



TRAINING MANUAL
FOR
DOCTORS AND NURSES
UNDER
NATIONAL PROGRAMME FOR
PALLIATIVE CARE
Facilitator Guide



The National Institute of Health and Family Welfare
New Delhi

(Supported by World Health Organization, Country Office for India)
Developed under WHO-Gol Collaborative Activities for Biennium 2016-17



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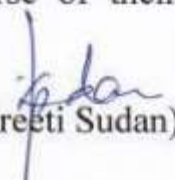
Dated : 27th February, 2018

MESSAGE

Advances in medical science, breakthroughs in technology and increasing consciousness of civil rights are some of the factors which have contributed to the thinking that the people who need palliative care deserve a better quality of life. The physical, psychological and spiritual aspects of patient care are best looked after by a partnership of different kinds of health professionals, community volunteers and family members. We need to spread a message that the core issues of relief of suffering and improvement of quality of life are salient throughout the course of an illness.

Human resources with adequate and appropriate training in palliative care are necessary for scaling up palliative care interventions throughout the country. The goal for human resources is simple but complex to reach – to get the right workers with the right skills in the right place doing the right things. I congratulate the program division for bringing out a training manual for non-specialist doctors and nurses, which shall facilitate in imparting standardized short-term training in palliative care to doctors and nurses working at district and sub-district levels.

I am sure that this endeavour will go a long way in ensuring the best possible quality of life to the patients throughout the course of their debilitating and life limiting illnesses.


(Preeti Sudan)

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MESSAGE

One of the main goals of medicine is to provide comfort and relief from pain and suffering. Unfortunately, a cure is not always possible particularly in this era of chronic diseases, and the role of physicians has become limited to controlling and palliating symptoms. Palliative care affirms life and regards dying as a normal process.

The key message that is to be conveyed this year is "Universal Health Coverage and Palliative Care – Don't leave those suffering behind". Universal Health Coverage is critical to achieving the Sustainable Development Goals and palliative care is essential and defining part of Universal Health Coverage. We need to ensure that all people have access to quality palliative care besides promotive, preventive, curative and rehabilitative health services.

For the large majority of people who require palliative services, primary care remains the first point of access. Primary care staff requires adequate training to identify, diagnose, treat and prescribe appropriately and when required, refer people to specialist care. I am happy that the program division is bringing out a training manual for imparting basic palliative care skills to non-specialist doctors and nurses working at district and sub-district levels.

I congratulate the team for this endeavour.


(Dr. B.D. Athani)



IMPROVING ACCESS TO PALLIATIVE CARE

WHAT IS PALLIATIVE CARE ?

It is care for patients with life-limiting illnesses & their families

It can be given in homes, health centres, hospitals and hospices

It improves quality of life



It benefits health systems by reducing unnecessary hospital admissions

It relieves physical, psychological & spiritual suffering

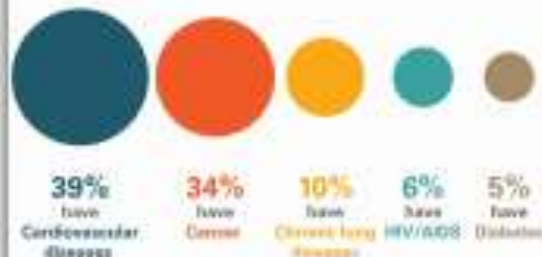
It can be done by many types of health professionals & volunteers

WHEN IS PALLIATIVE CARE NEEDED ?

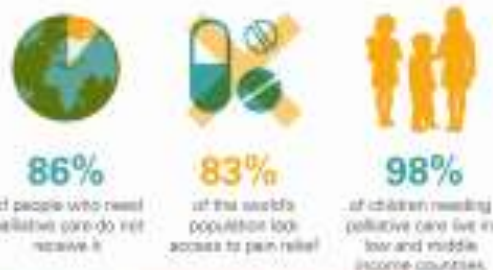


WHO NEEDS IT ?

Of the 40 million people who need palliative care each year:



WHAT ARE THE GAPS ?



WHAT ARE THE BARRIERS ?



WHAT CAN COUNTRIES DO ?

Implement the 2014 World Health Assembly Resolution 67.19 on palliative care, by:

INTEGRATING PALLIATIVE CARE INTO NATIONAL HEALTH POLICIES



Revise laws & processes to improve access to opioid pain relief



Include palliative care in the training for health workers



Provide palliative care services, including through primary health care centres and homes

Acknowledgement

We acknowledge the contributions of the team from National Institute of Health and Family Welfare, New Delhi, comprising of Dr. J K Das, Dr Utsuk Datta, Dr Sanjay Gupta and Dr Jai Prakash Shivdasani, officials from MoHFW, Mr. Navdeep Rinwa, Dr. Mohammed Shaukat & Dr. Alok Mathur and WHO officials Dr. Fikru Tullu & Dr. Atreyi Ganguli for their commitment and efforts towards the development of this training manual.

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CHAPTER 1

Introduction to Palliative Care

Background

More than 80% of all deaths occur after a certain period of debility. The conditions leading to these deaths and debility could be Non-Communicable Diseases (NCDs), notably cancer and also diabetes, cardiovascular diseases (non-acute), chronic respiratory diseases, renal failure, neuropsychiatric illnesses, Alzheimer's disease or other age related issues, certain chronic infections like HIV and drug resistant tuberculosis and other chronic incurable illnesses and conditions¹. The health care system traditionally focuses more on acute illnesses where the people affected mostly get back to their normal lives. The chronically and incurably ill people need regular supportive care but the system is not well equipped-both in terms of skills and facilities required- to provide this support. So these people are sent home saying 'we cannot do anything more for him/her'. The society also feel helpless as they do not know how to address the suffering of their fellow beings sent back from health institutions. Palliative care tries to address these issues.

What is palliative care?

'Palliative Care is an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illnesses, through the prevention and relief of suffering by means of early identification, impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual².'

Palliative care is applicable from the time of diagnosis of an incurable or life limiting illness and it helps the patient and family to come in terms with the situation, get good quality of life during the treatment and if do not get cured, during the advanced

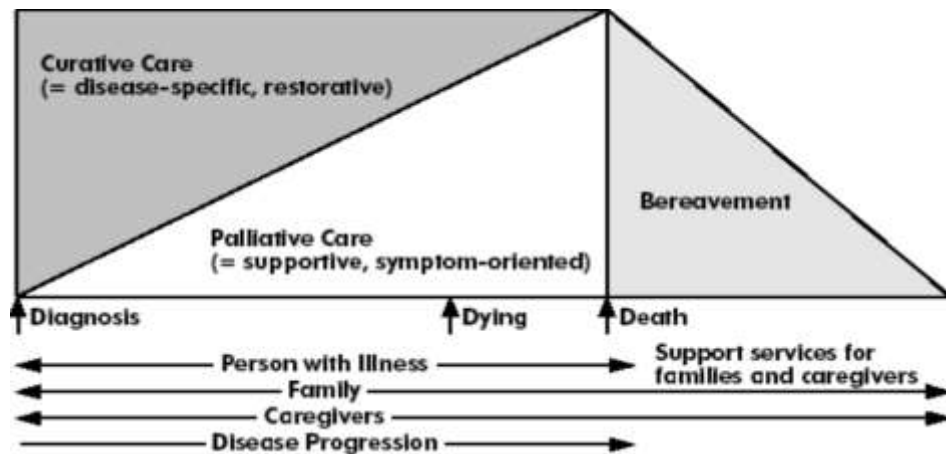
¹ Planning and implementing palliative care services: a guide for programme managers. WHO 2016.

http://www.who.int/ncds/management/palliative-care/palliative_care_services/en/

² Definition of palliative care. WHO. 2002. <http://www.who.int/cancer/palliative/definition/en/>

stages of the disease and death. The family is supported during the bereavement period. A chronic and incurable disease need not be immediately life threatening but can severely affect the quality of life and will benefit from palliative care interventions. Figure 1.1 illustrates a “continuum of care” for cancer, HIV/AIDS, and other life-limiting diseases.

Figure 1.1: “Continuum of care” for cancer, HIV/AIDS, and other life-limiting diseases

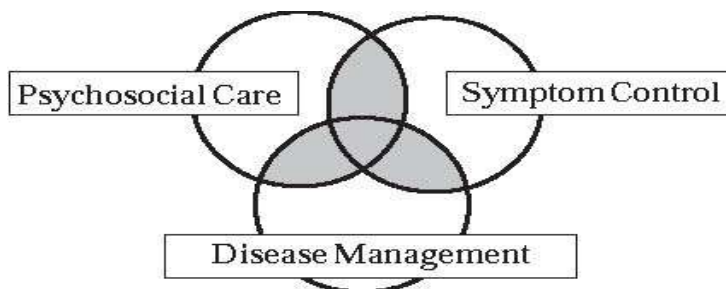


Source: MoHFW 2012. Strategies for Palliative Care in India³

Palliative care considers dying as a normal process. End of life care or terminal care is an important component of palliative care provided to those who are dying but the intention is not to hasten or postpone death. Palliative care helps people with life threatening or life limiting conditions live as actively as possible till the end.

Palliative care is concerned with all aspects of care, namely, disease management, symptom control and psychosocial support. No single sphere of concern is adequate without considering its relationship with the other two (Figure 1.2).

Figure 1.2: Interplay between psychosocial care, symptom control and data management



³ Strategies for Palliative Care in India (Expert group report). 2012. Directorate General of Health Services, Ministry of Health & Family Welfare, Govt of India.

In order to address sufferings, issues occurring beyond physical domain also need to be taken care of. The psychosocial stress from chronic illnesses adds to the physical suffering. The long-term care required and some of the expensive treatment options can have huge negative financial impacts on patients and their families which push people further in to poverty.

Providing supportive care in such complex situations, requires a multidisciplinary approach is required, in which, anyone – health care professionals, social workers, friends or community - who can help improve quality of life of the patient and his/her family can participate. In chronic illnesses needing palliative care most of the care can be provided at the community/primary level and institutions will be required as a back up to handle difficult situations or crises occurring during the course of the illness. This will reduce the stress on the existing health care systems and lead to their optimum use.

The need

Worldwide, around 40 million people need palliative care each year and more than three quarters of them live in low and middle income countries. Only 14% of them have access to palliative care. 83% of world's population has poor access to pain relieving opioid medications⁴. 69% of the people needing palliative care are above sixty years of age and 6% are children.⁵ More than two thirds of the countries in the world either have no palliative care services or isolated service provision^{4, 55}.

In India the palliative care is needed for more than six million people and only two percent of them have access to palliative care^{6,7,8}. The need for palliative care will continue to rise due to population ageing and increasing NCD burden.

⁴ Palliative care fact sheet. WHO. N 420. July 2015. <http://www.who.int/mediacentre/factsheets/fs402/en/>

⁵ Global Atlas of Palliative Care at the End of Life. WHO 2014.
<http://www.who.int/nmh/Global Atlas of Palliative Care.pdf>

⁶ Kumar S. Models of delivering palliative and end-of-life care. Support Palliat Care 2013;7(2), pp. 216–222.

⁷ Murtagh F., Bausewein C., Verne J., Groeneveld E., Kaloki Y., and Higginson I. How many people need palliative care? A study developing and comparing methods for population-based estimates. Palliative Medicine. 2014; 28(1), pp. 49-58.

⁸ Sallnow L, Kumar S, Numpeli M. Home-based palliative care in Kerala, India: the Neighbourhood Network in Palliative Care. Progress in Palliative Care. 2010; 18(1), pp.1-4.

Populations are ageing worldwide⁹. In India the life expectancy has doubled from 32 years at the time of independence. Currently there are 104 million people who are above the age of 60 years in India¹⁰. It is estimated that by 2050, there will be more than 320 million people above 60 years of age in the country, comprising 20% of the population¹¹. In the coming years the elderly population, with their age related issues and co-morbidities, will form the largest group needing palliative care.

Apart from most conditions requiring palliative care in the general population, children will also have neonatal conditions, congenital anomalies, neurological conditions like cerebral palsy and rare diseases. It is estimated that 98% of the 1.2 million children needing palliative care worldwide, live in low and middle income countries⁵. Only a fraction of them have access to palliative care. In India too, the children's palliative care programmes are patchy.

The first hospice in India, Shanti Avedana Ashram, was set up in Mumbai in 1985. The development of palliative care in India has been slow. Currently most of the palliative care services in India are run by the Non-governmental Organizations, with the exception of Kerala, where the government has taken an active lead to develop the service within the health care system. The first community based palliative care service, was established in Kozhikode, Kerala in 1993. The idea of community ownership evolved in to Neighbourhood Network in Palliative Care (NNPC), a network of community owned palliative care services providing care at community level with a thrust on home based care and supported by health care professionals and palliative care institutions^{1, 5}. The Kerala government's palliative care policy (2008) aimed at integrating palliative care in to the healthcare system¹². The Local Self Government Institutions (LSGI) now provide primary palliative care at the community level and secondary and tertiary health institutions provide care to people

⁹ World Population Prospects: The 2015 Revision, Key Findings and Advance Tables. United Nations Department of Economic and Social Affairs/Population Division. United Nations New York, 2015.

¹⁰ Elderly in India- 2016. Central Statistics Office Ministry of Statistics and Programme Implementation, Government of India (www.mospi.gov.in)

¹¹ State of elderly in India. HelpAge India. 2014. <https://www.helpageindia.org/images/pdf/state-elderly-india-2014.pdf>

¹² Palleri AK. Showing the way forward: Pain and palliative care policy of the Government of Kerala. Indian Journal of Palliative Care. 2008; 14(1), pp 51-54.

needing specialist care¹³.

Two other states in India (Maharashtra and Karnataka) now have palliative care policies and follow up activities have started. The National Programme for Palliative Care by the Government of India has been initiated in 2012 and is now being implemented through the National Health Mission³. The focus is to develop capacity and services, initially at the district level.



Figure 3: The proposed model for Long Term Care (TLC) and Palliative Care (PC).
Adapted with permission from Stjernseward 2005 (Indian Journal of Palliative Care (2))¹⁴

According to Figure 3, majority of people needing palliative care will be at the primary level. Hence there is a need for the health care professionals at this level to get trained to improve the clinical skills required for good symptom control and communication skills for crucial conversations. A sensitized and skilled community can look after the non-medical needs of these patients and provide a support system not just for the affected people but also for the health care professionals by helping to organize care provision locally. The role of the specialists will be to handle complex issues and to train the professionals at various levels.

¹³ GO (ORD) No.3217/2015/LSGI dated 29 October 2015. Government of Kerala; Local Self Government Department. Thiruvananthapuram, Kerala.

¹⁴ Stjernseward J. Community participation in palliative care. Indian Journal of Palliative Care 2005;11:22-7.

Medicine availability

Pain is a common symptom in conditions requiring palliative care. The incidence can be as high as 80% in cancer and contribute much to the suffering from the disease. Opioids have been the main stay for pain management but their use was very much restricted due to lack of availability, lack of adequate knowledge among professionals and misconceptions among public and restrictive policies aimed at preventing misuse of such medicines. All these three issues need to be addressed simultaneously to ensure appropriate use of opioids in chronic pain. In 2014, the Government of India amended the Narcotic Drugs and Psychotropic Substance (NDPS) Act to improve the access to opioids for medical use and this step is expected to improve the availability of pain medications in India.

Way forward

Palliative care is now considered as a human right issue¹⁵. People have the right to live with dignity and palliative care aims at helping the chronically and incurably ill people to live with dignity through their disease trajectories and end of life period. Palliative care is gathering momentum worldwide and is now considered as an integral part of universal health coverage. In the first ever global resolution on palliative care, the 67th World Health Assembly (WHA resolution 67.19) in May 2014, emphasized the need for 'strengthening palliative care as a component of integrated treatment within the continuum of care' and urged the member states to develop palliative care at all levels with emphasis on primary care, community and home based care along with appropriate policies, education and ensuring availability of medicines¹⁶.

Chronic and incurable illnesses are not simple health conditions. They cause tremendous social stress and put great demand on the financial and health resources. A good palliative care programme integrated in to the health care system will ensure continuity of care at all levels and at primary level family and community can get involved to provide basic care, emotional support, spiritual care etc. This will

¹⁵ Unbearable Pain: India's Obligation to Ensure Palliative Care. Human Rights Watch, (2009).

<https://www.hrw.org/sites/default/files/reports/health1009webwcover.pdf>

¹⁶ Strengthening of palliative care as a component of comprehensive care throughout the life course. 67th World Health Assembly resolution (WHA67.19). May 2014.

<http://apps.who.int/medicinedocs/documents/s21454en/s21454en.pdf>

put less stress on the limited health resources in the country. Along with this the awareness among health care professionals, policy makers and the public about palliative care and the benefits it can provide to people with advanced illnesses, has to be improved.

The 2017 health policy of the Government of India¹⁷ has identified palliative care as one of the key areas and this is a right step towards providing appropriate care for the millions in the country affected by life limiting illnesses.

Activity

There is a 32-year-old lady with advanced breast cancer in your neighbourhood. She has two children aged 8 and 6. Her husband is a manual labourer. The treating doctor has told the husband that her disease is not responding to treatment and the patient is likely to die in 6–9 months. You visited her yesterday. She complained of pain all over the body. She looked very worried. As a neighbour, what can you do to help this patient and her family?

Who all can you seek help from?

- Discuss in small groups
- List your suggestions.
- Exchange with other groups

Source: Institute of Palliative Medicine 2017. Palliative Care – A Workbook for Carers, accessed from <file:///D:/userprofiles/ganguliat/Downloads/Palliative%20Care%20Workbook%20for%20Carers.pdf>

¹⁷ National Health Policy. Government of India, 2017.

CHAPTER 2

Communication Skills

Learning objectives

At the end of the chapter, the candidate should be able to:

- Know about the basic skills in communicating with patients.
- Differentiate between good and poor communication techniques.
- Develop listening skills.
- Know how to break bad news.
- Know how to handle patient's reactions

Time: 30 minutes

Basic Communication Skills

Communication is a vital basic pre-requisite for all physicians to provide effective treatment for all patients and not just in the palliative care scenario!

Good and effective communication is not optional, but mandatory

Studies show that it is not the quantity of time involved in communicating but the *quality of communication* that makes the difference. Some of the busiest health care professionals in the world are also those with the best communication skills. It is a strange fact that although a good percentage of professional time is to be spent in communicating with patients there is very little emphasis in learning this skill. This module is aimed at giving an outline of the 'basics of communication' and candidates are requested and encouraged to make communication a priority in their day-to-day clinical practice.

Communication can never be neutral; it is either effective or ineffective, stress relieving or stress inducing.

Listening skills

It is very important to practice **active listening**, as it is the key to effective communication. The following methods help to enhance listening skills:

- ***Greeting and seating*** – Be naturally hospitable, allow the patient to take his/her comfortable position in a private area (room or cubicle.) Sit next to the patient at a

reachable distance without any 'barrier' (e.g. consultation table) in between, if possible.

- Ask open questions – Open-ended questions give freedom to the patient to decide what and how much he/she should tell. Here the agenda is set by the patient, and the listener i.e., the health care professional (HCP) waits for the cue.
- Encourage talking – Generally, in a doctor- patient communication, doctors talk more and the patients are forced to listen, unable to clear their doubts and uncertainties. In order to get more details and to develop better rapport, it is good to encourage the patient to talk about his concerns. At the same time it is important to bring the patient back to the discussion when he/she deviates from the central theme.
- Maintain eye contact–It gives confidence to the patient that he/she is being attentively listened to. It is all right to withdraw eye contact for a few seconds, when the patient looks away, starts crying, and also when the patient, overcome by emotion, becomes silent.
- Tolerate 'brief 'silence – HCPs tend to get impatient when patients slow down their narration and become silent. . It has to be understood that patients can become emotional as they narrate their past and describe a sensitive event or situation. They also need time to recollect certain events as they are telling their story. If we interrupt at this time, they can forget the chain of events or conclude that we are in a hurry and may not go on to ventilate their feelings adequately. This may only result in taking more time for communication as it may have to be redone again to satisfy the patient.
- Avoid unnecessary interruption – When patient's history is elicited, though questions need to be asked for clarification and details, it should not be too frequent in a way that it interrupts the flow of communication.
- Show them we are listening: The patients should get the feeling that we are listening to them by verbal and non-verbal means. This can be done by repetition, reiteration (paraphrasing) and reflection.
- Summarize & prioritize the agenda: Tell them the plan of treatment.
- Empathize & give realistic hope.

Examples of good and poor communication techniques

1. Ask open questions

Dr: “How are you feeling?”

This allows patients to ‘open up’ and ventilate their feelings.

Is your pain better today?

This is a *closed* question, which gives either *yes* or *no* as answer and it is less appropriate.

2. Be empathetic

Pt: “I feel scared when I am breathless”

Dr: “Take these tablets to ease your breathing”

Here the doctor is not responding to the patient’s emotions. A better approach could be

Pt: “I feel scared when I am breathless”

Dr: “Breathlessness can be very frightening. It is very understandable. Breathing medication should help”.

OR

Dr: “What scares you most when you get breathless?”

3. Be sensitive while telling the truth.

Pt: “The Doctor said my cancer is incurable”

Dr: “Don’t worry about such things, everything will be OK.”. Here doctor is giving false reassurance, which is not the correct approach. A better statement could be:

Dr: “It must have been very hard to hear that the cancer has spread but we will do our best to help you in whatever way we can”

4. Attempt to balance hope and truth

Dr: “There is nothing more we can do, your disease is incurable, and so there is no point in staying in hospital”

Here doctor is totally destroying hope, which is incorrect. Doctor should try to balance hope and truth as shown below:

Dr: “I am sorry that there are no more treatments available to cure your disease, but we can start other medicines to make you more comfortable. Then you can be at home with your family. If you need any help in the future, you must come to the clinic or contact me.”

5. Maintain confidentiality and avoid unhealthy curiosity.

Pt: “I have not told anybody before, but I think I got this cancer because I had an abortion when I was 17.”

Dr: “Were you not married at that time”?

Here doctor is getting curious on an irreverent matter. The right approach would be as follows:

Dr: “I think we need to discuss about this more as it is obviously very significant for you, but please know that everything we discuss will be kept confidential”

The doctor here assures confidentiality and at the same time he would like to have more details, which could be medically important.

6. Partnership between doctor and patient”

Dr: “You must take this medicine for your pain. Unless you take this, your pain will remain as such.

Doctor is imposing his agenda on the patient which is not appropriate.

Dr: “Your pain is caused by the disease and you need a pain medicine for that. How about giving it a try?” Here doctor is trying to establish a bond with the patient by soliciting his opinion.

Breaking bad news

Breaking bad news is an important aspect of communication. It takes time and most issues often need to be discussed in detail and clarified as and when more information is shared.

Reflective learning

- ***Should we tell the diagnosis to the patient or not?***
- ***If you had a diagnosis of cancer would you want to be told?***
- ***How would you feel if your family chose to hide the news from you?***

There is increasing evidence that patients would like to know about their illness.

Why should patients be told about their disease?

- Patients have the right to know about their disease
- It permits patients and families to plan their life
- Knowing the truth allows the patients to cope with the disease
- Reduces uncertainty
- Avoids false hope
- Builds trust between the patient and the physician.
- Helps compliance to treatment.

Collusion

Often in Indian scenario the patient's family would not want the patient to know about the diagnosis. Rarely, the patient himself may not want the family to know. The act of shielding information from the patient or family is called 'collusion'.

Understanding and dealing with Collusion:

When the family says "don't tell", we must understand that it is generally an act of love or a need to protect the patient from getting hurt.

It is our duty to try to convince the family to allow us to reveal the diagnosis. The following maybe a useful strategy:

1. Find out what the primary concerns of the family are
2. Acknowledge their concerns and feelings.
3. Explain the benefits of telling the truth.
4. Outline the possible harmful effects of not telling.
5. If necessary, challenge in a non- offensive manner
6. Assure the family that the diagnosis will not be revealed if the patient is not willing to know.

Denial

Not wanting to know the diagnosis is a form of *denial*. It implies that the patient is not mentally prepared to handle the news.

Denial is a coping mechanism, which helps to avoid painful thoughts and feelings which are difficult to deal with. This emotion has to be respected and therefore the information should not be forced onto the patient, *if he/she cooperates with the treatment. However it needs to be gently broken if the patient is **not** cooperating with the treatment and is in distress.*

Telling the prognosis of the patient:

“How long will I live?” or “How long has he got?” are not uncommon to hear from patients or family members. Avoid direct answers! There may be specific reasons for them to ask such a question which should be explored and ascertained.

Sometimes, advising patients and families with regard to prognosis may be necessary if they want to organize and plan for the time that is left, ***but it is impossible to be accurate.***

Overestimating or underestimating the time that someone has to live can cause untold anguish. It is therefore more sensible to talk in terms of days/weeks, weeks/months, and months/ years as appropriate. It is important to be aware that people have divergent attitudes while receiving bad news and this needs sensitive handling. As health professionals, we can be very critical of how our colleagues have passed on bad news. Some of this criticism may have validity, but before judging too quickly we need to remember that a patient’s understanding of what they have been told can differ greatly from what the nurse or doctor think they have said!

Strategy for breaking bad news:

Before breaking bad news it is important to know the skill of doing so and also know how to respond to any emotional reaction of the patient after hearing the diagnosis.

The process of breaking the bad news needs to be tailored to the needs of the individual concerned. It must be done in such a manner that it reduces the impact of the bad news and facilitates understanding and acceptance. The consequences of a bad performance can lead to immediate and long term damage to the patient and all involved.

Steps in Breaking Bad News

A 6-step protocol (SPIKES) described by Robert Buckman is generally helpful to learn the skill.

Step 1: S - Setting the context:

- a. Acquire all information possible about the patient and family. A family tree can be useful to know the important people in the patient's life and the kind of relationship with them.
- b. Making basic mistakes regarding the patient's illness will lower the patient's confidence in the doctor. Go through the case sheet and get details regarding the following:
 - Diagnosis
 - Patient's clinical history, investigation results
 - Plan of care and prognosis.
 - Support system for the individual.

Ensure the following

- Privacy and patient comfort
- Informal introduction about yourself
- Find out if patient wishes to have someone with him/her.
- Allot adequate time for the discussion
- Avoid interruption.

Step 2: P – Assessing the patient's Perception

How much does the patient know already?

"What do you know about your disease?" or, "What did the doctor tell you?" Ask a few questions, probe just enough to make sure you get as much information as possible to assess the patient's understanding of his/her disease"

Step 3: I – Obtaining the patient's Invitation

How much does the patient want to know?

“Would you like me to explain further about your disease?”

Note the patient’s expression.

Try to find out if there is anything concerning the patient which he/ she is not verbalizing?

If the patient does not wish to know further, the interview ends then and there, after assuring continuity of care and giving realistic hope. Remember that the patient has a right not to know and one must respect this wish. ***But he needs to be told that he is welcome at any time for further discussion on this matter***

If patient wants to know - he/she will say:

“Yes, I would like to know what it is”

Or

“Please tell me”

Then proceed to sharing of information

Step 4: K – Giving Knowledge and information

First give a warning shot to help the patient to prepare him.

Examples of warning shot:

“You seem to have a swelling (or “wound”) which is not the usual type”

Or

“It looks like the swelling you have is not a simple one”

Pause, observe patient’s expression/wait for the response and proceed. Sometimes the patient at this point may come forward with a question ... “not simple or serious, does it mean it is cancer/?!”

Then the answer should be

“The test results show that it is cancer”

Pause again after you have said the word “cancer”.

Try to be brief, sensitive and clear. Do not be either too abrupt or too long.

Avoid technical language and abbreviations, which are easily misunderstood.

Step 5: E – Addressing the Emotions

Be sensitive to the patient's emotional reactions. Encourage the patient to speak by listening carefully and responding empathically. Allow silence or questions. Listen to emotions of anger/ grief/ denial if expressed. Address the patient's real concerns, which may be very different from what you expect them to be. Do not give false hopes by saying, for example,

“Don't worry, everything will be alright!”

Acknowledge the patient's feelings

Guidelines for responding to patients' reactions and handling difficult questions

It is important that the HCPs should be prepared to work through the patients' emotional responses to bad news with them. It is very common for the relatives and patients to express their total distress rather than bringing out a particular or isolated concern. It is worthwhile to identify the distress and react accordingly. The following guidelines may be useful while responding to concerns of the patients and relatives.

- a. *Acknowledge the reaction* – The reactions are often directed to the situation, not to the HCP. Hence it is helpful to acknowledge that they are distressed. *We must learn to respond rather than react.* When we respond, we evaluate with a calm mind and do whatever is most appropriate and we are in control of our actions.

When we react, we are inadvertently doing what the other person expects us to do!!

Example: Patient says, “I knew it! I knew when I was not getting better while the doctor was giving me only medicines all the time!”

Identify the emotion as 'anger'.

The following response may help

“I can see how angry you are feeling that your disease should have been diagnosed much earlier.

Later you can explain what may be the best thing to do without going into further details of what happened in the past.

There may be a reason for the reaction of the patient and/ or caregiver. Identifying (e.g. anger) and helping the patient or caregiver to solve it will definitely ease the situation.

- b. Allow the patients to express feelings –This will help to ventilate feelings, so that this may relieve the stress he/she is undergoing.
- c. Help the patient to take a decision: Give options, explain what can realistically be done to suit his needs, respecting his agenda, rather than imposing ours.
- d. Remain silent if we do not have an answer. Do not always try to find solutions: There is a natural tendency for us to search for answers when the patient asks a difficult question.

For example, “Why did God do this to me? Often we preach philosophy or quote moral stories to pacify the patient. But we should realize that these are not taken up well by the patients who themselves know these things very well!! Silence is the best answer here as the patient only wishes someone to listen to his concerns and is not actually looking for answers. Our task should be to help the patient to find a solution rather than to suggest one. Solutions from our end may not be acceptable for the patients in most of the situations as they may not conform to their beliefs and thoughts.

Step 6: S – Strategy and Summary

Ensure that he/she has understood what was told. Clarify as follows

“Are there any points which you would like me to explain more?”

- The plan for ongoing care and support should be drawn up with the patient, if the patient is ready for a discussion
- Summarize the key points again. Identify any support group, which may be helpful, and make concrete plans for the future.
- Record details of the conversation in the patient’s notes clearly so that other team members understand the situation

Conclusion

Communication skills are not commonly taught to HCPs, though they are crucial for relieving total suffering of patients and their families. The skills needed to

communicate well with patients are not complex and they can make a significant difference to quality of life in both patients and professionals. Conversely poor communication can lead to increased stress for professionals and distress for patients and their families. Most often professionals who are pressed for time find it tough to communicate effectively.

Activity

Discuss the following in groups:

1. Are there any preparations needed from our part when we visit a patient?
2. What do you talk about with the patient?
3. What are the dos and don'ts in such a conversation?
4. How do you conclude the conversation and take leave?

Source: Institute of Palliative Medicine 2017. Palliative Care – A Workbook for Carers, accessed from <file:///D:/userprofiles/ganguliat/Downloads/Palliative%20Care%20Workbook%20for%20Carers.pdf>

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This chapter forms part of the Handbook on Palliative Care published by the Indian Association of Palliative Care. Grateful acknowledgements to the IAPC, the Editor and Authors

Activity

Discuss the following:

Are there any preparations needed from our part when we visit a patient?

- What are the key issues we discuss with the patient?
- What are the dos and don'ts in such a conversation?
- How do you conclude the conversation and take leave?

CHAPTER 3

Management of Pain

Learning Objectives

At the end of the chapter, the candidate should be able to:

- Define pain and differentiate different types of pain
- Understand classification of cancer pain and the concept of total pain
- Assess pain and plan pain management
- WHO pain ladder and its Indian adaptation for pain management

Time: One hour

I am afraid not of cancer but pain!

The International Association for the Study of Pain (IASP) defines:

Pain is “an unpleasant sensory and emotional experience associated with actual or potential tissue damage or described in terms of such damage.”¹⁸

- Pain is one of the most common and distressing symptom in cancer.
- An estimated one-third (24-60%) and two-third (62-86%) of patients with cancer and advanced cancer respectively suffer from pain with more than one third having moderate-severe pain.
- Pain is the *fifth vital sign* and has no clinically feasible objective means to measure it.¹⁹
- Pain is “*what the patient says it is and wherever the patient says it is*”.
- Pain can be classified based upon the:
 - Duration: Acute or Chronic (≥3 months, elaborated in Table 1)
 - Etiology (Elaborated in Table 1)
 - Quality (Elaborated in Figure 1)
 - Severity:
 - Mild Pain: 1-3,
 - Moderate Pain: 4-6 and
 - Severe Pain: 7-10.

¹⁸ International Association for the Study of Pain. IASP Pain Terminology , 1994

¹⁹ Pain: current understanding of assessment , management and treatments”. Joint Commission on Accreditation of Health Care Organization and the National Pharmaceutical Council, Inc. December 2001.

