TRAINING MODULE FOR PALLIATIVE CARE

(FOR DOCTORS AND NURSES)

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Chapter 1

Introduction to Palliative Care

Chapter 1: Introduction to Palliative Care

Today India is experiencing an epidemiological transition from the high burden of infectious diseases to an increasing incidence of chronic life threatening diseases; with cancer being the third most common cause of morbidity and mortality. The rising incidence in the non-communicable disease especially the chronic life threatening illnesses and unremitting infectious disease increase need for palliative care in order to ensure symptom control and good quality of life.

Palliative care is an approach and does not necessarily mean end of life care. It is a domain that looks after patients with life threatening illnesses (from the point of diagnosis of life threatening illness like cancer) to end of life and beyond, supporting the bereft family. It is essential that Palliative care be integrated at the point of diagnosis of a chronic life threatening illness irrespective of the stage of the disease this ensures seamless transition through the spectrum of the disease.

Definition of Palliative Care:

The World Health Organization (WHO) defines:

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

Goals of Palliative Care:

Provide relief from pain and other distressing symptoms.
Affirm life and regards dying as a normal process.
Intend neither to hasten nor postpone death.
Integrate the psychological and spiritual aspects of patient care.
Offer a support system to help patients live as actively as possible until death.
Offer a support system to help the family cope during the patient‘s illness and in their own bereavement.
Use a team approach to address the needs of patients and their families, including bereavement counseling, if indicated.
Enhance quality of life, which may also positively influence the course of illness.

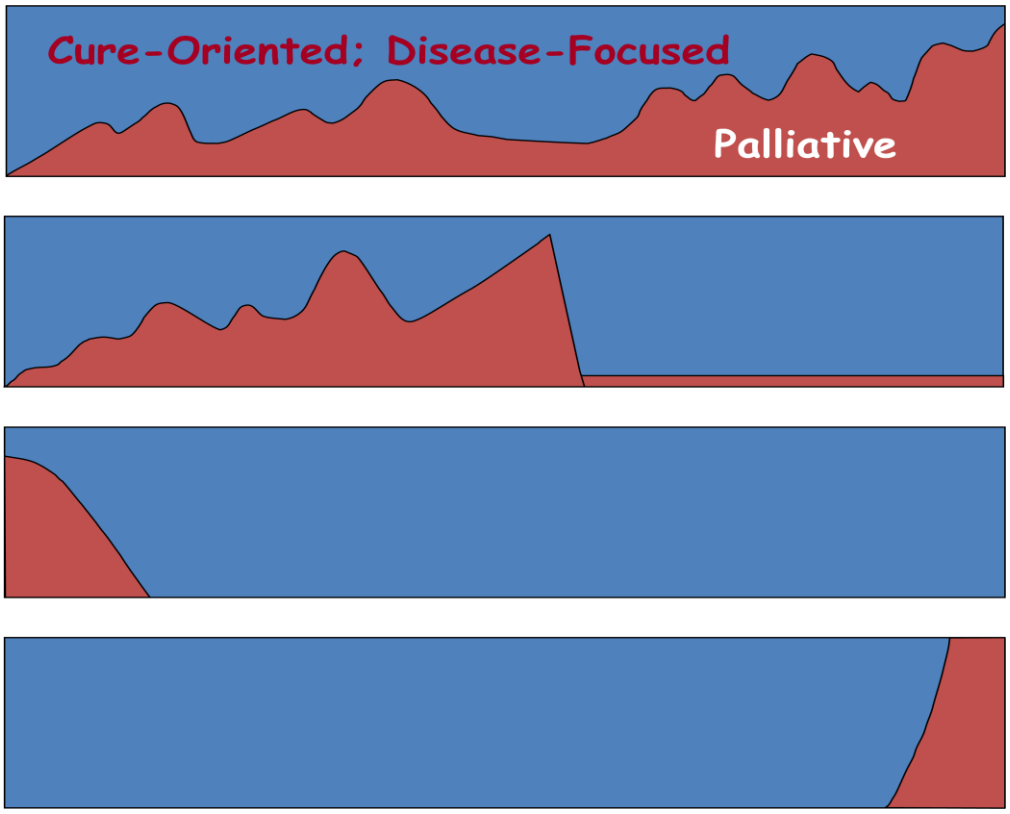
Barriers to effective Palliative Care:

Attitude towards palliative care: In the present day practice palliative care is considered as a spectrum of disease(end of life care) rather than an approach to comfort care. Which means that patients with symptoms, be it at diagnosis of a life threatening illness, must be provided palliative care parallel to the disease directed treatment.

Attitude towards Opioids: Some clinicians and patients ascribe opioid to end of life journey and think it is prescribed expedite the dying process. Certain doctors fear the adverse effects like respiratory depression and avoid prescribing opioids.

Lack of training: Communication which is the vital aspect of care(along the spectrum of the disease) often takes a backseat in medical practice and essential components of breaking bad news and prognostication are never taught in medical curriculum.
Availability of opioids: Policy makers are wary of the diversion of opioids thus acting as a major barrier in availability of opioids.

When can Palliative care be initiated?



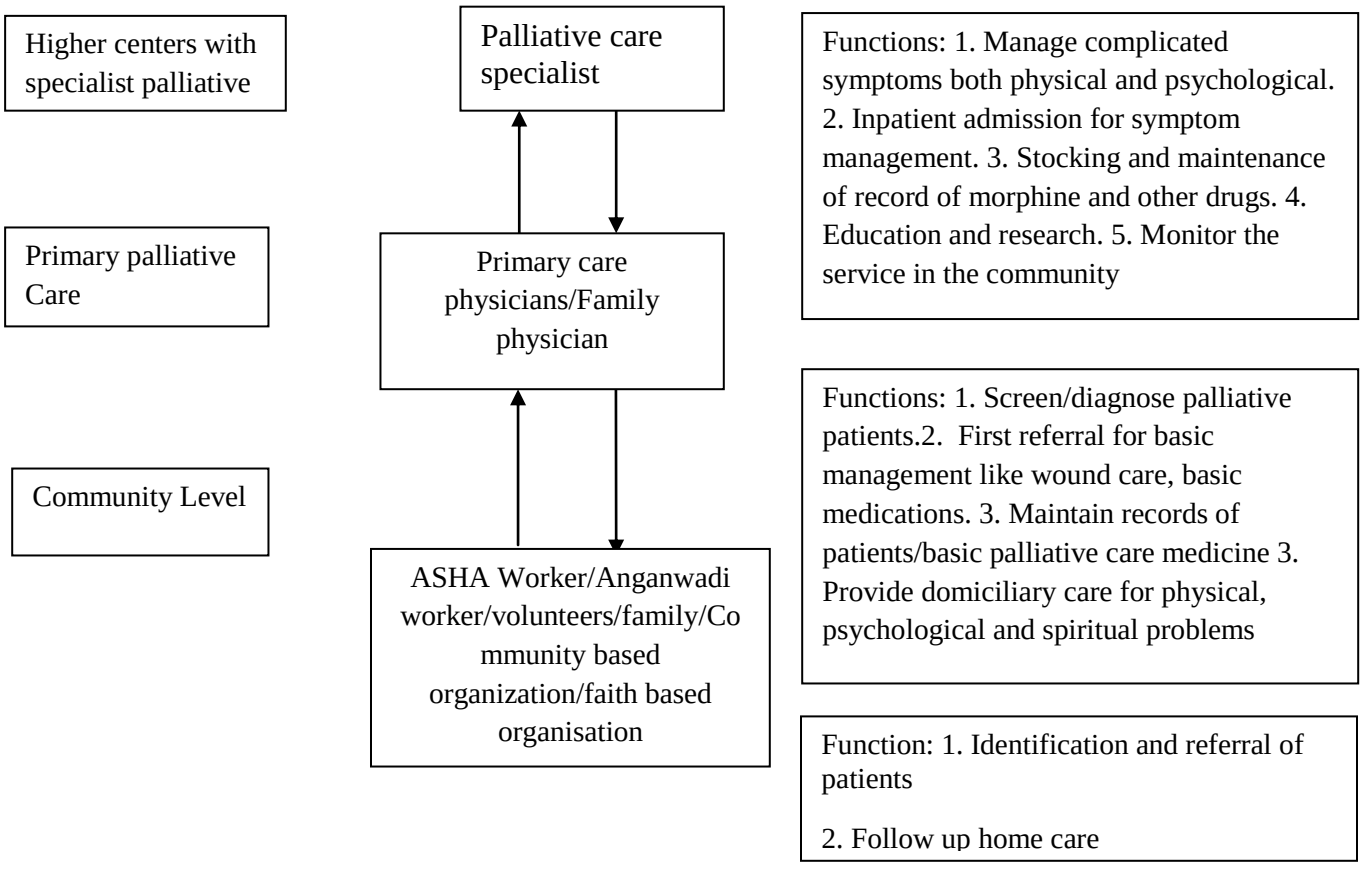
The picture above clearly demonstrates the stages at which palliative care can be initiated. Thus, palliative care can be initiated at an early stage of the disease if patient presents with symptoms while disease directed treatment is being contemplated. And palliative care can be given in small ripples once symptoms controlled patient can transition to curative care or can be given concomitantly with disease directed therapy.

How can Palliative care be provided?

Considering the vast expanse of the country and the disparate distribution of health services and health system hierarchy (between rural and urban area), it is difficult to develop a unified model of care across the country. Also the distance to cover to reach health center and cost of travel and treatment precludes utilization of service by the community. Integration of services into existing health systems seems to be a feasible solution considering the immense need for palliative care

in the community. Thus a model of care that empowers health care personnel right from the community to tertiary centres will be a practical approach to the present problem.
Learning from other community models, an 'integrated model of care'(Figure 1) with ongoing care provided by primary care physicians with expert inputs from specialist palliative care physicians seems a feasible approach. Primary palliative care in the community can be provided by general practitioners, family physicians, public health physicians in the outpatient clinics or through domiciliary care after obtaining mandatory training in basic palliative care. The training will include both theory and practical work and will encompass identification of patients with chronic life threatening illnesses, screening of symptoms, appropriate management and referral to specialist, communication skills and documentation and record keeping. The physician provides the first aid for emergencies and refers the patients to the specialist palliative care physician for more complex cases or cases demanding inpatient care. The specialist palliative care physician will provide care for more complex physical and psychological symptoms and admits patients who need inpatient care. The physician will also provide medical advice and education support to primary care physicians and volunteers in the community. Additionally, the specialist will be responsible for providing managerial input on the running of the program on a timely basis and amend the program as appropriate.

Fig.1. **Algorithm depicting the flow of patients**



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Chapter 2

Ethical Aspects in Palliative Care and End of life care

Chapter 2: Ethical Aspects in Palliative Care and End of life care

Introduction:

In 2011, there were approximately 54.6million deaths worldwide with 66% of these estimated deaths due to non-communicable diseases. The large majority of the patients which include cardiovascular disease(38.47%) and cancer(34.07%) followed by chronic obstructive pulmonary disease(10.26%), HIV/AIDS(5.71%) and diabetes mellitus(5.59%) will benefit from palliative care. 78% of the adults and 98% of children among this population live in middle and low income countries where only 6% of all palliative care services are located. A report on a study by the Economist Intelligence Unit that was commissioned by Lien Foundation ranked End of Life Care (EOLC) services in 40 countries across the globe from which data was available. The 75 outcomes of quality of death index showed that India ranked 40 out 40 in EOLC overall score, 37 out of 40 in basic end of life health care environment, 35 out of 40 in availability of EOLC, 39 out of 40 in cost of EOLC,37 out of 40 in quality of EOLC and scored 2 on a 1-5 scale on public awareness of EOLC where 5 being the highest score.(Murray et al, 2010). This report depicts the dismal state of palliative care provision in India and calls for a bridging this gap. In addition to this, due to the lack of legal protection, physicians are forced to provide many inappropriate interventions which in turn increase the suffering of the patients and family. Non-availability of EOLC and rising cost of inpatient care have forced up to 78% of patients to leave hospital against medical advice.(Mani et al, 2003)

Challenges of providing palliative care or end of life care in the country

Legal Challenges of End of Life care in India

There exists no legal framework for end of life care in the country, thus the physician has to provide support in the best interest of the patient following the ethical guidelines of medical practice.A position statement published by the Indian Society of Critical Care Medicine states "If the patient or family consistently desires that life support be withdrawn, in situations in which the physician considers aggressive treatment non beneficial, the treating team is ethically bound to consider withdrawal within the limits of existing law".(Mani et al,2005)

Cultural challenges in End of life care practice

Most of the ethical guidelines have been products of the western biomedicine. Contemporary Western bioethics tends to emphasise the values of access to information, autonomous decision-making and planning for end-of-life care.In the Indian setting,there is vast diversity in the culture, religion, family relationships and family obligations which majorly influence the decision making in the end of life care.Thus, the approach to care is generally a paternalistic approach as the concept of autonomy is weak in the prevailing cultural ethos. 76 Ethics In End Of Life Care Practice Patients have great respect for the doctors and dependence on family which influences their decision regarding the end of life. (Barnett et al, 2008)The families often wish to protect their patients from the knowledge of the seriousness of the disease as they perceive this to be harmful for their patient's physical and mental well being.(Shubha et al, 2007,Turner et al, 2002) Families are often driven by guilt, hope and may feel a loyalty to care

reverently for their patients and often insist on aggressive measures which the physician would consider medically inappropriate.(Barnett et al, 2008,Doorenbos et al,2003)

Ethical principles in End of life care practice:(Beuchamp et al, 2001)

The foundation of medical ethics is supported by the four pillars, namely;

Autonomy- Patient has the right to choose or refuse a particular treatment. In the event the patient has diminished decision making capacity, surrogates acting on the patient's behalf can communicate the patient's previously expressed wishes.

Beneficence- The doctor should act in the best interest of the patient. In the context of an advanced progressive illness with no scope for reversal, the best interests of the patient are controlling the patient's pain and symptoms, and reducing the sufferings of the patient and his family, providing emotional support and protecting the family from financial ruin.

Non-Maleficence- Do no harm to the patient. Thus, withholding and withdrawing of the life support, in this context, is a humane approach of 'allowing natural death,' that is, allowing the patient to die of the underlying illness, with symptoms well–controlled, in a dignified manner, in the presence of his family and loved ones and this in no way amounts to euthanasia.

Justice- Equitable distribution of service and equal right to care for all patients.

Added to the above four, are two more aspects which form the cornerstones of medical practice:

Dignity - the patient and the persons treating the patient have the right to dignity

Truthfulness and honesty - the concept of informed consent and truth telling should be engrained in the practice of end of life care.

Thus, it is crucial to integrate the ethical principles in practice of palliative care and end of life care in the background of cultural and social influence.

Process involved in providing good End of life care: (Chapman et al, 2011)

End of life care must be embedded in the ethical principles of palliative care.

The process include;

A. Recognize the dying process:

It is often a challenge to predict impending death, certain markers which include vital parameters like blood pressure, heart rate and respiratory rate, immobilisation, decreased food and fluid intake, decreased spontaneous verbalisation, greyish mottling and cooling of the peripheries will help recognise the limited life expectancy. However, it is always important to treat the reversible cause whilst accepting the impending death.

B. Recognise the medically inappropriate treatment

The term 'futility' is best avoided when communicating with patients and families as this could have a negative connotation. Also a recent systematic review studied the support or refute claims of medical futility; only less than one-third of the studies which showed that the treatment was futile met the common standard for quantitative futility. (Gabbay et al, 2010) Since sufficient data on evidence-based medicine on futility is lacking, the physicians may have to rely on their professional judgement and consider patient autonomy to make an informed decision.(Jiang et al, 2014) It is ethical for physicians to decline a particular treatment, which is judged to be

medically inappropriate, either where such treatment is not in the interest of the patient, or where there are insufficient resources to provide treatment of this level of benefit.

C. End of life decision making process and initiation of the end of life care pathway:

The End of life decision must begin at the point of diagnosis of advanced, progressive or metastatic cancer when the primary team is certain that the disease modifying treatment or intensive medical management will not benefit the patient or will lead to deterioration of the health. Once the primary treating team recognises the medical inappropriateness of a particular treatment; they could call upon the other teams involved in caring for the patient and the palliative care team and discuss all the possible options for correcting the reversible cause. If the team members have reached a consensus of saturating all the options, they could then call upon a meeting with the patient and the family members. The physician, however, must ensure that all the treatment modalities (curative or palliative in intent) have been discussed with the patient and the family in the language they understand. As discussed earlier that though the Indian legislation clearly reserves the right to the patient to decide to choose or refuse a treatment, however, considering the sociocultural background of the patients, family caregivers will need to be involved in the decision making process.(Shubha et al, 2007) Decision-making model vary across the globe; one extreme model is the traditional parental approach where the physician share the information but takes the primary responsibility for decision making.(Crippen et al, 2002, Levy et al, 2004) The other extreme is when the physician shares the information and the patient takes the final decision. The latter is what the Indian legislation mentions explicitly as it is must for the patients to give an autonomous decision.

The patient and family are formally invited to discuss the options of the treatment in the future. SPIKES (Baile et al, 2000) model of reflective communication will be used for communicating with the patient. This will include;

1. Set up: The set up should be a quite room free from any disturbance. There should be enough time given for communication.

2. Perceptions: It is essential to assess the perception of the patients and caregivers about the disease diagnosis, progression and prognosis. This gives us an understanding of how prepared the patients and caregivers are likely to be for the end of life decision.

3. Invitation: It is essential to confirm that the patient wishes to get the information about the diagnosis and prognosis.

4. Knowledge: Patients and caregivers are explained the prognosis and likely course of the disease in a language that is understandable to them.

5. Emotional support: Appropriate response to the emotions that the patient/caregivers express.

6. Strategy and Summary: Summarize the discussions, provide options of care and documentation of the discussion and give an appointment to meet again in case of uncertainties or further concerns.

The patient and family are given the time to ponder over the discussion and re-discuss with the team for the possible treatment options.

A. If the patient after discussing with the family opts for disease modifying treatment and the physician considers this against his professional judgement, the physician may decline to treat and the patient may opt to take second opinion.

B. If the patient after discussing with the family opts for aggressive medical measures, this will be documented and the patient's wishes will be fulfilled.

C. If the patient after discussing with the family opts out of aggressive measures or disease modifying treatment, this will be documented and appropriate supportive and palliative care measures will be provided in the best interest of the patient ensuring good quality of life and dignified death.

D. At any point during the course of the disease, the patient opts to change the decision and demands aggressive measures; this will be respected and documented.

Conflicts in End of Life decision

Conflict can arise when there is a gap in what is expected and what is as it should be. Conflict can arise within family, healthcare team, and between patient/family and health care team. "Conflict during End of Life Decision" is broadly defined as failure to achieve consensus on the goals of care and related treatment at the end of life despite allowing time (usually 48 h) and holding repeated discussions between involved parties. (CRELS, NSW Department of Health, 2010).

How to resolve conflict:

Good communication enriched with empathy, trust and hope can effectively resolve the conflict. The physician should take into account the patient/family perspective and hope when taking decision. Often physicians may need to conduct repeated meetings with family members to disclose the prognosis and the reason for the decision taken. A second opinion may be sought by the physician or the family member when there is no consensus between the patient/family and the physician. If the decision is still elusive legal recourse would be needed to resolve the conflict.

Documentation of the process of end of life discussion

It is imperative to document the case notes of the discussion between the physician, patient and the family. The documentation must include the names of the individuals with the relationship with the patient, details of the discussions, signature by the patient, next of kin(is not mandatory) and physician. This will ensure that the patient has been explained the prognosis and the treatment options. This document will also provide a security for the patient and the physician in case of a future conflict.

Ethical challenges in provision of palliative care in end of life care:

Patient in the end of life suffer from cluster of symptoms with pain being the dominant symptom. Poorly controlled pain can lead to miserable quality of life for patients and leave family members in remorseful grief. Palliative care is sparsely distributed across the country with major focus in western and southern states of the country. This skewed picture clearly depicts the

unpreparedness of the health system to cater to the ever expanding demands for palliative care. Palliative care service is often limited due to lack of knowledge in pain assessment and management in addition to the fear of side effects and diversion of opioids. (Mohanti, 2009) The public fear that drugs such as sedatives and opioids prescribed in the terminal stage of the disease may hasten the death process. (NIH Consensus State Science Statements, 2004, Myer et al, 2008) It is imperative for physicians to dispel this myth and educate the public regarding the importance of sedation for intractable pain and other symptoms. Terminal sedation must be prescribed only after the patient and the family have been explained about the 'double effects'(Mohanti, 2009) of terminal sedation and they have consented for the same in writing. Advance care planning which gives the patient the autonomy to plan the future care in advance must essentially be recorded. This will give the patient the opportunity to decide the level of care including the place of care and death. This will avoid terminal patients from being subjected to aggressive and unnecessary resuscitative measures. (NIH Consensus State Science Statements, 2004).

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Chapter 3

Communication and Breaking Bad News

Chapter 3: Communication and breaking bad news

INTRODUCTION

Communication skills are important in every aspect of day to day life including in the healthcare sector. These are of immense significance when dealing with people with life threatening illnesses and in chronic life limiting illnesses. Palliative care, as per definition by the World Health Organization, is ―an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual‖. It is important for good dialogue between palliative care providers and patients facing advanced disease and end of life, as well as their caregivers.

Effective communication while disclosing diagnosis, prognosis and treatment options leads to better decision making, reduced emotional distress and positive experiencing of care for patients. Poor communication results in anxiety and distress for the patient and dissatisfaction with treatment providers, impacting the quality of life. Competence in communication skills has been found to reduce job stress and burnout for physicians and other healthcare workers in palliative care. . For professionals involved in end-of-life care, dealing with patients physical, emotional and spiritual concerns requires patient centred communication skills.

Communication skills are, therefore, an integral component of palliative care.

TECHNIQUES FOR GOOD COMMUNICATION

THE C-L-A-S-S PROTOCOL

This is an acronym for communication technique in clinical interviews with patients, as propounded by Dr. Walter Baile in M. D. Anderson Cancer Center.

C - Context and connection – This is essential in building rapport with the patient. Greeting the patient, good eye contact and being attentive by minimizing distractions and interruptions in a setting of privacy help in making the patient feel comfortable.

L - Listening skills – Listening to the patient‘s concerns and his/her understanding of the illness are important before giving more information and decision making. Use of open ended questions like ―Tell me how you have been feeling‖ rather than ―Are you having any pain?‖ or ―Are you having any problems?‖ are better and give an opportunity for patients to express their worries. Good eye contact and body language are important components in listening skills. ―Active listening‖ helps in understanding what is not being said in words but being conveyed non-verbally. It is important to keep in mind that sometimes silence is the key to facilitation and listening.

A – Addressing emotions – Patients go through a range of emotions like shock, anger, sadness, anxiety, helplessness, etc while talking about their illness. Healthcare providers need to understand patients‘ emotions and help them cope. Emotions may affect the patients who then have difficulty in understanding or paying attention to the information being given or discussion about treatment strategies. Understanding and clarifying the emotion is the first step. One needs to be clear as to what and whose emotion is being addressed. It is important to separate the

emotions from the patient from the clinician's emotions. Acknowledging that the patient is feeling a particular emotion is important in the patient-clinician communication. Making empathic statements like "I can see that you are feeling upset" if the patient is distressed and tearful during the interview. Empathy is very important in providing psychological support.

S – Strategy – A management plan is necessary for the patient and his/her family to work on and follow. It is good practice to give information in small chunks and avoiding too much of technical language or "jargon" for better understanding.

S – Summary – This is the final step in which the clinician or healthcare worker can clarify what the patient understands and if he/she has any more questions. Also, the role of the clinician is explained as to what is required or expected.

THE S-P-I-K-E-S PROTOCOL FOR BREAKING BAD NEWS

"Bad news" is any news that seriously and adversely affects the patient's view of his or her future (Buckman, 1990). If bad news is delivered in an empathic manner, the impact of this goes a long way in alleviating to some extent the distress felt by the patient. In palliative care, the bad news is that of poor prognosis, advanced and terminal stage of disease with end of life issues. The S-P-I-K-E-S protocol is a modification of the C-L-A-S-S protocol for breaking bad news

S – The right setting – This is akin to Context in C-L-A-S-S protocol. The right setting helps in establishing rapport and making the patient feel comfortable. The clinician should plan prior to the interview as to how to proceed. Questions like whether the patient has some idea or is expecting bad news, does the family want to be present and if so, who, etc need to be kept in mind. Active listening is important.

P –Patient's perception – What the patient perceives about his disease, stage of disease, and treatment options is useful to understand before breaking the bad news. So any gaps in the knowledge, any mis-information, etc can be corrected. It also gives the clinician an opportunity to understand patient's concerns and fears, so that expectations can be realistic.

I – Invitation to share – The patient might express his/her wish to get the information. It is important to remember that the patient may not want it at that particular clinic or hospital interview. One cannot really proceed without the patient's consent.

K – Giving the knowledge – It is good practice to come to the medical facts gently, observing the person's emotional reactions and proceeding further. It is best to avoid medical and technical jargon.

E – Understanding patient's emotions and empathizing – It is essential to acknowledge patient's emotions and explore these. Using empathic statements like "I can see that this is very upsetting for you".

S – Strategy and Summary – This will be similar to the last steps in C-L-A-S-S protocol. Breaking bad news is a difficult task and has many implications. However, when handled well, much is achieved in reducing distress and increasing the perception of care for the patient and a sense of competence and satisfaction for the healthcare worker. Studies done worldwide have shown that 60-80% of patients wish to know about their diagnosis and prognosis. However, despite this, in about 25-50% of patients with a terminal illness, prognosis is not disclosed in

some of the developed countries. This percentage is higher in some countries in southern Europe and Asia.

Cultural practices do have an influence on _truth telling‘. In some cultures, it is accepted that bad news be told to family members first. It is believed that adult sons and daughters are caregivers who will take all the decisions regarding the discussion of the diagnosis and prognosis to the patients. The common feeling that some of our patients‘ family members say is that patients are going feel _shock‘ and do something untoward. Family members need to protect the patients from unpleasantness is understandable, but it should be generally discussed with them about the consequences and what should be the way to go forward. Engaging with the patient and collaboration with his/her family are both important. Hece, the health care worker needs to be able to handle situations which might be fraught with perceived difficulty. But with gradual _working through‘ with these issues, maybe over a few sessions, one can reach a comfortable stage wherein patient and family are both able to adjust psychologically to this _truth telling‘.

COMMUNICATION SKILLS TRAINING

Research has proved that communication skills do not necessarily improve with experience. Hence, there is a need for training in communication skills. Communication skills are important and these can be taught and learnt. Training programmes in communication skills utilize cognitive, affective and behavioral aspects and should focus on attitudes, skills, knowledge and tasks. Courses need to be tailored to needs of the patients with life limiting illnesses and their families as well as various health care worker groups involved in providing palliative care. With education and practice, the pivotal role of communication skills in palliative care will become more entrenched, leading to overall positive impact on health care.

Barriers for Effective Communication

Although key to the physician-patient relationship, many barriers to effective communication exist. Due to the emotional content of communication, these barriers are more likely to arise when the news is bad or when the patient is at the end of life. In their efforts to improve communication skills, consideration of these barriers may help all health care providers to discover problems that they can work to overcome. Barriers can be divided into those due to patients and families, due to health care providers and those due to circumstances.

Barriers due to patients and families

Patients and families may misunderstand the illness and the prognosis. These misunderstandings are more common when the news is bad and, when patients and families are physically, emotionally or psychologically stressed. Physicians should give information in small chunks, and check understanding. Even if patients and families seem to understand the news, physicians must be prepared to give repeated explanations and answer questions.

Biases over the role of palliative care within society and the medical profession may lead patients and families to misunderstand what palliative care involves. They may perceive involvement of palliative care as implying death is imminent and fail to understand that expertise in palliative care can help improve quality of life.

Patients and families may lack knowledge of social, cultural norms, roles and expectations regarding death. They may never have seen or had a loved one die. This confusion over what to do may result in refusal to recognize the severity of illness and prognosis, over-emphasis on treatments leading to possible cure and failure to accept palliative treatment which is seen to mean accepting death.

Faced with the stress of illness and threatened loss, family may struggle to realign their roles within the family community. They may lack support, may not be able to cope and may present in crisis. When in crisis, misunderstandings, confusion and conflict within family and with the health care team are more common.

The physical and emotional depletion that accompanies severe and/or prolonged illness also decreases ability to concentrate, retain information and decreases decision-making capacity.

Strong emotions: anger, guilt, denial over illness, threatened loss or unfulfilled dreams may consume the patient and family and result in inability or refusal to process information.

Differences in values, beliefs or culture may make it difficult for patients and families to express their emotions, needs and goals with health care providers

Barriers due to health care providers

Physicians may develop strong bonds with patient and family, whether they have known them for years or just a short time. These bonds may make breaking bad news or discussing issues around end-of-life care difficult since physicians may find it difficult to contemplate losing a patient they care for deeply

Physician's personal experiences with illness and death may affect their ability to care for a person who is at the end of life

Physical, emotional and psychological depletion may affect ability to communicate caring, empathy and compassion

Caring for someone who is dying leads to physicians confronting their own mortality and fears of death

A lack of training and role models results in poor communication skills and either a lack of awareness of patient's feelings and reactions or inability or fear of discussing these emotions.

Physicians are not taught how to show empathy and caring and may fear emotional outbursts

Many physicians have been taught that displaying emotion is a sign of weakness or unprofessional. These physicians may have difficulty in discussing end-of-life issues for fear of feeling or displaying emotion

Health care providers' personal beliefs and values may influence their ability to communicate and care for people at the end of life

When illness is due to or has been exacerbated by iatrogenic complications, physicians may be consumed with self-blame and guilt which may affect their ability to consider the patient's situation, i.e., How has this iatrogenic complication affected the patient's quality of life and is the patient likely to recover?

