

# Adolescent and female with a neuromuscular disorder: An unexplored issue

## A report about Danish experiences

*Ann-Lisbeth Højberg and Jørgen Jeppesen*

Improvements in medical care and rehabilitation have increased quality of life and life expectancy for many people with a neuromuscular disorder (NMD), including children and adolescents that previously would not become adults. Puberty and sexuality, education and employment, marriage and family life, are future facts for a majority of the young people. This development has revealed a lack of professional and scientific knowledge about a variety of transitional issues, in particular regarding female adolescents.

The research literature about how female adolescents experience life is rare (1). Studies about everyday living and surveys of quality of life mainly focus on adults, and when dealing with children and adolescents, primarily examine boys (2, 3, and 4). Often, studies rely on parents' perceptions and responses in a family and/or burden of illness perspective (5, 6).

Living with NMD in childhood and adolescence is challenging, among other things because the disorders are progressive. However, the limited evidence about what it really is like points in opposite directions. Participants in a study of health related quality of life among 38 boys and two girls (8-17 years old) with muscular dystrophy did not report more negative emotions compared to a control group (7). The researchers concluded that comprehensive disability does not necessarily lead to reduced quality of life, and called for investigations of what kind of coping resources these children and young people employ. In another study of health related quality of life among 32 boys and 11 girls (10-17 years old) with NMD, the participants had a higher score with regard to school performance and relationship with teachers, and a lower score with regard to leisure activities, compared to a control group without disability (1). In a number of other domains, the two groups were similar. The researchers concluded that medical, rehabilitation, and educational programs should be questioned with respect to the underlying ideas about what adolescents with NMD really need, dare, and tolerate. A study among 85 families with 71 boys and 56 girls (5-18 years old) with Charcot-Marie-Tooth showed that the children had widespread physical, emotional, and social impairment, in the view of the parents. The parents feared that the impairments would increase with age and disease progression (8).

In conclusion, previous studies of adolescents' experiences of living with NMD give opposite answers to the question about whether this life is 'harder or easier', 'better or worse' compared to the lives of adolescents without disability. It supports the need for "a more nuanced understanding of their lives" as put forward by Shakespeare et al. who challenged a universal concept of a "disabled child" (9).

In Denmark, the neuropediatric hospital departments refer all children and young people with a diagnosis of severe NMD to the National Rehabilitation Centre for Neuromuscular Diseases (RCFM). In the RCFM, a general and consistent experience has been a significant lack of knowledge regarding female adolescents compared to male adolescents. Females feature less prominently, due among other things to a long-standing focus on Duchenne muscular dystrophy. Teachers and parents have voiced concerns about 'quiet girls', leading to assumptions and speculations about specific female problems in living with NMD, e.g. regarding their well-being in school. In a study about living and aging with spinal muscular atrophy, in particular the women had experienced exclusion from classmates and reduced well-being in elementary school (10). The deterioration of physical abilities was also a major concern for the women compared to the men, and women at age 30 and above displayed a significant higher score with respect to problems with personal care and housekeeping.

With the aim of exploring female adolescent life with NMD in more detail, we carried out a systematic collection of interview data across NMD-diagnoses. To qualify assumptions and replace speculations, we interviewed a large number of the Danish female adolescent NMD-population about their strengths and resources, what they saw as troublesome, consequences of disease symptoms and progression, how they acted to meet challenges, and in what way the surroundings could support them.

### Sample

The World Health Organization defines adolescence as the period in human growth and development that occurs after childhood and before adulthood, from ages 10 to 19 (11). To obtain a relatively homogenous sample characterized by the challenges of core teenage years, we decided to include all female adolescents registered in the RCFM from ages 12-17 years. In total, 53 females across 19 NMD-diagnoses were identified per 29 November 2012. They all lived with their parents, who received a letter with information about the study and an invitation to participate. Thirty-two female adolescents across 12 diagnoses were included in the study (60 %). The number of individuals representing a diagnosis ranged from one to eight. Nineteen participants were completely or mostly ambulant, and 13 participants were permanently or for the most part wheelchair users. Twenty-six of the participants were referred to the RCFM between four and 12 years prior to the interview. The remaining six were referred to the RCFM between one and three years prior to the interview.

