Manuals for Training in Cancer Control

Manual for Palliative care

Directorate General of Health Services
Ministry of Health and Family Welfare
Government of India

November 2005

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Dated: 13th September, 2005

FOREWORD

India is one of the few countries in the world to have a National Cancer Control Programme. The programme was conceived with the objectives of providing preventive and curative services through public education and enhancement of treatment facilities.

We have been able to develop 23 Regional Cancer Centres and several Oncology Wings in India, which provide comprehensive cancer care services. One of the major limitations of the programme is the late stage at presentation of common cancers thus reducing the chances of survival. There is a need to increase awareness among the community regarding prevention and early detection of cancers. The programme is developing IEC materials for the same. Once the population is armed with the necessary information, it is expected that the health system should be geared to tackle the increased demand for care. There have to be trained health care professionals to support the needs of the community. This can be addressed by proper training and sensitisation of general practitioners and health care providers.

These manuals are developed for training health professionals and specific modules have been prepared for Cytology, Palliative care and Tobacco cessation. The facilitator's manual will assist the trainers to conduct the programmes. The manuals are self-explanatory and the health professionals will be able to use them on their own.

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PREFACE

Demographic and epidemiological transitions and changes in lifestyle are leading to the emergence of cancer and other chronic diseases as public health problems in India. Cancer pattern in India reveals the predominance of tobacco related cancers, which are amenable to primary prevention. Cancer Registries in different parts of the country reveal that majority of cancer cases present in an advanced stage and makes treatment options prolonged and expensive. Therefore, the National Cancer Control Programme has placed its emphasis on prevention, early detection, enhancement of therapy facilities and provision of pain and palliative care. Comprehensive legislation on tobacco by the Government of India will help to control the tobacco related cancers. The programme has been able to augment the treatment capacity and to address the geographical gaps in cancer care services. Awareness and early detection programmes are undertaken through District Cancer Control Programmes.

Health care personnel have a major role in providing awareness, promoting early detection, prompt referral to a cancer treatment facility and in providing pain relief and palliative care. The knowledge and skills in the above areas have to be enhanced and these manuals have been developed in response to this need. This set of manuals, which consists of a facilitators' manual and separate manuals for health professionals, cytology, tobacco cessation and palliative care, is an attempt at providing the minimum required capacity. The manuals are self explanatory and will help the trainers, who will be from Regional Cancer Centres and other cancer treatment centres.

The manuals and the compact disc will be widely disseminated and same will be available on the website of the Ministry of Health and Welfare. The National Cancer Control Programme will urge that these may be used in cancer control training programmes in various settings.

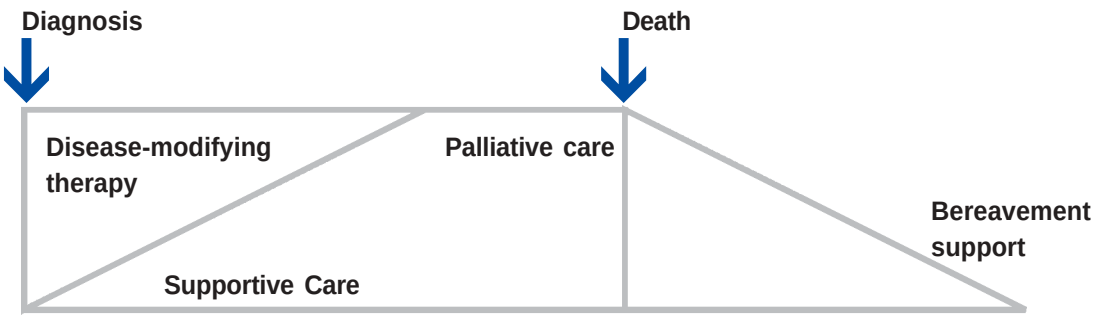
(K.RAAMAMOORTHY)
22.8.2005

1

Principles of Palliative Care

WHO defines palliative care as the active total care of patients whose disease is not responsive to curative treatment. Control of pain, of other symptoms and psychological, social and spiritual problems is paramount. The goal of palliative care is achievement of the best possible 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 treatment. Palliative care extends, if necessary, to support in bereavement.

Figure 1: The relationship between disease- modifying therapy, supportive care and palliative care



Palliative care

All patients should ideally be getting appropriate psychosocial and spiritual support in addition to the medical / nursing interventions. Palliative care can be seen as part of this continuum of supportive care. The term palliative care is used to describe supportive care when the disease is no longer responsive to curative treatment. Palliative care -

- Affirms life and regards dying as a normal process
- Neither hastens nor postpones death
- Provides relief from pain and other distressing symptoms
- Aims “To put life into their days and not just days into their life” - The idea is to help the person have a meaningful life, not just to live somehow till death

- Is concerned with quality of life. 'Quality of life is what a person says it is'. It relates to an individual's subjective satisfaction with life
- Aims at total care – physical, social, psychological and spiritual
- Is a team approach
- Is individual specific – depends on assessment of patient and family needs
- Shifts emphasis from technology to people – "high touch-low tech"
- Is a partnership between the patient & the team
- Emphasizes an open and sensitive communication

Need for palliative care

Patients diagnosed with a disease like cancer require not only physical control of disease and symptoms but also need help in coming to terms with their disease. If the stage of disease is such that chance of cure is remote, they also need assistance in planning for life. Patients with any chronic disease, and especially a disease like cancer, undergo a great deal of suffering. To be maximally supportive, it is also necessary to show that you care about the *patient as a person*, and that you are not just concerned about physical symptoms.

