

Healthcare Professionals' Perspectives on Barriers and Facilitators in Care and Rehabilitation of Adults with Myasthenia Gravis in Neurological Departments in Denmark

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Introduction: Myasthenia gravis (MG) is a rare, chronic autoimmune disease that causes various fluctuating symptoms. Healthcare professionals at neurological departments often focus on treating MG with the risk of overlooking other aspects of daily living. Rehabilitation seeks to enable people with disabilities to become as independent as possible in everyday activities. This study aims to explore how healthcare professionals at neurological departments perceive barriers and facilitators in care and rehabilitation of adults with MG in Denmark to target future rehabilitation initiatives.

Methods/Materials: A qualitative design using individual interviews with healthcare professionals employed at neurological departments was performed. The qualitative interpretive description methodology aimed at informing clinical practice and the critical psychology framework by Klaus Holzkamp guided the study. Ten participants were included.

Results: The results showed how “Supporting patient understanding and navigation through personalized care”, “Navigating responsibility and resources in clinical practice”, and “Organizational structures impacting on professional quality of care” were important areas for the healthcare professionals when considering barriers and facilitators to rehabilitation for their patients. The first two areas were the center of the participants’ clinical practice, and surrounding and impacting on this center was the participants’ perception of their ability to navigate responsibilities and resources in their clinical practice. The third area had significant impact on the quality of care, allocation of resources, and structural changes within the specialized healthcare services.

Conclusion: Healthcare professionals at neurological departments experience multiple facilitators and barriers to the rehabilitation of adults with MG. Their agency potential is deeply rooted in the relational, organizational, and structural settings that they engage in. Their ability to support adults with MG in coping with their condition depends on expertise, flexibility, continuity, and interdisciplinary collaboration both in and outside their organization. It is pivotal that organizational structures support these conditions. If not, it may have negative consequences for the patients’ agency potential, rehabilitation, and health.

Keywords: myasthenia gravis, healthcare professionals, rehabilitation, facilitators and barriers, patient-centered care, multidisciplinary care

Introduction

Myasthenia Gravis (MG) is a rare, chronic autoimmune disease that comes in a variety of forms and can cause a fatigue weakening of ocular, bulbar, axial, respiratory, and limb muscles.¹ A systematic review and meta-analysis showed a global prevalence at 12.4 per 100.000 individuals,² which makes MG one of the most prevalent conditions that interfere with neuromuscular transmission.¹ MG is treatable; however, the rate of complete remission without medication is very low, and pharmacological remission is about 26%.³ People with MG therefore need long-term and

often life-long medical treatment.^{4–6} Treatments targeting the symptoms of MG include steroid-sparing immunosuppressants, intravenous immunoglobulins, plasmapheresis, and thymectomy.⁷ Despite receiving treatment, many patients still struggle with symptoms^{4,8,9} that make them dependent on corticosteroids.⁷ A study found that the mean number of symptoms per person was the same (five symptoms) after treatment as it was at the time of diagnosis.⁴ The symptoms can be diverse and vary in degree throughout the day, impairing several aspects of people's everyday lives.^{5,6,10–14} The impairments are often related to disease severity, different kinds of muscle involvement, and poor treatment effectiveness.¹⁵ It is therefore not surprising that people with MG also present with a high prevalence of mood disorders like anxiety and depression.^{16–20} A study on quality of life found that 53.5% of people with MG reported mild restrictions and 26.3% reported severe restrictions in their daily routines, which had a negative impact on their quality of life.²¹ For instance, they often experienced changes in employment, involuntary job transfer, or unemployment due to MG, and this affected their income negatively.^{8,22} Cost-of-illness and the socio-economic burden of MG are important decision-making criteria in public health deliberation.¹⁵ The socio-economic burden of MG can be very closely linked to the organization and functioning of the health system.¹⁵ A real-world survey among physicians in the U.S in 2022 found that 2.5 healthcare professionals on average were involved in management of the same patient with MG and 5.0 consultations were made per patient over a period of 12 months.⁴ Causal factors leading to unsatisfactory outcome in MG treatment concern undertreatment, poor treatment compliance, infectious complication, and drug-induced adverse effects.²³

WHO defines rehabilitation as a set of interventions designed to optimize functioning and reduce disability in individuals with health conditions in interaction with their environment.²⁴ However, rehabilitation in MG is often associated with physical training, respiratory training, and balance training,⁵ in spite of research clearly showing that MG has a profound and multifaceted impact on the people affected.^{21,25} The National Rehabilitation Center for Neuromuscular Diseases (RCFM) in Denmark defines rehabilitation in line with WHO. The center supports people with neuromuscular diseases with rehabilitation counselling and guidance to become as independent as possible in everyday activities and enable participation in education, work, recreation, and family life.^{24,26} With this study, we aim to explore how healthcare professionals at neurological departments perceive barriers and facilitators to care and rehabilitation of adults with MG in Denmark to target future rehabilitation initiatives.

Materials and Methods

Design and Setting

The study design was qualitative using the interpretive description methodology and critical psychology framework by Klaus Holzkamp.^{27,28} The setting was neurological departments at four university hospitals in Denmark. The Danish guidelines on MG treatment recommend that people with MG are referred to RCFM.²⁹ Neurological departments and general practitioners refer people with MG to RCFM and currently 405 people with MG are registered at RCFM. RCFM is a publicly funded specialized tertiary hospital under the Danish Health Authority.^{30,31} RCFM offers highly specialized rehabilitation counselling and guidance to people with neuromuscular diseases, their families, and health professionals.²⁶ RCFM collaborates closely with the neurological departments in Denmark.³²

Recruitment and Participants

The sample was purposive. An invitation was sent via e-mail to the four specialized neurological departments with expertise in treating people with MG in Denmark. Named neurologists from a previous patient interview study (in review) were “cc” on the e-mail to make sure that they received the invitation for the current study. Two reminders were sent at three-week intervals. The inclusion criteria were as follows: (a) healthcare professionals (neurologists, nurses, occupational therapists and physiotherapists, speech and language therapists, dieticians, psychologists and social workers) employed at specialized neurological departments at university hospitals responsible for treating adults with MG in Denmark and (b) clinical experience with adults with MG. Ten healthcare professionals were included from four neurological departments in Denmark, eight neurologists, one nurse, and one physiotherapist (Table 1).

