

# Experiences in caring for the dying: a doctor's narratives

Tan Y S, Cheong P Y

## ABSTRACT

**The study of narratives is increasingly noted for its value in the professional and personal development of doctors. We present the narratives of one of the author's experiences in the care of dying patients over a span of three decades. From the narratives, we identified three paradigms with which doctors respond to and care for dying patients and their families: 'No death', where there is a general denial of death and dying; 'Death', where the care provider's focus is directed to the facilitation of a 'good' death; and 'Life', where the doctor responds to the patients' death and dying as integrated and inseparable aspects of the patient's and family's life. The origins and implications of the paradigms are discussed. In addition to good communication, these narratives underscore the importance of personal reflection and insight when providing end-of-life care.**

**Keywords: death, doctor, dying, end-of-life care, narration**

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## INTRODUCTION

The practice of medicine is inherently a narrative process. Usually, the encounter begins with the patient giving a personal account of his or her experience of the illness and treatment. Guided by convention or expectation, the doctor then applies logical and scientific generalisations to the story to derive the diagnosis and treatment. Often, this process is also accompanied by a certain extent of 'professional' detachment or neutrality. But emanating from these doctor-patient encounters, the doctor too will have his or her own personal stories, which embodies no less the richness and authenticity of the experience. Increasingly, attention to both our patients' and our stories has been recognised to be valuable in our development as professional healers and as individuals.<sup>(1-3)</sup> Stories frame the context and provide the insight and meaning to the experiences. In this article, we present three short stories about one of the author's (Cheong PY) experiences as a doctor to patients who are dying. Interestingly, these stories were set in three different periods of his personal

and professional life. These stories were selected, as they were salient milestones in his perceptual evolution with regard to caring for the dying. We then discuss these experiences with specific references to the doctors' perspectives and responses to caring for the dying.

## 1978: THE HEART THAT REFUSED TO STOP

It was the late 1970's, and I was working toward my Masters in Internal Medicine and Membership to the Royal College of Physicians examinations. I was delighted to be posted to a six-bedded intensive care unit (ICU) in a large public hospital. The set-up was impressive. There was this raised platform from where I can visually eye-ball every patient and also monitor their real-time electrocardiography (ECG) tracings from the gang of small cathode ray monitors before me. There was warm camaraderie in the team. Some of the nurses had just returned from specialised training overseas. Work was exciting—intubating patients, inserting central venous lines, treading cardiac pacing wires, inserting tubes into various body cavities—were all in a day's work.

It was during one of my night watches that a patient was rushed in directly from the Accident and Emergency (A & E) Department after her family had found her unconscious that night. The ECG in the A & E revealed an inferior myocardial infarct with very irregular rhythm. Tubes were efficiently inserted, both for monitoring and treatment. We were in control. Chest compression, ventilation, correcting electrolyte and acid-base abnormalities, and at times, cardioversion; we responded methodically to the vital parameters that were presented to us. When we were exhausted from protracted manual chest compression, the mechanical thumper was brought in. The thumper was obviously not built for Asian frames. This lady was extra small, but we got it working after a while.

Minutes turned to hours. Just as we thought we had stabilised her, the heart beat became chaotic again. Just as we wanted to stop resuscitating, the heartbeat returned to sinus. The cycles went on for more than two hours until the heart mercifully stopped beating.

I would not have remembered this lady at all. After all, she was just one of the patients in transit that I attended to. She was unconscious during the entire period, and

**Assisi Hospice,  
820 Thomson Road,  
Singapore 574623**

Tan YS, MBBS,  
MMedFM, FCFP  
Clinical Director

**Specialist Medical  
Clinic,  
76 Jalan Jurong  
Kechil,  
Singapore 598589**

Cheong PY, MBBS,  
FRCP, FACP  
Internal Medicine  
Physician and Adjunct  
Associate Professor,  
NUHS

