety, which calls for a family centric approach to care determination over and above individual autonomy, affect many elements of local care provision. However, given the complex psychosocial, political and cultural elements involved, the applicability and viability of this model as well as that of a physician-led practice is increasingly open to conjecture. This article will investigate some of these concerns before proffering a decision-making process based upon a multidisciplinary team approach. It will be shown that such a multidimensional and multiprofessional approach is more in keeping with the inclusive and patient-centred ethos of palliative care than prevailing practices. It will be shown that such an approach will also be better placed to deliver holistic, coherent and sensitive end-of-life care that palliative care espouses.

Keywords

Best interests, palliative care, familialism, Singapore, end of life

Introduction

Family orientated thinking cascades through the multiracial, multireligious and multicultural groups of Singapore to varying degrees.^{1–40} Loosely grouped and described as familialism such a mindset espouses the ascendancy of family interests over those of the individual.⁴¹ This in turn has significant connotations within the sphere of health care where the effects of familialism are felt through the practice of familial determination. Under this aegis, the family unit becomes the main arbiter of a patient's care needs, sometimes to the detriment of a patient's right to self-governance. Under this framework, the family divine significant influence upon the decision-making process of patients particularly those at the end of life.^{1–44} While believed to be inspired by the ideal that the family will act to protect and indeed advance the patient's best interests, the complexities of care considerations within Singaporean clinical practice have given pause for thought. Reliance upon physicians, the legal custodians of patient care, to tamper such decisions too, have been shown to be wanting. It is upon this background of familial led paternalism and cloistered medical oversight that this article seeks to venture a solution to prevent the continued relegation of the rights of the patient within end-of-life care determination in Singapore. In its place, this article proposes the requisite involvement of multidisciplinary teams within all end-of-life determinations as a better means of securing a holistic appreciation of a patient's best interests abetted by a framework designed to allow for cultural,

social, religious and local variances. To be clear, the Singaporean situation is complicated by not simply a familial centric approach but a complex interplay of clinical, cultural, social, ethical, religious and economic contemplations as well as prevailing health-care financing policy that needs to be clarified in order to state the basis of this posit.

Palliative care within the Singaporean setting

In order to crystallize its position, this article will focus its attentions upon local palliative care patients. To begin with some understanding of palliative care services in Singapore is called for. Local palliative care services, which began in 1985, is fashioned upon the Saunder's model of holistic end-of-life care and now sits at the forefront of palliative care services in the region.⁴⁵⁻⁵¹ Much of this success and progress have been largely due to forward-thinking governmental policy ably supported by voluntary organizations and the employment of an economically astute shared funding approach to health care.⁵¹⁻⁶¹ A recent Economist Intelligence Unit's Quality of Death Index acknowledged this success by awarding local end-of-life care provisions with a respectable standing in its rankings.⁶² However, such a health-care system is not without drawbacks, a situation compounded by the presence of varying sociocultural and religious practices.⁸⁻¹² A major consideration within this milieu is the impact of 'Asian Values'.

Asian values in decision making at the end of life in Singapore

'Asian values' adopted by all the major local races and transmitted by local governmental policy are drawn largely from the regnant family centric thinking.^{14-40,51-74} Indeed, the central framework of such policy arises from a Confucian reflection of the family position. Nonetheless rather than a wholesale import of Chinese nomenclature and taxonomy, this article will use comprehension of these facets from recently attained local clinical data to define and guide consideration. Indeed, much of the Chinese and specifically Confucian precepts have evolved over time, influenced in part by local and western thinking that has culminated in a nuanced understanding of familial role and practice. Although a multicultural, multiethnic and multireligious nation, Singapore's population is dominated by the people of Chinese descent.⁷⁵ Making up the biggest proportion of the remaining 25% of the inhabitants is indigenous Malays and the people of Indian origin.⁷⁵ Presiding over this culturally and religiously inclusive meritocracy is a government that has sought to embrace and instil within its policies a distinct flavour of these Asian Values.⁷⁵⁻⁸⁶

Within this formulation, the interests of the family unit are prime. Here the 'horizontal' aspect of this familial centric formulation envisages the individual as being part of a greater unit, and it is the interests of the family unit that sit at the fore of any consideration. As a result of this interconnectedness, any ill fortune that befalls a family member is seen to reverberate through the unit as a whole.⁷⁰⁻⁷² It is argued that as a result of this ripple effect and the ensuing implications upon all the members of the family, they retain the right to participate in any decision-making process.⁸⁻¹²