Barriers due to circumstances

If physicians have to discuss personal, difficult end-of-life issues when they just meet a patient and family, communication is often stilted and awkward

As hospitals lose more and more beds, privacy becomes more and more difficult to obtain

There may be unavoidable interruptions if the physician is the only one on duty in, for example, the ER or ICU

Examples of good and poor communication techniques

Ask open questions

Dr. - ―Is your pain better today?" (Closed question and hence not appropriate)

Dr. - ―How are you feeling? (Open question and hence appropriate)

Be empathetic

Pt. - ―I feel scared when I am breathless

Dr. - Take these tablets for your breathing.

Here doctor is ignoring patient's emotions and hence wrong approach

Right approach would be as follows

Pt. - "I feel scared when I am breathless"

Dr. - Breathlessness can be very frightening. It is very understandable. Breathing medications should help

Sensitive truth telling

Pt. - "The Doctor said my cancer is incurable"

Dr. - Don't worry about such things, everything will be okay.

Here doctor is giving false reassurance and hence not the right step.

The right statement would be something like the following

Dr. - It must have been very hard to hear that the cancer has spread but we will do our best to help you in every way we can"

Balancing hope and truth

Dr. - There is nothing more we can do, your disease is incurable. So there is no point in staying in hospital"....

Here doctor is totally destroying hope, hence 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 help you be more comfortable so that you can be at home with your family. If you need any help in the future, you must come to the clinic."

Respectful 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 being curious which does not serve any purpose.

The right approach would be as follows.

Dr. - "I think we need to discuss this more as it is obviously very significant for you, but please know that everything we discuss will be kept confidential"
Here doctor maintains confidentiality, but at the same time he would like to have more details which could be medically important
Partnership between doctor and patient"
Dr. - —You must take this medicine for your pain. If you don't take it, there is no point in coming back to see me."
Doctor is imposing his agenda on the patient which is not a right step
Dr. - Your pain is caused by disease in your bone, and because of this you need a special sort of pain medicine. Would you be willing to give it a try?
"Here doctor is talking as if to a friend and soliciting his opinion."
Listening skills:
It is very important to be aware of active listening as it is the key component of communication. The following are modalities used as good listening skills
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 (health care professional) waits for the cue.
Encourage talking - Generally in doctor- patient communication, doctors talk more and the patients are forced to listen. But 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 give a hint and bring the patient back to the main theme when he/she deviates from the central theme
Tolerate silence — health care practitioners tend to get impatient as the patients become slow in their narration. It has to be understood that patients need time to recollect certain events and may become emotionally overwhelmed when they have to describe a sensitive event or situation
Avoid unnecessary interruption — during history taking, we need to ask questions in between to clarify certain points and to get more details. But this should not be too frequent to interrupt the flow of communication.
Show that we are hearing by verbal and non-verbal means. This can be done by repetition, reiteration (paraphrasing) and reflection
Summarize & prioritize the agenda
Empathize & give realistic hope
Remember, as you are assessing the patient, he/she is assessing you. The following can help to maintain effective communication
Eye to eye level contact
Clear introduction
Avoid over familiarity
Explain what you plan to do
Summarize back to the patient, "Have I heard things correctly?"
Avoid patronizing
Use language and terms appropriate to the patient

Do NOT say:

I know what you are going through

I know this must be a shock

I know how hard this is

YOU DO NOT KNOW!!

Breaking bad news

Breaking bad news is an important aspect of communication. It takes time and issues often need to be discussed further and clarified as more information is imparted

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Counseling in Palliative Care

Introduction:

When a person is diagnosed with cancer, the entire family goes through severe stress. Advanced stage of cancer is stressful for patients as well as for their care givers as the hope of cure is limited. The care givers feel helpless and try to face the event by adopting varied coping strategies. The Palliative Care Unit attempts to understand their needs and offer care not only to the ill person but also to care givers in totality. The definition of palliative care is –an active and total approach to care, embracing physical, emotional, social and spiritual elements. It focuses on enhancement of quality of life for the patients and support for family and includes the management of distressing symptoms, provision of respite and care through death and bereavement‖(Lenton et al, 2006). In this service provision system, communication plays a major role. The trained counsellors of the Unit use the communication effectively to understand concern, worries and needs of the patients and family.

Definition:

Communication is defined by Oxford dictionaries (2011) as the imparting or exchanging of information by speaking, writing, or using some other medium. Communication is very important in our life because humans as social beings. All our socialization depends on communication so it has to effective. It is used as a tool for exchanging information, sentiments, social norms and so on.

Forms of Communication:

Communication may be verbal or non-verbal.

Verbal Communication: It involves the use of language. The words used might be written or oral. It is the most common form of communication. This might be direct (face to face) or indirect. The exchange of information, thoughts or feelings is quick in this type of communication and the feedback is also received immediately. In this type of communication, conscious use of spoken language is important. The selection of words is significant as it reflects the age, education, developmental level, culture. The simple, brief, clear, well timed, relevant sentence formation is effective as the decoding by receives becomes easy. Minimal usage of medical jargons is essential while imparting the information to a lay person.

Paralanguage: This term refers to the vocal qualities of oral communication. The ‗way' message is given and ‗how' effectively information is communicated depend on the following things. The rate of speaking (slow or fast) , pitch, loudness of voice, use of pauses, emphasis, voice clarity are few of the factors which are considered as important factors while communication orally.

Non-Verbal Communication: This is the way of communication in which the usage of words/language is nil. This is sort of silent language. This includes physical aspects such as facial expressions, eye contact, gesture, posture and so on. The gestures like eye contact denote the honest conversation. It is of course influenced by cultural norms. Usage of right gestures such as nodding the head, leaning the body, can be used effectively as it shows the willingness of listener.

This type of communication can be used more effectively while counseling the ill persons and their family. It is seen that sometimes it is hard to find words to empathize with them. In such situation, just patting on the back or gently touching the client help a lot to counselor. Usage of pause can be used effectively. The silence can be proved as important tool of communication if used appropriately. The pause or silence in counseling session helps client to think, understand and respond.

Communication in Palliative Care:

The palliative counsellor is an integral part multidisciplinary Team of the Unit. The role of palliative counsellors is not restricted only for the ill people but also to provide support to their care givers. While describing communication as a vital component of palliative care Seth (2011), mentions the importance of effective communication skill of medical practitioner helps to allay the fear of parents related to the unknown and provided empowering information. The task and responsibility of the counsellor is to help the patients to cope effectively with the life threatening situation. It is essential to make the patient and care givers aware of the prognosis of the disease. Awareness of the fact though bitter, helps them to cope with the eventuality. It is seen that fear related to uncertainty is reduced when the factual information is revealed to them. They get enough time to accept the poor prognosis.

The counsellor working with Palliative Care Unit has to deal with the issues of death and dying. Death is inevitable and it is still a taboo subject. Topic of death and dying is avoided by ill as well as healthy individuals. When the patients are nearing death it becomes extremely important

to deal effectively with physical, spiritual, social, psychological and emotional aspects of the patient and other family members at this stage.

Involvement of patients:

In Indian context, it is seen that care givers make efforts to protect the patients is from exposing to bad news. They try to shield the ill person by not involving him/her from the disease/prognosis related discussion. But the literature and own experience of author has found that person with disease uses his/her intuition to understand own disease condition.

Components of Palliative Counselling:

The essential component of the Unit is to break the bad news. The health professional is expected to break the bad news in sensitive and empathetic manner. When the patients are referred to the Unit, they approach the Unit with ray of hope of cure and expect the Unit to provide curative treatment. The role of counsellor begins before the medical health care givers. To assess the patients‘ awareness and understanding related to disease is the first responsibility of counsellor. To understand these sensitive issues of individuals, communication plays a vital role in the entire process.

Assessment areas in Palliative Counselling:

As the Units aims to provide care in totality, it is essential to assess the needs of the patients. Along with the physical discomfort, the patients undergo the emotional, psychological, spiritual and social pain. It is essential to assess the needs properly and understand the priority of needs for the patient and care givers as based on this need assessment by the counsellor, the Unit plans the appropriate intervention to help the patient in totality.

Emotional discomfort of the patient: the counselor attempts to assess emotional and psychological pain component of patient. The anticipated symptoms, uncertainty of future and fear associated with thought of permanent separation from the dear once are few of the important areas which a counselors need to assess.

Spiritual discomfort: The disease such as cancer is connected with punishment by God for the sins of this life or last life. _why me‘, _what I have done wrong?‘ are the questions which bother the patients.

Social discomfort: The social stigma attached to the disease such as cancer force the patients to hide the disease from community, neighbors or other family members. _now my friends do not play with me.‘, or‘ my HI status might influence my relationship with my peers‘ are the thought which they possess. To deal with this situation, they prefer to isolate themselves from others which results in stress.

Communication skills required by the palliative counsellor:

An empathetic approach is essential along with the effective communication skills to understand the patient. Palliative counsellor has to be patient listener and sensitive towards patients‘ pain. Proper use of body language, facial expressions, tone, and pitch of the voice and selection of proper words by the counsellor prove helpful in the Unit to understand the patient completely. Usage of small and simple sentences, avoiding medical jargons, providing information in parts

help patients to understand the information. The skill of counsellor to read between the lines, making appropriate use of pause and silence is useful.

Language: It is easy for a person to express himself or herself in her/his mother tongue. They feel comfortable communicating in the mother tongue when professionals make extra efforts to speak in the language of the patient and care givers to create better trust and build rapport.
Techniques used in Palliative Care Unit by the counsellor: To motivate the patient to ventilate his/her feelings, thought and concerns is the main job of the counsellor. This is done by providing conducive atmosphere to patients. When it is observed that the patient is not able to communicate, then he/she is helped by providing paper and pencil. When the patients write their concerns they feel less burdened
Observation: Observing the body language of the patient, a trained professional can understand the pattern of inter personal relationship within their family. The body language, if eye contacts are well maintained, if fidgeting is frequent are few of the cues which prove helpful to understand the current emotional and mental status of the ill person.
Listening: This is a wonderful technique which helps to strengthen the bond of trust with the patient. Assurance of patient listening encourages the patient to open up. Catharses of feelings help them to feel unburdened.
It is essential to understand that it might be difficult for a patient to express the self in words but several options of ventilation is necessary to offer to them. After receiving the oral consent from their care givers, the first towards breaking bad news is to assess the willingness of the patient to listen to the news. The age, gender, exposure and understanding of disease decide the content of communication. To provide enough time to think over the newly gained knowledge is a key of effective communication. To pass the messages hurriedly might affect the mental health of the patient.
To summarize, it can be said that, every patient shown willingness to be involved in the communication. The information should be provided without using medical terminology and preferably in the mother tongue of the patient. Non threatening atmosphere, assurance of privacy and confidentiality help them to open up. When they speak it is essential to acknowledge the emotional stress of the patient. Being a non judgmental person wins the half battle. Willingness to share and patient listener create a strong bond of trust. Communication is vital key aspect of effective patient care.

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BREAKING BAD NEWS

Introduction:

The patients who step into the hospital hope for complete cure. Patients and their care givers make all attempts to see their patient in the best of health. The hope of complete cure makes them go through financial, social, psychological, emotional and spiritual stress. The moment they are informed about either the poor prognosis of the patient or the advanced stage of the disease of the patient, the bad news breaks their heart. To break the bad news is accepted as the difficult task for health care practitioners. Bad news can be described as news, which changes someone's perception

of the future from being _good' to being _bad'. Unexpected news which alters the future affects the entire life of patients as well as the care givers.

Why is it important?

It is observed that patients go through anxiety and fear related to uncertainty. The awareness of facts helps them to reduce the stress. They get enough time to accept the poor prognosis. The patients also get a chance to identify, organize and prioritize their unfinished jobs. Decisions such as handing over responsibilities, handling personal financial issues, moving back to native (if they are residents of other than Mumbai) are based on this awareness. The care givers also use this time to make the patient happy by fulfilling his/her wishes. Small gestures by care givers such as calling old time friends of patients, helping the ill child to resume his/her school, arranging a family get together,

cooking the favorite food for patients, helping the patient to visit his dream places routine and so give immense pleasure to them. These memories help them to cope with the loss of the patient.

Why it is difficult:

Disclosing bad news is associated with imparting sadness. To accept the limitation of curative protocol is considered as defeat of medical science. The lack of adequate time, privacy and load of work makes the process of breaking bad news difficult. It becomes difficult to communicate with the patients from different regional and linguistic back ground. The language becomes the barrier while communicating with them. Few of the patients and their care givers lack the basic information such as diagnosis then it adds to the difficulty to disclose the poor prognosis as they approach the Unit with high hopes of cure.

Collusion, to conceal the disease related information from patients, or few of the family members is observed frequently in Indian culture. The intension to protect and project the love for other is expressed by hiding the sad information. On the other hand, patients guess the poor prognosis by witnessing the stress on the face of their care givers. The distressing physical symptoms also indicate their advanced stage to them. Decision of collusion from both sides restricts the direct conversation. The expression of feeling, thoughts and concerns is hampered resulting into stress.

TEN STEPS TO BREAKING BAD NEWS :(FROM KAYE 1996)

- **Preparation**
- **What does patient want to know?** **Is more information wanted?**

Give a warning.

- **Allow denial.** **Explain**
- **Listen to the concerns** **Encourage feelings**

Summary and plans

Offer continued support and availability

How the news is broken:

The situation of breaking bad news is handled in an empathetic manner. The knowledge of the care givers or patients is assessed before disclosing the bad news. Speaking to care givers and seeking permission from them to speak to the patients is practiced in the Unit. The care givers try to hide the painful facts from the patient. In such a case, counselors intervene and try to explain the importance of revealing the truth to the patient. If they consent to disclose the information then the meeting with the patient is scheduled. Some care givers wish to be present at the time of patient-counselor/doctor meeting. Their wish is respected. The feelings of patients are acknowledged. Some patients or their care givers refuse to listen to the disease related facts. In such case, the information is not forced on them. Enough time is provided to them to register the news. Generally the news is broken in parts

Adequate privacy and confidentiality is maintained while planning the counseling session. Initial phase of counseling focuses on checking the awareness of patient regarding his/her diagnosis. Some patients are informed by the treating Oncologist of their parent unit and few are totally uninformed. If they express their wish to know, then the information is imparted in parts.

At every short interval, their response is assessed. Their feelings, thoughts are attended to empathetically. Their expressions, unsaid words, pauses are notes as they speak more than the words. Their needs are understood and based on their needs and expectations, next intervention is planned. At the end of every session, the assurance of extended support is given.

Emotional Responses of patients and family when faced with Unexpected or Bad news: Disbelief

If it is unexpected, bad news is commonly met with disbelief. When patient or a family expresses disbelief, they are usually attempting to understand the information but can't quite accept it as true. Expressions of disbelief are not intended to be argumentative or to dispute the reality of the information and often disbelief is stated but actions, non-verbal communication show that news has been understood and accepted.

To show empathy, physicians need to respond to these difficulties in accepting such news: —I can understand that it must be very hard to accept (the seriousness of) illness.

Shock :

Shock is easily recognizable, even expected, but very difficult to support, respond to and help someone through. People in shock are not able to function, they can't make decisions because

they are not registering information. They may even not be aware of what they are doing because they are overwhelmed by such intense emotions. People in shock can best be supported by staying silent to allow them time to adjust.

Denial :

Denial is a refusal to accept news, a genuine belief that it's not real or that it is somehow a mistake. Often patients subconsciously fear and or know that the news is correct. Patients in denial often make clearly unrealistic plans. Denial is a subconscious defense mechanism that gives patients and families time to adjust by preventing damage to the patient's and family's view of the future.

Physicians need to recognize the protective nature of denial and that it is a normal initial reaction to an overwhelming threat to the person's sense of self and well-being. However, denial can become prolonged and affect the ability of the patient to ask for and receive quality end-of-life care. Families may become isolated from the patient in denial if they accept the news and try to prepare for the impending loss. Helpful approaches include asking: ―What is it that makes you feel this is a mistake? We will hope that the treatment will work but we need to plan what we will do if it doesn't.

Displacement :

Displacement is used to divert emotions into actions and activities. It is an important way of coping however it can increase distress. Displacement may result in a quest during which the patient attempts to fulfill a previous ambition. Quests may also be expressions of denial. Assess whether displacement is helping patient cope or not.

Fear and Anxiety

Fear is common and is caused by specific triggers as opposed to anxiety which is more diffuse, more chronic, and which takes longer to resolve even trigger is gone. Physicians should acknowledge the

emotion non-judgmentally and ask the patient and/or family what their fear, and /or anxiety is caused by.

Physicians must offer information and support but be careful not to over reassure and provide false hope.

Anger

Anger is a common response to unexpected or distressing news. It may also be a reaction whose goal is to disguise fear. Anger may be directed at many targets such as

against disease

loss of control or powerlessness

loss of potential

laws of nature/ God/randomness

self: if activities caused or contributed to illness, if they missed opportunities for earlier recognition and treatment of their illness or missed opportunities to fulfill their goals and dreams

friends and families: envious of their better health, anger about old disagreements/fights, anger over receiving their continuous advice,

medical team: who cannot cure illness or who are failing to alleviate their pain or other symptoms

Physicians should not reply to anger with anger: this response only escalates a bad situation. Instead, give permission to talk about their anger: ―You appear angry about this, let's talk about it.

Guilt

Guilt is defined as self-blame, sorrow and regret. Physicians need to be on alert – patients and families are often reluctant to share their feelings of guilt and yet may be deeply distressed by them. Source is often self- blame for not seeking medical attention sooner. In many situations, they can be reassured that their time of presentation may not have changed the ultimate course of illness: ― Even if you had come to the hospital sooner and we had diagnosed your infection sooner, you may still have become this sick. Can reinforce the importance of not dwelling on the past but the need to concentrate on issues here and now: ― It does not help you to keep dwelling on the past and blaming yourself for your illness. I can see how this is draining you emotionally. Physicians must be careful not to contribute to these feelings of guilt through messages conveyed verbally or non-verbally. Other sources of guilt may be due to things the person has left undone or, disputes they have not resolved. Physicians may be able to help them and support them as they attempt to heal these rifts or attain these goals (if realistic) in their remaining life.

Despair/ Depression

When a person confronts the end of life, it is not uncommon for them to alternate between hope and despair. Clinical depression may occur in 20% or more and may require psychiatric consultation. It is important to allow people to express these emotions and to express empathy, compassion and support but again physicians must avoid being over reassuring and providing false hope. Instead need to reinforce that they will not be abandoned. If the patient starts to cry, non-verbal communication can be a powerful way to convey support. Rather than attempting to change the subject, minimize the importance of the news and provide false hope or filling the air with words, physicians should not be afraid of silence and, having a box of tissues handy, should move closer.

Physicians may consider touching the person on the forearm to convey support: this depends on their personality (whether they are comfortable with such a gesture – if not it will seem awkward) and the patient's comfort with being touched

Relief

Physicians may be surprised when patients respond to bad or unexpected news with relief. This response does not mean person does not understand or has misinterpreted the information. Relief is usually seen if the illness was difficult to diagnose, or if the patient was worried about the diagnosis. Relief may also occur if the patient and family finally feel someone is telling them the truth.

Initial relief does not mean that the person will not experience a range of other emotions (guilt, disbelief, despair, anger etc.) in time. Physicians should not be complacent if met by relief but

should ensure follow up appointment is made and be prepared to address these other emotions as they arise.

Shielding or "Don't Tell"

When upset after receiving news, patients may seek to shield their family from the knowledge or families, anticipating new, may seek to shield the patient.

In some cultures, informing the patient of bad news is seen as harmful. These views should be respected and physicians should be prepared to talk to the person designated by the patient (see above). If a patient says ―don't tell‖ after his/her reasoning has been explored and physician has offered to help tell family, physicians have ethical and legal obligation to obey even though this may diminish the ability of the patient to be supported by their family. If the family says don't tell, physicians should explore their reasoning and allow them to express these protective emotions. However, physicians must explain that as physicians they have ethical and legal duty to tell the patient unless the patient waives this right and substitutes another to receive information and make decisions in his/her place. Physicians should offer to ask the patient these questions in private (see section on what they want/need to know) and ensure the family is present when news is conveyed so they can support the patient.

Service from Unit:

In this Unit, the patients are attended at the time of their need and not as per their appointments. The physical symptoms are unpredictable in the advanced stage of disease so might need frequent attention of medical professionals for medication. Other needs like getting nursing assistance, getting professional help from physiotherapist, occupational therapist is also satisfied. Their need to be supported emotionally and psychologically is also valued. The trained counselors speak to them at the time of every visit and help them express their worries. These services are managed as they get a chance to speak about their prognosis.

The patients who decide to move back to their native pace after understanding the bad news also receive support from the Unit. They get referral letter to the local General Practitioner so that they can get local medical assistance. The contact numbers of doctor and counselor are given to them. So at time of need they or their treating physician can ask for the help from the Unit. Open door policy of Unit helps the patients and their care givers o face the bad news positively. Patients receive the help in totality but at the same time they are empowered to take their own decisions. They get support to list their immediate needs and concerns. Help from other NGOs, volunteers and donors is also arranged to accomplish their wishes such as finding a safe shelter for their children, completing some legal formatives and so on.

Family Collusion :

At times, families will ask the physician not to tell the patient the diagnosis or other information. While it is the physician‘s legal obligation to obtain informed consent from the patient, an effective therapeutic relationship requires a congenial alliance with the patient.

Find out from the relatives what restricts them from speaking the truth to the patient;

Any concerns relating to personal, religious, cultural context.

Any fear about suicide or symptoms of anxiety like palpitations.

Past experience of tackling difficult crisis situation.

How to tackle the situation?

Acknowledge the concerns of the caregivers.

Discuss with them the importance of letting the patient know the prognosis.

Assure them that the discussion with the patient will be initiated only if they approved and in their presence.

These situations may require significant negotiation. Ultimately it will be decided after discussion with the patient, the details of the diagnosis and prognosis and treatment plan will be discussed only with the relatives unless the patient himself/ herself insists. In the latter case, where the patient insists, hiding the diagnosis and prognosis from the patients will thus be deemed unethical, in which case, other members of the team can be involved in the discussion.

Summary:

To summarise this importance of breaking bad news we can say that, though it is difficult to listen to and accept the bad news, but it has own importance. It is essential to break the news in sensitive and empathetic manner by imparting true information. Then patients get a chance to plan their future and put in the efforts to accomplish the unfinished responsibilities. Getting time to accept the eventuality helps them to cope with the event of life threatening condition. Receiving professional support to enhance ventilation of feelings and getting assurance of extended help influence the coping of patients and their care givers.

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Chapter 4

Principles of Symptom Management

Chapter 4: Principles of Symptom management

The term Palliative Care is derived from the word *"Palliare"* or to cloak. It considers patient and family as a single unit of care and ensures an enhanced quality of life through advancing disease, end of life and supportive care for bereft family.

Many factors preclude this:

Advancing disease
Decreasing general condition
Despair of patient and family
Diminishing Medical options
Depleted financial resources

Suffering is multidimensional and Dame Cicely Saunders, who is the founder of the Palliative Care movement once wrote that ―The only proper response to a person is respect, a way of seeing and listening to each one, thereby giving each his or her intrinsic value. In a world where technology threatens to undermine our sense of worth and meaning, the holistic approach of Palliative care has helped in the search for meaning of life and death".

Good symptom control begins with a good history and assessment

Dr. Robert Twycross, a pioneer in the spread of the Palliative Care Movement has enumerated the 5 cardinal principles of good symptom control.

Evaluation

A scientific recording of each symptom is imperative, if possible on a chart so that we can go back and assess response..(use the acronym PQRST for symptom assessment)

Explanation:

It is essential to explain the problem in the language that patients and family comprehend
Explain why a particular symptom occurs and provide a realistic goal of treatment.
Explain the effect and side effects of a particular intervention and patient's assent for treatment.
Reassure the patient and family about the goals of care and comfort

Individualize treatment

Every patient is unique and manifestation of a symptom may vary between individual patients and within the same patients at different time points.

Symptom management must be provided considering this point and individualized depending the patient manifestation and tolerance capacity

Supervision

At every visit, the symptom relief and side-effects of drugs must be assessed, recorded and titrated.

Sometimes it will be good to provide a combination of medications as this will treat the cause, reduce the dose of individual drugs and side effects.

The side effects may be counter-productive. However, sometimes the side effect of a drug is beneficial eg. Amitriptyline which if given for neuropathic pain has an antidepressant effect as well.

Always prescribe prophylactic drugs for the anticipated side effects of a drug.(always add haloperidol as antiemetic when giving morphine and stimulant laxative for preventing morphine induced constipation)
It is important to keep in mind that the patients do not have an appetite and too many drugs.
Attention to detail
Always pay attention to what patient says as however small it may be patient is directing us to the diagnosis of a problem.
Ensure that you listen to every information that patient provides as they feel re-assured and supported.
Always involve your patient and family in symptom control; this helps them take control over their situation
Do not ignore the fact that symptoms are always associated with psychological and spiritual distress. Address these issues while treating the physical symptoms.

In conclusion, there is a *"limit to cure"* as statistics prove, but there is "no limit for caring". Skilled palliative care can provide good symptom control to add ―Life to days ". In the forth coming chapters, many of the common symptoms will be addressed by individual authors, each an expert in their own field.

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Chapter 5

Pain Assessment and Management

Chapter 5: Pain Assessment and Management

Cancer pain is a complex pain composed of mixed pathophysiology and complex psychoneuroimmunology. It is said that greater than 70%patients in India present in the advanced stage of the disease and most significant manifestation is pain. More than 80-90% of such patients suffer from pain with 90%pain that can be controlled with simple measures. Pain is often under reported due to multiple psychosocial factors and constraints, under diagnosed due to scarcity in time, resources and expertise and undertreated.

Definition of pain:

Harold Merskey in the year 1964 defined pain as,"an unpleasant sensory and emotional experience associated with actual or potential tissue damage, or described in terms of such damage".

Pathophysiology and characteristics of pain:

Mechanism	Pathophysiology	Example	Quality of pain
Nociceptive pain	activation of the peripheral nerve fibers sensitive to noxious (Nociceptive) stimuli in somatic or visceral structures	Somatic: Bone pain/soft tissue Visceral pain: Liver capsular pain Mesentric stretch Bowel involvement	Sharp, Dull aching, gnawing, occasionally throbbing, localized pain Dull aching, sharp, gnawing, localized pain Diffuse, cramping or colicky pain
Neuropathic pain	Disease or dysfunction of somatosensory system	Brachialplexus neuropathy, Spinal cord compression, Phantom pain, Herpetic neuralgia Chemotherapy induced peripheral neuropathy	Shock like, burning, tinging pain Pain radiates along the distribution of the nerve Burning pain, tingling pain, sharp shooting pain. Paresthesia/dysesthesia, hypoeralgesia and allodynia present
Idiopathic pain Anticipatory pain	pain which is not explained by organic pathology Pain that occurs even before a particular procedure or treatment. This could be influenced by patient's past experience		Anti-anxiety drugs like benzodiazepines, antidepressant or antipsychotics may benefit

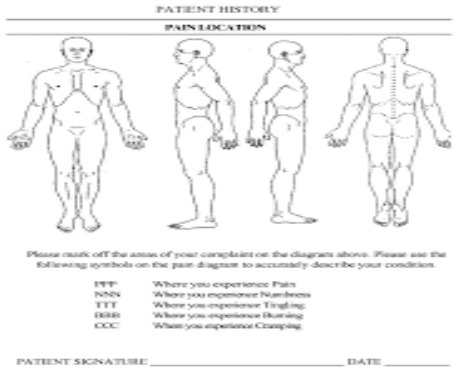
Assessment of pain:

A thorough pain history and shared goal setting are critical components of effective pain management that will lead to beneficial outcomes

Follow the acronym 'OPQRST'

Onset, duration and progress

Site: Patient can complain of pain at multiple sites at one time or different time points of assessment. One must be alert about the manifestation in order to scrupulously manage pain. It will be essential to know the underlying causative factor leading to pain.(for example a 65year old male patients with pancreatic cancer might have pain can have arthritic pain as well)



Severity:

Simple pain assessment tools can be used to assess pain severity.

Pain assessment tool:

Numerical rating scale /Edmonton Symptom Assessment/Visual analogue scale: Both assess score of 0-10

Wong-Baker Faces Scale:

FLACC behavioural scale for pain assessment:

The Face, Legs, Activity, Cry, Consolability scale (FLACC scale) is a measurement used to assess pain for children between the ages of 2 months and 7 years or individuals that are unable to communicate their pain. The scale is scored in a range of 0–10 with 0 representing no pain. The scale has five criteria, which are each assigned a score of 0, 1 or 2.

Criteria	Score 0	Score 1	Score 2
Face	No particular expression or smile	Occasional grimace or frown, withdrawn, uninterested	Frequent to constant quivering chin, clenched jaw
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

The FLACC scale has also been found to be accurate for use with adults in intensive-care units (ICU) who are unable to speak due to intubation. The FLACC scale offered the same evaluation of pain as did the Checklist of Nonverbal Pain Indicators (CNPI) scale which is used in ICUs.

