

Looking Beyond Life, Death and Dying

An Asian Perspective

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The poignant reflection by Margaret (see page 18) strikes a familiar chord with many of us who deal with the terminally ill. The reflection is a collective narrative of the issues we face in our daily lives in dealing with death, including dilemmas in care, extent of care, conflicts within us, and pain and sorrow, among others. More importantly, the narrative brings the patient with illness to the centrepiece of discussions. Such discussions then affect our decisions and their downstream implications.

Many a time, we provide aggressive care and treatment truly with the belief in its appropriateness and consistency with our own values. Sometimes, however, we are influenced by fear of litigation, guideline recommendations, peers' practice, our own religious and cultural alliances, the financing model and insurance coverage. We are indoctrinated to think that doing everything we can do within our means for the patient is the way. In the process, we sometimes ignore the paradoxical outcome in which our best intentions may not be congruent with the patient's values, preferences or goals. Balancing futility with quality of life remains difficult impasses we encounter, however much we believe our medical training helps us. As physicians, we may like to take heed of Atul Gawande's warning: "We've been wrong about what our job is in medicine. We think our job is to ensure health and survival. But really it is larger than that. It is to enable well-being."

As glowingly illustrated in these candid revelations – life and death are not just distinct entities in itself, but represent a spectral journey punctuated by a "dying process". We hold many conversations with family members and carers on end-of-life care in the course of our practice, but this beautifully written reflection from a loved one's perspective helps us to truly understand and shift our focus to pertinent issues on the dying, death and the care we

provide for our patients and their loved ones. We'd like to highlight some of these below.

Stigma of death and conversations on ACP

The reluctance to discuss death stems from a variety of motives with roots from our cultural and social value system: our unpreparedness to discuss about uncertainties, not wanting to traumatise our loved ones, fear of a consequential family dispute, yielding to unaccomplished desires, or even feeling bad about delegating unfinished work to the living relatives. As much as it seems easier to avoid discussion on these issues, it is worth reminding ourselves that non-discussion can make issues after death even more complex if the important contribution of the patient is left out of the equation. The Institute of Medicine has identified good clinician-patient communication as well as effective shared decision-making as components of a high-quality end-of-life experience.

Advance care planning (ACP) was introduced in Singapore in 1996, represented by the Advance Medical Directive Act. It is a continual process as values, wishes and conditions may change with time. It serves as a guide rather than the rule of the thumb. It also serves as a portal for patients to come to terms with their declining health and death. Studies have suggested that most patients with serious illness do not fully appreciate its progressive nature and incurability.^{1,2} Prior to ACP and the discussion of goals of care, it is imperative that the patient/caregiver appreciates the extent of illness and the likely progression trajectory.

ACP is a tool to engage the patient in deeper conversations and remove the stigma of talking about death. It also allows the family members to understand the values and wishes of the patient, removing the burden of decision-making and second guessing.

Paternalism vs mutualism

The doctor-patient relationship has shifted the pendulum from paternalism to one that places emphasis on patient autonomy and acknowledging that every patient has the right to choose the treatment he/she wants, as an informed decision. A mutualistic approach to discussions on death and dying has significant benefits for the entire family and community at large. To leave dealing with death entirely in the minds of physicians or in the hands of patients and/or their relatives is unfair. A mutualistic approach offers a good balance where the physician shares the burden of decision-making with his patient, through careful deliberation and collaboration.

With our population growing older and with multiple co-morbidities, it is inevitable many will grow old with deficits, disabilities and limitations. Early initiation of conversations on one's wishes will help their loved ones significantly, while accepting that they are given the right to change their minds at any point in time – provided that the decisions are medically sound and relevant to the patient's condition. We are seeing a shift from the paternalistic approach to a more mutualistic and consultative relationship. Either way, we continue to uphold the medical oath – protecting our patients from harm, benefiting them and guiding them in their decision-making.

