PALLIATIVE CARE

By

Fridah Njagi

WHO IS THE TERMINALLY ILL PATIENT

"*Terminally ill patient is one in whom, following accurate diagnosis, the advent of death is certain and not too far distant, and for whom treatment has changed from curative to palliative and supportive*".

Dame C. Saunders

DEFINING PALLIATIVE CARE
World Health Organisation

- "Palliative care is an approach to care 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 by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychological and spiritual".

DEFINING PALLIATIVE CARE

- Palliative care is:

  ….the active holistic care of patients with advanced, progressive illness. Management of pain and other symptoms and provision of psychological, social and spiritual support is paramount. The goal of palliative care is achievement of the best quality of life for patients and their families. Many aspects of palliative care are also applicable earlier in the course of the illness in conjunction with other treatments.

PRINCIPLES OF PC

- Focus on quality rather than quantity of life
- Life affirming but death accepting
- Effective communication at all levels
- Respect for autonomy and choice
- Effective symptom management
- Holistic, multi-professional approach
- Caring about the person and those who matter to that person

WHAT IS HOSPICE?

The word hospice is derived from a Latin word hospitium which means hospitality. It was first used in the middle ages to describe the places built along the route to the holy land to provide rest and care to the pilgrims. These places were known as hospice – traveler's houses of rest, place of refuge. Today hospice is much more than a building. It is a concept of care extending to the home, hospital or hospice

Hospice care

- Hospice is a program of care for terminally ill patients and their families.
- Most patients have cancer.
- In the hospice, the centre of interest shifts from the disease to the patient and the family, from the pathological process to the person.
- The patient and the family are the unit of care.
- In curing, the doctor is the General" whereas in the hospice, care is sovereign.
- Hospice care – the patient is empowered to be in control of the situation.

Patients with terminal disease often need more care than those whose sickness is curable.

The hospice offers intensive terminal care

Professional skills of a high order are required

Expert care that is individual to the details, sensitive and time consuming

Hospice care

- Hospice care focuses on improving the quality of life for persons and their families faced with a life-limiting illness.
- The primary goals of hospice care are to provide comfort, relieve physical, emotional, and spiritual suffering, and promote the dignity of terminally ill persons.
- Hospice care neither prolongs nor hastens the dying process.
- Care is palliative (not curative) to control pain and symptoms associated with the terminal illness.

What is hospice care?

- Hospice treats the whole person, not just the disease.
- It focuses on the needs of both the patient and the family.
- Care is provided by an interdisciplinary team including the physician, nurse, social worker, chaplain, nursing assistant, and volunteers.
  - Therapy and dietician services are provided per the patient's needs.
- Hospice addresses patient and family needs such as:
  - pain and symptom management
  - Emotional, psychosocial, and spiritual support
  - Help with funeral planning and arrangements
  - bereavement for family/ caregivers after the patient's death

Where is hospice care provided?

- Hospice care is a philosophy or approach to care rather than a place.
- Care may be provided in a person's home, nursing home, hospital, or independent facility devoted to end-of-life care.
- Hospice was originally designed to be a non-institutional benefit. However, it is possible to receive Medicare covered hospice care while residing in a nursing home.

Main goals of hospice care

- Relief of pain and other distressing symptoms
- Psychological and spiritual care for patients, so that the support system, helps the patient live as actively and creatively as possible until death, thereby promoting autonomy, personal integrity and self esteem.
- A support system to help families cope during the patient's illness and in bereavement

Hospice seeks to prevent the last days becoming lost days.

It attempts to do this by offering a type of care, which is appropriate to the needs of the dying.

Hospice care attempts to re-establish the traditional role of Doctors and other Health care professionals.

"To cure sometimes

To relive often,

To comfort always"

Hospice care aims to restore hope.

Hope diminishes when:

The patient is mentally isolated by a 'conspiracy of silence'

It is implied that there is nothing more which can be done

Pain and other symptoms remain unrelieved

Symptoms such as depression are ignored

The patient feels alone and unsupported

Spiritual distress is not recognized

The future seems to be more than a mountain of problems and/ or unrelieved catastrophe

WHY DO WE NEED PALLIATIVE CARE

To help people suffering from;

- Cancer
- HIV
- Progressive neurogical illnesses
- Other life limiting illnesses

Modern medicine first set out to cure diseases with drugs, surgery and other treatments. Then we realized that prevention is even better than cure, and set about putting in place public health measures, vaccination programmes and education. Most of our health services are designed for treatment and prevent on of disease. But as we work these services, many of us have found that there is a big need that is not being met: the ongoing care for those who do not get better.

PRINCIPLES OF PC

- Focus on quality rather than quantity of life
- Life affirming but death accepting
- Effective communication at all levels
- Respect for autonomy and choice
- Effective symptom management
- Holistic, multi-professional approach
- Caring about the person and those who matter to that person

Palliative Care conditions

Lifetime Risk of:

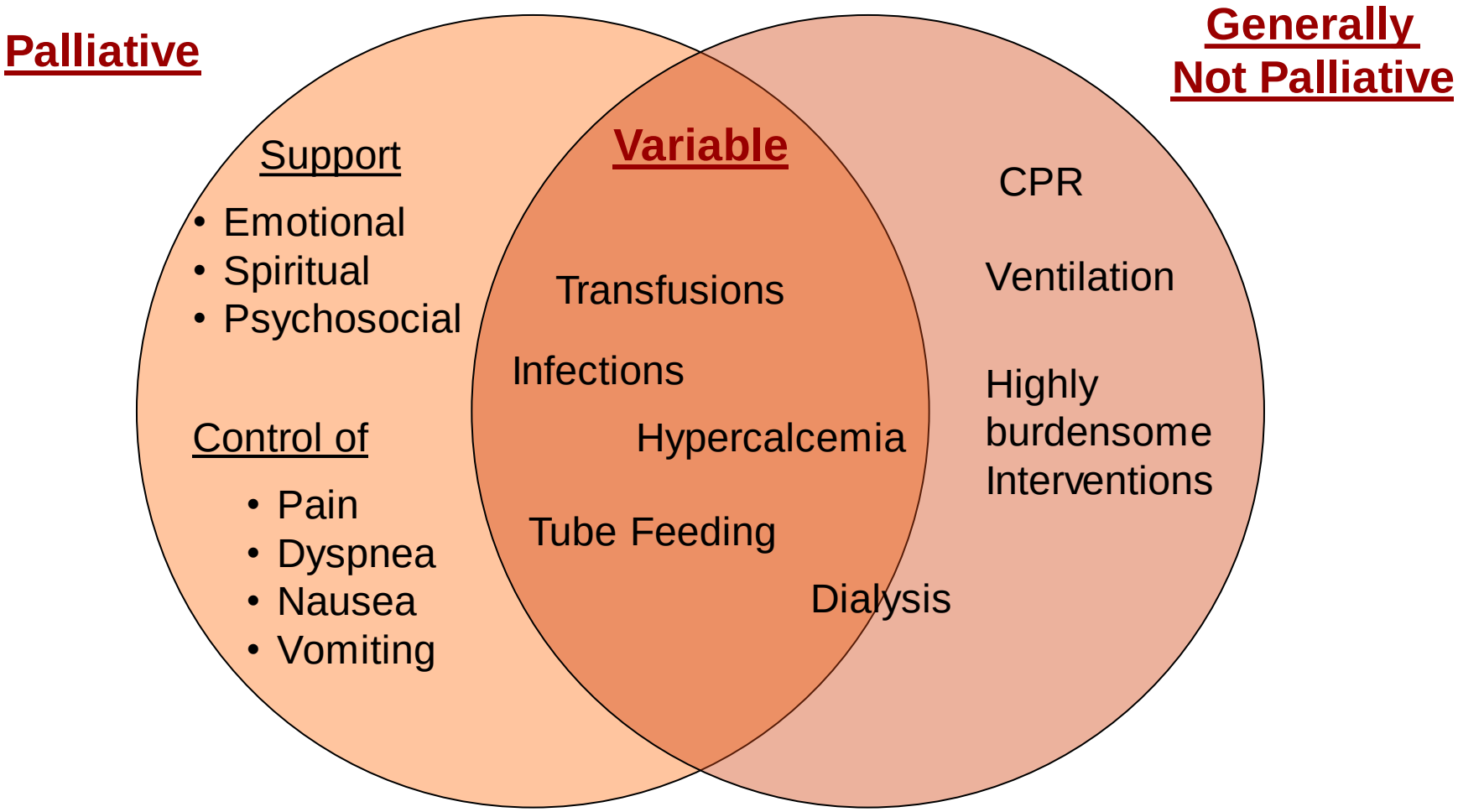
Heart disease:	**1:2 men; 1:3 women (age 40+)**
Cancer:	**> 1:3**
Alzheimer's:	**1:2.5 – 1:5 by age 85**
Diabetes:	**1:5**
Parkinson's	**1:40**