Quality of Pain:

Bone metastasis/soft tissue metastasis	Dull aching boring/nagging pain/gnawing
Pleural/liver capsular stretch	Dull aching boring/nagging pain/gnawing
Disease in the peritoneum	Dull aching pain
Intestinal obstruction/bladder irritation	Colicky abdominal pain or cramping pain
Nerve root/cord involvement	Shock like pain/burning pain/tingling May be associated with paresthesia/allodynia/hyperalgesia

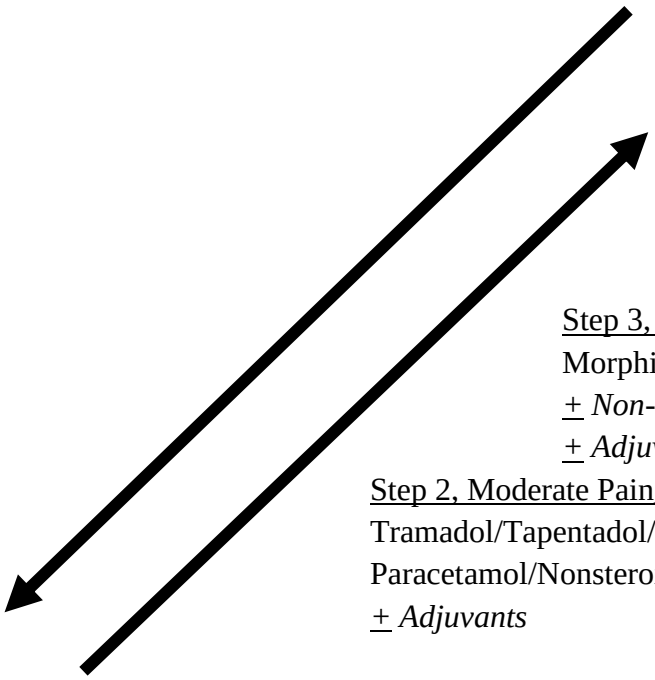
Radiating/Localised
Does the pain radiate? Where?
Does it feel like it travels/moves around?
Did it start elsewhere and is now localized to one spot?
Temporality of pain
When/at what time did the pain start?
How long did it last?
How often does it occur: hourly? daily? weekly? monthly?
Is it sudden or gradual?
What were you doing when you first experienced it?

When do you usually experience it: daytime? Night
Are you ever awakened by it? Does it lead to anything else?
Provocative/Relieving factors:
What makes it better or worse?
What seems to trigger it? Eg. Position? Certain activities?
What relieves it? Medications, massage, heat/cold,changing position, being active, resting?
Associated factors:
Does the pain affect his functional activities like going to the bathroom, walking, eating, restricting his hobbies etc.
Does the pain affect his sleep
Affect family, social, financial and spiritual factors and thus QOL

Examination:
Thorough examination including neurological examination relevant to the problem is important. Also important is to assess the functional abilities, looking for tenderness and associated findings which may aid in diagnosis. Imaging modalities X-ray or MRI could help in confirmation of diagnosis.
Pain Management:
Pharmacological management

Type of pain	Structure involved	Treatment
Nociceptive		
Somatic	Bone pain	NSAID+/- opioid+bisphosphonates
	Soft tissue	NSAID+/- opioids
Visceral		NSAID+/-opioids
	Liver capsular/renal pain/mesenteric	Anticholinergic medications/somatostatin analogue
	Intestinal cramps	
Neuropathic	Neuroma or nerve infiltration Spinal cord compression Herpetic/diabetic neuropathy Complex regional pain syndrome	Anticonvulsants/antidepressants NMDA Blockers Corticosteroids(if cancer) Paracetamol Opioids TENS

For cancer pain management one can adopt the WHO ladder for pain control with some modification. One must keep in mind that the ladder is flexible and decision on the step of the ladder to follow will depend on the pain characteristics and intensity of pain



Step 4 Interventional pain

Step 3, Severe Pain_____
Morphine/ Fentanyl/Methadone
+ *Non-opioid analgesics/*
+ *Adjuvants*

Step 2, Moderate Pain_____
Tramadol/Tapentadol/Codeine
Paracetamol/Nonsteroidal anti-inflammatory drugs (NSAIDs)
+ *Adjuvants*

Step 1, Mild Pain_____
Paracetamol/Nonsteroidal anti-inflammatory drugs (NSAIDs)
+ *Adjuvants*

WHO ladder for pain control

Drugs in the management of Pain

Step 1 (Pain +; Mild pain)				
NSAID	Paracetamol	Adults: 500mg-1gm Children:15mg/kg	Q6h-q4h Q6h	Contraindicated in hepatic failure(especially alcohol induced) Concurrent use with 5HT3blockers may reduce the analgesic effect
	Ibuprofen	Adult: 400mg-800mg Children: 5 – 10 mg/kg	Q8h	C/I:Peptic ulcer disease, thrombocytopenia and severe renal failure and Heart failure Caution: Renal impairment Severe Hepatic impairment*
	Naproxen*	5 mg/kg/day (max, 1gm)	every 12 hours	
	Etoricoxib	Adult: 60-120mg	Q24h-q12h	C/I: heart disease, platelet dysfunction
Step 2 (Pain ++; Moderate pain)				
Weak	Codeine	Adult: 15-60mg 0.5 – 1 mg/kg (max (1m-12y-240mg/day)	Q6h	Caution: Cardiac arrhythmias/acute abdomen Dose modification in liver and renal dysfunction

Opioid	Tramadol	Adult: 50-100mg Children: 1 – 2 mg/kg (max, 400mg/day)	Q6h-q4h	Caution: Raised ICT, epilepsy, Severe renal and hepatic impairment Lowers seizure threshold
Step 3 (Pain +++; Severe pain)				
Strong Opioid	Morphine@	Oral: SC : IV = 3:2:1		Side effect#
		0.2–0.5mg/kg	every 4 hours	Dose adjustment in renal and hepatic failure No major contraindication in palliative care
		<1year: 0.8–0.2 mg/kg	every 4 hours	
		1–2 years: 0.2–0.4mg/kg	every 4 hours	
	Fentanyl	Patch (in micrograms) 12.5 / 25 / 50 / 125 mcg	every 24 hours	Continue morphine(dose equivalent of the patch) for first 8 – 12 hours until which the steady plasma levels of fentanyl is achieved. Apply patch on non- hairy, non-inflamed areas: upper back or chest wall preferred Dose adjustment in liver failure. For breakthrough pain use the dose equivalent of morphine. For example for Patch strength of 12.5mics the dose of oral morphine for breakthrough pain will be 5mg.
		Patch dose calculation: (Cumulative 24-hour dose of oral morphine × 10) divided by 24 e.g., 30mg 24hour dose of oral morphine = 12.5 mcg fentanyl patch. This gives us an idea of the nearest possible dose of the patch to use.		

Note: There is no ceiling dose for morphine/fentanyl. The dose of morphine (escalation or de-escalation) will depend on the pain control achieved and side effects like excessive drowsiness or respiratory depression.The extended release morphine of 10mg/20mg/30mg should be used 12 hourly be sure not to crush or divide the tablet. Regular morphine (for 30mg ER Morphine the dose of plain morphine will be 10mg) should be used for breakthrough pain.

Breakthrough dosing

Transitory flares of pain, called "breakthrough pain," can be expected both at rest and during movement. When such pain lasts for longer than a few minutes, extra doses of analgesics, i.e., breakthrough or rescue doses, will likely provide additional relief. To be effective and to minimize the risk of adverse effects, consider an immediate-release preparation of the same opioid that is in use for routine dosing. When methadone or transdermal fentanyl is used, it is best to use an alternative short-acting opioid, e.g., morphine as the rescue dose.

An extra breakthrough dose can be offered once every 1 hour if administered orally, or possibly less frequently for frail patients, every 30 minutes if administered subcutaneously, or intramuscularly, and every 10 to 15 minutes if administered intravenously. Longer intervals between breakthrough doses only prolong a patient's pain unnecessarily.

Management of Opioid Side Effects#	
Side Effects	Drug of Choice(DOC)

Nausea and Vomiting	1st DOC: Metoclopramide(100mic/kg) and 2nd DOC: Haloperidol (25-85mic/kg over 24hours)$
Constipation	Combination of stimulant and stool softner is a must like Syp. Cremaffin Plus or Syp Laxit Plus (>3years- 10-40mg/day; 3-6years: 20-60mg/day; 6-12years: 40-120mg/day. All can be given in 1-4divided doses)#
Delirium	R/O other medical cause Use neuroleptics like haloperidol or risperidone
Myoclonus	Use benzodiazepine like lorazepam(100mic/kg per dose and repeat the dose as needed) or diazepam (100mic/kg perdose and repeat the dose as needed)
Pruritis	Use alternative opioid and can start on 5HT3 antagonist like Ondansetron
Drowsiness	Methylphenidate can be given
Respiratory Depression	This is an emergency; If RR <10-12/min, patient is cyanosed and non arousable then start Opioid antagonist Naloxone (0.4mg ampoule of naloxone should be diluted in 10ml NS to obtain 40mic/ml solution to be administered every 1-2mins till the respiration picks up. If the RR dose not pick up after 3-4doses we should look for other putative factor.

Adjuvants:

Drug	Dose	Remarks
Dexamethasone	Raised ICT: 8-16mg –early morning Intestinal obstruction: 6-16mg-eary morning Spinal cord compression:16mg-early morning Bone pain(metastasis): 4-6mg early morning	Side effects: Insomnia, Diabetes mellitus, myopathy, infection: candidial, herpes zoster shingles. Cushing's syndrome
Gabapentin	2-8mg/kg/dose q6h Adult: 50mg-100mg TDS to maximum dose of 3600mg/day Children: 50mg -400mg/day Increase the dose every 3days	Drowsiness and dizziness Nystagmus, sedation, tremor, ataxia, swelling
Pregabalin	Adult: 75mg-600mg/day Children: 1 mg/kg/dose (max 300mg/day) Increase the dose every 3days	
Amitriptyline	0.2mg/kg qhs increase every 3days 10mg-150mg	Antimuscarinic effects, sedation, delirium, hyponataemia C/I: recent MI, arrhythmias, mania, severe hepatic impairment

Non pharmacological:

The commonly employed autonomic blocks

Sr.No	Type of block	Common indications
1	Stellate ganglion block	Phantom limb pain, causalgia Cancer breast, Reflex sympathetic Dystrophy
2	Coeliac ganglion block	Cancer upper abdominal structures like Stomach, gall bladder, pancreas, liver .

3	Sup. Hypogastric block	Pelvic and genito-urinary malignancies
4	Lumbar sympathetic Block	Lower extremity malignancies, Perineal and pelvic malignancies

Other techniques include: hypnosis, relaxation and meditation, Transcutaneous electrical nerve stimulation, acupuncture.

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Chapter 6

Palliation of Gastrointestinal Symptoms

Chapter 6: Palliation of Gastrointestinal Symptoms

Introduction

Gastrointestinal symptoms are the most distressing problems for both the patient and the care takers. However theses are often neglected. Majority of them can by controlled if recognized and treated early. Malnutrition and cachexia worsen if GI symptoms are neglected.

Oral problems

Oral health is an important contributor to the health and well-being of patients and elderly. Recent associations between oral health and systemic disease have led to renewed interest in oral health and its contribution to health outcomes. Part of this success relies on a valid and reliable oral health assessment tool**.** A healthy mouth has an intact mucosa, which is clean moist and pain free. Terminally ill are usually reluctant about mouth care and hygiene. Dry mouth, dry lips, oral mucositis and oral candidiasis are the commonest problems in palliative care setting. Contributing factors include general debility, reduced immunity, poor oral intake, treatments like chemotherapy and radiation**.**

Problem	Etiology	Solution
Xerostomia	Medications(anticholinergics, sympatholytics-clonidine), opioids Radiation to Head and Neck Medical comorbidities such as HIV/AIDS, diabetes, renal failure, and Sjögren's syndrome. Psychiatric comorbidities such as mood and anxiety disorders. Dehydration from any cause including drug-induced.	Address the problem and treat it. Encourage oral fluids Salivary stimulant: sugarless gums and candies(vitamin C will reduce viscosity) Cholinergic drug: Pilocarpine 5-10mg TDS(C/I in asthmatic patients) Topical products containing olive oil, betaine, and xylitol Certain enzyme preparations such as lactoperoxidase, lysozyme, and glucose oxidase offer potential antimicrobial and moisturizing benefits.
Oral mucositis	Radiation, chemotherapy, candidial infection, herpetic infection	Treatment of infection: Prophylactic use of antifungal, antibacterial or antiviral medications does not decrease the incidence of mucositis. Pain Management: Local anesthetics such as bupivacaine Liquid oral or parenteral opioids may be required for adequate pain management

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Nausea and Vomiting

Nausea is a highly prevalent symptom in the palliative care setting. The prevalence of nausea is 20-30% in all patients with advanced cancer and increases to 70% in the last week of life. Approximately 20% of patients develop vomiting. The etiology of nausea and vomiting are often multifactorial, making it a challenging problem to manage. Nausea and vomiting are most common in advanced gynaecological cancers and gastric cancer. Thus, identification and treatment of other reversible contributing factors is the major key to management.

Pathophysiology of Nausea and vomiting

Area involved	**Receptor**	**First choice**	**Second choice**	**Third choice**
Vestibular	Muscarinic-Ach-M Histaminic H1	Cyclizine	Levomepromazine or olanzapine	Hyoscine butylbromide or prochlorperazine
Chemical (e.g., opioids, antibiotics, chemotherapy) **Metabolic** (e.g., hypercalcaemia, uraemia	Dopaminergic- D2 Serotonin 5HT-3	Haloperidol	Levomepromazine or olanzapine	5HT3 antagonist
Visceral Partial Bowel obstruction/ Gastric stasis	Cholinergic-M Histaminic –H1 Serotonin 5HT-2	Metoclopramide* Cyclizine#	Levomepromazine or olanzapine	Octreotide#
Cranial (e.g., raised intracranial tension, meningeal causes)	Histaminic (H1) Cholinergic-M Histaminic –H1 Serotonin 5HT-2	Cyclizine	Haloperidol	Levomepromazine or olanzapine

***Partial intestinal obstruction**
#Complete Obstruction
@intestinal obstruction has been dealt with separately

Note:

Phenergan is useful for vertigo and emesis due to infection and inflammation.
Prochlorperazine (phenothaizine) has weak (+) broad action on D2, muscarinic and H1receptors bit is not recommended due to alpha antagonist action causing hypotension
Dexamethasone is useful adjunct since it has antiemetic properties and it enhances the properties of other drugs.
Another useful third line antiemetic is methotrimeprazine(not available in India) or olanzapine(available in India) – it has actions on numerous receptors however research has proven less side effects with olanzapine as compares to methotrimeperazine;
There is no good evidence supporting the use of lorazepam as a sole agent for nausea except in anticipatory nausea and vomiting.

Neurokinin 1 receptor are widely distributed in the brain and its blockers- aprepitant has been used for cisplatin induced emesis, but its role in palliative care setting is yet to be explored.

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Constipation

Constipation due to multitude of factors can be a distressing symptoms for both patients and caregivers. In a palliative care patient, who has a metastatic disease on polypharmacy can have constipation. Constipation is defined as unsatisfactory defecation with infrequent stool (less than 3 /week) and difficulty in stool passage (Rome II criteria).
As with other symptoms, rational therapy should be based on a sound understanding of underlying physiology.

Solid waste	Bowel can clear the solid waste if fibres are added
Water content	This depends on the hydration status, secretions from the intestine and absorption of fluids from the GI tract. Hyperosmolar drugs like lactulose may help; be cautious it can worsen dehydration. PEG is safe.
Motility	Bowel movements are important for evacuation. In patients who are bed bound, have neurologic deficit or on opioids can have sluggish bowel movements. In this case prokinetics/ Senna/ sodium piscosulphate that stimulate the myentric plexus can be started either as a prophylactic or therapeutic medications.
Lubrication	Some agent that can grease the mucosal surface to allow easy passage of stools. Commonly used drug dioctyl sodium sulfosuccinate daily as BD or TDS dose.

Causes of constipation:

1. **Primary**: reduced fibre, fluid, mobility and privacy for evacuation
2. **Secondary**: structural causes such as tumor, neural infiltration of tumor, electrolytes (hypocalcemia, hypokalemia), endocrine – hypothyroidism and diabetes mellitus, neurological, pain, para-neoplastic syndrome
3. Medications that can cause/exacerbate constipation:
a. Opioids, morphine, codeine (95% of patients taking opiods)
b. Anticholinergics: Belladona, loperamide, tricyclic antidepressants, antispasmodics, scopolamine, oxybutinin, promethazine, diphenhydramine
c. Sympathomimetic: Ephedrine, terbutaline
d. Others: lithium, verapamil, bismuth, iron, aluminum (antacids) calcium salts - Calcium Carbonate, Barium Sulfate (xray), diuretics, ferrous sulphate, , antacids, 5HT3 Antagonist, Vinca Alkaloids, NSAID like Ibuprofen

Presentation:
1. Decreased stool frequency or volume, hard stools
2. Overflow diarrhea may present if liquified stool leaks past impacted feces
3. Symptoms of abdominal pain, nausea, vomiting, anorexia, restlessness, urinary retention or anxiety may occur

Diagnosis:
1. Requires high index of suspicion. Do not assume a patient is free from constipation because he/she has been hospitalized, on laxatives, or having occasional bowel movements.
2. History, abdominal exam (limited use), ***digital rectal exam*** to assess for retained stool or fecal impaction
3. Constipation Score: The constipation score is one such tool. Plain x-ray abdomen is often helpful to check for retained feces. A plain, supine x-ray of the abdomen is taken and image evaluated by dividing into four quadrants. The four quadrants being representative of the ascending, traverse, descending and recto-sigmoid colon segments respectively. Each quadrant is assessed for the amount of stool present and is scored from 0 to 3; score 0 being the absence of stool, while score 3 being complete stool impaction. The scores for each quadrant are totaled. Xray can be scored for stool presence, from none (=0/12) to complete (=12/12) filling of colon. A score of 7 or more indicates a more aggressive constipation management is necessary.

Prevention of constipation: Simple measures, which should be incorporated as part of the routine palliative care plan in all patients.

- Eating regular meals and making use of gastrocolic reflex.
- Check the patients perception of their bowel functions.
- Establish what is ―normal‖: Be mindful of bowel routine and comfort. Assess patient level of discomfort relating constipation and its management. The aim of treatment is comfortable defecation, and not increased stool frequency.
- Prophylaxis is better than treatment. Therapy should be regular and not intermittent, similar to the treatment of chronic pain. Always add a stimulant laxative with opioid prescription.
- Mobility: Activity is the key stimulus to colonic peristalsis and defecation. Mobility should encouraged as much as physical limitations permit.
- Regular toileting: keep a record of stool frequency.
- Maintain adequate oral fluid and fibre intake. Fibres must be avoided in severe constipation as it can precipitate colic.
- Provide privacy for going to the toilet, and maintain the same even if a bedpan is used.

- If after starting laxative patient develops loose stool once or twice a day, continue laxative at a lower dose than prescribed. If patient passed large volume water stool more than 4times a day, stop the laxative till still stool normalises, give ORS in the interim period.
- Even after regular laxative use, 40 to 60% of terminally ill patients need additional rectal evacuation measures on a continuing basis.

Step care management approach
Rectum empty: Exclude 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 faecal mass, for example, glycerine suppositories, olive, or arachis oil enema. It still may be necessary to perform a manual rectal evacuation, for which sedation or additional analgesia is often required. Alternatively, saline rectal lavage can be given.
- If the rectum is loaded with soft faeces: A predominantly peristalsis-stimulating laxative, for example, senna may be effective alone. Bisacodyl 10-20mg BID may be added.
- If there is little or no stool in the rectum, a peristalsis-stimulating laxative is the drug of choice, for example, senna, but the stools are likely to be hard and 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.
- Peripheral opioid receptor stimulation due to endogenous (ie. endophins) or exogenous (ie. morphine) stimulants may result in negative adverse effects, including constipation and pruritus. Methylnaltrexone (presently not available in India)subcutaneously, a peripherally acting opioid antagonist, offers the advantage of peripheral action only and thus not reversing analgesia in treatment of opioid –induced constipation in patients with advanced illness.

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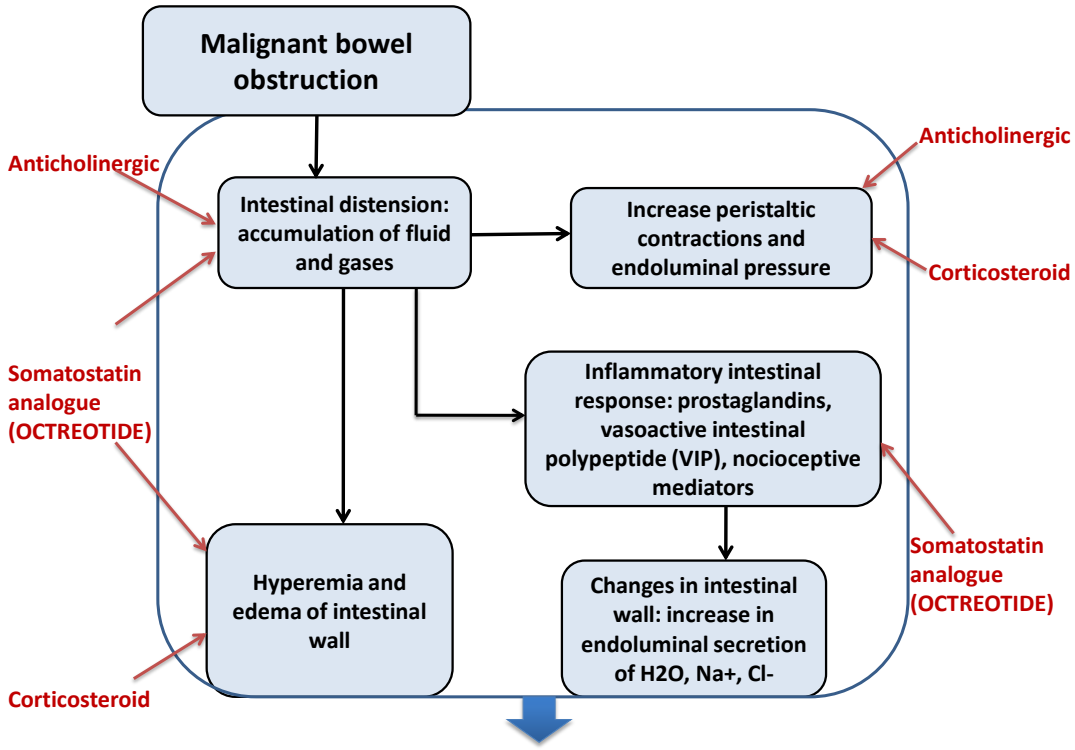
Medical Management of Intestinal obstruction

Gastrointestinal obstruction is a well-recognized complication and a complex problem in advanced gynecological and gastrointestinal cancer. Ovarian Ca.: 5-51%; Primary intestinal malignancy: 10-28%; Palliative medicine: 3-15%. The obstruction could be intraluminal(tumor protruding into the lumen of the bowel), intra mural(linitus plastic) or extraluminal(peritoneal/omental disease, adhesions etc.).

Pathophysiology:



Clinical features and management of obstruction

Supporting investigation:
Blood test for dyselectrolytemia(hypokalemia/hypocalcemia), sepsis, hypoglycaemia
Xray abdomen(supine and erect)
CECT abdomen (to identify level and number of levels of obstruction- for assessing the feasibility of surgical corrections)

Level of obstruction	**Sequence of symptoms**	**Approach**
Esophagus	Progressive dysphagia	Endoscopic stenting(SEMS)
Stomach	Abdominal boating/distension Stretching pain Vomiting(partially digested food) Constipation	**Gastric paresis:** Prokinetic agent(metoclopramide) **Gastric outlet obstruction** Steroid(Dexamethasone) Endoscopic stenting(SEMS)
Deodenal	Abdominal boating/distension Stretching pain Vomiting(partially digested food) Constipation	Steroid(Dexamethasone) Upto second part of duodenum: SEMS Beyond: Feeding jejunostomy(if no peritoneal disease) Or Naso-jejunal tube
Jejunal and ileal	Abdominal colic/cramps Vomiting(bilious) Constipation	**Medical Management:** Steroid(Dexamethasone) Metoclopramide(partial obstruction)/complete obstruction(Olanzapine mouth dissolving

		orondansetron/ octreotide) Hyoscine butylbromide(colic) If **single level of obstruction**: Surgical correction(resection and anastomosis; diversion ileostomy or colostomy If **multiple levels of obstruction**(extensive peritoneal or omental disease) Continue medical management
Lower GI obstruction	Constipation Abdominal colic/cramps Vomiting(occasionally feculent)	Medical Management to control symptoms Intractable vomiting and complete obstruction- octreotide Rectal or sigmoid colon block- SEMS

Diarrhea:
Diarrhea has been defined as the passage of more than three unformed stools within a 24-h period. Patients with uncontrolled diarrhea are at increased risk for dehydration, electrolyte imbalance, skin breakdown, and fatigue.
Diarrhoea is an uncommon problem in palliative care setting.

Causes: Diarrhea can usually be divided into different types and treatment will vary depending on cause: secretory, osmotic, mechanical, or disordered motility. Common causes in palliative care include:
1. Overuse of laxatives, typically seen when the management of constipation is suddenlystepped up
2. Severe (often a neglected) constipation and fecal impaction can also cause diarrhea as backed- up, liquefied stool may be all that the patient can pass (_overflow diarrhea‘).
3. Partial intestinal obstruction
4. Pancreatic insufficiency
5. Clostridium difficile infection
6. Chemotherapy and radiation enteritis.
7. Infective Diarrhoea- particularly candidiasis in debilitated and immunocompromised hosts
8. Contaminated or hyperosmolar feeds neglected constipation or partial bowel obstruction. Less common causes include infectious diarrhea due to, candidiasis and immunosuppressed host
9. Blind loops in patients undergone bowel surgery, radiation strictures

Approach and Evaluation:
Is the patient dehydrated?
Oral rehydration solution should be administered orally or through nasogastric feed. Intravenous hydration using ringer lactate should be administered if severe dehydration is present. If dehydration is moderate to severe, use 2-3 liters in the first 2-3 hours and 6-8 liters over next 24 hours or as long as the losses continue.
Is diarrhoea intermittent?
Exclude spurious diarrhea due to neglected constipation or partial bowel obstruction, irritable colon, anxiety and fear. Check nasogastric feeding – exclude high osmotic load in the feed, increase the feeding time and dilute the feeds and rule out any feed contamination. Exclude Gastric dumping in patients who have undergone total or subtotal gastrectomies. Exclude infection: Is there any focus of candidal infection such as poor oral hygiene and immnusuppression**?**
Has there been a previous surgery?
Post gastrectomy dumping syndrome: give small frequent meals, if severe consider Octreotide. Ileal resection leads to bile salt malabsorption: treatment includes cholestyramine 12-16 gms daily plus ranitidine. Blind loop syndromes lead to bacterial overgrowth: treated with tetracycline or metronidazole for 2-4 weeks and repeat with each episode.

Is stool mixed with blood or discharge?
Fungating rectal or colonic tumors: metronidazole 400mg 8-12 hourly or sucralfate paste PR for bleeding. Consider palliative radiotherapy for bleeding rectal tumors. Exclude infections and inflammation (NSAIDS, radiotherapy).
Is there history of long-standing constipation or bowel obstruction?
Examine the abdomen and rectum for any fecal impaction?
Was there a recent increase in laxative dose?
Check medication for those causing both diarrhoea and constipation
Are there any bowel strictures leading to bacterial overgrowth- radiation enteritis?
Treatment :
Ensure adequate hydration: encourage sips of clear liquids; parenteral hydration should be considered for severe dehydration.
Diet: Simple carbohydrates, toast or crackers, will add small amounts of electrolytes and glucose; milk and other lactose-containing products should be avoided.
Medications include bulk forming agents, antimicrobials, adsorbents, and opioids. Kaolin and Pectin (Kaopectate®) is a suspension of adsorbent and bulk-forming agents, which can provide modest relief from diarrhea. However, kaolin-pectin may take up to 48 hours to produce an effect and can interfere with the absorption of certain medications. Antibiotics: infectious diarrhea should be identified and treated with appropriate antibiotics, particularly C. difficile enteritis.
Aspirin and Cholestyramine can reduce the diarrhea in radiation-induced enteritis, as can addition of a stool bulking agent such as psyllium.
Pancreatic Enzymes such as pancrelipase are used for pancreatic insufficiency.

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Fatigue and Asthenia :
Definition:
1. Easy tiring and reduced capacity to maintain performance.
2. Generalised weakness, defined as the anticipatory senation of difficulty in initiating a certain activity
3. Mental Fatigue, defined as the presence of impaired mental concentration, loss of memory and emotional lability.

Multiple **factors** interact with each other and contribute to fatigue:
1. Direct Effects: Lipolytic factors, tumor degradation factors, proteolytic factors, invasion of brain or pituitary gland by tumor
2. Induce Host Factors: IL1, IL6, TNF
3. Accompanying Factors: psychological issues, anemia, cacnexia, infection, metabolic disorders, endocrine disorders, paraneoplastic syndrome.
Management:
Non Pharmacological Management: counseling, physiotherapy, occupational therapy.

Pharmacological Management:
1. Corticosteroids
2. Megesterol acetate
3. other management as described in cachexia
4. Psychostimulants: Methylphenidate and Modafanil are known to promote a sense of well being, reduce fatidue and alleviate depression. Methylphenidate is also known to reverse opioid induced fatigue and sedation.

Specific Measures:
1. Correction of Anemia: Blood Transfusion
2. Midodrine, specific alpha 1 sympathomimetic agent can be used autonomic failure in diabetic and neurological disorder.
3. Counselling and antidepressants for treating major depression
4. Correction of metabolic disorders like hyponatremia, hypercalcemia, hypokalemia, hypoxia, dehydration.
5. Treatment of endocrine abnormality like Addisons disease, hypothyroidism, hypogonadism.

Suggested Reading:
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Cachexia Anorexia syndrome

Introduction:

With advancing disease, the body loses its reserve of carbohydrates, proteins and fat. The body fat and muscles are utilised for metabolism leading to weight loss. As a result there is appetite loss leading to a vicious cycle of weight loss and anorexia.

Mechanism:

The anorexia/cachexia syndrome is a rather complex and multisystem syndrome that requires attention to various factors when being assessed and diagnosed. Anorexia is a multifactorial process and the exact cause and mechanism remains unknown. It is speculated pro-inflammatory cytokine – IL-8, TNF play a role. Treatment revolves around dietary alteration and taking care of personal food preferences the form snacks and drinks.

