Palliative Care from Age to Age

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ABSTRACT

The specialty of palliative medicine is undergoing transition. The specialty in Hong Kong has had her share of strive for existence, and is increasingly recognised for its worthiness and status. Yet more work needs to be done, to ensure palliative care is equitable and accessible to those with the greatest needs. Good death should be considered as a right rather than a luxury in every end-of-life care setting. Terminal patients in general wards should also be able to benefit from hospice approach. Old and young patients at extremes of age should not be neglected. End-of-life care is indeed a global public health issue, considering the disease burden and the number of family members affected. Conventional cancer palliative care is facing a changing scene, with the disease trajectory taking a more chronic course. Non-cancer palliative care needs to be developed, notwithstanding the difficulties and need for further research. Euthanasia will continue to be debated, and palliative care professionals should continue to uphold our patients’ rights in receiving appropriate palliative care. Through learning, experience and mutual support, a trans-disciplinary palliative team can be a model of a caring, harmonious, and resilient team to serve our patients with end-of-life care needs.

Building a heritage of palliative care from age to age

It is evident, though it may go unrecognised, that the specialty of palliative medicine is undergoing transition. Over the years, colleagues in the field have together been building undoubtedly a heritage from age to age. The hospice values are clearly laid out in the Palliative Medicine Curriculum of our Hong Kong College of Physicians. The doctor should affirm life. Dying should be recognised as a normal process. It should be remembered that all days of human life are deserving of dignity, meaning and concern. When cure is not possible, active total care of the patient and family is central to the management, where quality of life is often more important than the quantity. Privacy and confidentiality, and above all, patients’ autonomy should be respected.

Putting values into practice, our goals should at the minimum, be providing relief from pain and other distressing symptoms. We hope to provide support systems not just for patients and relatives, but also to our colleagues and staff. It is only through integrating also the aspects of psychological and spiritual care, that a true holistic approach can be proffered to our unfortunate patients facing the end of life. In the process of care, palliative care workers should not hasten death, and deprive the patients and their families of the opportunity to cherish and bond with each other. Neither should we postpone death for the sake of advance technology, prolonging unnecessary anguish and suffering. The science and art of this challenging and yet hugely rewarding spectrum of modern health care will no doubt be enhanced through further collective experience and research. “Learning from our patients” may seem an old cliché, yet it is entirely through this attitude and spirit, that our specialists can be nourished, and for our specialty to flourish. It is this heritage and legacy that our palliative medicine trainers would be keen for our trainees to inherit.

From an age of conception to an age of increasing recognition

Palliative medicine is still a young specialty, with its conception and incorporation only little more than a couple of decades ago. The specialty was established in the Royal College of Physicians in United Kingdom in 1989, and the notion of palliative care supported by World Health Organisation in 1990. The specialty in Hong Kong has had her share of strive for
existence, which is duly rewarded with the recognition of its status by policy makers, academia, health care providers and consumers alike. A short extract from a recent Hospital Authority statement helps illustrate:

“香港每年有近萬人死於癌症,當中90%是公立醫院的病人。秉承著醫管局「全人治療」的服務宗旨，寧養服務已由十多年前最初單一的住院服務模式發展至現今較為全面的綜合服務。感謝我們一班非常專業和熱心的前線醫護同事，在極度有限的公營醫療資源下，現在我們已可以為病者提供綜合性的服務，內容包括住院、紓緩、哀傷輔導、日間及外展等服務，並由醫管局扮演統籌角色。現時本港公立醫院的紓緩護理服務主要由分布在不同醫院聯網的十間紓緩護理中心及六間腫瘤科中心提供。這兩類中心的服務緊互聯繫。”

And amongst the various specialist centres, Bradbury Hospice continues to perform its precious role as the only stand-alone hospice in Hong Kong.

Only through recognition of its principles and philosophies, that education and training of palliative medicine can be supported in this field. Medical students can now gain experience and exposure e.g. Chinese University medical students regularly rotate to palliative care units in their final year. A certificate course, and now a post-graduate diploma course is also established under Chinese University, with the blessing and support of numerous friends and colleagues. Yet much work still needs to be done. Communication skills with the critically ill patients and families need to be more comprehensively taught. Life and death education should be incorporated in all major curriculums. The understanding of public on our aims and goals can be better promoted. Death is still a taboo subject for some and it will continue to be, as expressed in the quote by the film director Woody Allen: “I am not afraid to die. I just don’t want to be there when it happens”.

But at least the appropriate and timely introduction of hospice and palliative approach should be seen as a ray of hope, in the wake of coming to terms with an incurable illness with inexorable decline. The realignment of hope and expectations are crucial components of positive coping strategies. Hope of a cure can be reframed towards a hope of good palliation of symptoms. A hope of extending quantity of life can be shifted towards a hope of better quality of life. A hope of reversing disability can be reframed towards a hope of minimising handicap. A hope of hospital discharge, if not possible, can be reframed towards a successful home leave.

