

PALLIATIVE CARE OVERVIEW

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INTRODUCTION

Objectives

The objectives of this overview are to define what is palliative care, its context in healthcare delivery, and its principles and practice, all with a focus on Singapore.

Growing importance

With the ageing of people worldwide, Singapore included, people living with and dying from advanced progressive illness are steadily increasing in numbers. The provision of palliative care services for such patients has become an essential part of the healthcare system deliverables.

METHODOLOGY

Information for this overview has been gathered from the following sources in the months of June and July, 2016:

- PubMed searches using the keywords “palliative care”, “hospice care”, “end-of-life care”, “advance care planning”, “review”, and “update” based on the literature mostly of the last 5 years.
- Local documents related to palliative care — national strategy documents, speeches.
- Hand-searched information from articles retrieved, journal references, and book chapters.

RESULTS

1. Definitions — What Are Hospice Care, Palliative Care, End-Of-Life Care?

Hospice care. Much of our understanding and knowledge of the philosophy, science and art of palliative care has developed and grown through the work of the hospice movement, e.g. Dame Cicely Saunders who worked with people suffering from advanced cancer, and undertook systematic narrative research to understand what patients were experiencing and needed. (Faull, 2012)(1). Her work is instrumental in defining the understanding and meaning of the term “hospice care”.

Hospice care has been defined “as care focused on the dying process and helping individuals who are terminally ill (and

their family and friends) pass through this process more comfortably. The care may be provided in the patient’s home or at a facility designed for patients who are dying.” The goals of hospice care are: “Manage pain and any other symptoms that cause discomfort or distress; create a comfortable environment for the patient; allow the patient to be close to family and loved ones during the dying process; give relief to the patient’s caregivers; and offer counselling for the patient and those close to the patient.”²

Palliative care. It is accepted that palliative care is a broader concept than hospice care. The term “palliative care ” was coined by Canadian urological cancer surgeon, Belfour Mount, to apply hospice principles more broadly, including within the hospital setting.¹

Palliative care as a concept pays attention to both the patient’s and the family’s needs and “uses a team approach that involves the treating doctor, the family, and other health care professionals and health services”.³

WHO defines palliative care as “an approach of care that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.”⁴

End-of-life care. End-of-life care is care needed by everyone as they approach the end of their lives. It is usually regarded as a focus on the last 6-12 months of life. The overall aims are to optimise the quality of care of the patient in the last months of his or her life, support carers and families, provide ongoing information for patients and carers, and also provide spiritual care services. This is the strategy of care for end-of-life in UK as well as many other countries.¹

One practical difficulty is the prospective identification of patients in the last 12 months of their lives. Much thought has been given to how indicators may help identify people with advanced illnesses. One tool that has been developed is the SPICt (Supportive & Palliative Care Indicators Tool). There are 4 items in the tool:

- Look for 2 or more general clinical indicators for health deterioration.
- Look for 2 or more clinical indicators of advanced, progressive illnesses.
- Ask the question: Would it be a surprise this patient died in the next 6-12 months?

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- Assess and plan for end-of-life care.

SPICt was developed by the University of Edinburgh and Lothian National Health Service in Scotland and is available for download at the URL: www.spict.org.uk/.

End-of-life discussion

The clinical indications for discussing end-of-life care can be grouped into urgent indications and routine indications (see Table 1). What should be included in the end-of-life discussion is shown in Table 2.

2. Issues In Palliative Care Worldwide

There are several issues in palliative care worldwide. A multiplicity of challenges faces the development of palliative care globally, but the issues are more pronounced in developing countries. HIV as a cause of death is a problem in some countries. In the developed world too, there are unmet needs to be resolved from end-of-life care of non-malignant diseases, for example among migrant communities. Availability of opioids can also be an issue. Capacity building issues towards a multidisciplinary approach in palliative care is another issue.

Multidisciplinary approach

The review paper by Vissers⁵ provides a timely update on the changing present and future landscape of Palliative Medicine, namely the development of the multidisciplinary team approach. In the 19th and early 20th centuries, palliative care was originally mainly provided by religious workers and volunteers under the guidance of some idealistic professional healthcare providers. This landscape has evolved with the addition of multidisciplinary members because of the realisation that with the increasing input of multidisciplinary knowledge, the incurable patient's quality of life can improve. In today's multidisciplinary team are a number of team members: FP, Nurse practitioner, medical oncologist, internists, surgeons, and even the anaesthesiologist for pain control. In the institution sector, physiotherapists, social workers, social nurses, spiritual care providers, and nutritional specialists also participate.⁵

To have a functioning team, all members must have acquired the minimal theoretical and practical skills of assessing a patient's symptoms, identifying unexpected changes in the patient's condition, and proposing changes in the management plan.⁵

Table 1: Clinical Indications for Discussing End-of-life Care

Urgent Indications:

- Imminent death;
- Talk about wanting to die;
- Inquiries about hospice or palliative care;
- Recently hospitalised for severe progressive illness; or
- Severe suffering and poor prognosis.