Death: **1:1**

Potential Palliative Conditions

- "The Usual Suspects" – progressive life-limiting illness
  - Incurable cancer
  - Progressive, advanced organ failure (heart, lung, kidney, liver)
  - Advanced neurodegenerative illness (ALS, Alzheimer's Disease)
- Sudden fatal medical condition
  - Acute stroke
  - Withholding or withdrawing life-sustaining interventions (ventilation, dialysis, pressors, food/fluids…)
  - Trauma – eg. head injury
  - Ischemic limbs, gut
  - Post-cardiac arrest ischemic encephalopathy
  - etc…

Potential Palliative Care Interventions



KEY ISSUES

- Information needs
- Being treated as a human being
- Empowerment
- Physical needs
- Continuity of care
- Psychological needs
- Social needs
- Spiritual needs

WHOSE RESPONSIBILITY?

- It is the right of every person with a life-threatening illness to receive appropriate palliative care wherever they are

- Palliative care is the responsibility of all health and social care professionals delivering care

WHO TO REFER

Referral to a Palliative Care Team is appropriate for any patients with an incurable, progressive and fatal illness.

WHO TO REFER

Particularly recommended for:

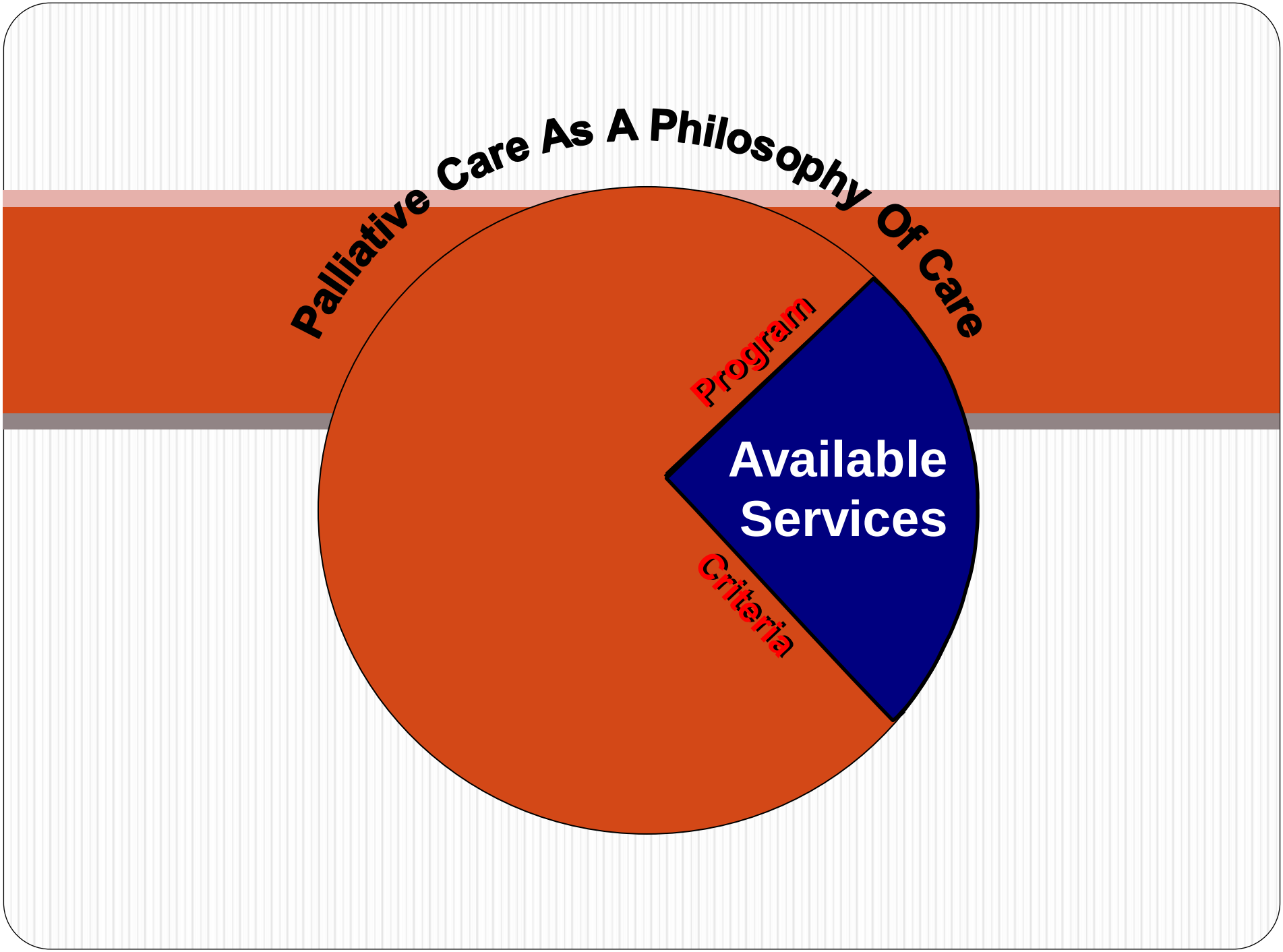
- Patients with rapidly progressive disease
- Patients with disease presenting unexpected, difficult to control, or rapidly progressing symptoms
- Distressing symptoms, when no relief has been achieved within 48 hours
- Psycho-social distress in patient or family relating to the diagnosis or in facing death
- Where reassurance of a second opinion is sought – by patient, family or other health care professional

KEY MESSAGES:
Philosophy of Palliative Care

- Should be available to anybody with a life threatening illness
- Focus of care is quality of life, with the autonomy and choice of the patient being upheld
- Care is extended to both the patient and those who matter to him/her
- A whole system approach is made when planning care with the patient

KEY MESSAGES: Philosophy of Palliative Care

- Palliative care should be delivered by any health/social care professional in care setting of patient's choosing
- Palliative care should begin at diagnosis of life threatening condition, continuing through to death/ bereavement
- Specialist Palliative Care is defined in terms of core services, delivered using multi-professional team with skills, knowledge and experience in palliative care
- Specialist Palliative Care is needed by only a minority of people with complex problems


Palliative Care As A Philosophy Of Care
Program
Available Services
Criteria

ETHICAL, LEGAL AND HUMAN RIGHTS ISSUES IN PALLIATIVE CARE

Ethical issues and dilemmas are inherent in care provided to patients and their families across the life span and facing the end of life

Professional codes and standards serve to facilitate resolution of ethical dilemmas

ctd

Members of the health care team, individually and collectively serve as advocates for ethical and legal practice at end of life.