Problems contributing to suffering in incurable illness

- Pain
- Nausea / vomiting
- Fungating wounds / disfigurement
- Anorexia
- Breathlessness
- Loss of social roles
- Social isolation
- Dependency
- Change in faith / beliefs
- Personality changes
- Sadness
- Depression
- Denial
- Anger
- Fatigue
- Anxiety
- Neglect
- Financial difficulties

Suffering in chronic diseases is more than just simple summation of the individual problems – the interaction of each problem with others causes suffering to multiply. Also, suffering caused by the same problem may differ among individuals. Therefore such patients require expert trained support that is holistic in scope. Patients' families also undergo a great deal of trauma while caring for the patient. Hence, palliative care includes support to patients' families also.

Principles of palliative care

The four cardinal principles are

- Non-maleficence (Do no harm)
- Beneficence (Do good)
- Patient autonomy (patient's right to be informed and involved in decision making)
- Justice (balancing needs of individuals with that of society)

The four cardinal principles need to be applied against a background of

- Respect for life
- Acceptance of the ultimate inevitability of death.
- The potential benefits of treatment as against the potential risks and burdens
- Striving to preserve life but, when the burden of life-sustaining treatments outweigh the potential benefits, withdrawing or withholding such treatments and providing comfort in dying
- Individual needs balanced against those of society.

Palliative Care & Hope

Setting goals is an integral part of caring for patients with an incurable disease, even if progressive. In patients close to death, hope tends to become focused on:

"Being" rather than achieving
Relationship with others
Relationship with God or a higher being

It is possible, therefore, for hope to increase when a person is close to death, provided care and comfort remain satisfactory. When little else is left to hope for, it should still be realistic to hope for a peaceful death.

2

Pain Relief

Pain Relief:

Cancer patients in India generally need pain relief at all stages of their disease. Pain relief measures and anticancer treatment should therefore go hand-in-hand. Relief from cancer pain is possible in more than 90% of the patients. **Unrelieved pain in cancer patients is unacceptable.**

Pain in cancer may be:

- Due to the cancer itself- primary or metastatic
- Because of treatment- surgery, radiotherapy or chemotherapy
- Unrelated to disease or treatment- eg. Chronic pain syndrome, herpetic neuralgia, trigeminal neuralgia
- Because of debilitating **comorbidity.**

Pain is a complex physiological and emotional experience.

"PAIN IS WHAT THE PATIENT SAYS HURTS" – Do not disregard patient's complaint of pain just because no physical cause is apparent.

Assessing pain

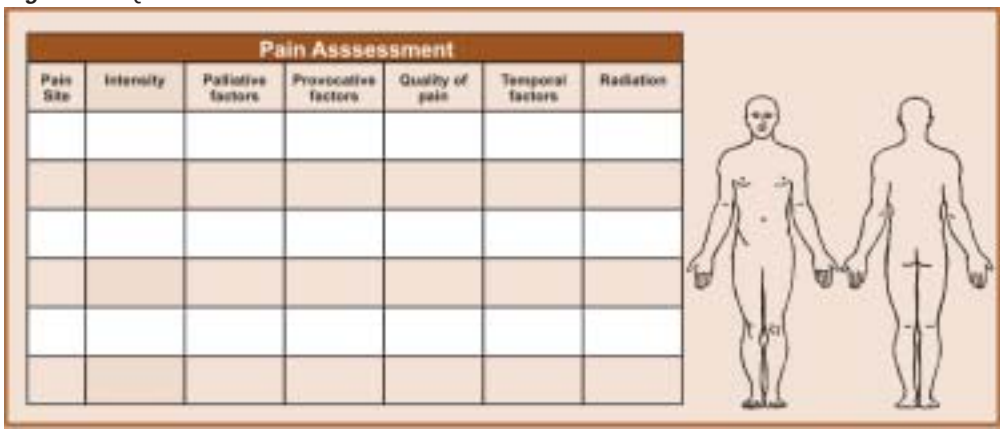
- Seek to establish a relationship with the patient
- Encourage the patient to do most of the talking
- Begin with a wide angle open question before focusing and clarifying specifics
- Watch the patient for clues regarding the pain
- Avoid jumping to conclusions

Pain assessment tools need to be valid, reliable and relevant.

Pain can be assessed using the PQRST characteristics

P -	Palliative factors	'What makes it better?'
	Provocative factors	'What makes it worse?'
Q -	Quality	'What exactly is it like?'
R -	Radiation	'Does it spread anywhere?'
S -	Severity	'How severe is it ?'
		'How much does it affect your life?'
T -	Temporal factors	'Is it there all the time or does it come and go?'
		'Is it worse at any particular time of the day or night?'

