



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

Rishi Agrawal, MD, MPH, Christopher Stille, MD, MPH, Editors

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District of Columbia.*



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Ask Questions!

We look forward to a lively discussion with our audience.
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Meet Our Speakers



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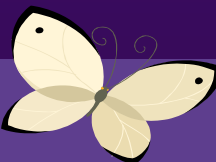
Supporting Self-Management in Children and Adolescents with Complex Chronic Conditions

Amy Houtrow, MD, PhD, MPH

Associate Professor of PM&R and Pediatrics

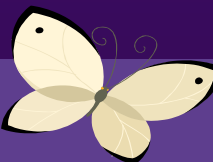
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Self-Management

- The set of tasks individuals with chronic health conditions perform to keep themselves as healthy as possible



Continuum of Self-Management Tasks

Condition
Specific

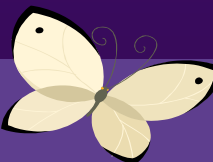


General

Wellness

Taking medication
Checking blood glucose
Wearing AFOs

Eating a healthy diet
Exercising regularly
Coping with stress





Unique Nature of Pediatric Shared Management/ Self Management

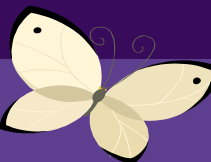


Parental

Giving medications
Donning AFOs

Youth

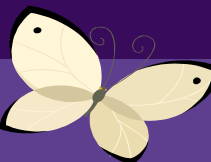
Calling in own
prescriptions
Checking skin





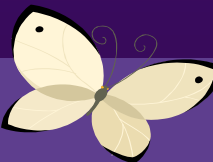
Other Pediatric Considerations

- **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



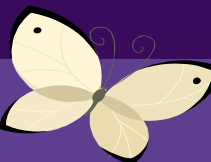
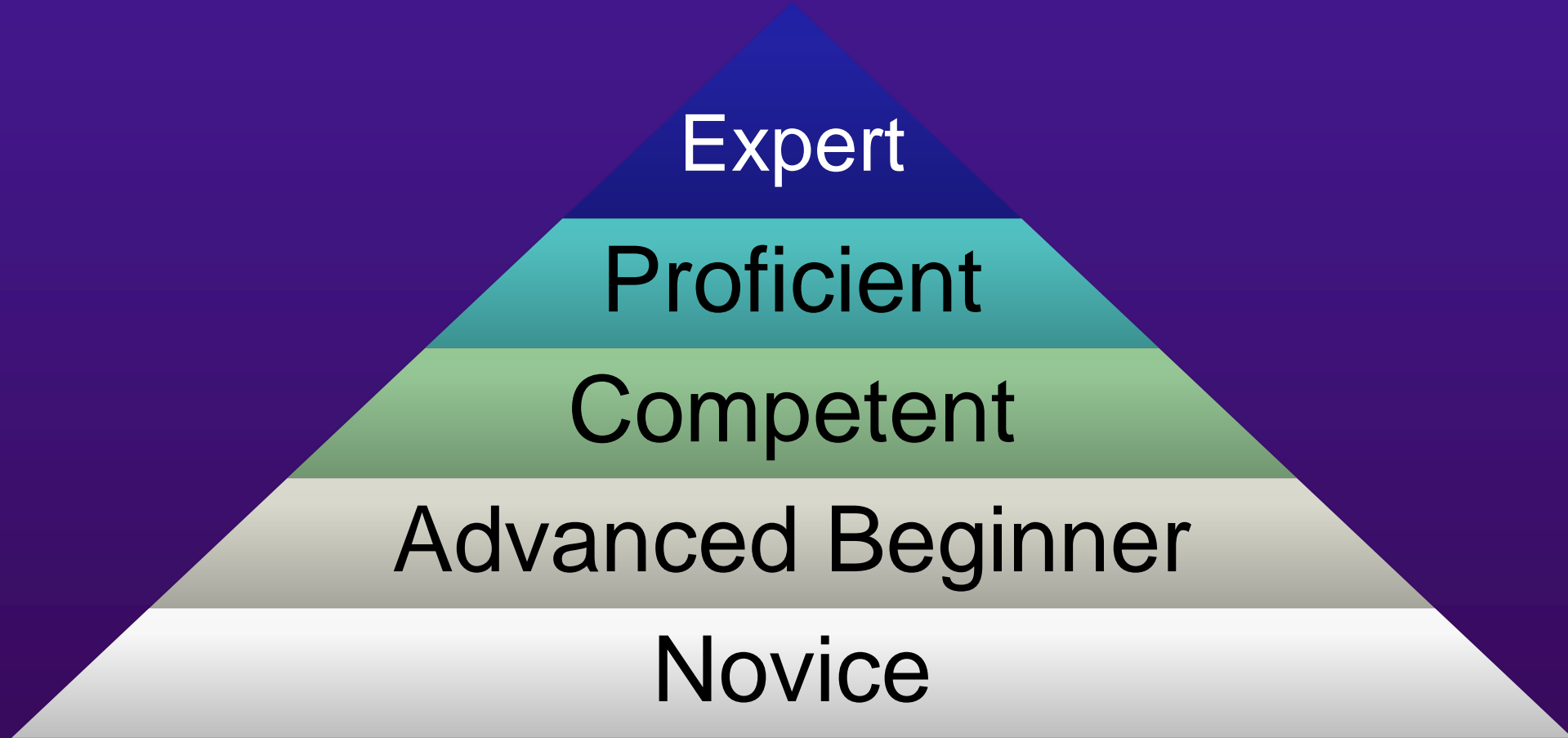


