

Perspectives of Young People with Neuromuscular Diseases Regarding Their Choice of Educational Programs and Possibilities to Complete Program Requirements

Global Qualitative Nursing Research
Volume 11: 1–12
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DOI: 10.1177/23333936241271126
journals.sagepub.com/home/gqn



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Abstract

Young people with impaired functioning and/or disability do not receive as much education or as high an education as fully functioning young people, thus limiting their job opportunities. Therefore, the aim of this study was to investigate perspectives of young people with neuromuscular diseases regarding their choice of educational programs and possibilities to complete program requirements to gain knowledge for use in future counselling and the development of a national questionnaire survey. The design for this study was qualitative using the interpretive description methodology and Anthony Giddens' theory on modernity and self-identity. Data were generated through two focus group interviews with seven people between 18 and 30 years of age. Beginning and completing an education was influenced by the creation of identity: the importance of experiencing demands and expectations, the meaning of social relations when learning, and the consequences of accessibility for educational opportunities. The participants' sense of self-identity was built by testing boundaries and developing images through social relations with peers, parents, and teachers. How they acted and behaved in the social arena of school and education influenced their choices and chances of completing educational programs.

Keywords

neuromuscular disease, education, adolescents, interpretive description, Giddens, Denmark

Received November 3, 2023; revised June 27, 2024; accepted July 1, 2024

Introduction

Early life determinants of health like living with a neuromuscular disease (NMD) may involve physical, emotional, practical, and social difficulties, which can affect health and social position negatively (Aho et al., 2019). Education is one of the most important determinants of doing well in life with regard to health, mortality, and quality of life (Udesen et al., 2020). Because of an impaired functioning young people with NMD are especially at risk of being absent from school and leisure activities due to various symptoms of their NMD, and frequent follow-ups at the hospital (Hughes et al., 2005). Some of the NMD diagnosis are associated with higher odds of lost labor market participation and long-term sick leave (Frost et al., 2016; J. H. Rudolfson et al., 2024).

Young people with impaired functioning and/or disability do not receive as much education or as high an education as fully functioning young people, thus limiting their job

opportunities (Knowledge Center on Disability, 2022; Larsen et al., 2022; Pihl & Salmon, 2021; Udesen et al., 2020).

NMDs are known to entail progressive loss of muscular strength, muscular atrophy, fatigue, pain, and bulbar symptoms, and moreover they have a negative effect on quality of life, all factors that can lead to limited job opportunities (Grootenhuys et al., 2007; Mary et al., 2018; Thompson et al., 2017). The term NMD is used for several chronic and progressive hereditary NMD subtypes. NMDs consist of a heterogeneous population of conditions with similar symptoms

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and impairment of functioning over time. (Grootenhuis et al., 2007; Handberg & Werlauff, 2022). Some of the NMDs progress rapidly, whereas others have a slower trajectory. Nevertheless, living with a NMD entails impaired functioning and an increasing dependency on help and assistive devices, which influences the ability of those affected to participate in school and in educational programs (Handberg et al., 2022; Weibel et al., 2023).

The prevalence and clinical course of specific NMDs differ between males and females (Vinciguerra et al., 2023). Some genetic neuropathies are more common and severe in women, and pregnancy is known to unmask NMDs or modify its course. Some dystrophies are more prevalent in men, and atrophies are known to be more severe in men (Vinciguerra et al., 2023). Children and youth with these progressive conditions are expected to live well into adulthood, underscoring their need for equal educational opportunities (Gibson et al., 2014). Nevertheless, research has shown that teachers of students with Duchenne muscular dystrophy (one of the larger groups of NMDs) tended to have lower expectations of their students with these diseases than students without it (Højberg & Jeppesen, 2012). In one study, only 63% of the teachers in regular schools and none of the teachers in special needs schools expected the students with a NMD to take a final examination (Højberg & Jeppesen, 2012).

Quality education is the fourth sustainable global development goal: to ensure inclusive and equitable quality education and promote lifelong learning opportunities for all by 2030 (United Nations, 2015). However, 86% of all fully functioning 18-year-olds start upper secondary education (10th–12th grades), whereas only 66% of people with a disability or psychiatric diagnosis do (Pihl & Salmon, 2021). In general, young people with a chronic illness or disabilities tend to be more absent from school and educational programs than young people without a chronic illness or disability, the reasons being poorer well-being or illness, insufficient compensatory education, and lack of opportunities to obtain a final examination (Danish Patients, 2016; Lund et al., 2019; D. R. Rudolfson & Mikkelsen, 2020). Furthermore, higher education is completed by fewer students with impaired functioning because they experience a lack of compensation and flexibility and difficulties with exemption applications and assistive devices (Danish Agency for Higher Education and Science, 2022).

