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Understanding Barriers to Participate in Specialized Neuromuscular Rehabilitation Experienced by People With Neuromuscular Diseases

Charlotte Handberg^{1,2} | Ulla Werlauff¹ ¹National Rehabilitation Center for Neuromuscular Diseases, Aarhus, Denmark | ²Department of Public Health, Faculty of Health, Aarhus University, Aarhus, Denmark**Correspondence:** Charlotte Handberg (chha@rcfm.dk)**Received:** 23 February 2026 | **Revised:** 27 April 2026 | **Accepted:** 11 May 2026**Keywords:** control | Goffman | neuromuscular diseases | normalcy | progressive diseases | rehabilitation

ABSTRACT

Rationale: There are many types of neuromuscular diseases characterized by considerable variation in disease progression and functional abilities depending on the specific diagnosis, leading to an increased need for specialized rehabilitation across the lifespan.

Objective: The objective of this study was to identify barriers to participate in specialized neuromuscular rehabilitation experienced by people with neuromuscular diseases to guide future targeted rehabilitation.

Method: The design for this study was a qualitative interview study using the interpretive description methodology and Erving Goffman's frontstage—backstage theory founded in the theory symbolic interactionism as the theoretical lens. The present study adheres to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines. The setting for this study was the Danish National Rehabilitation Center for Neuromuscular Diseases. Twenty-two persons with various types of neuromuscular diseases participated in interviews conducted online or by phone.

Results: We found that people with neuromuscular diseases experience various barriers to participating in specialized rehabilitation. The barriers were represented by an everyday flux between seeking normalcy by opting out rehabilitation or acknowledging the need for rehabilitation.

Conclusions: The participants opted out of rehabilitation partly out of fear of losing hope and control which they felt could be invoked by rehabilitation and partly because they were striving for normality. When planning future rehabilitation services, it is important to provide rehabilitation services in a safe environment for the participants where they can share thoughts and worries without feeling abnormal or fearing a loss of control.

1 | Introduction

The term neuromuscular disease (NMD) covers a broad group of disorders causing various symptoms like muscle wasting and weakness, most NMDs are hereditary, while others are acquired [1, 2]. NMDs entail complex rehabilitation needs, due to their impact on overall functioning, including respiratory and cardiac function as well as orthopaedic complications [1–4]. The NMDs in the present study have in common that they are hereditary progressive forms in terms of symptoms, functioning and

disease progression [2]. People with NMDs experience an increased need for specialized rehabilitation throughout life, because of the complexity and progression of their disease and its impact on their functioning [2].

The World Health Organization (WHO) defines rehabilitation as a *set of interventions designed to optimise functioning and reduce disability in individuals with health conditions, in interaction with their environment* [5]. The Danish healthcare system

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is divided into sectors with a regional sector responsible for hospital treatment and care, and a local community-based healthcare sector that provides home healthcare and rehabilitation after hospital treatment [6]. Specialized rehabilitation is provided in a third sector including private and tertiary hospitals and general practitioners [6, 7]. Lifelong specialized rehabilitation is offered for people with NMDs at the National Rehabilitation Center for Neuromuscular Diseases which is a highly specialized tertiary hospital under the National Board of Health [8, 9]. Prior research has indicated how people with NMDs continually must adapt to their shifting functioning due to multiple symptoms and consequences of their disease [6, 10, 11]. Despite this, nearly 500 patients with a lifelong referral at the National Rehabilitation Center for Neuromuscular Diseases had not been in contact with the center or had directly opted out of invitations to participate in rehabilitation. To understand the reasons why people with NMDs opt out of available rehabilitation services, it is necessary to understand possible barriers to rehabilitation. Therefore, the purpose of this study was to identify barriers to participate in specialized neuromuscular rehabilitation experienced by people with NMDs to guide future targeted rehabilitation.

2 | Methods

2.1 | Design

The design for this study was a qualitative interview study using the interpretive description methodology [12, 13] and Erving Goffman's frontstage—backstage theory founded in the theory symbolic interactionism as the theoretical lens [14].

