Management of the Complex Pediatric Patient in PCAVS

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Objectives

• Participants will understand the structure and role of a multidisciplinary aerodigestive clinic in the management of children with medical complexity
• Participants will be able to describe the importance of care coordination for children with a complex medical history
• Participants will be able to define the role of the APRN in care coordination of children with medical complexity
• Participants will be able to identify benefits and the importance that multidisciplinary and care coordinate have on our healthcare system

Meet Jacoby
A day in the life of Jacoby…

- 5 year old girl with a complex medical history
  - Born at 31 weeks; twin pregnancy born with known hydrops with severe bilateral pleural effusions, ascites, generalized edema and polyhydramnios at birth, chronic respiratory failure, trach/vent dependent, bronchomalacia & tracheal malacia, GTube dependent, and hypothyroidism, pulmonary hypertension, history of seizures, dysphagia, developmental delay
  - Multiple subspecialists
    - Neurology, cardiology, ENT, ophthalmology, pulmonary, gastroenterology, nutrition, endocrinology, opthamology, physiatry
  - Therapists: physical, occupational, speech
  - Nutritionist- GTube dependence
  - Home nursing
  - Medical equipment: feeding tube, ventilator, tracheostomy, suction machine, nebulizer, pulse ox, IPV…
  - 10 daily medications
  - A mom, a dad, and 3 siblings

A day in the life of Jacoby…

- 306 days in the NICU
- 5 months inpatient rehabilitation
- 15+ surgeries
- Therapies
- Numerous outpatient visits
- Unexpected admissions
What is the Complex Pediatric Patient

Children with Special Health Care Needs: CSHCN

• 1998 The Maternal and Child Health Bureau: Children who have or are at increased risk for chronic physical, developmental, behavioral, or emotional conditions and who also require health and related services of a type and/or amount beyond that required by children generally

Children with Special Health Care Needs (CSHCN)

• ~15% of US children
• ~23% of US households have ≥ 1 child who fits this definition
Children with Medical Complexity

- Children and youth with chronic conditions associated with medical fragility, substantial functional limitations, increased health and other service needs, and increased health care costs


Definition of Children with Medical Complexity*

- Multiple, chronic medical conditions
- Associated with functional limitations- often technology dependent
- Substantial family identified service needs
- High health care utilization
  - 1/3 total health care spending on children ($50-110 billion/yr)*
  - 1/2 of all Medicaid spending on hospital care for children
- Prevalence: <1% of all children
- Number of children is rising annually by 5% #


Defining the medically complex child

- How can we better define the most medically fragile subgroup?
- “Children with medical complexity” (CMC)
  - Multiple, chronic medical conditions
  - Associated with functional limitations
  - Substantial family identified service needs
  - High health care utilization
  - Prevalence: <1% of all children


Why Manage in a Multidisciplinary Clinic?

Addressing our Population Needs

- The number of children living with medical complexity is rising approximately 5% annually
- Although small in number, CMC account for a large proportion of health care spending
  - 1/3 total health care spending on children ($50-110 billion/yr)*
  - 1/2 of Medicaid spending on hospital care for children

Children with Medical Complexity

- 1/3 of all child health expenditures
- 1/4 of all hospital day
- Account for >40% of all hospital deaths


Children with Medical Complexity

- High risk for hospital readmission
- Adverse events
- Unnecessary variation in hospital care


Parents and Families

- Profound negative effects when family caregivers are in adequately supported
- Frequent (often extensive) travel to receive specialized care
  - Enormous stress
- Financial problems
  - More than 60% report a family member has to stop working to care for the child
  - Poverty
- Chronic stress of caregiver
  - Most frequently the mother

Goal as a broad health system

• Develop innovative effective patient/family centered medical homes to provide quality care in a cost effective manner
• Medical homes serve as a model of primary care that is “accessible, continuous, comprehensive, family centered, coordinated, compassionate and culturally effective” (AAP 2002)
• Desired Outcomes
  − Reduced hospitalizations- length of stay, readmissions
  − Reduced ED visits
  − Increased outpatient visits (general/subspecialty pediatricians, home health)
  − Improved quality of life, patient experience

