Partnering for Excellence in the Care of the Seriously III

Lindy H. Landzaat DO, FAAHPM Assistant Professor HPM Fellowship Program Director University of Kansas Medical Center

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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



Pal·li-ate

Latin, *palliāre* To cover up

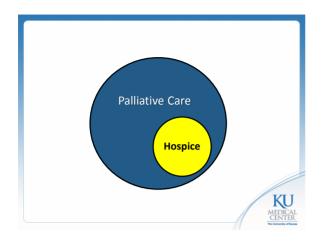
Latin, *pallium* A cloak

To relieve or lessen without curing; alleviate



The World Health Organization's Definition of Palliative Care

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

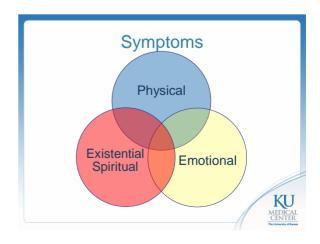


	Palliative Care	Hospice	
When	Anywhere in illness trajectory	Prognosis < 6 MONTHS	
Where	Usually in hospital, some outpatient programs	Goes to patient (Hospice is not a place)	
Goals of Care	Variable	Comfort Directed Usually avoiding hospitalization	
Availability	Depends on individual program	Planned visits 24/7 on-call	
Team Members*	Depends on individual program	Nurses, physicians, volunteers, chaplains, social workers, bereavement coordinators	
Levels of Care	Primary Secondary Tertiary	Routine Continuous Care General Inpatient Respite	





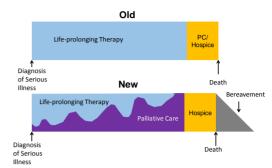




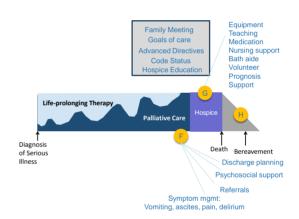
Possible Reasons for consulting Palliative Care

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

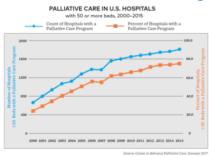
Old vs. New Models of Palliative Care







Palliative Care is Growing



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

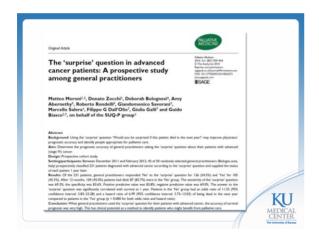


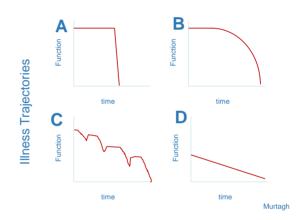
Advantages

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

KU MEDICAL CENTER

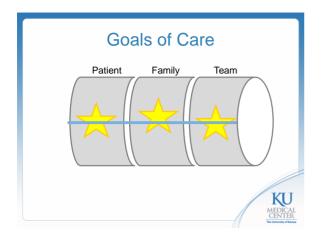




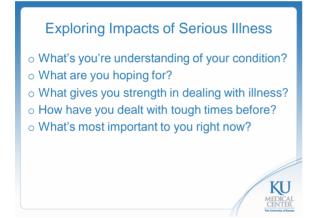


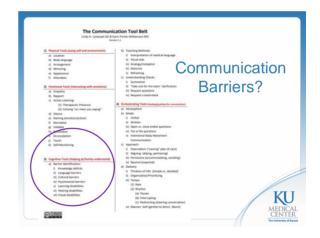
MATCHING RESOURCES
TO FIT THE GOALS OF CARE

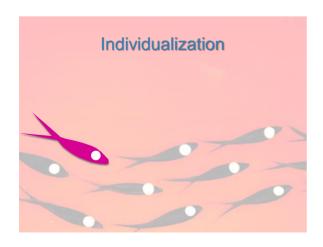


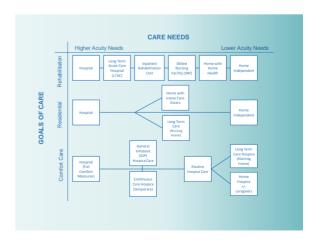


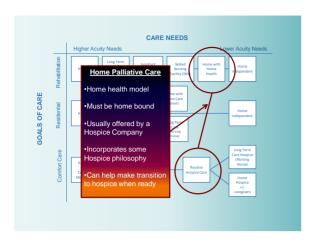


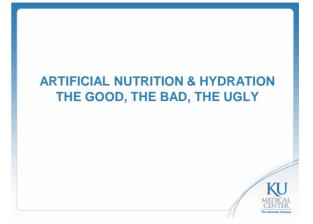












Benefits of AHN

- 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

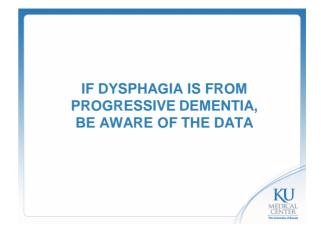
- · Your expertise!
- Any reversible causes of the dysphagia?
 - Infections
 - Myasthenia Gravis
- I tell other docs..."Make friends with your speech therapist"
 - They can help prognosticate the swallow
 - Rehab potential
 - Invite SLP to the family meeting



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 contradindications, begin enteral feeding within 72 hrs, parenteral not as urgent due to associated risks

 | MEDICAL
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Cochrane Database Review

"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)

ΚU

I want to eat but can't...

