

Palliative Care: Setting the scene for the future

A Position Paper of Hong Kong College of Physicians

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EXECUTIVE SUMMARY

This paper aims to review and project the role of palliative medicine from the professional and service planning perspectives in Hong Kong, taking references from the global development of palliative medicine as a subspecialty and palliative care service.

Palliative medicine was established as a subspecialty under the Hong Kong College of Physicians in 1998 in response to the needs of the terminally ill, in particular the advanced cancer patients. There is expansion and growth of palliative medicine globally. Palliative care needs of non-cancer patients are evident, and its relevance to doctors in general practice or other specialties is increasingly recognized.

There is considerable evolvement in the training curriculum of palliative medicine in other developed countries, including

1. a structured pathway with revision to mandate training in general and acute medicine as a foundation,
2. establishment of a general curriculum to ensure basic competency of other doctors in palliative medicine,
3. incorporation of palliative medicine in the undergraduate curriculum of medical doctors.

Global development in palliative care has been accelerated by

1. increasing trend in recognition of palliative medicine as a subspecialty,
2. establishment of specialist palliative care service,
3. enhancement of palliative care knowledge in all relevant medical practitioners,
4. evidence-based guidelines or guidance and audits to ensure standard and quality,
5. government policy in place to promote equitable, quality end-of-life care as fundamental for all citizens.

Globally, although Hong Kong is among the places with established palliative care service, the following summarize the gaps or challenges locally in the light of ageing population and prevalence of chronic progressive diseases:

1. development of health care policy for care for the dying and palliative care,
2. promotion of palliative medicine as a career,
3. promotion of palliative care knowledge to non-palliative medicine specialists,
4. integration of palliative care teaching in undergraduate medical curriculum,
5. extension of palliative care to non-cancer patients,
6. service remodeling in response to changes in needs and health care system,
7. upholding quality and standard.

The Hong Kong College of Physicians sees the need for a timely review of palliative medicine at 10 years of its establishment; and recognizes that there is a growing need for palliative medicine specialists and palliative care service. The global experiences and the local challenges identified provide us a framework to deliberate on the specific strategies and actions – the steerage in navigating the way to quality and equitable palliative care for patients in need.

TABLE OF CONTENTS	P4
<i>DEFINITIONS</i>	P5
I. DEVELOPMENT OF PALLIATIVE MEDICINE: A GLOBAL PERSPECTIVE	
A. Establishment of the subspecialty	P 7
B. Evolution of curriculum for training in palliative medicine	P 8
C. Delineation of role of palliative medicine specialist	P 9
II. ROLE OF PALLIATIVE MEDICINE IN MODERN HEALTH CARE	
A. Palliative medicine and goals of medicine	P10
B. Ageing population and palliative care	P11
C. Different patterns of dying trajectory	P12
D. Chronic progressive disease and palliative care	P13
E. Palliative care in acute hospitals	P15
F. Palliative care and dying in place of choice	P17
G. Palliative medicine and evidence-based medicine	P18
III. PALLIATIVE MEDICINE AND PALLIATIVE CARE: HONG KONG SCENARIO	
A. Planning and recommendations of palliative care service in HA	P19
B. Professional development for palliative medicine physicians	P20
C. Quality and standard of palliative medicine and care delivery	P21
D. Challenges for future development of palliative care in Hong Kong	P22
IV. POSITION OF HONG KONG COLLEGE OF PHYSICIANS	P24
REFERENCES	P26
ANNEX	
Figures on palliative care workforce: UK and HK	P30
Prognostic guidance on referring non-cancer patients to palliative care	P31

DEFINITIONS

Palliative care

Palliative care is an approach that improves quality of life of patients and their families facing the problems associated with *life-threatening disease*, 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 affirms life and regards dying as a normal process; intends neither to hasten nor to postpone death; and adopts an interdisciplinary team approach to address the needs of patients and families.¹ (World Health Organization, WHO)

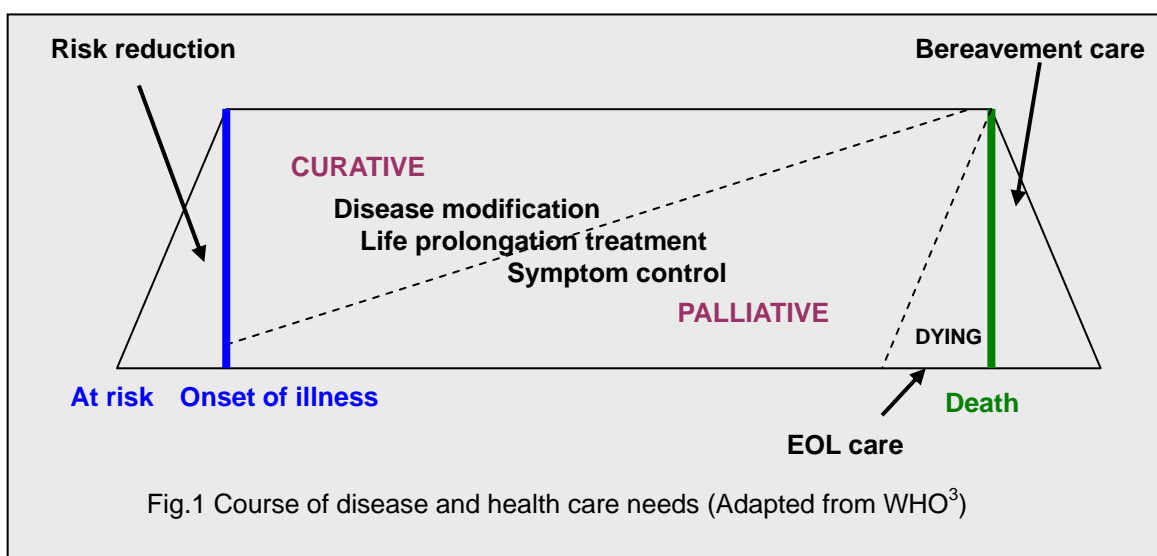
Palliative medicine

Palliative medicine is the branch of medicine involved in the treatment of patients with *advanced, progressive, life-threatening disease* for whom the focus of care is maximizing their quality of life through symptom management, psychological, social and spiritual support as part of a multi-professional team.²