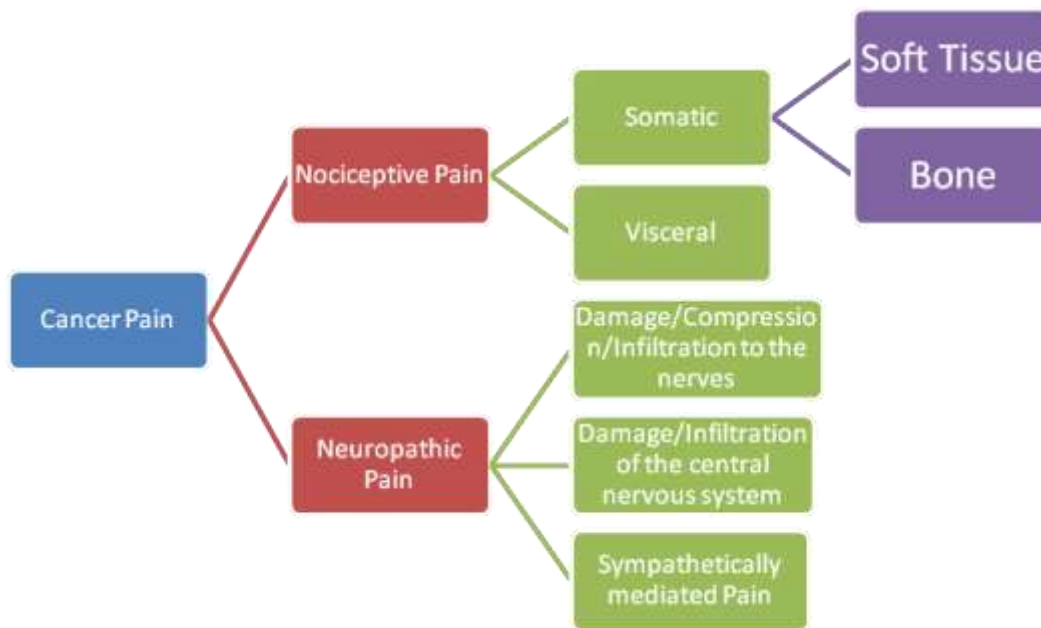
Table 3.1: Differencing pain according to duration:

| Acute Pain | Chronic Pain |
|---|--|
| Indicates tissue injury –potential/actual | Multi-factorial with neuro-chemical changes |
| Autonomic responses more dominant | Vegetative responses more dominant |
| Self-limiting | Unremitting, progressive |
| Intensity reduces as healing progresses | Constant reminder of a life threatening disease |
| Acute pain is protective; it is a symptom | Chronic pain takes on characteristics of a disease |

Table 3.2: Cancer Pain classified by Etiology and Putative Mechanisms

| Etiology | Mechanisms |
|--|--|
| 1. Due to tumor itself | a. Compression (of nerves/nerve plexuses/spinal cord/blood vessels causing ischemia etc). b. Infiltration (Nerves/Bones) c. Stretching (Liver capsule) |
| 2. Iatrogenic | a. Post-surgery (phantom limb pain/stump pain/post mastectomy pain/post-surgical chronic pain). b. Chemotherapy induced neuropathic pain c. Radiotherapy induced neuropathic pain |
| 3. Debility | Bed Sore, Constipation, bladder spasm etc |
| 4. Co-morbidities <i>Learning point: All pains in Cancer are not Cancer pain</i> | Sciatica, Back Pain, Arthritis, Angina |
| 5. Other Causes | Psychological pain Spiritual Pain Social Pain |

Figure 3.1: Classification of Cancer Pain



Concept of Total Pain

The theoretical concept of “total pain” is well accepted in the palliative care literature. For example, Montes Sandoval²⁰ and Al-Shahri et al²¹ recognized pain from a holistic perspective. Breitbart²² and Strang²³ described pain in cancer patients as multidimensional by nature. Allard and colleagues²⁴ mentioned the consequences of pain on physical, social, and spiritual functioning of patients, suggesting there may also be a bidirectional influence between these dimensions. Foley²⁵ discussed cancer as a chronic disease that requires social, psychological, and spiritual support. Easley and Elliot²⁶ described unrelenting pain at the EOL that extends beyond the physical realm into the psychological, social, and spiritual ones. The idea that pain at the EOL involves a consideration of the physical, psychological, social, and spiritual aspects is acknowledged, yet the physical determinants of pain often remain a predominant focus in clinical practice.

²⁰ Montes-Sandoval L. An analysis of the concept of pain. *J Adv Nurs*.1999;29(4):935-941

²¹ Al-Shahri MZ, Molina EH, Oneschuk D. Medication-focused approach to total pain: poor symptom control, polypharmacy, and adverse reactions. *Am J Hosp Palliat Care*. 2003;20(4): 307-310.

²² Saunders C. Introduction: history and challenge. In: Saunders C, Sykes N, eds. *The Management of Terminal Malignant Disease*. London, Great Britain: Hodder and Stoughton; 1993:1-14.

²³ Strang P. Emotional and social aspects of cancer pain. *Acta Oncol*. 1992;31(3):323-326.

²⁴ Allard P, Maunsell E, Labb2 J, Dorval M. Educational interventions to improve cancer pain control: a systemic review. *J Palliat Med*. 2001;4(2):191-203.

²⁵ Foley KM. Working Group 6: Palliative care, end-of-life care, and pain relief. Workshop Report: National Institute on Aging, National Cancer Institute. <http://www.nia.nih.gov/health/nianci/palliative.asp>.

²⁶ Easley MK, Elliott S. Managing pain at the end of life. *Nurs Clin North Am*. 2001;36(4):779-794.

Assessment should consider not only *physical* but also *psychological, social* and *spiritual* components of pain i.e. **total pain** (Figure 2).

Figure 3.2: Concept of Total Pain



- Always assess the cause, severity, type and any reversible cause before prescribing analgesics.
- Good communication (active listening, devoid of medical jargons, non-patronizing), building trust, portraying realistic goals and dispelling the patient and their caregivers myths and fears relating to pain and analgesics will help ensuring better compliance with the prescribed treatment regimen.
- The assessment of pain should be done regularly at least daily in patients with uncontrolled pain including assessment for treatment related side-effects.

Points to remember while assessment:

- Seek to establish a relationship with the patient.
- Encourage the patient to do most of the talking.
- Begin with a wide angle open question like “How are you feeling today?” before focusing and clarifying specifics.
- Watch the patient for non-verbal clues regarding the pain.
- Avoid jumping to conclusions. Pain assessment tools need to be valid, reliable and relevant.

- Pain can be assessed using the **OPQRST** characteristics.
- Various scales for pain assessment are as follows: Verbal Rating Scale, Numerical rating scale, Visual analogue scale, Percentage scale, Coin scale, Wong Baker Faces scale.
- A number of questionnaires such as pain detect tool and S-LANSS (Leeds assessment of neuropathic signs and symptoms) are available to determine pain of predominantly neuropathic origin.

Pain assessment

Pain assessment can be classified into:

- a) Symptom Assessment
- b) Physical Examination

a) Symptom Assessment: Use the **OPQRSTUV** mnemonic to assess pain. It is mandatory to conduct the following assessment for each and every site of pain in patients complaining of pain at more than one site. Table 3 provides the very specific OPQRST assessment questions.

Table 3.3: OPQRST assessment questions

| | | |
|----------|-----------------------------|---|
| O | Onset | When did it start? Acute or gradual onset? How long does it last? How often does it occur (continuous/intermittent)? |
| P | Provoking/Palliating | What brings it on? What makes it better or worse? |
| Q | Quality | What does it feel like (burning, electric shock like, tingling, numbness, itchy, etc?) |
| R | Radiation/Region | Does it spread anywhere else from the primary site of pain? |
| S | Severity | What is the severity on 0-10 numerical rating pain scale with 0 being no pain and 10 being most severe pain? Now? At its worst? Average? |
| T | Treatment | What medications are you taking or have taken for pain? Are they effective (completely/partially/not at all)? Did you have any side-effects from these medications? |
| U | Understanding | What do you think is the cause of pain? How is it affecting you and your family? |
| V | Values | What is your comfortable goal for this pain on a 0-10 numerical rating scale with 0 being 'no' and 10 'worst possible pain'? Are there any associated feelings about this pain that you would like to convey? |

Pain Measurement

Measuring pain is essential as it helps determining the severity, type, and duration of pain, which helps in making a more accurate diagnosis, draft out the treatment plan and also evaluate the effectiveness of treatment. Figure 4 provides one such scale where facial expressions are used to assess the intensity of pain. Face 0 is happy as it does not hurt at all, Face 1 hurts just a bit and the intensity increases with every face till it becomes excruciating.

Figure 3.4: Pain intensity scale



b) Physical Examination: Physical examination consists of:

Inspection: Change in color, swelling etc,

Palpation: temperature, tenderness, allodynia, hypoesthesia, guarding etc,

Percussion (e.g. abdominal pain): shifting dullness, fluid thrill, and

Auscultation (abdominal pain): bowel sounds.

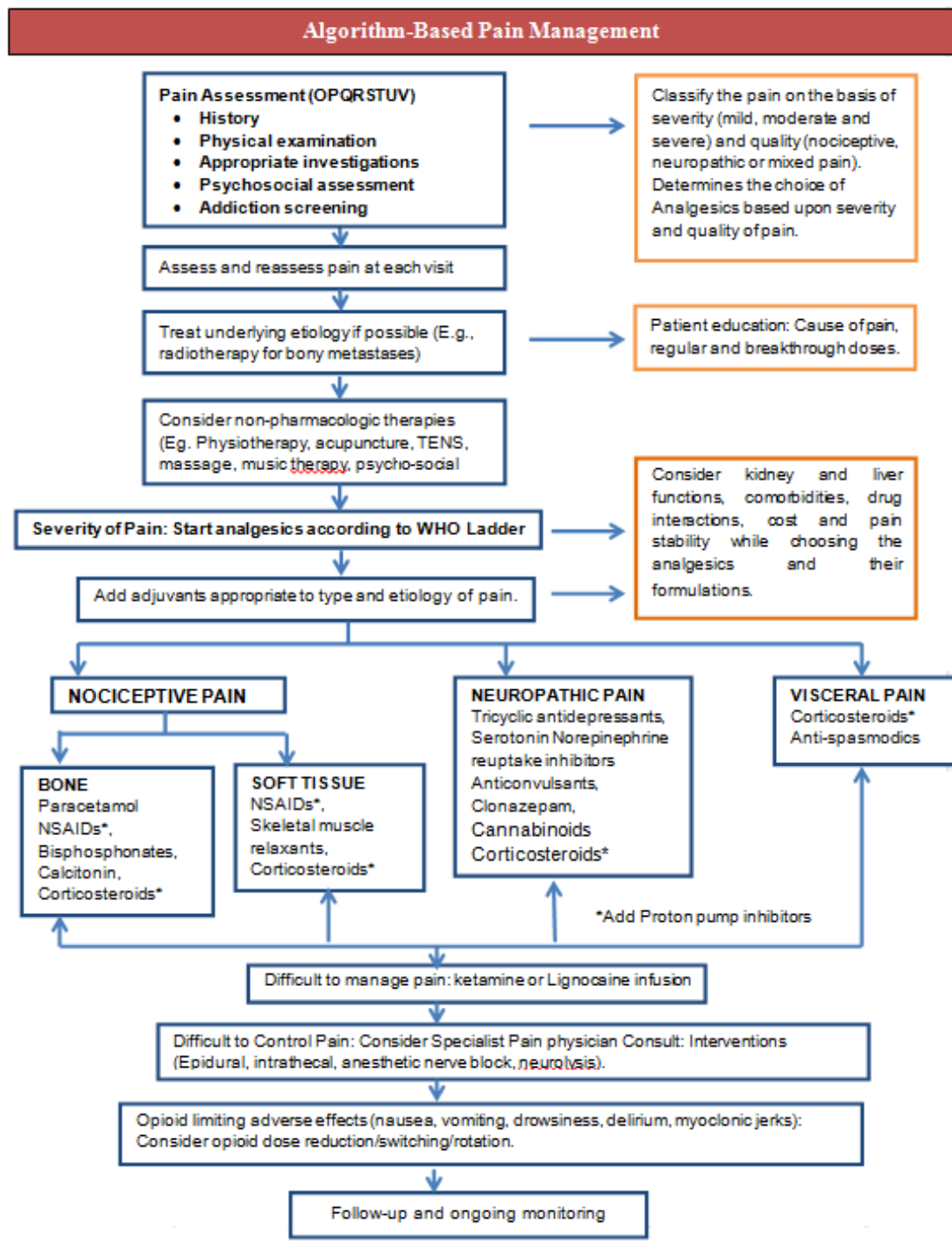
Pertaining to the site of pain

Algorithm-based pain management

Algorithm- based pain management is essential to ensure that consistency is maintained when guidelines or protocols are being operationalized. Algorithms have an added value as they provide a more complex "if-then" component to the guideline or protocol.

Figure 3.5 provides the guidance to pain management as algorithm-based in the form of algorithms.

Figure 3.5: Algorithm-Based Pain Management



Analgesic prescription according to WHO analgesic ladder

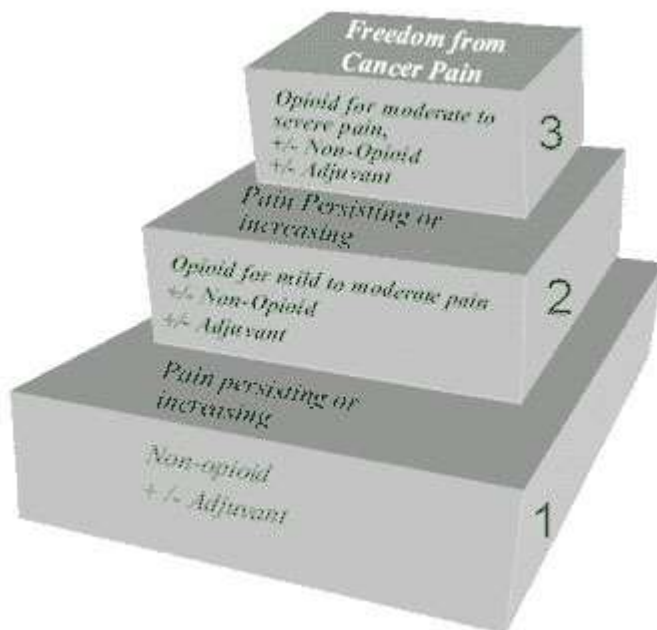
WHO's cancer pain ladder for adults

WHO has developed a three-step "ladder" for cancer pain relief in adults.

If pain occurs, there should be prompt oral administration of drugs in the following order: nonopioids (aspirin and paracetamol); then, as necessary, mild opioids (codeine); then strong opioids such as morphine, until the patient is free of pain. To calm fears and anxiety, additional drugs – “adjuvants” – should be used.

In order to maintain freedom from pain, drugs should be given “by the clock”, that is every 3-6 hours, rather than “on demand” This three-step approach of administering the right drug in the right dose at the right time is inexpensive and 80-90% effective. Surgical intervention on appropriate nerves may provide further pain relief if drugs are not wholly effective. In the case of cancer pain in children, WHO recommends a two step ladder²⁷. Figure 6 illustrates the WHO pain relief ladder.

Figure 3.6: WHO Pain Relief Ladder

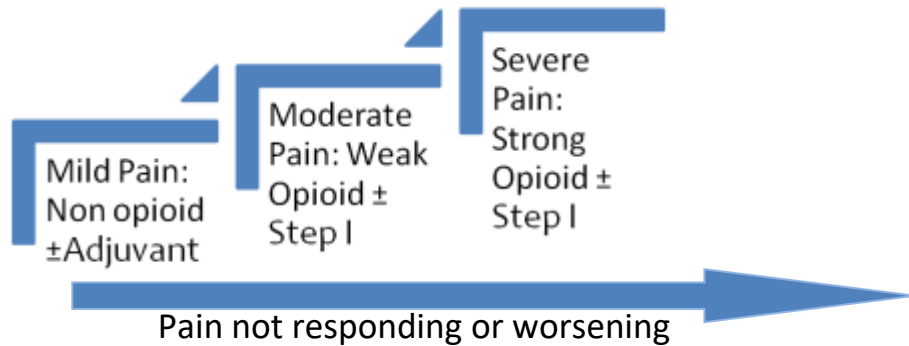


The Government of India, Ministry of Health and Family Welfare has constituted a committee consisting of experts from different centres of excellence in palliative care

²⁷ WHO 2017. WHO's cancer pain ladder for adults, accessed from <http://www.who.int/cancer/palliative/painladder/en/>

from different parts of the country, and has drafted the protocols for pain management, based on the WHO pain ladder, as shown in Figure 7.

Figure 3.7: Protocol for pain management



Mild Pain: Step 1

Non Opioid ± Adjuvant

- *Tablet Paracetamol* 500mg-1 gm (approximately 12 mg/kg/dose) q4h and/or *NSAIDS* (*Tablet Ibuprofen* 200-400 mg TDS or *Tablet diclofenac* 50 mg TDS or *tablet naproxen* 250-500 mg BD)
- The most common *side-effects* associated with NSAIDS are gastrointestinal (gastritis, gastric erosions, bleeding and perforation), renal toxicity (avoid in preexisting renal dysfunction or dehydrated patients) and platelet dysfunction (risk of bleeding). COX-2 selective inhibitors (*Etoricoxib*) although associated with relatively lower incidence of gastrointestinal side effects and platelet dysfunction; have been associated with cardiovascular adverse effects (Caution: Ischemic heart disease/ cerebrovascular disease)
- Always prescribe *proton pump inhibitors* with NSAID's (*Tablet Pantoprazole* or *Omeprazole* OD before breakfast). Ensure *adequate fluid intake* while the patient is on NSAID's.
- If the pain relief is inadequate in 24 hours switch to Step 2.

Mild to Moderate Pain: Step 2

Weak Opioid +Step 1

- *Tablet Tramadol* 50 mg PO TDS-QID or *Tablet Codeine* 30-60 mg QID.
- Always prescribe an *antiemetic* (*Tablet Metoclopramide* 10 mg TDS) while starting opioids.
- *Dextropropoxyphene*, another weak opioid is banned in India.

- If the pain relief is inadequate in 24 hours switch to Step 2.
- *Morphine* is currently the only oral strong opioid available for pain relief in India.
- *Codeine* to morphine conversion:

| | | |
|--------------|---|-------------|
| Codeine | = | Morphine |
| (240 mg/day) | | (30 mg/day) |
- Start with Tablet Morphine 5 mg PO four hourly and 5 mg SOS (breakthrough pain).
- For an opioid naive patient with severe pain crisis morphine trial with Injection morphine 5 mg intravenously (q10 minutes) or subcutaneously (q20-30 minutes) till adequate pain relief or till patient becomes drowsy which so ever is earlier can be tried in inpatient settings. Monitor carefully.
- If a patient is on opioids and present with severe pain crisis give the 4 hourly PO morphine dose IV q10 minutes or subcutaneously q 20-30 minutes till the pain is controlled or patient becomes excessively drowsy. Monitor carefully.
- Always prescribe a laxative (Tablet Dulcolax 2 tablet HS and/or Syrup lactulose 15 ml HS to start with) and an antiemetic (Metoclopramide/ Haloperidol) while prescribing morphine.

Management Principles:

- **By the clock:** Prescribe round the clock doses in contrast to SOS doses for effective pain relief.
- **By the mouth:** Start with oral immediate release opioids, titrate to effective dose before switching to sustained release opioids.
- **By the Ladder**
 - In accordance with the patient.
 - Once pain control is achieved, long-acting (q12h oral or q3days transdermal fentanyl) agents can replace oral preparations for better compliance and sleep.

- Always provide appropriate breakthrough **doses** i.e. 10% of total daily opioid dose dosed q1h SOS for breakthrough pain (pain that occurs spontaneously or in relation to a specific trigger in a patient whose pain is mainly stabilized).
- Record the prescribed medications, review the effect, any associated adverse effect and titrate or modify the medications accordingly.
- Use appropriate adjuvant analgesics at all the steps.
- Start with lower doses in elderly patients and those with deranged kidney or liver functions.
- Switch to another opioid when pain relief is inadequate despite dose-escalation or when associated with difficult to manage adverse effects as different opioids have different receptor agonist profile.
- Switch to an equi-analgesic dose of the another opioid, keeping in mind that recommended ratios are only a guide and that reassessment and dose modification are required.
- When switching because of adverse effects (e.g., delirium or generalized hyperalgesia), determine the equi-analgesic dose and reduce this dose by 25%.

Common opioid side-effects and their management

- **Constipation:** Stepwise escalation of oral stimulant (Tablet Bisacodyl 10 mg HS increased to TDS) or osmotic laxative (Syrup Lactulose) on opioid initiation.
- **Nausea and vomiting:** Usually self-limiting within 1 week. Prescribe Tablet Metoclopramide 10 mg TDS or Tablet Haloperidol 1.5-2.5 mg HS.
- **Drowsiness:** Initial drowsiness may be a sign of effective pain relief in a sleep deprived patient. Stimulants such as dextroamphetamine or modafinil may be helpful if sedation persists.
- **Delirium:** Assess for reversible causes like hypercalcemia and UTI. If no other cause apparent consider haloperidol 2.5-5 mg HS/PO.
- **Myoclonus:** May respond to benzodiazepines but may be a sign of opioid toxicity requiring hydration, opioid dose reduction or switching.

- **Pruritus, sweating:** Try opioid rotation or 5HT3 antagonists (e.g. ondansetron, granisetron).

Adjuvant Analgesics: Select based on type of pain and side-effect profile. Optimize dosing of one drug before starting another. Discontinue adjuvant drug if ineffective.

Severe opioid-resistant cancer pain: Consult a palliative care specialist for advice.

Table 3.4: Dosing and Opioid Conversion Chart and principles (According to Opioid availability in India)

| Drug | Route | Equianalgesic dose (mg) | Duration | Plasma half-life (hours) |
|----------|----------|-------------------------|----------------------------|--------------------------|
| Morphine | Oral | 30 | 4 | 4 |
| Morphine | IV/IM/SC | 10 | 4 | 2-3.5 |
| Codeine | Oral | 300 | 4-6 | 3 |
| Tramadol | Oral | 150 | 6.3 (immediate release) | |
| Fentanyl | IV | 0.1 | 1-2 | < 1 |

Table 3.5: Patch Conversion Doses* (Cost is a limiting factor)[16]

| Drug Name | Drug Dose | Equianalgesic Oral Morphine Dosage (mg) |
|-------------------------------------|---------------------------|---|
| Fentanyl 25 patch | 25micrograms/hour (µg/hr) | 30 mg to 134 mg/24 hours |
| Fentanyl 50 patch | 50 µg/hr | 135 mg to 224 mg/24 hours |
| Fentanyl 75 patch | 75 µg/hr | 225 mg to 314 mg/24 hours |
| Fentanyl 100 patch | 100 µg/hr | 315 mg to 404 mg/24 hours |
| Buprenorphine 5 patch | 5 µg/hr | 10 mg/24 hours |
| Buprenorphine 10 patch | 10 µg/hr | 20mg/24 hours |
| Buprenorphine 20 patch | 20 µg/hr | 40mg/24 hours |
| Transtec 52.5 patch (Buprenorphine) | 52.5 µg/hr | 94 mg to 145 mg/24 hours |
| Transtec 70 patch | 70 µg/hr | 126 mg to 193 mg/24 hours |

Opioid conversion tips

- Calculate the rescue dose: Prescribe 10% of the total daily opioid dose as an immediate release formulation.
- Opioid adjustments:
 1. Calculate the total oral 24-hour opioid taken by adding the amount of the sustained-release and immediate-release rescue doses.
 2. Divide total daily dose into appropriate intermittent doses based upon the specific opioid dosing intervals.
- Changing to another oral opioid:
 1. Calculate the total daily dose of current opioid (add the long-acting and breakthrough doses).
 2. Calculate the equi-analgesic oral dose of the alternative opioid.
 3. Divide total daily dose of the alternative opioid into appropriate intermittent doses based upon the opioid specific dosing intervals.
 4. Modify by reducing dose by 25%-50% for incomplete cross-tolerance.
- Changing an oral opioid to its IV/SQ route:
 1. Calculate the total amount of 24 hour oral opioid taken (add regular and breakthrough doses).
 2. Calculate the equi-analgesic total daily parenteral dose (e.g. divide the oral 24 hour dose of morphine by 3 to get 24 hour dose of IV morphine).
 3. Divide the equi-analgesic dose by 24 to get the hourly drip rate.
- Changing an oral or IV opioid to transdermal fentanyl:
 1. Calculate the total opioid dose (add regular and breakthrough doses).
 2. Calculate the equivalent total daily morphine dose.
 3. Determine the equi-analgesic dose of transdermal fentanyl using the patch conversion

Activity

- Discuss the reasons for the patient not taking medicines as prescribed (elicit comments from the group)

Source: Institute of Palliative Medicine 2017. Palliative Care – A Workbook for Carers, accessed from <file:///D:/userprofiles/ganguliat/Downloads/Palliative%20Care%20Workbook%20for%20Carers.pdf>

CHAPTER 4

Management of Gastrointestinal Symptoms

Learning objectives

At the end of the chapter, the candidate should be able to:

- Identify common gastrointestinal problems in palliative care;
- Identify, assess and manage problems like nausea and vomiting, constipation, diarrhoea;
- Manage halitosis, oral candidiasis/thrush, xerostomia

Duration: 30 minutes

General mouth care

The aim of good mouth care is to prevent problems before they arise and to control unpleasant symptoms. Mouth care should be undertaken routinely in all patients every 2-4 hours whether or not they are able to care for themselves. Particular attention need to be paid to patients who are comatose, on steroid therapy and receiving nasogastric tube feeding. Other patients who are less at risk need less frequent, but regular mouth care. Care includes cleaning the teeth with toothpaste and soft tooth brush after meals, regular mouth rinsing, keeping the mouth moist and looking for problems such as altered taste, halitosis, oral candidiasis, ulcers, denture problems and oral pain. It can be anticipated that a diligent search will often reveal a need for more meticulous mouth care.

Review of general dental hygiene should be done and request for professional help from a dental surgeon should be sought if necessary.

Halitosis

Halitosis is foul or unpleasant smelling breath

➤ Causes

- Dental/periodontal problems –poor oral hygiene, infected teeth, gums, oral mucosal or malignant growth/ulcer (Thrush alone is unlikely to cause halitosis)
- Sinusitis, malignant growth in sinuses
- Upper GI causes- gastric reflux or gastric stasis

- Bowel obstruction causing faecal vomiting
- Infection of the lungs e.g. bronchiectasis
- Dietary- a frequent cause especially the use of garlic or spices.

➤ **Interventions**

- Non-pharmacological-
 - Meticulous oral hygiene
 - Clean and soak dentures
 - Ensure adequate fluid intake
 - Flavored sweets e.g. Mints

- Pharmacological
 - Anaerobic infection of gums- oral metronidazole 400 mg BD.
 - Gastric hypersecretion- Metoclopramide 10 mg tds or Domperidone 10-20 mg tds.
 - Anaerobic infection of lings- parenteral Metronidazole.
 - Antiseptic mouthwash-
 - Chlorhexidine Gluconate 1% 10 ml QID.
 - Hexetidine 0.1% 10 ml QID.
 - Benzydamine 0.5% mouth wash
 - Debriding agents if indicated
 - Sodium bicarbonate mouthwash- 1teaspoon in 1 pint warm water and use a toothbrush on the tongue QID.
 - OR
 - Ascorbic acid (Vit C) - 250mg (1/4 of gram tablet) effervescent on the tongue QID.
 - OR
 - Hydrogen peroxide mouthwash 3% - 10 ml in half a tumble of water BD/TDS.

Oral Candidosis/Thrush

- Caused by Candida infection of the oral cavity.
- Patients may or may not have oral symptoms like pain and difficulty in swallowing (oesophageal Candidosis).

- Usually manifest as off white patches/plaques (pseudomembranous Candidosis) or reddened inflamed oral mucosa (erythematous Candidosis).
- Treatment involves management of infection, symptoms and cause of infection.
- Drugs:
 - Topical: Nystatin 1-5 ml suspension QID or clotrimazole mouth pain
 - Systemic: Tablet Fluconazole 50-200 mg OD
 - Duration: 7-14 days.

Xerostomia

- Subjective sensation of dry mouth.
- May be associated with loss of taste, difficulty in swallowing, speaking or chewing.
- May be due to:
 - Infection: Candidosis
 - Drugs: Anticholinergics, Antidepressants, opioids
 - Radiotherapy
 - Dehydration
 - Mouth breathing
 - Anxiety
- Treatment:
 - Correct the correctible: Treat infection or review medications
 - Frequent sipping of water, ice-chips or pineapple pieces
 - Good oral hygiene
 - Sugar free chewing gum
 - Consider saliva substituent (costly)

Nausea and vomiting

Nausea and vomiting are common symptoms being reported by 16-68% patients in palliative care and the incidence tends to increase as the disease progresses²⁸. There are multiple causes for nausea and vomiting in palliative care and it is

²⁸ Solano JP, Gomes B, Higginson IJ. A comparison of symptom prevalence in far advanced cancer, AIDS, heart disease, chronic obstructive pulmonary disease and renal disease. *J Pain Symptom Manage.* 2006;31:58–69

important to cater the management to the cause. The two main CNS areas involved in nausea and vomiting (NV) are:

1. **Chemoreceptor trigger zone** near the area postrema which sends signals to the vomiting centre.
2. **Vomiting centre** in the medulla oblongata which then initiates nausea and vomiting.

The vomiting centre also receives signals from higher centres (fear, anxiety), peripheral vagal and sympathetic stimulation as well as the vestibule.

It is important to distinguish nausea from vomiting:

Nausea: An unpleasant feeling of the need to vomit.

Vomiting: It is the forceful expulsion of gastric contents through the mouth.

The causes of NV in palliative care can be²⁹ :

Disease related: cancer, Congestive heart failure, chronic obstructive pulmonary disease, chronic renal failure.

Treatment related: chemotherapy, radiotherapy etc.

Debility related: Constipation, cachexia, anxiety, and oesophageal candidiasis or

Unrelated: Mesenteric ischemia

The most common causes of nausea and/or vomiting in palliative care are gastric, stasis, intestinal obstruction, biochemical disturbances, opioids /drugs and raised intra cranial pressure. An assessment to elucidate the likely cause and the neurotransmitters involved is essential for effective management as anti-emetics are predominantly neurotransmitter blocking drugs. Most often multiple causes and neurotransmitters are involved.

Clinical Assessment and Investigations

History: Most important to delineate the etiology of NV (Table 1).

²⁹ Glare P, Miller J, Nikolova T, Tickoo R. Treating nausea and vomiting in palliative care: a review. Clinical Interventions in Aging 2011;6 243–59.

Enquire about the:

- Duration, persistent/intermittent
- Provoking and the palliating factors.
- Any associated symptoms: pain, anxiety.
- The intensity (11 point “0-10 NRS”), frequency and psycho-social distress associated ¹².
- Review all the medications (both curative and palliative) taken by the patient.
- The bowel habits to rule out constipation.

Table 4.1: Delineating the etiology of NV based upon history ^{12,30,31}

| History | Most likely cause of NV |
|--|--------------------------------------|
| Persistent Nausea aggravated by sight and smell of food and unrelieved by vomiting. | Chemical causes (e.g. drug induced) |
| Intermittent nausea with early satiety and relieved by small volume forceful vomitus. | Impaired gastric emptying |
| Intermittent nausea with cramps, altered bowel habit relieved by large volume feculent or bilious vomitus. | Bowel obstruction |
| Early morning nausea and vomiting with headache. | Raised ICP |
| Nausea provoked by movement | Vestibular cause |
| NV exacerbated by anxiety | Cortical component |

³⁰ Stephenson J, Davies A. An assessment of aetiology-based guidelines for the management of nausea and vomiting in patients with advanced cancer. *Support Care Cancer*. 2006;14:348–53.

³¹ Bentley A, Boyd K. Use of clinical pictures in the management of nausea and vomiting: a prospective audit. *Palliat Med*. 2001;15:247–53.

Examination

- Look for signs of dehydration, oesophageal candidiasis, raised intracranial pressure, sepsis and drug toxicity and intestinal obstruction.
- Abdominal (organomegaly, bowel sounds) and per-rectal examination (constipation).

Investigations:

To identify the cause, any correctible causes and should be ordered only when they are going to alter the management.

- Kidney function tests
- Liver function tests
- Serum electrolytes including serum calcium
- Blood glucose
- Urine routine/microscopy for UTI
- Radiological examinations: X-rays, CT scan, MRI.

Management Strategies

- Following clinical assessment, *document the most likely cause*.
- Identify and *discontinue medications* that may be the cause.
- *Correct the correctible/exacerbating causes*: opioids, hypercalcaemia, UTI, pain, anxiety, constipation, dehydration etc.
- *Patient education*: Regarding the cause of NV, self-management strategies, to record the symptoms and the response to medications.

Non-pharmacological:

- Calm and reassuring environment.
- Diet (small bland meals) and environment modification (away from sight and smell of food).
- Control of malodor from fungating wounds, colostomy etc.
- Role reversal if patient is household cook.
- Maintain good oral hygiene,

- Acupressure (for chemotherapy-induced acute nausea but not for delayed symptoms).

Pharmacological:

- Prescribe the most appropriate anti emetic stat, regular and SOS.
- Titrate the dose to the effect.
- If no effect switch or add another anti-emetic from a different class. Review the choice and route of anti-emetic.
- Constantly review for effect and side-effects.
- Consider pre-emptive use of anti-emetics when starting opioids.

Consider the route of administration of medication as

- Persistent vomiting may reduce gastric emptying with resultant decrease in drug absorption.
- The parenteral route may reduce tablet burden which may be a contributing factor to NV.
- For persistent nausea/vomiting it is preferable to give subcutaneous infusion (pocket size syringe driver) rather than bolus injections which are more apt for single episode.
- Anti-emetics in suppository or tablet form can also be administered rectally.

