Palliative Care for Transitional Populations

Transition Medicine Conference

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Pediatrics

Goal

To understand the role of palliative care in adolescents and young adults (AYA) with special healthcare needs (SHCN) as they transition from pediatric to adult-based care

Objectives

- Define palliative care
- Identify palliative care needs for AYA with chronic medical conditions
- Describe changes in palliative care needs and delivery during transition
- Review advance care planning
- Apply knowledge in case-based format

Andrew

- 22 yo M with DMD
- Severe LV dysfunction (EF<20%), OSA on BiPAP at night, symptomatic hypotension, FTT, deconditioning with progressive immobility
- Spends most of his time in bed, 8h day in chair, discharged from PT for failure to progress

Pediatrics

Andrew

- Difficulty chewing/swallowing, refuses swallow study, misses coffee
- Down 10 Kg in past year, hates BiPAP, +N/V, + episodic syncope at home
- Younger brother died from DMD 14 months ago
- Co-managed by cards, pulm, neuro, gi. No PCP.

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Palliative care consulted

- Is Andrew appropriate to receive palliative care?
- Is Andrew appropriate to receive hospice services?
- Who should provide palliative care for Andrew?
- How should we provide palliative care for Andrew?

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Palliative Care

- Philosophy and method for delivering care to patients with chronic, complex and/or life-threatening conditions and their families
- Focuses on quality of life, minimizing suffering, optimizing function and providing opportunities for growth
- Collaborative efforts of an interdisciplinary team that is patient and family-centered
- Can be the main goal of care or provided concurrently with disease-modifying therapy
- Begins at time of diagnosis and continues throughout the entire course of a patient's life and beyond

Pediatrics

When is palliative care needed?

Pediatrics

Who should receive palliative care?

- Shifting away from palliative care diagnoses towards identifying palliative care needs
  - Pain and symptom management
  - Prognostic uncertainty
  - Complex decision-making
  - Care coordination
  - Psychosocial stressors
  - Spiritual care

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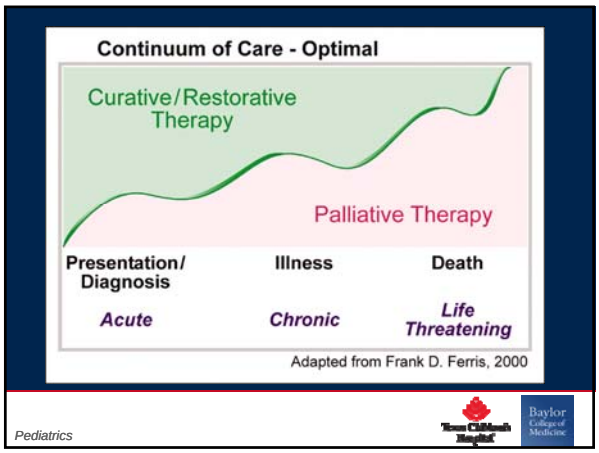
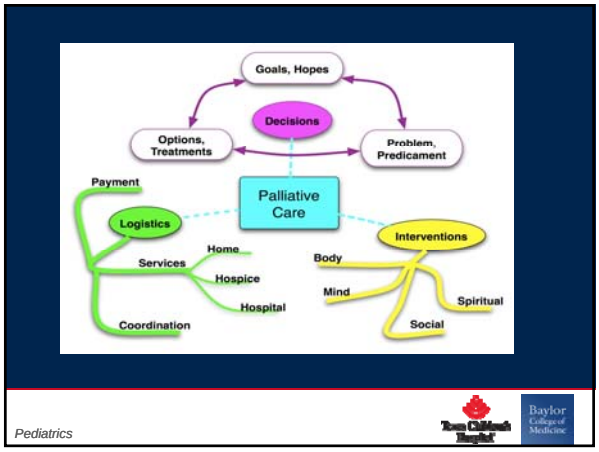
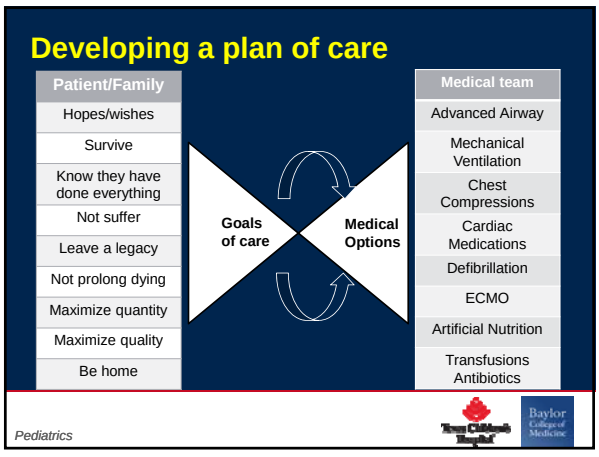

