Sometimes we can offer a cure, sometimes only a salve, sometimes not even that.

But whatever we can offer, our interventions, and the risks and sacrifices they entail, are justified only if they serve the larger aims of a person’s life.

When we forget that, the suffering we inflict can be barbaric.
When we remember it, the good we do can be breathtaking.

Atul Gawande, MD
Being Mortal

NATIONAL TRENDS IN PEDIATRIC PALLIATIVE AND HOSPICE CARE:
WHERE ARE WE, AND WHERE ARE WE GOING?

Sarah Friebert, MD
Director, Haslinger Family
Pediatric Palliative Care Division
Akron Children's Hospital
2nd Annual Pediatric Palliative Care Coalition Conference
October 27, 2016

DISCLOSURES

- Nothing, sadly
- The real version:
  - I have no relevant financial relationships with the manufacturers of any commercial products and/or providers of commercial services discussed in this CME activity
  - I do not intend to discuss any unapproved or investigative use of commercial products or devices
  - The pictures of children shown herein are actual patients, used with family permission
Other disclosures...

**Pediatric/Children** =

Prenatal, Infants, Children, Adolescents, Young Adults, Adults with Pediatric Conditions

Official Learning Objectives

- Describe the current landscape of pediatric palliative care in the US
- Identify 3 emerging national trends in pediatric palliative care that impact care planning and delivery
- Outline specific benefits to local, regional and national collaboration and strategies to achieve that collaboration through coalition building

Hidden Curriculum:

What I really hope you get out of this

- Caring for seriously ill children is everyone’s business
- Palliative care is evolving to be standard of care, and yet...
- Access to hospice & palliative care remains restricted
- But lots of great things are happening!
- Evolving payment reform models are favorable for this kind of care
- Palliative care can & should play a central role in improving value of healthcare for all
- The light at the end of the tunnel is NOT a train
CURRENT TRENDS IN PC

- Increasing medical complexity
- Early integration – from diagnosis forward
  - Focus on care coordination
- “Primary” vs “Secondary” or “Subspecialty” PC
- Volume of programs and growth
  - Creative models and measures of success
  - Workforce issues
- Financial
  - Concurrent care
  - Billing codes for Advance Care Planning (Medicare)
- Care across the continuum
  - Hospices and PC programs in ACOs
  - Outpatient
  - Community-based care
  - PCMH
- Business of Hospice/PC
  - Regulatory scrutiny

TRENDS, CONT’D

- Addiction/SUD/opioid epidemic
  - Secondary gain: non-pharmacologic/expressive therapies
  - “Medical” marijuana
- Going “deeper” beyond pillars
  - Trauma-informed care
  - Secondary trauma/moral distress
  - Social determinants of health
- Connectivity
  - Telehealth
  - Patients/families across social media
- Expanding professionalism, education & career opportunities
  - Subspecialty fellowships, NP role, certification
- Research
- Coalitions and Collaborations

WHAT’S BROKEN IN HEALTHCARE?

- Besides the obvious ($$$) ....
- Children with medical complexity are an increasing presence in our health care system
- People with serious illness consume a disproportionate share of health care resources
- Systems and structures to serve them are lacking
- Higher spending ≠ higher quality
  - Outcome measures are unclear, difficult
- Pall care services have not been linked effectively to efforts to improve value for high-risk patients
IF YOU ASK PATIENTS AND FAMILIES THIS ?...

- Lack of coordination of care within and among health care teams
- Lack of communication regarding options
- Pain (and other symptom) management is poor
- Little attention to social determinants of health (i.e. “my everyday life”)
- Families are challenged on and by the decisions they make ... or not asked to make them at all
- Inconsistent messages from the health care team
- Many health care workers are just not comfortable with this part of care
  - We need high tech AND high touch
- Even though we want to be home, 24/7/365 care of our chronically/seriously ill loved one is overwhelming

IF YOU ASK HEALTH CARE TEAMS THIS ?...

- We struggle with “doing too much” or too little
- Time and $ constraints: doing more with less
- Dealing with diverse populations (culture, ethnicity, language, social factors, etc.)
- Well-communicated, coordinated care is not always present
- Time and $ constraints
- The concept of bringing the best of each of our disciplines to the bedside is not being fully realized
- We lack skills and/or systems to do this well
  - We can’t get kids covered OR we can’t discharge them!
- Electronic health records
- How many hours are there in a day?