Figure 2: PQRST characteristics



Various scales for pain assessment are

- Descriptive scale
- Numeric scale
- Visual analogue scale
- Percentage scale
- Coin scale
- Face scale

The following format may be used for assessing pain in any given patient.

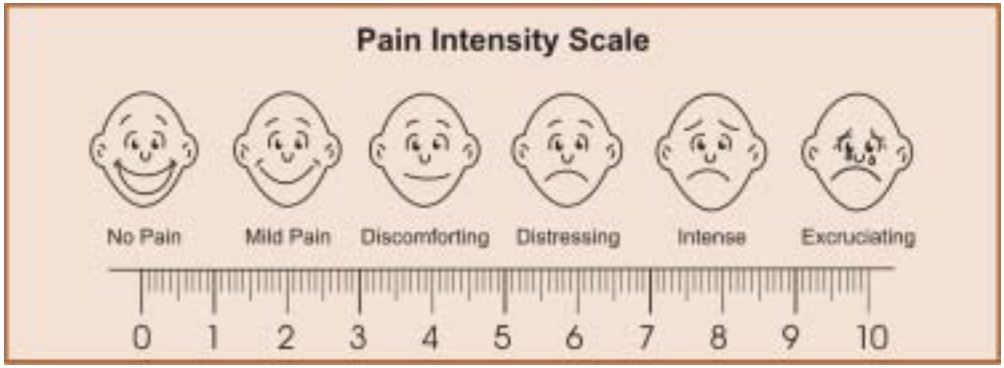


Figure 3: Pain intensity scale

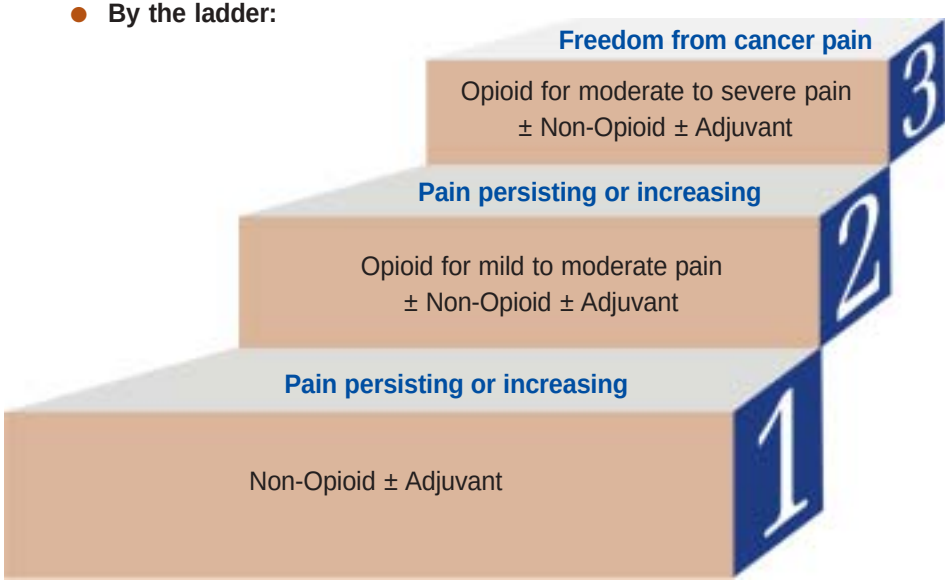
The scales are to be administered at each patient visit. Pain score is to assessed along with vital signs.

Management of pain

Analgesics are the mainstay of cancer pain management. Opioids are the main analgesics used in pain relief. **WHO has proposed that pain intensity rather than its etiology (cause) should be the prime consideration in the selection of analgesic. It has advocated the Step ladder approach to pain relief.**

Figure 4: WHO Ladder for Cancer Pain

- **By Mouth:** As far as possible, oral preparations are to be preferred.
- **By the clock:** Analgesics should be given at fixed intervals of time so that the next dose is given before the effect of the previous dose is worn off fully. This will ensure continuous pain relief.
- **By the ladder:**



- **For the individual:** The right dose is the dose that relieves the patient's pain. There is no other "right" dose for the opioid analgesic.
- **Attention to detail:** The need for regular administration of pain relief drugs should be emphasized. The drug regimen should be written out in full for the patient and family to work from.

Step 1: Patients with mild pain should be treated with a non-opioid analgesic, which may be combined with adjuvant drugs if indicated. Start with a Nonsteroidal Anti Inflammatory Drug (NSAID). e.g – Diclofenac 50 mg bid or tid, or Paracetamol 500 - 1000 mg qid or 4 hourly. If this is not adequate in 24 hours proceed to Step 2.

Step 2: Patients with moderate pain or who do not get adequate relief with non-opioids should be treated with a weak opioid like Codeine or Propoxyphene. Start treatment with Codeine or a combined preparation of Paracetamol with Dextropropoxyphene, retaining the non-opioid. Advise patients to take the medicines regularly and not attempt to assess their efficacy after a couple of doses.

Step 3: Patients with severe pain or who fail to get relief from step 2 are given strong opioids like oral Morphine or Buprenorphine.

Non-opioid analgesics:

These include paracetamol and other NSAIDs. They are particularly useful in the treatment of bone metastases.