Table 1 Sample Characteristics (n = 10)

Characteristics	Participants (n=10; %)
Gender	
Men	5 (50%)
Women	5 (50%)
Years of professional experience with patients with myasthenia gravis, mean (range)	13.5 (4–30)
Professional background	
Neurologists	8 (80%)
Physiotherapist	1 (10%)
Nurse	1 (10%)

Data Generation

Data were generated using individual semi-structured interviews. An interview guide containing open-ended questions aimed at hospital personnel in general was developed based on findings from previous studies,^{25 (in review)} and through patient involvement. The questions focused on the healthcare professionals' perceptions of facilitators and barriers to the rehabilitation of adults with MG in a hospital setting. Examples of questions asked; How do you collaborate with other stakeholders (general practitioners, municipalities, private physiotherapists, RCFM, etc.) to identify the support needs of adults with MG? How do you collaborate with other stakeholders (general practitioners, municipalities, private physiotherapists, RCFM, etc.) to follow up on and promote the rehabilitation of adults with MG? Interviews were conducted by the first author between June and September 2024. In accordance with the participants' preferences, eight interviews were conducted via the Microsoft Teams platform, and two interviews were conducted in-person at the participants' workplace. Interviews were digitally recorded and lasted between 29 minutes and 1h and 3 minutes and mean time was 39 minutes.

Methodology, Theoretical Framework, and Data Analysis

We used the inductive research methodology interpretive description (ID) as it focuses on clinical practice challenges with a purpose to inform and enrich practice through new insights and knowledge.²⁷ ID is a qualitative, inductive, flexible, and pragmatic methodology that allows the researchers to apply the methods that are best suited to unfold the research area.²⁷ We used the critical psychology framework by Klaus Holzkamp to inductively analyze and understand data.²⁸ According to Holzkamp, individual action is socially and historically situated and refers to the individual's ability to perceive and use their current situation in a way that enhances their scope of self-determined action, eg a person's real possibilities (motivation, capability, and practical options) to act in ways that improve their life conditions within a given context, for example their institutional environment.²⁸ The framework operates with a category called "agency potential" which is grounded in the individual's experience, knowledge, and reflection, and focuses on how individuals actively shape their lives and overcome constraints through conscious reflection and participation. People can act in ways where they manage or with constraints without changing the underlying conditions (restrictive agency) or they can act in ways that expand their possibilities or influence their situation (expansive agency). Agency potential refers to the conditions that make expansive agency possible or impossible.²⁸ The framework was used to explore whether the structures of the healthcare system were either supportive or limiting to the participants' agency potential when engaging in rehabilitation processes with adults with MG in hospital settings.²⁸

The analysis was guided by the four iterative steps prescribed by the ID methodology.^{27,33} First, all interviews were transcribed and uploaded to the electronic software system NVivoTM14.³⁴ Second, transcripts were read intensively by two of the authors, who individually coded for insights related to the participants' perceptions (Table 2). The two authors critically discussed and refined codes and agreed upon initial codes, which were systematically documented. In case of disagreement, the first author would have the final saying. Third, patterns and relationships were explored and discussed

Table 2 Illustration of the Analysis and Coding Guided by the Four-Step Process of the ID Methodology

	First Analytical Step	Second Analytical Step	Third Analytical Step	Fourth Analytical Step
<i>Description of analytical steps of Interpretive Description</i>	Initial coding: a process of discernment of circumstances and overall patterns related to the study aim	Primary categorization: A critical appraisal of relationships within data and relevance of thematic options	Final categorizing structure: extraction of main messages arising from key insight within data	A figure illustrating the relations and hierarchy of the themes and displaying the final findings outlined in the findings section
<i>Theoretical lens of Klaus Holzapf's critical psychology</i>	The relationship between the subject and the world is active and reciprocal because the subject is an active co-producer of their living conditions while, at the same time, living life within these conditions.	People think, feel, and act in relation to others and on the basis of given social conditions. These conditions are seen as neither static nor determining.	This means that conditions constitute both possibilities and limitations for human expression. Thus, people can participate in changing and developing their living conditions.	
<i>Codes and subthemes leading up to the final categorical themes</i>	Patient differentiation and adaption Teaching patients about MG The meaning of relations and life-long care Supporting patients navigating life with MG	Relational and individualized support Patient empowerment through tailored support in MG care	Supporting patient understanding and navigation through personalized care	Figure 1
	Professional experience with MG Professional identity and autonomy Contribution of different professional backgrounds Shared goals, different roles and responsibilities Systematic in clinical practice Collaboration internally and externally	Professional autonomy and identity in complex care for MG patients Professional interactions and knowledge sharing	Navigating responsibility and resources in clinical practice	
	Organizational structures within and across hospitals departments Structural changes impact on patient care Limited or lack of professional resources Dilemmas within a fragmented healthcare system Dilemmas regarding new costly therapies	Resources and structural changes in specialized healthcare	Organizational structure shaping professional quality of care	

within and between the data groupings and finally across the whole data set, leading to the definition of relevant, tentative thematic themes. An iterative process of going back and forth between raw data and tentative themes lead to the definition of the overarching themes. By identifying situations where actions became possible or constrained the themes were then indirectly associated with the critical psychology framework.²⁸ For example, which options did the participants perceive they had, what limited their ability to act, and what enabled them to act differently²⁸? Fourth, a visual depiction showing the main findings and the relationship between these was developed to present a coherent and conceptual interpretive description (Figure 1).

