Quality of Life and Emotional Health of the Family: A panel discussion

Erik Henricson, PhD
James Poysky, PhD
Rachel Poysky
Denise Gruender, BS
Jaime Jackson, BS
Jessica Rownd
Panel Introductions
Similar Approaches – DMD Care Recommendations and “Bioecological” Models of Family Development
What is Quality of Life?

As clinicians we might sometimes forget that we call many questionnaires “Quality of Life” forms. BUT, what many of those tools often ask about is MOBILITY or what we call FUNCTIONAL HEALTH. And, many research studies tend to focus mainly on the person with DMD.

Most people though are likely to say that ”Quality of Life” is more related to happiness or life satisfaction. That’s a complex concept, and doesn’t happen in a one-person bubble.
So maybe MOBILITY ≠ Quality of Life, at least not directly.

What impacts quality of life then?

Maybe instead it’s something like this:

**Strength -> Mobility -> Participation -> Quality of Life**

But there are other parts to this. What affects an individual’s *participation*?

• Strength?
• Fatigue?
• Mobility?
• Health?
• *Behavior*?
Impact of Behavior on Individual Quality of Life?

- There’s dystrophin in the brain, too.
- DMD not only affects strength and mobility, but *may* also affect *cognition and behavior*. This varies. Many describe “autism-like” features:
  - Socioemotional delay – not “acting their age”
  - Emotional outbursts
  - Anxiety
  - Behavioral rigidity
  - Challenges with attention
  - Compulsive or repetitive behaviors
  - Social disinterest / withdrawal
- *May* create challenges in social/peer group *participation*
- *May* lead to a frustrating mismatch between expectations and reality (at least for parents and family) that can also impact *participation*
- So at least in part, a *combination* of *mobility-related* and *socioemotional* challenges for people with DMD *can impact QoL of the family*. 
Impact on Family Quality of Life: Challenges

- **Caregivers**
  - Physical stress, fatigue and health
  - Emotional stress
  - Grief / chronic sorrow
  - Worry about the future
  - Financial stress / Job stress
  - Not enough time to get everything done
  - Dealing with regular disruption (illnesses, clinic visits, school meetings, etc.)
  - Role expectations - Balancing relationships with other family members (spouse, children, parents, etc.)
Impact on Family Quality of Life: Challenges

- **Siblings**
  - May have **less time with parents / caregivers** on their own individual activities
  - Role expectations - May have their own caregiving responsibilities or earlier adult-like roles
  - Worry / Stress / Grief
  - Independence and autonomy – can be more OR less?
Impact on Family Quality of Life: Challenges

- **Extended Family**
  - May have their own care needs / expectations
  - May not understand DMD or the challenges it brings
  - May not know they can play a key supporting role
Impact on Family Quality of Life:

Positive Factors from Mutual Supportive Relationships

Families can be incredible and supportive teams! Some see opportunities to:

- Share and discuss feelings / worries / anxiety
- Focus on health and wellness of the whole family
- Build resilience, autonomy and self-confidence
- Develop closer and more meaningful relationships
- Share responsibilities for care, but also share resources
- Focus on what is personally most important in life
- Advocate for each other
- Share in search for resources
The Bigger Picture
Looking Outside the Family to Enhance Participation

State / National
- State/Federal Government
  - Health Coverage, Disability Programs, Advocates
- Advocacy Organizations
  - Advocates, Peer and Support Groups, Care Guides, Etc.

Health Care Resources
- Medical, Counseling

School Resources
- IEPs, Therapy Services, Accessibility Services, etc.

Recreational Groups and Activities
- Church, Scouts, Hobbies, Etc.

Employers
- Family Health Insurance, FMLA, flexible hours

State / National
- Health Care Resources
- School Resources
- Recreational Groups and Activities
- Employers

The diagram shows connections between different areas including:
- Person with DMD: Mobility, Emotional Needs, Health, Behavior/Cognition, Stress/Fatigue, Resilience
- Family: Mobility, Health, Role Expectations, Behavior/Cognition, Stress/Fatigue
- Parents Caregivers: Health, Emotional Needs, Role Expectations, Career, Behavior/Cognition, Stress/Fatigue, Resilience
- Extended Family: Mobility, Health, Role Expectations, Behavior/Cognition, Stress/Fatigue

The diagram emphasizes looking outside the family to enhance participation through various resources and support systems.
Enhancing Participation

• It’s hard to ask for help and resources, or to even know what to ask for!
• Finding and getting those resources can sometimes be frustrating and time consuming. Team approaches can work best.
• Resources can be at the community, state or national level.
• Resources should support not just the person with DMD, but the entire family:
  • Medical care and insurance
  • Health and wellness (*physical AND socioemotional*)
  • Behavioral health
  • Educational support
  • Assistance from employers
  • Leisure activities
  • Peer support
Support “web” can enhance participation and facilitate positive Quality of Life

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- **Advocacy Organizations**
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- **Health Care Resources**
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- **Recreational Groups and Activities**
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- **Extended Family**
  - Mobility, Health, Role Expectations, Behavior/Cognition, Stress/Fatigue

- **Parents Caregivers**
  - Health, Emotional Needs, Role Expectations, Career, Behavior/Cognition, Stress/Fatigue, Resilience

- **Siblings**
  - Physical Needs, Emotional Needs, Health, Behavior/Cognition, Stress/Fatigue, Resilience

- **Person with DMD**
  - Mobility, Emotional Needs, Health, Behavior/Cognition, Stress/Fatigue, Resilience

- **Family**
Needs, resources and relationships also change over time. There’s a need for periodic “readjustment” to maximize participation and QoL. Some parts can vary in importance at different ages / life stages.
Discussion