Care Integration for Children with Medical Complexity

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Child Neurology Course
Boston Children’s Hospital

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Disclosure

I have no conflicts to disclose.
Learning Objectives

Understand how to implement a framework of care integration
• Be able to adapt it for implementation in response to COVID19 pandemic

Gain confidence in advancing implementation of care integration with measurable high value outcomes, especially for vulnerable populations
Evidence

• Integration reduces waste associated with fragmentation in care delivery
• Inter-professional integration essential to reduce disparities due to Health Related Social Needs—housing, food, poverty, violence
• Behavioral Health—**Hint: Commonality between Adult and Child Care!!**
  • Substance Abuse and Dependence
  • Mental Health
  • Developmental Disabilities
Strategies to Achieve Health Equity

No Equity, No Triple Aim: Strategic Proposals to Advance Health Equity in a Volatile Policy Environment

Geoffrey W. Wilkinson, MSW, Alan Seger, PhD, Sara Seltg, MD, MPH, Richard Antonelli, MD, Samantha Morton, JD, Gail Hinds, ME, Celeste Reid Lee, ME, Abigail Ortiz, MSW, MPH, Durrell Fox, CHW, Monica Valdes Lupi, JD, MPH, Cecilia Arefei, MSW, and Madeline Wachman, MSW, MPH
Miguel

- 4 year old Hispanic boy; he and mother immigrated from Guatemala
  - Diagnosed-- asthma by PCP at 9 months
  - Referred for “poor attention”
  - ED visit 3 times in prior year for asthma
  - No assessment/ intervention for attention

- All care quality measures were met
  - Referrals made
  - Care Coordination measures require completing a loop
Innovation Begins by Identifying an Opportunity

Some of the most fragmented care we have measured occurs for patients with complex needs receiving care in academic medical centers. Why?

Playbook

- Articulate Vision
- Leverage Interprofessional Relationships and Existing Resources
- Measurement, Repeat, …..
- Value Optimization
One Family’s Care Map

www.childrenshospital.org/care-coordination-curriculum/care-mapping
Mind the gap
Matching Services to Complexity
Including Social, Medical, and Behavioral

Children with chronic conditions
--Behavioral (ADHD, depression, anxiety, PTSD)
--Asthma
--Obesity
--Diabetes
--Social Risk Factors
--Adverse Childhood Experiences

Children with complex needs
--Neurodevelopmental (Autism, etc.)
--Behavioral/Psychiatric
--Hematology/Oncology
  • Sickle cell
  • Hemophilia
--Technology dependent
--Multiple Chronic Conditions
--Social Risk Factors
--Adverse Childhood Experiences

Value-Based Payment Models for Medicaid Child Health Services, Bailit and Houy, United Hospital Fund – July, 2016
## Current Activities

### Care Integration Collaborations

- Neurology/Epilepsy (CP, Ketogenic Diet, Rett)
- Urology (Spina Bifida, Bladder Exstrophy)
- Medicine - GI/Nutrition (Aerodigestive, IBD, HPN, Enteral Tube, GNP)
- Adolescent Medicine – Hybrid Transition Model
- NICU GraDS Program
- Genetics
- Complex Care Service
- Community-Based Integrated Model for Weight Management – funded by New Balance Foundation

### Primary Care Relationships

- Local and Regional Affiliations

### External Relationships

- National Care Coordination Academy (HRSA funded)
- National Center Care Coordination Technical Assistance (HRSA funded)
  - CHOP, Cincinnati Children’s, Nationwide, many others
- Global Partnerships
  - Australia, Chile, Canada, Germany, France
- Visiting International Fellow in Integrated Care
Measure What Matters
Domains of Integrated Care

Care Coordination
- Care Coordination Measurement Tool (CCMT)
- High Quality Handoffs: Clinician Reason for BCH Visit and Action Grid
- Inter-professional Education: Care Coordination Curriculum and Integrated Care Bootcamp

Person, Patient, Family, Caregiver Experience
- Pediatric Integrated Care Survey (PICS)