Palliative care and End-of-life care

End-of-life care is an integral part of palliative care but not the whole of palliative care. On the contrary, palliative care is applicable early in the course of disease, in conjunction with other therapies that are intended to prolong life, and includes those investigations needed to better understand and manage distressing clinical complications.¹ (WHO)

As the disease progresses, treatment of curative intent, disease modification, life prolongation treatment will become less appropriate with respect to goals of care. (Fig. 1) When death is inevitable, end-of-life care aims at maximizing comfort. Bereavement care begins before death, and will be continued for family after death of patient.³



Specialist palliative care

In some countries including United Kingdom and Australia, palliative care is differentiated into general palliative care and specialist palliative care in terms of service delivery and professional training. Members of the specialist palliative care teams should include palliative medicine consultants (specialists), palliative care nurse specialists, together with a range of expertise provided by physiotherapists, occupational therapists, dieticians, pharmacists, social workers and those able to give spiritual and psychological support.

1. Components of specialized palliative care service include:³
 - Assessment, advice and care for patients and families in all care settings, including hospitals and homes
 - Specialist in-patient facilities for patients who benefit from the continuous care of specialist palliative care teams
 - Home support for patients with complex needs who wish to stay at home.
 - Day care facilities that offer assessment, review of patients' needs, and enable the provision of physical, psychological or social interventions.
 - Bereavement support services for the families
 - Education and training in palliative care
 - Audits and research in palliative care

One may find a plethora of related terms in literature. Indeed some of the definitions still vary from place to place, and also evolving as palliative care develops globally.⁴ In Hong Kong, the term “hospice care” is often used interchangeably with “palliative care”, though palliative care is more of a contemporary one. For simplicity of discussion here, no distinction is made between the two terms when applied to local scene.

Abbreviations:

PC = Palliative care

PM = Palliative medicine

EOL = End-of-life

QOL = Quality of life

I. DEVELOPMENT OF PALLIATIVE MEDICINE: A GLOBAL PERSPECTIVE

A. Establishment of the specialty/subspecialty

1. Palliative medicine was established as a subspecialty in Hong Kong under College of Physician since 1998.
2. Palliative medicine was first established as a specialty in UK in 1987. This has been achieved in Australia (2005), United States in (2006), and other European countries including Germany, France, Ireland, Poland, Romania and Slovakia. In Asia, Hong Kong (since 1998) and Taiwan (since 2001) are the two places where palliative medicine is a specialty/ subspecialty.
3. The development of palliative medicine as a specialty is fueled by patients' needs and other pre-requisites. The American Board of Hospice and Palliative Medicine (ABHPM) and the American Academy of Hospice and Palliative Medicine (AAHPM) released the state of the discipline of hospice and palliative medicine in November 2004, reporting on the progress of palliative medicine in meeting the criteria for a new subspecialty⁵ :

....hospice and palliative medicine is now ready to move from an “evolving” discipline to a “ready” discipline in the United States (because)

- *There is steady progress in terms of interest, need and infrastructure.*
- *The evidence base for the field has developed sufficiently to support an upcoming NIH State-of-the-Science Conference on Improving End-of-Life Care, eight peer-reviewed journals, and a dedicated review group of the Cochrane Collaboration.*
- *The number of physicians seeking certification is growing, the professional association is strong, and the formal training programs are expanding rapidly.*
- *The appearance of regular features, clinical practice articles, and research reviews in journals with broad readership, such as JAMA and NEJM, demonstrate the interest of the wider medical community in this field.*

B. Evolution of curriculum for training in palliative medicine

1. Training in internal medicine has now been recognized as an essential component of the curriculum for specialist training in palliative medicine.
 - 1.1 This evolves from the facts that: (a) patients dying from cancer are also likely to have concomitant medical diseases, (b) palliative care for non-cancer is developing, and many are dying from chronic progressive medical diseases and (c) although symptoms of non-cancer diseases can overlap with that of cancer, symptom control techniques are not necessarily transferable between that for cancer and for the specific disease.⁶
 - 1.2 In UK, vast majority of PM specialists go through the route of MRCP(UK) before entry into higher specialist training. For those with other recognized qualifications (FRCR, FRCA, MRCGP or MICGP) to begin with, it is stipulated that 2-year training in internal medicine is mandatory, of which 6 months are involved in acute non selected intake of patients.⁷

2. Some countries established pathways to training at two levels: specialist and 'general'.
 - 2.1 Given the enormity of palliative needs at different levels of intensity and complexity, and the relevance of palliative medicine to doctors in other specialties and general physicians, there are practical and genuine needs to establish pathways to training at two levels.
 - 2.2 This serves to (a) provide structured training of non-PM specialists to meet the less complex palliative care needs of patients effectively; (b) to interface palliative medicine with other respective specialties; and (c) yet maintain a distinct role for palliative medicine specialist in palliative care service.³
 - 2.3 In UK, the Joint Royal Colleges of Physicians Training Board has established 2 curriculums for training in palliative medicine: (a) the specialist curriculum and (b) the generic curriculum.⁷
 - 2.3.1 The generic curriculum can equip the GPs who care for the palliative care patients in the community with the support of palliative medicine specialists.
 - 2.3.2 The Royal College of Physicians has also recommended all doctors in other specialties to go through the generic curriculum for palliative medicine training to ensure a core competency in palliative care.⁸
 - 2.4 The Australasian Chapter of Palliative Medicine (Chapter of Adult Medicine Division, The Royal Australasian College of Physicians) has also created the Clinical Diploma in Palliative Medicine to help GPs and non-specialists in their own practice.⁹