List of certain NSAIDs that can be used for pain relief:

Drug	Typical starting dose
Acetaminophen	650mg 4hrly.
Ibuprofen	200-800mg 6hrly
Diclofenac Sodium	50-75mg 8-12hrly
Naproxen	250-750mg 12hrly
Piroxicam	10-20mg daily
Ketorolac	10 mg qid

Adverse effects of NSAIDs –

Continued use of NSAIDs may cause damage to the gastrointestinal system, kidney and interfere with platelet function. The symptoms may include nausea, heartburn, dyspepsia, gastrointestinal (GI) bleeding, and ulcers.

Risk of GI events with NSAIDs *increase with*

- increasing dose of NSAIDs
- increasing age.
- NSAIDs used in combination with aspirin
- NSAIDs /aspirin taken with alcohol

Commonly used opioids for cancer pain relief:

Step II Weak Opioids (Oral)	Usual starting dose
Codeine phosphate	10 – 15 mg 4hrly
Tramadol hydrochloride	50mg 6hrly
Dextropropoxyphene (with paracetamol)	32.5 – 65 mg 12 hrly to 6 hrly

Step III Strong Opioids (Oral)	
Morphine Sulphate (oral)	5 – 10 mg 4hrly 30 – 60 mg 12hrly (sustained release)

These drugs are best given by the oral route and the dose is tailored to suit each individual's needs instead of trying to give the standard dose. The dose of morphine can therefore vary from 5mg to 1000mg given 4hourly! High doses are to be administered after appropriate titration against pain by an expert.

Alternate routes of administration when oral administration is not possible for some reason are rectal, subcutaneous, intramuscular and intravenous.

The risk of addiction with use of opioids is small, and has been traditionally exaggerated. Morphine and other opioids should not be withheld for fear of addiction when patient requires stronger analgesic.

Adverse effects of opioids

- Constipation 99%
- Nausea, vomiting 33%
- Sleepiness, tiredness 33%
- Urinary hesitancy 5%
- Itching 5%

Signs of overdose

- Drowsiness
- Delirium
- Myoclonus
- Respiratory depression (Very rare)

Adjuvant drugs

Adjuvant drugs are used in addition to analgesics in pain relief. Adjuvants may belong to one of two categories –

- Drugs used to limit the side effects of analgesics
- Co-analgesics useful in certain types of pain

To control side effects

When opioids are given, patients should usually receive laxatives and antiemetics to prevent and control the constipating and emetic effects of morphine and its congeners.

Co-analgesics

Corticosteroids, antidepressants, anticonvulsants, anxiolytics and muscle relaxants all help in dealing with specific complaints of pain.

Drug	Useful in
Corticosteroids	Pain due to oedema / raised intracranial pressure
Antidepressants	Pain due to damage to nervous system
Anticonvulsants	Pain due to damage to nervous system
Anxiolytic	Where anxiety complicates pain
Muscle relaxants	Pain due to muscle cramps

Along with drug therapy, it must be ensured that patient's activities are analysed, and those which precipitate pain are avoided or reduced. Non-drug measures like hot pads, relaxation, and music therapy may also be tried.

3

Relief From Other Symptoms

All health professionals will be confronted with a spectrum of symptoms in patients suffering from cancer. The aim of management is to make the patient as comfortable as possible, by understanding and treating the cause if possible, and/or by interventions to provide relief from the distressing symptoms. Apart from pain, the common symptoms are dyspnoea, nausea and vomiting, constipation, anorexia-cachexia syndrome, confusion, insomnia and depression.

Constipation

Constipation is characterized by difficult or painful defecation and is associated with infrequent bowel motions and small hard faeces.

Aim of management

- To maintain normal bowel function for the individual
- To encourage patient self responsibility
- Maximize patient comfort
- Minimise symptoms and avoid complications

Causes

- Opioids and other drugs
- Dehydration
- Immobility
- Change in diet
- Change in environment
- Lack of privacy
- Pain
- Weakness and fatigue
- Disease related
- Fear and anxiety

Interventions

- Assess for treatable causes – eg pain relief, haemorrhoids
- Use laxatives whenever indicated
- Encourage increased fluid intake
- Increase dietary fiber eg fruits
- Encourage mobility as feasible
- Listen to anxieties
- Assess environment and privacy issues
- Adjust medication

Diarrhoea

Diarrhoea is the passage of frequent loose stools and is far less common than constipation in cancer patients.

Aim of management

- To stop or manage Diarrhoea
- To maximise patient comfort and minimize patient distress

Causes

- Imbalance of laxative therapy
- Drugs – antibiotics , chemotherapy
- Disease related
- Radiotherapy
- Malabsorption
- Loss of sphincter control
- Unusual dietary habits

Interventions

- Assess for treatable causes
- Care of skin/hygiene
- Supportive clothing – pads
- Dietary advice
- Drugs if indicated – loperamide etc

Nausea and Vomiting

Nausea is a sensation of needing to vomit often accompanied by symptoms of salivation, cold sweat, pallor.

Vomiting is the expulsion of stomach contents through the mouth.