**Correspondence to:**  
Dr Tan Yew Seng  
Tel: (65) 6347 6446  
Fax: (65) 6253 5312  
Email: tan\_yew\_seng@assisihospice.org.sg

those were physically challenging times of overwhelming workload and inadequate sleep. However, flipping through the newspaper two days later, a familiar face in the obituary page caught my eye, and there was also a short article in the preceding page with a newsworthy headline, “*The oldest person in Singapore died peacefully in hospital.*” She was reported to be around one hundred years old! A peaceful death it certainly was not. Her last hours on earth were spent surrounded by strangers fixated on her heart rhythm in absurdity. We violated her body with tubes, broke some of her ribs, zapped her with electricity that also charred her skin. We infused all manner of chemicals into her. She was ‘traumatised’ in death all because her heart refused to stop.

### **1985: CONSENT FOR DEATH**

Mr D walked into my clinic in the mid-eighties with an unusual request, “Doctor, can you supervise the infusion of these bags of liquids from Hong Kong into my veins?” He was an Indonesian Chinese businessman in his early fifties who had homes in an Indonesian city, Singapore and Hong Kong. I gathered that he had advanced liver cancer, which was diagnosed when he fell ill while attending the Canton Spring Fair. He was under a medical oncologist in Hong Kong, and after initial intensive treatment, Mr D resumed his trading business, which required him to shuttle among the three cities.

I accepted his request and co-managed him, with the Hong Kong doctor taking the lead. I had a spare room in my clinic with a couch, and I improvised a hook attached to the ceiling to hang the bags. I would talk to him at times while monitoring the intravenous infusions. He was an earthy man of few words and spoke only accented Hokkien and Bahasa. He knew that it was advanced cancer, inoperable and the prognosis dismal. He wanted to make the most of life meanwhile. He would drop by my clinic for treatment whenever he was in Singapore. At times, I managed him as an inpatient in hospital. He contracted pneumonia that needed inpatient intravenous antibiotics. He also developed malignant ascites for which I had to aspirate palliatively. As months passed, he became increasingly cachexic.

I received a phone call from Mrs D the moment I stepped into the clinic after the Chinese New Year festivities. They had tried unsuccessfully to page me on Chinese New Year day when they arrived in Singapore from Indonesia. I was out of town. Mr D was thus taken to the A & E of a private hospital and admitted to the ICU under a cardiologist. Mrs D sounded frantic and distraught over the phone. “The doctor here asked me this morning to sign a consent to put a tube into my husband’s windpipe so

that a machine can help him breathe. He said that if I don’t sign, *my husband would die.*” Mrs D intimated.

The family was waiting outside the ICU when I arrived. His teenage daughter told me that a cardiac pacing wire was inserted on admission. The cardiologist told her that although her father’s heart was now beating normally, his lungs were bad. The laboratory results showed the blood gases had low oxygen saturation. Through the glass window, I saw Mr D propped up in an ICU bed with a gas mask over his face. He was already having Cheyne-Stokes breathing. I told the family that Mr D should not be intubated and advised Mrs D not to sign the consent.

Mr D’s life ebbed away a few hours later. The wife was relieved that I took the burden that the other doctor had imposed on her. She knew that intubating her husband would only torment him. Yet the words of the cardiologist, “your husband would die if you do not sign the consent” would forever haunt her if she refused. I took her ‘guilt’ and allowed Mr D to die with dignity. Revisiting Mr D’s last hours in the ICU, I am sure that the cardiologist had good clinical indications for admission, external cardiac pacing and intubation for assisted ventilation. However, what he did was, in my view, cruel, not just to the patient but to the family as well.

### **2006: HOPE AND DESPAIR**

The patient was in her late seventies, apparently well till she developed breathlessness after a week of fever and cough. She was rushed to the nearest A & E of a public hospital and admitted. I met the medical trainee in charge that night. “Her heart is ok but she has white-out lungs. The blood gases were deteriorating and my consultant said we should treat her as acute respiratory distress syndrome (ARDS).” The next step was obvious; assisted ventilation in the ICU. As a young doctor, I had encountered this clinical situation many times. Now as medical advisor of the family, I would have to answer many questions that do not have ready answers from the other divide. How long would she be in ICU? How long would the tube be in? I gave hope and counselled consent for intubation and admission to ICU. The next day, although speechless and hooked to various machines, the patient became more alert and a rosy flush returned to her cheeks.