Continuum of Care - Optimal
Curative/Restorative Therapy
Palliative Therapy
Presentation/ Diagnosis
Illness
Death
Acute
Chronic
Life Threatening
Adapted from Frank D. Ferris, 2000
Pediatrics


Goals, Hopes
Decisions
Options, Treatments
Problem, Predicament
Payment
Palliative Care
Logistics
Interventions
Services
Home
Hospice
Hospital
Coordination
Body
Mind
Spiritual
Social
Pediatrics


Developing a plan of care
Patient/Family
Hopes/wishes
Survive
Know they have done everything
Not suffer
Leave a legacy
Not prolong dying
Maximize quantity
Maximize quality
Be home
Goals of care
Medical Options
Medical team
Advanced Airway
Mechanical Ventilation
Chest Compressions
Cardiac Medications
Defibrillation
ECMO
Artificial Nutrition
Transfusions Antibiotics
Pediatrics

Hospice

- Package of services to provide home-based end-of-life care
  - Skilled nursing visits at least once a week
  - SW and chaplain visits at desired intervals
  - DME supplies and medications related to hospice diagnosis
  - Volunteer and respite services
  - Bereavement care for at least 1 year

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Who should provide palliative care?

- Primary palliative care
  - Basic skills and competencies required of all providers in areas such as pain management, guiding discussions about advance directives and assisting in end-of-life decision-making
- Secondary palliative care
  - Specialist clinicians and organizations that provide consultative and specialty care
- Tertiary palliative care
  - Academic medical centers where specialist knowledge for the most complex cases is practiced, researched and taught

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YOU should provide palliative care!

Every medical provider should practice palliative care to the extent of his/her abilities and comfort

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Recommendations for Andrew

- Liberalize oral intake with focus on quality of life
  - Coffee, stop studies that don't contribute to QOL
- Help communicate patient goals to healthcare team
- Incorporate hospice

Pediatrics

Leo

- 28 y/o male s/p OHT x2, s/p BiVAD placement with chronic systolic/diastolic failure
- Ongoing driveline mycobacterial infection
- End-stage renal failure with dialysis dependence (CRRT)
- Chronic respiratory failure requiring BiPAP
- H/o stroke, pancreatitis on chronic TPN, depression and malnutrition

Pediatrics

Leo

- No longer a transplant candidate
- Deemed to have decision-making capacity per a psychiatry consult, although becoming more confused
- ROS + for fatigue, dyspnea, cough. Arterial line is causing some discomfort. + anxiety and nervousness.
- Mostly in bed, able to OOB to BR and chair occasionally
- He would like to get better, go home and go on vacation

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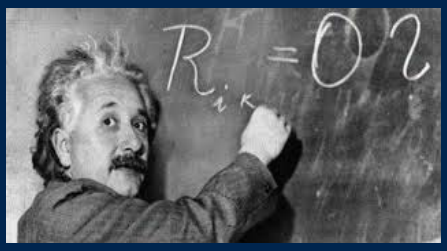
Palliative care consulted

- Prognostication
- Breaking bad news
- Disposition

Pediatrics



Pediatrics

Importance of prognostication

- Patients with advanced life-limiting diseases have high information needs regarding prognostication
- Most patients and families *want* to know specifics about length of survival, symptom burden, etc.

Pediatrics

Importance of prognostication

- Preparation
  - Control of situation; promotes autonomy
  - Important personal and family decisions influenced by time (treatment, finances, making certain memories)
  - Time to express wishes

Pediatrics

Communicating prognosis

- In ranges, "days to weeks"
- Honestly
- Revisit as clinically indicated or as requested by patient/family
- May *offer* prognostic information

Pediatrics

How to communicate bad news

- SPIKES
  - Situation, Perception, Information, Knowledge, Emotion, Strategy
- Other tips from the experts
  - Wolfe et al. encourage us to "understand the illness experience" and "provide anticipatory guidance"
  - Hauer challenges the provider to shift from a position of certainty to curiosity in these moments, letting the patient/family's voice be heard
  - Feudnter encourages the provider to help the patient and family "reframe hope"

Pediatrics

Leo

- Patient and family wanted to go home
- Accepted hospice but didn't want to give up long-standing relationship with cardiology and transplant teams

Concurrent Care

- As part of the Patient Protection and Affordable Care Act of 2010, all state Medicaid programs are required to pay for both curative and hospice services for patients under 21
- Adult patients can receive Medicare coverage for hospice as well as other services not related to the terminal diagnosis

Recommendations for Leo

- Held family and team meeting to convey prognosis
- Arranged discharge to home with hospice and plan to follow up with primary teams as desired
- Leo died at home after several days

