Palliative care
in primary health care

Module 4.2

Step 1
Non opioids +/- adjuvant

Step 2
Weak opioid + non opioid +/- adjuvant

Step 3
Strong upload + non opioid +/- adjuvant
WHAT’S INSIDE

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INTRODUCTION

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual. It is now well known that specialist palliative care services alone will not be able to address the enormous number of patients in need of palliative care. Availability of simple effective protocols for symptom relief and a low-technology approach on one hand, and inability of hospitals in offering “total care” for the rest of the life of a patient with advanced diseases make palliative care a much-needed component of primary health care. This module covers the skills for communication and management of patient with terminal diseases in primary health care.

LEARNING OUTCOMES

At the end of the session the participants will be able to:

- Effectively communicate with patients living with terminal noncommunicable diseases (NCDs) and their families.
- Manage pain, and diagnose and manage distressing symptoms in patients with terminal NCDs.

TOPICS COVERED

- Concept of palliative care and the public health approach for integrating it into primary health care.
- Role of effective communication in the management of diseases.
- Identification, assessment and documentation of chronic pain.
- WHO analgesic ladder for management of pain and neuropathic pain.
- Common distressing symptoms in terminal NCDs and their management.
- Prevention and management of pressure sores.

COMPETENCY

- Communicate effectively with patients and manage pain and distressing symptoms in patients with terminal NCDs.
TEACHING AND LEARNING ACTIVITIES

Total session time: 60 minutes

Activity 1. Introduction to palliative care: 15 minutes

Step 1. Start with the following statement.

Most people with advanced diseases approach primary health care (PHC) facilities at the end of life as they are more accessible and affordable than other facilities. But often PHC facilities are not able to do justice to these patients.

Step 2. Ask the participants to discuss the barriers to improving services for incurably ill, elderly and dying patients in their areas. Write the responses on a white board/flip chart.

Possible responses will include:

- lack of skills, knowledge and trained personnel
- lack of time due to existing workload
- lack of appropriate medications.

Step 3. Present the following case study.

There is a 48-year-old female with advanced breast cancer in your neighbourhood. She has two daughters aged 24 and 16. The elder daughter is away with her husband. The treating doctor has told the patient’s husband that her disease is not responding to treatment and that she is likely to die in 6–9 months. You visited her yesterday. She complained of pain all over the body. She looked very worried.

Step 4. Ask the participants to discuss the following questions related to the above case.

What can you do to help this patient and her family?
What skills/knowledge/contacts that you have can help?
Can further help be sought from anyone else?
Use a flip chart/white board to write down the responses.

Possible responses will include

- exploring her worries
- giving medicines for pain
Step 5. Present the powerpoint slides on palliative care.

Activity 2. Communication on palliative care: 15 minutes

Step 1. Start with the following statement.

Communication is part of our life. We talk to other people and we listen to other people talking. Sometimes we feel that the other person did not talk or listen to you well. We are spending a few minutes to discuss how other people should talk to us and how others should listen to us when we talk to them.

Step 2. Divide the participants into two groups. One group will discuss how people should listen when we talk and the other group will discuss how people should talk to us.

Each group to discuss for 5 minutes. One person from each group to report the key points after the discussion. Write down the responses on a flip chart/white board.

Group A: Attributes of a good listener: how do you want the listener to listen when you talk to him/her?

Possible responses include:
- take an interest in what the speaker is saying
- no distractions such as attending to the phone while listening
- do not interrupt the speaker
- don’t look the other way; maintain eye contact
- verbally and non-verbally encourage the other person to speak.

Group B: Attributes of a good speaker: how do you want the speaker to speak when he/she talks to you?

Possible responses include:
- speak clearly
- use simple language; do not use jargon
- prepare what you want to speak before speaking
- show interest in the listener. Don’t get distracted.
Step 3. Present the powerpoint slides on patient communication containing the following.

- Role of communication in patient care
- Good communication skills
- Do’s and don’ts in communication.

**Activity 3. Pain management: 15 minutes**

Step 1: Ask participants to list the commonly used and available painkillers and to classify them into opioid drugs and non-opioid drugs.

Step 2. Write down the responses down under two headings (opioids, non-opioids) on a flip chart/white board.

Possible responses include:

**Non-opioids**
- paracetamol
- non-steroidal anti-inflammatory drugs (NSAIDs)
- ibuprofen
- diclofenac
- ketanov
- meloxiccam
- mefanamic acid.

**Opioids**
- tramadol
- codeine
- buprenorphine
- pethidine
- morphine
- fentanyl.

Step 3. Enquire if morphine tablets/solution are available in the primary health care centre.

Possible response will be ‘No’, and if so, ask how they manage pain in chronic patient.

Step 4. Using powerpoint slides explain the WHO Analgesics Ladder and pain management.

Step 5. Refer to the two prescriptions in the workbook and ask participants how they want to modify the prescriptions in the light of the key points shown in the previous slide.

Note down the responses on a flip chart/white board.
Prescription I: Patient with carcinoma lung, post-radiotherapy, post-chemotherapy. The disease is progressive; pain relief is inadequate.

Tablet paracetamol 500 six hourly

Tab tramadol 50 mg eight hourly.

Correct response:
- Paracetamol needs to be given in 1000 mg dose four times a day.
- Laxatives to be prescribed with tramadol.
- Antiemetics to be prescribed for a few days when tramadol is prescribed for the first time.

Prescription II: Patient with carcinoma breast, post-surgery, post-radiotherapy, post-chemotherapy. Metastases to chest wall present; pain in chest wall present but pain relief is inadequate.

Tab ibuprofen 400 mg eight hourly

Tab morphine 10 mg six hourly and prn (SOS).

Correct response:
- Proton pump inhibitors to be given with ibuprofen.
- Morphine needs to be given every four hours.
- Laxatives to be prescribed with morphine.

Activity 4. Symptom relief in advanced diseases: 15 minutes

Step 1. Ask the participants to list names of available drugs to treat breathlessness. Note the suggestions on a flip chart/whiteboard.

Possible responses will include:
- oxygen
- broncho dilators (tablets/injections/syrup/inhalers)
- steroids.

Step 2. Present powerpoint slides on the management of breathlessness/ dyspnoea in advanced diseases.

Step 3. Refer to the case situation in the workbook.

A 56-year-old man with advanced cancer of the stomach has been pronounced incurable by the oncologist. He has nausea and vomiting and is diagnosed to have inoperable total gastrointestinal obstruction. Patient requests a glass of water. Will you stick to a policy of nil per oral or will you allow him to drink? Why?
The possible response is ‘No’. The facilitator explains that the gastrointestinal system normally has more than seven litres of fluid in it. At the time of obstruction, it can go up to 11 litres because of increased secretions. Addition of another 50–100 ml by way of a glass of water/tea/coffee is not harmful. Also, mention that patient’s mouth should be kept clean and moist to reduce thirst.

**Step 4. Present powerpoint slides on management of nausea, vomiting, and fungating wound.**

**Optional activity**

**Step 1. Refer to the case situation in the workbook.**

A 75-year-old male has cancer in his right lung. Admitted for radiotherapy to lower back for vertebral metastasis. He is on tablet morphine 10mg q4h, tablet paracetamol 1000mg q6h, tablet dexamethasone 16 mg once daily, tablet bisacodyl 10mg HS and capsule omeprazole 20 mg once daily. He spends most of the time in bed. He is seen to be behaving abnormally this evening. He is talking irrelevant things and attempting to get out of the bed and go out. What is happening to him? Why? How will you manage the situation?

(Possible response is delirium)

**Step 2. Present slides on delirium in advanced diseases.**

**Step 3. Explain that we all have to die one day and that most people die in distress and suffering. Participants are asked to list the main reasons for distress and suffering in death. Note the key points on a flip chart/white board**

Possible responses will include pain, physical symptoms, unfinished business, worries about family and the afterlife.

