Pediatric Chronic Illness and Responding to Problematic Adherence

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Chronic Illness

- 10-20% of youths under age 18 will experience one or more chronic health conditions
- Approximately 5% of these children suffer from a disease so severe that it interferes with daily activities
- Children with chronic illnesses are more likely to experience emotional and behavioral adjustment problems
- Adaptation to chronic illness is influenced by the nature of the illness, and also by personal and family resource
  - Parental adaptation is key

Health behavior change is demanding.

- Complex, unrelenting, sometimes expensive.
- Behavior is foundation of health
  - yet is *not* the only influence on health outcomes
- Patients/parents often feel out of control of health
- Different stages of readiness for change
- Arguments about adherence at home and in clinic are exhausting.

Variations in emotional distress

Distress

- Burdens of daily diabetes care
- Stresses and worries
- Feeling overwhelmed
- Twice as common as MDD

Burnout

- Feeling chronically overextended by burdens of living with diabetes
- At the point of giving up on diabetes care

Depressive Symptoms

- Any symptoms of depression that do not reach diagnostic levels
- Content may be related to diabetes or other stresses

Depression

- Major depressive disorder meeting DSM criteria
- Content may or may not be related to diabetes

Diabetes Example: Adapted from Fisher et al., 2014

When symptoms of non-adherence overlap with mental heath symptoms

- Irritability
- Mood – sadness, anxiety
- Cognitive impairments, difficulty concentrating
- Fatigue
- Weight loss
- Sleep problems
- Changes in appetite/thirst

….pretty similar to depressive symptoms.

Intervention Strategies

Psychosocial Treatments

1. Teach Skills and Behaviors
2. Increase Supervision and Feedback
3. Incentives for compliance
4. Increase family support and problem solving
5. Psychiatric treatments

Table 3. General approaches to the management of treatment adherence

1. Interventions that primarily emphasize learning new skills and behaviors
   These interventions, which are based primarily on educational approaches may be particularly helpful in short-term treatments, or at particular developmental stages, for example, when transferring greater responsibility for treatment to the adolescent patient.
2. Interventions that primarily emphasize supervision and/or feedback
   These interventions include increased levels of supervision by the medical team (more frequent medical visits or laboratory tests), the use of home-based visual cues or reminders (telephone calls), and self-monitoring (keeping calendars). These are generally not effective in complex treatment regimens when used alone.
3. Interventions that primarily emphasize incentives for improved treatment compliance
   Reinforcement strategies based on behavior modification principles have been shown to be effective in increasing rates of treatment compliance, at least in the short-term.
4. Interventions that primarily emphasize family support and/or problem solving
   These interventions are based on techniques that increase peer and family support, by increasing their level of involvement and by providing additional supervision.
5. Interventions that primarily emphasize conventional psychiatric treatments
   These interventions include the use of individual and/or family therapy to address issues such as depression, substance abuse, self-defeating behavior, or underlying family conflicts and issues.

Adapted from La Greca and Schuman (1995).

Strategies for Behavior Change, Decreasing Distress, and Building Strong Relationships in Outpatient Care

Strengths-based communication

- Review what is going well in health management:
  - Patient and family strengths
  - Ratings from resilience and self-management surveys
- Goal is to shift focus and tone of clinical encounters toward reinforcing strengths.

diabetes STRENGTHS study

Hilliard et al., 2018

Praise behavior, not health outcome.

- So many influences on heath outcomes
  - Punishing numbers → "Blame and shame" → not an effective strategy to change behavior or improve mood!

- Catch youth **doing well** with adherence:
  - More likely to happen again
  - Create positive atmosphere
  - Develop <u>confidence</u> & <u>ownership</u>

Set realistic goals.

- ☐Major changes can be daunting
- ☐**Small changes**, one step at a time
- ☐Focus on **behavior** goals
- ☐Each step achieved will reinforce management behaviors
- ☐**Celebrate each success**!