Palliative care staff play a critical role in legal/ethical issues.

Ethics in palliative care is a matter of practical reasoning about individual patients, specific cases and unique situations.

ETHICAL PRINCIPLES

- Autonomy
- Benefience
- Non-maleficence
- Justice

AUTONOMY

Respect for a person's right to make decisions concerning their care. Autonomy promotes the development of a trusting relationship between a healthcare worker and a patient. (Listen to their opinions)

It also means the patient becomes an active member of the management team, which restores a sense of control in the face of an illness that has deprived that person of control

In order to give due attention to this principle, there are several matters;

Communication

The patient has a right to know about the diagnosis,treatment that is proposed,its effect and any side effects.

It is then the responsibility of the healthcare workers to ensure that the patient is fully informed

This will involve an assessment by the healthcare workers both of the patient's understanding and of how much the patient wants to know.

ctd

Failure to communicate honestly with the patient can isolate the patient, preventing a therapeutic sharing of patients fears, anxieties and other concerns.

In the case of a child patient, especially an older child, opinions and concerns are often not sought. This increases the child's pain.

The child can be left to feel responsible for their parents suffering

It is most important for the health professional to include the child in communications with family about the illness and decision making

Consent

- Once the patient is given sufficient information, they have the prerogative to accept or not accept the care or treatment

Confidentiality

Confidentiality protects the autonomy of the patient by allowing them to control information about themselves.

Privacy

Central to a respect for a personal autonomy is the concept that the privacy of the individual must be respected

BENEFICENCE

- To ‘do good' health professionals should reflect on patient care decisions with this question in mind: Will this treatment benefit the patient? This requires considering risks versus benefits and deciding whether the benefits outweigh the risks
- Knowing the patient’s wishes is essential in deciding what will benefit them
- The patient needs truthful information from the health professional in order to make their own decisions.

- Although palliative care is concerned with the care of both the patient and the family, the healthcare workers must be careful not to subordinate the interest of the patients to the anxieties of relatives
- It is often the case that family members want ‘everything’ done for their patient, not appreciating that infact,prolonging the patient’s life with artificial hydration or other measures only acts to prolong their suffering.
- Families need to be informed about the consequences of different treatments and they also need to be encouraged to listen to what the patient wants.

ctd

- With regard to children, parents are presumed to have the ability to make decisions regarding a child's 'best interest'
- In general, the best interest of a child may require a plan that focuses on the child's need for comfort and symptom relief to ease the process of dying in a way that promotes the safety, comfort and dignity of the child.

NON_MALEFICENCE

- To,'do no harm',a healthworker needs to have adequate education and knowledge to ensure that the treatment they offer will not harm or endanger a patient
- In practice,many treatments carry some risk of harm and it is up to the health worker to weigh the risks versus the benefits.
- In essence,the intended effect of treatment must be a good one. For instance

ctd

- Artificial hydration at the end of life may appear to families to be good for a patient who is no longer taking oral fluids, whereas in fact it can cause great distress since the patient's body can no longer cope with these fluids
- The principle of 'double effect' forbids the achievement of good ends by wrong means. It forbids doctors to relieve the distress of a dying patient by killing them, but it permits the use of drugs which relieve the distress of dying even when they may hasten death.

JUSTICE

- Justice is concerned with the correct use of resources ,deal fairly and act in the best interests of our patients.
- Prolonging the dying process may be justifiable if the patient and family need extra time to achieve important personal goals
- It is the principle by which competing claims may be decided in fairness and is concerned with fair distribution of resources e.g.

  If a family has very limited resources, should the terminal patient be prescribed expensive treatment that will cause financial hardship for the rest of the family? In the days before antiretrovirals became free or more affordable, individuals sometimes sold all the families property to buy drugs for a limited period of time. The family was eventually left impoverished.

ISSUES OF LIFE AND DEATH

EUTHANASIA

- A pleasant death/mercy killing or the deliberate action by which a pleasant death may be produced (Wilkinson 1993)
- Euthanasia= death without suffering/bringing about the death of a human being on purpose as part of the medical care being given to him

  The administration of a drug or drugs deliberately and specifically to precipitate or accelerate death in order to terminate suffering (Twycross 1980)

TYPES OF EUTHANASIA

- Involuntary
- Voluntary
- Active-The death of the patient is the result of the administration of lethal medication or the deliberate ending of life of an individual who is suffering an incurable condition
- Passive-The death of the patient is the result of withholding of life sustaining treatment

Human rights in palliative care

- Human rights are entitlements that all human beings have by virtue of the fact that they are human beings.They are necessary for human beings to live a life of dignity .
- Everyone has human rights regardless of their age,sex,race,colour,language,tribe,social or economic class,religion or political beliefs.
- Access to pain relief is fundamental to human dignity and the rights to health and freedom from cruel,inhuman degrading treatment

ctd

- In Kenya, despite UN Convention on narcotic Drugs, there is no effective policy for supply and distribution of pain medication, and excessively strict regulations impede access
- There are no measures to ensure training for healthcare workers on pain management and palliative care
- In palliative care field there are legal issues related to disposition of property, planning for children, accessing social benefits and combating discrimination.

Examples of human Rights in palliative care

- Pain relief
- Symptom control for physical and psychological symptoms
- Essential drugs for palliative care
- Spiritual and bereavement care
- Family centered care
- Care by palliative care professionals
- To receive home based care when dying and to die in dignity
- Treatment of disease and to have treatment withheld or withdrawn
- Information about diagnosis,prognosis and palliative care services

ctd

- Name a healthy proxy for decision making
- Not to be discriminated against in the provision of care because of age,gender,national status or means of infection.
- Truth telling
- Confidentiality

Challenges to the provision of palliative care in Kenya

- Legal restrictions to opioids availability and access making people with life limiting illnesses to suffer unnecessary pain.
- Fearing prosecution for handling classified drugs, a doctor refuses to prescribe morphine to relief a patients pain
- Laws prohibit the prescription of morphine by other people other than the physicians
- Laws prohibit the prescription of morphine to drug users, therefore a former drug user in the advanced stages of AIDS suffers great pain

availability include the failure by state to;

- Ensure a functioning supply and distribution systems for fear of opioids medication
- Enact adequate policies on pain management and palliative care
- Reform excessively strict drug control regulations
- Address widespread fear of legal sanctions for prescribing opioids among healthcare workers

ctd

- Take reasonable steps to remove barriers which violate rights to health
- Take steps to ensure the affordability of morphine and other pain medications

Way Forward

- Countries have to provide pain medications as part of their core obligations under the right to health
- Make available in adequate quantities and accessible for those who need them
- Put in place an effective procurement and distribution system
- Create a legal and regulatory framework that enables healthcare providers in both public and private sector to obtain,prescribe and dispense these medications

CONTROL OF COMMON SYMPTOMS IN TERMINALLY ILL PATIENTS

1. Constipation – Hard and infrequent motions

   It is the biggest problem for terminally ill patients. The commonest cause of constipation in terminally ill patients is opiods used without adequate doses of laxatives

OTHER CAUSES

Poor diet

Low fiber diet

Dehydration

Reduced defecation

Reduced mobility

An important question is whether laxatives should be started at the same as opiods (or only later once constipation have occurred.) Alternating constipation and diarrhea is usually due to the increase of the use of laxatives. Intermittent use instead of regularly in a patient on opioids.

