

HOSPICE AND PALLIATIVE CONCEPTS

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Session objectives

By the end of this session, participants should be able to:

- Describe the concept of Hospice
- Define palliative care
- Discuss the history of palliative care
- Explain the scope and nature of palliative care
- Discuss the principles of palliative care
- Describe the different models of palliative care
- Discuss the concept of total pain
- Discuss the challenges in offering pc.

The Hospice Concept

- “Hospes” Greek
- “Hospitium” Latin

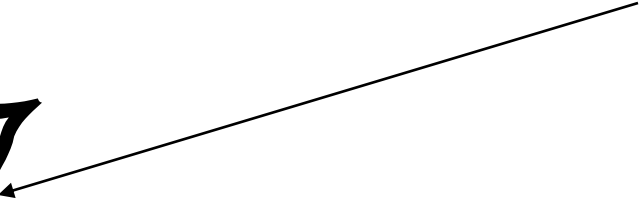
→ Hospitality



Hospice



Hospital:
(reformation)



The Hospice Concept

- Hospices date far back, they were looked at as guest houses for travellers.
- Fabiola, a holy woman from Rome provided **hospitality** for pilgrims to the holy land 300 years after Christ.
- She called the facilities for pilgrims and the sick, Hospices.

The Hospice Concept contd

- Hospice is not a building.
- It is a philosophy of care that focuses on patient comfort and quality of life.
- It incorporates pain and symptom relief allowing the patient to die with dignity.

WHAT IS PALLIATIVE CARE?



WHO definition of palliative care

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 **using a holistic approach**.

WHO 2002

palliative care ct'd.....

Palliative care has a different approach, it sees that people are more than just physical bodies and recognizes people have a mind , spirit and are part of a family, and community (holistic)

Palliative care is all about looking after people with incurable (life limiting) illnesses, relieving their suffering and supporting them through difficult times.

palliative care ct'd....

- *provides relief from pain and other distressing symptoms;*
- *affirms life and regards dying as a normal process;*
- *intends neither to hasten or postpone death;*
- *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 patients illness and in their own bereavement*
- *uses a team approach to address the needs of patients and their families.*
- *Is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life.*

History of Palliative Care (PC) movement

- Introduced in 1967, by Dame Cicely Saunders (a British) who was initially a Nurse, then became a Medical Social worker and later Physician.

History of Palliative Care in Uganda

- It started in September 1993 at Nsambya Hospital by Hospice Africa Uganda under leadership of Dr. Anne Merriman.
- Terminally ill patients were cared for in hospital and in their homes.
- In 1993, government of Uganda accepted to import morphine in the country to control pain.
- To deal with problem of inadequate competent staff, Dr. Anne started palliative care training sessions to health workers at Makerere University medical school.

History cont...

- In 1994, the first Palliative Care nurse joined the Palliative care team.
- In 1998, Palliative Care services were expanded beyond Kampala with establishment of Mobile Hospice Mbarara and Little Hospice Hoima.
- Other agencies like Kitovu Mobile Home Care and Mildmay Uganda came on board.
- Later, WHO declared pain relief as a Human right and this greatly contributed to successful introduction and roll-out of Palliative Care services in Uganda.

History cont...

- In 1998, the first Palliative Care Conference was held in Entebbe that resulted into a working committee to get established, chaired by Dr. Jack Jagwe, to discuss development of Palliative Care in Uganda.
- The committee influenced change of statute in Parliament that allowed Ugandan Nurses and Clinical Officers (trained in Palliative Care) to prescribe Morphine—this was 2002.

History cont...

- Thereafter, the Country Team Palliative Care Committee was established with members from Hospice Africa Uganda, Mildmay Uganda, TASO, Cancer Institute, Ministry of Health and Kitovu Mobile Home Care.
- 2003, PCAU registered as an NGO and first PCAU Conference happened the same year.
- 2005, APCA Secretariat opened in Uganda.

History cont...

- 2008, Mulago Palliative Care Unit got established with a Consultant Palliative care Physician .
- 2009, Mildmay Uganda became a Beacon centre in Paediatric Palliative Care with support from Diana Fund.

