

Research Article

Factors of Importance for Continuing Education After Primary School in Young People With Neuromuscular Diseases—Patient-Reported Outcomes From a National Survey

Charlotte Handberg ^{1,2}, Kristin Allergodt ^{1,2}, Annette Mahoney ¹,
 and Ann-Lisbeth Højberg ¹

¹Research and Development, National Rehabilitation Center for Neuromuscular Diseases, Aarhus, Denmark

²Department of Public Health, Faculty of Health, Aarhus University, Aarhus, Denmark

Correspondence should be addressed to Charlotte Handberg; chha@rcfm.dk

Received 7 June 2024; Accepted 14 May 2025

Academic Editor: Somashekhar Marutirao Nimbalkar

Copyright © 2025 Charlotte Handberg et al. International Journal of Pediatrics published by John Wiley & Sons Ltd. This is an open access article under the terms of the Creative Commons Attribution License, which permits use, distribution and reproduction in any medium, provided the original work is properly cited.

Rationale: Young people with neuromuscular diseases (NMDs) are especially at risk of being absent from school because of various symptoms, consequences of their disease, and frequent hospital visits. Growing up with a chronic disease can entail an increased risk of poor educational outcomes.

Aims: The study is aimed to investigate factors of importance for continuing with upper secondary and/or higher education after primary education when living with NMD, including expectations, support, and accessibility. In addition, we wanted to assess educational absence, discontinuation of studies, motivation, and sense of belonging.

Method: This cross-sectional study was founded in a national online questionnaire survey based on patient-reported outcomes from people with NMD. Five hundred and one persons were invited to participate. Data were analyzed using IBM SPSS Statistics 26. All variables were presented as numbers and percentages.

Results: Responses were obtained from 172 (34.3%) young people with NMD. Twenty (11.6%) answered that their parents'/relatives' educational expectations for them were lower than their own expectations. Forty (24.4%) answered that their teachers seldom or never planned the lessons in ways that were inclusive for them. Forty-five (27.7%) responded that they were always or mostly more absent than their classmates in primary and lower secondary education. Thirty-two (24.8%) respondents who had started upper secondary education had dropped out of one or more educational programs. Thirty-one (18.6%) answered they seldom or never had a sense of belonging at school.

Conclusion: Our results show novel knowledge on factors of importance for continuing education after primary school in young people with NMD. We found that teachers and parents carry a responsibility to show expectations to young people with NMD to ensure that the young people acquire adequate academic skills and actively participate in classroom activities. Supportive initiatives to prevent loneliness are important for keeping young people with NMD in the educational system.

Keywords: adolescent; children; disability; education; neuromuscular disorders; rehabilitation; support

1. Introduction

The term neuromuscular disease (NMD) covers a range of rare hereditary diseases, all progressive and sometimes with poor prognosis [1–3]. Moreover, the available treatment options for most of the diseases are limited or nonexistent [1–3]. The diseases are distinguished by a progressive loss of muscular strength, muscular atrophy, fatigue, pain, bulbar

symptoms, and negatively affected quality of life [1–3]. Early life determinants of health for this group of people involve physical, emotional, practical, and social difficulties, which may affect their health and social position negatively [4, 5]. Young people with NMD are at risk of being absent from school and leisure activities because of impaired functioning, various symptoms, and consequences of the NMD and frequent hospital evaluations and follow-ups [6].

The Danish educational system is financed for the larger proportion (around 92%) by the public welfare system [7]. Education is compulsory from 0 to 9 grade, with an optional 10th grade [8]. Upper secondary education includes general upper secondary education and vocational education and training. Students qualify for higher education with their grades from upper secondary education or through admission tests. Young people generally start Grade 0 the year they turn six [8].

In general, people with disabilities attain lower education and manage poorer in life [9]. Research has shown that educational absence due to chronic disease can lead to educational and social setbacks and enforce educational disengagement [10–12], and growing up with chronic disease can entail an increased risk of poor educational outcomes [11]. People with NMDs are known to have a more dispersed pattern of absence than the background population, with around 2–4 days of absence per month during their entire educational span and often without any possibility of receiving compensatory education [13]. Most people with NMD live well into adulthood, and thanks to new and improved treatment methods, this also applies to diagnoses that were traditionally associated with short life expectancy, such as Duchenne muscular dystrophy (DMD) where median life expectancy has risen to approx. 30 years [14–16]. Therefore, it is fundamental to ensure that young people with NMD get an education to enhance their quality of life and independence. The increased risk of absence from education is unfortunate for young people with NMD since education is a strong predictor of how well they do in life in regard to health, income, employment, social inclusion, and working life conditions [17, 18]. The aim of this study is therefore to investigate factors of importance for continuing with upper secondary and/or higher education after primary education when living with NMDs, including expectations, support, and accessibility. In addition, we wanted to assess educational absence, discontinuation of studies, motivation, and sense of belonging.

2. Methods

2.1. Design. This cross-sectional study was founded on a national online questionnaire survey based on patient-reported outcomes from young people with NMD.

2.2. Participants and Procedure. In January 2023, the online questionnaire survey was sent to 501 people (≥ 18 –30 years of age) with NMD and registered at the National Rehabilitation Center for Neuromuscular Diseases (RCFM) [19, 20]. The online questionnaire was developed in SurveyXact (Ramboll Denmark). Questions in the survey were developed based on two semistructured focus group interviews [21]. Furthermore, the questions for the survey were inspired by clinical knowledge from the professionals at RCFM, exciting literature, and various surveys on the background population in Denmark in the same age group. The link to the survey was sent through a secure digital mailbox ($n = 494$). Those who did not have a digital mailbox received a link to the survey by email ($n = 7$). A letter accompanying

the link to the survey questionnaire contained information about the project and stated that answering the survey would be counted as consent. People were asked to complete the survey regardless of their educational or employment status to reduce response bias. A reminder was sent to everyone after 1 week and again after 5 weeks. Two hundred and eight young people answered the survey, resulting in a response rate of 41.5%.

2.3. The Structure of the Questionnaire. The questionnaire consisted of questions that all respondents had to answer (in the following referred to as “all”) in addition to questions that respondents were routed to based on their previous answers, for example, questions related to higher education (bachelor’s and master’s program) that were only accessible for those who answered that they had attended or were attending higher education. This resulted in the following structure: (a) *demographic information* (all), (b) *primary and lower secondary education (0–9 grade)* (all), (c) *upper secondary education (10–12 grade)* (all attending or having attended one or several upper secondary education(s)), (d) *higher education* (all attending or having attended one or more higher education), (e) *only primary and lower secondary education (0–9 grade)* (all who had not moved on to upper secondary), and (f) *concluding questions* (all).

Participants attending or having attended higher education were asked to relate to statements about upper secondary school as well as higher education.

2.4. Questions in the Questionnaire and Patient-Reported Outcomes

- **Demographic information:** age, sex, diagnosis, primary and lower secondary education, enrollment in upper secondary education, the highest level of completed education, current employment, ambulation, and other functional levels (difficulties in writing or focusing, lack of concentration, and need for breaks).
- **Expectations, support, and reactions:** self-efficacy, expectations from parents, expectations from teachers, expectations from others and self, support from others (teachers, fellow students, student counsellor, parents, or siblings), social activities, sympathy from others, motivation, and one’s own and others’ reactions to NMD.
- **Accessibility and educational support:** assistive devices, personal assistance, mentoring, and exemptions.
- **Absence:** frequency of and reasons for school absence (illness, fatigue, pain, demands, treatment, money, and personal or practical help).
- **Discontinuation of studies:** reasons for dropping out (expectations not met, money, time, demands, dreams, and wishes).

2.5. Patient and Public Involvement. The project protocol and survey were qualified continuously by the author group in collaboration with an advisory group of people with NMD

($n = 4$) and professionals from clinical practice at RCFM ($n = 6$).

2.6. Statistical Methods. Data were analyzed using IBM SPSS Statistics 26. Participants who had only answered questions on demographics were excluded from the data analysis. All categorical variables were presented as numbers and percentages. Categories in which respondents could mark multiple answers were presented as numbers.

2.7. Ethics. The study was conducted in accordance with the Helsinki Declaration of 1975 [22]. According to the Central Denmark Region Committees on Biomedical Research Ethics, the project was not liable to notification (Request No. 68/2022, Jr.no. 1-10-72-1-22). According to the Consolidation Act on Research Ethics Review of Health Research Projects, Consolidation Act Number 1338 of 1 September 2020, Section 14 (2), notification of questionnaire surveys or medical database research projects to the research ethics committee system is only required if the project involves human biological material. Therefore, this study could be conducted without approval from the committees.