Ethics

Ethical approval was deemed unnecessary according to the Central Denmark Region Committees on Health Research Ethics [File no. 1–10-72-6-23]. Informed consent was obtained from all participants and data were anonymized by replacing participant names with ID numbers. MG treatment is centralized and performed at only four specialized hospital departments in Denmark and on “few” hands. To ensure participants’ confidentiality, only few characteristics are therefore being shared.

Results

To our knowledge, this is the first study to explore healthcare professionals’ perspectives on barriers and facilitators in care and rehabilitation of adults with MG in neurological departments in Denmark. We found that “Supporting patient understanding and navigation through personalized care”, “Navigating responsibility and resources in clinical practice”, and “Organizational structures impacting on professional quality of care” were important perspectives on barriers and

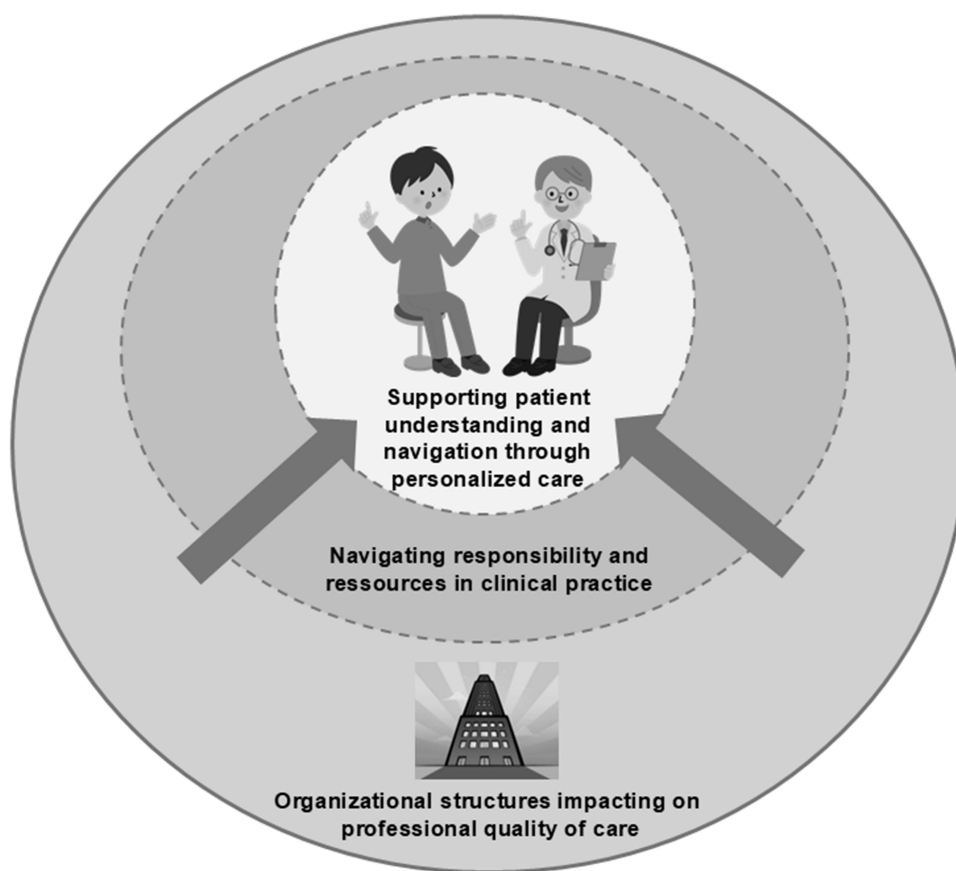


Figure 1 Healthcare professionals' perceptions on barriers and facilitators in care and rehabilitation of adults with myasthenia gravis in neurological departments in Denmark.

facilitators in rehabilitation of persons with MG according to the participants. *Supporting patient understanding and navigation through personalized care* was the center of the participants' clinical practice, its success being dependent on the relationship between the participants and the patients. Surrounding and impacting on this center was the participants' perception of their ability to *navigate responsibilities and resources in their clinical practice*, which entailed professional autonomy and identity, and the importance of collaboration in clinical practice. The *organizational structures* had significant impact on the quality of care, allocation of resources, and structural changes within the specialized healthcare services (Figure 1). An overview of barriers and facilitators across themes is provided in Table 3.

Supporting Patient Understanding and Navigation Through Personalized Care Empowerment Through Tailored Support in MG Care

Findings showed that the participants made a great effort and commitment to expanding their patients' understanding, management, and navigation of life with MG as a means to facilitate rehabilitation. They described patients with MG as a heterogenic group in terms of age, symptoms, cognitive capacity, health literacy, and psychosocial context which necessitated differentiated communication strategies and personalized educational efforts. Content and content delivery were therefore adapted to align with the patients' level of comprehension, life circumstances, and readiness to engage in long-term treatment processes.

If it's the fragile, older, and not especially tech savvy patient, I guess you have to be a little more protective and make sure to repeat things and supplement with paper lists, and when I do consultations over the phone, I sometimes send an Email to the patient's secure mailbox explaining about the changes we've made to the medical treatment to make sure they have some written information to lean on. (Healthcare professional)

Table 3 Barriers and Facilitators Influencing Healthcare Professionals' Rehabilitation of Patients with Myasthenia Gravis

