

The Psychology of Metabolic Conditions: The Key to Managing the Stress of FOD on Parents and Families

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The Stress of Chronic Conditions

- Coping with chronic illness requires substantial effort and a great capacity to adjust to new and changing circumstances on the part of the parent or individual with the illness
- Its hard...

The Stress of Chronic Conditions

- Its hard because FOD is relentless, it just keeps coming at you.
- Metabolic Disease is “unsolvable”
 - Asking parents/kids to solve the unsolvable
 - If you do a great job with treatment today, have to start all over tomorrow...
 - Unsolvable does not mean unmanageable

Adaptation vs Adherence

- Adaptation – How one copes with a diagnosis.
 - Parents must adapt at the point of diagnosis
 - Parents must also adapt at different points of development
 - First day of kindergarten...
- Adherence – How an individual follows the treatment regimen

Adapting to Diagnosis

- Newborn Screening is critical, but also adds stress to a stressful time
- A positive screen starts a new pathway that parents did not plan for or anticipate
 - It is appropriate to grieve the loss of a healthy child.
 - The FOD pathway is not what was planned, it is okay to be mad, sad, upset, and overwhelmed initially
 - But then we have to get to work...

Adapting to Diagnosis

- FOD can be frustrating to explain to people and they may not “get it...”
- Family and friends do not know how to respond to these situations and often fumble well intentioned responses
 - “You are living my worst nightmare!”
 - “It could be worse, they could have cancer.”
 - “Interesting...”

Adapting to Diagnosis

- Parents of Newborn
 - Have to repeatedly answer the question of “How’s the baby?”
 - Results in many more thoughts for a parent of a child with FOD than other parents.
 - “I don’t know, is the baby doing well with an FOD?”
 - “Do I tell them we had a positive newborn screen?”
 - “If I do not tell them am I being honest?”
 - “Do I want to get into it, or do I just want to get a loaf of bread and move on...”

Adapting to Diagnosis

- Parents of a Newborn (cont.)
 - May need a script for how to respond to questions
 - Parents may have to have a discussion on who gets what information (friends and family, etc)
 - May have to learn how to communicate if someone does not respond in a helpful manner

Factors affecting adaptation for parents(and kids)

- Developmental Factors as they become more aware
 - Age of child
 - Positive correlation between a children's knowledge of health concepts and general cognitive development
- 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.”



Coping with Chronic Illness

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

Family Variables that Promote Adjustment to Chronic Illness

- Family Environment
 - Adaptability, cohesion, communication, and conflict
 - Increased problem solving, respect
- Parental Mental Health
 - parental anxiety
- Family Interventions
 - Focus on enhancing parenting and family functioning
 - Goal of improving child's adjustment to the disease

Adaptation becomes Adherence

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

Reducing Barriers to Adherence/ Attitude

- Children and Adolescents report many obstacles to treatment management
 - Not wanting to look different
 - Being overwhelmed by the tasks
 - Forgetting
 - Feeling Hopeless

Transition

- Process of making change in:
 - Roles,
 - Child goes off to kindergarten with adults other than parent in charge
 - responsibilities,
 - frames of reference
 - How does the parent view the child; How the child views him/herself

Transitioning from parent managed care to individual-managed care

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

Reducing Barriers to Adherence

- Historically have not matched interventions to types of problems that child/adolescent encounters
 - Focus on Task Completion rather than Long-Term Health
- Setting an effective goal for disease management
 - What is the goal?

Interventions (Keys)

- Increasing family involvement
 - Stress effective family communication concerning disease specific situations
 - Reducing the potential for DISEASE POLICE
 - Parents may ask:
 - “Did you check your blood sugar?”
 - “What is your number?”
 - “Why is your blood sugar so high?”
 - Need to try to rephrase away from an interrogation
 - Reduces Just Do it Syndrome

Interventions (Keys)

- Reducing the Just Do it Syndrome
 - Need to try to rephrase away from an interrogation
 - “If you have not done the [task], lets do it now.”
 - “Meet me at the kitchen table so we can see if what we need to do.”

Interventions (Keys)

- Family support for adolescent's self-care
 - Not wanting to do care is okay at times, not doing it requires a discussion and help
 - Adolescent may have to help parents understand
 - Not responding or grunting does not help

Summary

- Metabolic Disease is hard
- Healthy behaviors are hard to establish
- Establishing effective communication is key
- Keep adjusting if it does not work