Fostering Treatment Adherence in Children and Adolescents with Chronic Health Conditions

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- No conflict of interests
- No relevant financial relationships with any commercial companies pertaining to this activity

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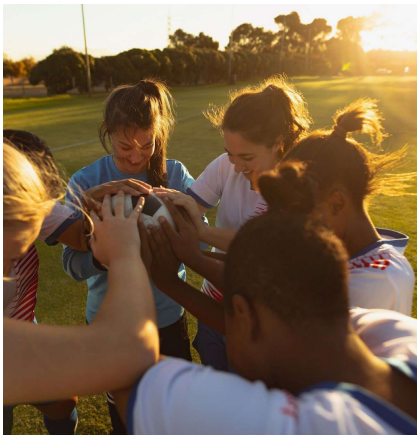
Objectives

1. Understand the psychosocial needs of children and adolescents
2. Explore the factors that contribute to nonadherence in children and adolescents
3. Identify strategies to increase treatment adherence and transitions of care in youth with chronic health conditions



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Psychosocial Development of Children and Adolescents

- Industry vs Inferiority
  - Peer group gains greater significance
  - Accomplishments measured by competency
  - Encouragement of initiative develops confidence
- Identity vs Confusion
  - Role identity for who they are as an adult becomes critical
  - Establish sense of identity based on values, exploration

Orenstien & Kaur, 2026

Erikson's Stages of Psychosocial Development

Approximate Age	Psychosocial Crisis/Task	Virtue Developed
Infant - 18 months	Trust vs Mistrust	Hope
18 months - 3 years	Autonomy vs Shame/Doubt	Will
3 - 5 years	Initiative vs Guilt	Purpose
5 -13 years	Industry vs Inferiority	Competency
13 -21 years	Identity vs Confusion	Fidelity
21- 39 years	Intimacy vs Isolation	Love
40 - 65 years	Generativity vs Stagnation	Care
65 and older	Integrity vs Despair	Wisdom

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Psychosocial Challenges of Childhood

- Cognitive Capacity and Executive Functioning
  - Concrete reasoning, theory of mind, development of frontal lobe
  - More likely to be impulsive, reactionary, lack forward/consequential thinking
- Caregiver Relationships
  - Caregivers and adult authority figures hold significance, reliant on secure base
  - Caregiver stress has significant impact on coping and modeling behavior
- Emotion Regulation
  - Less emotional intelligence, poor ability to regulate large emotions, burgeoning coping and emotional awareness

Bathlet et al., 2021; Culbertson et al., 2003

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Psychosocial Challenges of Adolescence

- Peer Behavior
  - Acceptance and rejection of peer groups dominates
- Risk Taking
  - Increase in need for exploration and experimentation
  - "It won't happen to me" mentality
- Impulsivity
  - Difficulty with long-term consequences
  - More emotionally driven
- Family Conflict
  - Increased need for privacy and desire for individuation
- Lack of Monitoring
  - Less time with family, more time alone/with peers

Bathlet et al., 2021; Culbertson et al., 2003

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How Might These Challenges be Further Complicated for Youth with Chronic Health Conditions?

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Common Psychosocial Complications Related to Chronic Conditions in Youth

Children

- Academic/Vocational Stress (Maslow et al., 2011)
  - May be less likely to graduate college
  - May be more likely to receive financial assistance and have a lower income
- Social Stress
  - Negative peer attributions associated with difficulties adhering to treatment, increased stress, and symptom control (Helgeson et al.,2019; Berlin et al, 2015)
  - Better perceived support from peers predicts better adherence (Pihlaskari et al., 2018)
  - Youth with chronic conditions at risk for increased isolation and poorer self-image (Gutgesell & Payne, 2004)
- Self-Monitoring/Self-Efficacy (Berlin et al, 2015)
  - Children with chronic illness experience increased difficulties with self-monitoring to manage their conditions
  - Children experience lower self-efficacy for managing their disease, primarily as they reach adolescence
- Mental Health Conditions
  - Higher rates of depression, anxiety, and externalizing behaviors than their healthy counterparts (Buchberger et al, 2016; Sweenie, et al., 2016)

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Common Psychosocial Complications Related to Chronic Conditions in Youth

Parents and Families

- Parenting Stress
  - Increased parenting stress related to both their child's behaviors and to the impact of managing their child's condition (Lowes, et al., 2005; Sweenie, et al., 2016)
  - Parents feel unprepared to care for their child and the perceived burden of having a child with a chronic condition (Lowes et al., 2005; Noser et al., 2018)
- Psychopathology
  - Parents who are more distressed by their child's diagnosis experience greater depressive symptoms (Noser et al., 2018)
  - Parents often experienced increased worry about their child's quality of life and future functioning (Bonner et al., 2006)
- Conflict
  - Disease-related conflict with their children and overall family conflict associated with poorer disease control and decreases in the quality of the parent-child relationship (Anderson et al., 2009)
  - Parental acceptance of an adolescent's separation from the family often enables the adolescent to return psychologically to the family (Gutgesell & Payne, 2004)