Theme	Facilitators	Barriers
Supporting patient understanding and navigation through personalized care	<ul style="list-style-type: none"> • Strong commitment to support patients in understanding and managing life with MG • Use of diverse communication approaches and personalized educational strategies • Adapting information and guidance to individual patient needs • Involving patients as active partners through a person-centered and dialogical approach • Establishing trusting and supportive patient–professional relationships • Validating patients' experiences and concerns • Supporting patients in reconceptualizing life with MG and strengthening autonomy 	<ul style="list-style-type: none"> • Variation in patients' understanding of the disease • Limited consultation time for individualized dialogue
Navigating responsibility, resources and meaning in clinical practice	<ul style="list-style-type: none"> • Extensive clinical experience and specialization • Sharing expertise through supervision and collegial learning • Strong professional responsibility toward patients • Clear division of roles and responsibilities within teams • Knowledge sharing through formal and informal professional networks • Local interdisciplinary collaboration 	<ul style="list-style-type: none"> • Time constraints in daily clinical practice • Limited knowledge about MG among some professionals • Difficulties in keeping up with new research • Limited interdisciplinary collaboration structures • Physiotherapists seeing too few MG patients to build expertise • Limited attention to psychological aspects of care
Organizational structures impact professional quality of care	<ul style="list-style-type: none"> • Centralized and specialized MG care support access to expertise 	<ul style="list-style-type: none"> • Organizational rigidity within healthcare structures • Unequal allocation of resources across hospitals • Increasing patient demand combined with limited staffing • Departments described as being “cut to the bone” • Staffing shortages

By adapting their approach to the patients and acknowledging them as co-subjects rather than objects to be treated, the participants adopted a person-centered and dialogical approach. They deliberately worked to ensure that patients felt heard, seen, and supported by being empathetic to the patients' clinical, emotional, and social challenges. They reflected on how their patients sometimes responded to such encounters by saying that patients in general were happy to come to see them. Establishing a secure and supportive relationship was seen as a facilitator and the foundation of effective care, especially in the context of a lifelong, fluctuating disease like MG. Creating a welcoming atmosphere and validating the patient's experiences were essential in promoting trust and autonomy, also when it came to questions regarding strict diet or non-MG-related symptoms. One participant elaborated: “if it's important to the patient, it's important for me to try and help the patient” to enhance patients' ability to act. As healthcare professionals, and mainly neurologists, they strived for the ultimate clinical outcome, which was well-treated patients, but they also highlighted how they aimed at enabling patients to reinterpret and act in a more autonomous and competent manner when not stable

Some people also show up with a lot of complaints, and all I can say to them is that, yes we could give you more medicine, but it would have some side effects, so maybe it would also be a good idea to change your lifestyle. Because if you keep pushing yourself this hard, you'll get in trouble. And this is a disease that you'll have to learn to live with. (Healthcare professional)

It appeared that the participants tried to strengthen their patients' insight into their illness and capacity to self-manage, particularly during the vulnerable early post-diagnosis phase where everything centered around uncertainty, dependency, and loss of control. Patients with MG frequently required intensive guidance during this phase, and some patients "needed to be taken by the hand". While offering medical treatment, the participants explained its benefits, risks, and long-term implications to the patients as a way of involving them in the decision-making. Rather than issuing directives, they made suggestions and invited patients to weigh in—fostering a sense of agency and ownership.

I'm not saying that "they must". I'm saying that "I suggest". And if there're more options and they're all equally good, they'll ask me, "What do you think?" And sometimes they'll think that it's not up to them to decide... So, it's more like me saying, "I suggest that we do this and that" and people will usually say, "Okay." (Healthcare professional)

The shared decision-making and dialogic approach to consultations was welcomed by and made sense to the patients. Some participants stressed that full patient adjustment to MG – including acceptance of its chronicity – often unfolded over several years. The continuous support at specialized neurological departments which extended beyond the initial diagnostic phase entailed regular consultations with the responsible treating neurologist and nurse (the latter, primarily through telephone follow-ups). The often-lengthy involvement in the care of patients with MG necessitated repeated explanations, social support, and a personalized approach, which focused on empowering the patients by enabling them to reconceptualize their lives with MG in ways that were meaningful and manageable to them despite living with a fluctuating and unpredictable illness. The long-term engagement in patient care was seen as a facilitator for rehabilitation, entailing both a privilege and a responsibility, which allowed the neurologists to build meaningful relationships and acquire in-depth clinical knowledge. The continuity provided an opportunity for them to empower patients through tailored support as they were able to anticipate challenges, monitor long-term treatment effects, and adjust care as needed. However, this continuity also created a collaboration between the participants and the patients with MG allowing both parties to expand their agency.

Navigating Responsibility and Resources in Clinical Practice Professional Autonomy and Identity in Complex Care for Patients with MG

The participants emphasized the importance of professional authority and experience in managing a complex disease like MG. Their expertise in MG was developed in an ongoing, dynamic process shaped by years of practical experience, learning, and reflection. The participants talked about the interplay between professional identity and accumulated experience and described how their role and identity within the team evolved in parallel with their deepening clinical insights.

I generally don't think that neurologists find this group of patients easy because they can get very ill and end up on a ventilator. Their medicine has a lot of side effects, so I don't think that MG is an easy patient group, but of course, if you've specialized in something very specific, it becomes easy. (Healthcare professional)

The participants had obtained their role as MG specialists through massive clinical insight – a role that meant that colleagues from their department and from other hospital departments would turn to them for advice and second opinions. This specialist role seemed to create a sort of hierarchy both within and across professions which meant they were often the ones who took initiatives in complex patient cases, guiding clinical decisions, and serving as knowledge resources for both peers, colleagues with different professional backgrounds, and junior staff. Actively sharing their expertise with others was regarded a facilitator that entailed offering advice, leading discussions, and supervising colleagues' clinical reasoning, and by sharing their expertise with others, they indirectly helped target and qualify the rehabilitation of patients with MG. Collaboration and respectful exchange of knowledge were seen as critical for fostering a supportive, interprofessional environment where everyone could contribute their strengths based on profession and experience while also being imperative for the success of the treatment given the clinical complexity and

variability of MG. One participant explained the importance of being able to “separate what is part of the disease from what isn’t”, a skill that one, in his view, would only develop through repeated, hands-on encounters with patients with MG.

