

Introduction to Palliative Care

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Introduction

The essence of palliative care is the relief of suffering.
—Derek Doyle

Advocates for both palliative care and human rights are increasingly recognising the link between these two powerful disciplines rooted in respect for human dignity.

The World Health Organisation defines palliative care as an 'approach that improves the quality of life of patients and their families facing problems associated with life-threatening illness, through the prevention and relief of suffering, the early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

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 bereavement;
- Uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- Will enhance the quality of life, and will also positively influence the course of illness;
- Is applicable early in the course of illness, in conjunction with other therapies that are implemented to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

(WHO August 2002)

Among the features of palliative care that make it conducive to a human rights approach are:

- The goal of palliative care is quality of life. Quality of

life relates to an individual's subjective satisfaction with life and a quality of life assessment usually looks at four domains: physical, social, emotional (psychological) and spiritual (existential). Quality of life changes as an individual's experience and expectations change.

- The unit of care is the patient and family. Patient-centred care requires open and honest communication with the patient, respect, sharing of information in words the patient understands, mutual agreement of goals of care and treatment options. The family's views are important but should not supersede the patient's wishes.
- Palliative care provides total care: physical, psychosocial and spiritual. No one element of care is more important than another, although it is true that when a patient is in severe pain, it is difficult for the patient to focus on psychosocial issues until the pain is controlled.

WHO definition of Palliative Care for children

Palliative care for children represents a special, albeit closely related field to adult palliative care. The WHO definition of palliative care, appropriate for children and their families, is as follows (the principles apply to other paediatric chronic disorders):

- Palliative care for children is the active total care of the child's body, mind and spirit, and also involves giving support to the family.
- It begins when illness is diagnosed, and continues regardless of whether a child receives treatment directed at the disease.
- Health providers must evaluate and alleviate a child's physical, psychological and social distress.
- Effective palliative care requires a broad multidisciplinary approach that includes the family and makes use of available community resources; it can be successfully implemented even if resources are limited.
- It can be provided in tertiary care facilities, in community health centres, and even in children's homes (the child's own home, community home or institution).

Terms you will read in this chapter:

Advocate: to speak on behalf of another person or group

Continuum of care: a gradual transition of care without abrupt changes in care or cessation of care

Dichotomy: separation between two different approaches

Existential: relating to or affirming human existence, concerned with one's place in the world

The WHO definition was developed with care of patients with advanced cancer in mind so that chemotherapy and radiation therapy are identified as important therapies intended to prolong life that should be offered in conjunction with palliative care. With other diagnoses, therapies that should be considered include antiretroviral (ARV) treatment in HIV/AIDS, anti-failure medication in heart failure and renal dialysis in renal failure.

Palliative care includes all aspects of care, medical and non-medical, and as such is described as total care. This aligns with the WHO definition of health as a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity. The requirement for a multidisciplinary team is clear in order to be able to provide this comprehensive care. Many health care professionals have viewed palliative care as a 'soft option' and equate it with withdrawal of care. However, palliative care is active therapy, assessing and managing difficult symptoms and psychosocial and spiritual issues. Appropriate assessment of patient problems enables the care team to develop an individualised care plan for each patient in consultation with the patient.

Palliative care can best be understood in its fundamental sense as a response to suffering – the suffering of patient and family members when faced with the diagnosis of life-threatening illness. Inasmuch as both are concerned with the alleviation of human suffering, palliative care has much in common with the modern human rights movement. Derek Doyle expresses suffering as the distress associated with events that threaten the intactness or wholeness of the person and describes the appropriate response to suffering as multidisciplinary palliative care, as described in the table below.

| Cause of patient suffering | Palliative Care response |
|----------------------------|-------------------------------------|
| Pain | Treatment of pain |
| + other physical symptoms | & other physical symptoms |
| + psychological problems | & psychological problems |
| + social difficulties | & social difficulties |
| + cultural issues | & cultural issues |
| + spiritual concerns | & spiritual concerns |
| = Total suffering | = Multidisciplinary palliative care |

Continuum of care

1. Traditional view of Palliative Care

The traditional view of palliative care developed in the 1960s, with disease-oriented treatment such as chemotherapy or radiotherapy for oncology patients (who were then told 'there is nothing more we can do'

before being referred to a palliative care service), has been challenged. Disease-oriented care and palliative care are not 'an either-or' option but a 'both-and' option.