**Step 4. Explain that most of the symptoms at the time of dying can be managed. Present slides on the common symptoms at the end of life and methods of symptom relief.**
**BACKGROUND INFORMATION**

**Palliative care**

Palliative care is an attempt to prevent and manage suffering, especially when the condition is incurable and progressive. Palliative care relieves suffering and improves the quality of life of patients and families of progressive incurable illness.

**WHO definition of palliative care**

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

**Current status of palliative care in world**

![Diagram of palliative care]

(1) http://www.who.int/cancer/palliative/definition/en/
Palliative care and noncommunicable diseases

Palliative care has become very relevant in recent years because of two reasons.

1. Noncommunicable diseases (NCDs) are having an increasing impact on the health status of populations globally. Of 56.4 million global deaths in 2015, 70% were due to noncommunicable diseases (NCDs).

2. Ageing of the population has caused the number of people in need of supportive care in the community to rise significantly. A United Nations report on ageing states that virtually every country in the world is experiencing a growth in the number and proportion of older persons in their population. Population ageing is poised to become one of the most significant social transformations of the 21st century.

The World Health Organization has been advocating for the need to promote a public health approach through the integration of palliative care programmes into the existing health systems and their being tailored to the specific cultural and social context of the target populations. Resolution WHA67.19 of the Sixty-seventh World Health Assembly appeals to Member States to strengthen palliative care as a component of comprehensive care throughout the life course, in line with the spirit of this approach.

Role of primary health care provider in patients with advanced disease at home

It is possible to manage patients with advanced diseases at home. The establishment of affordable, accessible and quality palliative care facilities in the community will reduce the duration and frequency of hospitalization of incurable patients. This will be a welcome step as people will be at home during the end-stage of their lives. The establishment of quality community-based health-care services at home will provide emotional and spiritual support to the patient, and help in preventing complications in bed-ridden cases. This can be done in partnership with the family/ Neighbourhood/local community that has a keen interest in the well-being of the patient.

Figure 1 shows the public health approach in palliative care.

**Figure 1: Public health approach in palliative care**

Palliative care as part of primary health care

Doctors, nurses and health workers at the primary health care level can easily master the skills and knowledge required to provide symptom relief and emotional support through simple short courses/training programmes. Table 1 presents a sample two-day training programme covering basic practical issues. Community members can be sensitized and trained to offer meaningful companionship to the patient and family at the time of crisis and to help them in social and spiritual issues. Social and spiritual support can be made available to patients by linking them up with interested and competent agencies/trained volunteers in the community.

Table 1: Suggested minimum training standards for the home care team

<table>
<thead>
<tr>
<th></th>
<th>Basic</th>
<th>Mid-level</th>
<th>Advanced</th>
</tr>
</thead>
<tbody>
<tr>
<td>Doctors</td>
<td>Foundation courses (3-10 days)</td>
<td>Residential course (6 weeks)</td>
<td>Fellowship/postgraduate qualification in palliative care (1-3 years)</td>
</tr>
<tr>
<td>Nurses</td>
<td>Foundation courses (3-10 days)</td>
<td>Residential course (6 weeks)</td>
<td>Certificate course (4 months), fellowship (1 year)</td>
</tr>
<tr>
<td>Community health workers</td>
<td>3-6 hours to supplement prior training</td>
<td>Basic course (3 months/400 hours)</td>
<td>Advanced communication skills/lymphedema management</td>
</tr>
<tr>
<td>Volunteers</td>
<td>Introductory course (3 hours)</td>
<td>16 hours theory + 4 clinical sessions</td>
<td>Advanced communication skills and train-the-trainer course</td>
</tr>
</tbody>
</table>


The success of the programme in terms of quality and coverage depends on the meaningful involvement of the maximum number of stakeholders. Since the problems of the patient are multiple – including physical, psychosocial, emotional and spiritual – it is possible to start action at any point depending on the availability of resources, and build capacity in other necessary areas in a phased manner. Figure 2 represents the matrix depicting the interplay between different components of community-based palliative care services.

Figure 2: Matrix of community-based palliative care services
Home-based care

Palliative care needs to be provided at the place where the person’s care takes place, which may be either the patient’s own home or a treatment/care facility. Since patients requiring palliative care are spread out in the community and tend to spend most of their time at home, a “palliative care approach” by all health-care professionals is needed in addition to specialist centres for training and referral. This will mean that all the health-care professionals need to be educated and skilled through appropriate training. For maximum effectiveness in terms of quality and coverage, the health-care professionals offering palliative care at the primary care level need to have a supportive environment in the community. This can be made possible by empowering the community to effectively intervene in psychosocial and spiritual issues and reorienting the health-care system to work with the community. Such a system of care should also be supported by specialist palliative care centres for referral of patients and training for health-care professionals and community volunteers. Such community-based palliative care services developed as a part of the comprehensive NCD programme should be available and accessible to people living with advanced diseases.

In most cases, patients with advanced NCDs can be managed at home with a trained nurse/health worker-led home care programme, supervised by a trained doctor. Services of the home care unit can be complemented by a network of trained volunteers in the community. Depending on the available manpower at the primary health care level, the grassroots-level professional can be a nurse with training in palliative care or a local person who has undergone a three-month “Basic Certificate Course in Community Nursing and Palliative Care”.

Home care programme will be based on protocols clearly defining documentation, areas and types of intervention and indications for referral.

Strategy for integration of palliative care with primary health care

The WHO Guide for Programme Managers on Planning and Implementing Palliative Care Services has identified key success factors for integration of palliative care to the primary care system.

1. WHO views that palliative care is part of the role of all health workers, rather than seeing palliative care as a speciality that requires separate health workers.

2. Palliative care is embedded in the health-care continuum, making it an essential component of primary care. It is seen as a normal health-care activity rather than a specialist one.

3. Opportunities in the national palliative care context (e.g. training, financing, legislation, regulation of drugs) are used to build ownership of them at district level.

Palliative care integrated with primary health care: Examples from the South-East Asia Region

Northeast Thailand

Thailand has a strong primary care network. The country has a three-tier system of health care in the public sector with primary care units, district hospitals and provincial hospitals. At least 99% of the population is covered through a universal health insurance.
Northeast Thailand has developed an effective network of nurse-led home-care programme integrated with the mainstream health-care system which is under the Ministry of Public Health. A specialist palliative care centre based in a university hospital serves as the training and referral unit. This tertiary care unit has trained health-care professionals and facilitated the development of nurse-led home-based care teams in the provincial hospitals, district hospitals and primary care units.

A successful pilot project in one service area (Service Area 7 with four provincial hospitals, 62 district hospitals and all their sub-district primary care units) has now been extended to all Northeast Thailand. Twenty provincial hospitals, 300 district hospitals and more than 3000 PHCs are under this initiative. The home-care units are supervised by palliative care units in district hospitals. About 95% of district hospitals in Northeast Thailand now have palliative care units. Palliative care units in the district hospitals are linked with the provincial palliative care unit above and with the primary care units below.

The success of the programme in Northeast Thailand can be attributed to three major supporting factors:

1. A strong existing primary health care network;
2. An effective universal health coverage programme; and
3. Effective training and facilitation programmes organized by the training and referral institution.

Kerala (India)

The southern state of Kerala in India has managed to establish an integrated health service delivery system in palliative care at the primary health care level. This state with a population of 33 million and a fairly well functioning primary health care system has already been drawing international attention for its health indices. A formal attempt to provide palliative care for the needy in Kerala was initiated by a civil society organization in Calicut in the early 1990s. This was later developed into the “Neighbourhood Network in Palliative Care (NNPC)”, a concept of wider and deeper participation by the community.

In 2008, the Government of Kerala declared a pain and palliative care policy highlighting the concept of community-based care and committing to develop palliative care integrated to the existing primary health care system in the Region.