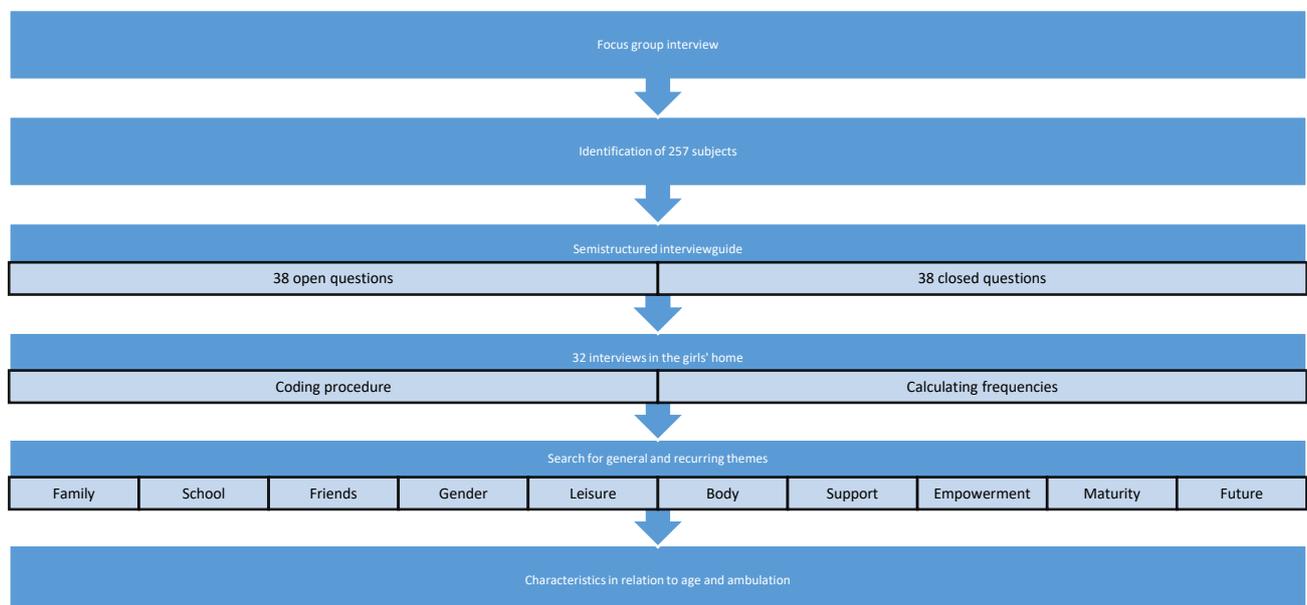
Twenty-one eligible females were not enrolled in the study, and three of these communicated that they did not want to participate, but gave no specific reasons. The parents of three other had consented to their daughters' participation, but ultimately the adolescents themselves did not want to be interviewed. One female was not yet fully informed about her diagnosis, and for that reason her parents chose not to let her participate. The parents of 14 non-participants never responded to the invitation letter and reminders. Approval for the study was obtained from the Danish Data Protection Agency (12).

### Interview guide and procedure

As there was no previous studies of the experiences of female adolescents across NMD-diagnoses, we consulted older peers to inform the construction and phrasing of pertinent questions (13). We developed a semi-structured interview guide based on a focus group interview with seven young women aged 19-24 years, covering five NMD-diagnoses, and encompassing different levels of functional abilities.

A content analysis of the focus group interview identified 257 subjects. We condensed the subjects into 38 open questions, and 38 closed questions. The open questions allowed for individual views, interpretations, and prioritizations; the closed questions made sure that participants across different NMD-diagnoses gave directly comparable answers to a number of similar questions (14). (Fig.1) We tested the guide twice with members of the focus group.