The literature is sparse on factors that promote the social participation of young people with NMD in educational life (Jeppesen et al., 2010; Mazzella et al., 2021; Schiøler & Dahl, 2012; Vuillerot et al., 2010; World Health Organization, 2024). To gain more knowledge about the opportunities for young people with NMD to complete a youth education or find suitable employment opportunities, it is relevant to investigate factors influencing these young peoples' way through the educational system and in the surrounding

society. Therefore, the aim of this study was to investigate perspectives of young people with NMDs regarding their choice of educational programs and possibilities to complete program requirements to gain knowledge for use in future counselling and the development of a national questionnaire survey.

Methods

Design

The design for this study was qualitative using the interpretive description methodology (Handberg & Jensen, 2021; Thorne, 2016). Interpretive description is an inductive qualitative applied research methodology aiming to address clinical challenges and bring back solutions to practice based on the research findings.

Theoretical Framework

We used the English sociologist Anthony Giddens' description of the modern person's self-identity (Giddens, 2013; Ravn, 2019) as our inductive analytical lens for the interview guide and the analysis process. This lens provided the means to elaborate on data while still analyzing inductively in the light of the how the social arena of school and the education influenced and shaped the participants' self-identity building (Giddens, 2013; Ravn, 2019). Giddens has described the modern person's self-identity as a dimension that, unlike in the past, will never be able to be definitively established (Giddens, 2013; Ravn, 2019), which was relevant for this study in which we aimed to gain insight into young people's thoughts on their choices of an education.

According to Giddens, it was previously thought that people were born into a certain identity because of their lineage or family's social status, whereas today, we recognize that a person's identity is a person's own responsibility (Giddens, 2013; Ravn, 2019). This weakening of traditions force individuals to make their own lifestyle choices, and these choices are of great importance for the preservation of self-identity. Giddens believes that people in late modern society are characterized by adapting to the social arenas they move in while they move in them—and they can quickly adapt to new environments. He believes that one's behavior in certain social arenas helps to define who one is—and thus give one an identity (Giddens, 2013; Ravn, 2019). One's way of being and identifying changes depends on which arena one is in without being confused about their role in that arena (Giddens, 2013; Ravn, 2019). We chose this specific theory as our inspiration for the inductive interpretive description analysis to gain insight into the fundamental forces driving young people with NMD to make choices in relation to their education (Handberg & Jensen, 2021; Thorne, 2016).

Setting

In Denmark, people with a NMD can be referred to the National Rehabilitation Center for Neuromuscular Diseases (RCFM) by a neurologist or general practitioner. RCFM is a highly specialized hospital that provides knowledge and counseling for most people with NMDs and their families as well as for collaborative partners at hospitals or in local community care settings (RCFM, 2017, 2024). The professionals at RCFM frequently encounter people with NMDs who, for various reasons, do not start an education or have difficulties in completing one. The three members of the research group are women based in the RCFM as researchers or clinicians and all have many years of experience with the field of NMD among them. Two of the authors (AH and HM) are occupational therapists (37 and 16 years of research and clinical experience within NMD), and one (CH) is a registered nurse, senior researcher, and associate professor (6 years of research experience within the NMD field). The research group did not know the participants before the study.

Sampling and Data

At the start of the study in May 2022, 517 persons with NMD, aged 18 to 30, were registered with the RCFM. We sent invitations to participate in focus group interviews by email to 102 persons, 51 persons (25 women/26 men) in the first invitation round and 51 persons (29 women/22 men) in the second. The invited persons were chosen by purposive sampling regarding age and educational background. In all, 16 responded to the invitation and 86 never responded. Nine of the 16 who responded opted out due to various reasons: did not wish to participate, had cognitive challenges, could not participate on the scheduled dates, doubted the relevance of participation, or did not have the energy or fell ill. Persons with amyotrophic lateral sclerosis (ALS) were excluded.

Focus group interviews were chosen as a method because we wanted the participants to be inspired by each other regarding how they understood and valued different educational choices. Moreover, the information from the focus group interviews was used to inspire and help develop the content of a national questionnaire survey on the same topic, which we plan to conduct after completion of the present study. Seven people participated in two focus group interviews conducted by the AH and HM (Table 1). One group consisted of three participants (2 women and 1 man) and one consisted of four participants (3 women and 1 man). Both interviews were carried out online on the Microsoft Teams platform and recorded. The interviews lasted between 1 hr and 58 min and 2 hr and 5 min. An advisory group that included people with NMD was involved in determining the interview questions. Key questions were What is your level of functioning? How would you describe your school years? What has been of importance to you regarding choosing how to go forward in the educational system? How would

Table 1. Sample Characteristics (n=7).

