CME MODULE

ON PAIN AND PALLIATIVE CARE

STATE INSTITUTE OF HEALTH AND FAMILY WELFARE

UTTAR PRADESH

AKNOWLEDGEMENTS

GUIDANCE

Shri. Partha Sarthi Sen Sharma, *IAS,*
Principal Secretary,
Department of Medical Health and Family Welfare,
Government of Uttar Pradesh

DIRECTION AND LEADERSHIP

Dr. Rajaganapathy R., *IAS,*
Director, SIHFW, Uttar Pradesh &
Director (Administration)
Medical and Health Services, Uttar Pradesh

AUTHOR (S): King George Medical University, Lucknow

Course Director:

Dr. Sarita Singh
MD, PDCC, NFPM, CCPPM.
Professor & Pain Medicine Unit I/C
Department of Anaesthesiology
King George's Medical University, Lucknow

Departmental Guidance:

Dr. G. P. Singh
MD, DHA
Professor & Head of Department
Department of Anaesthesiology
King George's Medical University, Lucknow

Co-Authors:

Dr. Manish Kumar Singh,
MD, PDCC (Pain Management)
Additional Professor
Department of Anaesthesiology
King George's Medical University, Lucknow

Dr. Rhythm
BDS, MDS
Additional Professor
Department of Conservative Dentistry & Endodontics
King George's Medical University, Lucknow

Dr. Akansha Sonal,
MD, DM
Assistant Professor
Department of Geriatric Mental Health
King George's Medical University, Lucknow

Dr. Richa Agarwal (Fellow)
MD, PDCC (Pain Management)
Department of Anaesthesiology
King George's Medical University, Lucknow

Dr. Neeraj Dahiya (Fellow)
MD, PDCC (Pain Management)
Department of Anaesthesiology
King George's Medical University, Lucknow

Nurse Viji Nair
Asst. Nursing Superintendent
Department of General Surgery
King George's Medical University, Lucknow

MESSAGE

Shri Brajesh Pathak

Hon'ble Deputy Chief Minister
Hon'ble Minister of
Medical Health and Family Welfare
Department
Government of Uttar Pradesh

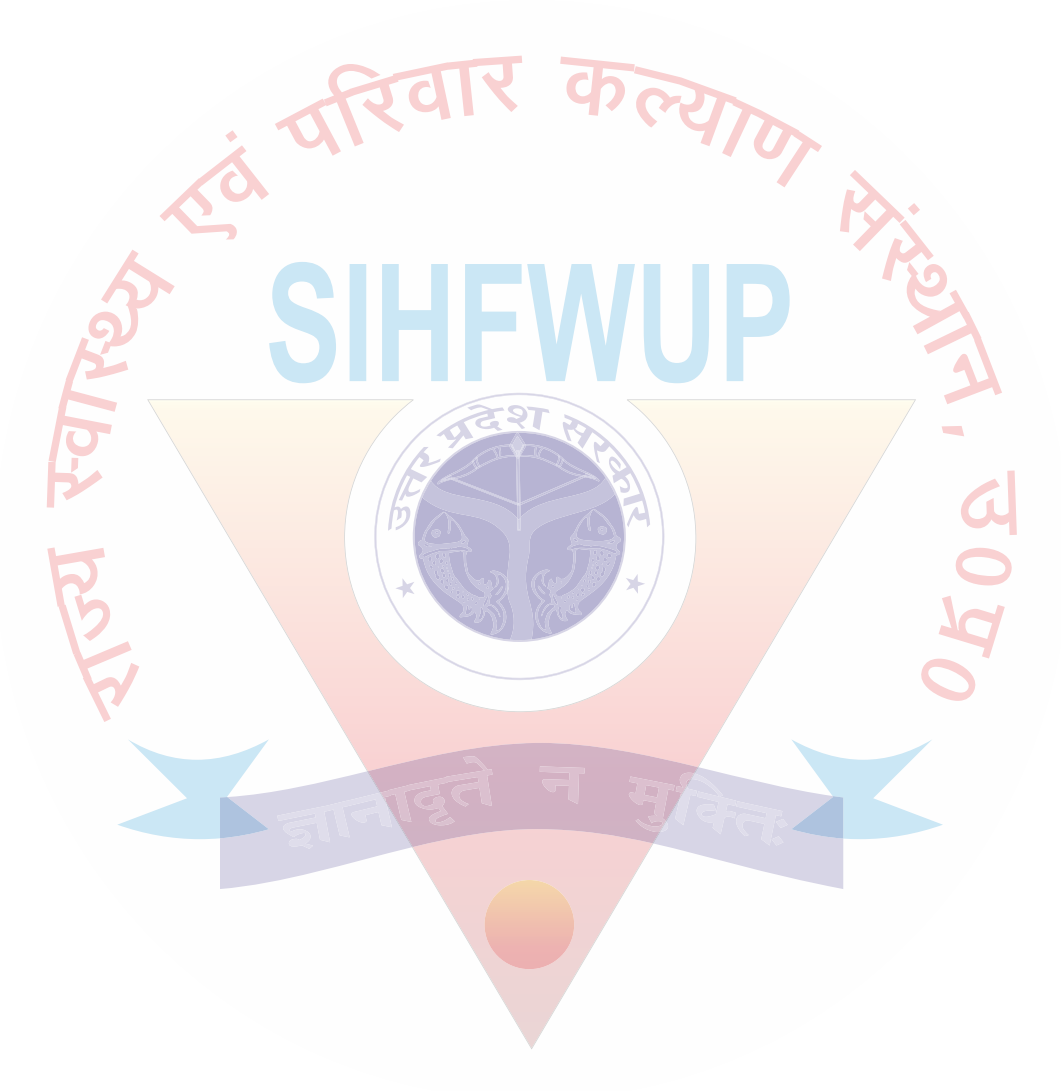
Palliative care has been an area in the medical field which has been neglected due other important engagements of the health workers, specially at the ground level.

Palliative care is specialized medical care for people living with a serious illness, such as cancer or heart diseases. Patients under palliative care may receive medical care for their symptoms, along with treatment intended to cure their serious illness. Palliative care is meant to enhance a person's current care by focusing on quality of life for them and their family.

As the situation stands, along with improving health infrastructure, skill up-gradation and knowledge enhancement of Medical Officers in Provincial Health & Medical Services in Uttar Pradesh is equally important, and hence this Continuing Medical Education (CME) on Palliative care will allow Medical Officers in Provincial Health & Medical Services in Uttar Pradesh, to update their knowledge base resulting in improved patient care, patient confidence and patient satisfaction.

I wish the team of State Institute of Health & Family Welfare, Uttar Pradesh and subject matter experts from Provincial Health & Medical Services in Uttar Pradesh, to continue developing such module on CME for the benefit of Medical Officers in Provincial Health & Medical Services in Uttar Pradesh that will ultimately benefit their patients too.

(Brajesh Pathak)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MESSAGE

Shri Mayankeshwar Sharan Singh

Hon'ble State Minister
Medical Health and Family Welfare Department
Government of Uttar Pradesh

Palliative care is specialized medical care for people living with a serious illness, such as cancer or heart failure chronic obstructive pulmonary disease, cancer, dementia. Patients under palliative care may receive medical care for their symptoms, or palliative care, along with treatment intended to cure their serious illness.

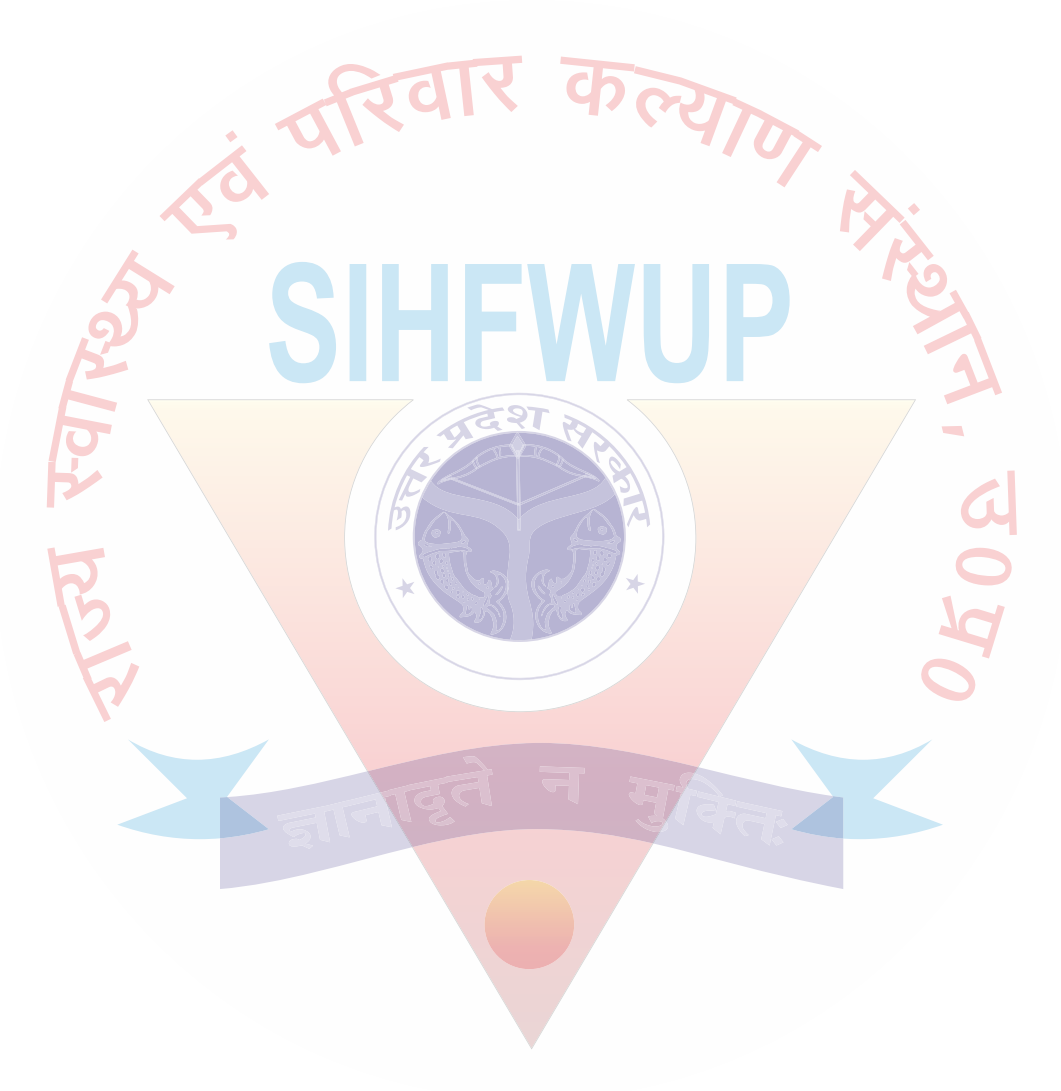
Thus, Palliative care is a resource for anyone living with a serious illness. Palliative care can be helpful at any stage of illness and is best provided soon after a person is diagnosed.

In addition to improving quality of life and helping with symptoms, palliative care can help patients understand their choices for medical treatment.

Due to these facts, it becomes pertinent that a more intensified approach be taken for the patients needing palliative care. Through this module on Continuing Medical Education (CME) on Pain and Palliative care, for Medical Officers in Provincial Health & Medical Services in Uttar Pradesh, State Institute of Health & Family Welfare, Uttar Pradesh with the help of Subject Matter Experts has provided a comprehensive and deep insight for Pain and Palliative care.

I wish team at SIHFW success in their endeavors of aiding an improved health service delivery system through such CME on palliative care.

(Mayankeshwar Sharan Singh)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FOREWARD

Shri Partha Sarthi Sen Sharma

Principal Secretary
Department of
Medical Health and Family Welfare
Government of Uttar Pradesh

Palliative care has been an area in the medical field which has not received its due to other important engagements of the health workers, especially at the ground level.

Palliative care is specialized medical care for people living with a serious illness, such as cancer or heart failure. Patients under palliative care may receive medical care for their symptoms, along with treatment intended to cure their serious illness. Palliative care is meant to enhance a person's current care by focusing on quality of life for them and their family

A palliative care team is made up of multiple different professionals that work with the patient, family, and the patient's other doctors to provide medical, social, emotional, and practical support. The team is comprised of palliative care specialist doctors and nurses, and includes others such as social workers, nutritionists etc.

As the situation stands, along with improving health infrastructure, skill up-gradation and knowledge enhancement of Medical Officers in Provincial Health & Medical Services in Uttar Pradesh is equally important, and hence this Continuing Medical Education (CME) on Palliative care will allow Medical Officers in Provincial Health & Medical Services in Uttar Pradesh, to update their knowledge base.

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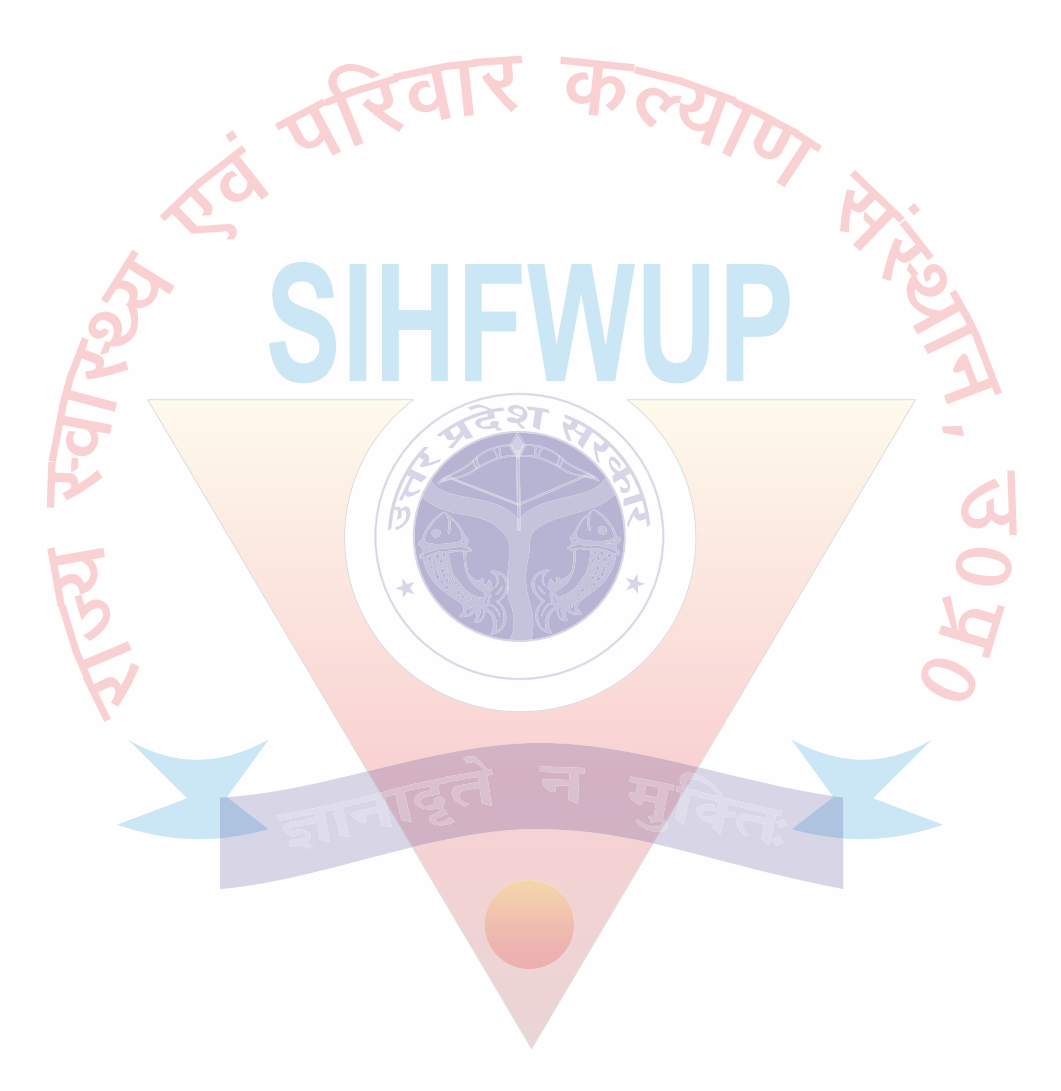
(Partha Sarthi Sen Sharma)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MESSAGE

Dr. Renu Srivastava Varma
Director General
Department of
Medical Health and Family Welfare
Government of Uttar Pradesh

Palliative care has been an area in the medical field which has not been given attention as it should have been, especially at the ground level.

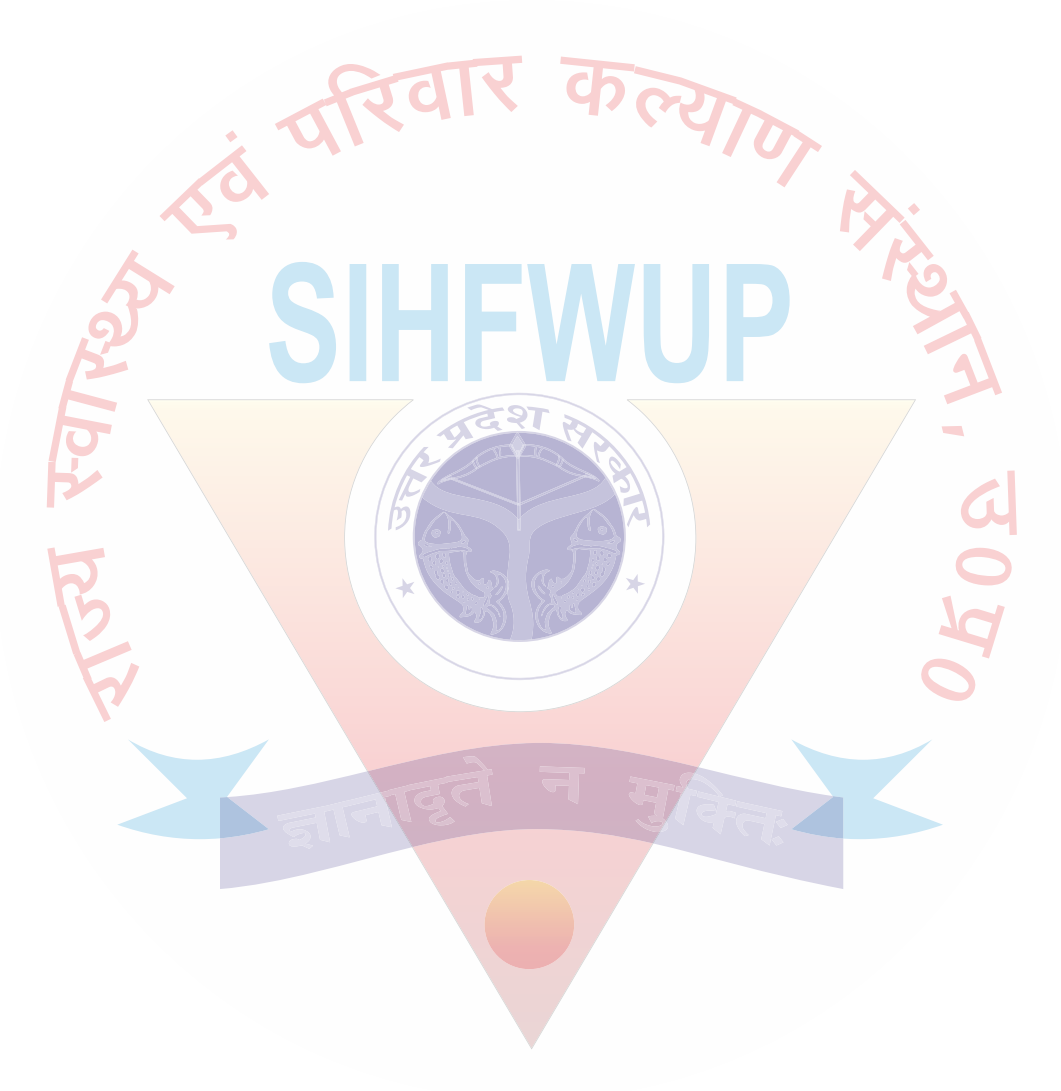
Palliative care is specialized medical care for people living with a serious illness, such as cancer or heart failure. Patients under palliative care may receive medical care for their symptoms, or palliative care, along with treatment intended to cure their serious illness. Palliative care is meant to enhance a person's current care by focusing on quality of life for them and their family.

Thus, Palliative care is a resource for anyone living with a serious illness, such as heart failure, chronic obstructive pulmonary disease, cancer, dementia, Parkinson's disease, and many others. Palliative care can be helpful at any stage of illness and is best provided soon after a person is diagnosed.

In addition to improving quality of life and helping with symptoms, palliative care can help patients understand their choices for medical treatment. The organized services available through palliative care may be helpful to any older person having a lot of general discomfort and disability very late in life.

Considering the above stated facts, it becomes pertinent that a more intensified approach be taken for the patients needing palliative care. Through this module on Continuing Medical Education (CME) on Pain and Palliative care, for Medical Officers in Provincial Health & Medical Services in Uttar Pradesh, State Institute of Health & Family Welfare, Uttar Pradesh with the help of Subject Matter Experts has provided a comprehensive, coherent and deep insight for Pain and Palliative care

(Dr. Renu Srivastava Varma)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MESSAGE

Dr. Anita Joshi
Director General Family Welfare
Directorate of Family Welfare
Government of Uttar Pradesh

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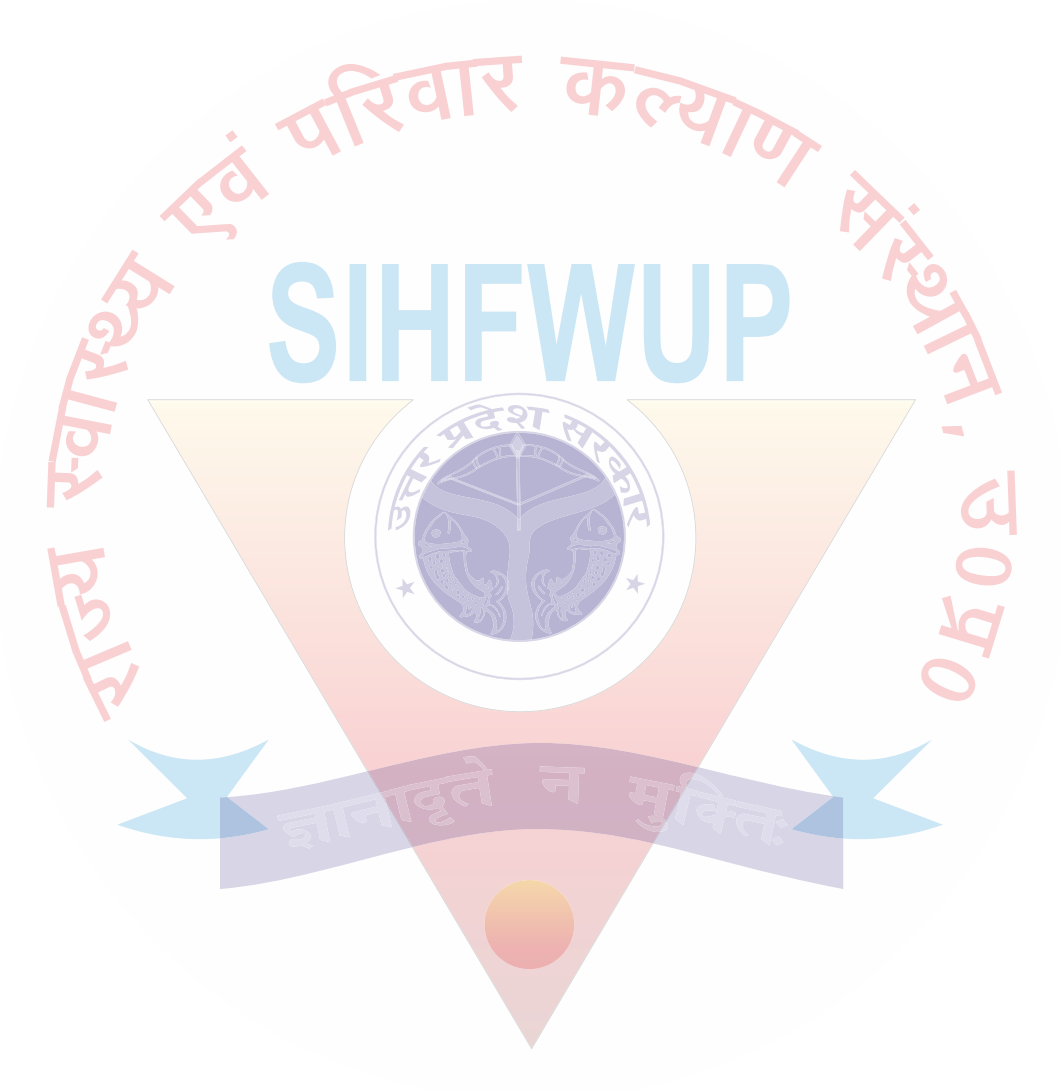
I congratulate the faculties at State Institute of Health & Family Welfare, Uttar Pradesh in developing this module. This module addresses the need to have a holistic view on public health.

