

The Implementation and Evaluation of a Care Management service for patients with neuromuscular diseases (Project Care-NMD-CH, Study Phase C)

Short Interim Report

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Background

Neuromuscular diseases (NMDs) are often associated with progressive muscle weakness and death at a young age due to loss of function of major organs such as heart and lungs. As there are no causal treatments for most NMDs, affected persons and their families experience serious health problems, financial hardships and psychosocial consequences. The management of NMD is complex and requires a coordinated, interprofessional care approach. Uneven resources, lack of expertise in treating these often rare diseases and inconsistent distribution of specialist services lead to disparities in clinical outcomes. Care Management (CM) has the potential to improve care and reduce costs. Care Manager can support patients and families and foster interprofessional collaboration through a coordinated, evidence-based, and family-centred approach. To be effective and sustainable, it is important to implement CM services for NMD patients strategically and sustainably and to evaluate its benefits.

Objectives

Therefore, the aim of this study phase C is to identify an implementation strategy, implement CM services into clinical practice and evaluate its benefits. Contextual, facilitating and inhibiting factors that must be considered when implementing NMD CM services into clinical practice will be explored and followed by service implementation. The impact of NMD CM services on patients and their families, on health care professionals and at a health care systems level will be investigated. Possible differences on patients' quality of life and self-efficacy, differences in family functioning and caregiver burden, changes in acute events, number of hospitalizations, and the impact on the care team as well as on the financial / organizational level will be illuminated.

Methods

A concurrent mixed methods study design will be used. The collection of quantitative and qualitative data will take place in different Swiss institutions between October 2022 and December 2024. Data collection includes one-on-one and focus group interviews, surveys, document analysis and a chart review. The principles of qualitative analysis, including inductive coding and comparative methods, will be used to analyse interview data. Data integration takes place during the interpretation phase. Quantitative data will be analysed descriptively, with inferential statistics and multi-level analyses integrating baseline data from study Phase A.

Results of study phase A (investigation of the care situation) can be found in the interim short report of phase A (Waldboth et al. 2021)¹. Based on these findings and incorporating evidence, an evidence-based and family-centered concept for NMD care management was developed in phase B (Waldboth et al. 2022)², describing the NMD care managers role and tasks.

¹ Waldboth, V., Hediger, H., Nemecek, G., Fröhli, R., Mezger, M., & Schubert, M. (2021). Eine Untersuchung der Versorgungssituation von Menschen mitneuromuskulären Erkrankungen in der Schweiz (Projekt Care-NMD-CH) Kurzbericht Phase A: Analyse der aktuellen Versorgungssituation. Zurich University of Applied Sciences (ZHAW). Retrieved 29.03.2022 <https://www.zhaw.ch/de/gesundheit/forschung/pflege/projekte/care-nmd-CH/>

² Waldboth, V., Nemecek, G., Bruschini, M., Hediger, H., Schuler, C., & Schubert, M. (2022). Konzept für das NMD Care Management Projekt CARE-NMD-CH: Phase B. Zurich University of Applied Sciences. Retrieved 29.03.2022 from <https://www.zhaw.ch/de/gesundheit/forschung/pflege/projekte/care-nmd-CH/>

Preliminary results

In 2022, study sites for implementation have been identified and professionals from these study sites participated in a context analysis during the preparation of phase C. Afterwards, the service implementation started in 2023. Hence, NMD care management services are currently being implemented in eight neuromuscular centers (NMCs) throughout Switzerland. Study sites involved in the implementation are the University Hospital Basel, Paediatrics, the University Hospital Berne, Paediatrics, the University Hospital Lausanne, Adults, the University Hospital Lausanne, Paediatrics, the Cantonal Hospital St. Gallen, Adults, the Children's Hospital St. Gallen, Paediatrics, the Hospital Ticino Paediatric/Adults and the University Hospital Zurich, Paediatrics.

To identify an implementation strategy and facilitate the service implementation a context analysis was performed. Therefore, focus group interviews took place in the eight study sites concerning topics such as resources, work culture, hindering and facilitating factors of the implementation.

Preliminary findings of the context analysis show that participants reported to feel motivated and enthusiastic about the new role and open to change and adaptations. However, they recognized the challenge of including an additional service into an already tight schedule where patients and their family members already meet a multitude of health care professionals. Study sites claimed that they want to make the best use of time and prioritize tasks. Expected CM services mentioned were assisting patients and their families managing everyday life, information after diagnosis and the transition to adult services. They would also like to improve the cooperation between adult and paediatric services and wished for a better interprofessional collaboration as well as for more networking opportunities with other NMCs and experts in Switzerland. Challenges that were mentioned included: reimbursement of services, long-term sustainability, duplication of services, space/rooms for services, establishing the nurse counselling service.

In their daily practice, CM will be supervised by their medical supervisors. They are currently attending a basic training course. The formation includes training sessions on NMD disease etiology, pathophysiology, diagnostics, and supportive interventions as well as treatment options. Further, Care Manager will learn about family centred care, effective counselling methods and care priorities for this population. The transition from child into adulthood and therefore the handing over from paediatric to adult care is another important topic that is covered in the course. The Care Manager will be taught how to improve the interprofessional collaboration and what it needs to effectively implement a CM concept from theory into practice. The basic course also serves as a resource for collaboration and exchange among the different NMCs across the whole of Switzerland.

In course of the project, additional data will be collected as described in the methods section. Thus, the services will be evaluated for their benefits for affected persons and their family members, for the treatment team, and for the health care organizations. First findings of the evaluation are expected for 2024.

Expected Project Outcomes

Through the implementation and evaluation of NMD CM services, health professionals will be able to manage the complex care of NMD affected persons and their families more effectively. This is expected to improve quality of care, interprofessional collaboration and patients' quality of life. A well-coordinated care process will lead to fewer complications and acute events which reduces the numbers of hospitalizations and therefore decreases health care costs.

Project team

Zürich University of Applied Sciences (ZHAW) is conducting the Care-NMD-CH project on behalf of the Swiss Muscle Society, in collaboration with the Cantonal Hospital St. Gallen, the University Children's Hospital Zurich, the University Hospital Zurich, the Inselspital Bern and the Swiss Foundation for Muscle Disease Research as well as other cooperation partners.

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[Schweizer Register für neuromuskuläre Erkrankungen](#)

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