Routine Indications:

- Discussing prognosis;
- Discussing treatment with low probability of success;
- Discussing hopes and fears; or
- Physician would not be surprised if the patient died in 6-12 months.

Table 2: What To Include in End-of-life Discussion

General: Goals of Treatment

- Relative emphasis on life prolongation;
- Relative emphasis on quality of life;

Specific: Range of Interventions

- Advance directives — living will; healthcare proxy;
- Do not (attempt to) resuscitate (DNAR) orders;
- Other life-sustaining therapies, such as — Mechanical ventilation; feeding tubes; antibiotics; haemodialysis
- Palliative care — Management of pain and other symptoms; relief of psychological, social, spiritual, and existential suffering; creating opportunities to address unfinished business.

In Western countries, (and increasingly in Asia-Pacific countries too), the FP has a role as co-ordinator within this team and the general contact person of the patient when residing in the home situation.

The European School of Oncology has proposed the distinction between 2 levels of palliative care:

1. Basic palliative care — the standard of palliative care which should be provided by all healthcare professionals, in primary or secondary care, within their normal duties to patients with life-limiting disease; and
2. Specialised palliative care — the higher standard of palliative care provided at the expert level, by a trained multi-disciplinary team, who must continually update their skills and knowledge, in order to manage persisting and more complex problems and to provide specialised educational and practical resources to other non-specialised members of the primary or secondary care teams.⁵

Training

Different team members have specific tasks regarding the care of patients with advanced diseases. Hence, the training will have common and specific elements. The details are given in Visser's paper.⁵

3. Principles & Practice

World Health Organisation⁴

WHO has identified 9 principles of palliative care in its 2011 Statement. Palliative care:

- Provides relief from pain and other distressing symptoms;
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or postpone death;
- Integrates the psychological and spiritual aspects of patient care;
- Offers a support system to help patients live as actively as possible until death;
- Offers a support system to help the family cope during the patient's illness and in their own bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Enhances quality of life, and may also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

Generic palliative care needs (NSPC, 2011)

Patients with life-limiting illnesses have physical, psychological, social and spiritual needs. These needs interact

with each other in complex ways. There is a need for a comprehensive assessment of the patient's needs, including the symptoms to be palliated. Finally, there are also the bereavement care needs of the family and caregivers that must be met.

- Physical needs. More than 70 percent of patients with cancer will experience pain and about one third will experience breathlessness in the last one to two weeks of life (NSPC 2011, Teunissen & Kruitwagen, 2007). They may also experience symptoms of vomiting, nausea, insomnia, depression and loss of appetite. Patients with non-cancer progressive illness also experience similar symptoms in the last year of life.
- Psychosocial needs. Patients with life-limiting illness often experience fear of the unknown, fear of dying, loss of role, concerns about coping with the illness, fear of being a burden to their families, loneliness, and also depression. These needs are translated into caregiver arrangements, financial issues, and caregivers coping with providing care for the sick family member at home.
- Spiritual needs. Spiritual needs are important for people at all stages of life and in particular during the terminal and dying phase. Life-threatening illnesses evoke many questions such as the meaning of life, the meaning of suffering and the perception of hope. The individual's beliefs and values help sustain the patient through the illness, and patients should be supported during the course of the illness.
- Needs of family and care givers. Family members and caregivers play a vital role in caring for the patient with life-limiting illness. Family and caregivers need information and training on how to provide care for the patient, have access to respite care, emotional support and bereavement support.
- Comprehensive assessment of palliative care needs. Comprehensive assessment of patient needs and intervention can help relieve symptoms and improve quality of life for patients with life-limiting illnesses. Improvement of symptoms results in enhancement of patient and family satisfaction, functional status and quality of life.
- Bereavement Care. Bereavement support should be provided to family members before and after the patient's death. Family members with complicated grief may require counselling or psychiatric services.