Parents and Providers Stay Involved

Strategies:

1. Adapt involvement over time
2. Stay involved in different ways – words and actions
3. Don’t transfer responsibility until ready
4. Create system for accountability

Supported by studies from Harris, Wysocki, Anderson, Laffel, and Weissberg-Benchell

Reduce Family Conflict

Strategies:

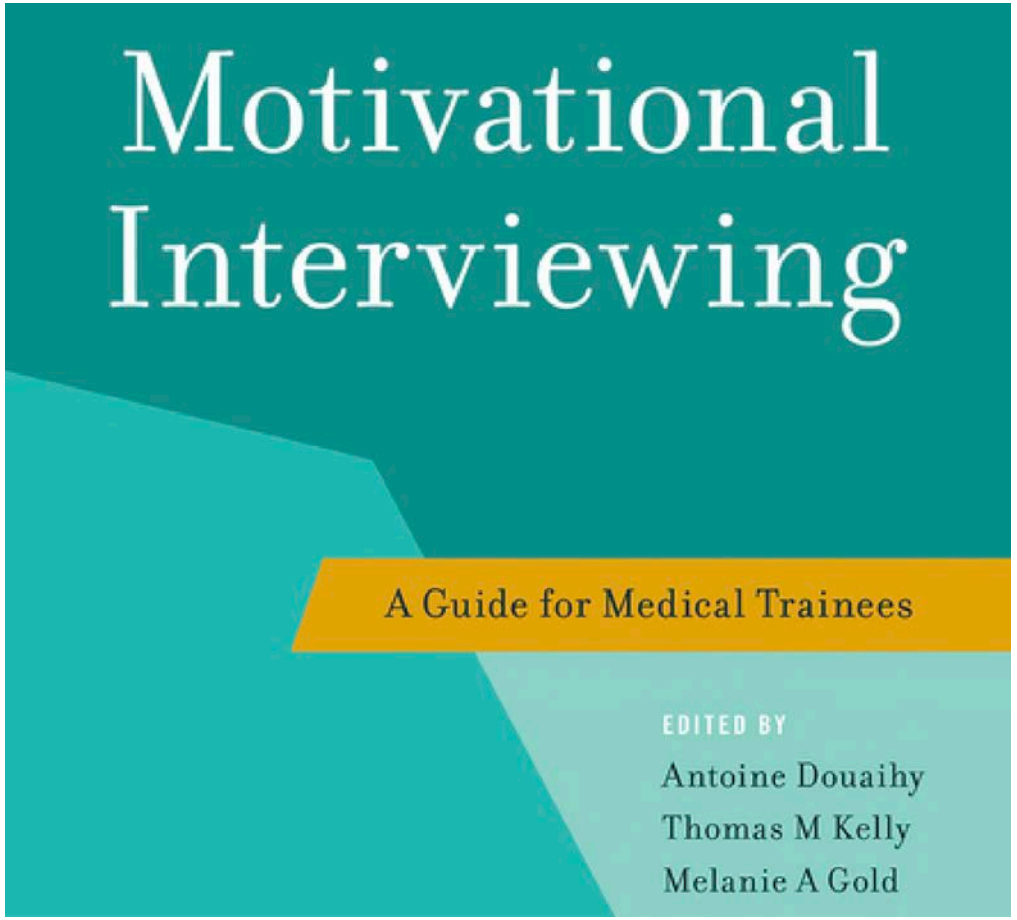
1. Calm, Care, and Consistency
   - Avoid displays of anger
   - Show empathy for struggles and praise often
   - Set clear rules and limits; set clear rewards and consequences
2. Refrain from “blame and shame”
3. Use general parenting strategies

Supported by studies from Rubin, Wysocki, Hood, Laffel, Grey, Berg, and Jacobson

Build Strong Relationships

- Empathy and respect for quality of life challenges
- Encourage social support building
- Repairing relationships when trust is lost
  - Identify common ground or goal
    - Return to it frequently
  - Make small plans towards that goal that fit expectations of both groups
  - Appreciate their frustrations while staying firm on non-negotiables

Motivational Interviewing



Motivational Interviewing

- Spirit of Motivational Interviewing
  - Partnership/Collaboration
  - Acceptance
  - Compassion
  - Evocation