Challenges

Community pediatricians
  − Rare conditions, short appointments
Subspecialty pediatricians
  − Variable access, focused on one system
Payers
  − Reimbursement changing, coverage of services varies
  − Inadequate ancillary resources
    − RN care coordinator, social work, dietician

Children with Medical Complexity and Medicaid: Spending and Cost Savings

2011 Health care expenditures for CMC and Medicaid

- 47% hospital care (13% of children used)
  − 25.1% outpatient subspecialty
  − 13.4% medications
  − 4.7% outpatient therapy
  − 3.4% emergency care
- 2.2% primary care
  − <2% each: home health care, lab/radiographs, equipment/supplies

Existing Health Care System

- Difficult for families with CMC to get the services that they need
- Families spend considerable time
  - Communicating among providers
  - Assimilating recommendations
  - Coordinating appointments
  - Addressing insurance and financial issues
  - Performing therapeutic activities

Solution

- Care Coordination the “answer” to health care and community fragmentation
- Affordable Care Act
  - Incentivized care coordination
  - Patient Centered Medical Homes

Care Coordination

- American Academy of Pediatrics defines the framework of care coordination:
  A patient and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the care giving capabilities of families. Care Coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes
Care Coordination

- Family Centeredness
- Planned, proactive, and comprehensive focus
- Promotion of self-care skills and independence
- Cross-organizational relationships

From the parent: “A care map for Lily at age 8.

Patient and family centered care coordination: a framework for integrating care for children and youth across multiple systems

AAP Policy Statement 2014: Council on Children with Disabilities and Medical Home Implementation Project Advisory Committee

- Coordination of care across settings permits integrated services
- Focuses on comprehensive patient/family needs
- Reduces in fragmented care
- Produces decreased health care costs
- Improved patient and family experience
Multidisciplinary Clinic for CMC

• The pediatric medical home model
  - Primary care
  - Demonstrated improvement in the quality of care and decreased cost for CHSCN
• Little research on coordinated specialty care for CMC
• This lead to our solution….

PCAVS: Pediatric Center for Airway, Voice, and Swallowing
PCAVS

• Pediatric Center for Airway, Voice, and Swallow
• Pediatric Aerodigestive Clinic
• Started in 2009
• The mission of the PCAVS is to provide a comprehensive family-centered approach to the evaluation and management of children with complex medical needs through a multidisciplinary team focused on patient care, education and research.

Who Do We Treat

• Most patients have multiple co-morbidities
  - Cerebral palsy, extreme prematurity, GERD, vertebral defects, anal atresia, cardiac defects, tracheoesophageal fistula, renal anomalies, limb anomalies, VACTERL, velocardiofacial syndrome, Pierre-Robin sequence, cleft lip/palate, subglottic stenosis

Aerodigestive Conditions

- Achalasia
- Airway obstruction
- Aspiration
- Bronchomalacia
- Bronchiectasis
- Bronchoalveolar dysplasia
- Cystic fibrosis with complications
- Chronic aspiration (tracheostomy dependent)
- Congenital syndromes that cause airway obstruction and associated feeding problems
- Drooling
- Dysphagia (feeding and swallowing problems)
- Esophageal reflux
- Environmental exposures
- Gastroesophageal reflex
- Glottic stenosis
- Hypoglossal palsies
- Interstitial lung disease
- Laryngeal atresia
- Laryngeal web
- Laryngeal stenosis
- Laryngotracheal (bronchial) papillomatosis (usually sexually transmitted disease)
- Malnutrition
- Sleep disordered breathing
- Subglottic stenosis
- Tracheal stenosis
- Tracheoesophageal fistula (TEF)
- Vocal cord paralysis
- Voice disorders
Esophageal Conditions

- Esophageal atresia (EA), including long gap esophageal atresia
- Tracheoesophageal fistulas (TEF)
- Esophageal duplications
- Bronchogenic cysts
- Esophageal strictures (narrowing of the esophagus)
- Caustic ingestion