Aim of management

- Relief of symptoms as soon as possible
- Provide essential teaching of self care to patient and family

Causes

- Drugs – antibiotics, NSAIDs, opioids, chemotherapy
- Radiotherapy
- Oral thrush
- Anxiety
- Gastric irritation
- Mechanical obstruction in the gut
- Constipation
- Low grade infection
- Irritation by copious sputum

Intervention

- Assess for treatable causes e.g.: cough – antitussive, constipation- laxative, infection – antibiotics
- Give appropriate antiemetic
- Provide vomit bowl
- Maintain oral hygiene, give mouthwash
- Ensure comfortable environment and minimize patient activity
- Observe for, and correct, dehydration

Dysphagia

Dysphagia is difficult or painful swallowing.

Aim of management

- To maximize swallowing and relieve stress
- To allow enjoyment of food and fluids

Causes

- Candidiasis (thrush)
- Cancer of mouth, throat, eosophagus
- Damage due to radiotherapy
- Neuromuscular involvement

Intervention

- Treat thrush
- Dietary advice
- Relieve anxiety
- Feed through nasogastric tube if appropriate
- Steroids may be of temporary benefit in certain situations
- If due to cancer, consider referral for palliative surgery or radiotherapy

Halitosis

Halitosis is foul or unpleasant smelling breath.

Causes

- Dietary - a frequent cause especially the use of garlic or spices
- Dental / periodontal problems - Infected teeth, gums, oral mucosal, or oral carcinoma (Thrush alone is unlikely to cause halitosis)
- Upper GI causes - gastric reflux or gastric stasis
- Bowel obstruction causing faecal vomiting
- Anaerobic infection of the lungs e.g. bronchiectasis

Interventions

Non-pharmacological -

- Meticulous oral hygiene
- Clean and soak dentures
- Ensure adequate fluid intake
- Flavoured sweets e.g. mints

Pharmacological -

- Anaerobic infection of gums - oral Metronidazole 400mg bd
- Gastric hypersecretion - Metoclopramide 10mg tds
  OR Domperidone 10 - 20mg qid (orally)
- Anaerobic infection of lungs - parenteral Metronidazole
- Antiseptic mouthwash - Chlorhexidine Gluconate 1% 10ml qid
  - ➤ Hexetidine 0.1% 10ml qid
  - ➤ Benzydamine 0.5% mouth wash
- Debriding agents if indicated
  - Sodium bicarbonate mouthwash - 1 teaspoon in 1 pint warm water and use a toothbrush on the tongue qid

  OR
  - Ascorbic acid (Vit C) - 250mg (1/4 of gram tablet) effervescent on the tongue qid

  OR
  - Hydrogen peroxide mouthwash 3% - 10ml in half a tumbler of water bd/tds

Breathlessness (dyspnoea)

Breathlessness is an unpleasant awareness of breathing. It is a common symptom in advanced disease.

Aim of management

- To maximize air intake and relieve anxiety

Causes

- Respiratory infection
- Fluid in the lungs (pleural effusion)
- Other coexisting diseases – asthma, COPD
- Lung collapse
- Anaemia
- Cardiac failure

Intervention

- Place the patient in the position he / she is most comfortable in – usually upright position supported by pillows
- Assess treatable causes
- Relaxation/breathing techniques
- Nebulisers
- Drugs – opioids, anxiolytics, steroids, diuretics etc
- Oxygen therapy

Cough

Persistent cough can cause anorexia, nausea, vomiting, and exhaustion.

Aim of management

- To relieve symptoms and associated distress
- To prevent complications

Causes

- Disease related
- Chest infection
- Other coexisting disease – asthma, COPD, heart failure
- Smoking

Intervention

- Assess for treatable cause
- Ensure suitable environment – comfortable temperature, humidification
- Soothing warm drink or lozenges
- For productive cough – encourage expulsion of secretions
- Drugs – cough suppressants, expectorants, antitussive, bronchodilators etc

Urinary incontinence

It is uncontrolled passing of urine of sufficient magnitude to create a problem

Aim of management

- To maximize patient comfort and relieve anxiety

Causes

- Infection
- Multiple drugs
- Diabetes Mellitus
- Constipation
- Anxiety
- Disease related

Interventions

- Assess for treatable causes
- Reassure
- Rapid and regular toileting
- Maintain hygiene
- Monitor hydration
- Catheterization if needed
- Drugs – for infection, constipation etc

Urinary Retention and Hesitancy

Retention is inability to pass urine. Hesitancy is prolonged delay between attempting and achieving urination.

Causes

- Disease-related
- Drugs
- Full rectum
- Weakness

Intervention

- Assess for treatable cause
- Reassure
- Ensure privacy
- Encourage voiding by – massaging lower abdomen, sound of running water etc
- Catheterization if needed

Insomnia

It is the lack of adequate sleep giving rise to an inability to function as usual.

Aim of management

- To restore normal sleeping rhythm and to allay anxiety

Causes

- Physiological – wakeful stimuli, sleep during daytime
- Psychological – anxiety, depression, fear
- Unrelieved symptoms – pain, nausea, breathlessness
- Drugs – diuretics, steroids

Interventions

- Physiological – proper setting to induce sleep – dim light, quiet surroundings
- Psychological – allay anxiety by sharing, listening, anxiolytics, sedatives
- Treat symptoms – pain, nausea etc
- Review and change drugs accordingly

Bed sores

Prevention and care of bed sores are the most challenging aspects of nursing care. Damage can occur due to pressure, friction, shearing and chemicals.