(Dr. Anita Joshi)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MESSAGE

Dr. Deepa Tyagi

Director General (Training)
Medical, Health & Family Welfare
Government of Uttar Pradesh

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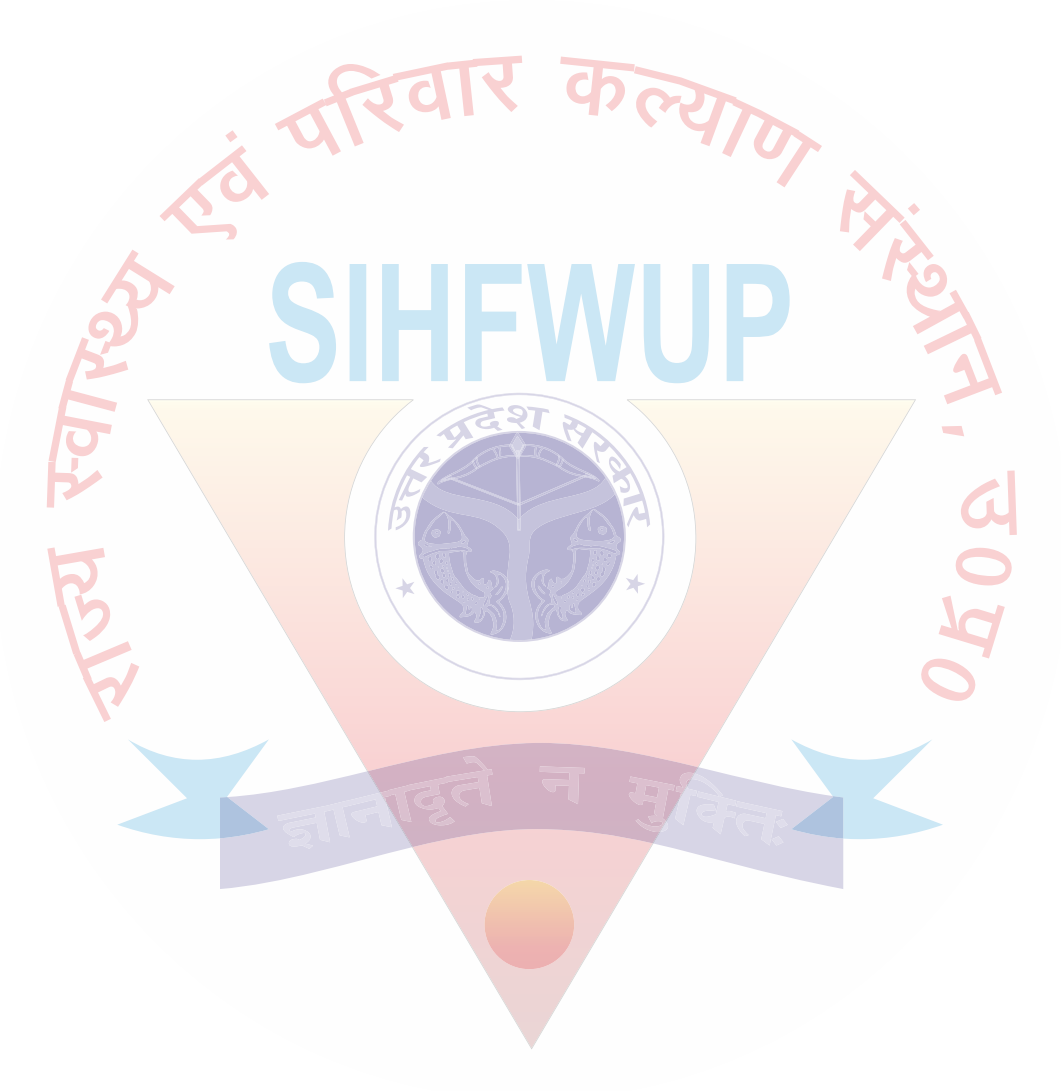
(Dr. Deepa Tyagi)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ACKNOWLEDGEMENT

Dr. Rajaganapathy R.
Director
State institute of
Health & Family Welfare
Government of Uttar Pradesh

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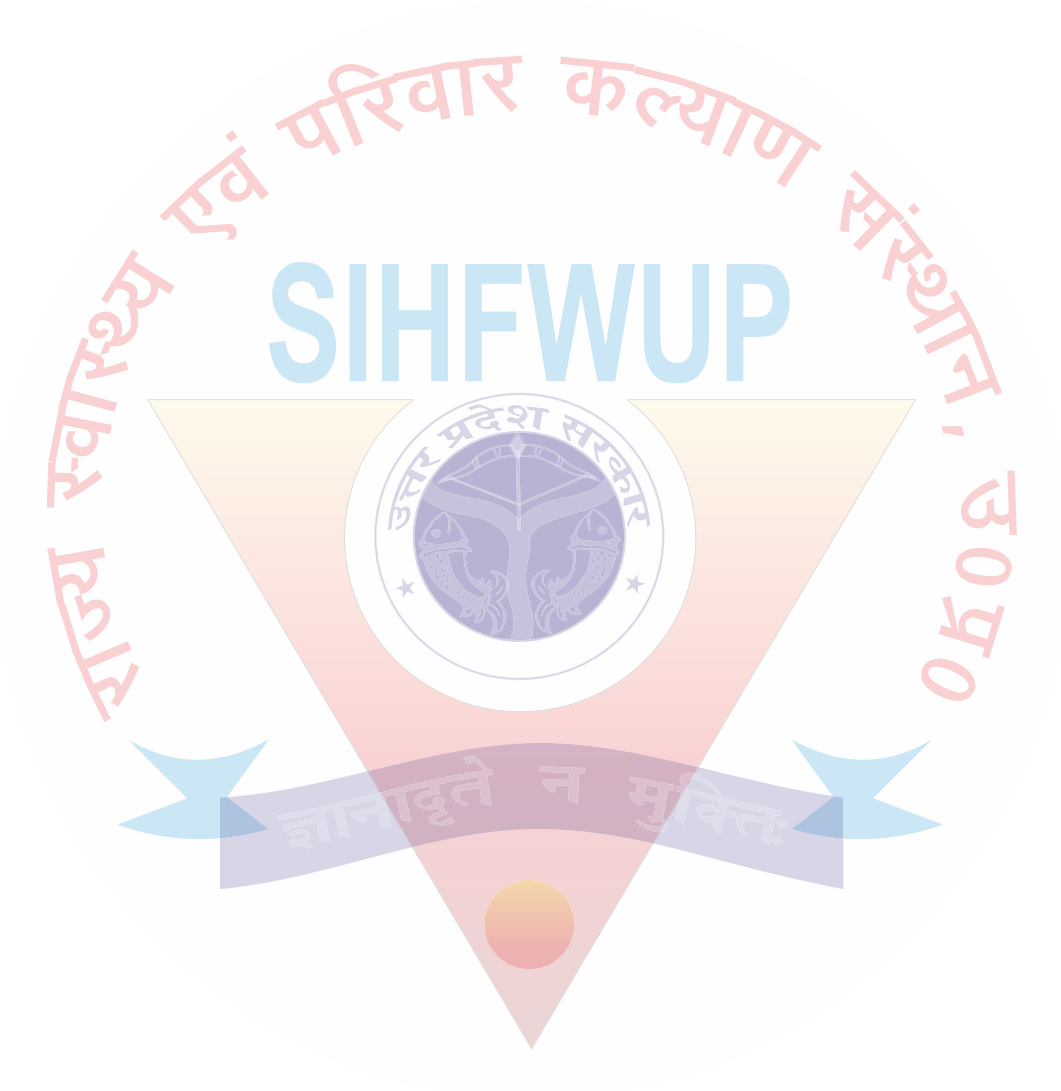
This module on Pain and Palliative care is a result of great efforts taken by the faculty of State Institute of Health and Family Welfare and the team of experts which has developed this very useful module. I am especially thankful to Dr. G. P. Singh Professor and Head of the Department of Anesthesiology and Dr. Sarita Singh, Professor and In Charge Pain medicine unit, KGMU for making this module a very useful tool for the health professional

(Dr. Rajaganapathy. R)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CONTENTS

CHAPTER 1

PALLIATIVE CARE: DEFINITION, MODELS OF CARE, NEED OF PALLIATIVE CARE, GOALS OF PALLIATIVE CARE AND ETHICS.

PALLIATIVE CARE: DEFINITION, MODELS OF CARE, NEED OF PALLIATIVE CARE, GOALS OF PALLIATIVE CARE AND ETHICS.

Learning Objectives:

By the end of this chapter, the learner must be able to tell

- Define palliative care
- A brief history of palliative care
- Goals of Palliative Care
- Need for Palliative Care
- Ethical issues
- Various models of palliative care

Today, India stands as the world's most populated country, with a high percentage of the geriatric population. Non-communicable diseases are largely responsible for death and disability in our population; and ischemic heart diseases, chronic obstructive lung diseases, and stroke are the leading disease conditions causing this. Cases of life-limiting conditions such as cancer, HIV/AIDS, and neurological conditions are on the rise and lead to poor Quality of Life (QoL) for patients and their caregivers. Such patients often need life-long support and care, and the role of Palliative care comes here.

Definition

Meaning to –To Cover up with the Symptoms

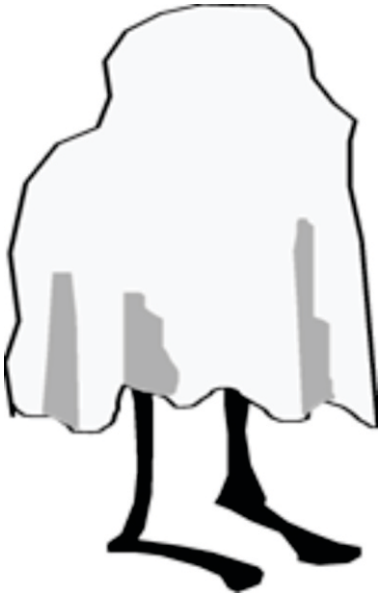


Fig.1 -"cloak"; meaning to cover up.

The World Health Organisation defines **palliative care** as “an approach that improves the quality of life of patients (adults and children) and their families who are facing problems associated with a life-threatening illness. It prevents and relieves suffering through the early identification, correct assessment, and treatment of pain and other problems, whether physical, psychosocial, or spiritual”.

According to the definition of terms by the Indian Association of Palliative Care's Palliative care is defined as “a holistic approach to treatment that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering”.

Brief History

The term “Palliative care” may have become more popular only recently, but this concept has its roots in ancient human history. The word Palliative is derived from “pallium”, the Latin word for “cloak”; meaning to cover up the symptoms of the disease without curing it, which translates to the idea of alleviating or reducing suffering, and the term “hospice” comes from the Latin word hospes, meaning guest. In ancient history, there are also references to care for the diseased and dying, and the earliest hospices and institutions for the dying were managed by religious groups, although the first time the term hospice was used to describe a place for the terminally ill was in 1842 in Lyon, France.

Modern Palliative Care

Fig.2- Dame Cicely Saunders 22 June 1918 14 July 2005

Dame Cicely Saunders of London, an Anglican nurse, physician, and social worker, is best known for initiating the modern hospice movement in the mid-20th century. In 1974, Dr. Balfour Mount, a surgical oncologist at The Royal Victoria Hospital of McGill University in Montreal,

Canada, coined the term palliative care. In India, the first hospice was established at Pondicherry, named after Count Debassyns De Richmont, in 1876, though the first modern hospice was set up in Mumbai in 1986 by Dr. L. J. De Souza. Dr. R. Rajagopal, the Founder and Director of Pallium India, is referred to as the “Father of palliative care in India" owing to his immense contribution in the field.

Who needs Palliative Care?

Fig.3- gross ascitis

Fig.4- **A patient of lower limb Lymphedema - pic from Pallium India patients**

Fig. 5- A patient of paraplegia - pic from Pallium India patients

It is estimated that more than 1 million cancer cases are reported annually in India. Moreover, as life expectancy has risen, a large number of geriatric patients are living with morbidities. With the increase in cases of non-communicable diseases, the need for palliative Care in India is immense.

Palliative care may be required for patients with life-limiting illnesses such as Cancer, HIV/AIDS, neurological disorders (Parkinson's disease, Multiple sclerosis, Motor neuron disease), Stroke, systemic diseases (COPD, Cardiac diseases, Liver and kidney dysfunctions due to various causes, Respiratory diseases), Geriatric patients with dementia, or other degenerative disorders.

Principles for Palliative Care

Fig. 6- Slideshare.net

The PC approach subscribes to the following principles in a variety of settings

The principles of Palliative care are based on holistic care and are applicable to all sectors of care: medical, nursing, paramedical, psychological, emotional, cultural, or spiritual. They can

be enlisted as

a. Palliative care is an attitude of care: that comprises sensitivity and empathy, revolves around all types of suffering: not only medical, and a non-judgemental approach towards the patient irrespective of personality, intellect, ethnicity, or religious beliefs.

b. Provides relief from intractable pain and other distressing symptoms

c. It affirms life and regards dying as a normal process

d. Palliative Care shows neither to hasten or postpone the death

e. Palliative care and support help the patient live as actively as possible until the end of his life.

f. Care that provides a support system not only for the patient but also for the patient's family and caregivers during the patient's illness and also in their own bereavement.

g. Care that enhances the quality of life for the patient.

When to start palliative care?

Palliative care is not a replacement for the treatment regimes, it runs along with them. It starts as soon as a diagnosis of a life-limiting illness is made. It is a part of the treatment regimen and is considered a continuum of care for any patient with a life-limiting illness.

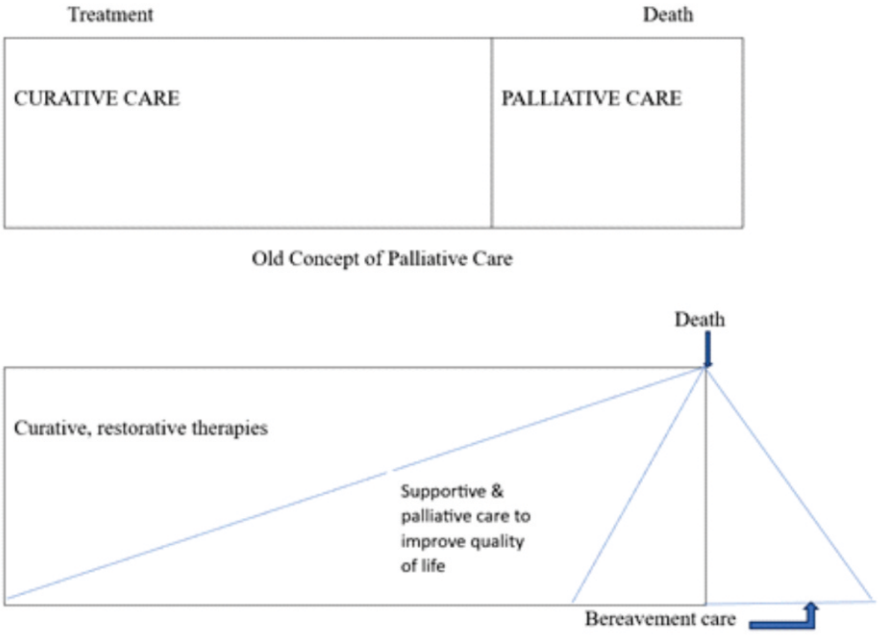


Fig. 7 - The new concept of palliative care

As time progresses, the role of palliative care becomes larger than that of curative care. It allows the patient to have a better quality of life even at life's end. Palliative care goes on beyond the death and allows bereavement care for the patient's family and caregivers.

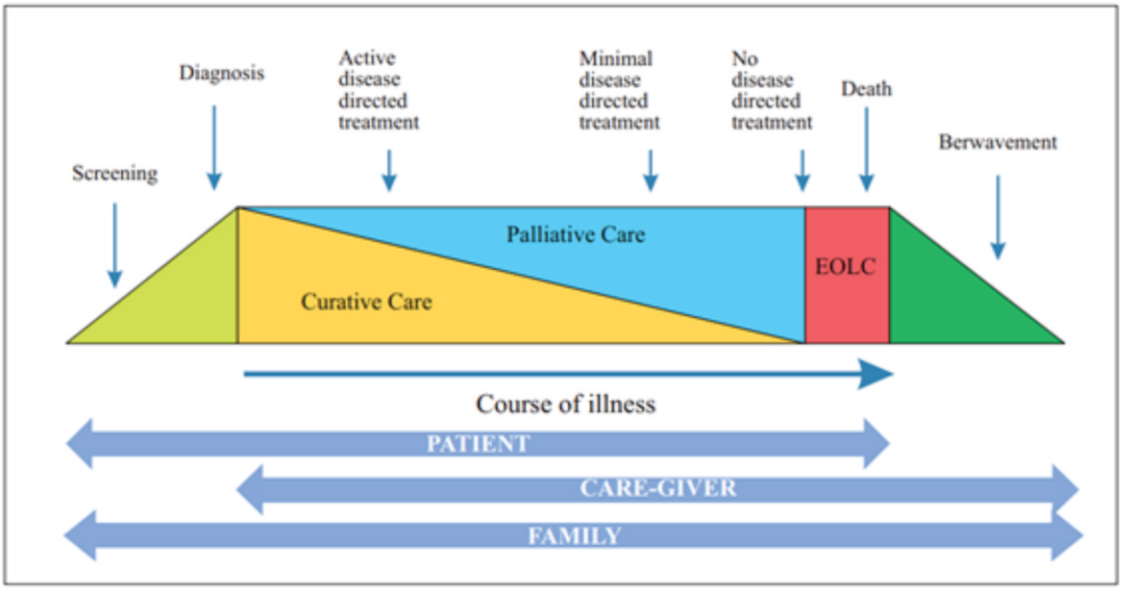


Fig. 8- Continuum of the Palliative Care

Stages of care

- At diagnosis
- During Treatment
- Post-treatment
- At Terminal phase
- Bereavement care

How is palliative care different from curative care?

The curative model of care focuses on the goal of achieving a medical cure for the diseased organ or organ system, on the other hand, PC looks at the patient as a whole and takes care of the aspects like health prevention & promotion, restoration of function, relief from suffering, and caring for the patient's dignity. According to WHO, Palliative care is “the total care of patients where patients are not responsive to curative treatment.”. But one has to understand that Palliative care is not always end-of-life care or only for cancer patients; neither is it the last option or euthanasia. PC is there throughout the course of the disease, for any type of life limiting illness and aims to relieve the patient from pain & suffering.

Types & Models of palliative care

Types:

A. Primary Palliative care

B. Specialist Palliative care

Models

A. Home based

B. Hospital Based

C. Hospice based

D. Day care palliative unit

E. Community based

Fig. 9 - Home Care

Fig.10 - Hospital Care Pic from Pain Medicine Ward KGMU Lucknow

Fig. 11 - Day care Pic from Pain Medicine Ward KGMU Lucknow

Fig. 12 - Community based
Day care Pic from Pain Medicine Ward KGMU Lucknow

CHAPTER 2

COMMUNICATION SKILLS

COMMUNICATION SKILLS

Learning objectives

At the end of this chapter, the reader should

- Know about the basics of communication while interacting with patients
- Be able to understand the importance of correct communication
- Be able to know about the barriers to effective communication
- Be able to develop listening skills
- Know how to break bad news and handle patient's reactions

Communication is the process by which a message or piece of information is exchanged from a sender to a receiver.

Types of communication

1. **Verbal Communication –** Communication is done through spoken words in what is called verbal communication.
2. **Non-Verbal Communication –** Communication that is done without speaking or writing is called non-verbal communication. It involves various types of body gestures and postures.

Keys to Remember

- ❖ Often neglected
- ❖ Anyone can be trained
- ❖ Active listening
- ❖ Plays an important role in alleviating psychological problems.

Communication skills in patient interaction

Communication may be defined as an exchange of thoughts between two or more people with a common background or agenda. Communication is a complex process comprising both verbal and non-verbal components, and it is estimated that more than 70% of communication is non-verbal in nature.

Inpatient interaction and effective communication are the basis for all treatment protocols, as treatment planning starts with a detailed history and patient interview. In PC settings, the need for communication is even greater, as a lot of emphasis is placed on listening, being sensitive, and being empathetic. Good communication skills will help the patient and the family respond to the illness in a better way.

Fig. 13-*counselling room*

Importance of correct communication

If there is a lack of communication, it may lead to:

- Poor compliance and thus poor symptom control
- Poor adjustment to illness, thus increasing patient distress
- Situations of conflict
- Medico-legal problems arise due to misinterpretations and misunderstandings

Effective communication will reduce stress in both patients and the health care provider, help in building trust and an unsaid bond, prevent any false hopes, and allow the patient and the family members to adapt to the challenges associated with life limiting illnesses.

Basic steps for effective communication

- Building a rapport/relationship: take care of the settings and privacy of the patient, make them comfortable.
- Start a discussion: Open the discussion by acknowledging the suffering or loss of the patient. Listen actively and take cognizance of non-verbal cues too.
- Collate information: explore data at the patient's level. Use open-ended questions.
- Understand the patient's point of view: try to empathise and understand what the patient might be feeling. Also, be prepared for emotions of anger, sadness, or despair.
- Communicate instructions and treatment plans: Avoid using technical terms, share your instructions or treatment plan with the patient in a simple, understandable language.
- Repeat or summarise: Allow questions from the patients' side. Reinforce the

instructions and check if anything was left out.

- Close the conversation very sensitively: Never be abrupt in closing the discussion. Instruct the patient when they are supposed to report again. By the end of the discussion, an unsaid bond of trust should have been formed between the HCP and the patient.

Barriers to effective communication in PC settings

Barriers at the HCP level

- Fear of being accused or blamed
- Fear of making the patient upset
- Fear of being thought of as incompetent
- Lack of surety while responding to difficult questions
- Uncertainty about handling patient's emotions and reactions
- Using too much technical jargon
- Talking down to patients

Barriers at the patient's level

- Language problems
- The patient might be afraid of talking freely
- They may think HCP don't have time to listen to their details
- They may be afraid of the truth being revealed to them
- Not being able to understand the situation and its implications completely

Listening skills

Listening is an integral part of effective communication. The basic steps for effective communication comprise preparing for listening, questioning, listening effectively (active listening), and responding.

Incorporating the following key points during listening can enhance listening skills:

- First of all, start the interview with a smile and a greeting. The patient should be allowed to be seated comfortably. Sitting next to the patient without any barrier like the table in between is even better.
- Open-ended questions: These questions allow the patient to decide how much to talk and make the patient comfortable.
- Encourage talking: If the HCP talks more and the patient doesn't get a chance to clear doubts, a rapport is difficult to form.

- Listen actively: The patient should get assurance that they are being listened to. This can be achieved by repetition of what the patient is saying, paraphrasing, and reflection. The assurance should be conveyed by both verbal and non-verbal means. Making eye contact, leaning towards the patient, and avoiding being fidgety are helpful.
- Allow brief silence: HCPs should try to keep patience when the patient sometimes becomes silent during a discussion, especially when narrating about an emotional or sensitive issue. If interrupted, they may forget what they were saying, or change the conversation.

While communicating, keep in mind

- Be empathetic
- Handle situations with the utmost sensitivity
- Do not give false hopes to the patient
- Maintain confidentiality

Breaking Bad News

As a HCP, situations arise when a diagnosis of a serious disease or the loss of a loved one has to be conveyed to the patient or family members. Before breaking bad news to the person concerned, the HCP should first prepare himself or herself. HCPs should be empathetic and feel the pain of the patient or family member before conveying the news.

Patients have the right to be informed about their disease. Also, it helps them and their family plan their lives ahead, avoids any false hope, and helps build trust between the patient and the physician.

Collusion

Sometimes in Indian families, the patient's family does not want the patient to know about the diagnosis. This act of shielding or hiding information from the patient or family is called collusion.

Denial

Denial is a coping mechanism wherein the patient tries to avoid thinking about any painful thoughts or feelings. Not wanting to know the diagnosis is a form of denial.

How to break bad news

The HCP should be trained in the skill of breaking bad news. It consists of not only conveying the message but also being able to respond to the patient's emotions and reactions after the news is conveyed.

The most commonly used protocol for breaking bad news is a 6-step SPIKES protocol (Baile et al., 2000).

Step 1. **S-S**etting the context

- First of all, the HCP should review the patient's records, and know the patient's clinical history, family background, and support system.
- The setting of the discussion should be such that the patient's privacy and dignity are taken care of.
- The patient's wish to have a relative along-with should be taken care of.
- Adequate, uninterrupted time should be allocated for the discussion.

