

Palliative Care in Intensive Care

Presented in Autumn Respiratory Seminar, Hong Kong Thoracic Society, November 2007, Hong Kong Convention Centre.

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Introduction

Palliative care and intensive care seem to be at the two extremes of the spectrum of medical care. It is true that one sees more differences than similarities when referring to their definitions.

Intensive care is a branch of medicines that involves supporting various human organs and systems in patients who are critically ill. In intensive care where technology is at the cutting edge, prompts people to associate the term with tubes, machines, and professionals with sophisticated skills. Because life is precious and if the illness is potentially reversible, it does worth all the effort to promote a recovery.

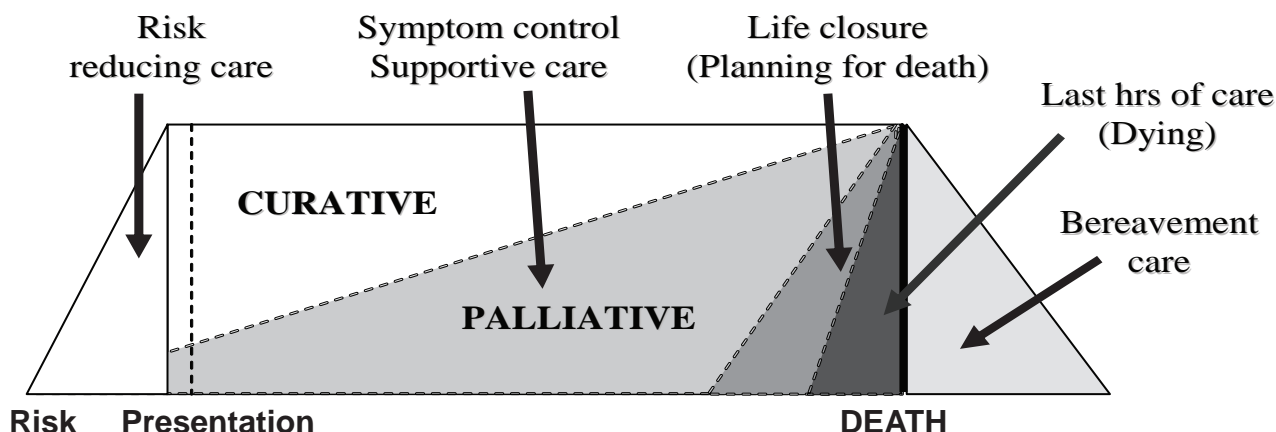
Palliative care integrates the psychological & spiritual aspects of care to support patients to live as actively as possible through an interdisciplinary approach. Families are also supported during patient's illness and in grief. Palliative care is not restricted as end-of-life care. On the contrary, WHO defines palliative care as care applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage distressing clinical complications.

Therefore palliative care and other life prolonging treatments are not mutually exclusive, nor are they in contradiction. Moreover, when it comes to death and dying, both intensive care and palliative care share common goals to meet the needs.

Trajectory of dying in modern era

Figure 1 is a schematic presentation of a disease trajectory from before clinical evidence to death and beyond.¹ One aims at disease prevention if possible. With clinical onset of illness, palliation is an intrinsic element which becomes more the focus as the disease progress. There will be a time when the condition becomes progressively downhill, where active planning for the dying is needed. The transition of predominately curative phase to that of predominately palliative phase is often one that evolves over a period of time, say in months or years, but can still be difficult for some patients to accept. However, in the context of intensive care, the last phase of life is often in rapid transition, posing a more challenging situation for patients, families and health care providers.

Figure 1: Trajectory of chronic illness¹



ICU deaths in Hong Kong

In the contemporary society of Hong Kong, death and dying is highly institutionalized and occurs mostly in public hospitals. In 2006, the total of deaths in HA hospitals were 30222. The ICU deaths of the same year were 1503, accounting for 5% of all HA deaths. There was a male preponderance of ICU deaths, with a male to female ratio of 1.9:1. The major causes of death were listed in Table 1, with cardiovascular, respiratory and digestive causes accounting for more than half of the deaths. One-third of the ICU deaths had been on mechanical ventilation