The Government followed this policy with a project aimed at sensitization and training of various groups of community volunteers, doctors, nurses and local politicians who are the potential policy-makers at the local self-government level. The philosophy and action plan has been in line with the public health approach in palliative care envisioned by the World Health Organization through various declarations starting with the one from Alma-Ata. The strategy was to facilitate the development of palliative care programmes through local self government institutions while taking care to maintain the spirit of community participation in the programme. The focus of the facilitation programme was on sensitization and capacity-building among various strata of society and health-care professionals at the primary, secondary and tertiary levels of the health care system.

Now, the 1000-odd primary health centres in Kerala deliver palliative care through their community nurse-led, volunteer-supported, home-care programmes. This is complemented by more than
200 programmes run by civil society organizations. Secondary palliative care programmes are being developed in the 14 district hospitals to support programmes at the primary health care level. Further improvement in quality and coverage at the primary health care level is needed, but the most difficult barrier of scaling up has been overcome. Kerala, with 3% of India’s population, now has more than 90% of palliative care units in the country.

The following factors seem to have contributed to the success of the programme:

- Improved awareness among the public because of efforts by various civil society organizations in the field, regular support by the media and sensitization programmes by the Government.
- High-level policy recognition resulting from awareness at the political level.
- State funding for palliative care through the Ministry of Health and local self-government institutions.
- The government’s innovative project in palliative care with the agency acting as facilitator and coordinating different governmental and nongovernmental agencies.
- Decentralized system of governance in Kerala with empowered local self government institutions.
- Better utilization of nurses as lead health-care professionals in home-based care.

For further reading

*The facilitator can go through the following documents if further information on setting up palliative care services or training of carers/volunteers is needed. Pdf copies of both documents are available for free download.*


Palliative Care – A Workbook for Carers, by WHOCC on Community Participation in Palliative Care and Long-Term Care [http://www.instituteofpalliativemedicine.org/downloads/Palliative%20Care%20Workbook%20for%20Carers.pdf](http://www.instituteofpalliativemedicine.org/downloads/Palliative%20Care%20Workbook%20for%20Carers.pdf)

**Pain**

**Definition**

The International Association for the Study of Pain defines “pain” as “an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage”.

Pain has a sensory component and an emotional component (effect) which encompasses emotions, moods and temperaments. The emotional component is subjective, essentially “private”, and often somewhat vague.

For all practical purposes, based on this definition, Pain is when a person says, “it hurts”, because pain is a subjective phenomenon.
**Acute and chronic pain**

Depending on the duration, it is customary to classify pain as acute and chronic. Acute pain is pain of less than 3 months duration (some text books say less than six months duration) and chronic pain is pain of more than 3 months duration.

Apart from duration of pain, there are a lot of important differences between these two types of pain. Acute is associated with subjective and objective physical signs such as hyperactivity of the autonomic nervous system (increased pulse rate, increased respiratory rate, increased blood pressure, increased muscle tone, sweating, etc.) and increased basal metabolic rate (BMR). Acute pain serves a biological function by helping in limiting the damage.

Whereas in chronic pain, the autonomic nervous system adapts to the situation and, as a result, none of the physical signs associated with acute pain will be manifested. Instead, we will observe changes in personality, lifestyle and functional ability of the patient. Chronic pain does not serve any useful biological purpose.

Chronic pain causes sleep disturbance, change in moods and restriction of social activities. It restricts household chores. Reduced functional status sometimes make people change jobs due to chronic pain. There have also been instances of jobs lost due to chronic pain.

Chronic pain can be a major financial burden for the patient and his family. Many patients with insufficient pain relief feel helpless and go for alternative methods. It is associated with anxiety and depression. Chronic pain causes reduced satisfaction and self-esteem, leads to difficulties within the family and also an overall reduction in the quality of life.

**Assessment and documentation of pain**

Assessment and documentation of pain is important to ascertain the efficacy of therapy, understand the pain better, provide encouragement and support to the patient, and for future reference.

Inadequate pain assessment is an important contributing factor in the undertreatment of pain. Assessment of pain is complex because pain is always subjective. The patient’s self-report of pain is the single most reliable indicator of pain. The basic principle in assessment of pain is that the clinician must accept the patient’s self-report of pain.

The following points should be explored while charting a history of pain.

1. Site of pain: where exactly is the pain?
   
   It is a good practice to use pain diagrams to document the pain during each visit.
Palliative care in primary health care setting

Figure 3: Pain diagram

(2) Character/quality of pain: Burning/Pricking, etc.
(3) Frequency
(4) Radiation: Does the pain spread from the original site?
(5) Intensity of pain (use a pain scale as described below)
(6) Aggravating factors: What aggravates the pain?
(7) Relieving factors: What relieves the pain?

Pain scales for measurement of intensity of pain
Two types of pain scales are available.

(I) Multidimensional

(II) Unidimensional

Multidimensional scales explore all dimensions of pain. Since they take time to administer, multidimensional pain scales are not suitable for use in busy outpatient settings.

Unidimensional scales assess the overall intensity of pain. These take little time to administer and hence are suitable for busy clinical settings.

Any one of the following scales can be used.

- numeric rating scale
- verbal rating scale
- visual analog scale
- verbal descriptor scales
- face pain rating scale (observation scale for kids).
Steps involved are:

(I) Explain the scale to the patient.
(II) Ask him/her to rate the intensity of the particular pain at the time of assessment.
(III) Document the intensity mentioned by the patient.

**Figure 4: Pain scales**

0–10 Numerical scale

Descriptive Pain Intensity Scale

Pain descriptive scale

**Visual Analogue Scale (VAS)**

Management of pain in advanced diseases

Basic principles of management of pain in advanced diseases include:

(1) Do not delay treatment; treat the pain immediately.
(2) Have a good understanding of the pharmacology of analgesics and adjuvant medications.
(3) Document properly.
(4) Educate patient and family.
(5) Follow WHO analgesic ladder protocol.
(6) Always prescribe additional “as and when required” doses to cover breakthrough pain.
**WHO analgesic ladder**

WHO analgesic ladder is a simple protocol for pharmacological management of pain in advanced diseases.

It is based on the theory that in 90% of patients, pain can be steeled by analgesic therapy:

- by mouth.
- by the clock (giving medicines at regular fixed intervals based on the half-life of the drug).
- by the ladder (following a three-step protocol).

Invasive procedures are used only when drug therapy fails.

**Figure 5: WHO analgesic ladder**

**Step 1. Non-steroidal anti-inflammatory drugs (NSAIDs) and/or paracetamol**

Key points:

- Use the NSAID you are most comfortable prescribing and use the optimum dose.
- Be aware of the side-effects of NSAIDs.
  - GI toxicity
    - consider prophylactic PPI
  - Renal toxicity
    - watch for signs and symptoms
    - avoid use in at risk patients
  - Interference with platelet function
    - avoid use in patients with risk of bleeding.
Never prescribe multiple NSAIDs.
Optimum dose of paracetamol as analgesic in an adult is 1g 4 times a day.
Paracetamol can be combined with an NSAID.

**Step II. Weak opioids**

Drugs commonly available in the South-East Asia Region are:
- codeine
- tramadol

**Step III. Strong opioids**

Strong opioids commonly available in the South-East Asia Region are:
- morphine
- pethidine
- fentanyl
- methadone.

Among the opioids, morphine needs special mention.
- Morphine is WHO’s strong opioid of choice for cancer pain management.
- Orally, no other strong opioid has a clear advantage over morphine.
  - Among the available drugs in the Region, Fentanyl is the drug of choice in renal failure as accumulation of the metabolite morphine 6-glucuronide can happen with morphine.
- Orally available in immediate release and long-acting formulations.
- Can also be given rectally, intravenously, subcutaneously, epidurally and intrathecally.

**Side-effects of opioids**

Clinician should be aware of the following common side-effects while prescribing opioids
- Constipation
  - always prescribe laxatives
- Nausea, vomiting
  - use small dose of haloperidol (1.5 mg at bedtime)
- Sleepiness, tiredness
  - improves with time
  - check for overdose
- Urinary hesitancy
  - alpha blockers may help

- Itching
  - may need to change the drug.

