PSYCHOSOCIAL STANDARDS IN DMD
MEAGHANN WEAVER, MD, MPH, FAAP

- Quality of Life
- Whole Family Care
- Longitudinal Approach
Bio-Psycho-Social-Spiritual Approach

Physical Issues - Symptom Burden

Psychological & Cognitive Issues
• Loss, Grief

Patient/Family Support Needs

Social and Familial - Psychosocial

Spiritual and Existential Issues
• Life meaning, connectedness

Practical and Tangible Issues

Disease Management

Interdisciplinary Team Approach

Adapted from Frank Ferris- EPEC-O
Almost 40% of young adults with DMD have pain on a daily basis.
NON-PHARMACOLOGIC PAIN MANAGEMENT

- Family presence
- Visualization/guided imagery
- Deep breathing
- Massage
- Heat/Cold
- Positioning
- Physical therapy
- Meditation
- Play therapy
- Reiki
- Hypnosis
- Aromatherapy
- Music Therapy
- Tai Chi or Yoga
- Labyrinth use
- Hydrotherapy
HRQOL of adult patients, the EQ-5D VAS score and EQ-5D index scores were 50.5 and 0.24, respectively. The corresponding EQ-5D VAS and EQ-5D index scores for caregivers were 74.7 and 0.71, respectively.

Wechsler Intelligence Scale for Children (WISC) and Full-Scale Intelligence Quotient (FSIQ) which approximated one standard deviation below mean siblings FSIQ scores in DMD group.
NEEDS: CHILD AND PARENT VOICE
Care considerations for the psychosocial care of individuals with DMD
(Reprinted with permission from Birnkrant DJ, Bushby K, Bann CM, et al; DMD Care Considerations Working Group.)

<table>
<thead>
<tr>
<th>Ambulatory stage or childhood</th>
<th>Early non-ambulatory stage, adolescence, or young adulthood</th>
<th>Late non-ambulatory stage or adulthood</th>
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<tbody>
<tr>
<td>• Consider baseline evaluation during first year of diagnosis</td>
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<tr>
<td>• Provide developmental (&lt;4 years old) or neuropsychological evaluation (&gt;5 years old) when social or emotional concerns or cognitive delays exist</td>
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<td>Provide evaluation by speech-language pathologist for children with suspected delays in speech or language development</td>
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<td>Provide evaluation by social worker at diagnosis and then as needed</td>
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<td>• Provide neuropsychological evaluation to identify cognitive or learning issues when concerns exist about school performance</td>
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<td>• Provide neuropsychological evaluation when transitioning to adulthood to assess whether government-based assistance might be needed</td>
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<td>Provide evaluation by social worker of the needs of the patient and family</td>
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<tr>
<td>Provide evaluation by speech-language pathologist for patients with loss or impairment of functional communication ability, chewing difficulties, or dysphagia</td>
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Psychosocial adjustment in siblings of young people with Duchenne muscular dystrophy.

Read J¹, Kinali M, Muntoni F, Garralda ME.
RELATIONSHIP BETWEEN SYMPTOMS AND SUFFERING
Longing: The Lived Experience of Spirituality in Adolescents with Duchenne Muscular Dystrophy

Shelley-Rae Pehler, PhD, RN
Martha Craft-Rosenberg, PhD, RN, FAAN
COMMUNICATING WITH THE CHILD OR ADOLESCENT . . .

Explore what the child/adolescent currently knows and understands
Assess what the parents think their child/adolescent knows
Assess what the parents want their child/adolescent to know
Consider use of bibliotherapy
Open, but non-forced conversation – foster questions/curiosities
CAREGIVER EXPERIENCE

Sleep Quality
58% of caregivers had diagnosis of sleep disorders - reduced sleep latency and efficiency, as well as daytime dysfunction due to sleep disruption

Well-Being
Increased feelings of guilt compared to controls – uncertainty and fear
Many caregivers to patients with DMD experience burn-out syndrome

Impact on Work Life and Productivity
>60% of caregivers reduce work hours
Provision of informal care, the mean number of hours of informal care per week (for some studies derived by multiplying daily estimates by seven to facilitate comparison) has been estimated at 35-65 hours in the UK and USA
Adapted with permission from Berger, A. NIH. Pain and Palliative Care – Comprehensive Approach.
Reviewed with Hand in Hand team the past 3 years of Needs Assessment data for palliative care patients (70 patients)

Journal of Palliative Medicine: “Pediatric Palliative Care Needs Assessments: From Paper Forms to Actionable Patient Care”

- Urie Bronfenbrenner
CONTINUE THE CARE! (longitudinal value)

Healthy/Functional Status Over Time

Predictable opportunities for care interventions

Needs Assessment!!!
GRATITUDE — to the Hand in Hand team!
REFERENCES