Table 1: Cause of HA ICU deaths in 2006

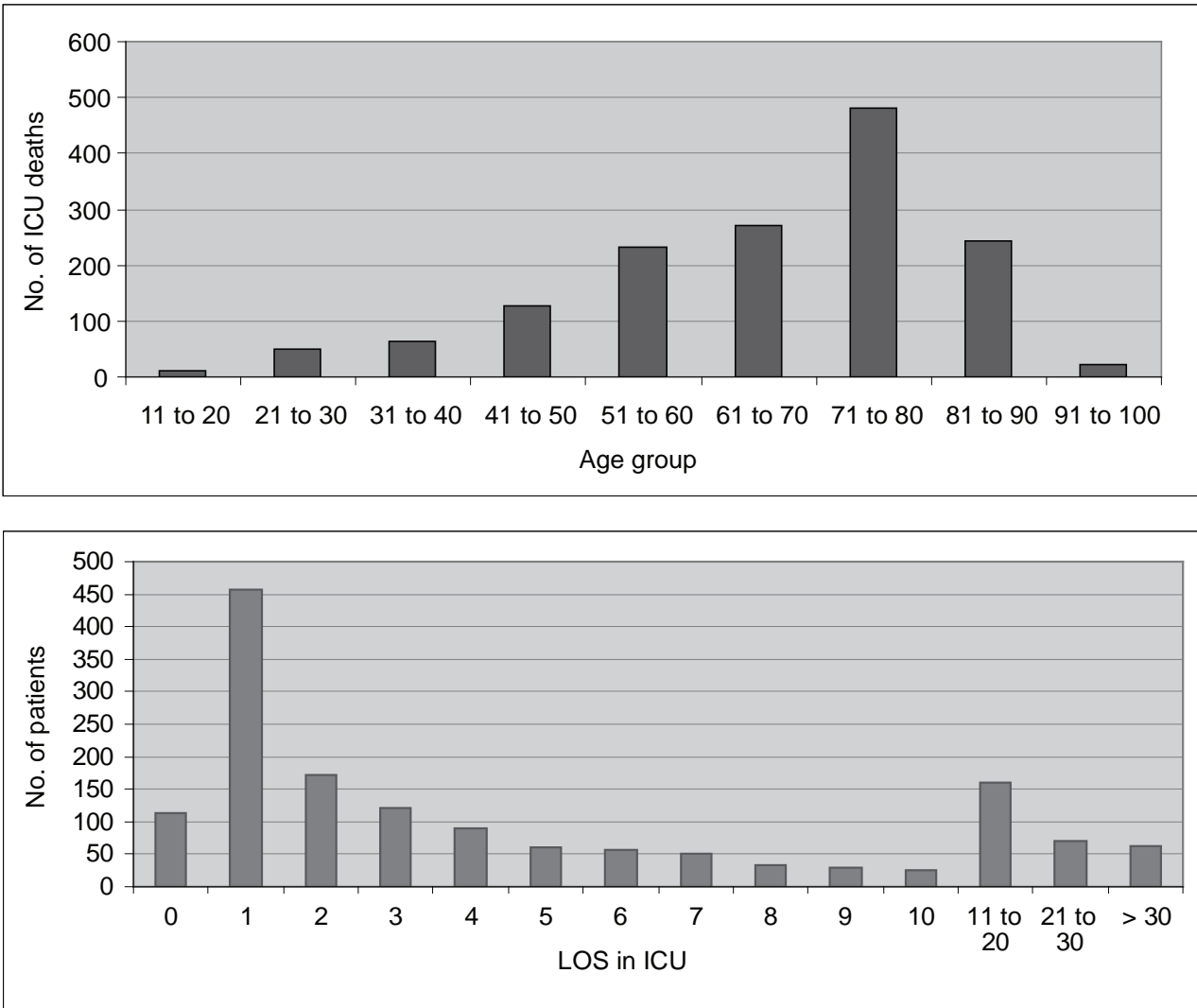
Cause of ICU death	No.	% of total
Cardiovascular	292	19.4%
Respiratory	285	19.0%
Digestive	276	18.4%
Cancer	128	8.5%
Injury & poisoning	129	8.5%

The age distribution of the ICU deaths was shown in Figure 2. The curve was skewed to the left with 50% of ICU deaths of age 70 and above. The length of ICU stay in days was shown in Figure 3. The mean duration of ICU stay was 6.8 days, but 50% of the deaths occurred within 2 days, and one-third occurred within a day. (Source: CDARS, HA)

Given this short time frame, one could imagine that it would be extremely difficult for one to accept or adjust to this rapid transition from curative to letting go. Difficulties are particularly encountered when patients are young, when family has discordance or unrealistic expectation. On the medical side, shifting medical decisions, unrealistic expectation of staff, and lack of training in communication and palliation are also contributing factors. ^{2,3}