I think it’s nice to have someone with a lot of experience in the department that I can look to, because there’re so many things you can’t read up on. Nobody has this kind of knowledge except for those who have seen many patients, and I mean a lot of patients. I greatly respect that. (Healthcare professional)

It appeared that being able to learn from and lean on colleagues who had great expertise in MG was regarded as a facilitator for the participants’ professional identity formation. Many participants emphasized their responsibility, noting that patients with MG can become severely ill and that treatment pathways were often complex, requiring nuanced clinical judgement and close monitoring. They underscored their role in tailoring care to the specific subtype and progression of the disease with the neurologists having the overall responsibility for the treatment and ensuring that patients were treated according to their clinical needs. They all felt a strong sense of accountability towards their patients, always striving to ensure that patients received timely, appropriate, and effective treatment. The clear division of roles and responsibilities acted as a facilitator for the participants’ agency potential, as they knew what fell within their own area of responsibility and where other healthcare professionals would take over. The clear division of roles seemed to be familiar to most patients; the participants stated that patients with MG deliberately chose to discuss some things with the neurologist and other things with the nurse. Yet, some participants described how they occasionally provided guidance in areas outside their expertise, eg on assistive devices, when brought up by patients. Furthermore, some elaborated how they deliberately abstained from asking specific questions even if they were relevant for the patients with MG because they did not have sufficient knowledge or time to address potential issues. The scope of their work was extensive, multifaceted, and deeply rooted in a specialized understanding of MG. The participants balanced high-level clinical decision-making with practical day-to-day management. Despite general confidence in their clinical abilities, some neurologists acknowledged the challenges of staying updated on the latest research as medical treatments for MG were developing rapidly.

Collaboration and Methods in Clinical Practice

The participants described how the multi-professional work and methodology in clinical practice had changed during recent years. The neurologists conducted consultations alone with nurses playing a vital role in ensuring continuity, communication, and medication adjustments, particularly through telephone follow-ups.

We use the nurses to save physician time. If I start up some kind of treatment, I will sometimes say that the next follow-up is with the nurse. And she’ll usually ask me, in case there’s an issue, and say “so, what can we do about that?”. But otherwise, she runs the business. So, that’s how we use the nurses. (Healthcare professional)

Transferring work from neurologists to nurses was necessary because of limited staffing and high workloads. The nurses had received training in MG. Patients were only referred to physiotherapists if they did not respond to their medication and needed pre- and post-medication (eg pyridostigmine and prednisolone) assessments, or if patients were included in clinical trials. The physiotherapist said there was some collaboration with the neurologists although he did not belong to the departments performing ambulatory consultations. The limited or lack of encounters between the physiotherapist and patient meant that the physiotherapist could not offer their expertise on training exercises, compensating strategies, assisting devices, etc. or collaborate with the local physiotherapist, as this was not part of their job description.

Dissemination of knowledge within the team was both structured (neurologists forums, morning conferences, and supervision of junior staff) and unstructured (spontaneous hallway conversations and dropping by each other’s office) and was considered meaningful and important for learning, care quality, and shared decision-making. However, efficiency could be a barrier to passing on knowledge: senior neurologists were sometimes quick to make autonomous decisions, limiting opportunities for junior colleagues to learn through shared reflection. One participant described how he wanted to initiate clinical practice:

At the moment, it's on my agenda to measure the Imurel treatment by doing pre-measurements to see how much the patients tolerate. We've only just begun to do this, but I'm trying to spread the practice and have discussed it with the nurses, and I will discuss it with our physicians too. They do it in other places, and it may optimize this part of the treatment. So, new things are happening all the time, they just haven't been fully implemented yet. (Healthcare professional)

The participants felt a responsibility to advance treatment and care by learning from the experience of others and implementing new promising initiatives locally as the specialized care changed.

Collaborating locally with other hospital departments was described as easy and relevant by the participants, as they could access the patients' records and refer them to different tests or surgical procedures. One participant described how two hospital departments focused on strengthening transitions for patients with MG through knowledge sharing between healthcare professionals and by developing a procedure to reduce insecurity among patients with MG and surgical personnel.

Surgical nurses sometimes have patients in the recovery room whose pharmacological treatments they have no idea about. So, right now we have a multiprofessional group of people working on guidelines for the follow-up and care of thymectomy patients. It's also because, when we inform patients about certain types of medication that they must be cautious with because of their MG, they might discover that the surgeons don't necessarily know anything about that, but maybe the anesthesiologists do. So, there are a lot of things that can make the patients feel insecure during the transitional phase. (Healthcare professional)

Time constraints and the lack of formalized structures made intersectional collaboration inconsistent even though some participants described this type of collaboration as valuable for providing holistic and aligned support that not only included medical assessment but also focused on lived life with MG. One participant collaborated with private physiotherapists who proactively informed the neurologists about their patients' exercise plans. Others said they did not engage in any formal intersectional collaboration but forwarded patient records upon request from the municipality or general practitioner or on their own initiative to inform the general practitioner about the patient's status and potential issues they should take care of. The rehabilitation center (RCFM) was highlighted as a valuable resource of support for patients with MG, although they did not find that all patients benefited equally from referrals to the center. As an example, one participant was concerned that the center's sole focus on rehabilitation might reinforce the patients' illness identity, thereby making them feel "more sick" than they actually were.

The neurologists highlighted the complexity of managing MG due to frequent medication adjustments and an evolving therapeutic landscape. The focus on pharmacological treatment therefore often dominated consultations, leaving limited time to address psychosocial issues like anxiety or depression—concerns frequently delegated to general practitioners or not touched upon.

