Concepts of Palliative Care
And PC Overview in Kenya
Palliative Care in Kenya - History
Global scenario

- According to the International Union against Cancer (UICC) report, CANCER is the leading cause of death globally.
- It accounted for 7.9 million deaths (around 13% of all deaths) in 2007.
- The number of deaths due to Cancer is set to surpass those of HIV/AIDS, Tuberculosis and Malaria combined.
- Cancer affects every body regardless of social class, race, gender or age.
Cancer and HIV/AIDS in Kenya: the reality

- **Cancer** and **HIV/AIDS** have become the commonest life threatening illnesses in sub-Saharan Africa in the 21st century (WHO 2002).

- **1.4** million Kenyans are living with HIV/AIDS and require palliative care (KAIS 2007).

- **7.8%** of Kenyan adults aged between 15-64 are infected with HIV (KAIS 2007).

- Every year, there are approximately **85,000** new cases of cancer in Kenya (WHO).

- Most cancers in Kenya are **diagnosed late** resulting in a shift of treatment goals from cure to palliation.
Disease burden in Africa

• Three-quarters of cancer deaths occur in developing countries where the resources needed to prevent, diagnose and treat cancer are severely limited.

• The World Health Organization (WHO) projects that over the next ten years Africa will experience the largest increase in death rates from cardiovascular diseases, cancer, respiratory diseases and diabetes

Most patients with cancer or HIV/AIDS will suffer from severe pain due to:

- the disease itself
- other concurrent illnesses
- the medication they are taking
- Over 80% of patients with cancer have moderate to severe pain
- Over 50% of PLWHIV have moderate to severe pain
## Estimate of the burden of pain and end of life care for Cancer & HIV/AIDS in developing countries

<table>
<thead>
<tr>
<th>Diseases</th>
<th>Terminal patients</th>
<th>Prevalence of moderate to severe pain in terminal phase</th>
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<tbody>
<tr>
<td></td>
<td>$N^\circ$</td>
<td>$%$</td>
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<tr>
<td>HIV/AIDS</td>
<td>2,866,000</td>
<td>50%</td>
</tr>
<tr>
<td>Cancer</td>
<td>3,600,000</td>
<td>80%</td>
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<tr>
<td><strong>Total</strong></td>
<td><strong>6,466,000</strong></td>
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PALLIATIVE CARE

Its origin is in the Latin word pallium, meaning a cloak. It means to mitigate the sufferings of the patient, not to necessarily effect cure.

HOSPICE

• Not a building.
• Is a philosophy of care,
HOSPICE

- “Hospes” Greek
- “Hospitium” Latin

Hospital: (reformation)

Hospitality

Hospice
PALLIATIVE CARE HAS TWO ESSENTIALS

• **Supportive care** (present in and home care teams before the advent of PC)
• **Pain and symptom control using the methods researched since 1967**

• The following are not palliative care:
  ➢ Supportive care without pain and symptom control using the researched methods
  ➢ Pain and symptom control without supportive and holistic care

• Pain and symptom control is being grafted onto supportive programmes in Kenya
Palliative Care

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.

Palliative care

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process;
- Intends neither to hasten or 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;
Palliative care......

- Uses a **team approach** to address the needs of patients and their families, including bereavement counseling, 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.
• **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. (WHO August 2002)
Special Principles of PC for patients with HIV/AIDS

Comprehensive PC for PLWH should integrate:

- HIV Prevention and Counselling
- OI prophylaxis and treatment
- ARV therapy
- Palliative care
There is no contradiction between ARV therapy and PC. A balance always should be sought between disease-modifying (ARV) therapy, curative therapy of acute complications such as OIs and palliative care.

- Every effort should be made to treat AIDS pts with ARV therapy
- **Pain & other distressing symptoms**, weather caused by the disease or side effects of medications, should be treated at any stage of HIV disease
- In later stages of progressive HIV Disease, many patients will have an increasing need for PC including comprehensive symptom control and psychosocial support
Essential components of palliative care

- Pain and Symptom control
- Effective communication
- Rehabilitation
- Continuity of care
- Breaking bad news
- Psychosocial care
- Spiritual care
- Social care
- Terminal care/ End of life care
- Support in bereavement
- Education
- Research
A MODEL OF COMPREHENSIVE PALLIATIVE CARE
Quality of life and suffering?