The separation of the two led to patients experiencing a sense of abandonment by their doctors and a sense of failure on the part of the doctors. The 'false dichotomy' between disease-modifying treatments for HIV/AIDS or cancer and palliative care must be overcome. In the HIV setting, even patients near death from AIDS may recover and lead functional lives with ARV therapy. Further, uncomfortable symptoms in AIDS patients are sometimes best treated with ARV therapy or aggressive treatment of opportunistic infections, while pain and symptom control may improve adherence to ARV therapy and quality of life (see Diagram 1 overleaf).

2. Palliative Care in the developed world

In the developed world, supportive and palliative care is (ideally) offered to patients alongside disease-oriented and life-prolonging care. Care is holistic and patient and family-centred. This results in better patient care, better bereavement outcomes and a more satisfactory professional experience. All clinicians are trained in palliative care and can provide this care to patients at the same time as providing disease-oriented care. So the oncologist will prescribe pain medication as well as chemotherapy. The HIV clinician will manage the pain of oesophageal candidiasis as well as prescribing fluconazole as antifungal treatment (see Diagram 2 overleaf).

3. Palliative Care in the developing world

In the developing world, with its limited resources, fewer disease-oriented options are available for patients and their families so that supportive and palliative care is an increasingly important part of holistic patient care. With more health care professionals training in palliative care, this can be integrated earlier into the caring relationship, creating better results for the patient, family and healthcare professional. Palliative care is then provided in other care settings and not only by hospices, although hospices remain the specialist centres for providing palliative care whether in the patient's home or in a hospice in-patient facility.

The result of early intervention, with active palliative care, is better quality of life for patients and families, a peaceful and dignified death for the patient and better bereavement outcomes for the family. The professional satisfaction of effective compassionate care results in a rewarding experience for the health care worker, both personally and professionally, and a lower incidence of burn-out.

The diagram also illustrates that disease-oriented care (chemotherapy, radiotherapy, antiretrovirals) is often not available to many people at the time of diagnosis because of limited resources and results in discrimination against the poorer members of society. This discrimination in

provision of health resources requires urgent attention and efforts to scale-up palliative care must be linked to or accompanied by efforts to simultaneously pilot and scale-up comprehensive HIV/AIDS care, including ARV therapy or cancer control programmes (see **Diagram 3 below**).

Diagram 1



Diagram 2

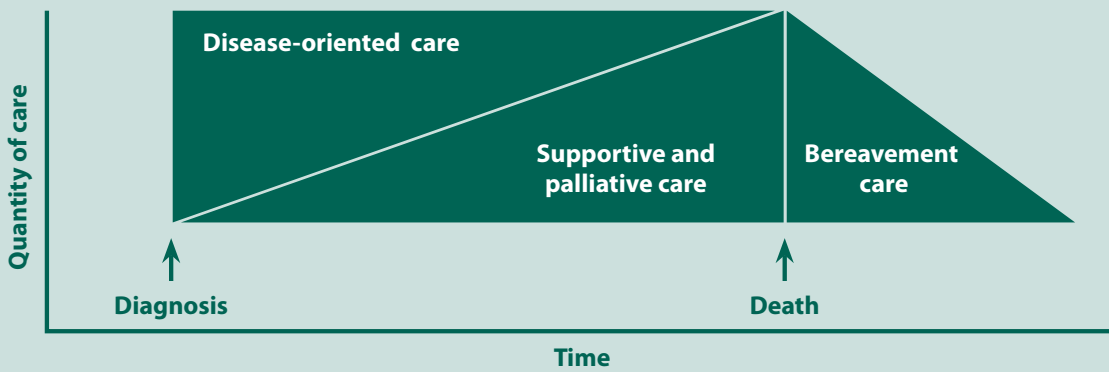
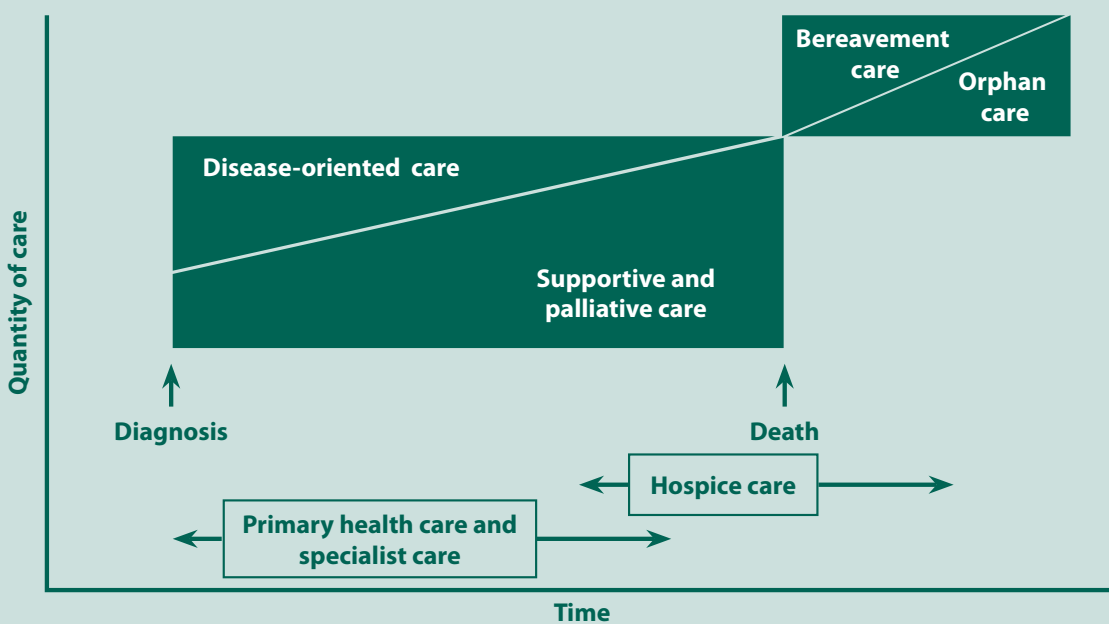