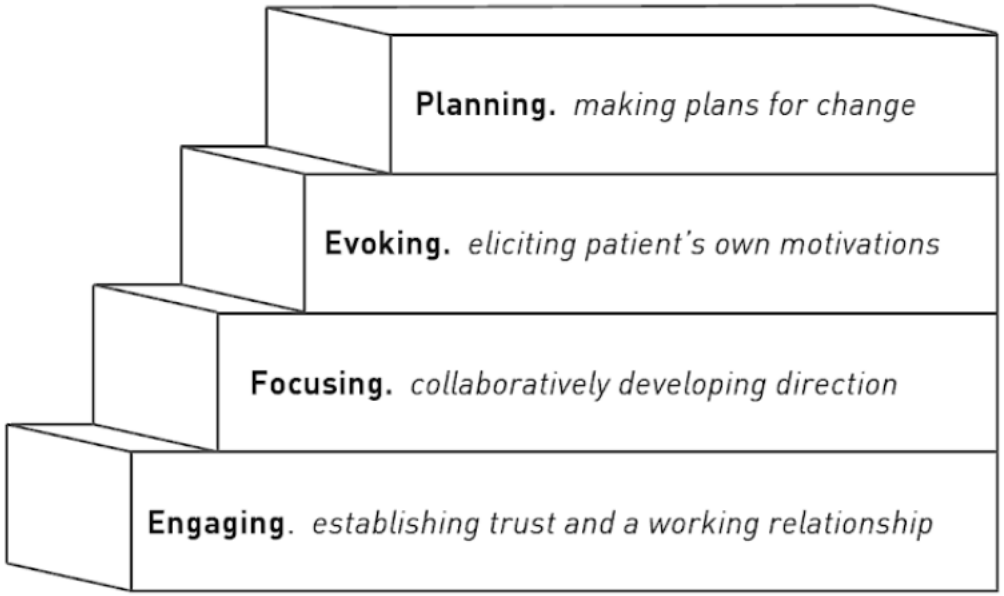


FIGURE 3.4 The four processes of motivational interviewing.

Motivational Interviewing

- Partnership!
  - Shift from expert/authoritarian to equal partnership
  - Focus on behavior change that patient and family wish to make
  - Explore and understand their perspective
  - Evoke their reasons to change
- Try instead:
  - “May I share my perspective?”
  - “We can discuss treatment options based on what makes the most sense for you.”
  - “Help me understand more about how you see it.”

Motivational Interviewing

Table 3.1 Change Talk: DARN CAT

Desire	"I really want to find a way."
Ability	"I could do that."
Reasons	"My family is counting on me."
Need	"I just can't keep doing this."
Commitment	"I must—no, I will make a change."
Activation	"I set my quit date."
Taking steps	"I joined a gym last week."

Communication about Medically Unexplained Physical Symptoms (MUPS)

- Symptoms are present in absence of medical evidence
  - Includes conversion, somatoform, chronic pain syndromes, IBS, some eating disorders and abdominal pain, pseudoseizure, chronic HA

- “Normal” findings increase clinical certainty that symptoms are functional, behavioral, or psychological

Communication about Medically Unexplained Physical Symptoms (MUPS)

- Children with MUPS present frequently.
- They are time intensive, demanding, and difficult to assess and treat.

- Families tend to deny any psychological factors, are wary of psychiatric services and as a result are difficult to engage.

- They are often upset with the medical team for failing to find an explanation for the symptoms and feel misunderstood.

Communication about Medically Unexplained Physical Symptoms (MUPS)

- MUPS is *any* clinical presentation of symptoms or impairment in the absence of medical evidence.
- MUPS requires combined medical and psychosocial elements in evaluation and treatment.
- MUPS is not simply a psychiatric illness, but rather physical symptoms that likely result from physiologic conditioning and the psychosomatic pathway (baseline ability to sense/perceive physical sensations).
- MUPS can arise without concurrent depression or anxiety (psychiatric symptoms associated with MUPS may be the RESULT of symptoms, rather than the cause).