Multidimensionality!

Somatic

Spiritual

Functional

Existential

Psychic

Social

Suffering
Total PAIN

PHYSICAL

PSYCHOSOCIAL

EMOTIONAL

SPIRITUAL
Who is Involved?

HEALTH WORKER

PATIENT

COMMUNITY

FAMILY
THE CARING TEAM

- Nutritionist
- Drs, Nurses
- Physio/Occup. therapists
- Volunteers/community
- Religious person
- Social worker
- Pharmacists
- Family/friends & Patient

patient
HOLISTIC APPROACH

• Refers to caring for a patient as a whole being, *in totality*, not only physically

• Attempts to understand the patient in the context of his/her environment:
  – Family
  – Social group
  – Employment/school
  – Culture
Holistic Care:

• Appreciates the patient’s specific needs and responds to them individually

• Uses a multidisciplinary team to achieve total care for the patient and family
Goals of Palliative Care

• Therefore the goal of palliative care is the achievement of the best possible quality of life for patients and their families

• Improve
  – Quality of
    • Living
    • Dying
    • Bereavement
  – Effectiveness of disease-modifying therapy

• Prolong life
  (Put life into their days, and not just days into their lives)
Multiple Issues Cause Suffering

- Disease management
- Loss, grief
- End of life / death management
- Physical
- Psychological
- Social
- Practical
- Spiritual
Who is Affected

- Family
  - Patient
  - Wellness
- Patient's diagnosis
- Family
  - Patient
  - Illness
- Patient's death
- Family
  - Bereavement
What People Want

• Live life to the fullest
  – “Fix” disease
  – Prevent, relieve suffering

• United States
  – 90% believe it is a family responsibility to provide care to a loved one
  – 90% want to die at home
    (NHO Gallup survey)
Palliative Care

- prevent & relieve suffering
- help people achieve their full potential

...in face of adversity

From a traditional towards a new care model:

From cure towards Care

Old concept

Terminal Care

New Care concept

Curative treatment
Palliative Care

Curative treatment
Palliative Care

Time

Death

Post Care

Lynn and Adamson, 2003
Integration of curative and palliative treatments

Old concept

Proactive treatment program

Disease oriented treatment

Symptom oriented care

Palliative Care

New concept

Death

Lynn and Adamson, 2003
Integration of curative and palliative treatments

Old concept

Proactive treatment program

New concept

Disease oriented treatment

Symptom support and bereavement

Lynn and Adamson, 2003
The continuum of palliative care

- Therapies to modify disease *(curative, restorative intent)*
- Therapies to relieve suffering, improve quality of life
- Life Closure
- Actively Dying
- Bereavement Care

- Diagnosis
- Death
Palliative care in the developing world

Disease-oriented care

Supportive & Palliative Care

Care of orphans & other vulnerable children

Bereavement care

 ↑ Diagnosis

Primary Health Care & Specialist care →

Hospice care ← Death

Adapted from WHO
Who Public Health Model
WHO Foundation Measures

- **Education**
  - Of the public
  - Of health care professionals (doctors, nurses, pharmacists)
  - Of others (health care policy-makers, administrators, drug regulators)

- **Drug Availability**
  - Changes in health care regulations/legislation to improve drug availability (especially of opioids)
  - Improvements in prescribing, distributing, dispensing, and administration of drugs

- **Government Policy**
  - National or state policy emphasizing the need to alleviate chronic cancer pain
Public Health approach to PC

Policy
- Palliative care part of national health plan, policies, related regulations
- Funding / service delivery models support palliative care delivery
  - Essential medicines
    (Policy makers, regulators, WHO, NGOs)

Drug Availability
- Opioids, essential medicines
- Importation quota
- Cost
- Prescribing
- Distribution
- Dispensing
- Administration
  (Pharmacists, drug regulators, law enforcement agents)

Implementation
- Opinion leaders
- Trained manpower
- Strategic & business plans – resources, infrastructure
- Standards, guidelines measures
  (Community & clinical leaders, administrators)

Education
- Media & public advocacy
- Curricula, courses – professionals, trainees
- Expert training
- Family caregiver training & support
  (Media & public, healthcare providers & trainees, palliative care experts, family caregivers)
Integrating palliative care

• To effectively integrate palliative care into a society and change the experience of patients and families, all four components of the WHO Public Health Model must be addressed. There must be

• 1) appropriate policies,
• 2) adequate drug availability,
• 3) education of health care workers and the public, and
• 4) implementation of palliative care services at all levels throughout the society.
Public Health Strategy

For public health strategies to be effective, they must be incorporated by governments into all levels of their health care systems and owned by the community.
Palliative care for all

3º: Palliative Care Experts
2º: Healthcare Professionals
1º: Community Care
palliative care should be part of a comprehensive care and support package, which can be provided:
• **At home** by caregivers and relatives.