Algorithm-Based Nausea/Vomiting Management

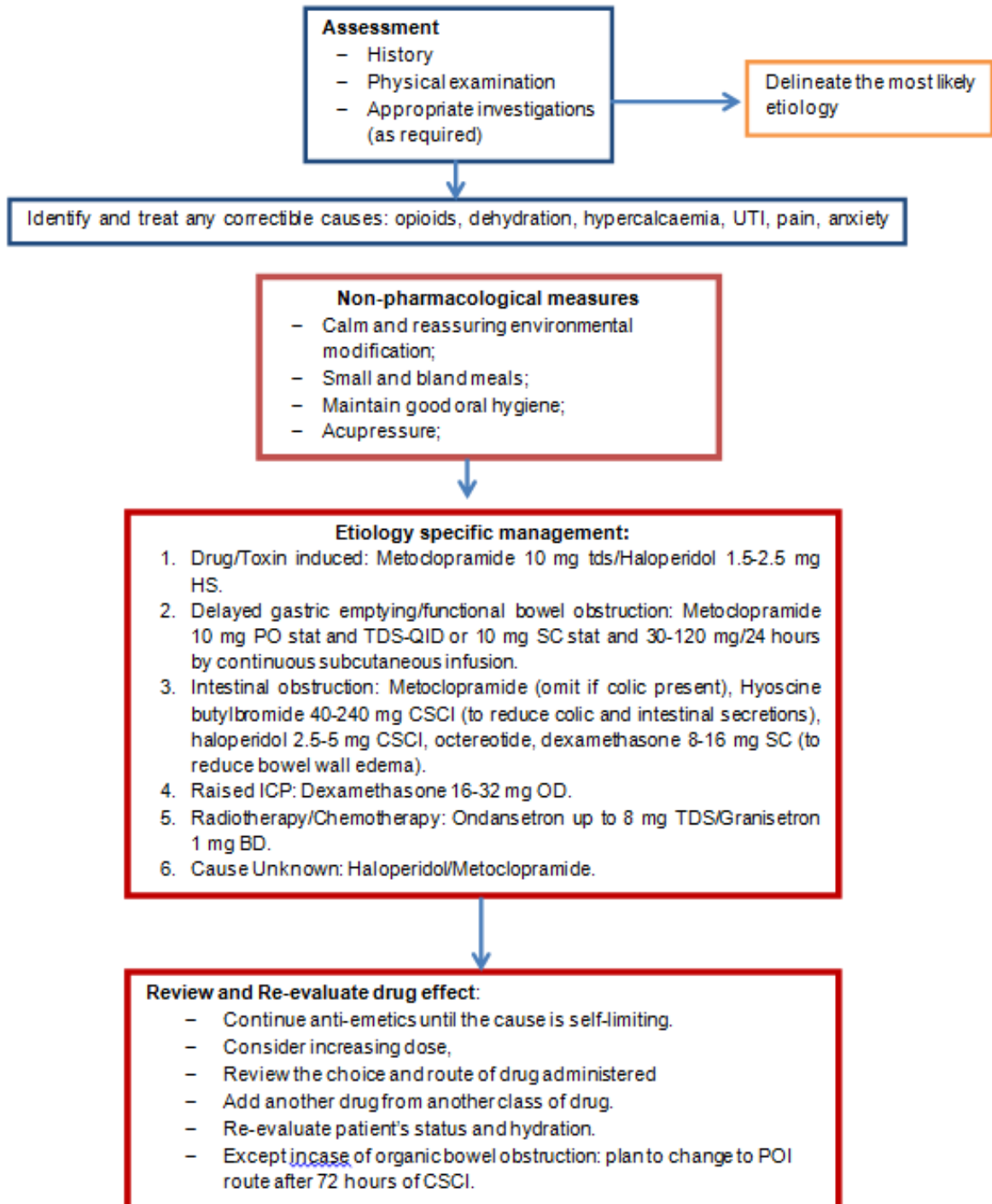


Table 4.2: Medications Used in Palliative Care for Nausea & Vomiting

| Drug | Route | Class and MOA | Available Dosage Forms | Standard Adult Dose |
|--------------------------|------------------|---|---|--|
| Dexamethasone | PO IV | Corticosteroid MOA: Anti-inflammatory, Acts on CNS | Tabs: 0.5, 0.75, 2, 4 mg Injection: 4mg/mL | Nausea: 4-8 mg/day. Malignant bowel obstruction/Raised ICP: 16-32 mg/day. |
| Haloperidol | PO/S C/ IV | Antipsychotic Antiemetic MOA: D2 Antagonist | Tablets: 0.5, 1, 2, 5, 10 mg, 20 mg. Injection: 5 mg/mL | Start with 0.5-1.5 mg stat and HS. Typical maintenance dose: 0.5-1.5 mg BD. Upper limit: 5-10 mg/day. |
| Metoclopramide | PO/S C/ IV | Prokinetic MOA: D2 Antagonist 5HT4 agonist | Tablets: 10 mg. Injection: 5 mg/ml. | 10 mg PO TDS-QID. 30-120 mg/24 hour CSCI. 10 to 20 mg SC/IV QID |
| Domperidone | PO | Prokinetic MOA: D2 Antagonist | Tablets: 10 mg | 10 to 20 mg PO BD to QID. |
| Granisetron | PO/IV | 5HT3 Antagonist | Tab: 1 mg Inj: 1 mg per mL | 1 mg to 2 mg PO/IV/SC* daily or 1 mg bid. |
| Ondansetron | PO/IV | 5HT3 Antagonist | Tablets: 4 mg, 8 mg. Injection: 2 mg/ml. | 4-8 mg PO/SC/IV BD- TDS. |
| Octreotide | SC/IM | Somatostatin Analogue | Inj: 50, 100, 200µg/ml. | 250-500 µg/24 hour CSCI. |
| Prochlorperazine | PO/IV | | Tablets: 5, 10 mg Injection: 5 mg per mL | 5 to 10 mg PO/IM/IV TDS-QID. |
| Hyoscine Butylbromide | PO/S C/ IV | Antimuscarinic | Tablets: 10 mg. Injection: 20 mg/ml. | Intestinal obstruction: 20 mg SC stat and 60-120 mg/24 hour CSCI. |

Constipation

Constipation can be defined as passage of small quantity of hard faeces infrequently and with difficulty³². It is a common symptom in cancer due to a multitude of reasons which can be disease related, low residue diet, immobility, weakness causing inability to go to the toilet, decreased fluid intake, drug related (opioids, octreotide, ondansetron, antimuscarinic agents and hyoscine derivatives) or hypercalcaemia/hypokalemia.

Clinical Assessment

- Constipation is subjective.
- Understand the patient's current bowel habit and compare it with before e.g., frequency of bowel movements, stool size, consistency, and ease of evacuation.
 - What is the usual stool frequency now?
 - What is the usual consistency of the stool: Loose, soft formed or small hard?
 - Do you feel the need to defecate but unable to do so?
 - Is the defecation painful?
 - Is there blood or mucus in the stools?
 - Do you often strain during defecation?
 - Enquire about any associated symptoms such as abdominal pain, nausea, bloating and halitosis.
 - Abdominal examination (palpable feces, organomegaly, bowel sounds) and rectal examination (if bowels have not moved for more than 3 days) are crucial in assessment for constipation. The findings on rectal examination have a major impact upon the management as discussed in the algorithm below.
 - Abdominal radiographs may sometimes be required.

³² Larkin PJ et al. The management of constipation in palliative care: clinical practice recommendations. Palliative Medicine 2008;22:796-807.

Constipation Management Strategies

Goal is to restore a patient's normal stool frequency, consistency, and ease of passage. In patients reduced food intake and activity, lower stool frequency is acceptable provided there is no associated discomfort.

Correct any correctible causes:

- a) Assess and ensure easy availability to the toilet/bed pan near to a debilitated patient.
- b) Ensure privacy.
- c) Caregiver education so as to be patient and compassionate towards the patient.
- d) Patient education regarding the causes for constipation and use of proper position for defecation.
- e) Ensuring adequate fluid and fiber intake.
- f) Review all the medications taken by the patient and prescribe laxatives along with liberal fluid and fiber intake when starting opioids.

With multiple ongoing risk factors as they are in most cancer patients, suggest laxatives regularly versus SOS.

Titrate the dose of laxatives according to the response (stool frequency and consistency).

Stimulant laxatives are the first choice of laxative for prevention and treatment.

Patients with irritable bowel syndrome may experience painful cramps with stimulant laxatives and often prefer osmotic laxatives such as lactulose or polyethylene glycol (PEG). However lactulose can taste unpleasant and also cause bloating.

- For patients with opioid-induced constipation, after a trial of first-line recommended stimulant laxatives and osmotic laxatives, methylnaltrexone may be helpful.

- The rectal interventions are both undignified and unpleasant however their short onset of action can be extremely satisfying. Rectal interventions should be avoided when there is potential for serious infection (neutropenia) or bleeding (thrombocytopenia), or when there is rectal/anal disease.

If rectal measures are required (when bowels have not moved for more than three days), generally a stimulant suppository is tried first, then an enema as the next option.

Algorithm-Based Constipation Management

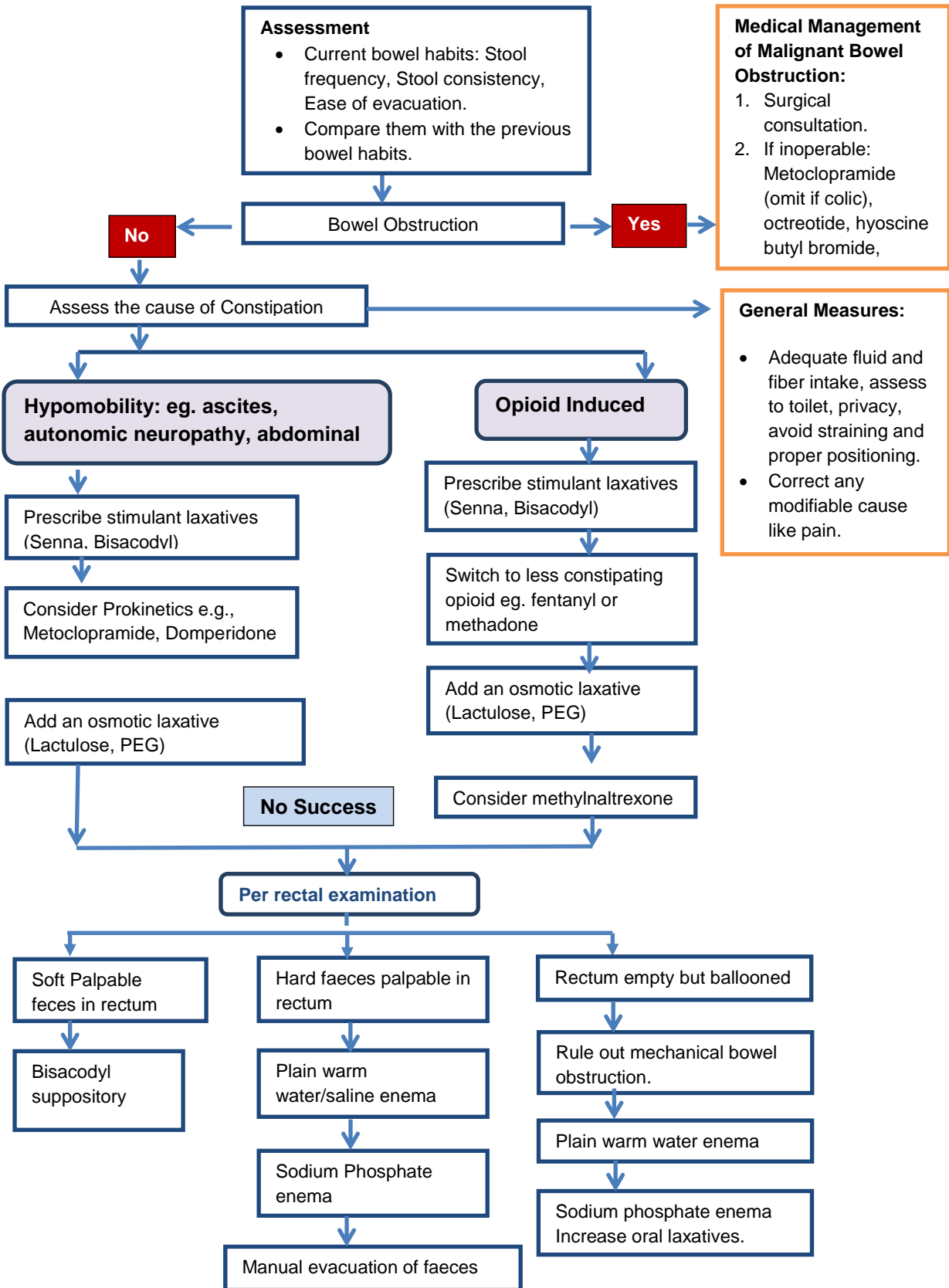


Table 4.3: Medications used for constipation in palliative care

| Drug | Classification | Onset of action | Available Dosage Forms | Standard Adult Dose |
|---------------------------|------------------------------|---------------------------------------|-------------------------------------|--|
| Bisacodyl | Stimulant laxative | PO: 10-12 hours PR: 20-60 minutes. | Tablets: 5 mg Suppository: 10 mg | 10-20 mg HS to 20 mg TDS. 10-20 mg PR OD. |
| Senna | Stimulant Laxative | PO: 8-12 hours. | Tablets: 7.5 mg. | 2-3 tablets BD |
| Glycerin suppository | Stool softener and Lubricant | PR: 1-6 hours. | Suppository: 2.65 g | 1 suppository PR |
| Lactulose | Osmotic laxative | PO: 48 hours. | Oral solution: 10 gm/15 ml | 15 ml BD to 50 ml TDS. |
| Polyethylene glycol (PEG) | Osmotic Laxative | PO: 48 hours | Powder: 17g sachets | 17 grams in 250 mL fluid PO daily |
| Methylnaltrexone | Opioid Antagonist | SC | Inj: 12 mg per 0.6 mL | 8 to 12 mg SC every 2 days |
| Mineral oil enema | Stool softener | PR | Enema: 130 mL | 120 mL PR x 1 dose |
| Phosphates enema | Osmotic Laxative | PR: 20 minutes. | Enema: 22 g per 100 mL | 120 mL PR x 1 dose |

Diarrhoea

- Diarrhea is the passage of frequent loose stools.
- Defined as passage of more than three unformed stools in 24 hours.

Causes

- Imbalance of laxative therapy
- Drugs-antibiotics, chemotherapy, NSAIDs, Iron preparations.
- Disease related-colonic, rectal or endocrine tumors.
- Radiotherapy
- Malabsorption: Ca head of pancreas, gastectomy, vagotomy, ileal or colon resection.
 - Fecal impaction (overflow/spurious diarrhoea)
 - Bowel fistulae
 - Loss of sphincter control
 - Unusual dietary habits

Clinical Assessment: Evaluate the cause of diarrhoea (Table 3)

Table 4.4: Delineating the etiology of Diarrhoea based upon History

| History | Most likely etiology |
|--|---|
| Profuse Watery stools | Colonic |
| Alternating diarrhoea and constipation | Poorly titrated laxative therapy Impending bowel obstruction |
| Pale fatty foul smelling stools | Malabsorbtion |
| Sudden diarrhoea after constipation | Overflow diarrhoea |

Interventions

- Assess for treatable causes
- Rule out fecal impactions, presence of fever and blood in stools.
- Reassurance as most diarrhoea is self limiting
- Increase fluid intake (as tolerated), use of homemade or commercial ORS. Parenteral fluids are rarely indicated.
- Care of skin/hygiene
- Supportive clothing-pads
- Dietary advice
- Drugs if indicated (Table 4)

Table 4.5: Drugs to be prescribed as per etiology

| Etiology | Pharmacological treatment |
|-----------------------------------|--|
| Non-specific anti-diarrheal agent | Loperamide |
| Radiation | Ondansetron |
| Secretory diarrhoea | Octereotide |
| Steatorrhoea | Pancreatin |
| Pseudo membranous colitis | Metronidazole 400 mg TDS or Vancomycin 125 mg QID. |

CHAPTER 5

Management of Respiratory Symptoms

Learning objectives

At the end of the chapter, the candidate should be able to:

- Acquire an understanding on the common respiratory ailments in patients receiving palliative care
- Identify, assess and manage problems like dyspnoea, and cough
- Use of oxygen in palliative care

Duration: 30 minutes

Cough

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

Causes

- Disease related: Ca lung, metastatic lung disease.
- Chest infections
- Other coexisting diseases - asthma, COPD, heart failure
- Smoking

Intervention

- Assess for treatable cause
- Ensure suitable environment – comfortable temperature, humidification
- Soothing warm drink or lozenges
- For productive cough– encourage expulsion of secretions, physiotherapy and postural drainage.
- Drugs -cough suppressants expectorants, anti-tussive, bronchodilators etc.
- Oral steroids in lymphangitis.

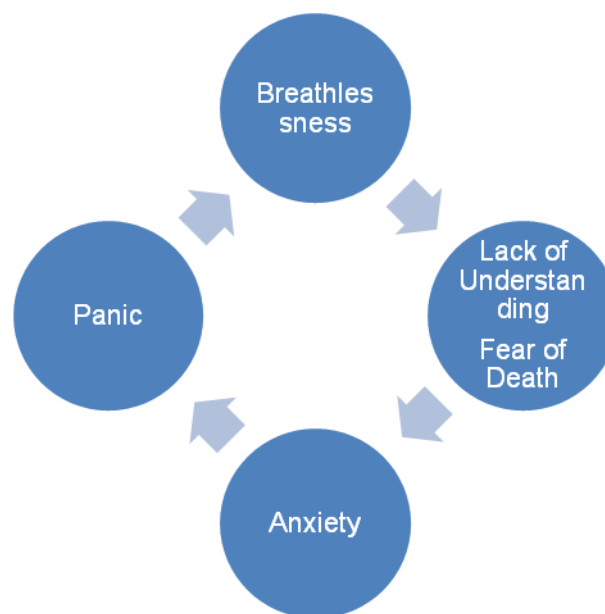
Dyspnea

Dyspnea is an unpleasant subjective awareness of breathing discomfort.

It is one of the most common symptoms in cancer patients, occurring in up to 80% of patients with advanced cancer.³³

The pathology of breathlessness is complicated and not fully understood. Normal breathing is maintained by regular rhythmical activity in the respiratory centre in the brainstem. This is stimulated by mechanical receptors(stretch receptors in the airways, lung parenchyma, intercostal muscles and diaphragm) and by hypoxia and high levels of CO2 (detected by chemoreceptors in the aortic and carotid bodies and in the medulla). In malignant lung disease, breathlessness is usually due to distortion and stimulation of the mechanical receptors and blood gases and often normal. It can restrict activities, can induce anxiety and panic attacks which can exacerbate breathlessness (Figure _)

Figure 5.1: Breathlessness- Panic: a vicious cycle



Clinical assessment and Investigations:

- History and physical examination can lead to accurate diagnosis in majority of the patients.

³³ Kobierski L et al. Hospice Palliative Care Program. Symptom Guidelines. Fraser Health Authority 2009 April. Available at: www.fraserhealth.ca/professionals/resources/hospice_palliative_care/hospice_palliative_care_symptom_guidelines

- Assess the severity of dyspnea on an 11 point Numerical rating scale with 0 being 'no breathlessness' and 10 being 'worst possible breathlessness'. Figure __ demonstrates the numerical scale.

Figure 5.2: Numerical Scale to assess the severity of dyspnoea




- Identify underlying causes and treat as appropriate.
- Identify any correctible causes and take appropriate measures to reverse them.
- Investigations: Haemogram, serum electrolytes, kidney function tests, pulse oximetry, ABG, pulmonary function tests and ECG when indicated. Order investigations only when they can influence the management.
- Imaging: Chest X-ray and CT scan chest when indicated and have an influence upon the management.
- Identify underlying causes and treat as appropriate.
- Identify any correctible causes (CHF, Bronchospasm, Pleural or pericardial effusion, ascites, anemia, infection, arrhythmias) and take appropriate measures to reverse them.
- Investigations: Haemogram, serum electrolytes, kidney function tests, pulse oximetry, ABG, pulmonary function tests and ECG when indicated. **Order investigations only when they can influence the management.**
- Imaging: Chest X-ray and CT scan chest when indicated and have an influence upon the management.

Principles of Dyspnea Management

The goal is symptomatic relief concurrently with correcting the correctible causes:

1. Patient education: Educate the patient and caregivers regarding the cause of breathlessness, available treatment options, self-management strategies and clarify misconceptions regarding dyspnea relieving medications so as to reduce the associated panic.
2. Reassure: “You are not going to die during an acute attack.”
3. Correcting the correctible Causes
4. Non-pharmacological measures and
5. Pharmacological measures
6. Identify and treat associated symptoms and stressors such as anxiety, depression and panic³⁴.
7. Continuous monitoring and review.



Step wise/Simultaneous approach depending upon the case and severity

Non-pharmacological Management

- Movements of air across face either by means of a hand held or a table fan has been shown to relieve dyspnea ³⁵.
- Encouraging patients to be involved in some form of exercise or activity as release endorphins which are beneficial in relieving dyspnea³⁶.
- Pulmonary rehabilitation (low to high intensity aerobic exercises) particularly in patients with COPD³⁷.
- Positioning the patient in the most comfortable position for the patient (propped up or left lateral).

³⁴ Mahler DA, Murray JA, Waterman LA, Ward J, Kraemer WJ, Zhang X, Baird JC: Endogenous opioids modify dyspnea during treadmill exercise in patients with COPD. *Eur Respir J* 2009;33:771–777.

³⁵ Galbraith S, Fagan P, Perkins P, Lynch A, Booth S. Does the use of a handheld fan improve chronic dyspnea? A randomized, controlled, crossover trial. *J Pain Symptom Manage* 2010;39:831–8.

³⁶ Mahler DA, Murray JA, Waterman LA, Ward J, Kraemer WJ, Zhang X, Baird JC: Endogenous opioids modify dyspnea during treadmill exercise in patients with COPD. *Eur Respir J* 2009;33:771–777.

³⁷ Casaburi R, ZuWallack R: Pulmonary rehabilitation for management of chronic obstructive pulmonary disease. *N Engl J Med* 2009;360:1329–35.

Pharmacological management of dyspnea:

Opioids

- Rationale: Opioids reduces respiratory rate, reduce ventilator response to carbon dioxide, inspiratory flow resistance loading, decreased oxygen consumption at rest and exercise and also cause intra-pulmonary vasodilation³⁸.
- If opioid naïve, start with morphine 2.5-5 mg PO (SC morphine dose = half the PO dose) q4-6h.
- If patient is already on Morphine for pain relief use 25% of the breakthrough dose as prn dose for breathlessness.
- If responsive to opioid, increase current dose by 25-50%.
- When initiating, start an antiemetic (metoclopramide) and laxatives.
- Therapeutic doses used to treat dyspnea do not cause respiratory depression or cognitive impairment³⁹⁻⁴⁰.
- Nebulized morphine has not been shown to be superior to saline and is not recommended⁴¹⁻⁴².

Anxiolytics

- Start SOS only when there is an element of anxiety or panic due to or exacerbating breathlessness²¹.
- Start with Tablet lorazepam 0.5-1 mg SL q2-4h SOS.
- Consider SC midazolam 2-5 mg, if patient not accepting orally.

Corticosteroids

- Dexamethasone 8-24 mg PO/SC/IV qid depending on severity and cause of dyspnea.
- Particularly useful in malignant bronchial obstruction, lymphangitis carcinomatosa, and superior vena cava obstruction syndrome; also for bronchospasm and radiation pneumonitis.
- Stop if no improvement in 1 week.

³⁸ Kamal AH, Maguire JM, Wheeler JL, Currow DC, Abernethy AP. Dyspnea Review for the Palliative Care Professional: Treatment Goals and Therapeutic Options. *Journal of palliative medicine* 2012;15:106-14.

³⁹ Clemens KE, Quednau I, Klaschik E. Is there a higher risk of respiratory depression in opioid-naïve palliative care patients during symptomatic therapy of dyspnea with strong opioids? *J Palliat Med* 2008;11:204–16.

⁴⁰ Currow DC, McDonald C, Oaten S, Kenny B, Allcroft P, Frith P, Briffa M, Johnson MJ, Abernethy AP. Once-daily opioids for chronic dyspnea: A dose increment and pharmacovigilance study. *J Pain Symptom Manage* 2011;42:388–9.

⁴¹ Fraser Health Authority. Hospice Palliative Care Symptom Guidelines - Dyspnea. 2009. Available at www.fraserhealth.ca/media/Dyspnea.pdf.

⁴² Jennings AL, Davies AN, Higgins JP, Gibbs JS, Broadley KE. A systematic review of the use of opioids in the management of dyspnoea. *Thorax* 2002;57:939–44.

Supplemental O2

- Indicated only for hypoxemia ($\text{PaO}_2 < 55$ mm Hg or < 60 mm Hg in cor pulmonale) or evidence of end organ damage due to hypoxia (cor pulmonale).
- Always ask: Is this what the patient wants?
- Use pulse oximetry to confirm presence of hypoxia and response to oxygen.
- Administer oxygen by nasal prongs @ 4L/minute. Use lower flow rates in a patient with COPD so as to preserve hypercapnic respiratory drive.
- It should be discontinued if no benefit is realized even after 3 days.

Palliative oxygen therapy should always be delivered with careful consideration of its benefit versus patient burden and cost⁴³.

⁴³ Uronis HE, Currow DC, Abernethy AP: Palliative management of refractory dyspnea in COPD. *Int J Chron Obstruct Pulmon Dis* 2006;1:289–304.

Algorithm-Based Dyspnea Management

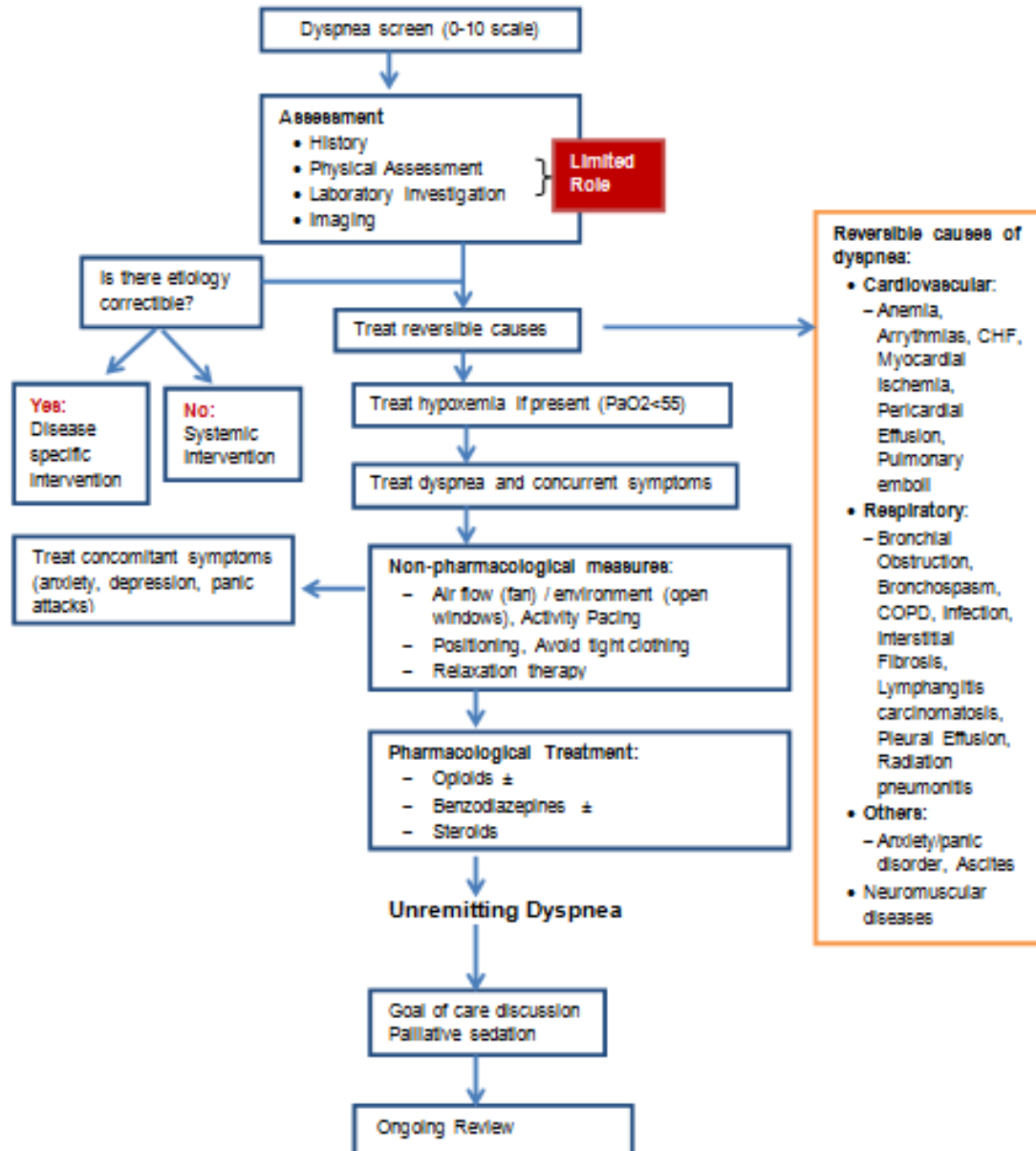


Table 5.1: Medications used for dyspnea in palliative care

| Drug Name | Route | Available Dosage | Standard Adult Dosage |
|----------------------|--------------|--|---|
| Morphine | PO/IV/SC | IR tabs: 5, 10, 20, 30mg. Injection:10/15 mg/ml | 2.5-5 mg PO q4h Crisis dyspnea: 5 mg IV/SC q5-10 min. Double |
| Lorazepam | PO/IV | Tabs: 0.5, 1, 2 mg. Injection: 4 mg/ml | 0.5-2 mg PO/ sublingual q2-4h SOS. 0.5-2 mg SC q2-4h SOS. |
| Midazolam | SC | Injection: 1 or 5 mg per ml. | 2.5-5 mg SC q5-15 min PRN. |
| Dexamethasone | PO/IV | Tablets: 0.5, 0.75, 2, 4 mg. Injection: 4mg per ml. | 8-24 mg PO/SC/IV every morning, taper if possible. |

CHAPTER 6

Management of Cardiovascular Symptoms

Learning Objectives

At the end of the chapter, the candidate should be able to:

- Acquire an understanding about the clinical features of cardiac failure and the need for palliative care in such patients.
- Acquaint themselves on New York Heart Association (NYHA) functional classification and its application to manage cardiovascular symptoms in patients with palliative care
- Plan steps for case management with focused attention towards disease specific management and symptom based management

Duration: 15 minutes

Long term challenges and burden of cardio vascular diseases can be very well managed with integration of palliative care and specialist care for patients as well as families. End-stage cardiac disease can be defined as patients with heart disease having a life expectancy of 6 months or less. Such patients usually have grade 4 breathlessness, hypotension, and clinical features of cardiac failure⁴⁴. Patients with advanced heart failure, sometimes experience poor quality of life because of deteriorating health, symptom distress, and complex care regimens. Apart from ongoing disease modifying agents, palliative care should be incorporated in the management plan.

Benefits of early integration of palliative care in cardio vascular disease:

1. Improved patient and caregiver understanding of disease, treatment and prognosis².
2. Better control of symptoms and less suffering
3. Effective doctor patient communication
4. Improved outcome of patient and caregiver

⁴⁴ Allen, L. A., et al. "Decision Making in Advanced Heart Failure: A Scientific Statement from the American Heart Association." *Circulation* 125.15 (2012): 1928-52.

Characteristics of the three stages in progressive heart failure⁴⁵

Patients with many cardiovascular conditions have palliative care needs, including patients with heart failure, ventricular assist devices, heart transplantation, advanced age and multiple comorbidities, patients who suffer from chronic angina ⁴⁶ .

Assessment

Patients with advanced heart failure have high cost implications and require repeated hospital admission. Chest pain, Breathlessness, fatigue, ankle swelling, nausea, cough, anorexia, anxiety and weakness are to be looked for in patients with advanced heart failure⁴⁷

Other symptoms like psychological morbidity, poor information communication, functional impairment in activities of daily living, and social isolation should also need proper guidance with palliative care specialist.

Box 6.1: New York Health Association (NYHA) functional classification

Stage 1: Chronic disease management phase (NYHA I-III)

- Regular primary disease monitoring and management with symptoms

Stage 2: Supportive and palliative care phase: (NYHA III – IV)

- The goal of care shifts to maintaining optimal symptom control and quality of life.
- Multidisciplinary holistic care is needed for patient and family with advance care planning and explaining prognosis.

Stage 3: Terminal care phase

- Clinical indicators include, despite maximal treatment, renal impairment, hypotension, persistent edema, fatigue, anorexia
- An integrated care planning and emotional support for patients is provided, with continuing bereavement support to family.

⁴⁵ Murray SA, Worth A, Boyd K, Kendall M, Hockley J, Pratt R, Denvir M, Arundel D. Patients', carers' and professionals' experiences of diagnosis, treatment and end-of-life care in heart failure: a prospective, qualitative interview study. London: Department of Health/British Heart Foundation Heart Failure Research Initiative. Final report, 2007.

⁴⁶ Braun LT, Grady KL, Kutner JS, Adler E, Berlinger N, Boss R, et al; on behalf of the American Heart Association Advocacy Coordinating Committee. Palliative care and cardiovascular disease and stroke: a policy statement from the American Heart Association/American Stroke Association [published online ahead of print August 8, 2016]. *Circulation*.

⁴⁷ Adler ED, Goldfinger JZ, Kalman J, Park ME, Meier DE. Palliative care in the treatment of advanced heart failure. *Circulation* 2009;120: 2597e606.

Management

- Disease specific management

Communication and reassurance to patient and carers with advice on diet (sugar, salt alcohol intake), exercise, weight reduction, and abstinence from smoking should be given by primary disease physician with involvement of palliative expert.

The mainstay of treatment is beta blockers and angiotensin converting enzyme (ACE) inhibitors. Diuretics help to control fluid overload⁴⁸.

- Symptom management

The symptoms can be managed as per the directions given in Figure .

Pain: Underlying cause of chest pain should be treated appropriately like anti angina medication for ischemic pain. Treat pain with WHO analgesic ladder. NSAIDs and COX II inhibitors should not be given as they can worsen heart failure.

Breathlessness: Apart from lung disease focused treatment, Propped up position of patient, supporting the patient in bed, opening windows and doors at home, relaxation techniques and applying fan with low flow oxygen therapy helps to reduce dyspnea. Digoxin can be offered as and when necessary under cardiologist supervision. Low dose opioids like 2.5 mg 5 mg oral or i.v. morphine helps in shortness of breath by reducing ventilator drive to hypoxia.

Anxiety and Depression: Benzodiazepines and Selective serotonin reuptake inhibitors (SSRIs) antidepressants like sertraline and mirtazapine is helpful in controlling these symptoms.

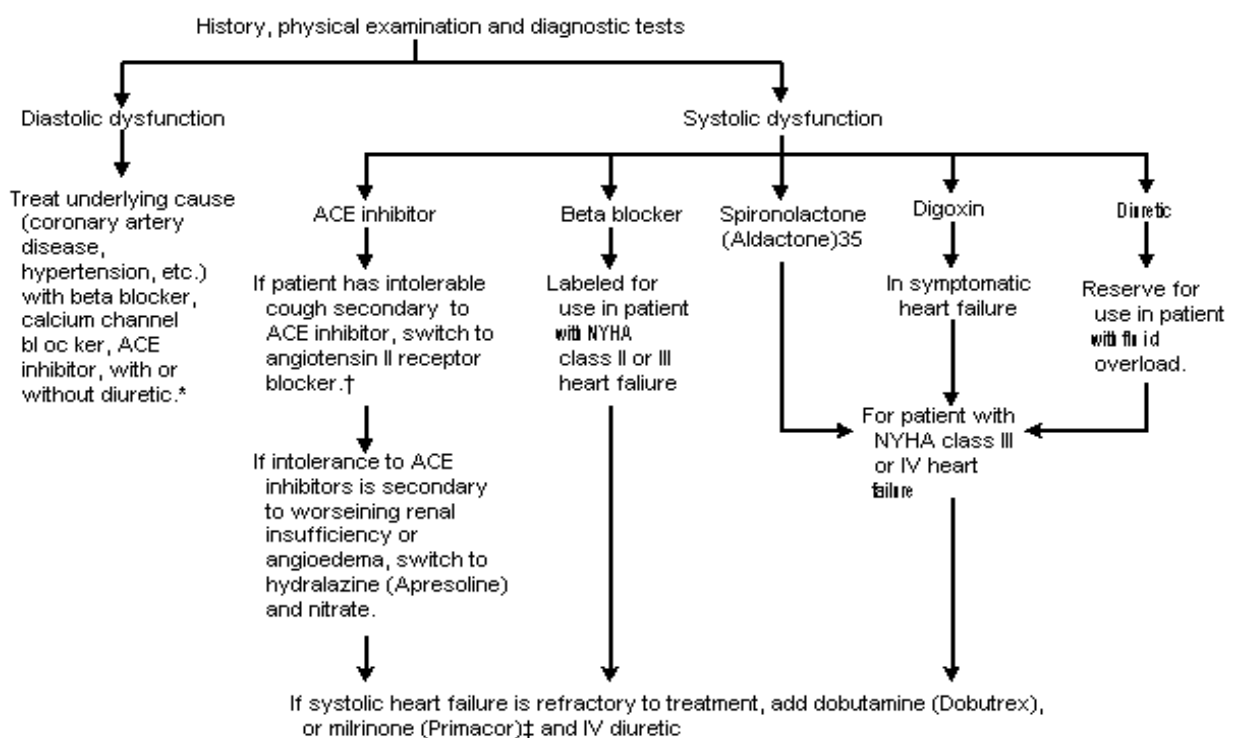
Fatigue & Weakness: Loss of muscle mass, poor intake, deconditioning and comorbid conditions contribute to fatigue and tiredness. Effective communication, relaxation, meditation, yoga, and improving nutrition help to reduce fatigue. Methlyphenidate may be beneficial in some cases⁴⁹.

