Approaches to Palliative Care in the Chronic Disease Patient

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Objectives

At the end of the session the participant will be able to:

1. Describe differences in palliative care and hospice care.
2. Explore the role of the nurse practitioner in communicating key concepts of living with a chronic, terminal illness to patients and their families.
3. Discuss use of evidence based guidelines in maintaining quality of life through adequate pain management- both pharmacological and non- pharmacological.

Palliative Care- WHO Definition

- "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. "

Palliative Care

- Provides relief from pain and other distressing symptoms
- Affirms life and regards dying as a normal process
- Intends neither to hasten or postpone death
- Integrates the psychological and spiritual aspects of care
- Offers a support system to help patients live as actively as possible until death
- Offers a support system to help the family cope during the patient's illness and in their own bereavement

Palliative Care

- Uses a team approach to address the needs of patients and their families, including bereavement counseling, if indicated
- Will enhance quality of life, and may also positively influence the course of illness
- Is applicable early in the course of illness

Hospice

Hospice

- Service, not a place
- If a patient has Medicare Part A, they sign off of Part A and on to the Medicare Hospice Benefit
- This election is reversible
- 2 doctors have to certify that the patient has a prognosis of less than 6 months
- DNR status cannot be used as a requirement for admission

Hospice Covers

- Care plan oversight by the Hospice Medical Director
- Nursing care, routine visits, and prn
- Social worker
- Chaplain
- All medications related to the terminal diagnosis
- DME
- Home Health Aid
- Bereavement for one year
- ST, PT, OT, Nutritional support as determined by the IDG

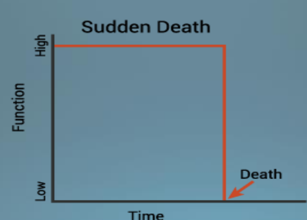
Hospice Does Not Cover

- Room and Board
- Medications not related to the terminal diagnosis or not medically necessary
- Treatments that are life supportive measures

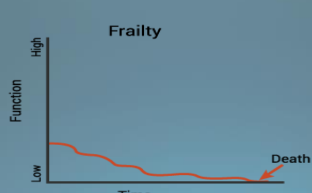
But When is End Of Life Care Needed?

Disease Trajectories can provide a framework for addressing patient and family expectations

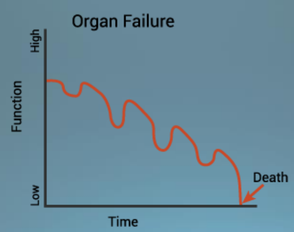
Sudden Death Trajectory



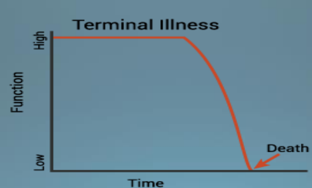
Dementia Disease Trajectory



Organ Failure Trajectory



Cancer Trajectory



Establishing a Prognosis

- Providers tend to be overly optimistic
  - Christakis asked 343 physicians to estimate survival for 468 terminally ill patients at the time of hospice referral.
    - Only 20% were accurate
    - Overestimated by a factor of 5.3
    - The longer the doctor-patient relationship, the less accurate the prediction

Establishing a Prognosis

- Undue optimism can harm patients
  - May delay Advance Directives
  - May lead to a late hospice referral
  - May lead to futile care

Establishing a Prognosis

- Provides information about the future
- Helps patients develop insight into the disease
- Assists in decision making
- Establishes hospice eligibility

Establishing a Prognosis

- The Surprise Question: "Would I be surprised if my patient died in the next year?"
  - BMC Medical 2017: On meta analysis, the overall accuracy of the Surprise Question was approximately 75%
- Don't be afraid to ask the specialists.