Provider Experience
- PCP Experience of Care Integration Survey

Utilization and Financial Outcomes
- Total Medical Expense (as relevant and available)
- Admissions, Readmissions, Emergency Department Utilization
Pediatric Integrated Care Survey

PICS

Five Core Domains
Access to Care
Communication with Care Team
Family Impact
Care Goal Creation/Planning
Team Functioning/Quality

Validated assessment of the family’s experience of integration across the care team: medical, behavioral, social, educational, and family support.
Improving Care and Decreasing Cost

Measuring outcomes of the BCH Urgent Epilepsy Clinic with the CCMT

Based on documentation of 50 encounters by Neurology staff conducted from July 2018 through April 2019 as part of the DSRIP project work. ED visit was avoided 72% of the time. Courtesy of Phillip Pearl, MD
BCH Rett Syndrome Clinic

Rett Patients with No Inpatient Admissions

3.0 Pts 1.7 Pts 1.37 Pts

Percent of Patients

0% 10% 20% 30% 40% 50% 60% 70% 80% 90% 100%

FY2013 FY2014 FY2015

30 Day All Cause Readmissions for Rett Patients with at Least 1 Readmission

26.7% 22.2% 13.6%

3 Pts 3 Pts 3 Pts

1 Readmit 2 Readmit 3 Readmit

FY2013 FY2014 FY2015

Courtesy of David Lieberman, MD, PhD
Quantifying the Value of Care Coordination

Use of the CCMT Instrument BCH Dept. of Urology

Based on documentation of 577 encounters by Urology staff across the Spina Bifida, Stone, and Bladder Exstrophy Clinics conducted from August 2018 through April 2019 as part of the DSRIP project work. Courtesy Rebecca Sherlock, NP, Rosemary Grant, RN
Results – Primary Care Perspective

Atrius Health– Community-based provider organization

• Reductions in ED utilization, hospital admissions, and overall total medical expense
  • Sustained beyond 3 years

• Aim to keep care in highest value setting
  • Primary Care

_Achieving High Value Outcomes: Care Integration at Atrius Health Pediatrics, Slater, D, Dvorkis, Y, Antonelli, R, Pediatric Academic Societies meeting, 2019._
PCP Experience of Care Integration

Connection with BCH Subspecialist

In the past 12 months, how often have you felt BCH subspecialists effectively addressed the reason you referred a patient to BCH for an outpatient consult?

- Always: 24%
- Almost Always: 68%
- Usually: 0%
- Sometimes: 6%
- Rarely: 0%
- Never: 0%

In the past 12 months, when recommendations for diagnosis and management were made, how often was it clear to you whose responsibility it was to implement each recommendation?

- Always: 11%
- Almost Always: 63%
- Usually: 0%
- Sometimes: 24%
- Rarely: 2%
- Never: 0%

Data represents 96 responses collected between 12/5/2017 and 2/22/2018 from referring providers associated with BCH’s key integration partners.
## Tool to Integrate Care: Action Grid

<table>
<thead>
<tr>
<th>Goal</th>
<th>Action</th>
<th>Who</th>
<th>When</th>
<th>Contingency</th>
</tr>
</thead>
<tbody>
<tr>
<td>Complete necessary genetic testing</td>
<td>Lab orders will be placed for ### Test</td>
<td>Genetics - Dr. Bodamer</td>
<td>One month</td>
<td>Parents should contact Dr. Bodamer’s office (123-456-7890) if unable to complete testing within one-month’s time</td>
</tr>
<tr>
<td>Maintain stable blood sugar</td>
<td>Test blood sugar 3 times per day and control with small, frequent meals</td>
<td>Parents, with guidance from Endocrinology and Nutritionist</td>
<td>Daily, beginning immediately and to continue until reassessed at next Endocrinology appointment</td>
<td>Blood sugars between XXX and XXX should be reported to Dr. Example’s office (123-456-7890). If a sugar is over XXX, parents will bring patient to the nearest Emergency Department</td>
</tr>
<tr>
<td>Take medication for epilepsy as prescribed</td>
<td>Order for medication will be sent to Longwood Galleria</td>
<td>Neurology, with follow up phone call by Nurse Jane Doe</td>
<td>RX to be started no later than 3/7/2020 and should continue until next appointment unless otherwise noted</td>
<td>Please call Nurse Jane Doe if any problems arise with the prescription at 123-456-7890</td>
</tr>
<tr>
<td>IEP documentation request will be updated with school system</td>
<td>Required school documentation and phone call to Teacher Smith</td>
<td>Neuropsychology and Teacher</td>
<td>Two weeks from most recent visit: XXXX/XXXXX</td>
<td>Teacher Smith should contact patient’s parents with any noticeable adverse changes in behavior or understanding</td>
</tr>
</tbody>
</table>