Step 2. **P**- Assessing the patient's **P**erception

- Build up the conversation gradually
- Try to find how much they already know and understand
- Some patients may want a detailed explanation, and some may avoid going into very vivid details.

Step 3. **I-I**nviting the patient

- Assess how much they want to know.
- Try and ask the patient a question like, “Would you like me to explain further about your condition?” or “Should we talk about your medical condition?”
- Note the patient's reactions as you ask them.
- If the patient does not wish to know further, the discussion may end here; but with the open note that he/she is always welcome at any point in time if further discussion is wanted.

Step 4. **K**- Sharing **K**nowledge and Information

- While delivering the news, use simple language
- Be gradual in delivering the news, give information in chunks
- Keep the tone of your voice kind and gentle.
- Give pauses in between to assess the patient's non-verbal reactions.
- Body language should also convey an empathetic message
- Don't use terms denoting hopelessness.

Step 5. **E-** Assessing the **E**motions

- Be sensitive to the patient's emotional reaction.
- Acknowledge the emotions experienced by the patient and if the patient is silent, use open questions
- Don't give false hopes, try to find a balance between too much hope and too much

despair.

- Allow the patient to ask questions, and vent their feelings.
- Sometimes a patient's reaction may be anger; acknowledge it and identify a way by which it can be managed.

Step 6. **S- S**ummarising/strategy

- At the end of the discussion, repeat and clarify things.
- Don't give over-information and leave the patient confused.
- If possible, give written patient information sheets to patients and caregivers.
- Always keep proper documentation of treatment options offered to the patient, and decisions taken for a treatment plan. Discuss the record with your team.
- Always keep the patient on follow-up.

What to avoid while breaking bad news

- Don't be judgemental
- Don't give a definite life span to the patient (like a few weeks or months)
- Don't say, “Nothing can be done.”
- Assure him that he will be provided comfort and that efforts will be made to keep him pain-free.

Conclusion

Communication is the cornerstone of patient management. It is a trainable skill, and all HCPs should be trained in effective communication. If done properly, it may have a significant beneficial effect on the patient's quality of life, and also on the success of the treatment provided to the patient.

CHAPTER 3

PRINCIPALS OF SYMPTOM MANAGEMENT

PRINCIPALS OF SYMPTOM MANAGEMENT

Correct the correctable

Non- drug treatment

Symptomatic drug treatment

PAIN

Fig. 14 - pic form IASP

Learning Objectives:

- Definition of pain
- Diagnosing and treating pain using pharmacological and non pharmacological methods.

Fig .15 - pic for TOT PPT

Definition of pain

"Pain is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage. Pain is always subjective for a person (International Association of Study of Pain, IASP 2020)". Uncontrolled pain can lead to unnecessary suffering, which negatively impacts the quality of life by interfering with activities of daily living and even affecting basic functions like mobility and sleep. Pain can be controlled in almost 80% of cancer patients using a simple, stepwise approach.

Management of pain

In 67% of palliative care patients having intractable pain the other symptoms in patients of palliative care are Dysponea in 50% patients, Nausea & Vomiting 27% to 30% patients, Constipation 30-32% patients, Bedsore 12-14% patients Loss of appetite 35-38% patients. These symptoms should be curedas early as possible to improve the quality of life of patients as well as their family members (Seale and Cartwright ,1994, the year before death , Avebury UK)

Generals Principals for management of Pain

Evaluation of Pain

Assessment of Pain

Explanation of Pain

Management of Pain

Monitoring of pain

Counselling of patients and family members

Counselling of finality member to cope-up with loss

Assessment tools - Pain scale

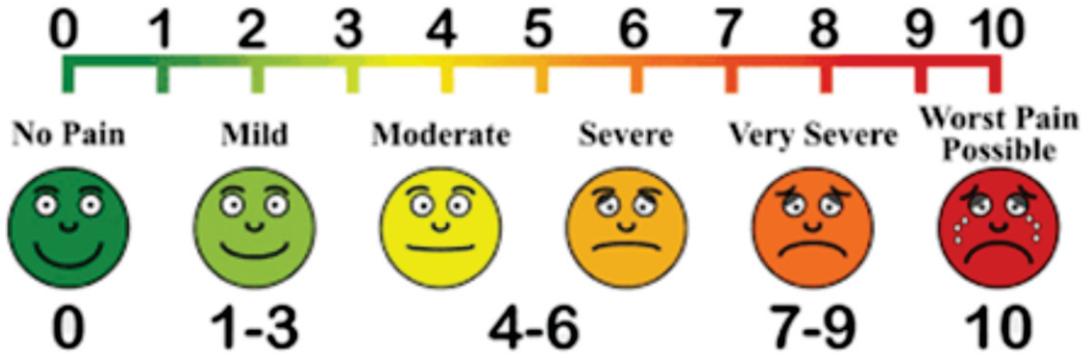


Fig.16 Pain scales Chart1 to 10 Levels disabled world

Pain treatment cannot be started until an assessment of the likely cause has been done. Most adults and older children can describe the pain and its nature. It is important to ask how the pain is affecting their feelings, daily activities, and relationships and also ascertain patients' expectations.

Clinical decisions can be made based on pain description, signs, or behaviours:

Evaluation of Pain

1. Severe or overwhelming pain?
2. Breakthrough pain?
3. Relation to movement?
4. Periodicity?
5. Relation to procedure?
6. Visceral pain?
7. Relation to eating?
8. Association with skin changes?
9. Worsening by touch?
10. Exacerbation on passing stool/urine?
11. Is it in the area of any peripheral nerve?
12. Persistence of pain despite treatment?

Explanation of Pain

1. Severe or overwhelming pain- urgent treatment is required.
2. Break-through pain- a brief worsening can “breakthrough” the analgesia, resulting in distress and perception of poor pain control despite good background analgesia. Its causes include movement or procedure-related, inadequate regular analgesia, the unpredictable occurrence of pain (e.g., pathological fractures), etc. It is commonly occurring in nearly 2/3 of cancer patients- oral/buccal opioids can be given.
3. Pain related to movement- pathological fractures are not always painful when they occur, but pain is always a feature within minutes to hours. Local tenderness suggests local weakness; osteoporosis is common, and infections must be excluded. Treatment includes weak or strong opioids, radiotherapy for bone metastases, NSAIDs, bisphosphonates, gabapentin, and stabilisation of the fracture.
4. Periodic pain-
    a) occurring regularly every few seconds, consider rib metastases, pleuritic chest

pain, or skeletal instability.

b) occurring every few minutes -smooth muscle colic

c) abdominal pain-bowel colic -treat the cause.

d) suprapubic with urinary frequency or urgency-bladder involvement-treat the cause.

5. Pain related to procedure-

a) Change the technique and distract the patient.

b) Topical application of anaesthetic creams for dressings.

6. Visceral pain- caused by disorders of internal organs caused by tumours, ischemia of inflammation-opioids, and neurolysis of nerve plexuses.

7. Pain related to eating-

a) Dyspepsia

b) Due to swallowing

c) Pain in mouth

d) Gastric stasis

8. Pain associated with elimination: causes include constipation or urinary involvement-

a) Periodic - can be colicky

b) Pressure from local tumour-tenesmus, proctalgia.

c) Dysuria

9. Associated with skin changes-

a) Look for ulcers

b) Radiation-induced

10. Unpleasant sensory changes at rest or touch (neuropathic pain)-

a) Look for dermatomal patterns

b) Look for peripheral nerve involvement

c) Pain in sympathetic distribution

d) Hemibody pain-CVA or metastases in the brain

11. Nerve compression- if the tumour is the cause, then radiotherapy, chemotherapy, or dexamethasone can reduce oedema around the tumour.

12. Persistent pain- consider these causes

a) Total pain

b) Poor compliance with treatment

c) Onset of new pain.

d) Inappropriate analgesic dosing.

e) Opioid-induced hyperalgesia.

THE CONCEPT OF TOTAL PAIN	
A.PHYSICAL PAIN	BY CANCER ITSELF
	CAUSED BY TREATMENT
	DUE TO CO-MORBIDITIES
B.PSYCHOLOGICAL PAIN	ANXIETY
	DEPRESSION
	FEAR OF SUFFERING
	PAST EXPERIENCES OF ILLNESS
C.SOCIAL PAIN	LOSS OF ROLE AND SOCIAL STATUS
	LOSS OF JOB
	FINANCIAL CONCERNS
	WORRIES ABOUT THE FUTURE OR FAMILY
	DEPENDENCY
D.SPIRITUAL PAIN	ANGER AT FATE
	ANGER WITH GOD
	LOSS OF FAITH
	FINDING MEANING
	FEAR OF UNKNOWN

Fig. 17- total pain

GUIDELINES FOR PAIN MANAGEMENT

Pharmacological Therapy

Choosing an analgesic-

Analgesics must be chosen based on the cause of pain, their pharmacokinetics, their route of administration, and their suitability for the individual patient.

Clinical decision and action checklist before prescribing analgesics:

a) Check the diagnosis for pain.

b) Is rapid control of pain needed?

c) Is the patient vomiting or unable to swallow?

d) Any medical precautions or contraindications?

e) Is there any preference for an opioid preparation?

f) Any adverse effects troubling the patient?

g) Is a combination needed?

Choice based on the cause of pain-use clinical decision in diagnosing and treating the cause of pain

Choice based on the analgesic ladder-

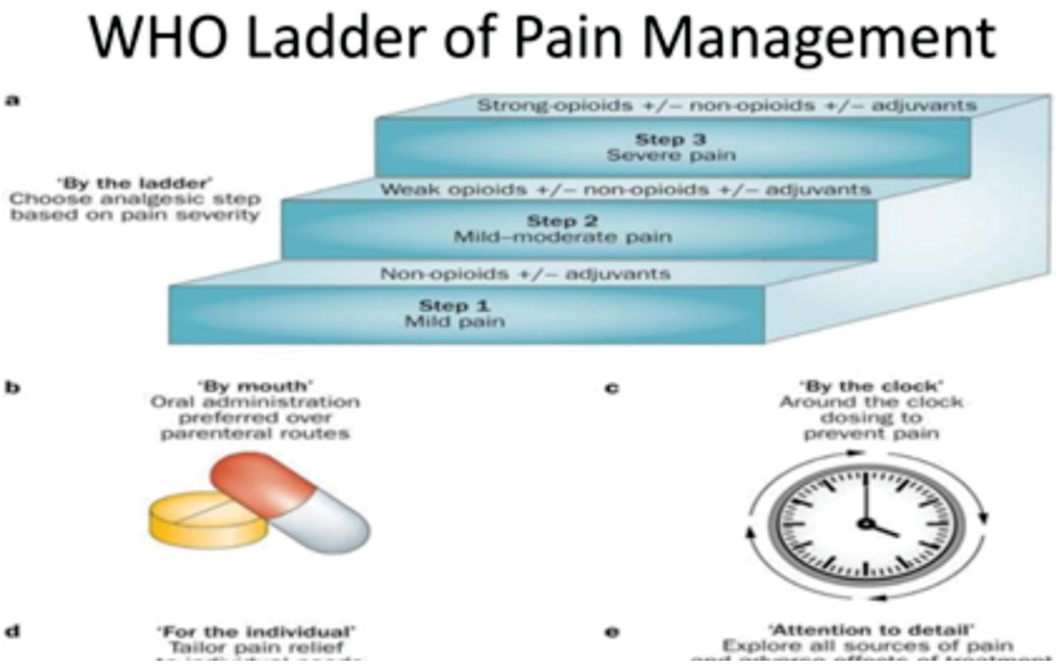


Fig.18 - NHSRC Module

WHO ANALGESIC LADDER

This analgesic ladder uses the key principle of broad-spectrum analgesia with non-opioids, opioids, and adjuvant analgesics.

However, the WHO ladder is a very broad principle that fails with pain unresponsive to opioids. It is necessary to individualise the ladder for each patient.

Choice based on pharmacokinetics and pharmaceutical issues.

The cause of pain often suggests the type of analgesic needed. Choosing a specific analgesic often requires the following:

a) Speed of response:

If a response is needed in less than 2 minutes- the intravenous route

If the response is needed in 5-10 minutes- intramuscular (deltoid), buccal, intranasal, and rectal route

If the response is needed in 20-30 minutes- a subcutaneous route

If the response is needed in 30-60 minutes-oral route

b) Is the patient vomiting or unable to swallow?

For opioids– use the subcutaneous route.

For other alternatives-

1. Rectal- paracetamol, NSAIDS
2. Transdermal– fentanyl, buprenorphine
3. Buccal– fentanyl

c) Is there any medical contraindication or precaution?

1. Renal impairment-NSAIDS best avoided, opioids can be used with extra vigilance.
2. Hepatic impairment-NSAIDs and paracetamol can be used with extra care. Morphine and derivatives can be used except for grade 3 hepatic encephalopathy.
3. Peptic ulceration- Avoid NSAIDS.
4. Children– dose accordingly.

d) Does the patient have any preference for opioids?

1. Controlled-release opioid preparation
2. Instant release opioid preparation

e) Are adverse effects troubling the patient?

Convert to an alternative analgesic.

f) Is a combination of analgesics indicated?

Review clinical conditions.

Using strong opioids

Choosing strong opioids can vary considerably depending on the source. The starting dose and titration rates are tailored to the individual. The frequency of doses depends on the preparation used. Conversion ratios between strong opioids are only guides, and dose adjustments may be needed. Final dose requirements cannot be predicted. Breakthrough doses may also need to be titrated for the individual.

Starting the dose:

Starting doses should be low. High doses can produce adverse effects and increase the chances of patients rejecting the analgesics.

Frequency of dose:

It depends on the half-life of opioids and the duration of controlled release preparation.

Oral morphine is normally given every 4 hours for instant release preparation.

Controlled-release morphine is given 12 hourly.

Morphine is the boon for the cancer pain it is cheapest drugs but not available frequently

Fig. 19 - pic for Google Image may be subject to copyright

Titration of analgesia:

Wait for five times the half-life of the drug and then increase in 25-50% steps.

For normal release morphine, this is every 24 hours.

For controlled release, this is every 2-3 days.

What is the median dose of opioids that is usually needed?

The median daily dose of oral morphine is 90mg/24hrs, or 15mg/4hrly.

When should I change to a different opioid?

Only convert to a different opioid if:

The reason is to reduce or avoid opioid adverse effects.

Parenteral preparation for that opioid is not available.

Familiar with other opioids and their conversion ratios.

Rules for opioid conversion:

1. Know the opioids.
2. Use the conversion factor with which you are familiar.
3. Be prepared to retitrate the dose.
4. If in doubt, ask for advice.

Conversion to transdermal fentanyl and buprenorphine:

Divide the 24 hour oral morphine dose by 3. The final result will be a dose of fentanyl and buprenorphine in micrograms.

Adverse Effects of Analgesics

Using NSAIDS is associated with various adverse effects. Tolerance develops to some opioids, e.g., nausea, but not to others. Sometimes co-analgesics can cause troublesome adverse effects.

Non-opioid analgesics:

Paracetamol- well tolerated but has hepatotoxicity

Nefopam – sweating, nausea, tachycardia, vomiting

NSAIDS - GI bleeding, renal impairment, cerebrovascular, and cardiovascular toxicity

Opioid analgesics:

Respiratory depression- if starting dose is high or there is poor titration of morphine

Constipation– 90% of patients, laxatives are essential for these patients

Nausea and vomiting- 50% of patients.

Delirium and hallucinations

Controlling pain in cancer patients is one of the prime tasks of palliative care, and it poses many challenges. We have to stick to a proper plan to get the maximum analgesic effect with the minimum adverse effects.

Non-pharmacological therapy

A majority of cancer patients can achieve optimum pain relief from the rational administration of pharmacological therapies alone. Some patients may not attain optimum pain relief on systemic drugs and may require the use of other modalities to control pain. In these patients, the application of one or more non-pharmacological therapies provides better pain relief, and these approaches become the primary analgesic therapy for the relatively small number of patients who fail to respond to systemic drugs. The non-pharmacological approaches used in cancer pain management include interventional therapy, oncological therapy, surgical therapy, physical therapy, and complementary therapy.

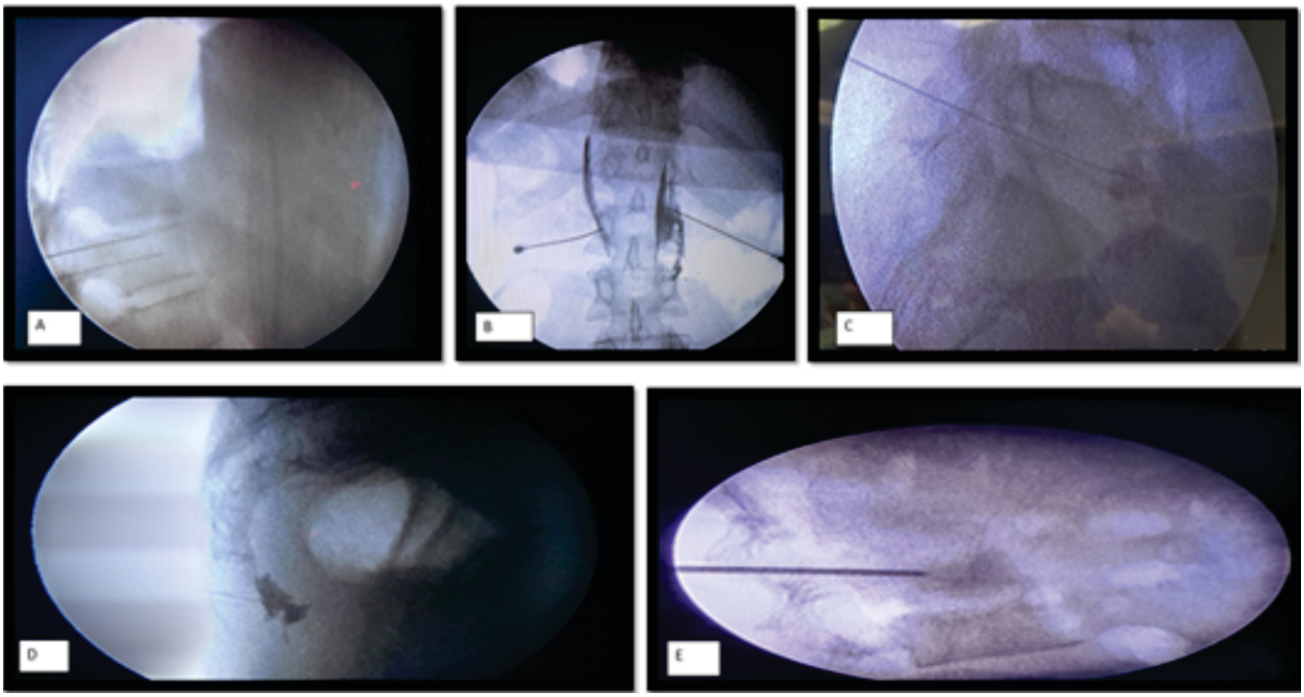


Fig.20 - Interventional procedure for cancer pain management: a) splanchnic plexus block; b) coeliac plexus block; c) superior hypogastric block; d) ganglion impar block; e) vertebroplasty.

Images courtesy- Pain medicine unit, King George Medical University, Lucknow

Monitoring of pain

Team Work

Review the patients timely

Assess value of each intervention

Risk/benefits

MANAGEMENT OF GASTROINTESTINAL PROBLEMS

COMMON ORAL PROBLEMS

- Stomatitis (mouth ulcers) - It may be caused by infection, candidiasis, ulceration (malignant or non-malignant ulcers), post radiotherapy and chemotherapy, dry mouth, iron or vitamin C deficiency
- Halitosis (foul smell from the oral cavity) – It occurs with poor oro-dental hygiene, infection and necrosis of ulcers, growth, dental caries, and sinusitis.
- Decreased mouth opening- often underdiagnosed as post-radiotherapy or chemotherapy with ongoing pain, gradually decreases mouth opening, leading to poor oral intake, poor oral care
- Dry mouth (xerostomia)

Fig. 21 -pic of Google oral thrush

Because of the above problems, the patient is not able to eat, is not able to talk properly, is irritable (a person who is hungry but cannot eat and food is in front), is not able to communicate his sufferings, express himself, and has become socially withdrawn due to a foul smell and disfigurement. It leads to poor nutrition, fatigability, and depression.

Management

Prevention

Prevention is always better than cure. Oral cancer patients should be educated about oral hygiene from the first contact with a healthcare worker or doctor

Oro dental care

- Brush teeth and gums with a soft bristle brush twice a day. Soak the brush in hot water for a few minutes before brushing to soften the bristles. A homemade brush with cotton and gauge can be used in cases of decreased mouth opening or sore mouth.

- Use a non-flavouring toothpaste, as flavouring may irritate the mouth.
- Rinsing the mouth every 2 to 4 hours or at least after each meal. Should be done with lukewarm water with pinches of baking soda or common salt.
- Application of petroleum jelly or vegetable oil on lips frequently to prevent cracking or drying of lips.
- Avoid tobacco, alcohol, and spicy food
- In cases of large oral wounds and/or decreased mouth opening early nasogastric tube (ryles) tube insertion is better for keeping oral cavity infection free as advised.
- Early dental checkup in case of toothaches
- Keep the mouth as moist as possible with frequent sips of water and semi-frozen drinks.

Treatment

if a patient develops a foul smell, increased pain, white patches and or toothache

- Dental, ENT and Oncologic review
- Rinse the mouth 2 hourly with the non-flavouring betadine mouthwash and solution made by 100 ml metrogyl with 100 ml normal saline/ cooled boiled water till foul smell persists
- Wound care- clean the wound with saline and metrogyl solution with a syringe properly. Use betadine and crushed metrogyl tablets applied to the wound and cover it with a gauge.
- Drug management: Local anaesthetics, xylocaine jelly 2% or 4% viscous, Choline salicylate gel, Sucralfate, Silver nitrate.
- Nystatin liquid 1 to 2 ml 4 hourly, Mycostatin lozenges, Clotrimazole mouth paint in case of candidiasis (white patch).

NAUSEA AND VOMITING

Nausea is an unpleasant feeling of the need to vomit and vomiting is the forceful expulsion of gastric contents through the mouth. Nausea and vomiting is very distressing for the patient as well as for caregivers and lead to debility, nutritional deficits, dehydration, electrolyte imbalance and aspiration pneumonia.

20-30 % in patients with advnce cancer and 70% in the last week of life / 30% patient can procedure vomiting on morphine during first week

Common Cause of Nausea & Vomiting

- Pain
- Anxiety
- Drugs (opioids, radiotherapy, chemotherapy)
- Intestinal obstruction
- Raised ICP
- Constipation
- Gastric stasis/ gastritis/ GERD

Others: Abdominal carcinomatosis, extensive liver metastases, ascites, hypercalcemia, uraemia.

Fig. 22- Nausea pic from PPT of Dr. Rakesh Garg AIIMS Delhi

Fig.23 -Vomiting pic from PPT of Dr. Rakesh Garg AIIMS Delhi

Aetiology

Underlying etiology of nausea and vomiting Clue and Hints for diagnosis and management

1. Obstruction:- Intermittent nausea with cramping and altered bowel habit. Nausea relieved with large emesis sometimes bilious/feculent.
2. Impaired Gastric Emptying:- Intermittent nausea with early satiety postprandial fullness or bloating nausea relieved with vomiting small amounts of undigested food.
3. Chemical cause:- Persistent nausea aggravated by sight/smell of food, unrelieved by vomiting.
4. Cortical component:- Nausea and vomiting associated with anxiety.
5. Vestibular component:- Nausea aggravated by movement (from degrees of turning of the head to motion sickness).
6. Increased Intracranial:- Early morning nausea and/or vomiting associated with headache

- Cancer-related like raised intracranial tension due to brain tumour or meningeal irritation, abdominal malignancies like Ca stomach, cancer of gallbladder or liver metastasis, physiological abdominal distension, bowel obstruction, constipation, gastric reflux, uremia.
- Treatment related - chemotherapy or opioid-induced or radiotherapy-induced or infection

MANAGEMENT

Pharmacological and Non- Pharmacological

Non- Pharmacological

- Patients should be educated about the possibility of nausea and vomiting during chemotherapy or radiotherapy and if opioids are given for pain management. During this period patient should eat or drink in a sitting posture.
- Patients should eat small frequent meals during treatment.
- Should avoid spicy, oily food. Lemon black pepper can be tried in food to make it tastier and prevent nausea.
- Avoid any trigger that can cause nausea or vomiting like any smell, spray etc
- Antiemetics advised should be taken half an hour before a meal.
- Avoid force-feeding the patient

Pharmacological management in palliative care

Haloperidol 1 mg PO or SC bid or tid, increase to 10 to 15 mg/day, as needed If needed, add:

Olanzapine

Antihistamine

Metoclopramide 10 mg thrice a day, Ondansetron 8 mg thrice a day, Granisetron 3 mg once a day, Dexamethasone 4-8 mg once a day, Domperidone 10 mg thrice a day, Haloperidol 1.5-2.5 mg twice a day.

