A Conversation on Supporting Self-Management in Children and Adolescents with Medical Complexity

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Moderator

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A SUPPLEMENT TO PEDIATRICS

Building Systems That Work for Children With Complex Health Care Needs

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Ask Questions!

We look forward to a lively discussion with our audience. Enter questions in the GoToWebinar question box.
Meet Our Speakers

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Supporting Self-Management in Children and Adolescents with Complex Chronic Conditions

Amy Houtrow, MD, PhD, MPH
Associate Professor of PM&R and Pediatrics
University of Pittsburgh
Self-Management

- The set of tasks individuals with chronic health conditions perform to keep themselves as healthy as possible.
Continuum of Self-Management Tasks

Condition
Specific
Taking medication
Checking blood glucose
Wearing AFOs

General
Wellness
Eating a healthy diet
Exercising regularly
Coping with stress
Rehabilitation Institute

Unique Nature of Pediatric Shared Management/ Self Management

Parental

- Giving medications
- Donning AFOs

Youth

- Calling in own prescriptions
- Checking skin
Other Pediatric Considerations

- **Dependency**: children start out as dependent on others
- **Development**: children and youth have evolving capacity
- **Differential epidemiology**: conditions of adulthood are common, conditions of childhood are often rare
- Capacity/Capability
  - What a person can do

- Performance
  - What the person actually does
Modi's Self-Management Model

![Diagram of Modi's Self-Management Model]

**ADHERENCE FREQUENCY**
- Treatments:
  - Medications (e.g., oral, inhaled, nebulized, intravenous, injections)
  - Airway clearance
  - Physical therapy
  - Vitamin/mineral supplements
  - Supplemental feeds (e.g., elemental, TPN)
- Lifestyle modifications:
  - Exercise
  - Diet
  - Fluid
  - Sleep
- Clinic appointment attendance
- Symptoms monitoring (e.g., blood glucose monitoring, peak flow meters)

**OUTCOMES**
- Individual:
  - Symptoms and symptom control
  - Complications
  - Quality of life
  - School/work days
  - Drug resistance
  - Mortality
  - Health care utilization (e.g., emergency room visits, hospitalizations)
- System:
  - Clinical decision-making
  - Financial costs (e.g., insurance rates, usage)
  - Treatment efficacy
  - Health care delivery

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**FIGURE 1**
In the Pediatric Self-management Model, self-management behaviors (pictured left) operate within individual, family, community, and health care system domains. Modifiable and nonmodifiable domain-specific influences impact self-management through underlying cognitive, emotional, and social processes. The degree to which self-management behaviors affect adherence, and ultimately outcomes, may result in changes in self-management behaviors.
Four Dimensions of Self-Management

1. Individual:
   - self-efficacy
   - autonomy
2. Interpersonal:
   - parenting relationship is a context for self-management
   - dynamic, two-way parent-child relationship: each member influencing and responding to the other
3. Temporal:
   - shift or transfer of responsibility from parent/caregiver to child/adolescent over time
4. Environmental:
   - multiple, complex factors at different levels: family, community, health care system
Supporting Youth Self-Management

- Instill the importance of independence from an early age
- Add self-management goals to care plans
  - Why the goal is important
  - What will it take to achieve that goal
  - Who is responsible for what
  - How will success be measured
  - When will progress be assessed
Behavior Change Counseling

- Centered around the personal action plan (care plan)
- **Assess** beliefs, behaviors and knowledge
- **Advise** and provide specific education
- **Agree** on goals
- **Assist** by addressing needs and barriers
- **Arrange** for follow up and supports
Shared to Self-Management

**SHARED MANAGEMENT OVERVIEW**

<table>
<thead>
<tr>
<th>Role of Parent</th>
<th>Youth Role</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent is <strong>PROVIDER</strong> of care</td>
<td>Youth <strong>receives</strong> care</td>
</tr>
<tr>
<td>Parent becomes <strong>MANAGER</strong> of care</td>
<td>Youth <strong>provides</strong> some self-care</td>
</tr>
<tr>
<td>Parent becomes <strong>SUPERVISOR</strong> of care</td>
<td>Youth becomes <strong>manager</strong> of care</td>
</tr>
<tr>
<td>Parent becomes <strong>CONSULTANT</strong> to youth</td>
<td>Youth becomes <strong>supervisor</strong> of care</td>
</tr>
<tr>
<td></td>
<td>Youth becomes <strong>CEO</strong> of care</td>
</tr>
</tbody>
</table>
Team Activity

- Not just a physician activity
- Parents
- Nurses
- Social workers
- Educators

- Team roles should be defined
- Billed when possible
What About the Children With Disabilities That Limit Their Abilities to Participate in Self-Management?

- Promote independence
- Simplify routines
- Provide adaptive supports
- Empower youth to develop new skills
- Set realistic goals
- Plan for transition and necessary supports
Key Thoughts

• How do we help families transition control from the caregiver to the youth? How do we calibrate this to the unique needs and skills of each medically complex youth and family?

• What are feasible, practical tools to bring self-management into practice today? Shared Plan of Care?

• Many providers innately partner with families to identify and address self-management challenges. How can we do this consistently, systematically, and proactively with each patient, each time?
Key Thoughts

• Pediatric self-management has been an important area of research for several decades, with a robust evidence-base. How have these strong research findings been translated into clinical practice? Who is best to lead the charge in translation from the bench to the bedside in self-management?

• In pediatrics, there is a larger system than the child his/herself regarding self-management. Parents, healthcare providers, schools, peers, and siblings can play critical roles. What are the barriers to self-management within these varying systems? How do we overcome some of these barriers?

• What is the evidence-base for assessment and treatment for pediatric self-management and adherence? What are the most promising treatment approaches currently?
Submit your questions in the question box

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Upcoming Conversations

Protecting Rights of Children with Medical Complexity in an Era of Spending Reduction

September 20

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