2.2 | Setting

The setting for the study was the National Rehabilitation Center for Neuromuscular Diseases, which delivers specialized rehabilitation and counselling for people with neuromuscular and motor neuron diseases [8, 9]. The National Rehabilitation Center for Neuromuscular Diseases act as a facilitator of cross-sectional collaboration among the persons with NMDs, the hospitals and the local community-based care settings with the goal to support the Danish health and social system with expert knowledge on rehabilitation of people with rare NMDs. The National Rehabilitation Center for Neuromuscular Diseases registers most people with a NMD in Denmark. The employees work in multiprofessional teams and meet people with NMD in their homes or in the outpatient clinic located at two sites in Denmark. The professionals are doctors, nurses, physiotherapists, occupational therapists, social workers, and psychologists [9]. The patients are referred to the hospital by a neurologist or a general practitioner and are when they are registered, offered lifelong affiliation to the center and can receive counselling when needed. The rehabilitation at the center is provided as, needs-based follow-up rather than through fixed follow-ups. Some patients like children are offered regular multidisciplinary follow-up, typically organised as coordinated appointments involving relevant professionals. Follow-up may consist of multidisciplinary home or clinic visits, group-based education courses and individual professional appointments, depending on patients' needs, disease progression and life situation [9].

In addition, patients and families may initiate contact with the hospital when new concerns arise or when reassessment is needed. The study was conducted by two experienced researchers within the field of rehabilitation of people with NMDs with professional backgrounds in nursing and physiotherapy.

2.3 | Sampling and Participants

The sampling was purposeful to get a broad representation in regard to age, gender and diagnosis [12].

From the register at the National Rehabilitation Center for Neuromuscular Diseases the first author and an administrative worker drew lists of persons who met the following inclusion criteria: (1) > 18, (2) had consented to be contacted by the National Rehabilitation Center for Neuromuscular Diseases, (3) were diagnosed with one of the following rare diagnosis with a specific progressive course: limb-girdle muscular dystrophy, congenital muscular dystrophy, spinal muscular atrophy, Charcot-Marie-Tooth disease or Emery-Dreifuss muscular dystrophy [3, 4, 15–20], (4) who had not been in touch with the National Rehabilitation Center for Neuromuscular Diseases within the last 3 years or more and were expected to be in need of rehabilitation, support and counselling. These diagnostic groups represent larger populations at the study site and share comparable rehabilitation trajectories and service structures.

Participants were excluded only if cognitive impairment constituted their primary clinical challenge.

The National Rehabilitation Center for Neuromuscular Diseases has a register of 3479 people from where we identified 466 persons (13.4%) who met all the inclusion criteria, and two rounds of invitations were sent out on March 11, 2022, and March 22, 2022, by secure email or regular post. The first round of invitations included every tenth person on the list starting with number 1, and the second round with every tenth person on the list starting with number 2. In all, 70 people were invited; of those 22 (31.4%) agreed to participate (Table 1) and were interviewed between March 14, 2022, and April 12, 2022. Forty-eight persons opted out (47 never answered the invitation and 1 agreed to participate but never answered the phone when contacted).

Data consist of individual, semi structured interviews conducted by the first author online or by phone due to the COVID-19 pandemic. The interviewer did not know any of the participants before the interviews. An interview guide was used (Table 2), and the recorded interviews lasted between 21 min and 1 h (mean 38 min).

2.4 | Methodology and Analysis

For this study we used the inductive interpretive description methodology [12, 13]. Interpretive description is an applied research methodology that seeks to investigate challenges arisen in clinical practice with the aim to reimburse the findings to improve clinical practice [12, 13]. Interpretive description was applied for this study to gain knowledge about barriers to

TABLE 1 | Characteristics of the participants.

| | Total participants (N = 22) (%) |
|--|---|
| Sex | Female (n = 11) (50) Male (n = 11) (50) |
| Age, mean (range) | 50 (24–76) |
| Age at diagnosis, mean (range) | 28 (1–49) |
| Diagnosis | Atrophy (n = 2) (9) Dystrophy (n = 10) (45,5) Neuropathy (n = 10) (45,5) |
| Occupational status | Working full-time (n = 5) (23) Working part-time (n = 9) (41) Retired (n = 8) (36) |
| Mobility | Ambulant without support (n = 10) (45,5) Ambulant with assistive aids (n = 5) (22,5) Non-ambulant (n = 7) (32) |
| Residence | Urban (> 50.000 citizens) (n = 7) (32) Rural (< 50.000 citizens) (n = 15) (68) |
| Reasons for opting out of rehabilitation | Did not have a rehabilitation need now (n = 7) (32) Did not know of the rehabilitation programme (n = 4) (18) Did not know the referral still applied (n = 3) (13,5) Could not identify with having a NMD ^a (n = 3) (14) The rehabilitation offered was not relevant (n = 2) (9) Managed without rehabilitation despite needs (n = 2) (9) Bad experience with the rehabilitation programme (n = 1) (4,5) |

^aNeuromuscular disease.