TAKEN TOGETHER:
WHAT ARE THE GAPS?

- People are suffering
  - Uncontrolled pain and other symptoms
  - Powerless over body and decisions
- Families and communities are suffering
  - Fragmented care, far from home
  - Burden of uninformed, lifelong decisions
- Caregivers are suffering
  - Witnessing unmitigated suffering
  - Powerless over barriers
  - Tremendous physical, emotional & spiritual toll
- Health care institutions/systems are suffering
  - Overburdened with high-cost care
  - Understaffed
WHY THE GAP?

Change is hard...
Especially culture
And silos...

UPSTREAM PALLIATIVE CARE
- 3 million CMC (of 76 million children in this country)
  - Increasing # of previously fatal conditions now chronic
    - Esp increase in NICU survival rates
  - Increasing at a rate of 5% per year, outpacing the growth rate of children as a whole
  - Utilizing an increasing % of medical resources
  - Becoming more complicated
  - Providers have less time to see/manage them
  - Higher risk of death
  - Majority still not receiving palliative care/hospice services

FINANCIAL IMPLICATIONS IN PEDS PC
- 2/3 CMC covered by Medicaid (2 million)
  - 6% of total # of children on Medicaid
  - Accrue 10X annual costs of "other" kids on Medicaid
  - 40% of total costs (~$30 billion)*
- Medicaid is largest payer because their care outstrips coverage from commercial plans

*Children's Hospital Association
BIGGEST GAPS FOR SICKEST PEOPLE

- Those w/medical complexity or serious illness often lack a comprehensive care plan and access to case management/care coordination
- Shifting burdens of care to families, communities
  - At risk for
    - frequent and prolonged hospitalizations
      - Preventable readmissions
    - fragmented care
      - Unnecessary ED visits
    - caregiver stress/burnout
      - 24/7/365 caregivers for years or lifetimes
    - unsafe care

INCREASING MEDICAL COMPLEXITY: IMPACT FOR US

- More expertise needed
- Longer periods of unclear trajectories
  - Fluctuating need for services
  - Difficult to staff for uncertainty/in advance of need
  - Blurry boundaries with Concurrent Care
- More services needed
  - Respite
  - Care coordination
  - Resources for long-term trach/vent care
  - Qualified and available home nursing
- More patients
- More upstream care: bigger chance of impact
TREND: EARLY INTEGRATION OF PPC

- Should not be “either/or” choice for family or transition to second best
  - Allows utilization of full scope of supports
  - Enables development of rapport
  - Family perceives care teams as one entity
- Goal is integration with primary team
- Disease modifying and palliative care strategies often synergistic

WHY INTEGRATE EARLY

- Prevents disruptive transition to new care team at worst possible time
  - Decreases feelings of abandonment
- Minimizes fragmentation of care
- Provides umbrella of support throughout entire draining process
  - Additional support for primary team too (time, resources, self-care, prevention of compassion fatigue)
- Allows patient and family self-determination about treatment options
- Empowers parents and families to be capable of maintaining dual goals of care concurrently
- Allows teams to bring full complement of services

EARLY INTEGRATION: IMPACT FOR US

- Longer periods of unclear trajectories
  - Fluctuating need for services
  - Difficult to staff for uncertainty/in advance of need
- More services needed
  - Respite
- More potential for role confusion/overlap
- More patients
  - Workforce issues
  - Burnout/compassion fatigue/secondary trauma
- More upstream care
- Improved communication
- More seamless/less fragmented care
A LOT IS HAPPENING IN THE DISCIPLINE

- Official board certification since 2008
- Fellowship required since 2012
- Growing # of accredited pediatric PC fellowships in US (1-2 yrs after residency)
  - Several more with "pediatric track"
  - Nurse practitioner and social work fellowships available
  - Post-doc fellowships
  - International fellowships: Australia, Canada, India
- Pediatric standards (www.nhpco.org/pediatrics)
- Joint Commission certification
- Commission on Cancer: Standard 2.4
- AAP revised Position Statement
- Multiple pieces of legislation in play (none this year)

