

# Muscular Dystrophy and Quality of Life: A Critically Appraised Topic

Raegan Avrit MOT/S, Courtney Aycock MOT/S, Keelie Johnson MOT/S, Lindsay Lampkin MOT/S, Cassidy Ozanich MOT/S

Faculty Advisor: Anita Mitchell, PhD, OTR, FAOTA, Clinical Mentor: Heather Clabo, OTR/L, BCP, C/NDT

University of Tennessee Health Science Center - Occupational Therapy Department



## BACKGROUND/RATIONALE

Muscular Dystrophy causes progressive muscle weakness and can lead to death

There is no cure and has a significant effect on others involved

Limited research regarding occupational therapy services for muscular dystrophy

Supports and education needed for caregivers/parents

## PICO QUESTION

For pediatric clients who are diagnosed with muscular dystrophy, what factors affect quality of life?

## SEARCH METHODOLOGY

**Databases** • CINHAL, Embase, PubMed

**Limits** • Humans, after 2005

**Inclusion Criteria** • Published in English, includes children with MD

**Exclusion Criteria** • N/A

## SEARCH TERMS

"Quality of life factors" AND "Muscular Dystrophy"

"Quality of life" AND factors AND "Muscular dystrophy"

## MAIN FINDINGS

Study	Factors associated with QoL
<b>Level II Studies</b>	
Grootenhuys et al. (2007)	<ul style="list-style-type: none"> <li>Differences in health-related quality of life</li> <li>Severity of MD</li> </ul>
<ul style="list-style-type: none"> <li>Non-Randomized Study with control group</li> <li>Quality Score= 90%</li> </ul>	
Uttley et al. (2018)	<ul style="list-style-type: none"> <li>Perspective</li> <li>5 domains most important for QoL:                             <ol style="list-style-type: none"> <li>(1) Physical</li> <li>(2) Psychological</li> <li>(3) Social</li> <li>(4) Well-being</li> <li>(5) Other</li> </ol> </li> </ul>
<ul style="list-style-type: none"> <li>Systematic Review of Non-RCTS</li> <li>Quality Score= 60%</li> </ul>	
<b>Level IV Studies</b>	
Wei et al. (2017)	<ul style="list-style-type: none"> <li>Parent education</li> </ul>
<ul style="list-style-type: none"> <li>Descriptive Study (cross sectional)</li> <li>Quality Score= 91%</li> </ul>	
Kohler et al. (2005)	<ul style="list-style-type: none"> <li>Physicality &lt; social, psychological, and mental health.</li> <li>Ventilators do not affect perception of health status.</li> </ul>
<ul style="list-style-type: none"> <li>Survey Study</li> <li>Quality Score= 62%</li> </ul>	
Baiardini et al. (2011)	<ul style="list-style-type: none"> <li>Lack of participation</li> <li>Wheelchairs and ventilators had an impact due to a lack of participation.</li> </ul>
<ul style="list-style-type: none"> <li>Survey Study</li> <li>Quality Score= 95%</li> </ul>	

## LIMITATIONS

Small sample

Perspectives of parents

Heterogeneity of participants

## CLINICAL BOTTOM LINES

HRQoL and QoL can be perceived differently by the same individual

Children only reported lower QoL scores when social interactions were restricted

Children viewed themselves as having a better QoL than their parents did

## RECOMMENDATIONS

Education and care focused on increasing social participation

Modified activities to enhance engagement for children with limited mobility

Social skills training

## RESOURCES



## REFERENCES