Poor prognosis in general if:

- Weight loss > 10% in 6 months
- Albumin <2.5
- Sleeping more
- Dysphagia, choking, poor oral intake
- Cholesterol less than 150
- Dependence in at least 2 ADLs
- Increasing ER, hospital or physician visits over the last 6 months
- Multiple comorbidities

End-Stage COPD

Ambulatory Patients

- FEV_1 of less than 35% of predicted
  - 25% will die within 2 years
  - 55% by 4 years

End-Stage COPD

Advanced age
Pulmonary HTN
Right heart failure
Dyspnea at rest

COPD

- Hospitalized COPD patients
  - 10% of patients admitted with a $PaCO_2$ >50 will die during hospitalization
  - 33% within 6 months
  - 43% in a year
  - If intubated, about a 25% mortality during hospitalization
  - Intubated more than 48 hours, had a 50% one year survival in one study
  - Poor indicators include
    - Comorbid diseases, APACHE II score, low albumin, low hemoglobin, previous intubation, failed extubation, intubation for more than 72 hours

COPD

- BODE Scale- Predicts survival over 1-3 years
  - BMI
  - Exercise capacity
  - Subjective estimates of dyspnea

Heart Failure

- NYHA Classification – 1 year mortality estimates
  - Class II- 5-10%
  - Class III: 10-15%
  - Class IV: 30-40%

Heart Failure

- Poor prognostic indicators:
  - Cardiac hospitalization
  - Elevated BUN
  - SBP < 100
  - LVEF < 45%
  - Ventricular dysrhythmias
  - Anemia
  - Na <135
  - Cachexia
  - Reduced functional capacity

Heart Failure

- Poor prognostic indicators:
- More than 64 years old
- Dilated cardiomyopathy
- CXR signs of left heart failure
- A prognosis of <6 months is likely if NHYA Class IV despite treatment with diuretics and vasodilators

Dementia: FAST

- 1. No difficulty either subjectively or objectively
- 2. Complains of forgetting location of objects. Subjective work difficulties
- 3. Decreased job functioning evident to co-workers. Difficulty in traveling to new locations. Decreased organizational capacity.
- 4. Decreased ability to perform complex tasks (for example: planning dinner for guests, handling personal finances-such as forgetting to pay bills), difficulty marketing, etc
- 5. Requires assistance in choosing proper clothing to wear

Dementia: FAST

for the day, season, or occasion (for example: patient may wear the same clothing repeatedly unless supervised.)

6. a) Improperly putting on clothes without assistance or cueing (for example: may put street clothes on over night clothes, put shoes on wrong feet, or have difficulty buttoning clothing) occasionally or more frequently over the past weeks

6. b) Unable to bathe properly (for example: difficulty adjusting the bath water temperature) occasionally or more frequently over the past weeks.

Dementia: FAST

- 6. d) Urinary incontinence (occasionally or more frequently over the past weeks)
- 6. e) Fecal incontinence (occasionally or more frequently over the past weeks.)
- **7. a) Ability to speak limited to approximately 1-5 intelligible different words or fewer, in the course of an average day or in the course of an intensive interview**
- 7. b) Speech ability is limited to the use of a single intelligible word in an average day or in the course of an intenisve interview

Dementia: FAST

- 7. c) Ambulatory ability is lost (cannot walk without personal assistance).
- 7. d) Cannot sit up without assistance (for example: the patient will fall over if there are no lateral rests on the chair).
- 7. e) Loss of ability to smile.
- 7. f) Loss of ability to hold head up independently

Dementia

- Unable to swallow
- Unable to hold a meaningful conversation
- Increasing frequency of complications such as aspiration pneumonia, decubitus ulcers, UTI, sepsis
- Weight loss > 10% in 6 months
- Albumin <2.5 g/dl

Stroke

- Impaired consciousness
- Lack of improvement within 3 months of stroke
- Age
- Incontinence
- Cognitive impairment
- Dense paralysis
- Dysphagia, especially if unable to take in enough calories to sustain life

End Stage Liver

- MELD Score gives a 3 month prognosis
  - Creatinine
  - Total Bilirubin
  - Bilirubin
  - INR