Characteristics	n (%)
Age, mean (range)	26 (18–30 years)
<i>Gender</i>	
Women	5 (71)
Men	2 (29)
<i>Diagnosis</i>	
Atrophies	1 (14)
Dystrophies	2 (29)
Neuropathies	2 (29)
Myopathies	1 (14)
Autoimmune diseases	1 (14)
<i>Mobility</i>	
Ambulant	4 (57)
Non-ambulant	3 (43)
<i>Education</i>	
Upper secondary education completed	2 (29)
Professional bachelor's degree completed	1 (14)
University education underway	3 (43)
Secondary education underway	1 (14)
<i>Residence</i>	
Jutland (around 2,237,000 citizens)	3 (43)
Zealand (around 836,700 citizens)	4 (57)

you describe your years of schooling compared to those of your peers? How has your functioning affected your possibilities to adhere to the educational program? How would you describe your social relations during your years at school? Who supported you when you made choices regarding your education? What are your wishes in relation to education and a future job?

Analysis

The analysis was guided by interpretive description, which is an inductive research methodology with a coherent conceptual description and in-depth interpretation of relationships and patterns within the phenomenon under investigation (Handberg & Jensen, 2021; Thorne, 2016). The methodology is grounded in a thinking and understanding that research must stem from challenges arising in or from practice and transferring new insights and knowledge back into practice (Handberg & Jensen, 2021; Thorne, 2016). The analytical process was conducted by the whole author group and followed the four-step process of interpretive description. The four steps in the analysis consisted of (1) transcription of all data and initial coding, uploading of data to NVivo™ 12, and coding data for each informant, (2) assessment and appraisal of particular circumstances and generalized patterns in relation to the study aim were identified, (3) a critical appraisal of relationships and thematic options leading to the primary categorizations, and (4) finally, an extraction of the main messages in the data forming the overarching categorical

Table 2. The Coding and Analysis Process Leading Up to the Final Categorical Themes—Guided by Interpretive Description Methodology and the Theoretical Lens of Anthony Giddens' Description of the Modern Person's Self-Identity.

Contents	First analytical step	Second analytical step	Third analytical step	Fourth analytical step
Description of the content and process of the four analytical steps in regard to interpretive description	A process of discernment of particular circumstances and generalized patterns in relation to study aim	A critical appraisal of relationships within data and relevance of thematic options leading to the primary categorization	Extraction of main messages arising from key insights within the data to be captured in the form of a final categorization structure	A model illustrating the hierarchy and interrelationships between the themes and displaying the final findings reported in the results section.
Theoretical lens of Anthony Giddens	Anthony Giddens' description of the modern person's identity, or self-identity	Anthony Giddens' description of the modern person's identity, or self-identity	Anthony Giddens' description of the modern person's identity, or self-identity	Anthony Giddens' description of the modern person's identity, or self-identity
Codes and subthemes leading up to the final categorical themes	The shaping of identity Self-esteem and self-confidence Empowerment—strength and control Dreams and reality Inner demands and expectations Outer demands and expectations Striving for normalcy Importance of social relations Being like no one else and everyone else Stigmatization and bullying Taking control of one's own situation Being alone versus being social Physical and academic accessibility Challenged by functioning	Self-esteem affected the choice of being open Balancing dreams and reality Demands and expectations of oneself Demands and expectations of others Guilt and stigmatization in social relations The influence of interactions with student peers Physical and educational accessibility	The creation of self-identity in relation to education The meaning of experiencing demands and expectations The meaning of social relations when learning The importance of accessibility for educational opportunities	

themes (Handberg & Jensen, 2021; Thorne, 2016) (Table 2). Saturation is not an endpoint in interpretive descriptive methodology since one can never know what information the next participant will bring forward (Saunders et al., 2018; Thorne, 2016). However, the data represented a reasonable range of experiences to address the aim of this study.

Ethics

The Central Denmark Region Committees on Biomedical Research Ethics determined that 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 interview surveys to the research ethics committee system is only required if the project involves human biological material. The study was conducted in accordance

with the Helsinki Declaration of 1975 (The World Medical Association, 2016). Oral consent and written informed consent were obtained directly from all individual participants included in the study. The participants were informed that participation was voluntary and that they were guaranteed anonymity. No identifying information is included in this article. The present study adheres to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines (Tong et al., 2007).