The ICU has indeed advanced over the years. Many more real-time data was available, including the patient’s weight. We now do not have to transfer patients bodily to the weighing bed circa 1970’s. Drugs can now be delivered precisely. The ventilators and monitors looked more sleek and sophisticated. The doctors and the nurses are certainly better trained. More importantly, each patient is nursed in a separate cubicle, socially isolated but more

humane. I remember the distraught faces of still surviving patients in adjacent beds on pronouncing the death of a patient after a dramatic but futile resuscitation.

The initial relief of the woman's relatives was short-lived. Yes, there was improvement in the plain chest radiographs, but a fever later developed and her urine output declined. Consent was taken for peritoneal dialysis. Antibiotics were prescribed and diarrhoea developed subsequently. Was it due to the medicine administered, or was it due to the dreaded vancomycin-resistant enterococcus (VRE) bug? It was a downward spiral medically and a draining roller-coaster ride of emotions for the relatives. Days turned to weeks. It was painful to see her tethered to the machines, speechless and immobilised by the diverse tubes that restrained her. Words of comfort and hope that had evoked smiles in her now fell on deaf ears. When she gestured that she wanted her favourite dress brought to her, the relatives sensed that she was prepared.

The ICU team attempted to wean her off the respirator so that she could be nursed out of the ICU, but each time, she turned blue. It was difficult relaying the consultant's request for consent for tracheostomy. Why put the patient through more pain when she was not improving? Why prolong the process of dying? After much anguish, the family agreed to proceed for the comfort and dignity of the patient. However, the situation turned ugly when the young resident doctor taking consent, who was not attuned to the anguish of the family, asked innocuously, "Are you really sure you want to sign this consent to fight on?" Those well-meant remarks triggered another surge of despair and a premature Kubler-Ross grief reaction of anger. I had to intervene to defuse the situation. The patient was still speechless after tracheotomy but was able to sit up in bed and smile. The end came a few days later.

## DISCUSSION

These stories represent a fascinating exposition of a doctor's experiences with his patients dying in acute care facilities over a span of almost three decades. It started with the doctor as a wide-eyed aspiring internist, full of confidence about his craft and the technology in the ICU, and doing what it takes to save a patient's life. Then he was the concerned personal physician who assisted a patient he had journeyed with die without the indignities of futile mechanical ventilation. In the final vignette, he was more of a doctor-advisor to a family he was close to, and as such, having to deal with the emotional investments and conflicted decisions not unlike any family member, and also appreciating the full complexities of a situation that did not have 'ready answers'. These

stories are so rich in content that they can be discussed from a variety of angles. We have decided in this article to turn our attention selectively to the author's narratives of his experience as a doctor as well as the experiences he had with other doctors. From these descriptions, we attempted to identify and derive insights into some of the stereotypical responses of doctors to the situations of death and dying. While stereotypes may help us identify the patterns expediently, we agree that they also inherently generalise and simplify. In reality, doctors are more likely to resemble them in varying degrees, vacillate between the modes, or shift modes over time. For the lack of better terminologies, we shall label these stereotypes as the 'No death', 'Death' and 'Life' paradigms.

### No death: the denial of death

This is a very familiar paradigm among those working in the acute care setting. Death is generally abhorred, and all measures are taken toward curing of the patient. However, it is useful to reflect on its origins. It was not too long ago that we were still dealing with acute and reversible causes of death, such as infectious diseases and accidents. The advent of medical science and technology helped overcome many of the acute conditions that led to premature deaths.<sup>(4,6)</sup> Indeed over two-thirds of the improvement of longevity from prehistoric times to the present occurred in the very brief period since 1900, and this has largely shaped how we respond to illness.<sup>(7)</sup> Presently, acute care continues to be emphasised in institutions and policies, as well as in research and training of medical professionals. It therefore comes as no surprise that much of the preoccupation in contemporary medicine would be in staving off death.