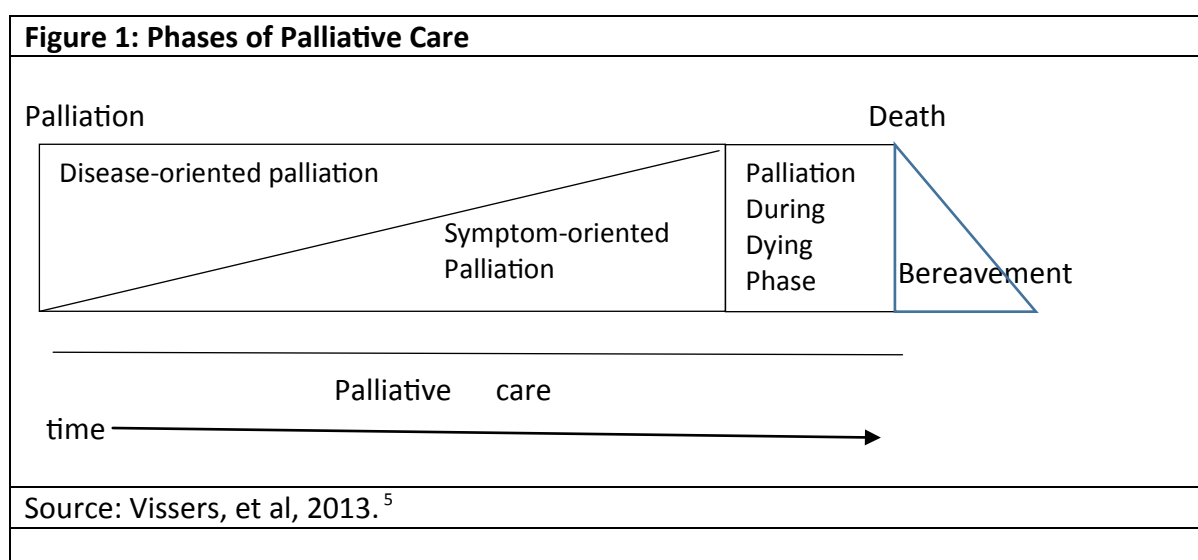
The palliative care journey

The palliative care journey that a patient goes through is made

up of three phases, namely, (1) Disease-oriented phase; (2) Symptom-oriented phase, where symptoms continue to mount and which require palliation; (3) End-of-life phase where the patient is dying and the journey ends with death. See Figure 1.⁵ Beyond the death of the patient is the bereavement aftercare phase that family members go through. Even for a destitute patient, those who looked after him or her in a long-term care institution will also need closure.

- Plan proactively and thoroughly for potential anticipated future problems.
- Use a team approach when listening to suggestions, views and involving resources for extra support at an early stage.

2. What do patients and their carers need? The uniqueness of each individual situation must be acknowledged and the manner of care adapted accordingly.



Three advanced disease illness trajectories

Initially palliative care concentrated on cancers. As the progress of medical care advanced and people lived longer, the advanced non-cancer diseases appeared in larger numbers — cases where, previously, death from short life expectancy prevented the unfolding of these non-cancer diseases. Chief of these are: end-stage renal, cardiac, respiratory, now also end-stage liver disease. Dementia has its own illness trajectory too. So today, there are three illness trajectories in palliative care. The symptom-time relationships of these three trajectories have been described by Murray.⁷ (See Figure 2.)

Achieving effective care

Several principles that add up to effective palliative care have been described by Christina Faull.¹ They are:

1. Know how to approach patients with advanced disease. There are 6 key principles here:

- Consider the patient and family carers as the unit of care while respecting patient autonomy and confidentiality, and acknowledge and encourage their participation.
- Perform a systematic assessment of physical, psychological, social, and spiritual needs.
- Communicate findings in the patient, providing information and support at all stages.
- Relieve the patient's symptoms promptly: "There is only today".