Constipation can cause anorexia, nausea, vomiting, abdominal pain, rectal pain, confusion, abdominal distention and sometimes even an obstruction. Pain tends to be colicky. It radiates to chest, back and upper legs (tenesmus)

- Advice on high roughage diet e.g. vegetables, cabbages, fruits and a lot of fluids.
- Use of stool softeners e.g liquid paraffin, castor oil e.t.c
- Use of suppositories if the patient has established constipation e.g glycerine, dulcolax and suppositories.

Vaginal discharge

Vaginal discharge is a common symptom of cancer of the cervix. It is usually smelly and causes embarrassment, distress and stigma, but it can be effectively managed.

Management

Prescribe flagyl solution for douching twice or once a day.Flagyl [200mg] can be inserted daily as a pessary. normally at bedtime.

Encourage proper hygiene by changing soiled linen

NAUSEA AND VOMITING

It occurs in 60% of terminal ill patients at some stage but tend to be intermittent.

Causes could be:

- Drug related e.g NSAIDS, opiods e.t.c
- Radiotherapy or chemotherapy
- Headache (brain metastasis)
- UTI and URTI
- Constipation
- Gastric irritation
- Intestinal obstruction

MANAGEMENT

- If drugs related causes, stop or change regimen
- Incase of brain metastasis, use steroids
- In UTI and URTI, use antibiotics
- For constipation use laxatives

Anti – emetics drugs includes:

- Oral anti- emetics e.g plasil 10mg TDS, Haloperidol 5mg OD, Dexamethasone tabs 0.5mg – 1mg BD, largactil 25mg BD or OD
- For severe nausea and vomiting give 1v, 1m or subcutaneous infusion

- injection plasil 10mg TDS
- injection dexamethasone 4mg TDS
- N/B Give little frequent appetizing food/ what the patient fancy

3. WEAKNESS

Usually occurs in 95% of patients and the cause is usually reversible and therefore establish the cause.

Anaemia – Blood transfusion or prescribe blood builders

Depression – Give antidepressants e.g laroxyl 25mg nocte

Infection – Give antibiotics

If caused by the drugs –review the regimen

OTHER REMEDIES INCLUDE:

- Physiotherapy – Maintains strength
  - Gives optimum mobility
- Wheelchair – can increase independency
- Occupational therapy – Removes boredom
- Explain – Caused by illness
  - Encourage periods of rest
  - That strength fluctuates
- Protect patient from excessive visitors or as he or she wishes
- Counseling

4. ASCITES- accumulation of Fluid in the peritoneal cavity

It causes abdominal distention. It is detected clinically by the sign of shifting dullness (the line of dullness to percussion shifts laterally as the patient turns on his side.

Pathophysiology – The sub phrenic or lymphatic plexus become blocked with tumor. Fluid is exuded by both tumor involved and normal peritoneum.

SYMPTOMS

- Abdominal distension Difficulty bending
- Heartburn
- Leg oedema
- Dyspnoea
- discomfort

Sodium retention also occurs in malignant ascites which explains why diuretics can be effective.

Ascitis due to peritoneal deposits can occur with almost any carcinoma, but is seen most often in carcinomas of ovary, pancreas and liver.

MANAGEMENT

Oral tablets of aldactone is initially commenced since it is potassium sparing.

It is used when ascitis is mild to moderate with a dose 25mg -100mg BD. If there is no decrease after one week, increase the dose or consider alternative management (Paracentesis)

N/B Do not give potassium supplement with aldactone (which is potassium sparing) because hyperkalemia can occur

Paracentesis (tapping) is done when the ascitis is so severe i.e. causing dyspnoea, abdominal discomfort, or inability to bend or sit upright. It is safe to drain off the first 4 liters slowly to avoid hypovolemic shock and the same time rehydrate the patient per I.v

Paracentesis can easily be performed in the home.

5. LYMPHEDEMA.The common question asked is the difference between Lymphedema and normal oedema

Lymphedema is a subcutaneous accumulation of protein rich fluid due ,to damage or blocked lymphatic vessels.

Causes: It is most commonly seen in the arms of post, Mastectomy ,prostate cancer , or following radiotherapy to the axilla.

.

Pelvic and prostate malignancy can cause lymphedema in one or both legs. Initially the oedema is pitting but the subcutaneous tissues eventually become thickened and fibrosed

MANAGEMENT

Physiotherapy – Massage and exercise sometimes helps.

Normally lymph flow depends on body movements can be encouraged by skin massage to increase the flow in proximal skin lymphatics.Daily self massage of the skin for 15minutes can help to reduce swelling. Daily limb exercise will improve circulation and reduce joint stiffness. Massage and exercise should be routinely used in conjunction with bandaging and compression garments.

Elevation of affected limb

Use of diuretic e.g. lasix, aldactone are seldom helpful. They reduce tissue tension, reduce the size of a heavy, aching, disfiguring arm or leg almost always improves the patients morale.

Applying a light surgical compression stockings and sleeves can be used to maintain a good fit and keep pace with reduction in limb size.

Proper fitting is necessary. In severe cases these have to be worn continuously and only removed for bathing and will need to be worn indefinitely.

6 Difficulty in breathing.

It is frightening and managing it is essential

Most patients have mild shortness of breath on exertion which part of the picture of increased weakness. Episodic shortness of breath is usually due to hyperventilation. Any patient with both dyspnoea and terminally ill is prone to episodes of anxiety or panic.

Positioning helps

Bronchodilators e.g. ventolin 4mg TDS

- 7.COUGH
- About 30% of patients with advanced illness admit to some cough, but as a troublesome symptom it surprisingly uncommon. Persistent coughing can cause anorexia, nausea or vomiting, Insomnia, musculoskeletal pain, exhaustion or cough syncope.
- Cough is caused by bronchitis, URTI, pulmonary infection, lung abscess, bronchospasm and pleural effusion.
-

Management

- Bronchodilators
- Pleural aspiration
- Radiotherapy
- Steroids
- Humidified air
- Soothing syrups
- Opioids
- Nebulization

8. Insomnia

Insomnia lowers the patients pain threshold, exhausts carers and is a common cause of breakdown in home care arrangements

It may be due to symptoms (pain, sweats incontinence, cough, itch, anxiety or depression.

Some patients fear dying in their sleep hence the need to discuss the anxieties about dying

Boredom or lack of activity during the day may worsen insomnia hence the need for occupational or recreational therapy. NB// hospital routine can often disturb sleep (eg waking patients to take drugs or for a procedure.

Management

- If depressed, prescribe antidepressants e.g. laroxyl 25mg nocte
- if anxiety, oral largactil at a low dose is very effective for some patients e.g. 25mg at bedtime

If patient is waking to take 4hrs morphine in the night, it is usually possible to achieve longer lasting analgesia by doubling the dose at bedtime

Nb// by using these three groups of drugs examples hypnotics(mogadone) anxiolytics(Valium) and opioids detailed adjustments (to doses and times given) it is usually possible to achieve a good right sleep in even the most intractable insomnia

9. Offensive discharge

Offensive smell is miserable and embarrassing for a patient. It is constant reminder of disease and isolates the patient from the close contact of family and friends. It may be due to fungation, fistula, stoma leakage, pressure sores, vaginal discharge.