The question is whether you get around to talk about some of the things the patients worry about. I have to focus on the medicine. But with chronic illness there are many other things, like depression, that we let the GPs take care of. Things that the patients might actually want to discuss with us – or some other group of hospital professionals – if we had more time... After all, it is a chronic disease that involves a lot of problems. (Healthcare professional)

It appeared as if psychological and social support within the clinical setting were missing although highly relevant and needed for this patient group. One participant said that their department had initiated a psychological intervention project targeting patients with MG and other chronic conditions, but that they needed more resources to efficiently treat all patients. Furthermore, the neurologists noted specific gaps in the evidence base for physiotherapy and occupational therapy, such as strength training and aids. This lack of research made it difficult for these professionals to justify or tailor their approaches based on strong scientific backing. Overall, multi professional collaboration was shaped less by formal structures and more by professional relationships, individual initiative, and the ability to "make the system work" despite its barriers. Although there were multiple instances of resourceful and committed practices, these were often maintained despite, rather than supported by, the organizational setup.

Organizational Structures Impact Professional Quality of Care Resources and Structural Changes in Specialized Healthcare Services

The participants described that guidelines for MG care were centralized under The Danish Health Authority's national clinical guidelines because of the complexity of patient needs, meaning that patients with MG were referred to and treated in one out of four hospitals specializing in MG care. Still, there were structural challenges and resource issues which impacted on the quality and delivery of specialized healthcare services. For instance, a strained healthcare system with rising patient numbers were not matched by corresponding increases in personnel or financial resources. One participant described how organizational rigidity and unfair working conditions affected specialized care.

I think it's an unfair setup for a relatively large group of patients with many young people who are part of the workforce who you can actually treat. Only, the treatment must be closely monitored and require frequent adjustments. So, the reason we don't offer a better and more coherent treatment plan is that you can't, for example, allocate a nurse, you don't have those resources. It's the big budget from above that's blocking it. (Healthcare professional)

Increasing demands and the lack of time and financial support to provide consistent interdisciplinary care evoked feelings of inadequacy in the participants who described how they were forced to continually prioritize tasks, patient groups, and treatment options—often under ethically and professionally challenging conditions. Furthermore, the structural setup of departments—including organization structures, staffing levels, and task delegation—strongly shaped internal and external collaboration and communication.

The way we collaborate has changed after we moved from the old hospital where the nurse was at the front desk and met the patients before they saw the doctor. It was much easier to involve the nurse then, they knew the patients better because they knew their faces, and they would often follow up with information about evaluations and side effects, and hand out information the same day as we saw the patient. But today, the nurses' schedules are so busy that they don't have time to join the clinical evaluation or follow up afterwards, so this is all done separately now. (Healthcare professional)

There had been a shift toward narrow, productivity-driven care models with which nothing was allowed to cost more unless efficiency was simultaneously increased. Some explained how they constantly had to balance resources while, at the same time, trying to deliver high-quality care which sometimes caused frustrations. Some participants pointed to an unequal allocation of resources between hospital departments in Denmark, which resulted in distinct regional differences in services and follow-up care.

At X hospital, they have more resources than we do which means they can offer something completely different from us. From a physician point of view, it really bothers me. It's now up to the doctors to consider when they want to see the patients again, knowing that at other hospitals they can just tell the patients that, "Okay, I would like to see you in a year or in six months", and then there'll be time for that. Well, not here. (Healthcare professional)

It appeared that while some departments could be flexible in planning and allocating time, others felt they were "cut to the bone" had minimal staff, low flexibility in organizing care, and limited opportunities for professional development. This compromised their ability to deliver timely, patient-centered care and increase professional insights and skills. The structural consequences were considerable, limiting the participants' agency potential and naturally affecting the patients' access to high quality and specialized, meaningful rehabilitation, treatment, care, and management.

The introduction of new, costly medications had shifted decision-making away from neurologists toward cost-efficiency assessments carried out by local task forces or national bodies.

I'm thinking, what will they allow us to treat the patients with? There are more and more biological treatments on the market and some look quite effective, but we're not allowed to use them for financial reasons. And as a physician, I think this is something we're experiencing for the first time – not being allowed to give the treatments we want to. To be honest, we no longer have a say, and I find it frustrating. (Healthcare professional)

While the participants acknowledged the need for prioritizing, they felt moral distress when being unable to offer patients effective treatments with fewer side-effects due to cost constraints, especially in complex cases where all other options

had been exhausted. Generally, they felt pressure to set priorities within and across patient groups and therefore expressed a strong desire for having stable resources, interdisciplinary teams, and a better digital infrastructure (eg patient databases) that would optimize care and give them sufficient time for patients and other tasks.

Discussion

The participants in this study identified a variety of barriers and facilitators to the care and rehabilitation of adults with MG in hospital settings. Our findings showed that the participants had an empathic approach to the patients, involving them in decision-making as a way of building trustful relationships and communication, empowering the patients, and enhancing their ability to cope with their condition. Within MG-management, there has been an enhanced focus on communication between patient and healthcare professional as a means to foster shared decision-making.³⁵ However, in general not all patients feel empowered to make decisions about their own health.³⁶ Healthcare professionals must therefore always be careful to support patients and relatives in shared decision-making.³⁶ First and foremost, all patients must be able to understand the information they receive to become autonomous in decision-making.³⁷ However, according to Cox et al (2023), there is a lack of consensus on how “understanding” should be defined or assessed, despite the fact that physicians are regularly required to judge whether a patient has understood medical information.³⁷ We found that the participants sought to enhance their patients’ agency potential and to empower them to make their own decisions by sharing information on different treatment options, including potential consequences and side-effects with their patients.²⁸ The procedure is regarded as one of the basic skills for patient-centered communication.³⁸ Conveying empathy, showing respect, and trying to understand the patients are found to be more important than providing medical advice.³⁹ Reyes Acosta et al (2025) also found that both patients with MG and healthcare professionals agree on the necessity of a compassionate and informed approach to care.³⁵ Understanding how MG symptoms affect patients’ everyday lives foster trust and improve treatment adherence.^{35,40} Research also underlines that when patients feel comfortable and trust the physician, they have better health, whereas poorer health is associated with lower levels of trust.³⁵ Furthermore, consulting a neuromuscular specialist instead of a non-specialist physician increases treatment outcome and compliance positively. This can be explained by the specialist’s experience in treating patients with MG which ensures increased visits and necessary adjustments of medication.²³ Nevertheless, it is also important that physicians show their humane side through understanding, respect, and support for the patient.⁴⁰ In line with this, our findings showed how the participants, instead of overwhelming the patient with medical information, took an open question approach, beginning the consultation by asking the patients if they had any questions that they would like to ask, repeating the cycle of “ask-tell-ask”.³⁸ This person-centered approach establishes a good relationship with the patient by creating a sort of therapeutic alliance that facilitates the exchange and understanding of information, and regulates of the patient’s emotions.⁴⁰ When healthcare professionals adjust information and create relationships by taking their point of departure in the patient’s understanding, they enhance the patients’ agency potentials.²⁸ However, healthcare professionals should be aware that some patients do not share their experiences and challenges if the healthcare professionals seem disinterested in listening to the symptoms. Patients may furthermore fail to mention symptoms that they believe are “only” cosmetic or expect that the healthcare professionals would ask about if they mattered (eg ptosis).³⁵ There is also differences in how patients and healthcare professionals perceive the success of treatment, which may hinder some patients from sharing how they actually feel as they believe they should be content with the treatment’s outcome.³⁵