3. Results

3.1. Study Population. Participant characteristics are presented in Table 1. Five hundred and one people with NMD received the questionnaire and 208 answered. Thirty-six had only answered questions on demographics and were excluded from the analysis. One hundred seventy-two (34.3%) people with NMD were included in the study; 136 people completed the questionnaire and 36 completed it partially. The people included were between 18 and 30 years old, with the majority being between 21 and 25 ($n = 70$, 40.7%). An equal number of women and men answered the questionnaire. Over 20 diagnoses were represented in the survey. The most common diagnoses represented were DMD ($n = 26$, 15.1%), Charcot-Marie-Tooth (CMT) ($n = 22$, 12.8%), myotonic dystrophy type 1 (DM1) ($n = 16$, 9.3%), and spinal muscular atrophy (SMA) types 2 and 3 ($n = 15$, 8.7%). One hundred thirty-seven (81.5%) respondents had attended ordinary primary and lower secondary school (0–9 grade), while 31 (18.5%) had attended a special needs class or other type of school (0–9 grade). One hundred forty-four (89.4%) respondents were or had been enrolled in upper secondary education (10–12 grade), while 17 (10.6%) respondents had not been enrolled in upper secondary education. The highest level of education completed by most respondents was upper secondary education ($n = 60$, 56.6%), followed by a bachelor program or academy profession program ($n = 29$, 27.4%). One hundred seven (62.2%) respondents could walk, while 65 (37.8%) used a wheelchair. Fifty-nine (34.3%) respondents had always or mostly had difficulties in writing for long periods of time. Twenty-eight (16.3%) respondents had always or mostly had difficulties in focusing on schoolwork or other tasks. Fifty-three (30.8%) respondents always or mostly needed many breaks during the day to keep up their energy.

3.2. Expectations, Support, and Reactions. Table 2 refers to results about expectations, support, and reactions from surroundings.

All participants were asked about educational expectations from parents/relatives and teachers. Twenty (11.6%) answered that their parents'/relatives' educational expectations for them were lower than their own expectations. Nineteen (11.1%) answered that their parents'/relatives' educational expectations were lower for them than for their siblings or other people at their age. Furthermore, 24 (14.0%) answered that their teachers' educational expectations were lower for them than for their classmates.

Respondents who were enrolled or had been enrolled in upper secondary education were asked about valuable support and lack of support during upper secondary education. They could choose between multiple answers. We identified 178 answers regarding lack of support. Respondents mostly lacked support from teachers ($n = 27$), student counsellors ($n = 20$), and fellow students ($n = 16$).

All participants were asked to consider statements about sympathy and reactions from other people. Responses were obtained from 17 respondents with only primary and lower secondary education, 138 with upper secondary education, and 45 with higher education. Six (35.2%) of those with only primary and lower secondary education answered that people had always or most of the time been overly considerate of their NMD. In contrast, 17 (12.3%) with upper secondary education and 15 (11.1%) with higher education answered the same.

3.3. Accessibility and Educational Support. Table 3 shows results about accessibility and educational support.

All participants were asked to answer questions about educational and physical accessibility in primary and lower secondary school (0–9 grade). One hundred and sixty-four responded to these questions. Forty (24.4%) respondents answered that their teachers seldom or never planned the lessons in ways that were inclusive for them. Additionally, 32 (19.5%) answered that they seldom or never had access to assistive devices and personal assistance when they needed it.

3.4. Frequency of and Reasons for School Absence. Table 4 presents results on the frequency of and reasons for school absence. All participants were asked about absence in school; 162 responded to questions about absence in primary and lower secondary education, 130 responded to questions about absence in upper secondary education, and 45 responded to questions about absence in higher education. Forty-five (27.7%) responded that they were always or mostly more absent than their classmates in primary and lower secondary education. Thirty-seven (28.4%) responded that they were always or mostly more absent than their classmates in upper secondary education. In contrast, the figure for higher education was only 8 (17.8%). Those who answered that they were always, mostly, or sometimes more absent than their classmates were asked to elaborate on the reasons. The most common reasons for having more absence were that they were more tired ($n = 47/45/12$), more

TABLE 1: Characteristics of the respondents.

| | n (%) | | | | | |
|--|------------|-----------|-----------|-----------|-----------|-------------|
| Age (<i>n</i> = 172) | | | | | | |
| 18–20 | 40 (23.3) | | | | | |
| 21–25 | 70 (40.7) | | | | | |
| 26–30 | 62 (36.0) | | | | | |
| Sex (<i>n</i> = 172) | | | | | | |
| Woman | 86 (50.0) | | | | | |
| Man | 86 (50.0) | | | | | |
| Diagnosis (<i>n</i> = 172) | | | | | | |
| Duchenne muscular dystrophy (DMD) | 26 (15.1) | | | | | |
| Charcot-Marie-Tooth (CMT) | 22 (12.8) | | | | | |
| Myotonic dystrophy type 1 (DM1) | 16 (9.3) | | | | | |
| Spinal muscular atrophy (SMA) type 2 + 3 | 15 (8.7) | | | | | |
| Limb-girdle muscular dystrophy | 13 (7.6) | | | | | |
| Facioscapulohumeral muscular dystrophy (FSHD) | 12 (7.0) | | | | | |
| Congenital muscular dystrophy | 10 (5.8) | | | | | |
| Myasthenia gravis (MG) | 9 (5.2) | | | | | |
| Becker muscular dystrophy | 6 (3.5) | | | | | |
| Congenital myopathy | 6 (3.5) | | | | | |
| Other neuromuscular diseases (NMD) ^a | 34 (19.8) | | | | | |
| Not stated | 3 (1.7) | | | | | |
| Primary and lower secondary education (0–9 grade) (<i>n</i> = 168) | | | | | | |
| Ordinary primary and lower secondary school | 137 (81.5) | | | | | |
| Special needs class/other type of school | 31 (18.5) | | | | | |
| Enrollment in upper secondary education (10–12 grade) (<i>n</i> = 161) | | | | | | |
| Yes | 144 (89.4) | | | | | |
| No | 17 (10.6) | | | | | |
| Highest level of completed education (<i>n</i> = 106) | | | | | | |
| Upper secondary education (10–12 grade (academic, vocational, or other upper secondary education)) | 60 (56.6) | | | | | |
| Bachelor program or academy profession program | 29 (27.4) | | | | | |
| Master's program | 9 (8.5) | | | | | |
| Other adult education | 8 (7.5) | | | | | |
| Current employment (<i>n</i> = 138) | | | | | | |
| Paid work (full time job, part-time job, job on special terms) | 36 (26.1) | | | | | |
| Exploring job opportunities (e.g., in a temporary job to test the ability to work) | 15 (10.9) | | | | | |
| Disability pension/job with salary subsidy to employer for people with disability pension | 29 (21.0) | | | | | |
| Enrolled in a further education program (academic or profession) | 35 (25.4) | | | | | |
| Other | 23 (16.7) | | | | | |
| Ambulation (<i>n</i> = 172) | | | | | | |
| Can walk unaided (no use of assistive device or help from another person) | 81 (47.1) | | | | | |
| Can walk but sometimes need help from a person or from an assistive device | 26 (15.1) | | | | | |
| Use a wheelchair and can manage most things without assistance | 4 (2.3) | | | | | |
| Use a wheelchair and sometimes or mostly need personal assistance | 61 (35.5) | | | | | |
| Other functional level (<i>n</i> = 172) | | | | | | |
| | Always | Mostly | Sometimes | Seldom | Never | Do not know |
| Difficulties in writing for long periods of time | 28 (16.3) | 31 (18.0) | 39 (22.7) | 37 (21.5) | 33 (19.2) | 4 (2.3) |
| Difficulties in focusing on schoolwork or other tasks | 7 (4.1) | 21 (12.2) | 75 (43.6) | 49 (28.5) | 20 (11.6) | 0 (0.0) |
| Need many breaks during the day to keep up energy | 19 (11.0) | 34 (19.8) | 66 (38.4) | 30 (17.4) | 20 (11.6) | 3 (1.7) |

^aOther NMDs represents diagnoses with < 6 respondents (e.g., collagen 6, Duchenne carrier, myotonic dystrophy type 2, Emery–Dreifuss muscular dystrophy, mitochondrial myopathy, myotonia congenita, paramyotonia, periodic paralysis, Pompe disease) and those answering “other” in the questionnaire. In all, over 20 diagnoses were represented in the survey.