OBSTRUCTION

- Consider Goals
- · Consider Prognosis
- Is the patient a candidate for:
 - surgery
 - laser ablation
 - radiation
 - stent +/- brachytherapy



I want to eat but can't... OBSTRUCTION

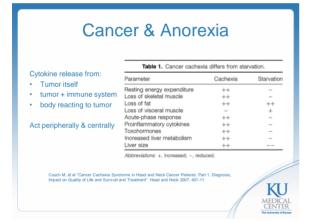
- If not available, not successful or not effective...
- Especially if patient is hungry and/or goals fit...
- · Consider:
 - Gastrostomy tube (PEG)
 - NGT
 - Trial of parenteral hydration
 - hypodermoclysis

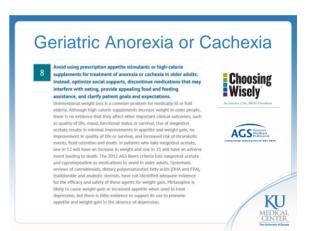


Cancer Anorexia-Cachexia Syndrome

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







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.

Perry A, Lee S, Cotton S, Kennedy C, Swallowing exercises for affecting swallowing after treatment in people with advanced-stage kU head and neck cancers 2016.



ALSO WORTH KNOWING ABOUT



Gastrostomy Tubes

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

How Placed	Technique	Location of Placement	Abbreviation
Percutaneous	Endoscopically	Gastrostomy	PEG
Percutaneous	Endoscopically	JeJunostomy	PEJ
Percutaneous	Radiographically	Gastrostomy	PRG
Surgically		Gastrostomy	G-tube

G tubes, sizes French (3 times diameter in mm) French Gauge 16 5.33 mm 18 6 mm 20 6.67 mm 24 8 mm 28 9.33 mm

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 vis 6.1 IV
- Cost: IV supplies 4x greater than for HDC supplies

Remington R, Hultman T, JAGS, 2007 55: 2051-55

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
- Drv mouth
- Hypervolemic, 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



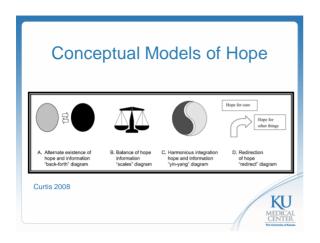
Emotional Aspects of Eating

- 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?

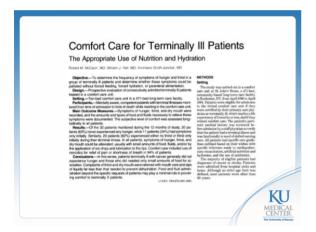


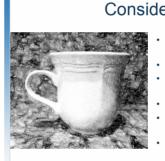


Wish/Worry statements

- 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 w/ favorite beverage
- Is mouth moist? Swab?
- Is the presentation pleasing?
- Is the setting appealing?





Comforting without food

- Music
- Reading
- Therapeutic Touch, Massage
- Reminiscing or Story **Telling**
- Being a Quiet presence
- **Providing Oral Care**

BUT AM I STARVING HIM?



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 thirty
 - Not awake

Landzaat, Sinclair. Principles and Practice of Hospital Medicine



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

Landzaat, Sinclair. Principles and Practice of Hospital Medicine.



Scripting

- 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.

Landzaat, Sinclair. Principles and Practice of Hospital Medicine



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:
 - PFG 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

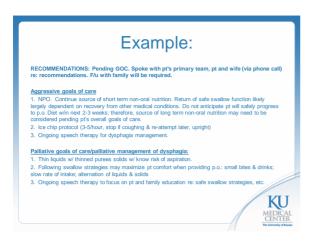
- · Patient & family informed of risks and benefits
- · Patient maintains control over this aspect of their QOL
- · Still want to try to make it as comfortable as possible
 - Sharing maneuvers, tips, coaching for family may still be
- · Some patients can not eat very comfortably
 - Autotitrate, how and 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"
- stay rehab when clear, realistic goals, need your help
- · Some hospices contract with rehab specialists
- · Helpful for us to "see" pt doing therpies
- We advocate for short
 Don't automatically sign off when goals switch to hospice



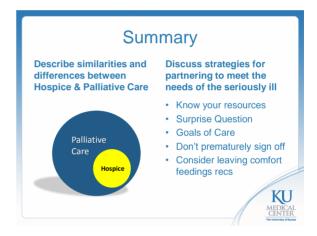




Palliative Care Fast Facts

www.mypcnow.org





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