Such a stance puts this Confucian inspired concept at odds with the western ideals of informed consent for four reasons. First, decision making becomes the express domain of the family as a whole, usurping the ideals of individual choice and self-determination so ardently promoted by western ethics.^{8-13,15-40,44-50,63-71,76-88} Second, the decision-making process could and does frequently dispense with the involvement of the patient as a whole.^{8-13,15-40,44-50,63-71,76-88} Third, even when patients are allowed to participate in the deliberative process, it allows and even endorses external influences particularly from the family. Such a stance leaves the decision-making process open to coercive factors that may frustrate or inhibit the patient's best interests.^{8-12,87,88} Fourth, this convention of partial and indeed no patient involvement in the deliberative process also propagates the practice of collusion, which significantly impacts treatment positions, interventional choices, care approaches and end-of-life practices locally.^{8-13,15-40,44-50,63-71,76-88}

Collusion is indeed a common feature in local clinical practice as a result of the belief that ‘staving off bad news will nourish hope and starve death of an early victory’.^{8–12,88} Collusion appears to stem from the belief that the family as whole is better equipped to deal with difficult situations and more adapt at adjudging the potential response and effects of the news upon the patient.^{8–12,88} This in turn leads to contention between familial collusion to protect the patient from ‘bad news’ that could potentially dent them to resolve and exacerbate their condition and efforts to respect the patient’s autonomous rights.^{8–12,88} In practice, it is the former that prevails and has led to the common praxis of limiting the involvement of the patient within the decision-making process and sometimes excising them completely from such considerations.^{8–12,88}

To be clear this, stark dichotomy arises as a result of the family unit’s continued role as the main providers of physical, emotional, spiritual and financial support for patients in the presence of both familial and sociocultural expectations.^{8–12,88} Parallel to and feeding into this expectation is the cultural and social belief that espouses that the family must act to ensure the maintenance of hope and the prevention of despondency and distress that is envisaged to bode poorly upon a patient’s outlook.^{8–12,88} This contrasts abruptly with the physical, emotional and financial demands placed upon the family that may engender a conflict between the patient’s interests and those of the family.^{8–12,88}

Patients too, frequently acquiesce to this state of affairs as a result of their ingrained beliefs and the idea that it is the family members, invested with their best interests, who will have to bear the burden and consequences of any undertaking.^{8–12,88} For some Buddhists and Taoists, deferring to the family is to be expected and indeed encouraged given an underlying belief that discussions about death and dying are considered inauspicious and even regarded as taboo.^{1,2} Here acceptance of familial determination is preferred.

It is important however to point out that rather than suggesting a homogeneity in the interpretation of traditionally held concepts, local audit data and increasing clinical experience appear to allude to the presence of significant variability in perceptions, transmission, practice and understanding of these family centric ideals amongst the races and even amongst family units.

Health-care financing as a rationale for family decision making at the end of life

One source of such variability in practice and one that has also been used to advocate persisting with family involvement in care deliberations have been the continued financial involvement of families in the care of patient. In reality, finance is but one of the greater considerations brought to bear in abjuring to the present dependence of familial determination. To begin with, Singapore practices a form of health care financing that see patients and the government entering into a co-payment scheme. Here despite heavy subsidization of costs, some expenses are being borne by patients and by default the family.^{8–13,25–40,51–61} To begin with, costs are recovered from a patient’s Medisave account.^{51–61} All working Singaporeans contribute into an individual pot of money that is designated for the cost of his or her medical costs, called Medisave, which becomes the first avenue to tap on as source of payment.⁶¹ When this is exhausted, family members can elect to draw on their own Medisave accounts to pay for the care of their loved ones. However, neither Medisave nor Medishield, the governmental health insurance policy, covers all care expenses.⁶¹ ‘Top ups’ that are required are sometimes passed on to the family. The implications of such a shared responsibility health policy have sometimes led to particularly fractious and inconsistent decision making and as a result have raised fears of the patient’s best interests being compromised.^{8–12,25–40,88}