Referrals

- NICU
- Hospitalists
- Children’s Rehab
- PCP
- Other sub-specialists
- Families

PCAVS Clinic

- Pre-Virtual visit 1 week prior to appointment
- Collect pertinent health information, update medical records, and gather any questions or concerns from caregivers.
- Information will be shared amongst team members prior to the appointment.
  - Pre-huddle
- Helps to increase patient satisfaction
  - Decreases time spent at appointment
  - More efficient appointments
PCAVS Clinic

- 2 clinics per month
  - 1st Thursday of the month – Full Team and Full day
  - 3rd Thursday of the month – ENT/GI/Pulmonary and half day
- 6-7 patients per clinic
- >140 patients currently enrolled
PCAVS Clinic

- Patients are roomed in an exam room and providers rotate their appointments
- Care Coordinators and Respiratory therapists assess patients
  - Equipment and nursing needs
- Procedures are completed in the exam rooms as needed
  - i.e: nasal endoscopies, tracheoscopies, trach changes, mickey button changes

PCAVS Team

- Team Members
  - Otolaryngology
  - Pulmonology
  - Gastroenterology
  - Physiatry
  - Nutrition
  - Speech Therapy
  - Social work

Pediatric Otolaryngology

- Improve upper airway obstruction, drooling, tracheostomy, optimize hearing
- Nasal endoscopy or tracheoscopy
- Medical and/or surgical management options
Tracheostomies

Pediatric Pulmonology

- Evaluation and management of respiratory issues including ventilatory support and supplemental oxygen, airway clearance therapies and sleep related breathing disorders
- Diagnostic flexible bronchoscopy to evaluate the airways and to obtain a respiratory secretions sample (bronchoalveolar lavage)

Ventilators
Airway Clearance

- Cough assist
- IPV
- PEP
- VEST
- Manual percussion
- Electronic percussion

Other Equipment

- Suction
- Pulse ox
- Compressor
- Concentrator
- O2
- Feeding pumps
Emergency Plan

- Contact information
- Insurance
- Allergies
- Medications
- Problems list
- Common Issues (Swallowing, communication, diet, physical anomalies, respiratory, etc)
- Medical History
- Surgical History
- Baseline (vitals, respiratory, cardiac, etc)
- Equipment
- Health Care provider team
- Special Information

Pediatric Gastroenterology

- Review feeding history
- Discuss reflux, stomach pains and bowel habits.
- Labs (blood work) might be ordered to assess nutritional status
- diagnostic studies and procedures may be discussed.
Pediatric Nutrition

- Work to meet the clinical nutrition needs of our patients.
- Assess nutritional needs, provide nutrition intervention and help individuals prevent and manage disease through informed nutritional practices

Pediatric Nutrition

- Assess for and diagnose malnutrition by evaluating growth velocity, anthropometrics, adequacy of nutritional intake, and through a physical exam to check for loss/absence of muscle/fat stores
- Assess nutrient, energy, and protein needs based on anthropometrics, malnutrition status, and medical hx to ensure feeding regimens are adequate and appropriate
- Assist families with formula selection and feeding schedules (oral or feeding tube) based on a child’s specific nutrient needs and presence of GI symptoms (eg: low or high calorie formulas, partially/fully hydrolyzed protein, presence of vomiting/reflux/constipation).
- Assist with care coordination for formula and tube feeding supplies
Pediatric Speech Pathology and Swallowing

• Communication Consult
• Inquire about swallowing and/or feeding issues, speech and language
• Communication options for children with tracheostomies can also be discussed

Pediatric Physiatry

• Rehabilitation Medicine
• Evaluate each child’s physical development
• Recommendations for any therapies, bracing, or equipment
• Medications to help with spasticity and chronic pain
Pediatric Physiatry

- AFOs
- Wheelchairs
- Gait trainers
- Walkers
- Tomato seat

- Braces
- Feeding Clinic

Social Work

- Identifies barriers to wellness
- Support and guide through episodes of illness
- Link with needed resources
- Teach skills
- Assess the psychosocial functioning of patients and families and intervene as necessary

