

Measuring and training of walking abilities in pediatric neurorehabilitation

Citation for published version (APA):

Ammann - Reiffer, C. (2018). *Measuring and training of walking abilities in pediatric neurorehabilitation*. [Doctoral Thesis, Maastricht University]. Datawyse / Universitaire Pers Maastricht. <https://doi.org/10.26481/dis.20181114ca>

Document status and date:

Published: 01/01/2018

DOI:

[10.26481/dis.20181114ca](https://doi.org/10.26481/dis.20181114ca)

Document Version:

Publisher's PDF, also known as Version of record

Please check the document version of this publication:

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INTRODUCTION

The term valorisation refers to the economic and societal impact that is created through the transfer of scientific knowledge. It is related to the term innovation, which describes the process of translating an idea or invention into a product or process that creates value. Thus, innovation only applies if an invention is put into practice. Similarly, researchers should strive to make scientific knowledge available to other organizations, interest groups or the general public. The valorisation addendum summarizes the societal and economic value of this dissertation besides the scientific aspects described in the previous chapters.

RELEVANCE

Mobility has become a buzzword in today's world. It is considered a prerequisite for a modern lifestyle. Mobility helps people to react quickly and flexibly and to move from one place to another without much effort. Being mobile is a requirement for achieving a goal, accomplishing something, finding one's way in life, and being worth something. With that, mobility is a significant criterion for human well-being.

Many children with neuromotor disorders are restricted in their independent mobility, which limits their possibilities to explore their environment actively and to interact with peers. Among the families concerned, their children's ability to walk is of particular importance. A vital part of rehabilitation is, therefore, to find the most effective interventions possible that have a positive impact on these walking abilities. By investigating the effectiveness of robot-assisted gait training (RAGT) in children with cerebral palsy, this dissertation has addressed one aspect from the wide range in this field.

Rehabilitation should further aim to enable children and their families to participate in society regardless of the children's mobility restrictions. It is, therefore, not enough to focus on improving walking capacity in the rehabilitation of gait disorders. To be precise, we need information that reflects children's mobility behavior in their everyday environment and should then address these individual circumstances in

the rehabilitation process. With the Functional Mobility Scale (FMS) and the Gillette Functional Assessment Questionnaire – walking scale (FAQ), this dissertation provides two instruments for German-speaking countries, which allow obtaining specific information on the status and changes of children's everyday life mobility.

TARGET GROUP

The framework of this dissertation - both of the measuring and the training part - was designed from the very beginning to be relevant for everyday practice. Thus, many different stakeholders can benefit from the results in one way or another.

The knowledge gained from the measurement part of the thesis is expected to contribute to a reliable and valid measurement battery for centers like ours. Thanks to the systematic review, clinicians now have a detailed overview of all commonly used measurement instruments and their psychometric properties for the evaluation of gait function in children with neuromotor disorders. They can use this information as a decision-making basis to decide which instruments are most appropriate for their specific purposes. With the FMS and FAQ, various disciplines of healthcare professionals such as physical and sports therapists, nurses, and medical doctors have access to additional measurement instruments to evaluate the progress or their patients' walking abilities. The provided tools are particularly valuable as they reflect the children's mobility in everyday life and thus take into account the barriers and facilitators of their surrounding environment. Furthermore, they are easy and quick to use, which makes them ideal for everyday clinical use, where time resources are becoming increasingly scarce.

By reflecting children's walking abilities in their usual environment, the perspective of the two measurement instruments is particularly meaningful for the child and their families, as the ratings refer directly to everyday life. Another noteworthy aspect is that the measures enable a common language between parents and healthcare providers, which further empowers the parent's position in the healthcare system. In fact, the psychometric studies were themselves a factor that made children and their parents feel taken seriously as their usual environment and the parents' rating was decisive and thus highly valued. Moreover, many parents highly appreciated that

they were contacted again by phone after the discharge of their child from the rehabilitation center.

While those mentioned above are the main stakeholders, the FMS and FAQ can also provide a more holistic view by considering the social and physical environment of the child regarding the communication with the health insurance companies when demonstrating the effectiveness of gait interventions. Furthermore, the instruments could also be implemented in various registries, such as the newly established Swiss cerebral palsy registry (www.swiss-cp-reg.ch).

Considering the training part of the dissertation, we discussed that a more holistic approach based on the International Classification of Functioning, Disability and Health (ICF), where RAGT is integrated into a whole treatment package, monitored by a sound measurement battery, is becoming more and more critical. Results of this thesis are supporting in finding an orientation for an improved basis for decision-making regarding optimal treatment for children and youth. This knowledge is not only of value for health care providers and health insurance companies but also meaningful for children with neuromotor disorders and their families. RAGT on the Lokomat requires a considerable effort from the child and their families regarding organization and time resources, as well as clarifying whether the health insurances will meet the costs. Gait training can take a smaller or more substantial part in rehabilitation, and RAGT can, but does not have to, be a part of it – depending on the individual needs and wishes of the children and their parents. Hopefully, our findings will remind families of the importance to carefully observe their child's progress and not merely blindly trust in the benefits of modern technologies. Besides, it was interesting to see how parents appreciated that interventions given to their child were questioned and scientifically examined. For this fact, they were also more than willing to invest the additional time required.