Aim of management

- To prevent further damage
- To promote potential healing
- To relieve pain and discomfort
- To prevent infection
- To control smell and discharge
- To minimise bleeding

Causes

- Reduced mobility
- Weight loss
- Incontinence
- Sensory loss
- Poor nutritional status
- Anaemia
- Steroid therapy
- Cytotoxic therapy

Interventions to prevent bed sores

- Nutritional support
- Ensure mobility or change of position at regular interval
- Good pain relief
- Good skin hygiene
- Assess and treat incontinence
- Assess the need for pressure relief
- Regular observation of pressure points
- Review medication

Interventions for management of bed sores

- Necrotic : Surgical excision
- Slough : Deslough; Irrigation with normal saline; Foam dressing
- Infected : Topical antiseptic; topical metrogyl; antibiotic; odour absorbing dressing
- Granulating : Foam dressing

Fungating wounds

The management of fungating wounds is based on the principles of -

- Palliation of symptoms
- Psycho social and emotional support
- Encouraging care at home: Involve the patient and family in wound care

Cleaning and Dressing

- Ensure adequate analgesia
- Irrigation with normal saline / water
- Syringing to remove slough
- Apply bacteriostatic drug
- Put a layer of non -adhesive gauze
- Apply gamjee pads
- Secure with bandage / adhesive tape

Controlling Foul Smell

- Clean and Dress the wound regularly
- Local Metronidazole - Crushed and powdered Metronidazole tablets are better and more cost effective than gel
- Systemic Metronidazole - may be required in some cases

Controlling Bleeding

- Apply local pressure
- Sucralfate powder (crushed and powdered tablets) topically
- Hemacrynium solution (Hemolok) 1:100 topically
- Systemic Ethamsylate
- Radiotherapy
- Surgical procedures

Lymphoedema

Lymphoedema is defined as swelling of interstitial tissue as a result of failure of lymph drainage when capillary filtration is normal.

Management of lymphoedema

- **Skin care**
  - ➤ Wash the skin gently; avoid harsh soap
  - ➤ Dry thoroughly, especially between digits
  - ➤ Moisturise regularly with bland cream
  - ➤ Take care to avoid burns, insect bites
  - ➤ Avoid Blood Pressure recording or venupuncture on the affected limb
  - ➤ Treat fungal infections promptly with antifungals

- **Exercise**
  - 3-4 times daily
  - Start gently
  - Pause on getting tired
  - Attention on proper posture
- **External support (bandaging)**

  Indications:
  - Long standing or severe lymphoedema
  - Awkwardly shaped limb
  - Lymphorrhoea
  - Damaged or fragile skin
  - Swollen digits
- **Contra indications:**
  - Arterial disease
  - Infection
  - Deep Vein Thrombosis
  - Cardiac failure
- **Massage**
- **Regular monitoring**

Nursing in Palliative Care

Palliative Nursing

- Requires an extension of basic nursing skills
- Requires individualised care planning
- Is based on the understanding that the patient is going through the most difficult time in life
- Works with the patient's family and friends

The role of the nurse is to create and implement a care plan for the patient and family based on -

- Observation of the patient
- Assessment of the patient's needs
- Evaluation of the results of interventions
- Regular reassessment of the situations and modifications to the plan

General care of the patient

Nutrition

Patients with advanced disease generally suffer loss of appetite, wasting and generalized weakness.Appropriate care should be provided to ensure adequate nutrition and prevent and manage symptoms from lack of nutrition.

Care includes –

- Ensuring intake of fluids, and dietary fibre
- Eating as much as the patient wants and as frequently as he / she wants
- Nutritionally complete foods and dietary supplements as needed
- Changing food consistency as needed
- Nasogastric feeding when patient is unable to accept oral feeding
- Prevention and management of oral thrush, nausea, constipation

Personal hygiene

Oral hygiene

- Promote brushing, using a soft toothbrush and rinsing mouth every 12 hours.
- Ensure proper fit of dentures, remove dentures at night
- Provide mouthwash
- Treat oral thrush with nystatin / fluconazole
- If medication is causing dry mouth – review drugs, provide ice chips and chewing gums to promote salivation

Skin care

- Wash body daily – bath/shower, sponge bath; shave daily; wash hair as often as feasible
- Ensure cleanliness of nails and mouth
- Provide clean clothing and bed linen
- Assess skin integrity – if pressure sores seem likely, change position frequently. Pad bony prominences, avoid friction and shearing forces
- Pressure sores – encourage healing by proper antiseptic dressing, antibiotics, removal of exudates and necrotic tissue, adequate nutrition

Spiritual care

Spirituality is our effort to find answers for life's fundamental mysteries, of which death is the most painful one.