The following are signs of overdose to be responded to by reducing the dose or stopping the opioid drug:

- drowsiness
- delirium
- myoclonus
- respiratory depression (extremely rare with oral opioids).

**Adjuvants in the WHO ladder**

Two groups of drugs are called adjuvants in the context of the WHO analgesic ladder.

- First one is the group of drugs used to limit the side-effects of analgesics. Common examples are laxatives/antiemetics/proton pump inhibitors.
- The second group of drugs which show analgesic potential in certain clinical situations are called co-analgesics. Antidepressants, anti epileptics and NMDA receptor antagonists which show analgesic properties in neuropathic pain are the common examples.

**Neuropathic pain**

The revised definition of neuropathic pain by the IASP Neuropathic Pain Special Interest Group (NeuPSIG) 2008 is "pain arising as a direct consequence of a lesion or disease affecting the somatosensory system".

The diagnosis is derived from three areas.

- A history-derived working hypothesis (possible neuropathic pain) +
- the presence of somatosensory abnormalities on neurological examination (probable neuropathic pain) +
- at least one positive confirmatory test (definite neuropathic pain).

Negative and positive sensory symptoms coexist in neuropathic pain.

- Negative symptoms include deficits of different somatosensory qualities:
  - tactile hypoesthesia or anaesthesia
  - thermal hypoesthesia
  - pinprick hypoalgesia
  - loss of vibratory sensation.
Positive symptoms include:
- spontaneous positive sensations
  - paraesthesia
  - dysesthesia
  - paroxysmal pain
  - ongoing superficial pain.
- stimulus-evoked positive symptoms
  - hyperalgesia
  - allodynia.

Different types of nerve injuries result in neuropathic pain.
- infections
- trauma
- metabolic abnormalities
- surgery
- radiation
- neurotoxins
- nerve compression
- tumour infiltration.

**Pharmacological management of neuropathic pain**

The following groups of drugs have been proven to be useful in randomized controlled trials:
- tricyclic antidepressants
  - imipramine or amitriptyline in a dose of 25–75 mg per day. Start with 25 mg at bedtime and increase up to 75 mg at bedtime.
- serotonin noradrenalin reuptake inhibitors
  - venlafaxine, starting with 37.5 mg twice daily; increase in 1 week to 75 mg twice daily
- opioids
- topical lidocaine
- sodium channel blockers
  - gabapentin 300–1200 mg per day

NMDA receptor antagonists (ketamine 25 mg three times a day per oral medication) and steroids (dexamethasone 8–16 mg/day) can also be useful.

**For further reading**

Respiratory symptoms in advanced diseases

Three common symptoms are
- dyspnoea (breathlessness)
- cough
- haemoptysis

**Dyspnoea (breathlessness)**

Dyspnoea is a subjective experience of breathing discomfort due to increased afferent inputs from chemoreceptors and mechanoreceptors, increased sense of respiratory effort and an afferent mismatch.

Dyspnoea is a common symptom in advanced diseases, particularly in cancer.

Steps in management at the primary health care level include:

- Assessment of dyspnoea
  - history
  - rating the intensity
  - physical examination
  - selective investigations if appropriate
    - X ray
    - ultrasonogram

- Correct the correctable
  - e.g. infections, anaemia

- Referral for management of specific dyspnoea syndrome if any
  - malignant pleural effusion
  - malignant cardiac disease and pericardial effusion
  - superior venacaval obstruction
  - pulmonary lymphangitis carcinomatosis

- Exploring the role of oxygen

Oxygen need not always be beneficial in breathlessness in advanced disease. The evidence of benefit comes from the management of chronic obstructive pulmonary disease and congestive heart failure. Many studies have shown that dyspnea at the end of life is not related to hypoxia.

A practical solution can be a therapeutic trial of oxygen. Administer oxygen (4 litre/ minute) for a period of 15 minutes after explaining to the patient that it can be continued if beneficial. It can be discontinued after 15 minutes if the patient does not find it helpful.

- Pharmacological treatment
Opioids are the drugs of choice in the symptomatic management of dyspnoea. They act through a multiple mechanism:

- central sedation
- reduction of anxiety
- reduced response to CO₂
- improved cardiac function
- analgesia.

Morphine is the most commonly used drug.

- If the patient is already on morphine for pain, the dose can be increased by 30%–50%.
- If the patient is not already on morphine, it is customary to start with 2.5 to 5 mg q4h – q6h.

Morphine can be supplemented by small doses of anxiolytics.

Other useful drugs include:

- corticosteroids (dexamethasone 4–8 mg/day) in
  - superior venacaval obstruction
  - lymphangitis carcinomatosis
  - airway obstruction (e.g. tracheal tumours)
  - pneumonitis (after radiotherapy).

- Bronchodilators have a role if bronchospasm is present.
- non-pharmacological management:
  - provide care to the patient in a well ventilated room
  - fan should be switched on or use a hand fan
  - loosen the garments worn
  - make the patient sit or lie down in his most comfortable position.
  - make arrangements for him to lean comfortably when seated. Give water as and when required
  - do not allow people to crowd in the patient’s room
  - breathing and relaxation techniques can be useful if patients had training on them before the acute episode of dyspnoea.

Cough

Cough is present at the time of diagnosis in >65% of patients with lung cancer. Non-opioid cough suppressants can be of help in a minority. Bronchodilators are often helpful. Inhaled sodium cromoglycate has been proven to be of benefit in patients with non-small cell lung cancer.

Opioids are the drugs of choice in symptomatic management of cough in advanced disease. Codeine is commonly used as a cough suppressant. Oral morphine is also effective. Corticosteroids are helpful in controlling radiotherapy-induced cough.
**Haemoptysis**

Coughing out blood is an alarming symptom for patient and family. Minimal haemoptysis is usually self-resolving. Patient needs reassurance and anxiolytics.

Massive haemoptysis, which by definition is expectoration of at least 100–600 ml of blood within 24 hours, often has poor prognosis. Other features associated with poor prognosis include:

- radiographic evidence of aspiration
- haemodynamic instability
- massive haemoptysis caused by neoplasm.

**Management at the primary health care level**

Management at the primary health care level consists of:

- General resuscitation and referral for possible invasive interventions/oncological treatment.
  
  General measures include:
  
  - suction, oxygen, intravenous fluids
  - stopping of NSAIDs or anticoagulants if any
  - if the bleeding side with lesion can be identified from previous records, keeping the patient in lateral position with the healthy side up can help in aspiration to the healthy lung.
  
  - commonly used drugs like vitamin K IV – 1.0–2.5 mg upto 5 mg/tranexamic acid – 1.5 g followed by 1 g TID/aminocaproic acid 5 g followed by 1 g QID are of little value.

- Palliative management of fatal haemoptysis.
  
  Fatal refractory haemoptysis as terminal event is usually manged by titration with sedatives and anxiolytics. Benzodiazepines can be used.

  - Midazolam 2.5–5.0 mg, lorazepam 1–2 mg sublingual. You can titrate this up till the patient is drowsy.

  Using dark coloured bedsheets and wipes to reduce the visual impact of bleeding has also been suggested.

**Gastrointestinal symptoms in advanced diseases**

Controlling symptoms related to gastrointestinal system is important in improving the quality of life in patients with advanced diseases.