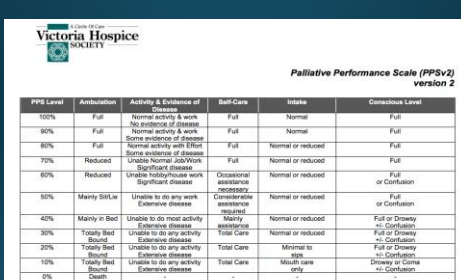
  - www.unos.org/resources/meldPeldCalculator.asp
  - INR > 1.5 and albumin <2.5

End Stage Renal Disease

Hospice criteria
- Cr Clearance < 10 cc/min(<15 with diabetes)
- Cr > 8 mg/dl(>6 mg/dl with diabetes)
- Discontinuing dialysis
  - On average, prognosis is one week

Prognostic Scales

- Karnofsky Performance Scale
- ECOG Performance Status
- Palliative Performance Scale


A Circle Of Care
Victoria Hospice SOCIETY

Palliative Performance Scale (PPSv2) version 2

PPS Level	Ambulation	Activity & Evidence of Disease	Self-Care	Intake	Conscious Level
100%	Full	Normal activity & work No evidence of disease	Full	Normal	Full
90%	Full	Normal activity & work Some evidence of disease	Full	Normal	Full
80%	Full	Normal activity with Effort Some evidence of disease	Full	Normal or reduced	Full
70%	Reduced	Unable Normal Job/Work Significant disease	Full	Normal or reduced	Full
60%	Reduced	Unable hobby/house work Significant disease	Occasional assistance necessary	Normal or reduced	Full or Confusion
50%	Mainly Sit/Lie	Unable to do any work Extensive disease	Considerable assistance required	Normal or reduced	Full or Confusion
40%	Mainly in Bed	Unable to do most activity Extensive disease	Mainly assistance	Normal or reduced	Full or Drowsy +/- Confusion
30%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Normal or reduced	Full or Drowsy +/- Confusion
20%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Minimal to sips	Full or Drowsy +/- Confusion
10%	Totally Bed Bound	Unable to do any activity Extensive disease	Total Care	Mouth care only	Drowsy or Coma +/- Confusion
0%	Death	-	-	-	-

Cancer Prognosis

Tumor size, grade, stage
Hormone status
Age
Biochemical or other tumor markers

Breaking Bad News- SPIKES

- S- Setting
- P-Perception
- I-Invitation
- K-Knowledge
- E- Empathy
- S-Summation

Breaking Bad News- S

- Setting
  - Prepare in advance
  - Face to face visit
  - Choose a private or quiet place
  - Have the right people there
  - Provide an interpreter, if necessary, and tell the interpreter the siruation

Breaking Bad News- PI

- Perception
  - Ask the patient what he or she knows or perceives
- Invitation
  - Seek the patient's invitation to break news
  - Ask how much the patient wants to know

Breaking Bad News- K

- Knowledge
  - Share information clearly and directly
  - Avoid medical jargon and technical language
  - Do not give too much information at one time
  - Listen to the patient's response
  - Frequently repeat and summarize points

Breaking Bad News- E

- Empathy
  - Observe how the patient reacts
  - Listen to the patient's emotions
  - Allow pauses for reflection and for the patient to verbalize feelings or ask question
  - Respond by identifying and validating patient's emotions

Breaking Bad News- S

- Summation
  - Summarize the delivered news
  - Review the patient's treatment options
  - Schedule follow-up visits

Goals of Care Discussions

- Set up the conversation
  - "I'd like to talk about what is ahead with your illness and do some thinking in advance about what is important to you so that I can make sure we provide you with the care you want- is this OK?"

Goals of Care Discussions

- Assess understanding and preferences
  - "What is your understanding now of where you are with your illness?"
  - "How much information about what is likely to be ahead with your illness would you like from me?"