Social Work

- Programs
  - Make a wish
  - Special wish
  - A Kid Again
- Help Me Grow
- BCMH
- County Assisted Programs
Team Meetings

- At the conclusion of the appointments, the status of your child’s airway, swallowing, and speech/voice development and any medical issues that are relevant will be discussed by the pediatric team to provide the best management plan.
- Family and PCP receive a letter outlining the team’s results and recommendations.
- Any surgical or airway evaluation is scheduled, coordinated with as many procedures as possible.
Care Coordination

- Patients are seen in between visits by NP or each specific specialty
- Work in coordination with or Complex Care Primary Care team
- Round on PCAVS patient when they are inpatient
- Work closely with Palliative Medicine
- NP/RN Care Coordinators make contact with family via phone, telemedicine, MyChart/emails

Other Team Members and Services

Children’s Rehabilitation Hospital

- Tracheostomy family teaching
- Provides inpatient care and rehabilitation to children and infants who require hospitalizations or need acute rehabilitation due to illness, injury or complex medical or congenital conditions
Feeding Clinic
• Considers all major issues interfering with oral feeding
• Varying intensities of treatment
• Team
  • Psychologist, nurses, nutritionists, OT, and SP

Seating and Wheelchair Clinic
• Assist children who require special adaptive equipment to improve positioning and promote functional independence
• Customize power and manual wheelchairs
• Equipment trial sessions

Complex Care Clinic
• Physicians
• Advanced Nurse Practitioner
• RN Primary Care Coordinator
• Additional part time team members
  - Pediatric dietician
  - Shared social worker
  - Billing representative
  - Family Engagement Committee
Complex Care Clinic

- Comprehensive initial assessment with our team
- Scheduled follow up every 3-6 months
- Easy access for families via dedicated phone line or electronic secure message
- Same day acute visits
- Care coordinator initiated non face to face check ins monthly

Complex Care Clinic

- Familiarity of the core team with patient and family
- Access for families: acute care vs. navigation
- Longer appointment times with dedicated team
- Collaboration with other clinicians
- Dietician and social worker support
- Assistance coordinating scheduling of multiple appointments
- Dedicated billing representative to assist with challenges
- Continuous improvement model

Palliative Medicine

- Focuses on children with life-threatening and chronic complex conditions and their families
- Enhancing quality of life
- Minimizing suffering
- Providing opportunities for personal and spiritual growth
- Pain management
- Medical decision making
Fresh Air Camp

• Campers are assigned a team of medical and non-medical buddies that assist
• MD and NP onsite
• Arts and crafts, swimming, horseback riding, games, squirt gun fights, camp songs, hikes, fishing, dancing, talent show, awards pranks, and more!

How Do Our Patients and Providers Benefit from a Multidisciplinary Clinic?

PCAVS Data

• Retrospective medical record review of 113 patients with aerodigestive disorders
• Enrolled from 2009-2013
• Admission data before and after enrollment in PCAVS
**PCAVS Data**

- No significant difference in number of admissions per year
- Significant decrease in inpatient days per year
  - Decrease of 4.1 inpatient days

**PCAVS Data**

- Aerodigestive admissions alone
  - Enrollment in PCAVS 0.57 hospital days per month or 6.8 hospital days per year
  - 70% reduction in technical direct costs

**Patient Data**

<table>
<thead>
<tr>
<th>Total Patients</th>
<th>113</th>
</tr>
</thead>
<tbody>
<tr>
<td>Discharge Date Range</td>
<td>4/13/1995 - 7/16/2014</td>
</tr>
<tr>
<td>PCAVS Enrollment Date Range</td>
<td>6/4/2009 – 12/12/2013</td>
</tr>
<tr>
<td>Total Aerodigestive (AD) Admissions &amp; Observation Cases</td>
<td>640</td>
</tr>
<tr>
<td>AD Admissions &amp; Observation Cases Prior to PCAVS Enrollment</td>
<td>353</td>
</tr>
<tr>
<td>AD Admissions &amp; Observation Cases Post PCAVS Enrollment</td>
<td>287</td>
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</table>
IP & Obs Days Per Month - Prior to PCAVs