TABLE 2: Expectations, support, and reactions of young people with NMD.

| | |
|---|-----------|
| Expectations from others and self | |
| <i>Which of the following descriptions fits your parents'/relatives' expectations to your education the best? (n = 172)</i> | |
| Participant category ^b | All |
| They were the same as my own expectations | 91 (52.9) |
| They were higher than my own expectations | 27 (15.7) |
| They were lower than my own expectations | 20 (11.6) |
| I do not know what my parents'/relatives' expectations for me were | 34 (19.8) |
| <i>Which of the following descriptions fits your parents'/relatives' expectations to your education compared to that of your siblings (if any) or other people at your age? (n = 171)</i> | |
| Participant category ^b | All |
| They were the same of me as they were of my siblings or other children my age | 86 (50.3) |
| They were higher of me than of my siblings or other children my age | 20 (11.7) |
| They were lower of me than of my siblings or other children my age | 19 (11.1) |
| I do not know what my parents'/relatives' expectations were of me compared to my siblings or other children my age | 34 (19.9) |
| I do not have any siblings | 12 (7.0) |
| <i>Which of the following descriptions fits your teachers' expectations to your education compared to that of your classmates? (n = 171)</i> | |
| Participant category ^b | All |
| They were the same of me as of my classmates | 86 (50.3) |
| They were higher of me than of my classmates | 16 (9.4) |
| They were lower of me than of my classmates | 24 (14.0) |
| I do not know what my teachers' expectations to my education was compared to that of my classmates | 45 (26.3) |
| <i>I think it is realistic that I will be occupied by the things I dream of in the future (n = 138)</i> | |
| Participant category ^b | All |
| Yes | 98 (71.0) |
| No | 14 (10.1) |
| Do not know/not relevant | 26 (18.8) |

TABLE 2: Continued.

| Support from others (questions asked in section about upper secondary education (10–12 grade)) | Who have you received valuable academic or social support from during your upper secondary education? (Mark as many as you want) | | | Who did you lack support from during your upper secondary education? (Mark as many as you want) | | |
|--|--|-----------|-----------|---|-----------|-------------|
| | Always | Mostly | Sometimes | Seldom | Never | Do not know |
| Teachers | | | 67 | | | 27 |
| Fellow students | | | 67 | | | 16 |
| Student counsellor | | | 30 | | | 20 |
| Mentor | | | 8 | | | 3 |
| Peers with a neuromuscular disorder | | | 10 | | | 5 |
| Other friends | | | 47 | | | 9 |
| Parents or siblings | | | 91 | | | 6 |
| National Rehabilitation Center for Neuromuscular Diseases | | | 12 | | | 6 |
| The Danish Neuromuscular Foundation | | | 11 | | | 6 |
| No one | | | 6 | | | 43 |
| Do not know | | | 6 | | | 36 |
| Other | | | 5 | | | 1 |
| Sympathy and reactions from others | | | | | | |
| <i>Which of the following statements have been applicable to you during your education/in general? (n = 17/138/45)</i> | | | | | | |
| Response category | Always | Mostly | Sometimes | Seldom | Never | Do not know |
| Participant category ^b | Low | Low | Low | Low | Low | Low |
| | Middle | Middle | Middle | Middle | Middle | Middle |
| | High | High | High | High | High | High |
| My neuromuscular disease has been visible to others | 8 (47.1) | 2 (11.8) | 3 (17.6) | 2 (11.8) | 2 (11.8) | 0 (0.0) |
| | 57 (41.3) | 9 (6.5) | 21 (15.2) | 25 (18.1) | 23 (16.7) | 3 (2.2) |
| | 21 (46.7) | 3 (6.7) | 4 (8.9) | 7 (15.6) | 8 (17.8) | 2 (4.4) |
| | 4 (23.5) | 4 (23.5) | 4 (23.5) | 1 (5.9) | 3 (17.6) | 1 (5.9) |
| I have thought about how others react to my neuromuscular disease | 20 (14.5) | 29 (21.0) | 44 (31.9) | 21 (15.2) | 18 (13.0) | 6 (4.3) |
| | 6 (13.3) | 10 (22.2) | 11 (24.4) | 9 (20.0) | 7 (15.6) | 2 (4.4) |
| | 11 (64.7) | 1 (5.9) | 2 (11.8) | 2 (11.8) | 1 (5.9) | 0 (0.0) |
| I have been open about my neuromuscular disease | 65 (47.1) | 31 (22.5) | 19 (13.8) | 9 (6.5) | 6 (4.3) | 8 (5.8) |
| | 29 (64.4) | 6 (13.3) | 4 (8.9) | 1 (2.2) | 3 (6.7) | 2 (4.4) |
| | 4 (23.5) | 4 (23.5) | 2 (11.8) | 4 (23.5) | 1 (5.9) | 2 (11.8) |
| It has been hard for me to find the right time to tell others about my neuromuscular disease | 22 (15.9) | 17 (12.3) | 16 (11.6) | 28 (20.3) | 38 (27.5) | 17 (12.3) |
| | 5 (11.1) | 5 (11.1) | 9 (20.0) | 6 (13.3) | 18 (40.0) | 2 (4.4) |

TABLE 2: Continued.

| | | | | | | |
|---|-----------|-----------|-----------|-----------|-----------|-----------|
| My teachers have been sympathetic of my neuromuscular disease | 42 (30.4) | 43 (31.2) | 16 (11.6) | 13 (9.4) | 5 (3.6) | 19 (13.8) |
| | 12 (26.7) | 15 (33.3) | 3 (6.7) | 2 (4.4) | 1 (2.2) | 12 (26.7) |
| | 11 (64.7) | 4 (23.5) | 2 (11.8) | 0 (0.0) | 0 (0.0) | 0 (0.0) |
| My fellow students/friends have been sympathetic of my neuromuscular disease | 49 (35.5) | 42 (30.4) | 18 (13.0) | 9 (6.5) | 4 (2.9) | 16 (11.6) |
| | 18 (40.0) | 17 (37.8) | 3 (6.7) | 1 (2.2) | 1 (2.2) | 5 (11.1) |
| | 2 (11.8) | 1 (5.9) | 1 (5.9) | 5 (29.4) | 3 (17.6) | 5 (29.4) |
| People have been reluctant to talk about my neuromuscular disease | 5 (3.6) | 12 (8.7) | 22 (15.9) | 38 (27.5) | 35 (25.4) | 26 (18.8) |
| | 1 (2.2) | 2 (4.4) | 11 (24.4) | 13 (28.9) | 11 (24.4) | 7 (15.6) |
| | 3 (17.6) | 1 (5.9) | 1 (5.9) | 2 (11.8) | 10 (58.8) | 0 (0.0) |
| I have been bullied because of my neuromuscular disease ^a | 1 (0.7) | 2 (1.5) | 9 (6.6) | 19 (13.9) | 93 (67.9) | 13 (9.5) |
| | 0 (0.0) | 0 (0.0) | 1 (2.2) | 3 (6.7) | 38 (84.4) | 3 (6.7) |
| | 3 (17.6) | 3 (17.6) | 6 (35.3) | 1 (5.9) | 4 (23.5) | 0 (0.0) |
| People have been overly considerate of me because of my neuromuscular disease | 7 (5.1) | 10 (7.2) | 43 (31.2) | 34 (24.6) | 27 (19.6) | 17 (12.3) |
| | 3 (6.7) | 2 (4.4) | 7 (15.6) | 13 (28.9) | 16 (35.6) | 4 (8.9) |

^aOnly 137 respondents in the category “middle” (one missing).

^bParticipant category refers to which respondents answered the question. All means all respondents answered the question. Low refers to all who had not moved on to upper secondary education. Middle refers to all attending or having attended one or several upper secondary education(s), as well as respondents moving on to higher education. High refers to all attending or having attended one or more higher education(s).

TABLE 3: Accessibility and educational support, for example, assistive devices, personal assistance, and mentoring, in young people with NMD.

