

# Why palliative care? Encountering challenging issues

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## Abstract

Palliative care is the active holistic care of patients with advanced disease. Management of pain and other symptoms and provision of psychological, social and spiritual support is important. Palliative care is multidisciplinary and aims to achieve the best quality of life for patients and their families. In this article, the concepts of palliative care and the current issues of particular interest including the debates about physician assisted suicide, end of life issues and the importance of raising awareness of these issues and the need for further development of palliative care skills with doctors are discussed.

## Introduction

The World Health Organisation (WHO) defined palliative care as 'an approach 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.'<sup>1</sup>

### *Palliative care aims to:*

- Affirm life and regard dying as a normal process
  - Provide relief from pain and other distressing symptoms
  - Integrate the psychological and spiritual aspects of patient care
  - Offer a support system to help patients live as actively as possible until death
  - Offer a support system to help the family cope during the patient's illness and in their own bereavement
- National Institute for Clinical Excellence (NICE)

## Who needs palliative care and who provides it?

Traditionally it has been thought that palliative care and hospice services only apply to those who are dying, but it has become increasingly evident that palliative care is often needed at all stages of the illnesses and in progressive diseases being malignant and non-malignant. Palliative care has been developed mainly for people with cancer but it can also help those with non-malignant diseases include respiratory, circulatory, renal and neurological diseases. Palliative care is a model that looks at a person as a whole that is, as an integrated combination of body, mind and spirit, situated within a particular family and cultural context.<sup>2</sup>

A hallmark of palliative care is often seen as expertise in pain and symptom control. Palliative care deals with all kinds of pain: physical, emotional and spiritual. Through assessment and management of such symptoms, in conjunction with therapeutic strategies where appropriate, palliative care adds life to years not necessarily years to life. This requires the investment of considerable amounts of time, effort and commitment. Good quality pain and symptom control should be a basic human right.

## Key words

Quality of life, interdisciplinary team, physician assisted suicide, end of life, medical education

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Because palliative care sees a variety of conditions in patients at different stages of their illness, it follows that palliative care teams offer a wide range of care. This may range from managing the physical symptoms in patients receiving active treatment for cancer, through treating depression in advanced disease, to the care of patients in the last hours of life. Palliative care may occasionally be used in conjunction with curative therapy while in some cases palliative treatment may be used to alleviate the side effects of curative treatment, such as nausea and vomiting associated with chemotherapy. Alternative medical treatments such as relaxation therapy, massage, music therapy, and acupuncture can relieve some cancer-related symptoms.