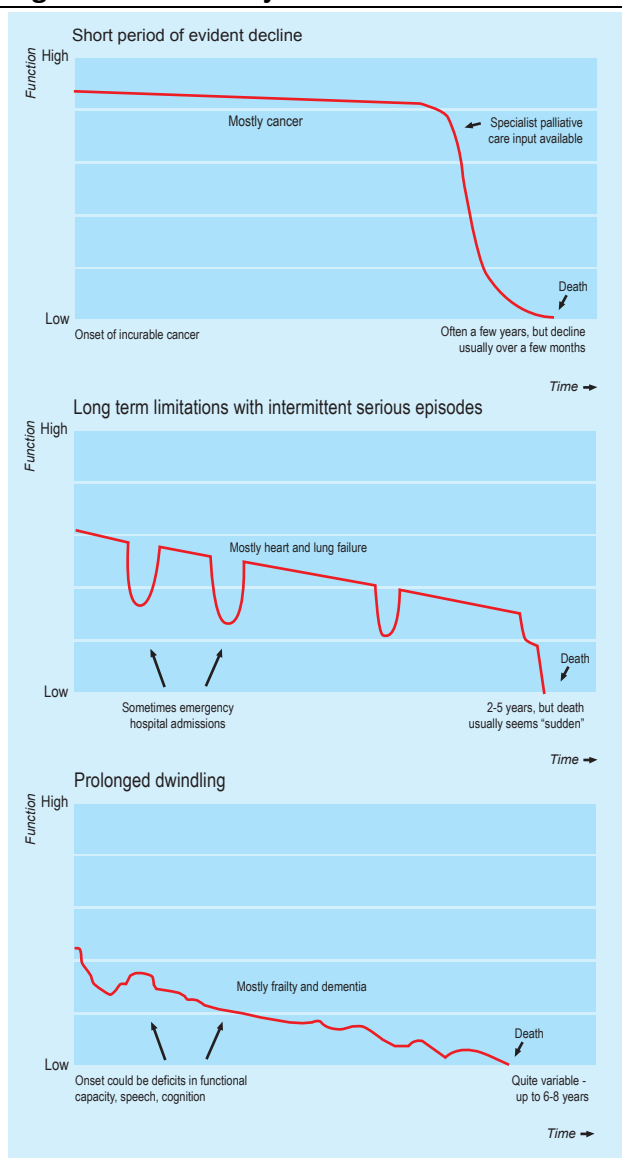
3. Achieve good symptom management. There are 7 points to note:

- Anticipation. Many physical and nonphysical problems can be anticipated and in some instances prevented. Example: Pain treated with opioids is likely to lead to constipation, unless steps are taken to prevent this.
- Evaluation and assessment. An understanding of the pathophysiology and likely cause(s) of any particular problem is vital in selecting and directing appropriate investigations and treatment. Examples: Sedation for an agitated patient with urinary retention is not as helpful as catheterisation; a patient who is fearful of dying may be helped more by discussing and addressing specific fears than taking benzodiazepines.
- Explanation and information. Management of a problem should always begin with explanation of findings and diagnostic conclusions. Example: A patient with advanced liver disease complains he has developed a tender lump in the chest. Examination showed it to be gynaecomastia, likely due to spironolactone. An explanation of this connection relieves his anxiety and he was prepared to continue with it, rather than risk ascites.
- Individualised treatment. Treatment options need to be shared with the patient.
- Re-evaluation and supervision. The symptoms of frail patients with advanced disease can change frequently and new problems can occur.

- Attention to detail. Example it is vital to ensure the patient has the prescription for the correct drug, can get it from the pharmacy, have adequate supplies to cover a weekend, and understand how to adjust it if the problem worsens.
- Continuity of care. No professional can be available 24 h and 7 days a week. To meet the patient's needs, transfer of information within teams and to those who may be called upon to provide care (e.g. out of hours services) is one way to ensure continuity of care.

4. Limits of symptom control. Symptom control can be problematic. Referral may be tried. There may come a time when the symptom is just persistent. Acknowledging to the patient how difficult the situation is, and not abandoning him or her because it is stressful for the professional to face is a point to remember.

Figure 2: Illness Trajectories



(1) Progressive cancer trajectory

Patients with progressive cancer have a gradual decline in physical ability over weeks, months or sometimes years. The patient's physical ability declines rapidly during the final days or weeks before death when the disease overwhelms the patient's functional reserves. There is a move towards initiating palliative care further upstream in the trajectory to interface with disease-modifying cancer treatment.

(2) Chronic organ failure trajectory

Patients with organ failure, especially heart and lung failure, have a gradual decline in physical function over many months or years, with episodes of exacerbations. During such acute exacerbations, the patient experiences worsening of the symptoms and is often needs admission to the hospital. Each episode may be severe and may result in death, although the patient often survives many episodes. The timing of death is often unpredictable and sudden. Specific needs for patients in this group include empowering patients and families on how to recognise symptoms and prevent the worsening of symptoms through the effective use of medications. Patients may require home oxygen and appropriate home adaptations. Home care teams can provide treatment at home to reduce the need for hospital admission.