From an age of palliative care for the privileged to an age of greater equity

The greatest inequity of all is that palliative care cannot be delivered to those with the greatest need. It is now readily accepted that a good death is a right rather than a luxury in the health care pyramid. Developing countries equally need palliative care. Terminal patients in general wards should also be able to benefit from hospice approach. Old and young patients at extremes of age should not be neglected. End-of-life care is indeed a global public health issue, considering the disease burden and the number of family members affected. Assuming 60% of the annual deaths would require palliative care, 33 millions in total in our modern world would be in need of basic palliative care.

The service model in the best delivery of palliative care to the wide spectrum of patients will depend on the local health care system and set up. Hospice support and consultative team is the direction forward to provide more backup and support. It is clearly not possible, nor is it the intention of palliative medicine specialists to provide cover for all deaths in a public hospital. A general palliative care approach is to be promoted amongst all specialties and disciplines. Akin to geriatrics, where the principles adopted for older persons are advantageous and can often be applicable for all, the principles of hospice approach would also be of benefit in symptom palliation and end-of-life needs for patients of all diseases.

From an age of cancer palliative care to an age of palliative care for all

It is increasingly known that non-cancer patients at end of life often have worse symptoms and distress than cancer patients. Advanced end organ failures e.g. cardiac, respiratory, liver, and renal failures, and neurodegenerative disorders like dementia, Parkinson’s, motor neurone diseases, and also incurable illnesses like HIV, all require good palliation. While the need for
non-cancer palliative care is beyond doubt, planning and provision of care has been said to be difficult due to its longer and more episodic course of trajectory, with unpredictable disease progression, and difficulty in coming to terms with the dying phases.\textsuperscript{6} Yet this is now also increasingly true for cancer palliative care too, with the advent of technology transforming cancer to more chronic conditions. The changing of disease course can be best approached as per the need, rather than an arbitrary stage of any particular condition. This is compatible with the notion proposed by the National Institute of Clinical Excellence in UK, that many aspects of palliative care are also applicable earlier in the course of the illness, in conjunction with other treatments.\textsuperscript{7} A young lady with breast cancer and metastases has palliative care needs right from the onset of presentation. An old patient newly diagnosed with dementia would have advance care planning needs. Meanwhile, progress is seen in better prognostication in non-malignant diseases.\textsuperscript{8} A better combination of cure and care, and a smoother transition from acute to palliative care can be facilitated.

With the ageing population worldwide, palliative care for older patients becomes an increasingly pressing issue. Pain is prevalent in the older age groups, yet ageism still exists in diagnosing and treating pain.\textsuperscript{9-11} Lack of proper pain assessment, potential risks of pharmacotherapy in elderly, misconceptions of relationship of pain in ageing and elderly compliance all contribute to under-treatment.\textsuperscript{12} Pain and discomfort in the cognitively impaired is not beyond assessment and treatment. Protocol in comprehensive assessment of discomfort in dementia in old age homes has been proven to be successful.\textsuperscript{13} Palliative care in older people especially needs to focus on dignity issues. A qualitative study on local old age home residents’ perspectives revealed the following concerns: respect from other people; worth of the person in the last days of life; whether being attended to; and preserving autonomy. (Lo R, unpublished data).

**From an age of concurrence to an age of debate**

The ultimate issue for contention is euthanasia. The discussion has been revived and again hotly debated lately. The crust of the issue has been the conflict between the right to demand death versus the duty to preserve life. Palliative care physicians believe that we can add quality to life when quantity can not be added. We are not aiming to preserve life at all costs, though we respect the value and sanctity of life. Palliative care professionals believe that palliative care is a better alternative than euthanasia to avoid a painful death; is a better answer to the fear of being kept alive at all costs; is a better way than euthanasia to die with dignity; is a better means to uphold patients’ autonomy than to giving up with euthanasia. Withdrawing or withholding futile treatment is not euthanasia, and neither is issuing a do not resuscitate order in terminal situations. Appropriate sedation of patients at the dying phase if necessary is not euthanasia either. The euthanasia debate will no doubt continue. While we must continue to listen with concern the plights of pro-euthanasia, colleagues should not shy away from the determination to uphold our patients’ rights in receiving proper palliative care. Euthanasia is not the option, when basic palliative care has not even been implemented.\textsuperscript{14}

**Challenges for palliative care in an age of transition**

There are challenges ahead facing all professionals caring for patients at end of life. There may be moments of helplessness facing intractable existential distress, the difficult pain syndromes, the suffering and indignity, the lack of time and resources and the facing of own mortality of death and dying. Yet strength will come from staff and colleagues support, successful control of patients’ symptoms, relatives’ support and appreciation, recognition of palliative care services and self awareness and enhancement. Through trans-disciplinary care and support, a team can evolve through learning and experience into a caring, harmonious, and resilient team. There is indeed a time for everything: a time for celebration and a time for grief; a time for perseverance and a time for letting go. Together with concerted efforts, we can develop our world to be a better place, not just to live but also to die, and continuing a heritage that our future generations can inherit.
References