- Capacity/Capability
 - What a person can do
- Performance
 - What the person actually does

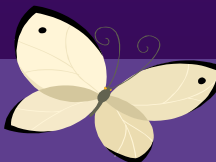
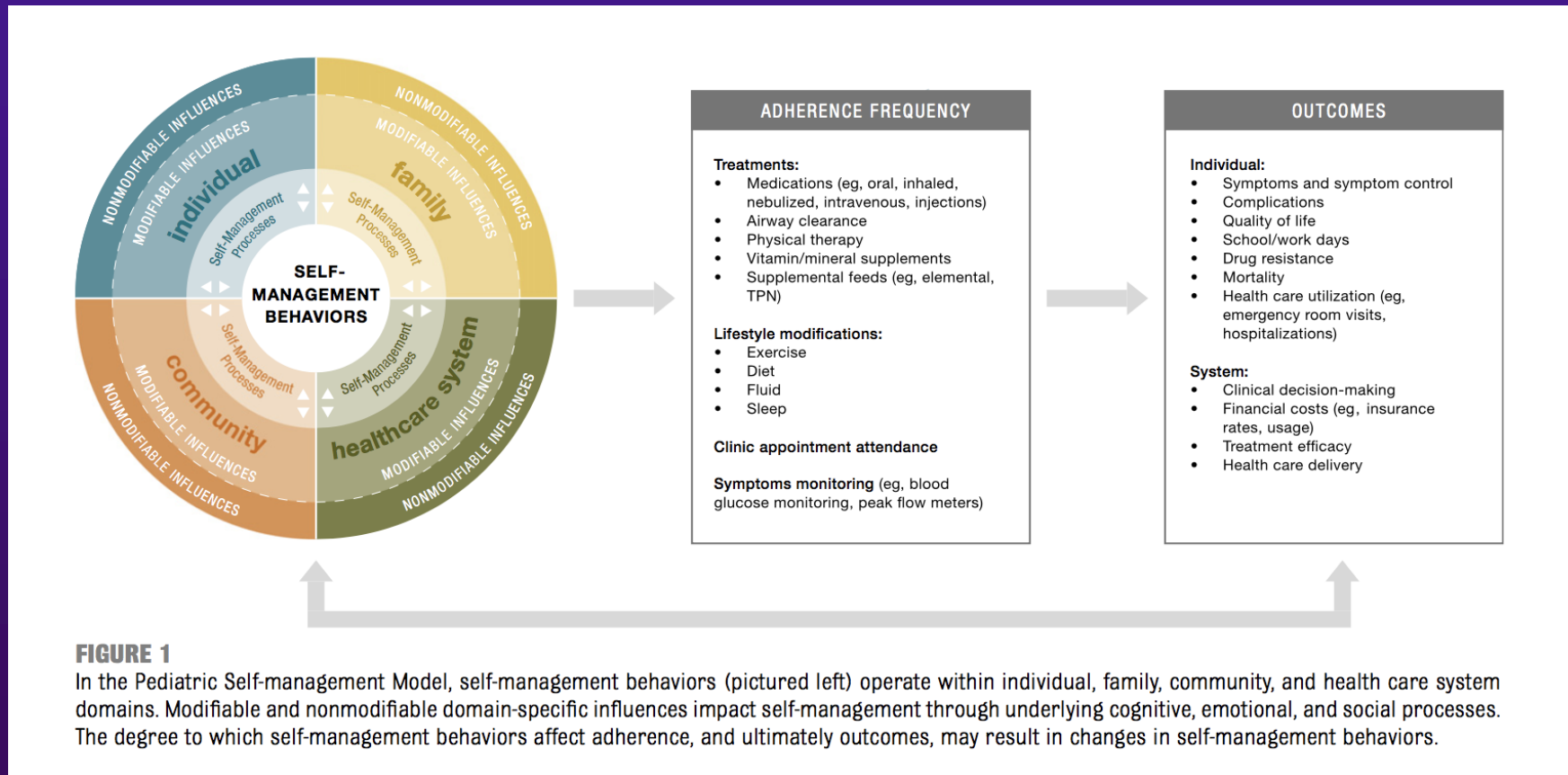




