



PERSPECTIVES: PAIN, PARADOX AND PALLIATIVE CARE

By Dr Tan Yew Seng

"I am ready to go. In fact, if I can die faster, the better."

Palliative care workers will attest that such declarations among patients are commonplace, especially when we ask our patients. This time, it came from Madam V, a 63-year-old patient with advanced ovarian cancer. Despite the advanced cachexia and a disproportionately protuberant abdomen that was laden with ascites and tumor, she continued most animatedly:

"The best is internal bleeding. I don't see the bleeding and there is no pain. Better still, I die in my sleep."

This apparent conviction belied the fact that just about 3 weeks ago, she was full of panic when bleeding occurred through the enterocutaneous fistula, and that a week ago, she was utterly miserable during a pain crisis.

A quick, painless death without having to go through dying - this is how this patient would like it to be. And she is not alone - another hospice patient recently said that he hoped to just "fall down and die", in other words, simply drop dead. Somehow, many patients found this period of physical and emotional limbo between life and death rather dreadful and objectionable, particularly when it is accompanied by symptoms of disease progression and physical deterioration. In the words of Woody Allen:

"It's not that I'm afraid of dying. I just don't want to be there when it happens."

But patients are not the only ones with this subjective trepidation and abhorrence to the dying phase. Many medical professionals are also not immune to the uncertainty and vexation when faced with dying in their patients, their own relatives and their own dying. To be fair, doctors are no less human. Moreover, much of the fodder during our

professional formative years has been based on the science of maintaining the physiology of life and in countering the pathophysiology of disease. And if the normal physiological systems fail to restore with our interventions, there are now the technologies that can take over their functions in order to maintain life. Maintaining destabilised and deteriorating physiological states and letting it continue taking its own course are seldom the points of interest for doctors. More likely, curing disease and saving life conforms more snugly as the doctors' mantra of professional existence. Yet it is not that we are not cognizant that our patients will die one day. However, it is more often the experience of the transition from life to death that often appears as a professional blur. A doctor working in the community said frankly, "When they (those with end-stage disease) come for review and we know that their prognosis may be short, we give them a longer interval to the next appointment. Hopefully they will end up in the hospital before the next appointment". For those patients who are followed up at the tertiary centers, it is still not uncommon to see that they can be simultaneously given a short prognosis of 1-3 months in the referral memo and an appointment to be seen at the specialist clinic at 3 months. For some doctors, it is always easier to say "*ban ban ho*" (Hokkien: "get well slowly") than "there is nothing that we can do for you". It is understandably a struggle of professional, personal, moral and even medico-legal dimensions to convey to desperate patients and their families that we have no curative solutions to their problems. For many other doctors however, there are just much more important things to do, such as saving and curing the other living sick.

On the other hand, there are also some who would recommend heroic measures to "fight on" despite the natural end being near and continue to offer hopefulness of recovery, so as "not to give up on them". Ironically, they may not be present when the fight is over to bear witness to the aftermath



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in the bereaved family with hopes unrealised, resources spent, and regrets that the remaining time could not have been spent with their loved ones, at a place of familiarity and comfort, and with some sense of control and dignity preserved.

In effect, all these approaches relegate the issues and needs of the dying person into the blind spot of biomedical practice. Is there much in the lexicon of our medical practice that legitimises the undaunted passing of a patient who has reached the end of his natural life?

PAIN

The old Chinese saying that describes “birth, ageing, disease and death” as the inevitable stages of human existence remains relevant today. The local statistics indicate that the majority of its population will die from diseases. But more importantly, they will die from chronic diseases such as strokes, heart disease, diabetes, lung disease and kidney disease. Cancers, especially with the advent of newer therapies may also well join the ranks of other diseases of significant chronicity, a protracted dying phase and no cure on the cards. The quick death which many fantasise about, is therefore an unlikely experience for most Singaporeans.

In many diseases, pain is often the cardinal experience of suffering. The notion of having unrelieved pain when one is dying provokes intense trepidation. And indeed, significant pain is known to afflict the majority of both cancer and non-cancer patients with terminal disease. But in spite of this, pain remains under-treated in many instances. There are diverse reasons for such an observation. For example, many people still subscribe to the belief that the use of strong pain relief medications such as opioids are only relevant to those who have exhausted all avenues for cure. Many associate opioid use with deterioration and demise of the patient, often to the extent of “opioidphobia”, even though there is much evidence and guidelines for its safe use. Another reason may be the reluctance to admit that the patient might have reached the end of his natural life, such that the focus of treatment is not so much to continually seek cure but to focus on symptom management instead. In addition, there are still persistent myths that pain and other symptoms may be unavoidable consequences in the seriously ill and further, that one should even be stoic and “brave” in the face of such suffering. Another barrier to appropriate pain control has been the notion that suffering at the end of life could be redemptive or a test of faith and therefore not necessarily undesirable.