Findings

The analysis resulted in a detailed understanding of how participants built an identity, and ways their choices related to school and education were part of this process. Both inner and outer factors were important in shaping these choices and for building and strengthening their self-identity in the social arena of school and education. The inner factors represented

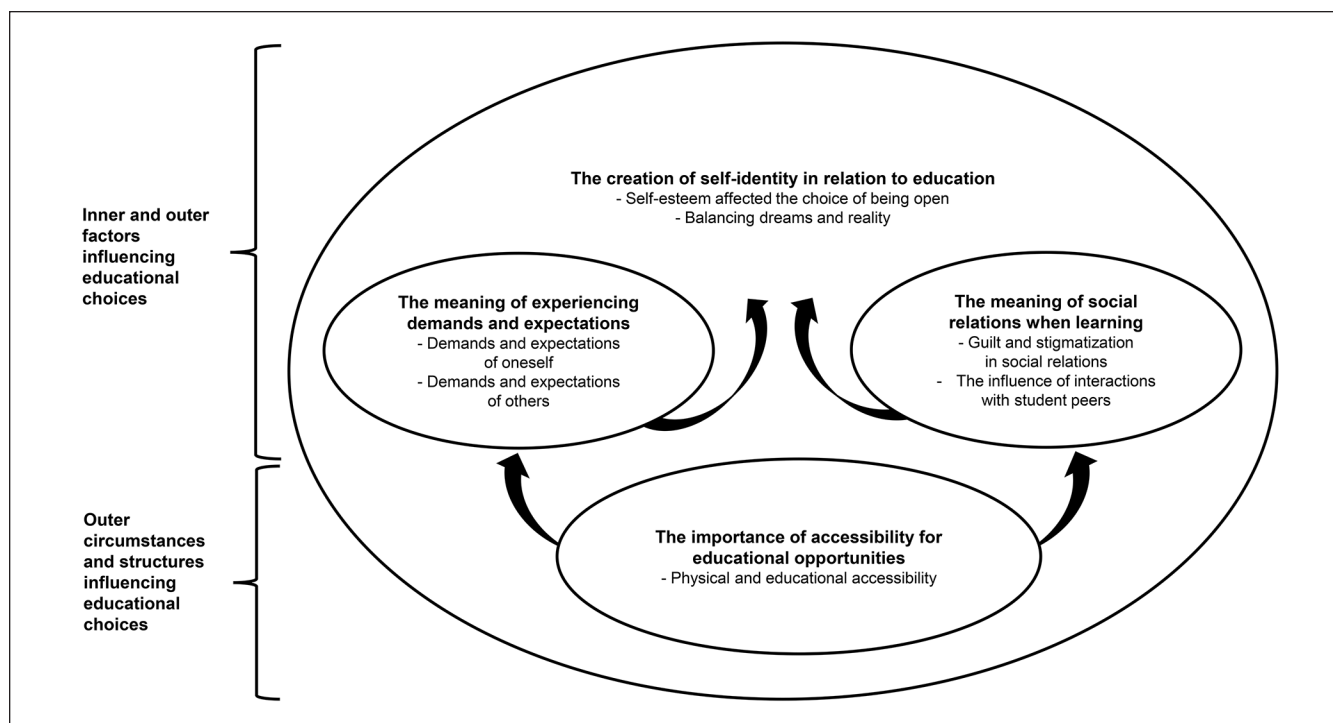


Figure 1. Perspectives of young people with NMDs regarding their choice of educational programs and possibilities to complete program requirements.

the factors experienced by the participants themselves, whereas the outer factors represented the contextual factors that affected the participants. The analysis helped to identify how the participants' sense of self-identity was built by testing boundaries and developing an image through social relations with peers, parents, and teachers. Living with a NMD affected the participants' self-identity. They worried about explaining to their fellow students that having a NMD was part of their identity. They described that their condition shaped them as a person, student, and friend and could both facilitate or hamper their educational possibilities and a future work life.

We identified four themes and related subthemes that reflect important influences on participants' choice of educational programs and possibilities to complete program requirements (Figure 1): three themes represent inner and outer factors influencing educational choices: (1) the creation of self-identity in relation to the education, shaped the participants' self-esteem affecting the choice of being open and balancing their dreams to their reality, (2) the meaning of experiencing demands and expectations including those one had of oneself as well as those emanating from others in one's surroundings, and (3) the meaning of social relations while learning when underpinned by guilt and stigmatization and influenced by interactions with student peers. The fourth theme represents the outer circumstances and structures influencing educational choices and focused on the importance of accessibility of educational opportunities.

