



MYOTONIC
DYSTROPHY
FOUNDATION

Care and a Cure



2018
MDF ANNUAL CONFERENCE
September 14-15, 2018
Nashville, TN

PROMOTING RESILIENCE: STRATEGIES FOR MANAGING DISEASE PROGRESSION

Missy Dixon, PhD, MS



HEALTH
UNIVERSITY OF UTAH

Strategies For Managing Disease Progression

- DM is also a brain disorder that affects thinking and behavior
- Knowledge of DM cognitive symptoms
- Awareness of how cognitive symptoms change
- Awareness of contributors to cognitive change
- BioPsychoSocial Model
- Building Resilience
- Promoting Resilience to Manage Disease Progression

Cognitive Symptoms

- Mood
 - ▣ Depression
 - ▣ Anxiety
 - ▣ Apathy
 - ▣ Flat affect
- Thinking and Concentration
 - ▣ Linear, Circular, Disjointed
- Attention
 - ▣ Visual
 - ▣ Verbal
- Language
- Information Processing Speed
 - ▣ Visual
 - ▣ Verbal
- Visuoconstructional
- Visuospatial
- Learning
 - ▣ Verbal
- Perseveration
- Personality



Cognitive Symptoms

- Executive Function
 - ▣ Working Memory
 - ▣ Planning and Organization
 - ▣ Monitoring
 - ▣ Inhibition
 - ▣ Shift
 - ▣ Initiation
 - ▣ Emotional Control
- Memory
 - ▣ Visual
 - ▣ Verbal
- Motivation
- Problem Solving/Decision Making
 - ▣ Too many choices



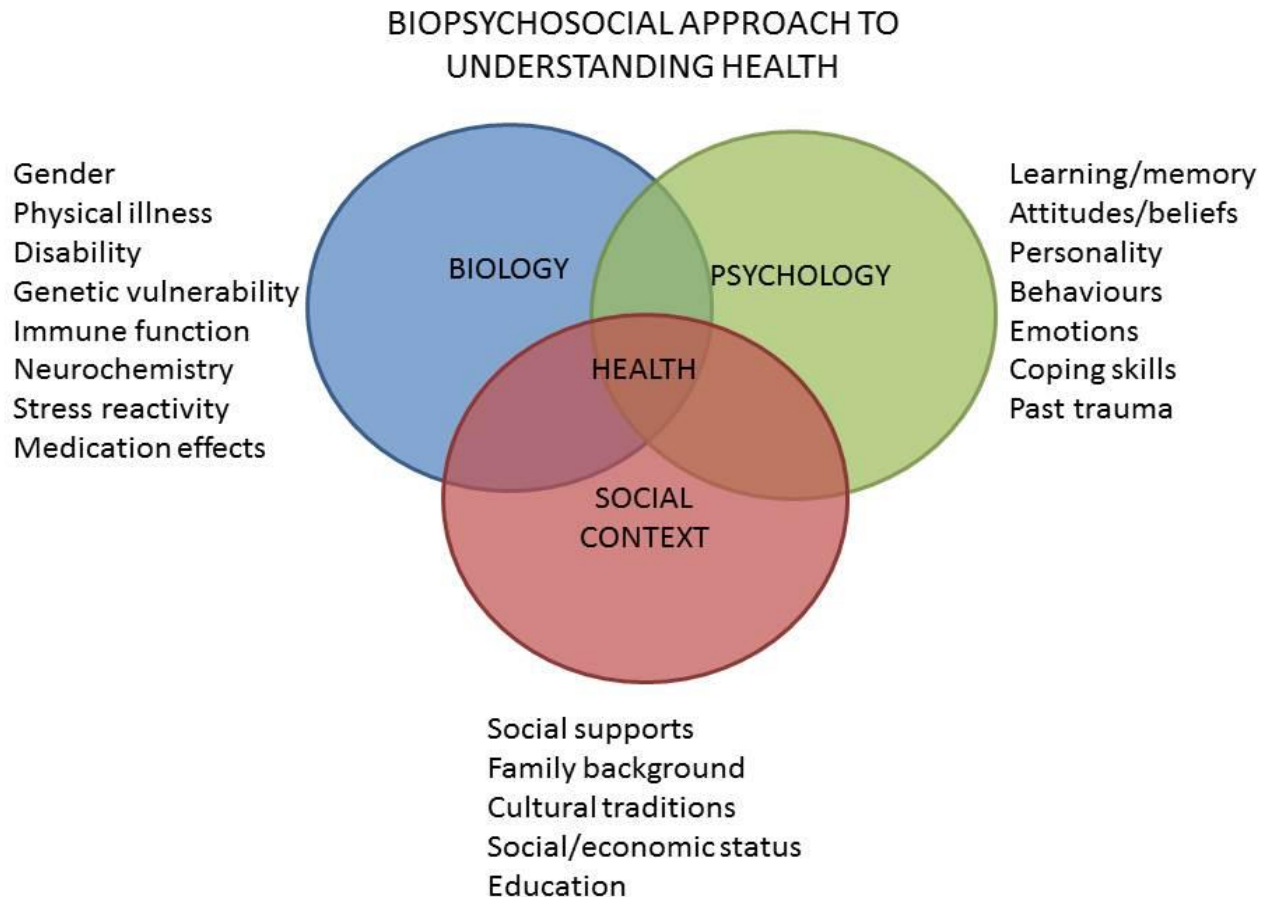
What Does Cognitive Change Look Like

- Gradual and subtle change
 - ▣ Appear extreme to outsiders
- What do symptoms look like at different stages of development and disease course
- Symptoms can wax and wane
 - ▣ Psychosocial
 - ▣ Environment
- Symptom commonalities/change unique to individual