⁴⁸ Lindenfeld J, Albert NM, Boehmer JP, Collins SP, Ezekowitz JA, Givertz MM, et al. HFSA 2010 comprehensive heart failure practice guideline. J Card Fail 2010;16:e1e194.

⁴⁹ Goodlin SJ. Palliative care in congestive heart failure. J Am Coll Cardiol 2009;54:386e96.

Integrating palliative care in the management of advanced cardiac disease patients may provide the following benefits: improved patient and caregiver understanding of disease, treatment, and prognosis; better symptom control and relief of suffering; shared decision making based on patient values, preferences, and goals; enriched bonding of patient-physician and family; personalized advance care planning based on benefits, risks, and burdens of care; improved outcome of patient and caregiver; improved preparation for end-of-life and associated care; and bereavement support²⁸.

Figure 6.1:



Source: Indian Association of Palliative Care 2015. Handbook for Certificate Course in Essentials of Palliative Care

CHAPTER 7

Management of Urological Symptoms

Learning objectives

At the end of the chapter, the candidate should be able to:

- Acquire a better understanding about the clinical features of common urological symptoms in a patient undergoing palliative care
- Acquint themselves to the management of neurogenic bladder and issues with long standing indwelling catheters
- Manage urinary tract infections

Duration: 15 minutes

Urological problems like voiding dysfunction are a major challenge to many of the patients with neurological disability, urogenital cancers, patients on dialysis, and geriatric illness patients. If not managed properly, these uncontrolled symptoms lead to psychological distress, with limited acidity of daily living. Involvement of palliative care physician to management of urological symptoms lead to better understanding of these complex issues, effective communication with patients and family members and overall better outcome and effective management strategy⁵⁰.

Common urinary symptoms:

- Burning perineal area
- Dysuria
- Frequency, urgency and incontinence
- Hesitancy and retention
- Blood in urine (Hematuria)
- Bladder pain

Some useful definitions

Frequency: Passage of urine seven or more times during day or twice or more during a night.

Urgency: A strong and sudden desire to void

Urge incontinence: The involuntary loss of urine associated with a strong desire to void.

Stress incontinence: The involuntary loss of urine associated with coughing, sneezing, laughing, jumping etc.

⁵⁰ Bratt O, Nilsson T, Stenzelius K. Palliative cancer care is an important part of urology. A study of the last year of life of patients who died because of urologic cancer]. Lakartidningen. 2002 Feb 21;99(8):765-7, 770.

Urological malignancies, like prostate cancer, are relatively common in population, but patients may live many years with one or other urological problems. Taking care of different urological issues is important and should be done effectively⁵¹. In majority of these patients, specific problems persist for a longer period of time and would have benefited from specialist palliative care as symptom control is major issue in this group of patients. Often it is very challenging to control symptoms like burning pain, dysuria and pain, as a result leading to many psychosocial problems⁵². Disease oriented therapy and integrated palliative care should be given simultaneously throughout illness. Current National Institute for Clinical Excellence guidelines for urological cancers recommends provision of palliative care for all patients with prostate cancer. Equal weightage should be given to symptoms such as pain, and psychological, spiritual and social problems are handled simultaneously. For managing pain apart from analgesic therapy, radiotherapy, hormonal therapy, chemotherapy and surgery should always be considered⁵³.

General management of urological problems

- Ensure adequate fluid intake.
- Change catheter every 2-4 weeks (silicone coated catheters can be placed for long term)
- Avoid traction on catheter while turning in bed
- Prevent reflux of urine into bladder
- Ensure good perineal care

Management of Neurogenic bladder

- Timed voiding at a fixed particular time
- Bladder stimulation method by Credes maneuvers (forcefully mechanical squeezing of urine by applying pressure over bladder).
- Urine collection devices like diapers or condom catheter.

⁵¹ Wu JN, Meyers FJ, Evans CP. Palliative care in urology. Surg Clin North Am. 2011 Apr;91(2):429-44

⁵² Brierly RD, O'Brien TS. The importance of palliative care in urology. Urol Int. 2008;80 (1):13-8. doi: 10.1159/000111723. Epub 2008 Jan 18

⁵³ Kaya E, Feuer D. Prostate cancer: palliative care and pain relief. Prostate Cancer Prostatic Dis. 2004;7(4):311-5

- Catheters can be placed suprapubic or urethral. For long term use, continuous urethral catheterization is less preferred due to risk of infection.

Urological issues with long term indwelling catheters

Repeated urinary tract infections, fistula, stricture, urethral trauma, impairment of sexual functions are few of the major issues with patients on long term urinary catheters. Clean intermittent catheterization (CIC) is suitable for patients who require long term intervention. It may be combined with anticholinergic if bladder is hyperreflexic.

24 hour Input output charting of urine is done to monitor the treatment.

Drugs used in the treatment of neurogenic bladder

- Incontinence due to hyperreflexic bladder, with urinary frequency, urgency, and urge incontinence anticholinergic drugs are useful.
 - Oxybutynine 5 mg orally 2,3 or 4 times daily (may start with 2.5 mg)
 - Propantheline 7.5-15 mg 3 times daily
 - Tolterodine 2 mg orally 2 times daily (long acting preparations of 4 mg for once daily use).
- Tricyclic antidepressants
 - Amitriptyline
 - Imipramine 25- 75 mg daily may be used as single dose at bedtime or in 3 divided doses. (higher doses up to 150 mg are occasionally needed)
- Alpha antagonists like terazosin or prazosin 1 mg orally at bedtime.

Urinary tract infection

Urinary tract infections are a common cause of morbidity. They usually present with fever, increased frequency, dysuria, hematuria and lethargy. In patients with spinal cord injury (SCI), may present as increased spasticity, new onset of urinary incontinence, autonomic dysreflexia, cloudy and odorous urine, malaise, lethargy or sense of uneasiness.

In elderly, the presentation may be subtle and atypical as confusion, lethargy etc.

In patients with long term indwelling catheterization or intermittent catheterization, asymptomatic bacteriuria is common and their eradication is difficult or almost impossible and not warranted usually. Prophylactic or frequent or long term use of antibiotics for this purpose is controversial.

On the other hand, prompt treatment is warranted in patients with symptomatic UTI. Empirical treatment with antibiotics, based on knowledge about antibiotic responsiveness of locally prevalent urinary tract pathogens if possible, is the first line of treatment.

Trimethoprim/sulfamethoxazole, nitrofurantoin, or oral fluoroquinolones are usual first line drugs for empirical therapy.

In refractory or more seriously ill patients, urine culture and sensitivity studies are indicated, and proper antibiotics should be used, in proper dose and for the proper duration. Oral or intravenous hydration is equally important.

Education to the family on the importance of perineal hygiene in the prevention of UTI is of paramount importance.

Other complications of voiding dysfunction are vesicoureteric reflux, hydronephrosis, pyelonephritis, renal stones, bladder stones, autonomic dysreflexia and increased risk of bladder neoplasms.

Routine evaluation of urinary system is recommended in patients with neurogenic bladder, at least once in every 2 years. It includes renal ultrasound with post void residual volume, serum creatinine, creatinine, 24 hour urine collection for analysis etc. Cystoscopy, CT, IVP and other urodynamic studies are sometimes indicated.

CHAPTER 8

Management of Psychological Symptoms

Learning objectives

At the end of the chapter, the candidate should be able to:

- Acquire an understanding about the psychological issues related to palliative care and in patients with chronic illnesses
- Manage delirium, anxiety and depression in patients undergoing palliative care

Duration: 15 minutes

Patients with advanced illness often experience psychological distress and symptoms. Psychological distress has been conceptually defined as a 'unique, discomforting, emotional state experienced by an individual in response to a specific stressor or demand that results in harm, either temporary, or permanent, to the person'⁵⁴. Psychological symptoms are common in palliative medicine and present in patients as well as in care giver. It is common to have these psychological symptoms and, it need rapid assessment and specific management.

Delirium

Definition: Delirium is a state of mental confusion that develops quickly, usually fluctuates in intensity, and results in reduced awareness of and responsiveness to the environment. It may manifest as disorientation, incoherence and memory disturbance.

Delirium Assessment

- Delirium is diagnosed based upon the clinical assessment and meeting the standard criteria (ICD 10 and DSM-V).

⁵⁴ Ridner SH. Psychological distress: concept analysis. J Adv Nurs 2004; 45(5): 53645.

| DSM-V criteria for diagnosis of Delirium ^{37, 55} | |
|--|---|
| 1. | Presence of disturbance in attention (reduced ability to direct, focus, sustain and shift attention) and awareness (Reduced orientation to the environment). |
| 2. | The disturbance develops over a short period of time and fluctuates in the severity. |
| 3. | Presence of disturbance in cognition (memory deficit, disorientation, language or perception). |
| 4. | Criteria 1 and 2 are not better explained by another preexisting, established or evolving neurocognitive disorder and do not occur in the context of a severely reduced level of arousal, such as coma. |
| 5. | There is evidence from the history, physical examination or laboratory findings that the disturbance is a direct physiological consequence of another medical condition, substance intoxication or withdrawal (i.e. because of a drug of abuse or to a medication), or exposure to a toxin, or is because of multiple etiologies. |

- Look for indicators of delirium (recent onset change in cognition, behavior, attention or presence of hallucinations or delusions) and if present use tools such as confusion assessment method (CAM) for diagnosis of delirium.
- Delirium may be hypoactive (sleepiness, quiet and withdrawn), hyperactive (restlessness, agitation, aggression) or mixed.
- Look for underlying reversible cause (dehydration, drugs, electrolyte imbalance, urinary retention, pain etc)

Causes:

- Infection: Pneumonia, sepsis
- Metabolic encephalopathy: organ failure, paraneoplastic syndromes
- Endocrine: Hyper/hypothyroidism, Cushing syndrome
- Drug withdrawal: Alcohol, narcotics, hallucinogens
- Immunologic: SLE, vasculitis
- Nutritional deficiencies
- Drugs: Chemotherapy: Methotrexate, 5FU, Vincristine, Steroids, Opioids, Benzodiazepine, Phenothiazines, Anticholinergics, Antiviral.

⁵⁵ Lawlor PG, Bush SH. Delirium diagnosis, screening and management. Curr Opin Support Palliat Care 2014, 8:286–95.

- Monitor and record consciousness level, temperature, pain scores, presence of pressure sores, findings of neurological and rectal examination.
- Ascertain stage of illness and whether delirium is likely to be reversible or terminal and irreversible.
- Consider investigations only when they can alter the management: haemogram, serum electrolytes, serum calcium, KFT's, LFT's, urinalysis, chest X-ray etc.
- Review advanced care plan and discuss goals of care with substitute decision maker.

Delirium Management Strategies

- Stop any offending Treatment
- Correct metabolic abnormalities
- quiet room, low lights, calendar, clock
- Family support
- Treat reversible causes (dehydration, hypercalcaemia etc) if consistent with goals of care.
- Use one drug at a time, start low and titrate according to the clinical response.
- Tailor the dose according to the age.
- Regularly review for the clinical effect and side-effects.
- Avoid initiating benzodiazepines for first line treatment
- Avoid use of antipsychotics in patients diagnosed with Parkinson's disease or Lewy Body Dementia.

Algorithm-Based Delirium Management

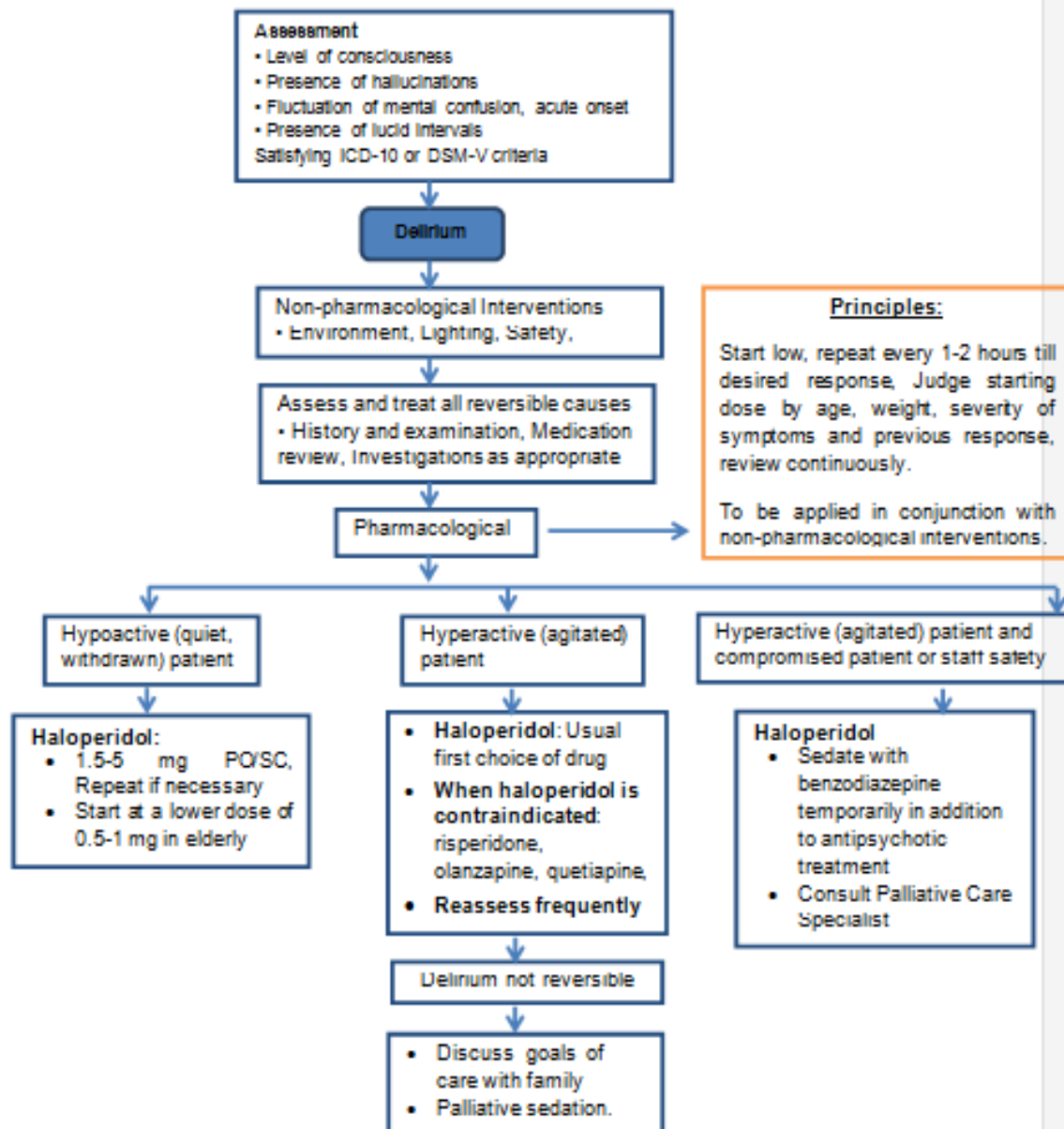


Table 8.1: Medications used for delirium and terminal agitation in palliative care

| Drug | Route | Class | Available Dosage Forms | Standard Adult Dose |
|-------------|-------------|-----------------------------|--|---|
| Haloperidol | PO/SC/IM/IV | Butyrophenone Antipsychotic | Tablets: 0.5, 1, 2, 5, 10 mg Injection: 5 mg per mL | Mild: Start with 0.5 mg stat and q2h SOS. If required increase dose: 0.5 mg 1 mg 2 mg. Severe distress: Start with 1.5-3 mg stat and q2h SOS. If required can increase to 5 mg. Review regularly. Usual maintenance dose is ≤ 5 mg/24 hours. |
| Clonazepine | PO | Benzodiazepine | Tablets: 0.5 mg, 2 mg. | 12.5-50 mg HS. Monitor blood cell count. |
| Olanzapine | PO | Atypical Antipsychotic | Tablets: 2.5, 5, 7.5, 10, 15, 20 mg | 2.5 to 10 mg PO HS titrated to effect. |
| Quetiapine | PO | Atypical Antipsychotic | Tablets: 25, 100, 200, 300 mg. | 12.5 to 50 mg PO daily to twice daily. |
| Risperidone | PO | Atypical Antipsychotic | Tablets: 0.25, 0.5, 1, 2, 3, 4 mg | Start with 0.5-1 mg/day to a maximum of 2-4 mg/day. |

Depression

Depression is a very common but under treated issue in palliative care. Both non cancer and cancer patients suffer from depression in their disease progression. Prevalence rate of depression in palliative care varies from 3.7 to 58%⁵⁶.

Major Depressive Disorder DSM 5 Criteria:

A person who suffers from a major depressive disorder (also referred to as clinical depression) must either have a depressed mood or a loss of interest or pleasure in daily activities consistently for at least a 2 week period. Clinical depression is characterized by the presence of 5 or more of these depressive symptoms⁵⁷.

⁵⁶ Stiefel R, Die Trill M, Berney A, et al . Depression in palliative care: a pragmatic report from Expert Working Group of the European Association for Palliative Care. Support Care Cancer 2001; 9(7): 47788.

⁵⁷ American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. 5th ed Arlington, VA: American Psychiatric Association; 2013.

- Depressed mood most of the day, nearly every day, as indicated by either subjective report (e.g., feeling sad, blue, “down in the dumps,” or empty) or observation made by others (e.g., appears tearful or about to cry). (In children and adolescents, this may present as an irritable or cranky, rather than sad, mood)^{39,40}.
- Markedly diminished interest or pleasure in all, such as no interest in hobbies, sports, or other things the person used to enjoy doing.
- Significant weight loss when not dieting or weight gain (e.g., a change of more than 5 percent of body weight in a month), or decrease or increase in appetite nearly every day.
- Insomnia (inability to get to sleep or difficulty staying asleep) or hypersomnia (sleeping too much) nearly every day
- Psychomotor agitation (e.g., restlessness, inability to sit still, pacing, pulling at clothes or clothes) or retardation (e.g., slowed speech, movements, quiet talking) nearly every day
- Fatigue, tiredness, or loss of energy nearly every day (e.g., even the smallest tasks, like dressing or washing, seem difficult to do and take longer than usual).
- Feelings of worthlessness or excessive or inappropriate guilt nearly every day (e.g., ruminating over minor past failings).
- Diminished ability to think or concentrate, or indecisiveness, nearly every day (e.g. appears easily distracted, complains of memory difficulties).
- Recurrent thoughts of death (not just fear of dying), recurrent suicidal ideas without a specific plan, or a suicide attempt or a specific plan for committing suicide⁵⁸.

Risk factors for Depression:

- History of depression
- Poorly controlled pain

⁵⁸ American Psychiatric Association. Diagnostic and statistical manual of mental disorders: DSM-5. 5th ed Arlington, VA: American Psychiatric Association; 2013.

- H/O alcoholism / drug abuse
- Advanced stage of Cancer
- Increased physical discomfort
- Chemotherapy with agents like: vincristine, vinorelbine, procarbazine

Common symptoms of depression are apathy, motor retardation, pain, sleep disturbances, fatigue, decreased appetite, concentration problems.

Management:

Indications for psychiatric referral:

- Suicidal intent / plan
- Oncologist not comfortable in treating
- Resistant even after 4 to 6 weeks medical treatment
- Symptoms worsening
- Symptoms interfere with medical treatment

Non Pharmacological treatment:

Use Basic Communication Skills:

- Listen, identify, acknowledge, offer information, observe, and continue to support.
- Brief supportive counseling to normalize feelings, mobilize support, and minimize stressors
- Adaptive Coping skills and Cognitive behavior therapy should be applied wherever applicable.

Pharmacological management:

- Tricyclic Antidepressants: Amitriptyline, Imipramine
- Selective Serotonin Receptors Inhibitors (SSRI) eg.
 - Paroxetine, Citalopram, Fluoxetine (may initially increase anxiety)
 - Neuroleptics: Haloperidol
- Antipsychotic drugs : Risperidone, Olanzapine (to be used with caution)

Anxiety

It is normal to have anxiety for the patient and family members. Anxiety is common in terminally ill patients. Reversible factors should be corrected to improve anxiety. Good communication, active listening, relaxation and other complimentary therapies should be provided.

Clinical features of anxiety

- Inability to relax
- Worrying excessively
- Tremulousness, motor restlessness
- Palpitations, excessive sweating
- Fear related to procedures
- Sleep disturbance

Management:

Non Pharmacological treatment:

Psychotherapy – cognitive behavior therapy is found to be as useful as drugs in milder cases. Other forms of psychotherapy, relaxation therapy, Yoga and meditation are found useful in addition to pharmacotherapy.

Reversible factors should be corrected to improve anxiety. Good communication, active listening, relaxation and other complimentary therapies should be provided.

Pharmacological management:

Pharmacotherapy: Pharmacotherapy to be started in consultation with a psychiatrist.

Benzodiazepines:

- Lorazepam 0.5 – 2 mg prn, p.o peroral/sublingual. short acting, less sedating, also helpful in breathlessness.
- Diazepam 1-5 mg prn per oral long half-life, sedative, anxiolytic
- Midazolam 5-10 mg prn. S.C. / intermit / Continuous.

CHAPTER 9

Management of Chronic Neurological Symptoms in Palliative Care

Learning objectives

At the end of the chapter, the candidate should be able to:

- Acquire an understanding of the need for palliative care in patients with chronic progressive neurological diseases
- Manage motor neuron disease, multiple sclerosis, spinal cord injury and stroke, in patients undergoing palliative care

Duration: 15 minutes

Many people with neurological diseases need palliative care. Many of these patients face difficulty in day to day activities and need symptom management. Neurologic diseases are often incurable, reduce life expectancy, and are associated with depression, pain and other symptoms that are difficult to control⁵⁹. There is a huge need of palliative care for patients suffering from amyotrophic lateral sclerosis (ALS)/motor neuron disease (MND), Huntington's disease, Parkinson's disease (PD), the associated progressive supra-nuclear palsy and multiple systems atrophy, and multiple sclerosis (MS)⁶⁰. Patients with stroke, brain tumors and brain injury may also benefit from palliative care. Some of the common conditions and need for palliative care is discussed:

Motor Neuron Disease (MND)

MND is a disease of unknown etiology, progressive and terminal disease, with involvement of upper and lower motor neurons leading to a variety of symptoms like weakness, and wasting of muscles. MND affects people with age group of 50-60 years with 40% mortality at 5 years. Symptom burden is huge and palliative care need is also huge. Even caregivers also have a lot of burnout and distress.

⁵⁹ Martinez-Martin P, Schapira AH, Stocchi F, et al. Prevalence of nonmotor symptoms in Parkinson's disease in an international setting: study using nonmotor symptoms questionnaire in 545 patients. *Mov Disord* 2007;22: 1623–1629.

⁶⁰ Oliver DJ, Borasio GD, Caraceni A, de Visser M, Grisold W, Lorenzi S, Veronese S, Voltz R. A consensus review on the development of palliative care for patients with chronic and progressive neurological disease. *Eur J Neurol*. 2016 Jan;23(1):30-8

Clinical Features:

- Upper Motor Neuron involvement leads to generalized spasticity, hyperreflexia, behavioral problems and often emotional lability.
- Lower Motor Neuron involvement leads to flaccidity, muscle wasting and fasciculation.
- Bulbar symptoms appear in elderly age group affected population and include dysphagia and dysarthria. Memory, intellect are preserved as well as 3, 4, and 5th cranial nerves.
- In addition to these symptoms, pain, constipation, insomnia, tongue fasciculations, breathlessness, and depression are also present.
- Weakness of legs is very prevalent symptoms in MND patients. Gait disturbance, inability to take load of the body.
- Pain because of joint pain, inflammation and tightness of muscles may be there.
- It is a degenerative disease and 10% cases are familial.
- Diagnosis is Clinical. EMG/Imaging may help sometimes.
- Multidisciplinary approach is needed to handle these issues of physical and psychological help including care of caregivers.
- Speech therapist may help in management of dysphagia and dysarthria. Dysphagia due to disease may need Gastrostomy or other feeding alternatives in early course of disease. Dietician advice on feeding consistency and food helps the patients with swallowing issues. Advice on speech therapy requires these patients to build confidence and communication. Multiple types of aids and device including electronic board can help these patients for communication.
- Breathlessness can happen due to diaphragmatic paralysis. Oxygen support, physiotherapy and rehabilitation with antibiotics as and when necessary can help to decrease the burden of dyspnea.
- In early stage of the disease, noninvasive ventilation can help respiratory distress to settle.
- MND patients die suddenly due to respiratory failure.
- Opioids in a low dose can help to reduce pain and distress associated with breathlessness.

- MND management team involves multidisciplinary management including the neurologist, physiotherapist, occupational therapist, speech therapist, dietician, local physician nurse, social worker, palliative physician and palliative home care team⁶¹.

Multiple Sclerosis

Multiple sclerosis is the most common chronic autoimmune inflammatory and demyelinating disease of the central nervous system. An unpredictable and potentially disabling disease, which interrupts the flow of information within the brain, and between the brain and body. Patients with MS have a large range of unmet needs, which need early integration of palliative care⁶². In a Delphi study, specialized palliative homecare was rated as very important (93.3%)⁶³

- Patients with MS suffer from a variety of symptoms such as fatigue, chronic pain, weakness, paralysis, immobility, physical dysfunctions, intense pain, and psychological distress.
- Management includes patient education, rehabilitation, counseling, and sometimes medical therapy. A multi-disciplinary team is needed to provide treatment of the wide range of progressive symptoms.
- Nearly 30% patients have weakness, paraplegia, hemiplegia, and/or, cognitive disturbances.
- Trigeminal neuralgia pain and other neuropathic pain is common in nearly 20-30% of patients.
- Burning pain half of the body or electric sensation in neck while neck movements are distressing symptoms and remain under diagnosed and under treated.
- Physiotherapy is needed to correct posture, gait training, pain management and spasticity or weakness related issues.

⁶¹ Oliver D. et al editors (2000) Palliative Care in Amyotrophic Lateral Sclerosis (Motor Neurone Disease) Oxford University Press.

⁶² Strupp J, Voltz R, Golla H. Opening locked doors: Integrating a palliative care approach into the management of patients with severe multiple sclerosis. *Mult Scler.* 2016 Jan;22(1):13-8

⁶³ Strupp J, Romotzky V, Galushko M, Golla H, Voltz R. Palliative care for severely affected patients with multiple sclerosis: when and why? Results of a Delphi survey of health care professionals. *J Palliat Med.* 2014 Oct; 17(10):1128-36.

- Splints and walker give a great support to patients. TENS help in reliving muscle spasm.
- Walking, spasticity, and gait disturbances need good rehabilitation program.
- Baclofen 10 mg twice a day and titration to 80 mg per day is helpful in relieving spasticity pain.
- Muscle relaxant like Tizanidine or benzodiazepines like Diazepam help in reducing spasm of muscles.
- Propranolol in dose of 20-80 mg per day is helpful in Ataxia control.
- Urinary symptoms like incontinence and hyper reflexia of bladder need medicinal management like anticholinergics.
- Fatigue and depression need psychological counseling and if needed then management with SSRI or Tricyclic antidepressants.
- Rehabilitation through physical therapy and occupational therapy can be of great value. Speech therapy, therapeutic exercise, and certain medical devices may also be useful in dealing with the symptoms of MS.

Spinal Cord Injury

- Traumatic spinal cord injury is a devastating event need physical and psychological empathy and support.
- Most common site of injury is thoracic segment followed by lumbar one. There may be complete or partial injury to cord injury to subsequent damage.
- Bowel and bladder problems in this group of patients are permanent and need special care. Laxatives use is for long lasting to keep bowel fresh.
- Bed sore and pressure sore in these patients need regular change of position in bed, moisture control, use of water or air mattress, regular dressing.
- Spasticity develop over a time and need physiotherapy to keep regular ADL.
- Neuropathic pain in these patients, present as central pain with burning, dysesthesia and need long term anti neuropathic medications like Gabapentin, Pregabalin, duloxetine etc.

Stroke

- WHO definition of stroke "Rapidly developing clinical signs of focal(or global) disturbances of cerebral function, lasting for more than 24 hours or leading to death, with no apparent cause other than vascular origin". It happens when the blood that goes to the brain is interrupted.

Causes:

- a. Ischemic (85%) : Thrombosis 60%, Embolism 20%, Others 5%
 - b. Hemorrhagic (15%): Intra cerebral 10%, Subarachnoid: 5%
- Factors that increase the risk of stroke include Smoking, diabetes, hypertension, family history of stroke, old age, physical inactivity, cardiac disease like atrial fibrillation, hyper coagulability states and high cholesterol. Most common pathology is atherosclerosis of vessels.

Clinical features:

- Symptoms vary and depend on which area of brain is involved. There may be presentation with numbness of one hand, or half body, weakness of half body or hand or leg only, paralysis, loss of consciousness, pain, aphasia, dyslexia, gait disturbance, loss of urine and bowel control, and other mental changes.

Challenges in patients with Stroke:

- Many patients suffer from residual neurological deficit or associated problems leading to decreased QOL and impaired ADL.
- Decreased activity and immunity leading to increased chances of infection, pneumonia, deep vein thrombosis, pulmonary embolism, GI problems like constipation, dysphagia, swallowing problems, difficulty in feeding, neurogenic bladder, bowel and bladder incontinence, bed sore, muscle spasticity pain, central neuropathic pain.
- Language and communication problems
- Delirium, depression and cognitive problems
- Seizures, increased risk of fall and other disability

Treatment of Stroke and Palliative Care role:

- In early stage of disease, hospitalization and intense care is required to enhance the recovery. Once the patient is out of hospital, a good care plan and goal of care should be made by the treating physician with involvement of palliative physician. Education to the family and community is necessary to speeding up the reversible damage.
- It is best to involve palliative care doctor from the beginning. Palliative specialist can help patients to explain and communicate whether their symptoms are temporary or permanent or likely to improve over time.
- Palliative care physicians are experts in managing central neuropathic pain either with use of holistic anti neuropathic medicines.
- Benefits and side effects of each treatment need to be understand and how they fit in your personal goal of care.
- Forming a realistic plan to take care of affected person at home under guidance of palliative expert can be made.
- Helping the patient and their family to cope with the challenges of living with stroke can be done by palliative care team.
- Good nursing and medical care is given throughout the period of recovery. Maintain good nutrition, vitals and hygiene is must.
- Physical, occupational and social rehabilitation have to be planned, involving the patient, family, community with realistic goals appropriate to the situation⁶⁴.

⁶⁴ Macaden S C. Manual book of Certificate course in essentials of palliative care. Management of Symptoms in Chronic Neurological Diseases. Page 176-92

CHAPTER 10

Management of Emergencies in palliative care

Learning objectives

At the end of the chapter, the candidate should be able to:

- Acquire an understanding of the common palliative care emergencies
- Differentiate between palliative care and other medical specialities
- Manage spinal cord compression, hypercalcaemia, superior vena cave obstruction, haemorrhages, seizures etc.

Duration: 30 minutes

Emergencies in palliative care refer to conditions which if left untreated threaten the quality of life (QoL). The differences with respect to emergencies in other medical specialties include (Table 10.1):

Table 10.1: Difference between Palliative care and other medical specialities

| Palliative Care | Other medical specialities |
|---|---|
| If left untreated, seriously threaten the QoL | If left untreated, immediate threat to life |
| Aim: Relief of suffering | Aim: Sustenance of life |
| Arise: Usually expectedly | Arise: Expected/Unexpected |

The management depends on the:

1. Nature of the emergency
2. General physical condition of the patient
3. Disease status & likely prognosis
4. Concomitant pathologies
5. Symptoms
6. Likely effectiveness vs. toxicity of treatment
7. Patient's & family's wishes & the goals of care.

Spinal Cord Compression

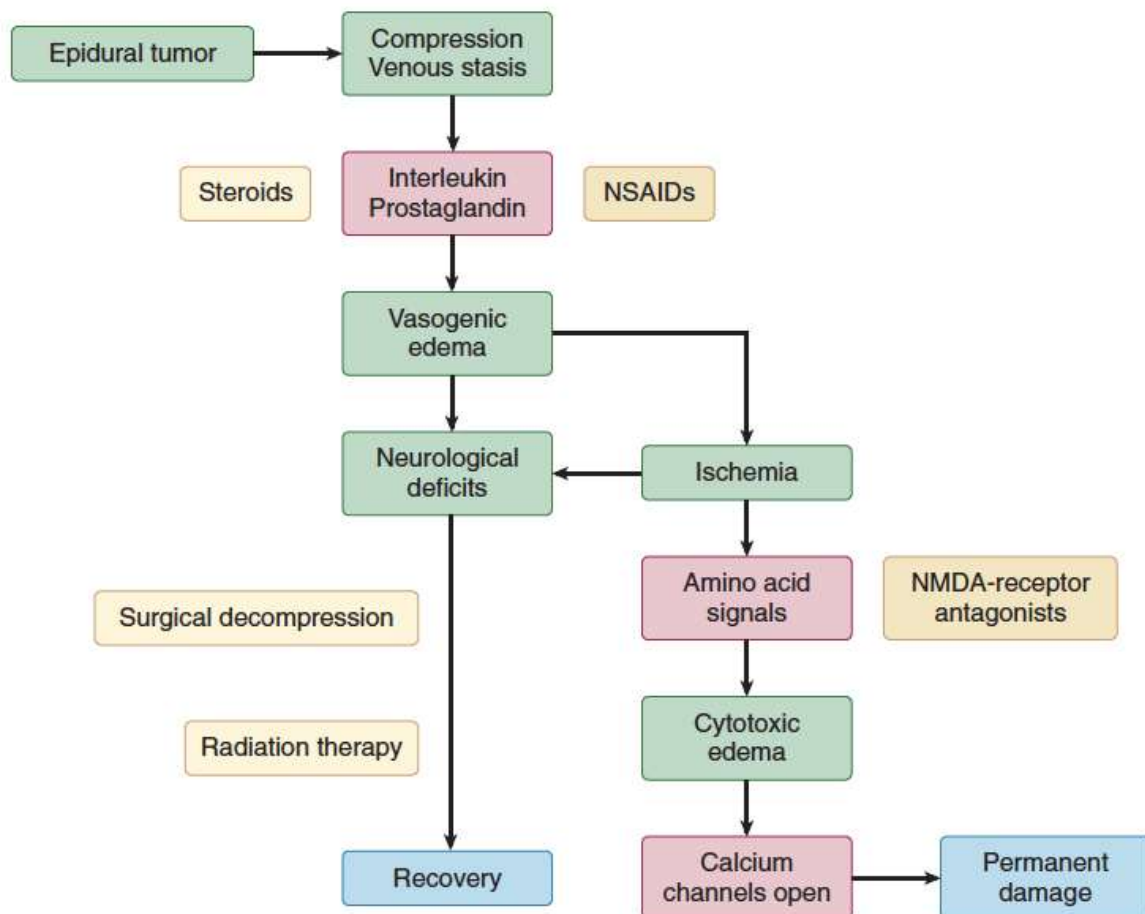
- May occur in about 5-10% of cancer patients.