- 3 Incorporation of palliative medicine teaching into undergraduate curriculum
 - 3.1 The best time to begin training in palliative medicine is at the undergraduate level. Instilling principles in palliative care foster a culture for acceptance of dying, while students also learn how to achieve cure or life saving. Though the content and the amount of related training in the undergraduate curriculum vary considerably from place to place, there has been progress in content and teaching method in some medical schools.
 - 3.2 In UK, a consensus syllabus is available for guidance of palliative medicine educators.¹⁰ Competing within a congested undergraduate curriculum is a known difficulty.
 - 3.3 In the medical school of Tzu Chi University in Taiwan, medical students learn their first lesson on death and dying in anatomy class. Dead bodies are donated by the bereaved families for dissection and medical students learn to know the corpse as a person and how to pay due respect to them. (Personal communication)

C. Delineation of role of palliative medicine specialist

1. The role or job description of a palliative medicine specialist helps in projection of workforce required as adopted in other countries:
 - leading role in a interdisciplinary palliative care team
 - clinical management of difficult and complex symptoms
 - delivery of palliative care in different settings, inpatient and home
 - administration of the service
 - conducting audit and research
 - coordination work with other stakeholders in the network of palliative care service
 - teaching and education
2. As the workforce of palliative medicine specialists is limited, clinical duties usually take priority when competing with other jobs. However, as teaching and education is important and yet time demanding, professional bodies have taken this into manpower projection explicitly.^{8,11}
3. The manpower projection, of course, also takes references from the epidemiology of the population, the modalities of service, and the projections of other common medical subspecialties. In UK, a comprehensive manpower projection of physicians and regular census of consultants in post are in place. The UK workforce data are included in Annex 1 for reference.¹²

II. ROLE OF PALLIATIVE MEDICINE IN MODERN HEALTH CARE

A. Palliative medicine and goals of medicine

1. Despite advances in medical science and technology, death is inevitable. While extending years of living is one of the triumphs of modern medicine, providing palliation and promoting comfort when cure is no longer possible are also the intrinsic goals of medicine since the times of Hippocrates (460BC -370BC). For patients whose life is limited, there is a need to improve the quality of life in the remaining days. A holistic approach is pivotal in order to address physical, psychological, social and spiritual needs; and this involves a paradigm shift from the biomedical model to one that is biopsychosocial-spiritual.
2. In November 2007, the Royal College of Physicians of United Kingdom released a report titled "Palliative care services: meeting the needs of patients".⁸ This report is visionary in giving recommendation on the development of palliative medicine and planning of palliative care service for the future, affirming the role of palliative medicine in present and future, taking into consideration factors related to ageing population, changes in disease epidemiology, increasing recognized palliative care needs, respecting choices of patients, effective models of care and more emerging evidences on best practice.
3. The foreword by Professor Ian Gilmore, President of Royal College of Physicians, succinctly pointed out the role of palliative medicine in modern health care – with much wider relevance both from patients' and physicians' perspectives:

"Palliative medicine has been recognized as a specialty by Royal College of Physicians since 1987...Originally born out of the need to improve the QOL for people with advanced cancer, the relevance of the specialty to any patient with advanced progressive illness requiring specialist input to improve their quality of remaining life is increasing recognized, and is one of the main themes of this report..."

A consequence of this underlies another theme of the report: that palliative care is relevant for most clinicians, not just palliative medicine specialists. The skills and knowledge required to give clinical palliative care during the final phases of a disease and to identify the point at which patients pass beyond remedy should be part of the training of all doctors....

How a society care for its dying is one indicator of its health...it is now time that the provision of clinical palliative care should be centrally supported with sufficient trained clinicians and adequate funding. The financial implications of this are significant, and the report makes recommendations for national funding and for workforce numbers."

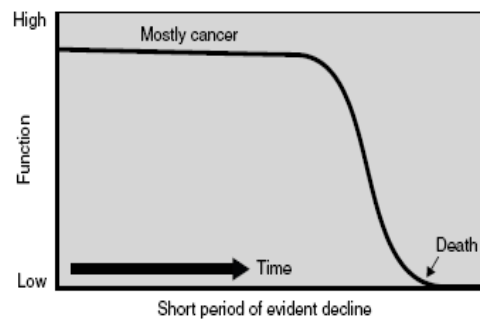
B. Ageing population and palliative care

1. The world is ageing, and the growth in population is greatest in the group of age > 60, and in some developed countries in the group of age > 80. Multiple chronic diseases and their accumulating effect on bodily function, and vulnerability to risks of treatment contribute to the complexity of health condition in older people. When it comes to the last year of life, mental confusion, poor bladder and bowel control, sight and hearing difficulties and frequent dizziness are common morbidities. Physical symptoms and psychological distress are often under addressed in the older people. *(Source: WHO)*¹³
2. Hong Kong is among the places with the longest life expectancy at birth. In 2006, life expectancy at birth was 85.5 yrs for female and 79.4 years for male.¹⁴ It is extrapolated that beyond year 2033, 27% of Hong Kong population is of age 65 and above, a significant rise from 11.7% in 2003.¹⁵ *(Source: Census and Statistics Department, HKSAR)*
3. Palliative care for older people has emerged as a public health priority and WHO emphasize on the importance of timely action to cope with the needs in future.¹⁶ Most deaths in developed countries occur in people of age 65 and above. Burdens on caregivers, who are also ageing, could be distressing. Older persons may have their own preferences or choices of life sustaining treatment, place of care and place of death, but these preferences may not be elicited or followed. Palliative care is appropriate to care of the older people in many ways, including symptom control, psychological support, care of the caregivers, respecting choices and facilitating advance care planning.
4. Advance Care Planning (ACP) refers to the process of communication among patients, their health care providers, their families, and important others regarding the kind of care that will be considered appropriate when the patient cannot make decisions. Patients' preferences for place of care and death, life sustaining treatment interventions and CPR are discussed and documented through this process. The advance directive (AD) serves more as a tool to achieve the goals in the broader process of ACP.
5. Modern medicine and health care postpones the age of death through healthy ageing. The expenditure in health care for older people is most intense in the last year of life, i.e. not when they are in healthy aging, but when they are not far from dying. It is well recognized that major health care savings could happen with policies to promote healthy ageing combined with that of appropriate end-of-life care.¹³