**Figure 1. Methodological design from construction of interview guide to analysis.**



Interviews were scheduled by telephone with the parents, and took place in the participant's home. To begin with the interviewer repeated information from the invitation letter about purpose of the study,

confidentiality, and the option of declining to answer at all if the participant did not feel comfortable about a question. At 25 interviews, one or both parents were present at the introduction, but no parent was present during the interview. At seven interviews, the participant was alone at home. The participant chose herself where in the home to be interviewed, and the majority chose their own room.

Regarding the closed questions, the interviewer read aloud a question and presented the response options on a laminated card to the participant. Each question had seven options: 1) Always; 2) Very often; 3) Sometimes; 4) Hardly ever; 5) Never; 6) Don't know, and 7) Not applicable. The interviewer then marked the option chosen by the participant. Regarding the open questions, the interview guide was not followed strictly but the interviewer made sure that all themes were discussed, and participants were encouraged to elaborate on her answers. All interviews were audio recorded, lasted 29-83 minutes (mean 47 minutes), and were conducted in the period March 2013 to February 2014.

## Analysis

The frequencies of answers to the 38 closed questions were calculated and tabled.

Through close and repeated listening to all interviews independent of the calculating results, we coded audio clips searching for patterns of recurring, general themes. This search identified the following themes: 1) Family, 2) School, 3) Friends, 4) Gender, 5) Leisure, 6) Body, 7) Support, 8) Empowerment, 9) Maturity, and 10) Future (Fig. 1). Then, we categorized all calculated and coded answers to closed and open questions in the ten themes resulting in an overall distribution of both numeric frequencies and contents of interviews.

In addition, we searched for characteristics in relation to age and ambulation. Seventeen participants aged 12-15 years were categorized 'Young', 15 participants aged 16-17 years were 'Old'. Nineteen participants completely or for the most part ambulant were 'Ambulant', and 13 participants permanently or for the most part wheelchair users were 'Non-ambulant'. We identified all questions where more than half of the Young or Old, Ambulant or Non-ambulant participants answered alike. Then, we compared the percentages of age-group specific answers, and reported the highest percentage as characteristic. Likewise, we identified all questions where more than half of the Ambulant or the Non-ambulant participants answered alike. Then, we compared the percentages of ambulation specific answers, and reported the highest percentage as characteristic.

In the following, we illustrate thematic contents of interviews with quotes, indicating age and ambulatory status with the following abbreviations YA (Young Ambulant), YN (Young Non-ambulant), OA (Old Ambulant), and ON (Old Non-ambulant).

## Results

### Family

Nearly all the participants emphasized the family as something they were happy about in their life. ('My family has been extremely supportive', OA). Two thirds said that they had a closer relationship with their parents than their friends had to their parents. Almost half felt that they caused trouble to the family, and a little more than half believed that their parents worried too much ('My mother turns small problems into big problems', OA). The family should try to be a normal family. ('Parents should not remove every rock that's in your way – they should allow you to try for yourself. They should be like a street sweeper that leaves bigger and bigger rocks on the road', OA).

### School

Almost all participants indicated that they did well in school, got good grades, and felt well socially. ('It's really great to be in high school', ON. 'I feel really good in school', YN). A small majority voluntarily did extra homework. Teachers did not demand less from pupils with NMD than from their classmates.

One third told about difficulties either in specific subjects or in general, among other things because of much sickness absence or change of school. ('It takes a lot of initiative to start in a new class', ON). Still, one third judged their change of school as a positive experience. ('I'm so happy I changed school, OA).

About half have remained silent in class because of lack of self-confidence. Almost one third gave expression to feelings of shyness, lack of friends in the class, a sense of being alone, and the exhaustion of constantly being active to avoid exclusion. ('It's not fair that you always have to struggle to be accepted', YN). One half said they often felt older than classmates were.

### Friends

The participants almost unanimously viewed relationships as essential, believing that their friends thought of them as of any other female adolescent. Nearly two thirds thought their friends regarded them as cool.

More than two thirds had minimum 1-2 friends or acquaintances with NMD. Most said that it was fun to do things with others with NMD. ('It's sometimes annoying, that if you hang out with normal people you tend to feel a little different', ON. 'Those who also have a muscular disorder are like real friends', YN). More than three quarters of the participants would like to meet female adolescents with NMD older than themselves. ('It would be cool to meet other girls like me', YA).

