The neuromechanical and behavioural adaptations to dynamic arm supports in neuromuscular disorders

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CHAPTER 7

Valorisation

The project was part of the STW-perspective Symbionics program (project 13523)[134] and we collaborated with various stakeholders to create value from the generated knowledge in this PhD project. They were mostly from a muscular dystrophy patient community, support developer, clinical, rehabilitation, and research setting. This chapter will elaborate on the collective value focusing on the evidence of knowledge of muscular dystrophy and user-device interactions and the established framework to describe them.

7.1 EVIDENCE OF DISEASE AND USER-DEVICE INTERACTIONS

From the evidence found in this work, it is clear that the manifestation of a neuromuscular disorder is heterogeneous and so is the respective interaction between user and support device. More specifically, the coordination of muscle activities of people with Facioscapulohumeral dystrophy (FSHD) was found to be more unique, yet simplified, than those of healthy participants. Likely, their muscle coordination was adapted as result of individual-specific weaknesses present in the muscle groups that mobilize the shoulder, upper arm, and scapula. On top of these unique variations of muscular weakness, the versatility of the shoulder's motions adds another layer of complexity in coordinating muscle activities. It is therefore clear that future research and treatment should focus on individuals-specific alterations of muscle coordination in people with Facioscapulohumeral dystrophy and likely in other muscular dystrophy types. Meanwhile, the use of a dynamic arm support did not generally influence FSHD people's muscle coordination, while this was true for healthy participants.

However, muscle coordination did become more similar between populations using the device. With training, it might be possible to fine-tune the user-device interaction and augment the benefits received from the support. Although users could undergo specific training to operate the device more efficiently, it also seems plausible that the user can extend the support's benefits by improving the muscle coordination to a more stable scapula. The lack of scapular motion and stability limits, among others, the available strength in motions against gravity and consequently the reachable workspace. Muscle activity-based biofeedback is a possible therapeutic approach to achieve this goal. This approach should be applied, evaluated, and adjusted based on the progressive nature of muscular dystrophy.

An alternative approach would be to adapt the device to the capabilities and needs of its user. At home, the dynamic arm support was most used to consume food and to perform personal hygiene tasks, household chores, and computer activities. Users indicated that the device provided no support for or even limited activities involving wrist movements, forearm rotation, and large motions of the arm. Unfortunately, the consequences for daily use, indicated in chapter 5 as 74% of all activities by the user but only as 18% by the activity monitors, remain unclear. Thus, efficient adjustments to the device require a better understanding of the disease and user-device interaction, as well as an understanding of the contributing factors for the discontinued use of the device. Collaboration between stakeholders is necessary to fill these gaps. By exploiting each stakeholder's strength, the patient community can formulate the users' needs, estimate the users' capabilities, and formulate the biomechanical adjustments of the dynamic arm support device to fulfil these needs. Consequently, a common ground of shared knowledge and environment is required to facilitate this collaboration.

7.2 FRAMEWORK FOR DISEASE AND USER-DEVICE INTERACTIONS

Previously, some of the stakeholders commonly used the ICF model components, body functions, activity and participation, and personal and environmental factors, to describe the characteristics of neuromuscular disorders and user-device interactions. To properly understand the context of these characteristics and interactions, additional information such as the setting in which they were established and consequences for their daily lives are required. However, from literature and collaborations with stakeholders it became clear that there was no structure yet in existence that would facilitate this understanding. Therefore, a framework was created from the ICF model and incorporated three contextual constructs, which explains what people can do in controlled (motor capacity) and home environment (motor capability), and what they do daily (motor performance). As a result, the gaps in knowledge became quite clear. For example, stakeholders expressed the necessity to understand what users do with the dynamic arm support, what the beneficiaries are, how that affects body functions and activity and participation, and the interactions thereof. Yet, current evidence was found to be more focussed on the controlled environment and greatly lacking in the home environment. After evaluation of the available evidence, it is established that gathering evidence in the home environment is very complex and only recently gaining traction. Therefore, this framework enables the stakeholders to tackle this and similar issues by identifying the collective strengths and remaining barriers in various framework areas.

7.3 TAKE HOME MESSAGES

The capabilities, needs, and interactions with a dynamic arm support should always be attuned to an individual's capabilities. This means that the device should be fitted to the user and adjustments should be made in due time, for example, following disease progression. However, the possibility to train the user to extend the support benefits should also be investigated. Furthermore, the proposed framework for disease and user-device interactions should be used to fill in remaining knowledge gaps stated in chapter 2, such as the connection between user's capabilities and performance of activities in daily life and the adaptations in user-device interaction over time and due to disease progression. Ultimately, we should strive towards the collection of evidence in a home environment and towards monitoring disease progression. To this aim, collaboration among stakeholders is necessary for a better understanding of disease and user-device interactions and the consequent improvements in quality of life.