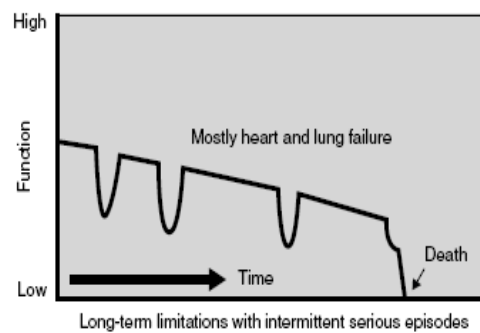
C. Different patterns of dying trajectory

1. In the older persons, the trajectory of their chronic illness falls typically into three patterns.¹⁷ (Fig. 2) The dying trajectory refers to the change in health status over time as a patient approaches death. Information about dying trajectories has implications for health care planning, medical decision making, and prognostication.^{17,18}

2. Patients with advanced cancer tend to have a predictable dying trajectory. They remain quite functional till the last 6 months, when they begin to decline at a rate which accelerates rapidly 2 to 3 months before death. Palliative care is appropriate in the last months.¹⁷



3. Patients who died from chronic diseases like COPD and congestive heart failure tend to have intermittent exacerbations among the long term limitations. Predicting death is generally more difficult, as each dip may well be the last. Ongoing disease management, advance care planning and palliative care approach will help to optimize care.¹⁷



4. Patients with marked fragility such as in recurrent stroke or dementia have a low functional capacity well before death occurs, and the last trajectory can be a lingering one lasting for several years. Substantial community support or institutionalized care is needed.¹⁷

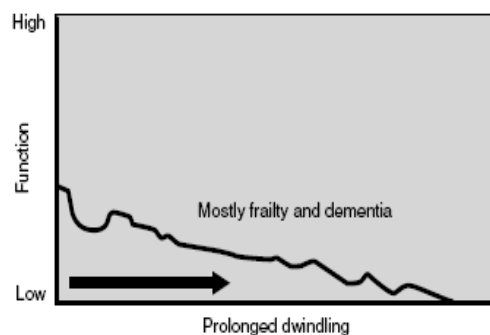


Fig.2 Trajectories of chronic illness in elderly. (Lynn J, Adamson DM. *Living Well at the End of Life: Adapting Health Care to Serious Chronic Illness in Old Age*, RAND WP-137, 2003. Reproduced with permission from RAND Corporation.)

5. In patients who died following aggressive life sustaining treatment in the intensive care setting, aggressive treatment may be continued till shortly before death. Data from a local ICU showed that transition from aggressive treatment to death occurred within 48 hours for half of the ICU deaths.¹⁹

- Overall, deaths from non-cancer diseases are far less predictable than deaths from cancer.²⁰ The transition from a curative to a palliative care phase can be blurred, and the end-of-life state may come unrecognized.

D. Chronic progressive disease and palliative care

- The disease pattern and the leading causes of death have changed considerably in the last century. Death from acute infectious diseases was superseded by that from cancer, heart diseases, stroke, chronic lung diseases and other chronic diseases.
- There are around 38,000 deaths in Hong Kong per year. Cancer is currently the leading cause of death in Hong Kong, accounting for one-third of all deaths. This is followed by heart disease, stroke, pneumonia, and chronic lung diseases.²¹ (Table 1)

Table 1: No. of registered deaths per 100,000 population²¹ (Source: Census and Statistics Department)

Cause of Death	2003	2004	2005	2006	2007
1. Malignant neoplasms	171.0	173.8	180.7	176.4	182.4
2. Diseases of heart	78.9	86.5	86.1	81.9	88.1
3. Pneumonia	57.6	54.2	63.0	61.3	68.6
4. Cerebrovascular diseases	51.4	50.4	50.4	48.2	50.2
All causes	541.1	550.2	567.8	545.6	577.0

- On further searching, deaths from cancer and from chronic diseases of lung, heart, neurological system and the kidney accounted for 50% of all deaths in Hong Kong.²²
- In the older persons with multiple chronic diseases, it may be difficult to identify with certainty a single disease as the major cause of death, though the system mandates so. Some diseases like dementia may remain undetected.¹³ This underscores the limitations of the mortality statistics in reflecting the change in disease epidemiology.²³
- Palliative care needs of patients dying from chronic progressive diseases are being increasingly recognized.²⁴⁻³³ Although these patients may suffer from different specific diseases, palliative care planning for these patients should base more on needs, and not the diagnosis. Evidences suggest that patients dying from non-cancer diseases also have palliative care needs or symptom burden no less than cancer patients; and yet with difficulty in access to palliative care.²⁴⁻²⁶ (Table 2)

Table 2: Symptom prevalence in cancer and other diseases (adapted from Solano et al ²⁶)

Symptoms	Cancer	Heart disease	COPD	Renal disease
Pain	35 - 96	41 - 77	31 - 77	47 - 50
Fatigue	32 - 90	69 - 82	68 - 80	73 - 87
Breathlessness	10 - 70	60 - 88	90 - 95	11 - 62
Insomnia	9 - 69	36 - 48	55 - 65	31 - 71
Anxiety	13 - 79	49	51 - 75	39 - 70
Depression	3 - 77	9 - 37	37 - 71	5 - 60