Goals of Care Discussions

- Share prognosis
  - "I want to share with you my understanding of where things are with your illness…"
  - "It can be difficult to predict what will happen with your illness. I hope you will continue to live well for a long time but I'm worried that you could get sick quickly, and I think it is important to prepare for that possibility."

Goals of Care Discussions

- "I wish we were not in this situation, but I am worried that time may be as short as……"
- "I hope that this is not the case, but I'm worried that this may be as strong as you will feel and things are likely to get more difficult"

Goals of Care Discussions

- Explore Key Topics
  - "What are your most important goals if your health situation worsens?"
  - "What are you biggest fears and worries about the future with your health?"

Goals of Care Discussions

- "What gives you strength as you think about the future with your illness?"
- "What abilities are so critical to your life that you can't imagine living without them?"
- "If you become sicker, how much are you willing to go through for the possibility of gaining more time?"
- "How much does your family know about your priorities and wishes?"

Goals of Care Discussions

- Close the conversation
  - "I've heard you say that____is really important to you. Keeping that in mind, and what we know about you illness, I recommend that we ______. This will help us make sure that your treatment plans reflect what's important to you."
  - "How does this plan seem to you?"
  - "I will do everything I can to help you through this. "

Goals of Care Discussions

- Document your conversation
- Communicate with whomever needs to know

- Serious Illness Conversation Guide: Adriane Labs and Dana-Farber Cancer Institute, April 2017
- www.talkaboutwhatmatters.org

Goals of Care Discussions

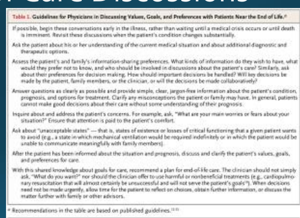


Table 1. Guidelines for Physicians in Discussing Values, Goals, and Preferences with Patients Near the End of Life.*

If possible, begin these conversations early in the illness, rather than waiting until a medical crisis occurs or until death is imminent. Revisit these discussions when the patient's condition changes substantially.

Ask the patient about his or her understanding of the current medical situation and about additional diagnostic and therapeutic options.

Assess the patient's and family's information-sharing preferences. What kinds of information do they wish to have, what would they prefer not to know, and who should be involved in discussions about the patient's care? Similarly, ask about their preferences for decision making. How should important decisions be handled? Will key decisions be made by the patient, family members, or the clinician, or will the decisions be made collaboratively?

Answer questions as clearly as possible and provide simple, clear, jargon-free information about the patient's condition, prognosis, and options for treatment. Clarify any misconceptions the patient or family may have. In general, patients cannot make good decisions about their care without some understanding of their prognosis.

Inquire about and address the patient's concerns. For example, ask, "What are your main worries or fears about your situation?" Ensure that attention is paid to the patient's comfort.

Ask about "unacceptable states" — that is, states of existence or losses of critical functioning that a given patient wants to avoid (e.g., a state in which mechanical ventilation would be required indefinitely or in which the patient would be unable to communicate meaningfully with family members).

After the patient has been informed about the situation and prognosis, discuss and clarify the patient's values, goals, and preferences for care.

With this shared knowledge about goals for care, recommend a plan for end-of-life care. The clinician should not simply ask, "What do you want?" nor should the clinician offer to use harmful or nonbeneficial treatments (e.g., cardiopulmonary resuscitation that will almost certainly be unsuccessful and will not serve the patient's goals[9]). When decisions need not be made urgently, allow time for the patient to reflect on choices, obtain further information, or discuss the matter further with family or other advisors.

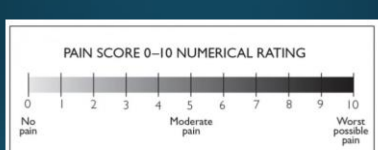
* Recommendations in the table are based on published guidelines.