Contributing factors to Poor intake:

Gastrointestinal: dry or sore mouths, oral thrush, poor dentition, altered taste, early satiety, nausea
Tumor relate: paraneoplastic syndromes, peptides produced by tumors
Treatment related: drug induced, post CT, post RT
Physical: pain, infection, anxiety, depression
Environmental: unpleasantly cooked food, forced bland diets, unclean linen and poor hygiene

Evaluation of Anorexia:

Traditionally the Functional Assessment of Anorexia and Cachexia Therapy, shortened 12 question version (A/CS12) is used for evaluation. It identifies anorexia/cachexia and also predicts survivial. A new simple two-item single point evaluation questionnaire has been also compared to A/CS12. This is convenient for both clinicians as well as patients to screen for symptoms. It was compared with respect to

reliability at one point in time, sensitivity to change over time, and prognostic accuracy. Agreement at one point in time was 0.64 (95% confidence
interval [CI] 0.63 – 0.66), however this simplified questionnaire failed to predict survival.

Approach and management of contributing factors:

1. A clear history and careful examination is essential to identify and treat reversible contributing factors like pain, anemia, infection, constipation, nausea and vomiting.
   How long has appetite been suppressed? Sudden or progressive?
   What factors improve or worsen anorexia?
   Does the patient have dysphagia?
   Has there been any weight loss? What is the time frame for weight loss? Is there distortion of smells/tastes?
2. Depression is often overlooked in patients with advanced cancer. A triad of fatigue, poor appetite and disturbed sleep is present in majority of patients. We need to additional assess if the patient will benefit from antidepressant therapy. Treatment of depression improves appetite, motivation and strength.
3. Review all drug history carefully and consider stopping or reducing drugs which contribute to weakness e.g. oral hypoglycemics, diuretics, steroids, and drugs which induce nausea vomiting or constipation
4. Assess oral cavity—mucous membranes, teeth, gingiva, lips - consider treatment for oral candidiasis and mucositis. Regular mouth care routine including mouth washes, daily brushing of teeth and gums, treatment of oral candida, change of ill-fitting dentures.
5. Patients often have altered taste due to the disease as well as medications andchemotherapy or radiation. Discuss the patient‘s preference regarding nutrition and hydration. Identifying foods which the patient enjoys is an integral part of managing anorexia.
6. Prepare soft easily chewable foods and feed in sitting up position or at the table rather than in semi-recumbent position. In patients with dysphagia due to head neck cancers or bulbar palsy, simple and economic tube feed plans which can be easily managed by the care takers and still provides adequate calories is useful in preventing distress symptoms of hunger and premature death from malnutrition and starvation.
7. Assess nutritional status (albumin, protein). There are conflicting views of the benefits of forced nutrition therapy in the palliative setting. Aggressive nutrition intervention is definitely not recommended as it failed to show any improve survival, quality of life or anorexia. Minimal calorie and protein requirement plan enough to sustain hunger, satiety and maintain health suffices. Percutaneous endoscopic gastrostomy tubes and nasogastric feeds are generally may be used. However parenteral or forced and expensive enteral nutrition therapy should be discouraged in cachectic and terminally ill patients. These patients are unable to utilize these calories and therefore it does not improve weight gain or functional capacity and quality of life.
8. Educate patient and family and explain that illness decreases appetite via chemicals and toxins.Allay family fears/anxiety regarding the patient “starving.” If the anorexia and cachexia are too distressing for patient and family, consider pharmacological measures. The family should be educated regarding treatment options, benefits, and anticipated effects.

Drug therapy of Anorexia: The syndrome continues to be a common problem for which there are limited and uncertain treatment options 3,4.

Drugs with unknown or controversial benefit:

Corticosteroids are perceived to improve appetite and sense of well-being in patients with advanced cancer. A trial of corticosteroids has been attempted. Effective doses vary. Starting dose is usually with prednisone 2 mg po QD. Titrate up by 2-5 mg at weekly intervals if needed. It may induce increased

appetite but effects are short-lived. May increase weight but not muscle mass. Whenever used they have been administered for short term and discontinued within 4-6 weeks, before major side effects develop.

Drugs with documented benefit in management of anorexia:

High-dose progestins:

A systematic review of 15 of randomised clinical trials (more than 2000 patients) has shown a statistically significant advantage for the high-dose progestins as regards improved appetite: pooled odds ratio (OR) = 4.23, (95% confidence interval (CI): 2.53-7.04) 9. Although the effect of high-dose progestins on body weight was less impressive, statistical significance was also reached for this outcome: pooled OR = 2.66, (95% CI: 1.80-3.92). Treatment morbidity was low, due to the brief period of the treatment in most of the studies. Although, effects of high-dose progestins on appetite and body weight were clearly demonstrated, further studies are undoubtedly warranted to investigate other aspects of progestin activity, especially as regards dosage, duration and timing with best therapeutic index. Progestins remain the therapy of choice for anorexia in cancer patients who have an expected survival of months. However, these agents do not reverse the cachectic process, and many patients who take them do not experience symptomatic benefit. Therefore, novel approaches that target the complex pathophysiology of this syndrome are needed.

Megastrol acetate: Has been found to increase appetite, food intake, and weight in randomized, placebo-controlled trials in patients with advanced malignancies and with AIDS 10. There is no impact or mortality. Optimal dose is unknown. Generally, 80-160 mg po QID is used. Also available in elixir 800 mg/20cc. Maximum daily dose is 800 mg. 400-800 mg QID has shown improved response over 100 mg QD. A randomized trial comparing oral megestrol acetate 800 mg/d liquid suspension plus placebo to oral dronabinol 2.5 mg twice a day plus placebo, or both agents showed megestrol acetate provided superior anorexia palliation among advanced cancer patients compared with dronabinol alone 11. Combination therapy did not appear to confer additional benefits.

Others include:Ondasetron,etanercept.

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Hiccoughs

Introduction:
Hiccups are a distressing symptom for both patients and families. A single episode can last for a few seconds to as long as several days. If they last longer than 48 hours hiccups are termed persistent; longer than one month, intractable. When chronic and intractable they diminish quality of life.

Pathophysiology:
A hiccup is an pathological involuntary respiratory reflex involving the respiratory muscles of the chest and diaphragm, mediated by the phrenic and vagus nerves and a central (brainstem) reflex center. It is characterized by spasm of one or both sides of the diaphragm, resulting in sudden inspiration and closure of the glottis. Accessory muscles of respiration (anterior scalene, intercostal, abdominal) are occasionally involved.

Etiology:
Stress/excitement due to cancer
Esophageal or gastric distension
Irritation of the vagus nerve or diaphragm
Intra-abdominal tumors
Ascites
Hepatomegaly and stretch of liver capsule
Liver failure, uremia, Sepsis
Extensive infiltration
IV steroids
CNS lesions
Idiopathic

Management
Once hiccups have lasted beyond a time-limited annoyance, deciding on therapeutic intervention should be based on a thorough clinical assessment and, if possible, treatment directed at the underlying cause.
A thorough history, review of medications, focused review of systems, and physical exam may help guide initial choice of treatment.
Many drug and non-drug treatments have been used, but there is little evidence of any one superior approach to management; virtually all current treatment data are anecdotal.
The patient‘s prognosis, current level of function, and potential adverse effects from any proposed treatment should be considered. Effective treatment should be directed first to alleviation of underlying cause.
Step1: Treatment of underlying cause:
If gastric distension is suspected, a 2-d trial of a defoaming antiflatulent (e.g. silica activated dimethicone/simethicone) before or after meals and at bedtime should be considered. Add a prokinetic drug (metoclopramide, domperidone) if needed. Relieve neglected constipation and consider adequate re-hydration
Step 2: Pharmacologic Therapy

Anti-Psychotics: Chlorpromazine is the only FDA approved drug for intractable hiccups. Dose: 25-50 mg PO TID or QID. Can also be given by slow IV infusion (25-50 mg in 500-1000 ml of NS over several hours). Haloperidol is a useful alternative to chlorpromazine, given in dose of 2-5 mg (SubQ/PO) loading dose followed by 1-4 mg PO TID.

Anti-Convulsants: Gabapentin at doses of 300-400 TID has been described as effective in multiple case reports. Phenytoin is reported to be effective in patients with a CNS etiology of their hiccups. It is used in a dose of 200 mg slow IV push followed by 300 mg PO daily. Other agents like valproic acid and carbamazepine have also been reported to work in selectd patients.

Miscellaneous:

1. Baclofen is the only drug studied in a double blind randomized controlled study for treatment of hiccups. 5 mg PO q8 hours did not eliminate hiccups but did provide symptomatic relief like reduced frequency in some patients.
2. Metoclopramide as 10 mg PO QID is an option, especially if stomach distension is the etiology.
3. Nifedipine in a dose of 10 mg BID with gradual increase up to 20 mg TID has been suggested as a relatively safe alternative if other interventions have failed.
4. Other drugs that have been tried with very limited success include: amitriptyline, sertraline, inhaled lidocaine, ketamine, edrophonium, and amantidine.

Step 3: Non-Pharmacologic Therapy

There are many well known, time-honored home remedies: gargling with water, biting a lemon, swallowing sugar, or producing a fright response. Other approaches are directed at

Vagal stimulation such as carotid massage or valsalva maneuver

Interruption of phrenic nerve transmission via rubbing over the 5th cervical vertebrae

Interrupting the respiratory cycle through sneezing, coughing, breath holding, hyperventilation, or breathing into a paper bag.

Other interventions such as acupuncture, diaphragmatic pacing electrodes, or surgical ablation of the reflex arc are anectodal measures when other treatments fail.

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Malignant Ascites:

Introduction:

Approximately 6% of patients in the palliative care clinic require active management for malignant ascites.

Etiology of ascites in cancer patients:

Malignant ascites is the accumulation of abdominal fluid due to the direct effects of cancer. Ten percent of all causes of ascites is due to malignancy. In 50% of patients with malignancies, ascites develops secondary to invasion of the parietal or visceral peritoneum and 15% due to liver invasion and portal venous compression, 15% are a combination of the first two, and the remaining 20% are attributed to chylous ascites secondary to lymphatic invasion.

Presentation and Diagnostic evaluation:

Symptoms include abdominal fullness/pain, early satiety, nausea, vomiting, and respiratory distress(look for concomitant pleural effusion), lower extremity edema, weight gain, and reduced mobility. Vomiting can occur secondary to the fluid causing external gastric or bowel compression and obstruction may occur. Ascites is often diagnosed by physical exam findings may include abdominal distention, bulging flanks, shifting dullness, and a fluid wave.

Plain abdominal x-rays are not specific, but may show a hazy or a ―ground glass appearance.

Ultrasound or CT scanning can confirm the presence of ascites and also demonstrate if the fluid is loculated in discrete areas of the peritoneal cavity.

Additional Investigation to confirm etiology and classify ascites:

Classification

The old classification of exudative versus transudative ascites has been updated through the use of the serum-ascites albumin gradient (SAAG).

SAAG = (the serum albumin concentration) – (ascitic fluid albumin concentration). A SAAG > 1.1 g/dl indicates ascites due to, at least in part, increased portal pressures, with an accuracy of 97%. This is most commonly seen in patients with cirrhosis, hepatic congestion, CHF, or portal vein thrombosis. A SAAG < 1.1 g/dl indicates no portal hypertension, with an accuracy of 97%; most commonly seen in peritoneal carcinomatosis, an infectious process of the

peritoneum, nephrotic syndrome, or malnutrition/hypoalbuminemia. Fifteen percent of cirrhotic patients have low SAAG ascites, however, and 20% of oncology patients have high SAAG ascites. Depending on the clinical presentation and expected survival, a diagnostic evaluation is usually indicated as it will impact both prognosis and treatment approach. Key tests include the serum albumin and protein level and a simultaneous diagnostic paracentesis, checking ascitic fluid white blood cell count, albumin, protein, and cytology. Cytological evaluation is approximately 97% sensitive in cases of peritoneal carcinomatosis, but is negative for malignant cells in other types of malignant ascites due to massive hepatic metastasis or malignant obstruction of lymph vessels. Oncology patients who have comorbidities of cirrhosis, liver invasion by tumor, congestive heart failure, or cardiac compromise secondary to chemotherapy need further evaluation of ascites to help differentiate the cause because medical management may be appropriate.

Medical Management:

In cancer, ascites is usually mixed form(transudative and exudative), medical management with escalating doses of Tablet furosemide(40mg-240mg) and spironolactone(100mg to 400mg) is controversial.

Procedures:

Abdominal paracentesis: Lethal hypotensive episodes after paracentesis typically do not occur in oncology patients because of the different physiologic mechanism of ascites accumulation. Large-volume paracentesis of 5 L/d is recommended as safe if necessary for patient comfort3 . Drainage of large-volume ascites can be accomplished without ultrasound guidance in an outpatient or office setting. Rare complications that may occur include infection, bowel perforation, and hemorrhage. Paracentesis offers the advantages of a quick, simple, low risk procedure with immediate symptom relief. Bleeding disorders and matted bowel loops are contraindications.

Pigtail insertion: For management of ascites, catheters typically are placed under ultrasound or fluoroscopic guidance. This can be done as an outpatient procedure or during hospital admission. After placement, the catheters can be capped and drained intermittently via gravity drainage bag or vacuum bottles. Alternatively, they can be attached immediately to gravity drainage bags for continuous drainage. Complications of pigtail catheter management for ascites occur in 35% of patients and include peritonitis, accidental removal, leakage around the drain, and catheter occlusion.

Tunneled Catheter Placement: Tunneled catheters have been used for vascular dialysis, apheresis, and peritoneal dialysis for many years. The catheters have Dacron cuffs that reside in the subcuticular tunnel. The uffs that reside in the subcuticular tunnel. The tissues heal and scar around the cuff, preventing a

conduit for bacterial growth along the catheter. The catheters are designed to have one, two, or three cuffs. The third cuff is located near the tunnel exit site and impregnated with an antimicrobial agent.

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Chapter 7

Palliation of Respiratory Symptoms

Chapter 7: Palliation of Respiratory symptoms

Introduction :

Palliation of respiratory symptom forms a small part of the whole field of palliative medicine but it surprisingly embraces a wide area of clinical practice. This is because the respiratory symptoms are more common and tend to become more important especially in the terminal phase of life. They are one of the poorly understood areas of palliative medical practice which raises the possibility of irrational, unhelpful and occasionally harmful interventions. This chapter will run through some of the complexities of respiratory symptoms which will help the reader to better comprehend and effectively palliate these symptoms.

Structure and Function of Respiratory system1

Airway:

Maintenance of patency of the airway is the most vital homeostatic mechanism in the body. Any obstruction to the airway due to mucus, tumor, foreign body or airway narrowing can lead to significant physical and psychological distress.

The presence of cilia along the bronchus acts to expel the foreign body from the airway. These are under the control of the cholinergic system. The bronchial smooth muscles which also react to irritants are both under the influence of the cholinergic and adrenergic system.

Control of Respiration:

Neural Mechanism

Lung parenchymal receptors: Juxtapulmonary capillary receptors (J receptors) present at the junction of the capillary and alveoli, is sensitive to rise in the pulmonary vascular pressure due to congestion secondary to microemboli or pulmonary edema. They are responsible for rapid shallow breathing. This is thought to act through the central mechanism via the cholinergic system.

Respiratory muscles: Role of skeletal and diaphragmatic muscles has been increasingly researched and known to influence respiratory drive.

Chemical Mechanism

Peripheral chemical receptors:

These include the aortic body (along the arch of aorta) and carotid body (at the bifurcation of the carotid artery). These are innervated by the IX and X cranial nerve which enter the brain at the medulla near the site of the central chemoreceptor. These are sensitive to fall in the oxygen level in the blood leading to hyperventilation.2

Central chemical receptors:

This includes the _respiratory centre‘ in the medulla oblongata of the brain. This is highly sensitive to acidic pH. Due to mechanisms that lead to retention of CO2, lead to rise in the pCO2 levels in the blood that in turn leads to fall in the pH of the blood. This leads to hyperventilation which eventually will lead to CO2 wash out (hypercapnic drive to ventilation). Either endogenous or exogenous opioids are known to attenuate the hypercapnic drive to ventilation, that is they render the medullary centre less sensitive to rising pCO2 levels.3,4,5

Dyspnoea

Dyspnea is a subjective experience of breathing discomfort that consists of qualitatively distinct sensation that vary in intensity. (American Thoracic Society).

Causes of Respiratory Distress: [6]

Anatomical Site	Pathological Change	Symptoms
Pulmonary	Tracheal Tumor Lung collapse Tracheo esophageal fistula Consolidation Fibrosis Lymphangitis carcinomatosis Pulmonary embolism	Dyspnoea, stridor,cough Dyspnoea, cough Cough, Hemoptysis Dyspnoea, cough, pleurisy Dyspnoea, cough Dyspnoea, cough Dyspnoea, cough, pain
Cardiac	Ischemic heart disease Cardiac failure Pericardial disease Superior Vena Cava syndrome	Pain, dyspnoea Dyspnoea, hemoptysis Dyspnoea Dyspnoea
Pleural	Effusion Tumor Pneumothorax	Dyspnoea Pain, pleurisy Dyspnoea, pain
Thoracic cage	Chest wall tumor Carcinoma en curaisse Diaphragmatic tumor Respiratory Muscle fatigue	Pain Dyspnoea, pain Dyspnoea, pain, hiccups Dyspnoea

Investigation of Dyspnoea:

The ‗gold standard' for diagnosis of dyspnea is patient self-report. There are no other reliable, objective measures of dyspnea. Respiratory rate, oxygen saturation, and arterial blood gas determinations do not correlate with, nor measure dyspnea. The severity scales developed for pain (numerical, visual analogue scale) have been reliably used to assess dyspnea. In addition to taking a history appropriate for the patient's situation, a physical examination may provide confirmatory information. Objective signs may include areas of pulmonary dullness, crackles, inability to clear secretions, stridor, bronchospasm (wheezing), cyanosis (central or peripheral), intercostals indrawing, and tachypnea. Investigations as mentioned below may help;

Test Making diagnosis Monitoring progress

Test	Making diagnosis	Monitoring progress
Chest X ray	Yes	Yes
USG(localize Pleural Effusion)	Yes	Yes
Ventillation Perfusion Scan (Pulm embolism)	Yes	Yes
Blood count	Yes	Doubtful
Lung Function Test	Yes	Yes

Management of Dyspnoea:

General Principles:

1. To determine and treat underlying cause of dyspnoea wherever possible and reasonable for the patient
2. To consider whether the treatment will be worthwhile for the patient and family (bearing in mind the prognosis, adverse effects, social and financial burden)
3. To discuss all the reasonable treatment options with the patients and the family allowing them to make the final decision as far as possible

Disease directed management of dyspnoea

Cause	**Treatment**
Respiratory Infection	Antibiotics Physiotherapy
COPD/Asthma	Bronchodilators +/- Steroids Physiotherapy
Hypoxemia	O2
SVCO Obstruction of Bronchus SVC thrombus	High dose Steroid + Diuretics Radiotherapy/ Laser to the bronchus/chemotherapy Stent
Lymphangitis Carcinomatosis	Steroids + Radiotherapy
Pleural Effusion	Thoracocentesis ICD+/-Pleurodesis
Ascites	Diuretics/Paracentesis

Pericardial Effusion	Paracentesis Diuretics
Anemia	Blood transfusion Erythropoeitin
CCF	Diuretics/ ACE inhibitors Digoxin(atrial fibrillitation)
Pulmonary Embolism	Anticoagulants
Bronchial Carcinoma	Radiotherapy/chemotherapy

Symptom Management of Dyspnoea:

To manage the experience of shortness of breath, both pharmacological and nonpharmacological interventions have been shown to be effective. Whatever the cause, elevating the head of the bed, keeping air moving using fans and open windows, and reducing environmental irritants are likely to be help. These strategies can be pursued simultaneously with strategies to manage the underlying causes.

Opioids:

Opioids are the most effective medication for symptomatic control of dyspnea.7 Opioids are known to cause depression of the respiratory centre in the medulla oblongata. They reduce the sensitivity of the respiratory centre to rising pCO2 levels. Also they are known to reduce secretions in the airways that might precipitate the distress. In addition to the above mechanism, there is controversial evidence about the use of nebulised morphine (proposed mechanism through the opioid receptors in the airway).8,9,10

Opioid naïve patients:

In opioid naïve patients, small amounts of morphine can relieve dyspnea.11

1. Morphine, start with 10 – 15 mg PO q 1 h PRN or 5 mg SC q 30 min PRN. Titrate to effect using standard opioid dosing guidelines

2. The duration of the effect is about 4 hours (consistent with the effective serum half-life of morphine and equivalent to that observed for pain relief).

For patients already using opioids:

I) For patients on baseline opioids:

Start by increasing the opioid dose by 25%, this often provides relief.

II) Chronic dyspnea:

Once the chronic dyspnea is controlled, provide:

An extended release formulation for baseline dyspnea control, and

An immediate-release formulation of the same opioid for breakthrough dyspnea, eg, 10% of the total dose q 24 h, offered q 1 h PRN.

Anxiolytics:

The role anxiety plays in dyspnea remains unclear. Patients frequently report anxiety concurrent with dyspnea. Dyspnea and anxiety are a viscious cycle. Anxiolytics, eg,

benzodiazepines are known to have an adjunctive effect to morphine.12 However, the evidence for their effectiveness is quite Anxiety itself may be responsible for only 10% of the sense of dyspnea. Therefore, do not use benzodiazepines alone as first line therapy for dyspnea. Benzodiazepines are also contraindicated in the frail or elderly as they may make short-term memory deficits worse. Lorazepam, start with 0.5 – 2.0 mg PO, SL, Buccal, or SC q 1 h PRN and titrate to effect. Once the total dose required in 24 hours has been established, provide 1/3 of the total dose q 8 h routinely. Additionally, chlorpromazine, a major tranquilizer, and buspirone, a non-benzodiazepine anxiolytic have also been reported to decrease dyspnea. 13,14

Nebulised furosemide are known to bring dramatic improvement dyspnoeic patients who present in the advanced stage of cancer.15,16 However,the research results will need to be supported by evidences obtained form randomized trials.

COUGH

Like dyspnea, cough is a normal protective mechanism mediated by the respiratory centre. However, when the cough is caused by a pathology like malignancy or infection, this can lead to significant distress.

Causes and Management

Causes	Management
Respiratory infection	Antibiotics Nebulisation with saline and/or bronchodilators
COPD/Asthma	Corticosteroids(oral and/or inhaled) Bronchodilators (Inhaled) Physiotherapy
Malignancy	Corticosteroids(oral and/or inhaled) Bronchodilators (Inhaled) Cough Suppressant Physiotherapy Nebulized Local Anaesthetic 17 (caution: bronchospasm will need management)
Aspiration of Saliva (in motor neuron disease and multiple sclerosis)	Anticholinergics Nebulised local anesthetics (especially in conditions where saliva pools in the hypopharynx)

Hemoptysis

Hemoptysis is the coughing up of blood. This may be a normal activity or a sequel to underlying lung pathology like malignancy or some chronic lung disease. One third of patients with lung cancer experience haemoptysis and 3% suffer fatal bleeds, often without warning.18

Causes:

Causes	Purulent sputum	Specks of Blood	Pleural Pain	Massive Hemoptysis
Acute Bronchitis	Yes	-	-	-
Pneumonia	Yes	Sometimes	Yes	-
Lung Cancer	-	Yes	-	Yes
Pulmonary Embolism	-	Yes	Yes	-

Management of Hemoptysis:

Mild to Moderate Hemoptysis:
The symptom is frightening for both the patients and families. Therefore allaying the fear and anxiety is a must. Start with a cough suppressant and observe for the improvement in the cough spells which inturn may help reduce hemoptysis. If the cough suppressant does not seem to help, give a course of oral hemostatic agent like ethamsylate or tranexamic acid, which may help in small streaks or moderate blobs of bleeding. These are known to act on the capillaries and arrest the bleed. Steroid(Dexamethasone at a dose of 2-4mg)could show some benefit.19
In recalcitrant cases, a trial or external or endo-bronchial radiation can be given in known case of lung cancer or metastasis to the lung. There is some evidence of the effectiveness of parenteral vasopressin for treating hemoptysis.20 Some studies have also shown controversial proof of nebulised vasopressin. 21
Diathermy or cryotherapy can be used for any endoscopically available site if they are available. However, cryotherapy requires a rigid bronchoscope and general anaesthetic to pass the liquid nitrogen probe and multiple treatments may be required. Haemoptysis is also amenable to vascular embolisation, provided the patient is stable enough to undergo such a procedure.22

Massive Hemoptysis:
Massive hemoptysis is defined as the expectoration of over 200 ml of blood in 24 hours.
The bleed is usually from a higher pressure artery than the venous or capillary systems. A trial of benzodiazepines with or without morphine enough to reduce the fear and anxiety and not rendering the patient sedated will help. If the patient‘s general condition is good and in a state where definitive treatment is possible, treatment should be directed to treat the cause.
If the bleed is uncontrollable and beyond correctable measures, continuous infusion with opioid

possibly with midazolam should be instituted to maintain gentle sedation. It is most helpful, if the patient is at all conscious, for all signs of blood to be covered by coloured towels or bedding as soon as possible, as the sight of it will acutely heighten his or her fear.23

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Chapter 8

Emergencies in Palliative Oncology

Chapter 8: Emergencies in Palliative Oncology: ―To Treat or Not To Treat‖?

Cancer patients on palliative care can deteriorate suddenly due to certain emergent conditions. Early identification and prevention of a rapid decrease in the quality of life is more important than a decision to intervene or not.

Spinal Cord Compression

Spinal cord compression from metastatic cancer remains an important cause of morbidity in patients with malignancy. Technical improvements in spinal imaging, radiation therapy, and surgery have allowed effective treatment of impending or frank spinal cord compression. Malignant spinal cord compression is defined as the compressive indentation, displacement, or encasement of the spinal cord's thecal sac by metastatic or locally advanced cancer. Compression can occur via posterior extension of a vertebral body mass, resulting in compression of the anterior aspect of the spinal cord, or through anterior or anterolateral extension of a mass arising from the dorsal elements or invading the vertebral foramen, respectively. Virtually any neoplasm capable of metastasis or local invasion can produce malignant spinal cord compression.

Primary malignancy	Prevalence% of bone metastasis at autopsy
Breast	**45-85**
Prostate	**54-85**
Lung	**32-40**
Thyroid	**28-60**
Kidney	**33-40**
GI	**5-13**

Multiple myeloma, Cancers of breast, Bronchus, Prostate, Bladder and Kidney are more commonly associated with spinal metastases in decreasing order of frequency.

Distribution of bone metastases in cancer patients is as follows

- 10% in cervical segment
- 70% in thoracic segment
- 20% in lumbo-sacral segment.

More than 10% of vertebral bone metastases present with spinal cord compression.

Clinical Presentation

By the time the classical signs become evident, it is usually too late. Early signs are subtle and it is imperative to maintain a high level of clinical suspicion.

The majority of patients who present with spinal cord compression have a known diagnosis of cancer. However, in 8% to 34% of cases it can represent the initial manifestation of cancer. Pain accompanies malignant spinal cord compression in 70% to 96% of cases. The pain may be local, radicular, or both. Local pain is present in the vast majority of cases and is caused by expansion, destruction, or fracture of the involved vertebral elements. The site of compression can usually be localized to the site of back or neck pain. Weakness, the second most common symptom at presentation, is usually what prompts the

patient to seek medical intervention. Weakness, which usually follows the development of local or radicular pain, can develop gradually in association with progressive balance disturbance and numbness. Initial unilateral weakness is common when paresis develops gradually. Complete loss of motor and sensory function below the affected level (cord shock) can occur abruptly as vascular insufficiency progresses to frank ischemia.

Diagnostic Evaluation

The diagnostic evaluation of suspected cord compression should include a careful history, physical and neurologic examination, radiologic evaluation including a sagittal magnetic resonance imaging (MRI) survey of the spine. Physical examination should emphasize localization of the level of suspected compression. This is often best initialized by asking the patient to point out the site of the back pain. Gentle percussion over the spine can confirm the site of involvement and help elucidate other sites of vertebral metastases.

Treatment

The diagnosis of cord compression requires emergent treatment. Delays in initiating treatment have been associated with deterioration in motor and autonomic function. Treatment of cord compression should be individualized, but started immediately (within 72hrs for neurologic recovery). Patients should be administered corticosteroids as soon as the diagnosis of cord compression is reached, regardless of whether diagnostic workup is complete. Surgical indications include spinal instability, retropulsion of bone fragments producing compression, previous radiotherapy at the site of compression. Patients with cord compression due to metastasis from radiosensitive tumors & in patients with multiple sites of compression where surgery is not possible are candidates for palliative radiation. Chemotherapy can be used as initial therapy for the highly chemosensitive adult or pediatric tumors in patients who are not candidates for surgery or radiation therapy.

Why is it important?

A patient who has an impending cord compression can continue to have a good quality of life if this particular emergency is identified and treated correctly at the right time without delay. Clinical diagnosis is sufficient for starting medical decompression with steroids and that can make the difference between a patient who continues to walk or becomes bed-ridden.

Corticosteroids

Corticosteroids (dexamethasone, methylprednisolone) are among the most effective treatments of neurologic dysfunction resulting from cord compression. In patients with frank compression, recommend an initial 10-mg dose of intravenous dexamethasone. Some centres recommend higher doses of 16 mg up to 60 mg to start with. The dose can be increased incrementally if no improvement is detected in the first 4 to 8 hours. After 2 days on a stable dose of intravenous dexamethasone, therapy can be switched to 4 to 8 mg of oral dexamethasone given every 6 hours. Corticosteroid doses are tapered every 4 days.

Surgery

Although radiation therapy is currently the treatment of choice for most spinal metastases, radio resistant and recurrent neoplasms remain therapeutic dilemmas. Accepted indications for surgery are (1) unknown diagnosis, (2) spinal instability or compression by bone, (3) failure to respond to radiotherapy, and (4) maximal allowable radiation dose already administered to the spinal cord.