participate in specialized neuromuscular rehabilitation experienced by people with NMDs to guide future targeted rehabilitation. The methodology allows for the use of a variety of methods fit for the study aim [12, 13]. The analysis was performed as the iterative four step process prescribed by interpretive description consisting of: step (1) all text is transcribed verbatim, uploaded to NVivo16 and an initial coding was done by both authors reading the transcripts, step (2) a distinction is made between specific conditions and general patterns in relation to the research question, step (3) critical assessment of relationships between data, as well as their relevance to the research question and step (4) the main messages and themes are determined by both authors and contributed new insights into the data, and thus the research field (Table 3). The final condensation and description are carried out with the definition of the final findings, their hierarchies and relationships, often illustrated in a figure or model [12, 13]. Saturation is not an endpoint in interpretive description since Thorne [12] argues that you never know what knowledge and insights the next participant will share with you and hence saturation not obtainable [12, 13]. When using the interpretive description methodology, it is common to apply a theoretical framework as the analytic lens. We used Erving Goffman's frontstage—backstage theory founded in theory symbolic interactionism [14]. According to Goffman (1) Frontstage symbolises keeping up appearances—how the person actively manages how they want other people to perceive them, sometimes behaving differently from the person he or she really is and (2) Backstage symbolises where the person can shed their public appearance

and be themselves when alone or in a 'safe space' [14]. According to Goffman, frontstage and backstage result in different types of social interaction that take place in our daily lives. Goffman describes frontstage as when we 'act' for an 'audience' and seek to present ourselves in certain ways, e.g. at work, while backstage represents a more relaxed space such as one's home, where a person does not have to pretending to be someone else or worry about being judged [14]. Goffman uses the theatre metaphor to demonstrate how people continually stage themselves in various social situations. The frontstage-backstage theory is a fluid concept depending on the context and the people with whom we interact [14].

2.5 | Ethical Approval and Informed Consent Statements

The present study was approved by The Central Denmark Region Committees on Health Research Ethics, and according to the Consolidation Act on Research Ethics Review of Health Research Projects, Consolidation Act number 1083 of 15 September 2017 Section 14 (1) the project did not require notification [Request no. 69191, Jr. no. 1-10-72-149-19]. Participants were informed about the study verbally and in writing and all gave verbal and written consent. The study was conducted in accordance with the Helsinki Declaration of 1975 [21].

To make sure the study would be relevant for people with NMDs we involved a patient panel consisting of six patients and

TABLE 2 | Semi-structured interview guide.

| Key interview questions in relation to study aim—inspired by meaning and social interaction |
|---|
| Try to describe your everyday life? |
| How does your NMD influence your everyday life? |
| What is important for you in your everyday life? |
| How do you deal with the symptoms? |
| What is your experience with others who have the same NMD? |
| What information have you received from healthcare professionals regarding your NMD? |
| How is your collaboration with healthcare professionals? |
| What is your experience of the different sectors collaborating on NMDs? |
| Which authorities and professionals have you been in contact with regarding your NMD? |
| What is your experience of collaboration with them? |
| What is important in relation to your collaboration with them? |
| Which help, support or rehabilitation have you been offered? |
| What considerations do you have in relation to this? |
| You have not been in contact with the rehabilitation hospital for the past 3 years or more—what is the reason for this? |
| Why do you not to use the rehabilitation hospital? |
| What do you think is the reason why some people with NMD opt out of rehabilitation? |
| What would be important if you were to ask for rehabilitation? |
| How did you first encounter the rehabilitation hospital? |
| What was your experience of the rehabilitation hospital at that time? |
| What do you think the rehabilitation hospital can offer? |
| How important is it to you that the rehabilitation hospital offers rehabilitation to people with NMD? |
| How do you think the collaboration on rehabilitation for people with NMD works the best/worst? |
| What advice do you have for the healthcare professionals at the rehabilitation hospital? |
| Concluding questions: |
| Is there anything you would like to add or elaborate on from what you have already said? |
| May I return and ask you to elaborate on your explanations if there are any ambiguities? |

two relatives in the initial phases of the project. The patient panel reviewed the project protocol and read and commented on the work. The panel were asked to focus on the project relevance and feasibility and on the project purpose, methods, and ethics. Finally, the first author interviewed the eight persons in the patient panel. They all assessed the purpose of project to be relevant. They further regarded the methods to be interesting and relevant.

The present study adheres to the Consolidated Criteria for Reporting Qualitative Research (COREQ) guidelines [22].