- Most common primary cancers include: Multiple myeloma, lung, prostate, breast and sarcomas.
- Most common cause is extra-dural compression (Figure __) by the extension of vertebral body metastasis (Figure __)⁶⁵.

Figure 10. 1: Extra-dural compression of spinal cord



Figure 10.2: Pathophysiology of spinal cord compression



⁶⁵ Quinn JA, DeAngelis LM. Neurologic emergencies in the cancer patient. Semin Oncol 2000;27:311–321.

- Less common causes include intra-dural metastasis, direct spread of tumor through the vertebral foramen, vertebral collapse and interruption of the arterial blood supply.
- The most common site of compression is Thoracic spinal cord (70%) followed by lumbosacral (20%) and cervical.
- More than one level of compression may be present in the same patient.

Clinical features:

- The signs and symptoms can be quite subtle; demanding a high index of suspicion.
- Back pain is the usually the most common and earliest symptom:
 - May be painless in upto 17% patients.
 - Usually precede neurological signs and symptoms by weeks to months.
 - Usual presentation is a band of pain encircling the body; worsened by coughing, straining and lying flat.
 - May be accompanied by radiating pain due to nerve root irritation.
 - Pain responds poorly to the increasing doses of opioids.
- Other symptoms include stiffness, weakness, perianal numbness, urinary retention/incontinence, tingling and numbness.
- Lesions above L1 produce upper motor neuron signs: spasticity, loss of balance and positive Babinski sign.
- Lesion below L1 produces lower motor neuron signs: muscle flaccidity, sphincter tone loss and numbness.
- The site of pain and level of compression may not always correlate
- X-rays and bone scans can be misleading.
- MRI of the whole spine is the investigation of choice.

Management:

- Outcome depends upon the neurological functions at the start of treatment.
- About 70%, 35% and 5% of ambulatory, paraparetic and paraplegic patients respectively retain/regain their ability to walk.

- Chances of return of motor function are better in those with partial/incomplete compression/damage of the spinal cord.
- Loss of sphincter function is a bad prognostic sign.
- Management is usually inter-disciplinary involving palliative care physicians, primary physician, radiologist, radiotherapist, neurosurgeon and physiotherapists.
- The goals of management involve:
 - Relieving compression: radiotherapy, surgery and dexamethasone.
 - Managing pain: opioids, non-opioids and adjuvants.
 - Retaining ambulation, bowel and bladder functions.
 - Care of the bowel, bladder and skin
- Give dexamethasone 16 mg stat followed by 16 mg/day (usually 8 mg BD with both doses before 2 pm). Continue dexamethasone 16 mg daily till after surgery or start of radiotherapy, then reduce dose over 5–7 days & stop.
- Consider giving proton pump inhibitor and thromboprophylaxis (unless contraindicated).

Table 10.2 provides various treatment options

Table 10.2: Treatment options in spinal cord compression

| Surgery | Surgery + RT | Radiotherapy (RT) | Chemotherapy |
|--|--|--------------------------|-------------------------------|
| RT ineffective or symptoms worsen after RT | Unknown cause to obtain histology | Radiosensitive tumor | Chemotherapy sensitive tumor. |
| RT resistant tumors: melanoma, sarcoma | Unstable spine | Stable spine | |
| Major structural compression | Acute and rapidly progressing symptoms in an ambulatory patient. | | |
| Solitary lesion | | | |
| Cervical cord lesion | | | |

Hypercalcaemia

- Commonest life threatening metabolic disorder in cancer patients (20-30%).
- Incidence varies with malignancy; highest in *multiple myeloma and breast cancer* (40-50%), less common in non-small cell lung cancer.
- Corrected serum calcium level \geq than 2.6 mmol/l is diagnostic.
- Bone metastases are common but are not always present.
- Paraneoplastic syndrome mediated by PTH-related protein, prostaglandins, IL-1 and TNF.

Clinical Presentation:

- Symptoms (Table 3) depend upon the rate of rise of serum calcium levels.
- Symptoms are usually mild till serum calcium levels less than 3 mmol/l.

Table 10.3: Symptoms of Hypercalcaemia

| Mild | Severe |
|--------------|---------------------|
| Nausea | Severe dehydration |
| Vomiting | Delirium |
| Thirst | Drowsiness |
| Polyuria | Confusion |
| Anorexia | Coma |
| Constipation | Cardiac arrhythmias |
| Malaise | Ileus |
| | Death |

- Onset of symptoms raising clinical suspicion should be investigated. Bloods should be checked for urea and electrolytes, estimated glomerular filtration rate, liver function tests and corrected serum calcium.

Management:

- Treatment is usually required if symptoms are distressing to the patient and may be inappropriate in an imminently dying patient.
- Goals of treatment are to improve symptoms and corrected serum calcium levels.
- Hydrate with IV fluids (normal saline); 3-4 L/24 hours.

- The rate and amount of fluid administered depends upon the clinical, biochemical and the cardiovascular status of the patient.
- Bisphosphonates to normalize serum calcium levels:
 - Zoledronic acid 4-8 mg IV over 15 minutes (lower doses and slower infusion in renal patients).
 - Disodium Pamedronate 60-90 mg IV in 500 ml normal saline over 2-4 hours.
- Corticosteroids (dexamethasone 4-16 mg/day) are probably useful only when the underlying tumour is responsive to this cytostatic agent – such as myeloma, lymphoma, and some carcinomas of the breast.
- Biochemical response takes 2-4 days, normalization in 80% within 1 week.
- Clinical response, especially confusion, may take 7-10 days.
- Consider treatment of underlying condition to prevent recurrence.

Superior Vena Cava Obstruction (SVCO)

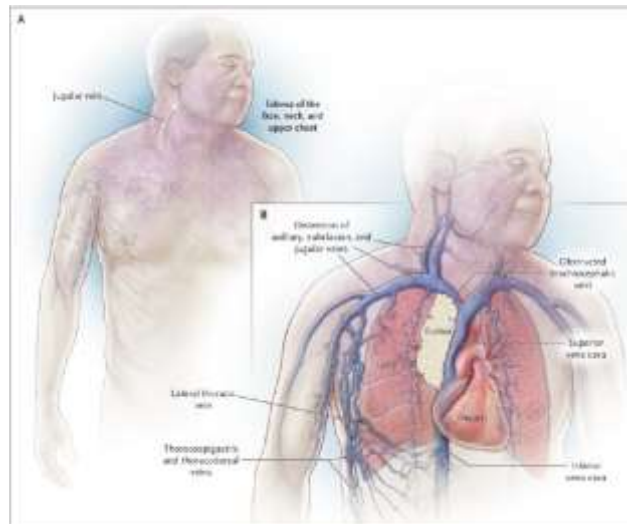
- Venous return of floor from the upper part of body to heart is impeded.
- Etiology:
 - Malignant: Carcinoma bronchus (65-80%), lymphoma (2-10%), others (3-13%).
 - Benign (rare): Goitre, aortic aneurysm, thrombotic syndromes and idiopathic sclerosing mediastinitis.
- Superior venacaval obstruction may arise from occlusion by extrinsic pressure, intraluminal thrombosis, or direct invasion of the vessel wall.
- Mostly due to tumour within the mediastinum, of which up to 75% will be primary bronchogenic carcinomas.
- CT Thorax normally reveals pathology

Clinical Presentation (table 4, figure 3):

Table 10.4: Symptoms and Signs in SVCO

| Symptoms | Signs |
|-------------------------------------|------------------------------------|
| Breathlessness (tracheal edema) | Rapid breathing |
| Headache (cerebral edema) | Periorbital edema |
| Swelling of the face, neck and arms | Suffused conjunctivae |
| Dizziness | Oedema of arms and hands |
| Syncope | Non-pulsatile distended neck veins |
| Blurring of vision | Cyanosis |
| | Collateral veins over the chest |

Figure 10.3: Clinical presentation in SVCO



Management⁶⁶:

- Dexamethasone 12-16mg stat followed by 16mg daily in divided doses.
- Urgent radiotherapy.
- Chemotherapy for very chemosensitive tumours e.g. small cell lung cancer.
- Stenting of the superior vena cava is an option if local expertise available.
- Dyspnoea may require management e.g. with positioning, small doses of morphine +/- benzodiazepine.
- Ensure restricting clothing is loosened and upper arms are supported on pillows.

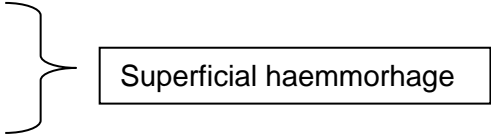
⁶⁶ Lynn D. Wilson et al. Superior Vena Cava Syndrome with Malignant Causes. N Engl J Med 2007;356:1862-9.

Haemorrhage

- Occurs in about 10% advanced cancer cases.
- Etiology:
 - a. **Cancer invasion:** Ca head and neck (catastrophic bleed, carotid blow out), lung (hemoptysis), gastrointestinal tract and gynecological.
 - b. **Bone marrow infiltration** and thrombocytopenia: Leukemia, lymphoma, prostate cancer.
 - c. **Treatment related:** chemotherapy or radiotherapy induced mucositis, thrombocytopenia, NSAIDs, anticoagulants.
 - d. **Advanced liver disease**
 - e. **Disseminated intravascular coagulation**
 - f. **Coagulopathy**

Management:

Mild-moderate haemorrhage:

- Pressure dressings
 - Adrenaline 1:1000 soaked dressings
 - Correct the correctible
- 
- Superficial haemorrhage
- Prevent recurrence: Radiotherapy, interventional radiology, Tranexamic acid 1 gm TDS (except in urinary tract bleeding), Tranexamic acid paste applied locally.
 - Gastric bleeding: Sucralfate, Proton pump inhibitor.
 - Blood transfusion as appropriate.

Catastrophic haemorrhage:

- Identify small warning bleeds.
- Identify patients at risk:
 - Head & Neck, Hematological
 - Lung Ca
 - Co-existing: Bleeding Varices, Liver Failure
 - Small Warning Bleeds
 - Local Infection at Tumor Site
 - Clotting Abnormalities
 - Anticoagulants

Prevention:

- Minimize trauma during dressing change
- Haemostatic Dressings: Alginate Dressings
- Radiotherapy
 - Controls hemoptysis in up to 80% lung cancer
 - Skin/vagina/rectum/bladder
 - Single fraction 10 Gy/Multiple fractions 20 Gy
- Antibiotics
- Can be a terminal event.
- Mask bleeding with dark colored towels; such linen should be prepared beforehand if risk known.
- Give injection of morphine equivalent to the breakthrough dose if there is pain.
- Sedate with injection of midazolam 5-10mg or rectal diazepam 10mg if patient is very anxious or symptoms such as suffocation are present.
- Stay with the patient and family.

Seizures

- 10-15% of Palliative Care Patients⁶⁷.
- Status Epilepticus: >5min of continuous or >2 seizures with incomplete recovery of consciousness.
- Etiology:
 - Structural Causes (Suspect if: Presence of aura before seizures, Focal or Neurological deficits): Primary brain tumor, Metastasis, Haemorrhage, Post radiotherapy, Paraneoplastic.
 - Systemic Causes: Hypoxia, Hypoglycaemia, Hypocalcaemia/Hypercalcaemia, Hypo/Hyponatremia, Uraemia, Drugs.

⁶⁷ Caraceni A, Martini C, Simonetti F. Neurological problems in advanced cancer. In: Hanks G, Cherny NI, Christakis NA, Fallon M, Kaasa S, Portenoy RK, editors. *Oxford textbook of palliative medicine*. 4th ed. New York, NY: Oxford University Press; 2010. p. 1034-58.

Management⁶⁸:

- Arterial Blood Gases (ABC)
- Put in recovery position.
- Remove objects likely to cause injury.
- Chronic seizures: Choice of anti-epileptic medicine is guided by seizure type, potential for drug interactions, co-morbidities and simplicity of the regimen.
- Partial or secondary generalized seizures: sodium valproate, carbamazepine, or lamotrigine.
- Primary generalized seizures (unlikely in palliative setting): sodium valproate or lamotrigine.

Alternatively:

- Midazolam (rapid onset and offset): 5 mg SC/nasal (0.15-0.30 mg/kg) or 10 mg buccal; 20-30 mg/24 hours CSCI as maintenance therapy.
- Lorazepam 2 mg IV or Diazepam 10 mg PR
- Repeat after 10 minutes if persist
- If persist depending upon the availability and circumstances:
 - Phenytoin 15 mg/kg IV (≤ 50 mg/min, max 1 gm) or
 - Phenobarbitone 15-20 mg/kg
 - Midazolam 20-30 mg/24 hours CSCI

Activity

Discuss in a group what the special considerations for managing emergencies are in palliative care, with respect to

- Resources and infrastructure
- Approach
- Communication skills
- Technical skills

⁶⁸ Twycross RG, Wilcock A, Stark Toller C. *Symptom management in advanced cancer*. Nottingham, UK: Palliativedrugs.com; 2009.

CHAPTER 11

Management of Nursing Issues in Palliative Care

Learning objectives

At the end of the chapter, the candidate should be able to:

- Acquire a better understanding of the common nursing issues in palliative care
- Manage sore mouth, oral candidiasis, xerostomia, altered taste sensation, skin care, pressure sores, nutrition, stoma care, suprapubic catheterization, wound care, etc.
- Strengthen the capacity to manage bedridden patients.

Duration: One hour

Oral Hygiene in palliative care

Routine mouth care

- Recommended daily assessment
- Brush and rinse mouth twice a day (12 hourly)
- Soak dentures overnight
- Apply lip balm for cracked lips

Dependent patients

- 2-4 hourly mouth care (Assess individually)
- Use of soft brush, foam, stick applicator, glove and gauze
- Use of syringe for gentle mouth wash
- Avoid lemon and glycerin, as glycerin dehydrates and lemon over stimulates salivary glands.

Sore Mouth

Figure 11.1: Tongue ulcers



Causes

- Thrush
- Loose dentures/dental problems
- Ulceration
- Gingivitis
- Infections
- Low immunity
- Malnutrition
- Drugs
- Radiotherapy

Management

- Always treat for thrush (Thrush may be present in throat).
- Assess teeth and fitting dentures for gingivitis that may be present (use metronidazole)
- Mouth ulcers (use fluconazole, kenalogin, orabase, vitamin C tablet)

Antiseptics / antibiotics

- Chlorhexidine, Metrogyl, Neem leaves (boiled in water) are good as mouth wash.

Local anaesthetics

Viscous lignocaine mouth rinse in case of oral pain and not able to take food orally (watch for swallowing of food and fluid 1 hour post treatment)

Considerations

- Dietary – Intake of soft palatable foods, reduce intake of hot and spicy food, preferably use a straw for fluid diet in case not able to chew the food in acute stage.
- Dental - part of interdisciplinary team in palliative care, maintain socio-cultural sensitivity when assessing the mouth
- Assess each patient, family and environment.

Oral Candidiasis:

Figure 11.2: Oral Candidiasis



Features

- White adherent patches, Coated on the tongue.
- May appear red and ulcerated.

Causes

- Corticosteroids
- Antibiotics
- Diabetes mellitus
- Dry mouth
- Immune suppression

Management

- Topical: Nystatin Suspension 1-2 ml Q4H.
- Systemic: Fluconazole 150mg stat or 50mg daily for 7-14 days depending on severity of infection.
- Herpes Infection: Topical Zovirax (Acyclovir)

Xerostomia:

Causes

Thrush, drugs, dehydration, radiotherapy, oral breathing, infection, and fever.

Xerostomia- assessment questions?

- Does oral dryness bother you?
- Do you need to take increased fluids?

- Is your mouth painful?
- Do you experience altered taste sensations?
- Is it difficult to speak or swallow?
- Do you use tobacco? What type? How much?
- Are you on any medications?

Management

- Treat underlying infection, such as thrush.
- Review and alter unnecessary current medications.
- Stimulate salivary flow.
- Replace loss of secretions with saliva substitutes.
- Protect teeth with hourly mouth care
- Rehydrate with ice chips.
- Modify diet. Consider chewing gums, make ice cubes of pineapple juice, mild citrus drinks, soda water and normal saline

Halitosis:

Foul or unpleasant breath

Determine the cause:

- Dietary - a frequent cause is the use of garlic or spices
- Dental/periodontal problems?
- Infected teeth, gums, and oral carcinoma? Thrush alone is unlikely to cause halitosis
- Anaerobic infection of the gums can cause halitosis
- Upper GI causes
- Gastric reflux, gastric stasis
- Bowel obstruction causing faecal vomiting?
- Anaerobic infection of the lungs such as bronchiectasis?

Non-pharmacological interventions:

- Meticulous oral hygiene 2 hourly and after each food intake.
- Clean and soak dentures
- Ensure adequate fluid intake
- Flavoured sweets e.g. mints

Pharmaceutical treatment:

- Anaerobic infection of gums - oral metronidazole 400mg BD
- Gastric fluid - metoclopramide 10mg TDS or domperidone 10 to 20mg QDS
- Anaerobic infection of lungs - systemic metronidazole
- Antiseptic mouthwash - Chlorexidine 10ml QDS
- Debriding agents if indicated

1st Line: Sodium bicarbonate mouthwash - 1 teaspoon in 1 pint warm water.

2nd Line: Ascorbic acid (Vit C) tablets - 250mg has to be placed on the tongue qds.

Altered taste sensation

Conditions such as Xerostomia and drugs administered to treat cancer patients may contribute to taste disturbances. Zinc deficiency has also been linked with abnormalities in taste sensation and zinc levels may be reduced in patients with malignant diseases.

Skin Care

Aim

- To maintain skin integrity using preventive measures.

Nursing interventions

Maintain daily hygiene – sponge bath, shower, hair care, shave (for male patients) trim nails.

- Maintain hygienic environment, such as clean clothing, and bed linen.
- Maintain oral hygiene.(as per needs)
- Assess skin integrity, especially pressure points, in areas such as sacrum, hips,

heels, ankles, ribs, vertebrae, spine, shoulders, elbows, and ears.

- Patient with poor mobility need change of position every 2 hours.
- Positioning of pillows.
- Massage (Avoid massage at pressure points as it can cause tissue damage)
- Pad bony prominences for protection,
- Use waterbed or air mattress.
- Awareness of friction and shearing forces.
- Health educates family members about care of bedridden patients.

Pressure Sores

A pressure sore or pressure ulcer or decubitus ulcer is an injury to the skin and tissue underneath, usually caused by unrelieved pressure. Pressure on a small area of the body can compress tiny blood vessels that normally supply tissue with oxygen and nutrients resulting in ischemia and possible necrosis of the area.

Aims

- To relieve the pressure.
- To prevent further complications

Purpose of care

With proper treatment, most pressure sores will heal. Healing depends on many things, general health and diet, relieving pressure on the sore and careful cleaning and dressing of the sore.

Pathophysiology

- A pressure of 70 mm of Hg applied for more than 2 hrs can produce tissue destruction.
- Friction contributes to pressure sore by causing abrasion of the stratum corneum
- Shearing force, produced by sliding of adjacent surfaces in the partial sitting position. The force ruptures capillaries over the sacrum
- Moisture on the skin causes epithelial maceration.

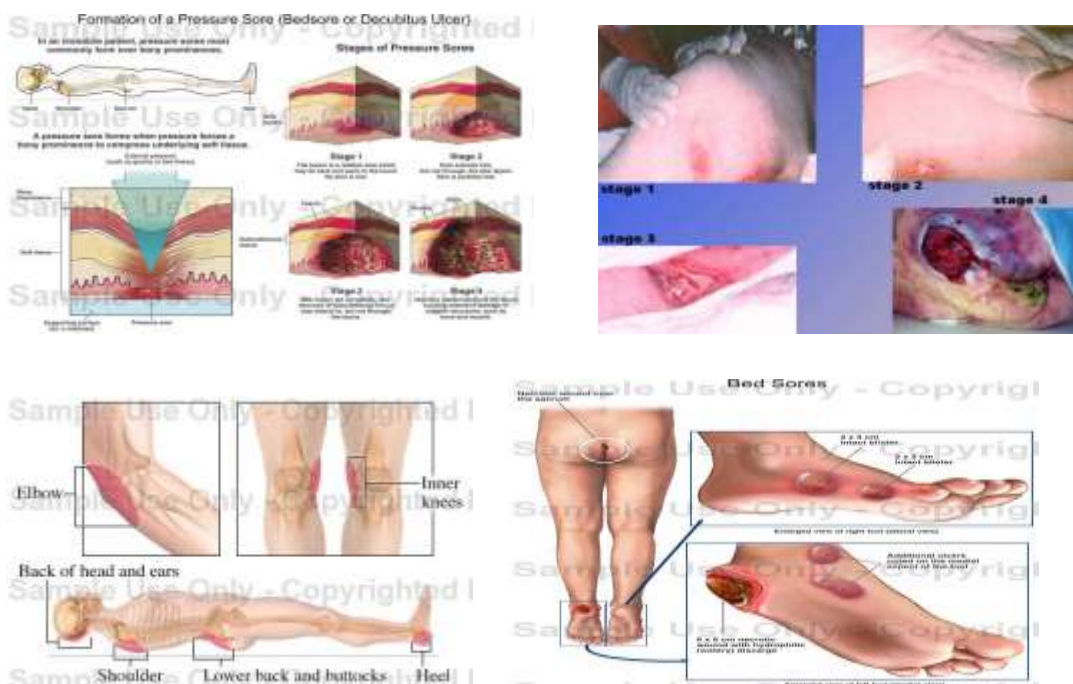
Risk factor for pressure sores

1. Bowel or bladder incontinence
2. Malnourishment or significant weight loss
3. Oedema, anemia, hypoxia or hypotension.
4. Neurological impairment or immobility
5. Altered mental status, including delirium or dementia.

Stages of pressure sores

1. Erythema: Skin is intact but red and does not turn white when pressure is applied
2. Breakdown of the dermis: Outer layer of the skin is broken, red and painful.
3. Full thickness skin breakdown: This involves damage or necrosis of subcutaneous tissues.
4. Breakdown of bone, muscle and supporting tissues: This involves deep wounds that are difficult to heal.

Figure 11.3: Sites of pressure sores



Nursing interventions

1. Prevent pressure sore development
 - Inspect skin daily
 - Daily bath
 - Keep skin soft and pliable
 - Avoid poorly ventilated mattress
 - Prevent incontinence of bowel and bladder.
 - Encourage ambulation and exercise
 - Encourage a balanced diet to keep tissues healthy
 - Educate family member about pressure sore prevention

2. Relieve the pressure
 - Reposition every 2 hours
 - Do not rest on hip bone directly; a 30° side lying position is best.
 - Avoid elevation of head end of bed greater than 30°.
 - Use special devices to relieve pressure such as air cushions, waterbed, foam pads or pillows.

3. Pressure sore care
 - Use normal saline for cleaning and irrigating the wound.
 - Remove dead tissues and scab
 - Use moist dressing material; this prevents damaging granulation tissue while changing the dressing.

Nutrition

Proper nutrition and balanced diet with extra protein and vitamin is important for quicker healing. Drugs can be used to relieve pain from dressing.

Points to remember

- Avoid direct pressure to bony prominences
- Use pillows and cushions to support arms, legs, ankles, heels and knees.

- Change bed linen as often as needed
- Bed bound person –change of position every 2 hours.
- Chair bound person –change of position every hour
- Reduce exposure to moisture
- Do not massage bony areas of the body
- Do not massage pressure sores
- Do not use Hydrogen peroxide or Betadine for cleaning pressure sore.

Bladder Care

Bladder care is an important component especially while caring for palliative care patients. Majority of these patients are bedridden and catheterization is a necessity. Due to the disease process and other concomitant factors, intake of fluid is less and the output is also less.

Clinical features

Dysuria, hesitancy and retention of urine, increased frequency of urination, incontinence, pyuria, haematuria, polyuria, oliguria

Assessment of clinical features

- Pain: onset of pain (before, during or after passing urine)
- Colour: dark coloured with presence of blood, pus, faecal matter (in rectovesical fistula)
- Passing air in urine (Pneumaturia)
- Smell: fruity smell (ketosis), foul smell (infection), faecal smell (fistula)
- Local examination of perineum and genitourinary tract
- Incontinence: (assess nature of incontinence – stress, urge, overflow or total)
- Fistula: site

Retention of urine

- Time of last voiding
- Drug (medicine) history

- Discomfort and pain
- Distension of lower abdomen

Psychological problems

- Financial problems
- Social problems
- Spiritual problems
- Sexual problems
- Problems associated with dependence and privacy

Management

- Advise patient to take medicines on time
- Increase intake of fluid
- Personal hygiene

Incontinence of urine

- Treat for pyuria or infection
- Give bedpan when patient asks for it or assist the patient to reach the bathroom.
- Encourage the patient to pass urine frequently so that he/she develops the habit of voiding once in 3-4 hours
- Intake of water during day can be increased so that frequent voiding in the night will not disturb sleep.
- Perineal area should be kept clean
- Assess whether the patient can pass urine. If not, catheterization should be done especially for cases of total incontinence and retention
- Perineal exercise to tone the muscles

How to help patient suffering from incontinence?

- Give privacy
- Provide bedpan, urinal or commode if needed.
- Provide massages for painful areas, if possible.

- Give hot water fomentation on lower abdomen or a wash with warm water.
- Stimulation by sitting patient next to running water.
- Patient should be given enough time to empty bladder completely

Points to remember

- Empty the bag when it is 3/4th full
- Cap the urobag after draining urine
- Change catheter every month or when it is blocked.
- Consider bladder wash if infection is present.
- Milking of the catheter (outer portion) prevents block.
- Observe if urine is draining freely
- Secure the urobag below the waist while walking.

Siliconized catheters last long and have to be changed only once in 3 months. These catheters are cost effective due to their longer use and hence are recommended.

What is the ideal size of catheter that must be used?

Male and female urethra have the same diameter and hence similar sized catheter (Usually 14 or 16) can be used in males and unmarried young female.

What is the ideal volume of sterile water to be injected to inflate the bulb - Is it different in different conditions? (For instance, old age, reduced bladder tone)

The ideal volume to be used for inflation is around 5-10 ml. If a higher volume is used, bladder spasm may occur and could be mistaken for infection. There is no possibility of non-uniform inflation of the balloon or kinking of the tip of the catheter within the bladder (even with less volume). Note that more the surface area of the catheter bulb, the higher the chances for calculi.

What is the ideal interval for catheter change to ensure reduction of infections?

Changing a catheter is necessary to minimize the chance of calculi formation. Phosphates and calcium form deposits on a foreign body in the bladder and chances for calculi if catheter is unchanged for a long time is higher. However, infection alone is not an indicator for catheter change and catheter to be changed every 3rd week or one month.

How to prevent peri-catheter leakage?

Good catheter care and perineal care and adequate fluid intake can prevent peri-catheter leakage. Bladder infections, calculi, loaded rectum and If the volume of sterile water in the bulb is more, bladder spasms and peri-catheter leakage can occur. If infection is the cause of frequent leakage bladder wash with isotonic (normal) saline can be done.

Are there any specific antibiotic policy?

Treat infection only if they cause symptoms. Infection with pus cells may always be present in a catheterized patient. There is no point in doing routine urine examination. Urine culture and sensitivity test should be done when patient is symptomatic and treatment should be started accordingly.

Infection is the most frequent cause of blockage. Bladder wash removes blockage and reduces infection.

Bladder wash

Indications

- Pyuria and catheter blockage.

Best solution

- Normal Saline – 100 to 200ml can be used twice/thrice daily and continued for 2 to 3 days.
- Intervals at which bladder wash is indicated for patients with regular UTI differ. For example, in the event of pyuria or catheter blockage, bladder wash must be done till urine clears.

Application of jelly in males & females

- For males, take 10 ml of jelly in a syringe and instill it in the urethra. Massage the tip of the penis. Wait for 5-10 minutes.
- For females, there is no need to instill jelly in urethra. Lubricate the tip of the catheter. (Female urethra is just 2-3 cms long.)

Difficulty in insertion

This occurs mostly due to insufficient lubrication. Trauma to the urethra leads to bladder spasms, which in turn lead to further difficulty in insertion.

Difficulty may also be encountered while insertion, due to stricture, benign prostatic hyperplasia (BPH) especially in elderly males. In cases with neoplasm, refer to urologist for a suprapubic catheterisation (SPC) or other urological interventions.

Deflating problems

Common when cheap catheters are used. Whenever possible push small amount of sterile water and deflate.

In Females - Pull the catheter since urethra is just 2-3 cm long and the bulb can be seen through the urethra. Bulb can be ruptured using a needle passed through the peri-catheter space. Another method is needle puncture by per vaginal approach. Bladder can be accessed through vagina and bulb ruptured through anterior fornix.

In Males - Do a rectal examination and push the bladder and the bulb anteriorly. A suprapubic puncture ruptures the bulb. If not possible patient should be referred to urologist. Alternatively, ether can be used to rupture the bulb. Push ether through the small tube and the bulb ruptures. Wait for 10-15 minutes for ether to escape out or there could be a chance of cystitis. (Malabar urology centre predominantly uses this method without any reported complications)

Bleeding and trauma during catheterization: Are there any simple measures for management?

To minimize trauma during insertion, insert the catheter completely and wait for some time. Bleeding will stop due to pressure effect. Trauma during removal- A "T" bandage should be applied over penis and scrotum. This arrests bleeding in mild cases. If severe, the patient should be referred to urologist.

Intermittent catheterization

- Company or brand of catheter used
- No specific options because catheter can be discarded any time if damaged.
- Size of catheter- 14/1 6

- Sterilization techniques: Clean with soap and water, dry and keep the catheter in a clean covered bag, Wash in warm water before next use.

What should be the daily frequency for catheterization?

Usually the recommended frequency is Q4H-Q6H. Frequent catheterization is required if fluid intake is more and during rainy season. The aim should be to maintain residual volume of urine at a level of less than 100 ml. Ensure adequate fluid intake of at least 1500 to 2000 ml. It helps to maintain an intake-output chart.

Condom catheter – Need to be considered when all other options fail/cannot be applied

How long can condom catheter be used?

Patients are usually provided with two condom catheters. It must be removed, cleaned and changed twice daily. Catheters can be used till they get damaged.

Should catheter free intervals be maintained to prevent penile ulceration? If yes, what is the duration?

Penile ulceration is due to the collection of urine in between the catheter and the penis. To prevent this, place the condom upwards towards the suprapubic region and not around the penis. Skin excoriation and penile ulceration is more evident when the catheter is stuck around the penis allowing collection of urine around the penis.

SPC (Suprapubic Catheterization)

5-10 ml of sterile water is required to inflate the bulb.

How frequently the SPC catheter has to be changed?

At least every 3 months. Chance of infection is less in SPC.

How to perform skin care or colostomy care?

Insertion of the catheter up to the bifurcation is unnecessary. Insert only up to the point where urine comes out.

Wound Care

Figure 11.4: Fungating tumours



Unsightly and painful wounds could adversely affect self-esteem and body image causing patients to isolate themselves. An understanding of the goals of palliative medicine is essential in developing a treatment plan aimed towards decreasing the effect that these lesions have on the patient's quality of life

The type and source of lesion must be ascertained since different lesions may require different treatment and management strategy. Malignant fungating wounds present both physical and emotional challenges to the patient, family and healthcare workers such as nurse, volunteer. A fungating wound with mal-odour, exudates, infection, and maggots and bleeding add to the misery of advanced and uncontrolled metastasis disease.

Etiology

When there is a proliferative (primary or secondary) malignant growth in the skin, it causes relative loss of vascularity, resulting in necrosis and ulceration. Infection due to anaerobic and aerobic bacteria could lead to exudates, malodour and bleeding.

Aim

- Promotion of comfort and palliation of symptoms (holistic care).
- Provision of treatment that is realistic, acceptable and affordable to the patient.

Assessment

- Physical problems – pain, mal-odor, bleeding, infection, exudates and maggots
- Psychological problems - shame, guilt, altered body image, fear of death, depression, anxiety and isolation.
- Social problems - isolation, stigma, effect on family, fear of contagion
- Spiritual issues - interference with religious rights, belief that it is punishment from God, losing or developing faith in God, existential dilemmas
- Wound location: whether on exposed part of the body
- Wound appearance - size, necrotic tissue, fistula
- Condition of surrounding skin
- Potential for complications such as hemorrhage
- Education of patient and family

Management

- Consider anticancer treatment- RT, CT, debriding surgery in the case of cancers
- Control of infection with systemic antibiotic.
- Deep pain- aching, stabbing or continuous pain. Adjust systemic analgesics. Give an extra dose of morphine half an hour before dressing.
 - Superficial pain burning/stinging - local application of 0.25% Bupivacaine, Lignocaine jelly or opioid and soak 10 minutes before dressing.
 - Incidental pain - Occurs only on movement. Ketamine can be given sublingually (0.25 mg - 0.5 mg/ kg/dose).

Maggots

Prevention of maggot infection is better than cure. The following steps should be used for infection, if present.

- Wound should be covered with dressing all the time and changed daily.
- If maggots are present apply or flush plain turpentine oil in the wound with a syringe. Protect eye, nose and ear with pad and instruct the

patient not to swallow if turpentine is spilled accidentally in the oral cavity, as there will be irritation. Wait for 10 minutes after application of turpentine. Remove maggots with the help of forceps.

- Maggots come out from the hidden pockets of tissue when there is a lack of oxygen supply and the irritation from turpentine vapor. Therefore, the procedure of flushing with turpentine has to be repeated for 3-4 days to remove all maggots. When completely removed, teach the carer the correct way of wound cleaning and dressing.