Management

From fungating wound/cancer wounds use flagyl solution

Preparation steps

- Prepare equipments –flagy solution (5tabs in 1ltr of clean, cooled, boiled water
- Patient explain
- Yourself

- Dip small pieces of cloth /gauze into solution each time while cleaning the wound from inside outwardly until clean wiping only in one direction
- Dry the wound with clean gauze
- Cover the wound with loose betadine gauze to allow fresh air circulation
- For infected wound, dress twice a day but once if not infected

- Decontaminate soiled items especially those to be reused eg cloths soak in jik for 10-15 min then spread in sun to dry. Wrap contaminated wastes in newspaper if available for disposal in a pit latrine.

Nb// flagyl solution does wonders in eliminating offensive discharge and smell in patients suffering cancer of the cervix

10. Hiccups

It is rare but distressing problem. Common in cancer of the liver, phrenic nerve irritation (in the neck or mediastnum, gross hepatomegally elevating the diaphragm, gastric distension due to food or gas and uremia

Management

- Plasil 10mg tds a day is often effective
- Largactil 25mg BD / TDS a day is also an effective drug particularly in uremia for severe hiccups try chlorpromazine IM 25mg

11 bleeding

- Management of bleeding depends on its site and severity

Most common

- Palliative radiotherapy – drys up surface bleeding
- Oral tranexamic acid / slyate tabs /500mg tds – if severe im/iv of tranexamic / slyate is given

- Blood transfusion is not usually considered for active bleeding in terminal illness unless the bleeding is controlled and the patient is left with symptomatic anaemia

12. Jaundice

This occurs due to obstruction of bile flow
bilirubin pigment strains the skin and eyes yellow
urine becomes dark(bile pigment bowel motions are pale (lack bile pigment

The main problems is that jaundice makes the patient feel the disease is advancing rapidly

It can be helpful to explain that jaundice in itself is relatively harmless eg explain to them that some people with liver disease such as chronic hepatitis can be jaundiced for years.

Itch is the main physical symptom. Some patients have severe itching others have very little. When itch is troublesome cholestyramine 500mg bd is prescribed which relieves itching

Urinary retention

Treat

Faecal impaction due to constipation

Urinary tract infection

Spinal cord compression

Drug induced[tricyclic antidepressants eg laroxyl, opiates]This is a temporary effect

Management

Catheterization will relieve the retention. If an underlying cause is treated, the problem may resolve a once the urine has drained away and the catheter can be removed.

Sometimes the catheter may be needed long term. It can blocked[eg by blood clots].Washing out the bladder can help. Change of catheter every 2/3 weekly is usually necessary.

PAIN ASSESSMENT AND MANAGEMENT IN TERMINALLY ILL PATIENTS

PAIN

Over 70%of people with advanced cancer or HIV disease experience pain. some pains are short term such as those caused by HIV related opportunistic infections. Many pains associated with advanced cancer and HIV are long term and may get worse over time.

Pain control is of utmost importance

- Tolerate the rigors of diagnosis and treatment.
- Simply allows them to live out their final days in peace and dignity.

Assessment of pain

It is important to ask about Pain in every patient.A person who has had pain for a long time may not show the usual signs of being in pain [facial expression,sweating,pale with fast pulse]They may just be depressed or quiet.

Careful assessment of pain is essential to identify causes of pain that can be treated and to determine what type of pain it is and how it can best be helped.

Questions

- How many different pains are there? it is useful to record them on a body map. Ask about each one.
- Where is the pain and what does it feel like?
- How long has the pain been there? What makes it better or worse?
- Has any medication helped?

- Does the pain get worse with movement? Are the bones or joints tender?][This may indicate bony metastases if the patient has cancer.]
- Are there any changes in feeling of the skin at the site of pain.[This may indicate nerve pain]
- Are the muscles tense or tender?[This may indicate pain from muscle spasm.

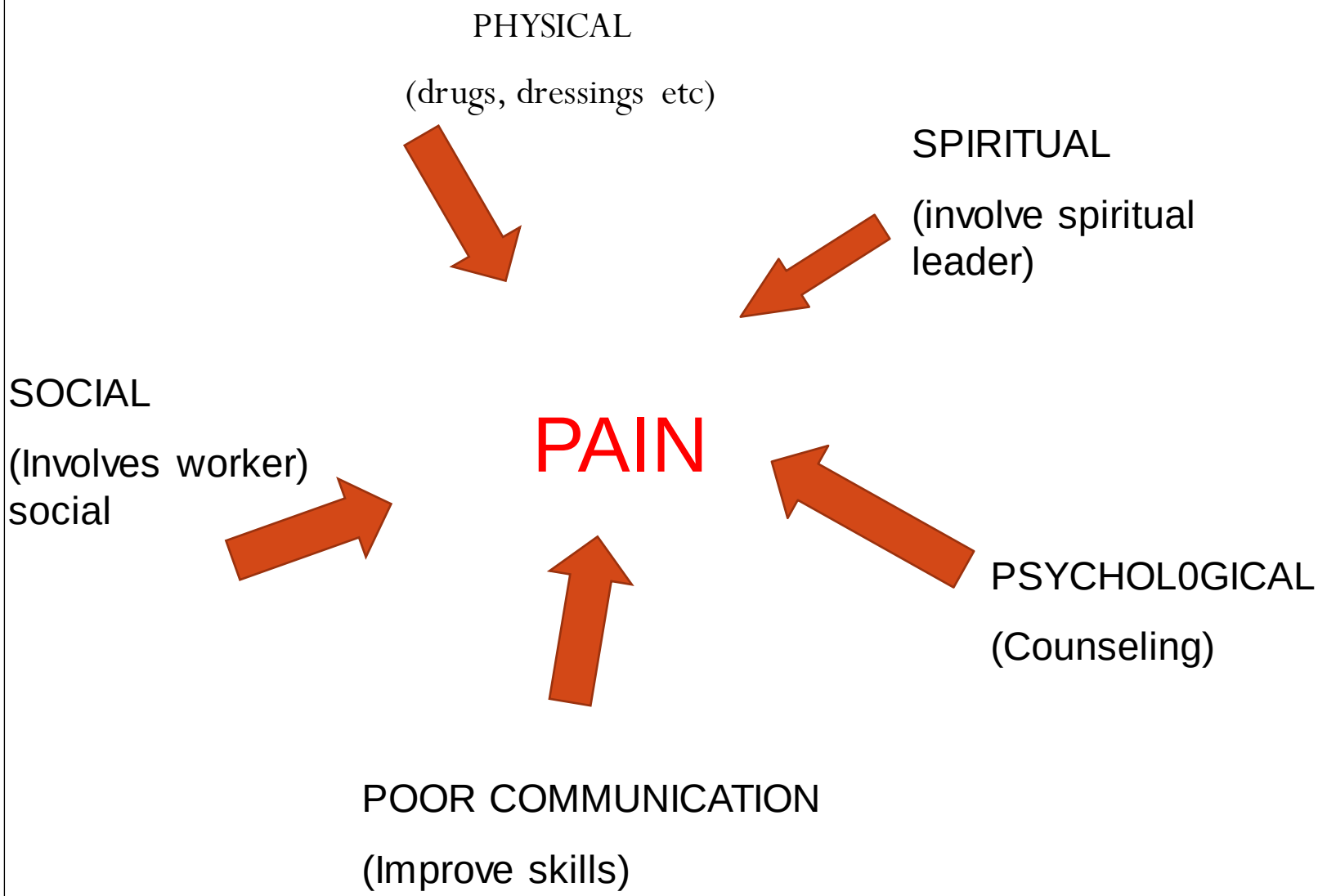
ctd

You can ask patients to score their pain to give you some idea of how bad it is. If they score their pain every day it will help you know whether it is getting better or worse and whether you treatment is effective. There are different ways of scoring pain to suit different people ,e.g. finger five score, faces score and number score.