Figure 2: Age distribution of HA ICU deaths 2006 (Top)

Figure 3: Length of stay of HA ICU deaths 2006 (Bottom)



From curative to letting go: prognostic uncertainties

This decision is not easy in the face of prognostic uncertainties. Various predictive systems are there to help clinicians to identify those who may not survive based on physiological and clinical parameters. Examples of these prognostic systems include the APACHE II and APACHE III (Acute Physiology and Chronic Health Evaluation), MPM II (Mortality Probability Model), and SAPS II (Acute Physiology Score). These scales are generally based on physiological and clinical variables on admission to ICU or 1st day of ICU admission and aim at identification of those who may not survive. However, these scales have their limitations and fall short of the degree of accuracy in prediction that will be useful in EOL decisions.⁴

However, prognostic telling is important in determining of goals of care, assisting medical decision making, in prioritizing agendas in limited precious time left, and preparing family to say goodbye. Families in grief do regret that they did not make best use of the last few hours of life of their loved ones, words not yet spoken, deeds not yet done.

Life decisions are difficult and dilemmas are common in ICU. Diverse factors are affecting the decision making process. The intrinsic difficulty in identifying the critical point when further intervention neither saves lives nor improves

quality of life is definitely one. Other factors include multiple referrers with different treatment goals; and ethical, legal, cultural, religious and organizational factors. Moreover, in the special case of ICU, one often encounters difficulty in getting to know patient's preferences. Studies have shown that low proportion of ICU patients has mental capacity to make decisions; there is lack of documentation of patient's preference; advance directive is only present in few patients; and family members are often overwhelmed.² In a prospective multicentre study in France, 863 family members of ICU patients were screened by Hospital Anxiety and Depression Scale. Near 70% of family members had significant anxiety while 35% of them were depressed; and among all, the spouse was more affected than the other family members.⁵ The results highlighted the vulnerability of family members when they are required to make major medical decisions and their psychological needs.

Withholding or withdrawing LST in ICU

Nowadays, dying is a managed process in ICU. The dying process is often preceded by withholding or withdrawing life sustaining treatment (LST) and DNR decisions, though the percentage may vary with different places (Table 2).⁶⁻¹¹

We have also performed a small scale survey in our own ICU from Jan to Sep 2007. There were a total of 515 ICU admissions, with 70 ICU deaths

Table 2: Percentage of withholding and withdrawing LST in various ICU

Year	Place	No. of ICU	No. of ICU deaths	WH/WD LST %	Remarks
97	US ⁶	2	200 (12%)	90% WH 20% WD 70%	cf 51% in same institution 5 years ago
98	US ⁷	131	6303 (8.5%)	48% WH 10% WD 38%	NA
01	Spain ⁸	6	644 (18%)	35%	None communicable at time of decision
01	France ⁹	113	1175 (16%)	53% preceded by WH/WD decisions	NA
04	HK ¹⁰	1	490 (18.5%)	59%	Family initiated in 11% Family concurred in 95%
05	UK ¹¹	127	25877 (22%)	WH 31% WD 28% 43%	NA

(13.6%) The mean age of ICU deaths was 69 years. In 46 patients (65.7%), death was preceded by WH / WD LST discussion before death at a mean time of 23 hours before death. The majority of discussions were initiated by the ICU team, in three initiated by family members, and in one by patient himself. Family was present at bedside at time of death in all cases.

In a local study of the ethical attitudes of ICU doctors, .doctors admitted more patients with poor prognosis than they should do, and doctors discuss DNR with patients not as often as they would like to. (Table 3) Nurses were involved in EOL decisions considerable less than what doctors desired for.¹²

Table3: Attitudes of Hong Kong ICU doctors

Items	I did	I should
Admit patients with no hope of survival > few weeks	69%	45%
Admit patients with poor QOL according to physician	86%	66%
Admit patients with poor QOL according to patient	81%	51%
Apply written DNR orders	60%	79%
Discuss DNR with patient	52%	88%
Discuss DNR with family	89%	92%
Discuss WH / WD LST with patient	83%	89%
Discuss WH / WD LST with nurses	28%	55%
Act against family in WH LST	69%	82%
Act against family in WD LST	8%	40%