More than half envied friends for not having NMD, and two thirds felt sad when friends engaged in activities that they could not take part in. ('I sometimes feel left behind if my friends don't want to wait', YA). Now and then, one third stayed at home and abstained from friends' activities because they believed they could not participate. ('I'm afraid of my friends' reactions – what if I slow them down or limit their

activities', YA). The reason could be tiredness, lack of energy, or they simply considered the activity impossible in practice.

### Gender

More than a third believed that it was more difficult to be a male adolescent with NMD because male adolescents must show strength, masculinity, and participate in physically demanding competitions. ('Boys are more competitive – they always want to be the best', YA. 'It's not so easy for him to be macho', OA). As females, they were allowed to be physically weak, and have delicate female appearances. ('It's ok for a girl to be small, chic and hot', YN).

Less than a quarter thought, it was easier to be a male adolescent with NMD. ('I don't think boys think about it as much as girls do – girls constantly worry about stuff like, why do I have NMD, what does it do to me and what do other people think of me', OA). Some said they had difficulties being feminine. ('It is very, very hard to wear heels and look great in them and that makes me feel really, really sad', OA. 'Bracelets easily fall off my arms because they're so tiny', OA). Some worried about social complications in girl groupings, fearing exclusion. ('It's important to believe that your girlfriends like you in spite of your disease', YN).

Some imagined that it would be difficult for them to get a boyfriend due to their NMD, and the possibility of becoming a mother was a concern to some. ('I think a lot about children – I just don't want to have a child with the same disease as my own', OA).

### Leisure

More than one third pointed out that they were skilful in creative activities like making earrings, collage, painting and drawing, inventing personal dances, and writing stories. About an equal number said they were good at sports like shooting, electric wheelchair hockey, or horseback riding. Some participants underlined skills in computing, film and television, cooking, and make-up.

When participants spent leisure time with friends, half of them went shopping, to the movies, a youth centre, or to other activities away from home. More than half told about being together using computer, watching movies or TV, and some said they just chatted, had fun and a good time together.

One fourth compensated for physical barriers or other hindrances by inventing creative solutions, or simply withdrawing. However, sometimes they crossed their limit of fatigue, to avoid focus on their special needs.

More than half would have liked to do something in their spare time that they presently did not do, in particular sports. They wished to practice gymnastics, riding, running, badminton, soccer, fitness, handball, dance, shooting, swimming, or electric wheelchair hockey. The reason for not attending these activities was primarily a lack of physical capability, energy, or inclusive opportunities ('I have no company', YN).

## Body

The participants reported a large number of bodily difficulties relating to the disorder. More than half told about physical limitations, for example a need for breaks or sleep, lack of endurance and energy. ('I spend all my energy in school – on keeping up with the others' – 'I never feel one hundred percent energetic', OA).

One third said that fatigue excluded them from participating in activities with others. ('I can't stand up for very long', OA. 'My legs hurt when I walk too much', YA). They spoke about respiratory problems, coughing, to lose one's balance, being cold, pains, troubles with fine motor control, and running, jumping, and rising from a sitting position. About one third would have liked to know more medically about their neuromuscular disease, progression and the future.

On the other hand, more than two thirds said that they now got along more easily with their diagnosis than two years before. The reason for this was diagnostic clarification, successful surgery, less fatigue, less pain, or slower disease progression. Typically, these participants earlier had less energy, were more ill and absent.

## Support

All but a few stated that they got the assistance they needed in school, and almost the same number received adequate assistance in leisure time. Two thirds said they were good at conveying what they needed help for, and several participants pointed out that having a competent helper was a great quality of life. ('My helper is my anchor', ON). Almost one half referred to the general societal and environmental conditions as a distinctive quality in their life. It was for example to live in a country like Denmark, to get food every day, not to be exposed to natural disasters, to be happy about one's school. About one third spoke about specific disability rights as a positive thing, and this could be the granting of a disability car, an accompanying person, or various aids. ('Getting a scooter has been a real blessing', OA).