Courtesy of Olaf Bodamer, MD, PhD
Don’t Let a Crisis Go to Waste

Our goal - Prove that virtual care is *added value* for:

- Patients/ families
- Clinicians
- Payers/ Policy makers
- Advocates

Characteristics of patients who benefit the most from virtual care

- Access issues (e.g., transportation)
- Behavioral health needs
- Care management for patients with complex needs whose services are coordinated within a Care Plan/ Action Grid
Value Capture Measurement Tools

**Care Coordination Measurement Tool (CCMT)**

- Captures activities during the “space” between encounters to coordinate care
- Implemented across BCH clinics (14 implementations and counting…)
- Quantifies value of care coordination activities (generally non-billable)
- REDCap link to survey in PowerChart
- Highly adaptable to clinic needs

**Care Management Measurement Tool (CMMT)**

- Captures activities and processes of the clinic encounter
- New survey instrument adapted from the CCMT
- Quantifies value of care management (i.e. telemedicine, phone, etc)
- REDCap link to survey in PowerChart
- Adaptable, with a standard template
CMMT: key outcomes of virtual care

14. As a result of this encounter, the following occurred (choose ALL that apply)

- Affirmed existing plan of care (no changes made)
- Progressed to the next step in the existing plan of care (i.e. due to a change in clinical status or lab results, etc.)
- Developed a new plan of care
- Conducted health literacy education
- Provided guidance or family support for behavioral or psychosocial needs
- Reconciled medication discrepancies
- Reconciled or addressed other discrepancies (e.g. miscommunications, adherence to plan of care, missing data)
- Referred back to PCP for ongoing management of care
- Assessed for adequacy of supplies
- Ordered medical supplies
- Provided/refilled prescriptions
- Assessed the home environment
- Assessed for the appropriate use of durable medical equipment
- Counseled on COVID-19 risk reduction strategies or advice given the patient’s presenting condition
- Managed care due to a disruption in receiving care services due to the COVID-19 pandemic
- Managed care for a patient with suspected or confirmed COVID-19 infection
- Some needs could not be addressed
- Other ____________________________
10. Would this encounter have typically occurred as an in person encounter prior to COVID-19 social distancing restrictions?
   - Yes
   - No

15. Compared to an in-person encounter, please rate your opinion on the level of difficulty or ease with which you provided care management services to the patient and/or family?
   - 1 – Significantly more difficult
   - 2 – More difficult
   - 3 – The same
   - 4 – Easier
   - 5 – Significantly easier

16. Please describe what made the visit easier or more difficult? (optional)
    [Free Text]
Spreading Care Integration: US

1) BCH Child Neurology Training Program
   Curriculum Development in collaboration with Dr. Bernson-Leung
   Care Integration and Interprofessional Education

2) Health Resources and Services Administration (HRSA)/ Maternal and Child
   Health Bureau funded National Care Coordination Academy

3) HRSA funded Award to develop policy recommendations for use of virtual
   care to improve outcomes for children, youth, young adults with complex
   needs, especially NDD/ autism
Spreading Care Integration: Global

Calgary: Children with Autism
- Families reported improved communication across care team, including school
- Decreased ED and in-patient care
- Fewer behavioral issues for children
- Improved child function at home and school

Courtesy V. Nadine Gall, MSc., Manager, NeuroDevelopmental Disorders
Integrated Brain Health Initiative, Child Development Services Alberta
Children's Hospital
Validation of a Spanish version of a Parent-Reported Experience Measure of Integrated Care

