Blended therapy

Impact paragraph

This thesis has generated new knowledge in the field of physical exercise training in patients with inflammatory myopathies (IM). In addition to the scientific value of this thesis, described in chapter 2-7, this section discusses the social and economic relevance of this work, identifies target groups for whom the results may be of interest, highlights innovation, and illustrates implementation and dissemination of our results.

Relevance

Physical activity and exercise has both preventive and curative effects on a number of different diseases such as diabetes, cancer (particularly breast and colon cancer), depression, dementia and cardiovascular disease (1). Furthermore, the scientific literature supports the idea that most physiologic systems are positively altered by physical activity and exercise, and thus exercise can be viewed as a medicine (2). This natural treatment enables the physiologic systems of the body to function optimally and therefore causes no side effects, as seen in traditional medicine (3). There is also evidence that exercise acts as an anti-inflammatory therapy (4, 5). As with other medications, the formulation and the dosage has to be prescribed individually for each patient. An instruction such as “you should exercise for your disease” is insufficient; the prescription must contain information about the frequency, type, intensity and duration of the exercise. According to the latest EULAR (European League Against Rheumatism) newsletter for health professionals in Rheumatology (Issue 7, 2020 spring), patients with rheumatic disease would like to be prescribed exercise as a natural medicine. They describe an unfulfilled need for advice on physical activity from their trusted healthcare professionals. On the other hand, healthcare professionals (doctors, nurses and physiotherapists) report not being confident in prescribing physical activity, due to lack in adequate knowledge. We made a similar experience in our daily practice with patients suffering from IM. Many of the patients we saw at our annual check-up were not advised and supported well enough with regards to their exercise training; they were simply told to “stay active and exercise” rather than getting clear recommendations and support. Especially in the field of rare diseases, keeping up to date with the relevant literature is a challenge for general practitioners. With this thesis, we provide two possibilities for patients with IM to get better support with their physical activities and exercise. On the one hand, there are published training guidelines which help the external therapists with giving relevant advice and supervising

their individual patients with this rare disease. On the other hand, the interactive exercise app provides specialized therapists with the possibility of giving patients remote advise and monitoring of their physical activity. In short, patients benefit from a training program that follows recognized training principles and is adapted to their individual (disease-related) needs. Physical activity and exercise is not only important as therapy, but also as prevention of secondary disease and potential disabilities. Thus, regular exercising may not only reduce the individual burden of the disease but may also decrease the consequential health care costs. Individually tailored promotion of the physical activity and exercise therefore makes an important contribution to public health.

Assessments are not only important for research, but also an essential part of evidence-based practice. Systematically measuring the effectiveness of therapeutic interventions provide an overview of the patient's progress and therefore provides a basis for adaption of the treatments procedure and possibly also a motivation for the patients. Only if we systematically record, evaluate and critically discuss our therapy results, we can prove the effectiveness of our therapies and continuously improve the quality of our treatment. This important process is only possible when valid and reliable assessments are available. Our results provide two reliable assessments for patient with IM, namely the Myositis Activity Profile and the hand-held dynamometer. Our work also demonstrated the limitations of the MMT. If muscle weakness is only measured by MMT, there is a risk that early or mild muscle weakness and moderate changes remain undetected.

Target groups

The results presented in this thesis are of interest to multiple target groups. The most important target group is people suffering from IM. While it is well accepted in popular and professional sports to take training theory into account and to adapt the training to individual needs and individual performance, it is often neglected in the therapy setting. However, the training principles need to be followed strictly in order to guarantee that the training dosage is balanced rather than under- or overdosed, which would be either a waste of time or a risk of overload for the patient. The disease-specific training recommendations given by the training guidelines described in this thesis may help the therapists in designing an efficient training program, which optimizes the chance of training success for the patients. In addition, this thesis offers a new therapy option which allows patients to exercise at

home, thereby saving time and reducing travel costs while still being supervised by a specialized therapist.

This work is also of interest for health care professionals, such as physical or occupational therapists and medical doctors. Firstly, it offers evidence-based exercise guidelines including a leaflet with the most important information about general training principles and disease-specific training recommendations for patients with IM. This leaflet can be used by medical doctors to prescribe specific exercise therapy and by therapist to compile an evidence-based, individually tailored exercise program for their patients. Secondly, our work offers new insights to outcome measurements. A validated disease-specific PROM is now also available for the German speaking countries. With this questionnaire, limitation of daily activities can be evaluated in the clinical practice. Moreover, this thesis motivates clinicians to focus not only on measuring maximum strength but also on muscle performance.

