Partnering with families to support integration of care

Care coordination and care planning

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Discussion points

• Central role of children and families
• Importance of care coordination (CC) to the entire care process
• Evidence: what do we have/need?
• Difficulty of CC for children with medical complexity (CMC)
• Solutions: what works?
• Policy and payment implications
Warning

This presentation contains 19 question marks.

As care coordination and care planning become major focus points in health system change, we are discovering many insights and some answers… but even more questions.
Foundational documents

• Antonelli, McAllister and Popp, *Making Care Coordination a Critical Component of the Pediatric Health System* (Commonwealth Fund, 2009)


• AAP Council on Children with Disabilities, *Patient and Family-Centered Care Coordination* (policy statement), revised 2014

• AHRQ *Care Coordination Measures Atlas*, updated 2014

• Bachman, Comeau, and Jankovsky, *The Care Coordination Conundrum and CYSHCN* (LPFCH, November 2015)
Definition

Pediatric care coordination is a patient- and family-centered, assessment-driven, team-based activity designed to meet the needs of children and youth while enhancing the caregiving capabilities of families. Care coordination addresses interrelated medical, social, developmental, behavioral, educational, and financial needs to achieve optimal health and wellness outcomes.

- Antonelli, McAllister and Popp, 2009
*Type 2 Diabetes, bilateral enucleation, central line infection, zygomycosis, chronic kidney disease (stage 3), obesity, venous thrombosis of upper extremities.
Family’s perspective

• Care coordination is much more than help in arranging appointments, especially for CMC

• Parents/guardians are ultimate coordinators (sometimes the only ones)

• Professionals’ tasks:
  ▪ Support and enhance parents’ roles
  ▪ Do things uniquely enabled by training and position
Why is CC so central in care?

• Current system:
  - Overall complexity of needs and services continue to increase
  - Fragmented care
  - Increased need for “system navigation”
  - Fee for service payment still predominant
  - Communication suboptimal/not reimbursed

• National policy changes: Triple Aim
  - Idea: Integration of care will improve quality, safety, and efficiency, while lowering costs and increasing met needs
Model: CC as central process in integrated care

Care Planning
- Assessment-driven, created by care coordinator and family, input by care team
- Anticipates needs and potential consequences

Care Coordination
- Use of care plan, response to needs
- Used by a few team members to inform team

Integrated Care
- Multiple team members including top-level clinicians adapt their care to changing needs of child, family, and other team members
- Informs changes to care plan
Care plan example

• 6 full pages, 1766 words: here is a small part

PCP Clinic XX/XX/2014, Special Care Clinic, Dr. XXXX:
PLAN:
1. Abdominal Pain
   - AXR to evaluate stool burden
   - UA for r/o UTI -- attempted clean catch x 3, also tried using collecting hat, however this was extremely distressing
   - did not pursue cath UA since she is not endorsing dysuria, hematuria, urgency, frequency
   - would also like to minimize traumatic interventions since pt immunosuppressed
   - advised MOC to monitor her peeing patterns
   - bowel clean out with miralax
   - 1 tablespoon in 6oz fluid q2h x 3 doses
   - may repeat as needed as long as staying hydrated
   - reviewed titrating miralax dose
   - recommended considering maintenance bowel regimen to achieve 1 soft stool daily

PCP Clinic XX/XX/2015, Special Care Clinic, Dr. XXXX:
Has had borderline BPs for the last 3 visits. – Cardiologist notified to follow-up at next visit

Cardiology Plan XX/XX/2015, XXXXXX, FNP
- 48 hour Holter to evaluate for any ectopy
- Continue with Q2 mo labs and Q4 mo clinic visits for cardiac surveillance
- Will need to change Standing lab orders if XXX tolerates the tacrolimus
- Be sure to practice good oral hygiene. You are at higher risk of gingival hyperplasia due to being on maintenance cyclosporine
- XXXXX will require SBE prophylaxis prior to any dental procedure
- Heart Cath: due May 2016
- Parents have agreed to change to pill form Tacrolimus for primary immunosuppression at end of the current bottle of Neoral.
- Immunosuppression Meds:
  CYCLOSPORINE 60 mg (0.6 ml) PO BID (goal 50-100), will finish bottle in about 1 week
  Start tacrolimus 0.5 mg PO BID (goal 3-5) once finished with Neoral bottle, recheck lab in 1 week
- Await antiplatelet antibody as recommended by XXXX, MD (Heme) from curbside discussion on X/XX/15, platelet count is WNL today
- Recommend f/u with Neurology regarding "spacing out" or starring spells
- Call the on-call Transplant Coordinator at (303) 890-3503 for sudden onset of nausea, vomiting, diarrhea, fever, fatigue, pallor, cold extremities, chest pain, difficulty breathing, heart palpitation, any missed doses or forgetting medications or other questions/concerns that arise
Care plans

• Can be simpler:
  - Problem
  - Status (active, urgent, stable, …)
  - Activity
  - Who responsible (include parents!)
  - Time frame for followup

• What’s the right balance of detail vs. practicality?
Role of care coordinator

• Expert team member

• “Glue” between different components of the health care system

• Doctors don’t do a very good job of CC (though they try hard!)

