Sharing the Care of your Complex Patients
Speakers

• CCP, Complex Care Program
  – Dr. Karen Fratantoni
• POCC, Pediatric Perioperative Care
  – Dr. Anjna Melwani and Dr. Sonaly McClymont
• HELP, Hospitalist Consult Service
  – Dr. Miriam Bloom
• PANDA Palliative Care Team
  – Dr. Melanie Anspacher
Learning Objectives

• Define the continuum of care services available for children with medical complexity at CNHS
• Identify referral criteria and process for CCP, POCC, HELP to PANDA Palliative Care
Children with Medical Complexity (CMC)

Our patient

FG is an 9 year old male with the following diagnoses:
- Neonatal HIE
- Global developmental delay
- Spastic quadriparesis
- Seizure disorder
- Temperature instability
- Central precocious puberty
- Chronic lung disease with baseline oxygen requirement of 1/4 L
- Dysautonomia
- Oromotor dysfunction
- GERD
- GJ tube dependence

He is on 17 medications.

He is followed by the following 7 pediatric subspecialists: Cardiology, Pulmonary, Neurology, PMNR, GI, Endocrinology, Neurology.

Due to his care coordination needs, his community primary care pediatrician referred him to the Complex Care Program.
What is the Complex Care Program?

• Developed in 2002 as a consultative-only model
• Provide ongoing medical care coordination between visits including communication with family, primary care providers, and specialists based on the needs of the family
• In 2011, Complex Care was integrated into primary care services in the Children’s Health Center, the largest health center within the Goldberg Center for Community Pediatric Health at Children’s Hospital.
• Provide a patient and family-centered “Medical Home” for children and youth with special health care needs.
• This integrated model allows us to provide both primary care and consultative services to children with complex chronic conditions.
What can Complex Care offer?

- Provide comprehensive care coordination through a team approach that includes physicians, nurse case management, parent navigators, and social work services provided in two (2) distinct formats.

  1. Established Community PCP:
     - CCP Physician sees the patient and family every 4-6 months for care coordination
     - Care team provides continual care coordination between CCP visits

  2. For those without a PCP, we will provide primary care including:
     - Well Child Care
     - Urgent Care
     - All CCP care coordination services
What can Complex Care offer?

- Medical management of patients with complex medical needs
- Work collaboratively with primary care provider, family, specialists, therapists, home care providers, and other members of the care team
- Help families negotiate the healthcare system and provide a link to community resources
- Create written care plans with the family to share with the primary care provider
Who is eligible?

- Child is medically complex and requires intensive hospital or community-based service needs, has two or more chronic conditions
- Followed by multiple specialists often within the Children’s system (three or more)
- Require multiple medications and/or home care
- Are technology-dependent (G-tube, ventilator, and tracheostomy)
- At risk of frequent and prolonged hospitalizations
Referrals

• May be made by Primary Care Providers, subspecialists, insurance case managers, early intervention programs and self referrals
  • Must communicate with PCP prior to referral
  • Family/patient must be aware of the nature of the referral
  • Evaluation of referral will be made to determine if child is eligible for the program

• **Contact Complex Care: 202-476-4664**
What did CCP do for FG?

• FG was referred by his PCP for care coordination
• At each care coordination visit:
  – Discussed and addressed parent concerns and care needs
  – Reconciled medications
  – Reviewed subspecialty recommendations
  – Discussed goals of care
  – Developed a plan of care, which is shared with the PCP
  – Identified new community resources/supports
• Between care coordination visits:
  – Interim medical management
  – Ongoing communication with patient/family, PCP, subspecialists, Parent Navigator, school nurses, and other members of care team
  – Completion of nursing and equipment orders
  – Medication reconciliation and refills
Pediatric Perioperative Care

Risk to Patient

Risk of the Procedure

Risk of Anesthesia
Pre-operative Care Clinic (POCC)

• Provide comprehensive assessment of perioperative risks for patients with medical complexity and provide specific medical recommendations
  
  ➢ Gather a detailed medical history and physical exam with a focus on identifying potential pre- and post-operative risk factors (Risk to the Patient)
  
  ➢ Coordinate care with amongst various specialists including the Surgeon (Risk of the Procedure)
  
  ➢ Evaluate patient in conjunction with an Anesthesiologist (Risk of Anesthesia)
  
  ➢ Assist in management of Postoperative Care of surgical patients that were identified in POCC
Pre-operative Care Clinic (POCC)

Hospitalist develops perioperative plan

Contacts subspecialists to add recommendations

Discusses plan with surgeon

Integrates recommendations and provides comprehensive plan prior to the operating room

Follows up post-operatively to assist with care
Family Centered Care

- Multidisciplinary clinic with family, Hospitalist, and Anesthesia to identify perioperative concerns/risks
- Discuss coordination of care with specialists
- Discuss anticipation of potential post-operative complications
- Prepare for observation (PACU) vs. hospitalization (PICU vs. Floor)
- Perioperative recommendations/instructions given to family
- Family given POCC contact information for questions or concerns and contacted by POCC with any changes/updates
- Documentation of encounter completed and sent to PCP
- Communication with the surgeon and subspecialists to ensure a clear perioperative plan

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How to Refer Patients to POCC

- Complex patient needs surgery*
  - Discuss with surgeon to refer to POCC hospitalist (preferred)
  - Contact POCC hospitalist DIRECTLY

*Consider medical/surgical complexity:
- Procedure Time
- Type of Procedure
- Post-Op Hospitalization
- Medications
- Co-morbidities
- Technologies
- ASA Score
- Recent Hospitalizations/Illnesses

Phone: 202-476-1016
Email: pocchospitalist@childrensnational.org

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HELP Team, Pediatric Hospitalist Consult Service

What we do.