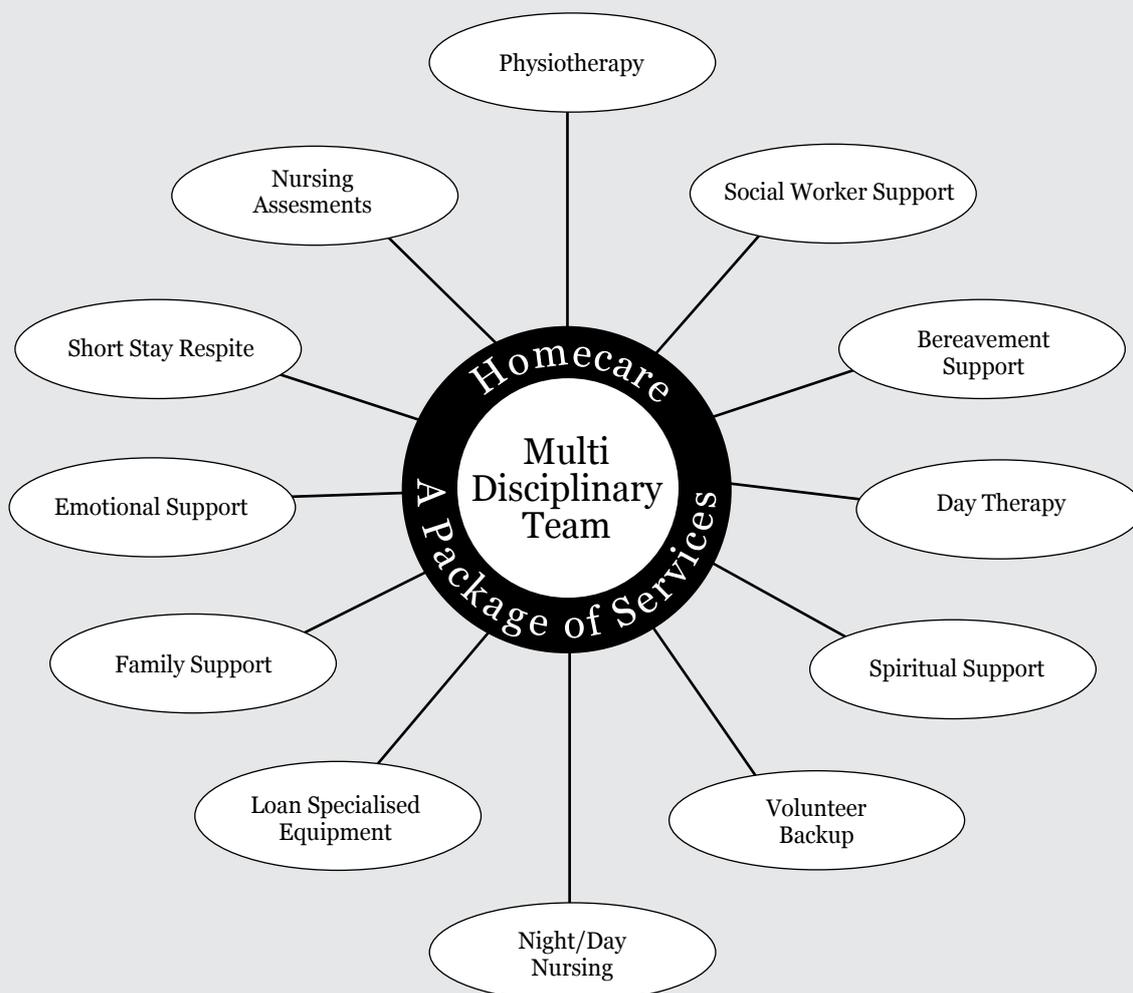
Palliative care has emerged as a specialised field. From the opening of the first modern hospice, St. Christopher's Hospice in London in 1967 under the leadership of Cicely Saunders, it has grown into a worldwide movement that has radically changed the approach towards death and dying.

So who provides palliative care? Palliative care draws heavily on a broad spectrum of disciplines, knowledge, skill, experience and creative thought. Medical practice has come

to a new understanding about the interplay of the physical, functional, emotional, psychological, social and spiritual aspects of wellbeing and more lately has supported the development of multidisciplinary approaches.<sup>3</sup> The team is usually made up of a specialist palliative care physician, nurses, pharmacist, social worker, occupational therapist, physiotherapist and spiritual and psychological counsellors. Other health professionals, such as complementary therapists, may be involved. Caregivers, both family and volunteers, are crucial to the palliative care system. The aim of the team is to treat individuals as unique and assess advice and care for patients and families in all care settings. Care is planned with patients in relation to their social and family contexts and extends to their carers, into bereavement.

The role of specialists in palliative medicine is to offer what has been learnt about palliation of malignant disease to those caring for patients with progressive, incurable, non-malignant conditions and to share and exchange best practice. Many symptoms experienced by cancer and non-cancer patients are similar: cancer patients' symptoms may be more severe, but those of non-cancer patients tend to be more prolonged.<sup>4</sup>

**Figure 1:** The Home Care Service offered by the Malta Hospice Movement



In Malta, the Malta Hospice Movement, within its young, fast-developing structure, continues to expand its vision of Palliative Care, by increasing its human, structural and organisational resources<sup>5</sup> (Figure 1).

Palliative care philosophy is becoming increasingly incorporated in medical education. Today, most people would have some contact with the health professionals prior to death and so all professionals should have some education in palliative care. Palliative medicine is a Speciality in the UK and there is specialist medical training programme. Training in basic palliative care should form part of the undergraduate and postgraduate curricula for healthcare professionals especially for doctors and nurses. In this way, health care students will have learnt how to care for the terminally ill and patients with progressive illnesses early in their course of studies, so that they will get sufficient exposure to cases as students. As Coles discusses, professional education is about preparing for practice, so caring for the terminally ill should start as early as possible.<sup>6</sup> Palliative care education is part of maintaining and continually develops quality in individuals and teams.

