

*Coastal Hospice
& Palliative Care*

Management of Pain and Non-pain symptoms in Palliative Care in persons with Intellectual disabilities.

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Objectives:

- Define Hospice and Palliative care
- Describe the neurobiology of pain and potential treatment targets
- Compare , contrast, nociceptive neuropathic pain
- Know steps of analgesic management
- Define “total pain”
- Assess and provide effective interventions for dyspnea, dysphagia, N/V and restlessness
- Nutrition and hydration issues in end of life
- Identify the need for and provide guidance and counseling to patients and families about Palliative sedation

Introduction to Hospice

- Both Hospice and Palliative care focus on the physical, social, cultural, emotional and spiritual needs of people who are terminally ill and their caregivers.
- Hospice; focus is on relieving pain and other symptoms of illness in last 6 months.
- A medical director determines that life expectancy is 6 months or less.
- The focus is on comfort care and improved quality of life and not cure.

Palliative Care:

- The term palliative care refers to whole-person care for patients whose diseases are not responsive to curative treatment at an early state of illness.
- Palliative care usually is provided by an interdisciplinary team of physicians, nurses, social workers, chaplains and other health care professionals.
- Symptom control is paramount and includes the alleviation of symptoms whether they are physical, psychological, social or spiritual.
- The goal is the achievement of the best possible quality of life for patients and their families.

Hospice statistics

- 41.6% off all deaths in US were under care of hospice program in 2009.
- Mean LOS ; 67.4 days
- Median LOS ; 20.0 days
- Location of death;
- Acute care hospitals; 10.1%
- Hospice inpatient facility ; 21.2%
- Residence; 68.6%

4 Levels of Hospice services

- Medicare Hospice Benefit specifies 4 different levels of hospice services to meet the diverse needs of dying patients and their family.
- Routine Home Care
- General Inpatient Hospice Care
- Respite Home Care
- Continuous Home Care

Life expectancy in people with IDD

- People with IDD are living longer due to advances in health care at all phases of life. In 1996, according to a study in California, the difference in projected life expectancy for people with IDD was only 10 years less on average than that of the rest of the population.

End of Life decision in IDD

- The decision to transition to end-of-life care should be based on a realistic prognosis for a cure; knowledge of the preferences of the people with disabilities or if those preferences are not known, preferences of the family, close friend, or direct care staff; and a balance of the benefits and burdens to the people with disabilities.

End of Life decision in IDD

- The end-of-life experiences and options for people with IDD should, and now more frequently do, mirror those of their peers without disabilities. Participation in the planning of one's own death needs to be carefully reviewed and orchestrated such that whatever the image be, the “good death” can be thoughtful and carried out with dignity and caring for the individuals and their families.

Healing vs. Curing

15th century definition of medical care:
to cure sometimes
to relieve often
to comfort always

“**Pain** is an unpleasant sensory and emotional experience, associated with actual or potential tissue damage...” (IASP, 1979)

“It is as important to know the person who has the pain as it is to know the pain that has the person”

Listen

Believe the patient

Many dying patients continue to suffer from unrelieved pain during the last months of their lives.

At the end of their lives, 62%-92% of children report pain.

A 2007 metanalysis found prevalence of pain in cancer patients was 64%. 1/3 of them rated pain moderate to severe.

Total Pain :

P- Physical pain.

A- Anxiety, anger and depression.

I- Interpersonal problems.

N- Not accepting approaching death.

Cancer pain can be managed effectively in up to 90% of patients

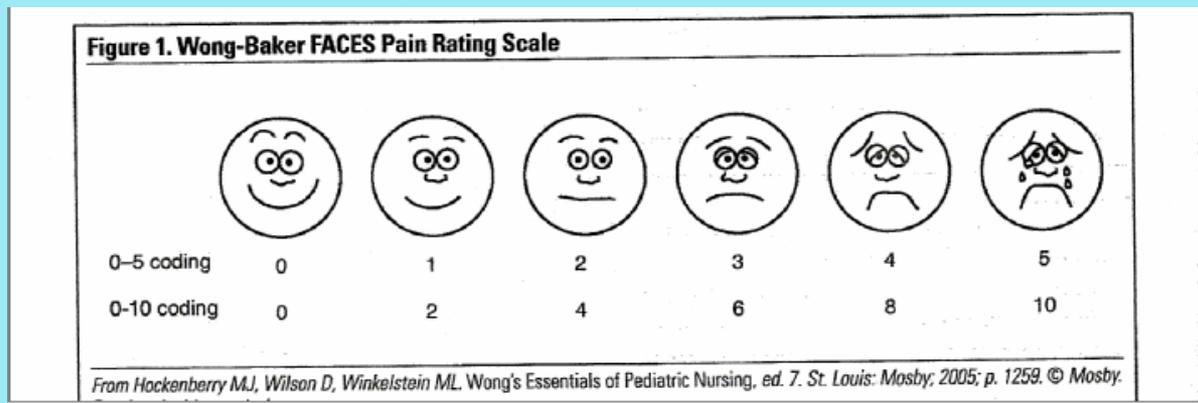
Effective pain management is a continuous 3-step process:

1. Thorough assessment of all types of pain.
2. Treatment of each type of pain with individualized etiology-specific interventions.
3. Continuous reassessment of treatment goals and tolerability including adverse effects.

Pain assessment scales;

-The use of a specific type of pain assessment scale is less important than ensuring that the scale is completed by the patient.

An effective assessment depends on the physicians ability to differentiate between types of pain.



Nociceptive and Neuropathic pain:

Nociceptive pain: Somatic or visceral pain resulting from actual or potential tissue damage.

Somatic pain: caused by activation of nociceptors in either body-surface tissues or musculoskeletal tissues. Described as aching, stabbing, throbbing or squeezing. E.g. Arthritis, metastatic bone disease, wounds and soft tissue tumors

Visceral pain: caused when receptors are activated as a result of compression, obstruction, infiltration, ischemia, stretching, or inflammation of thoracic, abdominal or pelvic viscera.

Described as spastic, cramping, gnawing, squeezing or pressure. When the capsule of organs is involved the pain may be described as sharp or stabbing. e.g.; liver Mets, bowel obstruction, coronary ischemia or bladder retention

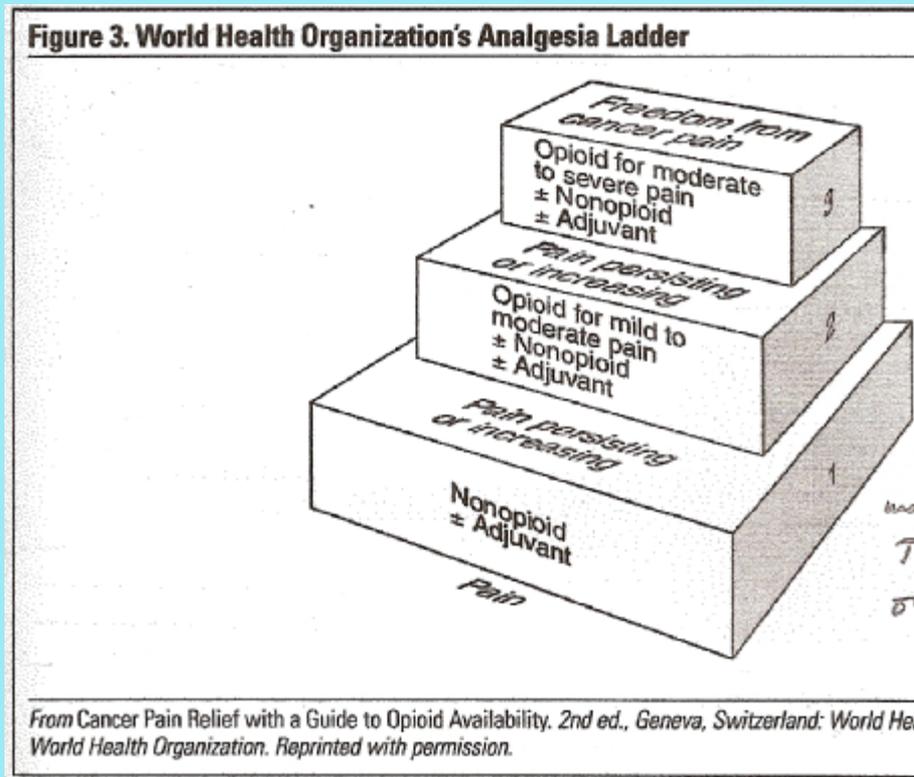
Neuropathic pain: results from direct injury or dysfunction of peripheral or central nervous system tissues.