IP & Obs Days Per Month - Post PCAVs

IP & Obs Days per Month

Financial Impact - Cost

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<thead>
<tr>
<th>Annual Days Avoided</th>
<th>Cost Per Day</th>
<th>Annual Cost Avoided</th>
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<tbody>
<tr>
<td>768</td>
<td>$1,660</td>
<td>$1,276,744</td>
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</table>

Estimated Annual Cost Per Year Prior PCAVs: $1,818,423
Estimated Annual Cost Per Year Post PCAVs: $541,678
% Cost Avoided: 70%
Financial Data

Total Patients: 71
Discharge Date Range: 1/12/2012 – 7/16/2014
AD Inpatient and Observation Encounters: 244
Average Technical Direct Cost Per Day: $1,660

Inpatient & Observation Days Per Month Reduction

<table>
<thead>
<tr>
<th></th>
<th>Prior to PCAVs</th>
<th>Post PCAVs</th>
<th>Change</th>
<th>% Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>IP &amp; Obs Days Per Month*</td>
<td>0.81</td>
<td>0.24</td>
<td>(0.57)</td>
<td>-70.2%</td>
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<tr>
<td>Standard Deviation</td>
<td>6.37</td>
<td>1.32</td>
<td>(5.05)</td>
<td>-55.8%</td>
</tr>
</tbody>
</table>

*Median

IP & Obs Admissions Per Month Reduction

<table>
<thead>
<tr>
<th></th>
<th>Prior to PCAVs</th>
<th>Post PCAVs</th>
<th>Change</th>
<th>% Change</th>
</tr>
</thead>
<tbody>
<tr>
<td>Admissions Per Month</td>
<td>0.12</td>
<td>0.08</td>
<td>-0.04</td>
<td>-36.8%</td>
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</tbody>
</table>
Financial Impact – Patient Perspective

<table>
<thead>
<tr>
<th>Estimated Days Per Year Reduction</th>
<th>Cost Per Day</th>
<th>Annual Cost Avoided Per Patient</th>
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</thead>
<tbody>
<tr>
<td>6.8</td>
<td>$1,660</td>
<td>$11,299</td>
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</table>

- Estimated annual cost savings for 113 patients: $1,275,544

Annual Cost Per Patient

| Prior to PCAVs | $16,092 | $4,794 | -70% |

Financial Impact

- Children with special healthcare needs (CSHCN) incur higher healthcare expenditures
- This study aimed to determine if enrollment in a multidisciplinary aerodigestive clinic with comprehensive and coordinated care improved outcomes and reduced healthcare costs
- Enrollment decreased inpatient days and reduced healthcare costs

Direct Patient Impact

- Improves provider communication
- Improves discharge coordination
- Improves patient communication
- Decreases time and travel to outpatient appointments
- One stop shopping
- One contact for multiple service lines
- Increased patient satisfaction
- Improvement in clinical outcomes
The Role of the APRN in Care Coordination for the Children with Medical Complexity

Care Coordination

- The Value Model of nurse dose to patient complexity (Looman et al, 2013)
- the depth and breadth of knowledge, data synthesis, intervention complexity, and interaction frequency required by populations with increasingly complex health care needs

Advanced Practice Nurse

- Autonomous scope of practice
- specialized education
- Ideal of high-intensity care coordination for CMC
- Relationship based-approach
  - complex problem solving with families instead of task oriented problem solving
APRN and Care Coordination

- Health care teams that utilize APRNs
- Improved outcomes
- Lower costs
- Reduction of hospital stays


Implications for Policy, Practice, and Research

- Reversing the exponential rise in health care costs
- New methods of delivering health care
  - Telemedicine
  - Relationship-based
- Shifting cost from high cost inpatient care to lower cost outpatient care

The End Goal
Jacoby’s Story

- [https://www.facebook.com/ClevelandClinicChildrens/videos/1246364978717469/](https://www.facebook.com/ClevelandClinicChildrens/videos/1246364978717469/)