| Physical and educational accessibility | | | | | | | | | | | | |
|--|------------|-----------|-----------|-----------|-----------|-------------|------------|-----------|-----------|-----------|-----------|-------------|
| <i>Which of the following statements match your experience of educational and physical accessibility in primary and lower secondary school (0–9 grade)? (n = 164)</i> | | | | | | | | | | | | |
| Response category | Always | Mostly | Sometimes | Seldom | Never | Do not know | Always | Mostly | Sometimes | Seldom | Never | Do not know |
| Participant category ^b | All | All | All | All | All | All | All | All | All | All | All | All |
| My academic performance in school was good | 41 (25.0) | 60 (36.6) | 39 (23.8) | 19 (11.6) | 5 (3.0) | 0 (0.0) | 41 (25.0) | 60 (36.6) | 39 (23.8) | 19 (11.6) | 5 (3.0) | 0 (0.0) |
| My teachers planned the lessons in ways that were inclusive for me | 36 (22.0) | 41 (25.0) | 20 (12.2) | 17 (10.4) | 23 (14.0) | 27 (16.5) | 36 (22.0) | 41 (25.0) | 20 (12.2) | 17 (10.4) | 23 (14.0) | 27 (16.5) |
| I was able to get around in the classrooms on equal terms with my classmates | 101 (61.6) | 42 (25.6) | 11 (6.7) | 4 (2.4) | 3 (1.8) | 3 (1.8) | 101 (61.6) | 42 (25.6) | 11 (6.7) | 4 (2.4) | 3 (1.8) | 3 (1.8) |
| I was able to get around in the schoolyard on equal terms with my classmates | 97 (59.1) | 50 (30.5) | 10 (6.1) | 2 (1.2) | 2 (1.2) | 3 (1.8) | 97 (59.1) | 50 (30.5) | 10 (6.1) | 2 (1.2) | 2 (1.2) | 3 (1.8) |
| I had access to assistive devices and personal assistance whenever I needed it | 57 (34.8) | 31 (18.9) | 9 (5.5) | 11 (6.7) | 21 (12.8) | 35 (21.3) | 57 (34.8) | 31 (18.9) | 9 (5.5) | 11 (6.7) | 21 (12.8) | 35 (21.3) |
| <i>Which of the following statements match you experiences of physical and educational accessibility in upper secondary school and further education? (n = 133/45)</i> | | | | | | | | | | | | |
| Response category | Always | Mostly | Sometimes | Seldom | Never | Do not know | Always | Mostly | Sometimes | Seldom | Never | Do not know |
| Participant category ^b | Middle | Middle | Middle | Middle | Middle | Middle | Middle | Middle | Middle | Middle | Middle | Middle |
| | High | High | High | High | High | High | High | High | High | High | High | High |
| I can/could participate in lessons/academic activities at my school ^a | 57 (42.5) | 62 (46.3) | 12 (9.0) | 1 (0.7) | 1 (0.7) | 1 (0.7) | 57 (42.5) | 62 (46.3) | 12 (9.0) | 1 (0.7) | 1 (0.7) | 1 (0.7) |
| I can/could participate in internships if they are/were part of my education | 22 (48.9) | 17 (37.8) | 3 (6.7) | 0 (0.0) | 1 (2.2) | 2 (4.4) | 22 (48.9) | 17 (37.8) | 3 (6.7) | 0 (0.0) | 1 (2.2) | 2 (4.4) |
| I can/could manage a student job if I want/wanted one | 62 (46.6) | 20 (15.0) | 10 (7.5) | 6 (4.5) | 4 (3.0) | 31 (23.3) | 62 (46.6) | 20 (15.0) | 10 (7.5) | 6 (4.5) | 4 (3.0) | 31 (23.3) |
| It was necessary to switch to another educational program or school because of poor accessibility | 28 (62.2) | 8 (17.8) | 1 (2.2) | 0 (0.0) | 3 (6.7) | 5 (11.1) | 28 (62.2) | 8 (17.8) | 1 (2.2) | 0 (0.0) | 3 (6.7) | 5 (11.1) |
| | 17 (12.8) | 11 (8.3) | 8 (6.0) | 17 (12.8) | 54 (40.6) | 26 (19.5) | 17 (12.8) | 11 (8.3) | 8 (6.0) | 17 (12.8) | 54 (40.6) | 26 (19.5) |
| | 10 (22.2) | 1 (2.2) | 4 (8.9) | 1 (2.2) | 21 (46.7) | 8 (17.8) | 10 (22.2) | 1 (2.2) | 4 (8.9) | 1 (2.2) | 21 (46.7) | 8 (17.8) |
| | 9 (6.8) | 2 (1.5) | 9 (6.8) | 7 (5.3) | 93 (69.9) | 13 (9.8) | 9 (6.8) | 2 (1.5) | 9 (6.8) | 7 (5.3) | 93 (69.9) | 13 (9.8) |
| | 2 (4.4) | 1 (2.2) | 3 (6.7) | 0 (0.0) | 34 (75.6) | 5 (11.1) | 2 (4.4) | 1 (2.2) | 3 (6.7) | 0 (0.0) | 34 (75.6) | 5 (11.1) |
| Educational support | | | | | | | | | | | | |
| Response category | Always | Mostly | Sometimes | Seldom | Never | Do not know | Always | Mostly | Sometimes | Seldom | Never | Do not know |
| Participant category ^b | Middle | Middle | Middle | Middle | Middle | Middle | Middle | Middle | Middle | Middle | Middle | Middle |
| | High | High | High | High | High | High | High | High | High | High | High | High |
| I was given sufficient information about educational support for students with special needs at my school (n = 49/27) | 15 (30.6) | 11 (22.4) | 3 (6.1) | 2 (4.1) | 8 (16.3) | 10 (20.4) | 15 (30.6) | 11 (22.4) | 3 (6.1) | 2 (4.1) | 8 (16.3) | 10 (20.4) |
| I have received sufficient practical and/or personal help at my school (n = 57/15) | 6 (22.2) | 6 (22.2) | 4 (14.8) | 6 (22.2) | 2 (7.4) | 3 (11.1) | 6 (22.2) | 6 (22.2) | 4 (14.8) | 6 (22.2) | 2 (7.4) | 3 (11.1) |
| | 26 (45.6) | 20 (35.1) | 6 (10.5) | 1 (1.8) | 2 (3.5) | 2 (3.5) | 26 (45.6) | 20 (35.1) | 6 (10.5) | 1 (1.8) | 2 (3.5) | 2 (3.5) |
| | 11 (73.3) | 3 (20.0) | 0 (0.0) | 0 (0.0) | 1 (6.7) | 0 (0.0) | 11 (73.3) | 3 (20.0) | 0 (0.0) | 0 (0.0) | 1 (6.7) | 0 (0.0) |

TABLE 3: Continued.

| Which of the following statements match the guidance and support you have received at your school? (n = 49/27) | | Always | Mostly | Sometimes | Seldom | Never | Do not know |
|---|-----------------------------------|----------------|----------------|----------------|----------------|----------------|----------------|
| Response category | Participant category ^b | Middle High | Middle High | Middle High | Middle High | Middle High | Middle High |
| I have been granted exemption from exams or taken exams on special conditions (e.g., additional time) if needed | | 23 (46.9) | 11 (22.4) | 2 (4.1) | 0 (0.0) | 2 (4.1) | 11 (22.4) |
| I have been able to prolong my studies if needed | | 8 (29.6) | 7 (25.9) | 1 (3.7) | 1 (3.7) | 2 (7.4) | 8 (29.6) |
| I have been in doubt about where to apply for special needs support and/or exemptions | | 13 (26.5) | 5 (10.2) | 2 (4.1) | 0 (0.0) | 5 (10.2) | 24 (49.0) |
| | | 10 (37.0) | 3 (11.1) | 0 (0.0) | 1 (3.7) | 2 (7.4) | 11 (40.7) |
| | | 7 (14.3) | 4 (8.2) | 8 (16.3) | 8 (16.3) | 12 (24.5) | 10 (20.4) |
| | | 3 (11.1) | 1 (3.7) | 5 (18.5) | 2 (7.4) | 9 (33.3) | 7 (25.9) |
| Which of the following statements matches your experience? (n = 52/17) | | | | | | | |
| Participant category ^b | | | | | | | |
| I have had the assistive devices I needed during my education | | Middle High | | | | | |
| | | 46 (88.5) | | | | | |
| I have not had the assistive devices I needed during my education | | 12 (70.6) | | | | | |
| | | 6 (11.5) | | | | | |
| | | 5 (29.4) | | | | | |

^aOne hundred thirty-four respondents in the category "middle."

^bParticipant category refers to which respondents answered the question. All means all respondents answered the question. Middle refers to all attending or having attended one or several upper secondary education(s), as well as respondents moving on to higher education. High refers to all attending or having attended one or more higher education(s).

TABLE 4: Frequency of and reasons for school absence in young people with NMD.

| Absence | | | | | | |
|--|-----------------------------------|------------------------------------|------------------------------------|-------------------------------------|-------------------------------------|---------------------------------|
| Response category | Always | Mostly | Sometimes | Seldom | Never | Do not know |
| Participant category ^a | All Middle High | All Middle High | All Middle High | All Middle High | All Middle High | All Middle High |
| Have been more absent than classmates/fellow students ($n = 162/130/45$) | 20 (12.3) 18 (13.8) 3 (6.7) | 25 (15.4) 19 (14.6) 5 (11.1) | 35 (21.6) 24 (18.5) 7 (15.6) | 26 (16.0) 30 (23.1) 12 (26.7) | 45 (27.8) 35 (26.9) 13 (28.9) | 11 (6.8) 4 (3.1) 5 (11.1) |
| The following has affected absence from school ($n = 57/61/15$) | | | | | | |
| | All/middle/high | | | | | |
| Was more tired than peers | 47/45/12 | | | | | |
| Was ill more often than peers | 36/31/6 | | | | | |
| Often in pain | 26/22/5 | | | | | |
| Had to spend more time on treatment (e.g., physiotherapy and hospitalization) than peers | 54/29/7 | | | | | |
| Activities of daily living (e.g., eating, getting dressed, and going to the bathroom) took longer time than for peers | 15/12/- | | | | | |
| Did not feel like participating in lessons + did not feel like participating in studies/I did not find pleasure in studies | 24/19/7 | | | | | |
| Did not have sufficient practical or personal assistance and/or assistive devices | 7/7/4 | | | | | |
| Financial situation was insufficient | -/3/3 | | | | | |
| Studies had to be prolonged because of the neuromuscular disease | -/12/3 | | | | | |
| Other reasons for absence | 28/18/5 | | | | | |

^aParticipant category refers to which respondents answered the question. All means all respondents answered the question. Middle refers to all attending or having attended one or several upper secondary education(s), as well as respondents moving on to higher education. High refers to all attending or having attended one or more higher education(s).

often ill ($n = 36/31/6$), often in pain ($n = 26/22/5$), or spent more time on treatment ($n = 54/29/7$) compared to their peers.