Described as burning shooting, tingling, stabbing, scalding and painful numbness. e.g.; diabetic neuropathy, post herpetic neuralgia, compression radiculopathy and phantom pain syndromes

Treatment of pain;

The WHO analgesia ladder;

The World Health Organization recommends a simple and effective 3-step approach for treating pain based on its severity. (Mild, mild-to-moderate, or moderate-to-severe)



**Misconceptions about Opioids; There are many,
The truth is that:**

Opioids rarely cause respiratory depression.

Opioids rarely cause addiction.

Opioids rarely cause rapid tolerance.

Opioids rarely cause death.

Opioids do not have a narrow effective dosage range.

Opioids are not ineffective by mouth.

Opioids rarely cause nausea.

Opioids rarely cause euphoria.

When nonopioid analgesics such as acetaminophen or NSAIDs no longer control pain; the appropriate action is usually to prescribe opioids.

Opioids are the safest and most effective agents for most types of cancer-related pain. However, they are effective only when prescribed in adequate dosages.

Commonly used opioids;

Hydrophilic (Morphine, oxycodone and Hydromorphone)

Metabolized by liver

Excreted by kidney

T-max dependant on Route

- PO = 1 hour
- SC-IM = 30 minutes
- IV = 6 minutes

T-1/2 all routes = 4 hours

Acute titration phase is important;

- We can redose at t-max
- mild-to-moderate pain increase 25%-50%
- moderate-to-severe pain increase by 50%-100%
- It takes 3-5 doses to reach steady state

Breakthrough dosing

use short acting opioids

5%-15% of 24 hour dose prn

Divide oral dose by 3 for IV conversion

Lipophilic opioids; (Fentanyl and Methadone)

Metabolized by liver.

Neither has active or known metabolites.

Fentanyl cleared renally, methadone 50% fecally and 50% renal excretion.

Fentanyl Transdermal onset at 12 hours, peak levels 36-48 hours, change Q 3rd day.

Methadone onset 6-8 hours, steady state 3-5 days

Converting from one opioid to another
-Use equianalgesic table:

Drug	Oral/Rectal (mg)	IV/SC (mg)
Morphine	30	10
Hydrocodone	30	N/A
Oxycodone	20	N/A
Hydromorphone	7.5	1.5
Codeine	200	120(IM only)
Fentanyl	N/A	100 mcg(single dose)

Opioid adverse affects

Common	Uncommon
Cognitive clouding	Pruritis/Urticaria
N/V	Urinary retention
Constipation	Respiratory Depression
? Delirium	Neurotoxicity
	Opioid-induced Hyperalgesia

Adjuvant Analgesics;

Dexamethasone: 4-8mg Am, avoid late dose,

Anticonvulsants: Gabapentin 100 Tid up to 3600
Pergaboline 50 tid up to 600.

Antidepressants: Nortriptyline and Desipramine.

Local anesthetics: Emla cream, Lidoderm patch.

Parenteral Lidocaine for intractable neuropathic pain.

NMDA receptor antagonist: Methadone and Ketamine.

Antispasmodic drugs: Baclofen, Tizanidine, Clonazepam



Management of Selected non-pain symptoms of life-limiting illness

Dyspnea;

Dyspnea can be defined as a discomfort in breathing.
(breathlessness and s.o.b etc.)

Prevalence:

21%-78% of cancer patients

70% with dementia

60%-70% with CHF

68% with HIV/AIDs

56% with COPD

50% with ALS

37% following CVA:

Assessment:

As with pain, dyspnea is subjective. The patients' self-report is the gold standard for assessing the presence and severity of dyspnea. A patient may have multiple causes of dyspnea.

Management: Non-pharmacologic measures:

Upright position

Avoid exertion

Better air circulation; fans; humidifiers etc

Decrease anxiety, relaxation interventions

Non-invasive ventilation CPAP-BIPAP

Oxygen:

Hypoxemic patients benefit the most.

In a study comparing the use of air and oxygen to relieve dyspnea for cancer patients, no significant difference was formed.

Discuss the benefits and risks with patients and caregivers.

Opioids:

Opioids are first-line agents for the management of dyspnea.

There are no studies that demonstrate one opioid having clear benefits over another.