And certainly, in the acute care situation, this paradigm would even be considered by some to be a necessary professional requisite. For who would not want their doctor to do everything to save them from an acute reversible disease? Indeed, many patients would willingly surrender their comforts, rights and dignity to be admitted into an acute care facility and be subjected to potentially agonising treatments and procedures in exchange for a chance of recovery, not unlike some of the decisions of the patients and families in the vignettes. Many patients also continue to expect that with advances in medical science, there will be a medical riposte to any threat on the physical being, such that they can return to their normal lives, even when that possibility is slim. Medical practitioners, empowered by their success in acute care and the availability of technological prowess to maintain complex physiological systems such as oxygen saturation, electrolytes, fluid balance, cardiac rhythm, may feel both attracted and obliged to 'fix things' and save the

day.<sup>(8,9)</sup> It was notable that both the young and older Cheong continued to admire and marvel at the technological advancements of the ICUs, perhaps from the sense of potency technology imparts to the doctors in control of it. While the role of the ‘ultimate rescuer’, as described by Yalom, may be socially imposed onto the doctor,<sup>(10)</sup> the sense of being in control and above the challenge of sickness and death is so much a part of the desired professional identity among doctors that they would accept rather than reject it.<sup>(11)</sup> Moreover, failure to perform that role could also become psychologically devastating to our sense of who we are and a punishment for rejecting the role.<sup>(11,12)</sup> “I took her guilt” was how Cheong described his experience of advocating withholding an intervention for the dying patient in the second vignette, as if there was some belief—at least on the part of the patient’s relative—that implied an intrinsic wrongness or immorality about such decisions. Notwithstanding, the role of the ‘ultimate rescuer’ can also be a powerful unconscious motivating force against the doctor’s own death anxiety. The paradigm of ‘No death’ thus takes on its own life and becomes the imperative itself. Like the protagonist in the article, the key objective was to save, or rather, attempt to save any life; that the patient was 100 years old and might have lived to her natural end of life was not initially a consideration. But during moments of clarity, especially when the patient can no longer be considered as “just one of the patients in transit”, one becomes painfully aware of the depersonalisation and misgivings about medical interventions that were destined to not have any favourable outcome – a disquiet that may unsettle patients, families and healthcare workers, like the young Cheong. Yet oftentimes we convince ourselves to prod on with the ‘good work’. Echoing Cassel and Demel, we may be “so caught up in our ability to cure disease that our healthcare system forgot that death is inevitable.”<sup>(5)</sup>

#### **Death: the ‘good’ death**

In the presence of such internal conflicts, it was therefore expected that some doctors would rather respond clinically to death and its inevitability than to deny it. This may sometimes manifest in what we call the ‘Death’ paradigm. In this paradigm, doctors believe that when death is inevitable, there is no reason to continue or attempt any active treatment to prolong life. Superficially, that does not sound too unreasonable, but in the ‘Death’ paradigm, the primary efforts and objectives resolve around an ending of life and the tasks in order to achieve a ‘good’ death. This may be accompanied by assumptions and beliefs that construe specific patient and family behaviours and disease or illness outcomes to be consistent with a routine

‘good’ death.<sup>(13)</sup> Sometimes, this position may even be surreptitiously disguised as or presumed to be palliative care, hospice care, ‘best supportive care’ or ‘comfort care’. When ‘futile’ interventions are continued in the face of life’s natural end, the ‘Death’ mindset often results in a profound sense of moral distress or indignation. It was interesting that Cheong, while reflecting about the incident in the second vignette, also felt strongly against the ICU interventions and thought them “cruel not just to the patient but to the family as well”. On the one hand, such reactions may have arisen because the cardiologist’s aggressive approach mirrored those of the ‘No death’ paradigm, which the older Cheong now detested. On the other hand, he may have considered the possible psychological bind and ramifications in asking a dying patient’s wife to give consent for intubation. How the options were laid out to the wife (“If I don’t sign, my husband will die.”) would more likely lead to acquiescence rather than true consent. Additionally, a key fact may also have been overlooked – while the patient may be physiologically sustained for a while, he was unlikely to eventually recover even with the intubation because of the underlying advanced malignancy. Asking the patient’s wife to ‘decide’ on his life and death was, therefore, neither apt nor fair. Cheong’s responses may therefore represent a kind of empathetic response toward the patient and family. He had after all journeyed considerably with them, enough for deeper feelings to emanate.