6. Development of palliative care for non-cancer lags behind that for cancer, and even in developed countries, equitable access is far from reality. In UK, a survey showed that palliative care provision for non-cancer such as ESRD is variable and still limited in some areas.^{34,35} In US, hospice admissions with non-cancer diagnosis are progressively increasing, accounting for 55.9% of all hospice admissions in 2006. (heart disease 12.2%, fragility 11.8%, dementia 10.0%, lung disease 7.7%, stroke 3.4%, kidney 2.9%, motor neuron disease 2.0%, liver disease 1.8%, HIV 0.5%, others 3.7%) (Source: *NPHCO*)³⁶

7. Developing palliative care for non-cancer patients share similar difficulties or barriers as that for cancer, if not more. Major attitudinal, behavioral, educational, and institutional barriers have been described, such as difficulty or reluctance of clinicians to identify the palliative phase; acceptability of palliative care among non-cancer patients; tension in resources, especially when trajectory of patients dying from non-cancer diseases can be longer and more unpredictable. Impediments to adequate pain treatment include health care providers' fear of inducing physical or psychological addiction, misconceptions about pain tolerance, and assessment biases.^{25,37}

8. Setting up referral guidelines for non-cancer patients based on more objective parameters for estimation of prognosis helps to identify and facilitate referral of these patients to palliative care service. In UK, the Prognostic Indicator Guidance was published for this purpose. The Guidance is part of the Gold Standards Framework (GSF) Programme, which is part of the national initiatives to achieve quality care for patients during their last year of life in the community.³⁷ The Prognostic Indicator Guidance serves to assist GPs who support these patients in the community. The Guidance includes the general predictors of end stage illness, and predictors for specific illness of cancer, heart failure, COPD, renal disease, motor neuron disease, Parkinson's disease, multiple sclerosis, dementia and fragility. (Annex 2)

E. Palliative care in acute hospitals

1. Deaths are prevalent in acute settings. The percentage of deaths in acute settings varies among places, but hospital deaths are usually higher in places where deaths in nursing homes or private residents are uncommon.
2. Provision of quality end-of-life care in acute setting is challenging.^{39,40} Barriers to EOL care in acute setting as identified include preoccupation with treatment or ward routine, negative perception of palliative care, difficulty in accurate prediction or diagnosis of dying, and difficulty in engaging in emotionally charging work of discussing withholding or withdrawing LST.³⁹ Other possible factors include lack of training of ward staff in palliative care approach; limitation of the physical setting and the visiting policy; and barriers to prescription of strong opioids for pain control. In US, the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatments (SUPPORT) is a multi-centered trial of intervention to improve EOL care.⁴¹ Phase one of the project involved an observational study of 4,301 hospitalized seriously ill patients. Results showed that only 47% of physicians knew their patients prefer no CPR; 46% of DNR orders were written only 2 days before death; 38% of deaths spent at least 10 days in ICU; and more than 50% of families reported moderate to severe pain in patients.
3. Access to palliative care in acute setting is necessary to improve end-of-life care to patients dying in different care settings, and ways to consider include:^{39,40,42}
 - Palliative care unit in acute hospitals
 - Consultative team to acute wards
 - Implementation of clinical pathway for care of the dying in acute setting
- 3.1 Palliative care unit in acute hospitals^{39,40,42}

As acute hospital admits the sickest group of patients, therefore the hospital is an important place for patients to access to palliative care. Historically hospice units first came into service as stand alone units. By now, many palliative care units have been successfully integrated into acute hospitals. A palliative care unit in an acute hospital has potential advantages:

 - 3.1.1 From the care perspective
 - Part of comprehensive care of cancer and non-cancer diseases
 - Continuity of care within same hospital compound
 - Smoother transition and exchange of information easier
 - Facilitate mutual referral between other specialties and palliative care

- 3.1.2 From a team perspective
 - Share of expertise within same hospital: other specialties, rehabilitation
 - Share of managerial support
 - Facilitate rotation of trainees
 - Flexibility of on call coverage
- 3.1.3 From sharing of common facilities and costing
 - Common central oxygen supply, blood bank, radiology, laboratory, mortuary
 - Reduces the burden of transferring patients to other places for investigation
 - Sharing overhead cost
- 3.1.4 From the perspective of promoting palliative care within the hospital
 - Acceptance by hospital management that PC is part of medical care
 - In-patient PC unit has an important educational role for staff in other units

3.2 Palliative care consultative team to acute wards^{39,40,42}

A palliative care consultative team serves needy patients in other sites; or when it is deemed inappropriate to transfer the patient out of the acute setting when death is imminent. The consultative team offers an alternative when there is no palliative care unit in place, but the actual implementation of palliative care measures often depends on that provided by the parent team.

3.3 Implementation of clinical pathway for care of the dying in acute setting

Clinical pathways can help to improve standard of care irrespective of place of death, more so when driven by policy and monitored by audits. One notable example is the Liverpool Care for the Dying Pathway (LCP), which is a key recommendation as stipulated in the NICE Guidelines for Supportive and Palliative Care.⁴³ The LCP provides an evidence based framework for the delivery of appropriate care for dying patients and their relatives irrespective of diagnosis and place of death. The pathway incorporates comfort measures, anticipatory use of drugs, and discontinuation of inappropriate interventions, psychological and spiritual care, and family support. The LCP has been rolled out across UK and national audit in acute hospitals is collaborated by the Marie Curie Palliative Care Institute Liverpool and the Royal College of Physicians.⁴⁴

4. Palliative care is also developing in the intensive care settings⁴⁵ – a place for aggressive life saving interventions. Nonetheless, a proportion of these ICU admissions will die in place and the transition to the point when interventions are futile often occurs within a short time frame. It is important that patients are offered palliation when life sustaining treatments are withheld or withdrawn.