But while there are exceptions, pain is generally neither inevitable nor intractable at the end of life with

the current medical expertise. In fact, the WHO step-ladder approach which is adaptable to most situations and care settings, has been found to be effective in managing almost all pains among patients.

Then again, pain is more than a physical experience. The suffering of the dying patient goes beyond the physical and encompasses mental, social and spiritual dimensions, as embodied in the concept of “total pain”. Implicit to this concept is the inter-relatedness of the various dimensions which influences how the suffering will be experienced. Hence, pain may be aggravated by fear and anxiety or may be assuaged by a sense of completion or fulfillment. Recent brain imaging studies also suggests overlapping patterns of brain activation induced by both psychological and physical pain. In practical terms, it may translate to having to explore pain as it is experienced in the various dimensions. This requires the doctor to leave behind his acute biomedical and disease centered model and adopt a more biopsychosocial approach that emphasises the subjective experience of the patient and family. Furthermore, the varied dimensions could also imply that effective pain management may have to involve a team of professionals working as an interdisciplinary team.

But pain really represents the archetype of other no less distressing symptoms among the dying patients such as dyspnoea, fatigue, anorexia, cachexia, nausea/vomiting, constipation, confusion, insomnia, anxiety and depression. There is also evidence that those who are dying from non-oncological conditions also experience many similar symptoms and distress as their cancer-stricken counterparts. It is perhaps in this arena of care that the EVERY doctor can contribute significantly to the alleviation of suffering in the dying. Of course, we have to believe foremost that dying need not be accompanied by suffering. We may also have to realign our focus away from one of disease centeredness to patient and family centeredness. And with the current technology and armamentarium, doctors need not be in a position to say that “there is nothing that we can do”.

PARADOX

Most people harbor the impression that the principal role of doctors is to preserve life and to stave off death. Playing with the pun on the Mandarin translation of ‘doctor’, a deejay of a Mandarin radio station once asked: “Aren’t ‘*Yi Sheng*’ (Mandarin: doctor) supposed to ‘*yi sheng*’ (treat (to) life) and not ‘*yi si*’ (treat (to) death)?”

Indeed preserving life should remain an important and valued aspect of the work of doctors, though what is not commonly emphasised enough is the ‘escape clause’. Often, the process of staving off



death has been mistakenly equated to preserving life. This frequently occurs when the concept of life is narrowly restricted to biological existence. Life comprises many more facets of existence, such as emotional, social, and spiritual existence. Death too, has corresponding facets. For example, death in the social sense might have occurred long before a person is biologically dead, when a dying person is no longer able to fulfill his social identity as a functioning member of the family, in the workforce or in the community. This can happen easily with prolonged institutionalised care. As a further example, a person who experiences abject loss of meaning and purpose in existence may well feel that they exist only in the realm of the walking dead. Therefore, what part of life then are we attempting to preserve when we intervene medically? Or for that matter, what sort of death have we been able to stave off? And what if prolonging an aspect of life leads to the hastened demise of another? There are often no easy answers to such highly ignitable questions.

But lurking in the background of many struggles between choosing life over death or vice versa is often the fallacious dichotomy of life and death. The tongue-in-cheek assertion that “life is an invariably fatal sexually transmitted disease” supports the non-duality of life and death. Life and death are really one inseparable package, where the price for life is death. In effect, the only way we can successfully cure death is to stop life – but the sheer absurdity of such a statement only further reinforces the futility of avoiding the inevitability of death when it comes.

But beyond the philosophical digression, deliberating death has practical implications. To translate to more mundane terms relevant to medicine men and women, if patients were resistant to death, would you have treated them with the same passion and urgency? Or for that matter, would they even want to see you? Those patients who are unable to appreciate the evanescence of life are often the ones who continue to engage in unhealthy or high risk lifestyles such as smoking, hell-riding, drug abuse and risky sexual behavior.

It is therefore the specter of death or the sense that life is finite that imparts the preciousness of life and the urgency to live and respect life. Some authors have described patients who had earlier been so hung up on unimportant matters, finally beginning to “trivialise the trivia” at the end-of-life. Much has also been written about people who seemed “awakened” to the true meaning of life when they started dying. Some patients even felt that their dying was the best part of their lives.

