Joanne C. Porter, MD
Albany Medical Center
Nori Giacchetta, RN, BSN
Community Hospice

FROM HOSPITAL TO HOME: A MODEL FOR PEDIATRIC PALLIATIVE CARE - COMMUNITY COLLABORATION
Growth of Palliative Care in US

American Hospital Association Annual Survey: 2000-2010
Palliative Care: a definition

Palliative care is specialized medical care for persons with serious illnesses. This type of care is focused on providing patients with relief of symptoms and pain, and address the stress of a serious illness, whatever the diagnosis. The goal is to improve quality of life for the patient and the family.
A New Vision of Care

Modifying Therapy, Curative, restorative intent

Risk

Disease

Condition

Palliative and Hospice Care

Death & Bereavement

Life Closure
Palliative Care

- Concurrent
- Comprehensive
- Pain and symptom management
- Across the continuum
- Patient centered
- Focused on goals of care and quality of life
- Care coordination with all providers
Hospital Medicine

- Complex Medicine
- Barriers to PC team involvement
- Unrealistic Goals
  - Not easily translated to home setting
  - Conflicts with what patient/family want
- Expectations
  - Identifying patient/family goals
  - Determining resources to deliver goals
  - Discuss expected outcome of goals set
Hospital to home: transitions

- Caregivers
- Prior authorizations
- DME
- Homecare planning
- Agency/cha
Palliative Care Team support

- Care coordination with d/c planning
- Communication with primary care
- Medication oversight
- Family centered; goal oriented
- Troubleshooting
- Re-entry navigation
Pediatric Case #001

- Parents worried about quality of life for child and rest of family
  - Case coordination - 10 doctors
  - Work with home care and doctors to arrange homecare antibiotics
  - Counseling for parents about uncertainty of medical path and balancing that with day to day
  - Care coordination for private duty nurse and school team for girl to attend regular school
Palliative Care Team Support

- Assess medical issues/treatment plan in hospital
- Coordinate community partners to provide svc
- Identify outpatient Doctor for oversight
- Create a link to PC team at discharge
- Track outpatient f/u to ensure continuity
- Exit as things settle down with care plan in place (available prn)
Case #001

2009-2011
- 10 day Hospital stay q 6 wk
- FTT from infection
- Separation from family
- Stranger anxiety
- Family stress-separation
- Anxiety about prognosis
- Work stress-absence and finances
- Mom and Dad out of work

2013-2015
- No hospitalizations – 3y
- Medically stable/growing
- Private duty nurse
- Mother out of work
- Dad at work consistently
- In school daily-thriving
- Planning summer camp
Community Partners: medical

- Pediatricians/Family Practice/Internists
- Specialists/Medical Clinics
- PT/OT/Speech/respiratory therapists
- VNA/VNS/Eddy
- Home Care agencies
- Palliative Care Programs
- Hospice
- Bereavement specialists
Community Partners: social

- Schools
  - Coaches/teachers/classmates
- Churches
  - Fundraisers/community dinners/emotional support
- Clubs
  - Kiwanis/Rotary/Knights/VFWs
  - Sports teams/gym
- Camps
  - YMCA/Double H Ranch/ diabetes/ dialysis
- Businesses
  - Restaurants/small businesses
- Ronald McDonald Hse
  - Nationwide connection for sick children/families
- Social Media
Camp Hole in the Woods
Caeden getting ready for zip line
Sheldon waiting his turn for zip line
Mary climbs cargo net with Dr. Porter
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Social Media

- Communication
  - Global-realtime-streaming
- Publicity
  - No more anonymity
  - Public access/ strangers
  - Other media uptick
- Connections
Social Media: wedding
Community Partners: foundations

- Ronald McDonald Foundation
- Make-a-Wish
- Go-fund-me
- Private foundations-examples
- Businesses
- Disease sp foundations support
  - American Cancer Soc; Alzheimers Soc; Kommen Found; MS Society;
Experience with peds cases limited

Available training for peds is limited
ELNEC is quarterly and expensive
literature is growing/ but limited
Education/Consultation: LOCAL

- Albany Med Children’s Hospital
- Journeys Pediatric Palliative Care Team
- ELNEC-peds
- Hospice - Nori Giacchetta/Joanne Porter
- Rotation with Journeys
Education/Consultation: Regional

- HYPCANYS
  - Pediatric specific educational forum
  - Pediatric Advisory Team

- University based
  - Syracuse: Choices
  - Buffalo:
  - Rochester: Compassionet
  - Downstate
  - UVM - annual meeting Burlington
  - Smith-pc cert for SW
  - St Rose-bereavement
Education/Consultation: national

- CAPC
  - Annual meeting
  - Online webinars

- NHPCO
  - Annual meeting
  - List serve/webinars

- CSU
  - Online courses

- University of Washington
HOW TO REACH US

Joanne C. Porter, MD
Director, Journeys Palliative Care Team
  office: 518-262-5636
  cell: 518-253-0884

Nori Giacchetta, RN, BSN
Clinical Leader/Case Manager;
General Inpatient Hospice RN
  office: 518-377-8846
  cell: 518-847-9990