Cancer pain

- Particularly in advanced stages of the disease, may be especially severe.
- Most cancer patients are enormously fearful of uncontrolled pain in then terminal period.

TOTAL PAIN DIAGRAM



Causes of Cancer Pain

Cancer pain is typically classified according to reasonably well-defined pain syndromes. There are many causes of cancer pain, including those related to the disease itself, to the treatment and to psychosocial factors. Careful investigation and precise delineation of the source of the pain may enable the physician to treat the underlying cause or at least choose the most appropriate analgesic.

causes of pain in cancer
Neoplastic process

- The most common cause is directly related to the neoplastic process;
- Within this group, tumor invasion of bone, either locally or by distant metastases, is most frequent,followed by infiltration or compression of nerves by tumor growth.

Causes of pain ctd

- Obstruction of hollow viscera or of the ductal systems of solid organs produces characteristic colicky or diffuse visceral pain
- Finally, occlusion of blood vessels and lymphatics may cause edema or ischemia; involvement of mucous membranes causes severe burning pain.

Anticancer therapies

- Chemotherapy (gastrointestinal, neurologic or hematologic effects),
- Radiation therapy (fibrosis of connective tissue) and
- Surgery typically account for 20 percent of the pain complaints, particularly in an outpatient population of cancer patients.

Psychosocial factors

- Must not be ignored.
- Anxiety, fear, depression, and feelings of uncertainty and isolation can profoundly lower the patient's pain threshold and alter his or her perception of pain.
- Patients may perceive far more discomfort from stimuli that in other circumstances would be of little consequence.

Psychological factors ctd

- For many patients, pain was the presenting symptom of cancer, and recurrence of pain may represent to them recurrence or progression of disease.
- Psychologic factors may play an even greater role in patients who have had chronic pain from a preexisting, noncancerous condition.

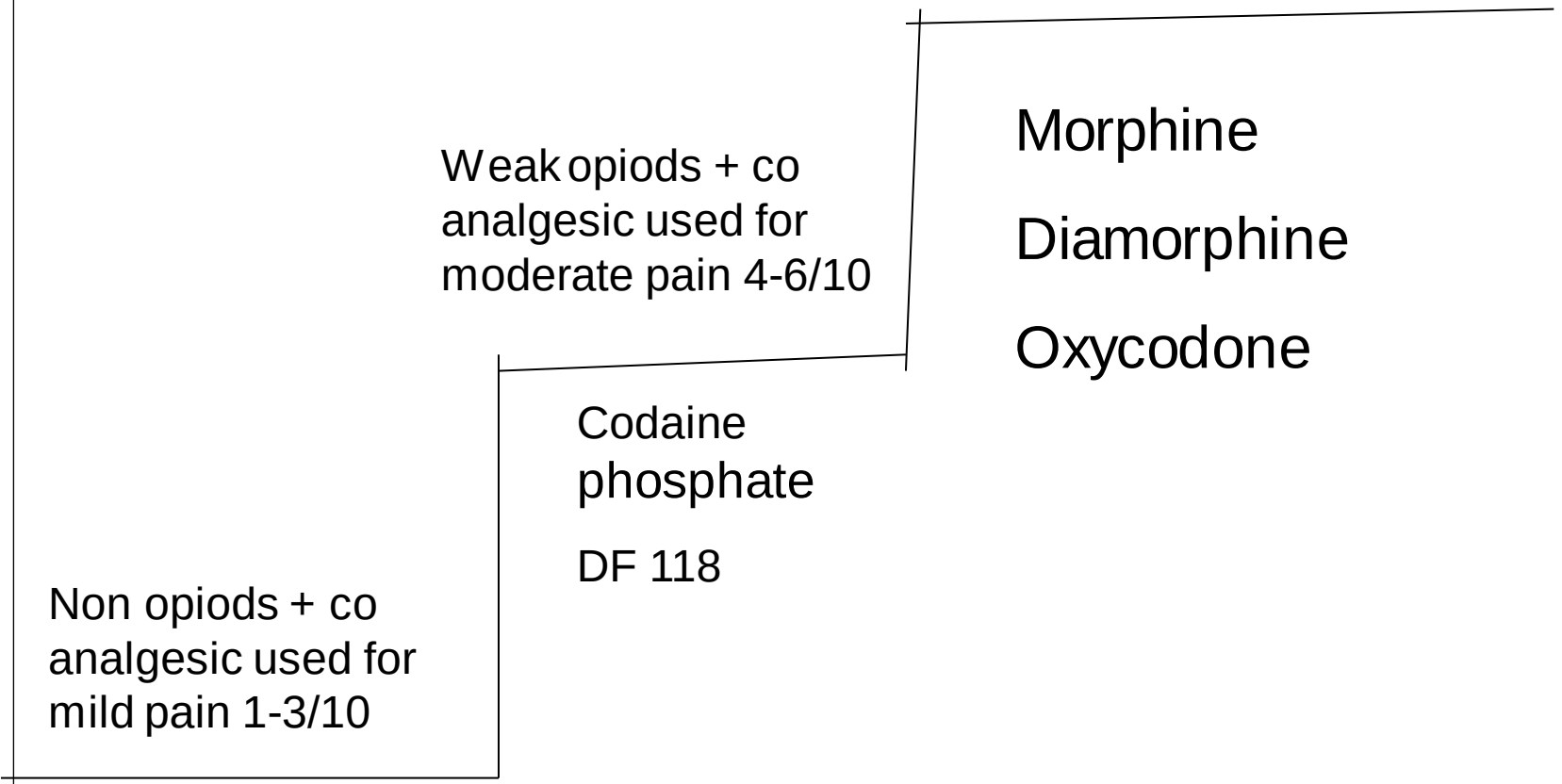
Pain management

- Commonly used analgesics for cancer patients are generally classified as

1. non narcotic,
2. narcotic (or opioid)
3. adjuvant analgesics.

- The WHO advocates the use of an "analgesic ladder". a stepwise approach to the use of analgesics in patients with cancer pain.

WHO Analgesic Ladder



Nonnarcotic Analgesics

- Nonnarcotic analgesics are typically the first-line treatment for mild to moderate cancer pain
- These include aspirin, acetaminophen and the nonsteroidal anti-inflammatory drugs(NSAIDs

side effects of non narcotics

- The side effects of aspirin are well known, particularly gastrointestinal ulceration, inhibition of platelet aggregation and aspirin hypersensitivity.
- Conversely, acetaminophen is usually safe and free of side effects when given in dosages under 4 g per day. Hepatotoxicity may occur at a higher dosage, but this is a rare complication.

Narcotic Analgesics

- The narcotic agents remain the gold standard for analgesia.
- These agents produce a much greater analgesic effect than the nonnarcotic analgesics.

MORPHINE

- In general, no other narcotic analgesics are superior to morphine.
- While sometimes useful in certain specific situations, most other narcotic analgesics are limited in their usefulness by side effects, by the accumulation of toxic metabolites or by overly complex pharmacology.

Adjuvant

These are drugs which were not designed as analgesic but may help in certain kinds of pain alongside standard analgesics. They can be started at any step of the analgesic ladder.

