PROMOTING RESILIENCE: STRATEGIES FOR MANAGING DISEASE PROGRESSION

Missy Dixon, PhD, MS
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

BIOPSYCHOSOCIAL APPROACH TO UNDERSTANDING HEALTH

BIOLOGY
- Gender
- Physical illness
- Disability
- Genetic vulnerability
- Immune function
- Neurochemistry
- Stress reactivity
- Medication effects

PSYCHOLOGY
- Learning/memory
- Attitudes/beliefs
- Personality
- Behaviours
- Emotions
- Coping skills
- Past trauma

HEALTH

SOCIAL CONTEXT
- Social supports
- Family background
- Cultural traditions
- Social/economic status
- Education
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 checklists for self-monitoring
- Repeat, Repeat, Repeat
Building Resilience by Addressing Cognitive Changes

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- 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 adjustment to illness (Reid & Renwick, 2001)
- Issues include uncertainty about what to communicate, caregiver burden, anxiety, financial strain, and grief 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

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<th>Family and Individual Factors</th>
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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

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