• Provide overriding continuity, consistency and family centered care while ensuring safety
  – Inpatient
    • Across transitions of care
  – Outpatient
    • Pediatric consultant in subspecialty clinics
    • Limited follow-up for:
      – Complex discharges
      – Ongoing acute issues
      – Transition of care to PCP and Complex Care Program
HELP Team, Pediatric Hospitalist Consult Service

- Continuity of care for children with complex medical problems
  - Across providers thru an admission
  - Across admissions
  - Inpatient to Outpatient care
  - At hospital transitions of care
    - ICU to floor –and floor to ICU
    - Surgical to medical teams
    - Across changes in care team on the general wards

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HELP Team, Pediatric Hospitalist Consult Service

• Provide family centered care through a comprehensive understanding of the child's:
  – Past medical history
  – Medical problem list
  – Correct medication regimen
  – Prior evaluations
• Provide a better understanding of a family’s:
  – Hopes for the child
  – Expectations for the admission
  – Resources as a family and community
• Advocate for the patient and family
  – Unifying subspecialty recommendations
  – Providing wrap around services over time
• Enhance communication:
  – Within team
  – Family and team
HELP Team, Pediatric Hospitalist Consult Service

• Focus on safety
  – Medication reconciliation
  – Home care orders to inpatient care order sets
  – Improve discharge planning
    • Adequacy
    • Completeness
    • Safety
    • Accuracy
    • Efficiency

• How we support you, the PMD
  – Continuity of information
  – Clean transition to PMD/community providers
  – Resources for ongoing care:
    • Letters of medical necessity
    • Nursing/Home care orders
    • Prescription refills
    • DME

• Contact HELP at (202) 476-1487
HELP Team, Pediatric Hospitalist Consult Service and patient FG

- HELP provider reviewed and summarized medical history
- Reconciled medications
- Regularly interacted with family
- Regularly interacted with medical team
- Attended family meetings
- Assisted with discharge planning and transition to palliative care
- Shared communication with PMD

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HELP Team, Pediatric Hospitalist Consult Service and patient FG

FG is admitted to the Hospitalist pediatric service for respiratory distress
• Tenth hospitalization, 3rd admission this year
• Medications
  – 12 on last discharge list
  – 15 on home care orders
• Since last admission has been seen by 8 subspecialty clinics and 2 ER visits
Palliative Care for the Medically Complex Child

What is palliative care?

The prevention and relief of suffering in children with life-limiting illnesses and their families across the continuum of care.

suffering = physical, emotional, psychological, spiritual

Not just...
– Hospice
– End of life care

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Palliative Care for the Medically Complex Child

Principles of Palliative Care

• Improvement of quality of life
• Child-focused, family centered
• Goal-directed
• Support for entire family during illness and bereavement
• Facilitation of informed decision-making
• Integration into continuum of care
• Provided concurrently with curative, disease-directed therapy
• Care across life span and illness trajectory

Early Referral is Recommended
Palliative Care for the Medically Complex Child

Identifying patients

- Medically complex children commonly referred
- Varied diagnoses → share complexity
  - Complications of extreme prematurity
  - Genetic/congenital conditions
  - Neurological disease (hypoxic, traumatic injury)
- Unique barriers/challenges with this population
  - Difficulty prognosticating
  - Decision-making regarding technology/interventions
  - Coordination of care

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Feudtner et al, 2011
Palliative Care for the Medically Complex Child

Triggers or criteria for referral

Primary Palliative Care – You are doing it!

Subspecialty Palliative Care – when to consider referral

• Advanced pain / symptom management
• Decision-making
• Advanced care planning / goals of care
• Ethical challenges
• Conflict resolution
• Additional support / continuity
Palliative Care for the Medically Complex Child

The PANDA Palliative Care Team

Physicians / NPs
Case Manager
Social Worker
Program Manager
Chaplain
Psychologist
Child Life
Integrative therapies
Volunteer Services

• Inpatient
• Outpatient
• Collaboration with hospice
• Home visits
• Telemedicine

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Palliative Care for the Medically Complex Child

How to refer

Email us
palliativecare@childrensnational.org

Call us
(202) 476-4256
(202) 476-5000 – ask for PANDA physician or NP on call

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Palliative Care for the Medically Complex Child

What we did for FG and his family

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Care of the Medically Complex Child
Children’s National Health System

Outpatient

Complex Care Program

POCC

Post-operative co-management

HELP

Palliative Care

Inpatient

Goldberg Center

Hospitalist Division
Thank you for your time!

Questions?