

Health-Related Quality of Life, Psychosocial Functioning and Sleep of Children with Duchenne Muscular Dystrophy in Hong Kong – A Pilot Study

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Duchenne Muscular Dystrophy (DMD) is the most common genetically caused neuromuscular disorder. We aimed to investigate the health-related quality of life, psychosocial functioning, and sleep of children with DMD. We also examined the agreement between parents' proxy reports and children's self-reports.

SUMMARY

1. In the study of health related quality of life, we found there was impaired physical functioning but relatively good psychosocial and emotional functioning in self-ratings of children with DMD.

Physical health was reported to be significantly lower than the controls in general, especially in older age groups, which is commensurate with the course of illness. Psychosocial and emotional functioning was relatively good, suggesting that DMD might not have magnified their negative emotions such as fear, sadness, and anger which are also noticeable in their healthy age-counterparts. Their school attendance and performance were largely comparable with their healthy age-counterparts.

2. There is no significant difference in behavioral functioning between DMD patients and controls.

There was no significant increase in behavioral problems reported in children with DMD as compared to controls.

3. There is poor agreement in perceived patient's functioning between children with DMD and their parents.

The scales with higher agreement were the more observable ones like physical and school functioning, while the other scales had only moderate to low agreement. Implications of such discrepancies on clinical decision-making and family counselling concerning HRQOL of DMD patients and their families warrant further investigation. More communication between parent and child may help the parent to understand the need of their child better.

4. Relationship between sleep, physical and psychosocial health.

Negative associations were found between sleep problems and quality of life in both child-reports and parent-reports. Routine monitoring and intervention for sleep-related conditions should be considered in clinical service for children with DMD.

Suggestions to parents

From our current study, we found that although children with DMD regarded themselves to be physical less able to their peers, their psychosocial and emotional functioning are still well maintained. They also do not have increase behavioral problems when compared with other children of similar age. Parents can adopt appropriate parenting approach according to their child's physical and psychological needs, such as setting realistic and attainable goals with their child, and using positive parenting when guiding their child so that they can learn in a positive environment with encouragement. We found the parents have similar understanding of the physical and the school performance as their children, however, their perspective about their children's psychosocial and emotional functioning could be quite different from their children. More communication between parent and child, with parents trying to first listen and validate their child's points of view, may help the parent to understand the need of their child better.