Position of the family and physician

Clinical practice in Singapore has adapted itself to the significant influence of patient’s families in delineating care approaches and goals of care, particularly at the end of life.^{1–13,15–40,63–71,76–92} Superficially, such

praxis could be said to be in the embrace of the central palliative care ideals of commensurate consideration for family and patients in its provision of holistic care.^{93–95} Deeper scrutiny aided by clinical evidence and experiential reports portend to a mismatch within this dichotomy frequently to the diminishment of patient autonomy and the hampering of their best interests.^{8–12,25–40,88} The effects are extensive ranging from collusion and partial disclosure of information in breaking bad news and discussions of future care to interference in the treatment decisions and the execution of a patient's best interests. The position of the family within this deliberation is complex.^{8–12,25–40,88} On the one hand, there is a social and cultural expectation to ensure the interests of the family while, on the other hand, there is the belief that imbued with the intimate knowledge of the character, emotional, psychological, spiritual and cultural narratives, values and beliefs of the patient and led by the dictates of familialism, the family will act to secure the best outcome for the patient.⁴¹

The combination of these factors and the 'family-first' attitudes evinced by prevailing sociocultural beliefs has impacted care provision locally.^{1–13,15–40,63–71,76–92} Veritably, there have been an increasing number of families who have shown a tendency to override medical advice in pursuit of their own, sometimes questionable goals, leaving it pursuant upon health professionals to arbitrate upon its acceptability and viability.^{8–12,88} Yet while it may be argued that families are ill equipped to cope with such duty and do on the surface make some decisions that appear biased or influenced by a wide range of economic, social, religious and cultural considerations; the credibility of physicians in the role of chief scrutineer within this decisional process is also not above reproach.

Here the influence of the 'professional judgment' model occupies a pivotal place in considerations of patients and families alike despite concerns of it being a reversion to a frequently misemployed *parens patriae* approach. Lacking accountability and reproducibility within the decision-making process, this practice has been seen as a means of 'rubber stamping' predetermined clinical decisions made by physicians who frequently employ a blinkered approach to appraisals.^{8–12,88,96–108} Indeed, in the recent study carried out at Singapore General Hospital, physicians, unlike their nursing colleagues, tended to be clinical rather than holistic in their appraisal of a patient's condition. This is especially worrisome given the premier position, local physicians enjoy as in local practice. Physicians within the local scene are frequently the singular source of medical opinion and the main determiners of a patient's quality of life (QoL), best interests and care stances, which from clinical experience and experimental data has been shown to appear narrow and detached. It is for this reason that this article holds to the pivotal place of the multidisciplinary team in such deliberations for its ability to gauge a thorough and context-dependent appreciation of the patient's situation and act in order to actualize better service of the patient's best interests.^{109–113}

Multidisciplinary team

The multidisciplinary team that may be seen as a 'group of people of different healthcare disciplines, which meets together at a given time (whether physically in one place, or by video or teleconferencing) to discuss a given patient and who are each able to contribute independently to the diagnostic and treatment decisions about the patient' as well as to elaborate upon the various biopsychosocial, spiritual and cultural determinants that may be relevant to the provision of care and support to patients and their families.¹⁰⁹ Within the context of this article, multidisciplinary teams are tasked with providing holistic care and improving the QoL for both patients and their families facing life-threatening illnesses.^{109–113} This necessitates a wide and varied approach to the assessment and treatment of physical, psychosocial, cultural and spiritual factors within the specific context of a case. This wide angled appraisal of goals of care and personal wishes also allows for the provision of support at all stages of illness and for the family, beyond this difficult time. The infusion of narratives, pregnant with their own individual understandings, elucidated from various sources in different settings by various members of the multidisciplinary team, only serves to add insight and

specificity into the proceedings. Multidisciplinary teams also meet their central role of arbitrators of dissenting voices between team members and a means of soothing any biases that may exist in the deliberations of a team. Through this work ethic, a multidisciplinary team would also ensure that there is proportionality in action and response to individualized care needs based that is context dependent.^{109–113}

It is difficult to envisage a singular health-care professional elucidating such an individualized, balanced and thorough approach to care of the patient and family. It is thus unsurprising that good palliative care appraisals continue to be met by teams of professionals entrusted with clear roles within a multidisciplinary team. In utilizing expert knowledge that encompasses a myriad of specialties ranging from nursing care, psychological and pastoral support to occupational therapy, physiotherapy, financial advice and social support, palliative care teams are better able to minister to the various aspects of physical, spiritual, psychosocial and cultural elements that constitute a holistic approach to patient and family care. This multifaceted multitalented multitrained complementary and interdependent approach has since been validated in a number of settings and found to be effective in meeting the goals and complex needs of palliative care patients and their families.^{109–113}