Three problems to be discussed here are:

- nausea and vomiting
- inoperable malignant bowel obstruction
- constipation
Nausea and vomiting

The unpleasant sensation of nausea along with uncontrolled regurgitation (vomiting) can be very depressing to the patient. Proper treatment depends on the mechanism and neurotransmitters involved. Causes of nausea and vomiting in advanced diseases can be classified as:

- **Chemical causes** (drugs including opioids, digoxin, anticonvulsants, antibiotics, cytotoxic chemotherapy, toxins like food poisoning, ischemic bowel, gut obstruction or metabolic organ failure, hypercalcemia, ketoacidosis uremia and hyponatremia are the common causes).
- **Gastrointestinal causes** (gastric stasis due to anticholinergic drugs/ascites/ hepatomegaly/ gastritis, stretch/distortion of GIT due to constipation, intestinal obstruction/mesentric metastases, serosal stretch/irritation (liver metastases, ureteric obstruction).
- **Cranial causes** (cerebral oedema, intracranial tumour, intracranial bleeding, cerebral infections skull metastases, meningeal infiltration).
- **Other causes** (common examples are movement associated nausea and vomiting, anxiety induced nausea and vomiting, anticipatory emesis)

Pharmacological management

Always try to address the underlying cause if possible.

A few drugs which can be useful in nausea and vomiting in advanced diseases are:

- prokinetics
  - metoclopramide
  - domperidone
  (Metoclopramide is more potent than domperidone)
- dopamine (D2) antagonist
  - haloperidol
  - metaclopramide/domperidone
- antihistamine and anticholinergics
  - cyclizine, hyoscine butylbromide, glycopyrrolate
- corticosteroids
- octreotide.

The choice of antiemetic for symptom relief depends on the cause of nausea and vomiting.

- Chemical causes
  - haloperidol
  - 5HT 3 antagonist with corticosteroid
- Gastrointestinal causes
  - prokinetic agents
  - drugs to reduce gastric secretions
  - corticosteroids
  - cyclizine
  - hyoscine hydrobromide

- Cranial causes
  - high-dose corticosteroids
  - cyclizine

- Others
  - movement associated
    - cyclizine/cinnarizine/scopolamine
  - Anxiety induced/anticipatory emesis
    - benzodiazepins

**Malignant Gastrointestinal obstruction**

Bowel obstruction is common in advanced gastrointestinal and gynaecological cancers. Obstruction can be due to extrinsic occlusion/intraluminal occlusion. Obstruction can be at the level of oesophagus, gastric outlet or intestines. Oesophageal obstruction presents with difficulty/inability to swallow. Obstruction below the oesophagus presents with multiple symptoms:

- abdominal pain
- distension
- vomiting
- constipation, sometimes later with paradoxical diarrhoea.

The intervention of choice is surgical management. But sometimes the patient will be inoperable, in which case the management is medical.

**Medical management of inoperable malignant obstruction includes:**

- hydration
  - intravenous fluids
  - subcutaneous fluids: One litre per day can be given through a scalp vein (butterfly) needle placed subcutaneously into the side of the abdominal wall.

- prokinetics in the case of partial obstruction
  - metocolpamide 60–80 mg subcutaneously over 24 hours. Can be changed to oral after 24 hours.

- antispasmodics in the case of total obstruction not responding to corticosteroids
- hyoscine butylbromide (buscopan) 60 mg subcutaneously over 24 hours in the case of total obstruction (colic).

- analgesics
  - opioids

- haloperidol
  - 5–10 mg subcutaneously over 24 hours if nausea is a significant symptom.

- Anti-secretary agents
  - Atropine/glycopyrrolate

- Octreotide is an expensive option. 300–600 micrograms subcutaneously over 24 hours can control frequent large volume vomits.

- Corticosteroids. Randomized controlled trials have shown that dexamethasone 6–16 mg i.v./s.c. may bring about resolution of obstruction without any side-effects.

**Eating and drinking in inoperable gastrointestinal obstruction**

Patients may eat and drink what they wish because they usually do not request large volume of food or fluid. Sufficient absorption across the GI tract can take place to prevent absolute dehydration, even in total obstruction. It is also to be remembered that patients will tolerate some degree of dehydration provided careful attention is paid to mouth care (keeping the mouth clean and moist).

**Constipation**

Constipation is common in advanced diseases. The use of opioid analgesics is the most common cause of constipation in palliative care, especially for the bedridden, immobile patient. Other possible causes in cancer patients include hypercalcemia, intestinal obstruction and spinal cord compression.

**Management of constipation through**

- laxatives.

- attention to:
  - other symptoms, especially pain
  - diet
  - fluid intake
  - mobility
  - privacy for toileting.
Delirium

Delirium is a common clinical problem in advanced diseases. The majority of the terminally ill patients develop delirium in the last hours and days before death. Delirium is also present in more than 30% of advanced cancer patients at the time of admission to an acute care hospital or palliative care unit.

Delirium is a multifactorial syndrome, resulting from the interaction of predisposing conditions such as old age, frailty, cognitive impairment, severe illness and visual/hearing impairment, and environment related insults such as medications and procedures in the hospital.

Common causes of delirium include:

- drugs (opiates, anticholinergics, steroids, benzodiazepines)
- drug withdrawal (alcohol, sedatives)
- dehydration, constipation, retention, uncontrolled pain
- infection, hypoxia, brain tumours/vascular, liver/kidney dysfunction, electrolyte imbalance.

Diagnosis

Delirium is always of acute onset and runs a fluctuating course.

Diagnostic features include:

- disorientation in time/place/person
- fluctuating levels of consciousness/awareness
- poor attention and concentration
- sleep disruption
- hallucinations: insects on the bed, imagining people around, become paranoid, hostile.

The problem is usually worse around sunset (a phenomenon called “sun downing”).

Delirium is also associated with psychomotor disturbances characterized by rapid unpredictable shifts from hypoactivity to hyperactivity and increased reaction time.

Management

Nonpharmacological supportive interventions play a major role in the management of delirium in advanced diseases.

- Since the patient is in a confused state, it is important to communicate clearly and concisely. Take care to give repeated verbal reminders of the day, time and location, and identify key individuals, such as members of the treatment team and family.
- Provide clear signposts to patient’s location, including clock, calendar, chart with the day’s schedule.
- Have familiar objects from the patient’s home in the room.
- Ensure consistency in staff (for example, a key health worker).
○ Involve family and caregivers to encourage feelings of security and orientation.
○ Avoid physical restraints, if possible, as they often increase agitation.
○ Identify and correct sensory impairments: ensure patients have their glasses, hearing aid and dentures.
○ Encourage self-care and participation in treatment. Take regular feedback from the patient (for example, on pain).
○ Arrange treatments to allow for maximum periods of uninterrupted sleep.
○ Maintain activity levels whenever possible.
○ Keep noise levels to the minimum.
○ Maintain hydration and nutrition.

**Pharmacological management**

○ Treat underlying causes (for example, infection).
○ Review and stop non-essential medications.
○ Check for opioid toxicity.
  ○ reduce dose/change opioid

○ Administer a low-dose antipsychotic.
  ○ drug of choice is haloperidol (0.5-3mg)
  ○ olanzapine (2.5–5mg) or quetiapine (25–100mg) can also be used, but do not have any advantage over low-dose haloperidol.

○ Benzodiazepines (diazepam 2–10 mg) preferable over anti-psychotics in delirium tremens and Parkinson disease

**Common symptoms at the end of life are:**

○ noisy and moist breathing
○ urinary symptoms
○ pain
○ restlessness
○ dyspnoea
○ nausea and vomiting
○ profound weakness
○ muscle twitching (myoclonus)
○ confusion (delirium).

Most of these symptoms can be settled with simple medication.
Route of administration of drugs needs to be changed when the patient cannot take medicines by mouth. Possible options at the primary health care level are:

- **sublingual**
  - many drugs used to control terminal symptoms gets absorbed through intact mucosa and so can be administered buccally/sublingually

- **subcutaneous**
  - A scalp vein (butterfly) needle placed subcutaneously over the arm/chest wall/abdominal wall and secured with a piece of transparent dressing can be used to deliver injections (ideally in volumes less than 2 ml) easily and painlessly. Most of the medicines usually given intravenously can be administered subcutaneously also. The needle can be kept in the same position for more than a week. The site needs to be inspected every day for any signs of inflammation. Change site if redness is seen at the injection site.