Our results may also be of interest for healthcare institutions such as hospitals, rehabilitation centers and private physiotherapy practices. Today, electronic support is an integral part of our everyday life and the digital revolution does not stop at the health care system. New technologies will influence the future of daily therapy routine, so health care institutions which deal with new technologies at an early stage will have a competitive advantage. This work therefore provides important information about the needs of patients and therapists and the conditions that must be met in order to apply new technologies in the clinical practice.

Finally, the results from the usability and feasibility studies about end-users perspectives of this exercise app and the blended therapy approach can be of interest for software designers. Such feedback is crucial for the development of effective, user-friendly and client-centered telerehabilitation (TR) solutions.

Innovation

This newly developed tablet-based exercise app and the blended therapy approach combining the use of this app with face-to-face physiotherapy sessions in patients with IM can be called innovative, as there has been no such approach for patients with IM until know. For some time now, TR has become increasingly important in the healthcare sector. Various sub-categories of TR, such as telephone counselling, online therapy via video telephony or the use of digital home programs (videos or documents that are transmitted to the patient electronically) has been evaluated. Except for the possibility of

monitoring patients per remote, the app provides detailed information about the performed training dosage and compares the performed training with the planned training prescription. It reveals whether the patients actually were able to carry out their planned training or whether they had to make adjustments to the described dosage. This particular comparison has not been possible until now, which renders this approach both valuable and innovative.

The app investigated in this thesis is part of a larger system. The goal of this system is to offer a holistic training concept, including endurance training, progressive resistance training and cognitive-motor training, which can be carried out on site or at home (with remote support). So far, the different parts have been evaluated separately, but in the future, these different parts will be put together. In this thesis we focused on RT, but future projects should combine the different training modalities.

Implementation and Dissemination

Some of the results in this thesis have already been implemented in the clinical practise at the USZ. Firstly, we adapted the assessments of the multiprofessional consultation sessions for patients with IM: the older, not-validated translation of the MAP was replaced by our new validated version of the German MAP and to evaluate changes over time we now use the held-dynamometer. Secondly, we give the flyer with the training recommendations to all patients who receive physiotherapy externally. Thereby we ensure that the therapists and the patients are informed about the importance of an individually tailored exercise program and a recommended training dosage. Since some study patients wanted to continue training with the exercise app, we conducted a pilot project using the new software application in the clinical setting. Both therapists and patients appreciated this therapy option, but unfortunately this promising approach cannot be implemented for accounting reasons. In Switzerland, physiotherapy has to be prescribed by a medical doctor in order for the health insurance coverage to apply. TR is currently not included in the collective agreement and therefore, the health insurance companies do not reimburse the patients for any costs for TR.

Besides these promising experiences made with the blended therapy option, a number of other steps are crucial in order to make TR a recognized therapy offer that can be included in the collective agreement. The feasibility and acceptance of this approach has to be evaluated in other patient groups. Until now, similar feasibility studies have been performed in patients with haemophilia and in patients with End Stage Renal Disease. None of the data

from these two studies have been analysed yet. Another step would be to analyse the cost-efficiency of this approach. Such an investigation would be important for future negotiations with health insurances and people handling the collective agreements. Except for the cost-efficiency studies, clinical pilot projects in which the implementation and costs of TR are evaluated in the clinical setting are essential. A suitable target group for such implementation projects are lung transplantation patients. These patients are going through the surgery at the USZ, but they do not always live in the canton of Zurich. Since exercise training is strongly indicated after such an intervention, but their immunosuppression prevents them from training in a fitness center or a hospital, they are instructed to follow an exercise program in their homes. Many of these patients, however, do not manage to perform these exercise programs regularly, since they do not get enough support. The use of our developed exercise app could thus improve adherence to exercise programs for these patients.

The development of new technologies has increased markedly during the current Corona pandemic. This is not only seen in the office world with increased home office and video conferences, but also in the therapy setting. During the lockdown, treatment of patients on site was prohibited, so the only possibility of treating patients was per TR. During this limited period, the costs of TR were covered by the health insurance. Hopefully, this predominantly positive experience of TR will help boost its implementation, but the long-term effect of the pandemic on this development remains to be seen. Actually, everyone could benefit from TR: the patients by having a therapy option which they can perform comfortably at home and still have professional support, therapists by being able to regularly care for patients who live further away, healthcare institutions by being able to offer innovative therapies and not having to transfer patients to other institutions, and health insurance by providing better care for patients and thus preventing follow-up costs.

Based on the work of this thesis, we were unable to recommend one single assessment to evaluate muscle weakness. As we confirmed several known limitations of the MMT8, we strongly recommend critically discussing the inclusion of this assessment in the myositis core set measures. To foster such a discussion it is important to disseminate our results at national and international conferences and in scientific journals. There are several other

promising assessments for measuring muscle strength and muscle performance, but most of them have not been conclusively validated. To fill this knowledge gap regarding clinimetric properties of these outcome measures, further research is urgently warranted.

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