

# PALLIATIVE CARE INTRODUCTION

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# Presentation outline

- History and overview of palliative care
- Aims of Hospice
- Definitions
- Objectives of palliative care
- Principles of palliative care
- Core members of palliative care
- The roles of a palliative care nurse specialist in Uganda

# HISTORY AND OVERVIEW OF PALLIATIVE CARE

- The original Hospice go back to Fabiola, a Roman matron who opened her home for the poor, travellers, hungry, thirst and the sick
- At that time the word Hospes(Greek) meant both host and guest, and the word Hospitium(Latin) meant the place where hospitality was given

# Con't

- Today hospice is a philosophy of care. Hospice is not a building but;
- A philosophy of care that believes that pts have rights and are able to help in caring for themselves. Hospice recognizes the rights of pts and their families in decision making
- Hospice has a variety of team members, may include nurses, Drs, social workers, community workers, physiotherapists & occupational therapists. This team works together as a family

# Introduction con't

- Palliative care: The word “palliative” comes from the Latin word “pall” meaning a blanket or cover.
- This denotes the all-embracing (holistic) and comforting aspects of palliative care.
- The word was used for the first time in exchange for the word Hospice, in Canada in the 1970's.
- The people of Canada had used the word Hospice to mean a house where people who had no other supports were sent to die

# WHO definition of palliative care

- Palliative care is an approach that improves the quality of life of patients and their families facing problems associated with life threatening illness, thru the prevention & relief of suffering by means of early identification & impeccable assessment & treatment of pain & other problems, psychosocial and spiritual.

# Goals of Palliative care

- To maximize the quality of life for the people living with HIV/AIDS and or cancer as well as their family members
- To minimize suffering through provision of a comprehensive health package

# Objective of palliative care

- It is to meet the physical, psychological, social and spiritual needs of the individuals and their families facing life threatening illness while remaining sensitive to their cultures and beliefs



# Objectives con't

- Uses a team approach to address the needs of the patient & their families, including bereavement, counseling & if indicated
- Will enhance quality of life & 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, & includes those investigations to better understand & manage distressing clinical complications

# Importance of Palliative care

- Provides relief from pain & other distressing symptoms
- Affirms life & regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychosocial & 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

# Con't

- **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

# Principles of palliative care

- There are majorly 4 principles of palliative care;
  1. Management of pain and other related symptoms. This involves the use of both modern and local interventions i.e. non pharmacological and pharmacological measures. Pain can be spiritual, social, physical, emotional and psychological. Therefore being free of pain is a human basic right.

# Con't

2. Psychosocial support. This involves psychological and social aspects i.e. a counselor, patient, and family members need to work together for a common goal
3. Team work and partnership i.e. no single health worker can adequately address a patient's problem or needs alone
4. Appropriate use of medical ethics w/c are;
  - Do good
  - Do no harm
  - Consider patient's rights to decision making (respect for the patient)
  - Maintain fairness

# Essential components of palliative care

- Pain and symptom control
- Support care; this includes all components of holistic care

# Core members of palliative care

- These include;
  1. Health professionals e.g. nurses, Drs, C/os etc
  2. Supportive staff e.g. social workers, occupational therapists, physiotherapists, counselors, auxillarystaffs etc
  3. Community members such as volunteers
  4. Community health workers, traditional healers, spiritual care supporters etc
  5. Family members e.g. all relatives, friends etc
- Note; All the above have an important role to play in provision of palliative services to patients

# Holistic care

- This is the care of the whole person incorporating physical, psychological, social & spiritual aspects.
- Holistic care approach understands the pt as whole being in the context of his/her environment
- The environment is made up of family members, friends, cultural leaders, spiritual leaders, traditional healers etc
- It also understands the pt's specific needs and responds to them individually. It uses a multidisciplinary team to achieve total care for the patient and family



# THE INTRODUCTION OF PALLIATIVE CARE IN UGANDA

- Hospice Uganda was established in Kampala September 27th 1993.
- The concepts of hospice and palliative care are well accepted in Uganda but the delivery of services have been severely contained by limited resources

# Palliative care in Uganda

- People living with HIV in developing countries can therefore expect a shorter life span, & their death is likely to be unnecessarily painful & undiagnosed
- Care for the dying is not new & different cultures have different approaches to help these people at the end of their lives
- Palliative care is based on a model developed in response to the needs of cancer patients. It aims to make death a pain free process which includes support, comfort & relief of symptoms making it possible for people to die with dignity

# Con't

- For people with HIV, palliative care is an essential part of treatment, not only as death approaches but also thru the treatment of potentially fatal symptoms of opportunistic infections
- Such treatment, while not curative, never the less prolongs life for considerable periods of time & restores quality of life
- The HIV epidemic has led to increased efforts to provide care & support for people in their homes.
- While this has been a great step towards the care that people need, many home care projects are unable to provide the pain relief & treatment of symptoms that are needed to prolong life & ease dying and death

# THE ROLE OF PALLIATIVE CARE NURSE SPECIALIST IN UGANDA

- The role of palliative care nurse specialist is multifaceted beyond prescribing drugs, their role is to deliver holistic care
- They encounter numerous challenges in their work but they also have the possibility to improve the quality of the patients' life

# Con't

- Palliative therapy was introduced in Uganda in 1993 by Dr. Anne Merriman, the founder of hospice Africa.
- When you go to a health centre, the health workers only focus on the disease, but there are other social, or even spiritual issues that affect the patient, which needs to be addressed

# Attributes of palliative care

- These include:

1. Total, active and individualized patient care
2. Support for the family
3. Interdisciplinary teamwork and
4. Effective communication.

Results reinforce that cure and palliation are not mutually exclusive categories.