3 | Results

We found that the participants experienced symptoms related to their impaired functioning, yet still reported various barriers to participation in specialized rehabilitation (Table 1). Their reasons for not participating in rehabilitation were initially described either as not having a present rehabilitation need, not knowing about the rehabilitation service, did not know the referral still applied or they could not identify with living with a NMD. However, during the interviews all participants reflected on all the above-mentioned reasons for opting out of rehabilitation. The participants' barriers to participation in rehabilitation could be seen as an everyday flux between avoiding the stigma of having a disability by maintaining a frontstage appearance of normalcy and opting out rehabilitation, and retreating to backstage, where they acknowledged living with a rare disease and the need for rehabilitation (Figure 1).

3.1 | Normalcy: I Am Like Everyone Else—Part of the Society

The participants emphasised how important it was for them to be like everyone else and be part of society by having a 'normal' everyday life with work and sports or leisure activities. Most of the participants had a job, and they explained how they used almost all their energy on working and keeping up appearances, only to collapse on the sofa or bed when they came home in the afternoon with no energy left for their families or children. However, having a job and good colleagues meant a lot to them, even though the price was high. The participants expressed how they did not want the illness stigma and would only agree to reduce hours or retire when their functioning became too impaired.

Of course, I'm impaired by my illness, I feel that downward curve all the time, but it's going slowly or something... there are certain things I can't do at work, but I can pretty much do my job. I've gone from working long hours to having normal hours now or... [...] I have difficulty walking or..., I hate when it snows and it's windy and walking on slippery surfaces when it's windy. I'm having trouble with that, and I tend to slip or fall if there's a gust of wind, it's like my legs can't compensate if something unforeseen happens, so in that way I'm also, a little impaired. I walk upstairs, but only if there's railing or a wall I can lean on [...]. And of course, I'm also having a bit of trouble getting up from a chair, uh, that also requires..., I don't sit on a chair unless there's a table or another chair in front of me because I can't get up.

I: 'So how do you manage a job that is physically demanding?'

TABLE 3 | Illustration of the coding and analysis process leading up to the final categorical themes—guided by the Interpretive Description methodology and the analytical lens of Erving Goffman's frontstage backstage theory.

| | 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 generalised 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 relations of the themes and displaying the final findings reported in the results section |
| Analytical lens of Erving Goffman's frontstage backstage theory | Frontstage: the person manages how other people perceive them and behaves differently from the person he or she really is Backstage: the appearance the person has when alone or in a 'safe space' | Frontstage: the person manages how other people perceive them and behaves differently from the person he or she really is Backstage: the appearance the person has when alone or in a 'safe space' | Frontstage: the person manages how other people perceive them and behaves differently from the person he or she really is Backstage: the appearance the person has when alone or in a 'safe space' | |
| Codes and subthemes leading up to the final categorical themes | A wish to be and look like everyone else A wish to maintain job despite challenges Acknowledging challenges due to disability Feeling alone with no one to emulate Does not want to be labelled as sick Does not want to be labelled abnormal Struggle to stay independent Acknowledge the need for help and support Fearing the future—avoid information Avoid help and support to maintain hope Too much information leads to lack of control Fear of being realistic regarding functioning | I am like everyone else—part of the society I am like no other—outside the society I cannot identify with the need for rehabilitation I acknowledge the need for rehabilitation | Normalcy versus living with a rare disease | |