The Creation of Self-Identity in Relation to Education

Self-Esteem Affected the Choice of Being Open. All the participants explained that their self-esteem and self-confidence could be influenced negatively due to many circumstances. Living with a NMD could affect them if others regarded them as ill, a role they did not want to take upon themselves. Experiencing being different from their fellow students could be overwhelming, chaotic, and lead to feeling lonely.

The participants elaborated on how they felt empowered if they chose to be open and frank about their NMD and their needs instead of concealing them. They explained that they had had several considerations regarding how and when to reveal themselves to others, how open they should be, and if they should share information about their NMD, which was especially the case for the participants who had an invisible disability. Having had the courage to tell their fellow students and teachers about their NMD and their needs often led to a feeling of empowerment, and the participants described a feeling of taking responsibility, which also affected them in their further educational life.

The first time I experienced saying out loud that I have a NMD was quite liberating actually. I wish I had known how much freedom it would bring, because then I would have been more open about it when I was younger. (Participant 3, Woman, Late twenties, Ambulant)

Participants explained that education was important for their overall identity building and independency, and that they experienced contributing to society and being a part of a larger community through education. In addition, the meaning of having something meaningful to get up to in the morning was important for them, but it also influenced their self-esteem positively.

Balancing Dreams and Reality. The participants' educational choices were based on considerations that had often been thought about for years. Dreaming of graduating from an educational program or being hired for a preferred job was something the participants were doing or had been doing before they made their educational choices. However, these dreams sometimes exceeded their abilities. For example, participants explained they lacked the self-knowledge to realistically evaluate their abilities for a job and simply chose to take up desired employment opportunities like their friends.

I worked as a waiter for several months, and that was very physically demanding. When I came home my body just hurt so much. I just went on and on, because I thought, if my friends can do it so can I. (Participant 5, Woman, Late teens, Ambulant)

The participants explained this lack of insight as being related to immaturity and a younger age. When they got older, a more realistic balancing occurred regarding educational choices and future work possibilities. The participants explained that experience gained from a student job would have benefitted their future job possibilities, but due to their disability and the consequences of it, this was difficult.

You usually get told over and over how important it is to have experience gained from a study-relevant student job alongside your studies, and I simply had to say that I can't do that. I barely have the energy to get through my studies. If I had to work on the side, then I would simply break down completely. (Participant 6, Woman, Early thirties, Ambulant)

The burden of the disease, for example, fatigue, lack of energy and pain, made it difficult for the participants to perform in the same degree as their peers in everyday life.

The Meaning of Experiencing Demands and Expectations

Demands and Expectations of Oneself. The participants emphasized that they had demands and expectations of themselves about considering educational choices and how these expectations could either put a strain on them or lead to a feeling of empowerment. They explained having grown up learning to think about possibilities instead of barriers and that this helped them stay positive regarding education and future job possibilities.

All the way back to the time I was in primary school, I've had the feeling that my NMD wasn't a disadvantage, it was more my superpower. Because if my legs didn't work, my head worked, and that's what enabled me to contribute to something, or with something, at school. (Participant 2, Man, Late twenties, Non-ambulant)

However, the participants expressed that they often had difficulties in relation to their demands and expectations of themselves, for instance, feeling guilty when they were away from school due to being ill or exhausted because of their NMD or having to attend hospital follow-up visits.

I really do recognize that shame and having a guilty conscience about missing out made me feel a little trapped. I also had periods in high school when I was hospitalized, and I kept that to myself. (Participant 3, Woman, Late twenties, Ambulant)

Often, they would find it hard to keep up at school, as absenteeism was an issue for all the participants, and they would explain that they felt ashamed when they had to struggle to keep up and performed poorly or failed a subject.

Demands and Expectations of Others. The demands and expectations of their parents or teachers were explained as being helpful. Their parents helped them understand and consider what was possible and what was not, emphasizing, for instance, choosing a job where they could use their cognition and not rely on their body.

One day my father ask me to sit down. . . , I think it was in the 6th grade, and then he said: "You're not going to be a cook." I responded: "Well okay." "You only have your head". I remember that as a very defining moment for me. . . This was the point where I started to get very serious about my homework. (Participant 7, Woman, Late twenties, Ambulant)

Some participants explained they that felt a pressure to keep up with their peers and get high grades so they would be able to get an academic education. The feeling of pressure could lead to stress and a feeling of defeat. However, they at the same time argued that expectations could push them forward and be a positive experience related to making choices for their future themselves.