• Increase met needs for families
More on coordination and integration

• **Coordination**: Designated care coordinator(s) use care plan and respond to family needs

• **Integration**: All team members use care plan to harmonize care they provide
  - Example: high risk spine surgery program

• Requires higher level of communication, thought, and WORK
“Care coordination” vs. “Case management”

• Care Coordination:
  ▪ Function of direct care team
  ▪ Need-focused
  ▪ Assessment-based
  ▪ Broader

• Case Management: (traditionally)
  ▪ Outside direct care team (e.g. payer)
  ▪ Resource-focused
  ▪ Criterion-based
  ▪ Narrower
Importance of CC: Questions

• How to get care team members to a common understanding of the importance and role of CC?

• How to change culture of team members toward coordination then integration of care?
Evidence: what’s known?

• Most positive outcomes from adult literature
  ▪ Disease-specific outcomes
  ▪ Nature of adults/adult disease

• Less known for kids
  ▪ “non-categorical” outcomes: ED visits, inpatient (re) admissions
  ▪ Quality: family-centered care, access to services, met needs

• CC affects processes > outcomes
Evidence: measurement

• Most CC measures survey-based
• Little to no relevant administrative data
• Most population-level data sources
  ▪ Service/resource use
  ▪ Not process focused
• Difficult to relate processes directly to “hard” outcomes
• Progress:
  ▪ AHRQ measures update
  ▪ AHRQ/CMS CHIPRA quality measures Centers of Excellence: Seattle Children’s COE4CCN
Measurement: Questions

• What kind of CC is most helpful for what kids, under what circumstances?

• What are some “care coordination sensitive outcomes” that cut across conditions and situations?
Challenges in CC for CMC

5 Ds: adult-child differences

• Differential epidemiology
  ▪ Greater number of less-prevalent conditions
  ▪ Longer and more dynamic time course

• Developmental change

• Dependency

• Demography

• Dollars
  ▪ CMC are poorer
  ▪ Medicaid (50 states) vs Medicare
Challenges in CC for CMC

5 Ds: implications

- Non-disease specific approach
- More frequent care plan updates
- Training and skillsets of coordinators
- More emphasis on consequences of poverty, other social determinants of health
- More variability between states
Challenges in CC for CMC

Silos of coordination
Challenges in CC for CMC

• Multiple care teams
  ▪ May not all be high functioning
  ▪ Multiple points of view
  ▪ Each may have a care coordinator

(22)
(22)
(22)
Challenges in CC for CMC

CC is often not driven by a care plan
• Time-consuming to create and update plan; often not reimbursed
• Kids don’t behave according to plans

Transitions to adult care:
• “Round peg in a square system”
• We know what we should do to fix this… but can we?
Solutions

• Primary “Care Coordinator”
  ▪ Based at Medical Home
  ▪ Face to face with parents
  ▪ Coordinate *across continuum of care including between organizations*

• Parent support and training in CC
  ▪ Curricula exist
  ▪ Parent-to-parent networks

• “Relational coordination”
  ▪ From organizational literature
  ▪ CC from RNs, SW, family navigators, others
Solutions

• Non “degree focused” care coordinators
  ▪ Based in care setting:
    • Family navigators (strengths: education, community resources)
  ▪ Not based in care setting: (strengths: community knowledge)
    • Home visiting services
    • Community health workers
    • Peer navigators
    • Challenge: how to communicate best with system?
Solutions

Caveat: innovative, resource-intensive CC solutions are hard to generalize/sustain!

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26
More questions

• How best to allocate CC resources? For whom?

• How to include social determinants of health in CC planning and resource allocation?
Policy and payment progress

• Difficulties with fee-for-service model:
  ▪ Do more, get paid more…
    • …except when you don’t get paid at all (CC not well reimbursed)
  ▪ Task-based
  ▪ Single-site based
    • Easy to attribute, hard to share responsibility
Policy and payment progress

• Population-based payment: per-member per-month (PMPM)

• Example: CO’s Regional Care Coordination Organizations (Medicaid “ACO”)
  - $4.50 PMPM to PCP practices to provide “delegated care coordination” for attributed kids
  - Salary of 1 FTE RN care coordinator: 1667 patients (100 CMC)

• Other states with some form of payment: MI, RI, OR, VT, MA, ?others
Questions

• Who can do CC and get paid for it?
  ▪ Qualifications: different for different kinds of CC
  ▪ Parents do the most CC. How do they (not) get paid?

• CC cuts across service sectors:
  ▪ How to divide payment?
  ▪ Which sector responsible/gets paid?
Holiday wish

By 2021, every child with medical complexity will have:

• A care coordination team, including a family navigator and other appropriate non-physician professional(s), to interact with children and families proactively with the goals of:
  ▪ Supporting CMC and families to promote meeting needs identified by them
  ▪ Promoting care integration
  ▪ Formulating, implementing and updating a practical, shared care plan
  ▪ Using services efficiently
Holiday wish

By 2021, every child with medical complexity will have:

• The team will be adequately paid for through non-fee-for-service methods that are portable between care settings and payers

• The process will be informed by enough data to:
  ▪ Determine how much of which services are needed, at what time
  ▪ Enable planning for the needs of other similar children in the population
Let’s get started!