Malodour

Usually caused as a result of anaerobic bacterial growth in dead tissues. This can be controlled as follows:

1. Daily bath before dressing
2. Cleaning with normal saline
3. Mop the wound gently with gauze. Apply metrogyl powder on the wound.
4. If the wound is dry and painful apply metrogyl powder mixed with lignocaine jelly (benefit will be noticed only after 12 hours).
5. Apply dressing at least twice a day until mal-odour settles.
6. Metrogyl gel is expensive and metronidazole content is less per gram of the gel compared to tablet. Tablets are preferred than gel for local application.
7. For exudates, frequent changing of dressing and application of absorbent pads

Bleeding

1. To prevent bleeding while removing dressing, soak with normal Saline and gently remove.
2. If bleeding is present apply pressure for 10minutes on the wound. If bleeding continues, continue application of pressure
3. Use dressing with sucralfate powder as it forms localized coating on the wound.
4. Injection feracrylum 1% (hemlok) can be diluted with water and used as a soak. 1ml of hemlok mixed with 100 ml of sterile water can be used for

localized use.

5. Adrenalin packs may be used with caution since adrenaline can get absorbed through a raw wound and this can cause elevation of pressure and bleeding. In addition, adrenaline's effect is for a short duration.

How to train the carer in wound management?

We can help the patient and the carers by teaching them the proper procedure and protocol to be used while caring for themselves or their loved one. Explain to the carer that fungating wound is non-healing and although will be present life long, the symptoms can be controlled. Provide the carer with support, counselling and practical demonstration of preparing dressing material at home. Carers can use the following protocol for home-based sterilization technique such as preparation of saline for cleaning and dressing:

- 2 teaspoon salt in 1 liter of water.
- From the boiling point, boil for five minutes.
- Keep this water in clean closed container and can be used as per need

Dressing Material: Simple dressing material can be prepared at home. Old cotton cloth that have been washed well with soap and water and dried in sunlight can be used. The clean cotton cloth should be cut into small pieces and steamed for half an hour and stored in a clean airtight container. Family members can be advised to preserve dark coloured clothes to be used to cover bleeding wounds. The following advices also should be given:

- Hand should be washed before and after dressing
- Waste materials should be properly disposed
- Regular follow up with healthcare worker is important.

Stoma Care

Stoma is an artificial surgical opening.

Types of stoma - Input and output

- Input – Tracheostomy, Gastrostomy.

- Output – Colostomy, Ureterostomy, Nephrostomy.
- Stoma is divided into temporary and permanent.

Colostomy

Figure 11.5: Colostomy wound



Indications for colostomy

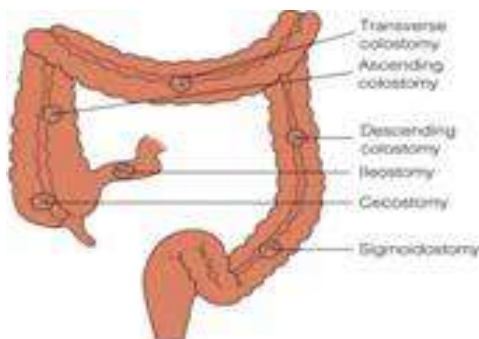
- Injury or trauma.
- Congenital abnormality.
- Obstruction.
- Malignancy (Cancer of Colon/ Cancer of Rectum)
- Chronic diseases like ulcerative colitis.
- Fistula (Rectovaginal fistula).

Aim

- Management of stoma as a normal activity of daily living
- Educating the patient and the carer about stoma and availability of properly fitting appliances

Types

Figure 11.6: Pre-operative Management



- Site marking and planning for post-operative rehabilitation.
- Explain to the patient and carer about necessary details

Post-operative management

- Provide liquid diet initially followed by soft diet
- Reduce intake of certain food that cause gas and mal-odour such as onion, cabbage, spicy foods, meat, egg
- Team work for good management between patient, family, surgeon, and nurse therapist.
- Bag care - correct size, proper cleaning with soap and water, optimum drying and emptying when 3/4th full.

Bowel Management

It is important to establish regular bowel movements after colostomy. Habit formation can be established by daily irrigation at a fixed time for 21 days. It may have to be continued throughout life. Irrigation is usually done with about 1 to 1.5 litres tap water. An irrigation set for the procedure is available. Irrigation can be started after 3 weeks to 3 months of surgery or RT/CT.

Management of Nursing Problems

Constipation

Laxatives, enema, suppositories.

Diarrhoea

Increase intake of fluid and provide hospitalization as early as possible.

Bleeding

It is usually seen at the time of cleaning or changing the bag. Apply local pressure for 10 minutes and use sucralfate powder to control bleeding.

Prolapse

Figure 11.7:



- A prolapse of 1.5 cm of stoma outside the skin level is acceptable in case of colostomy.
- 3.5 cm of stoma outside the skin level is acceptable in ileostomy.
- A prolapse of 5 cm needs surgical intervention

Hernia

Figure 11.8:



If there is no interference with bowel movement, intervention is not needed. Otherwise surgical correction is advised. Special attention is to be given to peristomal skin.

Skin care

Figure 11.9:



- Daily cleaning with soap and water.
- Dry with soft towel (mopping).
- If skin erosion is present, apply karaya powder mixed with egg white for 2 to 3 days.
- Zinc oxide paste can be used instead of karaya powder.
- Use correct size bag.

Malodour could be prevented by adding charcoal to the colostomy bag.

Sexual life

- Counseling for spouse.
- Support and encouragement.
- Avoid pressure being applied on stoma.

Games

Avoid outdoor games that require extreme physical activity.

Clothing

Loose clothes covering the stoma are preferred.

Traveling

Protect the stoma with book or handbag while traveling.

Colostomy bag care:

Figure 11.8: Colostomy bags



Irrigation of colostomy

Figure 11.9: Irrigation of colostomy



Points to remember – irrigation of colostomy

- Start irrigation after three months of surgery/CT/RT
- Do not irrigate if there is diarrhoea
- Do not irrigate ileostomy
- 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.

Tracheostomy

Stoma made in the trachea for breathing.

Aim

Encourage self-care of the stoma parts.

Figure 11.10-: Tracheostomy tubes



Routine Care Cleaning

- Inner tube should be removed and thoroughly cleaned with soap and water. Sterilization of the tube in boiling water for 10 minutes or in betadine or hydrogen peroxide solution also is advised.
- Outer tube should not be removed. Clean the tube plates with saline soaked gauze thoroughly.

Skin care

- Clean the skin around the tracheostomy tube with saline soaked gauze.
- Protect the skin with a gauze pad, make a slit in the middle of the gauze and place in between the outer tube and skin (Vaseline gauze can be used).

Suction

Suction is to be performed only when copious secretions are present for not more than 5 seconds.

Humidification of air

Place wet sterile gauze on the top of the tracheostomy tube. This helps to humidify the inhaled air and filter the dust.

Changing tie

- Train the patient to self-clean the tube using a mirror.
- The patient should be encouraged to talk by taking a deep breath and then trying to speak after closing the stoma with a finger.
- Tie is used to fix the tube in position. Tie should be changed when it is dirty. Preferably a black tie should be used and it should be tied neither very tight nor too loose. Maintain a one-finger gap between the tie and the skin.
- For male patients, educate him and his carers to cover stoma while shaving.

Care of bed ridden patient

Nursing care of bed ridden patients is quite challenging for nurses. Patient may be conscious or unconscious. A patient becomes bedridden due to a disease or aging. In both the cases, a patient needs complete care like

- personal hygiene
- nutrition
- exercise (passive & active)
- bladder care
- bowel care
- communication
- treatment
- education

The major problems in a bedridden patient is -

- corneal ulcer
- pressure sore
- malnutrition
- psychological problems
- electrolyte imbalance

a. Nursing care for an unconscious patient:

- Airway clearance
- Adequate fluid intake (Nasogastric tube or IV fluids to maintain fluid electrolyte balance)
- Incontinence of urine/ faeces
- Personal hygiene
- Impairment of mobility resulting in development of foot drop, muscle wasting and thrombophlebitis.
- Alterations in body temperature
- Impaired communication
- Impaired skin integrity which makes skin vulnerable to pressure sore.

b. Mouth care

Mouth care is provided to maintain the integrity of the patient's teeth, gum, mucus membrane and lips. If the patient is conscious, assist the patient to do mouth care by self .In unconscious patient demonstration to the care giver how to do mouth care at home.

Solutions which can be used are - Normal Saline, Soda bicarb, lime juice, Water in which neem leaves are boiled,

c. Bed bath

Bathing is an important intervention to promote hygiene

General Instructions for giving bed bath

- Maintain privacy
- Avoid giving unnecessary exertion to the patient.
- Remove the soap completely to avoid the drying effect.
- Only small area of the body should be exposed and bathed at a time.
- Support should be given to the joints while lifting the arms and legs for washing and drying these areas.
- Provide active and passive exercises whenever possible unless it is contraindicated.
- Wash the hands and feet by placing them in the basin because it promotes thorough cleaning of the finger nails and toe nails.

- Cut short the nails, if they are long.
- A thorough inspection of the skin especially at back should be done to find out the early signs of pressure sore.
- All the skin surfaces should be included in the bathing process with special care in cleaning and drying the creases and folds and the bony prominences etc. as these parts are most likely to be injured by moisture, pressure, friction and dirt.
- Cleaning is done from the cleanest area to the less clean area, e.g. upper parts of the body would be bathed before the lower parts.
- The temperature of the water should be adjusted for the comfort of the patient
- Creams or oils/paraffin are used to prevent drying and excoriation of the skin.
- Keep the patient near the edge of the bed to avoid over reaching and straining of the back of the care giver

d. Back care

Patients who are prone to pressure sores must have their back care 2 hourly or more frequently. Back is washed with soap and water, dried and massaged with lubricant to prevent friction. Massaging helps to increase the blood supply to the area and thereby prevent pressure sore.

- Attention to the pressure points.
- Dry the area by patting and not by rubbing.
- Stroking with both hands on the back.

e. Care of hair /head bath

Stimulating the scalp by massage & brushing improves circulation & maintains hair healthy

Points to remember

- Protect the bed linen and pillow cover with a towel and mackintosh.
- Place a mackintosh under the patient's head and neck. Keep one end of the mackintosh in a bucket to receive the water. Wash thoroughly with soap or shampoo.

- Rinse thoroughly and dry the hair. Braid the hair into two on each side of the head, behind the ears to make the patient more comfortable when lying on her back.

f. Care of eyes

The most common problem of the eyes is secretions that dry on the lashes. This may need to be softened and wiped away. Each eye is cleaned from the inner to the outer canthus with separate swabs.

g. Care of nose and ears

The nose and ears need minimal care in the daily life. Excessive accumulation of secretions makes the patient to sniff and blow the nose. External crusted secretions can be removed with a wet cloth or a cotton applicator moistened with oil, normal saline or water.

h. Care of perineum

Perineal hygiene involves cleaning the external genitalia and surrounding area. The area is prone to the growth of pathogenic organisms because it is warm, moist and is not well ventilated. Thorough cleaning is essential to prevent bad odour and to promote comfort. Perineum should be cleaned after each urination and defecation Patients with indwelling catheters.

i. Active and passive exercise

All the joints need physiotherapy. Family should be educated on active and passive exercises.

j. Bladder care

- Use of correct size Foley's catheter or silicon catheter (the latter needs to be changed only once every 3 months)
- The ideal volume of sterile water to be used to inflate the bulb is 5-10ml.
- Daily cleaning of catheter with soap and water or betadine
- Every month Foley's catheter has to be changed.
- Increase intake of fluid to about 2- 3L /day

- Urobag should be kept below the waist level
- Keep the urobag cap closed.

k. Nutrition

A well balanced diet and adequate fluid intake is very important in a bed ridden patient

l. Communication/psychological support

This is very important in a bed ridden or chronically ill patients. Good communication skill can improve patient quality of life.

m. Bowel management

Alteration in bowel function is common in the terminally ill. Constipation is more common than diarrhea. Efficient bowel management may alleviate distress. Carefully assess bowel function on a daily basis

Constipation

Take a detailed and accurate history. Comparison with an individual's normal bowel habit and usual use of Laxatives may highlight changes related to disease or treatment. A record of bowel habits will help in the management. Examination of the abdomen and the rectum may exclude faecal impaction or rectal pathology.

Management: Prevention is the key. If a cause is identified remove it, if possible. Regular exercise reduces the risk of constipation. So encourage it (deep breathing, abdominal massage etc...) Encourage intake of fiber rich diet and fluids.

Laxatives

When opioids are prescribed, anticipate constipation and prescribe an oral softener with a stimulant laxative e.g. docusate with senna or bisacodyl which may prevent the need for rectal intervention later.

- If a patient taking laxatives has no bowel motion for two days, give extra

laxatives.

- If a patient taking laxatives has no bowel motion for 3 days and this is not his normal bowel habit, a rectal examination should be carried out .If soft faeces is present give 2 bisacodyl 10mg.
- If hard faeces are found give high enema (after manual evacuation) with glycerine or sodium phosphate. Repeat abdominal palpation.

Prevention of constipation:

Simple measures should be incorporated as part of the routine palliative care plan in all patients.

- Maintain good symptom control.
- Mobility: Activity is the key stimulus to colonic peristalsis and defecation. Mobility should be encouraged as much as physical limitations permit.
- Maintain adequate oral fluid intake. Constipated stools have relatively low water content, rendering them hard and difficult to pass.
- Dietary fiber is useful in preventing constipation and management of mild constipation.
- Use of bedpans: It is mandatory to maintain patients' privacy and use of a commode or lavatory for defecation.
- Drugs causing constipation should be avoided or if needed laxative should be simultaneously prescribed.

Opioid induced constipation

Opioid are often blamed in palliative care for constipation. In fact, they worsen an existing situation rather than create a new one. Approximately 80%of patients on strong opioids need laxative, 75% on weak opioids and 60% still need a laxative even in the absence of opioids.

Laxatives: Majority of patients in the palliative care clinic require laxatives. The aim of treatment is comfortable defecation, and not increased stool frequency. Even on regular laxatives, 40 to 60% of terminally ill patients need additional rectal measures on a continuing basis.

Rules for using laxatives:

- Use the laxatives favoured by the patient.
- Keep a record of stool frequency.
- Keep the choice between adequate oral and rectal laxatives and between stool softener and stimulant drugs.
- Titrate dose avoiding both colic and diarrhea.
- If diarrhea occurs stop laxative for 24 hrs and restart the dose when diarrhea stops.
- Check the patient's perception of bowel functions.

Approach to Treatment

The need to treat constipation arises is usually due to failure to prevent it.

Step care approach:

- Rectum empty: rule out bowel obstruction before starting treatment.
- Rectum is full: follow the following guidelines.
- If the rectum is impacted with hard faeces, spontaneous evacuation is unlikely to be possible without local measures to soften the fecal mass, for example, glycerine suppositories,
- If the rectum is loaded with soft faeces A predominantly stimulating laxative, for example, Bisacodyl , 10-20mg HS
- If there is little or no stool in the rectum, a peristalsis-stimulating laxative is the drug of choice, for example, senna, but if the stools are likely to be hard, it is a reasonable policy to use a stool-softening laxative in addition.
- Paraplegic patients need regular manual evacuation. In these patients, evacuation is easier if stools are made firmer by using senna.

n. Diarrhoea

Diarrhea is the passage of frequent loose stools with urgency. Objectively, it has been defined as the passage of more than three unformed stools within a 24-h period. This is a relatively uncommon problem in palliative care setting. Rotation from morphine to fentanyl may result in a sudden reduction in opioid constipating effect resulting in diarrhoea. The commonest cause is spurious

overflow diarrhea in patients with neglected constipation or partial bowel obstruction.

Management depends on cause:

- Assess bowel habit and faecal consistency
- Maintain skin integrity around anal area -use barrier creams to prevent excoriation e.g. zinc oxide
- Think about overflow from impaction or partial obstruction
- Use abdominal examination or x-ray to rule out obstruction
- Restrict oral intake (except fluids) to rest the bowel
- Withhold laxatives where appropriate

If impacted, use manual removal followed by laxative or enema. In partial obstruction diarrhoea may be very unpleasant. In spinal cord compression a constipating drug may help e.g. Codeine (although patients already receiving morphine may not benefit) followed by regular suppositories.

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- Keep a record of stool frequency.
- Keep the choice between adequate oral and rectal laxatives and between stool softener and stimulant drugs.
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Activity

Demonstrate the following:

- Bed making
- Changing the position of a patient with poor mobility
- Changing the position of bed sheets of a bedridden patient avoiding friction and shearing forces
- How to fill up a waterbed

Source: Institute of Palliative Medicine 2017. Palliative Care – A Workbook for Carers, accessed from <file:///D:/userprofiles/ganguliat/Downloads/Palliative%20Care%20Workbook%20for%20Carers.pdf>

CHAPTER 12

Palliative Care in Children

Learning objectives

At the end of the chapter, the candidate should be able to:

- Identify pediatric conditions requiring palliative care
- Communicate effectively with children
- Assess and manage pain and other symptoms in children

Duration: One hour

Pediatric palliative care aims at ameliorating suffering of children with life-limiting conditions and their families. Those conditions include neurological disorders, congenital malformations, genetic disorders, HIV/AIDS, cancer, end-stage organ failure (respiratory, cardiac, hepatic or renal failure), etc. A multidimensional approach to pain and other symptoms is required. Effective symptom control starts with proper assessment. Specific needs of children and teenagers, such as age-appropriate communication, growth, play, schooling, differ from adults. Palliative care should be offered from the time of diagnosis of a life-limiting condition, until cure or death. At the end of life, specific measures help alleviating the suffering of the dying child and their relatives.

Pediatric conditions requiring palliative care

Palliative care is the active total care which provides relief of physical, emotional, social and spiritual suffering for those children and their families (parents, siblings and extended families). Holistic pediatric palliative care should involve child-life specialists, besides physicians, social workers, nurses, psychologists, and occupational therapists, in an interdisciplinary approach.

A growing number of children are living with chronic life-limiting conditions, leading to impaired quality of life. These conditions, often different from adult palliative care, include:

- Potentially curable but life-threatening conditions, palliative care should be offered as a complement to active treatment, in a continuum of care (e.g. cancer, irreversible organ failure).
- Advanced life-limiting conditions in which premature death is inevitable, with long periods of intensive treatment allowing normal life (HIV/AIDS, Duchenne Muscular Dystrophy, cystic fibrosis).
- Progressive conditions, where treatment is exclusively palliative and extends over many years (e.g. neuromuscular or neurodegenerative disorders).
- Irreversible non-progressive conditions causing severe disabilities, with complex healthcare needs (e.g. severe cerebral palsy, multiple disabilities).

Besides numerous barriers to palliative care delivery in India, pediatric palliative care provision is lacking⁶⁹. Pediatricians are not aware of the principles and benefits of palliative care; palliative care providers are little tuned to caring for children. Dealing with a dying child, and helping the family in their bereavement is both emotionally draining and rewarding.

Communication

- Children have various stages of mental and psychological development
- Communication with the child and relatives at all points of patient care improves compliance and satisfaction.
- Many parents unwilling to inform even older children about serious diagnosis or poor prognosis⁷⁰.
- Diagnosis may be revealed truthfully and tactfully in an age-appropriate way to children as young as 7 year, and certainly to teenagers.

⁶⁹Knapp C, Woodworth L, Wright M, Downing J, Drake R, Fowler-Kerry S, Hain R, Marston J. Pediatric palliative care provision around the world: a systematic review. *Pediatr Blood Cancer*. 2011;57(3):361-8

⁷⁰Seth T. Communication to Pediatric cancer patients and their families: a cultural perspective. *Indian Journal of Palliative Care*, 2010;16 (1):11-14.

Box 12.1: Communication with children

Types of communication

- Verbal: use of spoken or written words
- Non-verbal: gestures, facial expression, behavior

Modalities of communicating with children

- Body language
- Play language
- Spoken language
- Observation

Body language

- Read their body language: how they walk, eye contact, fidgeting, looking relaxed or tense
- Children are aware of our body language. They watch, understand and react accordingly. Adopt a friendly, open and relaxed posture.

Play language

- Adults speak, children play
- Children show, rather than telling about their life
- Use colors, drawing, dolls, toys. Sit, show interest, watch: they'll play their life
- Story telling builds trust and rapport, helps feeling expression

Spoken language

- Form short sentences easy to understand
- Children are afraid to say what is wrong and under-report their problems
- Use their mother tongue

Pain Management

PAIN IS WHAT THE CHILD SAYS IT IS

Pain assessment in children

- There may be more than one pain: physical, psychological, social, spiritual. Assess, quantify and treat each pain.
- Children may use the word pain for discomfort caused by other symptoms.
- 3 ways to assess pain:
 - ask the child (if able to tell)
 - ask the family (even if the child has already told)
 - assess yourself (least accurate)
- Use pain assessment scales adapted to age.

- In preverbal and nonverbal children, use observation methods based on behavioral response e.g., FLACC Behavioral Pain Assessment Scale⁷¹.
- In children above 4 years, use self-report pain scales facilitate communication from verbal children about pain, such as the modified Wong Faces Pain Scale⁷², and the Visual Analogue scale.
- The child can describe on the Eland Color Scale where the pain hurts more.

Table 12.1: FLACC Behavioral Pain Assessment Scale (Face Legs Activity Cry Consolability Scale)

| FLACC | Scoring | | |
|----------------------|--|--|--|
| Indicators | 0 | 1 | 2 |
| Face | No particular expression or smile | Occasional grimace or frown; withdrawn, disinterested | Frequent to constant frown, clenched jaw, quivering chin |
| Legs | Normal position or relaxed | Uneasy, restless, tense | Kicking or legs drawn up |
| Activity | Lying quietly, normal position, moves easily | Squirming, shifting back and forth, tense | Arched, rigid or jerking |
| Cry | No cry (awake or asleep) | Moans or whimpers, occasional complaint | Crying steadily, screams or sobs; frequent complaints |
| Consolability | Content, relaxed | Reassured by occasional touching, hugging or being talked to; distractible | Difficult to console or comfort |

Instructions for usage

In patients who are awake: observe for 1-5 min or longer. Observe legs and body uncovered. Reposition patient or observe activity. Assess the body for tenseness and tone. Initiate consoling interventions if needed. In patients who are asleep: observe for 5 min or longer. Observe legs and body uncovered. If possible, reposition patient. Touch the body and assess for tenseness and tone.

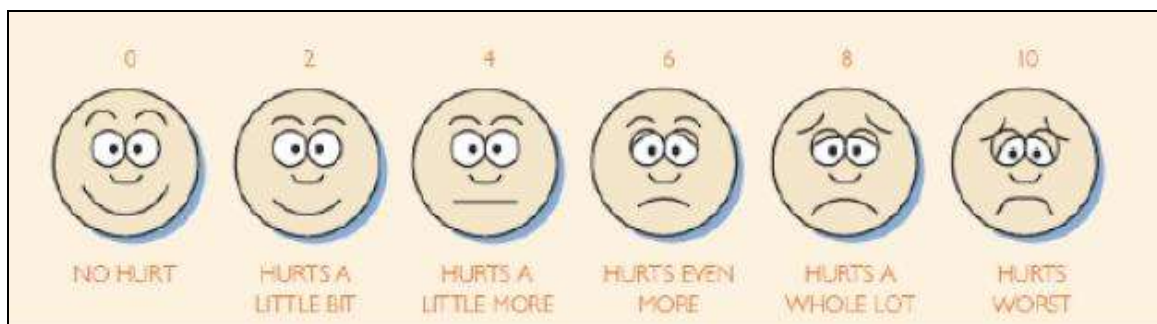
⁷¹Merkel SI, Voepel-Lewis T, Shayevitz JR, Malviya S. The FLACC: A behavioral scale for scoring postoperative pain in young children. *PediatrNurs* 1997;23 (3):293-7.

⁷²Hicks CL, von Baeyer CL, Spafford PA, van Korlaar I, Goodenough B. The Faces Pain Scale-Revised: toward a common metric in pediatric pain measurement. *Pain* 2001;93(2): 173-83.

Score:

| | |
|--------------|-----------------------------------|
| 0: | Relaxed and comfortable |
| 1-3: | Mild discomfort |
| 4-6: | Mode-rate pain |
| 7-10: | Severe discomfort or pain or both |

Figure12.1: Pain Assessment Scale in Children over 4 years of age – The modified Wong Baker Faces Pain Rating Scale

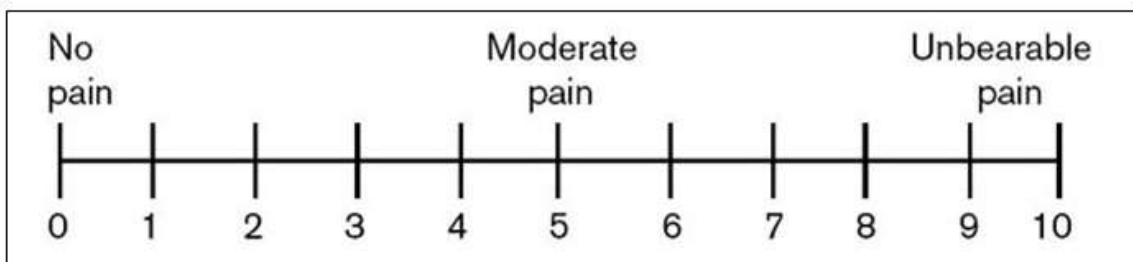


Instructions for usage

Explain to the child that each face is for a person who has no pain (hurt), or some, or a lot of pain.

“Face 0 doesn’t hurt at all. Face 2 hurts just a little bit. Face 4 hurts a little more. Face 6 hurts even

Figure 12.2. Pain Assessment Scale in Teenagers – Visual Analogue Scale

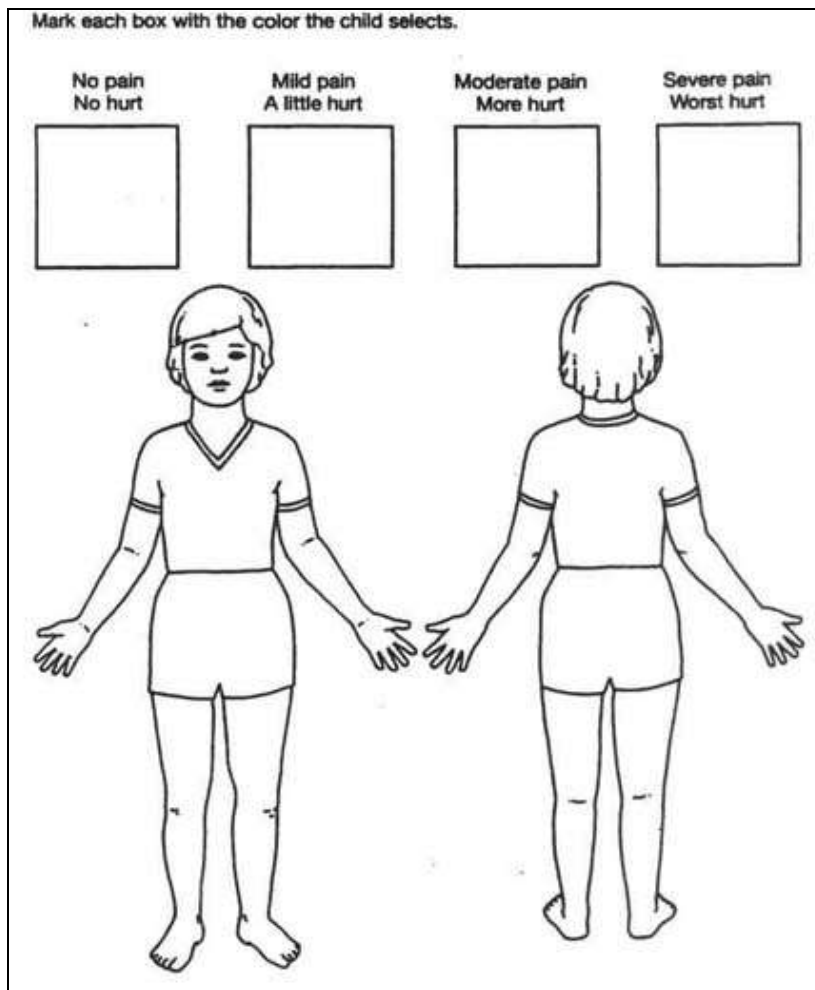


Instructions for usage

Ask the child: “On a scale of 0 to 10, with 0 meaning “no pain” and 10 meaning the worst pain you can imagine, how much do you hurt right now?”

0-no pain, 1-3: mild, 4-6: moderate, 7-10: severe pain.

Figure 12.3: The Eland Color Scale



Analgesic therapy

- Since pain is multidimensional, analgesic therapies should be combined with appropriate psychosocial, physical & spiritual approaches.
- Non-pharmacological analgesic measures
 - relaxation therapy, deep breathing
 - distraction, play therapy
 - occupational therapy, progressive muscle relaxation, massage
 - acupuncture, acupressure, aromatherapy.

WHO analgesic ladder for children

Whenever one drug provides no relief, then a drug combination or a change of drug is required.

Analgesic therapy should be given:

- By the ladder: WHO recommends a two-step ladder for pain control in children as many lack the enzyme needed to convert codeine into morphine, and there is no safety data of tramadol in children⁷³.
 - Step 1 for mild pain: paracetamol and non-steroidal anti-inflammatory drugs (contraindicated in children with thrombocytopenia).
 - Step 2 for moderate to severe pain: strong opioids in association with step 1 non-opioids, with or without adjuvants
- By the clock (at a regular schedule)
- By the appropriate route (least invasive route of administration)
- By the child.

Table 12.2: Analgesic medications in children above 6 months of age

| Drug classification | Analgesic | Formulation | Dose |
|-----------------------|---------------|---|---|
| Non-opioid analgesics | Paracetamol | Syp 125mg/5ml, 250 mg/5ml Drops 100mg/ml, 150mg/ml, Tab 500mg | 10–15 mg/kg p.o. q6h |
| | Ibuprofen | Tab 200/ 400/ 600 mg Syp 100 mg/ 5mL | 5-10 mg/kg p.o. q8h |
| | Diclofenac | Tab 25/50 mg; DT 46.5 mg | 1 mg/kg p.o. q8h to q12h |
| | Naproxen | Tab 250/ 375/ 500 mg | 10 mg/kg p.o. q12h |
| Strong Opioids | Fentanyl | Inj 50 µg/ml Patch: 12.5µg/h or 25µg/h Oral lozenges 200µg | IV bolus 0.5–1 µg/kg followed by IV continuous infusion 0.05–0.1 µg/kg/hr Transcutaneous patch |
| | Morphine | Tab 10mg, 20mg, 30mg SR Tab 10mg | 0.15-0.3 mg/kg p.o. q4h (opioid-naïve child) ^a . Increase by 30-50% till pain relief 30-60 µg/kg/h subcutaneous |
| | Buprenorphine | Patch: 5 mg/h or 10 mg/h | IV/IM 3-6 mg/kg Sublingual 5-7 mg/kg every 6 to 8 hours Transcutaneous |

Notes. Syp: syrup. DT: dispersible tablets. ^a 0.05-0.1 mg/kg in infants <6 months.

⁷³WHO guidelines on the pharmacological treatment of persisting pain in children with medical illnesses. World Health Organization, Geneva, 2012.

Strong opioids

Oral morphine

- Morphine does not hasten death.
- Starting dose in an opioid-naïve child:
 - 0.1 to 0.3 mg/kg 4 hourly above 6 months of age
 - 0.05-0.1 mg/kg 4 hourly in infants <6 months
- Double dose can be given at bed time, to avoid waking the child for the night dose.
- There is no liquid formulation available in India.
- Start with 5 mg of short-acting morphine (10 mg-half tablet) in any child weighing 17 kg or more, 4 hourly.
- For children under 17 kg, either try to break 10mg tablet so as to administer 2.5 mg per dose every 4 to 6 hourly, or crush a 10 mg tablet and suspend it in 10 ml of saline serum to make an oral suspension (mix it very well to obtain a clear solution; mix it well before each administration). It can then be mixed with small amount of juice/ soft food for easy administration. Injectable morphine can also be used orally.
- Increase by 30% to 50% till good analgesia is obtained.
- Night dose is usually doubled and next dose administered 8 hours later.
- There is no maximum acceptable dose to control severe pain.

Fentanyl

- Rapid onset, short acting, opioid of choice in hepatorenal dysfunction, useful alternative to morphine in children experiencing pruritis
- Transdermal patches: 12.5 µg/h (equivalent to oral morphine 5 mg 4 hourly), or 25 µg/h, for 3 days. Action starts 6-8 hours after initial application.
- In case of fever or excessive sweating leading to vasodilatation, transdermal drug absorption can be more rapid, leading to toxicity.
- Oral lollipops (200 µg): quick acting for breakthrough and incident pain, expensive.

Buprenorphine

- Longer duration of action than morphine, safe and effective
- 5 mg or 10 mg patches, for 7 days, cheaper than Fentanyl patches

Always add along with opioids:

- Antiemetics (ondansetron or metoclopramide) for the first 3 days of starting. Nausea and vomiting wear off after a few days.
- Laxatives (liquid paraffin or lactulose). Paraffin can be mixed with ice-cream or yoghurt; drink 1 or 2 glasses of any liquid after administration for proper bulk forming.

Table 12.3: Adjunctive therapy to opioid prescription

| Indication/ Drug classification | Drug | Formulation | Dose |
|---------------------------------|-----------------|---|--|
| Prevention of constipation | | | |
| Softening agent | Lactulose | Syr 10g/15ml | 5–15 mL q8h upto 1 ml/kg per dose |
| | Paraffin liquid | Syr | 3-12 yrs: 0.5-1 ml/kg OD (max-30 mL) >12 yrs: 10-30 mL OD |
| Nausea, vomiting | | | |
| Dopamine antagonist | Domperidone | Tab 5mg, 10 mg Susp 5mg/5ml Drops 10mg/ml | 0.2–0.4 mg/kg q4h to q8h |
| Dopa & serotonin antagonist | Metoclopramide | Tab 10mg, Syp 5mg/ml; inj 5mg/ml | 0.1 mg/kg q6h to q8h PO/IV/SC upto 1 mg/kg q6h, max 50mg/dose |
| Excessive sedation | | | |
| Piperidine | Methylphenidate | Tab 5mg, 10mg. 20mg | 0.3–2 mg/kg/day Start with 5mg before breakfast and lunch and increase |
| Pruritus | | | |
| Antihistaminic | Cetirizine | Tab 5mg, 10 mg Syr 5mg/5ml | 2–6 yrs: 2.5 mg BD or 5mg OD >6 yrs: 5 mg BD or 5mg OD |
| | Loratidine | Tab 10mg Syr 5mg/5ml | 2–6 yrs: 2.5 mg OD 6–12 yrs: 5 mg >12 yrs: 10 mg OD |
| Pruritus, nausea | Hydroxyzine | Tab 10/ 25mg Syr 10mg/5ml Drops 6mg/ml | 0.5 mg/kg q6h |

Other opioid side effects:

- Drowsiness: common in the first few days, it improves with time.
- Itching: oral anti-histaminics and skin emollients.
- Intractable itching: change the opioid or continuous morphine infusion along with low-dose infusion of Naloxone (0.5-2 µg/kg/h) in hospital setting.
- Urinary retention: alternate opioids.
- Rare risk of opioid-induced respiratory depression in children if:
 - accidentally high dose of intravenous opioid
 - sudden hepatic or kidney failure
- Hypotension, bronchospasm and chest wall rigidity are never seen with oral morphine.
- Over-sedation:
 - switch to another opioid⁷⁴
 - or add methylphenidate, prescribed by a psychiatrist.