F. Palliative care and dying in place of choice

1. In EOL care, one of the goals is to facilitate patients to live and die in the place of choice. This is a recommendation from WHO¹⁵, and also among the targets in the national policies for improving EOL care as in UK.⁴⁶ In UK, between 50% and 70% of people receiving care for a serious illness say they would prefer home care at the end of life, but the hospital or nursing home become increasingly to be actual place of death ⁴⁷ The actual place of death seems to be more related to delivery of service rather than patients' preferences.
2. Patients with preference expressed and recorded are more likely to die in place of choice, and promotion of advance care planning can help to respect choices of patients at EOL.
3. For patients who died in hospitals, and it is possible that with some strengthening of home care service, more patients are able to die at home as preferred.⁴⁸ Although dying at home may not be the preference of all patients, it is important that this is an available option and can be facilitated when so wished by patient. Dying at home requires coordinated support from the palliative home care team and other service providers in the community, in particular the family physicians and GPs.
4. Living and dying in place also requires a system and mechanism to ensure standard of care. The LCP as mentioned above is a tool that can be applied to different care settings, while the Gold Standards Framework as mentioned in section D para 6 of this paper adds to improve the palliative care for patients in community in their last year of life.⁴⁹ The GSF provides a range of tools, supporting strategies, training and accreditation standard in 3 streams: GSF for Primary Care programme, GSF for Care Homes programme, and GSF for other EOL care support.

G. Palliative medicine and evidence-based medicine

1. Palliative medicine, as in other branches of medicine, strives for evidence-based practice. Given the vulnerability of the dying patients, it is just as important for us to deliver care and practices that are substantiated by rationale, facts and evidences.
2. Despite difficulties in conducting studies in palliative care patients both in the methodological and ethical perspectives, evidences on palliative medicines are accumulating steadily in the past decades.^{50,51} Currently, there are eight peer-reviewed journals dedicated peer review group in Cochrane collaboration, systematic reviews in journals of high quality and wide readership.
3. More studies are now available to illuminate the best clinical practice in palliative care. Experts of professional bodies have played an important role in setting the standard of care by formulating recommendations according to the best evidence available. In UK, the NICE guidance on improving supportive and palliative care for cancer patients published in 2004 defines the standard of care in different levels and different settings.⁵² In Australia, the standard of accessible palliative care was developed by Palliative Care Australia, and published in 2005.⁵³ In US, the Clinical Practice Guidelines for Quality Palliative Care, a consensus paper of their five major Palliative Care Organizations, was published in 2004.⁵⁴ In 2008, the American College of Physicians published an evidence-based clinical practice guidelines in management of distressing symptoms in palliative care.⁵⁵ The American Thoracic Society published a clinical policy statement on palliative care of patients with respiratory diseases and critical illnesses, indicating the relevance of palliative care to patients in their own specialty.⁵⁶
4. There are more evidences to support the effectiveness of palliative care services. Various parameters have been employed, including clinical outcome of patients, well being of families, satisfaction with care provided, and cost effectiveness or savings.⁵⁷⁻⁶²

III. PALLIATIVE MEDICINE AND PALLIATIVE CARE: HONG KONG SCENARIO

A. Planning and recommendations of palliative care service in Hospital Authority

1. Palliative care service was first set up in Our Lady of Maryknoll Hospital in 1982. NGO played a major supportive role. It was not until 1994 that palliative care became centrally funded and coordinated by the government, under the auspices of Hospital Authority.
2. A comprehensive range of services has been developed in designated palliative care units, including inpatient care, out-patient care, home care, consultative service, day care and bereavement care. Inpatient palliative care beds were planned at a ratio of 38 beds per million population. Until now, palliative care is not well established in the private sector.^{63,64}
3. The recommendations for future palliative care service development in the MSDC paper on Service Development and Organization of Palliative Care (2004) is listed in table 3.

Table 3: Recommendations on future palliative care service in MSDC-P196, 2004

- i. **Each cluster should formulate a comprehensive palliative care service.** Patients who are highly symptomatic or distressed should be referred for Specialist Palliative Care. Inpatient units should have designated ward area served by a specialist-led multidisciplinary team. Projection of palliative care bed requirement should also take into consideration the age factor and distribution of cancer deaths.
- ii. Those who are less symptomatic or distressed can remain under the care of the original clinical team. A **cluster-based palliative care consultative program** should ensure provision of palliative care to all patients in need, and facilitate smooth transition from curative to palliative treatment. The palliative care team should offer advice and training to staff involved in care of cancer and other terminally ill patients.
- iii. **Career pathways** should be established for trainees in palliative medicine, so as to attract new trainees, and ensure sustainability of specialist-led palliative care service.
- iv. Apart from the training to **family medicine trainees**, further training to **private doctors** in palliative care could be arranged in the form of open lectures to course organized in collaboration with other organizations such as professional societies or academic institutions. This could enhance participation of private doctors in palliative care.
- v. Palliative care should be provided according to **established standards and guidelines** that are evidence based. Audits should be conducted to ensure adherence to guidelines and maintenance of standards.
- vi. In longer term, obstacles for **dying at home** would need to be rectified in order to smoothen the process of dying at home. Intensive multi-sectoral discussion and coordination will be required before such practice be accepted and realized as a norm.

4. Not all that were recommended have been materialized. Limitation of resources is one of the reasons behind. The future directions should be revisited, taking into consideration of the global development and the local factors. For example, palliative care for non-cancer patients should be included in planning with appropriate infrastructure to coordinate its development.

B. Professional development for palliative medicine physicians

1. Palliative medicine was first recognized as a subspecialty by the Hong Kong College of Physicians in 1998 and then by the Hong Kong College of Radiologists in 1999. The Hong Kong Society of Palliative Medicine was established in 1997.

