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

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A little about me…

- NP with the Pediatric Complex Care Program at American Family Children’s Hospital

- Provide enhanced, medical co-management and coordinated care for children with medical complexity that often involve multiple medical and surgical specialties

- Patients range from infants – adolescents, with a wide variety of medical conditions, functioning along a broad spectrum of cognitive, developmental, and physical abilities

- Provide both inpatient and outpatient services and support

- An important aspect of our program is our ability to build relationships with our patients/caregivers so we can help them build self-management skills as they navigate their complex medical conditions over time.
Participants attending will be able to:

- Define “self-management” and “self-management support”

- Describe key differences between self-management in children/adolescents and adults with medical complexity

- Identify two proposed frameworks or approaches to pediatric self-management

- Discuss other approaches and tools used to support self-management in the medically complex patient population
The inspiration for this presentation

Supporting Self-Management in Children and Adolescents With Complex Chronic Conditions
Paula Lozano and Amy Houtrow
Pediatrics 2018;141;S233
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The online version of this article, along with updated information and services, is located on the World Wide Web at:
http://pediatrics.aappublications.org/content/141/Supplement_3/S233
The rate of chronic conditions among children has doubled in the past 2 decades.

13 – 27% of children in the US have a chronic condition that requires ongoing treatment.

Most children with disabilities are living well into adulthood

Children with medical complexity are at high risk for adverse medical, developmental, psychosocial, and family outcomes

High prevalence of poor self-management and non-adherence across pediatric conditions.

With the prevalence of chronic conditions in childhood, there is an increasing need for children to learn how to effectively manage their health conditions.
Self-Management

The set of behaviors that people engage in as part of living with a chronic health condition

These behaviors fall along a spectrum and include…
- Those directly related to health care
- Social and lifestyle behaviors that impact/are impacted by wellness

<table>
<thead>
<tr>
<th>Monitor clinical status and/or symptoms</th>
<th>Prevent crises and/or flares</th>
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<tbody>
<tr>
<td>Avoid triggers</td>
<td>Problem-solve</td>
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<tr>
<td>Manage symptoms</td>
<td>Implement an action plan when needed</td>
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<tr>
<td>Administer medication and/or treatment</td>
<td>Accommodate activity limitations</td>
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<tr>
<td>Adjust medication and/or treatment regimen</td>
<td>Cope with the functional impact of the condition</td>
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<tr>
<td>Manage home health technology and devices</td>
<td>Cope with the emotional stress that is due to the illness</td>
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<tr>
<td>Attend to diet (restrictions and requirements)</td>
<td>Prevent and/or manage complications</td>
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</table>
The services that health systems and community agencies provide to persons with chronic illness and their families to facilitate self-management

A collaboration between patient, family, and care providers
Self-Management Support has the potential to...

- **Improve**
  - Adherence to treatment plans
  - Treatment efficacy
  - Health outcomes
  - The individual’s capacity to navigate challenges and solve problems
  - Quality of life and self efficacy

- **Reduce**
  - Morbidity
  - ER visits
  - Overall healthcare costs
Self-Management Support

- For adults with chronic conditions, self-management support is...
  - Associated with improved health outcomes and patient experience
  - An established part of high-quality care

- Care models and evidence based practices are available to help inform support for adult chronic conditions

- Models and practices are not as well developed for children/adolescents

- Self-management support not as readily integrated into pediatric care
Unique needs of children

**Dependency**
- Most chronically ill children depend on caregivers for some or all of their cares
- In pediatrics, self-management is really **SHARED** management between the child and the caregiver

**Development**
- There is a wide spectrum across all ages and areas of development (emotional, social, physical, cognitive)
- Children experience multiple periods of significant developmental changes and major life-related transitions
- A child’s capacity for self-management is always evolving

**Epidemiology**
- In children, there is a vast array of chronic illness diagnoses, each with relatively low prevalence
- Consequence: Health systems tend to create silos for the different pediatric conditions compared to the more generic approach taken with adult chronic illness
Clinicians need standardized approaches and tools to...

- Assess the self-management skills of youth and families
- Collaboratively set self-management goals
- Assess modifiable environmental influences on chronic conditions
- Promote competence and eventual autonomy in youth
International Classification of Functioning, Disability and Health

![Diagram of International Classification of Functioning, Disability and Health]

Youth Capacity and Performance

Capacity/Capability → what the child CAN do

Performance → what the child ACTUALLY DOES

If Capacity > Performance, look for BARRIERS

Personal factors such as health beliefs, motivation, and confidence can impact and prevent a capable child from performing effective self-management skills
Modi’s framework points to environmental factors at the levels of the family, community, and health care system.

These factors are then classified as Modifiable and Nonmodifiable.

Modifiable influences should be our targets for intervention.

It is not uncommon for health care providers to instruct patients/caregivers on self-management without taking into account contextual factors.

It is crucial that we ask about the home, school, and community environments to identify factors that influence a child’s health, as well as barriers that impact a child’s health.
Integrating Self-Management Support into practice
It takes a TEAM effort

- Caregiver
- Child/Adolescent
- Providers
- Nurses
- Social workers
- Teachers
- Therapists
- Community supports
- Family members
- And the list goes on...
How do we transition control from the caregiver to the youth?