Adjuvant therapy to analgesics

Neuropathic pain

Symptoms suggesting a neuropathic component in children

| | |
|---|--|
| Children able to describe pain <ul style="list-style-type: none">• shooting• stabbing• burning | Non-verbal children: triad of <ul style="list-style-type: none">• poor pain relief• and sedation• on strong opioids |
|---|--|

- Amitriptyline and gabapentin are safe in children and cheap.
- There is no pediatric formulation.
- Gabapentin. Open 100 mg capsule, approximately halve the content to administer half capsule (6 to 12 years) or a quarter (<6 years) in a spoon, mixing it in with a small amount of juice or soft food immediately before administration. Start with once daily dose at night before increasing slowly to twice or thrice daily.

⁷⁴Drake R, Longworth J, Collins JJ. Opioid rotation in children with cancer. J Palliat Med 2004;7(3):419-422.

- Second line: other antidepressants and anti-epileptics (carbamazepine, pregabalin). Pregabalin 50 mg capsules can likewise be opened to administer half (6 to 12 years) or a quarter (<6 years). Slowly increase to 3 daily doses.
- Muscle relaxants should be used in specific indications.

Bone pain:

- Add NSAIDs (after food, under PPI cover).

Pain related to raised intracranial pressure (ICP) or tumor compression:

- Add steroids (i.e. dexamethasone) to reduce inflammation and swelling, for a short duration only.

Colicky abdominal pain: hyoscine butylbromide, dicyclomine.

Table 12.4: Adjuvant analgesic medications in children

| Indication/ Drug classification | Drug | Formulation | Dose |
|--|---------------|--------------------------------------|---|
| Neuropathic pain | | | |
| Anticonvulsant | Gabapentin | Tab 100/ 300mg | 5 mg/kg p.o. at bed time, increase q12h than q8h till effective analgesia (max 60 mg/kg/day) |
| | Pregabalin | Cap 50/ 75mg | |
| | Carbamazepine | Tab 100/ 200/ 400 mg; Syp 100 mg/5mL | 3–10 mg/kg q8h |
| | Clonazepam | Tab 0.25/ 0.5/ 1/ 2 mg | 0.01–0.03 mg/kg/day q8h–q12h. Max dose 0.2 mg/kg/day |
| Antidepressant | Amitriptylin | tab 10/ 25mg | 2-12 yrs: 0.2 mg/kg at night (max 10 mg). >12 yrs: 10 mg at night. Slow increase every 3-5 days upto 1 mg/kg q12h (max 75 mg/day) |
| Anxiety, muscle spasm | | | |
| Benzodiazepine | Lorazepam | Tab 1/ 2mg | 0.025–0.05 mg/kg/dose qid, max 2 mg per dose |
| | Alprazolam | Tab 0.25/ 0.5/ 1mg | Dose not established <18 years. Start at 0.25 mg OD |
| Bony pain | | | |
| NSAID, Cox-2 selective inhibitor | Celecoxib | Tab 100/ 200 mg | >2 yrs, 10-25 kg: 50mg q12h or 100mg OD. >25kg: 100mg BD |
| Tumor compression, raised intracranial pressure | | | |
| Steroids | Dexamethasone | DT 2/ 4mg. tab 0.5mg. Drops 0.5mg/ml | 0.1 mg/kg q8h, increase upto 1.5 mg/kg/day |
| Depression | | | |
| Tricyclic antidepressant | Imipramine | Tab 25/ 75mg | 0.5 mg/kg q8h initially. Increase by 1–1.5 mg/kg/d every 3-4 days to a maximum of 5 mg/kg/day |

Table 12.5: Medications to relieve gastro-intestinal symptoms in children

| Symptom | Drug classification | Drug | Formulation | Dose |
|----------------------------------|---------------------------------------|---------------------|---|--|
| Nausea/ vomiting | | | | |
| | Dopamine antagonist ^a | Domperidone | | See table 12.3 |
| | | Metoclopramide | | See table 12.3 |
| | Antihistaminic ^b | Diphenhydramine | Syr 12.5 mg/5ml; inj 10mg/ml, 50mg/ml | PO/ IV: 0.5-1 mg/kg q6h |
| | Serotonin antagonist ^c | Ondansetron | Tab 4/ 8mg Syr 2mg/5ml | PO/ IV: 6 mg/m ² tid (<4 yrs: 2 mg per dose; 4-11 yrs: 4 mg; >12 yrs: 8mg) |
| | Corticosteroid ^d | Dexamethasone | Tab 0.5/ 1/ 2/ 4 mg; oral drops 0.5mg/ml | Start at 0.1 mg/kg tid, increase upto 1.5 mg/kg/day |
| | Muscarinic antagonist ^{b, e} | Cyclizine | | PO/IV: 1 mth–6 yrs: 0.5–1 mg/kg (max 25 mg); 6–12 yrs: 25 mg; >12 yrs: 50 mg, all OD to tid |
| | Antipsychotic ^e | Haloperidol | Tab 0.25/1.5/2/5/10 mg, drops 2mg/ml | PO 0.025-0.05 mg/kg/d, 2-3 doses |
| | Anxiolytic ^e | Lorazepam | | See table 12.4 |
| Gastritis or oesophagitis | | | | |
| | PPI | Lansoprazole | DT 15 mg syr 15 mg/5mL | 1mg/kg OD |
| | | Omeprazole | Tab 20 mg | 20 mg OD >12 yrs |
| | | Pantoprazole | Tab 40 mg | 40 mg OD >12 yrs |
| | Anti-acids | Aluminium hydroxide | Syr | 2.5ml in <2 yrs, 5mL 2-5 yrs, 7.5mL 6-9 yrs 10mL>12 yrs, all tid |
| | | Sucalfate | Susp 1g/10mL | 1 mth–2 yrs: 250 mg/dose; 2–12 yrs: 500 mg; 12-18: 1g, all tid or qid |
| Spasmodic abdominal pain | | | | |
| | Anticholinergic | Dicyclomine | Drops 10 mg/ml, susp 10mg/5mL | 6 mth–2 yrs: 5 mg before feeds >6 yrs: 10 mg tid |
| | Hysocine butylbromide | Buscopan | Tab 10 mg | 6–12 yrs: 10mg tid; 12–18 yrs: 10-20 mg tid to qid |
| Constipation | | | | |
| | Softening agent | Lactulose, Paraffin | | See table 12.3 |
| | Stimulant | Polyethylene glycol | 17 g sachet | 0.7 g/kg q24h, upto 1.5 g/kg OD (usually ½ to 1 sachet OD) |
| Infective diarrhea | | | | |
| | Quinolone (bacterial) | Ciprofloxacin | Tab 100/250/500 mg. Susp 125 mg/5mL; 250 mg/5mL | Oral: 10-15 mg/kg bid |
| | C. difficile | Metronidazole | Susp 200 mg/5mL, tab 200/400 mg | 15-20 mg/kg/d q8h |
| Anorexia/ weight loss | | | | |
| | | Megestrol acetate | Tab 40 mg | 7.5-10 mg/kg/day in divided doses |
| | | Cyproheptadine | Syr 2 mg/ 5mL, tab 4 mg | 0.25–0.5 mg/kg/day q8h to q12h Max dose 2–6 yrs: 12 mg/day Max dose 6–12 yrs:16 mg/day |

Notes. Nausea/ vomiting caused by ^agastric stasis ^bmovement, vertigo; ^cGastric irritants, abdominal radiotherapy, chemotherapy, intestinal obstruction; ^dmorphine, chemotherapy; ^eraised intracranial pressure; ^fanticipatory nausea-vomiting

Nausea/ vomiting

- Initial evaluation: look for an underlying cause
 - drug-related (opioids, antibiotics, NSAIDs, chemotherapy)
 - associated headache: raised intracranial pressure
 - oesophagitis, gastritis, gastric stasis, constipation
 - bowel obstruction
 - infection
 - renal or hepatic failure
 - nausea related to position or movement: vestibular infection or tumour
- Assess for dehydration

Non-pharmacological measures

- Explain, reassure, calm environment
- Keep away from the smell of food
- Feed frequent small quantities of food, attractive for the child.

Pharmacological treatment:

- Serotonin antagonists. Diphenhydramine+metoclopramide is an effective combination.
- Chemotherapy related nausea/ vomiting: oral or injectable ondansetron.
- Drug-related or metabolic cause: stop drug if possible; haloperidol.
- Features of gastritis: stop NSAIDs or steroids, use PPI and anti-acids
- Anticipatory nausea, anxiety: anxiolytic drugs.

Constipation

Identify the possible causes of constipation:

- Inactivity, decreased mobility
- Poor oral intake
- Drugs (opioids, anticholinergics drugs, 5-HT₃ receptor antagonists, iron, etc.)

- Complications of the underlying illness
- Faecal withholding due to anal fissure

Caution: constipation can trigger seizures and dystonia in children with severe neurological disability.

Pharmacological treatment

- Stool softener (lactulose) + stimulant (polyethylene glycol).
- Anal fissure: local anaesthetic or calcium channel blocker cream before defecation.
- Lubricants: glycerine liquid (half adult dose in 2-6 years old, a quarter <2 yrs)
- Only if no relief, give small volume enema (contraindicated in neutropenic patients, due to the risk of intestinal perforation).
- If no better, manual evacuation of hard impacted stools under mild sedation (midazolam/ diazepam).

Non-pharmacological measures

- Diet: increase fluids and fibres
- Improve mobility

Diarrhea

Identify treatable causes of diarrhea

- Enteral or non-enteral infection
- Malabsorption
- Constipation with overflow
- Drug-induced diarrhea (antibiotics, excessive laxative use, chemotherapy-induced mucositis).

Management of diarrhea

- Rehydration, correction of electrolyte and acid-base imbalance (ORS or IV fluids if severe)
- Dietary modifications

- Antibiotics are usually not required except in case of documented bacterial or parasitic infection
- Counseling about contaminated food, poor hand-washing technique and the use of contaminated toys
- No anti-diarrheal drugs in acute diarrhea.
- Antispasmodic for colicky pain.

Nutrition

Common causes of malnutrition in pediatric palliative care:

- The child is hungry
 - No enough food to eat
 - Inability to swallow (neurological or neuromuscular disorders)
- Anorexia, nausea
- Sore mouth

Enteral feeding should be encouraged as much as possible.

- Oral route
 - nutrient-rich foods and fluids providing a well-balanced diet
 - within the child's favorite dishes and preferences
 - at flexible timings
 - e.g. 3 meals and 3 snacks a day for a child with poor appetite.
- Liquid diet: soup, juice, milk, coconut water, curd, etc.
- Commercial liquid nutritional supplements can be advised when food is refused.
- Nasogastric tube feeding (rarely: tube feeding by gastrostomy or jejunostomy): milk, home-made food mixed and liquefied, or enteral formulae.
 - Initially, tube feed can be tried at night while sleeping, so that the child may eat during the day.
 - As anorexia progresses, feeds are given every 3 to 4 hours
 - Regular mouth rinsing and brushing is still required while on tube feed.

Parenteral nutrition is rarely indicated in case of intractable vomiting, e.g., intestinal obstruction, uncontrolled vomiting or diarrhea.

Sore mouth

- Causes: chemotherapy, oral candidiasis
- Keep mouth moist (ice cubes, ice chips)
- Tooth brushing after each meal
- Regular mouth wash and gargling

Dry mouth

- Ensure adequate oral or parenteral hydration
- Topical palliation: Xylocain viscous, ice chips, lemon drop candies, chewing gum.
- Spicy food should be avoided.
- Zinc syrup in radiotherapy-induced xerostomia (10 mg OD <6 months of age, 20 mg >6 months)

Cough

Identify cause and treat accordingly.

Pharmacological measures:

- Infection-specific therapy: pertussis (spasmodic whooping cough), TB (weight loss, fever), bronchopneumonia
- Simple linctus
- Saline or Salbutamol nebulisation, even if there is no bronchospasm
- Bronchospasm: salbutamol nebulisation, oral (prednisolone 1 mg/kg/d, short course) or nebulised steroids
- Post-nasal drip: upright position, antihistamines, saline nasal drops or spray.
- Gastro-esophageal reflux: PPI,
- Codein linctus or low dose morphine
- Lymphoid interstitial pneumonitis (HIV): pulsed steroids, bronchodilators, oxygen, ART, physiotherapy
- Airway tumor: nebulisation with local anesthetic (lignocaine), at least 1 hour before feeding to avoid aspiration.

Non-pharmacological measures:

- Sit up, air humidification
- Physiotherapy for drainage of secretions
- Avoid smoking, use of stoves, kerosene lamps

Hemoptysis

Hemoptysis is a frightening experience for all. Usually not life-threatening. Ensure it's a true hemoptysis (red frothy blood) and not bleeding from the nose, pharynx or hematemesis (dark blood mixed with food).

Management in all cases

- Stay calm
- Sit the child up (or lying on the side of the abnormal lung),
- Oxygen
- Assess if aggressive treatment is required or if it is an end of life event

Identify cause and treat accordingly

- Infection: aspergillosis, TB, lung abscess
- Lung/ airway malignancy
- Haematological malignancy
- Bleeding diathesis
- Pulmonary embolism
- Pulmonary hypertension (heart failure)

Aggressive therapy

- ABC principles, IV fluids
- Partial sedation: benzodiazepine + strong opioid
- Tranexamic acid, platelet/blood transfusion, octreotide for bleeding esophageal varices

Table 12.6: Medications to relieve other symptoms in children

| Symptom | Drug classification | Drug | Formulation | Dose |
|------------------|--|------------------------|---|--|
| Cough | Cough suppressant | Codein phosphate | Syp 15 mg/ml or 10mg/ml | 6-12 yrs: 2.5mg tid to qid >12 yrs: 5-10mg tid to qid |
| Bleeding | Antifibrinolytic agent | Trenexamid acid | Tab 500 mg | >1 month: 15–25 mg/kg 2–3 times daily <6 yrs 250 mg/dose, 6-12 yrs: 500 mg/dose, >12 yrs: 500mg to 1 g/dose |
| | Anti GH—for bleeding esopha-geal varices | Octreotide | Inj 50µg/ml, 100µg/ml | 1 mo–18yrs: 1µg/kg/hr IV infusion (max 50 µg/hr). Reduce dose over 24hr when there is no active bleeding. |
| Seizure | Benzodiazepines | Diazepam | Rectal solution 2mg/2.5ml, 5mg/5ml | Intrarectal: 0.3-0.5 mg/kg/dose, may be repeated once after 10 min <1 mo: 1.25-2.5 mg/dose; 1mo-2yrs:5 mg/dose; 2-12 yrs: 5-10 mg/dose; 12-18yrs: 10 mg/dose |
| | | Lorazepam | Inj 2mg/ml; 10mg/ml | 0.05-0.1 mg/kg/dose (max 4mg) over 2-5 min IV/IM, may repeat once after 10-15 min |
| | | Midazolam | Inj 1mg/ml, 5mg/ml Sublingual tab 0.25/0.5mg | Oral 0.3mg/kg until IV access. Status epilepticus: 0.2mg/kg IV/IM bolus, then 0.1-0.2mg/kg/hr |
| | Other antiepileptics | Levetiracetam | Tab 250/500/750mg. syr 100mg/ml | Start at 10 mg/kg/d q12h; increase by 10 mg/kg weekly upto 60 mg/kg/d. Can be given to new-borns. >18 yrs: start at 250mg BD |
| Spasticity | | Baclofen | Tab 10 mg, 25 mg | 0.3 mg/kg/d in 3–4 divided doses (max single dose 2.5 mg), s weekly increase to 0.75–2 mg/kg/d (max daily dose 40 mg<8 yrs, 60mg/d >8 yrs) |
| | | Diazepam | Tab 2mg, 5mg, 10mg Susp 2mg/5ml | 1–12 mo: 0.25mg/kg BD; 1–5 yrs: 2.5 mg BD; 6–12 yrs: 5mg BD; 12–18 yrs: 10 mg BD |
| | Muscle relaxant | Tizanidine | Tab 2 mg | 7 mth–6 yrs: 1 mg/day; 7–12 yrs: 2 mg/d; >12 yrs: 2 mg OD, increase every 3-4 days until 3-4 daily doses (24mg/d, max 36 mg/d) |
| Noisy secretions | | Glycopyrronium bromide | Tab 1mg; Inj 0.2mg, 2mg | Oral: 1mth–18yrs: 40 µg/kg tid to qid. Increase if needed to 0.1mg/kg, max 2 mg/dose tid. SC: 1mth-12yrs: 4 µg/kg q8h to q6h (max 0.2mg q6h; >12yrs: 0.2mg q4h) |

Breathlessness

Breathlessness is a subjective symptom, not necessarily proportionate to clinical signs.

Causes:

- Cyanosis: upper airway obstruction (stridor), bronchospasm (wheeze), aspiration: hypoventilation (neuromuscular disease, debility, CNS dysregulation)
- Chest infection, pneumothorax, pleural effusion
- Cardiac failure
- Superior vena cava obstruction

Non-pharmacological measures

- Sit up, reassure, relaxing and distracting techniques
- Air circulation: fan, open window
- Oxygen if cyanosis or low pulse oxymetry

Pharmacological management

- Morphine and/or low dose benzodiazepine for severe breathlessness (midazolam)
- If already on morphine, give a stat dose of 10-15% of the total 24-hour dose.

Seizures**Common causes:**

- Brain tumor, raised ICP, neurological diseases
- Hypoxia, hypoglycemia
- Fever

Management

- Do not panic. Check your watch.
- Avoid immediate danger, place in side-lying position to avoid aspiration
- If possible, check blood glucose and give oxygen
- Medicines required if seizure longer than 5 minutes or cyanosis
- Buccal midazolam or lorazepam (injectable ampoule can be given orally). Rectal diazepam works slower.
- If no response after 5-10 min, repeat the dose. If no response, hospitalize for IV antiepileptic infusion.

Spasticity and dystonia

Causes: birth asphyxia, encephalopathy, genetic disorders, infection, intracranial bleed, metoclopramide, etc.

- Muscle spasm is very painful.
- Spasticity and dystonia lead to profound fatigue, muscle contractures and joint deformity.

Non-pharmacological measures

- Avoid triggers: loud noises, bright lights, pain, urinary retention, constipation, unfamiliar contact.
- Ensure gentle handling by familiar people
- Treat all causes of pain
- Address problems of mobility, feeding, bathing, etc.
- Teach the care taker regular physiotherapy
- Warm bathing

Pharmacological management (Table 12.6)

- Baclofen or diazepam, Tizanidine
- Botulin toxin intramuscular injection

Psychological Distress

- Family members have different phases of reactions, i.e., denial, anger, grief.
- Children's emotional distress in reaction to the distress and emotions of adults,
- Empathetic listening, open communication and psychotherapy.

Anxiety

- Counselling
- Mild anxiolytic in moderate to severe anxiety.

Depression

- Chronic and terminally ill children are at risk of depression

- Symptoms: sadness, change in appetite or weight, sleep disturbance, fatigue and loss of energy, diminished ability to think or concentrate, lack of reactivity, feelings of hopelessness, suicidal ideation.
- Psychological counseling:
 - promote the child's autonomy
 - draw on their strength
 - discuss short-term goals.
- Pharmaceutical measures if counseling is not effective.

Weakness and fatigue

- Common symptoms among children on palliative care.
- Sleep cycle disturbance: having a timetable for meals, activities, and sleep.
- The importance of play should be emphasized.

End of life Care

Communication

Good communication is essential when the child is terminally ill.

- End-of-life discussions with care takers are necessary to avoid aggressive futile medical care:
 - poor quality of life
 - worse bereavement adjustment
- Help relatives express and correct unrealistic expectations.
- Document every communication.
- Facilitate communication between family members, particularly with teenagers
 - sharing of emotions
 - saying farewells
 - meaningful time for the family
- Allow a dying child to discuss with the treating team, answer their fears and questions in an age appropriate manner.
- Many children have an inner knowledge of their upcoming death, and may use symbolic language to refer to it.

- Honesty, compassion and reassurance of making things as pain free as possible.

Ethical Issues

- Every child has the right to a pain-free death, with effective symptom management by ordinary supportive measures.
- There are no guidelines in India regarding decisions to initiate or withdraw artificial nutrition or hydration. However, death should not be caused by malnutrition or dehydration rather than the underlying disease.
- Principle of double effect: the intended effect (relieving suffering) is allowable as long as any risks or negative effects (i.e., shortened survival) are unintended by the health care professional.
- The decision to start or withhold resuscitation, i.e. all interventions that provide cardiovascular, respiratory, and metabolic support to maintain and sustain the life, belongs to the parents. It should be taken before any acute event occurs. “Do not resuscitate” orders should be written and signed by the parents in advance.

Nutrition and hydration at the end of life

- A child with advanced or a terminal illness usually stops eating when he/ she is no longer able to process food and fluids.
- Anorexia and aversion to food cause distress to family members.
- Natural instinct to provide nourishment to a child.
- Counseling of parents/ care taker to reduce anxiety:
 - forcing food or fluids could lead to aspiration.
 - starting artificial nutrition and hydration does not help the child to live longer, feel better, stronger, or be more active.
 - not drinking doesn't cause suffering if the child is comfortable or unconscious.
- Encourage other ways for the family to stay in touch and provide care:
 - gentle massage
 - mouth care: moister the mouth with water, protect lips from dryness

- The majority of dying patients never experience hunger
- In those who experience hunger, small amounts of food and fluids, offered whenever the child wants, relieve the hunger
- Benefits of dehydration during the dying phase:
 - decreased respiratory secretions
 - decreased nausea, vomiting, bloating, diarrhea
 - decreased edema or ascites
 - decreased urine output
 - depressed level of consciousness, thereby decreasing pain and other distressing symptoms
 - most patients “slip away” quietly and comfortably.
- Electrolyte disturbances seldom cause convulsion in children without CNS pathology

Place of end of life care

The decision on where to care for a dying child depends on choice, home situation, beliefs and finances and should be discussed with the child, if old enough, and family. It should aim at providing relief in a secure and comforting environment at the end of life.

- Hospice care.
- In-patient care if the child needs round-the-clock care.
- Home care: provide proper analgesic and symptom control medications to the family and tie-up with local physician.

Symptom control

Most children in the terminal phase develop devastating physical symptoms for weeks to months before death e.g., pain, breathlessness, fever and bleeding. Patients with more severe symptoms usually present to a new tertiary care hospital or return to their treating centers. Caution in prescribing medicines, due to multiple drugs, malnutrition, hypoalbuminemia, decreased liver and kidney function, etc.

Blood component support

- Hemorrhage: tranexemic acid, local measures, platelet transfusions if required.
- Occasional packed red cell transfusions improve quality of life and activity in a dying child.

Palliative sedation

- Indicated in refractory symptoms, delirium, massive bleeding, seizures
- Often on a temporary basis
- Reversible in a quarter of patients
- Subcutaneous or intravenous infusion
- Dyspnea, pain, bleeding, anxiety: midazolam, second line: levopromazine.
- Refractory delirium: levopromazine + haloperidol
- Propofol, ketamine, Phenobarbital
- Continue analgesic therapy.

Table 12.7: Palliative sedation in children

| | Route of administration | Dose |
|---------------|--|--|
| Midazolam | SC or IV. Dilute and administer within 10 min. | Starting dose: <40 kg: 0.05–0.1 mg/kg/dose (max 5 mg/dose) >40 kg: 2.5–5 mg Administer every 4 hours If child is already receiving BZP, increase by 30%-50%. |
| Levopromazine | PO, SC or IV infusion, intranasal | Starting dose: <12 yrs: 0.5–1 mg/kg/day (max 40 mg) in 2–4 divided doses >12 yrs: 12.5–50 mg/day, in 2–4 divided doses (max 100-200 mg/day) |
| Propofol | IV infusion | Induction: 2–3 mg/kg, slow IV infusion. Followed by maintenance 0.5–4 mg/kg/h Reduce doses of BZP, neuroleptics and opioids by 50% |

Recognizing when death is near

- The child sleeps more, is confused and emotionally withdrawn.
- Skin is mottled, cold or pale.
- Irregular heart rate.
- Decreased or absent urine output.
- Labored respiration.
- Restlessness.
- Revise treatment for new or exacerbating symptoms.

Bereavement care

- Be empathetic and supportive.
- Help with formalities
- Provide bereavement counseling to help the family cope with grief.
- Siblings
- Make the family feel that their child was loved and cared for in the best possible way.

Conclusion

Despite the large number of children with chronic or life threatening diseases requiring palliative care, lack of awareness on the part of health professionals and small number of palliative care facilities in India are a major challenge. A holistic approach to physical, psychological, spiritual and social distress is the key to adequate management.

Types of communication

- Verbal: use of spoken or written words
- Non-verbal: gestures, facial expression, behavior

Modalities of communicating with children

- Body language
- Play language
- Spoken language
- Observation

Body language

- Read their body language: how they walk, eye contact, fidgeting, looking relaxed or tense
- Children are aware of our body language. They watch, understand and react accordingly. Adopt a friendly, open and relaxed posture.

Play language

- Adults speak, children play
- Children show, rather than telling about their life
- Use colors, drawing, dolls, toys. Sit, show interest, watch: they'll play their life
- Story telling builds trust and rapport, helps feeling expression

Spoken language

- Form short sentences easy to understand

Activity

What are the key elements that differentiate pediatric palliative care from that of the adult group? Discuss with reference to

- Approach
- Medications and treatment procedures
- Special communication skills required

CHAPTER 13

Palliative Care in Geriatric Population

Learning objectives

At the end of the chapter, the candidate should be able to:

- Acquire better understanding on the general issues of concern among a geriatric population
- Strengthen their capacities of providing palliative care for common health problems in the elderly

Duration: 30 minutes

The world is facing a silver tsunami. According to the World Health Organisation (WHO), the population of senior citizens has surpassed the population of children under the age of five years. The issue of aging is a matter of concern not only for those affected and their families but also for the societies they live in. According to the Census of 2011, India has 104 million elderly (defined as 60 years and above), constituting over 8% of the total population⁷⁵. This number is expected to reach 173 million by 2026 and will be more than 300 million by 2050 accounting for 20% of the population (UN Population Prospects, 2015 Revision)⁷⁶.

The challenges in Geriatric Care are Co-morbidities, **Geriatric Syndromes** (dementia, delirium, constipation, falls, frailty & depression), polypharmacy; poor wound healing, exposure to extremes of temperatures, psychological and social issues. It is estimated that this will impose a great burden on global health resources, especially in emerging economies. The answer is geriatric palliative care that is patient focused and family oriented as ageing is a unique process and the care of the aged will have to be tailored accordingly.

⁷⁵ http://www.censusindia.gov.in/2011census/Age_level_data/Age_level_data.html

⁷⁶ United Nations, Department of Economic and Social Affairs, Population Division (2015). World Population Prospects: The 2015 Revision.

General issues of concern among a geriatric population

1. **Physical issues:** these include diseases of various organs of the body (**Geriatric Syndromes**).
2. **Psychosocial issues:** these include loneliness, anxiety, insomnia, confusion, phobias, agitation, delirium, depression, forgetfulness, dementia and Alzheimer's disease. 25-30 % of those above 85 years of age will have dementia and need help in managing their daily activities of life. The elderly are also more prone to depression and may have problems communicating.
3. **Spiritual issues:** these include the need to receive & give love, to be understood, to be valued as a human being, to be forgiven, to have hope & trust, to explore beliefs & faiths, to express feelings honestly and to find meaning & purpose in life.

Besides the issues mentioned above, the palliative care team will have to respond to basic needs of the elderly as well as issues related to their growing frailty. These can usually be managed symptomatically and include preventive aspects. For example, timely cataract surgery can avoid later vision problems. Walking aids and hearing aids can facilitate functioning, while ensuring proper lighting, fixing handles in the bathroom and non-slip flooring can prevent falls. Dental hygiene in the elderly also needs special attention.

Anemia is also highly prevalent among the elderly – nearly 40% suffer from it. The causes are generally disease, poor diet and inadequate intake of food. On the whole, eating a balanced diet, maintaining appropriate weight, exercising regularly, Yoga, Meditation and not smoking or drinking excessively while getting enough sleep and taking a day time nap if necessary is the secret of good health at this age.

Specific Issues of Concern among a Geriatric Population

Frailty Syndrome

The person will have general weakness, loss of skeletal mass, weight loss, fatigue, slower activity and increased vulnerability to morbidity and mortality. Adequate nutrition, rest and mild exercise are helpful in Frailty Syndrome.

Cardiac Issues

The elderly are prone to heart attack and generally suffer from Hypertension and Dyslipidemia. This will need monitoring and medical management. They are easily fatigued and should be advised to rest frequently as well as sit and stand up slowly to avoid dizziness.

Respiratory Issues

COPD is one of the most common causes of mortality and morbidity among the elderly. Usually, COPD patients have poor health status and quality of life due to the presence of two or more co- morbidities and poor activities of daily living (ADL). Swallowing impairment is also a common cause of aspiration induced pneumonia in the aged.

Urinary Issues

More than 2.5 million persons over 60 years of age suffer from bladder control problems and keep on hiding it for years out of shame. Many also have repeated urinary infections. These must be reported to a doctor immediately.

Gastro- Intestinal Issues

The elderly are more constipation prone. This may be managed with or without drugs. Dyspepsia and GERD are also issues that require attention as they impact on quality of life. Dry mouth also troubles the old.

Skin Issues

In the elderly skin becomes dry and fragile and will need frequent moisturizing. Nail care can also become an issue as some may require a caregiver to trim their nails. Skin also becomes more prone to temperature variations and the elderly should avoid early morning walks in winters as well as exposure to the sun in summer.

Diabetes Mellitus

Diabetes is an emerging epidemic among the elderly. Early symptoms of diabetes such as polydipsia and polyphagia are usually absent in elderly patients. The

atypical symptoms of diabetes in this age group include confusion, a fall, failure to thrive, neuropathy, coronary artery disease, visual symptoms, and coma.

Cancer

The incidence of cancer increases with age. Regular checkups to detect cancer early are a must in this age group. While under treatment they will need careful monitoring and assessment.

Stroke

Prevention will need control of hypertension. Management would need physiotherapy and rehabilitation.

Bones, Joints, Muscles & Falls

The brittleness of bones can lead to falls and the risk of fractures. Preventive measures should include a balanced diet and daily intake of Vitamin D & calcium. Regular exercise, yoga should also be encouraged.

Less lubrication of joints causes arthritis. This will need conservative or surgical management. The prevalence of arthritis is quite high among the elderly. Studies show nearly 60% of the geriatric population is affected by it. Arthritis determines quality of life and ability to live independently. It leads to unstable gait and falls that are the most common causes of elderly morbidity and loss of independence.

The longer older people remain mobile less will be the cost to family and society. A fall prevention strategy is therefore of utmost importance. It must include the care of feet, staying active, care for hearing & vision, regular review of medications, making home and surroundings safe and use of walking sticks & walkers.

Maintaining Mental Health

Social interaction is the key to good mental health. For this the elderly must have regular contact with family and friends. If they cannot meet in person, a call or a letter can suffice. Today the internet and the worldwide web also keep people in touch with people and their interests.

The elderly should get involved in the activities of their local society. It is necessary to plan to do something new every day and have fun. Joining a walking or singing group, solving puzzles, learning a new language, attending concerts, gardening, etc., are activities that are pleasurable and can keep depression and dementia at bay. Volunteering for a cause and helping others also keeps people busy and involved.

Depression

Depression is often neglected in the elderly. The symptoms include loss of confidence and feeling low, anxious or panicky. People are unable to enjoy the things you usually do and have unexplained aches and pains. There is also a tendency to avoid people, even those close to you. Sleeping badly, loss of appetite and lack of interest in appearance and surroundings as well as feeling bad all the time about things of the past are all symptoms of depression.

Isolation

Due to breakdown of the joint family system and migration of the younger generation to towns and cities, elderly parents in villages are being left to fend for themselves. Too old to work and with little or no source of income they are struggling even to satisfy their basic needs. This also leads to isolation among seniors as there is no one to talk to. This makes them prone to depression.

Communication

About their needs, discussing death, spiritual needs, how they would like to exit, living wills, giving closure to life.

Safety

Elders are victimized in their own homes. Studies have shown that nearly 25% of crimes against the elderly are committed by family members - sons, daughters-in-law, neighbors, servants, etc. The causes are generally land and property disputes, caste rivalries, and rural factionalism. Nearly two-thirds of elderly women are widows whereas only 22% of elderly men are widowers. This comes with its own social and economic problems as women tend to be more dependent and consequently more subject to abuse.

Old Age Homes

There is a growing awareness in urban India about the needs of the elderly. Old age homes and special clinics for the geriatric population are being set up. This seems to be an attractive option for a certain section of the elderly who have the means and want to maintain their independence.

Polytherapy

This leads to various drug interactions, side effects and increases the cost of care. Changes in hepatic and renal functions will impact prescribing.

Poverty

Retiring at 60 years and living on till 85 years has led to the emergence of poverty in the geriatric age group. In India there is negligible support for the poor and aged from the government.

Concluding Remarks

As evident from the above, illness and disability in the geriatric population will require special health services while their unique psychosocial needs and concerns will require a wider societal response. They will require long term care which can become a burden for the family and lead to their neglect and abuse. There is a need to bring services to the bedside of elderly patients which is currently beyond the reach of our health system. Palliative care must become a part of the public health delivery system as only then will we be able to care for our elders with love and respect.

Activity

What are the key elements which differentiates geriatric palliative care from that of the adult group? Discuss with reference to

- Approach
- Medications and treatment procedures
- Special communication skills required

CHAPTER 14

Ethical Decision Making in Palliative Care

Learning objectives

At the end of the chapter, the candidate should be able to:

- Acquired better understanding of the four cardinal principles of medical ethics
- Obtain clarity on the ethics of end-of-life care, and skills on handling dilemma.

Duration: 30 minutes

Everyone in a medical system would want to do “the right thing” for the patient. But what is right and what is wrong may not always be very clear. This chapter will lay out the fundamental principles to guide us in the decision-making in the face of ethical dilemmas.

