Partnering for Excellence in the Care of the Seriously Ill

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Learning Objectives
1. Describe similarities and differences between Hospice & Palliative Care
2. Discuss strategies for partnering with palliative care providers to meet the needs of the seriously ill patient and family

Rehab & Palliative Specialists Share:
• Interdisciplinary
• Comprehensive Care
• Value caregivers
• Complex patients
• Improve Quality of Life
• Maximize Function

UNDERSTANDING HOSPICE & PALLIATIVE CARE

The World Health Organization’s Definition of Palliative Care
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.

Pal·li·ate
Latin, palliāre
To cover up

Latin, pallium
A cloak

To relieve or lessen without curing; alleviate
Palliative Care

Hospice

When
Anywhere in illness trajectory

Where
Usually in hospital, some outpatient programs

Goals of Care
Variable

Availability
Depends on individual program

Team Members*
Depends on individual program

Levels of Care
Primary
Secondary
Tertiary

Palliative Care | Hospice
---|---
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* Nurses, physicians, volunteers, chaplains, social workers, bereavement coordinators

**Primary Palliative Care**

- Basic skills/competencies
- Communication
- Symptom management
- All providers

**Secondary Palliative Care**

Specialist clinicians & organizational offerings that provide consultation & specialty care

**Tertiary Palliative Care**

- Academic medical centers where PC is practiced
- Researched
- Taught

Symptoms

Physical

Existential

Spiritual

Emotional
Possible Reasons for consulting Palliative Care

- Symptom management
- Disposition Planning
- Recurrent admissions
- Patient coping
- New diagnosis or prognosis
- Clarifying Goals of Care
- “Difficult” Patient/Family
- Communication Issues
- Psychosocial support
- Specific Decision Making Help and/or capacity
- Hospice Education/Planning
- Actively Dying Patient

Old vs. New Models of Palliative Care

<table>
<thead>
<tr>
<th>Old</th>
<th>PC/Hospice</th>
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<tbody>
<tr>
<td>Life-prolonging Therapy</td>
<td>PC/Hospice</td>
</tr>
<tr>
<td>Diagnosis of Serious Illness</td>
<td>Death</td>
</tr>
<tr>
<td>Bereavement</td>
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<table>
<thead>
<tr>
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Palliative Care Teams Vary A LOT

- Who is on the team can vary
- Workflows vary
- Access varies: M-F or 24/7
- Services vary: ACP/Symptoms/Hospice ed
- Who they care for: Peds/Adults/Both
- Institutional Culture
- Where they see patients: inpt/outpt
Advantages

- improved QOL (ASCO)
- improved symptom burden (ASCO)
- patient satisfaction (ASCO)
- reduced caregiver distress (Wright)
- more appropriate referral and use of hospice (Gweal)
- reduced use of futile intensive care (Wright)
- survival benefit in 1 study of NSCLCA (Temel)
- lower healthcare costs (Zhang)
- no trials to date have demonstrated harm to patients and caregivers, or excessive costs, from early involvement of palliative care (ASCO)

WHO IS APPROPRIATE?

MATCHING RESOURCES TO FIT THE GOALS OF CARE

Goals of Care

- Patient
- Family
- Team
Goals of Care

Patient  Family  Team

What do “Goals of Care” mean?

**Patient/Family**
- What do you HOPE that the treatment will achieve?
  - Cure
  - Better function
  - Reaching a milestone
  - Comfort
  - Help others

**Provider/System**
- What are we DOING? What is the focus of the medical plan?
  - Save/rescue
  - Optimize function
  - Extend life
  - Manage symptoms

Exploring Impacts of Serious Illness

- What’s your understanding of your condition?
- What are you hoping for?
- What gives you strength in dealing with illness?
- How have you dealt with tough times before?
- What’s most important to you right now?

Communication Barriers?