2. Under the Hong Kong College of Physicians, specialist training in palliative medicine is coupled with specialist training in advance internal medicine.⁶⁵ This confers adequate training and competence in internal medicine.
3. The current curriculum of physicians' training recognizes rotation of physician trainees to palliative care units. Some palliative care units are also recognized training centres for family medicine trainees. At present, only limited sessions on teachings related to palliative care are instilled into the undergraduate training of medical students.
4. The career path for palliative medicine specialist is not well defined, though there is modest growth in number of specialists and higher trainees in the past years. In HA 2008, there are 13 palliative medicine specialists and 9 higher trainees in palliative medicine under the Hong Kong College of Physicians. The local projection of PM specialists available in 2011 is included in Annex 1.

C. Quality and standard of palliative medicine and care delivery

1. As assessed and reported by an international network that monitors the palliative care development globally, Hong Kong falls in the category of the most developed places of palliative care i.e. one of the 35 places in this category among a total of 234 places assessed.⁶⁶
2. Regular territory wide audit projects have been conducted in the HA palliative care units in the past to drive for quality, but ultimately we would like to know whether palliative care has made a difference to those who received the care at 10 years after the establishment of palliative medicine as a subspecialty under the Hong Kong College of Physicians.
3. A study on 494 cancer deaths in 2005 was conducted in 4 hospitals under HA, each with a physician specialist led palliative care unit attached.⁶⁷ The specialized palliative care service under studied covered 67% of the cancer deaths in 4 hospitals, and 50% of all cancer deaths occurred in the palliative care units. During the last 6 months of life, patients who ever received palliative care had significantly less acute ward admissions, shorter stay in admission wards, and less ICU admissions. Within the last 2 weeks of life, patients who ever received palliative care patients had significantly fewer invasive interventions initiated, more symptoms documented, more opioid and adjuvant analgesics prescribed, but were of better conscious level at 72 hours before death. These patients also had more DNR order in place and less CPR performed.

D. Challenges for future development of palliative care in Hong Kong

1. *Development of health care policy for care for the dying and palliative care*

Meeting the needs of the dying is a basic human right. Although palliative care is integrated into the public health care system in Hong Kong, the service can be very vulnerable when it is perceived as 'optional' or 'luxurious'. Appeal for new resources from the government for developing palliative care service has not been successful during economic downturn; and competition within existing health care resources is difficult as life saving services have their own natural appeal.

2. *Promotion of palliative medicine as a career*

Popularization of palliative medicine among the physicians remains a challenge. The scarcity of palliative medicine specialist in acute medical units also limits the opportunity for cross exposure. The career path for palliative medicine specialists is uncertain, yet the curriculum demands a committed professional. The growth in number of specialists in palliative medicine falls short of the needs envisaged. (Annex 1)

3. *Promotion of palliative care knowledge to non PM specialists*

Spreading of the relevant knowledge and skills to other doctors is limited by training capacity of the existing palliative medicine specialists and other institutional and external factors. Rotation of physician trainees to palliative care units is a variable practice and that of the family medicine trainees is often patchy.

4. *Integration of palliative care teaching in undergraduate medical curriculum*

In the undergraduate medical training, teaching in care for the dying was never heard of in the past, but there has been some progress in recent years. Some elements intrinsic of palliative medicine, for example good communication skills with dying patients and their families are in fact highly relevant to doctors in the womb. Enhancement of their exposure in the undergraduate curriculum serves to prime those who may be interested in this relatively young subspecialty and to equip all with the needful.

5. *Extension of palliative care to non-cancer patients*

Palliative care service is largely dedicated to cancer patients in Hong Kong. Although there are local initiatives to extend palliative care to non-cancer patients, its scale and structure are far less than that for advanced cancer patients. Future planning should go beyond cancer patients, and take into consideration the factors of ageing population, and the prevalence and morbidity of chronic progressive diseases.

6. *Service remodeling in response to changes in patients' needs and health care system*

- 6.1 Different modalities of palliative care service have their own merits and specific functions. Designated inpatient palliative care beds have a distinct role, and community based care has become an important direction of health care provision. Palliative care patients are supported and encouraged to stay with their families at home if possible.
- 6.2 Home care is important to support patients to stay in their familiar place and being together with family members as far as possible. Provisions of home care beyond office hours, networking with NGOs, training of carers in elderly homes are strategies adopted by other countries to approach this goal.
- 6.3 Consultative service has its role of extending palliative care service to various ward settings in all cluster hospitals as deaths are never confined to palliative care beds. Health care professionals in the acute wards often feel perplexed and poorly equipped in caring for dying patients and their families.⁶⁸ However, palliative care consultative service is not widely available, and current provision involves a drain on existing resources.
- 6.4 Day care service offers opportunities for patients to receive social activities, support groups, respite care for caregivers, or therapeutic interventions for symptom relief.

7. *Upholding quality and standard*

Quality and standard are enhanced by regular audits, quality research, evidence-based practice, establishment of guidelines and standard of clinical care, education and training, and on-site supervision by specialists. To ensure adequate specialist training in palliative medicine, it is necessary to have on-site palliative medicine specialist who dedicate most of the time to supervision and training. Hurdles to such development should be addressed. Evidence-based guidelines should be established at territory level.