3.5. Discontinuation of Studies. Table 5 presents results on the discontinuation of studies and reasons for not completing education.

The participants who were or had been enrolled in upper secondary and higher education were asked about discontinuation of studies; 129 responded to questions about upper secondary education and 45 to questions about higher education. Thirty-two (24.8%) respondents who had started upper secondary education had dropped out of one or more educational programs. Thirteen (28.9%) respondents who had started higher education had done the same.

Seventeen participants who had only attended primary and lower secondary education were asked about reasons for not having moved on to upper secondary education. The most common reasons were that they did not have the energy ($n = 10$), had not found themselves smart enough ($n = 7$), or did not feel like it ($n = 6$).

3.6. Motivation and Sense of Belonging. Table 6 presents results on motivation and sense of belonging.

All participants were asked about their motivation in primary and lower secondary school. One hundred sixty-seven responded to the questions. Thirty-one (18.6%) answered they seldom or never had a sense of belonging at

school. Thirty-seven (22.2%) answered that it was always or mostly difficult to participate in social activities.

Furthermore, all participants were asked to consider statements about their motivation; responses were obtained from 17 participants with only primary and lower secondary education, 141 participants with upper secondary education, and 46 with higher education. Many respondents answered that they always or mostly felt bad if they could not overcome the same things as their peers: 7 (41.1%) with only primary and lower secondary education, 39 (27.6%) with upper secondary education, and 14 (30.4%) with higher education, respectively.

All participants were asked to answer statements about their social life: 17 participants with only primary and lower secondary education, 130 with upper secondary education, and 45 with higher education answered the statements. Six (35.2%) with only primary and lower secondary education answered that they had always or mostly given social activities low priority to save energy for their education/a job or other activities. This was a high percentage compared to those with upper secondary education (25, 19.3%) and higher education (8, 17.8%).

4. Discussion

To our knowledge, this is the first study to investigate factors of importance for continuing with upper secondary and/or higher education after primary education for people with

TABLE 5: Discontinuation of studies and reasons for not completing education in young people with NMD.

| Discontinuation of studies, reasons for dropping out | | |
|---|-----------|-------------|
| Response category | Yes | No |
| Participant category ^a | Middle | Middle |
| | High | High |
| Have dropped out of one or more educational programs (<i>n</i> = 129/45) | 32 (24.8) | 97 (75.2) |
| | 13 (28.9) | 32 (71.1) |
| Possible reasons for not going through with the studies (<i>n</i> = 32/13) | | |
| Participant category ^a | | Middle/high |
| Discovered that the program was not as imagined | | 10/3 |
| There were periods of illness or hospitalization related to the neuromuscular disease | | 10/3 |
| Struggling to keep up with the academic level | | 13/4 |
| Difficulties in participating in social activities at school | | 4/1 |
| Difficulties in participating in social activities outside school | | 3/3 |
| Did not have sufficient practical or personal assistance and/or assistive devices | | 1/0 |
| Did not have enough money to cover the expenses of daily living during education | | 1/2 |
| Did not have enough money to cover the expenses of daily living during prolonged education (e.g., was not granted additional funding from the State Education Fund) (further education) | | -/1 |
| Do not know the reason for dropping out | | 1/0 |
| Have dropped out for other reasons | | 12/7 |
| Reasons for not starting upper secondary education after primary and lower secondary education (<i>n</i> = 17) | | |
| Participant category ^a | | Low |
| Have not felt like it | | 6 |
| Have not had the energy | | 10 |
| Have not found oneself smart enough | | 7 |
| Have never planned on getting an education | | 4 |
| Needed time to figure out what want to do | | 3 |
| The desired upper secondary schools were lacking in accessibility | | 2 |
| Could not get the necessary support (e.g., assistive devices and personal help) to start upper secondary school | | 3 |
| Did not have enough money to start school | | 2 |
| Continuing with upper secondary education is not a tradition in the family | | 1 |
| Have not started upper secondary education for other reasons | | 7 |
| Measures needed for going back to school (<i>n</i> = 17) | | |
| Participant category ^a | | Low |
| More time for studies than peers | | 4 |
| More practical and/or personal assistance and assistive devices than is available right now | | 1 |
| Financial support | | 1 |
| More guidance and information on options | | 4 |
| None of the above | | 2 |

^aParticipant category refers to which respondents answered the question. Low refers to all who had not moved on to upper secondary education. Middle refers to all attending or having attended one or several upper secondary education(s), as well as respondents moving on to higher education. High refers to all attending or having attended one or more higher education(s).

NMDs between 18 and 30 years of age. Our findings represent over 20 different neuromuscular diagnoses.

4.1. Study Population. The most common diagnoses represented in our study were DMD with 15.1%, CMT with 12.8%, and DM1 with 9.3%. The large representation of people with DMD in our study was surprising, since it is one of the smaller diagnosis groups registered with RCFM with

around 4% [19]. Diagnoses like DM1 and DMD carry a risk of cognitive deficits and intellectual impairment, and the percentage of participants with this specific diagnosis was well represented in our study [23–26].

Out of all the respondents, 81.5% had attended ordinary primary and lower secondary school, while 18.5% had attended a special needs class. When looking at the background population in Denmark for the years 2022/2023,

TABLE 6: Motivation and sense of belonging in young people with NMD.

| Motivation and sense of belonging | | | | | | |
|--|-----------|-----------|-----------|-----------|-----------|-------------|
| <i>How do the following statements match your experience with primary and lower secondary school? (n = 167)</i> | | | | | | |
| Response category | Always | Mostly | Sometimes | Seldom | Never | Do not know |
| Participant category ^a | All | All | All | All | All | All |
| I liked going to school | 21 (12.6) | 84 (50.3) | 32 (19.2) | 23 (13.8) | 7 (4.2) | 0 (0.0) |
| I had good friends in school | 69 (41.3) | 56 (33.5) | 28 (16.8) | 12 (7.2) | 2 (1.2) | 0 (0.0) |
| I was alone during recesses | 4 (2.4) | 14 (8.4) | 33 (19.8) | 54 (32.3) | 62 (37.1) | 0 (0.0) |
| I was bullied in school | 11 (6.6) | 8 (4.8) | 22 (13.2) | 36 (21.6) | 87 (52.1) | 3 (1.8) |
| I was accepted for who I was | 65 (38.9) | 56 (33.5) | 20 (12.0) | 13 (7.8) | 9 (5.4) | 4 (2.4) |
| I had a sense of belonging when I was at school | 52 (31.1) | 54 (32.3) | 26 (15.6) | 14 (8.4) | 17 (10.2) | 4 (2.4) |
| It was difficult for me to participate in social activities | 13 (7.8) | 24 (14.4) | 62 (37.1) | 38 (22.8) | 29 (17.4) | 1 (0.6) |
| I was not sure what I wanted to do after completing lower secondary education (9/10 grade) | 30 (18.0) | 22 (13.2) | 28 (16.8) | 22 (13.2) | 60 (35.9) | 5 (3.0) |
| <i>How do the following statements about motivation match your experience? (n = 17/141/46)</i> | | | | | | |
| Response category | Always | Mostly | Sometimes | Seldom | Never | Do not know |
| Participant category ^a | Low | Low | Low | Low | Low | Low |
| | Middle | Middle | Middle | Middle | Middle | Middle |
| | High | High | High | High | High | High |
| | 5 (29.5) | 1 (5.9) | 10 (58.8) | 0 (0.0) | 1 (5.9) | 0 (0.0) |
| I have felt different from my friends/fellow students | 17 (12.1) | 14 (9.9) | 50 (35.5) | 34 (24.1) | 26 (18.4) | 0 (0.0) |
| | 4 (8.7) | 5 (10.9) | 14 (30.4) | 13 (28.3) | 8 (17.4) | 2 (4.3) |
| | — | — | — | — | — | — |
| It is important for me to continue with upper secondary/further education | 96 (68.1) | 22 (15.6) | 23 (16.3) | 8 (5.7) | 3 (2.1) | 0 (0.0) |
| | 36 (78.3) | 4 (8.7) | 2 (4.3) | 2 (4.3) | 0 (0.0) | 2 (4.3) |
| | — | — | — | — | — | — |
| I am/have been happy with the schools/educational programs I attend/have attended | 54 (38.3) | 53 (37.6) | 23 (16.3) | 8 (5.7) | 3 (2.1) | 0 (0.0) |
| | 19 (41.3) | 20 (43.5) | 4 (8.7) | 0 (0.0) | 1 (2.2) | 2 (4.3) |
| | — | — | — | — | — | — |
| I have/had to push myself to keep up with my peers | 18 (12.8) | 12 (8.5) | 43 (30.5) | 33 (23.4) | 31 (22.0) | 4 (2.8) |
| | 6 (13.0) | 9 (19.6) | 9 (19.6) | 13 (28.3) | 7 (15.2) | 2 (4.3) |
| | 4 (23.5) | 3 (17.6) | 3 (17.6) | 2 (11.8) | 2 (11.8) | 3 (17.6) |
| I have felt bad if I could not overcome the same things as my peers | 14 (9.9) | 25 (17.7) | 25 (17.7) | 28 (19.9) | 37 (26.2) | 12 (8.5) |
| | 7 (15.2) | 7 (15.2) | 7 (15.2) | 8 (17.4) | 14 (30.4) | 3 (6.5) |
| | 5 (29.4) | 2 (11.8) | 6 (35.3) | 2 (11.8) | 1 (5.9) | 1 (5.9) |
| I have felt sad | 6 (4.3) | 9 (6.4) | 52 (36.9) | 43 (30.5) | 29 (20.6) | 2 (1.4) |
| | 2 (4.3) | 4 (8.7) | 15 (32.6) | 13 (28.3) | 10 (21.7) | 2 (4.3) |
| | 4 (23.5) | 2 (11.8) | 7 (41.2) | 3 (17.6) | 1 (5.9) | 0 (0.0) |
| I have been edgy and in a bad mood | 4 (2.8) | 10 (7.1) | 50 (35.5) | 48 (34.0) | 25 (17.7) | 4 (2.8) |
| | 2 (4.3) | 2 (4.3) | 12 (26.1) | 19 (41.3) | 9 (19.6) | 2 (4.3) |
| | 3 (17.6) | 5 (29.4) | 3 (17.6) | 3 (17.6) | 2 (11.8) | 1 (5.9) |
| I have been nervous | 9 (6.4) | 17 (12.1) | 55 (39.0) | 32 (22.7) | 27 (19.1) | 1 (0.7) |
| | 4 (8.7) | 4 (8.7) | 14 (30.4) | 14 (30.4) | 8 (17.4) | 2 (4.3) |
| I have been able to talk to my parents if I was worried about something/I have had someone to talk to if I was worried about something | 9 (52.9) | 1 (5.9) | 3 (17.6) | 3 (17.6) | 1 (5.9) | 0 (0.0) |
| | 64 (45.4) | 39 (27.7) | 16 (11.3) | 9 (6.4) | 8 (5.7) | 5 (3.5) |
| | 16 (34.8) | 15 (32.6) | 3 (6.5) | 4 (8.7) | 4 (8.7) | 4 (8.7) |
| | 10 (58.8) | 5 (29.4) | 0 (0.0) | 0 (0.0) | 0 (0.0) | 2 (11.8) |
| I have wanted to contribute to society | — | — | — | — | — | — |
| | — | — | — | — | — | — |