Tara

- 18 yo F with CF s/p lung transplant complicated by chronic rejection, recent pneumonia, malnutrition and FTT admitted for progressive dyspnea and initiation of TPN
- Knows that she is dying, very scared, sad that she won't see her 7 yo brother grow up
- Parents divorced and bad relationship, somewhat mistrustful of mom
- In the midst of transitioning pulmonary team

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Palliative care consulted

- Advance care planning
- Need for transition

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Definitions

- Advance care planning- *process*
- Advance directives- *documents*
- Living will= medical power of attorney +directive to physicians

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Advance directives

- State specific
- Must be 18 or emancipated minor
- Notary or two witnesses
- Does not have to be done by/with lawyer
- Copies to doctor, hospital, surrogates, self
- Can change at any time

Pediatrics

Components of an advance directive

- Directive to physicians, family or surrogates
- Medical power of attorney
- Durable power of attorney
- Out of hospital DNR (OOH DNR)
- Declaration for mental health treatment
- Organ donation

Pediatrics

Directive to physician, family or surrogate

- Allows the patient to state their wishes about medical care in the event they develop a terminal or irreversible condition and can no longer make their own medical decisions
  - Terminal defined as "expected to die within 6 months" "even with available life-sustaining treatment in accordance with prevailing medical standards"
  - Irreversible condition AND not able to care for self or make decisions for self
  - THEN specify comfort or life-sustaining treatment
  - Space to write own narrative
  - In case of imminent death

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Medical and durable power of attorney

- Medical surrogate
- Financial surrogate
  - -Money, benefits, real estate, tax

Pediatrics

OOH DNR

- Patient's own document to use/not use at their discretion
- Can fill out for minors by parent IF the minor has a diagnosed terminal or irreversible condition
- Automatically revoked in a person known to be pregnant or in the case of unnatural or suspicious circumstances

Pediatrics

Organ donation and mental health

- Organ donation
  - What they would like to donate
  - If there exists an institutional agreement
  - The desired purpose of their donation
    - Any legally authorized purpose
    - Transplant or therapeutic purposes only
- Mental health declaration (expires in 3 years)
  - Psychoactive medications, convulsive treatment, emergency treatment

Pediatrics

Where to find advance directives

- Texas Department of Aging and Disability Services (DADS)
  - https://www.dads.state.tx.us/news_info/publications/handbooks/advancedirectives.html
- CaringInfo
  - www.caringinfo.org
- AARP
  - http://www.aarp.org/content/dam/aarp/relationships/caregiving/2015/ad/Texas-advance-directives-updated-2014-aarp.pdf
- Texas Hospital Association
  - http://www.tha.org/GeneralPublic/AdvanceDirectives/WhatareMyOptionsfor09C0/

ACP in AYA

- AYA patients with cancer tend to be more concerned with how they want to be treated and remembered (at the end of life) than about decision-making
- Unique psycho-social, developmental, legal and ethical issues in this population
- *Voicing My Choices* is a helpful guide
  - www.agingwithdignity.org/voicing-my-choices

Whose responsibility are ADs?

- The patient
- The family
- The medical team
  - Physician, care coordinator, social worker, nurse, chaplain
- The community

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Talking about advance care planning

- *Recognize* the potential difficulty and discomfort of this topic
- *Normalize* the conversation
- *Prognosis* is important
- Take into account patient's *values* and *wishes*
- *Specifics* are helpful to elucidate
- Remind patient that they are in charge (*autonomy*), but nothing wrong with offering your opinion (*paternalism*)

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Suggestions for phraseology

- "I talk about this with all my patients"
- "We hope for you to do well, but we need to prepare for all possibilities"
- "I want you to be in charge of your care, even if you are too sick to talk to us"

Pediatrics

Tara

- Tara unable to articulate an advance care plan
- Very fearful of actuality of dying
- Stressed at having to name a surrogate or place of care given familial discord
- Team was able to mediate with parents and Tara and make a plan based on her wishes; she was discharged to her father's house with hospice

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Decision making in AYA

- AYA may be developmentally or cognitively delayed as a result of their underlying disease
- Many have a more child-like mentality due to their protracted illness and physical dependence on caregivers
- Coping and decision-making skills may be at a developmental level that is below chronological age

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To transition or not to transition?

- Benefits and drawbacks of transitioning care in AYA with SHCN
- Not always the best or easiest choice

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Take home points

- YOU are your patient's *best* palliative care provider
- *Early* palliative care implementation is best
- *Concurrent care* is an option
- Difficult discussions require SPIKES and reframing hope

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Take home points

- Talk about advance care plans *early and often*
- May have to include parents or surrogates in AD discussions of AYAs
- Transition and palliative care don't always coexist

Pediatrics

References

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