IV. POSITION OF HONG KONG COLLEGE OF PHYSICIANS

1. The Hong Kong College of Physicians sees the need for a timely review of palliative medicine at 10 years of its establishment and to set the scene for the future.
2. The Hong Kong College of Physicians recognizes that medicine is not polarized to curative and palliative; or to aggressive and conservative. It is through interface, and not distinction, that palliative medicine and other relevant medical subspecialties can meet the complex needs of the changing population.
3. Palliative care applies to both cancer and non-cancer diseases, and is not restricted to the dying phase. Palliative care for non-cancer patients should be promoted. With ageing population and prevalence of chronic progressive diseases, there is a growing need for palliative medicine specialists and palliative care service.
4. However, the current numbers of palliative medicine specialists fall short of projected needs. Cultivation and exposure at undergraduate level is limited, and care for the dying is not attractive to most junior physicians. Career path for palliative medicine specialists is not well defined.
5. Training in general and acute medicine is a necessary part of training of palliative medicine specialists in response to the needs. The curriculum for specialist training in medicine should take this into consideration, and should be reviewed as needed so that specialist training in palliative medicine can be kept abreast of times.
6. The philosophy, skills and knowledge in palliative medicine are not just relevant to a few specialists but also to:
 - 6.1 undergraduates in medical school
 - 6.2 basic physician trainees
 - 6.3 higher physician trainees in acute internal medicine and specific subspecialties (such as: medical oncology, renal medicine, respiratory medicine, neurology, geriatric medicine, cardiology, critical care medicine)
7. The Hong Kong College of Physicians has its role as a prime mover in promotion of palliative medicine. While some of the goals can be achieved by coordination within the College, more has to be mediated through different platforms or stakeholders, including Hospital Authority, Hong Kong Academy of Medicine, University of Hong Kong and the Chinese University of Hong Kong.

8. While this paper outlines the future direction, a designated working group of professionals is required to formulate the strategies and action plans in details based on a framework applicable locally. (Table 4)

Table 4: A proposed framework for future planning

1. Needs assessment
 - Population
 - Disease pattern
 - Functional dependence

2. Professional training
 - 2.1 Palliative medicine specialists
 - Curriculum
 - Career pathway
 - Projected workforce
 - 2.2 Undergraduate training of medical doctors
 - Curriculum
 - Assessment
 - 2.3 Exposure to palliative medicine in basic and higher physician training
 - Rotation of trainees
 - Joint education programmes
 - Incorporation of palliative care modules in other subspecialty training

- 3 Service planning
 - Influence on policy and strategic planning
 - Advice on models of care and resource implications
 - Set up referral criteria for non-cancer patients
 - Interfacing with acute care
 - Collaborative model with other subspecialties

- 4 Quality and standard
 - Outcome measures or parameters
 - Evidence-based guidelines

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ANNEX 1: Figures on workforce in palliative care

(A) UK figures¹²

Ref: Royal College of Physicians. *Census of consultant physicians in the UK, 2006: data and commentary*. London RCP 2006. Available from <http://www.rcplondon.ac.uk/pubs/contents/7bbcd673-0492-4236-bbfd-39af3b72f918.pdf>. Accessed 18 May 2008.

UK figures as at 2006

No. of PC Service	Services: population (000) ratio	FTE PM consultants	Projected needs (FTE)	Projected FTE PM consultants to population (000)	Population (000)
1478	1:40	271	376	1:160	59668

Projected FTE consultants to population (000) ratio:

Cardiology	1:50
Endocrine	1:57
Gastroenterology	1:42
Geriatrics	1:36
Medical oncology	1:180
Neurology	1:43
Renal Medicine	1:102
Respiratory	1:42
Rheumatology	1:90

Percentage of projected FTE PM consultants to projected FTE consultants in all medical subspecialties as listed above = 3.7%

(B) Hong Kong figures

(Source: *Medical Manpower Planning*. Presented Dr. CS Li in *SMM Internal Medicine* on 23 October 2007)

	2007	2011
No. of PM fellows (private+HA)	14	23
No. of all physician fellows	1214	1780
% of PM fellows	1.2%	1.3%

Annex 2: Prognostic guidance on referring non-cancer patients to palliative care³⁸

Ref: Prognostic Indicator Guidance, Good Standards Framework, NHS. Available from http://www.goldstandardsframework.nhs.uk/content/gp_contract/Prognostic%20Indicators%20Guidance%20Paper%20v%202025.pdf Accessed 30 May 2008.

General predictors of end stage illness:

- Multiple comorbidities
- Weight loss more of than 10% over 6 months
- General physical decline
- Serum albumin <25g/L
- Reducing performance status / Karnofsky score (KPS) < 50%, dependence in most ADL

Heart disease – congestive heart failure

At least 2 of the following indicators:

- CHF NYHA stage III or IV – shortness of breath at rest or minimal exertion
- Patient thought to be in last year of life by care team*
- Repeated hospital admissions with symptoms of heart failure
- Difficult physical or psychological symptoms despite optimal tolerated therapy

Chronic obstructive pulmonary disease

- Disease assessed to be severe (e.g. FEV1 < 30% predicted)
- Recurrent hospital admissions (3 admissions in 12 months for COPD exacerbations)
- Fulfills LTOT criteria
- MRC grade 4/5: shortness of breath after 100meters on the level or confined to house through breathlessness
- Signs and symptoms of right heart failure
- Combination of other factors e.g. anorexia, previous NIV/intubation/resistant organism, depression

Renal disease

- Patients with stage 5 kidney disease who are not seeking or are discontinuing dialysis or renal transplant
- Patients with stage 4/ 5 kidney disease whose condition is deteriorating and thought to be in the last year of life*
- CKD stage 5 (eGFR < 15ml/min)
- Symptomatic renal failure (anorexia, nausea, pruritus, reduced functional status, intractable fluid overload)

Motor neuron disease

Indicators of rapid deterioration:

- Disturbed sleep due to respiratory muscle weakness in addition to dyspnoea at rest
- Barely intelligible speech
- Difficulty swallowing
- Poor nutritional status
- Needing assistance with ADL
- Medical complications e.g. pneumonia, sepsis
- Short interval between onset of symptoms and diagnosis
- A low vital capacity (<70% of predicted using standard spirometry)

* based on the surprise question: "Would you be surprised if this patient were to die in the next 6 to 12 months?" – an intuitive question integrating co-morbidity, social and other factors.