Individualization
Benefits of AHN

- Shown to prolong survival in some clinical situations—recovery from stroke, critical illness, MBO, ALS, coma
- Support patients with head & neck cancer during intense chemoradiation
- May help some symptoms, goals, emotional or spiritual needs

Risks of AHN

- Infection
- Thrombosis
- Aspiration with PEG tube feedings
- Pulling on tubes
- Pressure sores from nasal tubes
- Restraint risk
- Head of bed up → pressure sores
- Diarrhea
- Edema (renal failure)
- Bloating

Common Reasons AHN arises

- Dysphagia
- Too Sick!
- Mechanical Obstruction
- Cancer Anorexia Cachexia Syndrome
- Treatment-related sequale
- Fears or concerns related to starvation

Dysphagia

- Your expertise!
- Any reversible causes of the dysphagia?
  - Infections
  - Myasthenia Gravis
- I tell other docs… “Make friends with your speech therapist”
  - They can help prognosticate the swallow
    - Rehab potential
  - Invite SLP to the family meeting
Critical Illness

- Often preventing infection is more important than the nutritional value
- Mucosal lining is thin; presence of nutrients in bowel has protective effect
- Prolonged bowel rest creates risk for systemic sepsis
- If no contraindications, begin enteral feeding within 72 hrs, parenteral not as urgent due to associated risks

IF DYSPHAGIA IS FROM PROGRESSIVE DEMENTIA, BE AWARE OF THE DATA

www.choosingwisely.org

“There is insufficient evidence to suggest that enteral tube feeding is beneficial in patients with advanced dementia. Data are lacking on the adverse effects of this intervention.”

Sampson EL, Candy B, Jones L. Enteral tube feeding for older people with advanced dementia. Cochrane Database Syst Rev. 2009 Apr 15;(2)

Cochrane Database Review

I want to eat but can’t...

- Consider Goals
- Consider Prognosis
- Is the patient a candidate for:
  - surgery
  - laser ablation
  - radiation
  - stent +/- brachytherapy
I want to eat but can’t…

**OBSTRUCTION**

- If not available, not successful or not effective…
- Especially if patient is hungry and/or goals fit…
- Consider:
  - Gastrostomy tube (PEG)
  - NGT
  - Trial of parenteral hydration
  - hypodermoclysis

Cancer Anorexia-Cachexia Syndrome

- Anorexia = loss of appetite → inadequate calories
- Cachexia = catabolic state → loss of muscle and weight
- Involuntary weight loss
- Tissue Wasting
- Worsening functional status

Cancer & Anorexia

<table>
<thead>
<tr>
<th>Parameter</th>
<th>Cachexia</th>
<th>Starvation</th>
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</thead>
<tbody>
<tr>
<td>Resting energy expenditure</td>
<td>++</td>
<td>-</td>
</tr>
<tr>
<td>Loss of lean muscle</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Loss of fat</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Loss of visceral muscle</td>
<td>-</td>
<td>+</td>
</tr>
<tr>
<td>Acute-phase response</td>
<td>++</td>
<td>++</td>
</tr>
<tr>
<td>Proinflammatory cytokines</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Total hormones</td>
<td>++</td>
<td>+</td>
</tr>
<tr>
<td>Increased liver metabolism</td>
<td>+</td>
<td>+</td>
</tr>
<tr>
<td>Liver size</td>
<td>+</td>
<td>+</td>
</tr>
</tbody>
</table>

Abbreviations: +, increased; —, reduced.

Geriatric Anorexia or Cachexia

Cytokine release from:
- Tumor itself
- tumor + immune system
- body reacting to tumor
- Act peripherally & centrally

HEAD AND NECK TREATMENT

Cochrane Database Review

“There is not sufficient evidence to determine the optimal method of enteral feeding for patients with head and neck cancer receiving radiotherapy and / or chemoradiotherapy. Further trials of the two methods of enteral feeding, incorporating larger sample sizes, are required.”

Nugent B, Lewis S, O’Sullivan. Artificial tube feeding methods for use with patients with head and neck cancer who are receiving treatment with radiotherapy, chemotherapy or both JM, 2013
Swallow Exercises

- Before, During, or After Head and Neck treatments?
- Cochrane Review reported no evidence for improvement in swallow for patients undergoing head and neck treatments; need more high quality studies.


OUTPATIENT PALLIATIVE HEAD AND NECK CLINIC

Gastrostomy Tubes

PEG isn’t a brand or specific type of tube. For feeding or venting?