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Common Stressors Related to Chronic Conditions in Adolescents

Parents and Families

- Parental Guilt (Bonner et al., 2006)
  - Measures of parental adjustment to chronic illness shows that personal guilt about the child's condition is a significant factor
- Parental Attitudes and Beliefs (Butner et al., 2009; Moreira et al., 2014)
  - Parents who view their children as less competent experience poorer well-being and less cohesion with their child
  - This view can also foster increased support of adolescent autonomy and independence
- Other Children (Pearce, 2008)
  - Siblings have been found to be at risk of emotional problems, including resentment, aggressive behavior, confused thinking, guilt, embarrassment, and feelings of neglect

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Important Takeaways for Psychosocial Factors Related to Treatment Adherence

- Children and adolescents have different, but equally important, developmental tasks
- Chronic health conditions can significantly disrupt these developmental tasks and lead to both poor development and poor adherence to treatment
- Treatment adherence difficulties can manifest in the youth's environment
- Understanding which factors of non-adherence are most impactful to youth can help determine how to intervene

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Treatment Adherence with Children and Adolescents

How Do We Do It?

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Adherence Interventions for Children and Adolescents

- Structured to age and developmental level
- Reinforcement of health-related behaviors
- Active participation by adolescents
- Collaboration
- Feedback
- Multiple Exposures
- Problem-solving

Saxby et al, 2019

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Models for Enhancing Adherence

Five A's (Glasgow, et al, 2002; Whitlock, et al, 2002)

- Ask
- Advise/Agree
- Assess
- Assist
- Arrange

FRAMES (Bien et al., 1993)

- Feedback about personal risk
- Responsibility of patient
- Advice to change
- Menu of options
- Empathy
- Self-efficacy enhancement

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Models for Enhancing Adherence

- "SIMPLE" Conceptual Framework (Atreja et al., 2005)
  - Simplifying regimen characteristics
  - Imparting knowledge
  - Modifying patient beliefs
  - Patient communication
  - Leaving the bias
  - Evaluating adherence
- Motivational Interviewing (Miller, 1983)
  - Directly assesses stage of change
  - Meets patient where they are at
  - Open ended questions, affirmation, reflective listening, summaries

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Practical Skills for Treatment Adherence

- Youth-Driven Goal Setting and Problem Solving
  - Identify youth's personal goals and motivational factors
    - What do you want to do after high school?
    - If you woke up tomorrow and you weren't sick anymore, what is the first thing you would notice is different?
    - What is the first thing you want to do/accomplish once you are not sick anymore?
  - Tie treatment adherence and psychoeducation to these goals
  - Be willing to apply the 1% rule to solutions/goals
- Youth-Driven Reward Systems
  - Allow youth to determine what behaviors deserve reward and what rewards are meaningful to them
  - Use apps, fun visual charts, and encourage peer involvement
- Promote Reflection on the Disease Experience
  - Encourage youth to document their experience in a way feels authentic to them
  - Encourage independent research and treatment exploration and ask them to bring it to appointments

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Practical Skills for Treatment Adherence

- Teach Behavior Management Skills to Caregivers
  - Teach caregivers how to use positive praise and special time to improve relationships and encourage adherent behavior
  - Catch your child "being good"
  - Use effective commands and choices
  - Use reward systems at home and if the medical visit
- Teach Effective Communication Skills to Youth and Caregivers
  - Increase positive communication about disease fears and treatment concerns between youth and their caregivers
  - "I felt XXX when YYY happened."
    - Instead of: "You never trust me, you just think I'm a baby but I'm not!"
    - Try this: "I felt like you think I can't take care of myself when you questioned if I took my medication."
- Help caregivers manage their own anxiety around their beliefs about youth's autonomy and health outcomes

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Practical Skills for Treatment Adherence

- Implement screening practices within clinic workflow to catch psychological co-morbidities early
  - Pediatric Symptom Checklist
  - Parenting Stress Scale
  - Adolescent Harvard Flourishing Scale
- Default to child for opinions and thoughts on decision making first
  - What do you think about this part of your care?
  - Would taking your medication during lunch work for you?
  - Before we talk to mom, can you tell me what your treatment plan has been like?
- Start transitions of care as early as possible
  - Hand over ownership of treatment regimen early and increase responsibility as they show success
  - Make tasks match their own level of interest/personal goals
  - Model belief in youth's autonomy and competency for caregivers