AAP & OTHER PRIMARY & SUBSPECIALTY ORGS

PEDIATRIC PALLIATIVE CARE AND HOSPICE CARE

COMMITMENTS, GUIDELINES, AND RECOMMENDATIONS

LEAD AUTHORS
- Carol Feudtner, MD, PhD, MPH, FAAP
- Sarah Freibert, MD, FAAP
- Jennifer Sherid, MD, FAAP

IF YOU BUILD IT...:
INCREASING PENETRATION/AVAILABILITY

- Practitioners
  - Over 13,500 certified nurses (2014)
  - Over 6500 certified physicians (2013)
- Programs
  - # of PC programs nearly triple what it was in 2000
  - 6100 hospices as of 2014
- Peds: 69% of Children’s Hospital Assoc hospitals
- Adults:
  - 87% of NCI-designated comprehensive cancer centers
  - 72% of hospitals with ≥ 50 beds have programs (2013)
  - 1.66 million people received hospice care in 2013
HOSPITAL-BASED PPC PROGRAMS

- 2012 Survey
- OFKANACHRI: Children’s Hospital Association
- 72% response rate
- 69% of respondents with PPC program
- Sig dependence on institutional $ support
- Avg 2.33 FTE (0.85 LIP)
- Outpt consultation
- Across the lifespan (prenatal to adult)
- Bigger hosp/more beds, more FTE, more consults

Feudtner et al. Pediatrics 2013

FIELD EXPANSION:
IMPACT FOR US

- More potential for role confusion/overlap
- More competition for patients
- More “peeps”
- More access to care for pts/families with PC needs
- More credibility
- Less stigma/need for constant re-education
- More professional rigor

OPPORTUNITY

- PC as the bridge - the answer to the
  **Triple Aim** of Health Care

  1. IMPROVE QUALITY
  2. IMPROVE HEALTH
  3. LOWER COST
     for people with serious, life-threatening conditions
OPPORTUNITY

- PC as the bridge - the answer to the Quadruple Aim of Health Care

1. IMPROVE QUALITY
2. IMPROVE HEALTH
3. LOWER COST
   for people with serious, life-threatening conditions
4. Improve the work life of health care providers

VALUE = QUALITY/COST

Because of the concentration of risk and spending, and the impact of palliative care on Quality and Cost, its principles and practices are central to improving value

PALLIATIVE CARE IMPROVES VALUE

<table>
<thead>
<tr>
<th>Quality improves</th>
<th>Costs reduced</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Access</td>
<td>• Hospital costs/day</td>
</tr>
<tr>
<td>• Symptoms</td>
<td>• Use of hospital, ICU, ED</td>
</tr>
<tr>
<td>• Quality of life</td>
<td>• Unplanned readmissions</td>
</tr>
<tr>
<td>• Length of life</td>
<td>• Hospitality mortality</td>
</tr>
<tr>
<td>• Patient safety</td>
<td>• Labs, imaging, pharmaceuticals</td>
</tr>
<tr>
<td>• Family satisfaction</td>
<td>• Staff retention</td>
</tr>
<tr>
<td>• Less fragmentation</td>
<td></td>
</tr>
<tr>
<td>• Family bereavement outcomes</td>
<td></td>
</tr>
<tr>
<td>• Staff satisfaction</td>
<td></td>
</tr>
<tr>
<td>• Proactive, preventive care</td>
<td></td>
</tr>
<tr>
<td>• Community health</td>
<td></td>
</tr>
</tbody>
</table>
FRAMING:

- PPC as a disruptive innovation
- PPC as the medical home (or garage) for children with medical complexity

“THE TIMES THEY ARE A-CHANGIN”

- Current world: FEE FOR SERVICE
  - The more you do, the more you get paid
  - The more you have done to you, the more you or your insurance company have to pay
  - DRGs: Prospective payment
- What’s here or will be soon: Alphabet Soup
  - Value-based care or Pay-for-performance (P4P)
  - Accountable Care (ACO)
  - Shared savings or risk models (SSAs)
  - Patient-Centered Medical Homes (PCMH)
  - Population health
  - Global payment/capitation
  - Bundled, episode-based or episode-of-care payments