Aprepitant

Note - If a patient is having projectile vomiting along with headache, intracranial pathology should be ruled out first. If the patient is drowsy, serum electrolytes should be checked and corrected. If vomiting is associated with abdominal pain, distension or constipation with no flatus, obstruction should be ruled out - abdominal radiograph/USG abdomen. If the patient is having recurrent and continuous vomiting not controlled with oral medicines, injectable medicines are required and one should get admitted at a nearby centre.

MANAGEMENT OF CONSTIPATION

Fig. 24 - Pic from google slide share

Constipation is difficult, painful and infrequent defecation of hard stools. It leads to abdominal discomfort, nausea, decreased food intake and low appetite. Before labelling it constipation and starting treatment individual bowel habits should be asked as it is different for each individual. Change in frequency, consistency, diet, medications including laxatives or mobility of the patient is important to consider.

Constipation

Bristol stool scale

Often unrecognized and under treated

Occurs in 70% of the seriously ill patients

Causes

Spinal cord compression

Cauda equina syndrome

Poor nutrition

Poor fluid intake

Opioid induced

Management – The goal is to achieve near-normal bowel habits with or without the appropriate laxative.

Non-pharmacological Management

- Educating patients about the need for fibre in their diet is very important.
- Modifiable causes should be tried along with prophylactic laxatives like encouraging the patient to eat fruits in place of juices, including churned dal roti or daliya in place of only liquid juices if the patient is not able to take solid diet whenever possible.
- Adequate hydration is very important along with modification of diet before starting laxatives.

Pharmacological Management

Classification of laxative

Bulk forming

Lubricants

Osmotic Laxatives

Stimulant laxatives

- Laxatives can be osmotic like lactulose, sorbitol, polyethylene glycol
- Laxative like Magnesium hydroxide suspension (Milk of magnesia) Magnesium sulphate (Epsom Salts), Liquid Paraffin and magnesium hydroxide emulsion
- Contact stimulant laxatives like bisacodyl, dantron, senna
- Bulk-forming laxatives Ispaghula husk Methylcellulose Fybogel
- Surface wetting agents Docusate sodium Poloxamer
- In cases of faecal impaction and in spinal cord compression, Rectal laxatives are used as suppositories or enemas. A digital rectal examination should be done to assess if the rectum is full or empty, whether the stools are soft or hard, presence of rectal sensation and anal tone. A stimulant such as bisacodyl suppositories 10 mg or osmotic laxatives like glycerol suppositories or enemas can be used in soft or hard stool respectively.
- In cauda equina syndrome, the anacolic reflex is absent. An individualized combination of daily oral laxatives and suppositories or enemas every alternate day should be tried.
- Treatment of constipation should be individualized to achieve comfortable bowel habits.

Red flags- If constipation is associated with abdominal distension, visible peristalsis - plain radiograph to rule out obstruction. Causes of constipation- Cancer-related, Poor intake (food, fibre and fluid loss), vomiting, Opioid-induced constipation, Intestinal obstruction, Hypercalcemia. Opioids lead to constipation as they reduce propulsive intestinal activity and increase the absorption of fluid and electrolytes. Hence a combination of a contact laxative and stool softener is usually required. Bulk-forming laxatives should be avoided as this worsens constipation.

DIARRHOEA

Diarrhoea, or loose stool, is defined as the passage of more than three unformed stools in a 24-hour period. Fear of soiling and repeated visits to the toilet is very distressing to the patient, along with the risk of electrolyte imbalance, dehydration, and fatiguability.

Aetiology

The commonest cause of diarrhoea is inappropriate use of laxatives. Other causes can be cancer-related or infections. Multiple episodes of defecation without the ability to control may indicate anal incontinence. Patients with rectovaginal fistula also give a history of faecal incontinence with faeces coming out through the vagina.

Management

- Oral Rehydration – WHO-ready formulae, diluted fruit juices, tender coconut water, homemade solution
- Parenteral fluids IV normal saline or ringer lactate- if watery diarrhea with dehydration, tachycardia or oliguria with reduced skin turgor, lethargy
- Loperamide - not to be used in acute infective gastroenteritis and neutropenic enterocolitis In uncomplicated cases- 4 mg followed by 2 mg every 2-4 hours. Max dose 16 mg/ 24 hours.
- Probiotics - lactobacillus Opioids are preferred as analgesics Antibiotics - if fever, neutropenia, bloody diarrhea.

INTESTINAL OBSTRUCTION

Suspicion of intestinal obstruction should be raised if a patient presents with symptoms like abdominal distension, pain with or without colic, nausea, and constipation. Vomiting may occur at the later stages but is often limited in the initial stages. The severity of symptoms and treatment will depend on whether the obstruction is partial or complete. Not passing flatus for more than 72 hours with hyperactive or absent bowel sound suggestive of complete obstruction.

Management

- History of opioid intake with chronic constipation should be asked.

Investigations

- Abdominal X-ray erect/ USG/ Gastrografin study.
- Serum electrolytes - Serum potassium, serum calcium to rule out dyselectrolemia as a cause of obstruction.

Medications

- Analgesics: opioids – for the persisting pain due to cancer infiltration Morphine / Fentanyl/ tramadol according to availability.
- Anticholinergics/Antisecretory drugs – to reduce the distension & the colicky, spasmodic intermittent pain. Hyoscine butyl bromide- 10mg sixth hourly / Injection Glycopyrrolate 0.1 – 0.4 mg per day
- Injection Ranitidine 150-200mg per day- to reduce upper GI secretion and distension.
- Anti-inflammatory - Steroids Injection Dexamethasone 8-16 mg OD. Stop dexamethasone - if there is no improvement in 5 days or side effects appear. If obstructive symptom relieves - wean gradually over 2 weeks.

- Anti-emetics
- Fluids, electrolytes – for correction of dyselectrolytemia / hydration.
- Palliative surgical interventions – colostomy, ileostomy, feeding jejunostomy, venting gastrostomy – as appropriate.
- Self-expanding metallic stents can be considered for obstruction at the level of the gastric outlet, proximal small bowel and colon.

ASTHENIA

This means "absence or loss of strength". The term "asthenia" and "fatigue" are often used interchangeably. Fatigue is the most common symptom in palliative care patients who have advanced cancer or other serious life-threatening illnesses. It is also one of the most under-reported and undertreated symptoms. Fatigue has substantial adverse physical, psychosocial, and economic consequences for both patients and caregivers.

Aetiology

Primary fatigue is due to the tumour itself. This may either be through peripheral mechanisms such as energy depletion or by central mechanisms such as dysregulation of the hypothalamic-pituitary-adrenal (HPA) axis or serotonin metabolism. These mechanisms may ultimately be related to high levels of cytokines. Cancer-related concurrent syndromes and comorbidities such as anaemia, cachexia, fever, infections or metabolic disorders as well as sedative drugs for symptom control can result in secondary fatigue

Management

- Treat underlying causes - Cachexia, anaemia, depression, anxiety, infection, autonomic dysfunction
    - Non-pharmacological- Counselling, physiotherapy, occupational therapy
    - Pharmacological – Corticosteroids, megestrol acetate, amphetamines

In the final stage of life, fatigue may provide protection and shield from suffering for the patient and treatment of fatigue may be detrimental. Identification of the time point where treatment of fatigue is no longer indicated is important to alleviate distress at the end of life.

CACHEXIA

Multifactorial metabolic syndrome is defined as an ongoing loss of skeletal muscle mass with or without fat mass that cannot be fully reversed by conventional nutritional support and leads to progressive functional impairment. It is present in up to two-thirds of patients with advanced

cancer and is also associated with other chronic diseases including chronic obstructive pulmonary disease (COPD), chronic heart failure, chronic kidney disease, and chronic infectious and inflammatory diseases including AIDS.

Diagnostic criteria

5% weight loss in 12 months or a body mass index of less than 20 kg/m2 in the presence of a known chronic disease with at least 3 of the following factors:

- Loss of muscle mass
- Asthenia
- Loss of body fat, in the presence of inflammation as evidenced by albumen less than 3.2 g/dL or increased C–reactive protein.

Aetiology

Cachexia is characterized by a persistent increase in basal metabolic rate that is not compensated by increased caloric/protein intake. It is multifactorial including digestive factors, tumor factors and hormonal responses to the primary disease. Digestive factors resulting in poor intake include dysgeusia, nausea, dysphagia, mucositis, and constipation. Tumor-mediated factors activate proteolysis and lipolysis. Inflammatory mediators such as cytokines which include tumour necrosis factor and the interleukins induce anorexia while increasing glucagon, cortisol, and catecholamines producing a catabolic, hypermetabolic state. Hormonal anabolic mediators such as growth hormone, insulin-like growth factor-1 (IGF-1), testosterone, and ghrelin are reduced.

Management

Addressing cachexia at an earlier stage might ameliorate the destructive effects of the primary condition. A multimodal approach aimed at improving appetite, reducing the inflammatory response, and improving outcomes and quality of life is the focus of treatment.

Non-pharmacological Management

- Adequate nutrition remains an important aspect of this multimodal approach. However, increasing calorie–protein intake by definition does not reverse this abnormal metabolic state. To address malnutrition in the cancer patient, it is recommended that the nutritional regime should provide 30–35 kcal/kg/day, 1–1.2 g protein/kg per day, and 30–50% of fat covering the nonprotein calories.
- Psychological Counselling Management of the psychosocial consequences for both the patient and the family
- Physical activity attenuates the effects of cachexia by altering muscle metabolism through increased protein synthesis and reduced degradation pathways. In addition,

exercise increases insulin sensitivity, reduces oxidative stress, and reduces the response to inflammation.

Pharmacological management

- Corticosteroids - Dexamethasone 2-8 mg or Prednisolone 20-40 mg. In addition to appetite stimulation, steroids theoretically may reduce the inflammatory state. It is only indicated for less than 4 weeks due to side effects.
- Megestrol acetate 320 mg to 800 mg per day. Side effects include adrenal suppression and an increase in the incidence of DVT.
- Omega-3 fatty acids have anti-inflammatory cytokine effects. They may also limit muscle proteolysis. Two grams of eicosapentaenoic acid (EPA) daily, had favorable effects on inflammation, appetite, and lean body mass.
- Other medications including cannabinoids, non-steroidal anti-inflammatory drugs, ghrelin, beta-2 agonists, selective androgen receptor modulators, aliskiren, resveratrol, leucine, and thalidomide are all under active investigation with some positive early trends.

ANOREXIA

Anorexia is the involuntary loss of appetite or desire to eat that results in reduced caloric intake and is often associated with weight loss. Anorexia can be caused by cancer, AIDS, mental disorder (i.e., anorexia nervosa), or other diseases. Anorexia and reduced food intake are important issues in the management of patients with cancer because they contribute to the development of malnutrition, increase morbidity and mortality, and impinge on the quality of life. The significance of anorexia was reported in 85% of advanced cancer patients. It affects both the patient and the carer. It may be the first presenting sign of cancer.

Aetiology

Patients with cancer may also experience anorexia secondary to food aversion due to 2 reasons. It can result from the central integration of negative psychological experiences and olfactory and gustatory inputs. It can also result from direct disruption of the physiological neurochemical mechanisms which control energy intake. Aversion to food is highly adaptive and contributes to food selection and appetite dysregulation. Tumour growth is frequently associated with the development of anorexia. Thus, cancer anorexia should not be confused with nausea and vomiting induced by radiotherapy and chemotherapy regimens.

Fig.25- patient with anorexia

Management

Cancer anorexia is multifactorial. Hypothalamic neuronal signalling pathways modulating energy intake and cytokines triggering the complex neurochemical cascade lead to the onset of cancer anorexia. Thus, the optimum therapeutic approach to anorectic cancer patients should include changes in dietary habits, achieved via nutritional counselling, and drug therapy aimed at interfering with cytokine expression.

Non-Pharmacological Management

Look for and treat reversible causes like nausea, vomiting, constipation.

Dietary management involves the patient in menu planning. Offer small portions of the patient's favourite foods. Offer easy-to-swallow foods. Try sweets. Avoid foods with strong smells, flavours, or spices, unless the patient requests.

Counseling patient and family about illness and its effect on appetite. Anorexia is a symptom of the disease and the patient is not starving. Forced feeding often causes discomfort. Artificial feeding usually does not help. Patients are usually not uncomfortable from decreased intake and can live for long periods on little food. Family members and caregivers are more concerned about lack of appetite and may harass the patient about decreased intake, thus counseling is must.

Pharmacological management

The drugs are of limited or temporary benefit but worth considering as they improve quality of life. Curable factors should be identified and appetite stimulants may be added. Corticosteroids, Progestogens and Prokinetics are commonly prescribed. The potential side effects and risks of medication should be taken into account when prescribing the medications.

Management of Respiratory symptoms

BREATHLESSNESS

Dyspnoea is a subjective feeling

Fig. 25 PPT Palliative Symptom Management

Breathlessness is a subjective experience of breathing discomfort that consists of qualitatively distinct sensations that vary in intensity. Other terms used interchangeably are dyspnoea, shortness of breath, breathing difficulty, and laboured breathing. It is one of the most common symptoms experienced in late stages of diseases mainly COPD (Chronic obstructive pulmonary disease), heart failure, and terminal stages of cancer because of the disease itself, comorbidities and cachexia.

Aetiology

Breathlessness is a subjective experience that results from interactions among multiple physiological, psychological, social, and environmental factors

- Malignant
  - ❖ Direct tumour effects
- Airway obstruction
- Superior vena cava obstruction
- Lymphangitic carcinomatosis
- Venous thromboembolism
- Pericardial/ Pleural effusion

- Ascites
  - ❖ Treatment-related
- Pneumonitis from systemic therapy or radiation
- Lobectomy or pneumonectomy
- Nonmalignant
  - ❖ Cardiovascular
- Congestive heart failure
- Ischemic heart disease
  - ❖ Pulmonary
- Chronic obstructive pulmonary disease
- Interstitial lung disease
- Pneumonia
- Asthma
- Others
  - ❖ Anaemia
  - ❖ Anxiety
  - ❖ Obstructive sleep apnea
  - ❖ Neuromuscular disease

Management

Dyspnea is multidimensional in nature and often associated with depression, anxiety, tiredness, and lack of appetite. People adjust their activities of daily living to minimize their experience of breathlessness, this leads to increasing levels of social isolation that is distressing and a cause of suffering in itself. Dyspnea leads to considerable suffering for patients and caregivers and can be a cause of treatment interruption, frequent hospital visits, and death.

Management of reversible/specific causes of breathlessness

- Pleural effusion/ pericardial effusion -Therapeutic aspiration.
- Pulmonary embolism - Anticoagulate if appropriate, balancing risks and benefits
- Large airway obstruction - Radiotherapy in endobronchial tumours, debulking or laser therapy may be possible. In extrinsic compression, stenting may be possible

- Lymphangitis carcinomatosis - Trial of steroids (Dexamethasone 8 – 12 mg daily may be appropriate)
- Superior Vena Cava Obstruction (SVCO) - Steroids 8-16 mg daily. Radiotherapy /Chemotherapy depending on histology. Thrombolytic therapy may be considered if a thrombus is present.
- Respiratory infection – Antibiotics
- Anaemia - Blood transfusions. Erythropoietin in some situations (anaemia secondary to chemotherapy)
- Ascitis – therapeutic ascitic fluid drainage

Non-pharmacological management

Fig.26 - Positions to relieve breathlessness and reduce the effort of breathing

- Reassurance and explanation of the situation are important to allay anxiety and ease out doubts of the patient and the family. Also, explain the futility of invasive ventilation. It also helps in accepting the situation with positive thinking.
- Positioning – head-up position or prone or any position in which the patient is comfortable.

- Activity pacing – resting between activities, slowing down, and selecting activities carefully.
- Breathing retraining - Abdominal breathing, breathing out, deep breathing, practising 'pranayama'. Pursed lip breathing – this is generally very helpful in panic attacks.
- Distraction techniques – directing a stream of air/fan can reduce the sense of breathlessness
- Relaxation techniques – gentle massage of the back, relax shoulders, back, neck and arms. Concentrate on breathing out slowly (if breathing in seems difficult), acupuncture.
- Chest physiotherapy

Pharmacological management of breathlessness

- **Oxygen therapy** for managing breathlessness is controversial in the terminal stages of patients. Oxygen therapy is helpful in case of hypoxia and pulmonary hypertension. Nasal prongs rather than a mask can avoid some of the potential problems. Intermittent pulse oximetry should be done for assessment of oxygen need. If long-term need is anticipated then an oxygen concentrator should be used rather than a cylinder.
- **Opioids** are the first choice in the management of refractory breathlessness. It relieves dyspnea by reducing the respiratory rate, reducing anxiety associated with breathlessness and decreasing sensitivity to hypercapnia.
- **Benzodiazepines** are frequently used in the symptomatic management of breathlessness. They act by activating the inhibitory GABA pathways. The central and main effects of benzodiazepines are sedative-hypnotic, muscle relaxant, anxiolytic and anticonvulsant. The common drugs used are diazepam, midazolam, alprazolam and lorazepam. Shorter acting benzodiazepines like Lorazepam are preferred. Patients can be taught to take sublingual Lorazepam (0.5 mg) during anxiety attacks. For severe breathless episodes, Midazolam subcutaneous (starting dose 10mg/24 hours) is very useful. Starting dose for s/c use should be 2.5mg stat and gradually titrated upwards. Diazepam should not be used due to its prolonged half-life.
- **Corticosteroids** may be helpful in many situations. If the cause of breathlessness is unclear then a trial of 4-8mg of dexamethasone can be given and then stopped after 4 days if there is no improvement.
- **Nebulisation with steroids**, anticholinergics, bronchodilators or even saline may be helpful to dilate and loosen up tenacious secretions in the respiratory tract.

Terminal breathlessness- Patients often fear suffocating to death. No patient should die with distressing breathlessness. An opioid with a sedative anxiolytic action can be given by subcutaneous route or orally by ryles tube-like morphine with midazolam. If the patient becomes agitated or confused (sometimes aggravated by midazolam), haloperidol should be added.

COUGH

Cough normally protects the airways and lungs by removing mucus and foreign matter from the airway and is under voluntary and involuntary control but becomes problematic if it is persistent.

Aetiology

Breathlessness can trigger a cough and vice versa. A persistent cough can trigger vomiting, exhaustion, chest or abdominal pain, rib fracture, syncope, and insomnia.

Non Malignant

- Infection
- Airway disease - Asthma Chronic Obstructive Pulmonary Disease Irritant Foreign body
- Cigarette smoking
- Oesophageal reflux
- Cardiovascular causes - Left ventricular failure
- Chronic Infection Cystic fibrosis Bronchiectasis Post nasal drip Parenchymal disease Interstitial fibrosis Recurrent aspiration Motor neuron disease Multiple Sclerosis Drug induced ACE inhibitors Inhaled drug
- Airway obstruction Endobronchial disease Pleural disease Pleural effusion

Malignant

- Mesothelioma
- Malignant Interstitial disease
- lymphangitis
- Multiple pulmonary metastasis
- Radiation pneumonitis
- Vocal cord palsy
- Hilar tumour or lymphadenopathy

Management

Management of cough depends on the type and the cause of the cough, the patient's general condition and the prognosis of the underlying disease.

Pharmacological Management

- Opioids: They are the most effective antitussive agents. Mainly used opioids are Codeine sulphate (in the form of Codeine Linctus), Dextromethorphan, Morphine etc.
- Corticosteroids: Prednisolone and Dexamethasone; they may aid in reducing cough due to lymphangitis and radiation pneumonitis.
- Bronchodilators: Salbutamol and Ipratropium can help relieve cough due to COPD.
- Nebulised Local Anaesthetics: Nebulised Lignocaine and Bupivacaine are useful for intractable unproductive cough.

Pharmacological agents for productive cough

- Steam inhalation
- Nebulised saline
- Physiotherapy
- Postural drainage
- Antibiotics in case of purulent sputum
- In case of heart failure diuretics should be given

HAEMOPTYSIS

Lung cancer is the commonest cause of massive haemoptysis (>200 ml / 24 hours). Non-malignant conditions like bronchitis, bronchiectasis, cystic fibrosis and pulmonary embolism can cause mild to moderate haemoptysis. It is important to accept the fact that we cannot stop the haemoptysis from occurring. We may be able to control it for sometimes but the eventual process cannot be reversed.

Management

Management of haemoptysis should be aimed at reducing awareness and fear. An intravenous route should be used if there is a peripheral vascular shutdown. Proper prognostication and hence the likelihood of massive bleed should be anticipated and planning should be done to face such a crisis. Risks should be discussed with the patient and family. Accepting the fact that treatment of disease is not per se possible protects the patient from irrational and futile measures.

- Nurse the patient lying on his/her side on the side of the tumour.
- Mask evidence of bleed – with red or green towels
- Calm the patient and witnesses like family members, staff and other patients with lung tumours.
- Oral haemostatic drug in minor bleed
- Intravenous strong opioid & benzodiazepine

CHAPTER 4

MANAGEMENT OF LYMPHOEDEMA

MANAGEMENT OF LYMPHOEDEMA

Lymphedema is an accumulation of lymph in the interstitial space of subcutaneous tissue or is an excessive and persistent accumulation of extravascular and extracellular fluid and proteins in tissue spaces. It can be the result of an infection, injury, cancer treatment, inflammation of the lymph, or lack of limb movement.

Aetiology

Lymphoedema is caused by damage to the lymphatic system or problems with the movements and drainage of fluids in the lymphatic system.

- **Primary lymphoedema**- due to a congenital defect in the lymph conduction system.
- **Secondary lymphoedema**- It is an acquired lymphoedema secondary to malignancy (lymph node infiltration, tumour compression), surgery (lymph node dissection, scaring), trauma (circumferential wound, burns), infection (filariasis, lymphadenitis), venous disease (chronic venous insufficiency), immobility (dependency oedema)

Fig 27- Pic from slideshare net

Assessment for lymphoedema

- In assessment specific to lymphoedema onset and duration of the swelling with associated pain and fatigue should be documented.
- Stemmer sign is usually positive in patients with lymphoedema. The inability to pinch and raise the skin fold at the base of the second toe and middle finger is considered a positive Stemmer sign.
- Other skin findings observed in patients with lymphoedema are Peau d' orange appearance, hyperkeratosis, lymphorrhoea, lymphangiectasia and papillomatosis.

- A thorough psychosocial assessment is crucial in patients with lymphoedema. Coping with the treatment and adherence to treatment strategies will require a lot of resilience as the treatment of lymphoedema is usually lifelong. Exploring psychological issues and support structures available for the patients will enable them in choosing the appropriate treatment strategy for the patient and to prevent treatment failure.
- Limb volume measurement by circumferential limb measurement is vital in determining the severity of lymphoedema and the appropriate management plan. It should always be performed at the time of diagnosis. While performing limb volume measurement for unilateral swelling both affected and unaffected limbs should be measured. Their difference is expressed in millilitres (mL). More than 10% difference in the volume is considered as oedema is present. It is important to keep in mind that the limb volume of the dominant limb is 8 to 9% more than that of the non-dominant limb.

Stages of Lymphedema

Stage 0:

This stage may last for several months to years before the swelling becomes evident or more pronounced.

- Subclinical state
- Swelling is not evident but impaired lymphatic drainage is present

Stage 1:

- Early accumulation of fluid
- Pitting may be observed
- Accumulation resolves with limb elevation

Stage 2:

- Limb elevation alone rarely reduces the swelling
- Pitting manifests

Stage 3:

- Lymphatic elephantiasis
- Pitting is absent
- Skin changes (Hyperpigmentation and warts)
- Increased skin fold

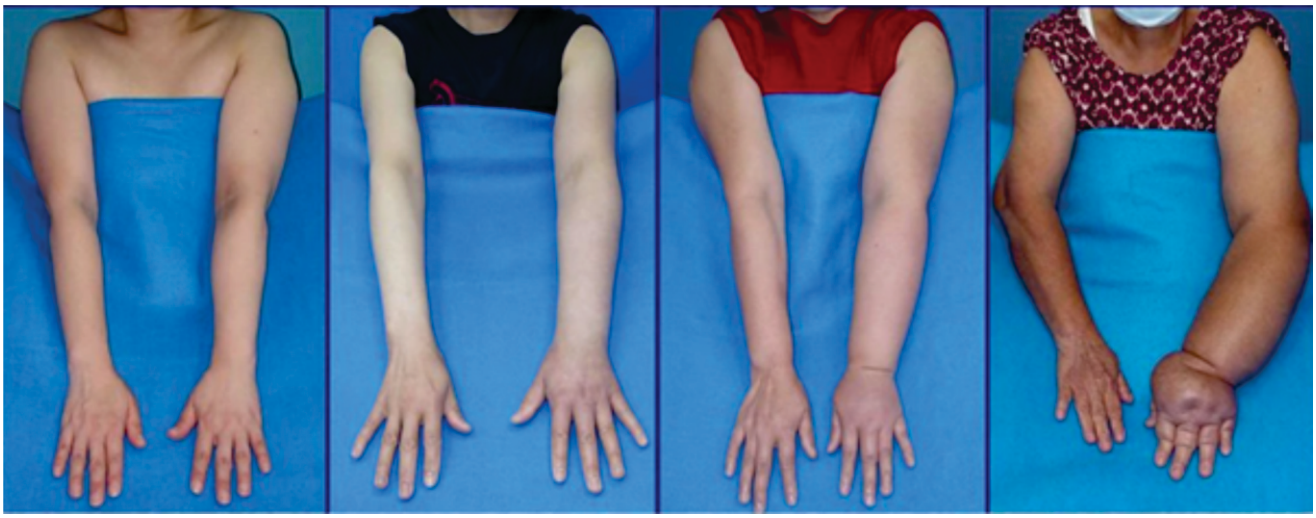


Fig.28- stages of lymphedema

Management

Unlike blood circulation, the lymphatic system has no central pump such as the heart to move fluid to the lymph glands. Instead, it uses the massaging effect of surrounding muscles to move the fluid and this is why exercise is important. Decongestive lymphatic therapy (DLT), massage and exercise are cornerstones of lymphedema management along with skin care. This stimulates lymph drainage more effectively. The combination of exercise and compression encourages the fluid to move out of the affected limb.