ACTIVITIES, PRODUCTS, INNOVATION

Before this dissertation, the FMS and FAQ were not yet available in German. Moreover, these two instruments reflect children's walking abilities in everyday life, which involves the influence of various environments that the children are exposed

to in real life. This perspective – although particularly meaningful for the child and their family - is underrepresented in practice and research compared to the assessment of children’s maximal walking capacity under standardized conditions. Finally, the FMS and FAQ are now some of the few pediatric functional mobility instruments with information on all their measurement properties, namely with positive evidence on their validity, interrater reliability, and responsiveness, and are easy and practical in use. Thus, clinicians and researchers can confidently apply both tools for the evaluation of children’s walking abilities in everyday life.

RAGT with the Lokomat was implemented in our rehabilitation center more than ten years ago and is applied within our neuropediatric treatment regime in the out- as well as inpatient setting. Our outpatient program currently includes 20 RAGT sessions spread over 4-7 weeks, optionally accompanied by physiotherapy and sports lessons in the child’s home setting. A comparable amount and intensity of sessions did not result in a measurable change in our intervention study that was part of this dissertation. These findings will therefore inevitably have to lead to a modification in the content of our RAGT outpatient program. The outpatient approach must be more oriented towards our 4-5 week-inpatient program, which already aims at gait training as a holistic package across all ICF dimensions with the aid of various therapeutic approaches. In a further step, the characteristics of the group to whom outpatient RAGT is recommended could be reconsidered to find those children that respond positively to this therapy method. Finally, an optimal assessment battery has to be assembled which allows recording the resulting changes at all ICF levels. As our center is one of the leading centers regarding robotic training in children, adaptations in our program will be noticed worldwide.

SCHEDULE AND IMPLEMENTATION

After the studies of this dissertation demonstrated positive evidence of their psychometric properties, the German FMS and FAQ have been implemented in the standard gait assessment of children performing RAGT on the Lokomat during their inpatient rehabilitation stay in our center. Additionally, they are becoming applied routinely in children undergoing a clinical 3-dimensional gait analysis in our gait

laboratory. Furthermore, the physiotherapy team of our center has been instructed and trained in the use of the two instruments and has now started to rate functional mobility with the FMS and FAQ in their inpatients.

The proposed changes regarding the holistic RAGT outpatient approach need to be discussed with different stakeholders involved, including therapists responsible for RAGT in our clinic, rehabilitation physicians and most important the families to get their opinions and feedback about the feasibility. The impact of a modified approach should also be monitored to document changes carefully. This scientific support is imperative to have the health insurance companies on board as well to ensure coverage of the costs of this program, which should be based on the currently available best evidence. To minimize the risk of a noticeable improvement not being recognized at group level in a clinical trial, alternative pragmatic research designs that are suitable in this population, such as n-of-1 trials, single case methodology designs or observational designs could be viable options to be considered and explored in future research.

TRANSFER OF KNOWLEDGE

Besides the instruction of our physiotherapists and the implementation of the instruments in our center, we aim for as wide a distribution as possible of the German FMS and FAQ in the German-speaking part of Switzerland as well as later on also in other German-speaking countries. For this purpose, we already approached and will further contact relevant organizations in Switzerland. These are for example persons responsible for the training of physiotherapy students in the field of pediatrics and the master's degree in pediatric physiotherapy, therapy teams of other children's hospitals and schools for physically and multi-disabled children in the German-speaking part of Switzerland. We also offer interested organizations the opportunity to present the instruments and their application to the interested teams at their sites. The aim is to inform them about the German versions of these two instruments and to promote their implementation in clinical practice. Furthermore, we provide the tools on our website free of charge (www.kispi.uzh.ch/rza/de/forschende/publikationen/downloads). Additionally, we

disseminated the results of our studies and distributed free copies of the German FMS and FAQ to interested people at various scientific conferences.

Related to the instruments' implementation in our rehabilitation center, an FMS and FAQ rating by the parents at their child's admission to the inpatient stay would be a medium-term vision to promote the common language between parents and healthcare providers and to largely underpin the perspective of parents in therapy goals and planning. Further medium-term goals are to implement the inclusion of FMS and FAQ into registries and other databases relating to pediatric neuromotor disorders to provide also information on children's motor performance at this level.