LIKE EVERYTHING, IT’S A SPECTRUM

<table>
<thead>
<tr>
<th>FFS</th>
<th>Capitation</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Note: Many models of this type of care already exist
VALUE-BASED CARE
Payment or reimbursement based on indicators of value such as patient health outcomes, efficiency and quality

ACCOUNTABLE CARE ORGS (ACOs)
- Healthcare org characterized by a payment and care delivery model that ties provider reimbursements to quality metrics and reductions in total cost of care for an assigned population of patients.
- Groups of doctors, hospitals, and other health care providers come together voluntarily to give coordinated high quality care to their patients.
- Goal of coordinated care: ensure that patients, especially the chronically ill, get the right care at the right time, while avoiding unnecessary duplication of services and preventing medical errors.
- Success in both delivering high-quality care and spending health care dollars wisely results in shared savings with payers

ACO MANDATORY ELEMENTS FOR PERFORMANCE
- Education
- Social Health
- Mental Health
- Physical Health
- Transparency
- Community Leadership
- Consumer Trust
- Tool: Medical Home

Doesn't this sound like Palliative Care to you?


**Patient-Centered Medical Home**

- Payment goes in to the system to cover the cost of coordination of care without specifying targets or outcomes to justify the cost.
- Reduces utilization and prevents higher cost episodes.
- Does not reduce costs within hospitalizations.
- "Measuring Medical Homes: Tools to Evaluate the Pediatric Patient- and Family-Centered Medical Home"
  - Malouin RA & Merten SL
  - National Center for Medical Home Implementation - AAP

**Medical Home Components**

- Primary care involved.
- Family-centered partnership.
- Community-based, interdisciplinary, team-based approach to care.
- Care that is: timely, accessible, family-centered, coordinated, compassionate, continuous, and culturally effective.
- Preventive, acute and chronic care.
- Quality improvement.

**Value Propositions**

- Integrating interdisciplinary PC into models of value-based care (esp PCMH) is:
  - Innovative health care delivery for our sickest citizens.
  - Building an evidence base.
  - Replicable/scale-able – expanding from small pilots.
  - Coordinating care to improve QOL and decrease costs.
  - Keeping high-risk patients as healthy as possible.
  - Keeping family members of high-risk patients as healthy as possible.
  - Saving $ and resources for all of us.
  - Fundable – Medical Home, ACA home visit initiatives, value/risk-based care.
THE BRAVE NEW WORLD OF HEALTHCARE: IMPACTS FOR US

- More potential for role confusion/overlap
- Less individuality
- More rigor esp around outcomes
- More inclusive of IDT members (not as much focus on the medical piece)
- More funding
  - Esp for “non-billable” components of care
- More resources
- More credibility

WHAT IS THAT?

- “…the conditions in which people are born, grow, work, live, and age, and the wider set of forces and systems shaping the conditions of daily life” (WHO)
- 80% of health care is about this dimension (est)
- Maslow’s hierarchy of needs...

Low Ratio of Social to Health Service Expenditures in U.S.
SOCIAL DETERMINANTS OF HEALTH:
IMPACT FOR US
- Need (and opportunity) to go deeper with families
- More potential for role confusion/overlap
- More potential for duplication of services
- Need for enhanced communication
- Need for structures to teach fishing skills
- More funding from other sources – less burden
- More support for breadth of work
  - Ex: Community Health Workers

WHAT’S THE TREND?
- Decentralization of American society
  - Families spread apart
- Increasing medical complexity and upstream integration mean more patients
- Focus on PROs/PCOs
- Increased length of involvement with families
  - Prenatal through long-term bereavement
- Creative models to spread impact

WHAT ARE WE SEEING?
- Telehealth with providers
  - Telementoring
  - Systems connecting multiple institutions
- Telehealth with patients/families
  - Funding and regulatory/documentation considerations not fully known or realized
  - HIPAA compliance essential
- On-line education and support groups
  - Esp bereavement, vulnerable populations
- Professionals connecting individually and in groups
  - Faster development of innovation
  - Informal and formal collaborations focused on structure and process outcomes
CONNECTIVITY
IMPACT FOR US
- More access and outreach
  - To patients/families in far-flung geographies
  - To expertise (esp for rare diseases, small populations)
- Economies of scale
- Enhanced support for professionals
  - Less moral distress, compassion fatigue
- Faster response times expected
- Multiple opinions, medical and not
  - Families talk with one another...about us...
- Safety and privacy issues
- Need for additional resources
- Potential for automatization – call centers vs hands-on