Skin care

- Keep the skin clean and supple.
- Wash skin with mild soap special attention to creases, between digits & joints
- Use oil or moisturizers (avoid perfumed creams)
- Pat dry with a soft clean towel
- Avoid tight clothing & jewellery, injection

Compression Bandage

- Compression can be given with proper bandaging or by using special hosiery.
- Before applying compression, measurement of both limbs should be recorded and repeated every six months. Bandaging helps in limiting fluid accumulation in the subcutaneous tissue. It also provides the muscles with a firm outer casting thereby stimulating lymph flow.
- Indication for hosiery application
  - ► Limb shape is not distorted.

- ► Mild oedema
- ► No deep creases
- ► Skin is tough enough to cope with hosiery
- ► No lymphorrhea

Massage

Specialised massages called Manual Lymphatic Drainage (MLD) are usually carried out by a specialist therapist. Simple Lymphatic Drainage (SLD) is a technique which the carer can do in-home care settings. It stimulates contraction of the skin lymphatics which are usually intact, thus improving superficial lymph drainage. This facilitates lymph flow from congested to non-congested areas.

Technique of massage

- Deep breathing before and after massage -10 times
- Do with compression bandage on
- Always clear the non-swollen side first
- Use dry hands while performing a massage
- Cream or powder should not be applied
- Each area is to be stroked 10 times

Contraindications

- Cellulitis/ discomfort and pain
- Patient refusal
- Deep vein thrombosis.

Bandaging

It helps in limiting fluid accumulation in the subcutaneous tissue. It also provides the muscles with a firm outer casting thereby stimulating lymph flow. It limits capillary filtration, increases interstitial pressure, improves lymph drainage through vessels and reduces inflammatory changes in the skin.

- Apply graduated pressure
- Reshape limb in a cylindrical manner with cotton & gamgee pad & crepe bandage.
- Low resting pressure increases during exercises.
- Hosiery is removed at bedtime.

Fig.29- stepwise lymphedema dressing

Exercise

An important role in fluid drainage is wearing compression bandage during exercise enhances lymph flow and protein reabsorption more efficiently. Exercise reduces soft tissue oedema and improves joint mobility which enhances the efficiency of the lymphatic pump.

Fig.30- lymphedema dressing

Psychological care:

Lymphoedema can have severe effects on the psychological well-being of the patient. The psychological issues in these patients can overtly manifest as anxiety, anger, sadness and depression. But in some groups, it manifests as inability to cope with the treatment, poor compliance and frustration. The palliative care team should never overlook psychological assessment and care for patients suffering from lymphoedema.

Lymphorrhea

- If any injury, clean with saline and apply a sterile pad.
- Apply compression bandage for 24 hrs

Cellulitis

- Discontinue massage & exercise and use of compression bandage.
- Give antibiotics

CHAPTER 5

OSTOMY & WOUND CARE

OSTOMY & WOUND CARE

Learning objectives:

At the end of this section, the candidate should be able to

1. Identify and manage different types of stoma
2. Educate the patient and family regarding stoma care.
3. Educate the patient and family regarding wound care.

STOMA CARE

The word stoma (Greek word meaning - mouth or mouth-like opening) is a surgically created artificial opening in the body. Stoma care is to improve the well-being and QoL possible. It is essential to involve the family in the plan of care. Management of stoma includes physical care as well as psychological and social care. The healthcare worker plays an important role in the guidance of optimum care, through skilled teaching, empathy, and communication. In planning the care of an individual with a stoma, it is necessary to understand the type of ostomy that was created, including the contents. Ostomy is an opening which is created in the body for the discharge of body wastes.

Types of ostomy:

Input: Tracheostomy, Gastrostomy, Feeding jejunostomy

Output: Colostomy, ileostomy, Urostomy

A colostomy is created proximal to the affected segment of the colon or rectum. It can be temporary or permanent, ascending, transverse, sigmoid, single barrel, double barrel, or loop. The portion of the colon used to create the stoma determines the location of the stoma and the consistency of the output. This may affect the nutritional and hydration status of the individual. Ascending colostomy is usually created on the right mid-quadrant of the abdomen and the output is semi-formed stool. The transverse colon stoma is created in the upper quadrant and the output is semi-formed to formed stool. The descending colon stoma is usually located in the lower left quadrant and the output is usually formed stools.

Fig.31 - colostomy bag

Care of colostomy

Pre-operative communication with the patient and family is important. Preparing the patient and the family to accept the colostomy is crucial. Site marking and what happens after the surgery need to be addressed properly. This usually helps the patient and family get adjusted to the stoma.

Fig.32- colostomy bag

Irrigation: Ideally, irrigation can be started after 3 weeks of surgery. However, if the patient is undergoing chemotherapy/radiation and if the patient's health condition is not good, irrigation should be started after 3 months of surgery. The maximum waiting period to start irrigation is 3 months. Do not irrigate if there is diarrhea. Use 1 to 1.5 litres of water for irrigation. To make it a habit, irrigation should be done daily at a fixed time for the first 21 days and continued throughout life. Disposable colostomy bags are expensive. Non-disposable bags are comparatively cheaper. A stoma care nurse can help the patient choose the bags.

Ileostomy- It is created to divert stool away from the large intestine, and the output is usually soft and unformed stool.

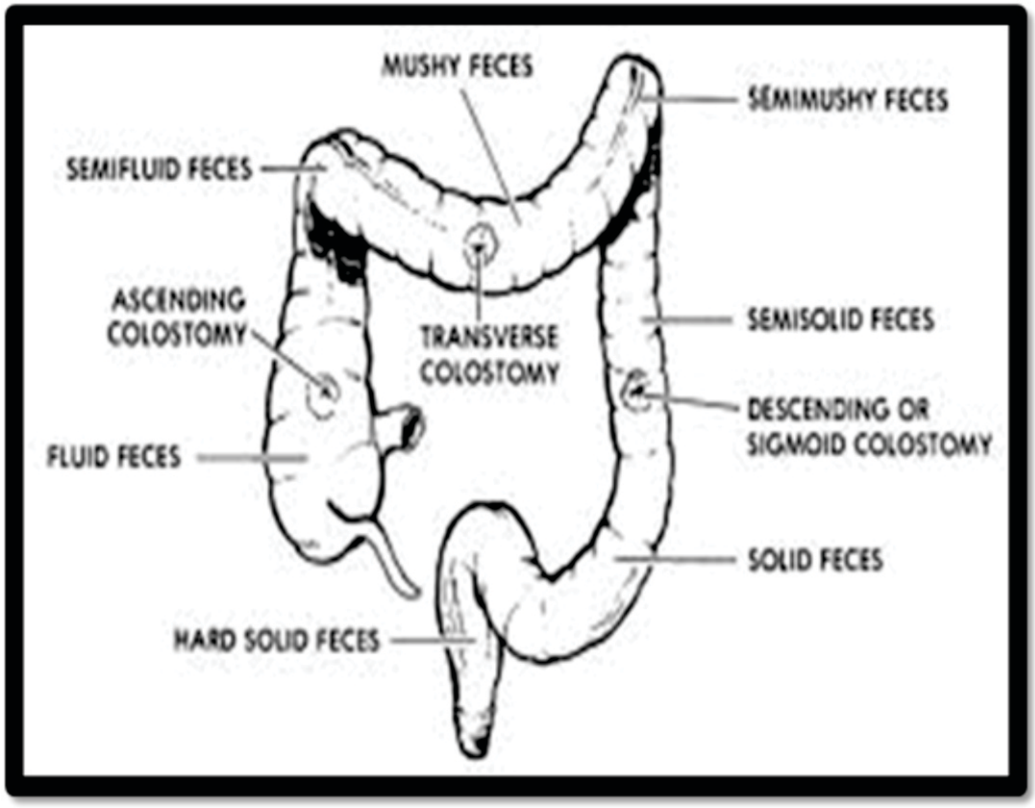


Fig.33- types of stoma

Assessment of stoma-

Characteristics:

a. **Stoma color**- shows the viability of the stoma. Normal color is deep pink to deep red; a necrosed stoma is dusky in appearance. An urgent surgical consultation is required if a necrosed stoma is found.

b. **Stoma bleeding**- stoma may bleed when rubbed because of the capillaries at the surface and can be managed by the application of pressure.

c. **Stoma edema**- edema in the early period is normal.

d. **Stoma herniation**- it occurs when the bowel moves through the muscle defect into the subcutaneous tissue. When the patient lies in the supine position, it usually reduces.

e. **Stoma prolapse**- occurs as a result of a weakened abdominal wall caused by abdominal distension and needs surgical intervention.

f. **Retraction of the stoma**- occurs due to tension on the bowel from the abdominal distension, and this needs surgical intervention.

g. **Stenosis of the stoma-** can occur at the skin level or at the level of the fascia, this requires surgical intervention.

h. **Peristomal skin problems**- skin complications commonly include mechanical breakdown (epidermal skin breakdown), chemical breakdown (prolonged contact with urine or faeces), rash (due to excessive moisture), and allergic reactions (caused by the barrier and tape).

Management-

1. **Care of the skin**: Clean the skin with soap and water. Keep it clean and dry with a soft cotton cloth. Use the correct size bag, and empty the bag when it is 3⁄4 full. Patients with sensitive skin should use a simple pouching system. Patients with severe blistering and hypersensitivity can use a temporary, non-adhesive pouching system. Avoid powder or cream on peristomal skin. Use antifungal powder in cases of fungal infection. To prevent a bad smell, a small piece of charcoal can be put in the colostomy bag.

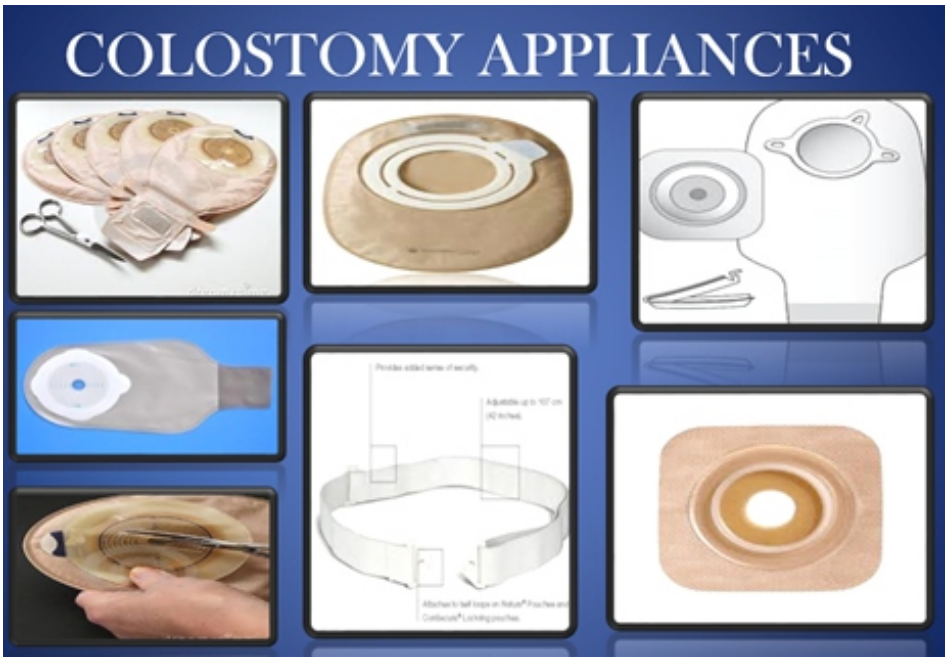


Fig. 34 - appliances required for changing colostomy bag

2. **Diet**: Gas formation can be reduced by limiting the intake of gas-producing foods. Peppermint may be effective for gas reduction. Reduce food items that give smell to effluent, e.g. cabbage, meat, garlic, onion, etc. Minimize the use of chilies and spices in food. Use the same type of cooking oil to prevent diarrhea. Colostomy patients should have a fibre rich diet and more fluid intake to prevent constipation.

3. **Games**: Avoid rough games to prevent stoma injury

4. **Travel**: protect the stoma with a bag or a book. Keep an extra colostomy bag while traveling.

5. **Sexual life**: Support, advice, encouragement, and counseling for patients and their partners should be done.

WOUND CARE

Fungating wounds are very distressing for patients. The term 'fungating' refers to a malignant process of both ulcerating and proliferative nature. Lesions that have a predominantly proliferative growth pattern may develop into a nodular 'fungus' or 'cauliflower' shaped lesion, whereas a lesion that is ulcerating will produce a wound with a crater-like appearance. These fungating wounds may develop during the last few months of life. They are caused by infiltration of the skin by a local tumour or metastatic spread from a primary tumour. Loss of vascularity is a major source of problems associated with these wounds. Because of the loss of tissue viability and consequent necrosis, anaerobic and aerobic bacteria proliferate in these conditions, which is probably the cause of the malodour and exudate that are commonly associated with these wounds.

Fig. 35 - fungating lesion

Aims of management

The ideal aim is complete healing through either local or systemic treatment, which may involve surgery, radiotherapy, hormonal manipulation, or chemotherapy. If such treatment is inappropriate or unsuccessful, as is often the case, then care is directed to minimize pain, infection, bleeding, odour, and psychological trauma. Treatment should be realistic and acceptable to the patient and carers. The primary aim is the promotion of comfort (as opposed to healing) and the enhancement of quality of life. Following assessment, choose a dressing regime to meet the needs of the patient. Be prepared to change and experiment since there are no 'rights or wrongs'. Vaseline gauze or a simple dressing material that can be sterilized in a 'pressure cooker' at home are affordable options.

There are numerous commercially available products for cleaning and dressing. The simplest products may be the best and most cost-effective. The criteria are comfort, acceptability, and availability.

1. Management of malodour

Wound malodour is probably the most distressing symptom for patients and is due to bacterial infection in devitalized tissue within the wound. This can also be devastating for the patient's family and caregivers as wound malodour may be constantly detectable and can trigger gagging and vomiting reflexes. The presence of a pervasive malodour can lead to embarrassment, disgust, depression, and social isolation and may have a detrimental effect on sexual expression, causing relationship problems.

a) **Debridement**: Malodour is usually due to the breakdown of proteins in dead tissue by anaerobic bacteria; therefore, debridement is important The main aim of management is to kill the anaerobic organisms that are responsible for odour formation and filter out any malodour. Debridement removes necrotic tissue and bacteria and is the primary treatment for malodourous fungating wounds.

b) **Antibiotic therapy**: Antibiotics destroy the bacteria responsible for malodour. The drug most commonly used is Metronidazole. This may be given systemically, but side effects such as nausea, neuropathy, and alcohol intolerance may affect patient acceptability. A poor blood supply to the wound may further reduce the effectiveness of systemic treatment. A topical preparation of Metronidazole powder has been used successfully. This powder is usually applied once daily for 5-7 days but may need to be repeated more often to keep malodour under control.

c) **Sugar paste and honey:** Recently, sugar paste and honey have come back into use mainly due to the emergence of many antibiotic-resistant strains of bacteria, and both have antibacterial and debriding properties. The high sugar content of these products produces a hyperosmotic wound environment that inhibits bacterial growth and assists in wound debridement. Honey also contains bactericidal hydrogen peroxide, which is slowly released as the honey is diluted in wound exudates, while specific types of honey may have plant-derived antibacterial properties.

d) **Activated charcoal dressings:** Can have an immediate effect on wound malodour. Activated charcoal acts by adsorbing the volatile odor-causing molecules, preventing their escape from the local wound area.

2. Management of exudates

Fungating wounds often produce excessive amounts of exudate, which can be difficult to manage. Increased permeability of blood vessels within the tumor and the secretion of vascular permeability factor by tumor cells are the most likely causes of high exudate levels. Exudate production may also be increased if infection is present. Large volumes of uncontrolled exudates may cause leakage from the dressing and staining of the patient's cloth, which cause significant psychosocial problems for patients and carers.

Effective management of wound exudate with a variety of dressings is likely to improve both patient confidence and comfort.

3. Pain

There are a number of mechanisms that can cause fungating wounds to be painful. The tumor, for example, may be pressing on nerves and blood vessels, or there may be exposure of the dermis. Patients often describe their pain as a superficial stinging sensation. Painful procedures such as the use of inappropriate cleansing techniques or the removal of a dressing that adheres to the wound bed may also have an impact on the pain experienced by the patient.

Management: Wound pain should be assessed using a numerical or categorical scale. Analgesic drugs should be prescribed using the WHO guidelines for the control of cancer pain and in accordance with local prescribing guidelines. It may also be useful to give the patient a pre-medication before dressing change or a booster dose of their usual opioid. Give an extra dose of morphine half an hour before dressing. If there is superficial pain/burning/stinging - local application of lignocaine jelly or opioid soaks 10 minutes before dressing. To minimize pain during dressing, previous dressing materials should be soaked and removed. Another method is the use of non-adherent dressings. Maintaining the wound in a moist environment will not only reduce dressing adherence but also protect exposed nerve endings. Pain can be kept in check by using a dressing material that requires fewer frequent changes. Irrigation of the wound with warm saline rather than cleaning with a gauze swab will, in some cases, reduce pain. Complementary therapies can play an important role in pain management; therapies such as relaxation and distraction may help anxious and stressed patients who have a heightened response to pain. Chemotherapy, radiotherapy, hormone therapy, or a combination of these anti-cancer therapies may help shrink the wound by destroying malignant cells, reducing pressure on nerves and other structures, and decreasing the area of exposed tissue. This may have a significant effect on the level of pain experienced by the patient.

4. Bleeding

Wound bleeding is common in fungating wounds. This occurs because malignant cells erode blood vessels, and may be compounded by decreased platelet count or function. Profuse, spontaneous bleeding can be distressing for both patients and their carers, while damage to fragile tissues during dressing changes may exacerbate bleeding.

Management: Preventive measures are important to reduce the risk of bleeding. Using non-adherent dressings that maintain a moist environment and cleansing by irrigation rather than swabbing will reduce the risk of trauma and subsequent bleeding. Gentle removal of the dressing after soaking with saline or water is a good practice. Oral antifibrinolytics such as tranexamic acid may also help. Ethamsylate 250 -500mg

(PO/IV) TDS or QDS is another option. Sucralfate powder may be applied to wounds with a small amount of bleeding. Topical adrenaline or tranexamic acid can also be applied, but they should only be used under medical supervision, and caution is advised as adrenaline may cause ischemic necrosis due to local vasoconstriction. Excessive, uncontrolled bleeding may require surgical consultation for cautery or ligation.

5. Maggots

If maggots are present, apply plain turpentine to the wound with a syringe. Wait for 10 minutes and remove maggots with the help of forceps. Repeat the dressing with turpentine for about 3 to 4 days to remove all maggots.

Fig.36- patients with maggots and dressing

6. Infection:

This is usually chronic and localized. A thorough bath before dressing reduces malodour, infection and washes off exudates. The wound should be cleaned with normal saline or preferably under running water. If the surrounding areas are inflamed, especially if there is spreading inflammation, antibiotics should be used. The commonest organisms grown in fungating, cancerous wounds and in pressure sores include coliforms, anaerobes, Staphylococcus aureus, and group G beta-hemolytic streptococcus. Staphylococcus aureus is probably the commonest pathogen.

Antibiotics such as ciprofloxacin, trimethoprim, or erythromycin should cover most common infections. Metronidazole may be needed for anaerobic infections. Topical metronidazole gel/solution or even powdered metronidazole tablets mixed with lignocaine gel is particularly useful for eradicating the associated noxious smell. Remember that agents such as cephalosporins which cover a wider spectrum of bacteria increase the risk of Clostridium difficile diarrhea.

7. Patient's comfort

By trial and error, a combination of dressings and top packing that will be most comfortable to the patient should be used.

8. Cosmetics

The best cosmetic effect possible should be achieved in order to boost the patient's confidence.

9. Psychological effects

Attention to all details of the wound, ensuring leakproof/odor-proof dressing, giving necessary information about wound care, and proper explanation to decrease the sense of isolation and to enhance the confidence and morale of the patients.

Simple measures for wound dressing

1. Instead of commercially available gauze, used cotton sarees or any soft cloth can be made into gauze pieces and gamgee pads. Colored pads have the advantage of masking the color of blood or exudates from wounds.
2. Preparation of Vaseline gauze: Gauze can be cut into desired sizes, smeared with vaseline, piled up, and autoclaved [or using a pressure cooker]. The vaseline melts and coats the pieces uniformly. This works out much cheaper than commercially available vaseline gauze/tulle.
3. Papaya as dressing material: Raw papaya can be cut into thin slices and placed directly on wounds when the surface is even before bandaging. If the wound surface is uneven, the central part of the raw papaya can be made into a pulp and applied as a paste on the wound. This is found to be very useful in promoting the healing of bed sores along with other measures.
4. Controlling malodour from wounds: Ayurvedic preparation: 2-3 drops of ginger grass oil, having a pleasant and soothing odour, is added to half a liter of water and smeared around the wound (not directly on the wound) to mask the foul odour.
5. To control the malodour for bed-ridden patients with Recto-vaginal fistula following measures can be tried. Place several sheets of newspaper under the bed sheet below the waist of the patient. The carbon in the newspaper is said to adsorb the malodour.

CHAPTER 6

CARE OF ELDERLY: DEMENTIA AND MANAGEMENT

CARE OF ELDERLY: DEMENTIA AND MANAGEMENT

"We ought to give those who are to leave life
the same care and attention
that we give to those who enter life, the newborns."

-Jan Stjernsward

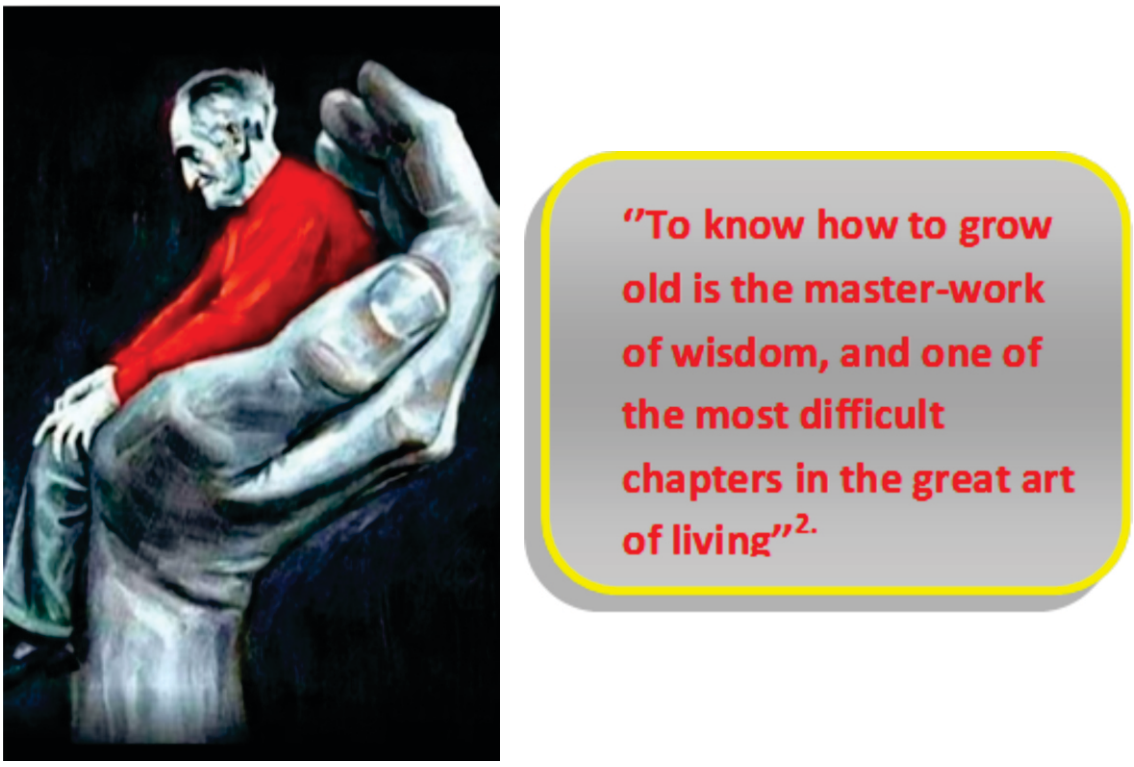


Fig. 37 Slide share net

Introduction:

Despite the fact that death is a universally acknowledged reality, the skill of providing scientifically sound care to patients who are nearing the end of their lives is grossly undervalued in educational programs for medical professionals. In most cases, this results in the failure of care providers when confronted with patients who are nearing the end of their lives.