Examples of commonly used adjuvants

- Corticosteroids;

E.g. dexamethasone 1mg,prednisolone 7mg.

They help relieve pain from severe swelling or inflammation. Cancer causes local inflammation and swelling. When it spreads to an area of the body where there is very little room for this swelling, it may result in considerable pain e.g. increased intracranial pressure, spinal cord compression and opportunistic infections in HIV e.g. severe candiadiasis.

- Tricyclic antidepressants;

E.g. laroxyl and imipramine. Used in pain as a result of nerve damage[neuropathic pain]

- Anticonvulsants;

E.g. tegretol,sodium valporate.Used in pain as a result of nerve damage.

ctd

Damage to nerves can cause pain that is greater than you would expect for the extent of injury. It is difficult to treat with opiods and NSAIDS alone.eg nerve compression, severe damage from drugs[some ARVS or TB drugs]and severe diabetes causing neuropathy of hands and patient describes the pain as burning, shooting or electric shock. There is an area of skin near the site of the pain which is either numb or very sensitive so that even light touch or clothes may be painful.

ctd

- Benzodiazepines;

E.g. Diazepam. .

Used in skeletal muscle spasm.

- Anticholinergics;

E.g. buscopan.Help in smooth muscle spasm,eg abdominal colic. Painful muscle spasm can occur in neurogical and in bed-ridden patients.

N/B ensure patient is not constipated when using buscopan as it will make this worse.

- Like the narcotic analgesics, corticosteroids pose little threat of long-term sequelae in patients with advanced cancer.
- fluid retention, hyperglycemia and proximal myopathy can occur relatively quickly in the debilitated patient, and the clinician must be alert to these potential complications.

- a relatively low dose of a corticosteroid can sometimes provoke profound hyperglycemia in the cachectic cancer patient with underlying mild glucose intolerance.
- The debilitated patient receiving corticosteroid therapy is also prone to the development of oral candidiasis;

Transcutaneus electrical nervestimulation (TENS)- a form of electroanalgesia.

- It stimulates skin mechanoreceptors producing a pre-synaptic spinal inhibition of pain transmission
- There has been little research into the use of tens in cancer pain, but reports suggest it can be helpful
- Many cancer patients have musculo-skeletal pains (cervical spondylosis, for example is a common condition for which TENS can be helpful

Final comment

- Providing effective analgesia for the patient with severe chronic pain due to terminal illness requires a systematic approach to diagnosis and rational use of various medication.
- Pain is neither inevitable nor unavoidable, and a pain-free state should be a management goal in every patient with cancer.
- By working closely with the patient, family and other caregivers, the physician will help the cancer patient make this last transition with peace and dignity

BREAKING BAD NEWS

Breaking bad news is the most difficult responsibilities in the practice of medicine. Unfortunately, Medical schools offer very little formal or informal training and sometimes none at all in how to discuss or even to break any form of bad news.

What is bad news?

‘Any news that drastically and negatively alters the patient view of his/her future’

Example: One patient when asked to describe what he understood by bad news simply replied,` I left my house as one person and came back another’

Facts

1. In communicating the diagnosis of a terminal illness most health workers are likely to have experienced problems
2. There is usually a feeling of inadequacy, concern about patients reaction etc.
3. As health workers we all know that breaking bad news is a difficult and unusual part of our job.

Why is it important to break bad news.

- To maintain trust
- To reduce uncertainty (which is the hardest of all emotions to bear.)
- To prevent inappropriate adjustment so the patient can make informed decision about the future
- To prevent a conspiracy of silence

Why breaking bad news is difficult?

Feel incompetent: especially in being able to communicate the information properly.

- Wondering how bad news will affect the patient, relatives etc. what we call` the negative effect' on the people concerned.
- The physician/Nurse is faced with challenges – their work is to give hope and they do not want to take the same hope away from the patient/relative.

- They are fearful of the patients/relative's reaction to the news because they are not sure of how to deal with the emotional distress and suffering.
- As a result, they succeed very well in lessening physical pain but fail miserably in lessening the psychological and emotional pain.

How should bad news be delivered / communicated?

Dr. Gregg K. Vandekieft, a medical Doctor and lecturer at Michigan state University, U.S.A. – has come up with a very good and simple model of communicating bad news – which he has called the A.B.C.D.E., Model.

1. **Advance preparation**

- Arrange for adequate time
- Ensure privacy in a comfortable room/ location
- Avoid all forms of interruptions (colleagues, friends, mobile phones etc)

- Prepare yourself emotionally and psychologically
- Choose your words and phrases easily
- Know what issues to avoid
- Involve family members for support at the discretion of the concerned person.
- Get your facts and data straight. Be ready to answer questions.

2. Build a Therapeutic Environment/ relationship

- Establish a therapeutic rapport
- Introduce yourself to the group present and ask them to do the same
- Ask for their relationship with the patient
- Assess the patient's preference- how much do they want to know. Individualize in order to determine the contents of your message.

- Avoid routine procedure which is very common in our medical institutions – i.e. giving information in a consistent, preset manner eg. The diagnosis, the relevant evidence, the need for further investigations, the treatments being considered and finally the probable outcome. This formula does not give any heed to the wishes of the patient ie

- .The issues he would have liked addressed first. Both patient's verbal and non verbal cues and expressions were not acknowledged and the patient's immediate concerns were not given attention or explored.
- This structure leads the patient to believe that they were not entitled to know the truth about their illness, to express their concerns, to ask questions or to express emotions.
- At times it results in clinical anxiety, frustration and sometimes depression

3. Communication Skills

- Before you tell –ask
- Ask the group to tell you what they know and understand about the disease
- Find out their expectations before giving the information
- Without causing unnecessary anxiety go straight to breaking the news e.g I am sorry but.. Speak frankly but show compassion

- Avoid medical jargon- use simple language but convey the actual facts.
- If need be allow for expressions of emotions
- Don't be overwhelmed by silence and tears
- Proceed at the patient pace

- Avoid giving false hopes
- Avoid hiding your own discomfort or over talking
- Empathize with the group and be there emotionally
- Touch if you feel it's appropriate but also be sensitive to cultural values/ differences
- Assure them that you will be available for them when they need your services
- Encourage questions

- Ask them to repeat what you have just said to confirm their understanding
- Be aware that they will not retain much at the initial stage
- Write down for them the key information or draw sketches
- Make a summary of what you have discussed
- Make follow up appointments

4. Dealing with patient/family reactions to the news

- Assess and respond to emotional reactions .e.g. cognitive coping strategies (defense mechanisms)
- Denial, blame, intellectualization etc
- Observe body language and non verbal communication e.g. tone of voice
- Be there emotionally for the patient, be empathetic
- Do not hide your emotions, be human

- Listen attentively and respond appropriately, I am sorry…
- Admit what you do not know
- Do not argue or criticize the patient/relative
- Avoid defending yourself, your colleagues or medical care at this point
- Avoid reflection of personal of personal issues

5. Encourage and evaluate emotions

- Even where there is no hope, offer realistic genuine hope and encouragement
- Talk of many available treatment options
- Talk of obeying doctors instructions and drug compliance
- Help them to make the right decision if need be.
- Explore with them the social support system e.g other members of the family

- The church group for spiritual needs and other groups with similar problems
- Encourage them to continue with counseling
- Finally after delivering bad news, organize for your own debriefing in order to reduce your levels of emotional pain which can result in burnout
- i.e share your bad experiences with your colleagues
- Avoid using the actual names of the patient in order to maintain professional ethics

Conclusion

- As we have seen, for a long time the medical personnel have been expected to break bad news without proper training. However, despite all the above challenges, breaking bad news can give tremendous satisfaction to both patients and physicians
- People have come to appreciate that there are limits in medical science, meaning there are some ailments that will not always be cured but rather will require management.