Hierarchy of Proficiency



Modi's Self-Management Model





Four Dimensions of Self-Management

1. Individual:

- self-efficacy
- autonomy

2. Interpersonal:

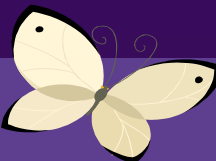
- parenting relationship is a context for self-management
- dynamic, two-way parent-child relationship: each member influencing and responding to the other

3. Temporal:

- shift or transfer of responsibility from parent/caregiver to child/adolescent over time

4. Environmental:

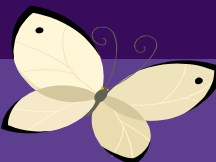
- multiple, complex factors at different levels: family, community, health care system





Supporting Youth Self-Management

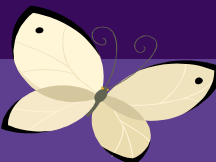
- Instill the importance of independence from an early age
- Add self-management goals to care plans
 - Why the goal is important
 - What will it take to achieve that goal
 - Who is responsible for what
 - How will success be measured
 - When will progress be assessed





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

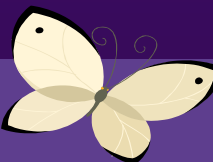
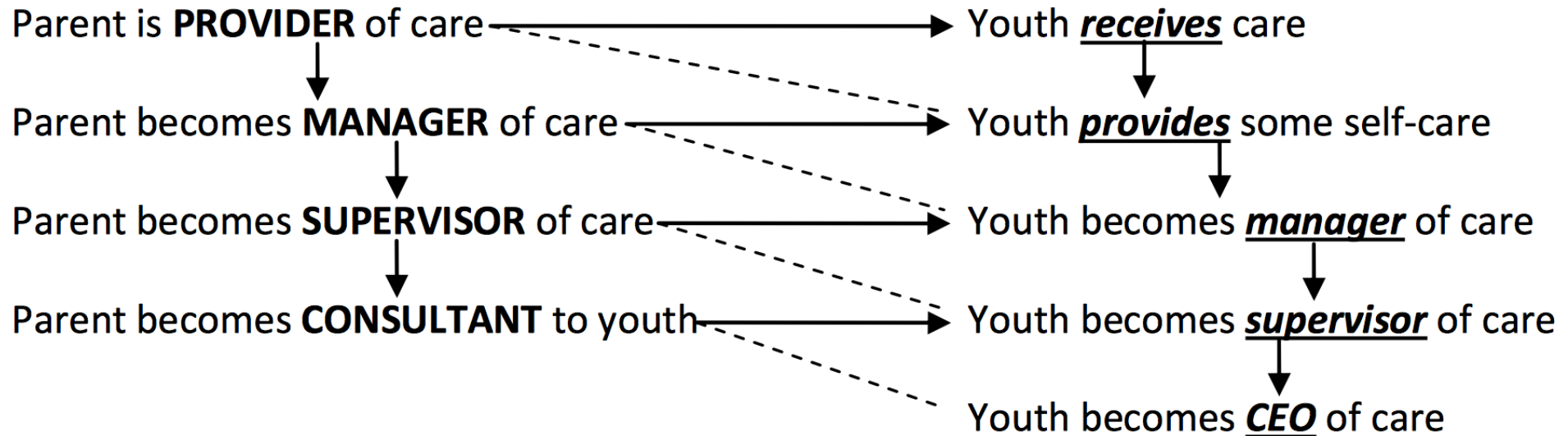


Shared to Self-Management

SHARED MANAGEMENT OVERVIEW

Role of Parent

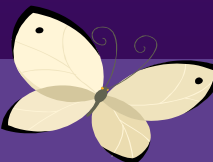
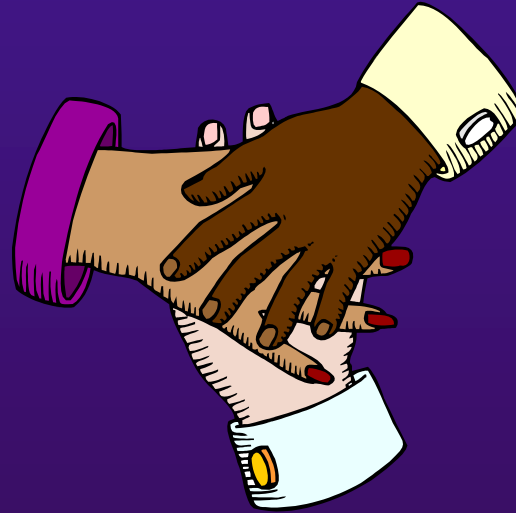
Youth Role





Team Activity

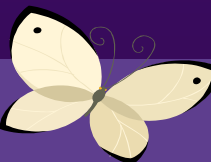
- Not just a physician activity
 - Parents
 - Nurses
 - Social workers
 - Educators
-
- Team roles should be defined
 - Billed when possible





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



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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?

Avani Modi, PhD

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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?

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Submit your questions in the question box



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