Scripting Content: Things to Avoid

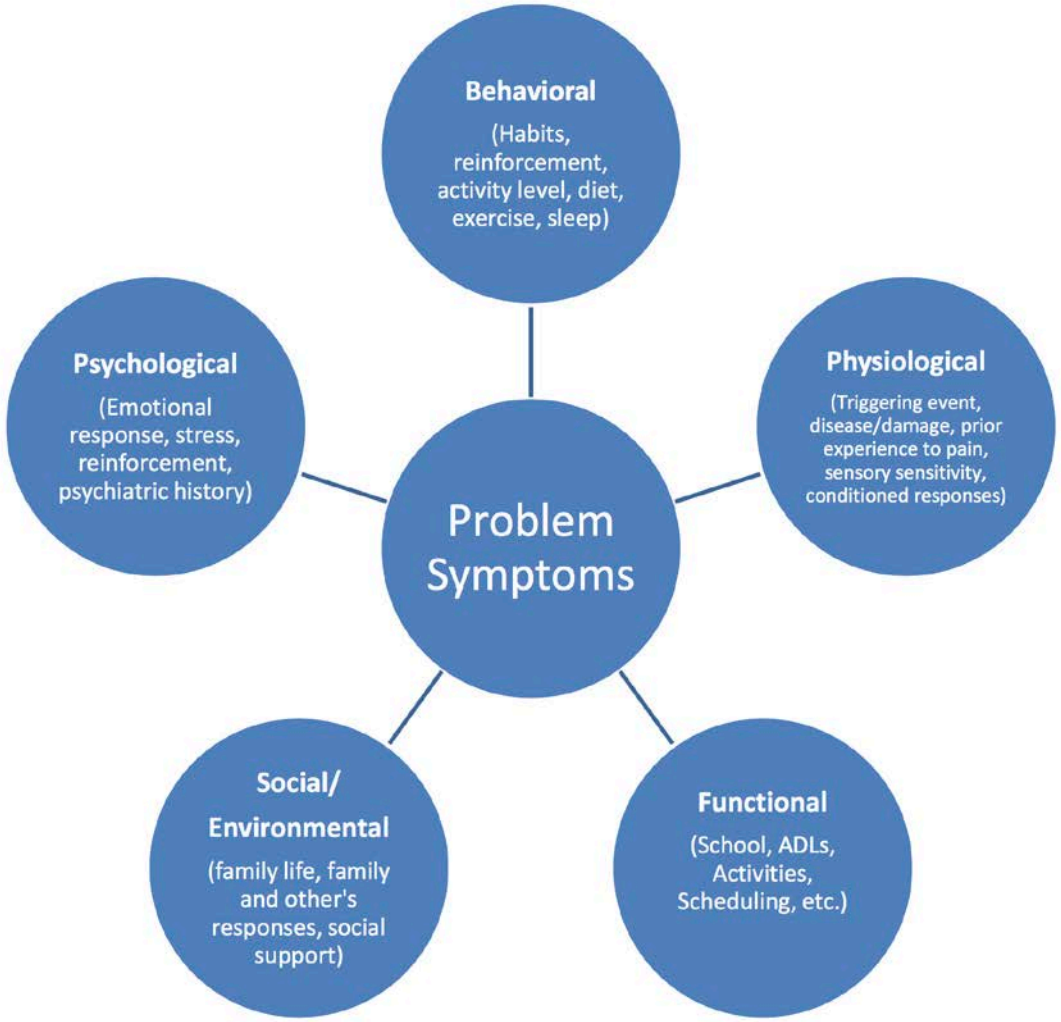
- It is clinically useless to state a cause and effect link between emotional and physical symptoms.

- Explaining negative findings as “normal” is not reassuring.
  - Families need to know you understand their illness experience.
  - Negative findings create uncertainty in diagnosis and prognosis for families.
  - Families need to know what IS wrong, an explanatory model for the likely cause of symptoms.

Scripting Content: Introducing MUPS

- Physical symptoms have a physical basis, but can be attributed to pathologic and functional processes.
- Multiple trigger and precipitants
  - This connection between brain and body means that anything mediated through the central nervous system can realistically “cause” symptoms to occur.
  - Many things can trigger a single symptom but the body has a limited number of ways to respond to triggers.
- Physiologic conditioning
  - Conditioned responses are patterns of normal physiology that occur when a repeated stimulus causes a repeated response.
- Psychosomatic Pathway
  - Everyone has a baseline ability to perceive physical sensations
  - Over time, these patterns can lead to greater somatic expression

Scripting Content: Introducing MUPS



Scripting Content: Introducing Treatment

- Treatment is most effective if it is multimodal and behaviorally/ functionally oriented.
- Take a “chronic treatable” approach: Focus is on functional improvement over symptom elimination.
- Treatment goal to recondition the body and mind to work towards return to function in physical, emotional, academic, and interpersonal dimensions.

Thank you!

- Questions?
- Case examples to discuss?
- Specific challenges you are facing now?

- Consultation?
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