In primary school, I did have some support from teachers who helped me. They also paid a lot of attention to. . . the fact that you need to use your head when you can't use your body. (Participant 1, Man, Late twenties, Non-ambulant)

All the participants underscored the important influence of others and the positive effect this had on their belief in themselves and in their capabilities regarding an education and a future work life.

The Meaning of Social Relations When Learning

Guilt and Stigmatization in Social Relations. All the participants explained that sometimes they felt guilt and stigmatization concerning their education. These feelings were described as feeling different, “unnatural,” and as an outsider among their peers. Some of the participants had experienced bullying because of being different when they were younger. They all explained how difficult this was as a young person who just wanted to fit in and be like everyone else. Participants shared experiences of guilt such as when their parents had to take time off from their work if they needed to be at home from school due to their NMD. This guilt led to participants believing it was their duty to make their education worth the sacrifices their parents made. They often felt stigmatized because fellow students and teachers they did not understand the consequences of NMDs like, for instance, interpreting fatigue as laziness. As a consequence, classmates sometimes hesitated to establish close friendships or personal relationships with them, which often led to isolation and loneliness.

All the way up to upper secondary education, I experienced people who still didn't quite dare to let go of their timidity and ask me about one thing or another, even though we had been to parties and been. . . , you know, “normal” young people. So, I still experienced a lack of openness in some way. (Participant 2, Man, Late twenties, Non-ambulant)

The participants described these feelings and experiences as being worse when they were younger and less open about their NMD and their needs. Although they tried to ignore their NMD and hide its symptoms in order to fit in, this often led to pressuring themselves to keep up socially, which could be exhausting, stressful, and sometime painful due to an excessive load on their bodies.

I can't put any more pressure on myself because the exams are beyond what I can manage within a time limit. . . , I feel that the situation is irredeemable, and not being able to do the exam gave me a guilty conscience because I didn't succeed, . . . it is enormously stressful. (Participant 3, Woman, Late twenties, Ambulant)

The participants often experienced guilt because their parents made many sacrifices, and therefore, the participants felt that it was their duty to make their education worth the effort.

The Influence of Interactions with Student Peers. Friendships and social relations were of huge importance for the participants in order to feel included and empowered and provided the energy to study. However, being young and having a NMD while getting an education was described as a strain on social relations. It could be difficult to have the energy to participate in social events after class. Sometimes social

events would take place where the participants were unable to take part because of either lack of accessibility or lack of energy. Taking the initiative to plan social events was one way to ensure they could participate, as explained by this participant.

It is extremely important to me to be a good friend, and I often invite my girlfriends to dinner. . . I'm often the one that arranges events and do things, and you can say. . . that I do it because I want to be with these people. But I also think that it is because of a kind of a survival instinct. . . being the one who invites and provides. . . Because if I invite, then I also make sure that it is under terms that make it possible for me to join in. . . Then I am sure that I won't be excluded. (Participant 4, Woman, Mid-twenties, Non-ambulant)

Exclusion from solidarity with fellow students was a constant worry, which typically demanded a lot of energy from the participants. When alone, for instance, during breaks or after school, knowing their fellow students were socializing led to loneliness or excessive studying.

I was challenged, especially during the breaks. I remember it being difficult for me to play with the others—participate in their games like running or sliding around—you know, the stuff children do. In that way I often felt left out or left alone during the breaks. (Participant 4, Woman, Mid-twenties, Non-ambulant)

The participants knew that they were different and maybe looked different because of their NMD. Consequently, they were concerned about how open and vulnerable to be with their friends, without exposing behaviors that might put at risk relationships with others who wanted to spend time with them, and the opportunity to be “normal” and “fit in.”

The Importance of Accessibility for Educational Opportunities

Physical and Educational Accessibility. All the participants explained that their functioning had played a role in their choice of education, but physical and educational accessibility had also been of huge importance for both their choice of an education and the possibility to follow the education through. Often, they experienced difficult or total lack of access to educational buildings and a lack of understanding of their needs by the educational staff.

The teachers don't understand this disease at all. Many people don't understand the disease because they can't see it. And I constantly must explain that it's not because I don't want to take part in a certain activity, I do, but I'm just not going to be able to participate in all of it. (Participant 7, Woman, Late twenties, Ambulant)

Lack of access to educational institutions made certain educational choices impossible. For instance, one participant was not able to go to the same school as his/her friends because of lack of accessibility. Furthermore, their disabilities could affect the learning process. If they had impaired arm and hand function, it could be difficult and time consuming to take notes during classes, which meant that they had to complete the notes at home. Several of the participants explained that they were unaware of what possibilities they had for compensation and support during their education and how important it was to be met with understanding by teachers and/or student counselors.