In general the following guidelines for starting dosages are useful;

For mild dyspnea in an opioid-naïve patient:

Hydrocodone, 2.5 to 5mg PO every 4 hours

Codeine, 30mg PO every 4 hours

MS, 2.5 to 5mg PO every 4 hours

For severe dyspnea in as opioid-naïve- patient:

MS, 5mg PO every 4 hours

Oxycodone, 5mg PO every 4 hours

Hydromorphone, 1-2mg PO every 3-4 hours.

Dosage may be increased by 25% to 50% every 12 hours. Scheduled and PRN dosages, opioid rotation. Incidence of respiratory depression is low if the opioid dose is managed appropriately. Monitor mental status. Significant depression of breathing unlikely to occur when the patient is alert or easily arousable.

Don't forget to add laxative for constipation (senna, colace, etc.)

Anxiolitics in dyspnea;

Vicious cycle: dyspnea -anxiety-dyspnea

Benzo's for breakthrough dyspnea;

Clonazepam 0.25mg every 12 hours

Lorazepam: rapid onset but last for 4-6 hours

Midazolam: may be added to opioids infusion

Alprazolam: may be too short-acting for this indication

Refractory dyspnea:

The goal should be to relieve dyspnea and not to hasten death. Palliative or therapeutic sedation should be offered.

Dysphagia: Difficulty swallowing;

Obstructive lesions: solids progressing to liquids.

Neuromuscular disorders: solids and liquids simultaneously.

Medications:

- Post chemo and radiation therapy

- ACE

- Anticholinergics

- Antihistamines

- NSAIDS, KCL

- Antibiotics (Doxycyclene and Bactrim)

Treat underlying cause;

Dry mouth by radiation etc: Pilocarpine 5-10mg tid; saliva substitutes

Oral candidiasis: nystatin suspension, clotrimazole 10mg, fluconazole 100mg bid for 10 days

Periodontal disease: chlorhexadine gluconate 30ml, magic mixture

GERD: PPI's, upright position

Apthous ulcers: magic mixture (benadryl, lidocain, loperamide, nystatin, and hydrocortisone etc.). Topical or parenteral opioids

Avoid glycerine swabs and lemon juice.

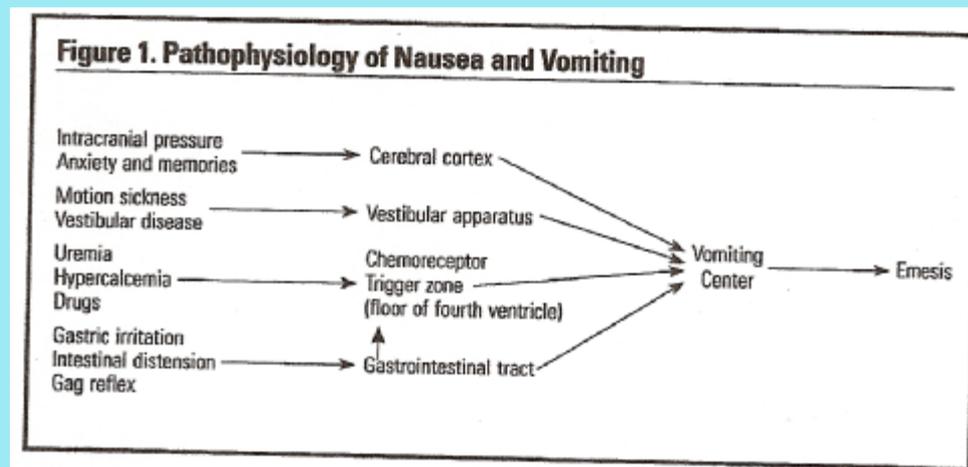
Increase liquids, frozen juice, popsicles, ice chips, water in a syringe or spongstick.

Nausea and Vomiting:

-60%-70% of terminally ill cancer patients

-50% of cancer patients treated with chemotherapy or radiation therapy

-Causes significant distress but can be controlled with simple interventions in 90% of the patients



CNS Tumor or Mets and increase intracranial pressure

Anxiety

Vertigo

Medications (Opioids, digoxin, theophyllin)

Metabolic (renal or liver failure)

Hypercalcemia

Tumor infiltration, radiation treatment

Constipation

Obstruction

Tube feeding

Chemotherapy induced

- Dexamethasone
- counseling, Lorazepam
- Meclizine, scopolamine
- decrease dose or D/C
- Haldol
- Hydration, pamidronate
- Promethazine, scopolamine
- laxative, disimpaction
- raglan, Vaseline balls
- reduce or D/C
- ondansetron

End of life restlessness/agitation;

Usually accompanied by skin mottling and cool extremities, mouth breathing, cheyne-stokes and periods of deepening somnolence.