However, half of the participants have also been embarrassed to receive help. ('It's frustrating having to depend on other people all the time', ON). About half have felt pressured by parents or other adults into using assistive devices. Some told about problems using certain aids or with specific treatments for example wearing splints or using non-invasive ventilator. They had also experienced problems when buying footwear due to foot deformities.

## Empowerment

In particular, the participants viewed communicative flair and abilities as their most significant competencies. More than two thirds indicated that other people turned to them, and they saw themselves as good listeners. More than half said that they were smart at wording, reasoning, debating, and telling one's opinion, and many of them planned for educations that correspond with communicative flair, such as

psychologist, social worker, and pedagogue.

A little more than a third described strategies of empowerment. This was for example to try to solve one's own problems before asking someone else, to search for knowhow, or to be able to say no. They also reflected prospectively and grown-up. ('At least it's better to participate in some things than not participating in anything', YN. 'I don't want to think about the disease – I leave that to my parents', YA).

Almost a third said that there were certain advantages in having NMD. Sometimes you got the opportunity to try something unique, for example to meet celebrities or participate in the summer camps of the neuromuscular member association. ('Being a member of a girl's group gives me strength and stamina', YN). They also mentioned the benefits of jumping a queue, or given priority at concerts.

Around three fourths believed that it was difficult for others to understand how it was to live with NMD, and despite self-confidence and self-reliance, more than two thirds thought it was a good idea to support female adolescents with NMD extraordinarily. About a third suggested the best timing to be around 12-14 years of age, while another third linked special support to certain events, for example at debut of disease, uncertainty of diagnosis, initial use of wheel-chair, or when feeling depressed. Extra support could also be necessary in transition to education or adulthood.

### Maturity

More than two thirds said that they felt better now than two years before. They had become older, more mature, and were no longer bothered by other people's opinion, prejudices, or staring gazes. ('If they want me, they will have to take me as I am', ON). Relations and friendships had improved, as it had become easier to talk with others. ('At this age, we sit down together with a cup of coffee, and we talk and have fun and listen to music and things like that. That way we are more equal than when it was more physical activity', YN).

Just a few participants said life was harder for them now than two years earlier. Some pointed out that the teenage years was the period in life when you belong the least to a place. A little less than one third chose clothing to conceal or diminish the appearance of NMD disease characteristics.

### Future

Well over a third expected that the next couple of years would be tough, especially concerning school and education. They would be busy, get a lot of homework, and meet many new people that they had to explain what NMD is.

A few participants foresaw that they would gradually lose functions and experience increasing challenges with mobility and fine motor control. They feared the uncertainty about future. ('I have to get used to the fact that there are things I can't do', YA). Possibly, they would need new types of aids and assistive

technology. A few of the participants voiced concerns about the speed of disease progression, implying an accelerating uncertainty about the future. ('I fear getting worse', OA).

#### Characteristics in relation to age and ambulation

In particular, the Young participants:

- received the help and assistance they needed in school
- had understanding teachers when they said they were tired
- envied friends because they did not have NMD
- felt embarrassed to ask for help though they were good at telling others what they needed help for
- missed out on leisure activities because they could not manage physically
- experienced misunderstandings from people who did not know them

In particular, the Old participants:

- experienced that other people came to them to talk
- thought that they were good listeners
- missed out on leisure activities because of lack of energy
- felt more comfortable in school now than two years earlier
- exerted themselves in extra homework
- worked harder than they felt they actually were able to
- believed that it was easier to be male than female adolescent with NMD

In particular, the Ambulant participants:

- worked harder than they felt they actually were able to
- exerted themselves in extra homework
- envied friends because they did not have NMD
- missed out on desired leisure activities
- believed it was more difficult to be a male than female adolescent with NMD

In particular, the Non-ambulant participants:

- had one, two or more friends with NMD and enjoyed being and doing things with them
- had understanding teachers when they said they were tired
- were good at telling others what they needed help for
- felt embarrassed to ask for help
- felt they were older than their classmates

- experienced that other people had difficulties to understand what it was like to have NMD
- missed out on desired leisure activities because of lack of energy
- refrained once in a while from activities with friends due to tiredness, or because they feared they could not participate, or they feared lack of adequate toilet facilities
- thought it might be difficult to get a boyfriend because of their NMD
- thought that being a male adolescent with NMD made some things harder and other things easier

Some of the oldest Ambulant participants thought it would be strange if someone would want to go to bed with them but they almost never considered their physical condition to be an obstacle for sleeping with a young man or having a baby (these questions were only asked the Old participants).