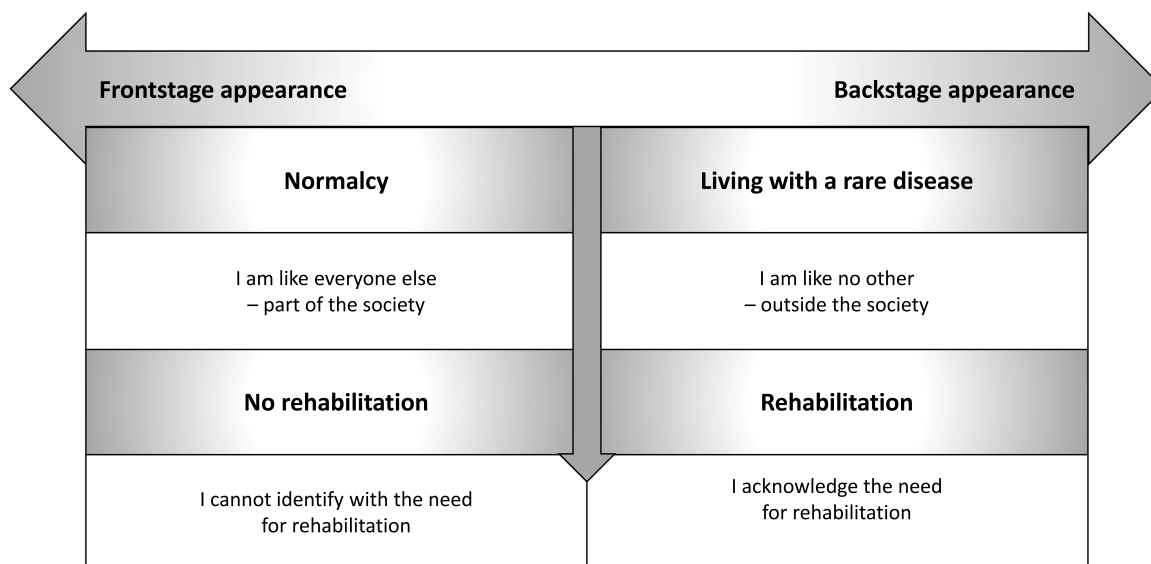


FIGURE 1 | Understanding how people with neuromuscular diseases experience barriers to participating in specialized rehabilitation—a flux between appearing frontstage or backstage in everyday life.

So, it's up and down a lot of the time, but there's equipment I can sit on and pull myself up with my arms or lean forward and then get up, uh, and that's what makes it possible for me to keep working, otherwise it wouldn't have been possible, I would have had a hard time with it.

(Man, in his early forties, limb-girdle muscular dystrophy)

The participants dreaded having to explain about their disease which would remind them of being different. They downplayed the challenges of their impaired functioning during work hours and activities at home. One participant explained that she relied on a trusted colleague's help when she had to go to the bathroom. The participants further explained that they did not like to point out when colleagues or friends again and again forgot to make sure that a restaurant or a meeting room was accessible. In everyday life at home, they also made an effort to be 'normal' despite repeated challenges.

We never made a big fuss over it. I fell a lot and couldn't get up again. My youngest child was only 3 or 4, and whenever I fell, she just looked at me and said: "What are you lying there for?", and then she found a blanket, a pillow and a book, and then she sat down and read a story until someone came and picked me up. That was part of her everyday life, so it wasn't something we made a big deal out of. Now she's an adult, and she and her siblings say that they didn't think about it because it was just their everyday life that I was sick, and not something they focused on.

Later in the Same Interview:

I think, at the last few neuromuscular seminars I went to, I experienced that people almost lived for their illness, and

that's so far from who I am, so it was like, "Try not to focus on it, and try to do something outside your comfort zone".

(Woman, in her fifties, Charcot-Marie-Tooth disease, ID 213)

What mattered to the participants was to keep up appearances and not stand out due to their NMD. They were grateful to be part of a social community at work, with friends or with family and to feel normal even if the price was exhaustion or having to sleep for hours or a whole weekend to be ready for the next weekday.

3.2 | No Rehabilitation: I Cannot Identify With the Need for Rehabilitation

Despite struggling with impaired functioning, the participants said they did not have a need for rehabilitation and that accepting rehabilitation would mean they acknowledged being 'abnormal'. Some participants explained that they would find their own solutions to problems related to their impaired functioning—even those who struggled a lot. They had thought up solutions to moving around, managing their job and family and explained that this was a way for them to stay in control of their lives. They elaborated that they were unaware of their options for seeking help and rehabilitation because they did not need it—they would rather handle everything themselves.

I know I won't last a whole day anyway. I get tired quickly – totally exhausted. I've got a job with reduced hours, and that's what I've found out I can handle. At work, I sit down almost the whole day, so that's fine because my muscular dystrophy is mostly in my legs, that's where I get tired quickly. I sit in a completely normal office chair. I

don't really use my wheelchair on ordinary days, it's more when we go on family trips and stuff, but I can walk. I think, well I think they've mostly said that I'm one of the lucky ones who isn't affected that badly. I don't think I've ever really needed help. I think it's just because I've been doing so well that I haven't really contacted the rehabilitation center, and I can't really remember the last time I was there.

(Woman, in her twenties, congenital muscular dystrophy, ID 209)

They talked about having attended patient education seminars at the rehabilitation center but had found them irrelevant at their stage of life, further some felt they had received an overload of information and counselling or that the seminar was being held too far away. The participants explained that agreeing to receive help and support would force them to think about their disease, as would meeting others at a rehabilitation seminar who might have a more progressive variant of their diagnosis. They feared what they would have to endure in life and confessed to being afraid of what the future might bring, which led them to avoid reality for as long as possible.