No doubt, physicians have the continuing dilemma of precisely defining what "futile care" is. Patients and/or their relatives may have different perceptions of futility from medical professionals, leading to profound disagreements and conflicts. McCabe and Storm³ have suggested addressing three major issues that include goals of treatment, likelihood of achieving the goals, and risk benefits and alternatives of treatment options. They also suggested that discussions on these should be initiated early and there should

be ongoing communication with careful attention paid to not mislead the patient. Despite the best communication efforts, disagreement may linger. As recommended by the American Medical Association, where conflict resolution fails, it would be prudent to bring issues to the institutional ethics committees.⁴

Feeding vs dying hungry

Feeding has always been a concern for families of patients with advanced conditions, such as dementia or malignancy, although most patients don't feel hungry at the end of their lives. Anorexia can be extremely agonising for loved ones to cope with. The cultural belief that we cannot "die hungry" causes distress to many families. Historically and culturally, food has often been paired with love, care, hospitality and support. Sharing the natural progression and the futility of artificial nutrition in some circumstances may require multiple conversations and discussions. Reassurance that there is no scientific evidence that food provides prolonged or qualitative life improvement in terminally ill patients, and that stopping eating is a natural event that is part of the normal dying process, would be useful for the caregiver. Sharing details on how tube feeds and parenteral nutrition can contribute to patient discomfort and possible need for restraints can also help allay anxieties. Involving the patient him-/herself in the conversations when he/she is mentally composed helps greatly in easing the fear and anxiety.

Filial piety vs keeping alive at all cost

In an Asian society, we struggle with the conflict between filial piety, translated to keeping parents or loved ones alive at all cost, and quality of life. It does not help when inexperienced healthcare workers dumbfound caregivers with the

dreaded question of whether they want the ill relative resuscitated. Almost instantaneously, the instinctive affirmative response is given, no doubt clouded by a lack of sufficient details and a very prevalent misconception that “non-resuscitation” equates to “non-care”. In a similar vein, the uninformed public tend to associate symptom management with doing nothing else, and avoiding an intensive care admission is tantamount to giving up.

Much as it takes soft skills (currently emphasised in all undergraduate curriculum), patience and tact, it is prudent for physicians to realise that a lack of aggressiveness, from a caregiver’s perspective, may be misconstrued as a lack of care. The emphasis should perhaps be that care and quality are not mutually exclusive. Doing everything does not mean offering every patient intubation and intensive care, but what is medically appropriate; failing which, it is to ensure death will not be painful for the individual.

More for the patient vs more to the patient

Patients and relatives must be fully aware of the purpose of the tests, treatment or procedures to be performed, including the benefits, limitations and, more importantly, the risks. In dealing with the issues of death, physicians must be prudent to have an honest discussion with the patient, especially if these will make a difference to his/her lifespan and quality of life. Physicians should take particular pains not to investigate at the expense of their patients just to satisfy their intellectual curiosity.

The other common dilemma we face is on the extent of investigations and treatment in patients with advanced disease or age. We have found it useful to ask ourselves three probing questions. Firstly, will the investigations or treatments be keeping with their goals of care or aid in their management? Secondly, am I doing more for the patient or to the patient?

Lastly, what would the medical and psycho-social burden of investigations on this patient be? One of us had the pleasure of having a lovely, well-loved 90-year-old lady with dementia under our care. She would come to the clinic in a wheelchair, beautifully groomed by her family members, despite requiring help with all daily activities and mobility. She had presented with weight loss but was otherwise asymptomatic and was found to have iron deficiency anaemia. Despite supplementation, she continued to lose weight. We made a joint decision with the family not to proceed with invasive evaluations and opted for expectant management. The difficult decision was made with all the more conviction when the family (and physician) recognised that she would not want or tolerate any intervention if needed.

Life remains a journey and the outcome of this journey is death. We tend to forget that the implications of what we offer in the patients’ death and dying can be significant for their loved ones when they carry on their journey beyond the patient’s passing. But as physicians caring for our patients holistically, we have to ask ourselves if we want to uphold our patients’ dignity and lives free from pain and discomfort with proper closure, or continue the anxiety and suffering to both our patients and their loved ones. Margaret’s perspective of her father’s life, death and the dying process best captures the entire journey and our mutual roles. ♦

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