IMPORTANCE OF PC

- Palliative care and pain treatment is a basic human right. (World Hospice day 2008)
- Prevents and relieves suffering for the patient and family.
- Improve Quality of living, dying and bereavement.



Principles of Palliative Care

- Holistic approach
- Patient centred care
- Teamwork and partnership
- Involve and support family
- Appropriate ethical considerations
- Continuum of care

Models of palliative care

- Health facility based
- Home-based
- Outreach services
- Day care
- Road side clinics.

Health facility-Based model

- The service is delivered at health facilities as an outpatient or inpatient, referrals made to ensure continuity of care. Patients access specialised services more easily.

Home Based Care (HBC) Model

- Involves delivery of a comprehensive package of care to the patient and the family at home.
- Be sensitive and respect the culture and beliefs of the patient and family.

Home based care



Outreaches Model

- Outreach care is provided away from the main health facilities to a designated centre facility mainly in the community.
- Outreach gives a chance to those who are too ill or too far to reach the health provider; encourages patient centred care.
- Allows palliative care providers to train, advise and support general health care workers and volunteers attached to palliative care outreach sites.

Day Care Model

- Day set aside for patients (and their carers) to spend time with other patients in a health facility or community environment
- Patients socialise
- Enables the patients and carers to relax
- Day care can be ran by a team of volunteers and clinical staff
- Day care also allows for meeting the patients psycho-social and spiritual needs