- **rectal**
  - most of the medicines usually administered by mouth can also be administered rectally

Management of terminal symptoms

**Noisy and moist breathing (“death rattle”)**

Death rattle refers to noise observed in patients too weak to expectorate or are moribund. It is produced in the upper airways by secretions (either saliva or the bronchial secretions) during the respiratory cycle. It does not cause hypoxia.

Non-pharmacological measures include semi-prone position, withdrawal of parenteral hydration, gentle nasopharyngeal or tracheal suction. Reassurance to family about the process is important.

**Pharmacological management**

Atropine 1 mg or glycopyrrolate 0.2 mg subcutaneously/sublingually. Can be repeated 3–4 times a day. Start drugs early because they do not affect existing respiratory secretions.

Hyoscine hydrobromide 0.4 mg or hyoscine butylbromide 20 mg are also helpful subcutaneously.

Noisy tachypnoea in moribund patients respond well to injection of morphine 1.5–3mg +/− midazolam 2–3mg subcutaneously.

**Urinary symptoms**

Retention of urine and overflow incontinence secondary to it are common in dying patients not on catheter.

Inattention, drugs with anti-cholinergic properties, weakness and hypertrophied prostate (in men) are the common causes.
Palliative care in primary health care setting

Pain

Pain in an unconscious/semi-conscious patient presents as restlessness. It is important to continue the analgesics even when the patient is unconscious. Doses of opioids can be reduced to half or one third of the original dose. Usual practice is to resort to subcutaneous route.

Restlessness

Restlessness in an unconscious/semiconscious dying person can be due to a variety of causes. The common reasons are:

- pain
- pruritis
- full bowel/full bladder
- anoxia/dyspnoea
- anxiety/akathesia/delirium
- dehydration
- addition or withdrawal of benzodiazepines/steroids
- withdrawal of alcohol/nicotine
- drugs reducing seizure threshold (phenothiazines/butrephenones/tricyclic antidepressants/opioids).

Detailed history and careful physical examination is needed to rule out these.

Management of restlessness

- Treat the cause if identified:
  - unrelieved physical symptoms
  - delirium
  - drugs causing restlessness
  - dehydration.

General symptomatic management

- If restlessness is not associated with delirium, it can be managed with subcutaneous midazolam (2–3 mg increments every 30 minutes till the patient settles).
- For restlessness associated with delirium, haloperidol 3–5 mg/day subcutaneously needs to be added to midazolam.
Dyspnoea

Terminal dyspnoea is most often NOT associated with hypoxia. Management includes

- trial of oxygen (see the chapter on dyspnoea)
- titrated doses of morphine (1.5 mg increments subcutaneously every 20 minutes) supplemented with small doses of 2–3 mg every 3–4 hours) of subcutaneous midazolam.

The idea is not to knock down the patient, but to achieve a fine balance between settling dyspnoea and deep sleep.

Nausea and vomiting

Appropriate anti-emetics (see the section on nausea and vomiting in the chapter on gastrointestinal symptoms) to be given subcutaneously.

Muscle twitching (myoclonus)

Frequent muscle twitching can be a pre-epileptiform phenomenon. Common precipitators/exacerbators include drugs (introduction/withdrawal – see section on restlessness above), organ failure, hypoxia, cerebral edema, hyponatremia and hypoglycemia.

Management

Correct the correctible

General symptomatic treatment with benzodiazepines.

- Midazolam 2–3 mg subcutaneously every 30 minutes, maximum daily dose of 30 mg.

Confusion (delirium): See the section on Delirium

Fungating wounds

Malignant fungating wounds presents both physical and emotional challenges to the patient, family and health-care workers. These wounds may be associated with pain, bad odour, exudates, blood and unsightly appearance. Cancerous skin infiltration with subsequent ulceration or fungating wounds is the most common cause.

Foul smell from the wound can be settled with local application of metronidazole either as gauzes soaked with metronidazole injection or metronidazole tablet crushed and made into a paste with a water-based gel.

Pressure sores

What is a pressure ulcer?

Through the ages, this entity was known by several names such as “bed sore”, decubitus ulcer, pressure sore, pressure necrosis or ischaemic ulcer. However, by definition, all these terms refer to “an area of localized soft tissue necrosis caused by prolonged pressure higher than capillary pressure with or without shear and friction, related to posture, usually occurring over bony prominences.”
Such ulcers become a nuisance as well as a matter of grave concern for the care givers when it occurs in an otherwise sick patient.

“If he (the patient) has a bedsore, it’s generally not the fault of the disease, but of the nursing”: Florence Nightingale

Risk factors for pressure ulcers

1. **Pressure**

Pressure is the primary factor responsible for the development of the ulcer. It varies with body weight and surface area of skin contact. When the incident pressure exceeds the normal capillary pressure for a critical duration of time, blood circulation to tissue is compromised leading to cell death and eventually to skin ulceration.

Pressure points over bony points in different lying postures
2. **Shearing**

When the body of a propped up patient tends to glide with gravity over a rough surface, skin and subcutaneous tissue remain stationary and in contact with the surface whereas the deeper tissues slide down. This differential movement will stretch and tear blood vessels to skin and cause ischaemia and ulceration.

3. **Friction**

Friction occurs between skin and stationary surfaces like the bed. A trivial breach in the epidermis of skin by friction causes loss of the protective barrier against infections leading to ulceration. Forceful pulls on bedsheets or clothes also lead to friction. Friction occurs together with shearing.

4. **Moisture**

Perspiration, discharges from wounds, urine or faeces due to incontinence all lead to skin maceration, blistering and eventual breakdown and ulcer. The excess moisture also weakens the skin barrier increasing the susceptibility to pressure, shearing, friction forces and infection.

5. **Abnormal posture**

Pressure points vary in sitting, supine, lateral and prone postures and take the brunt of pressure. Tissues get squeezed between the skeleton and supports such as beds, chairs, shoes, prosthesis or surgical appliances, causing pressure ulcers. A "hammocking" effect of an unsupported wheelchair, presence of contractures and spasticity will increase the propensity for pressure ulcers.

6. **Immobility**

Change of posture in normal individuals is a function of the unconscious mind. This function is impaired in sedated, comatose or neurologically compromised individuals. Unremitting pressure in such patients who sit or lie in the same position for prolonged periods cause pressure ulcers in susceptible areas.
7. **Neurologic factors**

Any abnormality affecting the sensorimotor feedback system between the brain and peripheral senses as in muscle paralysis, impaired pain and pressure sensibility or coma can make a patient prone to develop pressure ulcers.

8. **Nutritional factors**

Patients with rapid weight loss need closer observation. Poor nutrition will make a patient prone for pressure ulcers by loss of subcutaneous fat padding. Haemoglobin level is an important indicator of nutritional status. Anaemic patients with reduced oxygen-carrying capacity of blood are more prone to tissue hypoxia and ulceration. Blood transfusions in such patients would increase wound healing.

9. **Edema**

Soft tissue edema causes detrimental effects on tissues by decreasing tissue oxygenation, increasing interstitial fluid pressure and reducing blood flow. Hence areas of edema are prone for pressure sores.

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### Preventive measures for pressure ulcers

(a) **Pressure relief**

Pressure relieving mechanisms to reduce ambient pressure on the body by support surfaces and overlays must be used. There are several low-tech or high-tech devices available. These can be static surfaces such as air cushions, water bed or foam bed, or gel or silicon cushions, or even simple waterfilled gloves. Dynamic surfaces offer very good pressure relief but are expensive and need an electric power source. Pneumatic ripple bed overlays or low-air-loss (LAL) beds use alternating air pressure for pressure relief. Air fluidized mattresses have warm air circulating through ceramic beads which keep the patient-mattress interface warm and dry.
(b) **Regular inspection**

Careful inspection of pressure points of the body by the trained caregivers twice a day or more frequently in higher risk individuals is required. This will help in detection of pressure ulcers at early stages and prevent their progression to more severe grades.