TABLE 6: Continued.

| | | | | | | |
|--|-----------|-----------|-----------|-----------|-----------|-------------|
| | — | — | — | — | — | — |
| I have wanted to contribute to the school community | 52 (36.9) | 49 (34.8) | 29 (20.6) | 3 (2.1) | 4 (2.8) | 4 (2.8) |
| | 15 (32.6) | 19 (41.3) | 5 (10.9) | 3 (6.5) | 1 (2.2) | 3 (6.5) |
| | 8 (47.1) | 5 (29.4) | 0 (0.0) | 3 (17.6) | 0 (0.0) | 1 (5.9) |
| I have felt it was important to have something to wake up to | — | — | — | — | — | — |
| | — | — | — | — | — | — |
| Social life | | | | | | |
| <i>How do these statements about your social life match your experience? (n = 17/130/45)</i> | | | | | | |
| Response category | Always | Mostly | Sometimes | Seldom | Never | Do not know |
| | Low | Low | Low | Low | Low | Low |
| Participant category ^a | Middle | Middle | Middle | Middle | Middle | Middle |
| | High | High | High | High | High | High |
| I have given social activities lower priority to have energy for my education/a job or other activities | 3 (17.6) | 3 (17.6) | 4 (23.5) | 1 (5.9) | 4 (23.5) | 2 (11.8) |
| | 11 (8.5) | 14 (10.8) | 36 (27.7) | 28 (21.5) | 33 (25.4) | 8 (6.2) |
| | 4 (8.9) | 4 (8.9) | 15 (33.3) | 9 (20.0) | 11 (24.4) | 2 (4.4) |
| I have missed out on social communities because of my neuromuscular disease | 5 (29.4) | 5 (29.4) | 3 (17.6) | 2 (11.8) | 2 (11.8) | 0 (0.0) |
| | 5 (3.8) | 13 (10.0) | 40 (30.8) | 25 (19.2) | 36 (27.7) | 11 (8.5) |
| | 2 (4.4) | 1 (2.2) | 13 (28.9) | 7 (15.6) | 19 (42.2) | 3 (6.7) |
| I have felt lonely | 3 (17.6) | 5 (29.4) | 1 (5.9) | 6 (35.3) | 2 (11.8) | 0 (0.0) |
| | 7 (5.4) | 12 (9.2) | 42 (32.3) | 39 (30.0) | 28 (21.5) | 2 (1.5) |
| | 1 (2.2) | 7 (15.6) | 11 (24.4) | 11 (24.4) | 13 (28.9) | 2 (4.4) |
| It was necessary that I took the initiative to meet with friends | 4 (23.5) | 6 (35.3) | 4 (23.5) | 0 (0.0) | 2 (11.8) | 1 (5.9) |
| | 8 (6.2) | 21 (16.2) | 48 (36.9) | 34 (26.2) | 13 (10.0) | 6 (4.6) |
| | 1 (2.2) | 5 (11.1) | 13 (28.9) | 14 (31.1) | 7 (15.6) | 5 (11.1) |
| I have arranged social gatherings to make sure I could participate | 4 (23.5) | 2 (11.8) | 3 (17.6) | 3 (17.6) | 4 (23.5) | 1 (5.9) |
| | 2 (1.5) | 11 (8.5) | 18 (13.8) | 33 (25.4) | 60 (46.2) | 6 (4.6) |
| | 1 (2.2) | 3 (6.7) | 5 (11.1) | 11 (24.4) | 21 (46.7) | 4 (8.9) |
| I have had the friends I wanted to have | 7 (41.2) | 5 (29.4) | 4 (23.5) | 0 (0.0) | 0 (0.0) | 1 (5.9) |
| | 46 (35.4) | 51 (39.2) | 14 (10.8) | 10 (7.7) | 6 (4.6) | 3 (2.3) |
| | 20 (44.4) | 11 (24.4) | 6 (13.3) | 4 (8.9) | 2 (4.4) | 2 (4.4) |
| I have had friends who also had a disability | 5 (29.4) | 1 (5.9) | 3 (17.6) | 3 (17.6) | 3 (17.6) | 2 (11.8) |
| | 16 (12.3) | 13 (10.0) | 18 (13.8) | 18 (13.8) | 58 (44.6) | 7 (5.4) |
| | 5 (11.1) | 5 (11.1) | 3 (6.7) | 9 (20.0) | 21 (46.7) | 2 (4.4) |
| <i>The personal assistant has sometimes been a barrier to friendships, social activities, or group work (n = 14/58/15)</i> | | | | | | |
| Response category | Always | Mostly | Sometimes | Seldom | Never | Do not know |
| | Low | Low | Low | Low | Low | Low |
| Participant category ^a | Middle | Middle | Middle | Middle | Middle | Middle |
| | High | High | High | High | High | High |
| | 1 (7.1) | 3 (21.4) | 4 (28.6) | 1 (7.1) | 5 (35.7) | 0 (0.0) |
| | 1 (1.7) | 5 (8.6) | 14 (24.1) | 18 (31.0) | 13 (22.4) | 7 (12.1) |
| | 1 (6.7) | 0 (0.0) | 3 (20.0) | 7 (46.7) | 3 (20.0) | 1 (6.7) |

^aParticipant category refers to which respondents answered the question. All means all respondents answered the question. Low refers to all who had not moved on to upper secondary education. Middle refers to all attending or having attended one or several upper secondary education(s), as well as respondents moving on to higher education. High refers to all attending or having attended one or more higher education(s).

only 5.1% attended a special needs class [27]. There may be various explanations for the relatively high number of young people with NMD in a special needs class or other type of school. Around 34% had always or mostly had difficulties in writing for longer periods of time, and 31% stated that

they always or mostly needed many breaks during the day to keep up their energy. Literature shows that people with disabilities are more likely to be less educated due to challenges related to an impaired function [16, 28]. Our findings showed that 89.4% of the participants were or had been

enrolled in upper secondary school, and the highest level of education completed by most respondents was upper secondary education (56.6%), followed by a bachelor program or academy profession program (27.4%). The numbers for enrolling in upper secondary school in this study are lower than for the background population in which 91.6% applied for upper secondary education or vocational education in 2022 [29]. These findings are important since research has shown that educated people with disabilities seem to cope and function better with their disabilities in general [30]. Furthermore, education is known to be of importance for how well you do in life in regard to health, income, employment, social inclusion, and working life conditions [17, 18].