### **Palliative care: a solution for physician assisted suicide**

We are living in a complex world where ethical issues arise. The widely used ethical principles comprise respect for autonomy, beneficence, non-maleficence and justice.<sup>7</sup>

One particular ethical problem is that of physician assisted suicide. Recently in the UK, much attention has been paid to legalisation of the Lord Joffe's Assisted Dying for the Terminally Ill Bill that proposed giving doctors the right to prescribe drugs that a terminally ill patient in severe pain could use to end their own life. Under Lord Joffe's proposal, only people with less than six months to live (decision made by the attending physician), who were suffering unbearably and were deemed to be of sound mind and not depressed would be able to end their life. However on 12 May 2006, the House of Lords blocked this bill.<sup>8</sup>

A longitudinal study by Jaime Pacheco *et al.*, investigated whether attitudes toward physician assisted suicide and euthanasia are stable among 30 male patients with non curable malignancy. There was a trend for patients to become less supportive of legalising physician assisted suicide and euthanasia.<sup>9</sup> Among the terminally ill, a desire for death has been found to be common, but the desire tends to be transient and often linked to depression.<sup>10</sup> Furthermore, one cannot assume that the desire for death is synonymous with support for physician assisted suicide and euthanasia. A person may welcome death, but would not necessarily want to hasten death. Human beings can be remarkably resilient and adaptive in the face of negative life events, including illness and disability.

Even under the best of care, however, a small fraction of patients, probably less than 1%, will persistently wish to have death hastened.<sup>11</sup> These patients seem to be motivated more by concerns about not being able to function at a reasonable physical and mental level or about being a burden, rather than

because of physical discomfort.

No patient should turn to suicide because of treatable, reversible conditions such as pain or other physical suffering, loneliness, depression, anxiety, or concerns about being a burden on the family.<sup>12</sup> When patients ask for death to be hastened, the following areas should be explored: the adequacy of symptom control; difficulties in the patient's relationships with family, friends, and health workers; psychological disturbances, especially grief, depression, anxiety, organic mental disorders, and personality disorders; and the patient's personal orientation to the meaning of life and suffering.<sup>13</sup>

Palliative care is never futile. Physicians ought to use their skills to alleviate the medical conditions that cause suffering. Medical technology can be used to control symptoms and improve a patient's quality of life. Palliative care is a very active approach to symptom management and family support. When the patient's suffering is interpersonal, existential, or spiritual, then other health care professionals should be involved including the clergy, social workers, family, and friends in healing the aspects of suffering that are beyond the legitimate scope of medical care. We must solve the real and pressing problems of inadequate care, not avoid them through solutions such as physician-assisted suicide.

### **Life beyond a DNR order**

There comes a time when death is inevitable, so it is important to identify patients for whom cardiopulmonary arrest represents a terminal event in their illness and in whom attempted CPR is inappropriate. It is also essential to identify those patients who do not want CPR and who competently refuse it.

In a US study, SUPPORT, of dying patients held in a hospital setting, severe pain was common, decisions to withhold invasive treatments were made at the last minute, and physicians often had no knowledge of patient preferences not to have CPR.<sup>14</sup> This study was divided in 2 phases: a 2-year prospective observational study (phase I) with 4301 patients followed by a 2-year controlled clinical trial (phase II) with 4804 patients and their physicians randomized by specialty group to the intervention group or control group.

The phase I observation documented that only 47% of physicians knew when their patients preferred to avoid CPR: 46% of do-not-resuscitate (DNR) orders were written within 2 days of death; 38% of patients who died spent at least 10 days in an intensive care unit (ICU); and for 50% of conscious patients who died in the hospital, family members reported moderate to severe pain at least half the time. During the phase II intervention, patients experienced no improvement in patient-physician communication, no improvement in the incidence or timing of written DNR orders and the physicians' knowledge of their patients' preferences not to be resuscitated.

Aabom *et al* performed a retrospective cohort study in 3,445 patients who died as a result of cancer and showed that women and the elderly were less likely to receive a formal terminal

diagnosis (prognosis of death within 6 months). The formal terminal diagnosis reduces hospital admissions and increases the possibilities of dying at home.<sup>15</sup>

Palliative care is not simply a matter of withdrawing active treatment. Some palliative interventions may themselves be quite active (for example, paracentesis in tense ascites). A palliative approach does however mean proceeding with an intervention only when its benefit outweighs the burden it imposes. Refraining from resuscitation may be a choice that best respects the values and dignity of the patient and may reduce suffering or prolongation of the dying process. Palliative care can provide the supportive interventions and so the patient does not feel s/he is being ignored.