Recognized needs and the way forward

Changing concept

It is increasingly recognized that palliative care has an important role to play in intensive care. There is consensus among the intensive care experts and encouraging results from innovative palliative care programs implemented in ICU.^{1,13} It is beyond doubt that the primary goal of ICU care is to save and prolong life. With a disease based model of care, disease specific treatment and life supporting treatment should bdelivered to work towards this goal. However, in the need based model, one does not focus on the disease causing the admission, but the needs of the individuals irrespective of the specific illness. Needs arise from the disease related symptoms, the treatment related symptoms and burdens, and there are also needs in the family. Alleviation of distress and suffering would be an important secondary goal. When death is imminent or inevitable, patients have needs related to dying, irrespective of the specific primary illness and family members face the stress of anticipatory

grief. At this point in time, the primary goal of care will be to alleviate suffering, as that in palliative care. (Figure 4)

Quality indicators for EOL care in ICU

Defining quality is not easy, and this is more so in end of life care. However difficult it may be, experts have arrived at a consensus of seven domains of quality EOL care for reference in delivery and evaluation of the service, including:1) Patient & family centered decision making, 2) Communication with team and with patients and families, 3) Continuity of care, 4) Emotional and practical support for patients and families, 5) Symptom management and comfort care, 6) Spiritual support for patients and families, 7) Emotional and organization support for ICU clinicians.¹⁴

Cultivating an interdisciplinary approach

Needs at EOL are diverse, and covers the physical, psychosocial and spiritual dimensions of care. Only a well coordinated interdisciplinary team can serve this purpose well. The team also has much to contribute in decision making and ensuring consistency in information giving and discussion. Intensive care physicians, palliative care physicians, nurses, social workers and chaplains have a role to play.

Among the team members, nurses spend most time with the patients & family members, but nurses' opinions were often overlooked by physicians. More nurses value their role in EOL decision making. Studies have shown that nurses are more involved in decision making in European ICU (>78% of physicians include nurses) and less in non-European ICU (29% of physicians include nurses).¹⁵ In the Hong Kong study, 55% of ICU physicians thought that they should involve nurses, but only 28% did so. ¹²

Staff training and support

In order to improve EOL care, staff training and support are very important. Gaps to cover in training include: 1) Symptom assessment & control, 2) Holding family conference, 3) Handling emotions, 4) Conflict resolution, 5) Self care and staff support. Organization support is pivotal in facilitating good EOL care in ICU through cultural changes, modification of physical environment in ICU, and opening the visiting hours.

At individual staff level, caring for dying of patients could be emotional draining and distressing. A study comparing work stress of nurses in different settings found that nurses in ICU and palliative care unit had considerable more stress related to caring for death and dying than nurses working in other settings.¹⁶ In another survey on 2392 nurses from 165 ICU in France, 33% of nurses had severe burnout syndrome. From multivariate analysis, factors predisposing to burnout include EOL related factors such as no. of decisions in forgoing LST and caring for a dying patient.¹⁷

Palliative care programs in other ICU

Innovative palliative care programs have been initiated in ICU elsewhere. One example is a 3-yr multifaceted demonstration project which aimed at merging culture of palliative care in intensive care.¹⁸ In this project, the palliative care and intensive care clinicians joined together and training nurses were trained as "palliative care champions". Other measures included opening visiting hours; educating interns and other staff about relevant palliative practices; presence of a palliative care specialist during work rounds; teaching about and promoting family meetings; staff support efforts; and modeling of interdisciplinary teamwork.

Another project and study involved a communication strategy and brochure for relatives of patients dying in ICU.¹⁹ In this project involving 22 French ICUs, 126 family members were randomly assigned to the control group and the interventional group. The intervention included proactive and longer conferences. Family members in the intervention group had significant lower level of psychological morbidity in grief period as compared with control in terms of IES score ($p=0.02$), PTSD related symptoms ($p=0.01$), anxiety symptoms ($p=0.02$) and depressive mood ($p=0.003$).

Conclusion

It may take some time before such programs are implemented in a structured and widespread manner in local ICU. The needs of course are not limited to adult ICU patients. Palliative care for neonates and babies in ICU is even more challenging, and deserves another detailed discussion. Before changes take place, we have

to believe that In the light of inevitability of death & dying for some, there exist challenges and possibilities of alleviating suffering for all. Among the quality Indicators for ICU Care, one will definitely like to look at life saving; the quality of life saved in terms of functional recovery; but if death is inevitable, then a good dying in place is the greatest gift of all.

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