The effort of the health professional should be to

- Take care of patient's physical problems
- Try and gauge the depth of despair, distress or anger the patient is feeling and seek remedies
- Offer the patient opportunities to discuss his / her problems without inhibitions
- Support all decisions of the patient
- Show due concern for patient's interest e.g. in preparing wills and in conducting ceremonies

Lifestyle and habits

- Encourage patients to lead a normal life as far as possible.
- Facilitate their indulgence in activities they used to enjoy before the illness,as far as possible.
- Help patients feel they are still wanted and useful in the family – encourage the family to involve the patient in domestic affairs and decision making.
- Provide privacy and opportunity for the patient to spend time with life partner – sexual needs of the patient are usually neglected and may cause considerable suffering.

Involving the family

The role of families in palliative care is very important. The family may have very little knowledge about the disease and its prognosis, *very low expectations about pain relief and very high expectations of anticancer treatment.*

Every effort should be made to empower the family and the patient by:

- Involving them in decision making with regard to treatment
- Explaining treatments in such a way that they can give informed consent or *informed refusal.*
- Facilitating a continuing sense of their being in control by providing them appropriate advice and practical support.

End of life care

“How people die lives on in the memory of those left behind”

The terminal phase is defined as the period when day to day deterioration, particularly of strength, appetite and awareness, are occurring. It is notoriously difficult to predict when death will occur, and it is better not to do so.

The aim of care at this stage should be to ensure the patient’s comfort holistically, and a peaceful and dignified death. Provide support to the family and patient through this transition.

Patient’s comfort can be ensured by managing symptoms, stopping unnecessary drugs, upholding patient’s wishes, alleviating fear and anxiety, taking care that the family is around him / her at this time, and dealing with patient’s spiritual and religious needs.

Support must also be extended to the patient’s family. Help the family to come to terms with the fact that the patient will be leaving them soon. Let family members be around to see and talk to the patient. Certain things may be distressing to the family – removal of intravenous fluids, apparent restlessness of the patient, change in skin colour etc. Deal with their anxieties and fears gently. After the patient’s death, give the family time and space to deal with their grief. Answer any questions they may have, but do not offer unnecessary platitudes. Do not upset the family’s sensitivities by immediately removing support devices – ask them before doing so. Maintain dignity of the patient even in death.

4

Communication with Patients

Communication is a part of our everyday life. Yet at certain situations and times it may be difficult to communicate successfully and effectively. Conveying bad news is a task preferred by none, but health professionals are often faced with just this job. This is especially true if the bad news is that the patient in question has cancer or any life threatening disease.

Truth is one of the most powerful therapeutic agents available to us, but we still need to develop a proper understanding of its clinical pharmacology and to recognize optimum timing and dosage in its use."

Basic guidelines of communication

- Rely on realistic assurance and empathy
- Environment
  - Provide privacy and comfort
  - Get physical barriers out of the way
  - Sit down with the patient
  - Eye contact
- Communication
  - Appropriate greeting
  - Open ended questions
  - Pick up on verbal cues
  - Use simple language
  - Avoid complicated words
- **LISTEN-** to concerns and emotions
- Weave your agenda with the patient

Barriers to communication

When dealing with a sensitive issue there are certain barriers which prevent effective communication –

- Professional
  - shared distress
  - fear of blame
  - fear of patient's reaction
  - fear of our own reaction
  - not knowing what to say
  - fear of criticism from seniors
  - not enough time
  - poor role modelling
- Patient
  - fear of questioning professionals
  - fear of death and dying
  - fear of suffering
  - loss of control
  - protection of others
  - social
  - cultural
  - financial
  - death denial / acceptance
  - lack of experience of death and dying at home
  - expectation of medical miracles

Good communication must

- maintain trust of the patient in the health professional
- reduce patient's uncertainty
- prevent patient and his family from having unrealistic expectations about disease and treatment
- allow the patient to adjust to his disease status
- prevent a conspiracy of silence, by family members and health workers, around the patient

Breaking bad news

Patients and relatives need time to absorb information and to adapt to bad news. Health professionals need good communication skills, including sensitivity and empathic active listening.

Breaking bad news takes time, and issues often need to be discussed further and clarified as more information is imparted. *Breaking bad news should be done only as part of a plan for continuous emotional support.*

There is increasing evidence that most patients want to know about their illness. Many patients who have been denied this knowledge have difficulty in understanding why they are becoming weaker and are then relieved and grateful to be told the truth. They may be angry with the family members who have known about the illness all along and have not thought it right to tell them.

As professionals, we are often caught up in a potential 'conspiracy of silence' situation when the family catches us before we have had a chance to speak to the patient. They might say "Do not tell him the diagnosis / prognosis because he would not be able to cope with it. We know him better than you do". This can be an awkward situation. The family needs to know that we have understood their concerns of not wanting to cause any more hurt to the patient. They also need to know that we accept that some patients use denial as a way of coping.

However they need to know too that it would be unwise for clinical staff to be untruthful if the patient wants to know the truth and was asking direct questions, because of the inevitable breakdown in trust that this could cause.

Advising patients and families with regard to prognosis is important since they may want to try to organise their affairs and plan for the time that is left, but, it is impossible to be accurate. Overestimating or underestimating the time that someone has to live can cause untold anguish. It is therefore more sensible to talk in terms of days/weeks, weeks/months, months/years as appropriate.