I don't know anyone else nor am I in touch with anyone who has muscular dystrophy, so on the one hand, I'm super privileged that I have a sister who understands what I say when I say something about muscular dystrophy, it's good that we can share these things. The not so good thing is that she's older than me, and her disease has progressed further which means I have someone... I must be careful not to look too much in that direction. Then the thoughts become... She's in a wheelchair, and the thought of me being there in 10 years, that can really drive me crazy.

(Woman in her thirties, limb-girdle muscular dystrophy, ID 202)

Some of the participants had experienced receiving an overload of information about their disease at patient education seminars and therefore chose to avoid information to maintain hope. They compared rehabilitation with an overload of information and feared that it entailed losing control, and therefore they opted out of rehabilitation. They explained that they would eventually seek help and rehabilitation when their need would become essential.

I have to make sure I live life now, because I have a heart disease, and it might get really bad in five years, so there's no point in me having to stop living my life yet, I must live life while I can..., even with the prospect that it won't last that many years. So, that's really what I think about mostly, really just having a good everyday life where I do things I like and spend time with the people I like..., I haven't thought too much about what it might be like in five years. [...] I don't really feel I need rehabilitation.

(Man, in his fifties, Emery-dreifuss muscular dystrophy ID 203)

The fear of losing control led to the decision to opt out of rehabilitation, and the participants explained how they struggled with not getting help, but that it was a struggle worth living with to stay independent and in control.

3.3 | Living With a Rare Disease: I Am Like No Other—Outside the Society

The participants explained how living with a rare disease often meant feeling completely alone with no one to emulate or relate to. They stated how they wanted to be part of society and just to be like everyone else, but that they were constantly reminded that their NMD made them different.

Every now and then, I realize how I try to see myself as the same as everyone else, and then occasionally it dawns upon me that I'm not, for example at work. [...] Yes, it would be nice if people understood what my disease is like, and I wouldn't have to explain everything in detail every time I have a conversation with someone. [...] In the end, there's no one I can compare myself to. Not even my brother, so I do feel like I'm the last person on earth and always have to ask everyone about everything and explain again and again, because THERE'S NO ONE LIKE ME! Great, it's fantastic that I'm unique, I'm one-of-a-kind. No, it means I can't get any help at all because I'm the only one who's broken in the way I'm broken.

(Woman, in her thirties, Charcot-Marie-Tooth disease, ID 201)

The participants explained that being at patient education seminars with people with the same diagnosis could even give them a feeling of being different. Seeing other people with disabilities at these seminars reminded them of having a NMD, which was what they were trying to avoid. One participant said: *I do not have the need to be disabled, so I try to compare myself to my nondisabled friends*. Other participants felt that it was other people who made it difficult to live with a disability because they would stare, ask ignorant questions, or even avoid the participants.

You know, in my world I don't mind when people ask my girlfriend about my disability instead of asking me directly. Something like that doesn't ruin my day. People do it because they're ignorant. I think it's very problematic that people want to be seen as a normal person, but you're not normal, because you have a disability, and very few people have that. It's abnormal in my world, and that's why I think people should be more open about their disability and let people ask...

(Man, in his twenties, congenital muscular dystrophy, ID 211)

The participants expressed how participating in rehabilitation would draw attention to their disability and need of help. They accepted being different due to their rare disease and impaired

functioning which often made them feel alone in social settings. They grieved the physical and psychological barriers they encountered in society and addressed how this made them feel even more like outsiders.

3.4 | Rehabilitation: I Recognize the Need for Rehabilitation

Although they did not want to be reminded, the participants acknowledged that their NMD and impaired functioning would eventually require support, specialized counselling and rehabilitation services. They also emphasised that they knew where and how to get the support they needed when the time was right. They explained how navigating the healthcare system with a rare disease was challenging and how they wished they had a coordinator to support them in the complex system.

The hardest thing is to get rehabilitation across to people like me..., about available aids. I would like to learn to walk a little better [talks about a solution with braces to prevent his foot drop]. I could walk better if someone developed some better aids... to lift the foot two millimeters. Yes, that would be worth its weight in gold for us for sure. Because we fall and become clumsy because we can't lift our feet.

(Man, in his sixties, Charcot-Marie-Tooth disease, ID 222)

However, the participants also stressed that for them to participate, the rehabilitation they sought should be tailored specifically to them and their diagnosis. They avoided seeking support at the rehabilitation center despite their many needs, but being interviewed about their lives made many of the participants realise that they might need help sooner than they had thought. Nevertheless, they argued that now was not the time, but knowing they could get help at the rehabilitation center in the future was important.

Well, it's very important that the possibility of contacting the rehabilitation center exists. Otherwise, I wouldn't know who to turn to if I needed help. I am completely convinced that if I need help again, I would contact the rehabilitation center. Because either they can help me, or they can guide me through the healthcare system.