Radiation Therapy

Radiation plays a central role in the treatment of newly diagnosed epidural cord compression. The goals of treatment are decompression of the spinal cord and nerve roots through cytoreduction of tumor, prevention of progressive neurologic symptoms, relief of pain, prevention of further structural damage to the vertebral column, and the establishment of durable

local control. Radiation reduces pain in approximately 70% of patients, improves motor function in 45% to 60%, and reverses paraplegia in up to 11% to 21%.

Dose: 20Gy/ 5#/ 1 week 30Gy/ 10#/ 2 weeks

Chemotherapy

Neurologic recovery from spinal cord compression in response to chemotherapy has been reported in adults and children. In adults, cytotoxic chemotherapy and hormonal therapy have been used to successfully alleviate spinal cord compression from prostate cancer, Hodgkin's disease, myeloma, germ cell tumors, lymphoma, and breast cancer. The use of chemotherapy combined with radiation was associated with a prolonged survival in patients presenting with epidural cord compression from non-Hodgkin's lymphoma.

Outcome

- Regaining ability to walk
  - 70% of patients who are ambulatory at presentation
  - 30% of patients who are paraparetic at presentation
  - 5% of patients who are paraplegic at presentation
- 1/3 may survive for a year

SYMPTOMATIC BRAIN METASTASIS

Brain metastasis is a very common site of distant metastasis in patients suffering from cancer. The common causes of metastasis to the brain are from primaries in the Breast and Lungs.

Clinical features: The symptoms and signs associated with brain mets are primarily due to the associated mass effect and increase in intracranial pressure. These may be reflected in the form of a) headache b) projectile vomiting c) diplopia and blurring of vision d) altered sensorium e) seizures

Investigations: CT scan of Brain to confirm the diagnosis of Brain metastasis.

Management:

Reduction of raised ICT –

Steroids

Mannitol for management of the acute phase

ACE inhibitors

Radiotherapy: Palliative external beam radiotherapy is an effective modality for palliation of brain metastasis. It is effective in temporarily controlling disease in the brain and in palliating symptoms associated with it.

Dose: 30Gy/ 10#/ 2wks to whole brain

12Gy/ 2#/ 2wks (@ 6Gy per fraction & 1 fraction per week).

HYPERCALCEMIA

Hypercalcemia is a free calcium concentration above the upper limit of the normal.Calcium in the serum is protein bound as well as free (ionized). It is the ionized Ca^{2+} that is metabolically active and therefore needs to be calculated in patients with suspected Hypercalcemia and hypo/hyper albuminemia as most labs will provide only total serum calcium and serum albumin separately.
Corrected calcium (mmo/l) = measured calcium + 0.022 x (42 – albumin g/dl) (Oxford Radcliff Hospital Trust).

Incidence :

% of all hypercalcemias have a malignant pathology.

Squamous carcinoma of the lung, adeno carcinoma of the breast, genitor urinary cancers and myeloma are some of the malignancies associated with higher incidence of Hypercalcemia.

Pathogenesis

Hypercalcemia in malignancy is a paraneoplastic phenomenon. Solid epithelial tumours release parathyroid hormone related peptide (PTHrP) which causes increased bone resorption and Hypercalcemia.

In myeloma, the tumor cells release osteoclast activating cytokines like IL-6, TNF, and TGF which lead to increased resorption of calcium from the bone.
Some lymphomas also produce 25-vitamin D1 alfa-hydroxylase which activates Vitamin D increasing increased calcium and vitamin D absorption from the intestine.
PTHrP reduces distal tubular excretion of calcium and in myeloma, the renal dysfunction exacerbates the Hypercalcemia.
Hypercalcemia induced vomiting leads to sodium loss and the sodium linked proximaltubular calcium reabsoprtion is increased.

Why is it important?

Hypercalcemia is the most common life threatening malignancy related metabolic emergency/complication.
It is very often missed or mismanaged. If underdiagnosed and undertreated, it adversely affects the patient quality of life.
In one study, Hypercalcemia has been shown to be associated with inferior survival even in the palliative setting.

Clinical features:

Clinical presentation can be vague and overlapping with that of underlying disease progression, co-morbidities.

Symptoms: Fatigue, nausea, vomiting, thirst, polyuria, constipation, psychological disturbance. In severe cases, there can be delirium, drowsiness and coma.

Clinical Signs: Dehydration, neurological weakness, Hyporeflexia, Decreased consciousness.
Investigations: Serum calcium > 3.0 mmol/L, ECG changes :Bradycardia, prolonged PR, Short QT, Widened T waves and arrhythmia.
It is useful to remember that malignant Hypercalcemia,is associated withhypochloremic alkalosis and plasma chloride is generally <98 mmol/L whereas, pripary hyperparathyroidism is associated with hyperchloremic acidosis.
Hypercalcemia is not seen in occult malignancies and diagnosis is made by a high degree of clinical suspicion and relevant investigations.

Management:

–Stop and think! Are you justified in treating a potentially fatal complication in a moribund patient?‖ -Robert Twycross.

As in all conditions the decision to treat or not to treat should be based on sound clinical judgment of the durability of benefit from interventions (based on expected symptom relief and expected survival). It is good practice to consider the principles of medical ethics namely patient autonomy, beneficence, non-maleficence and justice.

The decision to correct clinical hypercalcemia must be considered within the context of therapeutic goals as determined by the patient, the caregivers, and the medical staff. As with hepatic or metabolic encephalopathy, untreated hypercalcemia will progress to loss of consciousness and coma. This clinical course may be desirable at the end of life in patients with

intractable suffering and/or unmanageable symptoms when no further active treatment is available or desired for reversal of the primary disease process.

Delirium, mental dullness, thirst, polyuria, constipation improve consistently whereas general malice, fatigue and anorexia show variable response.

1. Stop drugs that might reduce renal blood flow like NSAIDS, or reduce calcium excretion like thiazide diuretics.
2. Hydration: isotonic saline 3-4 L over 24 hours for 2 days and then 2-3 L per 24 hours along with oral potassium supplements. Saline therapy reduces serum calcium by 0.2-0.4 mmol/L.

Specific measures:

1. Bisphosphonates :Zolendronic acid is currently the most commonly used drug in India.
2. Mithramycin : in sub-therapeutic (Oncological) doses, is a potent inhibitor of osteoclasts.
3. Calcitonin : acts opposite to parathyroid hormone and
4. Phosphate
5. Corticosteroids
6. Octreotide

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DELIRIUM

Delirium or Acute confusional state is characterized by cognitive impairment. However dementia (chronic confusional state) is also characterized by progressive cognitive impairment. It is important to differentiate delirium from dementia and in some cases, delirium might complicate an underlying dementia.

Delirium	**Dementia**

Acute	Chronic
Mental clouding	**Brain damage**
Speech irrelevant	**Speaks less**
Aware and anxious	**Unaware and not concerned**
There are lucid intervals	**Progressive worsening with no lucid intervals**

Thus, the delirious patient has impaired understanding, is confused and anxious manifesting as

1. Poor short term memory
2. Poor concentration
3. Disorientation
4. Misinterpretation
5. Paranoid ideas
6. Hallucinations
7. Incoherent speech
8. Restlessness
9. Noisy aggressive behavior
10. Increased or decreased psychomotor activity (increase causes facial flushing, dilated pupils, sweating and tachycardia).

Why is it important?

Delirium causes a lot of distress to the patient as well the caregivers. The condition is often misdiagnosed as psychosis (madness), deafness, old age, disease progression etc. Lucid intervals are missed and explanations are not given.

Management*:*

The principles of good symptom control – correcting the correctable applies to the management of delirium also.

1. Explain to the care givers that the patient is not going mad.
2. Explain to the caregivers that there are lucid intervals.
3. Look for precipitating causes and correct them if possible
    a. Unfamiliar new environment – sudden change
    b. Uncomfortable environment – too hot, too cold, too dark, too bright, noisy etc , wet bed, creases in bed, crumbs in bed
    c. Alcohol, nicotine withdrawal, previous psychotropic substance abuse
    d. Underlying anxiety depression
    e. Worsening fatigue, pain
    f. Constipation, urinary retention
    g. Infection
    h. Dehydration, electrolyte imbalance
4. Use medications only if the patient or the family is distressed with symptoms or if symptoms persist.
5. Sedatives if prescribed need to be followed up as they can worsen symptoms (like hallucinations).

6. In case of a suspected brain metastasis or tumor progression, steroids can be tried.

Specifically, Haloperidol 1.5 mg – 5 mg OD is given PO or SC. The dose needs to be titrated to response and progression.

In case of terminal delirium, higher doses of haloperidol 10-30 mg and midazolam 10-60 mg SC infusion is needed to control terminal distress. If distress persists then SC levomepromazine or Phenobarbital has to be tried.

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CONVULSIONS

Seizures (generalised or partial) occur in 10-15% of palliative care patients most often due to primary or secondary(metastatic) brain tumours, cerebrovascular disease, epilepsy, or biochemical disturbances like low sodium, hypercalcaemia, uraemia.

Management:

Principles of good symptom control need to be adhered to. If the patient has wished that he/she be not admitted, then a care plan for management at home is essential as in other emergencies.

Assessment

1. Look for and Exclude other causes of loss of consciousness or abnormal limb/ facial movement. (eg fainting episode, postural hypotension, arrhythmia, hypoglycaemia, extrapyramidal side effects from dopamine antagonists, alcohol).
2. Previous history of epilepsy, previous secondary seizure, known cerebral disease.

Chapter 9

Role of Oncologic Treatment in Palliative care

Chapter 9: Role of Oncologic treatment in palliative care

Introduction

The purpose of palliative care is to improve the quality of life (QOL) for patients and families facing the multifaceted problems associated with life-threatening conditions. It relieves various aspects of suffering (ie, physical, psychosocial and spiritual). The oncological treatment in form of radiotherapy, chemotherapy and surgery either alone or in combination is an integral component of palliative care. The aim of such treatment is to relieve distressing symptoms and not to achieve cure from the disease.

Role of RT

Radiotherapy is an indispensable modality in the palliation of cancer. Around 50-60% of all patients in palliative care require some form of palliative radiotherapy. All palliative care program should be acquainted with its indications. A palliative care unit should have a close working relationship and coordination with a radiation oncology department. The main indications are: pain relief (particularly bone pain), control of hemorrhage, fungation and ulceration, dyspnoea and the shrinkage of any tumors causing problems by virtue of space occupancy. Radiotherapy also has an important role in the palliation of three oncological emergencies: superior vena caval obstruction, spinal cord compression, and raised intracranial pressure due to cerebral metastases. More pragmatic fractionation schedules are being developed that are compatible with good results in terms of palliative end points, giving shorter courses with fewer hospital attendances for patient and family comfort and convenience. Palliative radiotherapy is the most cost effective in alleviating symptoms related to various areas affected with cancer.

Radiotherapy can provides good *pain relief* in about 2/3rd of patients receiving for painful bone metastasis. A complete relief of pain can be achieved in about 25% of patients. Single fraction of radiotherapy (8 Gy / single fraction) provides equivalent pain relief as compared to longer fractionated schedules. Single fraction treatment is convenient to the patients by minimizing hospital visits and cost. It is logistically better for busy radiotherapy departments. The use of single fraction radiotherapy is increasing in treatment of painful bone metastasis.

Palliative whole brain radiotherapy is the current standard of care for patients with multiple *brain metastasis*. Commonly used fractionation include 20 Gy / 5 fractions over one week or 30 Gy / 10 fractions over 2 weeks. For up to three brain metastasis, decompression surgery followed by whole brain radiotherapy is preferred. The patients usually have good symptomatic relief post radiotherapy and survival is significantly improved as compared to best supportive care.

Spinal cord compression is an oncological emergency. Surgical decompression followed by palliative radiotherapy is the standard of care. However, surgical decompression may not be feasible in all patients especially in patients with poor performance status and disseminated cancer. In such cases only palliative radiotherapy is given. Multi fractionation regimens (20 Gy / 5 fractions over one week or 30 Gy / 10 fractions over 2 weeks) are commonly used for treatment of spinal cord compression.

Radiotherapy can be used to achieve *hemostasis* in cases of uncontrolled bleeding from tumour mass. The common clinical indications for hemostatic radiotherapy include cervical cancer, stomach cancer and head neck cancers. Hemostasis is achieved in about 5 to 7 days post radiotherapy in good proportion if cases.

The other indications for palliative radiotherapy includes inoperable disease, metastatic disease and large tumour mass occupying pleural or abdominal cavity. The fractionation for such cases vary and depends upon individual and institutional protocols.

Role of surgery in palliative care

Surgeons play an important role in the multidisciplinary care of palliative patients. Palliative surgeries are quite common and offer good relief from symptoms and improve quality of life in well selected patients. It should be emphasized to the patient and the care givers regarding the intent of the procedure being ―relief from symptoms and not cure‖. As surgery is an invasive procedure the goal should be predefined. The benefits of doing the procedure should be weighed against the predicted side effects. The expectations of the patient should be given due consideration and a realistic approach should be encouraged. It is imperative that the patient has a good understanding of the disease and its outcome. The extent on invasiveness of the procedure should be justified in the context of an incurable illness. A clinical scenario is at times encountered when the intent of the procedure is changed from radical to palliative on table while doing the surgical procedure depending on the intra-operative examination of the disease.Multiple indications of a surgical intervention in a palliative setting may range from relief of pain to procedures for drainage of effusions/ ascitis, relief from obstruction, gross tumoral excision, vascular ligations to arrest active bleeding and fixation of bony metastases.

Pleural/ pericardial effusions can be very symptomatic and often require intervention. Taping the fluid can cause immediate relief and can be done multiple times. For recurrent effusions placement of an indwelling catheter is a favoured option. Therapeutic paracentesis for malignant ascitis is effective but gives short term relief. Though the procedure can be repeated multiple times large fluid shifts may lead to hypotention, hypoproteinemia and electrolyte imbalance. For refractory ascitis indwelling catheters are safe and efficacious. These minimally invasive procedures may reduce the pain, sleep disturbance & discomfort, facilitate breathing& mobility and thus, improve quality of life.

Primary tumors or their secondaries can lead to *obstruction* of luminal or cavitary organ systems. External compression of vessels may lead to a myriad of symptoms ranging from mild limb edema to severe cardio-respiratory compensation. Intrinsic as well as extrinsic compression may lead to respiratory, gastrointentional and urological obstruction. Decision making with respect to the selection of the most effective but the least invasive technique is quite difficult in such cases. May also present as an emergency in cases of strangulated/ closed loop obstruction with impending ischemia. Bowel obstruction can be diagnosed clinic-radiologically and is managed conservatively by naso-gastric decompression and bowel rest. Multiple sites of obstruction is also encountered in cases of peritoneal carcinomatosis or due to adhesions. Management depends upon the severity of obstruction, response to conservative medical treatment, site (gastric outlet/small bowel/colorectal) and cause of obstruction (intrinsic growth/ external compression). Palliative resection & anastomosis, bypass procedures and stoma are the commonest of procedures performed. Stenting is also frequently performed as it is the least invasive procedure and is very well tolerated specially in esophageal cancers. Biliary obstruction due to primary tumors, pancreatic malignancies, or lymph nodes causing extrinsic compression can be the cause of considerable morbidity. Patients often complain of pruritus, jaundice, anorexia, and weight loss. Endoscopic stents, percutaneous transhepatic drainage procedures, and celiac plexus block constitute the preferred management in many patients. Intraluminal irradiation of the bile duct

for extrahepatic obstruction has been used following relief of biliary obstruction. Vascular stents are also used. Colostomy is performed for large bowel obstruction. Percutaneous gastrostomy is very useful for locally advanced esophageal cancers. Ureteral stenting or a per cutaneous nephrostomy frequently performed to aid the urinary function in cases of compressive uropathy.

A surgical procedure for *pain control* is resorted to when medical management and radiotherapy options fail.Advanced malignant diseases of the arm or leg that result in a painful and non functional limb can be considered for amputation. For vertebral metastases vertebroplasty and

kyphoplasty have shown good pain relief. Surgical decompression is often considered in cases of nerve compression. Spine decompression and stabilization procedures are performed for vertebral metastases causing spinal cord compression and neuropathic pain. Toilet resections are considered for painful, fungating and discharging lesions. Palliative surgery involves the evaluation, management, and care of patients who undergo operations performed largely for symptom relief, with little anticipated effect on long-term survival

Other surgical procedures involve vascular ligations for uncontrolled tumoral bleed, palliative amputations, management of fistulas, diversion surgeries, etc. Resection of a bleeding cancer of the colon is resorted to even in the presence of metastases. Vertebroplasty/ cementoplasty is also performed when indicated. Many other examples exist. _Tailoring‘ the type of surgery to the needs of the patient without undue morbidity is imperative.

Role of chemotherapy

Cytotoxic and sclerosing agents are used for intrapleural/ intraperitoneal/ intrapericaridial administration are effectively used in cases of malignant effusion and ascitis. Systemic chemotherapy is often used for reducing the bulk of tumor causing symptoms. Pain relief is the commonest indication for systemic therapy in palliative settings. However, it is of utmost importance that a cytotoxic agent is selected after evaluating the side effects. The doses and the intensity/ density should be non myelotoxic and easily tolerated. Oral route of administration is preferred over intravenous route.

Metronomic therapy is an emerging alternative to the conventional systemic therapy. Low dose oral cytotoxic agents as well as agents like celecoxib, tamoxifen, thalidomide, molecular targeted agents, etc are used. This therapy appears to be clinically effective and safe in a broad range of tumors. The toxicity profile is also very acceptable. The patients take these oral medications and home and due to the favorable toxicity profile hospital visits are significantly reduced.

Radiation therapy, surgical and chemotherapeutic procedures can significantly improve the symptoms and quality of life in select cancer patients. Successful outcomes are defined by treating oncologist and patient by careful selection.

Chapter 10

Palliative care for End Stage Cardiac Disease

Chapter 10: Palliative care for End Stage Cardiac Disease

Definition

End stage cardiac disease is defined as patients with heart failure who have Predicted life expectancy of 6 months or less. Such patients usually have grade IV dyspnoea (NYHA classification), hypotension, clinical features of heart failure and an ejection fraction of less than 20%. The extent of the disease will also depend on the number of hospital admissions. The patients in this category usually have had past history of hospital admissions and a group of patients who develop cardiogenic shock with renal failure following a Myocardial Infarction in whom palliative care is apt.

Epidemiology:

Heart failure is extremely common disorder that affects 1-3% of the general population. There is a rising trend from 10% in 2000 to beyond 20% in 2020. The overall survival in patients with congestive cardiac failure is equivalent to many types of advanced cancers with an estimated 1 year survival of less than 50%.

Guidelines for palliative care in heart failure

The newest American Cardiology society and American Heart Association endorse clear assessment and management strategies for every stage heart failure. Importantly these guidelines include a section on ‒end of life considerations in the setting of heart failure.‖ These guidelines advise that aggressive procedures like intubation, mechanical ventilation and implantable defibrillators are not recommended in the last days of life. In addition to this, they also provide an ongoing education for patients and families concerning prognosis, functional capacity, role of palliative care, implantable cardiac defibrillators, coordination of care and the use of opioids for symptomatic relief.

Pathophysiology of heart failure :

Heart failure is a clinical syndrome characterized by the inability of the heart to maintain a cardiac output adequate to maintain the requirements of the metabolizing tissues. This could be due to Left Ventricular systolic dysfunction or diastolic failure.

This is also a syndrome that is associated with complex inflammatory process like release of interleukin family and tumor necrosis factor. It also involves neurohumoral abnormalities like the activation of Renin-Angiotensin-Aldosterone system (RAAS) which increases the vascular tone by increasing the angiotensin II in the blood. The endothelin and adrenalin maintain the blood pressure by maintaining the ionotropic effect. In long term, there is RAAS dysfunction, cardiac and vascular fibrosis, sodium and water retention, arrythmogenesis and facilitate ventricular and vascular remodeling.

Types of Heart Failure :

Acute(MI)/ **Chronic**(Cardiomyopathy/ Cor Pulmonale)

Left(LVF-Pulm edema)/**Right**(Cor Pulmonale-RVF)/**Biventricular Failure**
Diastolic Failure(LVH-IHD),, and Systolic Failure (AS, AR)

High Output Failure:A-V fistula, Anemia, Thyrotoxicosis

Clinical Features :

Similarities to malignancy

- Dyspnoea
- Anorexia Cachexia
- Pain
- Fatigue
- Anxiety and depression
- Poor morbidity
- Insomnia
- Hypotension
- Jaundice with resultant liver abnormality
- Increased infection risk
- Anemia
- Polypharmacy
- Fear of the future

Differences from Malignancy

- Prediction of life expectancy is more difficult
- Misconception that condition is more benign than cancer
- Edema more prominent in heart failure
- Lack of local pressure effect

NYHA classification of Heart Failure

NYHA I (MILD)	NYHAII (MILD)	NYHAIII (MODERATE)	NYHA IV (SEVERE)
1. No limitation of physical activity	1. Slight limitation of physical activities	1. Marked limitation of physical activities	1. Unable to carry out any physical activities without discomfort
2. Ordinary physical activity doesnot	2. comfortable at rest but ordinary	2. comfortable at rest but less than ordinary	2. Symptoms of cardiac

cause undue fatigue, palpitations, dyspnoea	physical activity causes undue fatigue, palpitations, dyspnoea	physical activity causes undue fatigue, palpitations, dyspnoe	insufficiency at rest
Drugs: ACEI/ARB	Drugs: Diuretics ACEI/ARB Beta Blockers Digoxin	Drugs: Diuretics/spironolactone ACEI/ARB Beta Blockers Digoxin	Drugs: Diuretics/spironolactone ACEI/ARB Beta Blockers Digoxin

Specific Conditions:

Refractory Angina:

1. Anti anginals like Nitrates/ Beta Blockers/CCB
2. Balloon Angioplasty

Arrythmias:

Cause: Myocardial Infarction/Hypertensive Heard Disease/LV dysfunction
Atrial Fibrillation- Digoxin/Beta Blockers/RFA

Ventricular Arrythmias: Amiadarone

RFA not possible as no discrete arrythmogenic focus identified
Implantable Cardioverter defibrillator

Palliative care Issues:

Pain

Pain is common in patients with ischemia/infarction that can be reversed with nitrates. Other pain medications can be used as per the WHO guidelines. Avoid NSAIDs as it causes sodium retention, increases renal insufficiency. Morphine should be used with caution as the renal and liver function may be affected leading to prolonged excretion of morphine leading to its toxicity. Therefore, the dose should be reduced. When neurotoxicity develops with morphine, either rotate opioids or add a low dose of benzodiazepines. Neuropathic pain can be treated with anticonvulsants like pregabalin and gabapentin(dose to be modified based on the renal function or tricyclics.

Dyspnoea

Find the underlying cause and manage. For instance, if dyspnoea is the result of atrial fibrillation, use digoxin and Beta blocker. When associated with pain , use nitrates.

Depression

Prevalence in Heart failure is 24-42%. This may be associates with other social factors like social isolation, alcohol and drug abuse, poor health status and perception of medical care as a financial burden.

Selective serotonin reuptake inhibitors are safe. Tricyclics are to be avoided due to their cardiotoxicity. Some may benefit from psychotherapy.

Resuscitation Issues

The SUPPORT study revealed that DNR was written for only 5% heart failure patients, 47% malignancy patients and 52% patients with AIDS. There is lack of understanding among patients and physicians that heart failure is a lethal disease and there is lack of discussion on goals of care and prognosis in these patients. Similar is the case with Artificial Implantable Defibrillator.

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Chapter 11

Palliative care for Chronic Nephrological Condition

Chapter 11: Palliative care for Chronic Nephrological Condition

Introduction :

The incidence of end stage renal disease is increasing.

Definition*:*

Kidney damage for 3-4months, with or without structural or/and functional abnormalities, with or without decrease in GFR manifested by pathological abnormalities or markers of kidney damage including alteration in the composition of urine or blood.

Or GFR<60/ml/1.73m2 for 3 months with or without signs of kidney damage.

Stages of Chronic Kidney Disease (CKD)

Stage of CKD	**GFR (ml/min/1.73sq.m)**	**Comments**
Stage 1	Normal>90	Plus persistent albuminuria
Stage 2	60-90	Plus persistent albuminuria
Stage 3	30-59	Evaluation and management of renal disease and comorbidity
Stage 4	15-29	Suffer from complications of renal failure, increased mortality from cardiovascular disease, Preparation for Renal replacement.
Stage 5	<15	End stage renal disease

Conventional Modality of treatment

Renal transplant

Patients with renal transplant have the best prognosis, however in patients with comorbidities and those with osteodystrophy may continue to cause symptoms. These patients will be on immunosuppressants life long which increase the risk of malignancy and infection. Also some patients may need retransplant due to chronic rejection. All these affect the quality of life of patients.

Dialysis

Patients on dialysis are at a risk of metabolic complications, infections(peritoneal dialysis), negative body image, social isolation, high medication burden to maintain optimal cardiovascular function, calcium phosphate and erythropoietin.

Symptom management

Principles of Management:

1. Patients with stage 5 and 5 of CKD symptoms as patients with malignancy. Therefore prompt assessment and management of symptoms is a must in patients with CKD.
2. Symptoms will be due to comorbid condition, metabolic and complications of management and multidrug management.

Pain

% patients experience significant pain. Pain is moderate to severe in upto half odf the patients. This could be divided into the following category;

1. Concurrent comorbidity: Diabetic nephropathy, chest pain, peripheral vascular disease, arthritis, decubitus ulcer.
2. Primary Renal Disease:Adult Polycystic Disease: Pain from ruptured cyst from kidney, liver and bleeding, infected cyst.
3. Complications of renal failure: renal osteodystrophy, gout, dialysis amyloid arthropathy and calicphylaxis.
4. Infection: septic arthritis, epidural abscess, peritonitis in peritoneal dialysis
5. Dialysis related pain: ‗steal syndrome' from arteriovenous fistula, cramp, headache

Management of Pain:

Prompt assessment using the ‗PQRST' and drugs based on WHO ladder. The dose of opioid should be titrated considering the GFR and the dose should be reduced. Even the adjuvants like pregabalin and gabapentin should be titrated based on the GFR. Methadone is safer in these patients as it has a hepatic metabolism and fecal excretion. **Pruritis**

Management includes antihistaminics, ultraviolet B phototherapy, gabapentin and thalidomide.

Calciphylaxis

This results from calcification of the small blood vessels leading to pain, discolouration and ischemic ulceration of the thighs, buttocks, lower abdomen and lower limb. This needs adequate physical management of pian and counseling of patient and caregivers**.**

Restless leg syndrome

This is sensory syndrome with a persistent and extremely uncomfortable crawling sensation in the lower limb. This may occur in the night and can interfere with the patients sleep and relieved by movement.

Management: Benzodiazepines like clonazepam in the dose of 0.5-1mg at night, anticonvulsants like gabapentin can be tried.

Other symptoms like anorexia, fatigue, nausea/ diarrohea and constipation, depression and anxiety will be treated as discussed in the concerned chapters.

Suggested Reading:

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Chapter 12

Palliative Care for Chronic Neurological Conditions

Chapter12: Palliative Care for Chronic Neurological Conditions

Introduction:

Neurological conditions like stroke, multiple sclerosis, dementia, multiple sclerosis and amyotropic lateral sclerosis lead to premature death due to complications like pneumonia. In general, pain is uncommon in neurological conditions while impairment of mobility, cognitive and behavioural problems are common.

Different time course of neurological conditions

Sub Acute progressive(Days-Weeks)	**Progressive Stroke, Meningitis, CJD**
Chronic Progressive (Months- Years)	**Amyotropic Lateral Sclerosis, Brain Tumors, Multiple Sclerosis, Alzheimer's disease**
Chronic Disabling conditions	**Stroke, Multiple Sclerosis, Parkinson's Disease**

Stroke

Stroke is a chronic debilitating condition caused due to brain infarction(84%), intracerebral bleed(7%), subarachnoid haemorrhage(7%), vasculitis, dissection and sinus thrombosis.

Etiology:

Emboli (from heart, aorta, vessels of the brain), stenosis or occlusion of the ateries supplying the brain, thrombosis of intracranial arteries and microangiopathy by diabetes and hypertension.

Clinical Feaures*:*

Hemiparesis, hypoaesthesia, hemianopia, diplopia, visual loss, headache, vomiting, aphasia and loss of consciousness, convusions.

Predictors of functional recovery from stroke:

1. Age
2. Previous Stroke
3. Urinary continence
4. Consciousness at onset
5. level of social support

Unconsciousness at onset, hemiplegia or incontinence are poor prognostic indicators

The most common strokes with fatal outcome include;

Malignant middle cerebral artery infarction, basilar artery thrombosis (death in 50% cases) and intracerebral and subarachnoid bleed(50% cases).

Symptom Control

In stroke patients, 65% reported having pain out of whom 37% had inadequately judged pain and 25% had insufficient intervention, 56% had urinary incontinence, and 51% had confusion. Patient suffer from Central post stroke pain, a neuropathic pain syndrome which is thought to arise from the vascular lesion and is characterized by pain corresponding to the part affected. Amitriptyline and lamotrigine haven shown benefit in controlled effects.

Loss of Consciousness

A variety of patients slip from semicoma to coma, however, pain and other distress should be identified and managed. Patients give cues of distress by grimacing, blushing, stiffness of neck, or increased respiratory rate and blood pressure. Therefore adequate pain control and other distress management is a must.

Communication

This is often hampered by aphasia and dysarthria especially in patients with left temporo-parietal hemisphere lesion which may be further aggravated by apraxia, agnosia, neglect and visuo- spatial orientation. However, it is always essential to work on the assumption that patient understands everything that is being said to.