## Planning ahead

When a terminal illness has been diagnosed, clinicians have the opportunity to begin introducing palliative care concepts into the plan of care. The clinician should have ongoing transparent communication with the patient and the family about the patient's personal goals and the goals of treatment, provides the basis for truly honoring the patient throughout the course of disease until death. These care preferences can then be documented in a legal document.

Advance Directives or "living wills" are one category of anticipatory decision-making where a competent person makes known their views on what should happen to them medically if they lose the capacity to take their own decisions themselves. Advance Directives are only useful if they are legally binding and take effect only in situations where a patient is unable to participate directly in medical decision making.<sup>16</sup> If a patient changes his mind, as long as a patient remains competent to participate in medical decisions, the document can be amended.

Advance Directives to refuse treatment must refer to specified treatment in specified circumstances. Advance Directives which demand certain treatment, like resuscitation, are not legally binding. If a specified treatment is carried on despite that advance decision, the person carrying out that treatment would be liable for assault.

If the family disagrees with the patient's living will, the medical team should meet with the family and clarify what is at issue. The team should explore the family's rationale for disagreeing with the living will; however the family does not have much ethical basis and no legal power to sway the team.

Healthcare Research and Quality indicates that most patients do not participate in advance care planning, yet many are willing to discuss end-of-life care. One way to determine patients' preferences for end-of-life care is to discuss hypothetical situations and find out their opinions on certain treatment patterns. These opinions can help clarify and predict the preferences they would be likely to have, if they should become incapacitated and unable to take their own decisions.<sup>17</sup>

Living wills cannot cover all conceivable end-of-life decisions. For this reason it is recommended that patients communicate with their physicians and family members about their end-of-life wishes.

## Developing new skills

In order to help someone die with dignity, the clinician must understand the overview of the patient:

- His life and his views and who is important to him;
- The disease: the symptoms the disease is causing;
- The medical care system: what services are available;
- Understanding you own fundamental values.

## Doctors are commonly asked 'how long have I got?'

Communicating prognosis is a difficult task to do. When cure is limited, a prognostic judgment is often required for planning further medical/supportive care (e.g., timing of hospice referral), for counselling patients and families, and for establishing patients' eligibility to undergo specific clinical trials.<sup>18</sup>

Physicians know that their estimates are just estimates. Patients and families generally understand this as well. However, prognosticating carries with it some risks.

Overestimating the length of survival (the more common error, according to studies) leaves families feeling they have been robbed of time.<sup>19</sup> Underestimating the time left leaves the patient and family wondering when the end is about to appear, and perhaps questioning the credibility of the source of that information. All involved need to realise that estimates are not guarantees, and that conditions at this time of life may change rapidly.

Prognostic indices based on clinical predictors have been developed for use in estimating prognosis. Identifying the clinical markers predicting short-term survival is important to help develop prognostication skills. Some of these predictors have been combined to produce prognostic indices, such as the Palliative Prognostic Score, where combining performance status, anorexia, dyspnoea, and white cell abnormalities with the clinician's estimate, may help to guide towards an accurate prediction.<sup>20</sup>

In conclusion, when predicting length of survival it is most useful to have observed the patient over a period of time, to understand the illness, and to have a sense of psychological and social issues involved. It is of course important to have ongoing good communication with the individual and his family.<sup>21</sup> Good communication encourages openness and honesty with the patient and family.

## Conclusion

As Dame Cicely Saunders says ‘You matter because you are you. You matter to the last moment of your life and we will do all we can not only to help you die peacefully but to live until you die.’

It is easy to set up goals but in the real world one is faced with challenges and difficulties to achieve these goals. The healthcare professional should have a sensible attitude towards the terminally ill and the dying and must possess knowledge and skills in dealing with these patients. Palliative care is important not only because it aims to improve quality of life; many other skills in palliative care are useful in other health settings: empathy, listening, communication, identification of problems, developing priorities and working with, and developing, inter-professional teams so that the patient gets the right care at the right time.<sup>22</sup> The training for health professionals should include self-awareness about death, communicating bad news, guidance with paperwork and legal issues, the stages of grief, patient’s perspectives on dying, hospice care, and physician well-being.<sup>23</sup>

Physicians have a responsibility towards the patient, must have respect for human life, and must have a sensitive approach to care.

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