The four fundamental principles of medical ethics are⁷⁷

1. Individual autonomy: An individual is master of himself and has the ultimate authority to take decisions on his treatment.
2. Beneficence: Doing good.
3. Non-maleficence: Not doing harm.
4. Justice: Equitable sharing of available resources.

Though these principles are undisputed, often conflicting situations can occur. For example, autonomy would be limited in the following situations:

- The decision-making power will automatically pass on to the next of kin if
 - The person has limited cognitive or communicative ability.
 - A person does not want to exercise his autonomy.
- When one person’s autonomy is in conflict with someone else’s. In its simplest form a patient’s cannot smoke when another patient in the same room resents it.

⁷⁷ Beauchamp T L, Childress J F. *The Principles of Biomedical Ethics*. 5th ed. Oxford University Press, Oxford. 2001, 454.

- When the patient's wish is in conflict with beneficence or non-maleficence as perceived by the treating doctor. For example if the patient demands an intervention which in the doctor's perception is not beneficial or is harmful, the doctor is not bound to follow the patient's wish. In such a dilemma, the doctor should offer to pass on treatment to another doctor of the patient's choice.
- If the patient wishes for something illegal, as for example euthanasia, naturally it cannot be granted.
- Social factors may cause conflict between autonomy of the patient and the family's wish. This is a common scenario. In an effort to protect the patient, the family often hides the diagnosis and/or the prognosis from the patient. While ethically the patient has the right to know, blind exercise of autonomy by the doctor and disclosure of diagnosis to the patient against the wishes of the family might very well mean that the doctor or the team will lose the chance to help the patient. It is next to impossible to give proper treatment to a patient without the family's cooperation in the Indian social context. A rational approach would be to spend time with the family, understand their perspective and concerns (after all, palliative care is aimed at improving quality of life not only are the patient, but also of the family) and help them also to do the best for the patient. This may take time; but that time is well spent.

Understandably, the above list is not complete; just illustrative.

Ethical medical practice following the four cardinal principles of medical ethics, warrants some basic requirements.

- **Respect:** Every human being is superior to each one of us in some way and deserves our respect. This is often forgotten because the patient has been weakened physically, emotionally and socially by the disease while the doctor and nurse have the power of the medical system behind them. Wherever there is power there can be a tendency to abuse it.
- **Confidentiality:** Except when legally bound, the medical system has the responsibility not to disclose any personal information concerning the patient with others.

- **Non-judgemental approach:** It is unacceptable to label anyone “a good patient” or “a bad patient”. Whether the patient is and thankful or ungrateful, pleasant or grumbling, we have the duty to do our best.
- **Informed consent:** Ordinary everyday procedures, as for example injections, do not warrant a separate consent. The very fact that the patient is willing for treatment offers “deemed consent”. But for any interventions beyond the routine, say for example a peritoneocentesis, a nerve block or a surgical procedure, informed consent is necessary. “Informed” is taken to mean that the patient is given essential and relevant information and has the opportunity to clear doubts.

Ethics of end-of-life care:

Indian End-of-life care has a bad reputation for being unethical. The Economist intelligence unit in 2015 graded India among 15 worst countries to die in⁷⁸. There are two kinds of injustice done to people at the end of life:

- a. The poor are rejected when cure is no longer possible. They are often told, “There is nothing more we can do. Go home.” Their symptoms are not relieved and they are left to die miserable deaths without medical support.
- b. The rich are incarcerated in intensive care units and subjected to aggressive life-prolonging treatment which may extend life by a few days, but at the cost of a lot of suffering, deprived of the companionship of the family.

India does not have legislation yet on end-of-life care, though it is proposed by the government. In the meantime, guidelines jointly created by the Indian Society of Critical Care Medicine (ISCCM) and Indian Association of Palliative Care (IAPC)⁷⁹ give guidance regarding rational end-of-life care. Essentially, the process involves creation of advance directives whenever possible when the patient is still able to take decisions about himself, documenting them and implementing them at the

⁷⁸ . Beauchamp T L, Childress J F. *The Principles of Biomedical Ethics*. 5th ed. Oxford University Press, Oxford. 2001, 454.

⁷⁹ . Myatra SN, Salins N, Iyer S, Macaden SC, Divatia JV, Muckaden M, Kulkarni P, Simha S, Mani RK. End-of-life care policy: An integrated care plan for the dying. *Indian J Crit Care Med* 2014;18:615-35.

appropriate time. Naturally, this process will involve adequate communication with the family and offering palliative care as an alternative to intensive care.

Handling dilemmas:

In every-day practice, there are bound to be situations, where what is ethically right seems doubtful. There can be also situations like one ethical principle, say autonomy, violates another, as for example nonmaleficence or justice. In such situations when discussions within the team and discussions with the patient and family do not result in a satisfactory resolution of the dilemma, the matter may have to be dealt with by an “institutional ethics committee”.

CHAPTER 15

Handling Spiritual Issues in Palliative Care

Learning objectives

At the end of the chapter, the candidate should be able to:

- Understand spirituality, religion and beliefs
- Acquired capacity to address spiritual distress in palliative care

Duration: 30 minutes

Palliative care involves providing symptomatic relief and must include all symptoms of the patient including spiritual issues. Spirituality influences the way individuals cope with their illness and suffering. It also influences the process of dying. Handling spiritual issues, both of the patient and the family, is an important part of palliative care. Spirituality impacts quality of life of patients by improving one's will to live, coping skills, sense of coherence, stress management, pain management and also helps patients develop a realistic source of hope, thus increasing satisfaction with care. Spirituality and Religion are words that are often used interchangeably, yet there is a difference.

Definition:

Spirituality may be defined as *“a dynamic and intrinsic aspect of humanity through which persons seek ultimate meaning, purpose and transcendence and experience relationship to self, family, others, community, society, nature, and significant or sacred. Spirituality is expressed through beliefs, values, traditions and practices”*

What is “spiritual” to a person varies. Listening to music, going on a pilgrimage, walking in the forest, meditating, taking care of the elderly, cooking, artistic pursuits like painting, reading religious books, singing bhajans, etc. all can be considered spiritual activities.

Religion may be defined as a *“belief in and reverence for a supernatural power accepted as the creator of the universe; a specific unified system of belief”*. Religion

may be considered as a structured way of expressing our beliefs. People may belong to different religions, yet they have a common spirituality.

Spiritual issues faced by persons with advanced and terminal illness.

Some of the common issues are:

- Why me?
- Lack of meaning and purpose in life
- Hopelessness or demoralisation
- Despair
- Not being remembered
- Guilt/Shame
- Anger at God/others
- Abandonment by God/others
- Feeling out of control
- Lack of, or seeking, forgiveness/reconciliation

Assessing Spirituality:

Good palliation begins with holistic assessment. Spirituality though a personal choice, and subjective in nature, issues related to it need to be objectively assessed and understood. A recent study to develop a spirituality questionnaire was conducted in AIIMS New Delhi⁸⁰. In a literature review, they found that there are mainly three dimensions of spirituality/ religiosity in the context of palliative care in India:

- *Relational dimension:* Connectedness or disconnectedness with extended family and their own personal God. Often the sense of disconnectedness leads to feelings of loneliness, guilt, blame and anger
- *Existential dimension:* It is the patient's search for meaning, which can lead people to acceptance of their condition or a sense of loss of control. Acceptance is found to relate with the patient's religiosity and their belief in fate, karma, rebirth, salvation etc. But not all patients accept the answers provided by Indian religiosity. Some experience a sense of loss of control,

⁸⁰ Bhatnagar S, Noble S, Chaturvedi SK, Gielen J. Development and psychometric assessment of a spirituality questionnaire for Indian Palliative Care Patients. Indian J Palliat Care 2016;22:9-18

which manifests in the form of fear of death, uncertainty of the future, disease progression, concern for their family members etc.

- *Values dimension*: Importance placed on family and religiosity influences the acceptability of spirituality to be used successfully for coping.

Using this as a base, the study found four spiritual demeanors that can be frequently seen among palliative care patients in India:

- *Shifting moral and religious values* – after the onset of the illness, individuals could question their faith in their Religion, show anger with God or being confused about what they did was good or bad
- *Support from religious relationship*- if the person found solace from religious activities like prayer, meditation etc.
- *Existential blame* that includes self-blame, belief in Karma, belief in illness as a (divine) punishment for sin, and consideration of the illness as personal fate.
- *Spiritual trust* – lack of it demonstrated by questioning fate, sense of unfairness for the suffering, asking the question “Why me? What wrong have I done to deserve this”

Global meaning, global beliefs, global goals and subjective sense of meaningfulness⁸¹

In order to understand how an individual processes their spiritual issues and copes with them, one must get familiar with certain terminology including: global meaning, global beliefs, global goals and subjective sense of meaningfulness. Every individual has a general meaning to all aspects of life; this is referred to as a “*global meaning*”.

This consists of three components- beliefs, goals and subjective sense of meaningfulness.

- *Global beliefs* include fairness, justice, benevolence, personal vulnerability etc.
- *Global goals* include relationships, wealth, knowledge and achievements. Initial goals in life could be basic and may be of a higher level as life goes on.

⁸¹ Anandarajah, G. & Hight, E. (2001) Spirituality and Medical Practice: Using the HOPE Questions as a Practical Tool for Spiritual Assessment. *American Family Physician*, 63, 81– 92.

- *Subjective sense of meaningfulness* includes the sense of heading towards a desired goal.

It implies a sense of meaning or purpose in life. Global meaning is important, not only during good times, but also more importantly, in situations of adversity.

Tools to take a spiritual history

There are well-established tools from the West like *FICA5* (Puchalski) and *HOPE*⁸² (Anandarajah and Hight) that draw attention to various aspects of a spiritual history. Communicating about spiritual issues involves recognising spiritual themes in the conversation. One must demonstrate a genuine interest in/concern for the patient. A formal spiritual screening/ history/ assessment also helps in clarifying the various spiritual themes like hope, despair, faith community, dreams, goals, meaning which may be addressed.

What is needed is to practice a compassionate presence, listening to the hopes, fears, dreams, and pain of the patient. One must be attentive to all aspects of the person- body, mind and spirit or soul. It is an intuitive process, not something to be done in a routine manner.

The timing of this spiritual history is also significant and must be done by the **primary clinician or a spiritual care professional** at particular visits such as breaking bad news, end of life crisis etc. This not only exhibits the compassion of the clinician but also helps guide intervention for the patient by identifying sources of positive and negative spiritual coping. *This requires active listening and presence but it does not need the clinician to be an expert or have knowledge about the person's belief system.*

Some of the questions that can be asked include

- Would you consider yourself to be a religious/spiritual person?
- Does your faith play an important role in coping with your illness?
- Have your beliefs changed in anyway after your illness?

⁸² Bhatnagar S, Noble S, Chaturvedi SK, Gielen J. Development and psychometric assessment of a spirituality questionnaire for Indian Palliative Care Patients. *Indian J Palliat Care* 2016;22:9-18

- Any rituals/practices that are important to you?
- How do you view your current situation?
- How do you view your future?

A brief screening will often indicate that a more detailed history is required to establish relevant aspects of the patient's background, specific problems related to spirituality or religion, available spiritual supports and additional spiritual needs. This screening is done as a part of routine counselling by the primary clinician, nurse or professional counsellor depending on the available setup. The patient may make statements like "Why me?", "God has been unfair to me", "God has abandoned me", or become tearful and declare that life has no meaning any more. If such statements are made, the counsellor must gently probe further and have a more in-depth discussion.

Spiritual issues – What next?

- Having screened for spiritual issues and having identified them, the next obvious step would be to address them. There are multiple ways in which this may be done. In the model of life meaning, based on the *cognitive-relational theory of coping*, when a person is confronted with a stressor, he will process it based on what this means to him. This is dependent on how he has been conditioned to it based on life experiences. If the perception of the stressor threatens him, as it is not congruent with his thoughts, he is distressed. This will lead to the process of *meaning-making coping and reappraisal of the situation*. For example, one may be angry initially and then feel that the suffering has a reason. This may ultimately lead to reduction of the distress. This cycle continues till the stress is overcome. Figure 15.1 provides few practical points to address spiritual distress in palliative care.

Identifying one's own professional limitations and referring the patient to a trained spiritual counselor in case of severe spiritual distress is equally important.

Model of Life Meaning

Park CL. Religion and Meaning. In: Paloutzian RF, Park CL. editors. Handbook of the Psychology of Religion and Spirituality. New York: The Guilford Press; 2005. p. 297.

Figure 15.1: Practical points to address spiritual distress in palliative care

Practical points

Spirituality is a way one seeks meaning and purpose in life

Religion is a structured way of expressing our beliefs

To some, both may mean the same thing

Certain specific questions may be included during counselling. Answers to them will indicate if there are any spiritual issues bothering a person.

“Why me?” is a very common question.

Most of the time, many questions don't need to be answered. What is needed is only compassionate listening.

When spiritual distress is severe, seek the help of a trained spiritual counsellor.

Elements of spiritual care from a patient's perspective includes⁷

- An environment fostering hope, joy and creativity
- Being valued and trusted, treated with respect and dignity
- Sympathetic and confidential listening
- Help to make sense of, and derive meaning from, illness experiences
- Receiving permission, encouragement (and sometimes guidance) to develop spiritually

FICA⁸³

- Faith and belief (what gives the patient's life meaning)
- Importance (how important this is to their situation)
- Community (their place in any social or religious group)
- Address in care (how they would like their beliefs to be addressed in their healthcare).

⁸³ Puchalski, C. & Romer, A. (2000) Taking a spiritual history allows clinicians to understand patients more fully. *Journal of Palliative Medicine*, 3, 129–137

HOPE⁶⁴

Sources of **H**ope, meaning, comfort, strength, peace, love and connection

Organised religion

Personal spirituality and Practices

Effects on medical care and end-of-life issues

Activity

Based on the ethical principles mentioned, discuss the dos and don'ts while caring for a patient.

- Discuss in a group

CHAPTER 16

End of Life Care

This chapter addresses end of life care, and considers both the last few days of life and the last months of life. It is appropriate for patients, with not just cancer, but also to patients with progressive neurological diseases, organ failure (cardiac, respiratory and kidney disease) and other life threatening conditions.

The “terminal phase” of a patient’s illness may be preceded by a sudden acute event (e.g. stroke or acute cardiac / respiratory failure), however, for most patients it follows a period of progressive deterioration which may take several months. During this period, it is important to recognize that the goal of treatment changes from one of curative intent to that of good symptom control and support for the psycho-social and spiritual needs of the patient and family.

Whilst non-beneficial treatments (e.g.: third / fourth line, often expensive, chemotherapy) should be discontinued, there is still scope for emergency treatments and appropriate disease modifying therapies, (e.g. radiotherapy for painful bone metastases or haemorrhage) to run in parallel with good palliative and supportive care. During this time the aim is to provide a good quality of life to the patient and to enable them to retain some control and enjoyment in their lives.

Provision of such care is, by nature, a complex process, often involving input from a variety of sources. Of importance are family, volunteers and professionals (nurses, doctors, counsellors, social workers, physiotherapists) together with spiritual leaders, depending on the patient’s belief system. Ideally these inputs should be coordinated to give a cohesive approach and avoid conflicting information to patient and family.

Crucial to delivering good quality care during this period is the recognition that several issues are of importance:

Communication and information needs:

Patients and families often have mixed requirements for information, sometimes not having enough information, and other times being overloaded. A flexible approach is

essential and opportunities to discuss issues may need to be given repeatedly. Key components might include what the patient knows, what he wishes to know, what are the expectations / concerns and who else in the family should be involved in decision making.

Difficult questions often involve prognosis, particularly with family members who may want to be protective and enter into bargaining or collusion. Development of good communication skills is essential for handling all these issues.

Patient's current and evolving clinical needs

Careful assessment, judicious prescribing and monitoring of symptoms are essential. Depending on the underlying pathology, some problems may be reversible (eg drug toxicity, anaemia, hypercalcaemia, hyponatraemia, raised intracranial pressure) leading to rapid and sustainable improvement in condition. The dictum "correct the correctable" still holds true in these circumstances. Other, symptoms such as pain, respiratory distress or gastro-intestinal problems may worsen with time, depending on progression of the underlying disease, and require either dose escalation or a change of medication.

Patients' future needs

If possible anticipate and plan for problems as the condition deteriorates. Psychological issues may be helped by access to counselling and the spiritual issues which relate to the patient's own values, belief system and faith will also need to be considered. Trying to address these can be challenging but worthwhile if it reduces the existential suffering that sometimes accompanies incurable, progressive disease.

Personal and social care needs

It is worthwhile having open, honest discussions with the patient and family around future care. Whilst DNR (do not resuscitate) orders are not valid in India and the legal issues concerning withholding and withdrawing treatments are unclear, it frequently helps in decision making to know the wishes of the patient and family in advance, particularly if there are financial and social issues involved. Almost 85% of families pay for end-of-life treatments out of their own pockets, often going into debt

trying to cover the cost of, often wholly inappropriate, treatments⁸⁴. The type of social support needed will depend on the nature of the household, the dwelling, the immediate family, their availability, local neighbourhood and economic constraints.

During this period, it is important to recognise the advancing changes, and the goals of care should include good symptom control, identification of psycho-social and spiritual needs, and meaningful discussions with the patient and family about their own goals, including place of ongoing care.

Care in the terminal phase of life

Identifying the dying phase can be difficult especially if preceded by progressive, small, incremental changes. It is considered to be the time when the patient enters the last few days or hours of life and is usually characterised by some or all of the following:

- Profound weakness and weight loss (asthenia / cachexia)
- Increasing drowsiness
- Difficulty concentrating and sometimes confusion
- Reduced intake of fluid or food
- Difficulty swallowing
- Inability to take oral medication
- Increasing time spent in bed and dependency on others
- Progressively falling blood pressure and /or temperature
- Poor peripheral perfusion
- Cheyne- Stokes breathing pattern
- Loss of interest in surroundings / family
- Comatose state

It is important to identify and treat reversible causes of the deterioration (e.g. infection /dehydration) if appropriate. However, often the progression of disease may be so far advanced that this is not going to be of benefit or worse still may add to the burden for the patient. Factors that contribute to deciding not to treat include:

⁸⁴ India: not a country to die in. Gursahani R, Mani RK; 2016; Indian J of Medical Ethics; 13: 30-35

- Advanced age, coupled with poor functional state due to chronic debilitating organ dysfunction (e.g. end-stage pulmonary, cardiac, renal or hepatic disease that is refractory to standard treatments)
- Chronic severe neurological conditions with advanced cognitive or functional impairment and no prospect of improvement.
- Progressive metastatic cancer with no response to (or access to) treatment
- Other clinical situations with a low probability of survival
- The wishes of the patient or family

Although there should ideally be a continuum, Care of the Dying should not just be a replication of the care given in the weeks before. New problems commonly arise that need to be proactively sought out and addressed.

It would be tragic if a patient, having had high quality care to date, were to then die suffering with physical or mental distress. The memory of such distress lingers in the memory of relatives and carers, often overriding positive memories and complicating their grief. It is important therefore that the process of care is not limited solely to the person who is dying, but extends to the family/ carers as well.

Objectives⁸⁵

- To achieve a “good death” and be treated with respect
- Emphasis on quality of life and quality of death
- Every individual has a right to a, peaceful, pain free and dignified death

Perceived components of a good death include⁸⁶:

- Control of pain and physical symptoms
- Clear decision making by knowledgeable physician / palliative care teams
- Empowering the patient and family, taking into account their wishes
- Reducing fear and knowing what to expect

⁸⁵ End of life care policy for the dying: Consensus position statement of IAPC Macaden SC, Salins N, Muckaden M et al. 2014; *Ind J Palliat Care*; 20: 171-81

⁸⁶ In search of a good death : Observations of patients , families and providers. Steinhauser KE, Clipp EC, et al. 2000; *Ann Intern Med*; 132: 825-32

- Appreciating the importance of spirituality and meaningfulness at the end-of-life
- Time with family, saying goodbye and resolving conflicts
- Affirming the patient as a unique, whole person (ref)

To achieve these, good clinical knowledge and good communication skills are essential.

Principles for best care of the dying person⁸⁷:

1. Recognition that a person is in the last few hours or days of life should be made a by a multidisciplinary team and documented by the doctor in charge
2. This acknowledgement should be shared with the patient (where possible) and those important to them
3. The dying person / those important to him should have the opportunity to discuss their wishes beliefs and values
4. Anticipatory prescribing for common symptoms should be in place
5. Clinical interventions should be reviewed in the best interest of the patient
6. There should be a regular review of the hydration needs (start / continue / stop?)
7. There should be review of the nutritional needs (start / continue / stop?)
8. Prepare a Care plan and discuss it with Patient (if possible) and carer givers
9. Regular assessment (ideally daily at home and more frequently eg four hourly if an inpatient)
10. After death, ongoing support for the family / carers and respectful, dignified care of the body ⁴.

A feasibility study has indicated that these principles are appropriate and applicable in the Indian setting⁸⁸. (5)

- The Care Plan should take into account all of the above and also include the following:

⁸⁷ International Collaborative for Best Care of the Dying Person. www.mcpcil.org.uk

⁸⁸ Feasibility and acceptability of implementing the integrated care plan for the dying in the Indian setting: Survey of Perspectives of Indian Palliative care providers. Salins N, Johnson J, Macaden S; 2017; Ind J Palliat Care; 23: 3-12

- Routine observations such as Temp /BP and Pulse / Oxygen saturation should be discontinued, unless they specifically help with management.
- Similarly long-term medications such as anti-hypertensives, ACE inhibitors anti-arrythmics, oral hypo-glycaemics, thyroxine, bisphosphonatesetc may be discontinued as they are unlikely to contribute anything positive toward the well-being of the patient.
- However, laxatives and other medication addressing current symptoms may be continued if they are helping. For a patient is on steroids, it may be prudent to continue these (albeit at a lower dose) if they are contributing in a positive manner eg as an anti-inflammatory, reducing raised intra-cranial pressure or by reducing peri-tumour or bowel oedema.
- Similarly the need for artificial hydration and nutrition needs to be reviewed on a regular basis and where felt to be unnecessary, the reasons discussed with the patient and family.
- Any investigations at the end of life should have clear and justifiable purpose such as excluding reversible causes. They are rarely necessary.

Common problems at the end-of-life

1. Pain

The presence of pain is often overlooked at this stage. It is important to follow the principles of pain management used at other times of the patient's illness (see other Chapter).

As well as malignant pain, musculoskeletal pain from immobility should be considered together with discomfort from pressure sores, urinary retention and constipation.

If the patient has been on opioid analgesia this needs to be continued. *Morphine* is a highly effective medication and the dose used, titrated to the patient's needs. If the patient has never had opioids previously, a useful starting dose would be 2.5-5mg, 4hourly, sc.

Many patients are not able to manage the oral route; alternatives such as the transdermal (expensive!), sublingual/ buccal or rectal routes have been adopted. Perhaps the commonest is the subcutaneous route (via a “butterfly needle”) and the medication either given regularly as a bolus every four hours or by continuous s/c infusion via a syringe driver (if available). This route has been used very effectively in the home setting, for both regular dosing, or break-through pain,(after the family / carers have been trained). However, good monitoring by professionals is essential.

Where there is access by nasogastric tube, gastrostomy / jejunostomy, these can be used very effectively, provided the medication is in a soluble / crushed form. The intra-muscular route is generally not recommended as it is painful, but can be considered if nothing else is available.

If tolerated, NSAIDs are particularly effective for musculoskeletal and inflammatory pain:

eg Diclofenac 150mg /24 hrs or Ketorolac 30mg every 6 hours

2. Nausea and Vomiting

Try and identify the cause. Although 60% may respond to a single agent, often the causes are multi

factorial and two or more drugs may be needed. Commonly used are:

- *Metoclopramide*: 10mg every 4-6 hours, sc, (up to 120mg / 24hrs if necessary)
- Useful for its prokinetic intestinal effect or to facilitate gastric emptying
- Contra-indicated in established bowel obstruction (increases colic)
- *Haloperidol*: 1.5 to 3 mg stat, sc, and then regularly up to 20mg /24hrs
- Especially useful if N/V is due to chemical/ biochemical causes or is drug induced
- *Olanzapine*: 1.25 to 2.5 mg stat and two to three times a day (up to 10mg/24hours)
- Useful as a broad -spectrum medication

3. Agitation / delirium

- *Haloperidol* as above or

- *Midazolam*: 2 to 5 mg sc, regularly up to 60mg /24 hours
- *Lorazepam*: 0.5 to 2 mg repeated depending on need

4. Anti-secretory medication (all subcutaneous)

Useful for:

- “Death Rattle” (excessive secretions in the upper airways)
- Bowel obstruction
- Drooling

Hyoscine butyl bromide: 20mg q6h up to 240mg /24hrs

Glycopyrrolate: 0.2 to 0.4 mg two to four times per day

Atropine: 0.6 mg q6h

Octreotide: 0.6 to 0.9 mg /24 hrs (used for intestinal obstruction to reduce volume in GIT)

*Please see specific chapters regarding treatment of relevant symptoms

Anticipatory prescribing

In addition to using the above medications on a regular basis, for good symptom control it is important to anticipate problems and have medication written up for use on an “as necessary” basis.

This entails:

- An individualized approach
- Indicating the specific use, dosage and route
- Prescribing early and reviewing regularly as the needs of the dying person change
- Ensuring the drugs are available
- Monitoring the benefits and side effects and
- Adjusting as necessary

As they have multiple beneficial effects, can be given by different routes and can be mixed together s/c especially in a syringe driver, five really useful drugs to consider for end-of- life care include:

1. Morphine (analgesia, improving dyspnoea, anti-tussive effect and for diarrhoea)

2. Haloperidol (N/V and for agitation)
3. Olanzapine as an alternative
4. Midazolam for delirium and mild sedation
5. Hyoscine, (anti-cholinergic / anti-muscarinic) useful for colic in bowel obstruction and as anti-secretory agent in death rattle.

General Comfort

Good nursing care and attention to detail contribute considerably to the comfort of the patient. It is important to maintain good personal hygiene, and skin integrity. Bed-bound, incontinent, drowsy patients are at risk of developing pressure ulcers.

Similarly mouth care is important; dry mouth may be common either as a result of tachypnoea, mouth breathing or medication with anti-muscarinic side effects.

Candida is common in patients with mucositis, those using Oxygen and those on steroids. Simple measures such as regular cleaning, topical anti-fungal treatment and moistening with sips of water or crushed ice chips, all help decrease discomfort.

Bladder and bowel: Distress associated with the need to micturate or defaecate, or the consequences of incontinence, can contribute to agitation in the terminal phase. Most patients will require incontinence pads or urethral catheterisation. Bowel intervention may not be needed unless there is evidence that the patient is experiencing discomfort. Gentle rectal measures, such as a glycerin suppository may all that is needed.

Carers

Carers tend to feel helpless, sad and fearful. Physical exhaustion after a long illness can compound their emotional turmoil. They often focus on the needs of the patient, to the detriment of their own.

It is important to encourage them to take care of themselves (eating, drinking, rest), to be available to answer questions, provide explanations and reassurance where possible and include them in decision making.

Ongoing care includes the period after death when there may still be unasked questions, emotional lability and the need for counselling. Culturally appropriate and sensitive support via a bereavement service, may, for many, be absolutely invaluable.

Additional reading

- a) Introducing Palliative Care 5th Edition. Eds. Twycross R and Wilcock A, 2016; published by palliativedrugs.com Ltd
- b) End-of-life care policy: An integrated care plan for the dying. Myatra SN, Salins N, Iyer S, Macaden, SC; 2014; Ind J Critic Care Medicine;18: 71-91
- c) Care of the dying adults in the last days of life. Hodgkinson S, Ruegger J, Field-Smith A et al. 2016; Clinical Medicine; 16: 254-258.

3-Day Short-term Training Program in Pain & Palliative Care

Learning Objectives

1. Understand philosophy and principles of pain and palliative care
2. Pain definitions, types, classification
3. Pain pathway and pathophysiological basis for pain
4. Pain pharmacology and using WHO step ladder
5. Assessment of pain and concept of Total Pain
6. Major types of pain and its management
7. Rational and safe pain prescription
8. Pain related communication
9. Difficult and special pain situations
10. Opioid licensing, procuring, storing and dispensing

At the end of training the candidate should be able to

1. Recognize pain and suffering in patients with chronic and life limiting illness
2. Exhibit interest and openness in dealing with pain and symptoms
3. Perform a thorough history and examination and detailed clinical assessment of pain
4. Identify different kinds of pain and relate pain to underlying pathophysiological mechanisms
5. Know basic pharmacology of analgesics and able to plan rational pharmacological treatment
6. Write rational comprehensive pain prescription and exhibits care while prescribing medications for pain
7. Recognize the impact of pain and physical symptoms on activities of daily living, sleep, mood, sexual activity and other social domains
8. Identify difficult and special pain situations and seek appropriate help.
9. Communicate and advice patients on using both pharmacological and non pharmacological measures for pain management
10. Have the requisite knowledge about opioid licensing, procuring, storing and dispensing of strong opioids.

Duration of training and distribution

Duration of the training is 3 days (21 hours) that has 2/3 (14 hours) of classroom teaching and 1/3 (7 hours) of practical hands on training.

Course structure and curriculum (14 hours of Theory and 7 hours of Practical Training)

THEORY

PRACTICAL TRAINING

Day 1 (7 hours)

| Sl. No | Subject Topic | Activity | Duration |
|--------|---|-------------|----------|
| 1 | Introduction to Palliative Care Brief History, Concept of Illness and total suffering Principles of Palliative Care, Unmet Needs, Models and types of Palliative Care Delivery, Multi-disciplinary team, Home and Hospice Care. | Lecture | 1 hour |
| 2 | Introduction to Pain Pain definition and Taxonomy Pain Classification (Acute/Chronic/Cancer) Why is cancer pain unique? Concept of Total Pain Pain pathway and mechanisms Breakthrough pain Pain crisis | Lecture | 1 hour |
| 3 | Practical training/Bedside teaching (In Pain and Palliative Care OPDs/Home | Outpatients | 2 hours |

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| | visits/Hospice/Palliative Care Unit) Pain history taking and examination. Learn about comprehensive pain assessment. | Ward round Inpatient PCU Hospice | |
| 4 | Pain Pharmacology WHO Step Ladder Step 1 analgesics (NSAIDs and Paracetamol) Step 2 Analgesics (Weak opioids) Step 3 Analgesics (Strong opioids) Adjuvant Analgesics Detailed Pharmacology of Oral Morphine and Transdermal Fentanyl Opioid Titration | Lecture | 1 hour |
| 5 | Types of Pain Somatic Nociceptive Pain Visceral Nociceptive Pain Neuropathic Pain Central Pain Syndromes Malignant Bone Pain | Lecture/Case based learning | 2 hours |

Day 2 (7 hours)

| Sl. No | Subject Topic | Activity | Duration |
|--------|---|----------|----------|
| 1 | Assessment of Pain Emphasizing the subjective nature of pain. Introducing the “OPQRSTUV” model of pain assessment. Pain assessment tools (Unidimensional/multidimensional tools) How to identify neuropathic pain (patient | Lecture | 1 hour |

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| | <p>descriptors/tools)</p> <p>Assessment of pain in children, elderly and unconscious patients</p> <p>Evaluation of pain associated impact and disability.</p> | | |
| 2 | <p>Total Pain</p> <p>Pain and suffering</p> <p>Bio psychosocial approach</p> <p>Components and subcomponents of Total Pain</p> <p>Factors that increase/decrease pain tolerance</p> <p>Total pain management approach</p> | Lecture/Case based learning | 1 hour |
| 3 | <p>Hands on training/Bedside teaching</p> <p>See patients in the ward with pain and palliative care needs. Pain history taking and examination. Learn about comprehensive pain management.</p> | <p>Outpatients</p> <p>Ward rounds</p> <p>Hospice</p> | 2 hours |
| 4 | <p>Pain Communication</p> <p>Meaning of pain</p> <p>Basic health related communication in a patient with pain and palliative care needs</p> <p>(Breaking bad news, Collusion, Denial)</p> <p>Basic health related communication in a patient with pain and palliative care needs</p> <p>(Discussing prognosis, goals of care, advanced care planning, end of life care discussion)</p> | Lecture/Role Play based | 1 hour |
| 5 | <p>Pain Management</p> <p>Multimodal Pain management</p> <p>Management of somatic and visceral nociceptive pain.</p> <p>Management of neuropathic and central pain syndromes.</p> | Lecture/Case based learning | 2 hours |

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| | <p>Management of malignant bone pain.</p> <p>Principles of pain management</p> <p>Using WHO step ladder, titrating the doses, opioid conversions, managing breakthrough pain and pain crisis.</p> | | |
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Day 3 (7 hours)

| Sl. No | Subject Topic | Activity | Duration |
|--------|---|-----------------------------------|----------|
| 1 | <p>Safe prescribing of opioids and managing adverse effects</p> <p>Comprehensive pain prescription writing</p> <p>Spotting common prescription errors</p> <p>Safety in strong opioid prescription</p> <p>Common adverse effects of opioids and its management.</p> <p>Prevention of common opioid side-effects like nausea and constipation.</p> | Lecture/Problem Solving Exercises | 1 hour |
| 2 | <p>Practical aspects involved in handling strong opioids</p> <p>NDPS act and amendments</p> <p>Opioid Licensing, Drug Controller</p> <p>Opioid procuring (paper work needed), storing (double locking system and safety), record keeping, dispensing, prescription procedures, and safe disposal of unused opioids.</p> | Opioid Pharmacy | 1 hour |
| 3 | <p>Hands on training/Bedside teaching</p> <p>See patients in the ward with pain and palliative care needs. Pain history taking and examination. Learn about comprehensive pain management.</p> | Outpatients Ward rounds | 2 hours |
| 4 | <p>Cancer Pain Syndromes</p> <p>Cancer related acute pain situations (Diagnostic/Therapeutic interventions, anti-cancer therapy, complications)</p> | Lecture/Case based learning | 1 hour |

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| | Cancer related chronic pain situations (Direct tumor related, anti-cancer therapy, complications, Paraneoplastic) | | |
| 5 | Difficult pain situations Refractory and Resistant pain Prescribing strong opioids in presence of renal and hepatic dysfunction Pain situations needing parenteral opioids and interventional techniques Special pain situations | Lecture/Case based learning | 1 hour |
| 6 | Non pharmacological management of pain Role of OT/PT and other allied health professionals in pain management Integrative Medicine therapies such as relaxation, yoga, guided imagery, music therapy, acupressure etc. in pain management. | Lecture | 1 hour |

Assessment

At the end of 3 days, all students will have to appear in an exit MCQ examination and successful candidates with at least 60% of the total marks are eligible to receive the course completion certificate.

Certification

The competent authority of the Training Centre will issue the course completion certificate.