(c) **Positioning**

- nursing on pressure relief mattresses and cushions,
- pressure relief of at-risk areas by padding or silicone gel supports,
- careful handling of patients to avoid shear and friction,
- regular repositioning and turning every two hours or earlier in high-risk patients,
- alternate lying-down postures: right side, on the back and left side,
- use 30-degree side-lying position,
- offloading of the heel,
- special care for patients sitting in wheelchair:
  - use alternating air pressure cushions (avoid doughnut cushions),
  - support the feet in wheelchair on a padded surface,
  - avoid “hamocking” of wheelchair seat,
  - encourage patient to hoist himself on elbows at 15-minute intervals,
  - never allow patient to sit in wheelchair continuously for more than 60 minutes.

(d) **Nutrition**

Restoring nutrition and hydration, a positive nitrogen balance, replenishing trace elements, zinc and vitamin C are all essential prerequisites in pressure ulcer management. Recommended energy intake is 30–35 Kcal/kg/day and protein intake of 1.25–1.5 gm/kg/day. Patient weight, mid-arm circumference and skinfold thickness must be charted at regular intervals by the care givers. Haematocrit values must be kept corrected to improve oxygen carrying capacity of blood. Serum albumin values of 3.5–5 mg/dL or pre-albumin values of 16–35 mg/dL have to be maintained to ensure proper wound healing.

**Wound care**

If left uncared, pressure ulcers are capable of progressive involvement and destruction of underlying bones, joints and deeper structures. A patient can lose his life to spreading infection and septicemia. Most pressure ulcers, however, heal with pressure relief, wound care and attention to general health of the patients.

**Additional reading resources**

Palliative care in primary health care

Activity 1: Step 5

Suffering due to incurable illness

“Over 30 million people suffer unnecessarily from severe pain and other symptoms each year. So much is known in the management of these symptoms, but unfortunately this knowledge is not benefiting most of those in need of it. In spite of all the effort over the last two decades, the great majority of individuals with incurable diseases that need care are not getting it”

**Problems of patients with advanced diseases**

- Physical problems – pain, dyspnoea etc
- Social problems – financial problems, social isolation etc
- Emotional problems – sadness, anger, worries, anxieties etc
- Spiritual problems – religious or otherwise.

**Palliative care: definition**

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

— *World Health Organization*

**Community based care for the incurably ill**

- Patients with advanced diseases require continuous care and attention for the rest of their lives
- They are also in need of regular social, psychological and spiritual support in addition to the medical and nursing care
- Care should be readily accessible and available as close to home as possible
- Home care is the best option for most of them.
Primary health care team and community role

Many of the problems in advanced diseases are of a ‘non medical’ nature; Local community can play a major role in addressing these problems

Capacity building

- Improving our skills to ensure better care for our patients
- Better skills and knowledge for doctors, nurses and other health workers in diagnosing and treating symptoms
- Better communication skills for doctors, nurses and other health workers
- Ensuring better participation by the community
- Involving the family, neighborhood and local community in the care.

Examples from SEA Region

- Nurse led palliative care network in Northeast Thailand
- Palliative care integrated to primary health care in Kerala (India).
Activity 2: Step 3

Role of communication in patient care
- Relief of anxiety & better adjustment with the disease process
- Mutual exchange of ideas or feelings
- Proper guidance & better compliance
- Involvement of the family
- Reduce isolation (self & social)
- Acceptance & Trust.

Good communication
- Make your communication clear, and specific
- Recognize that each individual sees things from a different point of view
- Be open and honest about your feelings and accept others’ feelings
- Ask questions for clarification on an issue
- Learn to listen actively and allow time for the other person talk without interruption.
Communication skills

- No look book recipe!
- Everyone has his/her own communication skills which have individuals societal and experimental factors which framed it
- To develop better skills – “Know yourself”
- Identify your own ways of communicating with others
- Identify weaknesses and try to correct

Do’s in communication

- Have enough time for discussion with the patient
- Have timely reassurance when ever needed
- Listen... listen... listen
- Be Attentive to verbal and nonverbal communication
- Use simple words
- Have an open attitude
- Explain.

Don’ts in communication

Don’t
- Be in hurry
- Be a premature practitioner
- Pretend that you are listening
- Ignore what the patient says
- Interrupt more frequently than needed
- Use medical Jargon
- Be judgmental
- Patronize
- Compare with other patients.
### Look at your communication style

1. The way you talk – slow, fast, soft etc.
2. Your posture – close, distant
3. Your expression – happy, unhappy, ‘stone face’
4. Do you make eye contact
5. Do you feel anxious, angry or sad during communication?
6. Who starts first? You or him/her?
7. Do you find it difficult to respond effectively?
8. Do you interrupt often?
9. Do you advice or ask too many questions?
10. Do you try to comfort them saying “every thing will be alright”?
11. Is there any difference in the way you communicate at work & in your personal life?
12. Among these which are the points you feel good and which are the ones you feel needs improvement/change?

### Remember

- Do not withhold information if the patient wants it.
- Do not impose information if the patient does not want it.
- Gauge and respond to the patient’s reaction to the news.

### Active listening

- Let the other person speak
- Interrupt only when you have to ...
- Encourage the talk
- Yes... Ha, then...
- Tolerate short silence
- Listen for hidden questions
- Active hearing
- Repetition
- Paraphrasing
- Reflection
- Responding
- Further questions
- Clarification
- Summarizing.
Activity 3: Step 4

WHO Analgesic Ladder

Pain is a subjective sensation

- Pain is not purely a physiological process that is experienced the same way in every individual
- The perception and tolerance of pain vary widely from person to person
- Pain is what a person says “it hurts”
- Chronic pain is persistent or recurrent pain, lasting for more than three months, and adversely affecting the patient’s well-being.
Palliative care in primary health care setting

**Sample tools to assess intensity of pain**

- Descriptive Pain Intensity Scale
  - None
  - Slight
  - Mild
  - Moderate
  - Severe
  - Worst Pain

**Drugs used in WHO Analgesic Ladder**

- **Step I**
  - NSAIDs: Use the NSAID you are most comfortable prescribing, but Never prescribe multiple NSAIDs!!
  - Paracetamol: Paracetamol 1g qid is equianalgesic with Diclofenac 50 mg bd

- **Step II Weak opioids**
  - Codeine
  - Tramadol

- **Step III Strong opioids**
  - Morphine
  - Pethidine
  - Fentanyl
  - Methadone.

**Opioid doses**

- Codeine: Start with 15mg 4th hourly and SOS
- Can be increased by 50% everyday if patient is not pain free and not drowsy. No upper limit
- Tramadol: Start with 50 mg 8hrly. Can be increased upto 300mg/day
- Morphine: Start with 5 mg 4th hourly and sos
- Can be increased by 50% everyday if patient is not pain free and not drowsy. No upper limit.
### Opioid side effects

- Constipation 99%
  - Always prescribe laxatives
- Nausea, vomiting 33%
  - Use small dose of Haloperidol
- Sleepiness, tiredness 33%
  - Improves with time
  - Check for over dosage
- Urinary hesitancy 5%
  - Alpha blockers may help
- Itching 5%

### Symptoms of neuropathic pain

- Can be summarized as: “a sensory deficit and the presence of paradoxical pain in the same region”
- Allodynia
- Hyperalgesia
- Paroxysms (shooting, shock-like, stabbing pain occurring spontaneously)
- Paraesthesiae
- A pain (eg; in cancer) can present as a mixture of neuropathic and nociceptive features, making the situation more challenging.

