

Chances and challenges of home-based bimanual training in children with unilateral cerebral palsy

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VALORIZATION ADDENDUM

With the work presented in this dissertation we aimed to generate- scientific knowledge on the chances and challenges of home-based bimanual training in children with unilateral cerebral palsy (uCP). The theoretical and practical implications of our results were described in the various chapters throughout this dissertation. Below, our findings are discussed in a broader societal context. According to the 'Regulations for obtaining a PhD at UM', in this addendum I consider valorization as "the process of creating value from knowledge, by making knowledge suitable and/or available for social (and/or economic) use and by making it suitable for translation into competing products, services, processes and new activities" (definition taken from the report of the National Valorisation Committee, *Waardevol: Indicatoren voor Valorisatie* [Valuable: Indicators for valorisation] (2011) The Hague: Rathenau Institute, p. 8). The addendum will address 1) the social relevance of the research results; 2) the target groups to whom the research results are of interest; 3) the products and activities in which the research results will be applied and given shape; 4) the extent to which the research results can be called innovative; and 5) how the valorization plan will be implemented.

RELEVANCE

CP is the most common cause of motor disability in children. The impaired functioning of the arm and hand in children with uCP negatively affects independence, participation, and quality of life. In addition to the child itself, these consequences also impact the parents and siblings. Optimizing the care for children with uCP, to which the results of this dissertation contribute, is therefore valuable for the many families involved. Because no cost-effectiveness study has been performed, no conclusions can be drawn yet regarding the economic relevance of our findings.

TARGET GROUP

We intended to generate research evidence for the benefit of children with uCP and their parents. Hence, in addition to researchers, grant providers, and others within the academic community, the results of this dissertation are primarily of interest to these children and their parents. The research is also highly relevant for the rehabilitation teams that are involved in the care of these families. Pediatric occupational and physical therapists as well as remedial educationalists are important target groups, because they are the parents' coaches during the home-based training. Moreover, physiatrists can use the findings when discussing treatment plans with parents. It should be recognized that at this point no generalization is possible to children other than the population of interest in the study. To a lesser extent, policy makers can adopt our conclusions in the development or update of clinical guidelines, although the limited evidential value of the case series should be considered appropriately. Last, awaiting future research on the cost-effectiveness of home-based training, our results are of interest to health insurance companies who fund the program.

PRODUCTS AND ACTIVITIES

Our work has already been shaped into several products and activities. First, the paper as presented in chapter 4 provides a detailed description of the intervention protocol, in order for clinicians and fellow researchers to use a comparable home-based training program. Second, the translation and adaptation of the Lifestyle Assessment Questionnaire for children with cerebral palsy (LAQ-CP) resulted in a Dutch version of the questionnaire, which is freely available at: <http://links.lww.com/PPT/A165>. Last, dissemination activities included presentations and mini-symposia at national and international conferences. For the occasion of the defense of this dissertation, a one-day symposium is organized by the Centre of Expertise in Rehabilitation and Audiology of Adelante in collaboration with the Department of Rehabilitation Medicine (Care and Public Health Research Institute (CAPHRI)) of Maastricht University. The symposium targets researchers, clinicians, as well as parents. During the symposium both our results and work of others will be discussed.

There are various other opportunities to translate the insights of this dissertation into products and activities, apart from the scientific output. Given the complexity of the home-based training program, during the research we developed and provided a manual and instructional course to the healthcare professionals, and instructional videos to parents. These can be shaped into products to be implemented within the Netherlands or, after translation, internationally. The products should be amended using the results of this dissertation. The process evaluation pointed out the importance of a user-friendly tool to share videos and other data between parents and healthcare professionals. The existing system arQive was used in an inventive way to suit the needs within our intervention. It was concluded that arQive is promising to facilitate home-based training. A next step is to optimize its functionalities and implement it thereafter. In order to inform parents and the general population about the research results, lay information will be disseminated where possible, for instance through social media, and opportunities for media attention will be seized.

INNOVATION

As the systematic review pointed out, many home-based interventions have been investigated, although not in the Netherlands. Furthermore, our study was one of the first to apply bimanual training in the home-based setting. Another important innovative aspect was the interdisciplinary coaching by a therapist and remedial educationalist, which emerged to be a highly important component of the program. The distinction between an implicit and explicit motor learning approach, though not further recommended based on our results, was another novel facet. In addition to the intervention itself, the extensive process evaluation was an original research method in respect to home-based interventions.

PLANNING AND IMPLEMENTATION

Part of the research team recently started a new study: the #Eurekah project (Effectieve data-Uitwisseling tijdens de REvalidatie van Kinderen met Arm-/handproblematiek: een Haalbaarheidsstudie). In this feasibility study it will be investigated whether arQive is indeed suitable to exchange data effectively during rehabilitation of children with arm/hand problems.

More work is needed to confirm the effectiveness of the home-based training program, before valorization of the intervention-related products should occur. Based on the experiences during this project, as described in chapter 7, I would recommend a well-designed single-case experimental design study of the optimized home-based training program. Pending these developments, no planning to implement the program can be provided yet.