Incontinence and Constipation

These are common in patients. Impaired mobility and communication can lead to incontinence and distress for patients and family. Poor management of incontinence can lead to infection, skin changes and sores. Constipation can be aggravated by anticholinergics, opioids, immobilization and decreased oral intake.

Nutrition

Nutrition is affected due to facial weakness, delayed pharyngeal swallowing, disturbed lingual movement and reduced tongue base reaction. Management includes swallowing exercise like supraglottic swallowing. PEG insertion is better than NGT as researches have shown better feeding with PEG however does not reduce the risk of aspiration.

Care in the last days of life

Which could include end of life decision, transfer from intensive care to home or hospice care and that patient dies in the preferred place of care.

Dementia

Definition

A syndrome due to disease of the brain, usually of a chronic or progressive nature, in which there is disturbance of multiple higher cortical functions, including memory, thinking, orientation, comprehension, calculation, learning capability, language, and judgement. Consciousness is not impaired.

Impairments of cognitive function are commonly accompanied, occasionally preceded, by deterioration in emotional control, social behaviour, or motivation.(ICD 10)

Epidemiology

million world wide; 61% in developing countries. It is expected to rise to 71% by 2040. In developed counties, 92% expenditure is spent on dementia while Developing only 8% spent.

Types of Dementia:

Alzheimer's Disease: Symptoms include memory loss, progressive deterioration in the ability to perform basic activities of daily living (ADL), behaviour changes, mainly apathy and social withdrawal, but also behavioural disturbances. The average survival period for patients following diagnosis is 8 to 10 years.

Vascular Disease:The role of vascular disease in the aetiology of dementia is complex and

controversial. There appears to be a direct chronological relationship between significant cerebrovascular events and the onset of dementia. Onset may be abrupt or there may be periods

of sudden decline followed by relative stability. Physical problems such as urinary incontinence, decreased mobility and balance problems are more commonly seen in people with vascular dementia (VaD) than in people with Alzheimer‘s disease.

Lewy Body Dementia: Characteristic features of dementia with Lewy bodies (DLB) are fluctuation of awareness from day-to-day and signs of parkinsonism such as tremor, rigidity and slowness of movement or poverty of expression. Visual hallucinations or delusions occur frequently. Falls are also common. DLB has a similar pathological basis to Parkinson‘s disease dementia and both are associated with progressive cognitive decline and parkinsonism.

Fronto-Temporal Dementia: Represents a significant proportion of people who present with dementia under the age of 65. Changes in behaviour such as disinhibition, lack of judgement, loss of social awareness and loss of insight are much more common than memory problems.

Disturbance of mood, speech and continence are frequent. A positive family history of a similar disorder is not uncommon.

Mixed dementias: Mixtures of two or more of the active dementias can be found in the same person, with one or other usually dominating. Studies suggest that the interaction between vascular disease and the core features of Alzheimer‘s disease is extremely complex and that rigid boundaries between subtypes of dementia may be unduly

Creutzfeldt-Jakob disease: Creutzfeldt-Jakob disease (CJD) is a very uncommon illness in which an abnormal protein accumulates in the brain and leads to rapid destruction of nerve cells. Tremor, impaired mobility and balance problems are common as are behavioural and mood disturbance. Death within one to two years of the onset of clinical symptoms is common.

Clinical Features:

Severity	Clinical Features
Mild	Memory Loss, Personality changes and Spatial Disorientation
Moderate	Aphasia, Apraxia, Confusion, Agitation, Insomnia
Severe	Resistiveness, Incontinence, Eating Difficulty, Motor Impairement
Terminal	Bedbound, Mute, Dysphagia, Intercurrent Infection

Diagnosis and Investigation

Dementia is a clinical diagnosis made when acquired cognitive deficits in more than one area of cognition interfere with activities of daily living and represent a decline from a previously higher level of functioning.

Dementia is not usually diagnosed in the presence of delirium, although the two can coexist.

A detailed history is an important part of the assessment of someone with suspected dementia. Attention should be paid to mode of onset, course of progression, pattern of cognitive impairment and presence of non-cognitive symptoms such as behavioural disturbance, hallucinations and delusions.

Specific Diagnostic criteria exist: DSM IV, Hachinski Ischaemic Scale etc..
In individuals with suspected cognitive impairment, the MMSE should be used in the diagnosis of dementia. MMSE assesses assessment of memory, language, visuoperceptual function.

Laboratory Investigation

Reversible causes: hypothyroidism, Vit b12 def, hyperammonaemia, Syphillis
MRI, CT scan, PET/SPECT
MRI is superior to others and helps in identifying lesions.

Management of Dementia

Principles of Management:

1. Reinforce continuity of care
2. Emotional Support to patient and family
3. Involvement if specialists
4. Early and moderate dementia: Keep up the activity level, provide support(appraxia), manage depression and anxiety
5. Advanced dementia: PEG/ NGT : have also the risk of mortality

Pharmacological Management

Cholinesterase Inhibitor

Donepezil – is used for cognitive imparement especially in vascular dementia however no effect has been found on the rate or delay in institutionalisation and progression of the disease.

Galantamine is helpful in patients with MMSE <18
Mimentine: NMDA receptor antagonist (low affinity) helps improve memory and learning.

Antidepressants: Antidepressants can be used for the treatment of comorbid depression in dementia provided their use is evaluated carefully for each patient.

Antipsychotics*:*

1. If necessary, conventional antipsychotics may be used with caution, given their side effect profile, to treat the associated symptoms of dementia.
2. Atypical antipsychotics with reduced sedation and extrapyramidal side effects may be useful in practice, although the risk of serious adverse events such as stroke must be carefully evaluated.
3. An individualised approach to managing agitation in people with dementia is required.
4. Where antipsychotics are inappropriate cholinesterase inhibitors may be considered
5. In patients who are stable antipsychotic withdrawal should be considered.

Assessment and Management of Behavioural symptoms

Resistiveness to care

The patient is resistive to care by the caregiver especially with respect to undressing, bathing, being put to bed etc. in which case the patients feel the caregivers are aggressors and may become violent as an act to defend them. The non pharmacological method include, improvement in communication, delaying caregiving and modifying caregiving strategies. This can be also achieved. by distraction

like reminiscence music theray or art therapy. This also include making resistive activities more homelike and comfortable.

Apathy and Agitation

Apathy is decreased activity levels and agitation is unpleasant state of excitement due to external or internal stimuli.

Activities of daily living

The caregiver must provide care in a cooperative way as possible.

Physical Activities

Maintain optimum level of physical activities based on the degree of affection in order to improve mood, muscle strength and sleep. This will also prevent any complication due to disuse atrophy.

Cognitive activities

Reminiscence therapy will help evoke pleasant memories. This could be in the form of music, sense of smell, taste, touch, vision. This could also be in the form of involvement in activities like dance, drama, play music and drawing.

Caregiver Stress and Management

It is essential to identify stress among caregivers and provide appropriate management in order to prevent caregiver burden.

Parkinsons Diseases

This is a classical triad of tremors, akinesia, rigidity

Symptom Control:

Pain: This could be because of stiffness, dystonia and rigidity which if not responding to L-Dopa, can be treated with pain medication based on the WHO ladder for pain control. Avoid using haloperidol in opioid induced nausea and vomiting instead domperidone that has less cerebral effect can be used safely.

Motor Symptoms:

1. Gait disturbance, balance and freezing gaits can be ameliorated by ergonomic advice and physiotherapy.
2. In acute episodes of hypokinesia-subcutaneous apomorphine will help
3. Hyperkinesia- neuroleptics like olanzapine or resperidone will help.
4. In contractures botulinum toxins shows therapeutic effect.

Neuropsychiatric symptoms- These are caused by dopamineric and anticholinergic drugs which may need reduction in the dose or addition of atypical neuroleptics like quetiapine. These patients could develop dementia at a later stage. The ensuing reduction in competence should be anticipated by the early introduction of advance directives.

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Management of patients with dementia:Scottish intercollegiate guidelines network 4.Dementia: NICE/SICE guidelines on supporting people with dementia and their carers in health and social care.

Chapter 13

Palliative Care in HIV/AIDS

Chapter 13: Palliative Care in HIV/AIDS

Introduction :

It is an estimate that around 2.39 million people in India are living with HIV. Of these, an estimated 39% are female and 3.5% are children.(1)

Today, with antiretroviral therapy being provided at government ART centers free of cost, there is a marked improvement in the health and general well being of people living with HIV.Care for people with HIV/AIDS has changed dramatically in the past decade. As care has changed, so has the trajectory of HIV/AIDS shifted to a disease less like cancer and more like chronic diseases such as diabetes or heart disease.This has resulted in a continuum of palliative care that has much to offer the patient with HIV/AIDS.(2)

To ―palliate‖ means to alleviate or ease, and that is the main component of palliative care. It‘s not about treating the disease; it‘s about relieving symptoms and side effects and providing comfort care to the patient. It also involves relieving the burden of illness on both the patient and the family.
The use of highly active antiretroviral therapy (HAART) has dramatically reduced AIDS-related mortality and morbidity(3,4) . Patients with HIV/AIDS live longer with their illness, symptom management becomes an increasingly important health issue(5,6) . Symptoms like fatigue, sleep disturbances, and HIV disease and HIV treatment-related issues, such as anemia and pain management, can cause a deterioration in both physical and psychological well-being and reduce adherence to medication therapy.

What does palliative care provide?

Palliative care is a comprehensive response to the care and support needs of people living with and affected by HIV. It is ideally provided by a multidisciplinary team including medical and nursing professionals, people living with HIV, counsellors, professionals, community workers and volunteers. Appropriate referrals to other services are undertaken as required to achieve this. The comprehensive response involves:

- physical care, i
- ncluding the assessment and management of pain and other symptoms like fatigue, dyspnea and neuropathic pain, and treatment of side effects such as nausea, vomiting, and diarrhea
- psychological care, including emotional support for the person and his/her carers, assessment and care for psychosocial needs including depression and anxiety, and bereavement
- social support, including identification of financial needs, poverty alleviation, food security, coping with stigma and discrimination and identification and planning for orphans and vulnerable children
- legal support, including identification of legal requirements and human rights issues
- spiritual support, including spiritual assessment and appropriate spiritual care.

Why do people living with and affected by HIV need palliative care?

• People living with HIV, including those on antiretroviral therapy (ART), experience pain and other symptoms that affect their quality of life through all stages of the disease.
People living with HIV on ART report high levels of depression, fatigue, anxiety, pain and other

symptoms.

- Physical symptoms, including pain and depression contribute to significant reductions in ART adherence.
- An ageing population of people living with HIV requires increased care and support needs.
- Comorbidities such as cancer, hepatitis and cardiovascular disease contribute to symptom burden. People living with HIV are more likely to be diagnosed with cancer than the general population.
- Despite increased access to ART, people living with HIV continue to present late into care with a high symptom burden.
- Depression, anxiety, dementia and other mental health problems are prevalent in people living with HIV and highly under-diagnosed and treated.
- Despite increasing access to ART, many people still die from AIDS and comorbidities such as cancer.

How does palliative care help people living with and affected by HIV?

Palliative care:

- improves quality of life of adults and children living with and affected by HIV
- addresses physical, psychological, social, legal and spiritual issues
- supports ART adherence through identification and treatment of symptoms and mental health problems
- manages physical symptoms i.e. pain, other opportunistic infections
- addresses and provides care for emotional and social suffering including depression and anxiety
- addresses the specific care and support needs of older people and children
- provides community care and support services and ensures that an individualsneeds are being met andsupports family members and carers
- addresses mental health problems such as depression and anxiety, as well as tacklingthe root causes of mental health problems
- improves adherence to treatment by addressing the barriers that prevent it.
- provides end of life care and bereavement support.

	Medical	Management/ Palliative	Care	
Stages of HIV	Early HIV disease (stage II)	Intermediate HIV disease (stage III)	Advanced HIV disease or AIDS (stage IV)	D
Clinical problems	Frequent infections with common pathogens	Infections with common and opportunistic pathogens	Combination of health problems (e.g., chronic diarrhea, weight loss, fever,	E
General condition	Mobile and active. Rapid response to treatment	Mostly mobile with increasing periods of	Patients often at home or in bed illness	A
Rx	Curative anti-infectious treatment	Curative or causal treatment. prophylaxis or maintenance treatment.	Supportive treatment (skin lesions, anemia, diarrhea). Maintain nutrition. Discontinue causative treatment and prophylaxis?	T
Palliative care	Analgesics, antipyretics. Pre- and post-test counseling. Involve family member(s) or other persons of confidence	Analgesics, antipyretics. Follow-up counseling with family members. Address social issue	Narcotic analgesics when needed. Continuous (home) nursing care. Terminal counseling and support	H

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Chapter 14

Psychiatry in Palliative care

Chapter 14: Psychiatry in Palliative care

Recently a global campaign had a tagline 'No health without mental health'. Palliative care is no exception. Clinicians have to be aware and sensitive to psychological and physical health needs of patients and their family members while delivering palliative care. Modern palliative care starts from the time of diagnosis and stretches beyond the end of life looking after bereavement issues of those who are left behind. The common psychiatric diagnosis for patients receiving palliative care include depression, health and procedural anxiety, acute stress reaction, adjustment disorder and substance misuse problems. Sometimes they would also come across patients who have a severe enduring mental illness like schizophrenia or bipolar disorder in addition to the physical disorder that they are being treated for. Progressive dementia has now come under the umbrella of palliative care when other treatment options have been exhausted.

The next few pages have been written keeping in mind the training needs of non-mental health professionals to be able to develop some understanding of mental health problems in physically ill patients undergoing palliative care.

Depression

Depression is by far the most common psychiatric condition that is found in palliative care patients. Depression is a clinical syndrome characterised by low mood, reduced interest in activities that the person found pleasurable in the past and increased fatigue. The associated symptoms could be disturbed sleep, poor concentration, guilt or low self-worth, disturbed appetite, suicidal thoughts or acts, reduced libido and agitation or slowing of activities. The above symptoms when persists more than two weeks may prompt the clinician to diagnose a patient to be suffering from depression. However it is important to remember that patients can have subthreshold depressive symptoms and the various symptoms lie on the continuum (some patients being not depressed on one end of the spectrum to others who are severely depressed). The clinician is responsible for choosing the threshold for intervention according to the severity/persistence of symptoms and need of the patient.

Risk factors for depression in patients receiving palliative care:

1. Younger age
2. Female gender
3. Past history of depression
4. Poor social support
5. Increased functional disability
6. Increased pain and symptom burden
7. Metastasis to central nervous system
8. Metabolic complications
9. Existential concerns

Management of depression in patients with cancer:

1. Psychological treatment should include listening to the problems that the patient reports and allowing him the time and space to ventilate his emotional distress. Formal psychological treatment using techniques of cognitive behaviour therapy and other forms of psychotherapy could be used by specialists trained in those modalities of treatment.
2. Medications, namely selective serotonin reuptake inhibitors, like sertraline and escitalopram are often the mainstay of pharmacological treatment. Patients undergoing palliative treatment often

require lower dose of the anti-depressant medication as compared to those who do not have a diagnosis of cancer. On commencement of a low-dose antidepressant patients need to be reviewed regularly so that the dose of medication can be increased as felt appropriate by the treating doctor. The doctors need to be cautious about some of the side-effects of the above medications like SIADH causing hyponatraemia.

Anxiety disorders

Stress can have both psychological and physical effects. Anxiety disorders are often characterised by autonomic arousal manifested by palpitations, choking etc, cognitive symptoms like fear of impending doom, and bodily symptoms like increased muscle tension and tremors. When patients have free-floating anxiety, they may be diagnosed to have generalised anxiety disorder as opposed to when they have more specific symptoms as in panic disorder, social anxiety disorder, obsessive compulsive disorder etc. When patients fear any particular form of treatment like chemotherapy they may be diagnosed to have procedural anxiety.

Management of anxiety disorders:

1. Patients should be encouraged to practice relaxation methods such as slow relaxed breathing to reduce physical symptoms of anxiety.
2. When patients have procedural anxiety they may benefit from talking to other patients who have undergone that procedure in a group situation. Specialist mental health professionals may be able to undertake systematic de-sensitisation for procedural anxiety over a few sessions.
3. Medications should be used when the above psychological methods fail to alleviate the distress. The medications of choice are the SSRIs in low dose (Sertraline, Escitalopram, Fluoxetine etc). It is important to remember that the effect of medications may take a few weeks and the patient would need continued psychological support during and following this time. In case of acute attacks of anxiety, low dose benzodiazepines as Clonazepam maybe useful.

Substance misuse problems

Patients undertaking palliative care should be screened for comorbid substance use. Common substances that are used in West Bengal include nicotine, alcohol, benzodiazepines, cannabis and opiates.

Management of substance use:

1. While taking history regarding substance use the most important question that the clinician should remember to ask is about the approximate time of last use of the substance. It is not unusual to find that the patient may have used alcohol few months ago in which case one should assume that the patient would not go into a withdrawal state. The mainstay of treatment in this situation would be deaddiction.
2. In a more acute situation where the patient was actively using the substance, clinicians should decide on appropriate plans for detoxification followed by deaddiction. For substances like alcohol which produce physical dependence detoxification is done by a medication that can reduce the withdrawal symptoms over a short period of time. Once the detoxification phase has been completed, deaddiction begins. During deaddiction the emphasis is on psychological treatment that address craving, relapse, prevention and cue management.

Delirium

Delirium often makes patients and un-cooperative and fearful. During delirium patients appeared confused and are often disoriented to time, place and person. Delirium can have fluctuating course and be worse during the evening and night (a phenomena which is referred to as sun-downing). Clinician should be vigilant about the fact that delirium by nature is fluctuating and patients can have few hours every day when he or she behave completely normally.

Management of delirium

1. Delirium is always caused by an underlying medical condition that needs to be corrected.
2. Patient needs to be nursed in a quiet room preferably by the same set of nurses so that he or she doesn't get further confused.
3. It is important to re-orient the patient every now and then by reassuring him that he is being taken care by medically qualified team. It helps to tell the patient the day and the time, so that he or she can keep track of the day's event.
4. At times the patient may be agitated. One may need to use oral or intramuscular anti-psychotic medication like Haloperidol, Aripiprazole etc.

Conclusion

Managing patients such that the care of the mind and the body is integrated, is quite an art. However when done well, it improves patient satisfaction and reduces the stress of caring by the family members and the professionals. All palliative care physicians should aspire to look after the complete person and having a healing effect on the people they treat.

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Chapter 15

Nutrition in Palliative Care

Chapter 15: Nutrition in Palliative Care

Palliative care is a program of active compassionate care, primarily directed towards improving the quality of life for the patient.

An interdisciplinary team that provides sensitive and skilled care to meet the physical, psychosocial and spiritual needs of both the patient and the family delivers it. The largest team could involve several physician and nurses, therapist, psychologist, social worker, dietician and several volunteers.

Good and adequate nutrition is the basic component of healthy life and is also required in disease conditions. Maintenance and correction of nutrition is a major problem in terminally ill patients particularly when they are suffering from advanced malignant disease. Previous surgery, radiotherapy and chemotherapy worsen the problems. Hence the need for improved multinational intake is necessary for mental and physical health, proper dietary guidance is an integral part of a patients care.

Causes of deficient nutrient can be many.

- Anorexia
- Nausea and vomiting.
- Mechanical obstruction in food passage
- Poor obstruction from small instruction
- Excessive loss of nutrients
- Cancer cachexia
- Adverse effects of the treatment

Thus to help with proper nutrition for palliative patient one needs to pay attention to -

- Confirm and access the degree of nutritional deficiency.
- Decide on the type and quality of nutrients.
- Decide and arrange the route and method of administration.
- Access effects and side effects for further continuation.
- Consider social and psychological aspects of the patients and relatives.

One or more of the following routes- may administer the calculated quantity of nutrition to the patient.

Routes for feeding

- Oral route
- Enteral route or Tube feeding.
- Parenteral route or Central / Peripheral vein.

Oral route is the best, simplest, cheapest and most physiological methods to maintain the nutrition. Psychological factors like anxiety, depression and attitude of relatives are also contributing factors but they can be overcome, once the patients appetite improves which can be done by-Persuasion.

- Attractive presentation of food.
- Pleasant environment.
- Correct temperature and aroma of food.
- Small frequent feeds.
- Taste tolerance

- Nutritionally adequate
- Enteral feeding or tube feeding is employed when the gut continues to use by preserving mucosal digestion, pancreatic secretion and gall bladder emptying. Thus preserving mucosal integrity and reducing translocation of gut bacteria into circulation has fewer complications, infections and organ malfunction. It is cheaper than parenteral nutrition.

There are three main methods of enteral feeding-

- Ryle's tube or Nasogastric/nasoduodenal tube feeding-determined by the risk of jejunum aspiration.it is for short term-(<2 weeks).Ryles Tube Feeding: is easy to start, simple to maintain and can b discontinued without any problem. Liquids can be administered.
- Gastrostomy feeding: can be started on easily and thick liquids can be administered.
- PEG- Percutaneous endoscopic gastrostomy /jejunostomy are generally used for long term Enteral feeding(>2 weeks).

It is therefore essential to think of some home made formulations of improved digestibility and texture which can be of better nutritional support than blenderized or elemental diets.

Therefore great hypothesis is laid on malted cereals and legumes, which possess improved bio-availability of nutrients and at the same time enable preparation of nutrient dense and low bulk or less viscous which can be used for preparation of this particular diet.

Enteral Nutrition- With appropriate monitoring, complications associated with enteral feeding may be minimized or prevented. Enteral feeding complications can be categorized as-

- Mechanical-tube migration, tube clogging, aspiration, gastrophageal reflux.

- Infectious – infective diarrhea, aspiration pheumonia.
- Metabolic- electrolyte disturbance, micronutrient deficieny.
- Gastrointestinal-nausea, vomiting, diarrhea, bloating and cramps, constipation.

- Indications for EnteralNutrition
- Upper GI impediment
- Combined modality therapy
- Anorexia
- Psychologic inability

Inability to take large volume of oral feedsA registered Dietitian will plan and prescribe ideal quantity and quality of food which can be preparaed at home with the help of liquidiser, which can give all essential elements of nutrition without any intolerance and side effects.

A list of recipes which can be used as high calorie, high protein foods is given below-

LIQUID DIET	**SOFT DIET**	**FULL DIET**
Egg nog	All foods in liq. Diet	Everything accepted but restriction on spices, and fats.
Milk shakes	Porridges, kheer	
Plain milk	Khichadi,soft rice+ dal	
Buttermilk	Mashed veg.	
Lassi	Boiled/scrambled/poached eggs.	
Veg. Thick soup	Lean meats	
Non-veg soups	Fish [pomfret]	
Cream soups	Chicken [without skin]	

Minestrone soups Coconut water Kheers Thick Kanjis Dal water	Soft custards Puddings Plain gelatins Ice-creams	

Nutritive value of certain foods:

CALORIE CONTENT OF FOOD ITEMS IN CONVENIENT MEASURES

RAW FOODS

Item	Measure	Wt. Gm	Energy	Item	Measure	Wt.	Energy kcal
CEREALS Rice	1 cup (small)	150	520	Coconut (fresh)	1 no	115	510
				Coconut (dry)	1/2 no	45	290
Wheat flour	-–-	90	310	Groundnuts	50 no	15	85
Millet flour	-–-	90	300	Sesame seeds	1 tsp	3	15
PULSES Bengal gram dal	-–-	130	485	Oil/Vanaspati	2 tsp	10ml	100
				SPICES Chilly powder	1 tsp	7	17
Other dals	-–-	135	460				
WHOLE PULSES	-–-	140	470	Coriander seeds	1 tsp	7	20
				Cumin seeds	1 tsp	5	18
Cowpea (lobia)	-–-	135	440	Fenugreek	1 tsp	6	20
Rajmah	-–-	120	415	Mustard seeds	1 tsp	10	5
Soya bean	-–-	130	530	Garlic	7 pods	3	4
GREEN LEAFY	5 bundles	100	62	Onion	1 med	50	30
				ANIMAL FOODS	one	60	100
Other vegetables	--------	100	105				
NUTS AND OIL SEEDS Almonds	10 no	15	85	Mutton	----------	100	194
				Fish (lean)	----------	100	100
				Fish (fatty)	----------	100	150
Cashew nuts	10 no	15	95				

COOKED FOODS

Item	No of serving	Wt.	Energy kcal	Item	Measure	Wt.	Energy kcal
CEREAL PREPARATION	1 cup	100	110	Dahi vada	1	80	170
				Vegetable cutlet	1	30	70
				CHUTNEYS Coconut/ground			
Idli	-–-	60	75				
Plain dosa	-–-	40	125	Nuts / til /	1 tbsp	25	64
Masala dosa	-–-	100	200				
Phulka	-–-	35	80	Tomato	1 tbsp	20	10
Paratha	-–-	50	150	**NON-VEGETARIAN PREPARATI**	1	50	86
Upma	-–-	130	200				
Sevian upma	-–-	80	130				
Bread toasted	2	50	170				
Poha (Awal)	1 cup	100	200	Omlette	1	65	155
Dalia	-–-	140	165	Fried egg	1	50	155
Khichdi	-–-	100	210	Mutton curry	1 cup	145	240
				Chicken cury	-–-	125	260
Puri	1	25	80	Fish (fried)	2 pcs	85	220

PULSE PREPARATION		140	170	**BAKERY PDCTS** Biscuits	2	40	220
				Cake	1	40	220
Sambhar	-–-	160	81	Vegetable puff	1	60	170
Chole/sundal	-–-	150	115	Pastry	1	50	350
VEGETABLE PREPARATI	1 Cup	130	130	Mathri	1	75	300
				SWEETS Laddu,burfi etc	1	60	250
Dry	-–-	100	115	Halwa (suji)	1 cup	130	430
Bagara baigan	-–-	170	230	Double ka	-–-	105	280
Vegetable kofta	-–-	145	220				
FRIED SNACKS Bhaji	1	7	35	Custard /	-–-	110	180
				Chikki	2	60	300
Samosa	1	65	210	Jam / Jelly	1 tsp	7	20
Kachori	1	45	200	Sugar	1 tbsp	15ml	20
Potato bonda	1	40	100	Honey	1 tbsp	15ml	60
Sago vada	1	30	100	Jalebi	2 pcs	100	500
Masala vada	1	20	56	Gulam jamun	-–-	50	400
Vada	1	20	65	Jaggery	1 bsp	15	56

SALADS

Item	No.	Wt.	Energy	Item	Measure	Wt.	Energy kcal
Rice	1	65	30	Cabbage	1	250	70
Carrot	1	40	20	Cucumber	1	90	12
Lettuce	6	100	20	Onion	1	50	25
Radish	1	60	10	Totmato	1	50	10
Turnip	1	100	30				

FRUITS

Item	No.	Wt.	Energy	Item	Measure	Wt.	Energy kcal
Apple	**1**	**100**	**65**	**Banana**	**1**	**80**	**90**
Grapes	**30**	**100**	**70**	**Guava**	**1**	**100**	**50**
Jack fruit	**4piece**	**100**	**90**	**Mango**	**1**	**250**	**180**
Mosambi/ orange	**1**	**100**	**40**	**Papaya**	**1piece**	**250**	**80**
Pineappl	**1piece**	**100**	**50**	**Sapota**	**1**	**80**	**80**
Custard apple	**1**	**130**	**130**	**Watermelon**	**1piece**	**100**	**15**

BEVERAGES

Item	Measure	Wt.	Energy	Item	Measure	Wt.	Energy kcal
Coffee	1cup	150	100	Tea	1 cup	150	60
Carb. beverages	1 bottle	200	150	Fresh lime juice	1 glass	200	60
Squash	1 glass	200	80	Syrups (sherbat)	1 glass	200	200
Orange juice	1 glass	200	150				

MILK AND MILK PRODUCTS

Item	Measure	Weight	Energy	Item	Measure	Weight	Energy kcal
Milk (buffalo)	1 cup	150ml	300	Milk (cow)	1 cup	150ml	100
Curds	1 cup	150ml	45	Buttermilk/lassi	1 cup	150ml	45
Paneer	1 cup	100gm	350	Ghee	2 tsp	100gm	100
Butter	3 tsp	15ml	100	Skimmed milk	1 cup	150ml	45
Khoya (butter spread)		100gm	200	Khoya (from whole milk)		100gm	400
Cheese	1 pkt	30gm	100	Rabadi	1 cup	150gm	525

Cancer, a mal-nourishing disease requires nutrition as its basic principle of Palliative care in treatment of terminally ill. Also the co-operation of relatives, with good and pleasant environment, consideration of cost and liking of patients, goes a long way in giving psychosocial support

Guidelines:

- Complete bed ridden wioth Enteral feeding tube: Different liquid diet recipes but strained can be incorporated in the Enteral feeds.
- Very low appetite with mild dysphagia (head & neck): star on calories dense liquids (home based) feeds at small regular interavals. Followed by full soft, semisoft bland duty.

Semi-unconscious: either full RT, NJT, or NGT feeds are advised

Chapter 16

Rehabilitation in palliative care

Chapter 16: Rehabilitation in palliative care

The focus of Rehabilitation in Palliative Care is to support independence and quality of life by assisting patients to set and accomplish goals in the areas of their lives which are important to them. In cancer care, formalized Rehabilitation involvement was confined to restoration and directed at those patients with a relatively stable or encouraging prognosis. Today, the involvement of rehabilitation is diverse and includes specific roles which is evidence based and commonly applicable.

Usually the objective of treatment is to improve functions but for the terminally ill patients the objective is relief of discomfort. The goals are usually to help the patient adapt to physical limitations and permit the individual to function at the highest possible physical level. Palliative care should not be limited to the end stage of life.

The aim of the rehabilitation therapist is actually somewhat different from its aim in other patients. The rehabilitation therapist is required to demonstrate a high level of problem solving, clinical skills and communication ability in order to be a valuable member of the team that aims at optimizing the patient‘s quality of life.

