

Psychosocial Impact of Chronic Illness on Children and Families

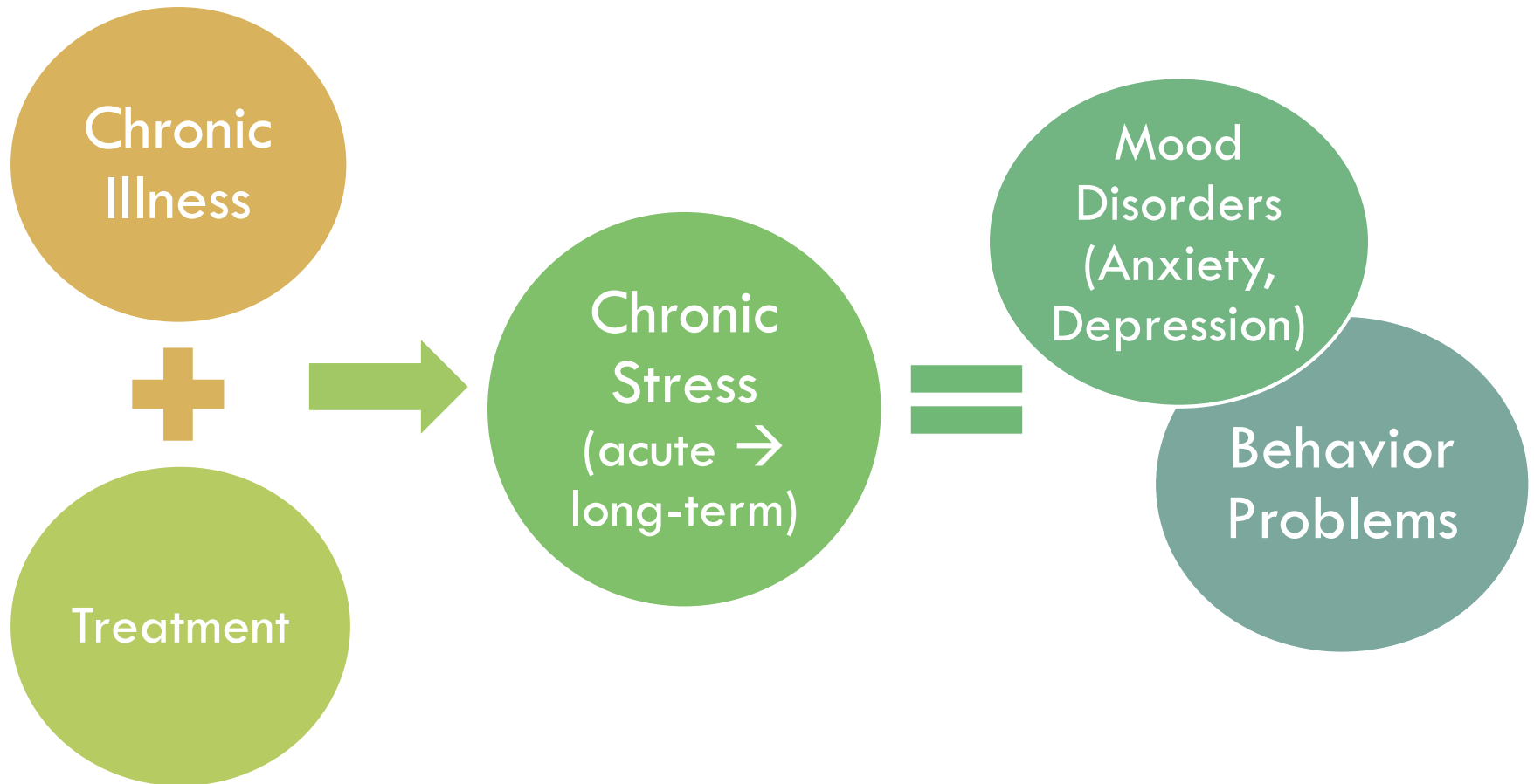
Parent Project Muscular Dystrophy-
Education Day
June 2, 2018

