Introduction

Part 1

Chapters

1 Setting the scene

Figure 1.1 Terms associated with caring for dying people

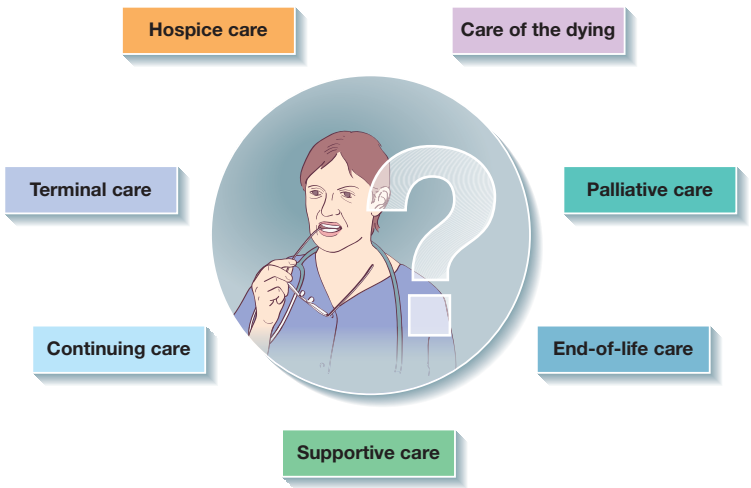

Figure 1.2 Palliative care workforce

Patient carers	Families, friends, neighbours and social care workers
Nursing care	General nurses and specialist nurses
Medical care	General practitioners Specialists in palliative medicine Specialists in other areas of medicine
Social care	Social workers, counsellors, social services, wide array of community-based services including non-registered health and social care workforce
Spiritual care	Chaplaincy, faith advisors
Therapists	Occupational therapists, physiotherapists, speech and language therapists, art, drama, music therapists, nutritionists
Volunteer workers	From a wide range of backgrounds, including patients, relatives

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Introduction

The aim of this book is to provide an overview of current issues in supporting dying patients and their families in the community (patient's own home, nursing/residential setting), hospice or in an acute hospital setting. This introduction to palliative care is about the care of people facing death, both those who will die and those who accompany them – families, friends, community workers, volunteer workers and healthcare and social care workers. It is estimated that every year more than 20 million patients need palliative care at the end of life.

What is palliative care?

The use of specialist palliative care services is based on an assumption that people share a common understanding of the terminology and purpose of palliative care. Definitions and terminology are poorly understood and not agreed. Some of the terms used to describe palliative care are shown in Figure 1.1.

There is now a drive in many developed countries, including the United Kingdom, to introduce palliative or supportive care much earlier in the course of an illness or the so-called 'illness trajectory'. One definition of palliative care is:

'Palliative care is an approach that improves the quality of life of patients and their families facing the problems 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.' (WHO, 2014)

Palliative care:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten nor 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;
- will enhance quality of life and may also positively influence the course of illness; and
- 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.

It is helpful to differentiate between 'specialist' and 'generalist' palliative care. The National Council for Hospice and Specialist Palliative Care Services (2002) differentiates between general palliative care, which 'is provided by the usual professional carers of the patient and family with low to moderate complexity of palliative care need', and specialist palliative care services, which 'are provided for patients and their families with moderate to high complexity of palliative care need. They are defined in terms of their core service components, their functions and the composition of the multi-professional teams that are required to deliver them.'

Who receives palliative care?

Access to palliative care typically relates to the availability of services, the funding models of healthcare and the nature of disease. In the United Kingdom, despite repeated calls to widen access to patients, whatever their diagnosis, who are nearing the end of life, approximately 95% of those referred to hospices have cancer.

Where is palliative care delivered?

Palliative care is a 'philosophy of care'; therefore, it can be delivered in a variety of settings, including institutions such as hospitals, in-patient hospices and care homes for older people as well as in people's own homes. Most patients with advanced illness are in the care of the primary healthcare team, consisting of general practitioners, community nurses and associated healthcare and social care professionals. Care is therefore delivered in patients' homes, where they spend the majority of their time during the final year of life.

Home is overwhelmingly the preferred place of care for the majority of people (Gomes and Higginson, 2011). General practitioners and community nurses may make referrals to specialist palliative care providers. Specialist palliative care services themselves offer a range of provision, from a single specialist nurse to a comprehensive multi-disciplinary team. Specialist palliative care services have developed an array of different types of provision and include the following:

- In-patient units – hospices
- Hospital teams
- Community teams
- Out-patient clinics
- Day care
- Respite services
- Bereavement support services
- Alternative and complementary therapies
- Counselling and psychological support
- Spiritual and religious support

Who provides palliative care?

There is a risk that in providing a list of who provides palliative care some people may be overlooked. With this in mind, Figure 1.2 offers a broad overview of the types of individuals and agencies that may be engaged in providing both paid and unpaid palliative care.

References

Gomes B and Higginson I (2011) International trends in circumstances of death and dying amongst older people. In Gott M and Ingleton C (eds). *Living with Ageing and Dying: Palliative Care for Older People*. Oxford: Oxford University Press. pp. 3–19.

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WHO (2014) http://www.who.int/mediacentre/news/releases/2014/palliative-care-20140128/en (accessed 1st July 2015).