WORKING WITH CHRONICALLY ILL CHILDREN & YOUTH

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OBJECTIVES

- Chronic illness in children and adolescents
- Stress related to chronic illness in youth
- Psychological complications of chronic illness in youth
- Coping with chronic illness related stress
- Psychologist roles in treatment of chronic illness
- Approaches to addressing chronic illness
Three important features define chronic illness

- Prolonged duration (usually lasting 3 months or more)
- Do not resolve spontaneously
- Rarely cured completely

Impacts child’s normal activities

Characterized by

- Acute phase surrounding diagnosis
- Prolonged stress associated with extended treatment and recovery cycles

Compas, Jaser, Dunn, & Rodriguez 2012; Stanton et al., 2007; Van Cleave et al., 2010
Epidemiologic studies suggest up to 1 in 4 children in the U.S. have chronic health problems.

In the United States alone:
- Over 13,000 children diagnosed with cancer per year
- 13,000 children diagnosed with type I diabetes per year
- 200,000 children live with type 1 or type 2 diabetes
- Sickle Cell Disease
- Type 2 diabetes rates rapidly increasing

Very common reason for psychological referral

CDC, 2009; Ogden et al., 2010; Van Cleave et al., 2010
IMPACT OF CHRONIC ILLNESS ON CHILDHOOD

- Discomfort or loss of energy
- Restriction of activities
- Disruption of his life due to medical treatment
- Isolation from family and friends
- Feeling self-conscious, embarrassed, or stigmatized if his disease makes him different from other people
Chronic illness vs. acute illness
- May be associated with higher levels of psychological and physical stress
- Resolve less quickly

Stressors related to diagnosis and course of chronic illness
- Unanticipated
- Uncontrollable
- Functionally impairing for youth and parents

Compas, et al., 2012; Martin et al., 2009
PSYCHOLOGICAL IMPACT OF CHRONIC ILLNESS IN CHILDHOOD

- Psychological adjustment
  - Family
  - Peers
  - Constructing self/ Self narrative
- Low self-esteem/self-efficacy
- Low quality of life
- Developmental issue
- Disrupted social development
- Anxiety
- Depression

Glover, 2014; Van Cleave et al., 2010
IMPACT OF ILLNESS ON FAMILY LIFE

- Family patterns
- Beliefs about illness
- Social function
- Financial difficulties
- Cultural implications
- Helplessness
- Acting out psychological problems

Glover, 2014
Children and adolescents with chronic illness have, on average, higher levels of depressive symptoms than their healthy peers.

Elements of chronic illness influencing depression:
- Symptoms of illness
- Treatment
- Brain Chemistry
- Course of disease

Some of the symptoms of depression may overlap the symptoms of the chronic disease making depression difficult to diagnose in a chronically ill child.

Depression compounds the difficulty related to chronic illness.
CASE EXAMPLES “AARON” AND “ASHLEY”

- Stem cell transplants – near complete isolation
- Preparation for transplant
- Adjustment to transplant
- Family role in treatment
- Depression developed after hospitalization
COPING WITH STRESS RELATED TO CHRONIC ILLNESS

- Wide array of stressors
  - Daily functioning
  - Physical effects of illness or treatment
  - Uncertainty about illness

- Coping responses and coping goals may be contextualized as related to the ability to control the stressor
  - Primary control coping
  - Secondary control coping
  - Disengagement coping

Compas, et al., 2012; Rodriguez et al., 2012
Rodriguez et al. (2012)

- Both child and parent reports all 3 types of stressors studied as moderately to highly stressful and relatively frequent
- Both children and parents rated daily functioning as more stressful than uncertainty about their disease
- Daily functioning stressors may require the most coping resources
Chronic illness creates significant stress for the entire family.

Role of parents in coping:
- Support
- Help shape children’s coping
- Model effective/ineffective coping
- Poor coping abilities lead to increased distress in children

Compas, et al., 2012; Glover, 2014
CASE EXAMPLE “DANNY”

- Presented with unknown back pain drastically impacting school attendance
- Six previous hospitals for testing in a little over one year
- Dad played a big role in modeling coping
- Relaxation
- Biofeedback
Grey et al. (2000)
- Improve stress management related to diabetes
- Coping skills emphasized
  - Assertive communication
  - Conflict Resolution
  - Positive Thinking
- Positive impacts on quality of life and metabolic control
Szigethey et al (2007)

- CBT approach to managing depressive symptoms in adolescents with IBD
- Primary and Secondary Control Enhancement Therapy
- Treatment group demonstrated improvement
  - Depressive symptoms (parent and child report)
  - Global functioning
  - Perception of control.
Children with chronic pain
- Report more daily stressors
- Miss school and extracurricular activities because of pain
- Pain itself is stressful
- Chronic pain is often perceived as unpredictable and uncontrollable

Research on coping with pain in childhood and adolescence
- Secondary control coping related to lower levels of anxiety and depression
- Accommodative coping decreased pain
- Passive coping related to higher levels of somatic complaints, anxiety, and depression
- Primary control coping related to lower levels of anxiety and depression but higher levels of pain

Compas & Boyer, 2001; Simmons et al., 2008 Thomsen et al., 2002 Walker et al., 2001; Walker et al., 2007
Cognitive therapy is not just about restructuring/changing maladaptive thoughts.

Cognitive therapy takes the patient out of “automatic pilot” and “reactivity.”

Cognitive therapy provides a means for emotion regulation.

Cognitive therapy provides a mechanism for acceptance.
Full Catastrophe Living
Using the Wisdom of Your Body and Mind to Face Stress, Pain, and Illness
Jon Kabat-Zinn, Ph.D.

Mindfulness-Based Cognitive Therapy for Depression
A New Approach to Preventing Relapse
Zindel V. Segal
J. Mark G. Williams
John D. Teasdale
Mindfulness Based Stress Reduction (MBSR)

Mindfulness-Based Cognitive Therapy (MBCT)
- preventing depression relapse
- addresses ruminative
- Addresses catastrophic thinking

- Adds experiential component to CBT
- May enhance Emotion Regulation piece of CBT
- Acceptance a

Thorn. 2009


REFERENCES