(Woman, in her fifties, limb-girdle muscular dystrophy, ID 206)

The participants knew they needed rehabilitation but at the same time opted out of it despite being contacted by the rehabilitation professionals. They emphasized that, for now, they could manage life on their own, but that they would seek help and rehabilitation when the time was right and they could no longer handle their challenges alone.

4 | Discussion

We found that people with NMDs experience various barriers to receiving specialized rehabilitation. The barriers were

represented by an everyday flux between frontstage appearance by opting out rehabilitation or backstage appearance and acknowledging the need for rehabilitation. The WHO defines rehabilitation as *a set of interventions designed to optimise functioning and reduce disability in individuals with health conditions, in interaction with their environment* [5]. The participants in this study perceived rehabilitation differently than WHO as our findings suggest that instead of thinking about rehabilitation as means to support an impaired functioning, the participants feared that by participating in rehabilitation, they would subject themselves to being abnormal and be confronted with the reality of living with rare progressive NMD. A study on physical activity in people with NMDs also found barriers to participation such as pain and fatigue, challenges integrating activity into daily life, environmental and financial barriers, limited social support and low motivation or disease acceptance [23]. None of the participants in the present study had been in rehabilitation for the last 3 years or more, although all of them lived with impaired functioning and needed support due to the progressive diagnosis. Their striving for normalcy and evasion of rehabilitation has also been found in studies on cancer patients [24, 25]. Research has shown how striving for normalcy can be important for patients' quality of life and for their illness experience [26–28] and how views of normalcy can be negotiated and endorsed when living with chronic disease like a NMD [26, 29].

According to Goffman's frontstage—backstage theory, people act in certain ways to manage how people perceive them which is in line with the participants in the present study who do not want to appear different or abnormal and therefore downplay their disability and their symptoms when being at work or with friends. When being home 'backstage' in a safe place they acknowledge that they have challenges due to their disability. Goffman argues that frontstage and backstage are a fluid concepts depending on the context and on who the people interact with [14]. This was also found in the present study where the participants stressed how being at home was a safe space, but when they were out, at work, or with friends, they felt a stronger need to keep up appearances. When planning rehabilitation services, it is important to develop services which provide a safe environment where the participants can share thoughts and worries whilst maintaining normalcy and without a fear of losing control. Meyrowitz, argues that, especially in the recent years, with social media becoming an integrated part of everyday life for most people, it has become more difficult to separate front- and backstage [30]. People are always available which can lead to a mixture of frontstage and backstage behaviour. This is in line with our findings showing how the participants were in a constant flux between acting frontstage—seeking to be like everyone else and avoiding rehabilitation—and being backstage feeling alone and in need of rehabilitation. The participants shared thoughts on how they met stigma in society which underscored their wishes to avoid seeking rehabilitation and help even more. This has also been proved in previous research stating that experiences and negative feelings related to stigma can increase psychological distress and decrease quality of life [31]. The Crip Theory is based on a critical approach to societal norms and arose partly through activism and as a response to experiences of societal and social injustices [32]. McRuer argues against the 'friendly' disability

movement, which, together with the authorities and ‘normal’ people, advocate for ‘normalcy’ and acceptance, thereby making visible the power relations and inequality that are based on the domination of able-bodied people [32]. This is in line with the statements from the participants in our study who expressed how they strived for normalcy to fit in and avoid feeling different. According to McRuer this strategy is unfortunate since no one is fully able-bodied and all will become disabled if we live long enough [32].

Chronic illnesses like NMDs and emotional distress have been shown to impact participation in rehabilitation [33]. The participants in the present study all lived with rare and progressive NMDs and experienced various degrees of impaired functioning but did not seek help or rehabilitation. Although some of the participants had rejected invitations to participate in rehabilitation prior to the interviews, they recognised the need for rehabilitation during the interviews. To ensure equality in rehabilitation there is a need to reframe access to rehabilitation as a disability equality issue and give special attention to those who do not actively seek help [34]. Regular contact with this patient group may provide support on their own terms and address unmet rehabilitation needs. Targeted follow-up should be tailored to disease progression and functional status to optimize time and resources. For patients with highly progressive NMDs or severely impaired function, extended rehabilitation follow-up can be offered in the home. Other groups of people with slowly progressing NMDs and impairment might be offered an online consultations which has shown to enhance access to specialized care and improve continuity [35, 36]. Research has shown how people with rare and very progressive diseases like amyotrophic lateral sclerosis, once they have crossed the barrier of participating, show perceived benefits from peer-support in rehabilitation facilitated by professionals [37]. These settings can be transferred to groups of patients with NMDs where the setting is small and the participants can get to know each other and feel safe when sharing their concerns and worries. Rehabilitation initiatives focusing on promotion of health and optimal functioning support the feeling of control and normality [24, 37].