Another facilitator for rehabilitation was the participants’ long-term involvement in the patients’ disease trajectory which resulted in meaningful relationships between the participants and their patients. According to Tsatsani et al (2024), this may illustrate how the physician becomes a companion on the difficult and chronic trajectory by being honest, trustworthy, and willing to collaborate.⁴⁰ In fact, a positive correlation has been observed between the length of the physician–patient relationship and health quality.⁴⁰ A study within rheumatology showed that patients whose relationship with their physician had lasted more than 10 years had better health quality within physical and social functioning than those whose relationship had lasted from 2 to 5 years.⁴⁰ By working with patients over long periods of time, being available, and building relationships, healthcare professionals have been shown to strengthen the patients’ participation in their own disease journey.⁴¹ Overall, this may underline the importance of securing continuity in patient care, especially in times of structural and resource barriers to ensure and enhance patients’ agency potential and health quality.

Our findings demonstrated the interplay between professional identity and accumulated experience, positioning some participants as specialists to whom colleagues and junior staff would turn for advice. Van Zuilekom et al (2024) investigate the definition and role of generalists, specialists, and experts in healthcare and found that the specialist and expert roles in practice are used interchangeably.⁴² Most healthcare professionals who describe themselves as specialists/experts do it based on their post-graduate education and work experience.⁴² Competencies linked to being a specialist/expert include consulting, leadership, and understanding the importance of collaboration.⁴² In line with this, our findings showed that the participants' work was multifaceted, extensive, and deeply rooted in specialist knowledge about MG, and that knowledge dissemination within and across professions was imperative for understanding the complexity of MG. This corresponds with the findings of a mixed-methods study conducted in Denmark, Germany, the USA, and the United Kingdom, which identified the vital role of healthcare specialists, including specialist nurses, physiotherapists, and psychologists, in bridging these gaps, particularly in the areas of mental health and emotional support.³⁵ Generalists must know what they can consult specialists/experts about, when to consult each other, and furthermore, be aware of their boundaries and limits, and know when it is necessary to call in a specialist.⁴² Generally, our participants felt confident about their clinical abilities. According to Mak et al (2022), this may indicate that they had a strong professional identity which enhanced their resilience.⁴³ Autonomy is regarded an essential element of professional identity,⁴⁴ and professional autonomy is multidimensional. Factors related to professional autonomy are independence in decision-making, ability to use one's competences, shared leadership, professional skills, inter- and intra-professional collaboration, and a healthy work environment.⁴⁵ These factors are imperative to create attractive work environments and enhance recruitment and retention of a skilled workforce,⁴⁵ especially in times of staff shortage and strained healthcare. Our participants described taking an interest in MG, being eager to help, taking on responsibility, and engaging with their patients. These actions, according to Holzkamp, are all facilitators that affect the participants' agency potential and, together with their professional motivation and identity, influence on their willingness and ability to strive for the patients' best.²⁸

We found a lack of formalized sectional and intersectional collaboration, despite the fact, that research clearly shows that patients with MG experience various challenges and rehabilitation needs regardless of their age or years with MG.²⁵ Implementation of best practice guidelines in health can improve professional consensus and diminish unwanted differences in clinical practice.⁴⁶ A study on cross-sectional collaboration among hospital professionals in rehabilitation showed that guidelines and multiprofessional collaboration (internal and external) were found to strengthen decisions and make them easier to endure.³² Nevertheless, our findings showed that no formal collaboration was present between the participants and the general practitioners (GP) and, on rare occasions, it only entailed sending patient records to GPs to inform about patient status and need for follow-up by the GP. A study on role distribution in long-term chronic conditions showed that specialists viewed collaboration with GPs as somewhat distant and focused on processes and patient pathways.⁴⁷ Furthermore, they found that collaborating with GPs might be challenged by unclear roles and responsibilities in patient care such as not knowing what to expect from the GP.⁴⁷ Specialists saw the GPs' role as complementary to their own with the GPs being the patient's primary carer and a gatekeeper for specialized services.⁴⁷ This role distribution should be aligned according to patients' holistic needs to improve collaboration and provide appropriate patient care.⁴⁷ Overall, our findings indicate that all types of collaboration and professional freedom may support the participants' agency potential but that this is also limited by resources and structures.²⁸ Our findings outlined how knowledge dissemination occurred in structured and unstructured formats. Interprofessional learning in neurology fosters understanding, communication, and teamwork which is critical in neurology and rehabilitation settings where patient care is inherently interprofessional.^{48–50} As a leading cause of disability and death, neurological disorders highlight the need to develop effective strategies for disease prevention and management.⁵¹ Evidence indicates that interprofessional collaboration in neurology may support these efforts.^{52,53}