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Development of Autonomy in Health Care

Infancy
- Parent-focused education of care
- Emphasis on stress management

Early Childhood
- Parent-focused education of care
- Emphasis on stress management
- Integration of young children

Middle Childhood
- Child-focused education of disease and coping strategies
  - Basic info about condition, recognizing/responding to symptoms, learning about treatments, healthy living skills

Younger Adolescence
- Focused on fostering autonomy and independence
- Similar to middle childhood but increase focus on independent problem-solving and decision-making

Older Adolescence
- Similar to younger adolescence
- Greater emphasis on independence and transition to adult healthcare services

Saxby et al, 2019

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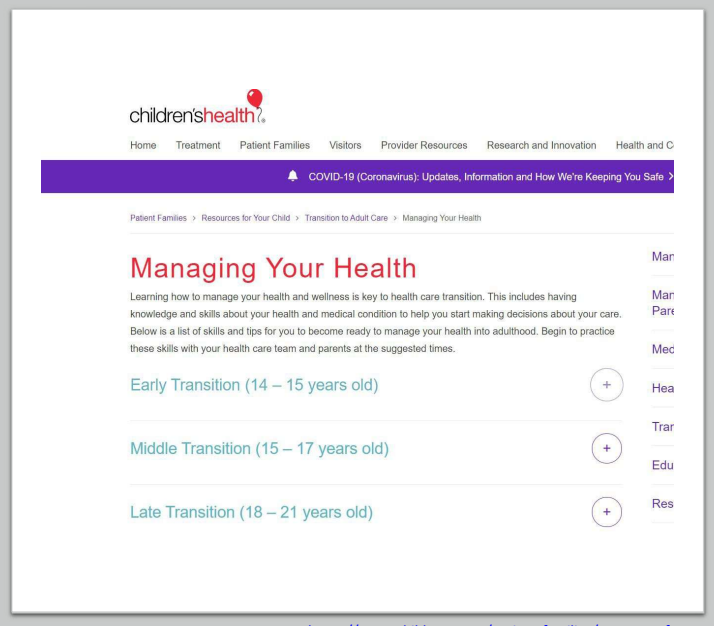
Integration Into Primary Care: Examples

- Early Transition
  - Know Your Health Condition and Medications
- Middle Transition
  - Manage your Health Condition
  - Engage in Wellness Behaviors
- Late Transition
  - Learn About Health Insurance and Community Resources



https://www.childrens.com/patient-families/resources-for-your-child/transition-to-adult-care/managing-your-health-patients

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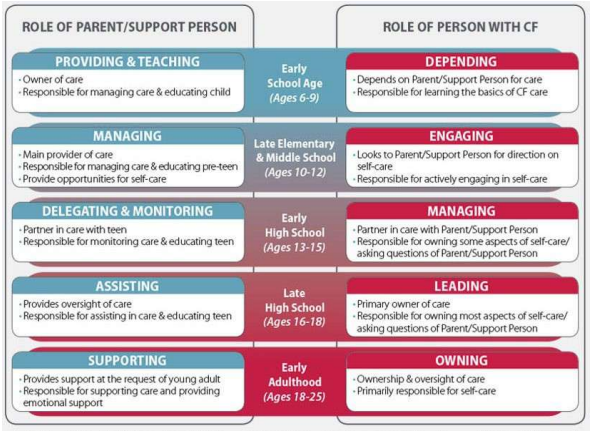
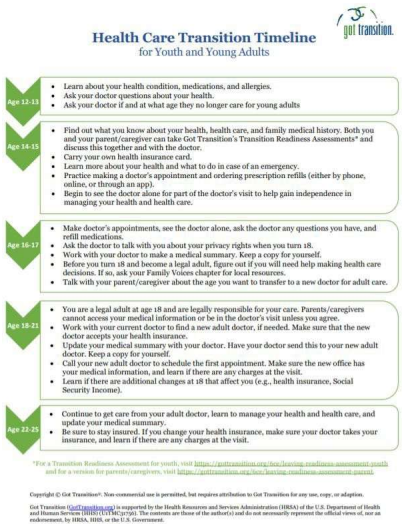
Integration Into Primary Care: Examples





https://www.cfrise.com/cystic-fibrosis-transition/
Kieckhefer GM & Trahms, 2000

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Implications for the Primary Care Setting

- We foster treatment adherence by focusing on youth's autonomy and the transition of care
- When working with family in your exam room
  - Start early!
  - Include youth in learning about and planning treatment regimen
  - Educate caregivers on importance of care-shift and autonomy
  - Engage youth in problem-solving barriers to treatment that are meaningful to them
  - Considering developing transitions of care systems within your practice
  - Repeat, repeat, repeat!

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Thank You!

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