4.1 | Study Limitations

For an interview study, the sample of 22 persons is considered large and hence a strength for the findings. The sample consisted of an equal distribution of men and women representing the various neuromuscular diagnosis. Employment patterns may vary across neuromuscular populations and settings; however, in this study employment status was recorded only as full-time, part-time, or retired, based on self-report. Detailed information on working hours, formal definitions, or sources of financial support was not collected. Consequently, it was not possible to assess whether working hours, financial circumstances, or the ability to take time off work influenced participants’ decision to take part in rehabilitation or the study.

Although several participants lived in rural areas, this is not considered a major barrier to participation in rehabilitation in the Danish context. Denmark is geographically small with relatively short travel distances, and importantly, in the present study rehabilitation was predominantly delivered through

outreach services, where healthcare professionals travel to patients’ homes. Distance and transportation therefore did not emerge as significant factors influencing participation in rehabilitation in this study which has been shown of importance to participation in other studies [38].

The study was conducted in the post-COVID-19 period. The participants were not asked about the pandemic’s influence on their decisions to attend rehabilitation. Although telephone and online interviews were used as a pragmatic adaptation, the potential impact of COVID-19 on participation was not systematically examined and can be considered a study limitation.

Both authors participated in the analysis, and the analytical logic and transparency was sought strengthened by a table illustrating the coding and analysis process leading up to the final categorical themes and display of interview guide. Interpretive description is an inductive methodology [12, 13], and hence it can be argued that applying a theoretical framework like Goffman’s frontstage—backstage theory as the analytical lens would be a deductive analysis [14]. Nevertheless, we have worked inductively and performed the initial analysis before applying Goffman’s theory as an inspiration for the final bits of the analysis. A criticism of Goffman’s concepts is that the boundaries between frontstage and backstage can be fluid and difficult to define [30]. However, we did find that the participants described themselves as being in a flux between frontstage and backstage. The participants in our study represent rare progressive diagnoses, but the findings might be transferable to other groups of people with chronic diseases, impaired functioning, and need for rehabilitation. The present study only included a selected group of hereditary NMDs. For future research, we suggest conducting the same study on acquired forms of NMD like inclusion body myositis, myasthenia gravis or amyotrophic lateral sclerosis. Moreover, we suggest that an investigation of the benefits of tailored diagnosis specific rehabilitation services where patients are matched in smaller groups be investigated.

5 | Conclusions

We found that people with NMDs opted out of rehabilitation partly out of fear of losing hope and control, which they felt could be invoked by rehabilitation, thus, hampering their pursuit for normality. The participants’ barriers to receiving rehabilitation were represented by an everyday flux between appearing frontstage and pursuing normalcy by opting out of rehabilitation and backstage living with a rare disease and acknowledging their need for rehabilitation. When planning future rehabilitation services, it is important to develop rehabilitation services that provide a safe environment where patients are matched in small groups in which they can share thoughts and worries without feeling abnormal or fearing a loss of control.

6 | Clinical Messages

To ensure that people with NMDs do not opt out of rehabilitation, it is important to:

- Balance rehabilitation counselling and advice with individual needs, diagnosis, and life situation through

collaborative goal-setting that supports quality of life, preserves hope, and maintains a sense of control.

- Implement systematic and timely follow-up with individuals with progressive NMDs who have not been in contact with rehabilitation hospital within the past 3 years, in order to reassess needs and prevent functional decline.
- Develop rehabilitation services that promote health, well-being, normalcy, and long-term optimization of functioning, rather than focusing solely on disease management.
- Offer flexible follow-up solutions, including telehealth, to support engagement, improve adherence, and reduce barriers related to participation and perceived loss of control.

Author Contributions

C.H. and U.W. have made substantial contributions to: (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, (3) final approval of the version to be submitted.

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Consent

Participants were informed about the study verbally and in writing, and all gave verbal and written consent.

Ethics Statement

The present study was approved by The Central Denmark Region Committees on Health Research Ethics, and according to the Consolidation Act on Research Ethics Review of Health Research Projects, Consolidation Act number 1083 of 15 September 2017 Section 14 (1) the project did not require notification [Request no. 69191, Jr. no. 1-10-72-149-19].

Conflicts of Interest

The authors declare no conflicts of interest.

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.

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