How do we calibrate this to the unique needs & skills of each medically complex child and family?
Shared to Self-Management

**SHARED MANAGEMENT OVERVIEW**

**Role of Parent**
- Parent is **PROVIDER** of care
- Parent becomes **MANAGER** of care
- Parent becomes **SUPERVISOR** of care
- Parent becomes **CONSULTANT** to youth

**Youth Role**
- Youth **receives** care
- Youth **provides** some self-care
- Youth becomes **manager** of care
- Youth becomes **supervisor** of care
- Youth becomes **CEO** of care
What are some feasible, practical tools to bring self-management into practice today?

- Social History
- Shared Plan of Care
- Goal Setting
- Youth-to-Adult Transition Planning
Learn about the child’s ENVIRONMENT

Social history
- Who does the child live with?
- Parental occupation(s)
- Housing and Transportation
- Daycare/School/Therapies
- What does the child enjoy doing?
- Family describes *** as source(s) of support. {private duty nursing, personal care worker services, respite care services}
- Religious or cultural considerations
- Preferences about sharing medical information/decision-making
- Appointment Scheduling Preferences {days of week, number of visits/day}
Shared Plan of Care (SPOC)

Shared document that includes the following sections:

- “Who am I?”/Patient Description
- Self-Management intake
- Plans of Action & Goals
- Complex Care contact information
- Detailed problem list
- Youth-to-Adult transition planning outline
- Medication list
- Family information & preferences (Social History)
- Other important items
Create GOALS with child & caregiver

PLANS OF ACTION:

Goals for “patient’s name”/You:
- Short Term:
- Long Term:
- Self-Management:
- ________________

Instructions/Follow Up “To-Do” Items:
Complex Care’s items...
- MD/NP will:
- Nurse will:
- CCA will:
- Social work will:

Family’s items:
- Please communicate with us at least monthly and come for a care plan update visit in ~6 months
- __________
- __________
“From my experience I find a few points handy when setting realistic goals. Breaking goals into shorter targets spread over a longer term.

My daughter’s neurologist explained this very well. He said that your child’s growth curve won’t be in a straight line, there will be high points and low points but overall the curve should be moving in an upward direction. Thus, for my daughter who has cerebral palsy and cannot walk independently, I have broken our goal to make her walk independently into several short run steps or targets:

walk functionally with a walker, walk with quad sticks, walk with single point canes, walk with a cane, walk holding furniture, stand independently, take two steps independently... She needs to cross all these phases to be able to walk independently.

Setting short run targets such as walking with quad sticks allows us to work towards a realistic target which can be achieved and celebrated, instead of setting a longer term goal which is so difficult that it is impossible for my four year old to comprehend at this point.” - Parent
SELF-MANAGEMENT / YOUTH - ADULT TRANSITION SUMMARY:
How do I communicate?
What hurts me / what helps me, and how do I show it?
What makes me anxious/upset (environment, sensory)?
What does a good day look like?
How do I get around?
How do I get nutrition?
My unique vital signs are:

Care that my family caregivers do:
Care that I do:
It takes a village to raise a child

- It is equally important for the people in the child's life to be aware of the goals.

- Align goals with schools, therapists, community supports, and all other involved parties.

- We encourage patients and caregivers to share their SPOC with their supports outside our health care system.
Youth-to-Adult Transition Planning
### Early Teen (ages 12-13)

#### Pediatric to Adult Transition Checklist

<table>
<thead>
<tr>
<th>Task</th>
<th>Provider Name(s)</th>
<th>Dates</th>
<th>Comments</th>
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<tbody>
<tr>
<td>Early Teen (Suggested Ages 12-13)</td>
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<tr>
<td>Introduce transition topic to teen/family</td>
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<tr>
<td>Discuss confidentiality with teen/family. Allow 1 on 1 time with teen during visit</td>
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### Middle Teen (ages 14-15)

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<th>Task</th>
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<th>Comments</th>
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<tbody>
<tr>
<td>Middle Teen (Ages 14-15)</td>
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<tr>
<td>Explain how to access healthcare after hours / on weekends, during weekdays</td>
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<tr>
<td>Discuss what &quot;healthy&quot; means?</td>
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<tr>
<td>Include independent time during visits</td>
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**Late Teen (ages 16-17)**

**PEDIATRIC TO ADULT TRANSITION CHECKLIST**

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<tr>
<td>Late Teen (Ages 16-17)</td>
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<tr>
<td>Discuss post high school plans</td>
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<td>Assess insurance knowledge / coverage after adulthood</td>
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<tr>
<td>Set expectations of hospitalization location (e.g., after age 18, location may be inconsistent and is determined by multiple factors, etc)</td>
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<tr>
<td>Encourage self-management (e.g., making appointments, calling about illness, meds)</td>
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<td>Discuss legal implications of turning 18 (e.g., verbal release)</td>
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# Young adult (ages 18-22+)

## Pediatric to Adult Transition Checklist

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<tbody>
<tr>
<td>Young Adult (Ages 18-22+)</td>
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<tr>
<td>Receiving providers identified and timing of transfer determined</td>
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<td>If needed, sign release(s) at age 18 for parent/guardian to communicate with healthcare team</td>
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<tr>
<td>Assess readiness and skills, provide support to patient needs</td>
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<tr>
<td>Provide handoff to identified receiving provider (determine most appropriate modality: letter, phone call, discussion, care conference, etc)</td>
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<tr>
<td>Identify &quot;what do I want provider to know about me&quot; from patient/family</td>
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<tr>
<td>Create a medical health summary document in medical record</td>
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Thank you!

Questions?