


Family Management of Chronic Disease: Improving adaptation and adherence by identifying and reducing barriers to treatment adherence

Christopher J. Boys, PhD, LP  
Pediatric Neuropsychologist

1

### Developing Therapeutic Alliances and Reducing Barriers to Adherence


- The development of a therapeutic alliance begins with the understanding of the stress of chronic disease
  - Coping with chronic illness requires substantial effort and a great capacity to adjust to new and changing circumstances on the part of the person with the illness.



4

### Learning Objectives


- Describe barriers to treatment adherence for chronic illness/Chronic conditions
- Discuss interventions for improving adaptation and adjustment to a new diagnosis
- Provide basic tool kit to families to improve communication between parents and the child regarding chronic illness



2

### Developing a Therapeutic Alliance


- Increasing family involvement
  - Stress effective family communication concerning disease specific situations,
  - Emphasize problem solving for disease management
  - Family support for adolescent's self-care



5

### Developing Therapeutic Alliances and Reducing Barriers to Adherence


- Adherence to a Chronic Disease regimen rests largely on how a patient and family copes with the stress and adapts to the diagnosis
- Any therapeutic alliance must focus on both the individual and family's adaptation to the disease and its regimen before adherence can become the focus.



3

### Basic Goals for Therapeutic Alliances

- Increasing family involvement
  - Stress effective family communication concerning disease specific situations
    - Avoid CHRONIC DISEASE POLICE
  - Emphasize problem solving for disease management
    - Help Adolescent to do more than "Eye Roll, Stomp Off, Door Slam"
  - Family support for adolescent's self-care
    - Not wanting to do care is okay at times, not doing requires a discussion and help
    - Adolescent may have to help parents understand their frustrations



6

## Professional's Role in Family and Individual's Readiness for Change

- Discuss typical development
- Assess and share appropriate trends
- Provide a guide to appropriate expectations and behaviors within those trends



7

## Adaptation (cont.)

- Several demands or adaptive tasks that are common to a variety of chronic illness (Kuijjer & Ridder, 2003):
  - Maintaining Emotional Balance
  - Maintaining Social Relationships
  - Maintaining Self-esteem
  - Adhering to treatment regimen
  - *Transitioning from parent managed care to individual-managed care*



10

## Adaptation to Illness

- The Patient, Chronic Illness, and Family Perspective
  - Chronic illness is very common (Celiac, Crohn's Disease, Diabetes, Asthma, Food Allergies, etc)
  - Younger children have more misconceptions about procedures, as well as fewer coping mechanisms
  - Chronic Disease in children places remarkable strain on the family communication patterns, as well as, increasing parental anxiety



8

## Impact of not developing effective coping and adaptation

- Increased risk for Psychiatric Problems
  - 27% of youths had an episode of Major Depression
  - 13% diagnosed with anxiety disorders
  - Increased risk for eating disorders
    - 31% of female adolescents reported purposefully omitting insulin, but less than 9% reported frequent omission



11

## Factors affecting adaptation

- Developmental Factors
  - Age
  - Positive correlation between a children's knowledge of health concepts and general cognitive development
    - However, having good knowledge of health concepts and good cognitive development does not insure adherence
- Coping Style
  - "constantly changing cognitive and behavioral efforts to manage specific external and/or internal demands that are appraised as taxing or exceeding the resources of the person."



9

## Achieving Adherence

- Self-care is a dynamic, multi-dimensional process
  - Associated with family characteristics
    - Illness knowledge
    - Family Relations
    - Environmental Support
    - Family Communication and Level of Conflict



12

## Reducing Barriers to Adherence- Diabetes Example

- Children and Adolescents report many obstacles to treatment management
  - Historically have not matched interventions to types of problems that child/adolescent encounters
  - Treatment goal is to help to fit the disease into the individual's lifestyle, rather than the lifestyle into the disease.
    - This achieved through a combination of barrier reduction and effective goal setting
- A notable barrier is the presentation of the "DISEASE POLICE" by parents and health care professionals
  - Typically is accompanied by accusatory tones and interrogations as to why something did NOT happen
- Reducing "Just Do It" Syndrome
  - Frustrated parents often resort to telling children and adolescents to "Just Do It" rather than engaging in problem solving strategies



13

## Summary

- Chronic disease places terrific strain on both the individual and the family.
- Improving adherence begins with effective alliances between professionals and families, as well as, parents and children
- The foundation of a therapeutic alliance is found in effective communication and problem solving.
- Chronic Conditions are often unsolvable, but can be managed.
  - This is an important distinction



16

## Transitioning from parent managed care to individual-managed care

- Beginnings of the CHRONIC DISEASE POLICE
- Increased Eye Rolling, Stomping, Door Slamming
- Increased Parental Craziness (per adolescent report)
- Just Do It Syndrome



14

## Interventions

- Increasing family involvement
  - Stress effective family communication concerning disease specific situations
    - Diabetes POLICE
  - Emphasize problem solving for disease management
    - Eye Roll, Stomp Off, Door Slam
  - Family support for adolescent's self-care
    - Not wanting to do care is okay at times, not doing requires a discussion and assistance
    - Adolescent may have to help parents understand



15