A strategy for breaking bad news

The actual process of outlining a strategy for breaking bad news is difficult because it turns a process which should be natural and unforced into something which seems constrained and awkward. This outline is not intended to make you feel self conscious but to give you an idea of what other people have found helpful so that you have more information with which to develop your own personal way of breaking bad news.

The goals of breaking bad news

The process of breaking bad news needs to be specifically tailored to the needs of the individual concerned, for every human being will have a different history and collection of fears and concerns.

The goal of breaking bad news is to do so in a way that facilitates acceptance and understanding, and reduces the risks of destructive responses.

The ability to break bad news involves skills which need to be coveted and trained for, and kept up to date. The consequences of performing the process badly may have immediate and long term damaging effects for all involved.

Having awareness of strategies to complete the process is vital, but breaking bad news must never become so professional that patients, or their families, detect little caring and compassion.

Preparing to tell bad news

Acquire all the information possible about the patient and their family.

Read the case notes for

- Diagnostic information
- Test results
- Understanding the patient's clinical history
- The support system for the individual
- Background knowledge of patient's life.
  (Making basic mistakes will undermine the patient's confidence.)

Discuss with other members of the team and then select the most appropriate team member to break the bad news. Decide which other member of the team should be present during the interview.

Check

- Place of privacy, and non-interruption.
- Time to carry out process, your own emotional energy to do so
- Complete pressing tasks so that there will be no interruptions.

Plan

Prepare a rough plan in your mind of what you want to achieve in the communication, and what you want to avoid communicating. Having a rough goal will bring structure to the communication, though it is important to avoid imposing your agenda on the patient.

Setting the Context

- Ensure a place of privacy.
- Introduce yourself clearly.
- Let patient know they have your attention.
- Ensure that the patient is comfortable and not distracted by pain or a full bladder etc.
- Give a “warning shot” indicating that this is not a social or routine encounter.
- Sit at the same level as each other within easy reach

Assess

- How much the patient knows
- How much the patient wants to know
- How the patients express themselves and what words and ways they use to understand their situation.

Acquire empathy with patient

- What would it be like to be this patient?
- How is the patient feeling?
- Is there anything which is concerning the patient which he/she is not verbalising?
- What mechanisms has the patient used in the past to deal with bad news?
- Does the patient have a particular outlook on life or cultural understanding influencing their approach to dealing with the situation?
- Who are the important people in the patient’s life?
- Respond to non verbal as well as verbal clues.
- Encourage the patient to speak by listening carefully and responding appropriately.

Sharing information

- Having spent time listening, use the patient’s words to recap the story of the journey so far, checking regularly with the patient that you have heard the story correctly.
- Slowly and gradually draw out the information from the patient while regularly checking that they are not misunderstanding what you are saying.
- Use the “warning shot” technique to preface bad news to help the patient prepare themselves.
- Use diagrams to help patient, if it is appropriate and the patient wants diagrams to understand better and retain the information.
- Avoid jargon and acronyms, which are easily misunderstood.
- Do not bluff. It is acceptable to say... *“I do not know, and I will need to try to get an answer for you for our next meeting.”*

Check for accuracy of understanding to ensure that:-

- The patient understands what is being said.
- The patient's fear of having bad news suddenly dumped on them is reduced
- The patient is in control of the speed at which information is being passed on.
- The patient can see that their emotional response to the news is also part of health professional's concern.
- Address the patient's real concerns, which may be very different from what is expected.

Responses

- Respond to the patient's feelings and their response to the news.
- Acknowledge the patient's feelings.
- Be prepared to work through the patient's emotional response to the bad news.

Plan

Long Term Planning

Even when treatment is very limited in its potential effectiveness, it is important that the patient knows that "treatment" is going to be continued, and that they are not going to be cut adrift to face the future without help.

Make concrete plans for the next step.
Try to help the patient make next move

Immediate Plans

"What are you doing now? How are you getting home? Whom will you tell? How will you tell them? What will you say? How will they cope"?

Such questions can help the patient to start formulating the answers that they will need for their family or friends.

Summarise

For the Patient:

- Try to get the patient repeat the key points to ensure they have understood.

For other Health Care Professionals:

- Record details of the conversation in the patient's notes clearly.
- Convey information quickly to those who need to know such as the family doctor.

Deal with questions

"Are there any questions which you would like me to deal with at this point?"

Summarise again the key points.

Contract for the future

Closing remarks and identification of support network, including contact telephone numbers and times of easy access.

Do's and Don'ts in Communication

Do

- ✓ **have enough time for discussion with the patient**
- ✓ **give timely reassurance when ever needed**
- ✓ **listen… listen… listen**
- ✓ **be attentive to verbal and nonverbal communication**
- ✓ **use simple words**
- ✓ **have an open attitude**
- ✓ **explain**

Don't

- ✗ **be in a hurry**
- ✗ **be a premature pacifier**
- ✗ **pretend that you are listening**
- ✗ **ignore what the patient says**
- ✗ **interrupt more frequently than needed**
- ✗ **use medical Jargon**
- ✗ **be judgmental**
- ✗ **patronize**
- ✗ **compare**

ACKNOWLEDGEMENTS

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