Diagram 3



Barriers to Palliative Care

Although it appears to be a straightforward exercise to ensure accessibility of palliative care to all patients requiring this service, there are still a number of significant barriers to access to palliative care. Clinical staff, doctors and nurses may not have the necessary training to understand or to provide palliative care. They do not see their role as providing palliative care and they see referral to a hospice service as 'giving up' on the patient. Many doctors do not have the communication skills to compassionately address end-of-life issues although this is changing as these skills are now taught in medical school and many doctors avail themselves of continuing professional development opportunities to develop these skills. There is a lack of institutional standards for the provision of palliative care.

Patients may continue in denial of the severity of their illness. They may have unrealistic expectations of disease response. There may be patient and family disagreements about treatment options and there may be lack of advanced care planning.

Social factors that are barriers to palliative care include discrimination against minorities and disempowered groups such as refugees, prisoners and homeless people. There may also be language barriers in accessing palliative care. Hospices may not be established in rural communities. Access to palliative care may equally be denied to wealthy patients whose doctors choose to continue active treatment even when futile.

There are other access factors that are barriers to the provision of palliative care, such as transport costs to health care facilities for seriously ill patients, the fact that there are no government subsidies for palliative care and no physician reimbursement for palliative care. There may be inefficient procurement processes in remote clinics/hospitals and some palliative care drugs not held at Community Health Centres in spite of their being on the Essential Drug Lists.

These barriers need to be addressed if all patients requiring palliative care are to access that care. This requires education of health care workers and policy makers; raising awareness of the benefits of palliative care within communities; and addressing patient and family concerns. The outcome of accessible palliative care is better quality of life for patients, compassionate support for patients and families and the development of caring communities.

Place of care

In South Africa, palliative care has traditionally been provided by hospices. This has led many people to view palliative care as *end of life* care. Hospice care and terminal care are important aspects of palliative care but palliative care starts from the moment of diagnosis of a life-threatening illness. Palliative care can be delivered in the most appropriate setting for the individual patient and his/her family as is specifically described in the definition of palliative care for children. The majority of patients are cared for in their own homes, but palliative care can also be carried out in hospitals, clinics, the frail care setting, hospice in-patient units and prisons (if the prisoner is not released home for terminal care). Patients do not need to travel to a facility to access palliative care. Palliative care staff take the care to the patient. Palliative care can be delivered as in-patient care, out-patient care and home care. Continuity of care depends on good communication between health care workers in the different settings and on co-ordination of care, usually by the patient's home care nurse.

The WHO public health model for the implementation of Palliative Care

In an attempt to increase access to palliative care for patients and families facing the diagnosis of life-threatening illness, the World Health Organisation has identified a public health strategy for effective national palliative care programmes that consists of four parts:

1. National palliative care policies and guidelines that incorporate palliative care into the public health system;
2. Laws and regulations that make readily and responsibly available opioid analgesics and other essential palliative care drugs;
3. Education in palliative care for healthcare providers, government officials, patients and caregivers;
4. Implementation of clinical palliative care programmes.

The time is right for the South African government to develop and implement a palliative care strategy to promote access to quality palliative care for all patients with a diagnosis of a life-threatening illness. The skills and expertise to achieve this are available within the palliative care community of South Africa and as described in Chapter 2 the foundation for palliative care as a human right is established.

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