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Problems in participation experienced by teenage girls with NMD

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BACKGROUND

Research on young people with neuromuscular disorders (NMD) usually focuses on boys (1, 2). So, how do girls with NMD experience their involvement in life situations?

AIM

This study examines whether Danish teenage girls with NMD experience NMD related problems with participating in life situations¹.

> ”When I'm really tired, I tend to be quiet and angry-looking” (17 years old)

STUDY POPULATION

In Denmark, most people suffering from a critical form of NMD are referred to the Danish National Rehabilitation Centre for Neuromuscular Diseases (RCFM), which is a highly specialized unit for neuromuscular rehabilitation. At project start, there were 53 girls with NMD in the age group 12-17 years registered with RCFM.

- 32 girls accepted to participate in the study (Participation rate: 60 per cent).
- 12 different neuromuscular diagnoses were represented: Charcot-Marie-Tooth hereditary neuropathy: 5; Myotonic dystrophy: 2; Manifesting carrier of dystrophinopathy: 1; Congenital muscular dystrophy: 8; Congenital myopathy: 1; Limb girdle muscular dystrophy: 6; McArdles Disease: 1; Mitochondrial myopathy: 1; Hyperkalemic periodic paralysis: 1; Pompe's disease: 1; Spinal muscular atrophy type II: 4; Spinal muscular atrophy type III: 1.
- At project start, 21 of the girls were primarily walkers and 11 girls were primarily wheelchair users.

> ”People don't understand – a neuromuscular disorder can be so many things” (17 years old)

METHODS

A qualitative interview study from a phenomenological perspective.

A semi-structured interview guide with 38 open and 38 closed questions was developed for this particular target group on the basis of focus group interviews with seven young women aged 19 – 24 years who had different kinds of NMD and levels of functionality.

Data analysis was carried out in three steps:

- The data were systematized based on the interview guide themes.
- Data which did not fall under one of the interview guide's themes but contained important information was grouped under supplementary themes.
- The data have been condensed with a view to identifying problem areas.

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¹As defined in WHO – International Classification of Functioning, Disability and Health (ICF)

RESULTS

Five problem areas were identified: Having NMD, Family and school, Social relations and participation, Lack of support and Future.

Having NMD

The girls described a wide range of physical limitations: reduced muscle strength, fatigue, lack of stamina, respiratory problems and pain.

They felt it was difficult for other people to understand what it is like to have NMD.

Family and school

The parents to the girls with NMD worried more about what their girls were doing than the parents of their healthy peers did, and the girls with NMD sometimes felt they were a burden to their family.

The girls had experienced academic difficulties as a result of missing school because of medical examinations and treatments.

Social relations and participation

- The girls had experienced problems with being excluded and lack of accept from others.
- They worked harder than their physique allowed them to, to be able to participate in things they wanted to do.
- They found it embarrassing not to be able to do the same things as their friends and to receive help.
- The girls felt sad if their friends did something they could not participate in and they envied their healthy friends.
- Sometimes they stayed at home because they expected they would not be able to participate in activities with friends.
- They did not participate in as many spare time activities as they would like to, and they dreamed of engaging in new activities, especially sports activities.
- The girls were worse off two years before the time of this study, both at school and in their spare time.

Lack of support

The girls primarily felt a lack of social and mental support

- during the age 12-14 years – or
- in connection with certain milestones such as time of diagnosis, disease progression or youth-related transitions.

Future

- Some girls feared that it would be difficult for them to find a partner because of their NMD and that it would be difficult for them to have children.
- They expected that changing schools would be a big challenge due to increased homework and the need to explain their disease repeatedly.
- They worried about the disease progression and felt uncertain about their future ability to participate.

1 Højberg, Ann-Lisbeth & Jeppesen, Jørgen. Examining the effect of networks for students with special educational needs. Scandinavian Journal of Disability Research, Vol. 14, No 2, 2012, p.126-147.

2 Abbott, David; Carpenter, John; Bushby, Kate. Transition to adulthood for young men with Duchenne muscular dystrophy: Research from the UK. Neuromuscular Disorders 22, 2012, p. 445-446.

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CONCLUSION AND PERSPECTIVE

Danish teenage girls with NMD describe a number of physical challenges which make involvement in life situations difficult, and they work harder than their physique allows them to in order to participate.

Problems are more frequent during their early teenage years when they still play physical games with their friends rather than talk, which they are capable of. Problems also arise in connection with disease progression and youth-related transitions.

Consequently, girls with NMD are in need of increased support during the early teenage years or when facing especially difficult periods of their lives.

> ”It is unfair that it's always me who have to show initiative to participate (14 years old)

> ”I fear that I'm getting worse” (15 years old)