Best interest principle and the multidisciplinary team

In order to proceed towards proffering a better means of protecting the interests of the patient particularly in a cultural context that does not always recognize the needs, beliefs and values of the individual, this article adapts the definition of best interest principle proffered within Singapore's Mental Capacity Act (MCA) 2010.¹¹⁴ It is supplemented by the English variant of the MCA, the General Medical Council (GMC)'s decision-making guidance within its 'End of Life Care Guidance – adults who lack capacity to decide' and Singapore Medical Council's Ethical Code to the specifics of local end-of-life decision making.^{114–116} Underpinning this definition of Best Interest Principle is Principle 4 of the MCA that calls for unbiased, holistic and objective assessment of the now incompetent patient's best interests taking into account any previous narratives, wishes, feelings, beliefs and values in enacting the best course of action for the specific patient who has not left an Advanced Medical Directive (AMD), a living will or a written statement of their choices and wishes.¹¹⁷ The minimum threshold for these decision-making processes is that of a 'reasonable person threshold' where decisions made are compared to 'what a reasonable person' might choose.^{114–117} Such analysis would clearly benefit from a multidisciplinary team approach where this determination must necessarily consider matters both clinical and nonclinical and to a depth and range required to best mirror the patient's specific circumstances, views, values and wishes.^{109–113,118–129}

Indeed, in order to carry out such complex balancing of various considerations, weight or value to each of these facets should then be assigned based upon the specific context of the patient's situation and a benefit-disbenefit analysis carried out for each option proffered. Here each option is reviewed upon objective, rational, complementary and dispassionate analysis to ascertain, which treatment modality will produce the greatest benefit that can realistically be provided to the patient. Such a conclusion guided in part by Krishna and Chin's ideal of the Duty of Palliative Care is then deemed to be the option that represents the best means of realizing, protecting or advancing a patient's best interest.^{8–10,117–128} This determination needs to take a nuanced view of the situation within the particular context of the patient's condition to determine the value ascribed to each of these facets. In turn, it assuages linking the determination of value or weight to a thorough and holistic assessment of the patient within their specific context while maintaining a 'minimum threshold of acceptable care' that ideally ought to be determined by the patient in concert with their family, carers and health-care professionals. This convention appears to be a means of considering the 'value of the life for the person who must live it' and must meet the 'reasonable person threshold'.

Thus, it could be said that this article forwards a position where the strong paternalism provoked by family-led decision-making process is simply replaced not by physician-led paternalism but by a flexible

and reflexive decision-making process that is consensus based and rooted in a multidisciplinary team approach. Here responsible, reproducible and accountable decision-making act to better ascertain that primacy is given to a patient's well-being. Grounded upon the need for a well-balanced deliberative process, this inclusive and context led process allows for flexibility of religious, psychosocial, cultural and financial considerations specific to the patient's individual situation to be given adequate deliberation. Conflicting conceptions of best interests forwarded by the various parties within this deliberative process are tampered and balanced within this larger deliberative body. Here it is the well-being of the patient as determined by the MDT that is given primacy particularly in light of the acceptance of the terminal nature of the illness, a waning of curative options and a shift of goals of care toward maximizing comfort.⁸⁻¹²

Best interest principle within the Singaporean context – a case study

Consider the case of Soi Lek, a 77-year-old Chinese man with suspected lymphoma. Given his frail state, physicians caring for him were keen to allow him to be discharged home as his family wished after it was determined in a family meeting (that did not include the patient himself, at the request of his family) that his best interests would be best served if he was not to undergo further investigations and treatments for his underlying complaint but instead be provided with symptomatic and palliative care. Indeed, throughout his admission, Soi Lek was not compliant with medical examinations nor investigations and had frequently voiced his wish to be discharged home, although he never elaborated as to why he was desirous of discharge nor why he was noncompliant with his medical care. His family declared that he had never liked hospitals and was very resistant to this admission but acquiesced to his son's request when they found that they could no longer manage his growing symptomology and care requirements at home. The family who anticipated a remedial cause for his suffering was shocked at the discovery of his underlying malignancy and felt that he was not able to cope with the knowledge of his diagnosis.

However, it was clear to the nursing staff caring for him that there were other factors to be considered particularly as so little of his psychosocial history was known. Indeed, they ascertained that while Soi Lek had been living in Singapore since independence, he had not altered his Malaysian nationality. This left him classified as a foreign national for the purposes of health-care financing and thus not amenable for local governmental subsidies towards his medical expenditure. As a result, his family was keen to reduce their financial liabilities incurred by his continued stay in hospital and sought to take him home despite being aware that there would be little support and care for him for much of the day as his children worked long hours leaving him home alone.