But the ‘Death’ paradigm is dissimilar to a simple act of empathy, and is definitely more problematic under its covers. Firstly, if one is not careful, there can be a paternalistic streak to it, perhaps as a vestige of the doctor-centric legacy in acute care setting. This was thinly veiled when the young resident in the third vignette asked, “Are you really sure you want to sign this consent to fight on?” when the family opted for the tracheostomy. In the hospice, we have often come across many stories of patients and families who felt much aggrieved after receiving metaphorical ‘death sentences’ from their doctors – statements that convey the notion that the patient should not or ought not to receive further active treatment. Of course, these could be consigned to interpersonal and communication skill issues, but what defines the ‘Death’ paradigm is more about the power differential between the doctor and the patient or family and the deterministic attitude that the doctor adopts. Secondly, by taking this role to the extreme, it is imaginable that one may come quite close to the slippery slopes of euthanasia. This may even occur more subtly in the form of physician-assisted suicide by invoking personal autonomy as a justification for a planned death. Although there is limited

local data regarding this area, the experiences elsewhere suggest that such occurrences may be more common than we are prepared to acknowledge.<sup>(14-16)</sup> This of course does not detract at all from the fact that such patients are experiencing significant suffering – a point which ‘Death’ paradigm practitioners often uphold to validate their rhetoric. But is death the only prescription? What is it actually prescribed for? What and who does it ‘treat’ and as with any treatment, what are the complications, and in particular, social ramifications of the treatment? Whose ‘good’ death is it? While a discourse in suffering would be beyond the scope of this discussion, how does the prescription of death relieve suffering? Or does it merely ‘remove’ the person from existence – a case of the end justifying the means, and yet human suffering remains, perhaps morphed to another form or transferred to the bereaved or other caregivers? Thirdly, the concept of futility is far from unambiguous in actual practice. A 1% chance might seem quantitatively futile, but to some patients and families, that represents their only hope. A Canadian survey of healthcare providers in ICUs revealed that a significant number of physicians and nurses reported the use of futile treatments, which were mostly requested by family members (followed by attending physicians).<sup>(17)</sup> But rather than delving into the intellectual and ethical arguments about whether it is right or wrong to treat in these circumstances, perhaps we should instead be asking if we have done anything to assist and support the patients and their families in processing and managing their hopes and expectations as well as in coping with the prospect of dying and death. This aspect of care was conspicuously scarce in our narratives.

It should be emphasised at this point that the ‘No death’ and ‘Death’ paradigms do not represent the poles of a spectrum of paradigms, such that an ‘ideal’ middle ground may be imagined to exist somewhere in-between. We contend that there is another separate entity that could be demonstrated by the narratives, which we have called the ‘Life’ paradigm.

### **Life paradigm**

This paradigm is essentially the realisation that death is much larger than merely a medical event. It is a complex of personal, social and even societal events, all rolled into one.<sup>(7)</sup> It views life and death as a poetic sequence that is played out by the patients, their family, friends and people around them. Doctors, nurses and other healthcare workers may be just as much actors in the unfolding drama as the patient and family. The point of physical death, as in the moment of cessation of heartbeat or respiration,

becomes only a segment in the unfolding drama that comprises the events that lead up to it, the experiences of all those involved and how the various participants make sense of it, and how life takes on new directions thereafter. It is therefore about life, without disowning death and dying, because they are really inseparable parts of life.