If the team providing care has received the appropriate training in end-of-life care, it is possible to provide subjects who are about to leave their mortal selves and their family members with high-quality care during their final moments on earth. This kind of all-encompassing and holistic care will not only be of great assistance to the people who are receiving it, but it will also give the people who are providing it a feeling of personal accomplishment.

Important Definitions:

Terminal care refers to the management of patients during their last few days, weeks, or months of life, from a point at which it becomes clear that the patient is in a progressive state of decline.

A good death is one that "is free from avoidable distress and suffering for patients, families, and caregivers; in general accord with patients' and families' wishes; and reasonably consistent with clinical, cultural, and ethical standards."

The changes that occur before death

Although each person experiences death in their own unique way, there are often telltale signs and symptoms that can help determine if someone is nearing the end of their life. Keep in mind that the events that will be described here are occurring in a person whose illness is already so severe that life is threatened and that any of these signs can be attributed to something other than dying.

The main changes are:

	Change	Explanation	Management
1.	Decreased intake	End-of-life (EOL) nutritional needs drop significantly. This leads to decreased appetite and decreased thirst. It is crucial to realize that this is natural and will not disturb the patient. However, seeing the patient not eat or drink may upset family caregivers.	Reassuring them and encouraging them to sip water and apply moistened cotton swabs to their lips can help them feel better, whereas forcing them to eat may make them feel worse. patient distress with little to no benefit.
2.	Increasing weakness	At EOL, the subject experiences a decrease in strength. There is a gradual decrease in overall activity, and by the end, even basic conversation and taking care of oneself can be difficult.	At this point, the objective is to provide care that is geared toward making the individual more comfortable while avoiding routines that upset them.

3.	Changes in cognitive processes- (drowsiness, decreased speech, withdrawal, and restlessness	The subject becomes increasingly fatigued, drowsy, and difficult to awaken as EOL progresses. The time spent sleeping gradually increases.	To help calm them down, medications such as ha loperidol or benzodiazepines may be administered. Family caregivers should be advised to talk to the patient when the patient is fully alert and talk calmly and gently.
4.	Changes in respiration	The respiration becomes shallow. In some patients, the resp iratory rate may increase, but usually, the respiration becomes shallow and spaced out. Jaw breathing can be seen in some patients.	Carers should be reassured that this is a typical process of dying, and it is not distressing to the patient.
5.	Death Rattle	It occurs due to the accumulation of salivary secretion and mucus at the throat as swallowing and coughing reflex disappear during the end of life phase. The gurgling sound produced by the oscillating fluid with each respiration can be distressing to the carers but not to the patient.	It can be managed effectively by turning the patient to the sides and draining the secretions. Anticholinergics like glycopyrrolate can be given sublingually or subcutaneously to reduce secretions.
6.	Change in Temperatur e	During the terminal stage, the body temperature drops. This may be due to reasons like decreasing metabolism and slowing down circulation. The feet and hands may appear pale, cold and clammy	An extra blanket if the person indicates that he/she is feeling cold. At this point, the room should be well ventilated and less crowded.
7.	Changes in excretion:	Urinary and fecal incontinence can be observed in few patients during the end of life phase. The urinary output decreases drastically; the urine may app ear dark and brown. There may be oedema due to fluid retention.	It is important to keep patients' comfort as a priority at this point. Maintaining good perineal hygiene and prevention of pressure sores is crucial to maintain comfort.

Fig. 38 - elderly care

Management

Important points in taking care of a person approaching death:

1. Allow the person and family to voice their concerns.
2. Clarify their expectations and explain the prognosis.
3. Discuss with the family about the place where they want to continue terminal care in the hospital.
4. Check if appropriate medicines have been ordered for troublesome symptoms, e.g. pain, breathlessness, dyspnoea according to Unitary policies and relevant to the care setting (home/hospital.)
5. Check if inappropriate interventions need to be tapered or discontinued.
6. Encourage the family to support the primary caregiver and allow him/ her respite.
7. Check that nursing care for the patient with attention to oral hygiene, skin, bowel and bladder care is continuing.
8. Remain sensitive to the changing physical and emotional needs of the patient and family.
9. Death Certification: Any doctor preferably from the treating unit, can certify death. He/she should Diagnose and declare the death. Inform the relatives. Certify death & fill the necessary forms. Seek permission & arrange for autopsy, if necessary. Assist the family in decisions regarding transportation, embalming, mortuary care, etc.
10. Last office/death care Purpose: To maintain normal body alignment before rigor mortis

sets in. To prepare the body for transport to the mortuary/residence. To reduce mental distress of family

Care after Death

Culturally appropriate and sensitive after-death care should be provided to all dying patients irrespective of the situation or the setting

- Information about the death is communicated early and sensitively to the family
- The primary team is informed
- The body of the patient is laid out in the culturally appropriate manner
- Provide presence and support to the family
- Privacy and space to the family
- Timely and correct verification and certification of death
- Timely and dignified transfer of the deceased from the hospital

In the end, consider that there may be no “perfect” death so just do the best you can. The deep pain of losing may be softened a little by knowing that, when you were needed, you did what you could.

Case Scenario:

At 80, Ms. M had been in a nursing home for two years following her stroke. Eventually, her health declined, and she was no longer able to communicate her wishes. Ms. M's physician, Dr. T, told her family she was dying. She said that medical tests, physical therapy, and treatments were no longer needed and should be stopped because they might be causing Ms. M discomfort. Also, so they would not interrupt her rest, Dr. T said the health care team would stop regularly checking vital signs, such as pulse and blood pressure. Then, Ms. M developed pneumonia. Her family asked about moving her to the hospital. Dr. T, explained that Ms. M could get the same care in the nursing home and that a move could disturb and confuse her. The family agreed, and Ms. M died two days later in familiar surroundings with her loved one's present.

Reflection

1. Discuss about prevailing concept of death and dying in the one's family and society at large?
2. Reflect on your own feelings regarding death and dying and on what you feel is important with respect to death with dignity?

CHAPTER 7

END–OF–LIFE CARE: GRIEF AND BEREAVEMENT

END–OF–LIFE CARE: GRIEF AND BEREAVEMENT

Palliative Care in Advanced Dementia

Introduction

There is an increase in the overall burden of dementia across the globe as a result of the ever-aging population as well as the rising prevalence of non-communicable diseases. Advanced dementia typically refers to a state of profound physical and cognitive disability that is the result of a variety of neurodegenerative diseases, the most common of which is Alzheimer's disease (AD). The clinical stages of dementia are well described, but the course of progression is variable.

A wide range of physical and psychological requirements complicate end-of-life care for patients with advanced dementia and their caregivers. The goal of palliative care, an interdisciplinary medical field focused on preventing and relieving suffering and bolstering the best possible quality of life for patients and their families dealing with advanced illness, is to improve the experience of living with a terminal illness.

The use of effective palliative care for patients with advanced dementia can improve patients' symptoms, lessen the burden on caregivers, and help ensure that treatment decisions are well-informed and weighed in the context of patient, family, and caregiver goals and needs.

Special prerequisites of palliative care in Advanced Dementia

Originally, palliative care emerged for cancer patients; later, conditions other than cancer were acknowledged as being in need of palliative care. Independent of specific diagnosis, palliative care should be provided for people with life-threatening diseases and their families “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,” to maintain or improve quality of life. Parallel to the development of palliative care, dementia care developed separately, both based on the same values for enhancing the care of people with dementia and improving quality of life.

Prognosis And Clinical Decision-Making

Clinical course: advanced dementia, according to ICD-10, is a state of profound physical and cognitive disability that is the result of neurodegenerative conditions, the commonest being Alzheimer's disease and dementia. Various scales are there to describe the clinical progression, namely:

1. The Global Deterioration Scale (GDS) describes the clinical progression of dementia.
2. Functional Assessment Staging (FAST) scale to identify patients with advanced dementia.

However, there is no proper tool for the prognostication of advanced dementia.

The decision for care in advanced dementia.

These decisions are mostly taken by surrogates and are often emotional and value-laden, based on limited outcome data, and influenced by many external factors. Faced with these challenges, health professionals are required to prepare to provide informative and compassionate decision support. Important considerations to keep in mind are the ethical framework reflecting the balance between benefits and burdens and respect for the autonomy or wishes of the patients whose care we are involved in. Other objectives of care include comfort care, which frequently comes before aggressive treatment care.

Advanced care planning for dementia patients:

1. start early (before the patient loses the capacity to make decisions),
2. decide goals of care (which should be based on the patient's preferences),
3. keep things in writing,
4. talk about the course of the illness,
5. finalize specific medical needs in advanced stages.

Discussion about future hospitalizations is a must. Providers should routinely counsel proxies and ascertain their preferences for hospitalizing their loved one with advanced dementia prior to the onset of an acute illness. The desire to avoid hospitalization should be formalized as a written advance directive or do-not-hospitalize order.

Hospice And Palliative Care

Hospice provides medical care and support to a patient with a limited prognosis from a serious medical illness and their family or loved ones, with a focus on quality of life rather than life prolongation or cure. In view of difficult prognostication in advanced dementia, it diverts the focus from the patients and their family's preferences for care rather than life expectancy.

Important concerns in care of the patients with advanced dementia are:

Concerns	Problem statement and cause	Management
Feeding And Nutrition	A telltale sign of advanced dementia is the onset and progression of eating difficulties. It can be due to multiple factors oral dysphagia (manifest by pocketing food in the cheeks or spitting food), pharyngeal	The first step should be the identification of the cause if possible. Followed by conservative measures to improve oral intake may be tried, including altering the texture of food; offering finger foods, smaller

	dysphagia (which may result in delayed swallowing and aspiration, frequently leading to aspiration pneumonia), and an inability to perform the task of eating. Depression, too, can present with disinterest or refusal to feed.	portions, or favorite foods; and using nutritional supplements. Many Patients with dementia ultimately require assisted or hand feeding when they can no longer feed themselves.
Infections And Fever	It accounts for approximately one-quarter of all treatment decisions and is often a terminal event. The respiratory and urinary tracts account for approximately one-half and one-third of all suspected infections, respectively. The cause can be multifactorial.	Cause identification, followed by judicious use of antibiotics and importantly steps should be taken to prevent infection.
Pain and symptom management (especially agitation)	Pain measurement is challenging in patients with profound cognitive impairment. Multifactorial. Pain Assessment in Advanced Dementia (PAINAD) instrument, a specific tool to assess pain and discomfort	Cause identification with standard management approaches to alleviate physical discomfort (eg, dyspnea, pain) should be pursued
Urinary incontinence	May or may not be due to dementia. Multifactorial.	Nonpharmacologic approaches are preferred in persons with dementia. Pharmacotherapies, particularly anticholinergic medications, should be used with caution
Discontinuing chronic medications		Discontinuing unnecessary medications can improve quality of life and reduce adverse effects
End of Life Care		Standard management guidance is given in a separate chapter

As a patient's dementia progresses through the different stages, consider the following guidelines:

1. Educate the caregiver on the nature of dementia as a progressive and ultimately fatal disease.
2. Initiate advance care planning conversations early, and revisit them periodically.
3. Ensure that the patient has an advance directive with an identified surrogate decision maker.
4. Offer palliative care in addition to other medical care early, or at least by stage 5 or 6.
5. Manage all symptoms (neuropsychiatric, pain, incontinence, and insomnia) appropriately.
6. Recommend caregiver assistance and support early to avoid caregiver burnout and depression.

Case Scenario:

An 87-year-old patient was brought to my office by her daughter. She has been my patient for 22 years and was diagnosed with Alzheimer disease (AD) eight years ago. Most recent evaluation indicates that she is in stage 6 of the disease; she requires assistance with activities of daily living, has increasing periods of disorientation and aggressiveness, and needs reminding of her name and those of her children. She is currently receiving treatment for advanced heart disease, chronic obstructive pulmonary disease, and multiple myeloma. Her daughter asks about her mother's prognosis and the appropriateness of palliative care.

Reflection:

How should determining the prognosis and applicability of palliative care for her mother be done? What might be the core management challenges in providing care for her?

CHAPTER 8

EMERGENCIES IN PALLIATIVE CARE

EMERGENCIES IN PALLIATIVE CARE

An emergency is defined as a serious, unexpected, and frequently dangerous situation demanding immediate action. However, management in palliative care should be considered more in terms of the patient's clinical background than of the event itself. For example, investigations may not be appropriate if the patient is not suitable for the definitive treatment that would follow. Decisions should consider the natural history, symptoms, and prognosis of the disease, the patient's performance status, the patient's and family's wishes, the burden, and the likely outcome of treatment. By understanding the pathophysiology and natural history of the clinical condition, most palliative care emergencies can be anticipated and treated pre-emptively with elective interventions. When intervention is inappropriate, early discussion with staff, patients, and families about what could lie ahead can avoid the stress of unexpected developments and the need for urgent clinical decisions. Such discussions should be approached sensitively in order to minimize anxiety about the upcoming event.

Palliative care teams treat patients with diagnoses that significantly impact their quality and quantity of life. These teams are often tasked with identifying when a patient might be dying from complications of their serious illness, identifying goals of care based on this information, and helping to provide goal-concordant care for patients and their loved ones.

This module cannot cover all potential emergencies at the end of life but provides a partial list to emphasize the importance of preparation for the most likely emergencies a patient and family may encounter. Although many people affected by hypercalcemia, status epilepticus (SE), hemorrhage, superior vena cava syndrome (SVCS), spinal cord compression (SCC), delirium and pathological fractures carry a primary oncologic diagnosis, these can also be complications of various other diagnoses.

1) HYPERCALCEMIA OF MALIGNANCY

Evaluation

Hypercalcemia of malignancy (HCM) is a complication commonly seen in patients with advanced cancer. Almost 30% of patients with cancer experience issues with hypercalcemia. Hypercalcemia caused by an underlying malignancy is most often humorously mediated, with parathyroid hormone-related peptides causing up to 80% of cases. Most commonly, it is associated with breast cancer, multiple myeloma, lymphoma, and lung cancer. Less commonly, osteolysis from bony metastases can cause hypercalcemia. HCM often presents as a syndrome that can cause stones, bones, abdominal moans, and psychiatric groans. There is a direct association between the rate of development of elevated calcium levels and symptom severity.

Symptoms in patients at the end of life can be nonspecific, making it challenging to make a diagnosis in this population. Generally, in patients of mild (10.5–11.9 mg/dL) to

moderate (12.0–13.9 mg/dL) hypercalcemia, they present with mild symptoms including constipation, nausea and vomiting, anorexia, polyuria, and thirst. Severe hypercalcemia (>14.0 mg/dL) causes more severe symptoms, including confusion, coma, neurologic symptoms, and sometimes lethal cardiac arrhythmias. Since this population may also have low albumin from malnutrition, it is important to adjust the calcium level because patients with hypoalbuminemia can have elevated serum total calcium but normal ionized calcium, which is more physiologically relevant. Some patients with severe HCM can develop posterior reversible leukoencephalopathy syndrome, characterized by headaches, seizures, and subcortical edema noted in imaging studies. It is well known that patients with HCM generally have a poor overall prognosis with a median survival of 30 days, regardless of treatments used.

Management

Treatment options are often based on the severity of symptoms and the degree of hypercalcemia.

In patients with mild symptomatic hypercalcemia (usually, serum-corrected calcium <12 mg/dL), reducing offending agents and close monitoring may suffice.

For more symptomatic patients or those with serum-corrected calcium of greater than 12 mg/dL, core treatments include intravenous (IV) hydration, calcitonin, bisphosphonate, steroids, hemodialysis, and possibly denosumab. Patients with advanced untreatable cancer, i.e., at the end of life, should be managed symptomatically. In situations where a patient has severely elevated calcium and has become comatose, the focus should be more on reassurance to family members along with continuous monitoring.

The most urgent step is rehydration with 0.9% sodium chloride. Subcutaneous calcitonin (4 IU/kg every 12 hours) can rapidly lower calcium levels within 6 hours. However, patients develop tachyphylaxis, and the efficacy is significantly reduced after 48 hours. For patients without renal impairment, IV bisphosphonates (pamidronate and zoledronic acid) can reduce hypercalcemia in about 2 to 4 days, and the effect lasts for a few weeks. Denosumab can be considered for patients who are refractory to bisphosphonates or have significant renal impairment.

Adjuvant medications should be selected based on a patient's constellation of symptoms. Patients with nausea and vomiting in addition to restlessness may benefit from regular low doses of antipsychotics such as haloperidol, benzodiazepines such as lorazepam, or some combination of the two agents.

Dexamethasone may also be helpful with nausea in some patients. Pain should be treated with available opioid and non-opioid medications. Medications that may worsen hypercalcemia, including thiazide diuretics, antacids, lithium, calcium-containing elements, vitamin D, and even total parenteral nutrition, must be avoided. The time to

relapse varies, with most patients experiencing only a single episode. Patients relapsing after 3-4 weeks can be considered for regular monthly infusions of bisphosphonate. Hypercalcemia that returns within 3 weeks and 'resistant hypercalcemia' (i.e., hypercalcemia that does not respond to treatment) are considered poor prognostic indicators.

2) STATUS EPILEPTICUS

Evaluation

Status Epilepticus (SE, incidence in general population of 41 cases in 100,000 people per year) is broadly defined as a continuous seizure lasting longer than 5 minutes without full neurologic recovery between seizures. The first time point (5 minutes) is the time at which an ongoing tonic-clonic seizure should be considered an “abnormally prolonged seizure”. The second time point indicates the point at which negative long-term consequences occur (alteration of neuronal networks, neuronal injury, and neuronal death) depending on the seizure type, usually regarded as 30 minutes for tonic-clonic seizures.

Theoretically, any type of seizure could evolve into SE. Although generalized tonic-clonic seizures are easy to recognize, other subtle forms can be quite difficult to identify. SE is commonly associated with primary or cerebral brain metastases but can also occur because of intracranial hemorrhage, ischemia, metabolic derangements due to organ failure (liver, kidney, lung), neurodevelopmental and neurodegenerative diseases, medication, and/or drug withdrawal. SE carries a mortality rate of up to 33% for the general population and can be a terminal event for those at the end of life and/or in hospice. The 1-year mortality rate for treated refractory SE in the elderly population can be as high as 80%. The most influential factor in outcome after SE is the underlying cause of disease, with old age, frailty, poor functional status, metastatic cancer, and multiple co-morbidities being other determining factors.

Classification

Further classification of convulsive seizures can help define which treatment options may be most effective. Premonitory, established, refractory, and super-refractory SE are terms that can be used based on the length of a seizure. Premonitory SE lasts for 5 to 10 minutes. Established SE generally lasts from 10 to 30 minutes. Refractory seizures are those that continue despite treatment, lasting between 30 and 60 minutes. Super-refractory seizures are those that last longer than 24 hours despite maximum medical therapy.

Non-Convulsive SE is usually challenging to diagnose in the end-of-life population, particularly when the patient is outside of a hospital setting. The only sign that may be clinically present in these patients is altered mentation.

Management

Although convulsive seizures are startling to observers, most often these events are self-limiting. Decisions to treat seizures at the end of life should be made keeping in mind the patient's wishes. It is reasonable to monitor patients and provide supportive measures (stabilize and monitor vitals, assess oxygen saturation and blood sugar) during seizures for patients known to have relatively short, recurrent seizures and even for patients experiencing their first seizure near the end of life.

Look for and exclude other causes of loss of consciousness or abnormal limb/ facial movement (e.g., fainting episode, postural hypotension, arrhythmia, hypoglycemia, extrapyramidal side effects from dopamine antagonists, alcohol). A previous history of epilepsy, secondary seizures, or known cerebral disease should be elicited. If the patient is a known epileptic and has been on anticonvulsants, compliance with anti-epileptics should be confirmed. Sometimes investigations like blood tests for electrolytes, blood sugars, and brain imaging (CT Scan/MRI Scan), might be needed.

Treating convulsive status epilepticus

General measures

Institute regular monitoring >>> Secure airway and resuscitate >>> Administer oxygen >>> Assess cardiorespiratory function >>> Establish intravenous access >>> Emergency anti-epileptic drug therapy >>> Emergency investigations.

Administer glucose (50 ml of 50% solution) and/or thiamine (250 mg) intravenously if there is history of alcohol abuse or impaired nutrition. Diazepam 10 to 20 mg can be given rectally, repeated once 15 minutes later if the seizure continues.

Management of early status

Lorazepam (intravenous) 0.1 mg/kg (usually a 4-mg bolus, repeated once after 10-20 minutes). Give the usual AED medication if the patient is already on treatment.

Established status

Phenytoin infusion at a dose of 15–20 mg/kg at a rate of 50 mg/minute and/or Phenobarbital bolus of 10–15 mg/kg at a rate of 100 mg/minute to be given.

Refractory status

General anesthesia, with one of the following: propofol (1–2 mg/kg bolus, then 2–10mg/kg/hour) titrated to effect; midazolam (0.1–0.2 mg/kg bolus, then 0.05–0.5 mg/kg/hour) titrated to effect; or thiopental sodium (3–5 mg/kg bolus, then 3–5 mg/kg/hour) titrated to effect. After 2–3 days, the infusion rate needs to be reduced as fat stores are saturated.

3) HEMORRHAGE

Evaluation

Massive hemorrhage in trauma, postoperative scenarios, or patients with cancer, although relatively uncommon, can be particularly distressing to patients and even more to their loved ones. Most often occurring in head and neck cancers, hemorrhage can also occur in people who suffer from hematologic malignancies, gastrointestinal tumors, and virtually any tumor that can cause a fungating mass. Significant bleeding may occur in up to 14% of patients with advanced cancer; terminal hemorrhage, or major bleeding from an artery (carotid artery, femoral artery, and pulmonary arteries) that can quickly result in death. There are no specific prognosticators to help inform the prognosis for patients with cancer at risk for bleeding at the end of life. Carotid blowout syndrome, a dreaded complication of head and neck cancers, has been reported to have a mortality rate of around 50%. Knowledge of risk factors that increase the chance of bleeding from the cancer site can help in goals-of-care discussions with at-risk patients and their families.

FIGURE 39- BLEEDING WOUND

FIGURE 40

FIGURE 41

Figure 1 and 2 shows hemorrage and figure 3 shows compression bandage after primary management

Management

For patients at the end of life, the management focuses on patients who have exhausted invasive interventions including surgery, radiotherapy, and stenting, and are on palliative treatment. Patients should be informed about the potential threat of bleeding while also acknowledging that such events can occur. Particular attention should be given to educating patients that major bleeding is not a painful occurrence, death usually happens quickly in these scenarios, and any medications used will not expedite the dying process. Discontinuing anticoagulants and continuing anti-hypertensives (even in normotensive or hypotensive readings) may help to decrease the risk of a massive hemorrhage.

Patients with high-risk factors should be discussed among the interdisciplinary team, including oncologists, surgeons, nursing staff, and any caregivers or hospice team involved, to ensure a unified approach to patient care. General supportive measures should be in place if a patient develops bleeding. Someone should always be with patients who have a high likelihood of bleeding, and assurance should be given to patients who develop bleeding. Patients should rest on a bed with dark linens, and dark towels should be available to apply pressure in the event of external bleeding. This measure will help to camouflage any major bleeding, making the event less distressing for those providing care. Suction should be available to help contain large volumes of blood. Specifically, for patients with centrally located lung cancers that develop massive hemoptysis, care should be taken to roll the patient into a lateral position with the affected side down to help control bleeding. Oxygen should be available if the patient is expected to have dyspnea. Last, the availability and use of emergency or crisis medication are suggested. Most often, these are in the form of a sedative, although the drug and dose vary by source. Midazolam is often cited as the first-line medication in a

dose of 5 to 10 mg given once IV or intramuscularly, with additional doses available every 10 minutes as needed after the first. This sequence of events has been cited as the ABCs of terminal hemorrhage, referring to Assurance, Being there, Comfort, and Calm.