### Management of neuropathic pain

- Opioids – can help partially
- Antidepressants – tricyclic anti depressants are the drugs of choice
- Gabapentin
- NMDA receptor antagonists – injection ketamine orally.
Anti-depressants - dosage

- Amitriptyline, imipramine
  - 25 mg HS generally. In elderly & very sick 10 – 12.5 mg HS can be a good starting dose.
  - Increase by every 3 days up to 75 mg HS
  - In case of early morning drowsiness take drug early in the night
- Citalopram
  - 10 – 20 mg daily. Low dose for elderly & very sick. Up to 20 – 40 mg per day
- Venlafaxine
  - 37.5 mg b.d. Increase in 1 week to 75 mg b.d
  - Reduce dose by 50% in renal/hepatic impairment

Anti-depressants – side effects

- Dry mouth
- Constipation
- Urinary retention
- Drowsiness
- Delirium, mental clouding
- Orthostatic hypotension
- Myocardial depression (very rare, avoid using in persons with major heart diseases, arrhythmias, cardiac failure)
- Glaucoma
- Withdrawal symptoms on stopping drug suddenly.

Gabapentin

- Slow: 100 mg tid, increase by 300 mg/week up to 1200mg tid
- Rapid: 300mg od and reach 1200 mg tid in one week
- Side effects: drowsiness, dizziness, ataxia, fatigue, tremors, nystagmus
- Dosing two hrs after aluminum/magnesium containing drugs.
N-methyl-D-aspartate (NMDA) receptor antagonists

- Ketamine (anaesthetic agent)
  - Oral/SL: 0.5mg/kg tid to qid
  - IV: 0.25 – 0.5 / kg bolus
  - SC Infusion: 0.1-0.15mg/kg/hr (100–500mg/day)
  - Side effects: delirium, dysphoria, hallucinations, nightmares
- Amantadine
  - 100 mg bd
  - Side effects: nervousness, poor concentration, insomnia.

Activity 4: Step 2

Dyspnoea in advanced diseases

- Prevalence shows large variation: 29–74% of all patients
- 25% in the last week of life
- More common with diseases affecting respiratory system
- Non-pharmacological management:
  - Address patient’s & family’s concerns
  - General measures (proper Positioning in bed, stream of fresh air such as fan, open window, change in daily activities)
  - Physiotherapy, breathing exercises & relaxations techniques.
Management of dyspnoea

- Correct the correctable:
  - Infections
  - COPD
  - Hypoxia
  - Obstruction (bronchial, SVC)
  - Lymphangitis carcinomatosa
  - Effusions
  - Anemia
  - Cardiac failure.

Pharmacological management of dyspnoea

- Oxygen: limited number of studies have shown minimal benefit
- Inhaled bronchodilators and corticosteroids: no evidence of beneficial effects
- Systemic corticosteroids: limited role
- Analgesics can help in relieving pain if associated
- Anxiolytics: no direct benefit, but can relieve anxiety
- Opioids: beneficial effect on oral/parenteral administration

Nausea and vomiting in advanced diseases due to chemical causes

- Causes:
  - Drugs (opioids, digoxin, anticonvulsants, antibiotics, cytotoxics)
  - Toxins (food poisoning, ischemic bowel, gut obstruction)
  - Metabolic organ failure, hypercalcemia, ketoacidosisuremia, hyponatremia
- Treatment
  - Stop/reduce the offending drug
  - Treat the underlying cause
  - Haloperidol 1.5 mg/day
  - 5HT 3 antagonist with corticosteroid.
Nausea and vomiting due to gastro-intestinal causes

- Causes:
  - Gastric stasis (anticholinergic drugs, ascites, hepatomegaly, gastritis)
  - Stretch/distortion of GIT (constipation, intestinal obstruction, mesentric mets)
  - Serosal stretch/irritation (liver mets, ureteric obstruction)
- Treatment
  - Treat the underlying cause
  - Prokinetic agents (Metoclopramide 40-60 mg/day) for gastric stasis
  - Corticosteroids for stretch of GIT
  - Cyclizine/Hyoscine hydrobromide for serosal stretch.

Nausea and vomiting due to cranial causes

- Causes:
  - Cerebral oedema
  - Intracranial tumour
  - Intracranial bleeding
  - Cerebral infections skull mets
  - Meningeal infiltration
- Treatment
  - Treat underlying cause
  - High dose corticosteroids (Dexamethasone >24mg/day).

Nausea and vomiting due to other causes

- Movement associated
  - Treat underlying cause
  - Cyclizine, Cinnarizine, Scopolamine
- Anxiety induced
  - Anticipatory emesis
  - Address anxiety
  - Psychological techniques
  - Relaxation
  - Benzodiazepines.
Fungating wounds

- Topical metronidazole for foul smell
- Inj metronidazole soaks
- Tab metronidazole crushed and made into a paste with gel (200mg/5ml) applied over the wound.

Optional activity

Malignant bowel obstruction

- Seen in advanced gynaecological and gastrointestinal cancers
- Symptoms:
  - Abdominal pain – colic if total obstruction
  - Distension
  - Vomiting
  - Constipation
  - Appearance of paradoxical diarrhoea.
Drugs useful in inoperable bowel obstruction

- Metoclopramide
  - 60 - 80 mg subcutaneously over 24 hours
- Hyoscine butylbromide (Buscopan)
  - 60 mg subcutaneously over 24 hours in the case of total obstruction (colic)
- Haloperidol
  - 5 - 10 mg subcutaneously over 24 hours if nausea is a significant symptom
- Dexamethasone
  - 8 - 16 mg intravenously for recent total obstruction
- Octreotide
  - 300 - 600 micrograms subcutaneously over 24 hours to control frequent large volume vomits.

Malignant bowel obstruction - management

Delirium at end of life

- Delirium is present in ~1/3 of advanced cancer patients at the time of admission to an acute care hospital or palliative care unit
- More than 75% of the terminally ill patients develop delirium
- 80% of patients with advanced cancer develop delirium in the last hours and days before death.

Bush & Bruera 2009
Delirium - diagnosis

AFCOS

A: Acute onset
F: Fluctuating course
C: Consciousness impaired
O: Orientation to time/place/person changed
S: Sleep reversal.

Delirium - causes

- Drugs (opiates, anticholinergics, steroids, benzodiazepins)
- Drug withdrawal (alcohol, sedatives)
- Dehydration, constipation, retention, uncontrolled pain
- Infection, hypoxia, brain tumours/vascular, liver/kidney dysfunction, electrolyte imbalance
- Sensory (vision/hearing) impairment is risk factor

Management of delirium

- Treat underlying cause: Bowel/bladder/infection
- Review and stop non-essential medications
- Check for opioid toxicity: Reduce dose/switch
- Drug Rx (oral preferred to injection)
  - 1st choice: Antipsychotic – use low dose. Haloperidol (0.5-3mg), Olanzapine (2.5-5mg), Quetiapine (25-100mg)
  - 2nd choice: Benzodiazepines (helps anxiety)- Diazepam 2-10mg
- In delirium tremens and Parkinson’s, benzodiazepines preferable.
Terminal symptoms

- Death rattle
  - Atropine 1mg/glycopyrrolate 0.2mg +/- Midazolam 2mg
- Noisy tachypnoea in moribund
  - Morphine 1.5-3mg +/- Midazolam 2-3mg
- Nausea & vomiting
  - Appropriate anti emetic + antisecretory.

Terminal symptoms - restlessness

Causes:
- Pain
- Pruritis
- Bowel/bladder
- Anoxia/dyspnoea
- Anxiety/akathisia/delirium
- Addition or withdrawal of benzodiazepines/steroids
- Withdrawal of alcohol/nicotine
- Drugs reducing seizure threshold (phenothiazines/butrephenones/TCA/opioids).

Management of restlessness

- Treat the cause if identified
  - unrelieved physical symptoms
  - emotional issues
  - delirium
  - drugs
  - dehydration
- If no delirium-midazolam
- If delirium-Haloperidol +/- Midazolam.
Terminal symptoms – myoclonus

- Pre epileptiform phenomenon (encephalopathy)
- Precipitators/exacerbators
  - drugs (introduction/withdrawal)
  - organ failure – hypoxia – cerebral edema
  - hyponatremia – hypoglycaemia
- Management:
  - Correct the correctable
  - General symptomatic treatment with Benzodiazepines.
  - Midazolam 2-3 mg subcutaneously every 30 minutes, maximum daily dose of 30 mg.