In the third vignette, Cheong described his difficulties as a medical advisor. From the perspective of the ‘Life’ position, this would only be natural because there are just no medical solutions to many of the issues; life and death are not merely medical events. Hence, while there may be medical indications or contraindications for tracheostomy, the decision to do so may come about from the sum effect of psychological, emotional and social processes involving the patients and their family. To some, life is a continuous valiant struggle and this attitude is carried all the way to death. Death in the ICU may then be perfectly acceptable or even expected to some as their last heroic bastion, if resources permit. It may also be important for the family to hear the words from their doctors that they have “done everything to save him”. But then again, the desire for ICU care or interventions may mask fears that some aspects of care would not be possible outside of the most technologically advanced place of care, or that they must recover at all costs because of some critical unfinished business or affairs. What is on the surface an irrational insistence for futile medical treatment could well be masquerading a psychosocially or culturally pertinent action or ritual that may eventually facilitate the process of dying and bereavement.<sup>(18)</sup> Hence, when we focus on impending death and dying, there seems little that can be done. However, if we pay attention to the needs of the living, which includes the patient, since he or she is, strictly speaking, still alive till the last breath, and those who have to live on in spite of the patient’s dying and death, then there are multitudes of things that we can do that will help them all live better.

In the third paradigm then, the doctor becomes part of the ‘social convoy’ in the patient’s life journey, leading it sometimes, supporting it mostly, but importantly, finding congruence in his or her role and maybe, even dealing with his/her own sense of morality and mortality. In the third vignette, Cheong was inescapably part of the convoy. This exposed him the complexities of the human struggle, its anguish, hopes and despair. He was also able to fully appreciate how a seemingly innocuous question from a young resident can have a deep impact on the family. At a practical level, operating in this paradigm involves extensive communication with the patient and the family, both to understand them as well as to negotiate with them about goals and care plans. We certainly have to

appraise our own skills and seek training or mentorship in a territory that is often unfamiliar to us.<sup>(19,20)</sup> It may also require us to at least occasionally step out of the comfort of our presumed professional roles and humanise ourselves with what is happening to the patients and their families.<sup>(20,21)</sup> Otherwise, how else can we fathom the depth of the patients' and their families' struggles, suggest solutions for them, judge their actions or decisions, or even make life-and-death decisions on their behalf?

### Limitations

The main limitation of this analysis was obviously the sample size of one subject. It was therefore not the authors' intention to provide a definitive or exhaustive discourse on the paradigms. Nonetheless, the series of narratives that spanned decades of the doctor's professional life was unique, and together with candour, provided a compelling window that revealed much insight into the inner world of a clinician involved in the care of the dying. Moreover, it is the authors' hope that the narrative and discussion in this paper will put words to the experiences of doctors so as to stimulate further reflection and investigation in an area that has significant impact on how we care for our patients, their families and ourselves.

### CONCLUSION

The three narratives have provided a rare and candid glimpse of a doctor's evolving cognitive journey in caring for dying patients. The evolution of ideas could be consigned to the accrual of new clinical experience and skills, but doctors' personal experiences that challenge or reinforce their assumptive worlds, such as personal experiences in tending to relatives with life-threatening or terminal illnesses, or their own spiritual journeys, would also be pertinent here. Notwithstanding such attributions, these narratives also illustrate the potentially far-reaching impact of the different doctors' responses on the outcomes of patients and their families. It may be insinuated that deeper and more sensitive engagement of the patients and their families at various points in the narrated sequences could have contributed to a more positive experience, from the perspective of the narrator. However, beyond communication techniques per se, the narratives also demonstrated the contrasting approaches to death and dying among doctors. Such differences may be influenced by the doctors' own values, beliefs and attitudes toward death and dying, prior training and factors in the work milieu such as time and resource constraints and organisational policies. The resulting dispositions to death and dying, which have been classified here as the 'No death', 'Death' and 'Life'

paradigms, may provide some clues with regard to the clinical decision-making processes in end-of-life care. Moving ahead, further investigations would be warranted to dissect the matrix of personal, interpersonal and environmental factors that influence these patterns among doctors in Singapore. Such understanding may provide valuable guidance on better end-of-life care provision that will benefit not just the patients and their families, but the healthcare providers as well. Ultimately, one must be mindful that the patients' dying and death is not, and should not be, about us and our agenda.

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