Liz Gunter, MA, LPC, NCC
Ashley Nichols, MD, FAAP

Chronic Illness (CI) in Children and Adolescence

- Any physical, emotional, or mental condition that:
 - ▣ Prevents attending school regularly or doing regular school work
 - ▣ Limits doing usual childhood activities
 - ▣ Or, requires frequent attention or treatment from a doctor or other health professional, regular use of any medication, or use of special equipment.⁷

Psychosocial Issues



Psychosocial Issues

- Research study:
 - ▣ Nearly half (45%) of the oldest males in each family affected with DBMD had at least one of three mental health concerns: behavior concerns, depressed mood, or ADHD
 - ▣ Males 1-29 years of age with DBMD:
 - who used steroids were more than twice as likely to have behavioral concerns as those who did not use steroids.
 - who were losing their ability to walk were more likely to have behavioral concerns, and more than three times as likely to have depressed mood as those who were still able to walk independently.
 - Those with steroid use or losing the ability to walk were not more likely to have ADHD.³

Psychosocial Issues

- Sibling Conflict
- Disconnect from Others/Social Isolation
- Grief (anticipatory)
- Non-compliance with treatments
- Depression/Anxiety

Case: Peter

- 15 year old male with DMD
- Mom upset as patient not doing homework, acting out at home and in school, doing poorly in school
- Patient is quiet, withdrawn in clinic
- “Why should I care? It’s not like I’m going to go to college or get a job anyway.”
- Lost older cousin with DMD at age 21

Anticipatory Grief

- Grief: emotional, cognitive, physical, and spiritual response to loss.
- Anticipatory Grief: experienced along the way
 - Natural response to receiving a life-threatening diagnosis
 - Grieving the losses associated with illness
 - “Normal” or expected life
 - Developmental or social milestones
 - Can look like frustration, sadness, tearfulness, anger, irritability, guilt, anxiety, or withdrawal
- While this can be a NORMAL part of grief, if left unchecked, it can have damaging consequences.
- Treatment: counseling



Case: Michael

- Michael is an 12 year old with DMD
- Fell and broke femur last year
- Stopped steroids after significant weight gain
- No longer able to walk independently
- Easily angry, acting out in school
- Mom calls Shea worried he's depressed and noted he asked, "Am I dying?"
- Interestingly, when seen in clinic, mostly resolved.

Adjustment Disorder

- Adjustment Disorder: abnormal and excessive reaction to an identifiable life stressor.
 - ▣ Stressor? Changing schools, decline in function (ex: needing a wheelchair), marriage or divorce of parents, death of family/friend
 - ▣ Usually associated with one or more:
 - Depressed mood, anxiety, disturbance of conduct, problems at work/school, or social isolation
 - ▣ Symptoms arise within 3 months of stressor and resolve within 6 months after stressor has ended
- Treatment: counseling, coping, time +/- short term medications

Depression

- Depression is more complex than “feeling sad.”
 - Diagnoses requires ≥ 5 of the following symptoms:
 - *Depressed (or irritable) mood
 - *Loss of interest/pleasure in most activities
 - Sleep disturbance
 - Weight/appetite change
 - Poor concentration or indecisiveness
 - Fatigue or loss of energy
 - Feelings of worthlessness or guilt
 - Psychomotor agitation or retardation (movement)
 - Suicidal thoughts
- Never normal.
- Treatment: counseling and medications combined

Psychosocial Issues

- Self-Image
- Anger
- Dependency/Autonomy
- School Issues
- Caregiver Burnout

Case: Ryan

- 17 year old male with DMD
- Recent changes in family structure
- Decreased motor skills
- Acting out in school
- Family frustration with behavior
- Voice = Control

Role of Coping

- Coping (verb):
 - ▣ The act of facing and dealing with responsibilities, problems, or difficulties, especially in a successful or calm manner.
 - ▣ Collection of purposeful, volitional efforts that are directed at the regulation of aspects of the self and the environment under stress.^{2,4,7}

Role of Parental Coping

- The role of parents' coping may be important to consider on several levels:
 - ▣ parents serve as resources to support children's coping
 - ▣ parents serve as important models of effective and ineffective coping for their children
 - ▣ parents who are ineffective in coping with the stress of their child's illness may contribute to increased distress in their children²

The Right Way of Coping?