There are several options for patients with a good performance status if active intervention is deemed appropriate. These depend on the type of cancer and the location of bleeding points. Decisions regarding fluid resuscitation and blood replacement should be made early. If the hemorrhage is not immediately fatal, such as with hematemesis or bleeding from the rectum, vagina, or superficially ulcerated wound, the aim of treatment is local control if possible. Palliative radiotherapy is useful for certain bleeding tumors. If radiotherapy is not appropriate, coagulation should be enhanced with oral tranexamic acid. The risks of encouraging hyper-coagulation need to be considered carefully in patients with a history of cerebrovascular disease or ischemic heart disease. Gastrointestinal bleeding from stomach or bowel tumors may require endoscopy, and local measures (e.g., endoscopic injection of adrenaline (epinephrine)) can be helpful. Some tumors, for example, gynecological cancers, can be managed by embolization under interventional radiology.

4) SUPERIOR VENA CAVA SYNDROME

Obstruction of flow through the superior vena cava from any source can lead to superior vena cava syndrome (SVCS). Malignancy has become the most common cause of SVCS, causing approximately 85% of all cases. Lung cancers and lymphomas (especially in children) are the most common causes, although any cancer that could metastasize to the pericaval area could cause SVCS. An increasing number of SVCS cases are thrombosis-related, owing to the number of IV devices used for patient care (central venous catheters, dialysis catheters, port catheters, etc.).

Patients with SVCS commonly present with facial edema and swelling of the upper chest and arms, with a characteristic bluish/red discoloration in these areas, largely related to mechanical venous congestion of the SVC. As the condition worsens, patients may also experience shortness of breath, coughing, chest pain, and hoarseness of voice possibly from laryngeal edema. SVCS can sometimes take weeks or months to be better appreciated as it is usually slow developing. As a result of this gradual onset, bodies are physiologically better able to compensate as a result of the development of collateral circulation. SVCS develops rapidly due to thrombotic complications over the span of days, there is a rapid onset of symptoms (dyspnea) as collateral vessels have not had time to form. The diagnosis is usually clinical, although a chest X-ray and CT scan should be done to determine the extent of the disease.

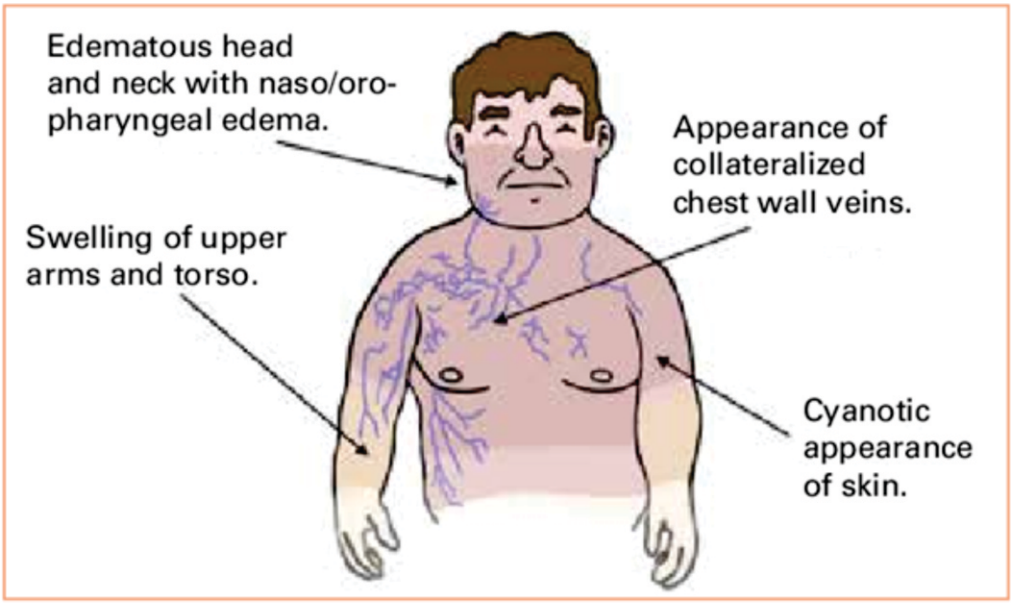


Fig.42- presentation in superior vena cava syndrome

Management

Rapidly developing symptoms attributable to SVCS without a known underlying etiology require advanced life support. An immediate workup is warranted. Often, intubation and hemodynamic stabilization are required with supportive treatment. Collaboration with intensivists and oncologists is important for providing optimum care.

Patients should initially be given dexamethasone (8 mg twice daily) to shrink the extrinsic cause of the SVCO. If thrombus is a factor, anticoagulation with low-molecular-weight heparin (LMWH) should be given. Immediate symptomatic relief can be achieved by inserting a stent into the SVC under radiological control. This technique is becoming more widely available in general hospitals and is the preferred approach in palliative care patients because of the immediate beneficial effect. Thrombolysis can be considered when SVCO is associated with extensive thrombosis but should be used with caution in patients at risk of bleeding. Thrombolytics are best given directly into the SVC via a cannula. Radiotherapy, previously the mainstay of treatment, can be considered if a tumor is causing compression, but its effect is delayed.

5) SPINAL CORD COMPRESSION

Malignant Spinal Cord compression (SCC) is a dreaded complication that occurs in approximately 5% of patients with cancer, increasing to about 10% of those with known spinal metastases. Primary sites for cancers in adults include lung cancer, breast cancer, prostate cancer, lymphoma, and myeloma, whereas, in children, diseases like sarcoma, neuroblastoma, germ cell lymphoma, and Hodgkin's lymphoma are more

common. Symptoms of back pain in cancer patients should arouse suspicion of an early differential diagnosis of spinal cord compression because the signs of lower extremity weakness and bowel and bladder dysfunction are often found later in the course of SCC. Patients often give a history of pain with or without radicular components, which is often worse when supine. Patients may also complain of neurological dysfunction. None of these findings are extremely specific or sensitive. Sites of compression are typically thoracic, accounting for more than 70% of all cases, lumbosacral in 20% of patients; and cervical in 10% of patients. Early diagnosis and immediate treatment are critically important for the management of SCC. MRI is the best imaging modality as eighty-five percent of these lesions originate in the vertebral body, and one must consider a scan of the entire spine because of the variable locations and multilevel metastasis. Functional status, availability of treatment options, stability of the spine, and extra-spinal disease status are additional factors to consider.

If the patient does have radiographic evidence of SCC, then many cases should be considered for hospitalization for urgent multidisciplinary evaluation by oncology, radiation oncology, palliative care, and surgery. The immediate goal is to determine the urgency of the case, which will inform the prognosis, treatment options, and ultimately the goals of care.

Management

The goals of SCC treatment are acute pain control, halting the progression of the disease, and decompressing the spinal cord to halt further neurologic damage and regain neurologic function. The choice of definitive treatment depends on the extent of the disease, life expectancy, and the patient's beliefs. Decompression is achieved through external beam radiation therapy, surgical intervention, or a combination of both. Systemic therapies are unlikely to accomplish decompression without external beam radiation therapy and/or surgery. A single fraction may be helpful for those with a shorter prognosis in the weeks-to-months range. If the prognosis is longer, then treatment may involve surgery and/or radiation. High-dose steroids (dexamethasone) with gastrointestinal prophylaxis may help decrease spinal cord edema and provide analgesia. Moderate dose strategies (10 mg loading dose, followed by 4 mg 4 times per day, with a 2-week taper) have similar outcomes to high-dose strategies but with fewer adverse events. There is no evidence that bisphosphonates improve outcomes in SCC. Beyond the immediate threat of SCC, the palliative care clinician should make sure to attend to bowel and bladder management, skin breakdown from immobility, and support in coping with this prognosis-altering complication with the application of physical therapy.

6) Delirium

Delirium (20–70% of cancer patients) is a common and distressing problem in palliative

care that implies a burden on the patient and their families. It has a wide range of symptoms that have an acute onset, like a fluctuating mental state, disorganized thinking, and an abnormal state of arousal (hyperactive and agitated or hypoactive and passive) that mimic those of other psychiatric disorders. Almost 90–95% of patients have delirium during the last 48 hours of life, which is a frequent cause of hospital admission towards the end of life. Diagnostic classification systems such as DSM IV (Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition), the Mini-Mental State Examination, and the Delirium Rating Scale might help to differentiate delirium from those other related disorders. However, delirium can be misdiagnosed as depression, especially the hypoactive subtype. It is usually difficult to differentiate between a patient with delirium, dementia, or delirium with pre-existing dementia. In acutely confused states that are not related to the dying phase, delirium might be a sign of severe physiological disturbance and should be approached as a potentially reversible episode. Some medical causes include drug effects (e.g., steroids, opioids, anticholinergic drugs, or cytotoxic agents); effects of drug withdrawal (e.g., benzodiazepines, opioids, nicotine, or alcohol); infections; CNS or meningeal metastases; dehydration; hypoxia; and paraneoplastic or metabolic disorders (e.g., glucose disturbances; hyponatremia; hypocalcemia; or hypercalcemia) or organ dysfunction (e.g., kidney, liver). In palliative care, diagnostic and therapeutic interventions to exclude reversible causes of delirium (e.g., MRI brain imaging or cytology of cerebrospinal fluid) should be considered for clinical prognosis on a case-by-case basis.

Management

Treatment of delirium includes calming the patient, withdrawal of the offending drug, adequate hydration, use of oxygen for hypoxia, correction of metabolic abnormalities, use of antibiotics for infections, non-pharmacological measures (e.g., adequate light, communication, and structuring of time and place), reassurance of the patient and relatives in a calm environment, and use of pharmacological measures. Stimulate the patient to perform easy tasks like eating in an empathetic manner. Delirium usually implies focused and pointed communication with relatives about aspects of dying or symptom-guided palliative sedation.

Symptomatic drug treatment is indicated in a patient who is agitated, confused, or has perceptual disturbances (hallucinations, delirium). It is important to inform relatives who provide home care for a patient with advanced cancer about possible delirious symptoms that might occur, especially during the final phase, which helps manage crises in palliative care.

Medication Summary

The most common medications used are neuroleptics. Benzodiazepines often are used for withdrawal states.

Neuroleptics

The medication of choice in the treatment of psychotic symptoms. Older neuroleptics such as haloperidol, a high-potency antipsychotic, are useful but have many adverse neurological effects. Newer neuroleptics such as risperidone, olanzapine, and quetiapine relieve symptoms while minimizing adverse effects. Initial doses may need to be higher than maintenance doses. Use lower doses for patients who are elderly. Attempt a trial of tapering the medication once symptoms are under control. Neuroleptics can be associated with adverse neurological effects such as extrapyramidal symptoms, neuroleptic malignant syndrome, and tardive dyskinesia. Doses should be kept as low as possible to minimize adverse effects. Paradoxical and hypersensitivity reactions may occur.

Haloperidol 0.5 mg–2 mg BD/ TID

Risperidone (Risperdal) 0.5–1 mg BD

Short-acting sedatives

Reserved for delirium resulting from seizures or withdrawal from alcohol or sedative hypnotics. Co-administration with neuroleptics is considered only in patients who tolerate lower doses of either medication or have prominent anxiety or agitation.

They may also be used when unknown substances have been ingested and may be helpful in delirium from hallucinogens, cocaine, stimulants, or PCP toxicity.

Use special precautions when using benzodiazepines because they may cause respiratory depression, especially in patients who are elderly, have pulmonary problems, or are debilitated.

Lorazepam 1 mg–2 mg SOS

Fig. 43*- depicts a patient with Carcinoma Gall bladder in delirium*

7) Pathological fractures

Bone metastases are most common in prostate, lung, breast cancers and myeloma. They are commonly diagnosed before the terminal stages and are therefore amenable to therapy to reduce the risk of fracture. The fracture risk is greatest when >30% of the bone cortex is involved, and prophylactic internal fixation should be considered. Elective fixation has better survival and complication rate than emergency surgery for a pathological fracture. Several studies have shown that regular bisphosphonate therapy reduces the incidence of skeletal morbidity, and it is commonly prescribed for several cancers with metastatic bone disease. The classical presentation of a fracture is sudden-onset severe pain in the affected area, in addition to possible swelling, bruising, and loss of function. Plain radiography is usually sufficient to diagnose a fracture.

Management

The main aim of treatment is to relieve pain and restore function. Surgical fixation is the quickest way of achieving both and should be considered for patients fit enough for surgery. If surgery is not possible, fixation with a cast can provide some pain relief. Radiotherapy can be indicated to improve healing and pain relief after fixation has been achieved. It is unlikely to help if fixation is not indicated (e.g., a fracture of the humeral head).

SUMMARY

A primary challenge facing palliative care teams is determining which patients are indeed in an end-of-life scenario. End-of-life refers to patients who have a disease that is no longer responsive to life-prolonging therapies and who have goals of care consistent with a comfort-based approach, knowing they are dying from their illness and are likely within days to weeks of death. Some patients with HCM can be treated with known interventions, whereas for others who are nearing the end of their lives, it may be reasonable to consider exclusively symptom control and reassurance. SE can develop from any prolonged seizure, and early recognition is critical for optimal treatment. Benzodiazepines are first-line treatment, and clear plans should be made for patients who do not respond to initial therapies. Terminal hemorrhage most often occurs in patients suffering from head and neck cancers, although it remains a rare occurrence. Care should be taken to balance the patient's and family's need to know about this dreaded complication with the fact that most people do not exsanguinate. SVCS can result from metastases from any malignancy to the pericaval area, causing compression and reduced flow. When possible, stenting can provide symptomatic relief for patients, and if patients cannot be stented, a combination of steroids and symptom medications can often comfort them. SCC can be debilitating, particularly if not recognized. Radiation therapy and/or surgery can often help patients maintain function with early recognition and treatment, and radiation and steroids can provide symptomatic relief even in patients who have lost function. Regardless of the diagnosis, collaboration with specialists to determine a prognosis for each patient can help patients identify goals of care for the remainder of their lives.

CHAPTER 9

CARE OF BEDRIDDEN PATIENTS

CARE OF BEDRIDDEN PATIENTS

PRINCIPLES IN CARING FOR A BEDRIDDEN PATIENT

- Preventing health complications.
- Promote Comfort.
- Build Confidence.
- Percent Isolation.
- Improve the quality of life.

PREVENTING HEALTH COMPLICATIONS

- Pressure sore prevention.
- Feeding and nutrition.
- Bowel and bladder problems.
- General nursing care.
- Psychosocial Issues.

PALLIATIVE NURSE

- Require an extension of basic nursing skills.
- Requires individualized care planning.
- Remember that the patient is going through the most difficult time in life.
- Work with the patient's family and friends.
- Need to reassess regularly as changes occur frequently.
- Health workers need training in Basic Communication skills.
- Assessment of symptoms and when and whom to inform.
- Team meeting once a month to clarify their doubles and for teaching.

NURSE'S ROLE

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.

PROBLEMS FACED BY BED-RIDDEN PATIENT

- Reduced Range of Motions of joints.
- Improper positioning.
- Deformities and contractures.
- Pressure sores.
- Malnutrition.
- Water starvation.
- Reconditioning.
- Bowel and bladder dysfunction.
- Infections.
- Sensory deprivation.
- Breathing problems.
- High Stress levels.
- Psychological dysfunction.
- Others.

SKIN CARE

A good skin care plan includes:-

- Attention to the patient's and family's dignity about QOL (Quality of life) and values.
- Preventing infections.
- Preventing skin breakdown.
- Clear instructions for wound care.

Principles of Skin Care:-

- The skin and mucus membrane defends the body against injury and diseases.
- Excessive moisture in contact with the skin resulting in tissue irritation.
- Pathogens grow well in a warm and moist environment and cause infection.
- Nurses take care to prevent the transference of micro-organisms from or to the patient.
- The skin that is dry is more prone to injury.
- Poor circulation cuts off nutrition to the skin and causes skin damage.

- Sensory receptors in the skin are sensitive to heat, pain, touch and pressure.
- Soap acts by lowering the surface tension of water and helps in the emulsification of fat.
- Systematic ways of working save time energy and material.
- Hygienic practices vary between individuals.
- Any familiar situations produce anxiety.
- Movements of the body take place by means of muscles and bones functioning on the principles of mechanical leverage and gravitational pull.

PREVENTION AND MANAGEMENT OF PROBLEMS

1. Abrasion:- (Superficial layer of skin a scraped).

- Proper bed making.
- Do not wear any rings or jewellery while providing care.
- Apply emollients.
- Apply emollients.
- Avoid friction.

2. Excessive Dryness:-

- Avoid soap/talcum powder.
- Encourage fluid intake.

3. Apply Moisturizes:-

- Keeps skin dry and clean.

4. Acne:-

- Treatment varies wildly.

5. Erythema:-

- Wash the area carefully.

6. Apply Antiseptic Spray or Lotion Hirsutism (Excessive Hair Growth):-

- Remove unwanted hair.
- Enhances clients self – concept.

BATH

Aim:-

To remove accumulated oils, perspiration, dead skin cells, and some bacteria.

Purpose:-

- To clean the body of dirt and bacteria.
- To increase elimination through the skin.
- To prevent bedsores.
- To stimulate circulation.
- To induce sleep.
- To provide comfort to the patient.
- To relieve fatigue.
- To regulate body temperature.
- To provide active and passive exercise.
- To give health education.
- To establish a good rapport with patient and family.

Nurse's Responsibility:-

- Remove the soap completely from the patient skin to avoid a drying effect.
- Avoid bathing a patient soon after a meal as it depletes the blood supply to digestive organs and interferes with digestion.
- Avoid the use of an excess of spirit as it care rapid evaporation and excessive cooling of the body and causes drying of the skin.
- The skin on the back of the hand sensitive is to assess the temperature of the water.
- Bathing is an important intervention to promote hygiene.
- While giving a bath nurse can observe the condition of the skin and the hidden where dirt can accumulate.
- Patients who are bedridden but can be moved out are placed in a wheelchair or a plastic armchair and sniffed to the boat room for bathing.
- Special attention to the pressure points given depending on the common position of the patient.
- **Supine –** Occiput, elbows, sacral region, heels scapula.
- **Side lying –** Ear, acromion process, ribs, greater trochanter, medial and lateral malleolus, lateral condoles.

Sitting – Ischial tuberosity.

Fig.44

- Special attention to the pressure points given depending on other positions of the patient.
- Back of the ears, and upper folds of the ear.
- Neck region in obese patients.
- Axilla (armpit, underarm).
- Elbow joint in contractures patient.
- Folds of the breast.
- Umbilicus.
- Groin.
- Folds of the buttocks.
- Back of the knee.
- In between the digits, fingers and toes.

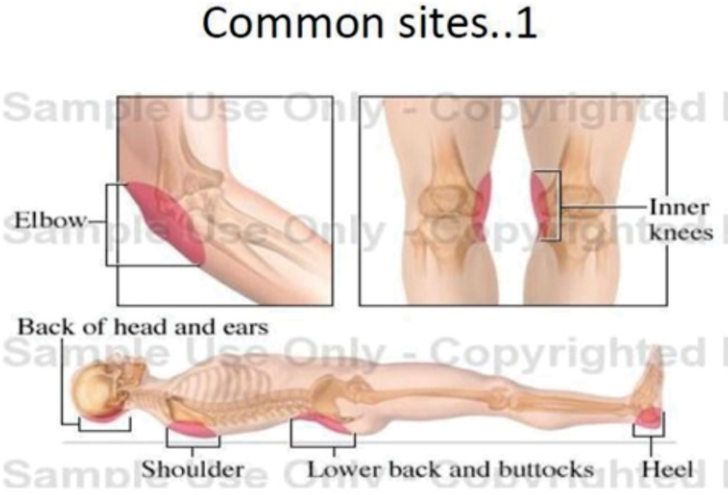


Fig.45

Common sites..2

Fig.46

BACK CARE

Purpose –

- To provide comfort.
- To stimulate circulation.
- To prevent pressure sore.
- Provide a therapeutic bed.
- Application of emollients.
- Discourage the use of talcum powder & spirit.
- Do not rub on the bony prominence.

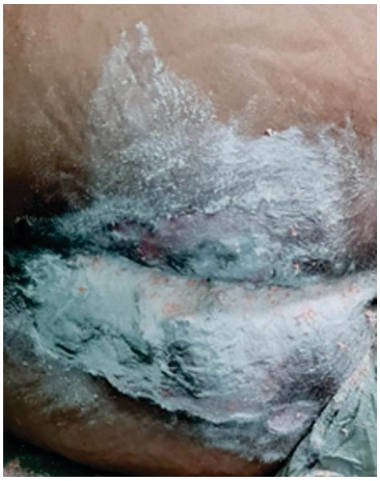


Fig.47- back sores

PERINEAL CARE

Purpose:–

- Promotes health and hygiene.
- Present infection.

Patients who need special attention to the perineal area:-

- Patient unable to do self-care.
- With genitor urinary tract infection.
- With, Incontinence of urine and stool.
- With indwelling catheters.
- Postpartum patients.
- After surgery on the genitor urinary system.
- With injury, ulcer or surgery on the area or rectum.

CARE OF EYES

- Daily at least 3 times the eye should be cleaned from inner to outer canthus.
- In unconscious patients eyes should be kept covered during sweeping and swabbing.
- We should not use gauze pieces for cleaning the eyes. We should always use cotton swabs dipped in normal saline for cleaning in a single troche process.

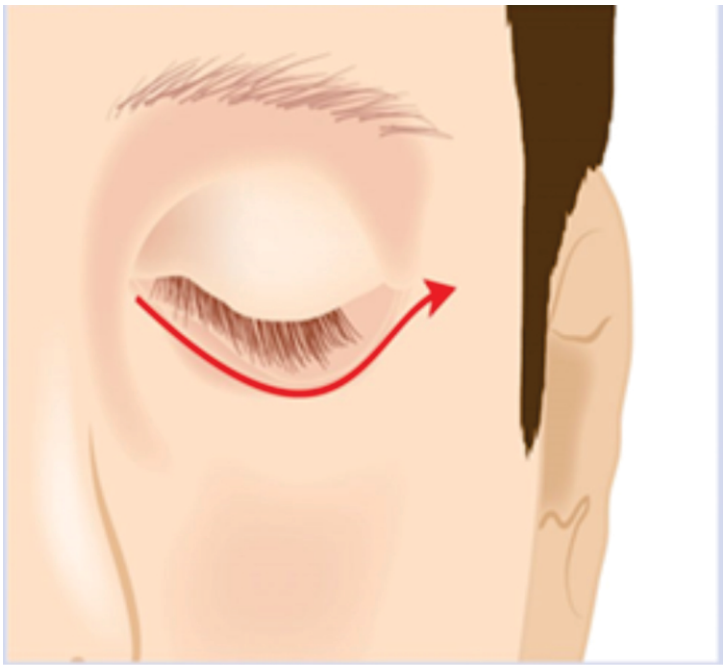


Fig. 48

CARE OF NOSE

- Assistance is needed to remove the secretions from the nostrils in some of the patients with wet wash clothes or a cotton applicator moistened with normal saline or water.
- A single stroke should be maintained during the cleaning of nostrils. If the other side is cleaned with the same portion, the infection will not be removed.

CARE OF EAR

Fig.49

- The collection of wax in the ear may cause hearing problems, liquid paraffin or vegetable oil can be instilled and it is easy to remove.
- In a single stroke with a cotton applicator, ears have to be cleaned.
- Folds of the ear and back of the ears have been cleaned during the process.

CARE OF HANDS AND FEET

- Hands and feet should be immersed in a basin containing water as it gives a good feeling to the patient.
- This makes the nails soft and easy to cut.
- It prevents the cracking of heals and if the crack is present apply any monitoring cream or liquid paraffin.

HAIR CARE

- Daily brushing and combing of the hair will keep the hair healthy.
- Daily head baths at least twice or thrice in a week will keep the hair and the scalp healthy.

- Prevention of pediculosis is important in bedridden patients.

ORAL CARE

Objectives:

- Promotes good oral hygiene.
- Promotes comfort.
- Promotes appetite.
- Prevents infection.

Oral hygiene is very important in bedridden patients. It can be given to both conscious and unconscious patients. The common things used to clean the mouth are soda-bicarbonate, saline water, neem leaves, lemon juice etc.

IMPORTANCE OF ORAL CARE

- Routine mouth care.
- Recommended daily assessment.
- Brushing and rinsing teeth every 12 hours.
- Soaking dentures overnight.
- Lip balm applied to lips or butter.

ORAL CARE GIVEN TO BED-RIDDEN PATIENTS

- 2-4 hourly mouth care (assess individually).
- Use of soft brush, foam stick applicator or glove and gauze.
- Use of syringe for gentle mouthwash.