New England Journal of Medicine 2015; 373:2549-2561

Pain Management at the End of Life

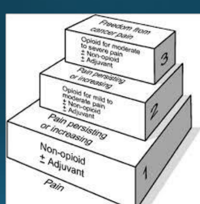
• O-Onset	When did the pain start?
• P-Palliative	What makes the pain better?
• P-Provocative	What makes the pain worse?
• Q-Quality	How would you describe the pain?
• R-Radiation	Where is the pain and where does it go?
• S-Severity	How bad is the pain?
• T-Temporal	Is it constant, or come and go?
• U-Understanding	What do you think causes the pain?

Numerical Pain Intensity Scale



Wong/Baker Faces Rating Scale

WHO Pain Ladder



WHO Pain Ladder

- Start with acetaminophen, 4000 mg a day in divided doses
- NSAIDs may have more risks than benefits in some
- Add Opiates (in short and long acting forms)
- Consider Adjuvants
- Consider Nonpharmacologic methods

Nonpharmacologic Pain Treatments

- Physical Invasive Approaches
- Physical Noninvasive Approaches
- Cognitive/Mind-Body Approaches
- Alternative/Natural Remedies

Physical Invasive Approaches

- Anesthetic procedures
  - Nerve Blocks
  - Infusions (intraspinal clonidine)
- Surgical Procedures
  - Neurologic: rhizotomy
  - Orthopedic spinal decompression
  - Oncologic: debulking
- Radiation therapy
- Chemotherapy

Physical Noninvasive Approaches

- Physical rehabilitation
  - Immobilization, movement, positioning, hydrotherapy
- Massage/manipulation/stimulation
  - Superficial heat/cold applications
  - TENS
  - Ultrasound
  - Acupuncture, Acupressure, Shiatsu
  - Myofascial, craniosacral therapy
  - Chiropractic, therapeutic massage
  - Reflexology

Cognitive/Mind-Body Approaches

- Interpersonal/spiritual
  - Therapeutic healing touch
  - Prayer
  - Bibliotherapy
- Attention/diversion
  - Music, humor, art, pet
- Imagery
  - Guided, incompatible, transformative
- Education

Cognitive/Mind-Body Approaches

Psychologic-physiologic
- Self-talk, distraction
- Meditation, relaxation, Yoga
- Guided Imagery
- Biofeedback, hypnotherapy
- Autogenic training, cognitive restructuring
- Rhythmic cognitive activity, problem solving

Alternative/natural Remedies

- Herbal remedies
- Neutraceuticals
- Aromatherapy
- Homeopathy

Choosing the Right Opioid

- Don't use morphine in renal failure
  - Fentanyl
  - Methadone
  - Hydromorphone

  Otherwise I usually start with morphine

Opioid Conversion

- WWW.compassionandsupport.org

- Resist the temptation to use an app

Morphine Equivalent Daily Dose

- The dose of morphine that is equivalent in strength to the opioid in use. It is usually calculated for the preceding 24 hours.

Opioid Conversion

Analgesic	IV dose	PO dose	Duration (h)
Morphine	10 mg	30 mg	4-6
Oxycodone	----	20 mg	3-5
Hydromorphone	7.5 mg	1.5 mg	3-4
Fentanyl	see chart		
Methadone	see chart		
Hydrocodone	----	30 mg	3-6
Codeine	200	130 mg	4-6
Tramadol	-------	120 mg	4-6

Opioid Conversion -Fentanyl

Recommended Initial Duragesic Dose Based Upon Daily Oral Morphine Dose
From product insert by Ortho-McNeil-Janssen Pharmaceuticals, Inc 2009[1]
TABLE C

Oral 24-Hour Morphine (mg/d)	Duragesic Dose (mcg/h)
60 – 134	25
135 – 224	50
225 – 314	75
315 – 404	100
405 – 494	125
495 – 584	150
585 – 674	175
675 – 764	200
765 – 854	225
855 – 944	250
945 – 1034	275
1035 – 1124	300

[1]The table should NOT be used to convert from transdermal Fentanyl to other opioid analgesics. Rather, following removal of the patch, titrate the dose of the new opioid until adequate analgesia is achieved.