- We all cope differently.
- Everyone has their own limits.
- We all cope and adapt to change in illness and function on our own timeline.
- Have grace for yourself and your family, especially when they respond differently than you.
- Ask for help before you reach a breaking point.



Ways to Help

- Listen to your child:
 - ▣ Be present and aware (of child and self).
 - ▣ Ask/give permission for them to talk about their concerns. Use open-ended questions to help.
 - ▣ Validate their worries, normalize what they're feeling, and reassure them you (and their team) will figure things out together.
- Include your child:
 - ▣ In decision-making, as possible.
 - ▣ Empower them by letting them take part and giving them control of the things they can control.

Ways to Help

- Ask for help:
 - ▣ Let the team know what you're dealing with so they can help you and your child troubleshoot or acclimate/cope with a “new normal.”
 - ▣ Counseling: children sometimes avoid talking with loved ones to avoid worrying/burdening them; they may be more open to a neutral third party.
- Take care to filter your own emotions and frustrations in front of your child.

Ways to Help

- Take care of yourself.
 - Take a nap.
 - Exercise. Get fresh air.
 - Meditate.
 - There's an app for that. (ex: Headspace)
 - Spend time with a friend (don't isolate).
 - Ask for help.
 - Personal counseling.
 - Journal.



Resources

- Muscular Dystrophy Association (<https://www.mda.org>)
 - ▣ MDA Care Center Team (MDA Clinic & other specialists)
 - ▣ MDA Summer Camp
 - ▣ MDA Young Adults Program
- Facebook group: Muscles Connect
- Camp ASCCA (<https://www.campascca.org>)
 - ▣ Young adult camps
 - ▣ Family camps

Resources

- Courageous Parents Network
(<https://courageousparentsnetwork.org>)
 - ▣ Care Plan Book
 - ▣ Guidelines for the Conversation(s)
 - ▣ Tips for Grandparents
 - ▣ Helping Siblings Cope
 - ▣ Coping with Anticipatory Grief
 - ▣ Self Care: A Parent's Guide to Taking Care of Yourself (as well as Your Child)



COURAGEOUS PARENTS NETWORK

Supporting families of seriously ill children

Questions? Thoughts? Concerns?



References

1. Compas BE, Boyer MC. Coping and attention: Implications for child health and pediatric conditions. *J Devel Beh Ped.* 2001;22:1–11.
2. Compas BE, Jaser SS, Dunn MJ, Rodriguez EM. Coping with chronic illness in Childhood and Adolescence. *Annu Rev Clin Psychol.* 2012 April 27; 8: 455–480.
3. Conway KC, Mathews KD, Oleszek J, Paramsothy P, Romitti PA, Trout C, Zhang Y, MD STARnet. Neurobehavioral concerns among males with dystrophinopathy using population-based surveillance data from the muscular dystrophy surveillance, tracking, and research network. *J Dev Behav Pediatr.* 2015; 36(6): 455-463.
4. Courageous Parents Network. CPN, courageousparentsnetwork.org/.
5. Eisenberg N, Fabes RA, Guthrie IK. Coping with stress: The roles of regulation and development. In: Wolchik SA, Sandler IN, editors. *Handbook of children's coping: Linking theory and intervention.* New York: Plenum Press; 1997. pp. 41–70.
6. Pollin, I. (1995) *Medical crisis counseling: short-term therapy for long-term illness.* New York: W.W. Norton & Company, Ltd.
7. Skinner EA, Zimmer-Gembeck MJ. The development of coping. *Ann Rev Psych.* 2007;58:119–144.[
8. Van Cleave J, Gortmaker SL, Perrin JM. Dynamics of obesity and chronic health conditions among children and youth. *JAMA.* 2010;303:623–630.

Contact Information

- Liz Gunter, MA, LPC, NCC
1600 6th Avenue South, Suite 200
Birmingham, AL 35233
205.638.6123
Liz.Gunter@childrensal.org

- Ashley Nichols, MD, FAAP
1600 7th Avenue South
Birmingham, AL 35233
205.638.7150
acnichols@uabmc.edu