- Your skills and attitudes during communication play a major role in determining how well the patient /relatives cope or come to terms with the problem and thus bringing healing.
- Professionalism in medical profession is all about proving hope and healing and this can only be achieved if proper training has been given to the medical staff.

The Experience of Loss, Death, and Grief

Definitions

• ***BEREAVEMENT :*** this is the situation of anyone who has lost a person to whom they are attached.

• ***GRIEF***: the psychological, social, spiritual, physical and emotional reactions to loss.

• ***MOURNING***: is the process of adaptation, including the cultural and social rituals prescribed as accompaniments.

• ***ATTACHMENT***: a strong tendency to remain close to or, from time to time, to return to another individual.

• ***ANTICIPATORY GRIEF***: psychological ,social, spiritual, Physical and emotional reaction to anticipation of loss.

Definitions...

- Pathological grief represents an abnormal

outcome involving psychological, social or physical morbidity.

- Disenfranchised grief represents the

hidden sorrow of the marginalized where there is less social permission to express many dimensions of loss.

- Grief is universal. However shape and content is culturally determined.

The five categories of loss

- Necessary loss – loss that is the result of the natural growth and development process
- Actual loss – any loss of a person or object that can no longer be felt, heard, known, or experienced by the individual

- Perceived loss – any loss that is less tangible and uniquely defined by the grieving client.
- Maturational loss – any change in the developmental process that is normally expected during a life time

- Situational loss – loss of a person, thing, or quality resulting from a change in a life situation, including changes related to illness, body image, environment, and death

- Death is the ultimate loss. Tell me your thoughts and feelings about your own death?

Grief

Grief – is the emotional response to a loss. It includes

- Mourning – the outward, social expression of a loss. It involves working through grief until the person can adapt to the loss and return to usual activities
- Bereavement – response to loss through death; a subjective experience that a person suffers after losing a person with whom there has been a significant relationship

- Bereavement – Person may move back and forth through a series of stages that may last years before the process is completed

Types of Grief

- Anticipatory grief – grief response in which a person begins the grieving process before the actual loss
- Complicated grief – when a person has difficulty progressing through the normal phases or stages of grieving, bereavement becomes complicated (

- chronic-long period,
- delayed-postponing due to responsibilities,
- exaggerated/ conflicted,
- masked/inhibited grief
- Abbreviated-very short,the attachment is replaced.

- Disenfranchised grief – person experiences grief when a loss is experienced and cannot openly acknowledge it

THE TASKS OF GRIEVING

- Task 1: Accepting the Loss
- Task 2: Feeling the Pain
- Task 3: Adjusting
- Task 4: Letting Go

Theories of Grief

- Kubler-Ross's stages of dying - behavioral oriented, 5 stages

denial – refuses to believe or understand the loss has occurred

anger – resists the loss by striking out at everyone and everything

bargaining – postpones awareness of the reality of the loss and may try to deal in a subtle or overt way as though the loss can be prevented

depression – mood disturbance characterized by feelings of sadness and discouragement. The person finally realizes the full impact and significance of the loss

acceptance – a person accepts the loss and begins to look to the future

Bowlby's phases of mourning

Numbing – the response to grief as a stunned or unreal feeling. It is the briefest phase of mourning

Yearning and searching – emotional outburst of tearful sobbing and acute distress in most persons

Disorganization and despair – endless examination of how and why the loss occurred.

Reorganization – the person begins to accept unaccustomed roles, acquire new skills and build new relationships

Worden's four tasks of mourning

Task 1: To accept the reality of the loss

Task 2: To work through the pain of grief

Task 3: To adjust to the environment in which the deceased is missing

Task 4: To emotionally relocate the deceased and move on with life

TEN WAYS TO HELP THE BEREAVED

1. By being there
2. By listening in an accepting and non-judgmental way
3. By showing that you are listening and that you understand something of what they are going through
4. By encouraging them to talk about the deceased.

Cont'

5. By tolerating silences
6. By being familiar with your own feelings about loss and grief
7. By offering reassurance
8. By not taking anger personally
9. By recognizing that your feelings may reflect how they feel
10. By accepting that you cannot make them feel better

Factors Influencing Loss and Grief

- Human development
- Psychosocial perspectives
- Socioeconomic status
- Personal relationships
- Nature of the loss
- Culture and ethnicity
- Spiritual beliefs

Assessment

- Type and stage of grief
- Grief reactions
- Factors that affect grief
- End-of-life decisions
- Nurse’s experiences
- Client expectations

Nursing Diagnoses

- Anticipatory grieving
- Dysfunctional grieving
- Hopelessness
- Powerlessness
- Spiritual distress

Palliative Care

- Symptom control
- Maintaining dignity and self-esteem
- Preventing abandonment and isolation
- Providing a comfortable and peaceful environment

Supportive Care

- Support for the grieving family
- Hospice care
- Care after death (postmortem care)
- Grieving nurse

Evaluation

- Client care
- Client expectations

  Am I helping you in the way you have hoped?

  Would you like me to assist you in a different way?

  Do you have a specific request that I have not been able to meet?

- Client care
- Client expectations

  What is most important for us to do for you at this time?

  Are we dealing with your problems in a timely manner?

Palliative care children

Children needs to be helped when they are diagnosed with a terminal illness because they have limited knowledge to understand the disease and the terminal illness.

They need to receive information regarding their health and should be involved in the provision of care where possible.

PAIN IN CHILDREN

- The physiologic response to pain is similar in adults and children although their perceptions and reactions differ .
- Children's perception of pain is influenced by age cognitive level and past experiences of painful episodes, parental response ,cause and expected duration of pain and extent of control over the Situation.

Physiologic response to pain

Physiologic responses include increased heart rate, respiratory rate, blood pressure and intracranial pressure.

Cardiac vagal tone, transcutaneous oxygen saturation , and peripheral blood flow are decreased.

- Autonomic signs include changes in skin color, vomiting, gagging, hiccupping, dilated pupils, and palmar and forehead sweating.

PAIN ASSESSMENT

- 3 main ways to assess a child's pain.
  - Ask the child – quickest and most accurate, provided the child is able to tell you
  - Ask the family–next best way and important as a cross check.
  - Assess it yourself–least accurate but better than nothing if you are stuck.

Remember if the injury, illness or procedure would cause pain in an adult, it WILL be painful to a child.

However...

- Some children may not report pain because of fears such as talking to doctors bothering or disappointing doctors, receiving an injection, returning to hospital, finding out that they are sick.
- For infants and non-verbal children –clinicians and caregivers have to interpret whether the distressed behavior represents pain, fear hunger or any other emotion.

WHO PRINCIPLES

- The broad principles of analgesic use in children (WHO)

✓by the clock (no PRN dosing)

✓by the correct route (prefer oral, avoid IM)

✓by the child (individualize treatment)

✓by the WHO ladder

Commonly used drugs

- Non opiods - paracetamol, ibuprofen, diclofenac
- Weak opioids –codeine, tramadol.
- Strong opioids – morphine, methadone, fentanyl
- Adjuvants – prednisone, amitryptilline,

tegretol, gabapentin, diazepam, haloperidol,