(3) Dementia and frailty trajectory

Patients in this group start with a low baseline of cognitive and physical disability due to decreased cognitive ability (such as Alzheimer's disease or other forms of dementia), or frailty as a result of decreased reserves in multiple organ systems. Patients may survive many years and may succumb to an acute event, such as pneumonia. Patients in this group require the caregivers at home to meet basic needs of patients. In the absence of caregivers, these patients will require quality care in long-term care facilities.

Source: Murray, et al, 2005.⁷

4. Singapore — Towards a National Strategy of Palliative Care

Need

Need for palliative care is going to increase in the coming years; from the current 5000–6000 people to about 10,000 in the year 2020. Government recognises the increasing needs and is ramping up efforts to increase capacity to meet the demand, including building more hospice beds and CH palliative care beds.

It is a known fact that healthcare expenditure in the last year of life is very high. In the US, 6 percent of Medicare patients who die each year make up a large proportion of Medicare costs, estimated at 27–30 percent. Many patients also require more hospitalisation in their last years of life, which may not be consistent with their goals and preferences.

Training

To cope with the demand, there is a need to build capability. Training of palliative care providers is more developed compared to 5 years ago, with the availability of the following courses:

- Nursing: Certificate in Basic PC Nursing, Advanced Dip in Nursing (Pall Care), Specialist Dip in PC;
- Post-graduate course in Palliative Care for doctors;
- Grad Dip in Palliative Medicine (GDPM);
- Staff Registrar Scheme;
- AST training in Palliative Medicine;
- ELNEC; and
- ACP Facilitators course.

National strategy

In 2011, MOH commissioned the Lien Centre for Palliative Care to formulate a National Strategy for Palliative Care. A workgroup was set up and tasked to develop guidelines that promote good palliative and end-of-life care. Members of the workgroup comprise healthcare professionals from restructured hospitals, hospices, home care, Agency for Integrated Care (AIC), and representatives from the Ministry of Health (MOH). The workgroup's report has since been adopted by MOH.

Singapore landscape in palliative care as of 2011

In its Executive Summary, the NSPC Workgroup noted that:

1. The provision of palliative care services for patients living with or dying from advanced progressive illness is an essential part of the health care system.
2. Palliative care has developed rapidly around the world over the last 50 years to meet the complex and multiple needs of patients with progressive and advanced illnesses. Palliative medicine is now recognised as a specialty in many countries, including Singapore.
3. There are trends internationally to extend palliative care

from cancer to non-cancer patients, introduce palliative care early in the course of a potentially life-limiting illness, extending the provision of palliative care to all health care professionals, and develop integrated systems to deliver palliative care in a coordinated manner with involvement of doctors in primary care.

4. With the ageing of the population, the number of patients in Singapore who require palliative care will increase. It is essential to structure the health care system to deliver such care efficiently to an increasing number of patients facing progressive illness and disability towards the end-of-life.
5. Palliative care services in Singapore have developed over the last 25 years. It is offered in hospitals, hospices and at home. Palliative care is increasingly becoming a part of mainstream medicine and acknowledged as an essential part of the healthcare system. We have dedicated and passionate health care professionals in the palliative care sector.
6. Areas in which improvements can be made include coordination of care, recruitment of manpower, strengthening of capabilities, establishing standards of care; promoting public awareness on end-of-life issues, and leadership to develop palliative care sector.

Ten goals

Ten goals of national strategy and key recommendations were identified by the NSPC. These are:

1. All patients with life-limiting illnesses should be identified and their palliative care needs assessed.
2. All patients with life-limiting illnesses should be cared for by health care professionals using a palliative care approach. Patients with complex needs should have access to specialised palliative care services.
3. Palliative care should be delivered in a co-ordinated manner that ensures continuity of care across settings and over time.
4. Palliative care should be affordable to all who need it and quality care should be provided in a cost-effective manner.
5. There should be adequate health care professionals with appropriate training to meet the needs of patients at the end-of-life.
6. There should be adequate capacity to meet the palliative care needs of patients.
7. There should be local standards of care to ensure the delivery of good quality palliative care.
8. The acceptance and public awareness of palliative care services, advance care planning and bereavement services should be promoted.
9. Palliative care research should be promoted to improve the quality of palliative care and inform policy making.
10. There should be leadership and governance to guide the development of palliative care services in Singapore.

CONCLUSIONS

In this overview, the terms of hospice care, palliative care, and end-of-life care have been defined. The contextual issues of palliative care are the concerted efforts needed to develop palliative care in every country and to adopt a multidisciplinary approach. Principles and practice of palliative care can now be clearly defined. Singapore has a workable national strategy for palliative care and effort will be needed to achieve the 10 goals set up.

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