

# Palliative And End Of Life Care

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## Abstract

### EPIDEMIOLOGY

The epidemiology of mortality is different in developed countries where cardiovascular diseases and cancer are the predominant killer while communicable diseases account for significant number of deaths among developing countries. AIDS is also emerging as an important causative factor, as one estimate accounted for <1% of all deaths due to HIV infection, and even the leading cause among youngsters.

While precise estimates are not available, it is estimated that in developed countries ~70% of all deaths are preceded by a disease or condition such that it is reasonable to plan for dying in the foreseeable future. However, cancer has served as the paradigm for terminal care, the many other conditions have recognizable terminal phases, a systematic approach to end of life care should be part of all medical specialties.

Over the past few decades, a significant change in the site of death has occurred that coincides with patient and family preferences. This trend has led to appropriate service centers in variety of settings, including non-institutional settings.

### HOSPICE AND PALLIATIVE CARE FRAMEWORK

Central to this type of care is interdisciplinary team approach that typically encompasses pain and other symptom management, spiritual and psychological care for the patient and support for family caregivers. The fundamental to ensuring quality and end-of-life care is a focus on four domains:

1. Physical symptoms
2. Mental or psychological symptoms
3. Social needs including interpersonal relationship, care-giving and economic concerns;

4. Existential or spiritual needs.

### ASSESSMENT AND CARE PLANNING WHOLE PERSON ASSESSMENT

The person should be assessed as a whole considering all the four domains as mentioned above. The questions asked should not be only elucidating symptoms but of comprehensive nature. Invasive nature tests and even examinations should be avoided.

### COMMUNICATION

When symptoms are life threatening, there are many situations when good communication is required while delivering bad news. An organized and effective procedure for communicating bad news with seven steps goes by the acronym, P-SPIKES;

1. Prepare for discussion
2. Set up a suitable environment
3. Patient/family understanding
4. Information – how much they want to know
5. Knowledge needed
6. Emotional response
7. Share plans for next steps

### CONTINUOUS GOAL ASSESSMENT

The major barriers to ensure palliative care are difficulty in providing accurate prognosis and emotional resistance of the family to accept the implications of poor prognosis. The practical solution is into integrate palliative care with curative care regardless of prognosis. The continuous goal assessment in these settings will help to ensure proper

patient-family-physician relationship and palliative care.

## **ADVANCED CARE PLANNING**

This is the planning of future medical care in case patient is incapable of making medical decisions. The steps involved are introducing the topic, structuring a discussion, reviewing plans that have been discussed by patient and family, documenting the plans and implementing the advance care directive.

## **INTERVENTIONS**

### **PHYSICAL SYMPTOMS AND THEIR MANAGEMENT**

Pain is the most common symptom and it has been quoted as vital sign. The variety of symptoms varies with the diseases and many other symptoms.

### **PAIN**

About 36-90% of advanced disease patients experience pain. In SUPPORT study of hospitalized patients with disease conditions and an estimated survival of <6 months, 22% reported moderate to severe pain and 56% had such type of pain during their last few days of life.

The interventions for pain must be tailored to each individual. The WHO three-step approach involving non-opioid analgesics, mild opioid and strong opioid, with or without adjuvant is accepted widely.

### **CONSTIPATION**

Upto 90% terminally ill patients have complaints of constipation. While poor diet and immobilization are important factors, hypocalcaemia and use of opioid and other medicines can contribute to the symptoms. Use of laxative and stool softener should be used regularly.

### **DYSPNOEA**

Nearly 75% of dying patients experience this symptom whenever possible reversible and treatable conditions should be diagnosed and treated accordingly. Usually treatments are symptomatic. Low dose opioid reduce the sensitivity of CNS and Dyspnoea. If patients are already on opioid, morphine should be used. Benzodiazepines should be used if anxiety is present. Bronchodilators and steroids are useful adjuvants.

### **FATIGUE AND WEAKNESS**

Fatigue and weakness in more than 90% of terminally ill patients. The goal of treatment is to fulfill the expectation of the patient. The patient and family should be explained the physiology of underlying disease and its course. Behavioral

and psychotherapy are essential part of the treatment.

## **MENTAL SYMPTOMS**

### **DEPRESSION**

75% of terminally ill patients have depressive symptoms. Less than 25% have major depression. The physician must treat physical symptoms which may be the cause of depression. Non-pharmacological intervention in the form of individual or group psychotherapy and behavioral therapy can be helpful especially in combination with drug therapy.

Pharmacological interventions remain the core of therapy.

Psycho stimulants as dextroamphetamine or methylphenidate and pemoline, selective serotonin reuptake inhibitors as fluoxetine, sertraline, etc. are useful adjuvants of terminally ill patients.

### **DELIRIUM**

It is common thing during last stages of illness. It is a global cerebral dysfunction characterized by alterations in cognition and consciousness in contrast to dementia, it has acute onset and reversible. Pharmacological agents like haloperidol, chlorpromazine and sometimes anesthetics like propofol or continuous infusion of midazolam may be used.

## **SOCIAL NEEDS AND THEIR MANAGEMENT**

### **FINANCIAL BURDEN**

Dying can impose substantial economic strains on patients and families, causing distress. It should not be ignored as it may be associated with several adverse health outcomes and other social problems.

### **RELATIONSHIP**

Setting personal issues and closing the narrative of livid relationship are unusual needs. The family and friends should give time to meet the ill patient and participate in all the activities around the patient.

### **FAMILY CAREGIVERS**

Three quarters of the caregivers of terminally ill patients are women. They may be the family member or paid professional. Community assistance from homes of worship or other groups can often be mobilized.

### **EXISTENTIAL NEEDS**

Religion and spirituality are important to dying patients. Nearly 70% of patients become more religious when they become terminally ill. Hardly has any evidence that these needs if fulfilled will alleviate physical symptoms. But, it

may be helpful to meet the psychological needs of the patient and comforting to the family itself.

### **MANAGING THE LAST STAGES**

For centuries, it has been deemed ethical to withdraw or withhold the life-sustaining interventions. The current legal consensus is that patients have a constitutional and common law right to refuse medical interventions. The next of kin can exercise this right if patient is incompetent.

### **FUTILE CARE**

No objective definition or standard of futility exists. Physiologic futility means that an intervention has no physiological effect. Many argue that physician can terminate futile treatment demanded by the family of terminally ill patients.

### **EUTHANASIA**

This is administering medications or other interventions to cause the patient's death. This can be voluntary with patient's consent, involuntary when patient is competent but not asked, no voluntary when patient is incompetent, passive when withholding or withdrawing life sustaining treatment, indirect when opioid or other medication incidentally causes death.

### **PHYSICIAN ASSISTED SUICIDE**

When a physician provides medication or other interventions to the patient with the understanding that the patient can use them to commit suicide.

### **FUTURE DIRECTIONS**

Care near the end of life cannot be measured by most of the available validated outcome measures since palliative care does not consider death as a bad outcome. Symptom control, enhanced family relationships and quality of bereavement are difficult to measure and are rarely the primary focus of

outcome measures. The field of end of life care is ready to enter an era of evidence based practice and continuous improvement through clinical trial.

### **SUGGESTED READINGS**

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