Finally, our findings showed that organizational conditions both limit and facilitate the participants' agency potentials. Several barriers were described: reorganization, shortage of staff and staff groups (eg psychologists and social worker), time pressure, economy, and priority issues that all affected patient care. This is supported by research showing that the healthcare sector is undergoing drastic transitions all over the world.⁵⁴ This not only impacts the way hospitals, clinics, special-care homes, etc. are organized, but also on patients, personnel, and other stakeholders involved.⁵⁴ Our findings indicate that the participants actively tried to navigate and compensate for organizational and systemic barriers by

sometimes performing off-record procedures. Andri et al (2014) found that health professionals have less freedom to decide how they interact with patients and less control over how they use resources.⁵⁵ Organizational structures directly influence on both patients' and professionals' possibility for meaningful action⁴¹ which is underscored by our findings. More initiatives are necessary to optimize the management of MG, and one Australian study recommends a shift to multidisciplinary care with clear referral procedures to ensure proper help and support in regard to unmet needs, and specific education on MG for healthcare professionals.⁵⁶

Methodological Considerations

Our inclusion criteria were broad which allowed for diverse inclusion of healthcare professionals in terms of profession, seniority, and geography. Despite great efforts to include various types of professionals affiliated with different hospitals, our sample size ended up smaller than anticipated and primarily consisted of neurologists which, we acknowledge, affects our variation and representation of data. Drawing on the work of Thorne (2025) and Malterud (2016), this study aims to gather enough information to provide a well-informed rationale based on the extent of the information contained within the sample.^{27,57} Furthermore, the sample composition reflects how Danish MG-hospital controls are currently being performed, with neurologists running the outpatient check-ups alone and the nurses typically assessing and supporting patients with MG remotely through phone calls. This imbalance in sample composition has naturally influenced on thematic emphasis, focusing more on pharmacology than rehabilitation which is inherently multidisciplinary. However, findings also showed that the focus of healthcare professionals was broader than solely therapy. They took a patient-centered approach that encouraged a dialogue with the patients about what mattered to them and looked at how they could best support the patients based on their expertise and area of responsibility. Furthermore, some participants stressed how they wished they had more time to ask questions related to everyday life as they knew that MG affected different and various aspects of the patient's life. We would have liked to include more nurses knowing that they play an important role in MG care in hospital settings and have different focus in patient care than neurologists or physiotherapists. We sent out invitations several times underlining our interest in different professional perspectives, and after each interview with the participants, we encouraged them to forward the invitation to other professions. Our data represent perspectives from both sexes of different age groups and show variation in professional clinical experience. This information has been left out after quotes to secure patient's confidentiality, as MG treatment in Denmark is managed by few people. The transferability of findings from the Danish healthcare context may be limited, as healthcare services in Denmark are publicly funded, universally accessible, and supported by well-established clinical infrastructures. In contexts, where patients must pay for hospital care, or where healthcare systems face shortages of specialized competencies and resources, access to services and continuity of care may differ substantially. Consequently, the feasibility and implementation of similar rehabilitation approaches may be constrained in such contexts.

We applied the same interview guide to all participants, regardless of professional backgrounds, responsibilities, and experience in supporting patients with MG. Interview questions were generic, focusing on subjective perceptions of barriers and facilitators in rehabilitation of adults with MG. The interviews were carried out by the first author (LKO) whose prior knowledge of MG and rehabilitation allowed for in-depth interaction and conversation with the participants. LKO's pre-understandings are not only seen as a source of bias for the findings (blind spots), but also as important for the data generation due to the contextual understanding of the area under study.⁵⁸ The author team represented different professional backgrounds, including two people with MG. The composition of the author team provided different angles to the research process, leading to critical methodological discussions and considerations which may have prevented personal or disciplinary biases of a single researcher.⁵⁸ We strived to make our analytic logic and interpretive authority more transparent and consistent by performing an inductive analysis process guided by the four iterative steps described by ID and by not being predetermined by the critical psychology to prevent overlooking important facilitators and barriers in MG care and rehabilitation.⁵⁸ However, the use of critical psychology supported the analysis and the interpretive authority by unfolding and enhancing adequate information within data to strengthen the credibility of the interpretation. Furthermore, we applied rich quotes to ensure the credibility and substantiate our findings.^{28,58}

Conclusion

Our study reveals how Danish healthcare professionals at neurological departments in hospitals perceive multiple facilitators and barriers to the rehabilitation of adults with MG. The healthcare professionals' agency potential is deeply rooted in the relational, organizational, and structural settings that they engage in. Healthcare professionals seek to compensate for the barriers and limitations they face within the healthcare system with relational adaptation and professional engagement as means to deliver high quality and person-centered care and rehabilitation. Their ability to support patients with MG in coping with their condition depends on flexibility, continuity, and interdisciplinary collaboration, which should be supported by organizational structures; otherwise, it may have negative consequences for the patients' agency potential, rehabilitation, and health. Finally, the findings point to the need for strengthening collaborations between healthcare professionals, municipalities, and the rehabilitation center to support the complex rehabilitation of patients with MG within a strained healthcare system. Future studies should include the perspectives of nurses employed at neurological departments as they might contribute with insights in the patients' everyday rehabilitation challenges and needs that extend beyond medical treatment. Attention should be made, as findings are shaped by the Danish healthcare context which may influence how transferable conclusions are to other systems.

Abbreviations

MG, myasthenia gravis; RCFM, National Rehabilitation Center for Neuromuscular Diseases; ID, interpretive description (methodology); GP, general practitioner.

Data Sharing Statement

Data in this study are not to be published due to the sensitive nature of the research.

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Disclosure

The authors declare no conflicts of interest in this work.

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