SUD: SCOPE OF THE PROBLEM
- Smallpox epidemic of our time
- “This is not our problem”
- Pain as the 5th vital sign
- “Life threatening” diagnosis
- We have a responsibility to be responsible
  - Prescription monitoring programs
  - Safe disposal
  - Deprescribing

SUBSTANCE USE DISORDER EPIDEMIC
IMPACT FOR US
- Restricted access to needed medication
- Unclear and varying (state, region) legal issues esp r/t marijuana
- Increased fear
  - Patients, families, clinicians, public
- More emphasis on non-pharmacologic therapies
  - Enhanced acceptance of expressive and healing therapies (massage, reiki, acupuncture, healing touch, etc.)
- Safety issues
  - In-home professionals at risk
- Need for additional resources
  - Enhanced education
  - Access to other treatment modalities, new meds
  - Team expansion to care for severely addicted
THE BUSINESS OF HOSPICE

- Medicare Hospice Benefit is perhaps too stagnant for today’s landscape
  - Most patients do not follow the cancer model on which it was based
- Hospice has become a profitable enterprise
- Increasing number of programs/agencies/teams
- Lower census = tighter margin
  - Less room for mission-driven programs
  - More focus on billable services
- Palliative care far less regulated, more flexible
- Shorter LOS and tighter regulations in hospice = increased pressures on PC teams to absorb #s

Get away from terminality
Increase access & acceptance
Upstream care
Enroll early
Better symptom mgmt

Patient improves in hospice care
Patient is stable
Concurrent care blurs
Regulatory says “d/c”
Bumpy road of disenrollment

THE BUSINESS OF HOSPICE/PC
IMPACT FOR US

- Constant scramble to keep up with the changes
- Less willingness to take on new programs
- Fewer adult patients to absorb “more expensive” peds patients on census
- Need for additional resources
  - Enhanced education
  - Staff devoted to compliance
  - Creative models to bridge transitions
MODELS OF LOCAL/REGIONAL PPC
- Children's hospitals
- Pediatric hospitals within hospitals
- Hospice agencies
- Community-based home health
- Primary care/medical home models
- Free-standing pediatric hospice/palliative care/respite facilities
- Long-term care facilities

COALITIONS AND COLLABORATIONS
- AAHPM
- NHPCO
- AAP
- CAPC
- PPCRN
- NPCRC
- PCQN
- NPHPCC
- State coalitions

TYPES OF COALITIONS
- Independent 501c3 organizations
- Programs of existing organizations:
  - i.e. state hospice or palliative care groups
- Formal alliance of like organizations
- Informal alliance
- Virtual alliance (PCNOW)
- Loose affiliation for topical purposes
  - Education
  - Concurrent Care
  - Advance Directives (Respecting Choices MN)
COALITIONS AND COLLABORATIONS: IMPACT FOR US

- Strength in numbers
  - Legislative and funding advocacy
  - Research/QI/PI (more patients, more hands on deck)
- Reduction of duplication, esp with education
- More access to care for pts/families with PC needs
  - Care itself
  - Pieces/parts of care (equipment, specialized services)
- Spreading the wealth of limited resources
- More professional rigor, impacts on quality
- Faster dissemination of innovation

Bringing it in for a landing...

It’s tough to be a trend-setter

- Flywheel concept

A flywheel is a spinning wheel or disc with a fixed axle so that rotation is only about one axis. Energy is stored in the rotor as kinetic energy or, more specifically, rotational energy.

The moment of inertia is the measure of resistance to torque applied on a spinning object i.e. the higher the moment of inertia, the slower it will spin when a given force is applied.

\[ E_k = \frac{1}{2} I \omega^2 \]
“Hope is a verb with its shirtsleeves rolled up”

David Orr

THANK YOU!