Highlighting these issues during a team meeting resulted in a significant change in treatment stance. In true Multidisciplinary Team style, the medical social workers attempted to uncover more about Soi Lek's past and found that Soi Lek had a forensic history and was involved in the Malayan communist movement. He was fearful that should he apply for citizenship, the Singapore government would deport him. Having clarified his legal status and put his mind at rest that there were not outstanding arrest warrants on him, the medical social workers managed to secure private sponsors to cover part of his medical bills and also managed to get the hospital to agree to waive some of its costs. With these financial support in place, a further family meeting was carried out during which time it was agreed that Soi Lek ought to be involved in the decision-making process and that he should, should he chose to, undergo further investigations and the option of treatment. Consequently, Soi Lek underwent chemotherapy to good effect and managed to survive a further 18 months with 'reasonable', as he described, QoL. As he deteriorated and his care needs increased, he was transferred to a local hospice where he was cared for until his demise.

This case highlights not simply the need for holistic appraisal of a patient's situation but also the need for a multidisciplinary approach. Here the confluence of nursing, social work and lay preachers brought the

matter to light and provided a viable solution that benefited not just Soi Lek but his family as well. Clearly, good care cannot come from continued focus upon the clinical facets alone but upon the care of the patient and their family as well.

Best interest principle checklist

Soi Lek's case replete with its many social, cultural, legal, financial, ethical and clinical considerations highlights the difficulties that palliative care professionals face in deliberations. Indeed, in the face of a myriad of considerations and sometimes conflicting obligations, some elements within the deliberation will undoubtedly take centre stage while others may be relegated in importance or even ignored. In order to aid appropriate deliberation of all these facets, this article will proffer a best interest principle checklist to aid with ascertaining the needful but that still requires petitioning to the respective contexts of the case.

This checklist is neither a new means of deciphering best interests nor a means of replacing prevailing decision-making models given the diversities of cultural, social, spiritual and physical considerations. It is merely a list of items that ought to be considered in any decision-making process in order to make it clinically relevant, culturally pertinent and ethically sensitive. The following facets are thus given credence within this checklist¹⁰²:

1. The strength of held values and wishes when the patient was competent
2. The strength of held values and wishes presently
3. The strength of held beliefs and wishes of the family
4. In order to elucidate the frequently misunderstood and poorly delineated phrases and terms and their bearings within this determination, strength is used to provide some determination of accuracy and validity to these considerations. Such determination needs to be carried out through excellent communication skills, sensitivity and with a good appreciation of the background of the patient and their families¹⁰⁹⁻¹¹³
5. The status of the patient's current condition and the likely effects it may have on the patient both presently and in the future
6. The potential effects of abiding by these wishes upon the patient and their families both presently and in the future
7. The weight or value to be placed on each of these concerns after a holistic assessment and discussion with the team, the family, other allied professionals and other stake holders whose names and inputs need to be clearly documented
8. The methodology and rationale for the determined means of maintaining and forwarding the best interest of the patient need to be clearly stated as should the rationales for the discarding of other options reviewed

Conclusion

The determination of a patient's best interests particularly at the end of life within the complexities of modern multicultural, multifaith societies is difficult. These deliberations are compounded by attempts to straddle traditional culturally inspired roles and beliefs with modern duties to patient-centred care. Vacillations between forms of medical paternalism and familial determination have been observed to merely complicate the situation further. It is proposed that rather than opting for either of these antiquated models, this role would be better met by the use of a multidisciplinary team whose inclusive and accommodating approach is better equipped to garner a holistic appraisal of the patient's condition, determine their goals of care and proffer support for the family in a objective, rational, complementary, dispassionate and individualized manner.

Aided by the loose framework suggested within the Best Interest Principle checklist, a comprehensive assessment can be meaningfully facilitated by the multidisciplinary team in the face of individual clinical, cultural, religious and social circumstances. It is hoped that within nations increasingly embracing multiculturalism, this framework will better meet increasingly heterogeneous communities such as that seen in Singapore without losing sight of the inherent individuality of each patient and family. Experience from hospital, hospice and home care settings in the United Kingdom would attest to this need to consider the thought processes, values and beliefs of a wide variety of cultures and ethnicity. Here patients as far and wide as Africa and the Asian Subcontinent for instance do not always subscribe to the regnant medical ethic giving rise to tensions. Through this proposed framework, it is hoped that the needs of these patients are not simply sidestepped or down played but met with the same vigour and rigorous consideration as other aspects of their care needs. The challenge it would seem is maintaining order in such flexibility and inclusiveness.

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Conflict of interest

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