Contributors to Cognitive Changes

- Biological
 - ▣ Disease mechanism & severity
 - ▣ Physical symptoms/limitations (Sleep, Fatigue, GI, Cardiac, Pain)
 - ▣ Health Complications/ medical regimens
- Psychological
 - ▣ Thoughts, emotions, behaviors (e.g., psychological distress, fear/avoidance beliefs, coping strategies, self-esteem and self-efficacy)
- Social
 - ▣ Environment (e.g., home, community, school, work)
 - ▣ Relationships (e.g., family, peers, support network)
 - ▣ Cultural factors (e.g., work, family, financial resources)

A Holistic Approach to Understanding Cognitive Change



Building Resilience

- Caring/supportive relationships (primary factor)
 - ▣ Build your team- healthcare, family, support network
- Communication and problem solving
 - ▣ Continuous open dialogue among your teams about your symptoms, progression, and impact
 - ▣ Start conversation early (never too early or too late)
 - ▣ Caretaking the caretaker
- Make realistic plans and steps to carry them out
 - ▣ Understand disease progression and symptoms
 - ▣ Talk about symptoms before they come on
 - ▣ Make an approach plan- preparedness vs. crisis mode
- Address strong feelings and impulses
 - ▣ Mourn the change/loss of function and move on
 - ▣ Use/find humor as healthy coping
 - ▣ Maintain perspective

Building Resilience by Addressing Cognitive Changes

- Strategize to find ways that work for the individual
- Memory: short sentences, clear instruction, divide information
- Visual cues to help process information
- Check-in: Does he understand?
- Ask for information to be repeated to synthesize and build verbal memory
- Summarize and repeat information
- Introduce new information in steps

Building Resilience by Addressing Cognitive Changes

- Extra time for instructions
- Break tasks into smaller parts
- Make lists and check off completed tasks (individuals can do)
- Extra time for transitions
- Help get things started
- Create a system for organizing and planning
- Use lists and calendars (agenda planning)
- Create a system with check lists for self-monitoring
- Repeat, Repeat, Repeat

Building Resilience by Addressing Cognitive Changes

- Extra time for instructions
- Break tasks into smaller parts
- Make lists and check off completed tasks (individuals can do)
- Extra time for transitions
- Help get things started
- Create a system for organizing and planning
- Use lists and calendars (agenda planning)
- Create a system with check lists for self-monitoring
- Reassess regularly
- Repeat, Repeat, Repeat

Building Resilience by Addressing Cognitive Changes

- Emotional reactions to progression is normal
 - ▣ Affected
 - ▣ Caretaker
- Mourn loss of function and move on
 - ▣ Not a linear process
- Activities that individual can complete (create positive experience)
- Increased sense of control leads to increased motivation to continue
- Create positive and healthy environment
 - ▣ Fosters healthy relationships
 - ▣ Positively impacts emotional and physical health

Building Resilience by Addressing Cognitive Changes

- Patient/child exists within a larger system
- Levels of family stress are related to patient's to illness (Reid & Renwick, 2001)
- Issues include uncertainty about what to comm caregiver burden, anxiety, financial strain, an reactions.
 - “Mutual pretense”
 - Parental/Caregiver accommodation



Building Resilience by Addressing Cognitive Changes



Building Resilience by Addressing Cognitive Changes

- Psychologist functions as part of multidisciplinary team
- Consults with neurologists and other medical, rehabilitation, and psychosocial providers
- Assesses emotional, behavioral, social, and adaptive functioning
- Proactive screening
- Brief, targeted intervention and referral



Building Resilience by Addressing Cognitive Changes

Family and Individual Factors

Self-determination and independence

Developmentally appropriate communication

Parent adjustment and healthy coping

Presence of social support

Engagement in social activities

Benefits finding

...among others!

Promoting Resilience by Addressing Cognitive Changes

- Individuals with DM can be at higher risk of experiencing psychological difficulties related to
 - Physical changes
 - Changes in cognitive and executive function
 - Emotional experience
 - Interpersonal relationships
- Importance of integrating psychology
 - Allows for preventative practices and early intervention
- Numerous factors are associated with resilience
 - Appropriate communication
 - Fostering independence
 - Increased social engagement
 - Support systems



Building Resilience by Addressing Cognitive Changes

- Contact Information:
- **Missy Dixon, PhD, MS**
- University of Utah, Utah Program for Inherited Neuromuscular Disorders
- Missy.dixon@genetics.utah.edu
- (801) 585-7606