Opioid Conversion- Methadone

Oral Morphine-Equivalent Daily Dose Ratio Conversions to Methadone
TABLE B

Oral MEDD (mg/day)	Initial Dose Ratio (oral morphine: oral methadone)
< 30	2:1
30 – 99	4:1
100 – 299	8:1
300 – 499	12:1
500 – 999	15:1
> 1000	20:1 or greater

Palliative Consultation highly recommended

Opioid Side Effects

- Respiratory Depression- Somnolence always precedes
- Allergy- true allergy is rare
- Constipation- tolerance does not develop
- Tolerance does develop in 2-3 days for
  - Nausea
  - Drowsiness
  - itching

Nausea and Vomiting

Prochlorperazine	10 mg PO q 6-8 h or 25 mg PR
Promethazine	25 mg PO/PR q 6-8 h or 12.5 mg IV
Chlorpromazine	10-25 mg PO q 4-6 h or 50-100 PR q 6-8
Metochlorpromide	5-10 mg PO/SC /IV AC and HS
Dexamethasone	4-8 mg PO/SC/IV q 6-24 h
Haloperidol	0.5-1 mg PO/SC/IV q 4-6h
Lorazepam	0.5-2 mg PO/SC/IV q 4-6 h
Hydroxyzine	10-25 mg po/SC/IV q 4-6 h

Constipation

Docusate*	50-100 mg bid
Magnesium Citrate	300 ml qd
Bisacodyl	5 mg PO or 10 mg PR qd
Senna	2 tabs qid
Lactulose	15-30 ml po qd-tid
Psyllium	1 tsp po tid
Methylnaltrexone	depends on weight

Dypnea

- Bronchodilators
- Corticosteroids, inhaled and oral
- Oxygen
- Opioids- example: Morphine 5 mg po every 4 hours prn
- Benzodiazepines

Delirium

- Look for the cause: the disease, dehydration, fecal impaction, urinary retention, MEDICATIONS
  - Haloperidol
  - Lorazapam

In Summary

- We can provide excellent care to our vulnerable chronic disease patients and families by using a palliative approach which includes knowledge of the disease trajectory, discussions about prognosis, discussions about goals of care, and symptom management.

Sources

World Health Organization (1990) Cancer Pain Relief and Palliative Care. Geneva: WHO 11 (World Health Organization technical reports series: 804)

www.who.int/cancer/palliative/definitionen

Oxford Handbook of Palliative Care, 2009, Introduction

Psychopharmacology Bulletin, 1988 24:653-659

Geriatrics.uthsca.edu/tools/Hospice eligibility card Ross and Sanchez Reilly 2008.pdf

New England Journal of Medicine 2015; 373:2549-2561

Sources

- End of Life Care: a practical guide/ editors, Barry M Kinzbrunner, Joel S. Policzer.- 2nd edition, Chapters 1, 2, 3 and 6. 2011.
- Ambuel B, Weissman D. Fast Facts and Concepts #6 and 11. Breaking Bad News. May 2015. Available at: https://www.mypcnow.org
- Barker P,Scherer J.. Fast Facts and Concepts #326. Illness Trajetories: Description and Clinical Use. December 2016. Available at: https://www.mypcnow.org

Sources

- White N, Kupli N, Vickerstaff V, Stone P, BMC Medicine 2017 15:139
- Reisberg B. Functional Assessment Staging (FAST). Psychopharmacology Bulletin 1988; 24: 653-659
- Palliative Performance Scale: Victoria Hospice Society
- Serious Illness Conversation Guide: Adriane Labs and Dana-Farber Cancer Institute, April 2017
- Buckman R. How to Break Bad News: A Guide for Health Care Professionals. Baltimore, MD, The John Hopkins University Press, 1992, pp 65-171