Community day care

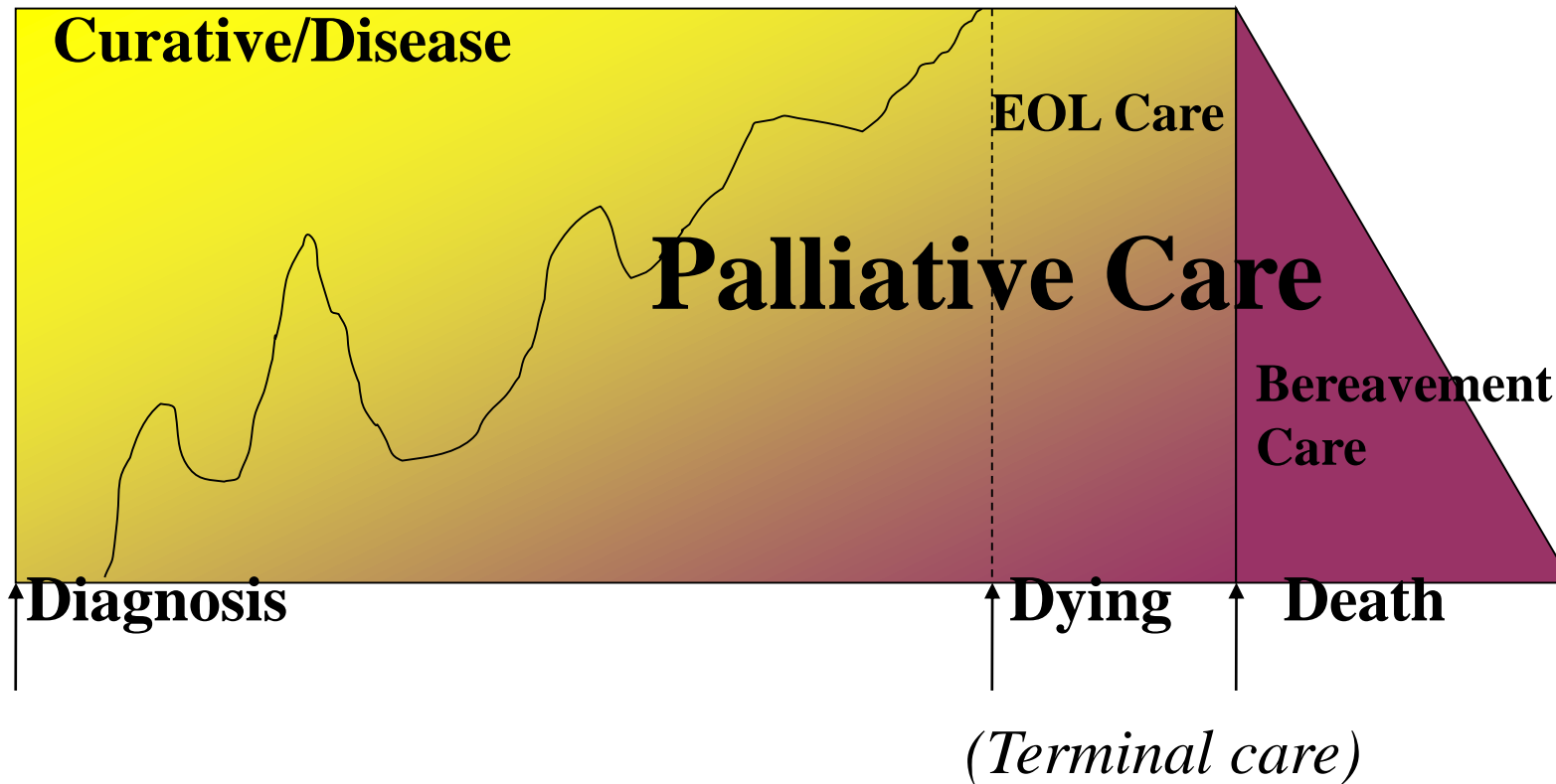


Road side Clinics

- These are stopover clinics on the way to an outreach



When is palliative care needed?



Who needs palliative care?

All persons with a life-limiting condition irrespective of age or setting.

- HIV and AIDS
- cancer
- end-stage lung disease
- Sickle cell disease.
- severe kidney or heart failure
- other progressive, incurable diseases

What is different about PC?

- holistic care (looking at the patient as ‘whole person’)
 - physically / psychologically / socially / spiritually
 - open communication
 - symptom control
 - family support
- Palliative care emphasizes that all these four areas of need are important.
- it aims not to prolong life or to shorten it, but to improve quality of life for all the time that is left.

Concept of Total Pain

physical



social

psychological

spiritual

Physical

Pain
Other symptoms
Drug side effects
Exhaustion

Psychological

Anxiety about future
Grief over losses
Fear of pain/death
Depression



Social

Worry about family
Loss of income
Loss of role in family
Social isolation
Stigma

Spiritual

Why me?
What will happen when I die –
is there life after death?
Why am I ill – is it a
punishment from God?
What value has my life had?

What issues does he have?



CHALLENGES

- PC is a new field of Medicine in Africa.
- Attitude - health professions have a negative attitude towards palliative care
- Lack of drugs
- Health System Issues - shortage of trained staff
- Educational Issues - health professionals' lack of knowledge

Challenges ct'd.....

- Myths & misunderstandings
- Funding
- Orphan crisis
- Increasing demand for PC

“The harvest is plentiful, but the workers are few.”

-Matthew 9:37

Summary of key points

- Hospice is a concept not a building.
- The patient and family are the centre of care.
- Palliative care uses a holistic approach to improve quality of life of patients and their families.
- Palliative care starts from the time of diagnosis till bereavement.
- Palliative care can be provided through different models.

Dame Cicely said...

“You matter because you are
YOU

You matter up to the last
moment of your life

And we will do all that we can
to help you

To LIVE until you die”



In Palliative care,

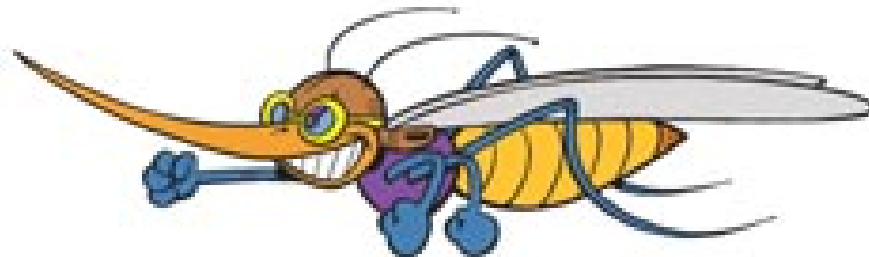
There is never nothing we can do

There is always something we can do

If you think you're too small to make a difference?

Try going to bed with a mosquito.

African Proverb



Together we offer Holistic care





Thank You