The only obstacle is that not all universities allow you to live stream or videotape lectures, which might have been convenient for me. So, I was happy during the COVID-19 pandemic, because I could sit at home with my computer and participate in the lectures in my own environment, in a chair or a sofa, where I know that it is ergonomically good for me and allowed for me to keep going a little longer. (Participant 6, Woman, Late twenties, Ambulant)

Discussion

To our knowledge, this is the first study that investigates perspectives of young people with NMDs regarding their choice of educational programs and possibilities to complete program requirements.

Education is one of the most important determinants of doing well because it is associated with health, lower mortality, and quality of life (Udesen et al., 2020). In addition, people living with disabilities who have completed higher education have better finances and better social coping than people with a lower level of education (Bengtsson & Datta Gupta, 2017). It is therefore important that everyone has the conditions and circumstances that are necessary for them to participate in and receive an education regardless of their functioning (Schiøler & Dahl, 2012; World Health Organization, 2024). Nurses and other health professionals in rehabilitation settings that support young people with NMDs or other disabilities can play a central role in providing knowledge and counseling regarding their educational capacity in relation to physical functioning and psychosocial issues (Handberg et al., 2022). In the present study, we found that the courage to be open about living with a special condition like a NMD is an important factor in determining a person's self-identity (Giddens, 2013; Ravn, 2019). Being open and socially active helped the participants feel more empowered and make bolder choices regarding their education. This is backed up by Giddens, who emphasized that individuals' need to make their own lifestyle choices because this is of great importance for the preservation of their self-identity (Giddens, 2013; Ravn, 2019). School and education can be regarded as a social arena for the young people undertaking educational programs, whether it be at primary and lower secondary or upper secondary schools or at a higher educational institution. Giddens has described that a person's

character is formed through adapting to social arenas during their interactions with their surroundings and their personal contacts (Giddens, 2013; Ravn, 2019). The participants' behavior in their educational social arenas will also help them to define who they are and to shape their identity. It is, therefore, important for people with a NMD to be met by understanding, expectations and openness from the people surrounding them. Unfortunately, this was not always the case among our participants.

People with chronic fatigue (which can be related to NMD) have a significantly higher degree of absenteeism, and if this gives rise to problems at school, it can have an effect on quality of life, reduce school attendance, cause a poorer sense of connectedness with school, and reduce school performance (Knight et al., 2018). Additionally, children with chronic conditions rate their school experiences and life satisfaction lower than children without chronic conditions (Sentenac et al., 2023), and children with a disability are more likely to be victims of bullying (Godeau et al., 2010).

The concept of social participation is an essential determinant of people's health and well-being, maybe even more so when living with a disability or a chronic disease. Social participation can influence the personal development of children and adolescents. In the International Classification of Functioning and Disability (ICF), social participation is defined as "involvement in a life situation" and represents the social perspective of functioning (Schiøler & Dahl, 2012; World Health Organization, 2024). In general, our findings pointed to the importance of social relations and participation with regard to feeling safe and included during school hours or in relation to social events with student peers. However, the participants in the present study had experienced bullying, isolation, and loneliness at school because of their NMD. This calls for initiatives to promote a secure environment involving support and openness for and around children and young people with disability.

The participants explained that they had to find a balance between their dreams and their reality when they chose an educational program. It is important for young people to be well informed about and supported in their educational choices—maybe even more so when they are living with a disability—which might narrow their choices to some degree. A recent review has shown the positive effects that result from engaging students with a higher education as education ambassadors to reduce barriers to education among people with disability (Bjørnerås et al., 2022). Of special importance are guidance from nurses, other health professionals, and supportive relationships; building strategies and transferable skills; and advocating for change (Bjørnerås et al., 2022; Handberg et al., 2022; Højberg & Jeppesen, 2012). This is in line with our findings that showed that encouragement at school or from parents was experienced as beneficial and had an influence on self-esteem and empowerment. Moreover, Steinprinz (2017) describes how young people who have more complex life challenges often appear more creative when dealing with

challenges or overcoming obstacles. Steinprinz (2017) argues that categorizing and labeling disabilities should be avoided, and that focus should be on strengths. The group of young people with NMDs often face challenges, difficulties and sometimes limitations because of their NMD, but focus should be on recognizing their diverse abilities (Steinprinz, 2017). By acknowledging diversability, the young people with NMD are more likely to achieve opportunities for personal development (Steinprinz, 2017).