Collaborators: Juan Carlos Flores1, Sonja Ziniel2, Richard Antonelli3, Maria A. Paul1, Marta Smith4, Fernando Gonzalez5

Division of Pediatrics, Pontificia Universidad Católica de Chile; 2. University of Colorado Denver - Anschutz Medical Campus, United States; 3. Integrated Care, Harvard Medical School, Boston, MA; Faculty of Medicine, Universidad del Desarrollo, Santiago, Chile; 5. Hospital Exequiel Gonzalez Cortes, Santiago, Chile

• General: Validation of a Spanish version of the Parent-Reported Experience Measure of Integrated Care (PICS).

• Specific:
  • Psychometrically validate the Spanish version of the PICS, in a sample of Chilean parents of children and youth with special health care needs (CYSHCN).
  • Describe measures of care integration among 3 different programs taking care of CYSHCN, in different settings of the healthcare system in Chile: public and private.
  • Identify factors associated with care integration among a sample of families of CYSHCN and varying degrees of healthcare utilization.

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Encuesta de Atención Pediátrica Integral
Para padres/cuidadores
Integrated Care at Boston Children’s Hospital

Integrated Care is Important to Everyone!

Family/Patient Perspective
A national sample of parents whose children have special health care needs reported that 37% of the time, their child’s care team members rarely or never explained who was responsible for different elements of their child’s care. Families expect this to be 100%.

Referring Provider Perspective
More effective care could be offered in the primary care setting if referring subspecialists would give clear and actionable information that addressed their concerns.

Subspecialist Perspective
Knowing why the primary care provider refers the patient to the subspecialty setting would allow them to know what has been done to date, and what is expected from them.

Today’s care teams are challenged to coordinate activities and recommendations across settings. Often, families must take the lead on these responsibilities. Along with adding substantial strain to families, these challenges often result in uncoordinated and inefficient care. Integrated care is the seamless provision of health services, from the perspective of the patient and family, across the entire care continuum and is essential to achieving the best health outcomes for every patient. Care coordination is the set of activities and functions that is necessary to create and implement a multidisciplinary plan of care in partnership with the patient and family.

The Integrated Care Program at Boston Children’s Hospital creates and validates processes, tools, and measures.
PEDiatric CARE COORDINATION CURRICULUM

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- **Transcripts**

**Curriculum Outline**

- **Module 1: Core Curriculum**
  - Lesson 1: Core Curriculum:
    - Introduction
    - Key Components of Care Coordination
  - Lesson 3: Tools and Processes that Support Care Coordination
  - Lesson 4: Application of Tools and Processes - Case Example

This course can be taken by logged in and registered users. Please Register.

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So…What can we do right now?

- Persist with Compelling, Civil, Global Advocacy
  - Bring Data!
- Build Capacity of Families and Work Force
  - Inter-professional education
- Implement Measures of Integration, CC, and Value
  - Assess equity by stratification while specific measures being developed
- Form alliances across disciplines, sectors
- Leverage Adult Priorities for Maternal and Child Health
  - Integrated Behavioral Health
  - SDoH
Select References


- **MA Child Health Quality Coalition Care Coordination Framework.** Funded by the Centers for Medicare and Medicaid Services (CMS) through grant funds issued pursuant to CHIPRA section 401(d). Contact: grogers@mhap.org www.masschildhealthquality.org/work/care-coordination/


- **AHRQ Care Coordination Atlas** (McDonald Nov 2010, June 2014) and companion document Care Coordination Accountability Measures for Primary Care (McDonald Jan 2012).


- **Care Coordination Curriculum and Care Mapping Tool User Guides**: Antonelli, Browning, Hackett-Hunter, McAllister, Risko; Lind. Boston Children’s Hospital; funded thru Family Voices/MCHB HRSA grant. 2012. www.childrenshospital.org/care-coordination-curriculum

- **Continuity and Coordination of Care: a practice brief to support implementation of the WHO framework on integrated people-centered health services.Geneva:World Health Organization, 2018. Licence CC-BY-NC-SA 3.0 IGO.**
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