Terminally ill patients prefer to receive care at home.

The provision of palliative care can be augmented significantly by the involvement of family and community caregivers.
Aim of symptom management including pain is to:

- improve the quality of life of patient and family
- reduce suffering
- reduce uncertainties, reduce request for euthanasia
- Comfort
- Sleep
- Prolong life
- pain free death
Palliative care respects the goals, likes, and choices of the ill /dying person. It...

• **Respects** patient’s **needs** and **wants** as well as those of their family and other loved ones.
• Finds out from the patient who they want to help plan and give care.
• Helps patients **understand** their illness and what they can expect in the future.
• Helps patients figure out what is important.
• Tries to meet patient’s likes and dislikes: where they get health care, where they want to live, and the kinds of services they want.
• Helps patients work together with their health care provider and health plan to solve problems.
Palliative care looks after the medical, emotional, social, and spiritual needs of the ill/dying person. It...

- Knows that dying is an important time for the patient and their family.
- Offers ways for the PT to be comfortable and ease pain and other physical discomfort.
- Helps the Pt and their family make needed changes if the illness gets worse.
- Makes sure the Pt is not alone.
- Understands there may be difficulties, fears, and painful feelings.
- Gives the Pt the chance to say and do what matters most to them.
- Helps the Pt look back on their life and make peace, even giving them a chance to grow.
Palliative care supports the needs of the family members. It...

• Understands that families and loved ones need help, too.

• Offers support services to family caregivers, such as time off for rest, and advice and support by telephone.

• Knows that caregiving may put some family members at risk of getting sick themselves. It plans for their special needs.

• Finds ways for family members to cope with the costs of caregiving, like loss of income, and other expenses.

• Helps family and loved ones as they grieve.
Palliative care helps gain access to needed health care providers and appropriate care settings. It...

- Uses many kinds of trained care providers--doctors, nurses, pharmacists, clergy, social workers, and personal care givers. (Multidisciplinary)

- Makes sure, if necessary, someone is in charge of seeing that patients needs are met.

- Helps the PT to use hospitals, home care, hospice, and other services, if needed.

- Tailors options to the needs of the PT and their family.
Palliative care builds ways to provide excellent care during illness and at the end of life. It...

- Helps care providers learn about the best ways to care for ill /dying people. It gives them the education and support they need.

- Works to make sure there are good policies and laws in place.
the Hierarchy of Needs (Maslow) and quality of life

- **Physiological**
  - Basic biological needs (food, drink, shelter, sleep, sex)

- **Safety**
  - Law, security, stability

- **Love/Belonging**
  - Family, affection, relationships, work

- **Esteem**
  - Achievement, status, responsibility, reputation

- **Self-Actualization**
  - Awareness, meaning

Start
Results from good palliative care?

**Good palliative care improves:**

- The early detection of symptoms and problems
- The early treatment of these symptoms (pro-active)
- The patient – caregiver relation
- Streamlines (medical) decisions (transmural)
- Organises safe and good (holistic)(home) Care

“We need to move from prognostic paralysis to active total care”

*D.Meier, BMJ, 2004 / S Murray, BMJ, 2005*

*P.Manfredi, J Pain sympt man, 2000*

*M Rabow, Arch Intern Med, 2004*
Conclusions: improving quality of life (or dying)

- Requires a holistic approach and care concept
- Depends on multidimensional aspects
- Depends on the crossing border from a curative towards palliative trajectory
- Depends on expectations vs possibilities
- Depends on good research programs
What you should do for and with your patient

• prepare an advanced care plan
• Ask your patient what he/she wants if your therapy fails or if there is a recurrence
• Discuss end of life decisions and scenarios
• Ask for preferences of the patient
• Ask what the disease has done with the patient
• Be clear and open, with basic information,
• Foresee problems
• Prepare the terminal phase