ORAL PROBLEMS

- Local infection.
- Halitosis.
- Oral thrush (Fungal infection).
- Sore mouth.
- Glossitis.
- Steatites.
- Xerostomia (Dry mouth).

NEED OF MOUTH CARE OF PATIENT

Patients who need care 2 or 4 hourly mouth care -

- Patients with high temperature.
- Seriously ill patients.
- Paralysed patients.
- Unconscious patients.
- Patients breathing through the mouth.
- Mal-nourished and dehydrated patients.
- Patient under anaesthesia or heavily sedated.
- Patients who are not taking oral feeds.
- Patients who are having mouth disorders.

MOUTH CARE OF CONSCIOUS PATIENTS

- Proper positioning of the patient.
- Assist in brushing.
- Rinsing the mouth makes the mucus membrane moist and prevents tissue trauma during brushing.
- Welting the brush makes the bristles soft and prevents tissue injury.

Fig.50

MOUTH CARE OF UNCONSCIOUS PATIENTS

- Proper positioning of the patient (Side-lying).
- Explain home remedies for mouth care. Do not pour water into the mouth of unconscious patients, so as to prevent aspiration of fluid into the lungs.

- Cotton is not to be used as it is slippery (when it is wet) and does not clean a coated tongue.
- Use a gauze piece for cleaning the teeth and a coated tongue.

NURSE'S RESPONSIBILITY

- Assessment – Check the condition of the oral cavity.
- Ability of self-care.
- General condition of the patient.
- Doctor's order – Frequency of mouth care needed.
- Articles available in the patient unit.

BOWEL CARE

- In a bedridden patient lack of exercise, privacy, reduced food intake, medication, etc. causes constipation.
- Encourage patients for bowel movements daily and give them time for the bowel movement.
- Patient should be encouraged to take a high-fibre diet, adequate fluid intake, and laxatives both stimulants and stool softeners.
- If this fails, per rectal examination, manual evacuation and high enema with a suction tube or an enema catheter.
- During per rectal examination if ballooning is found it indicates a loaded rectum go for Enema after PRE (Per rectal Examination).
- If patients complain of spurious diarrhea, ask about the history when it started and before the onset what was the condition. Here again Per Rectal Examination, Manual Evacuation and

ENEMA.

- Instead of diapers you can encourage them to use newspapers, easy to dispose of, and are cheap and easily available.
- Ordinary plastic covers, cut in a triangle shape and keep one or two sheets of paper on that tie on that tie this on the waist of the patient.

BLADDER CARE

- Patients who are able to void without help should be encouraged to do so.
- Pour water or open the tap, this may help the patient to pass urine.

- Patients who need indwelling catheters should be identified properly.
- Patients with indwelling catheters should be educated on how to prevent urinary infections.

PURPOSES:-

- Provided any assistance when the patient feel to urinate.
- Sound of hearing running water and flushing the toilet stimulates the reflex.
- Provide enough time passing urine.
- Reassurance /emotional support is helpful to relax the patient.
- If permitted hot enema should be given in the case of retention of urine.
- Give fluids freely unless contraindicated.

INCONTINENCE OF URINE

- Establish a regular voiding schedule for the patient.
- Increase physical activity.
- Perineal exercises.
- Arrange for a toilet/bed pan within easy reach of the patient.
- Medical and surgical correction of responsible factors (eg., treatment of urinary tract infections).

CATHETERIZATION

Fig 51 google slideshare net

Catheterization is divided into:-

- Indwelling Catheterization.
- Supra-pubic Catheterization
- Intermittent Catheterization
- Condom Catheterization

Indwelling Catheterization:-

- Should be the last resort.
- Even if the patient is with an indwelling catheter always ask "**Does this patient need to be on a catheter**".
- Look for ways to wean the patient off the catheter.
- Once the patient is on indwelling catheter bowel management should be aggressive.
- For those who can afford to prefer silicon catheters over latex catheters.

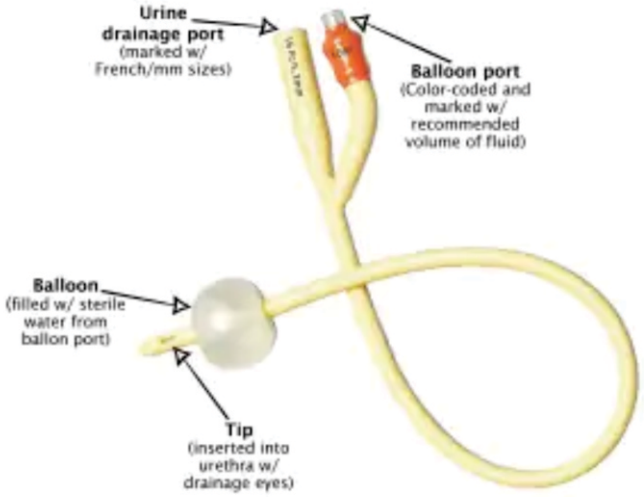


Fig.52 - foley's catheter

Key points to Remember:-

- Take all sterile precautions.
- Choose the smallest possible size (14F, 16F, 18F)
- It is always safe to do per rectal exam.
- Lubricate generously and wait.
- It is important to ensure that the bulb is in the bladder.
- How much to inflate?

- 10 to 15 ml (Ideally it is better to inflate and than deflate)
- Too much can cause bladder spasms.
- Antibiotic prophylaxis for urinary catheter insertion is not recommended.
- Injury while catheterization may warrant antibiotic courier.

Instructions:-

- Plenty of oral fluids (2 to 3 L per day)
- Anchor the bag to the sides to avoid traction.
- Empty the bag when it is more than half full.
- Ensure that the tube is not kinked.
- Nuer raise the bag above the hip level.
- Plan catheter change according to guidelines.

Health Education:-

- Catheter should be changed from 3 weeks to 1 month.
- Intake of fluid at least 2.5 to 3.0 litres in 24 hours.
- Prevention of constipation.
- Urobag should be always kept below the waist level.
- Any colour change in the urine should be reported immediately.
- Daily clear the umbilicus to the mid-thigh with soap and water at least 2 to 3 times a day.
- Clean the catheter with soap and water twice or thrice daily.
- Never detach the Foley's catheter and the connection of the urobag.
- Do not keep the cap of the urobag open. Urine should not be kept in the bag for more than 3 hours.

CONDOM DRAINAGE

Fig. 53 slide share net

- Comes in three sizes – small, medium, and large.
- Choose the right size to prevent leakage.
- Comes with an adhesive tape or Velcro strap.
- The strap should not be too tight or too loose.
- Do not apply a strap on the skin.
- Always secure the catheter on the lower abdomen and remove daily and wash it.
- Advantage is less infection, cheap, no internal injury can be used only during the night here the patients cannot move to the toilet, and no sexual problems.

CISC – CLEAN INTERMITTENT SELF CATHETERIZATION

- Schedule the intake of fluids and accordingly every 3 to 4 hours, self-catheterization. can be done.
- Advantage of CISC is no need for help, the patient can move around, no need to carry the urbane, the chances of infection are less, it is cheap and no sexual problems.
- But female patients need help if not possible to do it on their own.
- Nelton catheter is used, wash it with soap and water, flush and then keep it dry wrapped in sterile cloth.

RANGE OF MOTION

When the range of motion of joints is lost:-

- Patient loses mobility and function.
- Stiff joints become painful.
- Muscles become maladapted.
- Can lead to reflex dystrophy.
- Can contribute to other complications.
- With reduced ROM joints go into stiffness. Sometimes this can be permanent.

Importance of ROM joints:-

- Joint stiffness can be prevented by ROM exercises at least twice daily.
- Encourage the patient to have more activity.
- Exercises to be active and passive.
- When recovery occurs, joints are retained in the functional range.
- Infancies muscle reconditioning.

PROBLEMS OF BEDRIDDEN

Several problems can occur from neglect of positioning. They include:-

- Deformities, muscle tightness, contractures, wasting, and reconditioning.
- Slowly the patient tends to go into malnutrition.
- Loses the benefit of recovery.

Common problems of patients are:-

- Flexion contractures in hip and knee.
- Adduction tightness in hips.
- Ankles go into plantar flexion, shoulders lose abduction, and fingers lose part of the extension.

BASIC OF POSITIONING

Positioning devices:-

- Foam wedges, and pillows to prevent direct contact.
- Dough–nut Type devices cause venous congestion and edema – so contraindicated.
- Avoid positioning on the trochanter.
- Head of bed as low as possible.
- Do not drag during transfers.

PRESSURE ULCER

Definition:-

A pressure ulcer or pressure sore or decubitus ulcer or bedsore is a localized injury to the skin and other underlying tissue, usually over a body's prominence, as a result of prolonged pressure on the skin.

How to prevent pressure ulcers:-

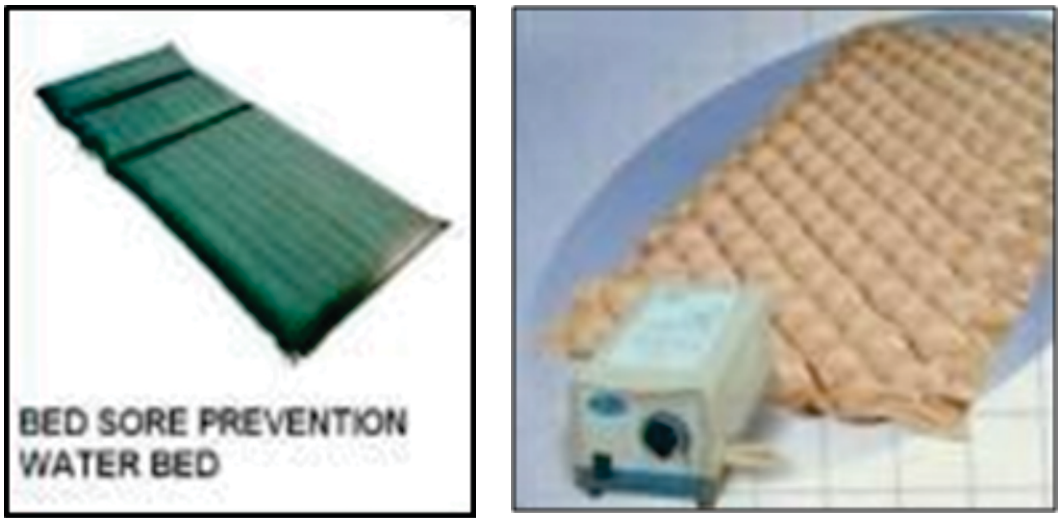
- Easiest, least expensive.
- Training of health care providers
- Skincare is paramount.
- Eliminate pressure in areas of persistent hyperemia.
- Eliminate shearing forces and friction.
- Removal of skin secretions and excretions.
- Avoid hot water.

How to take care of pressure Ulcers?

- Use mild cleaning agents.
- Moisturize Skin.
- Topical agents to act as a moisture barrier.
- Keep sheets dry and wrinkle-free.
- Maintain current levels of mobility/activity ROM.
- Avoid massaging body prominences.

PRESSURE ULCERS – POSITIONING

- Patients are to be turned/shifted every 2 hours.
- Patients can benefit from lying prone.
- Pressure relief every 30 munities while sitting patients do push ups and lean side to side for pressure relief.



Water Bed

Fig. 54 - various types of mattress

STAGES OF PRESSURE INJURY

Stage – 1.

- The first stage is the mildest. It discolours the upper layer of your skin, commonly to a reddish colour. The affected area may be sore to touch but has no surface breaks or tears. You may also experience mild burning or itching.
- One may notice that the area is red and the skin does not turn pole when pressed firmly.

This means there is an interruption in blood flow and that an ulcer is forming. The texture and temperature of this developing sore will likely also be different from the surrounding normal tissues.

Management:-

- The first step to treating an ulcer in this stage is to remove pressure from the area. Any added or excess pressure can cause the ulcer to break through the skin surface. If you are lying down, adjust your position or use pillows and blankets as extra padding.
- It's also important to keep the affected area clean and dry to reduce tissue damage. Stay well hydrated, and add foods high in calcium, protein and iron to your diet. These foods help with skin health.
- It is treated early, developing ulcers in stage one can heal in about three days.

Stage – 2.

- The second stage, you will likely experience some pain from the ulcer. The sore area of your skin has broken through the top layer and some of the layers below. The break typically creates a shallow, open wound and you may or may not notice any drainage from the site.
- A stage 2 ulcer may appear as a serum-filled (clear to yellowish fluid) blister that may or may not have burst. The surrounding areas of the skin may be swollen, sore, or red. This indicates some tissue death or damage.

Management:-

- Keep the area dry and clean. Clean the sore with water or a mild, sterile salt water solution to dry out the wound. One may experience some pain or stinging.

Stage – 3.

- The third stage has broken completely through the top two layers of the skin and into the fatty tissue below. An ulcer in this stage may resemble a crater.

Management:-

- Antibiotic therapy removes any dead tissue to promote healing and to prevent or treat infection.
- If patients are immobilized then a special mattress or bed to relieve pressure from the affected areas may be used.

Stage – 4.

- Stage 4 ulcers are the most serious. These sores extend below the subcutaneous fat into your deep tissues like muscle, tendons and ligaments. In more server cases, they can extend as for down as the cartilage or bone. There is a high risk of infection at this stage.

- These sores can be extremely painful. One can expect to see drainage, dead skin tissue, muscles and sometimes bone. The skin may turn black, exhibit common signs of infection and one may notice a dark, hard substance known as **ESCHAR** (hardened dead wound tissue) in the sore.

UNSTAGEABLE:-

- They are also hard on to diagnoses because the bottom of the sore is covered by slough or Eschar. Doctor can only determine how deep the wound is after clearing it out.
- The ulcer may be yellow, green, brown or black from slough or damage, it will need to be surgically removed. However, in certain areas of the body, if the covering is dry and stable, it should not be touched. This dry eschar is the body's natural layer of protection.

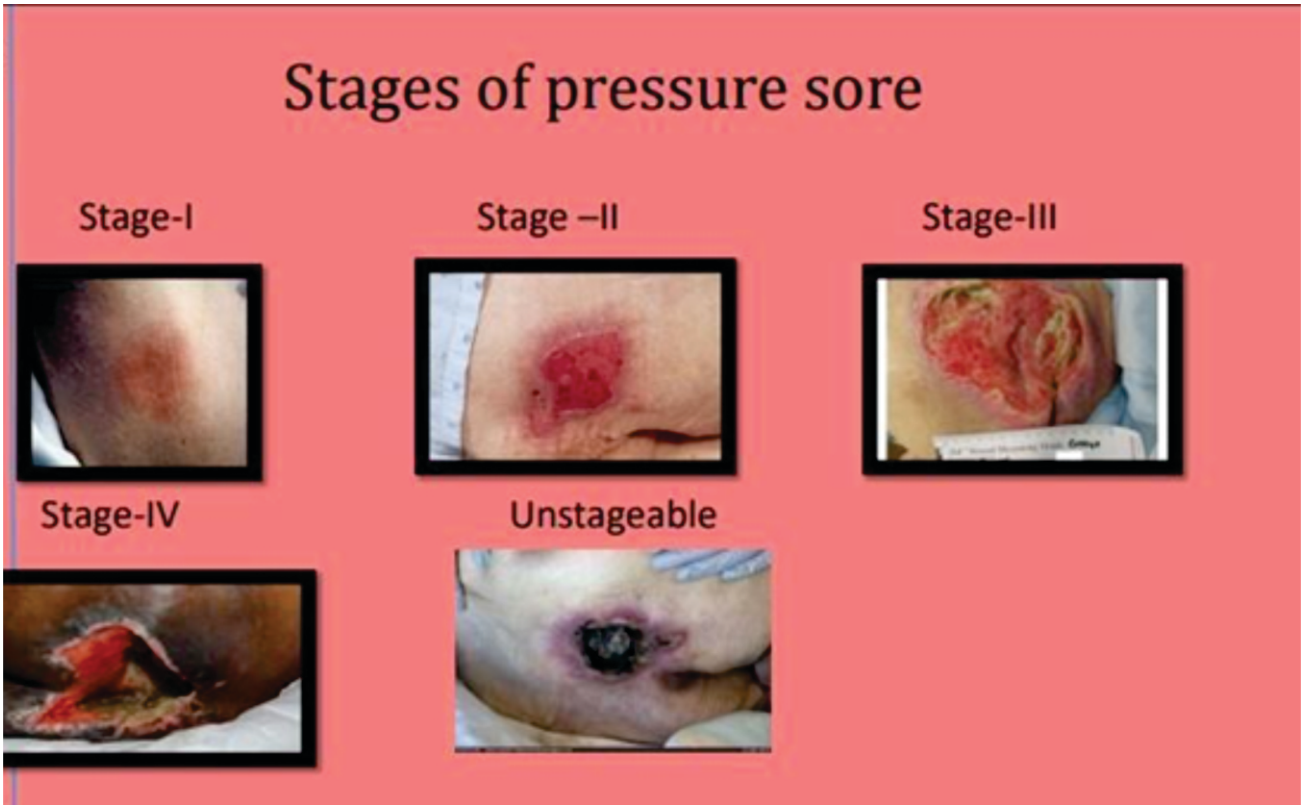


Fig.55- stages of pressure sores

General Management for Pressure Sore:-

- Always medicate the patient for pain before wound care.
- If slough, surgical Debridement.
- Use normal saline for wound cleaning (home-mode).
- If there is an odour or infection add metronidazole powder.
- Charcoal under the bed will absorb odors.

- Avoid hypochlorite, solutions like povidone iodine and hydrogen peroxide.
- Surgery consultation.

FEEDING AND NUTRITION

- Malnutrition and sarcopenia (A common presentation in long–term bedridden patients).
- Contractures result in prominent joints.
- Positioning becomes difficult.
- Nutritional requirement:-
- 1000 Cal/day if there is no pressure sore.
- 1300 to 1500 Cal/ day if there is a pressure sore.
- Protein requirement 0.8 to 1.5g / Kg/day (Based on the severity of illness).

NASOGASTRIC FEEDING

A nasogastric tube is a special tube that carries food and medicine to the stomach through the nose.

Purpose:-

To provide nourishment with food and/or medication.

Advantage:-

- An adequate amount of all nutrients and medication can be given.
- Adequate amount of fluids can be given.
- Danger of parenteral feeding is avoided.
- Tube feeding may be continued for weeks.
- Stomach content can be aspirated wherever needed.
- Overloading of the stomach can be prevented by a drip method.

General Instructions:-

- Give fowlers or semi-flowers position before feeding.
- Before every feed make sure the tube is in the stomach by aspirating a small quantity of stomach contents (5-10ml).
- While opening the cap of the tube pinch the tube or fold the tube for presenting the entry of air.
- Every 2 hourly give 200-250ml of fluid diet (home-made) and about 25l of plain water is given just before and after the feed.

- Total amount of fluid in 24 hers varies between 2000 and 3000 ml.
- Record intake – output correctly.
- Watch for any complications.
- Patients receiving tube feeding should be given frequent mouth care.
- Strain the feed before giving.
- Keep the patient in the same position for about half an hour and then make the patient lie down on a side-laying position slowly so as to expel the air.
- Keep the feed and medication ready for the patients.
- Flush the tube as soon as the feed is finished and clamp the tube for preventing entry of air.

Feeds:-

Feeds that can be given through NG feeding are:-

- Clear tea.
- Weak black coffee.
- Clear soups.
- Strained fruit juices.
- Milk and egg flips and this.
- Salt should be added unless it is restricted.
- Dal water, Rice water.

CHAPTER 10

SPIRITUAL AND ETHICAL COMPONENT OF PALLIATIVE CARE

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SPIRITUAL COMPONENT

Coping with a serious medical illness can be very challenging for patients. He/She has to confront pain, disability, lack of independence, and one's own fears and anxieties. This is apart from the concerns of loved ones. Nothing really prepares a patient for such a situation, Dreams are broken, plans left undone and several unfulfilled wishes remain.

Concerns at various stages of the disease.

Shock, emotional numbness, disbelief, denial, and anger are commonly expressed at the time of diagnosis.

1. **Psycho-social concerns/ issues**
2. **Fears**

   Pain/suffering- anxiety and fear that pain would become more leading to worsening of suffering.

   Family- concerns and fear regarding the future of the family.

   Leaving unfinished business- children to be educated or married, property and financial matters to be settled, pardoning, forgiving, and reconciling with the loved ones.

3. **Anger**

   Delay in diagnosis and treatment: Therapeutic failure, Disfigurement, Pain, Helplessness

4. **Losses**

   Composure- loss of control of emotions, Body functions, Disfigurement, Role in family/ society, Dignity- loss of respect and dignity in the family and society, Relationship, Sexual pleasures.

5. **Risk of suicide**

   Uncontrolled pain, Multiple physical symptoms, Post prognosis/advanced illness Helplessness/Hopelessness, Delirium, Burden, Finance, Guilt, Depression

6. **Spiritual concerns**

   Patients suffering from spiritual pain/concerns;

Why me?

"Why me!" is an expression of a troubled soul. It is a way of venting out deep concerns as " it is not fair that I am chosen to suffer the dreadful disease!"

Why is God letting me suffer?

Anger or disappointment with God is a spiritual pain that the patients suffer. Patients may lose their faith in God or may accept it as God's will.

What is the point? Meaning/purpose of life?

Feeling that life and existence are meaningless.

Guilt, Regret, Curse, Karmas

Coping mechanisms:- how a person will cope. Coping mechanisms enable the person to continue to function and adjust to the new situation. Coping styles can predict psychological outcomes. Some may accept reality. Some may swing between fighting and acceptance, some patients may use several coping mechanisms together or at different times during the period of adjustment.

Psychiatric disorders seen are adjustment disorders, major depression, organic mental disorders (delirium), and preexisting conditions (personality disorders, anxiety, disorders, etc.)

Distress

Definition

Distress has been defined as a multifactorial unpleasant emotional experience of a psychological, social, or spiritual nature that interferes with coping with cancer. It extends along a continuum and once identified, further delineation of psychiatric syndromes may be done.

Screening for distress

Many questionnaires have been used for this purpose but recently most attention has been foused upon the **"distress thermometer"**.prior to screen your patients, thought must be given ad to whether you are in a position to offer psychological help to those who are detected to have psychological problem.

ETHICAL COMPONENT

Ethics refers to the rules or standards governing the conduct of individuals or members of a profession. As members of the medical profession, our conduct is governed by medical ethics.

The four cardinal principles of medical ethics provide a framework for decision-making in difficult situations. They are-

1. Respect for the patient's autonomy
2. Beneficence or 'do good'
3. Non-maleficence or 'do no harm'
4. Justice or fair use of available resources.

- Autonomy is an expression of informed choices and preferences or consent to whatever we do or is done to us by others. It acknowledges the patient's right to know the diagnosis, to know the details of the treatment offered to him/her, and the right to refuse treatment.
- Beneficence means that whatever one does to the patient should be for the good of the patient.
- Non-maleficence means one should not do any harm to the patient while caring for or treating the patient.
- Justice is the principle of fair use of the available resources. The resources are limited and the demands are high. It concerns balancing individual needs with those of society.

Intended and foreseen effects- the doctrine of double effect:

Towards the end of life, the health condition is very fragile. A crisis situation or death itself can happen at any time. Drugs used or procedures done at that time, which have a potential for adverse effects may be blamed for the death. This can lead to avoidance of such drugs and procedures for fear of the foreseeable adverse effects and the potential for being blamed. Traditionally the 'doctrine of double effect' was cited as justification for instituting such therapy. The doctrine of double effect states- ”A single act having two possible foreseeable effects, one good and one harmful, is not always morally prohibited if the harmful effect is not intended”.

Appropriate treatment:

Medical interventions usually will have some benefits and some risks or burdens to the patient. Appropriate treatment is to start or continue a treatment whose benefit outweighs the risk or burden. It also means withholding or withdrawing treatment when the risk or burden outweighs the benefit. The doctor has to assess the situation individually and decide upon instituting a particular treatment when it seems to be beneficial and he/she should have the courage to stop the treatment when the burden or risk outweighs the perceived benefit.

Advance directives:

An advance health directive (also called a living will) is a document that states your wishes about what health care you want or don't want when you reach a state in which you can't speak for yourself. You can also appoint a person to take decisions on your behalf when you become unable to take a decision yourself. Advance directives are very useful in preventing futile treatment and the associated suffering and indignity when once life comes to a close.

Principles of Good death- End of Life Care

- To know when death is coming, and to understand what can be expected
- To be able to retain control of what happens

- To be afforded dignity and privacy
- To have control over pain relief and other symptom control
- To have choice and control over where death occurs
- To have access to information and expertise of whatever kind is necessary
- To have access to any spiritual or emotional support required
- To have access to hospice care in any location
- To have control over who is present and who shares the end
- To be able to issue Advance Directives, ensuring that one's wishes are respected
- To have time to say goodbye
- To be able to leave when it is time to go and not to have life prolonged pointlessly.

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