Finally, our findings showed the importance of accessibility in relation to educational possibilities.

Accessibility involves barrier-free educational buildings and environments, but also options for distance education when ill or unable to participate in classes in-person, as well as designing courses and using teaching styles that meet the needs of people with a variety of abilities, all of which are necessary to provide inclusive and equitable opportunities for everyone.

To improve educational possibilities for people with NMD, it is important to create secure and safe educational surroundings and circumstances that support openness. The young people need to be encouraged from an early stage to be open about living with a NMD and the needs this entails because they thereby experience empowerment and a positive influence iduals when they make their own lifestyle choices, and in this way support the preservation of their self-identity. Supportive educational environments with emphasis on building social relations and mentorships are important for young people with a NMD to feel safe and included during school hours and/or in relation to social events with student peers outside school hours. Structured support programs facilitated by nurses or other health professionals for families with a young person with NMD can on their self-identity. Furthermore, there is a need to support and emphasize the need to focus on strengths in the young individual and emphasize the importance of adjusted expectations in secure and safe educational environments. Showing expectations and providing the young people with encouragement and support in relation to educational choices has a positive influence on the young peoples' self-esteem and empowerment. It is of great importance to address the necessity of access and accessibility to education and associated resources in an equitable way for everyone, and in relation to this provide the possibilities to receive distance education when ill or unable to participate in the education in person. In future research, it would be relevant to conduct a national survey to investigate factors of importance for continuing educational programs and labor market participation in young people with NMDs.

Methodological Considerations

The sample for the present study was small even though we did invite 102 persons to take part.

Our participants represented people who had participated in advanced education. Although our sample was relatively

small, participants represented different ages, genders, and educational backgrounds. Additionally, the focus group interviews provided a rich source of data that enhanced our knowledge of the educational choices made by young people with NMD and its influence on their self-identify. The fact that the interviews were conducted online might have affected some of the interactions among the participants since nonverbal body language and signals are more difficult to read online versus being in the same room. Nevertheless, we had the impression that the participants were open and shared thoughts and feelings with each other despite the online format.

The analytical logic involved following the four steps of the interpretive description methodology, which secured stringency and systematic approach to the process of writing up the final findings supported by quotes (Thorne, 2016). All three authors collaborated to all the steps of the analysis and interpretation with different perspectives, which secured researcher triangulation. Our findings reflected factors of importance for the choices young people with NMDs make regarding beginning and completing educational programs. The experiences of participants in this study may be similar to other young people living with a disability in comparable settings.

Conclusion

This study revealed factors of importance for the choices young people with NMDs make regarding beginning an education and their possibilities to complete program requirements. Their self-identity was influenced by their choices regarding how to act and behave in the social arena of school and education. The analysis helped to identify how the participants built a sense of self-identity by testing boundaries and developing an image through social relations with peers, parents, and teachers. Living with a NMD affected the participants' self-identity because they worried about how to explain to their fellow students that their disability was part of their identity. They felt a relief when they could share knowledge of their condition in life because it shaped them as a person, student, and friend, either facilitating or hampering their possibilities for education and a future work life. Factors of importance for influencing and shaping the participants' self-identity were the creation of identity in relation to education, the meaning of experiencing demands and expectations, the meaning of social relations when learning, and the importance of accessibility for educational opportunities. Nurses and other health professionals in rehabilitation settings that support young people with NMD or other disabilities can play a central role in providing knowledge and counseling. The counseling can be related to specific knowledge sharing on educational capacity in relation to physical functioning and psychosocial issues. The results will be used in future counseling and the development of a national questionnaire survey.

Acknowledgements

We would like to thank the persons who generously shared both their time and stories and participated in making this study possible.

Author Contributions and Agreement

All authors contributed to the study conception and design. Material preparation, data collection and analysis were performed by [Charlotte Handberg], [Helle Munkholm] and [Ann-Lisbeth Højberg]. The first draft of the manuscript was written by [Charlotte Handberg] and all authors commented on previous versions of the manuscript. All authors read and approved the final manuscript.

Data Availability

The datasets generated during and/or analyzed during the current study are available from the corresponding author on reasonable request.

Declaration of Conflicting Interests

The authors declared no potential conflicts of interest with respect to the research, authorship, and/or publication of this article.

Funding

The authors received no financial support for the research, authorship, and/or publication of this article.

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