But many doctors would contend that discussions about death and dying are social taboos. It might be useful to realise that the sort of social taboos we encounter are relatively modern inventions. In the past, people were generally guided by well entrenched dogmas about life and death, usually with religious or cultural underpinnings. It is only in the last 2 or 3 generations that the dramas of life and the end of life have been shifted from the community to the modern hospitals. The absence of a socially sanctioned platform to discuss death could have accentuated our inherent fear of death, resulting in our preference to banish it to some secluded sectors in the society away from the public eye. Or else, we camouflage its existence with the profusion of such cultures of anti-ageing therapies, Botox, Viagra and nubile models in addition to the death defying antics mentioned earlier.

Perhaps dying and death are taboos not so much because of its nihilism, but because it overwhelms and immobilises us to acknowledge that this life will come to an end AND the corollary that we had all the while been and will continue to be ultimately and personally responsible for the way we live out this finiteness and irreversibility.

But going back to the question posed by the Mandarin radio deejay, a dying person is strictly speaking, quite alive until he is dead. For this reason and the others mentioned above, we will continue to be “Yi Sheng”, doctors of life, even as we delve in the care of the dying.

PALLIATIVE CARE

The World Health Organization defines palliative care as:

An approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;

- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient's illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Embedded within this comprehensive definition are medical, social and philosophical ideals, such as normative acceptance of life and death, family as a unit of social existence, quality of life and quality of death, respect for personhood and human dignity. Medical care, which is critically important in the alleviation of symptoms, is nonetheless only one part of the provision of palliative care. The flourish of palliative care in Singapore will no doubt translate to better care for the dying. But even so, doctors should not be transformed eventually into expert “symptomologists” or “symptomatherapists”, whose primary role is to seek and treat symptoms at the expense of the other ideals of palliative care. It has to be remembered that death itself is not a disease, and it should not be “medicalised”. There is really nothing to say that people could not have a peaceful death in the absence of medical intervention, or that having round-the-clock medical attention can necessarily ensure a better outcome for the patient and the family.

It is often heard, however, that the family or relatives request for or even insist on medical treatment. For example, many families think of rushing a patient at the end of his life to the hospital even as he quietly slips into coma and starts to gasp. It is known that although the majority of people with terminal conditions want to die at home if they had a choice, the statistics in Singapore suggested that only 25% actually succeeded in dying at their residences and more than half dying in the acute hospitals. The “medical solution” does no favor to the relatives either, whose real issues may be related to psychological or social coping with dying. So long that the problem is perceived as only solvable by “medical specialists or healthcare experts”,

the locus of control to care for their loved ones and to cope with dying and death will be taken away from their “lay” hands. This may eventually result in even more helplessness which continues to unsettle them in bereavement. Along the same vein, over-zealous dispensing of “expert” care under the guise of compassion may preclude the rightful involvement of the family to tend to their loved one thereby engendering helplessness, guilt and disconnection. And even for those relatives who seemingly express copious gratitude to the healthcare worker, how would they cope with the deaths that will inevitably happen in the future? There will definitely be those who are so much needier than others, but for the rest of them, and as difficult as it may intuitively seem at the beginning, it may be more desirable to help reinstate the sense of efficacy back to the patient and the family.

Therefore, those who aspire to become palliative care providers need some element of mindfulness about the self. It is certainly not about stoicism in the face of death. We are all entitled to feel anxious, fearful and grief in anticipation of or as a reaction to the demise of our loved ones, and even as a response to our own eventual demise. We can even conjecture that the whole idea of tending to the dying in many ways reflect the universal human need to process death and dying. The crux however, is whether we act out or project our own needs onto the patients and their families that we serve. To impose our values, beliefs and practices, medicalised or personal, onto this group of patients and their families who may be in troughs of vulnerability would have gone against the very ideals that palliative care was set up for.

Finally, perhaps palliative care can be construed as a piece of social engineering, as much as it is a medical or health care enterprise. Like it or not, the management of the dying has shifted partially from the clergy and the community onto the lap of the healthcare professionals and medical institutions. Think about this, when patients are dying, who do the families call first, the healthcare worker or the priest? In many ways, how we respond to the dying will impact on how the society deals with death and dying. And it should also be appreciated that doctors cannot and must not play this role alone. The evolving needs of the dying dictate that the key driver in the care of the patient and the family may be as much the doctor as the nurse, social worker, counselor, pastoral care worker, therapist and so on. It is only when we tend to, respect and address issues of the dying as a whole that we can normalise dying and death and disarm its fearfulness to others. Perhaps then, we will all appreciate and live life healthier and better. ■