Supportive measures;

- Soft music with family members and friends

- Music therapy

- Art therapy

- Clarification of concerns or problems

- Aromatherapy

- A change of scenery

Medications: Lorazepam, Midazolam, Phenobarbital.

Palliative or therapeutic sedation when all of the above measures fail (Continuous or respite sedation)

Artificial Nutrition and Hydration

- Like other medical interventions, ANH should be evaluated by weighing its benefits and burdens in light of the clinical circumstances and goals of care.
- Forgoing ANH can lessen discomfort at the end of life as a result of decreased oral and airway secretions with reduced choking and dyspnea.

ANH at end of life

- Chronically ill individuals often have no hunger when ANH is discontinued and the resulting ketosis produces a sense of well-being , analgesia, and mild euphoria. In contrast, carbohydrate intake, even in small amounts, blocks ketone production and blunts of the positive effects of total calorie deprivation.
- Life expectancy is 10 to 14 days after ANH has been discontinued

Palliative or Therapeutic Sedation;

Is to be considered as a last option to relieve the distress of intractable symptoms or refractory suffering.

Medication used: Midazolam, Phenobarbital, Propofol, and Thiopental

AAHPM Position Statement on Palliative Sedation

Background

Palliative care seeks to relieve suffering associated with disease. Unfortunately, not all symptoms associated with advanced illness can be controlled with pharmacologic or other interventions. Patients need and deserve assurance that suffering will be effectively addressed, as both the fear of severe suffering and the suffering itself add to the burden of terminal illness.

Statement

AAHPM believes that distinctions must be made among the following uses of sedatives in medical practice:

- **Ordinary sedation.** The ordinary use of sedative medications for the treatment of anxiety, agitated depression, insomnia, or related disorders, in which the goal of treatment is the relief of the symptom without reducing the patient's level of consciousness.
- **Palliative sedation (PS).** The use of sedative medication at least in part to reduce patient awareness of distressing symptoms that are insufficiently controlled by symptom-specific therapies. The level of sedation is proportionate to the patient's level of distress, and alertness is preserved as much as possible.
- **Palliative sedation (PS) to unconsciousness.** The administration of sedatives to the point of unconsciousness, when less extreme sedation has not achieved sufficient relief of distressing symptoms. This practice is used only for the most severe, intractable suffering at the very end of life.

Healthcare providers serving patients near the end of life have a responsibility to offer sedatives in appropriate circumstances, usually targeted at specific symptoms (ordinary sedation). PS is occasionally necessary to relieve otherwise intractable suffering, with the degree of sedation proportionate to the severity of the target symptom. PS to unconsciousness should only be considered in the rare circumstance that thorough interdisciplinary assessment and treatment of a patient's suffering has not resulted in sufficient relief (or is associated with unacceptable side effects), and when sedation to unconsciousness is needed to meet the patient's goal of relief from suffering. As with all treatment, the use of PS requires informed consent. Treatment of pain and other symptoms should be continued with PS, as sedation may decrease the patient's ability to communicate symptoms. PS should not be considered irreversible; reducing the sedation should be considered if clinical evaluation suggests that the symptom status may have changed.

Ethical principles and legal rulings support the use of palliative sedation even to the level of unconsciousness to relieve otherwise refractory suffering. With regard to PS, the key ethical features are:

1. The clinicians' intent is to relieve suffering,
2. The degree of sedation must be proportionate to the severity of suffering, and
3. The patient should give informed consent; if the patient is not capable of decision-making, the surrogate decision maker should give informed consent consistent with the goals of care and values previously stated by the patient.

In clinical practice, PS usually does not alter the timing or mechanism of a patient's death, as refractory symptoms are most often associated with very advanced terminal illness. The possibility that PS might hasten death as an unintended consequence should be assessed by the healthcare team in its consideration of PS, and then addressed directly in the process of obtaining informed consent. Institutional bioethics committees may be consulted in cases where there is disagreement regarding the provision of PS. ^{130,133,134,144-148}



“Never doubt that a small group of thoughtful, committed, citizens, can change the world. Indeed, it is the only thing that ever has.”

- Margaret Mead