<table>
<thead>
<tr>
<th>How Placed</th>
<th>Technique</th>
<th>Location of Placement</th>
<th>Abbreviation</th>
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<tbody>
<tr>
<td>Percutaneous</td>
<td>Endoscopically</td>
<td>Gastrostomy</td>
<td>PEG</td>
</tr>
<tr>
<td>Percutaneous</td>
<td>Endoscopically</td>
<td>Jejunostomy</td>
<td>PEJ</td>
</tr>
<tr>
<td>Percutaneous</td>
<td>Radiographically</td>
<td>Gastrostomy</td>
<td>PRG</td>
</tr>
<tr>
<td>Surgically</td>
<td>Gastrostomy</td>
<td>G-tube</td>
<td></td>
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ALSO WORTH KNOWING ABOUT

G tubes, sizes

<table>
<thead>
<tr>
<th>French (3 times diameter in mm)</th>
<th>Diameter</th>
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<tbody>
<tr>
<td>16</td>
<td>5.33 mm</td>
</tr>
<tr>
<td>18</td>
<td>6 mm</td>
</tr>
<tr>
<td>20</td>
<td>6.67 mm</td>
</tr>
<tr>
<td>24</td>
<td>8 mm</td>
</tr>
<tr>
<td>28</td>
<td>9.33 mm</td>
</tr>
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Hypodermoclysis

- Subcutaneously administered fluids
- Rate of 20 - 125 mL/h
- NS or isotonic dextrose most commonly
- Small catheters
- Sites: R/L scapular, Upper lateral arm, Lateral thighs, anterior thighs, upper abdominal wall, dorsal aspect of upper arms
Hypodermoclysis

- Metanalysis: 8 (1 USA, 3 Europe, 3 Canada, 1 Asia)
- Geriatric patients
- Duration of treatment 4-21 HDC
- Safety: safety profile of HDC comparable to IV
- Efficacy: equally effective
- Site Changes: similar, 2 days
- Infusion related Agitation: better with HDC (37 vs 80%)
- Nursing feasibility: nurse rating the same.
  - Nursing Time required: 2.4 min HDC vs 6.1 IV
- Cost: IV supplies 4x greater than for HDC supplies


When might Hypodermoclysis be indicated?

Maybe, if goals fit +
- Intractable Nausea
- Symptomatic dehydration, can’t do ORT
- Trial in delirium/altered mental status changes
- Weakness/malaise
- Opioid induced neurotoxicity/myoclonus
- Overwhelming need to try

Not indicated
- Goals are aggressive & IVF needed fast
- Dry mouth
- Hypovolemic, pulmonary edema, dyspnea
- Only prolonging dying
- When surrogate for untreated family anxiety

Proctolysis
(Rectal Hydration)

- Alternative ONLY when other resources are not available
- A 22 French nasogastric catheter can be inserted approximately 40 cm into the rectum.
- The patient can be positioned as for any rectal procedure.
- Tap water can be used, and the rectal infusion increased from 100 ml to a maximum of 400 ml per hour, unless fluid leakage occurs before the maximum volume is achieved.
- The majority of patients can successfully tolerate this approach at a volume of 100 to 200 ml per hour.

http://www.mypcnow.org  Fast Fact 134 Robin Fainsinger MD

DEALING WITH EMOTIONS

Emotional Aspects of Eating

- Nurturing
- Socialization
- Routines
- Pleasure
- History
- Healing when ill

When you’re feeling stuck

- Are the goals aligned?
  - Unrealistic goals?
    - Understanding of illness
    - Trust
    - Maladaptive coping
    - Caregiver issues
    - Need to witness a treatment or therapy?
Wish/Worry statements

- Words matter
- Avoid linking statements with “but”, it negates whatever you said first.
- “I wish that David will get strong enough for chemo too. I worry that may not be the case. Is that something you've allowed yourself to consider as well?”