The oldest Non-ambulant participants said that they very often thought their physical condition was an obstacle for going to bed with a person but they almost never considered it strange if someone would want to sleep together (these questions were only asked the Old participants).

### Perspectives and recommendations

We found that the female adolescents had talents, and were conscious of their particular resources. Family, school, friends, and the society in general was highly valued, and parents sometimes should show less concern. Still, they missed opportunities, for example in sports. Like other young people, they sometimes worried, and they encountered a number of problems that they saw as troublesome. Friends' activities quite often seemed difficult or impossible to participate in. The NMD diagnosis caused many problems and some were unsolvable, but the participants were also competent in finding solutions or compensating for what they were not able to do. The problems seemed to decrease with age, possibly because the participants learned to meet and overcome challenges.

'Do you think it is easier to be a boy than a girl with NMD?' we asked the participants. There was a tendency to view male adolescents' life as harder due to traditional gender roles and expectations of males' physical strength. Answers to other questions, e.g. about wearing heels and bracelets, also reflected, we think, mainstream gender roles among the participants. We conclude that female adolescents with NMD in general want to be more or less like other females.

Starting points for these explorative interviews were some assumptions among parents, teachers and rehabilitation professionals about 'quiet and shy girls'. A few participants said they were silent in school, but an equal number told about how they strived to be the best. Being quiet and shy were not dominant features.

A majority of participants experienced life to become easier with age, and especially the oldest said they had felt worse in school two years earlier. It is a remarkable finding, we think, though we are aware that

the participants do not say that life becomes easy. The finding indicates that although NMD progresses and impairments increase with age as many parents fear, it does not follow that the life as such becomes worse, on the contrary in fact.

Several participants mentioned the challenge of frequent change of school. We did not explicitly ask about this issue, which seemed unproblematic for some, but created a range of difficulties for others, especially when it happened unwanted.

NMD causes a range of physical problems that can create anger, envy, sadness, and anxiety. However, it stands out that the young females not only know how to overcome problems but also are also confident of their resources and talents. They see themselves as equal members of family and community, and not as victims of prejudices or oppression.

The female adolescents' perception of and perspectives on their life is important knowledge for both families and professionals occupied with transition to adulthood, as wanted by several researchers in NMD. The findings - including the age and ambulation related analysis - can nuance the knowledge of parents, schoolteachers, youth workers, rehabilitation professionals and policymakers. Moreover, possibly empower other females with NMD.

The overall aim of interviews was to gain knowledge about how female adolescents with NMD experience their life, and thereby contribute to insights needed for transition to adulthood. The results raise many new questions, and each of the 10 themes can bear its own in-depth study. Primarily, we recommend:

- More focus on the 12-14 years old adolescents that seem to be most vulnerable
- To create innovative activities that are inclusive and not sedentary; many demand accessible sports that do not exclude them from friends without NMD
- More focus on disease-specific information about heredity, disease progression, pregnancy, and consequences of reduced functions
- To research how young women with NMD master the transition to live independently. How do they manage the separation from their parents that often played a very significant role in childhood and adolescence? How do they move and furnish their own home? How do they cope with being responsible for physiotherapy, other treatments, and managing a helper scheme? How do they date a boyfriend? How do they start their education?
- A study demonstrating how society can use female adolescents' rich communicative skills.

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*Ann-Lisbeth Højberg (OT, MSI) and Jørgen Jeppesen (MPH, PHD) are researchers in the National Rehabilitation Centre for Neuromuscular Diseases, Denmark*

*Corresponding author: [anho@rcfm.dk](mailto:anho@rcfm.dk)*