Psychosocial Considerations in Duchenne Muscular Dystrophy

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Psychological / Psychosocial Concerns

- Impact on child with DMD
  - Development and Learning
  - Emotional: anxiety, depression, anger
  - Social

- What to look for, how to intervene

- General recommendations / testing

- Impact on family members
  - Parents
  - Siblings
DMD

- **Medical issues**
  - DMD impact
  - Medications
  - Medical procedures, frequent doctor visits
  - Physical functioning

- **Stress / trouble coping**
  - Classmates, peers
  - School (learning related)
  - Family: parents, siblings, others

- **Understanding diagnosis**
Recommendations for Child / Adolescent

- **Monitor neurodevelopmental functioning**
  - Increased rate of certain disorders
  - ADHD, learning difficulties, intellectual disability, anxiety, Autism Spectrum Disorder
  - Earlier intervention is warranted: screening for symptoms, testing for diagnoses, treatment plan for home and school
Recommendations for Child / Adolescent

- **School / learning**
  - Monitor academic functioning
  - Psychological or Neuropsychological testing
  - Accommodations and modifications in school, IEP

- **Social**
  - Help with confidence and strategies
  - Formal social skills interventions if needed
What to look for

- **Learning issues**
  - Language delays, trouble with language based tasks
  - Memory difficulties
  - Trouble in specific academic areas: reading, written expression, mathematics

- **Possible “red flags”**
  - Homework becomes “a battle”
  - School refusals
  - Worries/fears about certain subjects, tests, assignments
  - Easily upset or frustrated relative to other areas
How to help

- Learning issues
  - School can often conduct psychoeducational testing to address learning issues
  - Formal neuropsychological testing may be helpful
    - Areas of strength and areas of need
    - Identify ways child will learn best
    - Identify ways to support any specific needs or weaker areas
  - May need help addressing any behavioral or emotional issues related to learning struggles
What to look for

- **Social difficulties**
  - Difficulty interacting with others
  - Lack of interest vs lack of skills/knowledge
  - Frequently being teased or bullied

- **Possible “red flags”**
  - Getting into disagreements or fights with peers
  - May get along okay with younger children or adults, but not children their same-age
  - Preferring to play independently, not interested in others’ activities or games
How to help

- May benefit from formal assessment

- Social skills training for lack of skills/knowledge
  - Schools can offer (e.g., “lunch bunch”)
  - Community providers may offer groups too

- Peer support
General recommendations

- **Routines are important!**
  - Morning, bedtime, after school, homework

- **Consistency**
  - Across settings, across caregivers

- **Communication with**
  - Teacher
  - Therapists
  - Other caregivers / parent
  - Child
  - Siblings
  - Medical team
General recommendations

- Clear expectations
  - Break down tasks into steps, one at a time
  - State commands/requests positively
  - Ensure understanding
  - Follow through on consequences – both positive and negative
  - Reinforce appropriate behavior, ignore the negative behaviors if you can
What is “testing”? 

- Psychological or neuropsychological testing looks at a child’s level of functioning in specific areas
  - Cognitive ability (IQ)
  - Memory
  - Attention/concentration
  - Language
  - Executive functioning
  - Adaptive behavior
  - Social-emotional and behavioral functioning

- Used to help plan services or treatment
Impact on family - parents

- Parent well-being and health is
  - Influenced by child behavior and caregiving demands
  - Related to parent self-perception and family functioning
  - Affects child functioning

- Parents are models for their children – they will watch how parents cope and how they manage stress!
The circular relationship

Stressful, non-supportive or emotionally distressing family relationships

behavior and emotional issues in the child

behavior and emotional issues in the child

diminished sense of competence as a parent
Myths about self-care

- It’s selfish.
- People will think I’m weak.
- I can’t afford the time.
- I don’t have enough money to spend it on something like that.
Methods of self-care

- Take a walk
- Talk to a friend
- Go to bed early
- Play a game
- Go out for coffee (or take five minutes at home)
- Think about things you are grateful for
- Look at old photos
- Seek and accept help when you need it!
Impact on family - siblings

- **Why Siblings?**
  - By some estimates, 7 million people in the United States have a sibling with special needs/disabilities.
  - Probably first generation where children with special needs are more regularly outliving their parents.
  - Siblings are likely to have the longest-lasting relationship with a child with disabilities...they will be there long after the parents, special ed teachers, and medical doctors are no longer involved.
  - First studies found some negative effects, more recent have found some benefits as well
Siblings of children with special needs

- May seem more mature than same-age peers
- Develop an understanding of the challenges others go through
- Demonstrate increased frequency of pro-social behaviors
- May develop a deep sense of loyalty to and caring for family members
- Can show an increased tolerance for people who are different
How To Help Siblings

- Keep expectations realistic for sibs
- They have a right to their own lives, friends, and interests
- Acknowledge that they may have mixed emotions or feelings about their brother/sister and that’s okay
- Make sure standards and expectations apply across the board – for all children in the family
- Limit care-giving responsibilities
- Provide information about disability on a level they can understand...if and when they want it
How To Help Siblings

- **Find support for them if needed:**
  - Sibling support groups – give kids an opportunity to meet and interact with other children in their situation
  - Therapy for more significant difficulties/issues
What Siblings Would Like Parents and Service Providers To Know (Sibling Support Project)

- The right to one’s own life.
- Acknowledge sibling’s concerns
- Expectations for typically-developing siblings
- Expect typical behavior from typically-developing siblings
- Expectations for the family member with special needs
- The right to a safe environment
- Opportunities to meet peers
- Opportunities to obtain information
- Sib’s concerns about the future
- Celebrate every child’s achievements and milestones
- Parent’s perspective is more important than the actual disability
Mental Health

“Mental health is defined as a state of well-being in which every individual realizes his or her own potential, can cope with the normal stresses of life, can work productively and fruitfully, and is able to make a contribution to his or her community.”

World Health Organization
Mental health...signs to look for

- Eating or sleeping too much or too little
- Pulling away from people and usual activities
- Having low or no energy
- Feeling numb or like nothing matters
- Having unexplained aches and pains
- Feeling helpless or hopeless
- Smoking, drinking, or using drugs more than usual
Mental health...signs to look for

- Feeling unusually confused, forgetful, on edge, angry, upset, worried, or scared
- Yelling or fighting with family and friends
- Experiencing severe mood swings that cause problems in relationships
- Hearing voices or believing things that are not true
- Thinking of harming yourself or others
- Inability to perform daily tasks like taking care of your kids or getting to work or school
1. Connect with others
2. Do what you enjoy
3. Share your interests
4. Help out
5. Take care of yourself
6. Challenge yourself
7. Manage stress
8. Rest & refresh
9. Live in the present
10. Ask for help
Questions?

- Contact info

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