The ranges of therapeutic interventions provided by the Occupational Therapist include: Education and practical advice on how to manage symptoms associated with fatigue, breathlessness, anxiety and pain. This includes breaking down tasks into achievable steps, prioritising activities, introducing alternative techniques to promote or maintain independence, and advice on conserving energy

- Provision of Assistive Equipment to overcome problems experienced
- with every day activities
- Home Assessment as appropriate to identify what is practically possible
- to support a patient‘s choice to visit, return or remain within their home
- environment, this includes:
- Reviewing how clients manage in their own homes to maximise their independence, comfort and safety
- Advice on home modifications together with advice for carers is also provided
- Advice and provision of specialised seating wheelchairs and appropriate pressure care
- Adaptation for equipment where necessary, to increase independence, safety and enhance social communication
- Relaxation, Anxiety Management and Pain Management Techniques
- Prescribed Therapeutic Group or Individual Activity – This is designed to raise self esteem, increase self awareness and provide opportunities for creative expression and reflection

Habeck and colleagues offered 7 principals of rehabilitation.

- Comprehensive care is provided to address the needs of the whole person. Each person‘s life possesses a unique blend of psychological, social, vocational, economic and physical factors.
- A team approach is used to achieve co-ordination, inter-disciplinary care.
- Goals for rehabilitation are derived from the effect of medical problems in accordance with prognostic expectations.
- Education is a major component of rehabilitation process.
- Intervention occurs as soon as the likelihood of disability is anticipated.
- The unit of care includes both the patient and family.
- Rehabilitation needs must be reassessed on a continuing basis and met throughout all phases of care.

Treatment is directed at various phases.

- Prevention – through whole body and target specific exercise and education programs
- Cardiopulmonary intervention:--- return to physical function through targeted large muscle mass exercise programs; specific management for recovery of musculoskeletal and neuromotor function.
- Bio psychosocial approaches to pain management
- Institutional and community based rehabilitation – through simple measures (eg. wheelchair retraining after spinal cord compression, gait re-training following neurological dysfunction),
- Lymphoedema and incontinence programs, maintenance of mobility and physical function.
- Optimise quality of life and contribute positively to easing carer burden.

Yoga and therapeutic recreational activities help to overcome debility

The specific therapeutic measures for the various disabilities are as follows: Respiratory Insufficiency*:*

30% to 75% patients may suffer from dyspneoa. The therapist is often involved in the care of these patients. The causes are varied it could be due to pleural effusion, pneumonia, metatasis, COPD etc. Techniques commonly used are education in positioning, relaxation, breathing control, increased exercise tolerance through graded exercise, education and participation of the career. For excess bronchial secretions modified postural drainage, forced expiratory technique and humidification can be employed.

Head and Neck Cancer:

The main concerns in these patients are Pain, nutrition, self –care consideration.

Pain could be due muscle weakness and specific nerves being involved due to the extensive surgery involved causing disturbance in the normal alignment of the shoulder and neck. Hence active exercises for neck and shoulder joint and strengthening of shoulder girdle muscles help to improve Scapular stability and thus relieve pain to an extent.

Infrared and Transcutaneous nerve stimulator can also be used for relief of pain.

Patients who have undergone total glossectomy may have difficulty in swallowing. These patients are taught various means by which swallowing can be performed; specially modified feeding spoon with long handle can be used to facilitate swallowing.

When there is a permanent stoma it is important to guide them regarding hygiene and care of the stoma... specially designed shower bibs, made by us, help in protecting the tracheostome at bath time.

Breast Cancer:

Lymphoedema is probably the most painful and difficult problem to overcome during palliative stage.This is handled by providing accurate pressure sleeves. Skin care by applying anti-fungal powder, oils and antiseptic lotions free of lanolin, on cuts, creams should be applied with gentle strokes in retrograde direction. Precautions should be taken to protect the affected arm from cuts, bits burns injuries, tight clothing, carrying heavy bag, taking injection.

Treatment includes*:*

1. Deep breathing exercises,
2. Elevation and supporting the arm from time to time & exercises to molibilise all the joints
3. Superficial and deep massage in the direction of lymph nodes.
4. Special pressure bandaging in layers can be attempted. This can be done by applying at first cotton bandages, and then foam padding is applied over it to protect the joint flexors, finally high compression bandages are applied to give an evenly graduating pressure ranging from moderately high pressure distally to moderately low pressure proximally. The arm is then kept in elevation and active exercises within the closed space of bandages are carried out under supervision.

5. Training in unilateral activities with assistive devices in case of severe lymphoedema, Guidance in performing home activities and job activities, and finally explaining energy conservation techniques while they are on chemotherapy and radiation.

In cases of severe lymphedema and a flail limb, where a layer bandaging is not tolerated, it is possible to use a technique we have recently started to reduce edema. Magnesium sulphate and glycerin are mixed together. Cotton bandages are dipped in his mixture and applied to the limb. Starting distally and going over to the proximal area and ending near the axilla. However care should be taken that these are not applied over broken skin.

Wigs are also provided to overcome psycho-social problems.

Bone and Soft Tissue Cancer:

We believe in fitting and training of specially designed appropriate functional prosthesis, whenever possible, even in palliative cases, so as restore personality and independence. Upper extremity amputees, especially women, are trained in activities of daily living and other household activities, especially cooking with help of unilateral assistive devices. Appropriate orthosis like foot drop stop, knee guard ,cock-up splints are designed for limb salvage surgeries to restore body image and personality and to perform assistive functions.

Pediatric Conditions (Especially leukemia and Hodgkin‘s disease)

Remedial intervention is done to overcome neuro-psychological deficits, learning problems and handle incidental psychological stress. For minimizing the side effects of CNN prophylaxis in cases of acute lymphoid leukemia, therapeutic activities are employed to improve attention span, concentration, memory, perception and Visio-motor co-ordination to facilitate learning.

Patients Receiving Chemotherapy and Radiotherapy*:*

Strength, endurance and range of motions deficit occurs by cancer during prolonged periods of chemotherapy and radiotherapy. The patient is initially evaluated and suitable isometric and isotonic exercises with weight cuffs are used for strengthening limbs. Specially designed spinal braces like taylors brace with axillary support, total contact brace splints like knee guard, foot drop stop, cock-up help in functional restoration, mobility, pain relief and comfortable posture assist in independently living.

Special guidance and counseling is given to ca cervix cancer patients on use of Vaginal Dilator to remedy the vaginal stenosis after Radiation. Family and marital counseling is also given regularly.

Vesicovaginal Fistula (VVF) is a common complication reported in advance gynecological cancer. Radiotherapy is common cause of VVF. **Vesicovaginal Fistula** is an abnormal opening between the urinary bladder and vagina that result in continuous, involuntary dribbling (incontinence) of urine from the vagina.

The treatment for VVF is mainly surgical, in acute cases.

But in advance cases surgical repair is not feasible due to continuous leaking of fluid from vagina. Patients are emotionally, psychological and socially disturbed.

Standard catherization is not feasible in such patients.

In order to deal with such complication innovative device is designed which would give them better quality of life. The device is known as Vegicup.

The common sequel of groin node dissection and patients of Radiotherapy and chemotherapy for Genito-urinary cancers is lymphoedema of lower limbs. It is treated in same way as the lymphoedema of arm in breast.

Home visits are also conducted as part of this program.

Rehabilitation has been described as

–Making a patient into a person again. Someone who feels not only wanted and respected but once again useful and creative.‖

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Chapter 17

The Terminal Phase

Chapter 17: The terminal phase

Introduction

The terminal phase may present new aspects of physical, psychological, spiritual care of the patient. If the patient has received good palliative care it does not automatically mean that the terminal phase is taken care of. Poorly relieved suffering in the days before a person dies is always remembered by relatives and can cause intense distress to them for months and years to come, often obliterating their recollections of all the good care their loved one received before that.(1)

How do we recognize the terminal phase?

As the patient gets near to death he/she:

- Becomes increasingly weary, weak, and sleepy;
- Becomes less interested in getting out of bed or receiving visitors;
- Becomes less interested in things happening around him/her
- Often becomes confused, occasionally with features of agitated anguish.

It may be difficult to differentiate the terminal phase from an acute on chronic, potentially reversible condition. However it may help to know that many of the above signs will simultaneously present in the terminal phase.

Physical symptoms

Common symptom include- pain, asthenia, anorexia, nausea, constipation, confusion, agitation, ‗death rattle', breathlessness.

1. Pain:

Three-fourths of all dying patients will have pain requiring strong opioid analgesics when they enter the terminal phase. In their final 48 h, 13 per cent will then have their dose reduced, 44 per cent will have it increased, and in 48 per cent it will remain unchanged.(2)

Causes of pain in the terminal phase:

1. Disease progression
2. Change in dose or route of administration of analgesic
3. Pathological fracture
4. Constipation or urinary retention.
5. Bedsores

Pain control may require parenteral administration of analgesic-subcutaneous ,iv, patches, per rectal, sublingual as oral route may not be reliable. Do not use methods which interfere with access to the patient. The syringe driver can be effectively and conveniently used to infuse drugs subcutaneously. Pathological fractures can be treated by immobilisation. Pain due to bedsores can also be relieved with topical lignocaine.

2. Dyspnoea:

- Extensive lung metastases or carcinomatous lymphangitis;
- Anxiety or panic;
- Secondary chest infection
- Pulmonary oedema
- Pleural, pericardial effusion
- Anaemia

Treatment includes correction of reversible factors if necessary. Morphine is the drug of choice for symptomatic treatment of uncontrolled dyspnoea .The probable mechanism of action is reduced sensitivity of the medullary respiratory centre to carbon dioxide and decreasing the bronchial secretion through anticholinergic action. In patients with uncontrolled breathlessness small doses of midazolam (subcutaneous or intravenous) or lorazepam (sublingual or iv) can be added to reduce anxiety and panic.

3. Anorexia and cachexia:

Little is known about what causes anorexia in a patient. The elevated levels of cytokines like tumor necrosis factor, interferones alter the metabolic rates and result in wasting syndrome. Frequently, family caregivers believe that wasting is the result of their provision of inadequate care and nutrition. They can be taught to replace their ―need to feed‖ with behaviors that alleviate symptoms, such as moistening the patient's lips and oral cavity with a sponge, offering small amounts of food as desired by the patient, providing light massage, reading to the patient or playing soft music for the patient. Treatable causes of anorexia and cachexia in patients who are near the end of life include chronic pain, mouth conditions (dryness, mucositis resulting from chemotherapy, and infections such as oral candidiasis or oral herpes), gastrointestinal motility problems (e.g., constipation) and reflux esophagitis. In patients with cancer who are being treated with chemotherapy, radiation therapy and/or medications such as opioids or nonsteroidal anti- inflammatory drugs, an attempt should be made to determine whether anorexia and weight loss are due to mucositis, changes in gastrointestinal motility and nausea as the effects of treatment, rather than progressive disease. Parenteral rehydration may be attempted via subcutaneous or iv route in selected cases .A trial of iv fluids may be discontinued after 24 hours if the patient does not improve. Drugs like dexamethasone, megesterol and androgens can be tried.

4. Fatigue/asthenia:

This is the state in which the patient the symptoms of tiredness, a general lack of energy not relieved by rest, diminished mental capacity and the subjective weakness associated with difficulty in performing activities of daily living.

Pathologic fatigue can arise from both physical and psychologic stresses. Physical causes include the direct consequences of a disease process, such as diminished oxygen carrying capacity as a result of anemia or heart failure. Cancer, hepatic or renal failure, and many chronic illnesses (including chronic pain) can cause fatigue. In addition, treatments such as cancer therapy or antihypertensive and cardiac therapy can cause this symptom. Psychologic causes of fatigue include anxiety and depression.

Patient and family education can be of great value. For example, family members may interpret fatigue to mean that the patient is ―giving up,‖ when the symptom is actually beyond the patient's control. Medications notably corticosteroids like dexamethasone 2-20mg daily in the morning may give the patient a feeling of well being and energy. The drug can be tapered after 4-6 weeks. Other drugs like methylphenidate and dextroamphetamine can be tried. Erythropeoitin therapy may work in chronic anemia cases.

5. Nausea and vomiting:

Nausea and vomiting can be extremely debilitating symptoms at the end of life. With available methods, effective control of these symptoms can be achieved in most patients. The brain (chemoreceptor trigger zone, cerebral cortex, vestibular apparatus and vomiting center) and the gastrointestinal tract are the key organs involved in nausea and vomiting. Identification of pathophysiologic origin of nausea and vomiting is essential for prescribing treatment. Commonly

used drugs include metoclopramide, ondensetron, and dexamethasone. In refractory cases, Haloperidol 0.5-2mg can be given orally, SC, IV every 6 hourly upto maximum dose limit of 15-20mg daily.

Psychosocial and Spiritual Issues

1. Psychosocial suffering:

Hippocrates noted that, ‖Young men fear death, old men fear dying.‖ Most patients, if still able to articulate what they are feeling, speak of their fear of confusion, their fears about asphyxia, fighting for breath or bleeding to death. Most, given the chance, tell of their sadness at leaving loved ones and their anxiety about how they will cope. Almost all patients, once they feel able to speak of what lies ahead, seek reassurance that they will not be left alone, will not be allowed to suffer, and will not be a burden on those caring for them.

A gentle touch is often psychologically healing. Many dying persons are comforted when caregivers gently touch their wrist or arm, hold their hand, or hug them. There are evidence on the link between a patient‘s strong confidence and beneficial physiological counseling. Caregivers can help by allowing the individual to talk about his or her concerns, to think about options and ways to fulfill needs, and then by being an advocate for them. It is important to note that it is disempowering when caregivers take over the work of the dying person. It is sufficient to be present and to serve as a sounding board so that the individual can recognize options and think about ways to fulfill needs. Social workers, counselors, and lawyers may also be of help with social concerns.

2. Spiritual problems

For the patient, the terminal phase is a time to look back and a time to look forward. The spiritual problems faced by each individual vary and depend on previously held beliefs. Spiritual distress may be relieved by talking with a person with whom the patient feels comfortable.

Emergencies in the terminal phase

1. Acute Stridor

This may be caused by haemorrhage into a tumour pressing on the trachea or it may be the final stage of progressive tracheal compression. The patient needs to be sedated as

speedily as possible with IV midazolam 5 to20 mg or rectal diazepam solution 10 to 20 mg (which relatives can be taught to use in the home), both effective within minutes.

2. Massive Haemorrhage

It is a rare emergency**.** The commonest sites of such haemorrhage are the carotid (externally) and major veins within the chest (internally) the exact sites only identified at subsequent autopsy. So acute and catastrophic are such events that there is rarely time to do anything other than to curtain the patient off from the view of other patients and visitors in a hospital.

However, where it is recognized that such a haemorrhage might occur it is prudent to have nearby a dark-coloured towel to make the amount of blood lost less obvious to the patient and to have a fast-acting sedative drawn up for immediate sedation. Midazolam 5 to 20 mg IV or propofol usually, by the time the drug has been drawn up into a syringe and administered, the patient is unconscious and is within a minute or so from death.

3. Multifocal myoclonus

It is not uncommon in dying patients and can distress the relatives. Patients are often so ill that they seem unaware of it. It may be caused by dopamine antagonists such as metoclopramide and the neuroleptics and by high-dose opioids, as well as by the withdrawal of such drugs as benzodiazepines, barbiturates, anticonvulsants, and alcohol. The treatment should include:

Sedation with midazolam SC 5 to 10 mg every hour until the patient is settled. Alternatives are rectal diazepam solution 10 to 20 mg every hour or clonazepam SC 0.5 mg hourly until settled.

3. Convulsions

Ten per cent of patients experience grand mal convulsions in the terminal phase .Causes include known epileptics, post- neurosurgery or primary or secondary cerebral malignancies , sudden withdrawal of long-term anticonvulsants. Usually, anticonvulsants must be continued, using either rectal diazepam or SC midazolam via a syringe driver or aqueous solution of phenobarbitone.

4. Urinary retention

It is common in men with advanced disease and requires indwelling continuous catheter.

5. Confusion

Up to 40 percent of terminally ill patients experience confusion for a variety of reasons – primary or secondary brain tumour,epilepsy,metabolic encephalopathy,electrolyte imbalance,side effects of drugs,infection,nutritional deficiency,paraneoplastic syndromes.

Management

Treat any identifiable cause like hypercalcaemia, uraemia, hepatic encephalopathy, sepsis, hyper- or hypoglycaemia, or even a change in surroundings, changes in medication

If the patient is dehydrated it is always worth a short trial of subcutaneous infusion of saline. This will reverse confusion within 24 hrs. Create a quiet environment. Explain to the relatives and visitor the importance of this management. Explain to relatives how to converse with the confused person not trying to correct them, not arguing with them.

Consider a mild tranquilizer such as diazepam 5 to10 mg once daily, or midazolam via a syringe driver. For agitated confusion haloperidol 2.5 to 5 mg may be used. Consider music therapy.

6. Death rattle

It is seen in 25 to 92 per cent of dying patients. This term describes the gurgling, bubbling noise made when a terminally ill patient has secretions at the back of the throat and is too weak either to swallow them or expectorate them. Mechanical suction gives short lived relief. It is best to reduce the secretions with hyoscine hydrobromide, 0.4 tomg SC every 4 h, or continuously via a syringe driver. Glycopyrrolate is a good alternative.

Terminal anguish*:*

Occasionally, the suffering –physical, emotional, spiritual of the patient is so severe that it merits the term anguish. It may be caused by refractory symptoms or new symptoms. It may be difficult to distinguish between the different causes and components of the suffering (1).

The term refractory is applied to symptoms that cannot adequately be controlled despite aggressive efforts to identify a tolerable therapy that does not compromise consciousness. The diagnostic criteria for the designation of a refractory symptom include that the clinician must perceive that further invasive and non-invasive interventions are: (i) incapable of providing adequate relief; (ii) associated with excessive and intolerable acute or chronic morbidity; or (iii) unlikely to provide relief within a tolerable time frame. Terminally ill patients with such refractory symptoms may need sedation. (1)

In their 1990 paper, Ventafridda et al. in Milan reported that 63 of 120 terminally ill patients developed unendurable symptoms that required deep sedation for adequate relief. In almost half the problem was pain.(4) Fainsinger et al. in Edmonton found that 16 out of 100 patients dying in a specialist palliative care unit required sedation for symptom control, six of them for pain.(5) Stone et al.(6) retrospectively comparing two such units in London found that 26 per cent of 115 patients needed sedation, the commonest reasons being delirium, mental anguish, pain, and dyspnoea

Ethical considerations in terminal sedation:

The use of sedation in the management of refractory symptoms has been examined in several studies.(8)

Terminal sedation can have two effects. One is the desired effect to reduce physical and psychological suffering. The other is the undesired effect to shorten life. In this case it is the intention rather than the consequence that is important in judging whether the action is ethically acceptable or not. In other words, the principle of beneficence takes precedence over the principle of non-maleficence. (1)

Methods of sedation:

Only when all appropriate treatment has been given for pain and other symptoms, can sedation be tried. Midazolam, SC via a syringe driver, 20 to 200 mg over 24 h, bearing in mind that tolerance develops rapidly. If it is decided to reduce the dose, it should be remembered that midazolam has an anterograde amnesic effect. The patient will have no recollection of what happened before the sedation (including explanations and reassurances).

On the rare occasions when benzodiazepines cause paradoxical agitation, barbiturates might be tried instead .In skilled hands propofol, a pure sedative, is a useful drug at this time in a patient's life.

It is inappropriate to use escalating dose of opioids to tranquilize such patients. Opioids are analgesic agents, not primarily sedatives. Not only may they be ineffective but neuroexcitatory side-effects such as myoclonus or agitated delirium may develop only adding to the distress

Management in the terminal phase

Planning and teamwork are essential for proper management in the terminal phase The essential steps are-

1. **Review of all medication*:***

Certain drugs like antihypertensives, laxatives, antacids, hypoglycemics ,vitamins, antidepressants can be omitted .Usually analgesics , antiemetics ,anxiolytics ,sedatives are considered essential.

2. **Changing the route of administration of drugs:**

The oral route becomes increasingly unreliable. Other routes like subcutaneous infusion,iv infusion,per rectal administration sublingual may be tried.

3. **Communication:**

At this stage it is important to speak to the patient so that she can convey her hopes and wishes and express her fears. It is important to assure the patient that she will not be allowed to suffer and that her wishes (advance directives) will be respected.

4. **Communication with the caregivers**

It is also important to speak with the relatives to explain possible problems, line of treatment and why certain interventions may withheld .They may also need guidance about calling distant relatives or friends, particularly when they must travel some distance. It will also help to identify the team member who is best placed to provide support.

5. ***Place of care***

Upto 75% of patients may prefer to die at home in a familiar and non-threatening environment. In our country , most actually do, especially in rural areas where medical

facilities are sparse. Feasibility of care at home must be assessed. Options for care elsewhere are- hospital, hospice/palliative care unit, or nursing home must be explored. Particularly when the patient is in hospital must it be decided whether any further investigations (even simple blood tests or chest X-rays) are likely to help or are ethical. Nursing aids available at home must be assessed.

6. **Needs of the relatives as the patient is dying**

The relatives also face several difficulties at this time and need continued support explanations and guidance. Good communication is essential to help them .We must realise that the caregivers may

face the following problems-fatigue, anger at not being fully informed, not knowing how they can help the patient, not knowing whether the patient has died , financial problems.

Death itself:

In the days and hours leading up to the patient's death:
The pulse gets weaker but, blood pressure gradually falls, Respiration become shallower, slower and varies in amplitude, often in a Cheyne-Stokes pattern. Consciousness is slowly lost except in the few patients. The skin gets colder, from the periphery inwards, and feels clammy.
The colour of the skin of the extremities and round the mouth may become faintly cyanotic.
Eventually, all signs of cardio-respiratory function cease and the corneal reflex is lost. The presence of a doctor or a nurse at the patient‘s bedside is strongly recommended during this phase. However, it may not be always feasible.

The responsibility of the palliative care team does not stop when the patient has died and they have said good-bye to the grieving relatives. There is one last thing to do- review every aspect of the care they have given, from the time of first involvement, through the terminal phase to the death. (1)

Was all suffering relieved and if not, what more could have been done?
Was the patient given every opportunity to express their feelings and fears and were they addressed appropriately?
Was death peaceful and dignified in all respects?
Was everything possible done to support and care for the relatives? Where could the care have been better?
How does each member of the care team feel?
What lessons have been learnt that might lead to better care for others?

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Chapter 18

Advance directives and End of Life Decision Making

Chapter 18: Advance directives and End of Life Decision Making

Definition

Advance care planning is discussion with patient and caregivers about the diagnosis, prognosis, treatment alternatives, their risks and benefits and should be in the context of patient‘s goals, expectations, hopes, fears, values and beliefs in order to help the patient achieve sense of control over the situation, confront death and strengthen relationships.

Importance of Advance care planning:

1. Patients have the right to participate in decisions concerning their health care.
2. Physicians have legal and professional responsibility to assure this, even if the patient loses the capacity to make decision.
3. This helps build trust and team work between the patient, proxy and physician in several ways.
4. The invitation to discuss future care permits the patients to explore values, beliefs, goals and preferences of treatment.
5. This also helps prevent future conflict and confusion.

Advance care planning may involve writing ‗living will‘, a written advance directive to be invoked in the event a patient becomes incapable. For a patient to be able to take decision, patient should have the capacity to understand and appreciate the information and understand the consequence of the decision taken.

Capacity can be tested under the following headings:

1. Cognitive Function test; Mini mental scale examination
2. General impression; biased and not reliable
3. Specific capacity assessment (Aid to capacity evaluation)

End of life decision making in capable patient

End of life decision making is a process and not a one time event. Once after the physician has disclosed the diagnosis and prognosis of the disease, the patient and caregivers should be given the time assimilate the facts, ruminate over it and then take the final decision. The approach should be team based, involving physician, nurse, social worker, religious leader and appropriate intervention should be provided.

End of life decision making in incapable patient

When a patient is incapable, they lose their dignity and respect for their intrinsic value as persons since their beliefs, goals and cultures may not be honored. Therefore, written advance directives and the appointment of substitute decision makers are attempts that the incapable person is able to express the goals, choose treatments that he opts.

Substitute decision maker can be a 1). spouse or partner, 2) child(ren), 3) parent(s) 4) siblings, 5) other relatives or friends. Substitute decision maker (or power of attorney)has the authority over others to take decision for the incapable patient. They are asked to decide what treatment would patient have wanted if he or she was still able to communicate to the health care team. When a patient appoints a substitute decision maker, he/she should discuss with the latter what he/she would want in terms of good quality of life.

12 steps to End of life decision making

1. **Start the meeting:** Call for a meeting with the patient. Ask the patient who would he like be present for the meeting and ensure that they are present, ensure privacy and avoid interruptions. If at home, ask the patient whether he will be fine with the health care team to attend the meeting.
2. **Purpose of the meeting:** Explain to the patient that you want to discuss their illness, it course and work with them to decide upon the treatment options. If the patient disagrees, defer the discussion to a later date by emphasise to the patient that this discussion is important and need to occur in the near future.
3. **What do they know and understand about the illness:** Assessment of knowledge will help understand what the patient has been told or has understood about the diagnosis and prognosis of the disease as this will direct our treatment plan for the patient.
4. **What questions do they have?** Having known the diagnosis and prognosis patients and family will be concerned about the course of the disease, life expectancy, family concerns, social problems etc.
5. **Describe expected and likely course of the illness as much as possible:** Avoid false hope as this will affect future compliance or acceptance to treatment.
6. **Explore the patient's and families hopes, concerns, expectations and beliefs.**
7. **Explore the fears with respect to death, physical distress, body image problems and social concerns**
8. **Listen and show empathy by responding to emotions**
9. **Work with patient and family to as a team to develop realistic goal**
10. **Make a plan:** for instance what do we need to decide now? What do we have time to reflect on? What may we need to decide in the future? What may we need to decide in the future? What do we need to consult and what will their role be?
11. **Document what was discussed, what was decided, what issues are outstanding and reasons.** Comment on when remaining issues will be discussed.
12. **Review and Revise:** Document any change in the illness course with every visit. Document change in preference. Document intra-family conflict and resolve.

Written advance directives/Living wills

Some patients may not appoint a substitute decision maker instead they have only written advance directives that describes what kind of treatment they would want in the event of an acute or life threatening illness. This is effective if the person discusses his/her goals and values that would affect his/her decision making in the context of current or future illness with his or her physician and/or family and loved ones.

Problems with written advanced directives

1. Some people change their minds but do not have time to change their advance written advance directives.
2. Others may want to undergo life sustaining treatments; however, when they actually do not need these treatments, the likelihood of benefit in view of their values and goals are very small.
3. Written directives are vague that only define which medical interventions should be undertaken based on anticipated prognosis which at the time of acute deterioration may not be quite clear.
4. The actual situation or illness that occurs may not have been anticipated and written advance directives alone may not provide guidance.

Consent

Patient has the right to make decisions about the medical treatments and care at the end of life and in cases where the patient is incapable of making decision; substitute decision maker can make the decision. Therefore it is essential at the end of life, consent should be taken before doing any intervention or withdrawing or withhold treatment.

Three elements necessary for consent

1. Disclosure: This includes disclosing diagnosis, prognosis, treatment alternatives, their risks and benefits and limits of medical knowledge.
2. Capacity: as explained above
3. Voluntariness: Patients have the legal and ethical rights to make decisions without undue influence from intrinsic and extrinsic sources.

Application of advance directives in practice
Application of DNR(Allow Natural Death) or AND(Allow Natural Death)

If cardiopulmonary resuscitation(CPR) is not appropriate or not desired by the patient, physician should write DNR order. Full code: when you donot resuscitate at all or the patient prefers that in the end of life. Slow Code: CPR is attempted at a slower pace for a shorter duration when patient insists that he would want resuscitation.

Withholding/Withdrawing treatment

This is undertaken when the risk of a particular intervention or treatment outweighs benefit. This is ethically and legally permissible. The intention is neither to cause nor hasten death. And when consenting to treatment, the physician must ensure that the patient is capable when deciding to withhold or withdraw treatment or through a substitute decision maker if incapable.

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Chapter 19

Spiritual Dimensions of Palliative care

Chapter 19: Spiritual dimensions of palliative care

Spirituality holds different meanings for different people, and in India it is closely associated with organized religion. Spirituality and religion are often used as synonyms and as if they mean the same thing. One can consider it as a human being's relationship with God.

When a person is suffering from an advanced stage of a life-threatening disease, he has to come to terms with his own mortality. As Dame Cicely Saunders expressed it _The realization that life is likely to end soon may well give rise to feelings of the unfairness of what is happening, a desolate feeling of meaninglessness. This in turn usually leads to introspection about the meaning of life. It is a great coping mechanism as he looks for comfort and peace and hopes for a peaceful transition

The word –Spirituality‖ comes from the Latin root –Spiritus‖, which means –breath‖- breathe of Life. Broadly it can mean faith, hope, healing, inner peace, a quest into the meaning and purpose of life and a search for the perfect ―way of Life‖.

Spiritual care aims to bring harmony and balance back into the life of the individual. It helps Body Mind and Spirit (Soul) to function as an integrated whole. A person's spiritual growth is essentially a measure of his response and modification in behaviour and attitude to situations, objects and persons around him which may cause him either pleasure or pain.

Terminally ill patients always ponder about their life's pattern and the direction it is moving in and a person's spiritual journey begins with a quest for answers to questions such as:

1. –Why me?‖

When his spiritual needs are addressed he has to understand that it is important not to ask WHY, but learn instead HOW to accept and look beyond the situation. What can be done?

2. –What is the purpose of life in general and mine in particular?‖ This can be directed to Dr. Bernie Siegel's words about how to live.

–Those people who see dying as failure to hold death at bay do not know what success is. A successful life is not about dying. It is about living well. It is important for people to realize that although they may not be able to control all the events in their lives, but they can control their response to these events.‖

3. –What happens when life ends?‖

It is the fear of the unknown which holds people from acceptance of the situation and coming to terms with life and its inevitable end

Forgiveness and a search for peaceful transition are sought after and we caregivers have to guide them through this process. It may form the basis for their belief in afterlife.