Consider…

- Offering favorite foods in small amounts
- Flavoring ice chips
- Soaking oral swabs with favorite beverage
- Is mouth moist? Swab?
- Is the presentation pleasing?
- Is the setting appealing?
Coaching

- Prepare family for what is normal and expected at end of life
- Remind family of the underlying cause
- Prepare family for what the plan will be if:
  - Pt is hungry or thirsty
  - Not awake

Scripting

- “Many family members worry about this. What we know is:
  - Dying patients almost universally lose their appetite; his dying is a result of the cancer
  - Remember the last time you had the flu?
  - The body does not process food & drink the same at this stage of illness
  - A failing body typically starts to shift fluids to the wrong places; that can add discomfort

- If he becomes alert enough and wants something, we’re happy to start with sips and bites of whatever sounds good and see how that goes
- If he is not awake, it’s not safe to put food in his mouth. We will continue to provide oral care for comfort.

Support for caregivers

- Identifying what people “do” not just labeled relationships
- Reassess frequently
  - “What are you most worried about?”
  - “How are things going?”
  - “What is/isn’t working?”
  - “What would make this easier?”
  - Who can you talk to when you’re feeling stressed?

Supporting caregivers

- Family meeting
- Encourage them to see own provider
- May need counselor/support group
- Palliative Care intervention
- Partner with Social Work
- Partner with Spiritual Care

Caring for our patients and ourselves

- Work as a team
- Maintain Perspective
- Rotation of duties
- Respect Boundaries
- Recognize caregiving fatigue
- Advocate for team resources
TIPS FOR WORKING WITH DOCS

First...

- Be aware of preconceived notions about palliative care; these can skew behaviors and attitudes towards pts
- It may seem counterintuitive, but Palliative Care is actually about LIVING
- Must be engaged early enough for patient and family to benefit
  (i.e. the last 24 hours of life is too late)

Appreciate KUMC SLP experts who share:

- Prognosis of swallowing
  - Explain the motor/cognitive/practical constraints
- Ability of pt to meet caloric requirements
- The “safest swallow”
  - Consistency of fluids and solids
  - Facilitative maneuvers for successful swallowing
- Recs for aggressive vs comfort goals

SLP & Palliative Care

- This information guides shared decision making:
  - PEG or not
  - Trial of small bore feeding tube (Dobhoff/Corpak)?
  - Stay NPO
  - Comfort feeding: spend what limited time there is, enjoying the safest consistency of food and drink

SLP & Palliative Care

- Patient & family informed of risks and benefits
- Patient maintains control over this aspect of their QOL
- Still want to try to make it as comfortable as possible
  - Sharing maneuvers, tips, coaching for family may still be indicated
- Some patients can not eat very comfortably
  - Autotitrare, how and what they eat
  - Might need a PEG:
    - to help palliate hunger
    - to receive comfort directed medication

Tips for Collaboration

- We’re interested in your rehab prognosis
- Don’t presume PC reason is always “end-of-life”
- We advocate for short stay rehab when clear, realistic goals, need your help
- Some hospices contract with rehab specialists
- Helpful for us to “see” pt doing therapies
- Don’t automatically sign off when goals switch to hospice
Example:

RECOMMENDATIONS: Pending GOC. Spoke with pt's primary team, pt and wife (via phone call) re: recommendations. F/u with family will be required.

Aggressive goals of care:
1. NPO. Continue source of short term non-oral nutrition. Return of safe swallow function likely largely dependent on recovery from other medical conditions. Do not anticipate pt will safely progress to p.o. Diet w/in next 2-3 weeks; therefore, source of long term non-oral nutrition may need to be considered pending pt's overall goals of care.
2. Ice chip protocol (3-5/hour, stop if coughing & re-attempt later, upright)
3. Ongoing speech therapy for dysphagia management.

Palliative goals of care/palliative management of dysphagia:
1. Thin liquids w/ thinned purees, solids w/ knowledge of aspiration.
2. Following swallow strategies may maximize pt comfort when providing p.o.: small bites & drinks; slow rate of intake; alternation of liquids & solids
3. Ongoing speech therapy to focus on pt and family education re: safe swallow strategies, etc.

Free Resource on Palliative Care: Fast Facts

www.mypcnow.org

Summary

Describe similarities and differences between Hospice & Palliative Care

Discuss strategies for partnering to meet the needs of the seriously ill

• Know your resources
• Surprise Question
• Goals of Care
• Don't prematurely sign off
• Consider leaving comfort feedings recs

References

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