4.2. Expectations, Support, and Reactions. Some respondents found that their parents' expectations for their education did not match their own (11.6%) or those for their siblings (11.1%) and that their teachers had lower expectations for them than for their classmates (14.0%). This has also been found in prior research showing how teachers of students with DMD tended to have lower expectations of these students compared to their peers [31]. Another study illustrated how only 63% of the teachers in schools without special needs offers and none of the teachers in schools with special needs offers expected their students with a NMD to graduate [31]. This is unfortunate since research has shown a link between expectations and academic achievement and that teachers' expectations are of great importance for students' achievement [32]. Low expectations can have negative effects which can accumulate over time, adding up to significant differences in educational outcomes [32]. In a recent qualitative study on perspectives of young people with NMDs regarding their educational choices, the participants emphasized the importance of expectations of their parents and teachers and explained the expectations as helpful [33]. The participants all underscored the positive influence expectations had on making choices for themselves, their education, and a future work life [33]. The low expectations experienced by the participants in the present study might be related to overprotection of the child or student with NMD, but knowing that low expectations are harmful, the intention to protect may have the opposite effect. Therefore, parents and teachers must be made aware of the false assumption that young people with disabilities cannot achieve the same as their peers or be successful in school.

4.3. Accessibility and Educational Support. Of the respondents, 24.4% answered that their teachers seldom or never planned the lessons in ways that were inclusive for them and 19.5% that they seldom or never had access to assistive devices and personal assistance when they needed it. Learning disabilities among people with certain NMD diagnoses such as DMD and DM1 have been shown to affect academic skills and personal relations negatively [34]. In Denmark, education for students with special needs should, if possible, be implemented in mainstream schools, and all young people are entitled to education adapted to their prerequisites and needs [35]. Feeling academically and socially behind can make it difficult to catch up and entail feelings of being

excluded and alone. Being excluded can affect quality of life negatively, and therefore, it is important to intervene with supportive and inclusive measures in class and ensure that assistive devices and personal assistance are available when needed [34]. Teachers carry a responsibility to communicate with the young people with NMD and their parents and to ensure that the young people acquire adequate academic skills and that they can actively participate in classroom activities [36].

4.4. Absence and Discontinuation of Studies. Around 28% of all the respondents answered that they were mostly or always more absent than their classmates in primary and lower secondary school. Of the respondents, 28.4% who were or had been enrolled in upper secondary education answered that they were always or mostly more absent than their classmates. When looking at the background population, the average absence for a child in primary school was 8% in the school year 2021/2022 [8]. The most common reasons for being absent mentioned by the respondents in our study were that they were tired, ill, in pain, or getting treatment. A recent study has shown differences in the registration of school absence and requirements for attendance in Scandinavia, emphasizing the need to focus on opportunities for educational support for young people with disabilities and school absence [37].

Education and schooling have been shown to improve health and reduce adult mortality, making the importance of increased investment in education essential [38]. From our results, we do not know why absence is lower among respondents enrolled in higher education, but they may experience fewer symptoms from their disease and, thus, be more likely to continue in the educational system. Therefore, it is essential that schools and educational programs are inclusive and flexible to ensure that all students with NMD can attend school and continue in the educational system even if they experience symptoms like illness, fatigue, or pain [36]. Technologies like online education or telepresence robots may be means to secure adherence to education for those at risk of frequent or prolonged absences [13, 39].

4.5. Motivation and Sense of Belonging. Many respondents answered that they always or mostly felt bad if they could not overcome the same things as their peers; this was more common for those with only primary and lower secondary education. Asked about belonging at primary and lower secondary school, 18.6% of all participants answered that they seldom or never had felt a sense of belonging and 22% that it was always or mostly difficult to participate in social activities. This is unfortunate since it is important for people to feel valued and to belong to a social group as this creates a dimension of social identity [39, 40]. Our results showed that around 35% of the people with only primary and lower secondary education answered always or mostly to have given social activities lower priority to save energy for their education, a job, or other activities. This might indicate that people with low educational status are less prone to engage in social communities and, thus, at risk of becoming more isolated and lonelier. Therefore, it is important to ensure

that students with NMD receive help and support to cope with the symptoms of their disease in order to strengthen participation in school and academic activities all the way through the educational system. For future research, it is relevant to investigate whether students with certain diagnoses are more exposed to educational absence and/or drop out of their education. Moreover, it would be relevant to investigate which paths those who drop out of the educational system choose in life.

4.6. Strength and Limitations. Out of 501 invited participants, 172 people with NMD were included in the analysis, resulting in a response rate of 34.3% which is considered good in a survey. Our sample represents participants of various ages within the inclusion criteria and a broad spectrum of NMD diagnoses vouching for the transferability to other contexts, countries, and populations of young people with disability. Unfortunately, we do not know who the nonresponders were and whether they differ from the respondents in terms of age, sex, educational level, or function. Furthermore, the sample of our study population with only primary and lower secondary education was small with only 17 respondents (out of the total sample of 172), making it difficult to draw strong conclusions based on this group.

The study is based on a patient-reported questionnaire in which participants were asked to answer questions about their schooling. For some respondents, recall bias might have affected their answers since it can be difficult to remember exactly how they experienced their schooling after several years. Additionally, the questions about schooling alternated between general and more specific educational questions, which might have been difficult to navigate. Finally, some of the participants were not diagnosed with NMD until after they had finished school, and this might also have affected their answers. Nevertheless, our results present novel and important information on factors of importance for continuing education after primary school in young people with NMDs.

5. Conclusion

Our results show novel knowledge on factors of importance for continuing education after primary school in young people with NMDs. We found that a higher percentage of young people with NMD were attending special needs classes than the background population, special needs that may be related to cognition, functioning, and/or fatigue. We also found that teachers carry a responsibility to communicate with young people with NMDs and their parents and to ensure that the young people acquire adequate academic skills and that they can actively participate in classroom activities. Supportive initiatives to prevent loneliness, including social skills training, increased social support, opportunities for social interaction, and cognitive behavioral exercises, are important for keeping young people with NMD in the educational system. It is essential to ensure inclusion in education by informing about options for help and assistance, including the possibility of prolonging studies if needed. Additionally, it is important to ensure accessible education

adapted to specific needs to support young people with NMDs and school absence. It is important to integrate technological solutions such as online lessons or telepresence robots to ensure education for students hindered by illness or fatigue. Finally, parents and teachers must be made aware of the importance of expressing expectations to young people with NMDs to influence their choices regarding education and future work life positively. We believe that our findings can be transferred to other groups of people with disabilities, contexts, countries, and chronic diseases.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

Conflicts of Interest

The authors declare no conflicts of interest.

Author Contributions

All authors have made substantial contributions to all of the following: (1) the conception and design of the study, or acquisition of data, or analysis and interpretation of data; (2) drafting the article or revising it critically for important intellectual content; and (3) final approval of the version to be submitted.

Funding

There is no funding to report.

Acknowledgments

We would like to thank all the people with NMD who participated and filled out the questionnaire survey, making this study possible.

References

- [1] M. A. Grootenhuys, J. de Boone, and A. J. van der Kooij, "Living With Muscular Dystrophy: Health Related Quality of Life Consequences for Children and Adults," *Health and Quality of Life Outcomes*, vol. 5, p. 31, 2007.
- [2] P. Mary, L. Servais, and R. Vialle, "Neuromuscular Diseases: Diagnosis and Management," *Orthopaedics & Traumatology, Surgery & Research*, vol. 104, no. 1, pp. S89–s95, 2018.
- [3] R. Thompson, A. Robertson, and H. Lochmüller, "Natural History, Trial Readiness and Gene Discovery: Advances in Patient Registries for Neuromuscular Disease," *Advances in Experimental Medicine and Biology*, vol. 1031, pp. 97–124, 2017.
- [4] A. C. Aho, S. Hultsjö, and K. Hjelm, "Perceptions of the Transition From Receiving the Diagnosis Recessive Limb-Girdle Muscular Dystrophy to Becoming in Need of Human Support and Using a Wheelchair: An Interview Study," *Disability and Rehabilitation*, vol. 41, no. 19, pp. 2289–2298, 2019.
- [5] C. Handberg and U. Werlauff, "Cross-Sectorial Collaboration on Policy-Driven Rehabilitation Care Models for Persons