It is important to understand that not everything can be explained. There may not necessarily be answers to the questions. . You may not know the answers but you can help the person express the questions. It is sufficient if one can pave the way for him to reflect on these issues and to come to terms with his/her situation

The spiritual needs of a person should be addressed in order that he may come to terms and they can be enumerated as

- The need for forgiveness
- The need for source of hope and strength
- The need for trust
- The need for expression of personal beliefs and values
- The need for spiritual practices

Spiritual Pain can be the result of an experience that completely shatters a person‘s view of life. It takes the meaning and focus out of their existence, leaving them desolate and helpless.

- It is manifested by a deep sense of hurt

Feeling of loss or separation

- Letting down by God or deity

Sense of personal inadequacy

- Loneliness of spirit that may be a lasting condition

In India the family plays a very crucial role in the life of a patient and very often:

1. The family learns about the diagnosis/prognosis before the patient does.
2. Decisions regarding treatment options are often taken by family elders often without consulting the patient.
3. Families tend to be over protective of the patient and often prefer to withhold the truth regarding his condition from him.

Caregivers and patients under palliative care usually find acceptance of the situation extremely difficult. It is important to allow them to vent their feelings. Their emotions may range from disbelief, despair and anger to a complete breakdown. The palliative care team can initially only be there while the parents struggle with acceptance, hoping to win their confidence.

In India, people attribute most things that happen to them to their _karma‘. This simply means the result of one‘s past action. Since Hindus believe in rebirth, patients and their families often attribute their present situation to their actions in some past life

There is also a tendency to be passively fatalistic; believing whatever has happened is in their _naseeb‘ or _kismet‘. The belief is that what they are going through is preordained and they will have to go through to it no matter what. This is a form of acceptance but usually with a depressed frame of mind, not acceptance which is proactive and can lead making the most of whatever life there is left.

The role of the caregiver and quality of care is determined greatly by the caregivers own spirituality. We need to be full of compassion/empathy/ in touch with our inner selves. We will all agree how important it is to say a small prayer before our duties in order to stay FOCUSSED.

Spiritual Care requires:

- An understanding of the patients religious and philosophical views
- Respecting the beliefs and practices even if it differs from the care givers own beliefs
- Care givers must establish the trust that allows the patient to disclose/ventilate his feelings
- Care givers should recognize and acknowledge one‘s limitations in the understanding of these beliefs, and could seek help when necessary

The essence of Spiritual Care is not about DOCTRINE or DOGMA, but the capacity to enter into the

world of others and to respond with feeling. This fundamental capacity involves touching another at a level that is deeper than ideological or doctrinal differences.

Death and Dying is not the ultimate tragedy of life. The

tragedy

- Depersonalization
- lack of spiritual care
- alienation from a desire to experience the things that make life worth living separation from Hope

–May we live by the awareness, Lord, that life, death and love is three aspects of the same reality‖.
Elizabeth Kubler-Ross

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Chapter 20: Bereavement

'A man's dying is more the survivor's affair than his own.'

Thomas Mann

Care for the family and bereavement follow-up is considered part of good palliative practice. It implies that Palliative Care does not cease with the death of the patient. It offers a support system to help the family cope not only during the patient's illness, but also through their bereavement.
The key concept for understanding bereavement is therefore ‗loss'. Before we

begin:

- **Bereavement**: This is the state of loss resulting from death. Bereavement is a natural phenomenon, affecting persons of any age, and all social classes.
- **Grief**: This is an emotional response to associated with loss. It is the feeling of reaching out to the departed one, only to find the loved one will never be there physically again.
- **Mourning**: This is the process of adaptation including cultural and social rituals prescribed as accompaniments.
- **Anticipatory grief**: This precedes the death and results from expectation of that event.
- **Pathological grief**: This represents an abnormal outcome involving psychological, social and physical morbidity.
- **Disenfranchised grief:** This is the hidden sorrow of the marginalized where there is less social permission to express many dimensions of loss.

Stages of GRIEF: Bereavement as a process

1. **Initial shock**: Initially there is total numbness even if the end stage has been lingering. This is because there is finality to Death. The loss doesn't seem real. Unable to take in the reality of the loss. Lasts hours or days.
   Numbness or Blunting / Disbelief / Relief (To accept the reality of the loss Initial reactions;

Relief	70 %
Numbness	22 %
Disbelief	8 %

2. **Yearning**: All the physiological symptoms of anxiety and fear. Going over the build up and how it really happened. Finding faults with situations or people. The Behavior is such: because they have never felt like this before.
   Sadness / anger / guilt / restlessness / insomnia (Experience the pain of grief) Common emotions and experiences during Grief

Sadness	77 %
Anxiety	15 %
Insomnia / Guilt	8 %

3. **Apathy & despair**: The bereaved starts feeling empty. I am half the person the other half is gone. Not found anything to replace the void. Loss of meaning in life.
   (Adjust to environment in which the deceased is missing)
   In India the loss of meaning in life factor was found to be negligible
4. **Recovery / resuming** Adjustment and Acceptance. The functioning of mourning is to detach the survivor's memories and hopes from the deceased painful inner process of letting go. Appetite for food / sex / happiness starts to return.
   (The Road Ahead: Acceptance)

Studies show overwhelming preference for dying at home, a gradual and peaceful death. With caregivers, the first reaction is most often of relief and sadness. Despair and loss of meaning in life was rare and abnormal grief seen only in 11 cases. Only half of the deceased had been principal bread earners for the family.

Theoretical models explaining bereavement phenomena

Name of the Model	**Main Features**
Attachment Theory	The bonds of close relationships are severed by loss
Psychodynamic Theory	Early (childhood and early life influences) relationships lay down template that guide future relationships
Interpersonal Model	Relational influences are dominant in grief outcomes
Psychosocial Transition	Alteration in the individual's sets of ideas and beliefs are central to adaptation
Sociological Model	Cultural influences shape he form and content of grief
Family system Theory	Family are the main source of support; family functioning determines outcomes
Cognitive Stress coping theory	Conditioned and Learnt patterns become entrenched
Traumatic Model	Intrusive aspects of trauma dominate

Ethology	Biological and physiological processes underpin the phenomena across species

Normal grief

The expression of normal grief is evident from its emotional, cognitive, physical and behavioural features.

Emotional distress occurs in waves that last for minutes at times and involves unavoidable crying, loss of concentration, purpose while preoccupied with thoughts about the deceased and range of associated effects including sadness, anger, despair, anxiety and guilt. Cognitive process become dominated by memories reflected in story telling, reminiscences and conversation about the deceased. Physical responses included numbness, tension, tremors, sleep disturbances, anorexia, weight loss, fatigue and aches. Finally, behavioural aspects include social withdrawal, wandering, searching and seeking company and consolation. Grief and depression lie on biological continuums that are characterized by both somatic and psychological component.

Clinical presentation of pathological grief

Inhibited or delayed Grief

According to Bonnano, some individuals show little distress or disruption following loss with relatively stable and health functioning. He refers to this group as resilient.

Complicated Grief

The clinical features include

a. Disbelief regarding the death
b. Yearning and longing for the deceased
c. Loss of meaning in life
d. Distrust for others
e. Excessive irritability and anger
f. Feeling the future is bleak
g. Unable to carry on with regular activities

According to DSM V criteria, above features must last for a period of atleast 6 months to be diagnosed as complicated grief.

Risks of complicated grief include cardiac distress, hypertension, alcoholism, drug abuse/smoking and suicidal ideation.

Who are the individual at risk of complicated grief?

Attachment process plays a central role in predicting the grief response especially so in individuals with childhood neglect or abuse.

Traumatic Grief

When the death has been unexpected or shocking, its integration and acceptance may be interfered by the arousal and increased distress that memories can trigger. The features merge fully with the features of PTSD and may persist for years contributing to substantial morbidity.

Depressive and Anxiety disorders

Both present in the range of 15-30% may present with features of either or both the symptoms.

Alcohol and Substance abuse

This group takes to alcohol, cigarette smoking, substance abuse including benzodiazepines.

Psychotic Disorders

Grief leads to relapse of psychotic disorders, though mania has been reported to occur for the first time.

Greif therapies

Those at risk of maladaptive outcome or those in whom complicated grief can be predicted will need therapy.

Guided mourning

The method includes narrative review with repetitive recollections of the deceased being actively encouraged to relive and eventually revise the relationship experienced, ultimately redefining the reality of self and situation. Worden emphasized the accomplishment of 4 basic tasks of mourning;

a. Accepting the reality of loss
b. Working through the pain of grief
c. Adjusting to the new environment without the loved ones
d. Establishing a collection of positive and useful memories of the deceased for future reference.

Interpersonal psychotherapy

This places emphasis on the nature of relationships and how the bereaved functions within this. Depending on the degree of attachment and insecurities of loss, the bereaved could easily be vulnerable to suicidal ideations, alcoholism and drug abuse.

Cognitive Behavioural Therapy

This approach helps optimize socialization through activity scheduling, moderate inappropriate drug and alcohol use, graduated involvement in new roles and responsibilities. All these steer towards a constructive adaptation.

Family Focused Grief therapy

This aims at enhancing cohesion, promoting open communication of thoughts and feelings, teaching effective problem solving to reduce conflicts and optimize tolerance to different opinions, the improved functioning of the family as a unit becomes the means to adaptive mourning

Pharmacotherapy

Benzodiazepines allay anxiety and sleep problems, however to be used intermittently so to avoid tachyphylaxis and dependence. Antidepressants like tricyclics may help in depression with insomnia, SSRI/SNRIs are indicated. Occasionally antipsychotics are needed in hypomania or other forms of psychosis.

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Chapter 20

Self Care

Chapter 20: Self Care

Caring for people with chronic illnesses is very stressful, whether you are a health worker, a volunteer or a family member. Sometimes carers can become overwhelmed by the work and feel unable to carry on; this is called _burn out'. It is important that we look for signs of stress both in our team and ourselves and in the families we are caring for.

Definition of Burn Out

Burnout can be defined as exhaustion in a person because of over-work and long term stress. It can result in a drop in the efficiency and performance of the person. It is seen in all fields of life, like work pressures at offices, in competitive sports.

In a health care situation we may come across burnout during long term caring of patients with advanced diseases like cancer, which are being treated palliatively. Hospital staff can come under require prolonged stress due to overwork. Burnout is often seen in younger staff. Members of the patients' family can very often suffer from burnout for the same reasons, particularly as they are emotionally involved with the patient as well.

Causes of Stress and Burnout in Hospital Staff

- Stress in Palliative Care is a Result of Nature of Work
- Continually forming new relationships with patients
- Simultaneously preparing for termination of the relationship
- Emotional exhaustion due to over involvement with patients
- Unrealistic expectations of outcome and of what they can offer patients
- Guilt at lack of success
- Damage to Self esteem
- Demoralization; Feelings of helplessness and hopelessness
- Dealing with Demanding Patients and/or Demanding/Difficult Relatives
- Work Overload
- Team Communication Problems

Stress in Palliative Care is a result of the nature of work it involves, namely dealing with terminally ill patients. The doctor, nurse and rest of the team have to continually form new relationships with different patients. At the same time however they have to be prepared for termination of the relationship when the patient passes away. Most of them try to do the most they can for the patient in what may be a short duration.

Very often they get very close to these patients and are involved in many non –medical problems concerning the patient and his family. This can lead to stress because of emotional exhaustion due to over involvement with patients. Another reason for stress is the unrealistic expectations of outcome of the treatment or support. .they offer their patients. They are often disturbed that they may not be doing enough.

Despite the knowledge of the very nature of palliative care, staff often suffers from guilt at lack of success in treating the patient. This leads to damage to their self esteem and can even be demoralizing. They often have feelings of helplessness and hopelessness. Other causes of staff stress can be dealing with demanding patients and/or relatives. Most palliative care units are short staffed and there is always the stress of work overload.

The Palliative Care unit is a team and sometimes there may be personal differences between the members. Problems of communication or interaction between various members of the team can lead to a lot of stress.

Warning Signs

- Lack of Motivation
- Avoidance of Duty/ Dying Patient
- Distancing or Depersonalization
- Excessive Anxiety
- Irritability
- Physical signs of Stress
- Raised BP and pulse rate
- Sweating
- Displaced Anger
- Error in Judgment

Very often the staff members show no interest in the work they do. This lack of motivation is often an early sign of stress. Sometimes because of their involvement with the patients, they may find their loss difficult to handle. This can lead to avoidance of duty or attending to a dying patient. This can also be demonstrated by acts of distancing or depersonalization. This should not be mistaken for callousness particularly in members who have always been very dedicated. Theses are all signs of stress build up or burnout.

Stress is also manifest as excessive anxiety, irritability and other common physical signs such as raised BP and pulse rate and sweating. It is not uncommon to come across displaced anger, when the stress of something is released by losing temper with someone else. A person under stress can make an error in judgement while dealing with the patient or even in other non-medical situations.

The role of the team leader in anticipation and prevention of such situations is very crucial. They have to take note of warning signs and take steps to prevent stress build up and burnout

Prevention of Burnout

- Establish Boundaries
- Accept you can care without helping
- Not curing does not mean failure
- Self awareness even of negative feelings
- Limit hours of involvement
- Take time out for recreation, picnics or outings with team

While there are several steps that the authorities can take to reduce or prevent burnout among the staff certain techniques can be adopted by the staff as well. It is important to establish boundaries while working with palliative patients. Accept that there are limits to the results you can achieve and also do not get too involved emotionally with the patient or family. Sometimes just spending time or listening gives a lot of satisfaction to the patient. Further these patients are not going to get better- but not curing does not mean failure.

Do not get carried away in your enthusiasm to serve and help these patients. It is difficult to sustain and leads to stress and irritability. It is important to be centered and develop self-awareness even of negative feelings. Take care to restrict or limit hours of involvement. Take time out for recreation. The department should organize picnics or outings for the team.

Dealing with Stress and Possibility of Burn out:

- Supervision and Sharing with others
- Debriefing at the end of the day
- Staff Support Meetings with a Facilitator
- Facilities for Meditation, Yoga at work

- Art and Music
- Redistribution of Work Load – not deal only with Dying Patients
- Continued Education to improve and increase Skills
- Develop own Sense of Self Worth
- Have Personal Philosophy and/or Deep Spirituality

The authorities and department can offer facilities that help to prevent burnout or deal with stress. Supervision is important in spotting any signs of stress. Staff should have opportunities to share their experiences with others. Debriefing at the end of the day is another important way of reducing stress. Regular staff-support meetings with a facilitator help to achieve this.

Hospitals should offer facilities for Meditation and Yoga at the place of work. Hobby courses such as art and music are also welcome. The coordinator should consider redistribution of work load so that certain staff members do not deal only with dying patients. Authorities should offer facilities for Continued Education to improve and increase skills. All this helps to develop own sense of self worth and prevents the staff from feeling de-motivated.

Finally staff working with terminally ill patients should have a personal philosophy and/or deep spirituality, which help them accept death as a part of life.

Care Givers' Stress and Burn Out Causes

- Long term or Continuous Caring
- Anxiety of other associated family problems
- Finances
- Family Situation and needs
- Over Responsibility
- Lack of Acceptance of Medical Condition of Patient
- Unrealistic expectations of outcome
- Guilt
- Secrecy and Lack of Open Communication
- Anticipatory Grief
- Difficulty in Expressing Negative Feelings

Long term or continuous caring can lead to burnout of caregivers. This is often compounded by the stress and anxiety of other associated family problems.
Finances, needs of other members of the family particularly children can cause intense worry and stress. Sometimes the primary caregiver refuses to share the burden and the over-responsibility towards the dying patient can lead to burnout.

Other causes of stress and burnout are lack of acceptance of medical condition of the patient and unrealistic expectations of outcome of treatment. They still hope the patient will recover. Another cause for stress is anticipatory grief when the caregiver behaves as if the patient is already no more. Further there is a feeling of guilt when they are away from the ptient and cannot enjoy anything in life. This can lead to resentment but they have difficulty in expressing negative feelings like resentment and anger which are bound to arise at times.

A major cause of stress is secrecy and lack of open communication within the family. Everyone thinks they are protecting the patient by not telling him the truth about his condition. This causes a lot of tension for all including the patient

Warning Signs

- Excessive Anxiety
- Tears
- Irritability
- Physical signs of Stress
- Raised BP and pulse rate
- Sweating

- Displaced Anger
- Unwillingness to Acknowledge One‘s Distress

Warning Signs of stress and burnout include excessive anxiety, tears without reason, irritability and other physical signs such as raised BP and pulse rate. There is also unwillingness to acknowledge one‘s distress and a tendency to continue with routine.

Prevention

- Accept Help of any type
- Take Time Off
- Retain old contacts and habits
- Eat and Rest well

Prevention of burnout in caregivers is possible if they continue to take care of themselves as well. Caregivers should eat and rest well and take time off from caregiving. They should not hesitate to accept help of any type from family and friends. They should try and retain old contacts and social activities at least to some extent.

Dealing with Stress and Burn Out

- Accept reality of Situation
- Regular Respite from Caring
- Take Some Time Away
- Share the Care giving
- Yoga and Meditation
- Support Groups

One can help deal with stress and burnout by first of all accepting the reality of the situation. Then one will be able to enjoy whatever time is spent with the patient.
It is important to take regular respite from caring – both for the patient and caregiver. The primary caregiver should not be over-responsible and should share the caregiving. Yoga, meditation and other relaxing techniques help both patient and caregiver; so do Support Groups.

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Chapter 21

NURSING ASPECTS IN PALLIATIVE CARE

Chapter 21

NURSING ASPECTS IN PALLIATIVE CARE

INTRODUCTION

A nurse has a unique role in the multidisciplinary team, because of her frequent contact with patients and their family members. Palliative nursing combines a scientific approach with a humanistic approach to care. The caring process is facilitated through a combination of science, presence, openness, compassion, mindful attention to detail, and teamwork. The patient and family is the unit of care. The goal of palliative nursing is to improve the quality of life across the illness through the relief of suffering, including care of the dying and bereavement follow – up.

DEFINITION: Palliative care is defined as-"The active total care of patients and their families by a multi- professional team (Doctors, Nurses, Social Workers, Clinical Psychologist and Volunteers, voluntary organizations) , when the patients disease is no longer responsive to curative treatment."

PRINCIPLES OF PALLIATIVE CARE

- Best possible quality of life.
- Accept that dying is inevitable.
- Palliative care neither hastens nor delays death.
- Palliative care covers all aspects of patients care.
- Support for the family.
- Ideal in home situation.
- Palliative care is team- work.

ACTIVITIES OF THE PALLIATIVE CARE CLINIC

- Registration of patient.
- Psychological assessment of care giver and patients.
- Nursing assessment of patients.
- Doctor's assessment for symptom management and plan of treatment.
- Providing home care services.
- Reference: for hospice care.
- Responding to phone calls.
- Follow – up.
- Maintain the records.

NURSING ASSESSMENT

- Assessment of general condition of patient.
- Activities of daily living.
- Eating habits like and dislikes.
- Bladder and bowel habits.
- Sleep and mood.
- Personal and oral hygiene.
- Psychological needs.
- Financial crisis, economical status.

- Spiritual concerns.

NURSES ROLL IN SYMPTOM MANAGEMENT

- Counseling
- Explanation
- Management
- Education
- Supervision
- Attention to detail

SYMPTOM MANAGEMENT

PAIN:

Pain is common 'pain is what the patient says hurts' it is an unpleasant sensory and emotional experience associated with actual or potential tissue damage or describe in terms of such damage.

CAUSES:

- Physical
- Psychological
- Social
- Spiritual

ASSESSMENT:

- Words to describe pain
- Intensity (0-10)
- Location
- Duration
- Aggravating and Alleviating Factors?
- How does pain affect your daily living?
- Are you experiencing any other symptoms?

MANAGEMENT

Pain relief often requires a broad- spectrum approach.

- Relief at night.
- Relief at rest during the day
- Relief on movement (not always completely possible

THE 3- STEP ANALGESIC WHO LADDER FOR CANCER PAIN

PRINCIPLES OF GIVING DRUGS

- By the mouth
- By the clock
- By the ladder

INSTRUCTION ABOUT THE USE OF OPIOID

- The importance of drugs must be emphasized to patients and careers
- Explain about the timing and effect/ side effect of the drugs.

Using transdermal Fentanyl patch

- Trasdermal fentanyl is an alternative strong opioid which can be used in place of both oral morphine and subcutaneous morphine.
- Indication for using fentanyl patch include
- Intractable morphine-induced constipation.
- Intolerable adverse effects with morphine
- Difficulty swallowing oral preparations
- Poor compliance with oral medication
- Transdermal fentanyl is contra- indicated in patients who need rapid titration of their medication for severe pain.
- Fentanyl patches are available in four strengths: 25,50,75,100 ug/h for 72hrs.
- Place patch on the upper body in a clean,dry,hairless area
- Choose a different site when placing new patch, then remove the old patch
- Wash hands after handling patches.

NAUSEA AND VOMITING:

It is very common and unpleasant symptoms due to disease, drugs and immobility

MANAGEMENT

- Make an assessment
- Consider the causes
- Choose the antiemetics.

NURSING MANAGEMENT

- Explain the cause of the symptoms
- Explain how to take anti- emetics
- Provide oral care after each episode of emesis
- Decrease noxious stimuli such as odors and pain
- Restrict fluid with meals.
- Eat small frequent meals
- Eat bland, cold or room- temperature food
- Wear loose- fitting clothes.
- Have fresh air with a fan or open window.
- Avoid sweet, salty, fatty and spicy foods.
- Limit sounds, sights, and smells that precipitate nausea and vomiting

CONSTIPATION:

- Constipation (difficulty in defecation) is common in advanced cancer.
- Causes are due to disease, drugs, local anal / rectal pathology

MANAGEMENT

- Remove any underlying cause if possible
- Use of oral laxative and consider the use of per rectal measures.

NURSING MANAGEMENT

- Explain the medication properly
- Assisting with oral fluid intake as well as dietary interventions
- Discuss pt about the management needs, as well as personal cultural perspective
- Advice proper diet
- Encourage more fiber and carbohydrates in the food
- Advice physical exercise if possible.

DYSPNEA

Breathlessness / Dyspnoea is an unpleasant awareness of difficulty in breathing. It is a subjective experience; common in terminal stage in 70% of patients .It is more severe in the last few weeks before death.

Non-Drug Methods:

- Explanation of causes of breathlessness
- Assurance that breathlessness is not damaging to the heart or lungs.
- Assurance that the patient will not die during an acute exacerbation
- Allow expression of grief over loss of physical abilities and roles.

General Measures:

- Modify way of life – sit to wash – shaving - cooking
- Organize daily activities eg.eat –rest, wash-rest, dress-rest etc.
- Space around bed
- Loose clothing around neck
- Avoid excessive hot environment
- Ventilation
- Cool wet flannel wipe over face

Physiotherapy:

- Positioning
- Breathing exercises e.g. Breathing of slowly through pursed lips can help patients with expiratory obstruction
- Relaxation Therapy : slow regular deep breathing – reduces anxiety
- Relaxed shoulders, back, leg and arms
- Massage

DEATH RATTLE:

It is the term applied to describe the noise produced by the turbulent movements of secretions in the upper airways that occur with the inspiratory & expiratory phase of respiration in patients who are dying.

Noisy, rattling breathing in patients who are dying is commonly known as death rattle. This noisy moist breathing can be very to visitors & health workers. Because it may appear that the patient is "drowning in his or her own secretions". It occurs in 23 to 92 % patients in the last hours of death.

Assessment: If the onset is sudden and is associated with acute shortness of breath and chest pain.

Management of death rattle:

Change positions
Suctioning
Hyoscine hydro bromide
Family teaching

ORAL CARE

Mouth care involves the washing of the oral cavity with stream of solution.

Purpose:

- Reduce the odor
- Provides antiseptic effect
- Relives inflammation, congestion and pain

Procedure:

1. Take one glass of Luke warm water and antiseptic solution in proper strength or take a pinch of edible soda bicarbonate or common salt. Ask the patient to gargle every two hours and after meals. Do not use alcohol-based mouthwashes.
2. Use an extra-soft toothbrush, rinse toothbrush after use
3. Brush tongue
4. Eat a soft diet. Avoid foods that are acidic, salty, spicy or dry
5. If mouth is sensitive, use dentures only at mealtime
6. Suck on sugarless candy or gum to keep mouth moist
7. Avoid very hot foods
8. Use systemic and/or local analgesia for pain
9. Medicated mouth rinse as prescribed by physician

NUTRITIONAL SUPPORT

Various criteria can be used to help identify the patient who is at high risk of malnutrition. High calorie and high proteins drinks, liquidizing food, eating and drinking little and often are helpful.

Nasogastric feeding

Nasogestric feeding is useful for short- term use, various difficulties can be encountered

- Accidental displacement of tube
- Aspiration
- Blockage
- Irritation of nasal tissue
- Patient dislike

Percutaneous endoscope gastrostomy (PEG)

This technique allows fixed placement of feeding catheter through the abdominal wall into the stomach under sedation. PEG is use full for long term use.

TUBE CARE

- Advice semi Fowler's (propped- up)position
- Use "Asepto" syringe for feeding
- Give the feed at room temperature and strain each feed
- Rinse the tube before and each use.
- Always remember that any medication administered via tube should be dissolve properly
- Never attempt force in case of blockage
- Cleanse the tube once a week using cooled boiled water with sodabicarb

TRACHEOSTOMY CARE-

A tracheotomy is a surgical opening in the anterior wall of the trachea for providing a patent airway. Many patients manage effective self- care and will wish to do so even in advanced disease

- Counseling
- Wear a bib over the stoma
- Humidification
- Mobilization and reduction of secretion
- Suctioning
- Changing and cleaning of tube

PERINEAL CARE

VAGINAL DOUCHE
The word "douche" means when a stream of fluid is directed into a body cavity. "Vaginal douche" is the washing of the vaginal cavity by a antiseptic liquid at low presser.

Purpose

- To clean the vaginal canal and remove the offensive discharges.
- To relive inflammation congestion and pain.
- To minimize hemorrhage
- PROCEDURE
- Collect the articles.
- Use clean technique. Hands should be washed before and after the procedure to prevent cross infection.
- Use gloves
- Carefully remove and destroy pads used by patient.
- Clean the perineum before the douche.
- Use solution at correct strength.

- Apply lubricant to nozzle of the douche than insert the nozzle into vagina .
- Push the solution slowly.
- Clean the perineum and apply the medication .

LOOKING AFTER THE FAMILY

- Counseling
- Availability of resources
- Social and financial problems
- Help from other voluntary organizations

FOLLOW – UP

- Explain the imp of follow up
- Palliative card and pall no
- Contact no and timings to contact
- Contact to local GP
- Reference letter for out station patients

CONCLUSION

The nurse plays a key role in the management of palliative care patients. Good communication, nursing skills are essential in order to deliver optimal care and to improve the quality of life for both patient as well as the family members and to meet the needs of the patient.

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Management of Fungating wound

Fungating wounds are one of the very distressing problems for many patients with advance cancer. These lesions are commonly known as 'fungating wounds', the term 'fungating' referring to a malignant process of both ulcerating and proliferative growth. Anaerobic and aerobic bacteria proliferate in these conditions and are probably the sources of the malodour and exudate that are commonly associated with these wounds.

The nature of the damage includes proliferative growth, loss of vascularity and necrotic ulceration and can extend to sinus and fistula formation. Thus for some cancer patients the presence of a malodorous, exuding, necrotic skin lesion can be a constant physical reminder that their disease is both progressive and incurable wounds.

MALODOUR:

Wound malodour is probably the most distressing symptom for patients and is caused by bacterial infection in devitalised tissue within the wound. This can also be devastating for the patient's family and caregivers, as wound malodour may be constantly detectable and can trigger

gagging and vomiting reflexes. The presence of a pervasive malodour can lead to embarrassment, disgust, depression and social isolation and may have a detrimental effect on sexual expression causing relationship problems.

MANAGEMENT

Debridement:

Debridement removes necrotic tissue and bacteria and is the primary treatment for malodorous fungating wounds. Surgical or sharp debridement, however, is not recommended because of the increased tendency of these wounds to bleed.

Antibiotic therapy:

Topical preparations of metronidazole gel have been used successfully. This gel is usually applied once daily for five to seven days but may need to be repeated more often to keep malodour under control.

Sugar paste and honey:

The high sugar content of these products produces a hyperosmotic wound environment that inhibits bacterial growth and assists in wound debridement. Honey may also contain bactericidal hydrogen peroxide, which is slowly released as the honey is diluted in wound exudate, while specific types of honey may have plant derived antibacterial properties.

Activated charcoal dressings:

Can have an immediate effect on wound malodour. Activated charcoal acts by adsorbing the volatile odour causing molecules, preventing their escape from the local wound area.

Natural live yoghurt

There is little research to support the use of live yoghurt, it may help for debride the wound and prevent the growth of bacteria, there by encoring healing. It also lowers the PH of the wound environment .The yoghurt is applied to the wound and left for 10 minutes than thoroughly rinsed off and apply appropriate dressings.

Exudates

Fungating wounds often produce excessive amounts of exudate which can be difficult to manage. A variety of dressings have been evaluated for the management of exudate from fungating wounds.

Low Exudates wounds:

It should be managed with dressings that have a low absorbency so as not to dry out the wound, for example hydrocolloids, semi-permeable films and low adherent absorbent dressings.

High Exudates wounds:

More commonly fungating wounds produce moderate to high levels of exudate and it is important to choose a dressing that will absorb excess exudate, but still maintain a moist wound environment. Suitable dressings for wounds with high exudate levels include hydrofibre dressings, foam dressings and non-adherent wound contact layers, such as soft silicone with a secondary absorbent pad. For wounds with a small opening and high exudate, a stoma appliance or wound manager can be used.

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