- With Neuromuscular Diseases: Reflections and Behavior of Community-Based Health Professionals,” *BMC Health Services Research*, vol. 22, no. 1, p. 1168, 2022.
- [6] R. A. Hughes, A. Sinha, I. Higginson, K. Down, and P. N. Leigh, “Living With Motor Neurone Disease: Lives, Experiences of Services and Suggestions for Change,” *Health & Social Care in the Community*, vol. 13, no. 1, pp. 64–74, 2005.
- [7] Statistics Denmark [Danmarks Statistik], “Statistics Denmark,” 2024, Available from: <https://www.dst.dk/da/>.
- [8] Ministry of Children and Education [Børne- og Undervisningsministeriet], “Key Figures About the Schools. [Nøgletal om skolerne],” 2023, <https://uddannelsesstatistik.dk/Pages/main.aspx>.
- [9] A. Ø. S. Amilon, *Living Conditions Among People With Disabilities [Levevilkår blandt mennesker med handicap]*, VIVE The International Research and Analysis Center for Welfare [Det internationale forsknings- og analysecenter for velfærd], 2023.
- [10] A. Lum, C. E. Wakefield, B. Donnan, M. A. Burns, J. E. Fardell, and G. M. Marshall, “Understanding the School Experiences of Children and Adolescents With Serious Chronic Illness: A Systematic Meta-Review,” *Child: Care, Health and Development*, vol. 43, no. 5, pp. 645–662, 2017.
- [11] G. R. Maslow, A. Haydon, A. L. McRee, C. A. Ford, and C. T. Halpern, “Growing Up With a Chronic Illness: Social Success, Educational/Vocational Distress,” *Journal of Adolescent Health*, vol. 49, no. 2, pp. 206–212, 2011.
- [12] A. E. Martinez-Santos, J. D. C. Fernandez-De-La-Iglesia, G. Sheaf, and I. Coyne, “A Systematic Review of the Educational Experiences and Needs of Children With Cancer Returning to School,” *Journal of Advanced Nursing*, vol. 77, no. 7, pp. 2971–2994, 2021.
- [13] M. Weibel, S. Skoubo, C. Handberg et al., “Telepresence Robots to Reduce School Absenteeism Among Children With Cancer, Neuromuscular Diseases, or Anxiety—The Expectations of Children and Teachers: A Qualitative Study in Denmark,” *Computers in Human Behavior Reports*, vol. 10, Article ID 100280, 2023.
- [14] B. E. Gibson, B. Mistry, B. Smith et al., “Becoming Men: Gender, Disability, and Transitioning to Adulthood,” *Health*, vol. 18, no. 1, pp. 95–114, 2014.
- [15] B. E. Gibson, H. Zitzelsberger, and P. McKeever, “Futureless Persons’: Shifting Life Expectancies and the Vicissitudes of Progressive Illness,” *Sociology of Health & Illness*, vol. 31, no. 4, pp. 554–568, 2009.
- [16] J. H. Rudolfsen, J. Vissing, U. Werlauff et al., “Burden of Disease of Duchenne Muscular Dystrophy in Denmark—A National Register-Based Study of Individuals with Duchenne Muscular Dystrophy and their Closest Relatives,” *Journal of Neuromuscular Diseases*, vol. 11, no. 2, pp. 443–457, 2024.
- [17] C. H. Udesen, C. Skaarup, M. N. S. Petersen, and A. K. Ersbøll, *Social inequality in health and illness - The development in Denmark in the period 2010 - 2017 [Social ulighed i sundhed og sygdom - Udviklingen i Danmark i perioden 2010 - 2017]*, The Danish Health Authority, 2020.
- [18] WHO (World Health Organization), “Social Determinants of Health,” 2023, Available from: https://www.who.int/health-topics/social-determinants-of-health#tab=tab_1.
- [19] RCFM, “National Rehabilitation Center for Neuromuscular Diseases [RehabiliteringsCenter for Muskelsvind],” 2024, <https://rcfm.dk/>. 2023.
- [20] RCFM, “National Rehabilitation Center for Neuromuscular Diseases [RehabiliteringsCenter for Muskelsvind],” 2017, Coperate plan 2017-2021 [Virksomhedsplan 2017-2021]. <http://rcfm.dk/wp-content/uploads/2017/01/Virksomhedsplan-2017-2019.pdf>.
- [21] C. Handberg, H. Munkholm, and A.-L. Højberg, “Perspectives of Young People with Neuromuscular Diseases Regarding Their Choice of Educational Programs and Possibilities to Complete Program Requirements,” *Global Qualitative Nursing Research*, vol. 11, 2024.
- [22] The World Medical Association, “WMA Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects,” vol. 2016, 2016 <https://www.wma.net/policies-post/wma-declaration-of-helsinki-ethical-principles-for-medical-research-involving-human-subjects/>.
- [23] J. N. Miller, A. Kruger, D. J. Moser et al., “Cognitive Deficits, Apathy, and Hypersomnolence Represent the Core Brain Symptoms of Adult-Onset Myotonic Dystrophy Type 1,” *Frontiers in Neurology*, vol. 12, Article ID 700796, 2021.
- [24] S. Jean, L. Richer, L. Laberge, and J. Mathieu, “Comparisons of Intellectual Capacities Between Mild and Classic Adult-Onset Phenotypes of Myotonic Dystrophy Type 1 (DM1),” *Orphanet Journal of Rare Diseases*, vol. 9, no. 1, p. 186, 2014.
- [25] S. Vicari, G. Piccini, E. Mercuri et al., “Implicit Learning Deficit in Children With Duchenne Muscular Dystrophy: Evidence for a Cerebellar Cognitive Impairment?,” *PLoS One*, vol. 13, no. 1, Article ID e0191164, 2018.
- [26] M. G. D’Angelo, M. L. Lorusso, F. Civati et al., “Neurocognitive Profiles in Duchenne Muscular Dystrophy and Gene Mutation Site,” *Pediatric Neurology*, vol. 45, no. 5, pp. 292–299, 2011.
- [27] Ministry of Children and Education [Børne- og Undervisningsministeriet], “Rules for special education [Regler for specialundervisning],” 2024, Available from: <https://www.uvm.dk/folkeskolen/laering-og-laeringsmiljoe/specialundervisning/regler-for-specialundervisning>.
- [28] M. J. V. Larsen and C. H. Mikkelsen, *Disability and Employment [Handicap og beskæftigelse]*, VIVE-The Danish Center for Social Science Research, 2022, Available from: <https://www.vive.dk/da/udgivelser/handicap-og-beskaeftigelse-2022-yz21gq0v/>.
- [29] Ministry of Children and Education [Børne- og Undervisningsministeriet], “This Year’s Application Figures for Youth Programs Have Now Been Calculated [Årets søgetal til ungdomsuddannelserne er nu opgjort],” 2023, Available from: <https://www.uvm.dk/aktuelt/nyheder/uvm/2023/april/230417aarets-soegetal-til-ungdomsuddannelserne-er-nu-opgjort>.
- [30] S. Bengtsson and G. N. Datta, “Identifying the Effects of Education on the Ability to Cope With a Disability Among Individuals With Disabilities,” *PLoS One*, vol. 12, no. 3, Article ID e0173659, 2017.
- [31] A.-L. Højberg and J. Jeppesen, “Examining the Effect of Networks for Students With Special Educational Needs,” *Scandinavian Journal of Disability Research*, vol. 14, no. 2, pp. 126–147, 2012.
- [32] R. F. Quenemoen and M. L. Thurlow, “Students with Disabilities in Educational Policy, Practice, and Professional Judgment: What Should We Expect? NCEO National Center on Educational Outcomes,” 2019, Available at: <https://nceo.umnn.edu/docs/OnlinePubs/NCEOReport413.pdf>.

- [33] C. Handberg, H. Munkholm, and A. L. Højberg, "Perspectives of Young People with Neuromuscular Diseases Regarding Their Choice of Educational Programs and Possibilities to Complete Program Requirements," *Global Qualitative Nursing Research*, vol. 11, Article ID 23333936241271126, 2024.
- [34] G. Astrea, R. Battini, S. Lenzi et al., "Learning Disabilities in Neuromuscular Disorders: A Springboard for Adult Life," *Acta Myologica*, vol. 35, no. 2, pp. 90–95, 2016.
- [35] European Agency for Special Needs and Inclusive Education (EASNIE), "Country Information for Denmark-Systems of Support and Specialist Provision," 2025, Available from: <https://www.european-agency.org/country-information/denmark/systems-of-support-and-specialist-provision>.
- [36] K. Berry, T. Frahm, A. McArthur, C. Trout, and B. Wojciechowski, *A Teacher's Guide to Neuromuscular Disease*, Muscular Dystrophy Association, 2017, Available from: https://www.mda.org/sites/default/files/Teachers_Guide_booklet.pdf.
- [37] S. Skoubo, C. Handberg, M. Weibel, and H. B. Larsen, "School Absence Legislation Governing in Norway, Sweden and Denmark for Children With Chronic Illness in Compulsory Education-a Comparative Study," *Scandinavian Journal of Caring Sciences*, vol. 38, no. 4, pp. 936–947, 2024.
- [38] IHME-CHAIN Collaborators, "Effects of Education on Adult Mortality: A Global Systematic Review and Meta-Analysis," *Lancet Public Health*, vol. 9, no. 3, pp. e155–e165, 2024.
- [39] A. McNicholl, D. Desmond, and P. Gallagher, "Feeling Valued: The Interplay of Assistive Technology and Identity," *Disability and Rehabilitation. Assistive Technology*, vol. 19, no. 7, pp. 2580–2591, 2024.
- [40] B. Garcia-Lee, I. Strnadová, and L. Dowse, "Researching Belonging in the Context of Research With People With Intellectual Disabilities: A Systematic Review of Inclusive Approaches," *Journal of Applied Research in Intellectual Disabilities*, vol. 37, no. 1, Article ID e13178, 2024.